Exploring the experience of older people in care homes with the administration of oral medication, a hermeneutic phenomenological study.

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Abstract

This thesis reports a hermeneutic phenomenological exploration into the experience of care home residents with the administration of their medication. Residents of care homes for older people experience multi-factorial problems when being given oral medication. A systematic integrated mixed-methods review of the literature revealed that practices of modifying tablets, crushing and mixing with food, in attempts to administer medication, remain widespread internationally. There is a high prevalence of swallowing problems. Care home routines are time pressured, and there are incidences of disempowering practices and language associated with processes of medication administration. The literature presented very little from the residents' experience, largely representing them as passive recipients in the activity.

The aim of this study was to explore the experience of residents of care homes for older people who need help from care staff to take their medication. Its purpose was to answer a single research question, 'What is the experience of residents of care homes when oral medication is administered?'

Observation of an episode of medication administration and semi-structured interviewing were conducted with eight residents between the ages of 84 and 95 from care homes in Scotland. Data was analysed in accordance with a Gadamerian philosophy of hermeneutics, with a commitment to understanding and representing the participants' experience.

Four themes emerged from the data, 'Being in control/relinquishing control', 'Being comfortable in routine', 'Trusting', and 'Swallowing'. Interpretive exploration of these themes revealed the importance of facilitating individual routines when taking medication, and that a trusting relationship with staff and with the medication can be an indicator of vulnerability. The risks to autonomy in relation to taking medication, and an imbalance of power for care home residents who are given medication to take emerged as an overarching concept. Recommendations for practice focus on the potential for empowering practices in relation to taking medication.

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Chapter 1 - Introduction

This chapter provides an introduction to the purpose of the study and why it was conducted. The methodology of hermeneutic phenomenology will be introduced, with explanation of some of the key features which affect the style of the thesis content. I will introduce myself and make clear my professional and personal motivations for the choice of topic. The final section will summarise the structure of the thesis and the content of each of the chapters.

1.1 Purpose of this research

The aim of this study is to explore the experience of residents of care homes for older people who need help from care staff to take their medication. Its purpose is to answer a single research question, ‘What is the experience of residents of care homes when oral medication is administered?’

1.2 Clarifying key terminology.

The process of a person being given medication by a nurse or carer is termed ‘administration of medication’ in professional academic literature and in policy documents (Care Inspectorate, Royal Pharmaceutical Society Scotland, Social Work Scotland 2015). This term is used for the title and throughout the body of this thesis. However, lay reviewers of the documents designed for residents in this study felt that the term ‘administration’ was potentially confusing to people unfamiliar with the use of the word in this context. Therefore, a simplified term ‘taking medication’ was used for all the documents for participants, and terms such as ‘taking’ or ‘being given’ medication were used when interviewing residents.

1.3 Theoretical framework

A social constructionist perspective underpins this study, with the choice of Gadamerian hermeneutic phenomenology as methodology which places the care home resident at the forefront.

A key feature of this approach is the acknowledgement of the place of the researcher within the research (Dibley et al. 2020). As a consequence, the use of personal pronouns, ‘I’ and ‘my’ will feature within the writing, to make it clear when I am drawing on my own interpretation within the research (Jiang and Hyland 2020).

1.4 Why this research?

Older people who live in care homes have complex physical and mental health needs (Barker et al. 2021). They are often prescribed large amounts of medication (Morin et al. 2016). They frequently have problems swallowing (Pu et al. 2017) and swallowing medication in particular (Liu et al. 2016). Guidance for care home staff and prescribers lacks consideration of the experience of residents during the process of being helped to take their medication.

1.5 Introducing myself – personal motivation.

Who I am and where I come from provided the initiative for this research project (Frechette et al. 2020). I have a background as a nurse in primary care, case-managing care for older people in care home settings and in their own homes. I have a special area of expertise in reviewing and optimising medication for this population. Twenty-five years of experience has provided a wealth of anecdotes which have contributed to my interest in this research topic. For many years, I have scheduled routine visiting to care home to arrive around 10 or 11am, after the busiest period of the morning. Many, many times I would find residents with residue of chalky white tablets lodged in the mouth or around the lips, tablets they must have been given some time earlier in the day. It looks unpleasant to an observer, but what does it feel like for them?

Certain individual patients for whom I have provided care in the past will always be there in my memory, the ones I have never forgotten. Many experiences like these two retold here, stayed with me and sparked my interest.

> I recall being asked to see a lady with advanced dementia who had gradually stopped eating and drinking, for no obvious reason. She was curled up in her bed, looking unwell and miserable. Examination revealed that the inside of her mouth was horribly ulcerated and blackened. No wonder she was unable to eat. It transpired that over a period of many weeks or months, the care staff had been giving her iron tablets as prescribed, three times daily. She did not swallow them, but rolled them around in her mouth, sucking on them, lodging them inside her cheek until they eventually dispersed. This oral ulceration caused by iron tablets is a known problem, and well documented in the literature. I stopped the tablets, she slowly recovered, but I never stopped wondering what that might have been like for her if she could have told me?
>
> On another occasion, care staff called me, asking if I could visit for a medication review for a new resident. She had so many tablets to take, and some very complex postural difficulties such that it was taking the staff an hour and a half to help her to

> take her morning tablets. They had to bring in an extra member of staff to cover the breakfast duties, to be able to have time to give this lady all her tablets. Whilst it was the staffing problem for the home which had triggered the request, I was thinking, what is this all about? What does she think about this? What is most important for her?

Reflecting on these experiences I also began to feel that perhaps this was something which was unknown to many other health professionals, and wondered had anyone else taken a professional interest in these things. This gradually led to a desire to explore this as an area of practice, with the hope of eventually contributing towards practice improvement.

1.6 A multi-disciplinary problem

Early reading indicated that this was a topic which did not really sit within a single professional group (Kelly et al. 2010). I am a nurse by profession, with a particular interest in this field but this is certainly not wholly a nursing issue. Having relevance to pharmacy, geriatric medicine, general practitioners, nursing, social care, swallowing specialists from speech and language therapy, it is a truly multi-disciplinary problem. I inevitably viewed it through the lens of nursing, but made an effort to draw on knowledge from across these boundaries.

1.7 Reflexivity

A proactive approach to reflexivity has been adopted as integral to the conduct of a hermeneutic phenomenological study (Spence 2017). Reflexivity requires an awareness of my own contribution to the construction of meaning throughout the research process (Willig 2013). It involves recognising my role and my impact in any situation, considering how my values and experiences have shaped the research and its outcomes. A reflexive research journal was kept throughout the study, to maintain transparency in acknowledging such potential influences on the data (Biggerstaff and Thompson 2008). I was aware that my own pre-understandings, my background, experience and prejudices, will always bias my thinking (Smythe 2011). It was important that I was always mindful of my assumptions and how they may have influence throughout the study. I participated in a pre-understandings interview with one of my peers (Smythe 2011; Spence 2017), at an early stage of developing the research proposal. During this process, I was asked to consider aspects of my experience, my values and expectations of what I anticipated the findings of the research might be. I have continued to reflect on these initial assumptions as the study progressed, to ensure that I am not over-valuing my own pre-conceptions, and keeping the participants' voice to the fore.

1.8 Structure and organisation of the thesis

This thesis consists of eight chapters:

Chapter two will give background and contextual information for the study, introducing key concepts relevant to the administration of medication to residents of care homes for older people. Definition and explanation will be given of terminology which will be used throughout the study. The complex health needs of care home residents will be discussed, including difficulties with swallowing, and the concept of polypharmacy, the large amounts of medication which may be prescribed for them.

Chapter three reports the conduct of a systematic search of the literature using an integrated mixed methods approach. The findings from this literature search will be discussed, presented in the form of four themes. 1) The practice of altering medication by crushing or mixing with food to facilitate medication, 2) the prevalence of swallowing problems, 3) time pressures associated with care home routines, and 4) disempowering attitudes of staff. A clear gap in the knowledge relating to the direct experience of the residents will be identified. An update to this literature review undertaken in 2022 has been added, which supports the findings of the original review.

Chapter four describes the theoretical underpinning for this study. Justification will be given for the choice of a Gadamerian hermeneutic phenomenological methodology. An overview will be given of some of the philosophical concepts which will be used to guide the research process.

Chapter five will describe the methods by which the study was designed and conducted using a hermeneutic phenomenological approach. Procedures for recruitment will be discussed , and how ethical issues were addressed including capacity to consent were explored. An account will be given of the two methods of data collection, interview and observation. A framework will detail the process for data analysis using a hermeneutic approach. This chapter will close with the explicit declaration of my pre-understandings which may have influenced the findings which follow.

Chapter six presents an interpretive account of the findings from the study. It will introduce the eight participants who were care home residents between the ages of 84 and

95. The findings will be shown in the form of four themes, 1) ‘Being in control/relinquishing control’, 2) ‘Being comfortable in routine’, 3) ‘Trusting’, and 4) ‘Swallowing’. Extensive extracts from the interview data will be used, with vignettes constructed from some of the observation data, providing sufficient evidence from which a reader can also make their own interpretations.

Chapter seven discusses issues which emerged from the findings. The importance of individual routines, the nature of trusting relationships, and the concept of autonomy in the context of care home culture, will be explored. The imbalance of power for care home residents who are given medication to take emerged as an overarching concept. The discussion will draw on relevant research, reflecting back to earlier literature review, and linking the findings to currently accepted knowledge. The unique contribution of this study will be demonstrated.

Chapter eight is the concluding chapter, discussing the strengths and limitations of the study, and giving recommendations for practice and suggestions for future research. The final section closes the thesis with my personal reflections on the research journey.

Chapter 2: Background – Framing the Research

2.0 Introduction

This chapter will give background and contextual information for this study which explores the administration of medication for residents of care homes. Relevant concepts will be introduced, with explanation of key terms, beginning with defining the term 'care home' and going on to detail the complex health status of the care home population. An overview will be given of the problem of polypharmacy for care home residents, with a summary of current practice guidelines for reviewing medication. Difficulties with swallowing which residents of care homes experience, and particularly issues around the swallowing of medication will be discussed in this context. Finally, the term 'administration of medication' will be introduced, in relation to its use in a care home setting, leading to the identification of the defined topic of interest around which this study is designed.

2.1 Defining 'Care Homes'

This research is exploring a topic within the setting of care homes for older people. The term 'care home' will be used throughout to apply to both care homes with and without nursing provision, known as nursing and residential homes, respectively. A care home service is defined in Scotland as 'providing accommodation, together with nursing, personal care or personal support for persons by reason of their vulnerability or need' (Scottish Government 2010 Schedule 12 p.2). Within this broad definition, care homes throughout the United Kingdom are required to register with a regulatory body, and state which services they provide. There is considerable overlap in the clinical needs of the populations, regardless of the registration status of the homes (British Geriatric Society 2011, Gordon et al. 2013). In a wider context, there are very different models of care internationally, for example the largely state-funded and doctor-led Dutch model of nursing home medicine (Achterberg et al. 2015) is very different from the social care model which predominates in the United Kingdom. There is no consensus internationally about nomenclature for long-term care facilities (Burton et al. 2017), and there is evidence that even health professionals do not understand the different terminologies (Sanford et al. 2015). Despite differences in medical, nursing, or social care models globally, consensus has been expressed to work across boundaries to focus on improvements in evidence-based practice in care home settings (Gordon et al. 2022; Shepherd et al. 2017; Tolson et al. 2011).

2.2 Morbidity and mortality of residents of care homes for older people

Life expectancy for residents following admission to a care home is likely to be limited, with 80% of residents considered to be in their last year of life (Gold Standards Framework 2016; Highet et al. 2014; Liyanage et al. 2018). Estimates range from just over two years from admission to death (Reilev et al. 2019), with a third of residents dying within six months of admission (Gordon et al. 2013).

Multi-morbidity, the presence of two or more long term conditions, is present in more than 80% of people over 85 years (Barnett et al. 2012). Gordon et al.'s (2013) cohort study of care home residents in the UK identified that residents in both nursing and residential homes had profound levels of dependency, multi-morbidity and cognitive impairment. Stewart et al. (2014) also found a dementia diagnosis in 75% of care home residents, whilst 89% have been shown to have significant cognitive impairment even without a formal diagnosis of dementia (Lithgow et al. 2012). Communication difficulties are common, with speech disorders such as dysarthria and dysphasia being compounded by hearing and visual impairments (McCreedy et al. 2018; Nichols et al. 2015). A third of care home residents in a large European study, were found to have visual or hearing impairment, whilst another third had both hearing and visual impairment combined (Yamada et al. 2014). A recent review of longitudinal studies (Barker et al. 2021) found that the levels of disability and complexity of problems in care home residents have continued to increase significantly over the past 20 years.

This prevalence of multi-morbidity in older people, with the overlap of physical and mental health disorders, culminating in overall frailty, has led to changes in the focus and aims for treatment, aiming to reduce treatment burden and improve quality of life (Calderwood 2016; National Institute for Health and Care Excellence 2016; Yarnall et al. 2017). 'What matters most' became a key component of a framework for a holistic assessment of older people (Tinetti et al. 2017). However, as one of the consequences of attempts to manage multiple concurrent diseases and symptoms, the problem of polypharmacy has become prevalent.

2.3 Polypharmacy

Older people in care homes are often prescribed large quantities of medications, which may or may not be appropriate for their needs (Chen et al. 2019; Morin et al. 2016; Parsons et al. 2012). Early definitions of polypharmacy centred around the notion of ‘too many drugs’ (Aronson 2004). Definitions have been based on widely varying numerical counts of four, five, nine, ten or more items on prescription, or on numbers of different drug classes in use (Guthrie et al. 2015; Lenaghan et al. 2007; Tamura et al. 2012a). It is acknowledged that sometimes polypharmacy can be appropriate, as on occasions many drugs may be needed to manage complex multiple conditions and symptoms (Hughes et al. 2014; O’Mahoney et al. 2015).

The highest rates of polypharmacy are found in care home residents (Tamura et al. 2012a). The Care Homes Use of Medication Study (Barber et al. 2009) identified that a mean of eight medications per resident was prescribed. Guthrie et al.’s (2015) study of a 310,000 population in Tayside in Scotland found that one in four people over the age of 80 were prescribed 10 or more drugs over a three month period. The highest rates of polypharmacy in this study (over 10 drug classes per patient), were to be found in care home residents (Guthrie et al. 2015). Chen et al. (2019) identified that the most dependent and most frail residents of Australian care homes, had the most complex of medication regimens. More recently Lundby et al. (2020) report a median of 8 drug classes in use amongst a large cohort of 5179 Danish nursing home residents. Whilst the prevalence of polypharmacy in the United Kingdom is beginning to show signs of decline, global trends are increasing, with a steady increase in Asian regions (Lee et al. 2023).

The problems of inappropriate polypharmacy in older people may lead to increased risks of adverse drug reactions, interactions and detriment to quality of life (Barber et al. 2009; Duerden et al. 2013; Pirmohamed et al. 2004; Tamura et al. 2012b). When increasing frailty and polypharmacy are concurrent, medication-related harm which requires a healthcare intervention also increases (Stevenson et al. 2022). However, even when polypharmacy is deemed to be appropriate, it may present a burden to the individual. The time taken for, and difficulties with the administration of large quantities of medications can be burdensome particularly when the medicine round dominates the morning and potentially interferes with more pleasurable activities, including eating, drinking and social interaction (Barnes et al. 2006; Kelly et al. 2009).

2.4 Current guidelines for practice, reviewing and optimising medication

Guidelines for practice in the UK have been devised to help clinicians consider more carefully the risks and benefits of medicines, particularly when prescribing for the very old and frail. The emphasis is moving away from a focus on numbers, which considered polypharmacy as being inherently harmful, and instead working towards ‘Medicines Optimisation’ (Duerden et al. 2013; NICE 2015a), or Realistic Prescribing (Scottish Government 2018).

Medicines Optimisation is defined as ‘a person-centred approach to safe and effective medicines use, to ensure people obtain the best possible outcomes from their medicines’ (NICE 2015a p. 6). Whilst an element of optimising medication may include reducing the numbers of medicines prescribed, it also includes emphasis on shared decision making with patients. The term Realistic Prescribing is derived from the Realistic Medicine initiative (Scottish Government 2017), which aims to put the person receiving health and social care at the centre of decisions made about their care. In the United Kingdom, the Scottish Government Model of Care Polypharmacy Working Group (2018), the STOPP/START tool (O’Mahoney et al. 2015) and the King’s Fund (Duerden et al. 2013), alongside the internationally recognised Beers criteria (Beers et al. 1991, updated American Geriatric Society 2019) have been designed to help clinicians make risk and benefit decisions about prescribing for older people, and reduce over-prescribing.

However systematic reviews (Alldred et al. 2016; Almutairi et al. 2020; Forsetlund et al. 2011; Rankin et al. 2018) of multiple initiatives to improve appropriate medication use for older people found no evidence that clinical benefit resulted from any from these initiatives. Tools to support medication review predominantly take the form of lists of recommendations for clinicians and tend oversimplify the process (Welsh et al. 2020).

The most recent recommendations in the UK for reviewing and optimising medication use give only limited consideration to patient involvement, advising discussions with patients about compliance aids, dosing regimens and instructions (NICE 2015a; Kings Fund 2013; Scottish Government 2018). The Kings Fund (2013) proposes a pragmatic approach, and suggests focusing on patients who have evidence from clinical records of problems with medicine-taking, although it is not clear how such patients would be identified, or what the problems might be. The Scottish 7 step approach, described as a patient-centred medication review, does include at Step 7, the question “Is the patient able to take the medicines as intended?” (Scottish Government 2018, p. 13). The phrase ‘tablet burden’ is introduced but no guidance is given as to what this might mean, or how it might be assessed. Acknowledging that a clinician’s perspective dominates the guidance, patient centred approaches to managing polypharmacy have been proposed (Barnett et al. 2016, Reeve at al. 2014), but are thought to be time-consuming for those conducting such reviews and have yet to be implemented or evaluated (Welsh et al. 2020).

The Scottish Guidelines (Scottish Government 2018) advise the targeting of care homes for particular attention when considering rationalising medication. However, in McDerby et al.’s (2020) qualitative study, health professionals acknowledged that more time needs to be allocated for face-to-face reviewing of medication for residents of care homes, and that existing systems were not person-centred, and not meeting residents’ needs.

2.5 Swallowing difficulties in older people

The prevalence of dysphagia (swallowing difficulty) in care home residents has long been established. Steele et al. (1997) first identified that 68% of care home residents showed signs of swallowing difficulty at mealtimes, such as coughing, choking, drooling, spitting, evidence of oral residues, all of which merited formal assessment for dysphagia. Since then, estimates of the prevalence of dysphagia in care home residents vary from 40% (Easterling et al. 2008) up to as high as 65% (Jackson et al. 2008), and possibly higher in view of the silent nature of the problem (Nogueira and Rice 2013; Park et al. 2013; Pu et al. 2017). Swallowing difficulties in older people are multi-factorial, and may be associated with stroke, neurological conditions such as Parkinson’s disease, but also with dementia, and the sarcopenic dysphagia which is associated with frailty (Shiozu et al. 2015; Stegeman et al. 2012; Morley 2015). Overall functional dependence levels and dementia have been shown to be the most significant risk factors for swallowing difficulties in care home residents (Nogueira and Rice 2013; Park et al. 2013). In addition, conditions which cause dyspnoea (breathlessness), such as heart failure and chronic obstructive pulmonary disease, can contribute to a subjective dysphagia, and dry mouth conditions can be exacerbated by the side-effects of many drugs themselves (Chalmers and Pearson 2005; Stegeman et al. 2012).

Diagnosis of dysphagia by video-endoscopy is considered the gold-standard (Stegeman et al. 2012) although is not practical for routine use in primary care. In a care home context, simple signs such as coughing or voice changes after eating, drinking, or taking medication are sufficient to indicate that a resident may have swallowing difficulty and risk of aspiration (Santos et al. 2016; Hammond et al. 2009).

2.6 Swallowing medication

Older people have particular difficulties with swallowing solid oral medication, which may be related to size or surface texture (Kelly et al. 2010; Liu et al. 2016; Marquis et al. 2013; Shariff et al. 2020). Unsafe strategies such as tilting the head backwards to aid swallowing can increase the risks of aspiration of the medication into the lungs (Marquis et al. 2013). Schiele et al. (2013) and McGillicuddy et al. (2019) describe community-dwelling older people experiencing a wide variety of problems trying to swallow medication, and using multiple strategies, to ‘keep on till I got it down’(p.1430). There is risk of actual harm for patients who struggle to swallow medication effectively, including aspiration pneumonia and oesophageal and oral ulcerations (Morley 2015; Schiele et al. 2015). Tablets lodging in the mouth or throat with the potential for hazardous consequences were commonly reported amongst older people in a Dutch community (Notenboom et al. 2014). Chewing tablets is also common, leading to the potential for harmful effects in the same way as the hazards of crushing, including documented cases of death caused by chewing tablets which were not intended to be chewed (Logrippo et al. 2017). Liabeuf et al. (2014) also describes a series of cases of serious oral and pharyngeal ulceration caused by tablets remaining in the mouth.

Stegeman et al. (2012) concluded that a third of residents of long-term care facilities experienced serious difficulties with swallowing solid medication. The differing pathological origins of the problems for each individual resident necessitated careful individual assessment of each person’s needs. Schiele et al.’s (2015) small but in-depth video-endoscopic study of 52 patients provided compelling objective evidence of significant and hazardous ineffective swallow in patients where bedside testing and self-evaluation failed, with over 40% of patients demonstrating severe difficulties and 20% being left with tablets seen lodged in the pharynx after apparently successfully swallowing. Jani et al. (2022) found that almost half (47%) of solid medication given to care home residents was not able to be taken as intended, required breaking into pieces, or mixing with foods in some way. Awareness of difficulties with swallowing tablets, and with processes of modifying them to facilitate swallowing, varies amongst health professional groups, with General Practitioners being much less likely than nurses to be aware of these issues, or to ask patients if they have any such problems (Nguyen et al. (2014).

2.7 What is 'administration of medication'?

It has been established that residents of care homes for older people are likely to be taking a large number of medications (Chen et al. 2019; Lundby et al. 2020; Morin et al. 2016; Parsons et al. 2012), which may present difficulties with swallowing (Jani et al. 2022). Recommendations are in place for the review of the appropriateness of medication for individuals, both in terms of its action, and its formulation. For care home residents the process of administration of medication is an additional factor to consider. Guidelines for best practice start from the principle that residents of care homes should be presumed to be able to manage their own medication unless a risk assessment precludes this (NICE 2014). The proportion of residents able to self-administer medication in the care home population appears to be currently unrecorded in the literature, and enquiries with the Care Inspectorate and Care Quality Commission indicate that this data is not collected. However, anecdotally, and from my own clinical experience, most residents are reliant on care staff to help them with at least some of the practical aspects of taking their medication.

Where a resident of a care home is unable to take responsibility for managing their medication, care staff may be needed to ensure that the person is given the correct medication, at the correct time, in the correct way. This is defined as 'medicines administration', as is defined by the Care Inspectorate, the Royal Pharmaceutical Society Scotland and Social Work Scotland 2015:

Administration of medicines is one, all, or a combination of the care worker doing the following:

- Deciding which medicine(s) have to be taken and when this should be done
- Being responsible for selecting the medicines
- Giving a person medicines to swallow, where the person receiving them does not have the capacity to know what the medicine is for or identify it.
- Giving medicines where a degree of skill is required to be exercised by the care worker to ensure it is given in the correct way.

(Care Inspectorate, Royal Pharmaceutical Society Scotland, Social Work Scotland 2015)

The most recent guidance for practice, specifically focussing on administration of medication, centres on procedures and policies for storage and record-keeping, safety checks and risk assessments (Care Inspectorate 2012; Centre for Policy on Ageing 2011; NICE 2014; Royal Pharmaceutical Society/Royal College of Nursing 2019). The Care Inspectorate guidance (2012) does mention that medication may be ‘refused or spat out’ and that GPs should be informed about this. It also advocates ‘understanding a resident’s medicine taking behaviour’ as part of a formal medication review (Care Inspectorate 2012 p.14). There appears to be no guidance available which considers the detailed process of medication administration, how the tablets, capsules or liquids are actually given to, and swallowed by, individual residents.

2.8 Summary of the background

The context and guidance which informed this study has been explored and summarised. It has been identified that residents of care homes for older people are likely to be prescribed large quantities of medication, which may be difficult to swallow and potentially present hazards to them. They are likely to have complex multi-morbidities and be functionally dependent on care staff, who take responsibility for the practical process of administering this medication to them. Guidance for practice appears to lack consideration of the experience of the individual residents throughout these processes. A systematic search of the literature follows, seeking to establish what is already known about the experience of older people in care homes with these practical aspects of taking their medication.

Chapter 3: Literature Review - A Systematic Search for Evidence

3.0 Introduction

It has been identified in the previous chapter that residents of care homes for older people are more likely to be taking multiple medications and may have some difficulties with swallowing them. A search for evidence was designed, to establish what is known about the residents' experience of this process. In this chapter, the rationale for a systematic search of the literature will be given, using an integrated mixed methods approach. This was conducted in 2019 to provide evidence which informed the design of the subsequent research study.

The findings from this literature search will follow, with a discussion of the themes which emerged from a process of data extraction and thematic analysis. The pressure which staff felt to administer medication to care home residents pervaded the literature with the need to modify tablets and mix them with food. Swallowing problems were common. Care home routines were time-pressured, and there was evidence of disempowering language and attitudes from staff. Very little first-hand information from the residents has been reported, leading to the identification a clear gap in current knowledge, and providing a well-defined focus for a research question.

Finally, an updated search for evidence from 2020-2022 will be reported. This was conducted after the conduct of the data collection and analysis of the findings of my own research study. It confirms similar findings to the earlier literature review and provides current context for this study.

3.1 Rationale for the choice of an integrated mixed methods review approach.

The term 'systematic review' aligns with a positivist epistemology, and is strongly linked to the evidence-based movement in professional practice (Punch 2014). A systematic review aims to minimise bias and provide an audit trail of the researcher's decisions, procedures and conclusions (Tranfield et al. 2003). In contrast, approaches such as hermeneutic research acknowledge that the researcher will bring their own prejudices in selecting, refining and interpreting the literature, with few rules to be followed (Smythe and Spence 2012). Hermeneutic approaches may advocate a completely unstructured approach to a review, or even not looking at the literature until the end of a study (Smythe and Spence 2012). However, being systematic in a search of the literature, and incorporating some elements of systematic review practices in alternative approaches, can be seen as desirable (Bryman 2016). Conducting a thorough review demonstrates if there is a gap in the knowledge and that the proposed research is necessary (Dibley et al. 2020). Prior to conducting this review, I had made assumptions that very little work had been done in this field, but wished to undertake a rigorous search to establish if this was indeed the case. Whilst the initial idea for this study arose from my own personal motivations, I also wanted to establish without doubt that this work needed doing, not solely because I personally thought it was important.

Cerigo and Quesnel-Vallee (2020) use the term ‘systematic mixed studies review’ advocating the use of an integrated design for exploring a single, specific question. This concept of integrating qualitative and quantitative research was described by Sandelowski et al. (2006), beginning with a process of retrieving empirical qualitative, quantitative or mixed methods studies which address the same aspects of a target phenomenon. By including diverse forms of evidence from different types of research, this approach to a literature review aims to maximise the findings (Pearson et al. 2015), and provide a potentially more complete picture of the research landscape in a particular topic (Grant and Booth 2009).

3.2 A systematic search for evidence

3.2.1 Introduction

The introduction and background provided in the first two chapters of this thesis describes an initial stage of thinking which developed into one of problem identification. Ganong (1987) advocates that personal experience and clinical problems encountered will play a part in this conceptual stage of the research process. From these elements arose a clear focus and boundaries for the subsequent literature search. A systematic search of the literature was designed, seeking to establish what is known about the administration of medication for residents of care homes for older people with specific focus on the experience of the resident themselves. Identifying any research specifically considering this topic proved challenging.

3.2.2 Search Strategy

A modified PICOS format was used to structure the initial database searches. The PICOS acronym stands for Population, Intervention, Comparison, Outcome and Study design. It is a tool which assists in devising search terms and is endorsed by the Cochrane Collaboration (Centre for Reviews and Dissemination 2009). It was originally designed for use principally with quantitative studies. The Comparison (C) component which is typically not part of a qualitative research study becomes irrelevant (Cooke et al. 2012) and has therefore been omitted. Other tools have been trialled, specifically designed to support a systematic process to qualitative data synthesis. The SPIDER tool (Sample, Phenomenon of Interest, Design, Evaluation, Research Type (Cooke et al. 2012) was designed for qualitative and mixed methods research. Methley et al. (2014) compared PICOS and SPIDER for specificity and sensitivity and found PICOS to be more comprehensive in identifying key papers, although the numbers of articles identified was greater, necessitating more time-consuming sifting. It was anticipated that little work had been done previously in this field, so the aim of this search was to be as comprehensive as possible including both quantitative and qualitative studies. Therefore, a modified form of the PICOS strategy was used as illustrated in Table 1.

Table 1: Initial search terms with MeSH synonyms

Population	Intervention	Outcome	Study Design
Care homes Or Residential Care Or Nursing Homes Or Long term care	Drug administration Or Medication Administration Or Administration, oral	Patient attitudes Or Patient perceptions Or Patient experience Or Quality of life	Any

The process for sifting through potentially relevant studies is potentially subjective. In order to improve objectivity and transparency, inclusion and exclusion criteria were defined (Table 2). The inclusion criteria ensured that papers included in the review were empirical studies which focussed on practical aspects of medication administration for residents of care homes for older people, and were available to read in English.

Table 2: Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Primary research studies focussed on care homes for older people.	Studies in acute hospital settings, community dwelling individuals, or younger people. Papers which are not reporting primary research e.g. Systematic Reviews, Editorials, Protocols/Guidelines
Studies incorporating a focus on a practical aspect of the administration of medication.	Studies focussed wholly on record-keeping and electronic systems. Studies focussed wholly on prescribing issues/pharmacology/physiology.
Studies reported in English	Studies not available in English

3.2.3 Initial scoping searches

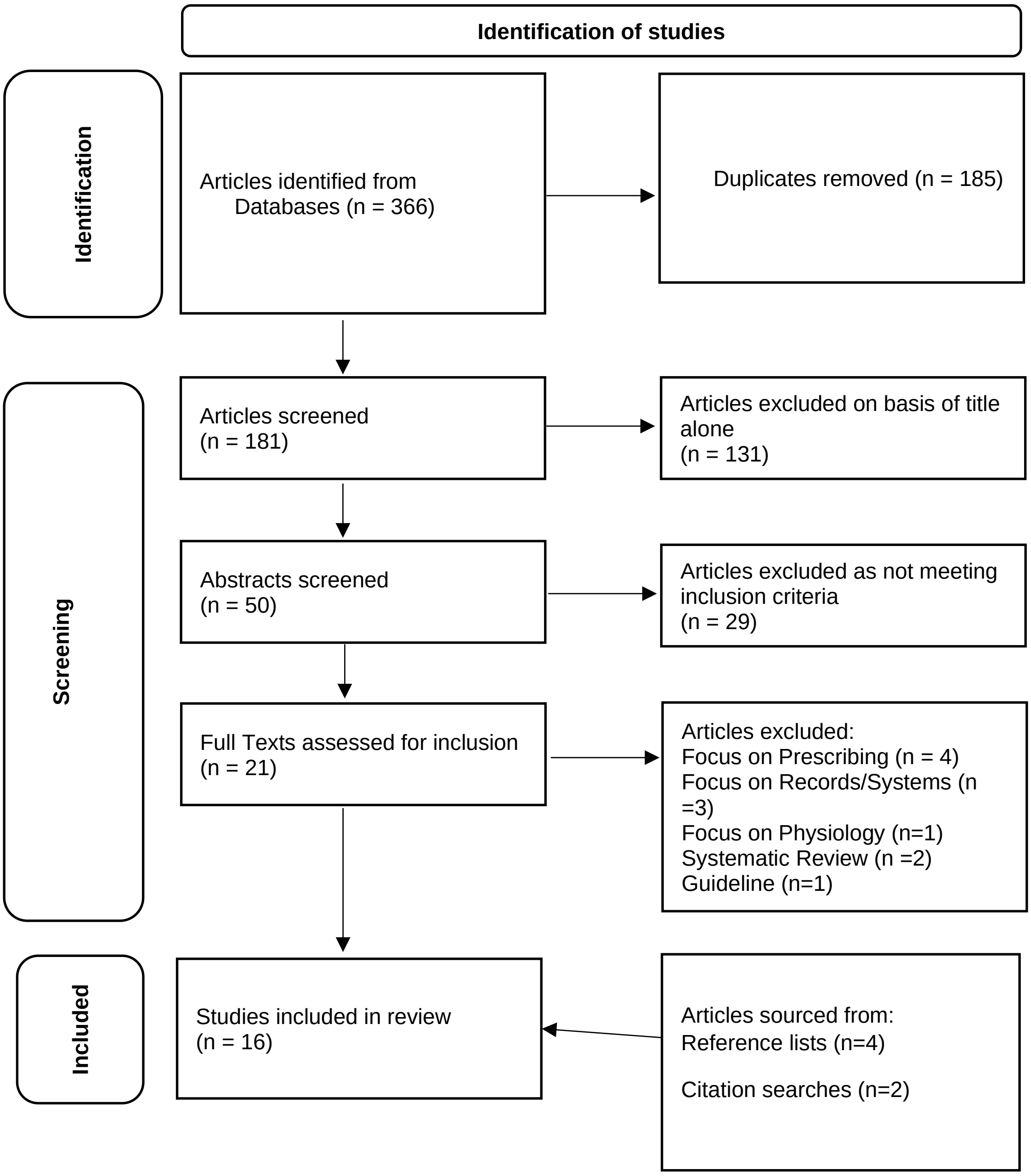
Initial searches were undertaken in 2019 of the databases CINAHL, MEDLINE, Health Source Nursing and SCOPUS. These databases were chosen as they include a comprehensive range of literature across multi-disciplinary health-related fields. Boolean operators were applied with keywords ‘care homes’ AND ‘medication administration’ AND ‘patient experience’ using MeSH synonyms throughout as in Table 1. MeSH (Medical Subject Headings) provides a hierarchical thesaurus of terms to aid effective searches for evidence. No date restriction was applied. These initial searches identified nothing. The MeSH headings were scrutinised, and appeared to be appropriately inclusive, particularly for the scope of terms used internationally to describe long-term care facilities for older people (Sanford et al. 2015). An experienced university librarian specialising in searching health databases was consulted, who confirmed that the search methodology was appropriate. The absence of literature identified at this stage is in itself of interest, as it demonstrates both the lack of published work directly relating to this topic within care home sector, and also the difficulty of identifying studies of care home research because of terminology variations (Burton et al. 2017). Being unable to find any primary research specifically focussed on the phenomenon of interest, there was a need to adopt a broader approach, seeking to explore any associated material which might shed light on the subject.

3.2.4 Refining Search Terms

A change was made to continue with the broad initial search terms of ‘Care Home’ AND ‘Medication Administration’, but excluding the terms related to ‘patient experience’. The same MeSH synonyms were used, and the same databases searched, identifying 366 papers, of which 181 remained after duplicates were removed. This was a manageable number to read through at the level of title. Many of the papers identified at this stage were studying areas such as innovations in systems and record-keeping which were clearly not directly relevant to the review question. Some were in the context of homes for younger people with learning disabilities, or children’s homes. These were excluded on the basis of titles alone.

50 abstracts were then screened, and 21 were then obtained as full-text articles. 11 of these were excluded as not reporting primary research, or having a focus outside the inclusion criteria. 10 pieces of primary research which met the inclusion criteria remained. Being a small number, it was possible to hand search the reference lists from these articles, and citation searches were also conducted from these key papers. This led to a further 6 papers being identified which met the inclusion criteria. Ultimately, 16 pieces of original research were identified which gave some insight into the experience of residents who, for whatever reason, needed help to take medication. A summary of the process which led to these 16 papers in provided in Figure 1. This was undertaken using the 2009 PRISMA flowchart (Moher et al. 2009), which was the version in use at that time.

Figure 1: PRISMA flowchart



3.2.5 Quality Assessment

The papers identified used a range of qualitative and quantitative designs. In keeping with an integrated review process, a generic framework for quality assessment was chosen which could be utilised across all the studies to appraise the research for validity and relevance of the results. Pluye et al. (2009) devised the Mixed Methods Appraisal Tool (MMAT) a minimal-criteria framework for appraising qualitative, quantitative and mixed methods studies specifically for mixed studies reviews. This appraisal tool, revised by Pace et al. (2012) and validated by Souto et al. (2015) was used to provide a structured approach to this process. The tool provided separate appraisal checklists for qualitative and quantitative studies of various designs. For mixed methods studies, three checklists were assessed, qualitative, quantitative and a mixed-methods set. Each of the criteria is rated on a yes/no scale, with items rated ‘yes’ contributing to an overall score, which is listed in the final column of Table 3. Whilst all the articles were scrutinised using this tool, none were excluded at this stage on the basis of low methodological quality, however the scores are reported for transparency (Hong et al. 2018). Given the small number of papers identified, it was considered possible that the worth of individual studies might only become recognisable at the point of synthesis, where valuable insights might be revealed (Heyvaert et al. 2017). Specific issues arising from scrutiny of individual studies will be discussed within the review findings below. A summary of the studies included in the review is given in Table 3.

Table 3: Summary of studies identified for review.

Authors (Year)	Country	Participants	Study Aim	Study Method	Analysis	Key findings (with relevance to resident experience)	Study quality
Paradiso et al. (2002)	Australia	586 residents in total from across 10 care homes for older people	Determining extent/methods of altering medication	Observation of Medicine Rounds (1207 occasions of medication administration)	Quantitative descriptive	High prevalence of medicines being altered (crushed and/or mixed with food) Medicines mixed together Vessels shared amongst residents without cleaning	100% 5/5
Wright (2002)	United Kingdom	540 nurses employed in care homes	To describe difficulties administering medication to patients with swallowing difficulties, and methods used to overcome these	Supervised questionnaire with closed questions	Quantitative descriptive	Difficulty swallowing tablets Spitting out medication Chewing tablets Mixing with food Crushing/altering	60% 3/5
Barnes et al. (2006)	Australia	11 nurses in total from across 10	To explore nursing practice of	Semi-structured interview	Qualitative descriptive	Nurses felt under pressure to administer medication to residents	100% 5/5

		care homes for older people	altering medication			who 'could not or would not' swallow tablets. Crushing/altering/mixing with food. Individual complex needs of residents. Time management: Competing demands during administration, multiple interruptions, time pressures of home routines	
Hughes and Goldie (2009)	United Kingdom	17 residents and 9 nurses in total from across 9 nursing homes for older people. 8 General Practitioners	To explore adherence to medication and resident involvement in prescribing and decision-making regarding medicines	Semi-structured interviews – residents and GPs Focus groups – Nurses	Qualitative descriptive	Themes of control – controlling of the processes by professionals, and controlling of the residents by nurses. Residents' acceptance of this control. Pressures of home routines.	100% 5/5
Stuijt et al. (2012)	Netherlands	290 residents in total from across	Evaluation of a safety programme for medicine	Before and after design with observation of	Quantitative analysis	Crushing medication Mixing with food	80% 4/5

		2 Nursing Homes	administration in dysphagia.	medicine rounds (629 occasions of medication administration)		Pressure of routines. Small improvements in rates of unsafe crushing practices after education, but not sustained at one year follow up.	
Mercovich et al. (2014)	Australia	160 residents in total across 2 care homes for older people. 6 nurses	To observe medicine modification, and assess staff knowledge	Observation of Medicine Rounds (160 occasions of medication administration) Staff - questionnaire	Mixed methods	Crushing Medication mixed together Mixing with food Vessel shared among residents and not cleaned. Staff not using available information resources.	45% 7/15
Santos et al. (2016)	United Kingdom	166 nursing home residents, from across 6 homes. 23% with swallowing difficulties.	To observe the administration of medicines to patients with swallowing difficulties	Observation of Medicine Rounds (738 occasions of medication administration)	Quantitative descriptive	Prevalence of dysphagia Chewing tablets Signs of aspiration	80% 4/5
Carvajal et al. (2016)	Spain	1875 residents in total across 10 nursing homes	To evaluate the effects of a pharmacist intervention to	Before and after interventional study. Observation of	Quantitative analysis	Prevalence of swallowing difficulty Crushing	80% 4/5

			improve practice	medicine rounds.		"Lack of co-operation by the patient" (with or without cognitive impairment)	
McGillicuddy et al. (2016)	Ireland	111 residents of a single Aged Care Facility	To investigate the appropriateness of oral drug modifications.	Retrospective study of medical records and drug charts.	Quantitative descriptive	Prevalence of swallowing difficulties Crushing/splitting tablets	100% 5/5
Qian et al. (2016)	Australia	7 nurses in 2 residential care units	To examine nursing time spent of administration of medication, and factors which influence this	Observation of medicine rounds	Quantitative descriptive	Pressures of time, High tablet burden, half of residents taking 6-10 tablets. Crushing	80% 4/5
Fodil et al. (2017)	France	155 patients with swallowing problems across 17 geriatric units (predominantly rehab/long term/palliative care)	To assess the prevalence and practice of crushing medication, and staffs' knowledge	Observation of Medicine Rounds	Quantitative descriptive	Prevalence of swallowing difficulties High rates of crushing/altering medication Mixing together Mixing with food.	80% 4/5

						Vessel shared among patients and not cleaned.	
McGillicuddy et al. (2017)	Ireland	18 nurses working with older people. 12 in long term care 6 in acute care. From 16 different care sites.	To investigate the knowledge, attitudes and beliefs of nurses about oral medicine modification for older adults	Semi-structured interview	Qualitative descriptive	Modifying tablets seen as a routine practice, ‘a necessary evil’ Crushing, mixing with food. Mixing all together. Prevalence of swallowing problems. Individual complexities. Pressures of time/home routines.	100% 5/5
Odberg et al. (2018)	Norway	54 staff across 2 nursing homes	To describe the medication administration process and its interruptions	Observation of medication rounds	Qualitative descriptive	Time pressures and interruptions Patients described in passive terms.	100% 5/5
Qian et al. (2018)	Australia	7 nurses in 2 residential care units for older people	To understand the medication administration process in aged care homes	Observation of medication rounds	Qualitative descriptive	Pressures of home routines. Multiple competing demands on staff/time pressure.	40% 2/5

						Crushing/mixing with food. Strategies for residents who refuse medication. Positive strategies for individual complexities/preferences	
Odberg et al. (2019)	Norway	16 staff across 2 nursing homes	To describe the nurses' role during medication administration	Participant observation and semi-structured interview	Qualitative descriptive	Pressures of time. Interruptions Disempowering language	100% 5/5
McDerby et al. (2019)	Australia	117 residents across 2 care homes for older people	To investigate the effect of a pharmacist on medication administration practices	Observation of medication rounds	Quantitative	Crushing/mixing with food Pressures of time	80% 4/5

3.3 Findings

3.3.1 Data extraction and analysis

The 16 studies used a variety of methods of data collection, nine were quantitative, five qualitative and one mixed-method. Grant and Booth (2009) acknowledged the challenges of synthesising both qualitative and quantitative research and that there is no consensus on the point at which these components should be integrated. Following Sandelowski et al.'s (2006) framework for conducting integrated reviews, the methodological differences between the studies were ultimately minimised, focussing solely on how the findings might address the same aspects of the target phenomenon. The quantitative data was translated into descriptive themes, and assimilated into the qualitative data, aiming to summarise what was already known about the topic. A thematic analysis process within a qualitative approach was selected as most appropriate for maintaining rigour when translating quantitative to qualitative statements (Pearson et al. 2015). Manual data extraction, coding and clustering of emerging concepts was performed using paper and pen, identifying four themes which recurred frequently in the literature. Only one of the studies (Hughes and Goldie 2009) used any material directly from interviews with residents. Given this lack of reporting of first-hand experience, data from the remaining studies was utilised, and interpreted as indirectly giving some insight into the possible experience of residents with the administration of their medication.

3.3.2 Study characteristics

The 16 studies had been conducted in a range of countries, six from Australia, three from the United Kingdom, two from the Republic of Ireland and Norway, and one from each of the Netherlands, France and Spain. It is possible that two of the Australian studies published by Qian et al. (2016/2018) may have arisen from the same research project, as the stated participant population would appear to be the same.

In seven of the studies, the participant population was recruited from care home staff. A further seven reported that their participant population were care home residents. The remaining two studies (Mercovich et al. 2014; Hughes and Goldie 2009), recruited a mixture of residents and those involved in their care. However, from the total of nine studies where the residents were stated to be the study participants, only one (Hughes and Goldie 2009) actually collected any data directly from the residents. The remaining eight were observing the practice of medication administration to the residents, focussing wholly on practice issues and were not gathering any data from the residents themselves. This focus on staff practice was the key issue for the majority of the studies (n=15) with Hughes and Goldie's (2009) exploration into issues of adherence and decision-making being the only exception.

Quantitative methodologies predominated, being used in 10 of the studies, seven of which were simply descriptively reporting practice-related factors in terms of incidence, prevalence or time taken, whereas three were reporting results of pharmacy-led practice-improvement projects. With the exception of Hughes and Goldie (2009), the qualitative studies focussed on data collection from staff, exploring their role, knowledge and practice in the process of medication administration. Generic qualitative designs were used for the qualitative studies, using terms such as thematic analysis, without any specific methodological framework.

11 of the studies used observation as the principal method of data collection. Between 150 and 1207 incidences of medication administration were observed in these studies, and over 3500 incidences reported in total. However, all of these studies used various forms of purposive or convenience sampling. Whilst this is commonly used in qualitative studies, its use in quantitative studies can be seen as limiting the reliability and validity of the findings (Ritchie and Lewis 2003). The use of observation as a tool in itself is described by some of the authors (Paradiso et al. 2002; Santos et al. 2016) as having potential for affecting the results, and therefore as a limitation, however Paradiso et al. (2002) considers this to strengthen their findings, theorising that practice is probably improved during known observation. Concern about validity of observational methods for studying medication rounds has been dispelled for similar reasons in other contexts. Dean and Barber's (2001) observation of medication rounds in a hospital setting demonstrated no difference in practice whether or not staff were aware of being directly observed. Consistent and recurring themes emerged across all the observational studies, supporting the strength of the evidence.

3.4 Thematic synthesis

3.4.1 The practice of altering medication/the pressure to administer.

This was very much a dominant theme throughout all the papers. The widespread practice of crushing and/or mixing medicines with foods, pervades through most of the studies (Barnes et al. 2006; Carvajal et al. 2016; Fodil et al. 2017; McDerby et al. 2019;

McGillicuddy et al. 2016; McGillicuddy et al. 2017; Mercovich et al. 2014; Paradiso et al. 2002; Qian et al. 2016; Qian et al. 2018; Santos et al. 2016; Stuijt et al. 2013, Wright 2002). Nine of these studies (Carvajal et al. 2016; Fodil et al. 2017; McDerby et al. 2019; Mercovich et al. 2014; Paradiso et al. 2002; Qian et al. 2016; Qian et al. 2018; Santos et al. 2016; Stuijt et al. 2012) used observation of medicine rounds, demonstrating staff modifying medication to facilitate administration, with up to 40% of medicines being altered in some way, most commonly by crushing. Whilst three of these studies were undertaken in the UK (Hughes and Goldie 2009; Santos et al. 2016; Wright 2002), research has also been undertaken in Australia (Barnes et al. 2006; McDerby et al. 2019; Mercovich et al. 2014; Paradiso et al. 2002; Qian et al. 2016; Qian et al. 2018), the Netherlands (Stuijt et al. 2013), Ireland (McGillicuddy et al. 2016 and 2017), Spain (Carvajal et al. 2016), and France (Fodil et al. 2017), with strikingly similar findings. Only the Norwegian studies (Odberg et al. 2018/2019) did not mention this practice.

Mixing medication with foods such as fruit puree, jam, milkshakes or yoghurt was a common finding in ten of the studies (Barnes et al. 2006; Fodil et al. 2017; McDerby et al. 2019; McGillicuddy et al. 2017; Mercovich et al. 2014; Paradiso et al. 2002; Qian et al. 2018; Santos et al. 2016; Stuijt et al. 2013, Wright 2002). On one occasion crushed medication were seen to be sprinkled onto toast (Mercovich et al. 2014). Fodil et al. (2017), noted 30 occasions where crushed tablets were mixed with liquid laxatives and all administered together. Ten of the studies (Fodil et al. 2017; McDerby et al. 2019; Mercovich et al. 2014; Paradiso et al. 2002; Santos et al. 2016; Stuijt et al. 2013; Wright 2002; Carvajal et al. 2016; McGillicuddy 2016; Qian et al. 2018) were principally reporting numerical counts of incidences where medication was crushed and/or mixed with food. Such incidences were seen by these authors as issues of poor practice and described in terms of errors or adverse events.

Three of the studies where staff were interviewed (Barnes et al. 2006; Hughes and Goldie 2009; McGillicuddy et al. 2017) go some way to explain why the practice of modification of medicines is so prevalent. All but one nurse of the 11 interviewed in Barnes et al.'s (2006) study described the need to ensure that prescribed medications were administered as the dominant imperative. The central issue presented by nurses was the pressure they felt under to find ways to get residents to take their medicines, no matter how difficult this might be. This was seen as an inevitable part of caring for older people, described as 'a necessary evil' (McGillicuddy et al. 2017 p.4).   Crushing, mixing, and using covert methods to administer medication was widely practised, sometimes despite nurses feeling that this conflicted with providing good care. Carvajal et al. (2016 p.517) reported, from questioning of staff, that the main reason for crushing tablets was ‘lack of co-operation from the patient’, followed by difficulty in swallowing. Individual residents sometimes requested their medication to be crushed, finding it easier to swallow them all at once than one by one (Barnes et al. 2006).

3.4.2 The prevalence of swallowing problems

Three of the studies identified in the literature review had been specifically designed to examine the relationship between dysphagia and oral medication (Stuijt et al. 2013; Santos et al. 2016; Wright 2002). Given this close association therefore, the prevalence of swallowing difficulties was a core part of their findings. However, in much of the work (Barnes et al. 2006; Carvajal et al. 2016; Fodil et al. 2017; McGillicuddy et al. 2017; Mercovich et al. 2014; Paradiso et al. 2002), medication was being altered for varied reasons including ease of administration. Clinical dysphagia was not the primary focus for the researchers, but was frequently identified and discussed within the context of administering medication.

Incidences of chewing, pouching, pooling, along with deliberate rejection and spitting out of tablets, have all been included in the literature as ‘swallowing problems’. Wright (2002) collected data from 540 nursing home nurses, 100% of whom reported providing care for residents who had difficulty swallowing tablets or capsules. 90% of staff also described caring for residents who always chewed their tablets before swallowing. Santos et al. (2016) also observed so many incidences of residents chewing tablets, that this was added to the classification of errors witnessed in their study, having not originally been anticipated. Signs of aspiration or chewing may not be immediately obvious, and it was recommended that careful observation may be needed to identify these difficulties (Santos et al. 2016). In Barnes et al.’s (2006) qualitative study, staff described residents ‘pocketing’ tablets under the tongue, spitting them out, and the worry that staff had about the potential for choking. It is important to note here that the work by Wright (2002) and Santos et al. (2016) was funded by Rosemont Pharmaceuticals – the principal manufacturer of liquid medicines in the UK, which could be interpreted as having potential to introduce bias. Nevertheless, as their findings were similar to other international studies, they have been included as part of the best available evidence.

McGillicuddy et al. (2017) interviewed nursing staff who reported residents' fluctuating ability to swallow tablets, necessitating frequent reassessment of their needs. At different times of day an individual's ability to swallow could vary, and sometimes a change in mood seemed to precipitate difficulty swallowing a particular medication (Barnes et al. 2006). Highly individual differences in ability to manage specific tablet shapes and vehicle textures were identified (Barnes et al. 2006, McGillicuddy et al. 2017), and individual physical and behavioural characteristics of patients necessitated personalised planning to facilitate successful administration. The qualitative data added information about patient preferences and choices, with Barnes et al. (2006), reporting incidences of patients who requested tablets be crushed or mixed with food, as they found it easier to manage, or had become accustomed to the method and specifically wished to continue. Nurses caring for residents in long term care felt that they knew their residents so well, knowing each individual and their differing complex needs. Subtle changes in ability to swallow were recognised, and procedures adapted, sometimes on a day-to-day basis (Barnes et al. 2006; McGillicuddy et al. 2017; Qian et al. 2018)

3.4.3 The routines of living in a care home.

The routines of care home living were evidenced in two distinct but related elements. The first can be identified as factors associated with pressures of time, whilst the second is a specific feature involving the use of common equipment, shared amongst multiple residents.

3.4.3.1 Factors associated with pressures of time.

Five of the papers discuss the effects on the residents of having to fit in with home routines, the inevitable 'medicalisation' of the home environment to accommodate the need for supervised administration of medication (Barnes et al. 2006; Hughes and Goldie 2009; McGillicuddy et al. 2018; Qian et al. 2018; Stuijt et al. 2013). Yet this was also seen as a positive factor by General Practitioners in Hughes and Goldie's (2009) study, because it meant that residents were seen to be getting their medication as prescribed, which is often not the case in a domestic setting (Haynes et al. 2008).

Pressure of time was a recurring feature internationally, being mentioned in studies from Australia (Barnes et al. 2006; Qian et al. 2016/2018), the UK (Hughes and Goldie 2009), the Netherlands (Stuijt et al. 2012), Norway (Odberg et al. 2018) and Ireland (McGillicuddy et al. 2017). Qian et al. (2016) found that the average time spent to administer medication to a resident was just 200 seconds. This included preparing and bringing the medication to the resident, chatting with them and returning to the trolley. One of the quality improvement outcomes from McDerby et al.'s (2019) study was to reduce staff time on medication administration from 4.8 minutes to 3.2 minutes per resident, by implementing administrative time-saving measures. Staff in Odberg et al.'s (2019) study felt under considerable pressure, 'we have more tasks and demands than ever' (p.387). They reported having to prioritise medication to the patients who needed it most when very busy, and that medication sometimes had to be postponed or interrupted. They also sometimes had to delegate administration of medication to staff who were not familiar with the patients.

Yet nurses also described using the medication round as an opportunity to be 'with' each resident, 'It's more than a medication round for me, it's an everything round' (Barnes et al. 2006 p.194). A further respondent in Qian et al.'s (2018) study of the processes of medication administration, mentioned that it was important at least not to appear to be worried about time, because of negative effects on the resident, even to the point of their refusing medication.

Continuing this theme, the observational studies from Paradiso et al. in 2002 through to Qian et al. in 2018 reported multiple interruptions during medication rounds, with nurses answering telephones and directing care activities. In one home, the nurse administering medication was obliged to carry a mobile phone to answer calls (Odberg et al. 2018). Stuijt et al. (2013), ascribed difficulties encountered in involving nursing staff in an improvement project, to high workload and lack of time. Time restraints led to staff ignoring some of the planned improvements to the individualisation of the medication administration process for specific residents' needs. From the qualitative data, a nurse reported her concern that the time she took to administer everything individually to a particular patient would be affecting other patients as well, 'time is everything' (McGillicuddy et al. 2017 p.5). Interviews with staff by Barnes et al. (2006) reiterate this aspect, where the need to complete the medication round in a timely manner also affected nurses' ability to attend to the individual requirements of the residents, compounded by the fact that medication administration is often scheduled simultaneously with the provision of meals. These findings appear to have a direct link with a second element of care home routines described below.

3.4.3.2 The use of common equipment

Observational studies from Australia and France reported that mixing all the medication together in one vessel and/or vehicle was a common practice, from 61% of medicines mixed together (Paradiso et al. 2002) to 86% (Fodil et al. 2017). Mercovich et al. (2014) observed administration of crushed medication for 29 residents, noting that in all instances, the equipment was shared amongst residents without cleaning. Similar practices were observed by Fodil et al. (2017) and Paradiso et al. (2002), with a shared vessel being used between patients in 86% of incidences. Staff were observed in 56% of incidences to be going from one resident to another with the same mixing vessel without cleaning it out (Paradiso et al. 2002). This is interpreted by the authors of these studies as an issue of poor practice, with potential risks of cross-contamination between residents.

Paradiso et al. (2002), and Qian et al. (2018) also witnessed a tendency for staff to be preparing medication for more than one resident at the same time, or preparing medication for a second resident, whilst trying to supervise a first with administration. Whilst the studies where staff were interviewed (Barnes et al. 2006; Hughes and Goldie 2009; McGillicuddy et al. 2017; Odberg et al. 2019) did not report any direct information about these practices, their findings about nurses struggling with time management would support the observational data.

In summary therefore, it appears the routines of care home life may be resulting in a time-pressured environment around administering medication for individual residents. Use of shared equipment without cleaning between residents may be a consequence of this, and could be seen as a depersonalising feature. Residents have no control over these factors. There is also a loss of control evidenced by the language used, which will be discussed in more detail in the final theme.

3.4.4 Disempowerment of residents

Some disempowering language emerges throughout the review literature, in describing strategies used when residents refuse medication, with repeated attempts being made to ‘persuade’ (Barnes et al. 2006). Some of this is evidenced in direct quotes from staff, but is also present in the procedural aspects which were observed by researchers. Qian et al. (2018 p.4) in their Australian study of the processes of medication administration, described detailed procedures for staff to attempt administration to a resident who refuses medication. Written in terms of ‘Rules’ for practice, the necessary steps of trying and re-trying were listed. If 'resistance remains', another member of staff was to try, with further steps to be taken if 'meeting with consistent refusal'. Sometimes staff did not explain anything at all about what they were doing or why, when giving medication to a resident (Qian et al. 2018).

Some of the language used by the authors themselves also places residents in completely passive roles, for example Qian et al. (2018 p.9) also used the term 'medicating the residents', whereas from Norway, Odberg et al. (2018) described the staff as 'overseeing the residents ingesting administered drugs' (p.1117). One of the nurses in Odberg et al.'s (2019) study reported how they 'distribute the patients among themselves' (p.388). The study from Spain by Carvajal et al. (2016 p.517) described 'lack of co-operation' by residents, which was given as a main reason for the staff crushing tablets. This links back to the dominant imperative identified by Barnes et al. (2006 p.193), to 'make sure they get their medications' no matter what is needed to achieve this. The 'strategies to persuade' which are described by Qian et al. (2018 p.6), were also self-reported by nurses in Barnes et al.'s (2006 p.195) study. 'When they won't take more tablets or another spoonful, they'll say, *'That's it, I'm not taking any more',* I suppose you could go back later'. McGillicuddy et al. (2017 p.6) records a nurse in Ireland describing residents to colleagues in terms of their medication formulation, such as, 'this person is liquid', and 'this person is suspension'. One of Barnes et al.'s (2006 p.195) Australian respondents described residents in term of, 'the odd dementia who hates taking tablets'.

Findings from Hughes and Goldie's (2009 p.510) qualitative study in the United Kingdom reiterated the use of language by care-givers which placed the residents in passive roles, with descriptions such as 'most of our residents are very compliant'. Assumptions were made that they do not want to take any responsibility for any decision-making about their medicines (Hughes and Goldie 2009). A General Practitioner in Hughes and Goldie's study stated, 'They don't have much choice…. They just take their tablets and say nothing' (p. 512). All of the residents interviewed by Hughes and Goldie (2009 p.512), were perceived to accept their loss of control seemingly without question, 'I just take what I'm given' and 'I do as I'm told'. For one resident this was considered to be a positive factor, accepting the medication happily, feeling confident that the staff know what they are doing. This identification of residents as passive in the process was supported from another aspect by McGillicuddy et al. (2017), who explored administration of medication from the staffs' perception. They found that nurses saw themselves strongly as advocates for their residents, which was seen as intrinsic to their professional responsibly, ‘None of them can speak for themselves, so you have to have somebody that knows them to be able to’(McGillicuddy et al. 2017 p.6).

3.5 Discussion

Research from some diverse locations has been identified, and as was initially speculated, the research teams represented a range of professional disciplines, dominated by pharmacy and nursing, but with some input from medical practitioners. The field of social care, which provides the majority of care home facilities in the United Kingdom, appears to be entirely absent from this body of research. Reasons for this are unknown, but may be linked with the wider under-representation of care homes in research (Johnstone and Donaldson 2018).

The findings of this review have confirmed that care home residents may have difficulty with swallowing medication, an issue that is already known (Jani et al. 2022). Whilst Barnes et al. (2006) had first reported the feeling of pressure that staff were under to administer medication, this review has shown that this imperative had pervaded through much of the literature in this field. Covert administration, where medication is concealed within foodstuffs or drinks, is common practice. What the findings showed about depersonalising practices within care home routines and disempowering language around the administration of medication has not been previously demonstrated. This section will explore these issues in more depth and will conclude with reflecting on the limitations of adopting an interpretive approach to exploring evidence, in the absence of first-hand experience of the residents.

3.5.1 Problems associated with altering and/or covertly administering medication.

This review of the literature has shown that the practice of altering medication by crushing or mixing with food is a widespread and frequent practice in care homes for older people. Crushing or otherwise altering the original form of a drug is potentially a risk for residents. The structure of tablets and capsules is increasingly complex, being designed to control the rate of drug release, the stability of the drug, and the site of its release within the body (McGillicuddy et al. 2016). Crushing can alter the rate of absorption of the drug, with the potential to cause over- or under-dosing (Schiele et al. 2013). In addition, substances that irritate the mucus membranes of the gastro-intestinal tract can be released by crushing (Fodil et.al 2017). In light of these known problems, it is recommended (Fodil et al. 2017) that prescribers consider liquid forms of medications if needed, but also to consider carefully whether each drug is absolutely necessary for some residents, or may be safely stopped, following guidance such as the STOPP/START criteria (O'Mahoney et al. 2015).

The crushing of medication and/or mixing with foods may be acceptable practice if it is agreed to by the prescriber and pharmacist and is consented to by the resident or their proxy if they lack the capacity to consent (Guidry-Grimes et al. 2021). As found by Barnes et al. (2006), some residents may actively choose these methods as being easier for them. However, on other occasions, crushed medications were being administered covertly to residents. Covert administration occurs when a resident is unable or unwilling to take medication, and staff devise ways to administer the medication despite the refusal (Garratt et al. 2021). Covert administration may on occasions be authorised, and guidance for best practice (NICE 2015b) advises that this should only happen following a 'best interests meeting'. This should involve relevant professionals and the resident's appointed advocate, and lead to the formulation of an individualised management plan. Without this authorisation, covert administration of medication raises ethical and safety issues (Garratt et al. 2021).

Informed consent to any treatment, including medication administration, is typically a legal requirement in Western nations (Munden 2017), and a fundamental element of autonomy in the context of health care (Tuckett 2006). However, healthcare staff may see covert medication to be the kindest and most humane option of administration to frail individuals who they perceive may otherwise become more unwell, or even require administration of medication by force (Guidry-Grimes et al. 2021). As staff in McGillicuddy et al.'s (2017) study describe it, as a necessary evil, knowing that they were in a conflicting moral position. Guidry-Grimes et al. (2021) raise an additional level of concern about the use of food to deliberately disguise medication, which was such common practice in the findings of this literature review. They considered that the significance of food as pleasurable, comforting, and as an opportunity to make free choice, along with the trusting relationship between the person being fed and the one who feeds, is significantly undermined by this practice.

3.5.2 Depersonalising practices as a consequence of workload

The widespread use of communal mixing vessels, shared amongst all the residents in a home, was reported by authors of the studies in this review as poor clinical practice. It could also be interpreted as an act of depersonalisation, as in a failure to treat a person as an individual. This culture of depersonalisation has been described in the wider context of institutionalized care for older people (Holman et al. 2004). However, as the individual resident may be unaware of these practices, they could be seen as unimportant in relation to their own experience. It could also be speculated that practices such as the sharing of mixing vessels and the need to mix medication for one resident whilst attending to another comes as a consequence of the time pressures which the staff described. Thomson et al. (2009) found that one third of nursing time in long term care facilities was occupied with medication administration, and that time required for the medication administration increased with the degree of dependency of the residents. The workload burden of nurses in care homes has been shown to create feelings of conflict, with an expectation of assignment of medication administration to untrained staff in order to be able to manage the daily work (Craftman et al. 2016). The effect of this pressure of time on the residents themselves, and how they experience the process, remains unknown.

3.5.3 Disempowering language and practice

Disempowering language was used by both staff and researchers. This is unsurprising given that the prevalence of ageist language is embedded in research literature (Bowman and Lim 2021), and in the way which professionals communicate with residents of care homes (Shaw and Gordon 2021). The stereotypical image of older people, especially residents of care homes, as frail and vulnerable, can lead to a tendency for professionals to infantilize or patronize the older person (Hughes 2008). However, the evidence identified in this review does not give any insight as to whether the residents experience includes any awareness of this disempowering language, or whether it was detrimental to them in any way.

The assumption that none of the residents can speak for themselves (McGillicuddy et al. 2017) is in contrast to the law in Scotland (Adults with Incapacity Act 2000), which has at its core the principle to encourage individuals to exercise residual capacity even if they are cognitively impaired. This places a responsibility on professionals to make efforts to enable a person to exercise self-determination wherever possible. Many of the direct quotations which staff used to describe residents appear disempowering or demeaning to a reader. However, the staff saw themselves as well-meaning, in a positive role here as care-providers, strongly as advocating for ‘their’ residents’ individual needs.

The supervised administration of medication is a ‘medicalizing’ aspect of what is meant to function as a home, leading to a loss of control and powerlessness of the care home residents in respect of their medication (Hughes 2008). This has been defined as ‘enforced compliance’, where residents cannot opt out of the process even if they wish (Hughes 2008). Such residents as being unable to exercise ‘intelligent non-compliance’, which they may be able to practice when in their own homes if for example, they felt they were experiencing adverse effects from a medication (Hughes 2008, p. 448). The findings from this review in relation to disempowering language would support Hughes’ conclusion that residents lack control over the process of being given their medication.

3.5.4 The reliance on an interpretive approach to reviewing the evidence.

Only one of the studies identified in this review (Hughes and Goldie 2009) included any direct reporting of the residents’ voice. The other studies, principally focussing on staff activity and experience, were interpreted by me as possibly providing some insight into the resident experience from a third-party perspective. I initially termed these ‘proxy measures’, but on reflection, came to learn that this notion of interpreting and questioning whilst engaging with the literature, is fundamental to a hermeneutic approach to literature review, the key purpose of which is to provoke thinking (Smyth and Spence 2012). I have inevitably interpreted the literature from a perspective which already has a relationship with the field of study (Austgard 2012). There is currently no way of knowing how some of the key issues identified in the literature directly affect the residents. For example, the overarching theme throughout the literature reviewed was the pressure which the staff felt to administer medication, with all the practices that followed on from this imperative, however, how the residents experience this can only be speculated.

3.6 Limitations to the literature review

The process of searching for evidence had its limitations. There is the possibility of omissions, particularly given the known difficulties with terminology relating to care homes (Burton et al. 2017). Although as much care as possible was taken, relevant studies may have been overlooked. The decision to only include studies which were available in English may also have influenced the findings, which were limited to European countries and Australia. This may result in a cultural bias and could limit the generalisation of the findings across the different models of care globally.

The analysis of the evidence and considering its relevance to the review topic as a lone researcher has potential for bias. In the context of a hermeneutical study, my place in the interpretation is made explicit, and it is clear that I brought my experience to the process and to the development of a research question (Dibley et al. 2020). However, the conduct of the review has been reported as fully as possible for transparency.

3.7 Overview of literature to 2019

When analysed and synthesised, this evidence-base provided justification to support the subsequent identification of the gap in the knowledge. Accepting that overall, the number of studies contributing to the evidence is small, it can be speculated that the themes identified could be shared across the wider population of residents of care homes for older people. Considering these findings in terms of the view of the resident, however, there remained very little insight into how the identified themes may be experienced.

The evidence has indicated that there is widespread altering of solid medication forms to facilitate administration of medicines to older people in care homes. This population has a high prevalence and diverse range of swallowing problems, which are not always easily identified. The routines of institutional life can result in time-pressures and depersonalisation of the medication administration process. Residents are portrayed as disempowered and are seen as playing a passive part in the activity.

3.8 The gap in the knowledge

The literature identified prior to the conduct of my research contained predominantly exploratory, prevalence-type studies and studies focussed on the ergonomics of the medication administration process. A striking gap in knowledge was identified through this review, in the paucity of information from the residents' perspective. Given this dearth of evidence, there is demonstrated a clear need to explore more directly the experience of older people in care homes, in relation to the administration of their medication. This provided an impetus to consider redressing the balance by designing a study which concentrated wholly on the residents themselves with the aim of answering the question:

What is the experience of residents of care homes when oral medication is administered?

3.9 Updating the literature 2022

The review which has been described in the preceding sections was conducted in 2019, and was based on an earlier review dating back to 2018 which had underpinned the earliest proposal for this research study. Being aware of the need to consider the relevance of my own work in relation to developments in the field (Ridley 2012), the search for evidence was updated in September 2022. The process detailed earlier in this chapter was replicated, using identical search strategy and quality appraisal and thematic analysis steps as described above, but restricting the date criteria to papers published between 2020 and 2022. This was completed after the findings of my own study had been analysed, to be able to situate my study in the current field of knowledge.

The PRISMA diagram in Figure 2 summarises the study selection process, providing further evidence of the limitations of database searching to identify studies in this field (Burton et al. 2017). Only three new studies were identified from database searches, but an additional five were sourced by citation searches and screening reference lists.

3.10 Findings

3.10.1 Study characteristics

Table 4 summarises the 8 new papers which were identified from this updated search. As in the earlier review, Australasian studies dominated, with five new studies having been published, however it is possible that the three Australian studies by Forough et al. (2020a, 2020b, and 2021) may have part of a larger research project. This was not made explicit, but Forough et al. (2021) stated that their study was part of a project with an overall aim to design an intervention program to improve medication administration to residents with swallowing difficulties. The remaining three studies originated in Norway, and again, although not explicit, may have been part of overarching studies. Two were published by the same team (Solberg et al. 2020 and 2021), and one (Odberg et al. 2020), was the third in a series from a Norwegian team whose papers had featured in the earlier review (Odberg et al. 2018, 2019), however they appeared to focus of different groups of participants, so have been included as separate studies.

Similarly to the findings to the initial review, seven of the eight papers recruited staff as their sole study population, with the exception being Garratt et al. (2021) who also included some residents in addition to staff as participants in a study of covert administration practices. All of the studies focussed on the work of the staff in relation to administration of medication, with Forough et al. specifically investigation administration to residents with swallowing difficulties, and Garret et al. (2021) having a focus on the covert administration of medication. Observation of medication rounds was used for data collection in four of the studies (Odberg et al. 2020; Forough et al. 2020a; Chen et al. 2021 and Solberg et al. 2021), with the others using interview, focus groups or survey methods. Two of the studies (Odberg et al. 2020 and Chen et al. 2021) adopted an ergonomics approach to exploring the medication administration process, an approach which focusses on the study of safety and efficiency in the working environment (Werner et al. 2021). This approach had also been used in three of the later studies in the initial review (Qian et al. 2016/2018; Odberg et al. 2018). Reasons for this focus in a total of five of the studies since 2016 can only be speculated, although Chen et al.'s (2021) time and motion study was designed specifically with the aim of identifying time-saving efficiencies.

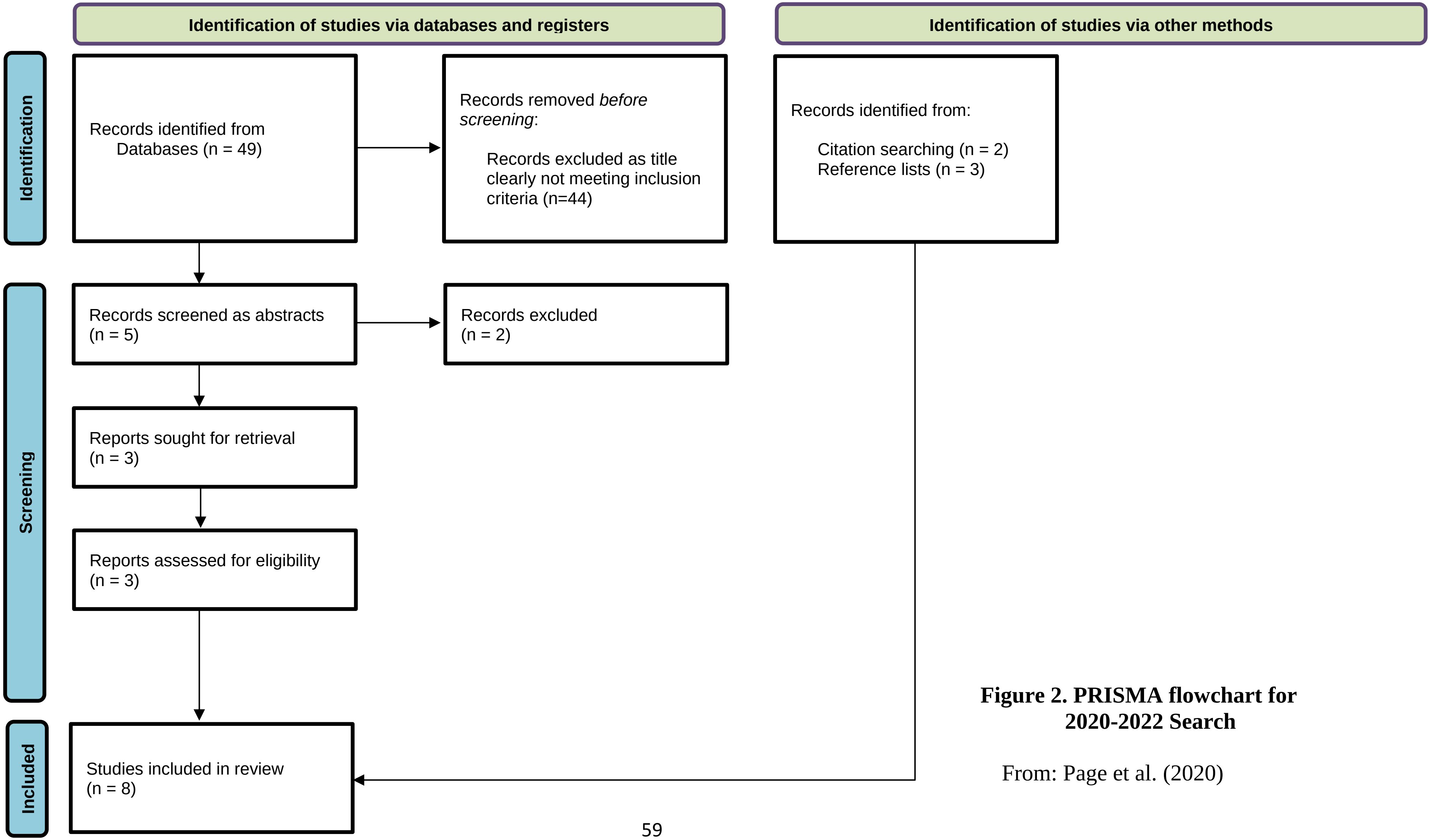


Figure 2. PRISMA flowchart for 2020-2022 Search

From: Page et al. (2020)

Table 4: Summary of studies identified in updated search 2020-2022

Authors (Year)	Country	Participants	Study Aim	Study Method	Analysis	Key findings (with relevance to resident experience)	Study quality
Odberg et al. (2020)	Norway	9 staff members from one nursing home	To explore the interaction of stakeholders and systems in the medication administration process	Observation and Interview	Qualitative descriptive	High staff workload. Patients described in passive terms, disempowering language.	60% 3/5
Forough et al. (2020a)	Australia	12 healthcare workers across 4 aged care facilities	To identify the incidence, methods and appropriateness of oral drug modification practices	Video-recorded observation	Quantitative descriptive	Crushing/mixing tablets together/mixing in food. Mixing whole tablets in food. Communal crushing devices shared between residents.	80% 4/5
Forough et al. (2020b)	Australia	17 healthcare workers across 3 aged care facilities	To explore factors affecting workers in the practice of	Interview	Qualitative descriptive	Time pressures. Delegation to less skilled staff.	100% 5/5

			medication administration to residents with swallowing difficulties			Crushing/Mixing with food. Residents' individual needs. Pressure to administer	
Chen et al. (2021)	Australia	30 nurses across 14 aged care facilities	To investigate the time taken for medication administration	Observation of medicine rounds	Quantitative descriptive	Competing time demands Crushing Swallowing difficulties.	80% 4/5
Garratt et al. (2021)	New Zealand	20 staff and 12 residents across 3 care homes.	To explore the experiences and perceptions of staff and residents about unauthorised covert medication administration	Focus Groups and interviews	Qualitative descriptive	The pressure to administer. Crushing/mixing with food. Residents wanting to be involved in decision-making, and respected. Building a trusting relationship.	100% 5/5
Forough et al. (2021)	Australia	355 health care workers from	To understand the barriers and facilitators of	On-line survey	Mixed methods	Swallowing difficulties Modifying medication	60% 9/15

		aged care facilities	medication administration to residents with swallowing difficulties	Closed and open questions		Mixing in food Time constraints	
Solberg et al. (2021)	Norway	31 Nurses and 8 auxiliary nurses in 8 nursing homes	To describe the occurrence, methods and causes of nurses' drug modification in nursing homes	Observation of medicine administration	Quantitative descriptive	Modifying medication, more common in cognitive impairment. Crushing/mixing with food Mixing drugs together Swallowing difficulties	80% 4/5
Solberg et al. (2022)	Norway	11 nurses across 3 nursing homes	To explore nurses' experience of dispensing drugs to older people in nursing homes	Focus Group interviews	Qualitative descriptive	Adapting busy home routines for individual resident needs. Making 'exceptions to the rule' Swallowing difficulties. Time pressures.	100% 5/5

3.11 Thematic Synthesis

This updated review was conducted after the data analysis from my own study. At that stage I was inevitably considering this literature both in light of the earlier literature review, and of my own research findings. This is integral to a hermeneutic approach as I continue to bring my past and experience to reading the literature (Smythe and Spence 2012). I made efforts to be open-minded for any new insights, however, the themes which had been identified from the earlier literature review were essentially reinforced. New material supporting these themes will be briefly summarised here with reference to their relationship with the earlier findings.

3.11.1 Altering medication/the pressure to administer.

Forough et al. (2020a, 2020b, 2021) and Solberg et al. (2021) explored issues around modification of medication and swallowing difficulties. Findings from earlier studies were confirmed, with widespread crushing of medications and mixing with foods. There were some potentially hazardous practices observed including giving dry crushed pills on a spoon and dropping whole pills into food for residents with swallowing difficulties. Medication was modified because of behavioural difficulties (Forough et al. 2021), cognitive impairment or ‘lack of understanding’ (Solberg et al. 2021 p353), but sometimes for the residents’ own wishes (Solberg et al. 2021). Solberg et al. (2022) were looking more broadly at the medication administration process, but also observed the combining of giving medication with meals, crushing tablets with jam and swallowing difficulties, whilst Chen et al. (2021) also observed crushing of tablets.

In keeping with the dominant theme of earlier studies, the pressure which the staff felt to administer medication was evident. Forough et al. (2020b) described repeated attempts to administer to residents with swallowing difficulties, with staff describing how they keep on trying, and use different strategies at different times. Staff felt they ‘had to persist’ even though they felt they may be infringing the resident’s rights (Garratt et al. 2021 p.6), whereas residents in the same study were concerned about staff making repeated attempts to residents who refused medication.

3.11.2 Swallowing Difficulties

Similarly to earlier studies, swallowing difficulties were common. Swallowing difficulties were the focus of study for Forough et al. (2020b; 2021), but were also a feature of Chen et al. (2021) and Solberg et al. (2021; 2022), as an underlying reason for modification of medication. Staff felt that residents sometimes rejected medication because of change in taste or texture (Forough et al. 2020b), and, like earlier findings by Barnes et al. (2006), assisting with individual needs such as small changes in position of the resident, or giving one pill at a time were found to help (Forough et al. 2021).

3.11.3 Care home routines – Time pressures

Like the earlier studies by Qian et al. (2016; 2018) and Odberg et al. (2018), Chen et al. (2021), Odberg et al. (2020) and Solberg et al. (2022) were studying medication administration from an ergonomic perspective. This focus on streamlining and time-saving measures seemed to result in objectifying the resident, such that they were barely mentioned as a minor part of the process, or are even portrayed as a hindrance to the smooth running of the medication round.

Pressures of time for staff was a problem, with multiple interruptions during medication rounds (Chen et al. 2021) and high workloads limiting time spent with residents (Forough et al. 2021; Odberg et al. 2020). Average time for administration of medication for each resident was 5 minutes (Chen et al. 2021). Residents in Garrat et al.'s (2021) study were aware of these time pressures for staff, who they described as having to do too many things at once whilst trying to administer medication. However, Forough et al. (2020b), consistent with the earlier study by Barnes et al. (2006), described the time-consuming nature of giving medication as positive feature. Knowing that it took time to give medication meant dedicated time with the individual resident. As in earlier studies, the lack of cleaning of crushing devices between any of the residents was also observed (Forough et al. 2020a).

On a positive note, Solberg et al. (2022) identified that nurses did adapt routines for individual residents, acknowledging that the very busy home routines had to be changed to deal with real people. However, administration of medication was sometimes delegated to non-qualified staff (Solberg et al. 2022) or junior staff who did not understand the complexities of dysphagia (Forough et al 2020b). Agency staff may be also used who did not know the individual preferences of residents (Forough 2020b). Resident focus groups viewed getting to know residents as critical, both to understand all their individualities, but also to build mutual trust (Garrat et al. 2021).

3.11.4 Disempowerment

Disempowering language remained a feature in these most recent studies. Odberg et al. (2020) repeatedly described staff in terms of supervising, or overseeing residents whilst they ingest their medication. Staff in Forough et al.'s (2020b) study described 'talking the residents into taking their medication' amongst their strategies for those who were reluctant. A new insight was gained from Odberg et al. (2020) who stated that they included patients as stakeholders in their study of the medication administration process. However there was only brief mention of patients playing a part, in that they were imparting their clinical information to the staff. The patients were somehow seen as having a value to help the staff rather than the other way round. However, Odberg et al. (2020 p.9) also observed a positive feature for the experience of the resident, that 'patients are informed of effects and encouraged to report changes'. Residents who were interviewed by Garrat et al.'s (2021) study of covert medication practices, were concerned about their decisions not being respected if they wished to refuse medication.

In contrast, and alone in all the studies which have been reviewed, one of the nurses in Solberg et al.'s (2022) study placed importance on empowering practice,

> 'It's so important that the patients can do as much as possible for themselves so that they experience mastering. And taking your own tablets is also a mastery. But of course it takes time… when grandma is used to eating half a slice of bread first, then she takes one of her tablets, whereupon she takes a little more slice of bread, and then a new tablet again' (p.232).

3.12 Overview of 2022 update of the literature

Updating a search for evidence confirmed the findings from the earlier literature review which had preceded the design of this study. The recent studies have continued to focus on staff practices and workload issues, and it appears that no real change in practice or knowledge has occurred since this research study was proposed. However, the inclusion of the residents' voice in one study (Garratt et al. 2021) provided some insight into their perceptions specifically in relation to covert administration of medication. Residents saw the staff as being very busy and they had concerns about being treated with respect, and about being able to trust the staff. This updated review provides further support and current context for this research study, confirming that the lack of data from the residents' experience, which was identified in the earlier review, remains the clear gap in the knowledge, and that this study remains relevant to current practice.

3.13 Summary of literature review chapter.

The literature has identified similar practices and problems internationally, being widespread across several European countries and Australia. The chronology of the narrative is revealing, as different parties have been looking at similar problems, with similar methodology but seemingly without any improvement in practice over a long period of time. Paradiso et al. (2002) and Solberg et al. (2021) being 19 years apart, have essentially used the same methodology and demonstrated the same findings, of a high prevalence of crushing medication, mixing medications together, and mixing medication with foods in the effort to administer medication to residents.

As discussed earlier in Chapter 2, it is known that residents of care homes for older people are likely to have complex physical and mental health difficulties resulting in high levels of functional dependency, and limited life expectancy. They may have a large number of medications prescribed, and need help from care staff to be able to take these. The physical act of swallowing medication may be difficult and potentially hazardous. However, very little is known about what it is really like to be a care home resident and receive help to take medication. Only one study prior to the design of my research, which focussed on adherence (Hughes and Goldie 2009), had sought anything of the resident's voice in relation to their medication. Almost nothing is known about how the administration of medication might be experienced by the residents themselves.

Chapter 4: Methodology

4.0 Introduction

The previous chapters have placed this study in the context of the background and research literature. A clear gap in the evidence has been demonstrated, leading to the design of a study to explore the experience of older people in care homes, in relation to the administration of their medication.

This chapter will describe the theoretical underpinning for this research study. A justification will be provided for the selection of a Gadamerian hermeneutic phenomenological approach, with appraisal of alternative methodological approaches that were considered during the development of the study. A brief account will be given of the history of phenomenology and hermeneutics, introducing major philosophers who have contributed to its evolution. An overview will be given of some of Gadamer's philosophical concepts which were used to guide the subsequent research.

4.1 Theoretical positioning of the research

The aim of this study is to explore the experience of older people in care homes with the administration of oral medication. This study asks a single question:

What is the experience of residents of care homes when oral medication is administered?

The philosophical foundations for developing a plan to answer this question is described in four levels (Creswell and Plano Clark 2011, p. 39):

1. Paradigm world view – ontology/epistemology
2. Theoretical stance (Perspective)
3. Methodological Approach
4. Methods of data collection

The first three levels will be discussed in the following sections. The methods of data collection will be discussed in detail in the Chapter 5.

4.2 Ontology, epistemology and perspective

Ontology asks the question, 'What is the form and nature of reality and what can be known?' (Punch 2014, p.15). Ontological positions can be broadly divided into realist and relativist. A realist ontology maintains that the world is made up of structures and objects that have direct cause-and-effect relationships with each other, whereas a relativist ontology questions this, and emphasises that interpretations of reality can be diverse

(Willig 2013). In ontological terms, this study arises from my own relativist stance, with a social constructionist perspective. Constructionists believe that we, as individuals, seek understanding of the world and develop subjective meanings of our experiences. These meanings may be varied and multiple (Creswell 2014) and are historically and culturally situated. The same phenomenon or event can be described in different ways, with differing perceptions or understandings, but without any being necessarily right or wrong (Willig 2013). From this stance, this study relies as much as possible on the views that individual care home residents have of their own experience of taking medication. My role as a researcher is to make sense of, or interpret, this experience,

Epistemology goes on to ask, ‘What is the relationship between the knower and what can be known?’ (Punch 2014, p.15). Epistemological stances can be broadly divided between interpretivism and positivism. Interpretivism respects the researcher’s perspective and values in attempting to understand subjective meanings of social action (Bryman 2012). Positivism opposes this view, asserting that the world is independent of and unaffected by the researcher, hence it is possible to conduct objective and value-free inquiry (Ritchie and Lewis 2003). This research study is being undertaken from an overtly interpretivist epistemology, in keeping with my own point of view, in that I cannot separate myself and my background from this exploration of a problem within my clinical field of practice. The whole process from its initial idea, through the literature review and the generation of a research question, is inextricably connected to me as the researcher (Dibley et al. 2020).

A core characteristic of the interpretive paradigm is idiography, which can be described as the concern for the particular (Lincoln and Guba 1985), with a commitment to explore in detail how a ‘particular experience is understood by a particular group of people, in a particular context’ (Smith et al. 2009, p. 29). Idiography is in contrast with nomothesis, which attempts to explain phenomena in terms of statistics, laws, or generalisations (Lincoln and Guba 1985). Greenhalgh et al. (2015) argue that the traditional hierarchy of evidence-based medicine tends to devalue the individual patient experience, and may result in inherent bias in published research, as studies are designed and published within this hierarchy, which places individual case reports at the bottom of the list (Guyatt et al. 1995). This disproportionately affects the oldest old and people experiencing frailty, who are excluded from the majority of nomothetic research (Cherubini et al. 2011; Richardson et al. 2020). Greenhalgh et al. (2015) also advocate that, in an attempt to minimise these biases, personal evidence from individuals should be captured, suggesting the use of narrative, phenomenological or ethnographic designs to complement epidemiological evidence. A phenomenological approach has therefore been chosen, which seeks to place the experience of residents at its core.

4.3 Methodological Approach

4.3.1 Justification for a hermeneutic phenomenological approach

The principal identified gap in knowledge in this field is the resident experience. The resident's voice is either absent or represented passively in much of the literature. Hermeneutic phenomenology has been chosen as a methodology which places the resident firmly in the forefront. Creswell (2014) defines phenomenological research as describing the lived experiences of individuals about a phenomenon, as described by participants. It culminates in the essence of the experiences for several individuals who have all experienced the same phenomenon. There are a broad range of phenomenological approaches to knowledge generation, ranging from the purely descriptive, to the interpretive. Hermeneutic phenomenology has been chosen as an interpretive approach which specifically rejects the notion that I, as a researcher can suspend personal opinion and accepts that all description is essentially my interpretation. The implicit assumptions of the researcher are acknowledged and made explicit (Kafle 2011). Gadamer calls these 'fore-understandings', pre-conceived knowledge and judgements (Gadamer 1960). My own fore-understandings as a researcher in relation to this topic will be described in detail before the presentation of the findings.

Some of the key concepts from Gadamer's philosophical approach to hermeneutics underpin this research, from its earliest motivation, through to the methods of data collection and the interpretation of the findings (Gadamer 1960). These concepts will be discussed in more detail later in this chapter. However, a brief history of the development of phenomenology as a philosophy and the fundamental differences in approach to research methodology which subsequently evolved will be described in the next section. This will help to explain the place of Gadamer in this evolution, and lead to my own decision to utilise Gadamerian hermeneutic phenomenology as the underpinning methodology for this study.

4.3.2 Historical development of the philosophy of phenomenology

In the 19th and 20th Centuries, in the West at least, philosophy was dominated by a logical empiricism, the positivist paradigm (Giorgi 2005). The development of phenomenology was a significant shift of focus in the field of philosophy (Giorgi 2005), directly opposing the Cartesian scientific methods (Sadala and Adorno 2002). The Encyclopaedia of Phenomenology (Embree et al. 1997) lists 28 significant figures, and a wide range of phenomenological branches, a rich tradition that is not easily condensed into one or two paradigms (Pernecky 2016). However, key figures dominate the evolution:

4.3.3 Edmund Husserl

Edmund Husserl (1859-1938), is typically depicted as the father of phenomenology. Husserl's aim for phenomenology was to capture experience in its origin, or 'essence', without interpreting, explaining or theorizing (Van Manen 2017a). This has been translated as 'going back to the things themselves' (Husserl 1901/1970, p. 252). Fundamental to Husserl's method is the concept of suspending or 'bracketing' (Crotty 1996), putting aside pre-conceptions and presuppositions. Husserl suggested it was possible to transcend any such presuppositions and biases (transcendental phenomenology), to experience a state of pre-reflective consciousness which would allow us to describe phenomena as they present themselves (Willig 2013). Husserl has been criticised as being almost positivist in his scientific paradigm, with a deep need for certainty that directed him to pursue philosophy as a rigorous science (Laverty 2003).

4.3.4 Martin Heidegger

Martin Heidegger (1889-1976) was a student of Husserl, but his work diverged considerably from his predecessor. He challenged Husserl's construction of phenomenology as a purely descriptive philosophy and questioned any knowledge of the world outside interpretation (Mackey 2005). For Heidegger, we live in an interpreted world, we are ourselves interpreters, understanders, and hermeneutics (Ashworth 2008). This signalled the move to hermeneutic phenomenology and away from descriptive. For Heidegger, interpretation is always founded essentially on fore-conception. The analyst cannot help but bring their own experiences. Heidegger's definition of phenomenology 'to let that which shows itself be seen from itself in the very way in which it shows itself from itself' (Heidegger 1927/1962, p. 58).

4.3.4 Hans-Georg Gadamer

Hans-Georg Gadamer (1900-2002) was influenced by both the work of Husserl and Heidegger and moved to extend Heidegger's work into practical applications

(Polkinghorne 1983). Gadamer believed that understanding and interpretation are bound together. Interpretation is an evolving process, thus a definitive interpretation is likely never possible (Annells 1996). He was emphatic that methods cannot be totally objective, separate or value-free from the user (Laverty 2003). Bracketing is not only impossible, but absurd (Annells 1996). Gadamer's position supports prejudice as a condition of understanding, based on our own historicity (historical authenticity) of being (Koch 1996).

The central element of Gadamer's understanding of interpretation is that it intrinsically involves the human being who is doing the interpreting, and this person's interaction with the world (Austgard 2012). This is a fundamental difference from the positivist paradigm, and from the concepts of bracketing of other phenomenological approaches, and is congruent with both the subject of this research study and the epistemology of myself as a researcher.

4.4 Gadamer's hermeneutic phenomenology - Translating to method

Smythe et al. (2008, p.1392) use the term 'Translating to Method', when attempting to create an orderly approach to research from the philosophical underpinnings of hermeneutics. For the purpose of this study, key concepts from Gadamer's philosophy will be applied to provide such a methodological approach to interpretation of the data. It is important to consider that Gadamer's hermeneutics is not a research method, he did not write one, but he provides a set of guiding principles aiding the search for truth concealed in language (Regan 2012).

Gadamer concluded that scientific methodology which does not take into consideration the human conditions of historicity (historical authenticity) and prejudice was in essence crooked and needed to be straightened (Gadamer 1960/2004, p.559). The most basic of Gadamer's concepts which will be used in this study to guide the interpretation of data can be summarised into two elements:

4.4.1 Fore-structures of understanding

According to Gadamer, our background and tradition play an essential part in the research process. The most basic of all hermeneutic preconditions is an awareness of one's own pre-suppositions and prejudices. At a fundamental level, it is inevitable that the researcher who wants to understand a particular topic, already has a relationship with the field of study (Austgard 2012). My own fore-structures, background, prejudices and expectations, were established and written down before the commencement of data collection, and will be made explicit prior to any discussion of the findings of the research. This has been important for my own self-awareness, but is also key to providing the reader with an understanding of how my background will inevitably have affected the design and conduct of this study.

The concepts of temporality, historicity and authenticity are intrinsic to a researcher's fore-structures. Our understanding is influenced by everything that is handed down to use, from the day we are born, the society in which we are brought up, its cultures and traditions (Austgard 2012). Gadamer believed that the past and the present are so inextricably linked that they cannot be separated (Gadamer1960/2004). Leading on from the awareness of personal fore-structures, the interpreter must also remain conscious of being affected by their situation, their place in time and history, which will also be acknowledged. Gadamer believed that humans are so immersed in the world that they are naturally in-authentic, accepting social norms, the habits, beliefs, values and prejudices of society. Aspects of life tend to be embraced without question (Regan 2012). As a consequence, the consideration of fore-structures cannot be seen as a single event, but is a "first, last and constant task", which has been revisited at every stage throughout the research process (Gadamer 1960/2004, p.269). A reflexive research journal has been used at every stage throughout the development and conduct of this study, to facilitate and provide evidence of my own self-awareness and this continuous revision of my pre-conceptions (Dibley et al. 2020).

4.4.2 The hermeneutic circle

Gadamer believed that every dialogue has a potential for 'inner infinity', a reading between the lines (Gadamer 1977, p.68). He describes this as play (*spiel),* a moving back and forth between parts of the text and the whole, but also between the text and the researcher's fore-understandings (Austgard 2012). There is therefore the potential for infinite dialogue with any language, with other people, with a transcript, even with a reflexive journal entry.

Engaging with the hermeneutic circle entails reading and re-reading, listening, observing, challenging, reflecting, avoiding hasty conclusions, being always open to more possibilities (Regan 2012). This may lead to the revealing of the unexpected, the surprise of the text which may challenge pre-supposed expectations (Iser 1972). This search for meaning is how the truth concealed within the words can be revealed (Regan 2012).

Without hermeneutics, the phenomenon would not be seen. The ‘thing itself’ is covered over, may be taken for granted. The concept of uncovering, of bringing into the light, illuminates, reveals, explores that which is taken for granted in everyday experience (Crowther et al. 2014). Hermeneutic phenomenology therefore provides an appropriate methodology to answer this previously unexplored research question.

4.5 Criticisms of hermeneutic phenomenology

Criticisms of hermeneutic phenomenology appear to arise from the differing understandings that individual authors have of the original readings of the philosophers. Arguments centre on ‘what is and what is not phenomenology’ (Van Manen 2017a; Zahavi 2019). Van Manen’s criticism is largely concerned with level of insight and depth of interpretation, which he feels is superficial in much published work. He counter-argues strongly in favour of phenomenology if practiced well. Zahavi (2019) criticises the polarised and insular arguments amongst writers in the field for promoting confusion concerning the value of phenomenology. Crotty (1996) also argued that many interpretive researchers had fundamentally misread the philosophy and were conducting more conventional social inquiry, seeking meanings of phenomena at face value, but not within his interpretation of Heidegger’s work. Darbyshire et al. (1999) responded to Crotty’s criticism as narrow and misguided in the way that Crotty himself was interpreting the meaning of Heidegger’s writing.

More generally, Paley (2017) is highly critical of hermeneutic phenomenology as a methodology. He uses the term ‘meaning attribution’, in essence the fabrication of a meaning by a researcher and pasting it on top of an experience. This meaning attribution is, in Paley’s opinion, largely an invisible process in many studies, and his concerns can be overcome by strategies to demonstrate rigour (de Witt and Ploeg 2006). Such strategies which have been used within this study centre on making the process of analysis as transparent as possible, thus demonstrating trustworthiness (Austgard 2012). In addition, the use of extensive direct quotations from the participant’s data will help a reader to make a judgement as to whether the subsequent interpretations are plausible (Fleming et al. 2003).

4.6 Consideration of other methodologies

From a constructionist stance there are other possible study designs which could have been adopted to fulfil the aim of this study. A case study approach was considered, following

Stake (1995) or Yin’s (2018) framework. However, both Yin and Stake stress throughout the need to use multiple sources of evidence as a major strength of the method, allowing triangulation of the findings and converging towards a single reality. This is incongruent with the commitment to value the experience of the individual, and hence was rejected. A Grounded Theory approach had also been considered, as a method of generating theory about the phenomenon from within its context. It has been advocated as a useful approach to use when there is a topic about which little is understood, without satisfactory existing theory (Punch 2014). The goal of grounded theory is explanatory rather than exploratory, seeking to explain a phenomenon. For this research question, which is previously wholly unexplored, it was felt that a purely exploratory approach was more appropriate.

4.7 Summary

This chapter has provided justification for the use of an interpretive approach. Through consideration of the specific aim of this research, hermeneutic phenomenology has been selected as an appropriate methodology. In the following chapter, the research design and methods will be described in detail, within this theoretical framework.

Chapter 5: Study Methods

5.0 Introduction

The previous chapter provided justification for the choice of hermeneutic phenomenology as an approach to answer the research question:

What is the experience of residents of care homes when oral medication is administered?

This chapter will present the design of the research study which sought to answer this question, using strategies which focussed wholly on data collection directly from the residents themselves. The procedures for recruitment by purposive sampling of the study population of eight care home residents will be discussed. Care home staff were integral to the medication administration process, necessitating the incorporation of additional procedures for them to give informed consent to be observed in the study. A detailed account will be given of the two separate data collection methods using open, non-participant observation and semi-structured interviews. Ethical issues and how they were addressed in the design and conduct of the study will be discussed, including issues of capacity to consent. The significant impact of the COVID-19 pandemic which delayed the progress of recruitment to the study for over a year will be described. A stepwise framework will be given explaining how the data was analysed using a hermeneutic approach. The chapter will conclude with an explicit declaration of my pre-understandings which may have influenced the conduct of the study and the processes of data analysis.

5.1 Study population

5.1.1 Defining the study sites.

As described in the background section, there is ambiguity in nomenclature for care homes, both in the United Kingdom and globally (British Geriatric Society 2011, Gordon et al. 2013, Sanford et al. 2015). Homes may be titled variously ‘Care Home’, ‘Nursing Home’, or ‘Residential Care Home’. Even within homes which are registered to provide nursing provision, the administration of medication is frequently delegated by nurses to care assistants (Craftman et al. 2016). It was therefore decided to invite recruitment from any home which was registered to provide care for older people, without stipulating any definition or title of the institution. This was deemed to be appropriately inclusive of all older people who met the inclusion criteria. The study population were recruited from among any independent care homes which were registered to provide care for older people, and from a mix of rural and urban areas in Highland Scotland.

5.1.2 Sampling strategy

The care home residents who participated in this study were identified by purposive sampling, intentionally seeking individuals who were likely to give insight into the experience of medication administration (Creswell and Plano Clark 2011). This was used as the method of choice within hermeneutic phenomenology because it selected people who were most likely to be able to address the research question (Dibley et al. 2020). Within this strategy the aim was for a homogeneous sample (Holloway and Wheeler 1996), chosen to give a detailed picture of a particular phenomenon. The allowed for detailed exploration of the process of medication administration in the specific context of care homes (Ritchie and Lewis 2003). The term homogeneous does not preclude diversity within the defined inclusion criteria, which were deliberately set to be as inclusive as possible, within the boundaries of a care home population. No age range criteria were set. This was in accordance with the Scottish regulatory body, the Care Inspectorate, whose position assumes that services for 'older people' will be for adults over 65 years of age but may vary according to the needs of an individual (Scottish Government 2017).

The exact number of participants to be recruited was not pre-determined. There was no aim to generalise from the sample, but to develop an in-depth understanding of the experience of a small number of people in a particular context, and to provide an interpretation of that experience (Dibley et al. 2020). Smith et al. (2009) suggest that between three and six participants will be sufficient to develop meaningful points of similarity and difference between participants, whilst still maintaining manageable amounts of data, whereas Creswell (2014) suggests anywhere between three and ten would be typical for a phenomenological study. There were risks that the larger the number recruited, the less detail could be expected to emerge (Creswell and Plano-Clark 2011), as the richness and depth of the data from which insights and meaning could be derived may have been lacking (Dibley et al. 2020). The priority was to respect each individual participant by working intensively with their data, and Smythe (2011, p.41) cautions against the risks of 'overflowing the banks' with trying to manage too much data.

5.1.3 Inclusion and exclusion criteria

The inclusion criteria detailed in Table 5 were designed to be as inclusive as possible, maximising the possibility for any care home resident who required help from staff to administer their oral medication to take part if they had capacity to consent and wished to do so. Due to the constraints of a small-scale study, it was not possible to offer an interpreter or materials in other languages. Issues around determining capacity to consent to participate will be discussed below.

Table 5: Inclusion and exclusion criteria for participants

Inclusion Criteria	**Exclusion Criteria**
Residents of care homes for older people, who are administered oral medication by care home staff.	Residents who are able to administer their own medication.
Ability to communicate in English.	Residents who cannot communicate in English.
Capacity to give informed consent to participate.	Residents who lack capacity to give informed consent to participate.

5.2 Ethical Approval

The study was approved by the NHS, Invasive or Clinical Research (NICR) Committee at the University in September 2019, and by the Social Care Research Ethics Committee of the NHS Health Research Authority in December 2019 (Appendix 1). Minor amendments were made to procedures and documentation as requested by the Social Care REC before commencement of recruitment as detailed in Appendix 2.

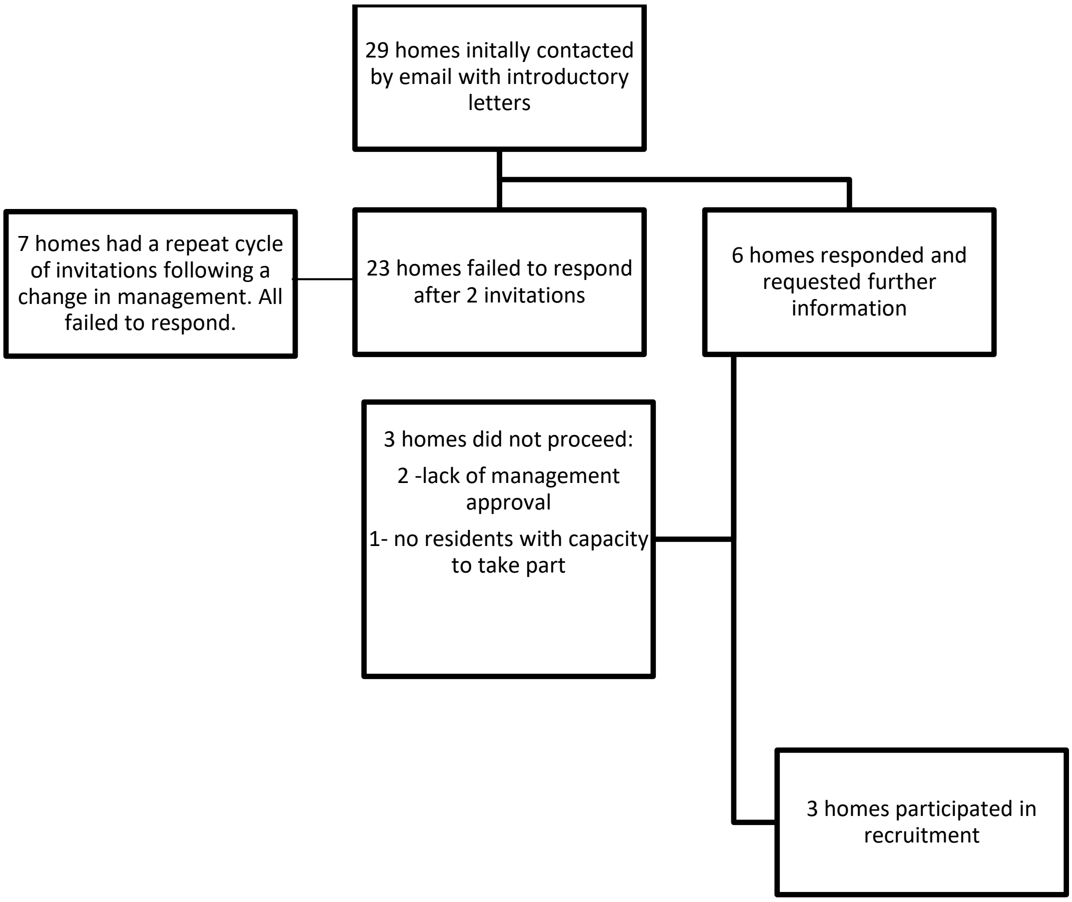
5.3 Negotiating access to care homes.

Once ethical approval had been granted, managers were identified through the Care Inspectorate website, which places their names and contact details in the public domain. Initial email contact was made with 29 care home managers across the whole of Highland Scotland. This included a brief outline of the proposed study, with copies of supporting documents (Letter to Care Home Managers, Appendix 3). A week later, a reminder email was sent, requesting to arrange a meeting to discuss the study with the manager further in person or by telephone. Care home managers had a vital role as gatekeepers, having responsibility for providing access to the homes, and facilitating the conduct of the study.

It is known that such gatekeepers are integral to the recruitment process and can see themselves as protectors of vulnerable people in their care (Kay 2019). In addition, care home managers face their own challenges of heavy workload and staffing pressures and may be wary that allowing access for research may compound these issues (National Institute for Health Research 2017). This may explain the numbers of homes where managers failed to respond to invitations. A careful approach was taken to build a trusting relationship with those managers who did respond (Crowhurst 2013), explaining the purpose of the study and what would be involved for themselves, their staff, and the residents in their care.

A summary of the process for negotiating access to the care homes is provided in Figure 2.

Figure 2: Flowchart of recruitment of participating care homes



5.3.1 Consent of care home staff

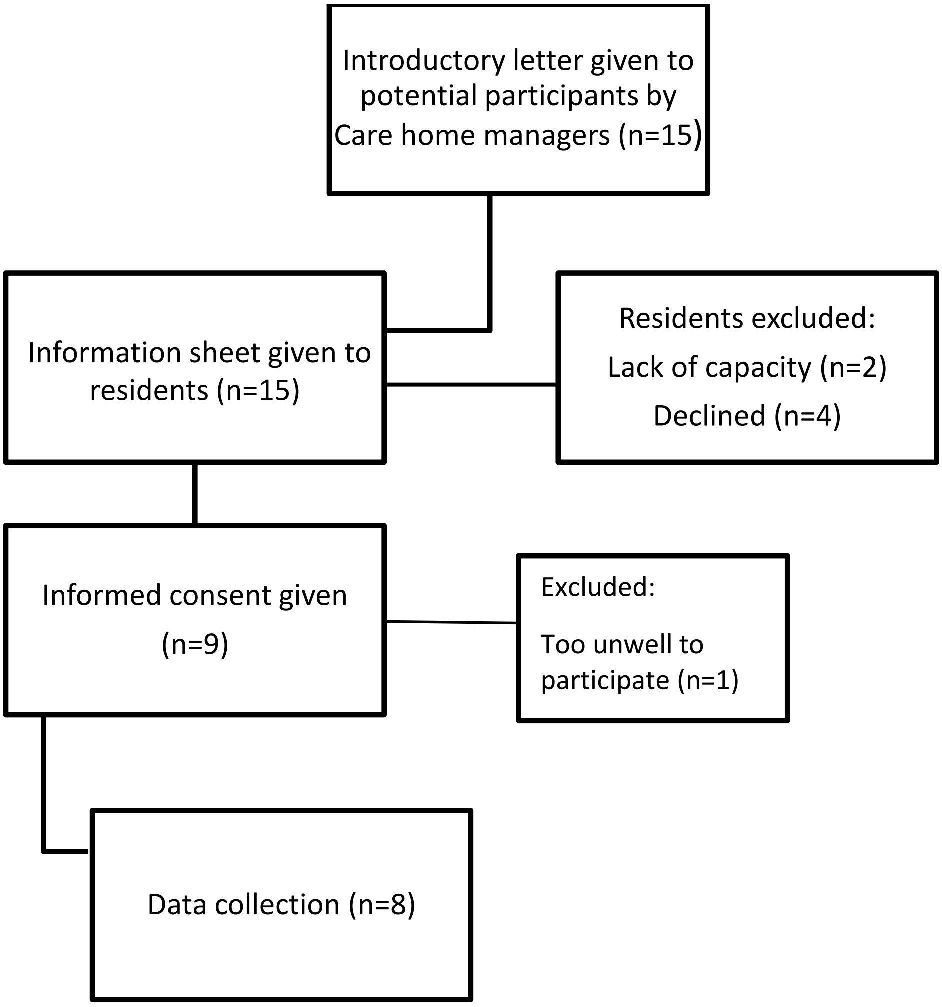
The process of administration of medication involved at least one member of care staff for each participant. During the observation I would be recording details of their interactions with the resident, including their spoken words. Consent was therefore required from any care staff who were involved in the observation phase. Written information was designed specifically for them about their involvement in the study, and the use of the data generated from this element. A staff information sheet and consent form are included in Appendix 6 and 9.

In one of the homes it was the manager herself who was administering the medication. In the two other homes the manager was able to identify from the rota which member of staff would be on duty on the morning of data collection, enabling information and consent procedures for the staff to be planned ahead of time. I was aware that staff could feel under pressure to agree to take part, having been introduced to me by their manager. However, I conducted the information-giving and consent procedures in private with them and gave explicit opportunity for them to opt out if they chose.

5.4 Recruitment processes for residents

The care home managers who agreed to facilitate recruitment of participants were asked to identify residents who they felt met the inclusion criteria, to invite expressions of interest. An introductory letter of invitation to participate was provided (Appendix 4). The care home manager then sought permission to pass on personal details of the interested residents to the researcher. Appointments were then made to meet with each of these residents individually, enabling more detailed discussion of the implications of participation, prior to seeking consent. This process is summarised in Figure 3.

Figure 3: Summary of Recruitment Process for Residents



5.4.1 Information giving for residents.

An initial visit to meet the residents and obtain informed consent took place between one and two weeks prior to any data collection. Potential participants were provided with an information sheet in large print (Appendix 5) which stated the purpose of the study, what would be involved and any potential risks to taking part. A photograph of the researcher was included to aid recall through the period between consent procedures and data collection. Overall, 15 residents were introduced to me by care home managers as possibly being interested in taking part. Four immediately declined as I began to explain the study in more detail. A fifth had very severe dysphasia, and despite spending over an hour trying to ascertain their level of understanding, I was unable to be sure that they could express informed consent. A sixth did not meet the inclusion criteria, being unable to maintain focus on the conversation for more than a few seconds, and could not engage sufficiently with me for me to be able to assess her understanding further as detailed below. Two of the participants had significant visual impairment, necessitating that the information sheet was communicated verbally and in short sections, to ensure that the implication of each part was understood and agreed. The remaining seven were able to read the information unaided.

5.4.2 Consent process for residents

Capacity to consent to participate was a key inclusion criterion. A diagnosis of dementia or known cognitive impairment however, did not preclude capacity to consent to participate in this study. Indeed, the law emphasises that a person should be considered to have the capacity to consent unless proved otherwise (Scottish Government 2000) and strengthens the case that people will be actively enabled to make their own decisions for as long as possible. Some degree of cognitive impairment is found in the majority of residents in care homes (Lithgow et al. 2011; Stewart et al. 2014). This necessitated that potential participants be carefully assessed if there was any doubt about capacity to consent to participate. Ethical approval was granted for me to assess capacity to consent myself using the approach detailed below.

Gilbert et al. (2017) reviewed 14 tools designed to assess capacity to consent for research, six of which had been specifically evaluated for use with older people. This systematic review found that the MacCAT-CR (Appelbaum et al. 2001) was the most used and best validated tool, however, it was also acknowledged to be difficult to use, time-consuming, and ‘too severe’ for the participants, tending to underestimate the subjects’ competency to decide. The lack of a clear gold standard and differences of interpretation even by experts was identified as a problem which has yet to be addressed. Given this lack of consensus, and after considering a range of different tools, I used the University of California Brief Assessment of Capacity to Consent (UBACC) tool (Jeste et al. 2007) to determine capacity to participate. This was recommended by Gilbert et al (2017) as a brief screening tool which can reliably identify subjects whose capacity to consent is questionable, assessing understanding, reasoning, and appreciation of what the study entails (Appendix 7).

The majority of the participants who had been identified by care home managers were not cognitively impaired, being able to read the Participant Information sheet and asking appropriate questions about their potential involvement with the study. The UBACC tool was not used in these cases. Only one participant had obvious difficulties with short term recall of information. In this case I used the UBACC tool to confirm her understanding, reasoning and appreciation of what the study involved.

Three participants who were physically unable to write were able to give informed consent verbally, with the care home manager acting as witness. This element was agreed during ethical approval. A copy of the residents' consent form is included in Appendix 8.

5.4.3 Confirming on-going consent.

Data collection took place a week after the consent procedure. This timeframe was considered to be long enough to allow participants to change their minds about being involved, but also a short enough period for it to be unlikely for their capacity to have changed significantly in that time. Having established an understanding of the resident's abilities and based on how consent was established initially, consistency of ongoing consent was confirmed on the morning of the data collection. Particular care was taken with the resident who had some memory difficulties. I reintroduced myself on the morning of the data collection, reminded her of the purpose of my visit, and then repeated the questions from the UBACC tool to be sure that her consent remained valid. At this stage one resident of the nine was excluded as I was advised by staff that she was too unwell to participate.

5.5 The impact of COVID-19 pandemic

Two care homes agreed to participate in the study early in 2020, leading to recruitment and data collection from the first five participants between January and March 2020. The global COVID-19 pandemic was declared in March 2020, which had devastating impacts on the care home population, and also impacted recruitment to the study. All fieldwork was prohibited by the University, and visiting to care homes was severely restricted by Public Health guidance. Care home residents were particularly vulnerable to the effects of the disease, and as such, it was anticipated that there could be a prolonged delay to any further recruitment which could prove impossible to overcome within a realistic time-frame to complete the research. As a consequence of the COVID-19 pandemic, an amendment was submitted to the Social Care Research Ethics Committee in August 2020 requesting that recruitment be permitted from care homes where I may already have been known in a clinical role and had regular access. This had not been an exclusion criterion during the original study design, however it had previously been declared on the IRAS application under a heading of ‘potential risks to the researcher’ that I would avoid recruiting from homes where I held a clinical role, to avoid the potential for role conflict for myself.

A change to focussing recruitment in this way was requested in order to avoid unjustified visiting to other homes outside of my usual clinical boundaries, and reduce potential for transmission of COVID-19. This amendment was approved in September 2020. Recruitment eventually resumed in May 2021, once general restrictions on care home visiting for families were lifted by Public Health Guidance, and necessary risk assessments conducted. This resulted in the recruitment of the final three residents.

5.5.1 The decision to cease further recruitment.

Qualitative methodologies often use the term ‘data saturation’, to describe an achievement of completeness, when nothing new is found (Glaser and Strauss 1967). In hermeneutic phenomenology, there is an appreciation that achieving data saturation is fundamentally impossible (Dibley et al. 2020). As a researcher I am not aiming to provide a definitive answer of ‘this is what this experience is like for everyone’ (Dibley et al. 2020, p.61). There will always be more to discover, and every individual’s experience will bring different insights. Ironside (2003) suggested that the term philosophical consistency or comprehensiveness may be more appropriate to decide when data is sufficient to answer the research question.

In practical terms, the decision to cease recruitment was made on the basis of the time available to complete the study within the limits of an academic programme, along with the difficulties in identifying further participants with capacity to take part. It is possible that recruitment from small numbers of sites could result in data which reveals features which are specific to the staff and culture of the individual care homes. However, as what was being sought is insight into the individual resident experience, without any aim for generalisability, the use of small numbers of study sites is justifiable. It is the experience of each resident which is of central importance. The three homes from which participants were ultimately recruited were however, diverse in nature. One was a larger 40 bed home, managed by a large national company. One was a smaller home of 23 beds, managed independently. The third was a home of 24 beds, managed by a charitable foundation.

5.6 Data Collection Methods

Two distinct methods were used for data collection from each of the eight participants. An episode of administration of medication was observed, using a framework that incorporated descriptive data with my own reflexive notes taken at the time. This was followed by a semi-structured interview with the resident on the same day. Whilst interviewing is commonly associated with the tradition of hermeneutic inquiry (Walker 2011), observation is less often utilised. Both of these data collection methods will be described in detail, with justification for decisions which supported their use.

5.6.1 A hermeneutic approach to observation.

The central topic of interest in this study, is the residents' experience of medication administration. The literature reviewed in chapter 2 provided evidence that administration of medication in care homes can present problems and is highly individual to each resident. Whilst observation is not often used within phenomenological approaches, it can be justified if it is used as part of the experiential analysis of the situation (Smith et al. 2009; Van Manen 2016). Observation was chosen as a way to come closer to experiences that might be hard to capture and may be hard to verbalise (Dahlberg 2011). It provides 'here and now experience in depth' (Lincoln and Guba 1985, p.273).

There are questions as to whether hermeneutical observations are possible (Naden 2010). Observation inherently involves a turning away from oneself and concentrating on the participant, but there follows a translation from what is seen by the eye to what is written down in words (Naden 2010). At this point there is inevitably an element of interpretation, with an interaction between my pre-understanding and the witnessed events, influencing the notes which were made. In addition, the written text is never able to fully convey what is seen in an observation. Gadamer's hermeneutics is strongly associated with language and the written word, 'making the text speak' (Gadamer 1960, p.370). In the choice to use observation in a hermeneutical study, I become both the creator and interpreter of the text, whose origin is a mental image (Naden 2010). This is acknowledged, but it is nevertheless an important method to convey the observed phenomena in a way that brings out as much as is possible of the meaning.

The existing evidence described in Chapter 3 indicated that residents were likely to have a range of practical issues, postural problems, particular swallowing strategies and personal preferences. The purpose of the observation element in this study was not to establish prevalence or describe problems, which have been previously demonstrated in the literature, but as part of a process of gathering information from within the richness of the context. In contrast to all the pre-existing work in this field, the focus was clearly defined away from identifying staff errors, and towards achieving an holistic understanding of the lived experience of the resident whilst they were being helped to take their medication.

5.6.2 Observation

An unstructured, open approach was used for the observation, with the process of administration of medication being observed naturally as it unfolded (Punch 2014).
A protocol was produced and a paper observation template (Appendix 10) was devised with two parallel columns for recording data (Cresswell 2014). Descriptive notes about the act of medication administration were recorded in one column, with reflexive notes about my thoughts and feelings at the time being recorded in the second column.
With consent of staff involved, an observation of a single episode of administration of oral medication for each individual participant was conducted. This took place in whatever was the usual location for the individual. Five participants were observed in their personal rooms, whilst three were in a communal dining area. As the aim was to observe what was as close as possible to an everyday experience for each resident, it had been anticipated that some of the residents may be receiving their medication in the context of communal breakfast routines, with many other residents and staff likely to be present in the room. This element was discussed in depth at the Social Care Research Ethics Committee. It was agreed that it was within ethical principles to observe a single resident in a communal area, provided it was made explicit to other residents and staff who I was and what I was doing. The advice from the Committee included the design of a poster with my photograph and information about the study, which was displayed in a prominent position in each home in the week prior to and on the day of data collection (Appendix 11).

The administration of morning medication was observed for each participant. The morning medication round was selected to maximise the opportunity for data collection as it is known to be the most complex and time-consuming (Tehewy et al. 2016) with once daily doses being advised as best practice (Joint Formulary Committee 2022). Staff were instructed to continue with medication administration as their normal procedure. My presence could be seen to have potential to influence the event, causing a change from usual behaviours, commonly referred to as the Hawthorne effect (McCambridge et al.

2014). However, observational methods have been used to study medication administration errors many times, and the observation has been demonstrated to have an insignificant effect on practice (Dean and Barber 2001).

When the observation was concluded, I withdrew from the building to allow usual care and breakfast routines to continue. This gave me the opportunity to make additional notes on the observation template, both descriptive and reflexive, as soon as possible after the event, resulting in data that was a near as possible in memory to the actual events (Naden 2010). The duration of the observation varied in accordance with how long it took each participant to take their medication, ranging from 2 minutes to 45 minutes.

5.6.3 Semi-structured interviews

Interviews followed for each participant later on the same morning of the observation. These were semi-structured, with open questions. This is in keeping with Smith et al.'s description of 'a conversation with a purpose' (Smith et al. 2009, p.57), the purpose being to answer the research question, with time to for the participant to tell of the experience in their own words. The degree of structure involved in interviewing can be seen as being on a continuum, rather than strictly defined between structured and unstructured (Minichiello et al. 1990). The use of a tightly structured interview involves pre-established questions with pre-set response categories (Punch 2014). This approach was rejected as being unsuitable for exploring the research question in sufficient depth. A wholly unstructured approach to interviewing was considered initially. This approach is advocated to generate rich and valuable data without limiting the field of inquiry (Punch 2014). However, it is also acknowledged that it is difficult to do well, and demands particular expertise and training to be successful (Punch 2014). For this reason, and to be sure to achieve the aims of the study in answering the research question (Walker 2011), an unstructured approach was rejected.

A semi-structured interview has often been a preferred choice in phenomenological research (Reid et al. 2005), where an interview schedule prepares a broad agenda of topics for discussion, rather than a rigid set of questions. This approach was adopted, and an interview guide illustrated in Figure 4 was used flexibly to prompt conversation. Whilst the questions provided a general direction to the conversation, they were not necessarily asked in order. The first question was used as an opening, with subsequent questions being used as needed to encourage respondents to lead the way, telling their own pre-reflective story as they wished (Dibley et al. 2020). The questions were designed to engage the participants in describing their experiences, drawing out what was important to them without directing or leading to an expected answer (Dibley et al. 2020). The aim was to stay as close as possible to the experience itself by encouraging them to recounting their story (Smythe 2011).

Figure 4: Indicative interview questions/prompts:

1. Tell me about how you had your medication today
2. Can you tell me more about that, describe the stages in what happens?
3. Tell me what the staff do when they help you with the medication?
4. …… And what do you have to do?
5. Can you describe a time when taking your medication was difficult
6. Can you describe a time when taking your medication went well
7. What are the differences between a good example and a bad example
8. Do you have any other stories to tell about taking your medication since you have been here?

Interviews took place in a location of choice for each individual participant. Most chose their personal rooms, but other communal areas were used, ensuring sufficient privacy was arranged and adequate noise levels to enable undisturbed recording of conversation. The interviews were digitally recorded and subsequently transcribed. Non-verbal communication such as gesture and facial expression were recorded as annotations on the interview schedule, and added to transcripts where they contributed to a representation of the resident's experience. During one interview there was a failure of recording equipment. Written notes were made from memory of the substance of this interview within half an hour after the event.

5.7 Additional ethical issues

Particular difficulties for residents with cognitive impairment, or with fluctuating capacity have been discussed above within the context of consent to participate. Additional ethical issues were taken into consideration in the design and conduct of this study. It was anticipated that practical issues associated with the routines of communal living would inevitably be encountered (Hall et al. 2009). Reliance on practical assistance from staff was inherent to the conduct of the study, and careful co-ordination was required to ensure that appropriate time was built into the day for participants to be able to take part without causing detriment to their care or to the care of other residents in the home.

Beauchamp and Childress (2009) include the concept of ‘voluntariness’ when recruiting participants for research. This needed careful consideration when it has been found in other studies (Goodman et al, 2011; Hall et al. 2009*)* that residents of care homes may volunteer for participation simply as a diversional activity, out of boredom, or from a fear of upsetting staff by declining. Clear explanation of my position as external to the care home institution was given, with explicit opportunity to opt out at any stage.

Participants were not excluded on the basis of being unwell or in a terminal phase of illness, provided they had capacity and wished to take part. In the context of a care home, this is a likely occurrence, and individuals in these situations are typical of the study population. Nevertheless, as a specialist nurse with extensive clinical experience in this field, I was vigilant to avoid unnecessary distress throughout, and would have sought support of senior staff from the home if needed. The care home manager was always made aware when I was in the building and was made aware of such a possibility, however in practice, there was no need to seek this support.

Consideration was given to the potential for distress to participants as the interview process may have brought out material which some may have found upsetting. Participants may have found themselves considering awareness of loss of independence, loss of dignity, thinking about their failing health and approaching the end of life. These feelings could not be wholly guarded against, but awareness and preparation, allowing adequate time, including time for pauses, ensured a sensitive approach. Provision for appropriate follow up was made with the care providers should any distress have been evident, but was not needed.

Ethical principles include being aware of the need to check back with participants that they remain comfortable with their data being used throughout the project. Data must not be included which participants feel mis-represents them. The likelihood of participants in this study suffering a decline in their cognitive ability over a relatively short time-scale limited their power of redress regarding the ways in which their words have been used and analysed (Nind 2008). This placed greater responsibility on myself as a researcher to exercise the ‘ethics of representation’ (Booth 1996), where it needs to be absolutely clear whose voice is being communicated in the study. This has been addressed by using verbatim interview data where the source is clearly identified throughout the findings. The permission to use data from individuals who lose capacity or die during the study period was explicitly discussed as part of consent to participate.

5.7.1 Role Conflict

I was aware of the potential for having to intervene if particularly hazardous practice was witnessed which could present harm to a resident. My professional code of conduct (Nursing and Midwifery Council 2018) as a registered nurse, provides a duty of care to act if for example a serious medication error had been witnessed, or a resident was at risk of choking. Serious concerns about practice, either witnessed, or disclosed by a participant, would have been discussed with supervisors and potentially reported through authorities external to the care home (Care Inspectorate/Social Work Adult Support and Protection Team).

On another level, as a clinician-researcher I was prepared to feel the need to intervene in a helping role (Hay-Smith et al. 2016). This was guarded against by working out of uniform and in homes where I was not known in a nursing role. I was certainly aware of uncomfortable feelings of role conflict at times. There was often a desire to help a resident in minor actions, but I found it most difficult to be unable to offer teaching and advice to the care staff. Having many years of experience in supporting carers to improve their knowledge and practice, it felt wrong not to be able to do so, when opportunities arose.

As noted earlier, the COVID-19 pandemic led to the submission of an ethical amendment which permitted recruitment from a care home where I was already known in a clinical role and had regular access. Additional measures had to be taken in this home to avoid role confusion, by visiting out of my usual uniform, wearing a University ID badge with my role as a student displayed, and by choosing a different day outside my usual clinical responsibilities. However, the feelings of role conflict were particularly prevalent in the one home where I was already known. The challenges of these shifting social identities were managed by being self-aware and extensive use of written reflexive notes in my research journal (Chavez 2008; Greene 2014).

5.8 Data Management and Security

Residents' names have been changed throughout to protect anonymity. However, the nature of phenomenological research, with its focus on the richness of an individual's lived experience, and its use of verbatim reporting, makes it particularly difficult to completely protect participants from recognition. This was explicitly explained to potential participants during consent procedures, and was included in the Participant Information Sheet (Appendix 3).

All data management and storage was conducted in accordance with the United Kingdom General Data Protection Regulation (Information Commissioner's Office 2018), and my professional code of conduct (Nursing and Midwifery Council 2018). Paper copies of consent forms and expressions of interest which contain identifiable personal data were kept in a locked filing cabinet in a secure area of an NHS Primary Care premises. All electronic data was stored on password protected computers, to which only I had access. Audio recorded interviews were transferred on the same day to a secure network on a password protected NHS computer to which only I had access. Data was immediately deleted from the audio recorder once transferred.

Audio recordings were deleted once transcribed and any participant identifiable data was anonymised, initially being allocated a participant ID number and subsequently a pseudonym. Due to the nature of the fieldwork, it was necessary to transport potentially identifiable information from the care home and back to NHS premises for secure storage by car. This was undertaken alone in a direct journey, minimizing any potential for loss or mishandling. Personal data such as expressions of interest and consent forms were not transported or stored together with data transcripts. Research data will be kept for 10 years after last use in accordance with Stirling University policy.

5.9 Methods of Data Analysis

The process of analysis in hermeneutic phenomenology is not linear, but is a back and forth movement between my pre-understandings and the new evidence which has been gathered, gradually revealing meanings (Dibley et al. 2020). Systematic frameworks of analysis are paradoxical to the philosophical background (Van Manen 2017b). However, there is acknowledgement that a 'non-methodical method' (Van Manen 2017b, p.820) is needed to support the process of gaining insight into the phenomena, whilst maintaining an open perspective. Such a framework is provided by Dibley et al. (2020), and this was used to give structure to my analysis. It is described as a series of steps, but its conduct is iterative. A summary of the process of analysis is illustrated in Figure 5. The method of analysis of the observational and interview data will initially be described separately, although ultimately the data for each participant was combined to be analysed as a whole.

5.9.1 Step 1: Transcribing

The data from each participant was allocated a meaningful pseudonym rather than a number, as an aid to reading and identifying each of them as individuals (Vandermause and Fleming 2011).

a) Transcribing observational data

The observational templates were originally in the form of handwritten notes which were then typed out to provide a clear narrative of the sequence of events in one column and my reflexive comments which were made at the time in an adjacent column. A hand-drawn sketch which was made of the setting to aid my memory of the observation was retained in the original document.

b) Transcribing interviews

Verbatim transcription was done by myself, the recordings being played many times to be sure to capture all nuances of speech, pauses and non-verbal utterances.

5.9.2 Step 2: Beginning phase of interpretation

a) Observation Data

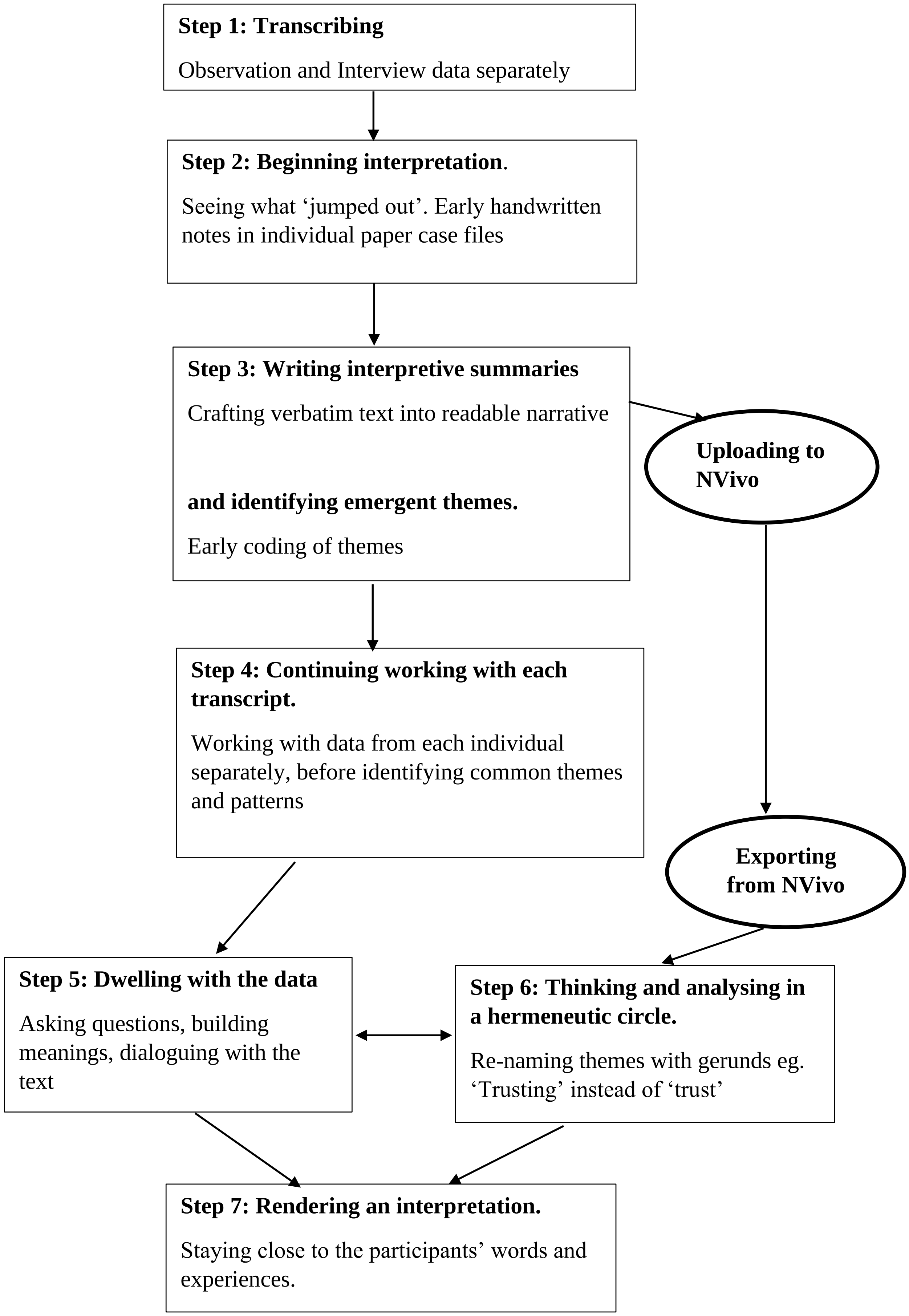
Soon after transcription, the data from each participant’s observation was read and re-read as a whole. I made notes about what stood out from the text, initial thoughts and emotions which occurred to me. This initial reading was quite superficial, noting things that ‘jumped out’ at me (Smythe et al. 2008). These early notes were handwritten as I was reading and thinking.

b) Interview Data

The text from each participant’s interview was read and re-read as a whole. Initial notes were made of early thoughts in the same manner as for the observational data.

The whole of the data from each participant was read and annotated in this way in a single session for each individual, then filed together in separate paper case files. This ensured

Figure 5. Summary of the process of analysis (Headings from Dibley et al. 2020)



Step 1: Transcribing

Observation and Interview data separately

Step 2: Beginning interpretation.

Seeing what ‘jumped out’. Early handwritten notes in individual paper case files

Step 3: Writing interpretive summaries

Crafting verbatim text into readable narrative

and identifying emergent themes.

Early coding of themes

Step 4: Continuing working with each transcript.

Working with data from each individual separately, before identifying common themes and patterns

Step 5: Dwelling with the data

Asking questions, building meanings, dialoguing with the text

Step 6: Thinking and analysing in a hermeneutic circle.

Re-naming themes with gerunds eg. ‘Trusting’ instead of ‘trust’

Step 7: Rendering an interpretation.

Staying close to the participants’ words and experiences.

time for thinking and reflection before moving on to the next participant some days or weeks later.

5.9.3 Step 3: Writing interpretive summaries and identifying emergent themes

a) Observation Data

The observational data was re-written from the two-column table format, into a narrative text. This combined the whole of the detail of what was observed, with my reflexive comments made at the time of the observation into a readable account of the events in logical order, creating a text from what was seen and felt (Fleming et al. 2003).

b) Interview Data

A summary was written from the interview text for each participant, crafting the verbatim data into a coherent story which stayed close to the original text, but was easy to read and re-read as a narrative (Smythe 2011, Crowther et al. 2017). I used the process described by Caelli (2001) as deriving narratives from transcripts. I began by removing sections which wandered off the subject and were not relevant to the topic of medication administration. I deleted my own questions after making sure that any that were relevant or could have directed a participant to answer in a particular way were retained. I then reconstructed the story in chronological order using the participants own words verbatim.

5.9.4 Working with NVivo 12

At this stage a decision had to be made about the use of the software programme NVivo 12 to assist with data management. The use of software programmes is considered by some to be incongruent with phenomenology, potentially providing a barrier between the reader and the text, and disrupting the ability to work deeply with the text (Goble et al. 2012, Van Manen 2014). There are also arguments that when the amount of textual data is large, it may be helpful to use software to help organise files and show the progression of interpretations and record analytical decisions (Dibley et al. 2020). I decided that I would use NVivo as a data management tool, particularly for the ability to provide an audit trail of my processes over time.

The narrative summaries of the observations and interviews were therefore uploaded into NVivo. I also typed up and uploaded the early handwritten interpretive notes which I had made about each participant’s data during the initial listening to the recordings and reading the transcripts in Step 2 above. Using this data I began a process of early coding. I used a selective highlighting approach to identifying emerging themes, asking the question 'What statement or phrase is particularly revealing about the experience described?' (Van Manen 2016, p.93).

5.9.5 Step 4: Continuing with each transcript, distilling themes and coalescing similarities in common themes.

Named 'Case' folders were created in NVivo, using the pseudonyms which had been allocated to the participants. The data for the observation and interviews and my interpretive notes were kept as separate files, but stored together within a Case. This helped to maintain the connection to each individual's experience, and to continue the commitment to only working with one individual at a time. Within each Case I used a linked 'memo' to help track my personal reactions to the data for each individual. Any additions to these memos were dated and timed, and retained a link to the part of the data which generated each personal interpretation or thought, noting what provoked the thinking.

Inevitably the first named codes were identified whilst considering the first individual, and were reviewed many times as I proceeded case by case. As each new participant's data was reviewed, common themes and patterns began to be identified. Only when all the cases had been read and coded separately, was there a further level of interpretation, looking for emergent patterns amongst all the material as a whole. I went on to look at the data which had been collated under the thematic headings, recording my thoughts and interpretations relating to these each emergent theme, both in my research journal, and in linked 'memos' attached to the codes in NVivo.

Steps 5/6 are described as if they were separate steps but are not intended to be linear, but moving back and forth.

5.9.6 Step 5: Dwelling with the data.

Heidegger describes a stage of 'dwelling' with the data, not as a passive activity, but as 'doing business, travelling with it' (Heidegger 1993, p.349). This is a phase of pondering, wondering, asking questions and building meanings and understanding. I took time, not rushing, being careful not to jump to conclusions too soon. Themes were identified and then revised in a process of writing, thinking and dialoguing with the text (Dibley et al. 2020). I made extensive notes as my interpretations developed, keeping careful dated records of all the twists and turns of my thought processes along the way. Some of the thoughts which were directly connected to emerging themes were recorded in the memos to their codes within NVivo, dated and timed to provide a record of my developing interpretations. My research journal was also used to record personal reflections and tentative links between themes, as my interpretive journey proceeded.

5.9.7 Step 6: Thinking and analysing in a hermeneutic circle, examining the parts and the whole of each text, back and forth.

As patterns developed, the initial coding was reviewed and revised many times, until firmer themes were generated. I collated all the material relating to each theme and reviewed it again with my research question firmly in mind, reminding myself that I was looking specifically for things which gave insight into the particular experience of medication administration and not wider issues. Sometimes I felt I was ‘stuck’ and went back to reading the original source data again, disciplining myself to working with data from only one individual at a time on any given day, reflecting on the whole feeling of the experience for each individual.

I followed Dibley et al. (2020) who suggested that the naming of hermeneutic patterns and themes should relate to ontological experience rather than concrete categorical ideas. They advised that the use of the gerund form of words (words ending in -ing) in the naming of patterns can be helpful to convey ideas which keeps the experience of the participant in sharp focus. I found this to be a very helpful step in changing my writing style to stay close to the participant experience and not just my descriptions. For example, I had been working with a theme entitled ‘Autonomy’, which I changed to ‘Being/Being in Control’, which was very effective in shifting my perspective in interpretation.

As the process of thinking and analysing continued, I began to feel that NVivo was no longer useful to me. It had undoubtedly been helpful in organising the data and identifying patterns, but I began to feel I was losing connection with the original text in its context. I had so much material which was broken down into isolated sentences and repetitions of my own thoughts. I therefore decided to export all the data for each theme into word documents, printing them off on paper. I went through them all with a highlighter pen, highlighting everything that was verbatim text of the participants, making a clear distinction between their voices, and everything else I had written from my interpretations. This was immediately a useful exercise, as it made it very obvious that some of the themes which I had identified contained a lot of the participants words, and some very much less. Indeed, two of the themes on which I had been working, contained nothing at all of their words, and became clearly much more about my experience, rather than theirs.

5.9.8 Step 7: Rendering an interpretation or fusion of horizons (participant and researcher)

Gadamer (1960, p.305) used the metaphor ‘fusion of horizons’, proposing that understanding evolves following a fusion of horizons between the researcher and the participant. Whilst it is accepted that interpretations are never finished (Crist and Tanner 2003), a meaningful result is achieved. This cannot be claimed to be ‘the truth, but is a representation of the fusion of horizons of myself as a particular researcher with these particular participants at that moment in time (Dibley et al. 2020).

The NVivo coding process had resulted in disjointed phrases and sentences, whose chronological order had been lost, and the connection with the individual was not always easy to see. I reviewed all the interview data again and placed the participants words back into the context of their original transcripts to create meaningful sections from the verbatim text to illustrate each of the themes identified. Some of the findings from the observations are incorporated in the presentation of the themes. However, I felt I was unable to convey the depth of the experience that I had witnessed in this way. I decided to form the whole of the observational data for each participant into the form of a vignette (Reay 2019), a chronological re-telling of the experience, interwoven with my reflexive notes which were written on the observation template at the time.

The report of the findings in Chapter 6 attempts to stay close to the experience itself, as I have seen and heard it. It provides sufficient excerpts from the data to present a credible account of the phenomenon which makes sense to a reader, who will go on to make their own interpretations (Crist and Tanner 2003; Diekleman and Ironside 1998).

5.10 Addressing Rigour

Rigour in hermeneutic phenomenological studies has been seen as a controversial topic (de Witt and Ploeg 2006). The disagreement suggests that criteria of rigour which have been developed for general application to qualitative research such as Sandelowski ‘s (1993) are not necessarily applicable to expressing the rigour of hermeneutic phenomenology. De Witt and Ploeg (2006) proposed using the term ‘expressions’ of rigour, rather than ‘criteria’, as being more appropriate in this context. De Witt and Ploeg (2006) suggest that key components to assess rigour are balanced integration, openness, concreteness, resonance and actualisation. How these have been demonstrated within this study are detailed below:

5.10.1 Balanced Integration.

Balanced integration requires a coherent argument to be developed through the study, from the design, through methods and the findings, with a balance between the voices of the participants and interpretations (de Witt and Ploeg 2006). This is demonstrated throughout, with congruence of the research topic, the placing of myself as a researcher with my motivations, presuppositions and the philosophical underpinnings of the research.

The new understandings that are presented in the findings and subsequent discussion arise from a combining of past knowledge and new experience, for both the participants, and myself as a researcher, intertwined with the theoretical concepts and the wider literature.

5.10.2 Openness

Openness is the systematic and explicit process of accounting for the decisions made throughout the study process (de Witt and Ploeg 2006). I have provided a description of what I have done and why. This is made evident through my reflexivity and meticulous record-keeping, from raw data, through analysis and interpretations. An example of the process from transcription to narrative summary to coding of both interview and observational data is provided in Appendix 12 and 13.

5.10.3 Concreteness

Concreteness reflects the relationship between the findings and the real world. The findings are presented in an understandable format, so that the reader can appreciate and relate to the situation within the participant’s world and everyday life. In reporting the findings, the participants’ words have been used extensively, with commitment to their experience at the core.

5.10.4 Resonance

Resonance refers to the impact that the findings have on the reader, the extent to which they make sense and are meaningful. This can only be evidenced by the effect on the reader of the work. In addition, I have witnessed from my own experience presenting the findings to others and being told that ‘my stories are so powerful’, receiving what Smythe (2011, p.38) calls, the ‘phenomenological nod’ of resonance.

5.10.5 Actualisation

Actualisation is a further level of impact, the potential future impact of the findings. This cannot be evidenced until dissemination after the study completion (Dibley et al. 2020), and will be discussed in more depth in the concluding chapter.

5.11 Declaring Pre-understandings.

In hermeneutic phenomenology, it is considered that I as a researcher am integral to the analysis (Dibley et al. 2020). Gadamer believed that understanding can only be possible in relation to awareness of our own history and place in the world. Gadamer used the term ‘prejudices’ to describe this, but in this context, the concept does not have the negative connotations of the modern use of the word (Fleming 2003). It is more in keeping with the word ‘pre-understanding’. Gadamer (1990) considered that unless I recognise my pre-understandings, there will be a risk that I will fail to understand or misjudge the meanings of the participants (Fleming 2003). My pre-understandings were identified at an early stage in the development of the proposal. I undertook a ‘pre-suppositions interview’ with a peer research student, following guidance by Spence (2017, p. 838), where I was asked to explore my pre-understandings in relation to my research, reflecting on my past, my present and future expectations. Heidegger’s (1962) terminology was used to help guide my thinking for these notes which are reproduced verbatim from my research journal:

Fore-having – the past:

I am coming from a background of some 25 years of experience as a nurse working with older people who are living with frailty. I have had a 20-year interest in polypharmacy and medicines optimisation for older people, especially those living in care homes. I have many, many anecdotes in my memory and have seen older people struggling with taking medication, and of staff finding ways to assist with this. I have now reached a senior clinical position, with a level of knowledge about what is ‘best practice’ in my field, and have been seen as an expert in rationalising prescribing for care home residents. The literature review conducted and reported in chapter 2 also informed my knowledge, and I am aware that this in turn will have been influenced by my prior experiences.

Fore-sight – the lens through which I am looking at the present:

I am aware that I am viewing medication for older people in care homes as a negative thing. I wrote ‘prescribing bad/de-prescribing good’ in my journal when thinking about this, as a description of my stance. This is my day-to-day work. I am inclined to think, particularly when working with care home staff, that my way of doing things is right. Whilst I strive to think that my practice is always informed by evidence and knowledge, I also accept that I risk shutting out other opinions in favour of my own.

Fore-conception – the future, as I think I am going to find it:

I anticipated that participants in this study will also have negative feelings about taking their medication, and that by choice they would not wish to be doing this. I anticipated that they may express feelings of loss of autonomy and helplessness. I predicted that I may make interpretations of the data that reflect my negative feelings, and my line of questioning may draw out more negative aspects, as this is what I am expecting, perhaps even hoping to see.

These pre-understandings were made explicit long before the beginning of any data collection, and were revisited regularly. I took particular care to think about them again as I began analysing the data, preventing me from over-valuing my pre-conceptions, ensuring that the voice of the participants remains the most prominent.

5.12 Summary

This chapter has detailed the design of this study which focussed on data collection directly from eight care home residents. The procedures for and challenges in the recruitment of the study population have been given, along with processes for care home staff who gave their informed consent to be observed in the study. Ethical issues and how they were addressed have been discussed with particular reference to assessment of capacity to consent to participate in research. The two separate data collection methods of observation and interview have been specified, and the framework which supported the data analysis within a hermeneutic approach has been explained. Finally, I have declared my pre-understandings which may have influenced both the conduct of the study and the processes of data analysis, ultimately resulting in the emergence of findings which will be presented in the next chapter.

Chapter 6: Findings

6.0 Introduction

In this chapter I will present an interpretive account of the findings from the research. I have explicitly acknowledged my own pre-understandings in the previous chapter and recognise that these may have influenced how I have identified and interpreted thematic patterns as they emerged from the data. As the data from the observation and interviews was ultimately combined and analysed together, the findings from both methods will be integrated within the reporting.

I will begin by introducing the participants and their demographics. I will go on to give justification for the structure of the thematic sections which follow. Four themes emerged from the data, ‘Being in control/relinquishing control’, ‘Being comfortable in routine’, ‘Trusting’ and ‘Swallowing’. Each of the themes will be introduced and discussed separately, presenting emergent meanings, understandings and insights, using the words of the participants as the core material, with added interpretive commentary to clarify the meaning (Dibley et al. 2020).

6.1 Introducing the participants

Table 6 below provides an introduction to the care home residents who took part in the research. Basic demographic information is given along with the allocated pseudonym in order to preserve the confidentiality of the participants.

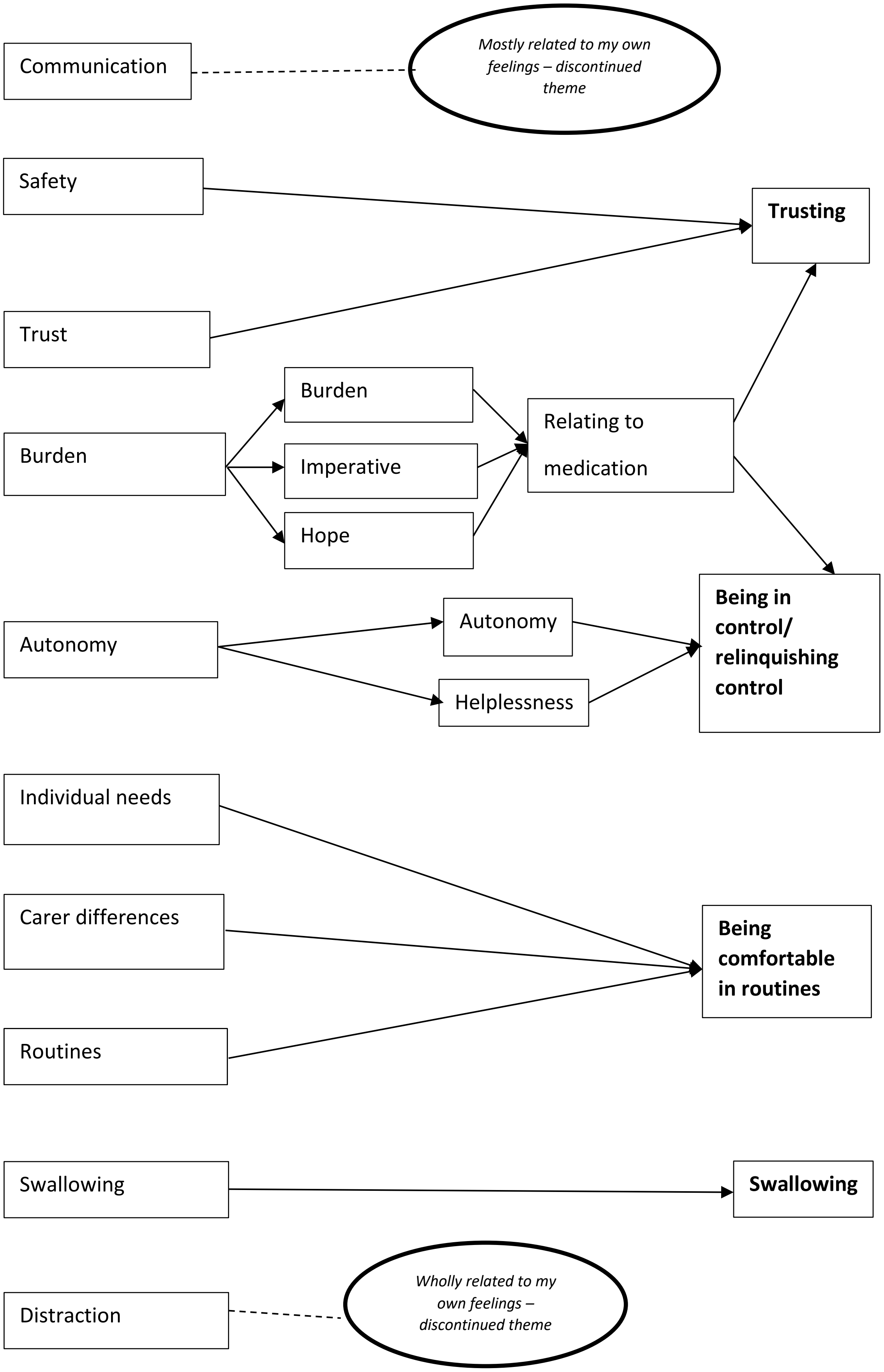
Table 6: Demographics of participants

Allocated Name	Age	Gender	Care Home
Marion	85	Female	A
Norman	94	Male	A
Barbara	87	Female	B
Morag	88	Female	B
John	86	Male	B
Annie	95	Female	C
Renee	84	Female	C
Donnie	85	Male	C

6.2 The development of themes

The findings from the analysis are presented as a search for meaning in the form of four themes. Whilst some hermeneutic phenomenologists are comfortable with using the terms ‘themes’ and ‘thematic analysis’ (Van Manen 2016), others use different terminology which reflects the notion that interpretations are constantly changing and not fixed. Themes or patterns can be seen as keys to interpretations, to open up a deeper understanding or meaning (Austgard 2012). Austgard named these keys ‘meaningful assumptions’. I have chosen to use the term themes, for clarity of reading, although with the understanding that they are not to be seen as essential truth (Rolfe 2006). Through the iterative process of analysis some of the early themes were merged, some expanded, others eventually discarded completely. Extracts from my research journal and NVIVO notes recording the detail of these decisions are presented in Appendix 14. The flowchart in Figure 6 summarises the development from initial codes to final themes which will be presented and discussed below. Whilst these are described as final themes, it is important to be aware that the interpretive process is always unfinished business, and that by presenting as much as possible of the participants’ words and direct observational data, each reader will be able to participate in their own further interpretation (Crist and Tanner 2003; Diekleman and Ironside 1998).

Figure 6: Flowchart showing development of themes.



6.3 Presentation of the findings

The findings from hermeneutic phenomenological research are presented differently than in traditional methods, as I will be relaying the findings as an interpretation. The interpretation is in itself a result, being a product of the study (Dibley et al. 2020). It is therefore inherently impossible to separate purely descriptive findings from a search for meaning. To be congruent with the methodology, a richly descriptive account of the findings will be given, to allow the phenomenon to show itself. The participants' words from the interview data will be used as much as possible, with interpretive commentary interwoven to clarify the meanings. Participants' direct quotes will be clearly identified using *italics.* Data from the observations with text from the descriptive and reflexive elements, has been combined into the narrative. Some particularly illuminating excerpts from the observations will be presented in the form of vignettes. These have been created from the observation transcripts and my reflexive notes which were made on the templates at the time, crafted into a narrative format which will provide 'word pictures' to illustrate the themes for the reader (Reay 2019).

6.4 Theme 1: Being in control/relinquishing Control

6.4.1 Introduction to the theme

Early in the analytical process, I made a code which I called 'Autonomy' as it captured some of the recurring expressions of 'I can do it'. The participants wanted to tell me what they could do, what they took control of, in relation to taking their medication. I also worked separately with an opposing theme, which I called 'Helplessness'. As I continued to work with the data, I began to see how there is a fragile balance between the two. They are not the polar opposites that I initially thought, but a continuum, with a series of steps and choices along the way. Four distinct threads emerged which shed light on this theme, which will be presented under headings of 'knowing what I am taking, 'having a sense of achievement', 'letting go of control', and 'losing control'.

6.4.2 Knowing what I am taking.

Knowing what their medication usually looked like in terms of numbers and shapes of tablets was important to several of the participants, a demonstration of their maintaining some element of control over the process. In every case the medication was prepared, taken from packets and put into pots, out of direct sight of the residents, but it was important to the participants to check the contents themselves.

Morag told me, "*I know what tablets I'm supposed to be on",* whereas Annie said, "*I just pick the smallest one and put them in….. I just pop them in one at a time, start with the smallest one…. And then just… take the bigger ones at the end. And then I get the two at lunchtime, and just have them, where I get more in the morning".* Observing Annie, she looked out especially for the smallest one first, and her carer pointed out the "*wee diddly one*" to her as she tipped the whole pot of pills into Annie's hand so that Annie could be sure it was there. I made a note on her observation template that perhaps that wee one is easy to lose, and I wondered if Annie fretted about that.

Barbara is almost blind. When I observed her, she was sitting in a seat by the window giving her the best light to maximise what little she could perceive with her low level of vision. She picked her tablets out carefully one by one. I presumed that she was checking and counting as she goes, to be sure that it all felt like it should. In her interview she said, "*I can tell the sizes and the shades of colour, so I know each one as I am picking them up".* The staff helped her by putting the tablets in the palm of her hand, but she was able to exercise some control during the process of picking up and checking.

Marion knew that she had 8 tablets to take. She knew the pattern - 5 tablets one at a time and then 3 small ones all together last, telling me at interview, "*I've 8 tablets to take, after every tablet a drink, a tablet and a drink, and the last, the three wee ones, all in my hand together".* The same every day. Observing Marion, she picked up her pot of tablets to have a look at the contents twice whilst she was finishing her breakfast, checking that all was there as she expects it. Checking and double checking. She knew what tablets should be there and what they should look like. Then, after she had taken them all one at a time, she checked again that the pot was empty.

Norman let me know from the start of his interview that he was aware of what to expect from his morning medication*, "There's a wee glass vial….. a wee glass container, one contains soluble aspirin, which dissolves in water. The other four tablets do not dissolve. They're in a separate container. There were four tablets".* He was keen to demonstrate that he knew what his tablets are, and he repeated the phrase about the four tablets several times. Renee gave a detailed account of how she was affected by perceiving changes in the medication she was presented with, saying,

Because there were different pills to take, combinations of tablets that need to be taken.…It seems to be that sometimes they give you a different medicine, it just looks different, or its shaped different. That throws me slightly… You do it for a couple of months, and you don't think anything of it, and then suddenly somebody comes along, and gives you tablets, and you have to say to them, 'what are they?', because you're not sure what they are. Well, I do. 'Cause I like to know what I'm taking…..The only thing that, it does niggle, cause I like to know what I'm shoving down my mouth.

Later on in the interview, she repeated much of the same material, wanting to tell me again,

You know, you're not very sure who's taking, giving you what, and you'll very often hear me saying 'what are those'? Cause they look different. Might be a different colour, might be a different shape. But it catches me. And I want to know what it is that I'm taking. I don't know, I suppose it's just being nosey really. But I take them, and get on with it, and see what happens next time.

She seemed to be experiencing the anxiety of being on a fine line of balance between trying to exercise some control over the process of taking her medication, along with being subject to change in the routine. A predictable routine helped her to keep hold of that feeling of control. When something little changes in the routine and it upsets her equilibrium, it 'throws' her into annoyance and insecurity.

6.4.3 Having a sense of achievement.

I noticed several references to a sense of achievement when taking tablets. John told me,

I've been doing that for the last two years now, and I find that's the most… easiest way. It works for me, it wouldn't work for anyone else, probably, but it's the only way it works for me now. I take tablets three times a day, no bother. And, I feel most successful that way. That's the way I do it, the way I find easiest. The quickest way to get them down, is put them all together. I've no bother.

He had a sense of achievement, feeling "successful" - as if he had managed something difficult.

There were also occasions when residents were congratulated after taking their tablets, as if they had overcome something challenging. Annie's Carer said, *"Gone? Well done!"*, when the tablets had been swallowed. Donnie felt that he is managing his own medication by himself, telling me, "*No problem. They didn't really have to help, I can manage it myself. She emptied it into my hand, and most of them I took at one time".*

Morag had significant physical challenges which are best illustrated in the vignette below:

Vignette 1 - Morag

Morag has a severe tremor. She could not hold a pen to sign her consent form. She sits crouched over in her chair, her face almost parallel with her thighs. I presume she has a fixed kyphosis, her spine is so bent that she is unable to lift her face from this position.

I watch her, wondering how on earth she is going to manage to take her medication.

The carer standing beside her passes Morag a glass of water with a straw. Morag is wearing a thick tweed-style skirt. She can somehow balance the glass on the fabric of the skirt stretched taut between her thighs. She steadies her hands by bracing them on her thighs. She cannot lift the glass at all, but she can then lower her head down to meet the straw to drink. She takes a good drink of water first.

I am thinking that this looks to be a well-practised manoeuvre.

The carer says, "will I put them in your lap?"

I am thinking I have misunderstood, what does she mean?

Morag nods in assent (She is busy drinking)

The carer then tips the pot of pills onto the fabric of the skirt on Morag's lap.

She cannot keep her hands from trembling at all, but she braces them on her lap to maintain enough control. She steadies the glass with one hand. Then, one at a time, she manages to flip a tablet from her skirt into the upturned palm of the other hand. She then bends her head to meet her hand, to take the tablet into her mouth.

An amazingly intricate procedure. I am fascinated.

I counted 8 repetitions of the cycle, bending her head down to suck from the straw between each tablet.

Then she drained the whole glass of water down

The whole event was really very relaxed, despite its intricacies and the concentration. The carer just stands by – she knows it will all be alright?

This vignette illustrates how Morag undertook an astonishingly intricate procedure to take her tablets, yet when I interviewed her afterwards, she said, "*I just pop them over. It's easy enough for me.. I don't think it's difficult. I don't think it's difficult to manage".* She went on to describe what I thought meant that the carer put tablets directly in her mouth at times.

When I asked her to explain if this was the case she said, “*No* [with a very definite emphasis]*, she wouldn’t help me, she wouldn’t, but she may help some people. I can do it. I can do it, as far as touch, and that sort of thing is concerned. I can do it”.*

I found it astounding that Morag describes how she took her medication to me as '*easy enough*'. I would never have imagined when I met this lady, that she could do this by herself. Yet I wrote in my observation template on the day, ‘a relaxed and well-practised manoeuvre’, so perhaps it actually is easy. It all works well for her. However, with the knowledge of observation of other participants, it is really interesting that her verbal account may sound quite similar to other people, whose observations were very much less complex. She is telling me that everything is fine. I can do it, it’s not difficult, it’s easy, but visually some very different things were happening.

Norman also overcame some difficulties with the practical aspects of taking his medication, illustrated in Vignette 2.

Vignette 2 - Norman

Norman is at the breakfast table in a busy communal dining room.

A carer brings over 2 little medicine pots, one with tablets, one with liquid. She put them on the table in front of Norman with a few words between them. She quickly moved on to attend to others in the room.

Norman used the medicine pot to tip the tablets into his mouth. He followed this with a drink of orange juice. The glass looked heavy, one of those squat heavy-based glasses. He held the glass between the whole of both hands. There was obviously some difficulty with his grip, which looked to be between the very base of his hands at the wrist. I guess that he had to do that to be able to get enough power to hold the glass and lift it securely.

(I am not sure of this man’s medical history, but objectively he looks to have some sort of neurological problem, motor neurone disease or similar.)

He then tipped his head back awkwardly.

This looked to be a pretty tricky manoeuvre. I think some carers (me included), would be inclined to try to ‘help’ him with it. I guess he prefers to do this by himself.

Then came the pot of liquid. Again, had to use the flat of the two hands together to bring it up to his mouth, then tip his head to get it in. It was actually more of a tipping back of the whole upper body than the head itself.

Then a bout of coughing to clear his throat [Clinically looked to be a risk of aspiration]

I observed that Norman could barely manage the heavy glass in both hands which clearly did not have the strength to grip it properly. I wrote in my observation notes at the time that I guessed he preferred to do this by himself. He was demonstrating his self-efficacy and autonomy, despite his obvious physical difficulties. Now I can see how much of this was about me, and my perceptions and assumptions. I saw him as dependent, as not able to manage, when he was showing me clearly that this is not the case.

Marion used the phrase, "*I can manage, I can manage, fine".* She stressed to me how she could manage, and she could, such that I thought that perhaps she could manage the whole of the administration of her medication by herself? I started to wonder why she didn't, would she want to?

6.4.4 Letting go of control

I had begun by making the assumption that the participants would always want to do things for themselves if they were able to do so. After reading some of the data again, I began to question that, thinking that maybe they don't always want to take responsibility for everything, perhaps they may be happy enough to relinquish some things. Certainly, some of them described voluntarily relinquishing control, and that this was a relief to them. There was an air of contentment to some of what I originally coded as helplessness. Yes, there is a passivity, but associated with trust, and making life easier for them. Donnie and John both expressed this kind of contentment. Donnie said, "*They've got all my medication there. They just give me it, and I swallow it".* In the notes which I made during Donnie's observation I wrote down 'acceptance'. He came across as accepting of his situation, maybe resigned, but perhaps because he feels secure?

John was comparing how he gets his medication now, from how it used to be when he was at home,

> *They set them, put them in the container for me…. Quite frankly I don't know what they're all for, but I take what they, they know what they're giving me. It's so much better. I wouldn't go back to that again. I'd never manage that now.*

He sounded grateful to the staff that they 'all laid out' for him, he does not have to take any responsibility for them.

The participants in this study all had capacity to take part, and some were physically more able in comparison to the wider care home population. It seemed to me that they could have taken a more active role in the process of administration. I continued to wonder why they did not do this. Perhaps this was their choice? Annie sometimes took an active role and I saw that she was able to pick up the tablets and put each one in her mouth unaided, but sometimes she was more passive,

Well, the girls are very good, and they give me it in the little cup, and just put it on my hand, and just feed them, the wee tablets, in one at a time. Other ones, they stand and feed each one to me.

She lets them feed her tablets in, even though she can do it for herself, she just goes along with it. She voluntarily surrenders her independence and I wondered why that would be. She used the word 'feed' twice which seemed a particularly passive term. Sometimes they feed them to her, when she is quite capable of 'feeding' herself. My impression of observing her was that she was really very capable. I wondered that she could have taken responsibility for the whole process of self-administration of her medication. I do not know if this choice been offered to her, or perhaps she had chosen to hand over the responsibility. Barbara also found taking her medication was easier because the staff get the tablets all ready for her, and which she appreciated, but does that mean that she has she lost her independence? Whilst she could do this by herself, maybe she made a choice to relinquish this responsibility.

I began to consider that resigning responsibility for something, in exchange for a feeling of security and comfort can be an active choice, an exercising of autonomy in itself and not a straightforward loss of control. However, is managing one’s own medication one of the first things we presume to take away from people in care, because it is seen as too difficult, too important to get wrong? Is it that the staff are fearful too, of where their responsibility lies? There may also be a connection between the resigning of responsibility and the importance of a trusting relationship with the staff. It seemed to me unlikely that an individual would voluntarily hand over responsibility for managing their own medication, unless they felt able to trust the staff who are providing their care, but there may be other reasons for this. These issues will be considered in more depth in the discussion chapter which follows.

6.4.5 Losing control ‘I let them get on with it’

There is a fine line between accepting what is given, and feeling comfortable with that, and with feeling a sort of defeated helplessness which is more negative and was expressed by some of the participants. I was struck by a resigned helplessness which did not seem to have any positive features. Control has been relinquished, and not always voluntarily. Norman told me explicitly how he felt it was a lack of respect to have the tablets taken away from him, things he used to deal with himself, "*You feel like you are no longer in control of your own activities, and dependent on other people which you've never been all your life, it's very difficult"*. He was very clear about his sadness with his loss of independence. I expect that this manifests itself in many aspects of care home life, but he was talking about his medication as a particular example.

Morag told me about how one time her tables had been changed but she did not understand why, **"***Oh dear no, probably to discover this, that and the next thing. Yes, well I don't know, I let them get on with it……and it was a bit annoying to myself it was".* Feelings came across of passivity and loss of control, but then also with a spark of annoyance about that at times in her voice.

I found the observation and interview with Renee quite difficult. Her whole posture was passive and helpless as described in vignette 3 below. She just lies there as they are "*dishing things out*" and lets them "*shove things in*" as she told me later.

Vignette 3 - Renee

Renee is in her bed, the curtains are drawn, it is dark. The light takes a while to brighten enough to see. She is sleeping soundly.

Does she really want to be wakened like this? Pills the first experience of the day?

She is lying very flat down on her back, arms tucked under the covers. I wonder if she can use her hands at all?

The carer opens the curtains. Renee appears to be still sleeping, eyes closed. The carer approaches her head,

Carer says, "Are you ready? Ready as you'll ever be."

She does not wait for any reply at all.

Renee's first pill was a Controlled Drug, so the carer had brought it separately to the room from a cupboard elsewhere. It was tipped by the carer straight back into Renee's mouth. She is lying flat on her back and very sleepy. I am momentarily alarmed by watching this, it looks potentially hazardous. I had a natural wish to offer help – to see if she wanted help at least to sit up.

Carer, “There’s your painkillers” (She is told this after she has been given them)

The carer passes Renee a glass of water. She can manage to hold the glass herself and take a drink.

Renee exclaims, “Oh God” (as she tries to get the pill down)
Carer, “Still there, eh?”
Renee takes more water. Then a spell of grunting noises.
This all sounded to have been a great effort. I thought that was the process over...

Carer, “I’ll just get the rest of your tablets”
She goes over to a little cupboard in the corner of the room and gets packets and charts ready on a little table beside Renee’s bed.

Renee is just beginning to wake properly now and open her eyes whilst the carer is preparing the rest of the tablets. Then she is staring vaguely at the ceiling, the drifting off again.

Carer, “You look awfully tired today, did you no sleep?”
Renee, “I’m not sure, maybe…”

The carer then tipped another pot of about six pills straight into Renee’s mouth all at once. She followed this immediately with a little pot of medicine, a thick, syrupy consistency. All this went in together whilst Renee was lying on her back almost flat.
I could hear her rolling the tablets all around in her mouth, rattling them altogether – like a mouthful of rattling pebbles against her teeth. (I was thinking this looks pretty ghastly)

Then the carer gave Renee a glass of water. Renee held this herself and took several gulps. Got it all down. More throat clearing.

Renee was up in her chair later on in the morning when I interviewed her, but she was slumped backwards and barely moved. Only her face animated. At times she sounded defeated, and made several comments where she felt that she had really no control of her own. She was trying hard to keep some control of the situation, but accepted that she did not have much. She placed herself in an inferior position from the start, saying “*I fall in line with whatever it is they give me, ‘cause I have to, and that they know better than me.”* She described some of the difficulties she had with swallowing her tablets, but made a conscious decision to not let it trouble her, “*But they don’t bother me to any great extent. I don’t let them anyway…. (laugh). It’s no use, it's just a waste of space, a waste of time, I think…. ”.* By not letting it bother her, she made a choice to switch off from something which would otherwise trouble her. In the same way, she did not like to complain about difficulties she had when taking her tablets. When Renee struggled to manipulate the little medicine pots in her arthritic hands, she said,

Those pots are a pain, they really are because they are so tiny, they're so tiny, you don't have much room for manoeuvring them. My hands are very stiff first thing in the morning. The glass is a lot bigger, sometimes, it feels too big, so its just… oh I don't know…You feel as if you are just being a pest, well I do, you know…..

Later in the interview, she reiterated a resignation with her situation,

And I don't see the point of complaining……. I, just get on with it. Ok, I have a moan now and again, lose my temper now and again, so, I can't help it, it's just the way of getting round the day I suppose.

It was manifest that being given medication was an unpleasant experience for Renee. Both her language, her non-verbal expressions and the carer's language demonstrated that she found the experience a burden. In the middle of the observation Renee's carer turned to me and said, *"Now then, Renee, she is one of the good ones, she hates taking tablets, so she has them all at once."* I found it hard to believe she used the term 'one of the good ones', and it made me think, who are the 'bad ones', if Renee is a 'good one'? The carer knew that Renee hated her tablets and wanted to find a way to get them taken as quickly as possible. My initial reflections on Renee's story were very negative. I made a note at the end of my record of Renee's observation to be careful to be open-minded when interviewing her and to try not to be influenced by what I had watched. However, even before we began the interview recording, she was telling me how she hated her tablets as she was being wheeled down the corridor to her room.

Renee described a clear link between change of routine and her feeling of loss of control, it was the change that '*threw her'*. The presence of familiar routine seemed to help with the preservation of a sense of autonomy. The place of 'routine' will be demonstrated in greater depth in the next theme.

6.5 Theme 2: Being comfortable in routine.

Observing morning medication was inextricably merged with the routines of breakfast in the care homes. For some participants it seemed an oddly public activity, with residents sitting at meal-tables and the medication administration just going on around. There was no privacy at all, which jarred with me, as a clinician steeped in the notion that confidentiality is paramount. But perhaps this is not a concern in this homely setting? It may be that medication is not seen by staff as a confidential issue, and perhaps this is how the residents like it, or do they just accept it? Several times during observation I felt that I was getting diverted into making notes about breakfast rather than specifically about taking medication, but the two processes were so interconnected it was impossible to separate them.

Annie was given her medication in her room. When I observed her she was up in a chair in her dressing gown, with a part-eaten tray of breakfast in front of her. The television was on loudly, positioned between Annie and the carer who was preparing her medication. Annie was watching the morning news whilst she ate her breakfast. I found the TV very intrusive, it was really dominating the scenario, but I had to tell myself that this is part of Annie's normal routine, so I assume that it makes for a relaxed atmosphere for her. Taking her pills was just another part of the easy routine. Whilst I made notes on my observation template about the loud TV and the half-eaten breakfast, I quickly realised that all this is fine for Annie, and she showed no sign at all of any disturbance to her comfort. She was just enjoying the routine, and the security of it all. She knew the pattern of the tablets she expected, and she enjoyed the way things are done. Later on in her interview she actually uses the word enjoys, saying, "*I've really quite enjoyed the routine".*

Observing Donnie, he was alone at the breakfast table. He was given a bacon sandwich and a cup of tea first, with no communication at all as it was put down. No-one asked him what he wanted for his breakfast, I wondered if perhaps he has the same thing every day and the carers maybe just know. The carer fetched his medication, saying, "*I've got you some water*". She tipped a little pot of pills all together into the palm of his left hand, saying "before I do your eyes" as she did it. I wondered how she knew that was how he took his pills. He had his upturned palm out ready, showing that he knew what to expect. He didn't even look at the tablets on his hand at all, just put them in his mouth.

John had not quite finished getting washed and dressed for the day when I observed the carer bringing his medication. The whole process was completed very quickly. He did not check at all what was in the pot, and could not possibly have done so in the swift movement he made from pot to hand to mouth. There looked to be an element of just getting it over with, something that just had to be done, like any other element of morning routines. There were quite a lot of painkillers there, including morphine. There was no mention if he needed them all, nobody asked him. Does the carer just know him so well, or does she presume? I thought about what is taken for granted between them – mutually.

Observing Marion gave an illustration of the integration of medication into breakfast routines, shown in vignette 4.

Vignette 4 – Marion

Marion is sitting in a wheelchair at the breakfast table, with another resident sitting close beside her. Marion is facing a large bay window, she looks to be enjoying watching the world go by. She is chatting with the lady beside her. I guess that they are usually together at the same table like this.

It is a busy dining room, with 7 residents around 3 tables, and staff about, getting on with preparing breakfast at a sort of 'breakfast bar' along one side of the room. The atmosphere is busy but calm.

A large television is on at the other side of the room, playing a morning show quite loud. No-one is watching it.

The senior carer who is administering medication has the medicine trolley just outside of the dining room, in the corridor.

The Carer actually had very little interaction with Marion, she walked over and took her pulse, without any communication at all *[common practice before certain tablets are administered]*. I presume that this is a regular activity, and that Marion is well aware of what is happening. It still seemed a little odd that she said absolutely nothing.

The Carer put a pot of pills on the table in front of Marion with the comment, "Here's the cocktail"

Marion picked up the pot to have a look at the contents twice, presumably to check that all is there as she expects it. She knows what tablets should be there?

Breakfast eventually arrived, with tea and prune juice to drink for Marion. At one point the carer popped back in and peered over Marion's shoulder to see if the tablets were still in the pot. There was no interaction. Marion was not aware of this at all. Was this any element of control, of her being watched without her knowledge?

Only when breakfast was finished did the tablet-taking begin, a meticulous routine, done with great care, and took about 10 minutes, slow and steady.

She placed a pill just between the teeth each time,

Pill 1, then a drink of tea

Pill 2, a drink of tea, throwing the head back, more tea

Pill 3, juice, more juice
Pill 4, juice.
Pill 5, juice
Pill 6, juice

Pill 7/8 (and more?) tipped out into her hand, brought to her mouth, more juice

Finally, she checked that the pot was all empty

Marion told me at interview*, "I have my breakfast before I take my tablets, once I'd finished my toast, I take them".* The way she described this made me feel that this must be how it happens every morning. The step of taking the pulse seemed to be an important part of the routine for her, she mentioned it three times during her interview "*She takes my pulse every morning, she takes my pulse, she has to do the pulse first, and then if it's ok I get the tablets".* I thought that maybe she found this a reassurance that she is in safe hands. It was the 'security in routine' which was in my mind the most for Marion. I may have thought of this in the past as 'institutionalisation', but the feeling with this lady was that this provided a comfortable state for her. The whole practice of taking medication was an important part of her day, almost seeming to be an enjoyable routine, something important for her to take part in. She had a meticulous routine which left me feeling that it will all go well for her so long as the routine is followed. I wondered how things would feel for her if routines were disturbed in any way, perhaps with an unfamiliar carer or a different location.

Again, I noted that I was somehow shocked at the level of distraction, the TV, the breakfast chatter; I found it very distracting indeed, but that was my feeling and not hers. I was concentrating on the medication aspect, whereas she was just having her usual morning. The integration of the breakfast and medication was inescapable, but the carer did have the medicine trolley positioned outside of the breakfast room, so it was perhaps not so intrusive to the mealtime, not letting medicines dominate too much. How odd it seemed to me at the time that there was so little communication between the carer and Marion. But again, this was probably my observation and not Marion's experience. I had to remind myself that Marion lives this experience every day. She does not need the explanation, and she certainly does not look at all alarmed or disconcerted that something unexpected is happening.

When observing Barbara, I had been told beforehand that she is blind, and I made immediate assumptions that she would need more verbal communication. I expected that the carer would need to talk her through the process of administering her medication in detail. In reality, the carer said very little throughout. Yet Barbara appeared to be comfortable with the routine without any verbal explanation of what was happening.

I was initially quite disturbed by the lack of communication between carers and residents overall, writing down 'no communication at all' several times throughout my observation notes. It seemed obvious to me that this must be a bad thing. Then I reminded myself that this may be just because the care staff know the individual needs of the residents so well, that no-one feels the need to ask or be specific about describing things? Then the more I saw of the 'just routine' sort of thing - without communication, the more I began to swing my feelings to see this as a more positive (or potentially positive) factor.

In contrast, Norman gave an account of an experience when his routine was disrupted,

For instance, my second dose of tablets, I usually get about 6 o'clock. Two or three nights ago I was wakened at half past 9 at night, by the girl who'd forgotten to give me my afternoon dose. You're waiting for it, there's no harm done. They're not all as meticulous, as M….. And that can be a bit frustrating…..It's a long day, when you're sitting doing nothing, and your eyesight is such that you can't really enjoy reading anymore, it's a long day, and you tell yourself.. they'll come eventually, but, when you're waiting for somebody and they're not showing up, it can be very frustrating [raises his hands in a sort of shrug].

Norman placed great importance on his medication when it did not arrive as expected. It dominates his mind, "*when you've nothing else on your mind but when your next tablets are coming, it can get very frustrating".*

Renee's experience of a change in routine was also difficult for her. She had got used to things being one way, then something different happened. Her phrases, 'it throws me slightly' and 'it catches me' are very descriptive of a feeling of loss of equilibrium. Norman got understandably cross when expected routine was not followed, and Renee gets upset when the tablets don't look the same, but then it is the lack of routine which is the problem. Is this just a natural human trait? I began to question fundamental opinions which I had long held about the nature of institutional living. This feeling of 'security in routine', where elements can remain unspoken because individual needs are known, links with the trusting relationship which is described in the third theme.

6.6 Theme 3: Trusting

The placing of trust was a powerful theme, evidenced in two distinct threads. Residents described and showed trust in the staff, and also trust in the medication which they were being given to take.

6.6.1 Trusting in others

There is a huge amount of trust in accepting medication prepared by another person, usually unseen. In addition, some residents expressed a mutuality in the trusting relationship. They trusted the staff, but they felt that the staff in return trust them. Several of the participants described trust explicitly, and my observations supported the existence of a trusting relationship.

Barbara is almost completely blind. I observed her demonstrating great trust in the staff, putting out her palm for her tablets, believing that she is being given everything properly. She said, "*I trust the staff. I used to know exactly what I was taking, now I find that I cannot recall the names, but I know they will be right".* Donnie did not even look at his tablets in his hand at all. They were tipped in his hand and into his mouth in such a way that he could not possibly have been aware of what he was taking. He told me,

They could be poison maybe and I would nae know it. (laughter). It doesn't bother me. I've got to go sometime (laughter). I know they'll not give me anything that'll harm me. I'm quite content to take the tablets as they give me them.

He was completely trusting, and would take whatever they gave him. Whilst he was aware of the possibility that tablets could be harmful - he trusted that the staff would not do anything to harm him.

The way in which John took his tablets is illustrated in Vignette 5. The whole process was so quick, and provided a visible demonstration of a trusting relationship.

Vignette 5:

John is in his own room. He is sitting in a chair by the window. A table is in front of him, with a glass of water ready. I have already watched the carer prepare a pot of what looks to be around 10 large tablets in another room.

The carer put 2 pots on the table in front of him, one is full of tablets, the other holds liquid morphine.

He tipped the tablets into his palm, then all in his mouth together. A swig of water, then another swig. Followed by the pot of liquid.

The whole process was very quick and routine indeed. He did not check what was in the pot, and he could not possibly have done so in the swift movement from pot-hand-mouth.

John went on to describe his absolute trust in the carer administering his medication, saying,

> *They set them, put them in the container for me, what I have to take…… I trust them. Oh absolutely, I absolutely trust, when I get them in the morning, or at midday, that what they give me, I, oh I trust them implicitly… it's so much better.*

His relationship with the staff was such that he did not know what he was taking, but he did not feel that he needed to know. Morag also said, "*I just take it for granted that they know just what they're doing".*

Marion and Norman both described the building of a relationship of trust between themselves and their carers. Norman described how the staff left the tablets on his table for him,

> *They don't do that with everybody, they do that with me because they trust me, with my medical history, some people have to be watched and supervised… But M (named carer) knows that I won't slip up.*

Marion told me,

> *When I came here first, they won't leave the tablets with me, until they knew, what I was like, and then, they just left the tablets. If I'm no through with breakfast, they'll just leave them here, and then I take them. They know me.*

Both of them seemed to be describing this as an achievement, a positive fact about their self-efficacy. Norman's use of the phrase "*I won't slip up"* indicates that the medication is something important that has to be done properly. Marion knows that she has that capability, but she has had to be able to prove it, to demonstrate it, earning the right to be trusted to take her own medication unsupervised. This has clear links back to the earlier theme of 'being in control', and will be explored further in the Discussion chapter which follows.

6.6.2 Trusting in the medication.

I had initially made a code which I called 'hope' to record anything which residents told me about taking medication which could be seen as positive. I did this consciously as soon as I became aware that I was at risk of over-emphasising any negative factors, and in an effort to understand more about the relationship that residents had with their medication. I began to think that expressions of hope, or belief in the worth of the medication, could also be interpreted as a trusting relationship. Residents trusted that the medication was important, and that it must be doing them good in some way.

Two of the participants who lived with pain looked to their medication for relief. When John spoke about 'having' to take something, it is sometimes for a painful problem, so although he said that he has to take it, it is a relief, "*Sometimes at night, if I'm awake and my back is painful, they give me Paracetamol, two, and of course I just take them at once".* And Renee who lives with constant pain says,

I know I've got to take them, and it's the only way I can get through the day.... I miss them if I don't take them, if I don't take them, I'm in a bit of trouble....I certainly couldn't do without them.

Morag had hopes of being better, and believed that the tablets would do her good, "*I take them, yes, but what can I do? I take them with the……..* [long pause, word finding].... *prospect …… of improving my situation."*

I remembered the long pause when she struggled with word-finding. Eventually she came out with the word *'prospect'*. I really expected that she was going to say 'I take them with milk' or some other such practical thing. She had such faith in these tablets to help her improve.

Renee gave a sort of justification for why she had "all these pills", as if she had to explain herself. It was almost as if she felt a sense of shame that she had so many pills to take, she had to somehow validate this and presented reasons for it,

Doped to the eyeballs, is the expression…I like to use, which is…they don't….. it doesn't go down very well [she chuckles]*…..Well, doesn't bother me. I know, I've taken them for so long, I've had arthritis for 40 or 20 odd years, so… I just take it.*
I have enough of them, as you see. I mean people often say, you don't need all those pills? Well if I don't need them, why am I taking them? And then I don't take them, I'm in a bit of trouble, you know…. So I just take them and forget about it [laughing]…

Does this shed light on how she can tolerate being woken in the morning to face a process she hates? Maybe she looks forward to it in part because of the pain she lives with. Will the tablets bring her relief? She knows there are a lot of tablets, but they are so very important, even so important that she says the staff will 'borrow' from others to make sure she gets them. She told a story about staff taking stock from other residents' boxes, *And I know if I've forgotten, and they know I need them, because if they're short, they'll go and get them out of somebody else's box on the wall, and pinch them out of there, one dose, two doses, until they get the supply back again.*

I can assume that this probably does happen. In the home where Renee lived each resident had a little locked cupboard for their medication in their own room. I could imagine a scenario as she watches them going to her little cupboard, and if something has run out, the staff might say - "I'll go and fetch one from XYZ", and then come back with a supply. Renee would be aware of this if it happened. Renee repeated phrases describing the importance of her tablets to her several times, opening her interview with,

I take them because I know I've got to take them….. There were different combinations of tablets that need to be taken……I just take them because I have *[*definite emphasis*] to take them. And then I've taken them for so long, I know I've got to take them.*

I noticed similar recurring words and phrases which speak of taking tablets as an imperative. Phrases such as 'I have to take', were common. Something about the compulsion to take the tablets, for whatever reason, seemed to run as an underlying thread. Why does anyone feel that they *have* to take something? Who or what makes them do that? John told me,

The tablets are laid out for you, what you have to take, I take them all at once, swallow them, and that's them done. And I have to get morphine, well, I take morphine as you saw. I take that, and tablets for…. Oh, I can't… quite frankly I don't know what they're all for, but I take what they, they know what they're giving me.

Throughout his interview, he repeated the phrase of 'having to' three times, as if it was some sort of duty, a compulsion.

Donnie described the staff as, "*They're just seeing that you take your tablets".* Whilst this could be interpreted as an element of the staff being concerned for his welfare, it also sounds somehow as if a person wouldn't take their tablets properly without being watched? Overall, the repeating phrases such as 'what you have to take', 'I had to take' came back again and again. When I have read through again all the actual words spoken, this pattern is very clear. There are elements of the situation just being taken for granted, but mostly tablets are taken just because 'I have to take them'. Is this because of an inherent belief that the medication is powerful and important? These issues will be explored further in the discussion chapter which follows.

6.7 Theme 4: Swallowing

This was such a clear theme in my literature review, and the assessment of swallowing is part of my everyday clinical experience, that I think I was inevitably attuned to look out for swallowing problems throughout the observations. I knew that the prevalence of swallowing problems is high amongst the study population, so I was undoubtedly being vigilant for signs. However, bearing in mind the requirement for capacity to consent to the study, several of the participants were more able than many care home residents. Those who told me that they had 'no bother' swallowing their tablets did not seem to have any difficulty seen during the observation. Annie took six tablets, each one at a time, with a drink of water from a bottle between each one. Each picked up carefully herself and put in her mouth. She could manage this herself and drank a full bottle of water to get them down. She says, "*I have a drink of water, and that's really… there's no difficulty there.…I just get them over, I don't have any bother. Yes, I've never had any problem with them".* Barbara also has no trouble swallowing her tablets, saying, "*I am actually amazed that I can swallow them, as I have some trouble with regurgitation after meals with a hiatus hernia."*

John also found swallowing his tablets easy. He had to take a pot of what looked to be around 10 large tablets. When I saw them, I presupposed that they might not be easy to take but John surprised me. However, I observed that he tipped the whole pot of tablets into his palm, then all in the mouth together. A swig of water, then another swig. Followed by a pot of liquid. He swallowed the whole lot down in a few seconds. He told me at interview:

> *I take them all at once now…. and with a drink of water, I can swallow the whole lot, just without any further ado. I take them all, that's the only way I can take them now. If I was to do what I used to, one at a time, I'd never get them…. I couldn't do that now. And it doesn't matter what size they are, tiny, or large, a drink of water with them and that's it. So long as I've got a glass of water, that simply, is water to take, to down them, and they all go down. And its, I find it much easier, the whole. The quickest way to get them down, is put them all together. I've no bother. I'm on quite a few tablets, …. I had quite a few this morning, yes. Yes, I can't remember how many were in it but, but there'd be seven or eight I'm sure, but that's the way, that's the only way I take them.*

Marion had 8 tablets to take, and she managed to swallow them one at a time with a drink between each one. She described the swallowing as if it is a bit of a nuisance, but nothing more than that, and she has ways round it, with several mentions of the little 'tricks' she had to get things down,

> *They break, some of them breaks the paracetamols. M always breaks them, but some folk, some of them doesn't. They have to stick…At tea-time I take milk, with Paracetamol, gets it down easier with milk. The wee tiny ones, they go down, aye. Well sometimes there's always one left in my mouth…..there…. like there….*

In observing Norman, the swallowing difficulty he had was much clearer than he would later describe in his interview. It was obvious to me, as an experienced clinician that this was potentially a risky manoeuvre, causing him to cough. Norman told me about his swallowing difficulty, but stressed that he was able to manage the tablets he had,

> *These tablets, are all tablets, but they're all very small tablets, which I can manage, but I can't manage anything bigger than that. I've got a throat condition, I've got a narrowing in my throat…..*[he gestures at his throat, making a narrow, squeezing movement]*……. and a pouch in my gullet…..So I can't swallow capsules……And I can't swallow large tablets. These, the ones I take are very small, I can get them over, but I can't swallow anything larger than that. They're only small, I can swallow these, but I can't swallow anything like co-codamol, which is a big tablet, or anything… I put four together……Like I said, I repeat, they're very small tablets, I just force them down with a drink. I tend to throw them back, so they go to the back of my tongue…. And swallow them from there.*
>
> *I have to choose very carefully what I try to swallow. You only get one chance. That's truthful (laughing…) I've choked once and it's a very alarming experience. Something stuck in your throat, it's a horrible experience....I certainly can't swallow capsules, of any kind. Yes, small tablets are easier, but capsules are very difficult* [gestures with fingers – long/big tablet shape] *They stick…They stick, where you think it's not funny.*

Renee told me,

> *The only time it's any difficult, there is any difficulty, is when I've been really tired…… I'm struggling to get the …… pills, yes, the pills, sometimes just don't go down, because they seem to get stuck. And I have to take 2 or 3 gulps of water or whatever it is, to get rid of it. That's the only time I have a little bit of problem. I don't consider medicines to be a problem. Sometimes they're easier to get swallowed, other times they just don't want to go. And I have to take 2 or 3, or sometimes even 4 attempts, to get them to swallow.*

Donnie did not say anything about his ability to get his tablets down, but was seen to have a few coughs as he was eating his breakfast, and he rolled the tablets around a bit in his mouth, shifting them, and taking several drinks of water to get them down. Morag undertook an intricate process to get her tablets down which has been described in the vignette earlier. Yet when I interviewed her, she made light of any difficulty, saying,

> *Well, I know what tablets I'm supposed to be on, and there were about…a dozen of them there….and I just swallow them all down. I just swallow them, because I had to swallow them ….I mean, if you have ten tablets to take, well you just take the ten at a go…* [shrug].

Well, she expects me to do it. I just take my tablets for granted. For granted. Let's put it that way… I'm taking my tablets as I'm told to take them.

There is an underlying thread in this theme of swallowing, linking to the compulsion that tablets just have to be swallowed somehow, because of their intrinsic importance or as some sort of duty. This will be explored further in the following chapter.

6.8 Summary

In summary, analysis of the data has brought to light an interwoven pattern of themes in the experience of these care home residents when they were being given their medication. There was a fine balance between keeping some control over the process, finding individual ways to manage the physical aspects and keeping track of what was being taken, to handing over that responsibility and sometimes having responsibility taken away. The routines of care home life around taking medication contributed to a feeling of security, and in some ways facilitated the ability for residents to maintain control over aspects of taking their medication. A trusting relationship between residents and staff was clearly important to the participants who also trusted that the medication they were being given was important to them. Whilst swallowing medication could sometimes be a problem, residents managed to find ways to overcome this. The following chapter will provide an in depth discussion of these interconnected themes and the concepts which underpin and connect them.

Chapter 7: Discussion

7.0 Introduction

This research has explored the experience of residents of care homes with the administration of their medication. The exploration has revealed interconnected themes concerning control, routines, swallowing and trusting. This chapter will discuss some of these issues in more depth, and is structured into four sections. The first three sections will focus on three of the key discussion points which arose from the analysis of the findings.

The first point will discuss the importance of individual routine in person-centred care. Secondly, the nature of trust, both in people and in medicines, will be explored as an indicator of vulnerability. The third section will discuss the threats and facilitators of autonomy for older people in the context of care home culture and in wider society. There is interplay between the sections, all intrinsically suggesting a power imbalance for care home residents who are given medication to take. The final section of this chapter will therefore discuss power, powerlessness, and empowering practice as elements of this overarching concept, which has emerged as the most significant finding from this study.

Each discussion point will draw on relevant research, reflecting back to findings from the literature review in Chapter 3, but will also draw on additional literature, linking the findings from this study to knowledge from wider fields. The unique contribution and implications of this research will be clearly demonstrated.

7.1 Discussing the findings within a hermeneutic phenomenological approach

Hermeneutic phenomenology seeks to surface unspoken meaning in the data, through dialogue with the text and with wider literature, taking what Crowther and Thomson (2020, p.6) call an ‘interpretive leap’, towards revealing new understanding. The interpretive analysis of the experience of medication administration has revealed an underlying phenomenon of power imbalance that was previously unknown. The Greek word ‘phenomenon’ originally meant something which shows itself by bringing itself into daylight (Fleming et al. 2003). Heidegger called this, ‘that which shows itself within itself’ (Heidegger 1962 p.51). A phenomenon may be hidden and need uncovering, sometimes it will appear or emerge clearly, and sometimes it may appear to be something that it is not, what Heidegger called a ‘semblance’ (Heidegger 1962). Hence, in the discussion which follows, some of the threads will be clear and obvious to a reader, some may be tentative speculation, and others will be exploring the possibility of hidden meanings. All are open to further interpretation by the reader, and are not intended to convey an impression of essential truth (Rolfe 2006).

7.2 Section 1: The importance of individual routine

One of the key and unexpected findings from this study was that the routines around being given their medication could be a positive factor for the residents. Some of these routines could be experienced as helpful, facilitating independence, and contributing to a feeling of security and control. Routines were so familiar that little verbal communication was needed as staff assisted residents each with their own individual needs. Routines that did not follow a familiar plan were experienced as upsetting and even felt destabilising for some residents.

What this research has shown clearly that the little things of everyday routine really do matter. Three elements will be explored in this section, the importance of routines associated with taking medication, the lack of verbal communication between staff and residents, and the positive influence of routine in care home life.

7.2.1 Routines associated with taking medication

Residents in this study all had highly individual routines when being helped to take their medication. This has been established in other contexts which will be explored below, but has never previously been reported directly from the experience of care home residents. Individual routines specifically relating to taking medication are known to contribute to the ability of older people in community settings being able to manage their own medication successfully (Tordhoff et al. 2010a; Tordhoff et al. 2010b; Vatcharavongvan and Puttawanchi 2022). Conversely, in these three studies, disruption in daily routines was shown to be detrimental to safe medication-taking practices, being a common cause of people missing doses. Older people in one study kept their medication in up to four different locations, helping them to remember the association between particular tablets and specific daily routines such as meal-times or bed-time (Vatcharavongvan and Puttawanchi 2022). All the participants in Tordoff et al.'s (2010a) study reported that they had a system or routine to help them remember to take their tablets, sometimes putting them out the previous evening, or putting them in a prominent place. Embedding the taking of morning medication with detailed breakfast routines was also identified by Sanders and Oss (2013) as the most common way that older people at home managed to take their medication as intended. Sanders and Oss (2013) found that each person's routine had a unique sequence of behaviours that determined the exact integration of taking medication with other elements of the routine. Swanlund et al. (2008) used the term ‘living orderly’ (p. 241), to encompass factors which older people at home described to help them manage their own medications, including establishing habits and schedules, placing visual cues and prompts. Conn et al. (2016) reviewed 53 studies into interventions to improve medication adherence in the general population, concluding that the use of behavioural strategies such as prompts and linking medication to habit were key to helping people to take their medication as intended.

Similarly, studies in hospital settings have also established the positive effects of creating a link between administration of medication and daily routine (Vanwesemael, Boussery et al. 2020), with particular importance when aiming to maintain independence and continuity for patients in transition between home, hospital, and home again (Murray 2011). These hospital and community focussed studies were all specifically considering factors to support self-administration of medication. The findings from my study do not indicate that complete self-administration would be an important aim for all care home residents, indeed some of the respondents in my study expressed clearly that they were glad to hand over some of the responsibilities to the staff. However, the importance of facilitating even some small elements of control of the routines of the process emerged as a key factor.

Whilst the context of the findings from my study are different from previous work, it is possible that supporting these routines, identifying cues which can trigger taking medication could help promote elements of self-care for residents, and that such strategies could potentially be transferable to a care home setting.

7.2.2 Lack of communication may not be a negative feature.

The lack of verbal communication between staff and residents was also an interesting finding. Whilst I found this disturbing, the only indication from the residents was that this was all normal and to be expected. It may be that I was placing too much emphasis on any verbal communication, whereas the non-verbal cues of the familiar procedure were sufficient to maintain the routine for each individual. Communication in its wider sense means simply the conveying of information through signals and includes the behaviour of one individual influencing another, with language, non-verbal behaviour, and also situational context (Mandal 2014). The objects of the administration of medication themselves play their own part in communicating their role (Pena- Alves 2020). Objects used in everyday life have the ability to convey meaningful information without words. Pena-Alves (2020, p.386) termed this ‘object-mediated communication’. In my study, this was seen clearly when carers approached with the familiar medication pot, and the participant held out an open palm to receive tablets, without any words being exchanged. The communication with the residents was effective, even without verbalising. Whilst initially seen as a negative factor, it could be interpreted as demonstrating that staff and residents knew each other, and their routines, well enough to not need any additional words.

7.2.3 Routines associated with care home life – a positive feature.

'Being comfortable in routine' was a key theme of the residents' experience in this study. One of the respondents even used the word explicitly, "*I've really quite enjoyed the routine".* Medication-taking routines were both meticulous but also relaxed. When considering the experience wholly focussed on the residents, these positive findings are strikingly different from those seen in the literature review which underpinned this study. The routines of care home life had been seen to be a very negative element in the existing research. Medication rounds were busy, and staff were experiencing multiple time pressures and interruptions (Barnes et al. 2006; Paradiso et al. 2002; Qian et al. 2018; Stuijt et al. 2013; McGillicuddy et al. 2017). They had to support several residents at once (Paradiso et al. 2002; Qian et al. 2018) which meant that equipment was sometimes shared between residents (Fodil et al. 2017; Mercovich et al. 2014; Paradiso et al. 2002). However, this prior evidence all came from observational studies of staff practices, where researchers were focussed on staff workload and behaviours. By adopting a hermeneutic approach to observing the residents being given their medication, a different experience of routine became evident, which was almost wholly positive.

Individual routines are part of maintaining personal identity and self-determination, giving meaning to life (Heintzelman and King 2019). Maintaining personal routines has been shown to be associated with feelings of comfort, confidence, safety and control (Avni-Babad 2011) which was evident in my findings. Continuing to perform daily activities which are deeply embodied provides connection to a familiar world (Sovde et al. 2021). This positive value of routine is entirely contradictory to the role of institutional routine which had been a feature of the pre-existing literature which had been reviewed in chapter 3. However, two of the residents in this study did provide evidence of their distress when their own routines did not follow the usual pattern. Renee found it upsetting when small changes were made to her medication-taking routine, and Norman found it difficult to wait a long time for medication which had apparently been forgotten. This adds strength to the argument that maintaining individual routine is a positive factor for residents.

Recent work researching medication administration in care homes has been examining the process from an ergonomic perspective. Odberg et al. (2018 and 2020) prioritised the smooth workflow for staff, seeing interruptions from residents as a hindrance to this workflow. Qian et al (2018) acknowledged that staff did sometimes adapt the process of administering medication to meet the needs of individual residents, but saw these adaptations in terms of their effects on the efficiency of the activity. Qian et al. (2016) and Chen et al. (2021) were researching the time taken for medication administration, focussing on potential for time-saving efficiencies. Whilst efficiency and staff workload issues have their importance, there is a need to rebalance the focus of research in this field, given insights from my own research demonstrating the importance of routine to each individual.

Bradshaw et al. (2012) found that when routines were amended to give more control to residents, this contributed to a sense of well-being. Any value judgement about the presence of routines perhaps depends on who is in control of the routine, or if an individual has to unwillingly submit to routine that is imposed upon them. Evidence from Nakrem et al.'s (2012) study suggested that there was a tension between maintaining necessary institutional routines and accommodating individual residents' personal habits. Adjusting institutional routines to the residents needs contributes to feelings of overall well-being (Nakrem et al. 2012). The conflict between meeting personal needs within an institutional setting reflects an inherent imbalance of power for care home residents which will be discussed further in the final section of this chapter.

7.3 Section 2: Trust as an indicator of vulnerability

7.3.1 Trusting in staff.

A second key finding which emerged in this study was that residents expressed and demonstrated remarkable levels of trust in the staff who were helping them to take their medication. This was something entirely new and surprising to me. Trust was not a theme which had been identified earlier in the literature review in chapter 3 which may have been because no previous study had focussed solely on giving the opportunity to residents to describe their experience first-hand. Whilst residents in Hughes and Goldie's (2009) research had described themselves as being happy to take what they were given, because they felt that the care staff knew what they were doing, they did not use the word trust explicitly. This therefore is a particularly unique contribution of this study and has been brought to light by a combination of interview and observation. Whilst many of the studies discussed in the literature review in chapter 3 observed administration of medication, this trusting relationship between resident and staff has not previously been seen. The hermeneutical approach to observation which was used revealed clear evidence of trust in addition to that which was spoken explicitly by residents.

Initially this theme of trust felt like a positive feature, with connotations of comfort and safety. However, exploring the literature about the concept of trust led to the conclusion that a trusting relationship between the residents and staff may be founded on the residents' position of powerlessness and vulnerability. I began to think that the manifestation of trust in the relationship between resident and staff may be a semblance (Heidegger 1927/1962), not what it seems to be, or just a manifestation of institutional compliance. It seemed illogical that an individual can express trust when they do not fully understand what it is that they are trusting about. It seemed to be a false trust, somehow a false relationship.

Trust can be defined as a response to, and a way of managing vulnerability (Gilbert 2020), the 'optimistic acceptance of a vulnerable situation in which the trustor believes that the trustee will care for the trustor's interests' (Hall et al. 2003 p.615). Trust is inseparable from vulnerability (Hall 2003), and Gilbert (2020) argued further that the act of conferring trust actually increases the trustor's vulnerability by making them more dependent on the trustee, and that this vulnerability intrinsically implies asymmetry in the relationship. Gilleard and Higgs (2018) describe this asymmetry in term of an imbalance of power, which the residents being unable to resist the institutional systems of governance in the home. A definition of trust has been condensed to 'the opposite of power' (Rortveit et al. 2015 p.196), and Greener (2003) describes a coercive form of trust, where there is a lack of choice and an obligation to co-operate. In effect, there can never truly be a choice to trust (Brown and Meyer 2015). Alternatives to trusting for a vulnerable individual may contribute to a state of stress and anxiety. A conscious decision can be made to bracket out uncertain or negative possibilities to enable a focus on the positive in the face of heightened anxiety (Brown and Meyer 2015). In his account of his experience, Donnie told me that he was aware that the staff could be giving him ‘poison’, but he made a joke of it, laughing and going on to describe how he trusted that they would not harm him.

Trust has been regarded as the foundation of any therapeutic relationship (Dinc and Gastmans (2013). However, Meyer and Ward (2013), writing in the context of trust in health professionals, make the link between trust, knowledge and power. They suggest that the knowledge asymmetry between patients and professionals created a certain form of dependence upon the expert through which the trust was compelled. Participants in this study expressed this dependence clearly in phrases such as *‘they know better than me’*. John told me that he trusted the staff implicitly, such that he did not need to know what he was taking. Whilst this placed him in a dependent position, it is also possible that this conferring of trust was an active choice for him. In placing his absolute trust in the staff, he may have been exercising his autonomy in a different way.

From another perspective, two of the participants, Marion and Norman, had a sense of achievement in being trusted by the staff to be left to take their medication unsupervised. This was a reciprocal trust which had to be earned. Ibrahim and Davies (2013) argue that amongst organisations caring for older people, there is a presupposed default position of distrust of a person to manage their own vulnerability. ‘If they were trusted, they may not need care at all’ (Gilbert 2020, p.2360). This is an indicator of a wider ageism which can lead to doubts of credibility or trustworthiness of older people within society (Doran and Georgantzi 2018).

Dinc and Gastman (2013) suggested that training for nursing staff should include developing an awareness of the nature of trust, ensuring that nurses understood that trust inherently involves vulnerability and dependency on the part of the people for whom care is provided. No developments in this field appear to have ensued since that time. In addition, no literature has been identified in relation to training about trust for social care staff working in the care sector. It is possible that this may be even more important for care home staff who may not be aware of the power imbalance in their relationship with residents. Care home staff are accustomed to disrespect and negative stereotypes and are not likely to see themselves as a powerful or high-status group (McGilton et al. 2020; Woodward and Ruston 2022). They may be unaware that the trust which the residents confer on them, does place them in a position of power.

7.3.2 Trusting in medication

Trust was not only expressed when residents were directly speaking about the staff, it was also demonstrated in the relationship with taking medication which the residents described. Tablets were often taken without question. The phrase '*I'm taking my tablets as I'm told',* which Morag used is strikingly similar to the title, 'I just take what I'm given', of the only previous paper which included some residents' opinion about their medication (Hughes and Goldie 2009).

Initially, I was undoubtedly looking for signs that taking medication was in some way a burden to the participants. However, what was brought to light were very different expressions of how these residents felt about taking their medication. This research revealed that the experience of taking medication is underpinned by a belief in the inherent importance of the medication itself and all that it symbolises for the individual. Overcoming any difficulties that the residents had with swallowing tablets can be seen as a physical demonstration of this important relationship. The highly individual coping strategies to swallow medications has been described in other studies of community dwelling older people (McGillicuddy et al. 2019; Schiele et al. 2012; Kelly et al. 2009). The overarching theme from their findings was that their respondents would try all sorts of different methods, but 'keep on trying 'til I get it down' (McGillicuddy et al. 2019, p.1430). The respondents in McGillicuddy et al.'s (2019) study also expressed feelings of compulsion, being resigned to the fact that they just had to take their medication, there was no choice.

The pressure to administer medication, along with the prevalence of modifications to tablets was a major theme from my earlier review of the literature. Barnes et al. (2006) called this the dominant imperative from the staff's point of view. All of this earlier evidence came from observation and interviewing of staff, and could be explained by referencing both the constant fear of regulatory bodies and 'getting into trouble' which was described by nurses in Ostaszkiewicz et al.'s (2016) study, and the feeling that they are doing their best for their residents (Barnes et al. 2006). Yet the residents in my study also appeared to experience a similar dominant imperative, a feeling that they were compelled to take their tablets.

The term 'burden', a value-laden term, is commonly used in relation to medicines and treatment regimens, with tools having been designed to measure and quantify it (Spencer-

Bonilla et al. 2017). Mohammed et al.'s (2015) systematic review of medication-related burden and patients' lived experience identified considerable levels of burden related to medication in the routines of taking medication, the numbers and characteristics of the products could be problematic, but there were also expressions of faith and hope in the medication.

Participants' expressions of 'I have to take', and the justification they spoke of in relation to their tablets suggest that their medication had a powerful role in their lives. Van der Geest and Whyte (1989) wrote about the 'charm' of medicines, that because of their concrete existence as a representation of healing, and the connection between the person who prescribed them, they carry complex cultural meanings. People believe medicines to be powerful, and the fact that access to them is limited by regulations reinforces this view. Nasciemento and Ramalho-de-Oliveira (2021) argue that medications are seen as markers for illness, indications that something is not right. This could explain why some residents in my study expressed a sense of justification about the medication they had to take. It also somehow confirms the individual as being in a vulnerable situation, they are unwell, they are in the role of 'patient'. Medications are symbolic of an individual's inability to cope with life's problems without their power (Nasciemento and Ramalho-de-Oliveira 2021). Shoemaker and Ramalho de Oliveira's (2008) exploration of the experience of taking medication in younger age groups, revealed that for them, medication was strongly linked with a feeling of aging and loss of control. Taking medication changed them from a person into a patient.

The term 'lay pharmacology' (Webster et al. 2009) describes how individuals construct meaning for their medication, and Cohen et al. (2001) wrote that these meanings are much more than their biological function. Both these authors consider medication to be a social and cultural phenomenon. Ross and Gillet (2021) described them as 'social actors with the capacity to organise behaviour, foster and mediate social relationships, and even signify and shape the meaning of illness identities (p. 2584). In my study, Renee felt that she had to justify the amount of medication that she took, by explaining it as an indicator of the severity of illness with which she suffered.

Marion's meticulous routine when taking her medication seemed like a ritual, a visual demonstration of the importance of the medication in her day. I had used the word 'talisman' among my early journal notes but find that this concept of medication as a modern-day talisman has been recognised in the literature. Cohen et al. (2001) cite several studies dating back to the 1960s which use this terminology. As Morag expressed her hope and faith that the tablets would *'improve her situation',* patients in Nascimento et al.'s (2020) study used religious terms to express the meaning of medications in their lives, along with feelings of gratitude, faith and hope. Individuals' experience of medication is real and powerful, and different for each one, affecting their decision-making processes (Nasciemento et al. (2019).

Medications provide a tangible a link to the doctor (Cohen et al. 2001) even taking on the role of the doctor in some way, and symbolising medical authority (Ross and Gillett 2021). This helps to explain why individuals might feel that they must take their medications as they are told to do, as a compulsion. Cohen et al. (2001) discussed this in terms of a power relationship. The medication is representative of the interface between the doctor and the patient. Ouellet et al. (2022) interviewed very old people living at home, finding that they had great confidence in their medication, and trusted without question that their doctors prescribed it for their own good. Parekh et al. (2019) summarised this relationship in the title of their study of patient's experience of medication in a wider context, 'They must help if the doctor gives them to you'.

Hence, the findings from my research confirm something that is already known in the wider population. It may be my own prejudice which led me to expect otherwise (Gadamer 1960). I had expected the participants to tell me that they did not want their tablets, but the wider literature would support an expectation that they will consider them important and believe in their power. There is however an added consideration to be taken into account which relates specifically to care home residents. It is accepted that individuals should be encouraged and empowered to take responsibility and contribute to decision-making about their health, particularly in relation to their medication (Manias et al. 2021). Yet in studies of care home residents, the majority did not know what medication they were taking (Manias et al. 2021), sometimes being aware of the numbers of pills they were required to take, but having little idea what they were for (Palagyi et al. 2016). They also had complete trust in the prescribing decisions of their GPs, and believed that their doctors should not be questioned (Palagyi et al. 2016). Whilst residents in my study were not directly questioned about their relationship with the medical profession, their expressions of trust in taking their medication would indicate a trusting relationship with those who prescribed it. There is a paradox here, in that it is difficult to understand how a resident can place such trust in taking a medication, when they may not know what that medication is.

7.4 Section 3: Autonomy and threats to autonomy in the context of care homes

The concept of autonomy, from its origins, means self-rule or self-governance, widely interpreted in ethical terms as self-determination over one's own actions (Tuckett 2006). The importance of respecting the right to self-determination in residents of long-term care facilities has long been accepted (Boyle 2008; British Geriatric Society 2011; Kane 2001; Knight et al. 2010) and is no different from the wider principle of presumption in favour of capacity for decision-making in any context (Scottish Government 2000). This section will begin by discussing in more depth the exercising of autonomy in the activity of taking medication, and go on to explore the possible threats to autonomy of a risk averse culture in care homes. Finally, the concept of compassionate ageism as a threat to autonomy will be considered.

7.4.1 Demonstrating autonomy in taking medication

The findings from my study showed that residents were trying to exercise control over the processes of being given medication. They wanted to know what they were taking, even if only by checking the numbers and appearance of their tablets. Some expressed a sense of achievement, as if it were a skill, with some demonstrating mastery of intricate procedures which they liked to manage by themselves. Sometimes they willingly handed over responsibility for aspects of managing their medication, as if it was a relief, but others felt powerless over the whole process, as they had relinquished responsibility, or had it taken away.

These expressions of self-determination and self-efficacy contrast sharply with the earlier review of literature, which provided evidence of disempowerment of care home residents in relation to their medication. This previous research had been largely based on data from staff observation and interview, where staff used disempowering language, placing the residents in passive roles. Assumptions were made by staff that the residents in their care did not really having any opinion about taking their medication (Barnes et al. 2006; Hughes and Goldie 2009; McGillicuddy et al. 2017; Qian et al. 2018). Hughes and Goldie (2009), who did interview residents, also found that they seemed to accept their loss of control without question. The findings from my study would indicate that this is not always the case.

Looking at the wider literature about the exercising of autonomy, my findings are not surprising. Retaining personal authority and control has been a core finding from previous research into older people's wishes for their future care (Bowers et al. 2009; Granville et al. 2011), and older people maintain their sense of autonomy despite becoming frail and moving into institutional care (Becker 1994). It is also known that older people moving into a care setting associated this with a potential for loss of autonomy (Shin 2015), and residents in a study by Tuominen et al. (2016) felt that being in a care home presented many barriers to their ability to exercise their free will. Boyle (2008) also found that those living in long term care reduced their expectations for autonomy downwards, to fit in with what they perceived as the rules of the care home. However, it is perhaps significant that in relation to medication specifically, there seems to have been a presumption that care home residents do not want to exercise any control over the processes. The findings from my study refute these assumptions.

All the participants in my study wanted to talk about what they could do for themselves when taking their medication. Using two methods of data collection was a valuable feature in this respect, because at times, observation revealed that participants were not as independent as they wished to portray themselves in interview. However, even the two residents who were the most physically impaired wished to stress the elements that they were, or were trying, to remain in control of. When questioning was directed specifically towards what the staff did for them, the participants told me what they themselves could do, rather than what anyone else did for them. They told me of their sense of achievement, of accomplishment of something which might be challenging, 'I can do this'. They naturally placed themselves at the centre and focussed on their abilities rather than their limitations. This reflects the findings of Becker (1994), who found that older people whose autonomy was constrained by disability, shifted their attention to other traits that maintained their sense of autonomy. This has been confirmed by frail older people in more recent studies, who continued to hope and strive for meaningful activities and also to keep on learning new things, even though there was a decline and loss in some of their physical abilities (Hjaltadottir and Gustafsdottir 2007; Sovde et al. 2021). Pan et al. (2019) emphasised that frail older people identified their independence by the performing of daily tasks. This might go some way to explain the sense of achievement which some of the participants in the study expressed when talking about taking their medication, which I had found unexpected.

Collopy (1995) distinguished between ‘autonomy of execution’ and ‘decisional autonomy’. Decisional autonomy is characterised by the capacity to make personal decisions and choices, irrespective of being able to carry them out independently (executional autonomy). The participants in this study would not be able to exercise fully the autonomy of execution, being physically unable to manage all the aspects of administering their own medication, reading labels, manipulating packets, or pouring out measured doses. However, they retained decisional autonomy, with capacity to make decisions about their personal choices and values. Boyle (2008) found that older people who lacked executional autonomy also had their decisional autonomy constrained, as care staff tended to make decisions for them. This is reflected in my findings, particularly for those residents who felt that they had had to resign themselves to giving up their own control over their medication. Lindberg et al. (2014) saw autonomy as not being absolute but more be as a continuum, from independence to dependence. It should be thought of as a process as an individual continuously reacts to different care contexts. This is very much what was illustrated in the findings of my study, in that every individual was as a different stage in this process, and needed individualised support.

Staff in my study sometimes demonstrated great skill in finding ways to facilitate self-care for residents where possible, in situations where I felt a desire to help more than was necessary. I saw these incidences as reflecting ‘being in control’ as carers were empowering these individuals to remain in control of aspects of their care. There is also a clear link between facilitating individual residents to continue their medication-taking routines and how this contributes to the preservation of autonomy. The predictability of repeating an act routinely can be interpreted as acquisition of skill, as individuals feel familiar with a routine, feel they have the expertise to avoid any problems and keep themselves safe (Avni-Babad 2011). However, whilst nurses in Hedman et al.’s (2019) study knew that they had a crucial role in promoting autonomy and participation in the everyday activities in care homes, they also were aware that these opportunities to be attentive to detail were sometimes limited by organisational restraints and costs.

When Hughes and Goldie (2009) interviewed both residents and staff about taking medication, they concluded that the theme of control was their superordinate finding. All their residents accepted control without question, and staff prioritised the need to maintain control of the processes. It is also known from the literature that staff experience a pressure to administer medication (Barnes et al. 2006), considering it to be very important to them that this is done properly. This creates an essential dichotomy in that meeting the needs of the staff has a consequence of denying the control that residents in my study clearly wished to retain.

7.4.2 Autonomy in a risk averse culture

The balance of facilitating versus hindering self-directed care is a reflection of a wider problem for older people in a risk-averse care home culture and in society more generally. There is a heightened sense of responsibility, fear and anxiety amongst staff concerning medication management, and medication is routinely taken away from residents and locked up for safekeeping (NICE 2015b). Writing in the context of hospitals, Watson (2006) described this as ‘a ritual confiscation’, and that staff would do all in their power to prevent the patient having access. Murray (2011), writing in the context of an older peoples’ mental health unit, also reported a severe reluctance of staff to relinquish control of medication management, fearing for the safety of the unit.

Hughes and Goldie’s (2009) overarching theme of needing to control medicine processes within the home was to ensure safety and efficiency. The staff also knew that the need to control medication processes was perhaps at the expense of resident autonomy. Current guidance for care homes presents a contrasting approach. The National Care Forum (2019) identified that when a person enters a care home, staff often automatically assume responsibility for managing their medicines. They recommended that supporting self-administration as far as possible should be a starting principle for all residents, with risk assessments to determine the level of support needed. However, resident choice is stated as the first issue to be considered during this assessment. NICE (2015b) also produced quality standards specifically encouraging care homes to consider self-administration of medication to be the default position. However, they also stipulate that there is a need for individual risk assessments to determine the level of support needed for each resident. The Care Quality Commission (2022) also supports this approach and gives practical guidance to care homes on how to achieve these standards.

There are directly conflicting ethical principles here, which may present challenges for care homes who have to balance the need to minimise risks to protect a person from harm versus maximising their independence and capacity to take risks. This right to take risks in order to achieve higher quality of life has been described as the ‘dignity of risk’ (Ibrahim and Davis 2013). Senior care home policy makers and resident advocates in Woolford et al.’s (2019) research were invited to discuss the principles of dignity of risk. They accepted that taking risk is an important part of daily life, and that implementing risk averse strategies may impact on the residents’ well-being. However, whilst they all agreed this in principle, there was a disconnect between the theory, and how it might be implemented in practice. The assigning of responsibility for any potential adverse events was seen as a crucial problem. The conflicting nature of this problem for front-line care staff is highlighted in a study by Li et al. (2021). In this study, a potentially risky scenario was presented to a range of staff. Nurses and care workers were less than half as likely to agree with the principle to help a resident take risks, compared to executive level staff and senior nurse leaders. This may be because these more junior staff are the ones who to make the day-today-decisions for the residents in their care, and may be more wary of being held accountable for any adverse outcomes.

Care home staff in Ostaszkiewicz et al.’s (2016) study were described as working in a climate of fear, constantly concerned about getting into trouble, both with their own management and with regulatory bodies. This led to them adopting overprotective behaviours towards residents in their care in what was described as a zero-tolerance approach to risk. This Australian study confirmed findings of earlier studies from Canada (DeForge et al. 2011) and the United States (Colon-Emeric et al. 2010), who found that the strong fear of regulatory bodies could paradoxically lead to reduced quality of care. Struthers (2017) raised concern about an over-emphasis on what he called an ‘audit’ culture in care homes, where hard, quantifiable measurements are seen as key for measuring quality of life, with authorities arguing for ever tougher enforcement. It is difficult to see how this can be reconciled with the principles of ‘dignity of risk’ (Ibrahim and Davis 2013) when considering enhancing self-care in relation to taking medication.

Consideration of these principles in relation to medication is particularly challenging, in view of the real risks of serious harm from medication-related adverse events. The residents in this study all had different abilities and expressed their wish for control in different ways. Some would perhaps not wish to be involved at all in managing their own medication, but the potential to offer them more of an active role remains.

7.4.3 Compassionate ageism as a threat to autonomy

There were occasions illustrated in the findings from this study, when care staff demonstrated assumptions that the residents in their care were not able to manage something for themselves. Annie could pick up her own tablets and put them in her mouth, yet some of the carers did that for her, ‘feeding’ them in, when she was quite able to do this for herself. Sometimes incompetence was initially presumed, as when Marion had to earn the right to be left with her own tablets. My own notes in Norman’s observation template record my feeling that I wanted to help him with taking his drink of water. He managed by himself, so why would I have felt I needed to help?

There is a delicate balance between respecting the right to autonomy and caring for residents’ safety which staff see as a core mandate of their job (Sims-Gould et al. 2014). There may be a disparity between care providers’ determinations about their residents’ best interests, and the residents’ actual best interests (Tuckett 2006). The stereotypical image of older people, especially residents of care homes, as frail and vulnerable, can lead to a tendency for carers to infantilize or patronize the older person (Becker 1994; Tuckett 2006; Vervaecke and Meisner 2021). The older person is labelled as incompetent or dependent, ‘doddering but dear’ (Cuddy and Fiske 2002, p.2). A benevolent desire to protect them from risk may be denying their capacity for autonomy.

The term ‘compassionate ageism’ has been used to describe this benevolent but patronising attitude to older people, attributing them with incompetence, dependence and passivity, which can result in over-responsive helping behaviours (Vervaecke and Meisner 2021). Whilst care staff may be well-meaning, they may be overly protective, placing the residents in their care in the role of vulnerable adult, taking possession of their abilities and their decision-making, albeit for altruistic reasons. Frail people are seen to be permanently at risk and unable to manage their day to day lives without the kindly protection of others (Gilleard and Higgs 2010). There has been a focus on the provision of what are seen as protective measures upon an older person showing signs of cognitive impairment, effectively denying their identity as a person (Quinn et al. 2018). Naughton et al. (2021) go on to consider whether those who see themselves as advocating on behalf of older people, may be inadvertently reinforcing ageism, with negative stereotypes of vulnerability and dependence. Several of the residents in my study do appear to have been affected by this type of over-protective behaviour. Sometimes carers fed the tablets directly into Annie's mouth, when she was quite capable of doing this for herself. Both Norman and Marion were presumed by the staff to be incompetent to be left unattended with their medication, and had to earn the right exercise this ability.

For the nursing profession, the requirement to 'act as an advocate for the vulnerable' is integral to The Code of Conduct (Nursing and Midwifery Council 2018) and is seen as a traditional virtue (Beauchamp and Childress 2013). However, Zomorodi and Foley (2009) argue that there is only a thin line between advocacy and paternalism, where nurses may think that they are acting in the best interests of a patient, and unwittingly cross the line from advocacy into denying autonomy. Zomorodi and Foley (2009) go on to advise that by taking time to understand the life experiences, values and beliefs of people in their care, staff can better negotiate this fine line between advocacy and paternalism, which is inherently contradictory and difficult to manage. The findings from my study reinforce the need to consider individual needs and wishes, and indicate that the activity of administration of medication may currently be a missed opportunity to enhance the ability of residents to exercise their autonomy.

7.5 Section 4: Imbalance of power for residents of care homes - power, powerlessness and working towards empowerment.

7.5.1 Introduction

Exploring the experience of medication administration in this research has ultimately brought to light a single overarching phenomenon, which was seen to pervade all the concepts of trust, routine and autonomy which were seen in the findings. The experience of residents of care homes in administration of medication overall is one of powerlessness. This was identified in earlier work by Hughes (2008), specifically in relation to compliance with medication in care homes, but can now be shown to have much wider implications.

This section will discuss the imbalance of power for residents of care homes which has been revealed in my study in relation to the wider literature in this field. It will explore how residents of care homes feel that they have to conform to the rules of the institution. The hierarchical levels of power which affect residents of care homes will be discussed, including the powerful culture of medicine and the medical model of care.

Finally, the concept of empowerment and empowering practice will be introduced, culminating in consideration of the possibility of empowering practices specifically in relation to the administration of medication.

7.5.2 Power and powerlessness

Bowers et al. (2009) concluded that a care home is an environment where there is a great imbalance of power between the residents and those who care for them. This imbalance is between the autonomy of the individual and the power of the professional and institutional culture that has its own values and expectations (Collopy 1995). The word autonomy in its literal sense means ‘self-rule’, and encompasses self-rule that is free from controlling interference, and limitations that prevent meaningful choice (Beauchamp and Childress 2009, p. 101). In the process of analysing the findings from this study, the code which was initially used for autonomy was eventually changed to ‘being in control’, which seemed a more appropriate and person-centred description at the time. It has been shown that the residents in this study were very often not in control, being subject to external powers on many levels.

7.5.3 Conforming to the rules

Care home residents are known to conform to what are seen as the rules of their situation. Granville et al. (2011) found that care home residents were sometimes so affected by a feeling of disempowerment that they could not speak up to ask about things which concerned them. Sometimes this was for fear of upsetting the equilibrium, and also because of uncertainty about what was, or was not allowed within the care home, or a need to seek permission. Residents in Tuominen et al.’s (2016) research felt that they had to conduct themselves politely and obediently with the staff, to be able to have the opportunity to exercise free will, but that sometimes they just settled into institutional procedures so as not to cause trouble. A resident in Nakrem et al.’s (2012) study said that they had to conform to the routines, ‘sometimes we are forced… staff want to have their way’ (p.6). Nakrem et al. (2012) wrote that the care home environment is bound by institutional rules and procedures, both physical and cultural. Wiersma and Dupuis (2010) also found that staff place great importance on the home routines, and that residents had to gradually learn to fit in with what was expected of them. Staff found ways to let residents know that they must conform. Having interviewed staff and residents in depth they drew a stark conclusion that the ‘residents’ bodies became institutional property, managed and defined by the institution and staff’ (Wiersma and Dupuis 2010, p. 2890)

In a hospital context, patients in Manias et al.’s (2004) study of self-administration of medication, felt that there would be a ‘power struggle’ if they were allowed to perform this role (p.198), but they also said that the role of the patient was to allow the nurse to deliver the care for them. This new social role is forced upon individuals who see themselves as unwell (Shin 2015) which compounds the powerlessness of the patient. The findings from my study support this concept within a care home context also, with some of the residents specifically expressing such feelings, as when Morag said that she “*let them get on with it, even though it was a bit annoying*” for her, and Renee, who felt that that she had to, *“fall in line, cause I have to…. and I don’t see the point of complaining”*. Their conforming to their situation against their wishes was obvious.

7.5.4 A hierarchy of institutional power

The care home itself is subject to regulation and commissioning authorities. It also operates its own systems of power, with corporate governance and staff regulation, a hierarchical structure of power which leaves the residents the most powerless (Gilleard and Higgs 2017). Shin (2015) argued that the building itself communicates power relations, directing the residents how to behave accordingly. The power of regulatory bodies to which staff are subject is known to have adverse consequences for the residents (Colon-Emeric et al. 2010; DeForge et al. 2011; Ostaszkiewicz et al.’s (2016). Staff in Kalaitzidis and Harrington’s (2018) study felt that imposed regulations directly influenced the ability of residents to exercise choice and control, and that their practice was limited by organisational policy.

However, an interesting observation was made by Woolford et al. (2019), that senior policy makers from the care sector all agreed that the individual residents’ rights were paramount. At no time did they consider that an organisation had any rights, yet the multiple levels of power appear to place the resident at the bottom.

7.5.5 The power of the culture of medicine

The trusting relationship which residents in my study demonstrated, with both their medication and with the care home itself, is in turn influenced by the power relationship with the medical profession and the medical model of care. The medical profession traditionally holds expert power and status by virtue of their knowledge, skills and abilities

(Saxena et al. 2019), and medication holds real and symbolic power as discussed earlier (Nasciemento and Ramalho-de-Oliveira 2021; Van der Geest and Whyte (1989).

A medical model culture also predominates in care homes, overemphasising safety, uniformity, and medical issues (White-Chu et al. 2009). Drivers of quality of care led to unintended consequences of an increased medicalisation of care homes. Medicalised structure still prevails in long-term care facilities, with care and medication scheduled to be given in rounds (Lanoix 2017), and an established hierarchy amongst staff and visiting health professionals which hinders effective communication (Heinrich et al. 2022). The medical model emphasises a person's disease and deficits rather than the person themselves. It places the person as a passive recipient of treatment, although co-operation with treatment is expected (Wade and Halligan 2005). This aligns with a paternalist model of practice, where a health professional makes decisions which they consider to be in the best interest of the patient, and the patient is expected to co-operate (Silverman et al 2005). Whilst there is evidence that some older people welcome this model of care, they may also find this patronising, and that they feel treated as objects (Casado et al, 2020; Hestevik et al. 2019).

The Foucauldian perspective of the power of the medical profession can be viewed as even more pervasive, because power is enforced as much by authority figures as unconsciously, by individuals who are in positions of powerlessness (Lupton 2012). They may also choose to take on the 'good patient' as an active decision (Lupton 2012, p.11), maintaining the power differential between them.

In summary, there are multiple reasons why care home residents are at risk of being subject to an imbalance of power. There is also however, considerable work being undertaken to restore that balance, and facilitate their empowerment, which will be discussed in the next section.

7.6 Empowerment

7.6.1 Defining empowerment.

In a healthcare context, the World Health Organisation (1998 p.190) defines empowerment as a process through which people gain greater control over decisions and actions affecting their health. There is considerable overlap of terms in the literature, describing initiatives to promote empowerment, autonomy, or person-centred care. Van Corven et al. (2021) felt that it was unclear what empowerment meant in the context of older people living with dementia, both at home and in care homes. In collaboration with older people and care-givers, they defined four aspects of empowerment:

1. Having a sense of personal identity - being the person you have always been

2. Having a sense of choice and control

3. Having a sense of useful and being needed – doing what you are used to for as long as possible, and being challenged

4. Retaining a sense of worth

Whilst empowerment is not synonymous with autonomy, it can be a way to promote autonomy, as peoples' participation in decision-making concerning their health care is an important part of exercising autonomy. In addition, the term person-centred care has also been used to describe the empowering approach that emphasizes older peoples' personalised preferences, abilities and strengths (Yee at al. 2021).

7.6.2 Empowering practice – person-centred care

Yee et al.'s (2021) systematic review of person-centred care for older people in long-term care concluded that there was a discrepancy between residents and staff opinions on what constituted good person-centred care, and that each group had different interests and values. Yee at al. (2021) felt that overall, the voices of residents were largely still being ignored. Bradshaw et al. (2012) conducted a systematic review of studies seeking to find what contributed to a feeling of 'living well' in care homes. They identified that residents taking an active part in their daily living felt more in control of their lives. Molony (2010) concluded that residents want to be more independent and self-determined and that the long-term care environment should aim to seek to learn the 'meaning of me' (p. 305) to provide true person-centred care.

Initiatives in the United Kingdom such as 'My Home Life' (Owen and Meyer 2012) and internationally in 'Re-imagining Long-Term Residential Care' (Banerjee et al. 2011) are encouraging improvements in person centred care. White Chu et al. (2009) reported on several homes where changes were being made to give residents increased choice and autonomy in daily routines, meal-times, personal hygiene and activity. However, recent work by Verbeek and Mitchell (2022) indicates that a task-oriented approach prevails, although staff are changing their focus to encourage residents to exercise their remaining capacities were possible.

There is much written advising a shift in emphasis to empowering practices, enhancing mastery and decision making with regard to daily life within care homes. Specific mention of many areas where person-centred practices could be focused recur through the literature without mention of taking medication. Improving flexibility about what to eat and when, is a common theme when residents and staff were asked (Bouman et al. 2019; Hedman et al. 2019; Kalaitzidis and Harrington 2018; van Corven et al. 2021; Nakren et al. 2012; Tuominen et al. 2016; Yee et al. 2021). Being able to choose when to take a shower or a bath was also a priority (Hedman et al. 2019; Tuominen et al. 2016; Yee et al. 2021), then choosing what to wear (van Corven et al. 2021) and getting themselves dressed even if it was more time-consuming for staff (Hedman et al. 2019). Freedom of movement was considered empowering (van Corven et al. 2021; Tuominen et al. 2016), as was being able to control what time to get up and go to bed (Hedman et al. 2019; Tuominen et al. 2016). Respect for privacy and personal space was mentioned as being important in several studies (Hedman et al. 2019; Kalaitzidis and Harrigton 2018; Nakrem et al. 2012; Tuominen et al. 2016), whilst many studies highlighted the need to facilitate residents to participate in activities of their choice (Hedman et al. 2019; Nakrem et al. 2012; Tuominen et al. 2016; van Corven et al. 2021; Yee et al. 2021).

Bouman et al. (2019) concluded that all aspects of living in residential care needed examining, for opportunities to facilitate empowering practices. Yet, despite many studies reaching similar conclusions, there has been no mention found in the literature of the potential for empowering person-centred practice in the process of administration of medication. This may be significant in that staff and residents had perhaps not thought of it as an option for which empowering practice could be extended, and also because researchers as yet have not seen it as a topic for inquiry. However, from a different perspective it has been suggested that manufacturers of medications could have a part to play in optimising the characteristics of medication in terms of colour and shape to aid visual identification and facilitate independent medicines management for older people (Shariff et al. 2020)

Considering the four aspects of empowerment which were identified from van Corven et al.’s (2021) study, and in the light of the findings from my own research, it can be assumed that the principles of empowering practice could, and should, be extended to the practice of medication administration.

7.7 Summary

This study has been unique in being the first to seek to understand the experience of residents of care homes with the administration of their medication. This discussion has explored the findings of this research and related the experiences of these residents to relevant wider evidence. The findings of this study are not surprising when examined in the context of the wider literature about routines, trust, autonomy and power. However, this is the first study to explore this topic and to demonstrate the relationship between administration of medication in care homes and these concepts.

Exploring the experience of this specific activity within this specific context has highlighted the importance of facilitating personal routines when administering medication in a care home setting, and that these strategies may be helpful in promoting self-care. Residents' expressions of trust in the staff and in their medication, may be an indication of their vulnerability. Whilst residents may wish to maintain elements of control over the processes of medication administration, there are considerable cultural and structural barriers to their autonomy in this area. Overall, the phenomenon which rose to the fore, is the experience of powerlessness which care home residents experience at the bottom of a hierarchy of power.

However, there are positive aspects of the findings, particularly the incidences where residents were supported with their individual medicine-taking routines. Reflecting on this in the light of knowledge about autonomy, trust and power, opens the possibility that even small adjustments to practice could have a significant influence on the quality of life for an individual resident. Consequently, the activity of administration of medication could be seen as having potential to be an empowering process, and a focus for person-centred care.

Chapter 8: Conclusion

8.0 Introduction

This chapter will begin by discussing the strengths and limitations of this research. It will go on to consider implications for practice, both for providers of care and for clinicians who prescribe medications for residents of care homes. Suggestions will be given for possible future work to address some of the questions which arose in this study. A brief summary of the study will close this section, before some concluding personal reflections about its conduct.

8.1 Strengths and limitations of this research

Before discussing any limitations of this study, its particular strengths can be highlighted. The existing knowledge in this field was very sparse, and the choice of a methodology which sought solely to obtain in-depth information from care home residents themselves about taking their medication is unique. Whilst observation of medication administration had been previously used as a method of data collection, the innovative use of observation within a hermeneutic approach was particularly revealing. This study is the first to date to bring to light an understanding of the experience of the residents during this activity in their daily lives.

This research was conducted with a small sample of eight care home residents, with a purposely selected group of participants, from a three care homes who agreed to take part. The geographical location was restricted to a single health board area of Scotland. These factors have implications for any attempt at generalisability from the findings. However, generalisability is not the purpose of a hermeneutic phenomenological study (Peoples 2021). All that was sought was a sample of people who knew something about the phenomenon in question, and the potential for transferability of these finding will be discussed further in the next section.

Recruitment to this study was also restricted to those with capacity to consent to research. This additionally had the effect of limiting recruitment to the more able residents who were perhaps not typical of the wider care home population given the prevalence of dementia (Lithgow et al. 2012; Stewart et al. 2014). This may be a limiting factor for its transferability of the findings across the general population of care home residents, but also provides impetus for further research.

8.2 Recommendations and implications for practice

Transferability of findings is, in the strictest sense, impossible from a small-scale hermeneutic study. The findings have been presented with as much rich description as possible to enable a reader to reach their own conclusions as to whether transfer could be a possibility (Lincoln and Guba 1985). The text which is derived from the participants' experience is intended to provoke thought, raising questions which need to be answered (Austgard 2012). Nevertheless, some application of the issues uncovered in this study throughout the wider care home population can be recommended. Although each participant had their individual has their own needs and wishes, there are also common features. The findings from this study have implications for practice across three different fields, for those who provide the care, those who prescribe medication, and for those who educate and train practitioners in these fields.

For providers of care:

1. It is recommended that attempts should be made to establish what level of control over their medication administration that each individual resident might want to take, leading to strategies to facilitate individual needs and wishes.
2. Care planning should support individual routines, considering providing prompts and cues to help residents who wish to manage some or all of their own medication-taking processes. This should be seen as an extension to the scope of person-centred, empowering practices.
3. Awareness should be raised of the potential for unintended consequences of an overly protective safety culture regarding medication. This may need addressing at every level in the care sector, from individual care homes through senior management and to regulatory bodies, as the current hierarchy of levels of power, may effectively be contributing to a denial of power to the residents in their care.
4. Care staff involved in medication administration need to be made aware the levels of trust which resident place in them during this process, and the potential consequences of this relationship.

For prescribers of medication there are two main points to consider:

1. There was a striking contrast between what some of the residents said in interview, with what was witnessed in observation, particularly with regard to the

practicalities of ingesting oral medication. A routine medication review might currently include a question such as, “Do you have any trouble taking your tablets?” However, the resident who managed an extraordinarily complex process to get her tablets down, when questioned told me that she just ‘pops them over.. it’s easy’. Acknowledging that it would be very time consuming to include observation of taking medication as part of every routine review, prescribers may wish to consider more carefully how challenging the procedure may be for the individual resident for whom they are prescribing. Care-providers who support medication administration should be included in information-gathering as part of this assessment. Observation of administration of medication could be a useful element of the training programme for prescribers, to help make a connection at an early stage of training, between the act of prescribing and the person who has to take the medication.

2. The trusting relationship between residents and staff, coupled with the paradox of feeling that they have to take their medication, even if they are not sure what it is, presents an ethical problem to prescribers for care home residents. For those who are deemed to lack capacity for decision-making in this context, the situation is more straightforward, as ‘best interest’ decisions can be made. For those who retain some decision-making capacity there remains a duty on the part of the prescriber to ensure informed consent to treatment, including discussion about potential risks and benefits of any medication taken.

For educators:

There are implications for those who provide education and training across wider fields, including those who train carers in both residential care settings and in care-at-home, but also for pre-registration nursing students who will be involved in administration of medication in hospital and community settings.

Educators should consider how they can actively incorporate the principles of empowering practice when preparing nurses and carers to administer medication, including introducing the concept of compassionate ageism, and the significance of the trusting relationship between residents/patients and those who administer their medication.

8.3 Recommendations for future research

An exploratory hermeneutic phenomenological study is never an end of the story (Smythe 2011) it is just a beginning, opening the way for further research (Austgard 2012). The style of questioning was purposely very open, in an attempt to bring to light what was important to the residents. These findings are then used as a foundation for further enquiry. There is a lack of evidence base for much of the care provided to older people in care homes (Shepherd et al. 2017; Gordon et al. 2022), and there is significant scope for further research exploring this topic in more detail. Possible areas for future work could include:

- This study could be extended to include those without capacity to consent to research, which would give further depth and breadth of data, and be more representative of the wider care home population.
- Basic data collection is needed about numbers of care home residents currently able to administer their own medication. At present this appears to be unknown. How many care home residents wish to be more involved in administering their own medication? Are they asked about this, or given this choice?
- What do care home residents understand about the medication that they are being given, its risks and benefits?
- Would it be feasible to include an element of observation of medication administration into an enhanced medication review for care home residents with complex needs? If so, would it be worthwhile? Would there be any measurable benefits?
- What is the experience of residents of care homes of the medication review process?

Ideally there would be an element of direct involvement of care home residents and staff in any proposal and design of future work in this field. Despite increasing emphasis on service-users' involvement in research processes, marginalised groups such as care home residents and staff are often overlooked, even when studies are directly care-home focussed (Backhouse et al. 2016)

8.4 Summary of the study

Before this study was undertaken, very little was known about the experience of older people in care homes with taking their medication. A review of the literature established that staff used various strategies to ensure that medication was taken as prescribed, even if it was difficult for the residents, who often had swallowing problems. It was also known that medication administration occurred within a time-pressured environment which sometimes led to depersonalising practices and language. Residents are portrayed in the literature as disempowered and passive.

This study sought to explore the essence of the experience for the participants. We now know that the routines around taking their medication are important to the residents, and contributed to a feeling of security and being in control. Trying to maintain some control over the process of taking medication was important to some of the residents, whereas others seemed content to hand over this responsibility. Whilst they demonstrated, and verbalised, great trust in the staff, this revealed the nature of their vulnerability. There was a strong compulsion that they must take their tablets, almost as an act of faith, or a duty. Underpinning all the findings is the relationship of power and powerlessness on many levels, from the power of the medication and all that it represents, through the powerlessness of having to trust, and to the powerlessness of being in the role of a care home resident with all the potential threats to autonomy that this brings.

8.5 Personal reflections

In this final section I will reflect on my own journey through the conduct of this research. I will revisit my initial prejudices and discuss how these have been questioned and challenged throughout the research process, leading to the development of a new perspective which will be carried forward into my clinical practice.

8.5.1 The history which brought me to this research

A key feature of Gadamer’s philosophy is that we are all part of history, it is not possible to step outside our own history to be completely objective (Fleming 2003). Yet Gadamer also wrote of the aim of ultimately achieving a fusion of my own horizon as a researcher, with all the prejudices of my history and with the data with which I was entrusted by the participants (Fleming 2003). I inevitably brought my own background, my own history, with me whilst undertaking this study. The initial motivations which led to the desire to explore this topic, arose from this history.

The literature review which was undertaken at an early stage of developing this study will also undoubtedly have been influenced by my preconceived knowledge and prejudices. These will have affected my interpretation of that literature (Smythe and Spence 2012).

After conducting a formal exploration of the evidence, I had concluded that care home residents' experience of being given medication was overall fairly negative, perhaps even worse than I could have imagined. This literature review was conducted prior to any data collection or analysis, therefore becoming part of the history which I brought with me into the fieldwork.

I made a conscious decision to try to set aside thinking about the themes which had arisen from the literature review, as I wanted to immerse my mind wholly on the data which the participants were giving to me. I wanted to be certain that I heard their voices. From my epistemological stance, it is impossible to 'bracket out' fully the knowledge gleaned from the literature (Dibley et al. 2020, p.42). However, I purposely distanced myself from it, physically filing away the literature review chapter and source evidence, and leaving a 9-month time period during which I did not revisit it. Only once my analysis and findings had been written, did I reconsider the themes from the literature review, to be able to comment on their relationship to the new findings.

8.5.2 The transformative effect of the findings

As I worked with the findings from this study, whilst I did notice some resonance with pre-existing evidence from the literature, other elements of the findings were completely unexpected, challenging opinions and assumptions that I had long held. Some of the findings were entirely contradictory to the original expectations which I recorded in my pre-understandings. I had expected that the findings would mainly be about participants not liking to take their tablets, and wishing that they did not have to take them. That is ultimately not what was revealed at all. The findings which are essentially about power, or lack of power, surprised me. The submission to the power of the medical model and the medication itself, the power imbalance of the trust relationship, and the paradox of the contradictory ethical principles of autonomy and safety were all challenging to my expectations. In addition, they challenged my perception of myself as a health professional caring for residents of care home.

8.5.3 What I have learned about myself and about the topic - seeing with a new lens

Throughout this investigation I have been learning. At a fundamental level, in learning about the philosophical concepts I have gained a different understanding of what is knowledge, and what is truth. From a starting point where I accepted the hierarchy of evidence, where empirical science is held irrefutably as the only source of truth, I have learned that this can be questioned (Goldenberg 2009).

Awareness of my own prejudices grew at every stage of the research process, and was increasingly difficult to manage. I have had to be open to something new, arising directly from what these participants showed me. It has been uncomfortable to acknowledge the reality of what I am now aware has been my own career-long ‘compassionate ageism’. In adopting a professional role of care and concern for residents of care homes, I have viewed them as ‘other’, and as people in some way in need of my protection. I have certainly been guilty of feeling that, in the words of one of my participants, ‘I know better’, when it comes to making decisions for them about their medication. This was a major motivation for the choice to undertake this research. I thought of myself as an expert in this field, and ultimately came to realise that my understanding was naïve and superficial. They, the residents, are the experts in their experience, and they have helped me to learn about myself. This is why this study has been so important. What I have previously assumed as a health professional is not necessarily the experience of the care home residents. Hermeneutics has helped to reveal this.

I began to be more aware of my attitude. At one point early on during the analytical process I had made a note in my research journal saying, ‘avoid pity’. I had described one of the voices on a recording as ‘pitiful’, it was breathy and weak, difficult to listen to without feeling compassion. My description now feels very wrong, and says so much about me and my assumptions and nothing at all about this individual’s experience. He came across with dignity and spirit, despite his great physical challenges.

In the conscious endeavour to view the world through someone else’s eyes, I have really changed my perception. Subsequently, I have had to reconcile the discomfort of acknowledging my prejudices, with a commitment to making the best use of what I have learned in my future practice. I have been in such a privileged position to be able to be part of the participants’ life experience. It became part of my experience, and some of the material inevitably provoked an emotional response in me. I have had to find a way to express what I have seen, thought and experienced in words on the page.

8.5.4 Ending the research journey – and the way forward

Ultimately something new and something old merged into new knowledge (Austgard 2012). I cannot know if I managed to achieve real fusion of understanding with the participants. I can only say that I worked with their data as thoroughly and carefully as I could. My prejudices both enabled me to make sense of the situation, but may also have limited my understanding and ability to come to a new way of thinking (Spence 2017). In hermeneutic inquiry, there is potential to continue revising the search for knowledge endlessly, but in practical terms, an end-point has to be reached. The hermeneutic circle has to be closed, if only for now (Debesay et al. 2008).

Gadamer asserted that any findings are temporal in nature, essentially a snap-shot in time (Fleming et al. 2002). This study, and everything I have thought and learned along the way, now becomes part of my historical awareness. I brought myself to this and now I have to take this with me going forwards. Gadamer also said that there can be no ‘last word’ for a hermeneuticist (Gadamer 1975, p. 581). If anything can be seen as a final point, it is reached when there is a view of further research and understanding to come (Austgard 2012).

Whilst the potential meanings of this study are inexhaustible, I hope that my interpretations can be seen as plausible, and go on to resonate in wider contexts as the findings are disseminated. I presented some of the data to professional colleagues prior to any formal analysis, in the form of some of the observation vignettes, with the narrative transcripts of the interviews, giving voice to the participants as early as possible in the research process. I was given feedback that, “your stories are incredibly powerful”, and “you need to tell these stories over and over”. By sharing these participants’ stories, I am optimistic that they can go on to achieve a difference in clinical practice.

References

Achterberg, W., Caljouw, M. and Husebø, B.S. (2015) Academic nursing home medicine: a Dutch example for Norway. *Omsorg* 1.

Alldred, D.P., Kennedy, M.C., Hughes, C., Chen, T.F., Miller, P. (2016) Interventions to optimise prescribing for older people in care homes. *Cochrane Database of Systematic Reviews*, Issue 2. Art. No.: CD009095

Almutairi, H., Stafford, A., Etherton-Beer, C. and Flicker, L. (2020) Optimisation of medications used in residential aged care facilities: a systematic review and meta-analysis of randomised controlled trials. *BMC Geriatrics*, *20*(1), pp.1-19.

American Geriatric Society Beers Criteria Update Expert Panel (2015) Updated Beers Criteria for Potentially Inappropriate Medication use in Older Adults. *Journal of the American Geriatric Society* 63(11), pp. 2227-2246

American Geriatric Society (2019) Updated Beers Criteria for Potentially Inappropriate Medication use in Older Adults. *Journal of the American Geriatric Society* 67, pp. 674-94

Annells, M (1996) Hermeneutic Phenomenology: Philosophical perspectives and current use in nursing research. *Journal of Advanced Nursing* 23(4), pp. 705-713

Applebaum, P.S. and Grisso, T. (2001) *MacCAT-CR: MacArthur Competence Assessment Tool for Clinical Research.* Professional Resource Press. Sarasota, FL.

Aronson, J.K. (2004) In defence of polypharmacy. *Br.J.Clin. Pharmacol. 57(2)*, pp. 119-120

Ashworth, P. (2008) Conceptual foundations of qualitative psychology. in J.A. Smith (ed.) *Qualitative Psychology: A Practical Guide to Research Methods 2nd ed.* Sage.

Austgard, K. (2012) Doing it the Gadamerian way – using philosophical hermeneutics as a methodological approach in nursing science. *Scand J Caring Sci* 26(4), pp. 829-834

Avni-Babad, D. (2011) Routine and feelings of safety, confidence, and well-being. *British Journal of Psychology* 102(2), pp. 223-244

Backhouse, T., Kenkmann, A., Lane, K., Penhale, B., Poland, F. and Killett, A. (2016) Older care-home residents as collaborators or advisors in research: a systematic review. *Age and ageing*, *45*(3), pp.337-345

Banerjee, A., Armstrong, P., Armstrong, H and Rosenau, P. (2011) Re-Imagining Long-Term Residential Care: An International Study of Promising Practices. Social Science Research Network http://dx.doi.org/10.2139/ssrn.1909126 [accessed 08 August 2022]

Barber, N.D., Aldred, D.P., Raynor, D.K., Dickinson, R., Garfield, S., Jesson, B., Lim, R., Savage, I., Standage, C., Buckle, P., Carpenter, J., Franklin, B., Woloshynowych, M. and Zermansky, A.G. (2009) Care homes' use of medicine study: prevalence, causes and potential harm of medication errors in care homes for older people. *Quality and Safety in Health Care* 18, pp. 341-346

Barker, R.O., Hanratty, B., Kingston, A., Ramsay, S.E. and Matthews, F.E. (2021) Changes in health and functioning of care home residents over two decades: what can we learn from population-based studies? *Age and Ageing* 50(3), pp. 921-927

Barnes, L., Cheek, J., Nation, RL., Gilbert, A., Paradiso, L. and Ballantyne, A. (2006) Making sure the residents get their tablets: medication administration in care homes for older people. *Journal of Advanced Nursing* 56(2), pp. 190-199

Barnett, K., Mercer, S.W., Norbury, M., Watt, G., Wyke, S. and Guthrie, B. (2012) Epidemiology of multimorbidity and implications for health care, research and medical education: a cross-sectional study. *Lancet* 380(9836), pp. 37-43

Barnett, N.L., Oboh, L. and Smith, K. (2016) Patient centred management of polypharmacy: a process for practice. *Euro J Hosp Pharm* 23(2), pp. 113-117

Beauchamp, TL. and Childress, JF. (2009) *Principles of Biomedical Ethics* 7th ed. Oxford University Press

Becker, G. (1994) The Oldest Old: Autonomy in the Face of Frailty. *Journal of Aging Studies* 8(1), pp. 59-76

Beers, M.H., Ouslander, J.G., Rollingher, I., Reuben, D.B., Brooks, J. and Beck, J.C. (1991) Explicit criteria for determining inappropriate medication use in nursing home residents. *Archives of Internal Medicine* 151(9), pp.1825-1832.

Biggerstaff, D. and Thompson, A.R. (2008) Interpretative Phenomenological Analysis - A qualitative methodology of choice in healthcare research *Qualitative Research in Psychology* 5(3), pp. 214-224

Booth, T. (1996) Sounds of still voices: issues in the use of narrative methods with people who have learning difficulties. In L. Barton (ed) *Disability and Society: Emerging issues and insights*. London, Longman (pp. 237-55)

Boumans, J., van Boekel, L.C., Baan, C.A. and Luijkx, K.G. (2019) How can autonomy be maintained and informal care improved for people with dementia living in residential care facilities: A systematic literature review. *The Gerontologist*, *59*(6), pp. 709-730.

Bowers, H., Clark, A., Crosby, G., Easterbrook, L., Macadam, A., MacDonald, R., MacFarlane, A., MacLean, A., Patel, M., Runnicles, D. and Oshinaike, T. (2009) Older people’s vision for long-term care. Joseph Rowntree Foundation, York.

Bowman, C. and Lim, W.M. (2021) How to avoid ageist language in aging research? An overview and guidelines. *Activities, Adaptation & Aging 45*(4), pp.269-275.

Boyle, G. (2008) Autonomy in long-term care: A need, a right, or a luxury? *Disability and Society* 23(4), pp. 299-310

Bradshaw, S.A., Playford, E.D. and Riazi, A. (2012) Living well in care homes: a systematic review of qualitative studies. *Age and Ageing* 41(4), pp. 429-440

Brocki, J.M. and Wearden, A.J. (2006) A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health* 21(1), pp. 87-108

Brown, P.R. and Meyer, S.E. (2015) Dependency, trust and choice? Examining agency and ‘forced options’ within secondary healthcare contexts. *Current Sociology* 63(5), pp.729-745

Bryman, A. (2016) *Social Research Methods.* 5th ed. Oxford University Press.

Burton, J. K., Quinn, T. J., Gordon, A. L., MacLullich, A. M., Reynish, E. L., and Shenkin, S. D. (2017). Identifying published studies of care home research: an international survey of researchers. *Journal of Nursing Home Research*, 3 https://doi.org/10.14283/jnhrs.2017.15 [Accessed 06/01/22]

Caelli, K. (2001) Engaging with Phenomenology: Is it more of a challenge than it needs to be? *Qualitative Health Research* 11(2), pp. 273-281

Calderwood, C. (2016) *Realistic Medicine: Chief Medical Officer's Annual Report, 2014-15*. Scottish Government.

Care Inspectorate (2012) *Guidance about medication personal plans, review, monitoring and record-keeping in residential care services.* Care Inspectorate. Scotland

Care Inspectorate/Royal Pharmaceutical Society/Social Work Scotland (2015) *Prompting, assisting and administration of medication in a care setting: guidance for professionals.*

Care Quality Commission (2022) Self-administered medication in care homes (cqc.org.uk) [Accessed 12 November 2022].

Carvajal, FA., Martinez, MG., Santamaria, EC., Hernandez, BC., Orbis, IC., Casanova, RM., Sanchez, EM., Oyarzabal, AA., Alcantara, MJC. and Martos, EC. (2016) Adaptation of oral medication in people institutionalized in nursing homes for whom medication is crushed: The ADUCA Study. *Farmacia Hospitalaria* 40(6), pp. 514-528

Casado, T., Sousa, L. and Touza, C. (2020) Older People’s Perspective about their Participation in Health and Social Care Services: A Systematic Review. *J Gerontol Soc Work.* 63(8), pp. 878-892

Centre for Policy on Ageing (2011) *Managing and administering medication in care homes for older people: A review of information and literature.* cpa.org.uk [Accessed 20 June 2020]

Centre for Reviews and Dissemination (2009) *Systematic Reviews: Guidance for undertaking reviews in health care.* University of York.

Cerigo, H. and Quesnell-Vallee, A. (2020) Systematic Mixed Studies Reviews: leveraging the literature to answer complex questions through integration of quantitative and qualitative evidence. *International Journal of Public Health* 65(5), pp. 699-703

Chalmers, J. and Pearson, A. (2005) Oral hygiene care for residents with dementia: a literature review. *Journal of Advanced Nursing* 52(4), pp. 410-419

Chavez, C. (2008) Conceptualizing from the inside: Advantages, complications, and demands on insider positionality. *The Qualitative Report.* 13(3), pp. 474-494

Chen, E.Y.H., Bell, J.S., Ilomaki, J., Keen, C., Corlis, M., Hogan, M., Van Emden, J., Hilmer, SN. and Sluggett, J.K. (2019) Medication Regimen Complexity in 8 Australian Residential Aged Care Facilities: Impact of Age, Length of Stay, Comorbidity, Frailty, and Dependence in Activities of Daily Living. *Clinical Interventions in Ageing* 14, pp. 1783-1795

Chen, E.Y.H., Bell, J.S., Ilomaki, J., Corlis, M., Caporale, T.; Hogan, M., Van Emden, J., Westbrook, JI.; Hilmer, SN. and Sluggett, J.K. (2021) Medication administration in Australian residential aged care: A time-and-motion study. *Journal of Evaluation in Clinical Practice* 27(1), pp. 103-110

Cherubini, A., Oristrell, J., and Pla, X. (2011) The persistent exclusion of older patients from ongoing clinical trials regarding heart failure. *Arch Intern Med.* 171(6), pp. 550-556

Cohen, D., McCubbin, M., Collin, J. and Perodeau, G. (2001) Medications as Social Phenomena. *Health* 5(4), pp. 441-469

Collopy, B.J. (1995) Power, paternalism and the ambiguities of autonomy. In Gamroth, L.M., Semradek, J. and Tornquist, E.M. (Eds) *Enhancing autonomy in long-term care, concepts and strategies.* Springer. New York.

Colón-Emeric, C.S., Plowman, D., Bailey, D., Corazzini, K., Utley-Smith, Q., Ammarell, N., Toles, M. and Anderson, R. (2010) Regulation and mindful resident care in nursing homes. *Qualitative Health Research*, *20*(9), pp.1283-1294.

Conn, V.S., Ruppar, T.M., Enriquez, M. and Cooper, P. (2016) Medication adherence interventions that target subjects with adherence problems: systematic review and meta-analysis. *Research in Social and Administrative Pharmacy* 12(2), pp.218-246.

Cooke, A., Smith, D. and Booth, A. (2012) Beyond PICO: The SPIDER Tool for Qualitative Evidence Synthesis. *Qualitative Health Research* 22(10), pp.1435-1443

van Corven, C.T., Bielderman, A., Wijnen, M., Leontjevas, R., Lucassen, P., Graff, M. and Gerritsen, D. (2021) Defining empowerment for older people living with dementia from multiple perspectives: A qualitative study. *International Journal of Nursing Studies.* 114, p.103823

Craftman, A.G., Grape, C., Ringnell, K. and Westerbotn, M. (2016) Registered nurses' experience of delegating the administration of medicine to unlicensed personnel in residential care homes. *Journal of Clinical Nursing* 25(21-22), pp. 3189-3198

Creswell J.W. and Plano Clark, VL. (2011) *Designing and Conducting Mixed Methods Research.* 2nd ed. SAGE

Creswell, J.W. (2014) *Research Design.* 4th ed. SAGE

Crist, J.D. and Tanner, C.A. (2003) Interpretation/Analysis methods in Hermeneutic Interpretive Phenomenology. *Nursing Research* 52(3), pp. 202-205

Crotty, M. (1996) *Phenomenology and Nursing Research.* Churchill Livingstone. Melbourne.

Crowther, S., Smythe, E. and Spence, D. (2014) The joy at birth: An interpretive hermeneutic literature review. *Midwifery* 30(4), pp. 157-165

Crowther, S., Ironside, P., Spence, D. and Smythe, L. (2017) Crafting Stories in Hermeneutic Phenomenology Research: A Methodological Device. *Qualitative Health Research* 27(6), pp. 826-835

Crowther, S. and Thomson, G. (2020) From Description to Interpretive Leap: Using Philosophical Notions to Unpack and Surface Meaning in Hermeneutic Phenomenology Research. *International Journal of Qualitative Methods.* 19, p.1609406920969264.

Cuddy, A.J.C. and Fiske, S.T. (2002) Doddering but dear: Process, content and function in stereotyping of older persons. In Nelson, T.D. (Ed). *Ageism: Stereotyping and prejudice against older persons.* The MIT Press

Dahlberg, K. (2011) Lifeworld phenomenology for caring and health care research. In: Thomson, G., Dykes, F. and Downe, S. (Eds) *Qualitative Research in Midwifery and Childbirth: Phenomenological Approaches.* Routledge.

Darbyshire, P., Diekelmann, J. and Diekelmann, N. (1999) Reading Heidegger and interpretive phenomenology: a response to the work of Michael Crotty. *Nursing Inquiry* 6(1), pp. 17-25

Dean, B. and Barber, N. (2001) Validity and Reliability of observational methods for studying medication errors. *Am J of Health-System Pharmacy* 58(1) pp. 54-59

Debesay, J., Nåden, D. and Slettebø, Å. (2008) How do we close the hermeneutic circle? A Gadamerian approach to justification in interpretation in qualitative studies. *Nursing Inquiry,* 15(1), pp. 57-66

DeForge, R., Van Wyk, P., Hall, J. and Salmoni, A. (2011) Afraid to care; unable to care: A critical ethnography within a long-term care home. *Journal of Aging Studies* 25(4), pp.415-426

Dibley, L., Dickerson, S., Duffy, M. and Vandermause, R. (2020) *Doing Hermeneutic Phenomenological Research: A Practical Guide.* SAGE

Diekelmann, N. and Ironside, P.M (1998) Hermeneutics. In Fitzpatrick, J. (Ed.) *Encyclopedia of Nursing Research.* pp. 243-245 New York, Springer.

Dinç, L. and Gastmans, C. (2013) Trust in nurse–patient relationships: A literature review. *Nursing ethics*, 20(5), pp.501-516.

Doran, I. and Georgantzi, N. (eds) (2018) *Ageing, Ageism and the Law.* Elgar Publishing

Duerden, M., Avery, T., and Payne, R. (2013) *Polypharmacy and Medicines Optimisation. Making it safe and sound.* The Kings Fund. London.

Easterling, C.S. and Robbins, E. (2008) Dementia and Dysphagia *Geriatric Nursing* 29(4), pp. 275-285

Embree, L.E., Behnke, E.A., Carr, D., Evans, J.C., Huertas-Jourda, J., Kockelmans, J.J., McKenna, W.R., Mickunas, A., Mohanty, J.N., Seebohm, T.M. and Zaner, R.M. (eds.) (1997). *Encyclopedia of phenomenology.* Dordrecht. Kluwer.

Fleming, V., Gaidys, U. and Robb, Y. (2003) Hermeneutic research in nursing: developing a Gadamerian-based research method. *Nursing Inquiry* 10(2), pp. 113-120

Fodil, M., Nghiem, D., Colas, M., Bourry, S., Poisson-Salomon, AS., Rezigue, H. and Trivalle, C. (2017) Assessment of Clinical Practices for Crushing Medication in Geriatric Units. *Journal of Nutrition, Health and Aging* 21(8), pp. 904-908

Forough, A.S., Lau, E.T.L., Steadman, K.J., Kyle, G.J., Cichero, J.A.Y., Santos, J.M.S., and Nissen, L.M. (2020a) Appropriateness of oral dosage form modification for aged care residents: a video-recorded observational study. *International Journal of Clinical Pharmacy*. 42(3), pp. 938-947

Forough, A.S., Lau, E.T.L., Steadman, K.J., Kyle, G.J. Cichero, J.A.Y., Santos, J.M.S. and Nissen, L.M. (2020b) Factors affecting Australian aged care facility workers in administering oral medication to residents with swallowing difficulties. *Research in Nursing and Health* 43(4), pp. 419-430

Forough, A.S., Lau, E.T.L., Steadman, K.J., Kyle, G.J., Cichero, J.A., Santos, J.M.S and Nissen, L.M., (2021) Factors that affect health-care workers' practices of medication administration to aged care residents with swallowing difficulties: an Australia-wide survey study. *Australasian Journal on Ageing*, 40(1), pp.79-86.

Forsetlund, L., Eike, M.C., Gjerberg, E. and Vist, G.E. (2011) Effect of interventions to reduce potentially inappropriate use of drugs in nursing homes: a systematic review of randomised controlled trials. *BMC Geriatrics* 11(1), pp.1-19

Frechette, J., Bitzas, V., Aubry, M., Kilpatrick, K. and Lavoie-Tremblay, M., (2020) Capturing lived experience: Methodological considerations for interpretive phenomenological inquiry. *International Journal of Qualitative Methods*, 19, p.1609406920907254.

Gadamer, H-G. (1960) *Truth and Method.* Translated Weinsheimer, J. and Marshall, D.G. (2004) 2nd ed. New York. Continuum.

Gadamer, H-G. (1977) *Philosophical Hermeneutics.* Translated Ling, D. University of California Press.

Ganong, L.H. (1987) Integrative Reviews of Nursing Research. *Research in Nursing and Health* 10(1), pp. 1-11

Garratt, S.M., Jonas, M.F., Peri, K. and Kerse, N. (2021) To crush, or not to crush? Unauthorised covert administration of medication in nursing homes. *International Journal of Older People Nursing*, 16(5), p.e12393.

van der Geest, S. and Whyte, S. R. (1989) The Charm of Medicines: Metaphors and Metonyms. *Medical Anthropology Quarterly* 3(4), pp. 345-367

Gilbert, A.S. (2020) Conceptualising trust in aged care. *Ageing and Society*. 41(10), pp. 2356-2374

Gilbert, T., Bosquet, A., Thomas-Anterion, C., Bonnefoy, M. and Le Saux, O. (2017) Assessing capacity to consent for research in cognitively impaired older patients. *Clinical Interventions in Ageing* 12, pp. 1553-1563

Gilleard, C. and Higgs, P. (2010) Frailty, disability and old age: A re-appraisal. *Health* 15(5), pp.475-490.

Gilleard, C. and Higgs, P. (2017) An Enveloping Shadow? The Role of the Nursing Home in the Social Imaginary of the Fourth Age. In Chivers, S. and Kriebernegg, U. (Eds) *Care Home Stories.* Transcript. Verlag.

Giorgi, A. (2005) The Phenomenological Movement and Research in the Human Sciences. *Nursing Science Quarterly.* 18(1), pp. 75-82

Giorgi, A. (2009) *The Descriptive Phenomenological Method in Psychology: A Modified Husserlian Approach.* Pittsburgh. Duquesne University Press.

Glaser, B.G and Strauss, A.L. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research.* New York. Aldine.

Goble, E. Austin, W., Larsen, D., Kreitzer, L. and Brintnell, E.S. (2012) Habits of mind and the split mind effect: When computer assisted qualitative data analysis software is used in phenomenological research. *Forum: Qualitative Social Research* 13(2)

Gold Standards Framework (2016) *Gold Standards Framework Care Homes Training Programme* http://www.goldstandardsframework.org.uk [Accessed 08/04/2018]

Goldenberg, M.J. (2009) Iconoclast or creed? Objectivism, pragmatism, and the hierarchy of evidence. *Perspectives in Biology and Medicine.* 52(2), pp. 168-87

Goodman, C., Baron, N.L., Machen, I., Stevenson, E., Evans, C., Davies, S.L. and Iliffe, S. (2011) Culture consent costs and care homes: enabling older people with dementia to participate in research. *Ageing Mental Health* 15(4), pp. 475-481

Gordon, A.L., Franklin, M., Bradshaw, L., Logan, P., Elliott, R. and Gladman, J.R.F. (2013) Health Status of UK care home residents: a cohort study. *Age and Ageing* 43(1), pp. 97-103

Gordon, A.L., Rick, K., Juszczak, E., Montgomery, L., Howard, R., Guthrie, B., Lim, W.s., Shenkin, S., Leighton, P. and Bath, P.M. (2022). The Covid-19 pandemic has highlighted the need to invest in care home research infrastructure. *Age and Ageing.* 51(3) pp. 1-4

Grant, M.J. and Booth, A. (2009) A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information and Libraries Journal* 26(2), pp. 91-108

Granville, G., Runnicles, D., Barker, S., Lee, M., Wilkins, A. and Bowers, H. (2011) *Increasing the Voice, Choice and Control of Older People with High Support Needs.* HM Government, Office for Disability Issues.

Greene, M.J. (2014) On the inside looking in: Methodological Insights and Challenges in Conducting Qualitative Insider Research. *The Qualitative Report* 19(29), pp. 1-13

Greener, I. (2003) Patient choice in the NHS: The view from economic sociology. *Social Theory and Health* 1(1), pp.72-89

Greenhalgh, T., Snow, S., Ryan, S., Rees, S. and Salisbury, H. (2015) Six 'biases' against patients and carers in evidence-based medicine. *BMC Medicine* 13(1), pp.1-11

Guidry-Grimes, L., Dean, M. and Victor, E.K. (2021) Covert administration of medication in food: a worthwhile moral gamble? *Journal of medical ethics*, *47*(6), pp.389-393.

Guthrie, B., Makubate, B., Hernadez-Santiago, V., and Dreischulte, T. (2015) The rising tide of polypharmacy and drug-drug interactions: population database analysis 1995-2010. *BMC Medicine* 13(1), pp.1-10

Guyatt, G.H., Sackett, D.L., Sinclair, J.C., Hayward, R., Cook, D.J and Cook, R.J. (1995) Users' guides to the medical literature: IX. A Method for grading health care recommendations. *JAMA* 274(22), pp. 1800-4

Hall, M.A., Dugan, E., Zheng, B and Mishra, A.K. (2001) Trust in Physicians and Medical Institutions: What is it, can it be measured, and does it matter? *The Millbank Quarterly* 79(4), pp. 613-639

Hall, S., Longhurst, S. and Higginson, I.J. (2009) Challenges to conducting research with older people living in nursing homes. *BMC Geriatrics* 9(1), pp.1-8

Hammond, C.A.S., Goldstein, L.B., Horner, R.D., Ying, J., Gray, L., Gonzalez-Rothi, L. and Bolser, D.C. (2009) Predicting aspiration in patients with ischaemic stroke: comparison of clinical signs and aerodynamic measures of voluntary cough. *Chest* 135(3), pp. 769-777

Hay-Smith, E.J.C., Brown, M., Anderson, L. and Treharne, G.J. (2016) Once a clinician, always a clinician: a systematic review to develop a typology of clinician-researcher dual-role experiences in health research with patient-participants. *BMC Medical Research Methodology* 16(1), pp.1-17

Hedman, M., Häggström, E., Mamhidir, A.G. and Pöder, U. (2019) Caring in nursing homes to promote autonomy and participation. *Nursing ethics*, 26(1), pp.280-292.

Heidegger, M. (1927) *Being and Time*. Translated Macquarrie, J. and Robinson, E. (1962). Oxford Blackwell.

Heidegger, M. (1993) 'Building dwelling thinking', in Krell, D.F. (ed) *Basic Writings: Martin Heidegger.* London: Routledge, pp. 347-363

Heinrich, C.H., Hurley, E., McCarthy, S., McHugh, S. and Donovan, M.D. (2022) Barriers and enablers to deprescribing in long-term care facilities: a 'best-fit'framework synthesis of the qualitative evidence. *Age and Ageing* 51(1), pp. 1-19

Heintzelman, S.J. and King, L.A. (2019) Routines and Meaning in Life. *Personality and Social Psychology Bulletin* 45(5), pp. 688-699

Hestevik, C.H., Molin, M., Debesay, J., Bergland, A. and Bye, A. (2019) Older persons' experiences of adapting to daily life at home after hospital discharge: a qualitative metasummary. *BMC health services research*, 19(1), pp.1-13.

Heyvaert, M., Hannesa, K. and Onghena, P. (2017) *Using Mixed Methods Research Synthesis for Literature Reviews.* SAGE

Highet, G., Crawford, D. and Murray, S.A.(2014) Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study *BMJ Supportive & Palliative Care* 4(3), pp. 285-290.

Hjaltadóttir, I. and Gústafsdóttir, M. (2007) Quality of life in nursing homes: perception of physically frail elderly residents. *Scandinavian Journal of Caring Sciences* 21(1), pp.48-55.

Holloway, I. and Wheeler, S. (1996) *Qualitative Research for Nurses.* Oxford: Blackwell Science

Holman, C., Meyer, J. and Cotter, A. (2004) The Complexity of Loss in Continuing Care Institutions for Older People: A Review of the Literature. *Illness, Crisis and Loss.* 12(1), pp. 38-51

Hong, Q.N., Pluye, P., Fabregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M-P., Griffiths, F., Nicolau, B., O'Cathain, A., Rousseau, M-C. and Vedel, I. (2018) *Mixed Methods Appraisal Tool (MMAT) Version 2018.* Canadian Intellectual Property Office, Industry Canada

Hughes, C.M. (2008) Compliance with Medication in Nursing Homes for Older People: Resident Enforcement or Resident Empowerment? *Drugs and Ageing* 25(6), pp. 445-454

Hughes, C.M. and Goldie, R. (2009) "I Just Take What I am Given". Adherence and Resident Involvement in Decision Making on Medicines in Nursing Homes for Older People: A Qualitative Survey. *Drugs and Ageing* 26(6), pp. 505-517

Hughes, C.M., Cooper, J.A. and Ryan, C (2014) Going beyond the numbers – a call to redefine polypharmacy. *British Journal of Clinical Pharmacology.* 77(6), pp. 915-916

Husserl, E. (1901) *Logical Investigations Vol II.* Translated: Findlay, J. (1970) Routledge and Kegan Paul. London.

Ibrahim, J.E. and Davis, M-C. (2013) Impediments to applying the 'dignity of risk' principle in residential aged care services. *Australasian Journal on Ageing* 32(3), pp. 188-93

Information Commissioner's Office (2018) *Guide to the UK General Data Protection Regulation (UK GDPR).* Available at: https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr [Accessed 7 July 2021].

Ironside, P.M. (2003) New pedagogies for teaching thinking: The lived experiences of students and teachers enacting narrative pedagogy. *Journal of Nursing Education, 42*(11), pp. 509-516

Iser, W. (1972) The Reading Process: A Phenomenological Approach. *New Literary Theory* 3, pp. 279-299

Jackson, D.J., Little, J., Kung, E., Williams, E.M., Siemiatkowska, K. and Plowman, S. (2008) Safe Medication Swallowing in Dysphagia: A Collaborative Improvement Project. *Healthcare Quarterly* 11(3), pp. 110-116

Jani, Y.H., Liu, F., Orlu, M., Desai, N., du Chayla, F., Ruiz, F. and Vallet, T. (2022) Medicine acceptability for older people in hospital and care home: the influence of setting. *International Journal of Pharmacy Practice*, 3(1), pp. 67-74.

Jeste, D.V., Palmer, B.W., Appelbaum, PS., Golshan, S., Glorioso, D., Dunn, LB., Kim, K., Meeks, T. And Kraemer, H (2007) A New Brief Instrument for Assessing Decisional Capacity for Clinical Research. *Archives of General Psychiatry* 64(8), pp. 966-974

Jiang, F.K. and Hyland, K. (2020) Prescription and reality in advanced academic writing. *Ibérica* 2(39), pp.14-42.

Johnstone, A.M. and Donaldson, A.I. (2018) Care home research: future challenges and opportunities. *Geriatrics*, *4*(1), p.2.

Joint Formulary Committee (2022) *British National Formulary 83.* London. BMJ Publishing and the Royal Pharmaceutical Society.

Kafle, N.P. (2011) Hermeneutic phenomenological research method simplified. *Bodhi: An interdisciplinary journal* 5(1), pp.181-200

Kalaitzidis, E. and Harrington, A. (2018) Resident decision-making in the context of residential aged care. *Collegian* 25(5), pp. 509-515.

Kane, R. (2001) Long-term care and a good quality of life: Bringing them closer together. *The Gerontologist* 41(3), pp. 293-304

Kay, L. (2019) Guardians of research: negotiating the strata of gatekeepers in research with vulnerable participants. *Practice*, *1*(1), pp.37-52

Kelly, J., D'Cruz, G. and Wright, D. (2009) A Qualitative study of problems surrounding medicine administration to patients with dysphagia. *Dysphagia* 24(1), pp. 49-56

Kelly, J., D'Cruz, G. and Wright, D. (2010) Patients with dysphagia: experiences of taking medication. *Journal of Advanced Nursing* 66(1), pp. 82-91

Knight, C.S., Haslam, A. and Haslam, C. (2010) In home or at home? How collective decision-making in a new care facility enhances social interaction and well-being amongst older adults. *Ageing and Society,* 30(8), pp. 1393-1418

Koch, T. (1996) Implementation of a hermeneutic inquiry in nursing: Philosophy, rigor and representation. *Journal of Advanced Nursing* 24(1), pp. 174-184

Lanoix, M. (2017) Home Interrupted. pp. 39-52 in Chivers, S. and Kriebernegg, U. (Eds) *Care Home Stories.* Transcript

Laverty, S.M. (2003) Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations. *International Journal of Qualitative Methods.* 2(3), pp. 23-35

Lee, H., Baek, Y.H., Kim, J.H., Liao, T.C., Lau, W.C., Man, K.K., Qin, X., Wood, S., Ilomäki, J., Bell, J.S. and Lai, E.C.C. (2023) Trends of polypharmacy among older people in Asia, Australia and the United Kingdom: a multinational population-based study. *Age and Ageing*, *52*(2)

Lenaghan, E., Holland, R. and Brooks, A. (2007) Home-based medication review in a high-risk elderly population in primary care - the POLYMED randomised controlled trial. *Age and Ageing* 36(3), pp. 293-297

Li, Y., Bugeja, L., Bhullar, N. and Ibrahim, J.E. (2021) Attitudes towards dignity of risk in older people: A survey following a short narrative film. *Australasian Journal of Ageing*. 40(3), pp. 317-322

Liabeuf, S., Gras, V., Moragny, J., Laroche, M. and Andrejak, M. (2014) Ulceration of the oral mucosa following direct contact with ferrous sulphate in elderly patients: a case report and a review of the French National Pharmacovigilance Database. *Clinical Interventions in Ageing* 9, pp. 737-740

Lincoln, Y.S. and Guba, E.G. (1985) *Naturalistic Inquiry.* SAGE

Lindberg, C., Fagerström, C., Sivberg, B. and Willman, A. (2014) Concept analysis: patient autonomy in a caring context. *Journal of Advanced Nursing*, 70(10), pp. 2208-2221

Lithgow, S., Jackson, GA. and Browne, D. (2012) Estimating the prevalence of dementia: cognitive screening in Glasgow nursing homes. *International Journal of Geriatric Psychiatry* 27(8) pp 785-791

Liu, F., Ghaffur, A., Bains, J. and Hamdy, S. (2016) Acceptability of oral solid medicines in older adults with and without dysphagia: A nested pilot validation questionnaire based observational study. *International Journal of Pharmaceutics* 512(2), pp. 374-381

Liyanage, T., Mitchell, G. and Senior, H (2018) Identifying palliative care needs in residential care. *Australian Journal of Primary Health.* 24(6), pp. 524-529

Logrippo, S., Ricci, G., Sestili, M., Cespi, M., Ferrara, L., Palmieri, G.F., Ganzetti, R., Bonacucina, G. and Blasi, P. (2017) Oral drug therapy in elderly with dysphagia: between a rock and a hard place! *Clinical interventions in aging*, 12, pp. 241-251

Lundby, C., Jensen, J., Larsen, S.P., Hoffman, H., Pottegard, A. and Reilev, M. (2020) Use of medication among nursing home residents: a Danish drug utilisation study. *Age and Ageing.* 49(5), pp. 814-820

Lupton, D. (2012) *Medicine as culture: Illness, disease and the body*. SAGE.

Mackey, S. (2005) Phenomenological nursing research: methodological insights derived from Heidegger’s interpretive phenomenology. *International Journal of Nursing Studies.* 42(2), pp. 179-186

Maher, C., Hadfield, M., Hutchings, M. and de Eyto, A. (2018) Ensuring Rigor in Qualitative Data Analysis: A Design Research Approach to Coding Combining NVivo with Traditional Material Methods. *International Journal of Qualitative Methods* 17(1), pp. 1-13

Mandal, FB. (2014) Non-verbal Communication in Humans. *Journal of Human Behaviour in the Social Environment* 24(4), pp. 417-421

Manias, E., Beanland, C., Riley, R. and Baker, L., (2004) Self-administration of medication in hospital: patients' perspectives. *Journal of Advanced Nursing 46*(2), pp.194-203.

Manias, E., Bucknall, T., Hutchinson, A., Dow, B. and Borrott, N., 2021. Resident and family engagement in medication management in aged care facilities: A systematic review. *Expert Opinion on Drug Safety*, *20*(11), pp.1391-1409.

Marquis, J., Schneider, M-P., Payot, V., Cordonier, A-C., Bugnon, O., Hersberger, K.E. and Arnet, I. (2013) Swallowing difficulties with oral drugs among polypharmacy patients attending community pharmacies. *International Journal of Clinical Pharmacy* 35(6), pp. 1130-1136

McCambridge, J., Witton, J. and Elbourne, D.R. (2014) Systematic review of the Hawthorne effect: new concepts are needed to study research participation effects. *Journal of Clinical Epidemiology,* 67(3), pp.267-277.

McCreedy, E.M., Weinstein, B.E., Chodosh, J. and Blustein, J. (2018) Hearing loss: Why does it matter for nursing homes? *Journal of the American Medical Directors Association*, *19*(4), pp.323-327.

McDerby, M., Kosari, S., Bail, K., Shield, A., Peterson, G. and Naunton, M. (2019) The effect of residential care pharmacist on administration practices in aged care: A controlled trial. *Journal of Clinical Pharmacy and Therapeutics* 44(4), pp. 595-602

McDerby, N., Bail, K., Kosari, S., Shield, A., Peterson, G., Dawda, P. and Naunton, M. (2020) Canaries in the Coalmine: Stakeholder perspectives of medication management reviews for residents with dementia. *Research in Social and Administrative Pharmacy* 16(9), pp. 1220-1227

McGillicuddy, A., Kelly, M., Sweeney, C., Carmichael, A, Crean, AM. and Sahm, LJ. (2016) Modification of oral dosage forms for the older adult: An Irish prevalence study. *International Journal of Pharmaceutics.* 510(1), pp. 386-393

McGillicuddy, A., Crean, A.M., Kelly, M. and Sahm, L. (2017) Oral medicine modification for older adults: a qualitative study of nurses. *British Medical Journal Open* 7(10), p. e018151

McGillicuddy, A., Kelly, M., Crean, A.M., and Sahm, L.J. (2019) Understanding the knowledge, attitudes and beliefs of community-dwelling older adults and their carers about the modification of oral medicines: A qualitative interview study to inform healthcare professional practice. *Research in Social and Administrative Pharmacy* 15(12), pp. 1425-1435

McGilton, K.S., Escrig-Pinol, A., Gordon, A., Chu, C.H., Zúñiga, F., Sanchez, M.G., Boscart, V., Meyer, J., Corazzini, K.N., Jacinto, A.F. and Spilsbury, K., (2020) Uncovering the devaluation of nursing home staff during COVID-19: are we fuelling the next health care crisis? *Journal of the American Medical Directors Association* 21(7), pp. 962-965.

Mercovich, N., Kyle, G.J. and Naunton, M. (2014) Safe to crush? A pilot study into solid dosage form modification in aged care. *Australasian Journal on Ageing* 33(3), pp.180-184

Methley, A.M., Campbell, S., Chew-Graham, C., McNally, R., and Cheraghi-Sohi, S. (2014) PICO, PICOS and SPIDER: a comparison study of specificity and sensitivity in three search tools for qualitative systematic reviews. *BMC Health Services Research* 14(1), pp.1-10

Meyer, S.B. and Ward, P.R. (2013) Differentiating between trust and dependence of patients with coronary heart disease: Furthering the sociology of trust. *Health, Risk and Society* 15(3), pp. 279-293

Minichiello, V., Aroni, R., Timewell, E. and Alexander, L. (1990) *In-depth Interviewing: Researching People.* Melbourne: Longman Cheshire.

Mohammed, A.M., Moles, R.J. and Chen, T.F. (2016) Medication-related burden and patients' lived experience with medicine: a systematic review and meta-synthesis of qualitative studies. *BMJ Open* 6(2), p. e010035

Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7)

Molony, S. (2010) The Meaning of Home: A Qualitative Metasynthesis. *Research in Gerontological Nursing.* 3(4), pp. 291-307

Morin, L., Laroche, M.L., Texier, G. and Johnell, K. (2016) Prevalence of potentially inappropriate medication use in older adults living in nursing homes: a systematic review. *Journal of the American Medical Directors Association* 17(9), pp.862e1-9

Morley, J.E. (2015) Dysphagia and Aspiration *Journal of the American Medical Directors Association* 16(8), pp. 631-634

Munden, L.M. (2017) The covert administration of medications: legal and ethical complexities for health care professionals. *Journal of Law, Medicine & Ethics*, *45*(2), pp.182-192.

Murray, A., (2011) The implementation of a self-administration of medication programmes within Older Persons Mental Health. *Journal of Psychiatric and Mental Health Nursing* 18(2), pp.113-121

Naden, D. (2010) Hermeneutics and Observation – a discussion. *Nursing Inquiry* 17(1), pp. 74-80

Nakrem, S., Vinsnes, A.G., Harkless, G.E., Paulsen, B. and Seim, A. (2012) Ambiguities: residents' experience of 'nursing home as my home'. *International Journal of Older People Nursing.* 88(3), pp. 216-225

Nascimento, Y., Silva, L.D. and de Oliveira, D.R. (2020) Experiences with the daily use of medications among chronic hepatitis C patients. *Research in Social and Administrative Pharmacy* 16(1), pp. 33-40.

Nascimento, Y. and Ramalho-de-Oliveira, D. (2021) T Subjective Experience of Using Medications: What we Know and the Paths Forward. *Pharmacy* 9(1), p. 50

National Care Forum (2019) *Medication Safety in Care Homes* Medication safety project summary report-FINAL-v3-120312.docx (nationalcareforum.org.uk)[Accessed 03/12/2022]

National Institute for Health and Care Excellence (2014) *Managing Medicines in Care Homes. Social care Guideline (SC1)* NICE. London.

National Institute for Health and Care Excellence (2015a) *Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes (NG5).* NICE. London.

National Institute for Health and Care Excellence (2015b) *Medicines Management in Care Homes – Quality Statement (QS85): Self-administration*. NICE. London

National Institute for Health and Care Excellence (2016) *Multimorbidity: Clinical Assessment and management (NG 56).* NICE. London.

National Institute for Health Research (2017) *Advancing Care: Research with care homes.* NIHR Dissemination Centre.

Naughton, L., Padeiro, M. and Santana, P. (2021) The twin faces of ageism, glorification and abjection: A content analysis of age advocacy in the midst of the COVID-19 pandemic. *Journal of Aging Studies* 57, p.100938.

Nguyen, T.M.U., Lau, E., Steadman, K., Cichero, J., Dingle, K. and Nissen, L. (2014) Pharmacist, general practitioner, and nurse perceptions, experiences, and knowledge of medication dosage form modification. *Integrated Pharmacy Research and Practice* 3, pp 1-9

Nichols, B.G., Varadarajan, V., Bock, J.M. and Blumin, J.H.(2014) Dysphonia in Nursing Homes and Assisted Living Residents: Prevalence and Association with Frailty. *Journal of Voice* 29(1), pp. 79-82

Nind, M. (2008) *Conducting Qualitative research with people with learning, communication and other disabilities: Methodological challenges.* ESRC National Centre for Research Methods

Nogueira, D. and Reis, E. (2013) Swallowing disorders in nursing home residents: how can the problem be explained. *Clinical Interventions in Ageing* 8, pp. 221-227

Notenboom, K., Beers, E., van Riet-Nales, D.A., Egberts, T.C.G., Leufkens, H.G.M., Jansen, P.A.F. and Bouvy, M.C. (2014) Practical problems with medication use that older people experience: A qualitative study. *Journal of the American Geriatric Society* 62(12), pp. 2339-2344

Nursing and Midwifery Council (2018) *The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates.* London. Nursing and Midwifery Council.

Odberg, K.R., Hansen, B.S., Aase, K. and Wangensteen, S. (2018) Medication administration and interruptions in nursing homes: a qualitative observational study. *Journal of Clinical Nursing* 27(5-6), pp. 1113-1124

Odberg, K.R., Hansen, B.S. and Wangensteen, S. (2019) Medication administration in nursing homes: A qualitative study of the nurse role. *Nursing Open* 6(2), pp. 384-392

Odberg, KR., Hansen, BS., Aase, K. and Wangensteen, S. (2020) A work system analysis of the medication administration process in a Norwegian nursing home ward. *Applied Ergonomics* 86, p. 103100

O'Mahoney, D., O'Sullivan, D., Byrne, S., O'Connor, M.N., Ryan, C. and Gallagher, P. (2015) STOPP/START criteria for potentially inappropriate prescribing in older people: version 2. *Age and Ageing* 44(2), pp. 213-218

Ostaszkiewicz, J., O'Connell, B. and Dunning, T. (2016) Fear and overprotection in Australian residential aged-care facilities: The inadvertent impact of regulation on quality continence care. *Australasian Journal on Ageing* 35(2), pp. 119-126

Ouellet, N., Bergeron, A. S., Gagnon, E., Cossette, B., Labrecque, C. A., & Sirois, C. (2022) Prescribing and deprescribing in very old age: perceptions of very old adults, caregivers and health professionals. *Age and Ageing* 51(11), pp 1-8

Owen, T. and Meyer, J. (2012) *My Home Life: Promoting quality of life in care homes*. Joseph Rowntree Foundation.

Pace, R., Pluye, P., Bartlett, G., Macaulay, A.C., Salsberg, J., Jagosh, J. and Seller, R. (2012) Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *International Journal of Nursing Studies* 49(1), pp. 47-53

Page, M.J., McKenzie, J.E., Bossuyt, P.M., Boutron, I., Hoffmann, T.C., and Mulrow, C.D. (2020) The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71.

Palagyi, A., Keay, L., Harper, J., Potter, J. and Lindley, R. (2016) Barricades and brickwalls – a qualitative study exploring perceptions of medication use and deprescribing in long term care. *BMC Geriatrics* 16(1), pp.1-11

Paley, J. (2017) *Phenomenology as Qualitative Research: A Critical Analysis of Meaning Attribution.* Routledge.

Pan, E., Bloomfield, K. and Boyd, M. (2019) Resilience, not frailty: A qualitative study of the perceptions of older adults towards "frailty". *International Journal of Older People Nursing*. 14(4), p.e12261.

Paradiso, L.M., Roughead, E.E., Gilbert, A.L., Cosh, D., Nation, R.L., Barnes, L., Cheek, J. and Ballantyne, A. (2002) Crushing or altering medications: what's happening in residential aged-care facilities? *Australasian Journal on Ageing.* 21(3), pp. 123-127

Parekh, N., Gahagan, B., Ward, L. and Ali, K. (2019) 'They must help if the doctor gives them to you': a qualitative study of the older person's lived experience of medication-related problems. *Age and Ageing* 48(1), pp.147-151

Park, Y.H., Han, H.R., Oh, B.M., Lee, J., Park, J., Yu, S.J. and Chang, H.K. (2013) Prevalence and associated factors of dysphagia in nursing home residents. *Geriatric Nursing* 34(3), pp. 212-217

Parsons, C., Johnston, S., Mathie, E., Baron, N., Machen, I., Amador, S. and Goodman, C. (2012) Potentially inappropriate prescribing in older people with dementia in care homes: A retrospective analysis. *Drugs and Ageing* 29(2), pp. 143-155

Peace, S., Kellaher, L. and Willcocks, D. (1997) *Re-evaluating residential care.* Buckingham UK. Open University Press.

Pearson, A., White, H., Bath-Hextall, F., Salmond, S., Apostolo, J. and Kirkpatrick, P. (2015) A mixed -methods approach to systematic reviews. *International Journal of Evidence-Based Healthcare* 13(3), pp. 121-131

Pena-Alves, S. (2020) Outspoken objects and unspoken myths: The semiotics of Object-Mediated Communication. *Symbolic Interaction* 43(3), pp. 385-404

Peoples, K. (2020) *How to write a phenomenological dissertation: A step-by-step guide. Qualitative Research Methods (Vol. 56).* SAGE.

Pernecky, T. (2016) *Epistemology and Metaphysics for Qualitative Research.* SAGE

Pirmohamed, M., James, S., Meakin, S., Green, C., Scott, A.K., Walley, T.J., Farrar, K., Park, B.K. and Breckenridge, A.M. (2004) Adverse drug reactions as cause of admission to hospital: prospective analysis of 18,820 patients. *British Medical Journal* 329(7456), pp. 15-19

Pluye, P., Gagnon, M.P., Griffiths, F. and Johnson-Lafleur, J. (2009) A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *International Journal of Nursing Studies* 46(4), pp. 529-546

Polkinghorne, D. (1983) *Methodology for the human sciences: Systems of Inquiry.* Albany: State University of New York Press.

Pu, D., Murry, T., Wong, M.C.M., Yiu, E.M.L. and Chan, K.M.K. (2017) Indicators of Dysphagia in Aged Care Facilities. *Journal of Speech, Language, and Hearing Research* 60(9), pp. 2416-2426

Punch, K.F. (2014) *Introduction to Social Research Methods* 3rd ed. SAGE

Qian, S., Yu, P., Hailey, D. and Wang, N. (2016) Factors influencing nursing time spent on administration of medication in an Australian residential aged care home. *Journal of Nursing Management* 24(3), pp. 427-434

Qian, S., Yu, P., Hailey, D., Wang, N. and Bhattercherjee, A. (2018) Medication administration processes in a residential aged care home: An observational study. *Journal of Nursing Management,* 26(8), pp. 1033-1043

Quinn, G., Gur, A. and Watson, J. (2018) Ageism, moral agency and autonomy: getting beyond guardianship in the 21st century. In: Doran, I. and Georgantzi, N. (eds) (2018) *Ageing, Ageism and the Law.* Elgar Publishing

Rankin A, Cadogan CA, Patterson SM, Kerse N, Cardwell CR, Bradley MC, Ryan C, Hughes C. (2018) Interventions to improve the appropriate use of polypharmacy for older people. *Cochrane Database of Systematic Reviews,* Issue 9. Art. No.: CD008165.

Reay, T., Zafar. A., Monteiro, P. and Glaser, V. (2019) Presenting Findings from Qualitative Research: One Size Does Not Fit all! *In: The Production of Managerial Knowledge and Organisational Theory: New Approaches to Writing, Producing and Consuming Theory.* Emerald Publishing Limited

Reeve, E., Shakib, S., Hendrix, I., Roberts, M.S. and Wiese, M.D. (2014) Review of deprescribing processes, and development of an evidence-based, patient centred deprescribing process. *British Journal of Clinical Pharmacology* 78(4), pp. 738-747

Regan, P. (2012) Hans-Georg Gadamer's philosophical hermeneutics: Concepts of reading, understanding and interpretation. *META: Research in Hermeneutics, Phenomenology and Practical Philosophy* 4(2), pp. 286-303

Reid, K., Flowers, P. and Larkin, M. (2005) Exploring lived experience: An introduction to Interpretative Phenomenological Analysis. *The Psychologist.* 18(1), pp. 20-23

Reilev, M., Lundby, C., Jensen, J., Larsen, S.P., Hoffman, H. and Pottegard, A. (2019) Morbidity and mortality among older people admitted to nursing home *Age and Ageing* 49(1), pp. 67-73

Ridley, D. (2012) *The Literature Review: A Step-by-Step Guide for Students.* SAGE.

Richardson, S.J., Carroll, C.B., Close, J., Gordon, A.L., O'Brien, J., Quinn, T.J., Rochester, L., Sayer, A.A., Shenkin, S.D., van der Velde, N., Woo, J. and Witham, M.D. (2020) Research with older people in a world with Covid-19: identification of current and future priorities, challenges and opportunities. *Age and Ageing* 49(6), pp. 901-906

Ritchie, J. and Lewis, J. (2003) *Qualitative Research Practice* SAGE

Rolfe, G. (2006) Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of advanced nursing,* 53(3), pp. 304-310.

Rørtveit, K., Hansen, B.S., Leiknes, I., Joa, I., Testad, I. and Severinsson, E. (2015) Patients' experiences of trust in the patient-nurse relationship—A systematic review of qualitative studies. *Open Journal of Nursing*, 5(03), pp.195 -209.

Ross, A. and Gillet, J. (2021) Forms of trust and polypharmacy among older adults. *Ageing and Society* 41(11), pp. 2583-2598

Royal Pharmaceutical Society/Royal College of Nursing (2019) *Professional Guidance on the Administration of Medicines in Healthcare Settings*

Sadala, M.L.A. and Adorno, R.C.F. (2002) Phenomenology as a method to investigate the experience lived: a perspective from Husserl and Merleau-Ponty's thought. *Journal of Advanced Nursing.* 37 (3), pp. 282-293

Sandelowski, M. (1993) Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science* 16(2), pp.1-8

Sandelowski, M., Voils, C.I. and Barroso, J. (2006) Defining and Designing Mixed Research Synthesis Studies. *Research in the Schools* 13(1), p. 29

Sanders, M.J. and Oss, T.V. (2013) Using daily routines to promote medication adherence in older adults. *The American Journal of Occupational Therapy* 67(1), pp.91-99

Sanford, AM., Orrell, M., Tolson, D., Abbatecola, AM., Arai, H., Bauer, JM., Cruz-Jentoft, AJ., Dong, B., Ga, H., Goel, A., Hajjar, R., Holmerova, I., Katz, PR., Koopmans, RTCM., Rolland, Y., Visvanathan, R., Woo, J., Morley, JE. And Vellas, B. (2015) An International Definition for "Nursing Home" *Journal of the American Medical Directors Association* 16(3), pp. 181-184

Santos, J.M.S., Poland, F., Wright, D. and Longmore, T. (2016) Medicines administration for residents with dysphagia in care homes: A small scale observational study to improve practice. *International Journal of Pharmaceutics.* 512(2), pp. 416-421

Saxena, A., Meschino, D., Hazelton, L., Chan, M.K., Benrimoh, D.A., Matlow, A., Dath, D. and Busari, J. (2019) Power and physician leadership. *British Medical Journal Leader* 0, 1-7

Schiele, J.T., Quinzler, R., Klimm, H-D., Pruszydlo, M.G., Haefeli, W.E. (2013) Difficulties in swallowing solid oral dosage forms in a general practice population: prevalence, causes, and relationship to dosage forms. *European Journal of Clinical Pharmacology* 69(4), pp. 937-948

Schiele, J.T., Penner, H., Schneider, H., Quinzler, R., Reich, G., Wezler, N, Micol, M., Oster, P. and Haefeli, W.E. (2015) Swallowing tablets and capsules increases the risk of penetration and aspiration in patients with stroke-induced dysphagia. *Dysphagia* 30(5), pp. 571-582

Scottish Executive (2000) *The Adults with Incapacity Act.* Edinburgh.

Scottish Government (2010) *Public Sector Reform Act* www.legislation.gov.uk/asp/2010/8/ [Accessed 11/01/2023]

Scottish Government Model of Care Polypharmacy Working Group (2018) *Polypharmacy Guidance:Realistic Prescribing* 3rd Ed. The Scottish Government

Shariff, Z.B., Dahmash, D.T., Kirby, D.J., Missaghi, S., Rajabi-Siahboomi, A. and Maidment, I.D. (2020) Does the formulation of oral solid dosage forms affect acceptance and adherence in older patients? A mixed methods systematic review. *Journal of the American Medical Directors Association* 21(8), pp.1015-1023.

Shaw, C.A. and Gordon, J.K. (2021) Understanding elderspeak: an evolutionary concept analysis. *Innovation in aging*, *5*(3)

Shepherd, V., Wood, F. and Hood, K. (2017) Establishing a set of research priorities in care homes for older people in the UK: a modified Delphi consensus study with care home staff. *Age and Ageing 2017.* 46(2), pp. 284-290

Shin, J.H. (2015) Declining body, institutional life, and making home—Are they at odds? *Health Care Ethics Committee Forum* 27(2) pp. 107-125

Shiozu, H., Higashijima, M. and Koga, T. (2015) Association of sarcopenia with swallowing problems, related to nutrition and activities of daily living of elderly individuals. *Journal of Physical Therapy Science* 27(2), pp. 393-396

Shoemaker, S.J. and Ramalho de Oliveira, D, (2008) Understanding the meaning of medications for patients: the medication experience. *Pharmacy World & Science* 30(1), pp. 86-91

Silverman, D. (1993) *Doing Qualitative Research: A Practical Handbook.* London. SAGE

Silverman, J., Kurtz, S. and Draper, J. (2005) *Skills for Communicating with Patients.* Radcliffe. Oxford

Sims-Gould, J., McKay, H.A., Feldman, F., Scott, V. and Robinovitch, S.N. (2014) *Journal of Applied Gerontology* 33(6), pp. 690-709

Smith, J.A., Flowers, P. and Larkin, M. (2009) *Interpretative Phenomenological Analysis.* SAGE

Smythe, E., Ironside, P.M., Sims, S.L., Swenson, M.M. and Spence, D.G. (2008) Doing Heideggerian hermeneutic research: A discussion paper. *International Journal of Nursing Studies* 45(9), pp. 1389-1397

Smythe, E. (2011) From beginning to end. How to do hermeneutic interpretive phenomenology. In Thomson G, Dykes, F and Downe, S (Eds) *Qualitative Research in Midwifery and Childbirth.* Routledge

Smythe, E. and Spence, D. (2012) Re-viewing Literature in Hermeneutic Research. *International Journal of Qualitative Methods* 11(1), pp. 12-25

Solberg, H., Devik, S.A., Bell, H.T., Zeiss, D.H. and Olsen, R.M. (2021) Drug modification by nurses in Norwegian nursing homes: A cross-sectional study. *Geriatric Nursing* 42(2), pp. 351-357

Solberg, H., Devik, S.A., Bell, H.T., and Olsen, R.M. (2022) The art of making the right exception to the “rule”: Nurses’ experience with drug dispensing in nursing homes. *Geriatric Nursing* 44, pp. 229-236

Souto, R.Q., Khanassov, V., Hong, Q.N., Bush, P.L., Vedel, I. and Pluye, P. (2015) Systematic mixed studies reviews: updating results on the reliability and efficiency of the mixed methods appraisal tool. *Int J Nurs Stud*, *52*(1), pp.500-501.

Søvde, B.E., Sandvoll, A.M., Natvik, E. and Drageset, J. (2022) In the borderland of the body: How home-dwelling older people experience frailty. *Scandinavian Journal of Caring Sciences* 36(1), pp.255-264.

Spence, D.G. (2017) Supervising for robust hermeneutic phenomenology: Reflexive engagement within horizons of understanding. *Qualitative Health Research* 27(6), pp. 836-842

Spencer-Bonilla, B.A., Quinones, A.R. and Montori, V.M. (2017) Assessing the Burden of Treatment. *Journal of General Internal Medicine* 32(10), pp. 1141-5

Stake, R.E. (1995) *The Art of Case Study Research.* SAGE

Steele, C.M., Greenwood, C., Ens, I., Robertson, C. and Seidman-Carlson, R. (1997) Meal-time difficulties in a home for the aged: Not just dysphagia. *Dysphagia* 12(1), pp. 43-50

Stegeman, S., Gosch, M. and Breitkreutz, J. (2012) Swallowing dysfunction and dysphagia is an unrecognized challenge for oral drug therapy. *International Journal of Pharmaceutics* 430(1-2), pp. 197-206

Stevenson, J.M., Parekh, N., Chua, K.C., Davies, J.G., Schiff, R., Rajkumar, C. and Ali, K. (2022) A multi-centre cohort study on healthcare use due to medication-related harm: the role of frailty and polypharmacy. *Age and Ageing* 51(3), pp. 1-9

Stewart, R., Hotopf, M., Dewey, M., Ballard, C., Bisla, J., Calem, M., Fahmy, V., Hockley, J., Kinley, J., Pearce, H., Saraf, A. and Begum, A. (2014) Current prevalence of dementia, depression and behavioural problems in the older adult care home sector: The South-East London Care Home Survey. *Age and Ageing* 43(4), pp. 562-567

Struthers, J. (2017) Home, Hotel, Hospice. In *Care Home Stories.* (eds) Chivers, S. and Kriebernegg, U. Transcript. Verlag.

Stuijt, C.C., Klopotowska, J.E., van Driel, C.K., Le, N., Binnekade, J., van der Kleij, B., van der Schors, T., van den Bemt, P. and Lie-A-Huen, L. (2013) Improving medication administration in nursing home residents with swallowing difficulties: sustainability of the effect of a multifaceted medication safety programme. *Pharmacoepidemiology and drug safety* 22(4), pp. 423-429

Swanlund, S.L., Scherck, K.A., Metcalfe, S.A. and Jesek-Hale, S.R. (2008) Keys to successful self-management of medications. *Nursing Science Quarterly* 21(3), pp. 238-246.

Tamura, B.K., Bell, C.L., Inaba, M. and Masaki, K.H. (2012a) Factors associated with polypharmacy in nursing home residents. *Clinics in Geriatric Medicine* 28(2), pp. 199-216

Tamura, B.K., Bell, C.L., Inaba, M., and Masaki, K.H. (2012b) Outcomes of polypharmacy in nursing home residents. *Clinics in Geriatric Medicine* 28(2), pp. 217-236

Tehewy, M.A., Fahim, H., Gad, N.I., Gafary, M.E. and Rahman, S.A. (2016) Medication administration errors in a university hospital. *Journal of patient safety*, *12*(1), pp.34-39.

Thomson, M.S., Gruneir, A., Lee, M., Baril, J., Field, T.S., Gurwitz, J.H. and Rochon, P.A. (2009) Nursing time devoted to medication administration in long term care: Clinical, safety and resource implications. *Journal of the American Geriatric Society* 57(2), pp. 266-272

Tinetti, M., Huang, A., and Molnar, F. (2017) The Geriatrics 5M's: A new way of communicating what we do. *Journal of the American Geriatric Society* 65(9), p. 2115

Tolson, D., Rolland, Y., Andrieu, S., Aquino, J-P., Beard, J., Benetos, A., Berrut, G., Coll-Planas, L., Dong, B., Forette, F., Franco, A., Franzoni, S., Salvà, A., Swagerty, D., Trabucchi, M., Vellas, B., Volicer, L., Morley, J. E. and The International Association of Gerontology and Geriatrics/World Health Organization/Society Française de Gérontologie et de Gériatrie Task Force (2011). A global agenda for clinical research and quality of care in nursing homes. *Journal of the American Medical Directors Association* 12(3), pp. 184-9.

Tordoff, J., Simonsen, K., Thomson, WM. and Norris, PT. (2010a) "It's just routine": A qualitative study of medicine-taking amongst older people in New Zealand. *Pharmacy World and Science* 32(2), pp. 154-161

Tordoff, J.M., Bagge, M.L., Gray, A.R., Campbell, A.J. and Norris, P.T. (2010b) Medicine-taking practices in community-dwelling people aged≥ 75 years in New Zealand. *Age and Ageing* 39(5), pp. 574-580.

Tranfield, D., Denyer, D., and Smart, P. (2003) Towards a methodology for developing evidence-informed management knowledge by means of systematic review. *British Journal of Management.* 14(3), pp. 207-222

Tuckett, A.G. (2006) On paternalism, autonomy and best interests: Telling the (competent) aged-care resident what they want to know. *International Journal of Nursing Practice* 12(3), pp.166-173

Tuominen, L., Leino-Kilpi, H. and Suhonen, H. (2016) Older peoples' experience of their free will in nursing homes. *Nursing Ethics* 23(1), pp. 22-35

Vandermause, R.K. and Fleming, S.E. (2011) Philosophical hermeneutic interviewing *International Journal of Qualitative methods* 10(4), pp. 367-377

Van Manen, M. (2014) *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing.* Walnut Creek CA: Left Coast Press

Van Manen, M. (2016) 2nd ed. *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy.* Routledge

Van Manen, M. (2017a) But is it Phenomenology? *Qualitative Health Research* 27(6), pp. 775-779

Van Manen, M. (2017b) Phenomenology in its original sense. *Qualitative Health Research* 27(6), pp. 810-825

Vanwesemael, T., Boussery, K. and Dilles, T. (2020) Self-administration of medication in hospital: A literature review. *Nursing Science Quarterly* 33(3), pp.249-257.

Vatcharavongvan, P. and Puttawanchai, V. (2022) Medication management at home in older patients with polypharmacy: In-depth interviews with home visits. *Pharmacy Practice* 20(1), pp.1-8.

Verbeek, H. and Mitchell, G. (2022) Changing the long-term care spectrum. *BMC Geriatrics* 22(1), pp.1-3.

Vervaecke, D. and Meisner, B.A. (2021) Caremongering and assumptions of need: The spread of compassionate ageism during COVID-19. *The Gerontologist (*61)2, pp. 159-165

Wade, D.T and Halligan, P.W. (2004) Do biomedical models of illness make for good health care systems? *BMJ* 329(7479), pp. 1398-1401

Walker, W. (2011) Hermeneutic inquiry: Insights into the process of interviewing. *Nurse researcher* 18(2), pp. 19-27

Watson, R.E. (2006) Self-medication: whatever next? *Journal of Clinical Nursing* 15(8), p. 935

Webster, A., Douglas, C. and Lewis, G. (2009) Making sense of medicines: 'Lay Pharmacology' and narratives of safety and efficacy. *Science as Culture* 18(2), pp. 233-247

Welsh, T.J., McGrogan, A. and Mitchell, A. (2020) Deprescribing in the last years of life – it's hard to STOPP *Age and Ageing* 49(5), pp. 723-724

Werner, N.E., Ponnala, S., Doutcheva, N. and Holden, R.J. (2021) Human factors/ergonomics work system analysis of patient work: state of the science and future directions. *International Journal for Quality in Health Care, 33*(Supplement 1), pp.60-71

White-Chu, E.F., Graves, W.J., Godfrey, S.M., Bonner, A. and Sloane, P. (2009) Beyond the Medical Model: The Culture Change Revolution in Long Term Care. *Journal of the American Medical Directors Association* 10(6), pp. 370-378

de Witt, L. and Ploeg, J. (2006) Critical appraisal of rigour in interpretive phenomenological research. *Journal of Advanced Nursing* 55(2), pp. 215-229

Wiersma, E. and Dupuis, S.L. (2010) Becoming institutional bodies: Socialization into a long-term care home. *Journal of Aging Studies* 24(4), pp.278-291

Willig, C (2013) *Introducing Qualitative Research in Psychology 3rd ed.* McGraw Hill. Open University.

Woodward, A. and Ruston, A. (2022) Empowerment of care home staff through effective collaboration with healthcare. *Journal of Interprofessional Care* 37(1), pp. 109-117

Woolford, M.H., de Lacy-Vawdon, C., Bugeja, L., Weller, C. and Ibrahim, J.E. (2020) Applying dignity of risk principles to improve quality of life for vulnerable persons. *International Journal of Geriatric Psychiatry* 35(1), pp.122-130.

World Health Organisation (1998) WHO guidelines on hand hygiene in health care**.**

Wright, D. (2002) Medication administration in nursing homes. *Nursing Standard* 16(42), pp. 33-38

Yamada, Y., Vlachova, M., Richter, T., Finne-Soveri, H., Gindin, J., van der Roest, H., Denkinger, M.D., Bernarbei, R., Onder, G. and Topinkova, A. (2014) Prevalence and correlates of hearing and visual impairments in European nursing homes: Results from the

SHELTER study. *Journal of the American Medical Directors Association* 15(10), pp. 738-743

Yarnell, A.J., Sayer, A.A., Clegg, A., Rockwood, K., Parker, S. and Hindle, J.V. (2017) New Horizons in multi-morbidity in older adults. *Age and Ageing* 46(6), pp. 882-888

Yee, J., Souza, M., Horta, N. and Kartoz, C. (2021) Person-Centred care for older adults living in long-term care facilities: a systematic literature review. *Journal of Public Health Issues and Practices.* 5(2), pp. 184-187

Yin, R.K. (2018) *Case Study Research* 6th Ed. SAGE

Zahavi, D. (2019) Getting it quite wrong: Van Manen and Smith on phenomenology. *Qualitative Health Research* 29(6), pp. 900-907

Zomorodi, M. and Foley, B.J. (2009) The nature of advocacy vs. paternalism in nursing: clarifying the ‘thin line’. *Journal of Advanced Nursing* 65(8), pp.1746-1752.

Appendix 1: Ethical Approval Letter

NHS
Health Research Authority

Social Care REC
Ground Floor
Skipton House
80 London Road
London
SE1 6LH

16 December 2019

Mrs Helen Davies
Aultbea and Gairloch Medical Practice
Achtercairn
Gairloch
IV21 2BP

Dear Mrs Davies

Study title:	**Exploring the experience of older people in care homes with taking medication**
REC reference:	**19/IEC08/0055**
IRAS project ID:	**260398**

Thank you for your letter of 27 November 2019, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise). Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, ‘clinical trials’ are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol

- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

Ethical review of research sites

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Interview schedules or topic guides for participants [Interview topic guide]	1.0	08 September 2019
Letter from sponsor [Sponsorship letter]		27 September 2019
Letters of invitation to participant [Introductory Letter]	3.0	16 November 2019
Other [Supervisor 2 CV]		01 August 2019
Other [Insurance Certificate]		07 August 2019
Other [Observation Guidance notes]	2.0	16 November 2019
Other [Letter to Care Home Managers]	1.0	16 November 2019
Other [REC Response table]		27 November 2019
Participant consent form [Residents' consent form]	3.0	16 November 2019
Participant consent form [Staff consent form]	3.0	16 November 2019
Participant information sheet (PIS) [Residents'information sheet]	3.0	16 November 2019
Participant information sheet (PIS) [Information sheet for staff]	3.0	16 November 2019
REC Application Form [REC_Form_07102019]		07 October 2019
Research protocol or project proposal [Protocol]	3.0	27 November 2019
Summary CV for Chief Investigator (CI) [Helen Davies CV]		28 January 2019
Summary CV for supervisor (student research) [Supervisor CV]		27 July 2019

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form

available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/IEC08/0055	**Please quote this number on all correspondence**

With the Committee’s best wishes for the success of this project.

Yours sincere

S. O'Neil

pp.

Dr Martin Stevens
Chair

Email:nrescommittee.social-care@nhs.net

Copy to: Rachel Beaton

Appendix 2: Ethical Review Response Table

Ethical Review – Further Information Required	Response from the Applicant
1. The Committee requested that a clause is added to the PIS and protocol to be able to report the disclosure or witnessing abuse or malpractice external to the care home	Clause added to PIS and protocol as requested – highlighted on updated documents v3.0
2. The Committee requested that a safeguarding clause is added to the PIS, making it clear at what point confidentiality could be broken. The Committee offers a form of words for this purpose that could be used or adapted: 'Everything you say/report is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else.'	Clause added to PIS – in combination with the cause above, highlighted on updated v3.0
3. The Committee requested that the invitation letter that will be sent to care home managers, listing what would be involved if they took part and the other information included, is produced and sent to the Committee for review.	Letter attached as Appendix 8.
4. The Committee requested that all documents are updated so that the study is only interested in medicines taken in the mouth – this includes both medicines that are swallowed as well as those that are put under the tongue.	All documents amended to include the word 'oral' when mentioning medication. Protocol amended to specify in more detail the types of medication included (highlighted on Protocol v 3.0
5. The Committee requested that it is made clear in the PIS that participants have the option to only take part in the interview and not the observation.	Sentence added to PIS v 3.0 to this effect - highlighted

6. The Committee requested that the researcher submit a brief plan for how she is going to make sure that other residents and staff are aware of the nature of, the location and timing of observations. The Committee suggested that other researchers wore a name badge to help make the non-participating residents aware of who they are. Another means of raising awareness about the observation would be to put up posters about the research, which made it clear when and where observations could take place.	Additional information added to Observation Guidance Notes (Appendix 8 v 2) Highlighted.
7. The Committee requested that a statement is added to the PIS and consent form that complete anonymity cannot be guaranteed from the anonymised quotations due to the very rural area and the amount of verbatim data used.	Clause added to PIS v3.0 to this effect
8. The Committee requested that it is made clear in the PIS that the interviews will only be audio-recorded.	Word 'audio' inserted in PIS v 3.0 to make this clear
9. The Committee requested clarification on whether the recorder being used for the interviews in encrypted.	The University audio-recorder being used for interviews is not encrypted, however audio-recorded interviews will be transferred on the same day to a secure network on a password protected NHS computer to which only the researcher will have access. Data will immediately be deleted from the audio-recorder. Amendment has been made to Protocol v 3.0 (highlighted) to clarify procedures for storage and transfer of this data, and to align with details already stated on the IRAS form.

-

Appendix 3: Letter to Care Home Managers

Dear Care Home Manager

I am a nurse and researcher, writing to invite your Care Home to take part in a research study, as part of my Clinical Doctorate at the University of Stirling:

Exploring the experience of older people in care homes with taking oral medication

What is this research about?

We know that many older people in care homes are prescribed a lot of medication, in solid or dispersible tablets, medicines and syrups. Research has already shown that it can be difficult to swallow medication, especially as residents get older. Most of your residents will not be able to manage their own medications, and rely on your staff to help them.

Very little research has ever been done to find out what the residents themselves feel about this.

This study intends to invite a small number of care home residents to talk about their experience of being helped to take their oral medication.

How would residents be involved?

Any resident who wishes to take part will be observed whilst staff help them with their medication. This will be oral medication only, medicines and tablets which are swallowed, chewed or dispersible.

They will then be asked some questions in a short interview which will be audio-recorded.

It is hoped that each resident who takes part will be observed and interviewed in the same way again, 3-5 weeks later.

How would staff be involved?

It is important to be clear that this research is focussed on the experience of the resident, however, staff are integral to the process of medication administration. Therefore, any care staff who are helping residents with their medication as part of their normal routines will be asked permission to be part of the observation. I will explain what is involved in more detail and request consent to observe this from individual members of staff who are willing to participate. Care staff will have no other involvement in this study.

What will I be asked to do to help?

I am requesting your help in identifying residents who may be interested in taking part in this research. To be able to take part, they must be:

- Needing help from a care provider with the administration of oral medication
- Able to understand and express themselves in English
- Able to give informed consent to participate

This does **not** exclude residents with a diagnosis of dementia or cognitive impairment, who will be individually assessed for their capacity to consent if they express a wish to take part.

Interested residents should be given an Introductory Letter (enclosed sample), and their contact details passed to me with their agreement.

If you are interested in helping with this research, or have further questions:

Please contact me, using the email below. I will make arrangements for a preliminary visit to the home to discuss the practicalities with you in more detail.

This does not commit you to taking part, only to finding out more about the study.

Thank you for your attention,

Helen Davies

(email and telephone contact details attached)

UNIVERSITY of STIRLING

Introductory Letter of Invitation to Residents

I am a nurse and researcher, writing to invite you to take part in a research study, as part of my Clinical Doctorate at the University of Stirling:

Exploring the experience of older people in care homes with taking oral medication

I am interested to explore through observing and talking to you, more about what it is like for you to take medication, particularly when you need staff to help you with this.

Taking part in research is voluntary and if you would prefer not to do so nobody will be upset and your care will not be affected.

If you would like to hear more about this study or are interested in taking part, please speak to your Care Home Manager, who will make arrangements to pass on your details to me.

This does not commit you to taking part, only to finding out more about the study.

Thank you for your attention,

Helen Davies

(email and telephone contact details attached)

Appendix 5: Participant Information Leaflet – Residents

UNIVERSITY of STIRLING

Participant Information Sheet A (Residents)

Helen Davies – Nurse/Researcher

Exploring the experience of older people in care homes with taking oral medication.

I would like to invite you to take part in a research study exploring your experiences with taking medication.

What is this research about?

We know that many people in care homes are prescribed a lot of medication. Research has already shown that it can be difficult to swallow medication, especially as people get older. Sometimes older people cannot manage their own medication, and have to rely on help.

Very little research has been undertaken to consider how residents themselves feel about this.

This study intends to invite a small number of care home residents to talk about their experience of being helped to take their medication.

It is hoped that this will help in the future, when decisions are made about medication for people in similar circumstances.

What would taking part involve?

If you agree to take part, I will arrange to observe whilst your usual care staff help you with your tablets and medicines, just as normal.
I would then ask you some questions about how you felt about taking the medication. This would be a short interview, taking up to half an hour. I will ask you if I may audio-record it and make some notes to be sure to remember everything just as you said it.

If you would prefer not be observed, you will be given the option just to take part in the interviews.

What are the possible benefits of taking part?

There will be no direct benefit to you. However, doing this research may help others in similar situations in future.

What are the possible disadvantages and risks of taking part?

You may find it tiring to be answering questions and it might be upsetting to have to think about your illness or disabilities.

If you feel this is too much for you at any time, you can stop. We can take a break if you need to, or you can finish whenever you wish.

Do I have to take part in the study?

No. Taking part is entirely voluntary.

What if I don’t want to carry on with the study?

You can say at any time if you don’t want to be involved. I will ask your permission if you are still happy for me to use anything you have already told me about. If you wish, it will be destroyed.

However, if you are not able to carry on for other reasons, perhaps because you are too unwell or tired, whatever you have said will still be valuable, and I would like to be able to use this information if you agree.

How will my information be kept confidential?

Any identifiable personal information will be kept in a locked filing cabinet in a secure area of an NHS Primary Care premises. Recordings of your interviews will be deleted once transcribed. Quotations from your words will be used in writing up the research, but will be anonymised. However, because I will be directly using your words, it will not be possible to guarantee your complete anonymity.

What will happen to the results?

The results will be shared with professionals who have an interest in medicines for older people. This will include General Practitioners and pharmacists as well as nursing and care home staff. Participants will be able to receive a copy of the results if they wish.

A paper will be published in an academic journal, which helps the results to be widely read.

Who is funding this research?

There is no external funding for this study. This research is self-funded by the researcher as part of a clinical doctorate programme of study at the University of Stirling

Who has reviewed the study?

Research Ethics committees from both the NHS and the University of Stirling will have ensured that this study is appropriate and that your interests are protected.

Safeguarding you and others:

Everything you say is confidential unless you tell me something that indicates that you or someone else is at risk of harm. In the same way, if I witness any serious malpractice, I have a duty to inform authorities outside of your Care Home. I would discuss this with you before telling anyone else.

Further information and contact details

If you have any further questions or concerns, please contact:

Helen Davies, Researcher. *(email and telephone contact details added)*

Supervisors: *(email and telephone contact details added)*

Study Sponsor: *(email and telephone contact details added)*

Contact for complaints: *(email and telephone contact details added)*

Appendix 6: Participant Information Leaflet – Staff

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Participant Information Sheet B for Care Staff

Exploring the experience of older people in care homes with taking oral medication.

Some residents in the care home have been invited to take part in a research study exploring their experiences with taking medication. You are being invited to be involved with this research.

What is this research about?

We know that many older people in care homes are prescribed a lot of medication. Research has already shown that it can be difficult to swallow medication, especially as people get older. Sometimes older people cannot manage their own medication, and have to rely on help.

Very little research has ever been done to find what residents themselves feel about this.

This study intends to invite a small number of care home residents to talk about their experience of being helped to take their medication.

It is hoped that this will help in the future, when decisions are made about medication for people in similar circumstances.

How would staff be involved?

For each resident who agrees to take part, I will request permission from relevant care staff to watch whilst their tablets and medicines are administered, just as usual.

Depending on shift patterns, this may involve you.
You may see me making some notes as I am watching you at work. It is important to be aware that I am seeking to understand how the resident experiences the process, rather than focussing on what you are doing. I hope you will feel able to carry on with the medication administration routines as you normally would, and I will not delay you in your work.
I would then have some questions for the individual resident about their experience. This would be a short interview, taking up to half an hour. I do not need to talk to you about this process.

I will visit again 3-5 weeks later, to repeat the observation, when medication is administered to the same resident.

What are the possible benefits of taking part?

There will be no direct benefit to you or your residents. However, doing this research may help others in future.

What are the possible disadvantages and risks of taking part?

The study is designed to find out about the experience of the residents, so as staff your involvement will be limited to carrying out your normal care activities. As such, there should be no disadvantages or risks.

What if I don't want to take part in the study?

You are under no obligation whatsoever to take part in this study. It is entirely voluntary.

How will my information be kept confidential?

Any identifiable personal information will be kept securely in a locked cabinet in a secure area of an NHS Primary Care premises. Quotations from your words may be used when writing up the research, but will be anonymised. However, because I will be directly using your words, it will not be possible to guarantee your complete anonymity.

What will happen to the results?

The results will be shared with professionals who have an interest in medicines for older people. This will include General Practitioners and pharmacists as well as nursing and care home staff, in forums such as meetings and conferences. Participants will be able to receive a copy of the results if they wish.

A paper will be published in an academic journal, which helps the results to be widely read.

Who is funding this research?

There is no external funding for this study. This research is self-funded by the researcher as part of a Clinical Doctorate programme of study at the University of Stirling.

Who has reviewed the study?

The Research Ethics committee from the University of Stirling will have ensured that this study is appropriate and that your interests are protected.

Safeguarding:

If you tell me something that indicates a risk of serious harm to someone, or if I witness any serious malpractice, I have a duty to inform authorities outside of your Care Home. I would discuss this with you before telling anyone else.

Further information and contact details.

If you have any further questions or concerns, please contact:

Supervisors: *(email and telephone contact added)*

Study Sponsor: *(email and telephone contact added)*

Contact for complaints: *(email and telephone contact details added)*

Appendix 7: Modified UBACC Tool

1. What is the purpose of the study that was just described to you? *(Understanding)* Response (2=Understanding what it is like to take medication for people in care homes)	Score 0 1 2
2.What makes you want to consider taking part in this study? *(Reasoning)* Response (2=To help others, to talk about my experiences)	Score 0 1 2
3. Do you have to be in this study if you do not want to participate? *(Appreciation)* Response (2= No)	Score 0 1 2
4. If you take part in this study, what are some of the things that you will be asked to do? *(Appreciation)* Response (2= Be observed taking my medication. Answer questions)	Score 0 1 2
5. Please describe some of the risks or discomforts that people may experience if they take part in this study. *(Understanding)* Response (2=Tiring or upsetting talking about things)	Score 0 1 2
6. Please describe some of the benefits of this study. *(Understanding)* Response (2= to help other people)	Score 0 1 2
7. Will being in this study have any benefit to you? *(Appreciation)* Response (2= No)	Score 0 1 2

Adapted from: Jeste, DV., Pamer, BW., Appelbaum, PS., Golshan, S., Glorioso, D., Dunn, LB., Kim, K., Meeks, T. And Kraemer, H (2007) A New Brief Instrument for Assessing Decisional Capacity for Clinical Research. *Arch Gen Psychiatry* 64 (8) pp 966-974

Appendix 8: Consent Form – Residents

Participant Identification Number:

PARTICIPANT CONSENT FORM A (Residents)

Title of Project: **Exploring the experience of older people in care homes with taking oral medication.**

Name of Researcher: Helen Davies Please Initial Box

1.	I confirm that I have read (or been assisted to read) the information sheet dated November 2019 (version 3) for the above study	
2.	I confirm that I have discussed the purpose of the study and understand my involvement	
3.	I have had the opportunity to think about the information, ask questions, and have had these answered satisfactorily	
4.	I agree to being observed when medication is given to me by care home staff	

5.	I agree to being interviewed after I have been given the medication	
6.	I agree to the interview being audio-recorded	
7.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, and without my care being affected.	
8.	I agree that if I become too unwell to participate in the study, information I have given may continue to be used.	
9.	I understand that measures will be taken to ensure that my identity will not be revealed, unless I am at risk of serious harm, when confidentiality may have to be breached.	
10.	I understand that complete anonymity cannot be guaranteed, because my own words will be directly quoted.	
11.	I agree to take part in the above study	

Participant

______________ ______________ ______________
Name Date Signature

Witness -Only if participant unable to sign

______________ ______________ ______________
Name Relationship to Signature

Participant

Date ____________ Mode of confirming consent ____________________________
(e.g verbal/gesture)

Person taking consent

Name ____________________ Date ______________ Signature ______________

Appendix 9: Staff Consent Form

Study ID Number:

PARTICIPANT CONSENT FORM B (Staff)

Title of Project: **Exploring the experience of older people in care homes with taking oral medication.**

Name of Researcher: Helen Davies

Please initial box

1.	I confirm that I have read the information sheet dated November 2019 version 3 for the above study	
2.	I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily	
3.	I consent to being observed during administration of medication	
4.	I consent to the use of notes taken by the researcher during this process, being used for the purpose of the research.	
4.	I understand that measures will be taken to ensure that my identity will not be revealed, unless there is risk of serious harm to residents, when confidentiality may have to be breached.	
5.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason	
6.	I agree to take part in this study.	

______________________ ______________ ________________

Name of Participant (Staff) Date Signature

________________ ______________ ________________

Name of Person taking consent Date Signature

Appendix 8: Observation Guidance and Template as submitted for Ethical Approval

Observation Guidance Notes

Exploring the experience of older people in care homes with taking oral medication.

- The researcher will be a non-participant observer.
- The researcher's role will be overt to both staff and residents. A name badge will be worn clearly identifying the researcher's name and role.
- Posters will be displayed in the home during the preceding week, making it clear when and where observation will take place.
- The location will be the usual place for oral medication administration for the individual
- The duration of the episode of observation will be for the period of administration of oral medication for the participant, anticipated to be no more than 30 minutes
- The focus of the observation will be narrow, but with added contextual data
- Descriptive and Reflexive notes will be kept using pen and paper (Outline Template below), separating description from interpretation and judgement
- Direct quotations from participants will be gathered where possible
- A sketch of the setting will be made to aid recall and contextual information

Observation template

Date: Time: Participant No: Duration of Observation:	
Descriptive Notes	**Reflexive notes**
Physical Setting: visual layout sketch	Reflexive comments, questions to self, my interpretations etc.
Description of participants Description of activity Sequence of events	Reflexive comments, questions to self, my interpretations etc.

Interactions Participants’ comments: expressed in quotes Observations of non-verbal behaviour Unplanned events	

Appendix 11: Observation Information Poster

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A Researcher may be seen working in the home this week

Helen Davies – Nurse/Researcher

Exploring the experience of older people in care homes with taking oral medication.

You may see her in the home observing and taking notes whilst some residents are taking their medication. This will only affect residents who have specifically given consent for this to happen.

Further information and contact details. If you have any further questions or concerns, please contact:Helen Davies, Researcher *(email and telephone contact details added).* Or ask your Care Home Manager.

Appendix 12a: Sample Interview Transcript

Participant 7 Interview

Int: *(inaudible ? starting the recorder and she began speaking immediately)*

P7: I take them because I know I've got to take them.

Int: Yes, so when I was watching you this morning, can you tell me how that goes, what the staff do, and how you have to do that…

P7: It doesn't bother me

Int: Can you remember, the actual practical things that they do for you

P7: ***(****puffing – exclamation)* **No** *(laughing)*

Int: You can't remember?

P7: I don't think its up to me to remember. I feel its their job to do it.

Int: Oh, yes, I know you don't have to remember what the pills are…..

But you know how, you were in the bed here…. *(prompting gesture)…* They were sort of .... passing things…

P7: Dishing them out

Int: Dishing them out…

P7: No other word for it

Int: And there was quite a lot of different things happening, wasn't there?....

P7: Because there were different pills to take, for different……. Erm……. How would you put it…… I suppose there just……. I don't know, combinations… of tablets that need to be taken.

Int: Yes

P7: For various…. what are they…..measures …. *(sigh)…* That's not the word…. Its too early in the morning……. I don't know….. I can't remember

Int: Is it sometimes easier? The staff do something that makes it easier, or sometimes its more difficult?

P7: No, they just do it automatically….. and I fall in line with whatever it is they give me. Cause I have to, and that they know better than me

Int: Yes. And sometimes is it difficult to take them?

P7: No…. the only time its any difficult, there is any difficulty, is when I've been really tired…… I'm struggling to get the …… pills, yes, the pills, sometimes just don't go down, because they seem to get stuck

Int: Yes

P7: And I have to take 2 or 3 gulps of water or whatever it is, to get rid of it

Int: That's right

P7: That's the only time I have a little bit of problem

Int: Yes

P7: I don't consider medicines to be a problem

Int: No. But the tablets sometimes are a bit…..

P7: It seems to be that sometimes they give you a different….. medicine….. different…. cope, cope?.... sorry, that's another word I keep getting wrong, erm…. *(long pause and sigh as she cannot find the word)*

Int: You said sometimes they give you a different medicine or….

P7: Not necessarily, it just looks different, or its shaped different

Int: Different shape

P7: That throws me slightly

Int: Yes.. Some shapes go down easier than…

P7: Yes, sometimes they're easier to get swallowed, other times they just don't want to go

Int: No

P7: And I have to take 2 or 3, or sometimes even 4 attempts, to get them to swallow.

Int: Yes

P7: But they don't bother me to any great extent

Int: No

P7: I don't let them anyway…. *(laugh)*

Int: So, is there anything that you wish was different, or…..

P7: Its no use, its just a waste of space, a waste of time… I think

Int: Yes

P7: You do it for a couple of months, and you don't think anything of it, and then suddenly somebody comes along, and gives you tablets, and you have to say to them, 'what are they?', because you're not sure what they are… well I do

Int: Yes

P7: Cause I like to know what I'm taking….

Int: Yes, and when they put them in the pot like that…

P7: Oh, those pots are a pain

Int: Why is that?

P7: Well they really are because they are so tiny, they're so tiny, you don't have much… room for manoeuvring them

Int: Yes, I thought that, when I was watching you, you would not be able to hold that, yourself,

P7: Yes, because my hands are very stiff first thing in the morning

Int: But you could hold the glass couldn't you?

P7: The glass.. a lot bigger, sometimes, it feels too big, so its just… oh I don't know……. You feel as if you are just being a pest, well I do, you know…

Int: Yes?

P7: Yes

Int: What, about your tablets?

P7: Yes

Int: Why are you being a pest?

P7: I just take them because I have to take them

Int: Yes

P7: And then I've taken them for so long, I know I've got to take them, and it's the only way I can get through the day.

Int: Yes

P7: And that's all I do

Int: Yes…. That's fine.

P7: Doped to the eyeballs, is the expression…I like to use, which is…they don't….. it doesn't go down very well *(she chuckles)*

Int: So is there anything else you'd like to tell me, about taking your tablets since you've been here, any stories you'd like to tell me about it

P7: Well, doesn't bother me. I know, I've taken them for so long, I've had arthritis for 40 or 20 odd years, so… I just take it.

Int: Yes

P7: I miss them, if I don't take them, I know if something's missing.

Int: Yes

P7: So I … *(huffing expression)* **Could be a lot worse. I look around, and see people in a lot worse state than I'm in….**

Int: Yes

P7: And I don't see the point of complaining……. I, just get on with it. Ok, I have a moan now and again, lose my temper now and again, so, I can't help it, its just the way of getting round the day I suppose.

Int: but in terms of those tablets then, there's nothing else that you'd want to say?

P7: No, that's all… *[pause here with break in recording as she stopped a few seconds and then carried on talking* **That's the only thing that, it does niggle, cause I like to know what I'm shoving down my mouth.**

Int: Yes

P7: I have enough of them, as you see. I mean people often say, you don't need all those pills? Well if I don't need them, why am I taking them?

Int: Yes

P7: And then I don't take them, I'm in a bit of trouble, you know…. So I just take them and forget about it *(laughing)*

Int: Yes

P7: And I know if I've forgotten, and they know I need them, because if they're short, they'll go and get them out of somebody else's box on the wall, and pinch them out of there, one dose, two doses, until they get the supply back again.

Int: Yes

P7: So, you just play it by ear really. It takes a bit of getting used to when you move

Int: I'm sure it does. Yes

P7: You know, you're not very sure who's taking, giving you what, and you'll very often hear me saying 'what are those'? Cause they look different.

Int: Yes

P7: Might be a different colour, might be a different shape. But it catches me.

Int: Yes, I'm sure

P7: And I want to know what it is that I'm taking. I don't know, I suppose its just being nosey really.

Int: Yes

P7: But I take them, and get on with it, and see what happens next time

Int: Right

P7: Well I certainly couldn't do without them

Appendix 12b: Narrative Summary derived from interview transcript

I take them because I know I've got to take them. It doesn't bother me. I don't think its up to me to remember. I feel its their job to do it…… Dishing them out. No other word for it. Because there were different pills to take, for different……. Erm……. How would you put it…… I suppose there just……. I don't know, combinations… of tablets that need to be taken. For various…. what are they…..measures …. ***(sigh)…*** **That's not the word…. Its too early in the morning……. I don't know….. I can't remember.**

They just do it automatically….. and I fall in line with whatever it is they give me. Cause I have to, and that they know better than me.

The only time its any difficult, there is any difficulty, is when I've been really tired…… I'm struggling to get the …… pills, yes, the pills, sometimes just don't go down, because they seem to get stuck. And I have to take 2 or 3 gulps of water or whatever it is, to get rid of it. That's the only time I have a little bit of problem. I don't consider medicines to be a problem

It seems to be that sometimes they give you a different….. medicine….. different…. cope, cope?.... sorry, that's another word I keep getting wrong, erm…. *(long pause and sigh as she cannot find the word),* **it just looks different, or its shaped different. That throws me slightly. Sometimes they're easier to get swallowed, other times they just don't want to go. And I have to take 2 or 3, or sometimes even 4 attempts, to get them to swallow. But they don't bother me to any great extent. I don't let them anyway….** *(laugh).* **Its no use, its just a waste of space, a waste of time… I think.**

You do it for a couple of months, and you don't think anything of it, and then suddenly somebody comes along, and gives you tablets, and you have to say to them, 'what are they?', because you're not sure what they are… well I do. Cause I like to know what I'm taking….

Those pots are a pain, they really are because they are so tiny, they're so tiny, you don't have much… room for manoeuvring them. My hands are very stiff first thing in the morning. The glass.. a lot bigger, sometimes, it feels too big, so its just… oh I don't know……. You feel as if you are just being a pest, well I do, you know…..

I just take them because I have to take them. And then I've taken them for so long, I know I've got to take them, and it's the only way I can get through the day. And that's all I do.

Doped to the eyeballs, is the expression…I like to use, which is…they don't….. it doesn't go down very well *(she chuckles)*…..**Well, doesn't bother me. I know, I've taken them for so long, I've had arthritis for 40 or 20 odd years, so… I just take it. I miss them, if I don't take them, I know if something's missing. So I …** *(huffing expression)* **Could be a lot worse. I look around, and see people in a lot worse state than I'm in…. And I don't see the point of complaining……. I, just get on with it. Ok, I have a moan now and again, lose my temper now and again, so, I can't help it, its just the way of getting round the day I suppose.**

The only thing that, it does niggle, cause I like to know what I'm shoving down my mouth. I have enough of them, as you see. I mean people often say, you don't need all those pills? Well if I don't need them, why am I taking them? And then I don't take them, I'm in a bit of trouble, you know…. So I just take them and forget about it *(laughing)*…**And I know if I've forgotten, and they know I need them, because if they're short, they'll go and get them out of somebody else's box on the wall, and pinch them out of there, one dose, two doses, until they get the supply back again. So, you just play it by ear really. It takes a bit of getting used to when you move.**

You know, you’re not very sure who’s taking, giving you what, and you’ll very often hear me saying ‘what are those’? Cause they look different. Might be a different colour, might be a different shape. But it catches me. And I want to know what it is that I’m taking. I don’t know, I suppose its just being nosey really. But I take them, and get on with it, and see what happens next time. I certainly couldn’t do without them.

Appendix 12c: Example of early coding of narrative interview summary

Narrative Summary	NVIVO Code Name
I take them because I know I've got to take them. It doesn't bother me. I don't think its up to me to remember. I feel its their job to do it…… Dishing them out. No other word for it. Because there were different pills to take, for different……. Erm……. How would you put it…… I suppose there just……. I don't know, combinations… of tablets that need to be taken. For various…. what are they…..measures …. *(sigh)…* That's not the word…. Its too early in the morning……. I don't know….. I can't remember. They just do it automatically….. and I fall in line with whatever it is they give me. Cause I have to, and that they know better than me.	Imperative Trust Routine Autonomy Imperative Routine Trust Helplessness Imperative
The only time its any difficult, there is any difficulty, is when I've been really tired…… I'm struggling to get the …… pills, yes, the pills, sometimes just don't go down, because they seem to get stuck. And I have to take 2 or 3 gulps of water or whatever it is, to get rid of it. That's the only time I have a little bit of problem. I don't consider medicines to be a problem	Swallowing Burden
It seems to be that sometimes they give you a different….. medicine….. different…. cope, cope?.... sorry, that's another word I keep getting wrong, erm…. *(long pause and sigh as she cannot find the word),* it just looks different, or its shaped different. That throws me slightly. Sometimes they're easier to get swallowed, other times they just don't want to go. And I have to take 2 or 3, or sometimes even 4 attempts, to get them to swallow. But they don't bother me to any great extent. I don't let them anyway…. *(laugh).* Its no use, its just a waste of space, a waste of time… I think. You do it for a couple of months, and you don't think anything of it, and then suddenly somebody comes along, and gives you tablets, and you have to say to them, 'what are they?', because you're not sure what they are… well I do. Cause I like to know what I'm taking….	Routine Autonomy Swallowing Helplessness Routine Autonomy Relationship to Medication

Those pots are a pain, they really are because they are so tiny, they're so tiny, you don't have much… room for manoeuvring them. My hands are very stiff first thing in the morning. The glass.. a lot bigger, sometimes, it feels too big, so its just… oh I don't know……. You feel as if you are just being a pest, well I do, you know… **I just take them because I have to take them. And then I've taken them for so long, I know I've got to take them, and it's the only way I can get through the day. And that's all I do.** **Doped to the eyeballs, is the expression…I like to use, which is…they don't….. it doesn't go down very well** *(she chuckles)***…..Well, doesn't bother me. I know, I've taken them for so long, I've had arthritis for 40 or 20 odd years, so… I just take it. I miss them, if I don't take them, I know if something's missing. So I …** *(huffing expression)* **Could be a lot worse. I look around, and see people in a lot worse state than I'm in…. And I don't see the point of complaining……. I, just get on with it. Ok, I have a moan now and again, lose my temper now and again, so, I can't help it, its just the way of getting round the day I suppose.** **The only thing that, it does niggle, cause I like to know what I'm shoving down my mouth. I have enough of them, as you see. I mean people often say, you don't need all those pills? Well if I don't need them, why am I taking them? And then I don't take them, I'm in a bit of trouble, you know…. So I just take them and forget about it** *(laughing)***…And I know if I've forgotten, and they know I need them, because if they're short, they'll go and get them out of somebody else's box on the wall, and pinch them out of there, one dose, two doses, until they get the supply back again. So, you just play it by ear really. It takes a bit of getting used to when you move.**	Burden Helplessness Imperative Helplessness Relationship to Medication Hope Helplessness Helplessness/Autonomy Burden Imperative Routine
You know, you're not very sure who's taking, giving you what, and you'll very often hear me saying 'what are those'? Cause they look different. Might be a different colour, might be a different shape. But it catches me. And I want to know what it is that I'm taking. I don't know, I suppose its just being nosey really. But I take them, and get on with it, and see what happens next time. I certainly couldn't do without them.	Helplessness/Autonomy Routine Imperative

Appendix 13a: Sample Observation Template

Date: 26/05/21

Time: 08:30

Participant No: 8

Duration of Observation: ~ 6 minutes

Descriptive Notes	**Reflexive notes**
Physical Setting: (visual layout sketch in notes) P8 is up in a chair in her dressing gown, has part-eaten tray of breakfast in front of her. Carer is across the other side of the room, preparing the medication, ticking things off on a chart. TV in on loudly – positioned between them. P8 is watching the morning news. Carer – listening to the news also as she preps the meds, and commenting on the news as she goes.	Reflexive comments, questions to self, my interpretations etc. Partly I found the TV very intrusive, it was really dominating the scenario, but then perhaps this is part of her normal routine, so makes for a relaxed atmosphere for her? Pills also part of the easy routine?
Description of participants Carer administering medication Description of activity, Sequence of events, Interactions, Participants' comments: expressed in quotes, Observations of non-verbal behaviour. Carer turns from preparing medication towards resident. P8, notices that she is ready and prompts her "the water is over there", with a gesture across to the other side of the room. Carer goes around to fetch a little water bottle with a 'sport'-cap. Looks like a brand designed for children's lunch-boxes – fruit-flavoured water? Carer: 'There's your wee diddly one'	Reflexive comments, questions to self, my interpretations etc. She is taking control of the situation. I was wondering if it was her breakfast tea which was to be used. Carer presumably knew what to expect

She points out a tiny one to P8 as she (C) tips the whole pot of pills into P8's hand. Then a steady process of P8 picking up the pills between finger and thumb and drinking from the bottle Pill 1 Drinks water Pill 2 Drink Pill 3 Drink. Drink. Pill 4 Drink Pill 5 Drink Pill 6 Drink, Drink. Each picked up carefully. She can manage this herself and drinks a full bottle of water (~200mls) to get them down. Carer: "Gone? Well done!"	I guess that wee one is easy to lose, I wonder if P8 frets about that? She is very capable and meticulous. Is this an achievement? Something to be congratulated on?

Appendix 13b: Observation Narrative Summary

Annie is up in a chair in her dressing gown, has part-eaten tray of breakfast in front of her. Carer is across the other side of the room, preparing the medication, ticking things off on a chart.

TV is on loudly – positioned between them. Annie is watching the morning news. Partly I found the TV very intrusive, it was really dominating the scenario, but then perhaps this is part of her normal routine, so makes for a relaxed atmosphere for her?

Pills also part of the easy routine?

Carer – listening to the news also as she preps the meds, and commenting on the news as she goes. Carer turns from preparing medication towards resident.

Annie, notices that she is ready and prompts her “the water is over there”, with a gesture across to the other side of the room. She is taking control of the situation

Carer goes around to fetch a little water bottle with a ‘sport’-cap. Looks like a brand designed for children’s lunch-boxes – fruit-flavoured water? I was wondering if it was her breakfast tea which was to be used.

Carer presumably knew what to expect

Carer: ‘There’s your wee diddly one’

She points out a tiny one to Annie as she (C) tips the whole pot of pills into Annie’s hand.

I guess that wee one is easy to lose, I wonder if Annie frets about that?

Then a steady process of Annie picking up the pills between finger and thumb and drinking from the bottle. She is very capable and meticulous.

Each picked up carefully. She can manage this herself and drinks a full bottle of water (~200mls) to get them down.

Carer: “Gone? Well done!”

Is this an achievement? Something to be congratulated on?

Appendix 13c: Example of early coding of Observation Narrative Summary

Narrative Summary	NVIVO Code name
Annie is up in a chair in her dressing gown, has part-eaten tray of breakfast in front of her. Carer is across the other side of the room, preparing the medication, ticking things off on a chart.	Routine
TV is on loudly – positioned between them. Annie is watching the morning news. Partly I found the TV very intrusive, it was really dominating the scenario, but then perhaps this is part of her normal routine, so makes for a relaxed atmosphere for her? Pills also part of the easy routine?	Routine Distraction
Carer – listening to the news also as she preps the meds, and commenting on the news as she goes. Carer turns from preparing medication towards resident.	Distraction
Annie, notices that she is ready and prompts her "the water is over there", with a gesture across to the other side of the room She is taking control of the situation	Autonomy
Carer goes around to fetch a little water bottle with a 'sport'-cap. Looks like a brand designed for children's lunch-boxes – fruit-flavoured water? I was wondering if it was her breakfast tea which was to be used. Carer presumably knew what to expect	Routine
Carer: 'There's your wee diddly one' She points out a tiny one to Annie as she (C) tips the whole pot of pills into Annie's hand I guess that wee one is easy to lose, I wonder if Annie frets about that?	Relationship to medication
Then a steady process of Annie picking up the pills between finger and thumb and drinking from the bottle. She is very capable and meticulous.	Autonomy
Pill 1, Drinks water. Pill 2, Drink. Pill 3, Drink, Drink. Pill 4, Drink. Pill 5, Drink. Pill 6, Drink, Drink. Each picked up carefully. She can manage this herself and drinks a full bottle of water (~200mls) to get them down	Swallowing

Carer: “Gone? Well done!” Is this an achievement? Something to be congratulated on?	Communication Burden

Appendix 14: Extracts from data analysis journaling to illustrate development of themes

Early Code Names	Iterations of Naming	Extracts from analysis notes
Autonomy		People really felt that they were keeping control over at least some aspects of the situation, the counting, the checking, managing as much as they could. (Journal 7/10/21)
		Autonomy needs breaking down because it contains 2 polar opposites – expressions of autonomy/ expressions of loss of control (Journal 10/10/21)
		Noted the sense of achievement, John describing himself as successful as if he has managed something difficult. Somewhere in the data there is also ‘well done’, a sort of congratulations as if you have overcome something bad – does that relate to ‘burden’, something unpleasant? (Journal 14/12/21)
	Being in Control	Renamed using gerund terms – thinking about ‘Being’, ‘Relating to Self’. (Journal 15/12/21)
		When I have collated all the material coded with ‘autonomy’, these seems to be the biggest section of data – not that I am supposed to be counting numbers, but it seems to be an obvious theme. The participants wanted to tell me what they can do, and stress the elements that they are, or try to remain in control of. (NVIVO memo 3/1/22)
	Helplessness	Split this code from autonomy - decision made after reviewing Morag’s case notes as a whole. She says ‘I just..’ 6 times, like she is belittling her achievement. A resigned helplessness, ‘you just have to do it’. ‘I let them get on with it’. Loss of control, relinquishment. Brings to the fore some rather depressing expressions of helplessness which do seem to be real (Journal 13/12/21)
		I coded as helplessness where John described trusting implicitly, how he does not need to know what he is taking, but again, is this his active choice, is he exercising autonomy in his own way? (Journal 14/12/21) Renamed using gerund terms (Journal 15/12/21)
	Relinquishing Control	Should helplessness be ‘relinquishing control’, or is this implying an active choice? There is a link between change of routine and helplessness, tipping the balance to feeling out of control

		Some have an air of contentment, acceptance, is that another way of describing what became coded as helplessness. Perhaps not wholly a negative term. Yes there is a passivity, but associated with trust, and with making life easier. (NVIVO memo 3/01/22)
	Autonomy/ Helplessness	Can this become one theme? The fragile balance between the two (Journal 14/12/21) There are not really 2 polar opposites, but a sore of continuum. Something about balance of power, with steps and choices along the way (Journal 31/1/22)
Burden		Things I coded as burden often had my value placed on them. Wrote the word 'imperative' on a bit of paper. Not sure if this is the right word, but something about the compulsion to take the tablets, for whatever reason, seems to underly things (Journal 10/10/21) Reclassified some of the material that really was not given a value judgement by the participants, but was more about duty, or a sense of imperative (Journal 10/12/21) Kept this code if they clearly describe something in a negative fashion (Journal 13/12/21)
	Tolerating	Renamed using gerund terms Journal (15/12/21)
	Relationship to Medication	A clunky title, but best I can think of to encompass burden/hope/imperative for now. It takes away <u>my</u> value judgement. (Journal 13/12/21) Still not quite right – should be more like 'relationship to being given medication'? (Journal 3/1/22) This whole theme is clearly still a muddle. Feedback from supervision – they just don't get it, not clear what it means. I would agree and struggle with the title too. Subheadings still a bit developmental, I am not sure of them myself. This section had seemed to be one of the key points, but perhaps it is not key to other readers, perhaps it is my perception/bias again about medicine optimisation etc Consider unpicking this theme altogether and fitting it in with the other themes? (Journal 15/7/22)

		Found that quite a lot of it could be interpreted as a ‘trusting relationship with the medication’. Some elements were recoded with swallowing and some with loss of control.. May be ‘relating to medication’ was never right, but what does that data tell me about being vulnerable, under pressure, dominated? (Journal 3/9/22)
	Imperative Needing?	Thinking now about the faith in the tablets rather than the pressure to administer, placing them in an important position (Journal 7/10/21) If I am trying to seek out the experience, then the experience is all entirely as a result of this imperative, ‘the power of the pills’. Does this underly everything? Is this the phenomenon, a talisman of some sort? All the routines and little habits set up to enable the pills to get down? A sense of duty – links with compulsion, and also something about societal norms and institutionalised behaviour (Journal 10/10/21) “Because I have to” (Journal 13/12/21) Trying to name in gerund terms – need a better word than this? (Journal 15/12/21) This node grew – originally from the code burden – developed into a more generic relationship to medication, then ultimately the greater part of what participants words actually described was a sense of imperative. I can’t think of a better word – although ‘needing’ came in somewhere. There is something of a taken-for-granted thing, but mostly just because ‘I have to take them’ Who makes those rules, where does that imperative come from? Something about the ritual/paraphernalia associated with medication – giving it this overriding importance? (NVIVO memo 3/1/22) I’m not sure I ever asked anyone why they take their tablets, but yet the ‘I have to’ and all the imperative phrases came through very strongly – Is this still a ‘relationship to taking medication?’ Is it actually the most important, that the experience of medication administration is that I take it because I have to take it – no choice? Is there any connection between the themes of Autonomy/Helplessness and Imperative? (Journal 4/1/22) I feel that I might be contriving thing to make everything fit with ‘imperative’, I could relate a lot of things back to this, but do I have to?

		The imperative could certainly be underpinning swallowing, routines, relationship to medication, but trust? Control? Not so sure. (Journal 26/6/22)
	Hope Believing?	There is a hope for being better – felt I should code this if something clearly positive is described (Journal 13/12/21) Renamed using gerund terms. (Journal 15/12/21) I made this code to try to find if there was an opposing theme for what I had coded as burden- did some people have a more positive relationship to taking their medication? (NVIVO memo 3/1/22)
Carer Differences		Made this code quite early on, but barely used it, can be absorbed into Routines. (Journal 15/12/21) Code closed – broken down to merge with routines (Journal 3/1/22)
Individual Needs		Things I have coded as 'individual needs' definitely need linking with autonomy. (Journal 10/10/21) This code became redundant in the exercise to rename using gerunds – need revising into routines/autonomy (Journal 15/10/21) Code closed – broken down to merge with routines. Maybe need to write something separately about this in the context of the observation, as it was definitely during the observation that I saw the individuality. (Journal 2/1/22)
Routines	Being Comfortable in Routines	I think these people almost all felt some security in the routines, a positive, safe feeling. Are routines all bad, or is that just what humans do? (Journal 7/10/21) Connection between the themes of routine and autonomy. The reliance on routines seems to somehow help with the preservation of autonomy (Journal 11/12/21) Renamed using gerund terms ? being safe in routines (Journal 15/12/21) There is a link with the lack of communication – no need to say anything because nothing needs to be said?

		Integrated some of the data from the code called ‘individual needs’ and the ‘carer differences’, as this seems to be what is core to the experience of the individual (NVIVO memo 03/01/22)
Safety		This was an early code I created which looks to have become redundant. Most of the material can be integrated into other themes – mostly trust, some things to do with elements of imperative- how things have to be. Seeing that you take your tablets. Also the ‘security of routine. (NVIVO memo 3/1/22) Needs to be integrated with ‘trust’. Code closed (Journal 3/1/22)
Swallowing		Not so evident because of the level of dependency that these participants have. (Journal 7/10/21) Seems a bit of a different style of theme than the others, more ontic than ontological? (Journal 3/1/22) Seems increasingly too ontic for a HP study – I wonder if some of it will be assimilated into the imperative? (Journal 12/1/22) This is the nitty gritty of the actual act, the ontic aspect, so it is still a helpful start – leads into some of the more theoretical concepts? (Journal 30/1/22)
Trust	Trusting in others	The link with trust and resigning responsibility. I see now that this is connected – of course, why would you give up the responsibility for something consciously unless you trust the people you have given it up to? (Journal 14/12/22) Renamed using gerund terms. (Journal 15/12/21) Trust remains a strong theme, it is clear in the language of the participants and in the observations – tablets taken without question. Respect for the staff. Morag also had trust in the goodness of the tablets themselves, links with the theme of hope. 7 out of 8 of the participants described trust explicitly, and I witnessed it in all the observations – is this going to be a major theme? (NVIVO memo 03/1/22)
Communication		I need to be careful to think how the communication affects the participant, and not how it affects me. (NVIVO memo 10/12/21) Exercise of renaming in gerund terms clearly made this code redundant – it is mostly related to my feelings. (Journal 15/12/21) Merged some of this material into ‘Trust’, and some kept for my own reflection, code closed. (Journal 03/01/22

Distraction		This distraction theme which I made initially seems to simply reflect that this is my distraction, there was no sign at all that the participant was distracted by things which I found distracting. This is nothing about their experience. (NVIVO memo 10/12/21) Exercise of renaming in gerund terms clearly made this code redundant – it is wholly related to my feelings. (Journal 15/12/21) Closed this as a theme – but kept notes to refer to in my reflections. (Journal 03/1/22)