AN EXPLORATORY SECONDARY DATA ANALYSIS OF THE IMPACT OF HETEROGENEITY ON ASSISTIVE TECHNOLOGY TO REDUCE SAFETY AND WANDERING RISKS FOR PEOPLE WITH DEMENTIA LIVING AT HOME

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Abstract

Introduction: There is an acknowledged gap between the potential and achieved benefit of assistive technology in the care of people with dementia. In order to make better use of this resource, this research aimed to investigate the heterogeneity of population characteristics of people with dementia living at home who have safety and wandering risks and how this is related to assistive technology recommended and installed to meet their needs.

Methods: This research consisted of two studies; a systematic review and secondary data analysis. Initially, published quantitative data describing the needs of people with dementia living at home was subjected to meta-analysis in order to explore the prevalence of needs reported by people with dementia and their caregivers and associated heterogeneity. Following univariate analyses, ordinal models were developed using secondary data which described the needs of people with dementia, and their level of wandering and safety risk, to explore the relationship between needs and risks in this population. The possibility of grouping participants according to data describing multiple needs, predisposing characteristics and enabling resources was investigated using cluster analysis. Associations between these groups and recommended and installed Assistive Technology were investigated.

Results: Prevalence estimates for twenty-four needs reported by people with dementia and their caregivers were provided for the first time. Heterogeneity was associated with the person reporting the needs and age of onset. Level of need was often not recorded in the dataset indicating limited assessment. Wandering risks were shown to be associated with posture and mobility, routine and cognition needs, whilst safety risks were associated with posture and mobility, and problem-solving needs. Partitioning Around Medoids cluster analysis demonstrated that robust clustering solutions could be created from data describing participants. Clustering solutions were then validated through exploring their association with recommended and installed Assistive Technology data and the published literature. Caregiver support and living situation impact Assistive Technology installed for people with dementia.

Discussion: This research advances understanding of the impact that needs, safety and wandering risks, caregiver support and the living situation of the person with dementia have on variation in the assistive technology interventions recommended and installed for people with dementia. Results have implications for needs assessment and for the tailoring of Assistive Technology for this population.

Keywords: dementia, assistive technology, community dwelling, meta-analysis, cluster analysis, ordinal regression, wandering, safety, risk, needs.

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GLOSSARY

Assistive Technology (AT): Devices or systems that support a person to maintain or improve their independence, safety and wellbeing. (Alzheimer's Society 2019).

ATTILA: Assistive Technology and Telecare to maintain Independent Living at Home for people with dementia. Randomised Controlled Trial investigating the effect of Assistive Technology and Telecare on institutionalisation for people with dementia living at home (Leroi et al. 2013).

Cluster: Set of objects or points with similar characteristics.

Cluster Analysis: Data exploratory technique used for discovering groups or patterns in a dataset (Kassambara 2019).

Cross-sectional: Research looking at data from a population at a particular time point.

Dementia: Umbrella term for a range of progressive conditions that affect the brain. The five most common types of dementia are Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia and mixed dementia. Symptoms may include memory loss, and difficulties with thinking, problem-solving and language (World Health Organisation 2016; Dementia UK 2019).

DerSimonian and Laird method: Method used for the estimation of random-effects model in meta-analysis (Munn et al. 2014a; Wang 2017).

Euclidean Distance: The ordinary straight-line distance between two points.

Fall Detector: Type of AT that is normally worn by the person with dementia and typically uses accelerometers to detect sudden change in orientation occurring during a fall and trigger an alert (Gibson et al. 2016).

Fixed Effects: Model of analysis used within meta-analysis which assumes that included studies are functionally equivalent and share a common true effect size (Wang 2017).

Gower Distance: The average of partial dissimilarities across individuals (Filaire 2018).

Heterogeneity: Variability in the participants, interventions and outcomes studied may be described as clinical diversity (sometimes called clinical heterogeneity), and variability in study design and risk of bias may be described as methodological diversity (sometimes called methodological heterogeneity). Variability in the intervention effects being evaluated in the different studies is known as statistical heterogeneity, and is a consequence of clinical or methodological diversity, or both, among the studies. Statistical heterogeneity manifests itself in the observed intervention effects being more different from each other than one would expect due to random error (chance) alone (Higgins and Green 2011).

Leave1out analysis: Deletion diagnostic which can be used to identify influential studies and heterogeneity (Higgins et al. 2003; Wang 2017).

Manhattan Distance: The distance between two points measured along axes at right angles.

Medoid: An object that represents a cluster (van der Laan et al. 2002).

Meta-analysis: The use of statistical techniques to integrate and summarize the quantitative results from multiple studies which have investigated the same research question (Wang 2017).

Need: Capacity to benefit from services (Asadi-Lari et al. 2003; NHS Health Scotland 2019).

Ordinal Regression: Model for ordinal scale observations (Christensen 2018).

Prevalence: The proportion of a population who have a certain disease or characteristic (Munn et al. 2014a).

Partitioning Around Medoids (PAM): Clustering algorithm (Krysnka 2018).

Random Effects: Model of analysis used within meta-analysis which takes account of within and between study variance (Wang 2017).

Risk: The possibility of something bad happening (Cambridge English Dictionary 2019).

Safer Walking Technologies to Alert a Responder of Movement: Type of sensor based AT which triggers an alert when its path is crossed (Lin et al. 2014).

Safer Walking Technologies to Locate the User: Type of AT which includes GPS trackers that are worn by the person with dementia. They identify the current location and can be used to find the person with dementia or to guide the person with dementia to a specific location (Dunk et al. 2010; Wood et al. 2015).

Secondary Data Analysis: Any further analysis of an existing dataset which presents interpretations, conclusions or knowledge additional to, or different from, those produced in the first report on the inquiry as a whole and its main results (Hakim 1982).

Sensitivity analysis: Statistical analysis which determines if findings are robust to the decisions made in the process of obtaining them (Higgins and Green 2011).

Silhouette value: Measures the degree of confidence in the clustering assignment of a particular observation (Brock et al. 2011).

Silhouette width: An aggregated measure of how similar an observation is to its own cluster compared to its closest neighbouring cluster (Kaufman and Rousseeuw 1990; Reynolds et al. 2006).

Telecare: Technology that enables you to remain independent and safe in your own home (Think Local Act Personal 2019).

Telehealth: Technology that sends information about your health to your doctor from your home, to help manage long-term conditions such as diabetes or chronic heart failure (Think Local Act Personal 2019).

A NOTE ABOUT LANGUAGE

Throughout this thesis the author has made an effort to use language and terminology which is preferred by people with dementia and their caregivers and which is as accurate, balanced and as respectful as possible. The author has found the following documents useful in this regard:

http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf

https://www.dementia.org.au/files/resources/dementia-language-guidelines.pdf

CHAPTER 1. INTRODUCTION

1.1 The Needs of People with Dementia

It is estimated that by the year 2025 there will be over one million people in the UK with dementia (King's College London et al. 2014). Dementia is one of the main causes of disability in later life ahead of cancer, cardiovascular disease and stroke. People with dementia experience a wide range of intense care needs (Prince et al. 2015) which are further exacerbated by the multi-morbidity associated with dementia (Banerjee 2015). Currently, it is estimated that two-thirds of these needs are met by people with dementia themselves who pay privately for some £5.8 billion worth of care services, in addition to unpaid care provided by informal family caregivers which is estimated to have a value of approximately £11 billion (King's College London et al. 2014). In order to provide effective support for people with dementia it is therefore prudent to take account of their individual needs (Farmer et al. 2016). Needs, which can be defined as the ability of people to benefit from health care provision (Asadi-Lari et al. 2003), are strongly associated with risks and, when unmet, can lead to adverse consequences including falls, impact upon the caregiver, institutionalisation or even death (Gaugler et al. 2005; Black et al. 2013; Seden 2016). Until recently, research into the needs of people with dementia has focussed upon proxy reports from formal and informal caregivers (van der Roest et al. 2009; Kerpershoek et al. 2017), and researchers have expressed difficulty in gathering accurate information regarding the prevalence of the needs of people with dementia reported by themselves (Morrisby et al. 2018). Further understanding of the range of needs experienced by people with dementia and their caregivers is therefore required in order to facilitate the development of services to meet their needs (Farmer et al. 2016; Morrisby et al. 2018).

1.1.1 Safety and Wandering Risk

Throughout the literature, unmet needs are associated with increased risk of harm for the person with dementia and there is a requirement for this relationship to be explored further with regard to particular risks associated with anxiety for people with dementia and their caregivers (Dewing 2005; Gaugler et al. 2005). Understanding which needs or risks are related to particular adverse outcomes will enable the informed refinement of assessment and intervention provision processes thereby increasing their effectiveness and efficiency to meet needs and therefore reduce risk. Two areas of anxiety strongly associated with adverse outcomes for people with dementia throughout the literature, are safety and wandering risk (Douglas et al. 2011). These risks are selected as the focus for this research as they are important within this population, affect many areas of the lives of people with dementia, are frequently assessed by clinicians, and are modifiable in that the likelihood of injury can potentially be reduced by interventions including assistive technology (AT) (Douglas et al. 2011). Effective assessment of safety and wandering identifies those in need of support and at risk of injury (Douglas et al. 2011). However, Amjad et al. (2016) report that whilst a comprehensive assessment of needs is recommended in dementia care, safety (including wandering) is often insufficiently addressed and care can therefore be inconsistent and reactive. This inconsistency may be due to needs assessments not directing clinicians towards appropriate interventions, as one study found that 70% of patients with mental disorders did not receive interventions matching their assessed needs (Cummings and Kropf 2009). Schmid et al. (2012) suggest that this may result from available validated needs assessments lacking the comprehensiveness and reliability required for optimal treatment selection. Schmid et al. (2012) further suggests that there is a requirement to elevate the accuracy and concordance of needs assessment tools, to improve individual needs assessment and to find the best fit between assessed need and intervention.

1.2 Assistive Technology

AT incorporates a wide range of devices, including monitoring systems, and technology which can be used to support care functions and household tasks (Gibson et al. 2015). Additionally, AT has the potential to assist in increasing safety, promoting wellbeing and supporting the participation of people with dementia (Boger et al. 2014; Riikonen et al. 2013), by compensating for physical and cognitive deficits (Fleming and Sum 2014) potentially reducing their risk of injury (Douglas et al. 2011). The possibility of meeting the care needs of people with dementia, increasing choice, and reducing care costs has been recognised by UK Government. Wanless (2006) and Poole (2006) reviewed evidence for the effectiveness of AT and recognising its potential benefit concluded that AT should be moved into the mainstream. Whilst evidence for the cost benefit of AT was still limited, this review was able to draw conclusions from the range of available pilot studies paving the way for further analysis of the benefits offered by AT. Policy and legislation aimed at facilitating AT use will now be discussed.

1.2.1 Policy and Legislation guiding Assistive Technology Intervention

Following the national Dementia Strategy for England: Living Well with Dementia (Department of Health 2009) which promoted the rights of people with dementia to retain their independence whilst remaining within their own homes, the potential benefits of AT to meet the needs of people with dementia in a cost-effective and efficient manner have been more widely recognised by the UK Government. Current legislation associated with facilitating the provision of AT for people with dementia in England includes the Care Act 2014 and the National Health Service Act 2006.

The Care Act 2014 which applies to adult social care was implemented throughout England in April 2015 replacing the NHS and Community Care Act 1990 and the Chronically Sick and Disabled Persons Act 1970, states that Social Services have a general duty to promote the wellbeing of the individual (Mandelstam 2016). Wellbeing is defined within the act as encompassing nine components;

- Personal dignity
- Physical and mental health and emotional wellbeing
- Protection from abuse and neglect
- Control by the individual over day-to-day life (including over the care and support provided to the adult and the way in which it is provided).
- Participation in work, education, training or recreation
- Social and economic wellbeing
- Domestic, family and personal relationships
- Suitability of living accommodation
- The adult’s contribution to society

The act places a legal duty on local authorities to provide arrange or otherwise identify services, facilities and resources to prevent, delay or reduce the needs of adults for care or support.

To be eligible under the act, the adult must meet three requirements:

(1) Have care and support needs arising from or related to a physical or mental impairment or illness.
(2) Be unable to achieve at least two of the following outcomes.
    a. Managing and maintain nutrition
    b. Maintaining personal hygiene

   c. Managing toilet needs
   d. Being appropriately clothed
   e. Being able to make use of the adults home safely
   f. Maintain a habitable home environment
   g. Developing and maintaining family or other personal relationships
   h. Accessing and engaging in work, training, education or volunteering
   i. Making use of necessary facilities or services in the local community including public transport, and recreational facilities or services
   j. Carrying out any caring responsibilities the adult has for a child

(3) Experience significant impact on the adult's wellbeing as a consequence of the above.

The person must also be ordinarily resident within the area of the local authority and have resources under a set threshold (at time of writing £23250).

If the adult meets the above requirements, the local authority has a duty to meet those needs by way of care and support unless there is an informal carer able and willing to meet them.

The act also describes statutory assessment stating that it should be accurate and proportionate, for example, the act states that simpler needs may be amenable to assessment on the telephone. Regulations also state that assessors must be skilled, knowledgeable, competent and appropriately trained (Mandelstam 2016).

Additionally, health care equipment for adults and children is provided under the NHS Act 2006. This act states that clinical commissioning groups must arrange for the provision of such other services or facilities for the prevention of illness, the care of persons suffering from illness and the after-care of persons who have suffered from illness as the group considers are appropriate as part of the health service (Mandelstam 2016). Services should be provided to such extent as it considers necessary to meet the reasonable requirements of the local population. (Mandelstam 2016).

Further, legislation has been drafted in response to policy developments in this field (NHS Executive 1998), which first introduced the notion of telecare technology. The main policy documents which provide more specific guidance on the development of services to provide AT are summarised below.

Guidelines for the infrastructure required by local authorities to successfully implement telecare services including training, equipment and response services were developed (Department of

Health 2005; Roulstone et al. 2013). References to AT were then extended to include specific association to people with dementia within the national dementia strategy (Department of Health 2009; 2009b). More recently, UK Government (2010) suggested that AT should be central to future social care policy. Simultaneously, guidance has worked to change attitudes towards the care of people with dementia (Department of Health, Manthorpe and Moriarty 2010) which promote the notion of positive risk-taking and risk enablement.

1.2.2 Problems with Assistive Technology Service Delivery

However, there is an identified a gap between the required intervention and care, and the services actually provided for people with dementia (World Health Organisation 2017). Further, AT interventions for people with dementia have not been well studied, and the evidence for their effectiveness is inconsistent and generally demonstrated through small, poorly designed trials that are not situated in the real world (Fleming and Sum 2014; Khosravi et al. 2016; Kenigsberg et al. 2017; Landry and Keller-Allen 2017). Therefore, despite the potential of AT to provide cost-effective and unobtrusive care support in response to increasing demand from a growing number of people with dementia, evidence to support the use of AT with this population is limited (Leroi et al. 2013). Further research into the acceptability of AT to assist people with dementia and their caregivers has been identified as a national priority (James Lind Alliance 2013).

Where AT is available, acceptance of AT is influenced by a range of factors including positive perceptions of AT, level of anxiety, perceived benefit, choice, level of cognitive impairment, gender, living situation and social support (Weilandt et al. 2006; Boger et al. 2014; O'Neill et al. 2014). But there is a need for further understanding of the differences in the requirements of this population in order to provide AT which is acceptable to them (Landry and Keller-Allen 2017). Unfortunately, there is currently no guidance available regarding the priority of any one factor over another in the selection of an appropriate AT intervention, or how they relate to each other, or to the needs of people with dementia (Lauriks et al. 2007). Additionally, Topo (2009) identifies a lack of understanding regarding the appropriateness of AT installed in response to a particular need, and how the AT may be changed according to the different characteristics or wishes of people with dementia and their caregivers.

Heterogeneity of people with dementia and their caregivers will likely affect their need for care and support. In order to understand how services can accommodate this diversity there is a recommendation that research should increase awareness and understanding of variation of people with dementia and their caregivers (Landry and Keller-Allen 2017). Consideration of the individual needs and other population characteristics of people with dementia will assist in identifying interventions which can provide them with optimal support (Farmer et al. 2016; Landry and Keller-Allen 2017). Accurate, up to date descriptive information regarding the care need of people with dementia and their caregivers is required (Landry and Keller-Allen 2017; O'Keeffe 2017). By understanding the specific characteristics of people with dementia and how these relate to AT, service providers can take a client centred approach to service delivery (Rothera et al. 2003; Raivio et al. 2011). Therefore, in order to plan optimal care services to meet the needs of people with dementia, further knowledge regarding the range and frequency of needs in this population is required together with information on characteristics associated with the occurrence of needs (Landry and Keller-Allen 2017; Gitlin et al. 2018). There is an additional requirement to understand the relationship between the needs of people with dementia, and other population characteristics, and then how these characteristics relate to the specific AT interventions which may best meet their needs (Fleming and Sum 2014).

Despite the above expressed intentions to provide services which meet the needs of people with dementia, there is evidence of deficiencies within the community care system possibly arising from underfunding, difficulties in accessing services and confusion about the role and responsibilities of different members of the community care team (Newton et al. 2016; Jarvis et al. 2017). The economic pressure to deliver cost-effective care for people with dementia, alongside the desire to provide alternative means of care which increase the choices available to people with dementia, are driving forces towards the development of AT to meet the needs of people with dementia (Kenigsberg et al. 2017).

However, in order to be in a position where there are sufficient interventions which can be adapted to meet the needs of people with dementia and their caregivers, there must be further work on multiple levels to ensure that AT providers are aware of the specific requirements of people with dementia and produce AT which can be tailored and "personalised" (Woolham et al. 2006; Newton et al. 2016). Further, assessment of needs in this field is poor (Bonner and Idris 2012). Additionally, previous research has identified that older people with severe mental illness such as dementia mostly do not receive the intervention which is indicated by their assessed needs (Cummings and Kropf 2009). This may be because health professionals lack the knowledge and confidence to offer accurate assessment and advice (Newton et al. 2016; Jarvis et al. 2017;

Kenigsberg et al. 2017), and there are technical issues associated with the implementation of AT (Nauha et al. 2018).

The method of matching individuals with appropriate AT, although acknowledged as important, appears complex and is also not well understood (Khosravi et al. 2016; Landry and Keller-Allen 2017; Collins 2018; Hansen et al. 2018; Guisado-Fernandez et al. 2019). This may be due to limited comprehension regarding the individual AT needs of people with dementia (Landry and Keller-Allen 2017; Morrisby et al. 2018). Improved understanding of the specific requirements of individuals will inform the development of services to meet these needs. This requires the adoption of research methods which facilitate the study of complex multi-component services intended to accommodate multiple factors which affect care and service needs (Landry and Keller-Allen 2017). Additionally, the understanding of how AT is affected by the individual characteristics and needs of people with dementia, their situation and their caregiver requires further investigation (Gillespie et al. 2012; Fleming and Sum 2014; Landry and Keller-Allen 2017). In order to fully exploit the potential of AT to increase the care options for this population, these aspects of current practice in the field of AT interventions require to be more fully explored (Bharucha et al. 2009).

Information and training should be available to people with dementia and caregivers to facilitate the integration of AT into their lives (Bonner and Idris 2012; Arntzen et al. 2016). However, limited understanding of factors which facilitate the adoption of AT prevent the provision of this information (Riikonen et al. 2013). It has also been identified that funding and service delivery require to be focussed upon the needs of people with dementia and caregivers (Hansen et al. 2018).

1.3 Significance of the Research

In order to advance knowledge in this field, this research will explore the relationship between heterogeneity in characteristics of people with dementia and AT. This will include examination of the relationship of needs and risks to AT interventions for people with dementia (Seden 2016). To enhance available information regarding the use of AT to meet needs and thereby reduce safety and wandering risks of people with dementia living at home this research will for the first time provide prevalence estimates of needs of people with dementia living at home together with an exploration of the heterogeneity associated with those needs.

Previous research examining the effectiveness of AT interventions is weak, and is criticised for failing to account for the view of people with dementia; being laboratory based; and that sample sizes are too small (Fleming and Sum 2014). Initially, scientists explored the effectiveness of AT within controlled conditions to prove their effectiveness (Fleming and Sum 2014; Greenhalgh et al. 2016). Larger studies such as the Whole System Demonstrator Study found that telecare reduced hospital admissions although in exchange for great financial expenditure, but did not specifically include people with dementia (Davies and Newman 2011).The results of the ATTILA (Assistive Technology and Telecare to Maintain Independent Living for People with Dementia) randomised controlled trial (RCT) are unpublished at time of writing but are anticipated to be inconclusive (Leroi et al. 2013).

The multi-site pragmatic ATTILA RCT aimed to examine the effects of needs assessment followed by provision of AT services in prolonging people with dementia living at home. However, early indications suggest that ATTILA provides no evidence that AT delays the institutionalisation of people with dementia, or provides a cost benefit. Preliminary publication indicates disregard for assessment recommendations, and AT deployment inconsistent with local authority goals, suggesting that benefit for AT recipients is unlikely (Forsyth et al. 2019). These factors suggest reduced efficacy of the AT intervention and indicate a requirement for further investigation. Further, as the ATTILA RCT did not account for individual differences and their impact on the use of AT there is a compulsion for further exploration (Greenhalgh et al. 2016). Additional investigation such as this research, may determine the impact of variation in specific characteristics of people with dementia on the installation of specific types of AT.

There is a need to close the gap between previous research which has been carried out in experimental situations, and the real-world where AT users are placed within wider social, political and policy contexts (Greenhalgh et al. 2016; Newton et al. 2016). Following consideration of relevant literature, this research will explore multiple characteristics of people with dementia and their relationship with AT based upon data which describes current AT practice. Specifically, data describing needs, safety and wandering risks, level of cognitive impairment, caregiver support and living situation will be considered. This will advance understanding of the influence that these personal characteristics have upon recommended and installed AT.

The strength of this research will be enhanced by the size of the dataset derived from the ATTILA RCT which provides rich, unique data describing locally provided AT interventions recommended and installed for participants with dementia living at home. Consideration of both recommended and installed AT will facilitate understanding of the factors which influence AT. These influences include the views of the person with dementia, their caregiver and other social supports, and the person conducting the AT Needs Assessment. Thereafter, the research results will be discussed in relation to previously published literature in order to enhance validation, and to understand the wider relevance of the research findings. This will also allow the researcher to explore limitations relating to the study.

1.4 Methodology

In order to justify or explain the use of particular methods within research, it is traditional within many disciplines to explore the researcher's theoretical perspective and epistemology. Epistemology refers to the nature of the relationship between the researcher and what is known (Antwi et al. 2015), and determines which research methods are appropriate (Darlaston-Jones 2007).

Positivism adopts the ontological position of assuming that there is a stable, quantifiable reality, and that continued observation will enable researchers to achieve an understanding of this highly systematic and well organised reality (Crotty 2003; Green and Thorogood 2004). This stance is associated with an organised method for combining deductive logic with precise empirical observations of individual behaviour which allows the researcher to confirm causal laws and ultimately to predict patterns of human activity. Truth in positivist enquiry is achieved through the verification and replication of observable findings (Guba and Lincoln 2005). Fundamental to qualitative studies is trustworthiness (Lincoln and Guba 1985).

Traditionally, health researchers have focussed upon establishing truth through positivist assumptions that knowledge is objective, and research involves hypothesis testing and identifies causality (Rowe and Oltmann 2016), believing that their experimental research would translate directly into healthcare practice improvements (Braithwaite et al. 2018). This has become the standardised view of the scientist and its wide acceptance has resulted in methodology rarely being discussed (Evans et al. 2014). Advantages of quantitative methods include the use of reliable, measurable data, transparent research methods ensure rigour, methods aim to explain cause and effect or inference and association depending on the method, findings can be generalised to a large population, and transparency of research methods ensures that research studies can be replicated by other researchers (Allsop 2013). Key questions within the positivist paradigm include those beginning with "what" and "why". "What" questions aim to obtain an accurate description and provide a foundation for research.

However, critics claim that this approach can fail to acknowledge the dynamic and complex nature of healthcare systems and recently Greenhalgh and Papoutsi (2018) called for health care research to acknowledge the uncertainty and unpredictability found within healthcare and to adopt new complexity-informed paradigms which attempt to capture and explore information regarding the tensions and imperfections associated with this field. They reason that this would increase the usefulness and generalisability of research findings (Bonell et al. 2012).

Theory, background knowledge, values and previous experiences can all influence the nature of research (Robson 2002). Therefore, post-positivism strives to adopt the advantages of quantitative research methods whilst accepting that evidence can be imperfect and fallible. Other principles of post-positivism include the reduction of research bias, and an acceptance that people have to be guided by best available evidence which explains a particular situation or describes causal relationships but which ultimately may be refined or abandoned when new evidence becomes available (Robson and McCartan 2016).

This study is concerned with increasing understanding of human activity relating to the practices surrounding assessment and installation of AT for people with dementia who are experiencing safety and wandering risks. As AT interventions require an understanding of the many characteristics and behaviours of people with dementia, their caregivers and family, together with interactions between these groups and health and social care services, this intervention can be described as complex (Craig et al. 2008).

This cross-sectional observational secondary data research will not produce information regarding causality. It is however anticipated that any generated findings can be placed within their appropriate context through detailed description of the participants and the AT interventions with which they are provided, and will therefore be useful in understanding the impact of particular factors in regard to these outcomes. Scientific principles were adhered to throughout the research design and analysis, and these processes are fully described within the text. However, the researcher acknowledges that to detach these research focussed decisions, from previous experience and context was not always possible nor desirable. To do so would distance the research from the situation which it is intended to inform (Greenhalgh and Papoutsi 2018; Heinze at al. 2018). As this study used secondary data the researcher was not involved in decision making regarding the design of the original RCT study or the data to be collected.

However, the AT interventions provided for participants were not part of the original research study and reflect local practice. Research questions for this study draw upon findings from the literature and direct the focus to the associations between the characteristics of the people with dementia population, and the AT interventions in order to understand the contextual factors (Long et al. 2018).

It is intended that the positioning of the findings of this research within the context of complex health and social care systems and therefore within society as a whole, will assist readers to understand the extent of their applicability and generalisability.

1.5 Research Aims and Objectives

Knowledge regarding the impact of individual differences of people with dementia and their environment upon AT installation is limited. There is therefore a requirement to better understand the processes which surround the recommendation of appropriate AT to meet the needs of people with dementia and their caregivers. This research aims to facilitate a better understanding of the processes surrounding AT interventions through exploration of the heterogeneity of individual needs; enabling resources; and the personal and environmental factors of people with dementia (Toseland et al. 2002; Fleming and Sum 2014). The rigorous study of the differences between individual people with dementia can lead to the discovery of general principles that may guide future practice in this field (Hibberd 2009; Greenhalgh et al. 2016). Further, identifying high risk or amenable groups enables interventions to be developed and targeted to meet their needs in a cost effective and efficient manner (Clatworthy et al. 2005). This will contribute to the development of practice surrounding AT for people with dementia, and will identify groups of people with dementia who have particular issues which may be amenable to AT interventions, leading to opportunities for enhanced outcomes for this population.

This research will be conducted in two parts or studies. Firstly, the researcher will conduct a systematic review and meta-analysis study to determine the prevalence of needs experienced by people with dementia living at home as quantified in the published literature. Thereafter, the researcher will conduct secondary data analysis of data collected during the ATTILA RCT in order to investigate the relationship between the assessed needs of people with dementia and their level of safety or wandering risks, and the relationship of multiple participant characteristics upon recommended and installed AT. The researcher previously worked as a research practitioner on the ATTILA RCT and therefore has access to data describing the characteristics of the RCT participants and the AT interventions, they received from their local service provider. Access to this data provides this researcher with an opportunity to investigate the relationships between multiple characteristics of people with dementia living at home who were recruited to the ATTILA RCT and their AT interventions.

Analysis is therefore restricted by the range and quality of data included within the dataset. The dataset contains information regarding people with dementia living at home who were recruited from 11 Councils with Adult Social Service Responsibilities (CASSR) areas within England. Data was collected during the ATTILA pragmatic multi-centre, RCT between 2014 and 2016. The primary objective of the ATTILA RCT was to establish whether AT assessment and intervention extend the time that people with dementia can continue to live independently in their own homes and whether this is cost-effective (Leroi et al. 2013). Secondary objectives examined; (1) whether AT can reduce the number of incidents involving serious risks to safety and independent living, and; (2) the experience of people with dementia and their caregivers of using AT (Leroi et al. 2013).

Collected data includes demographic details of participants and their caregivers, needs assessment documentation, and information regarding the category of AT recommended and installed by health and social care services following the initial needs assessment. The AT was deployed by CASSRs in line with their normal practice and was not funded, assessed or deployed by the RCT (Leroi et al. 2013). This dataset derived from data collected during the ATTILA RCT study examining the benefits of locally provided AT for people with dementia therefore presents a unique opportunity for investigation.

This secondary data will be analysed using statistical methods including ordinal regression in order to provide greater understanding of the needs of people with dementia living at home who have wandering and safety risks. Thereafter the data will be subjected to cluster analysis in order to determine if it can be robustly clustered into groups of people with dementia according to demographic data which includes their level of safety and wandering risk.

Details of the aims, objectives and research questions which provide the foundation for the following research will now be presented.

1.5.1 Aims

The overall aim of this research was to investigate the heterogeneity of people with dementia living at home who have safety and wandering risks and how this heterogeneity is related to AT recommended and installed to meet their needs. This will be achieved through the completion of two studies:

Study 1: Systematic Review and Meta-analysis will explore the needs experienced by people with dementia living at home, their prevalence, and characteristics associated with heterogeneity.

Study 2: Secondary data analysis to investigate the relationship between needs and safety and wandering risks of people with dementia living at home; and the characteristics of people with dementia and recommended and installed AT.

1.5.2 Research Questions

In order to more fully understand the relationship between the individual needs and characteristics of people with dementia and AT interventions, this research will: (1) explore the range and prevalence of needs experienced by people with dementia as reported in the literature, and the heterogeneity associated with needs in this population; (2) investigate the association between AT needs, and wandering and safety risks, in the ATTILA RCT dataset; (3) explore the possibility of creating robust clusters of participants based on data describing population characteristics within the ATTILA RCT dataset; (4) analyse the relationships between ATTILA RCT data describing AT recommended and installed and different levels of safety and wandering risk, then; (5) describe the relationship between the groupings of ATTILA RCT participants according to population characteristics including their level of safety or wandering risk, and the AT recommended and installed for them.

The aim of this research will be met through the investigation of four research questions.

- **What needs are experienced by people with dementia living at home, what is their prevalence and which characteristics are associated with heterogeneity?**
- **How are needs associated with level of safety and wandering risks in people with dementia living at home?**
- **Are there distinct groups of people with dementia living at home?**
- **Do these clusters of people with dementia living at home have different AT recommended and installed?**

These will now be described in more detail.

Systematic review and meta- analysis: What needs are experienced by people with dementia living at home, what is their prevalence and which characteristics are associated with heterogeneity?

In order to establish the prevalence and range of needs experienced by people with dementia, the researcher will examine published quantitative data which describes the needs of people with dementia who are living at home, through systematic review and meta-analysis. Whilst the needs of people with dementia have been described in the literature, there has been limited synthesis of this information (Morrisby et al. 2018). Quantitative synthesis of information regarding the needs of people with dementia will contribute to what is known about individual differences in this field, the variation in needs for this population, and the characteristics associated with variation (Song et al. 2001). Meta-analysis also provides prevalence estimates for the reported needs for the first time, and will allow robust investigation of the heterogeneity of those needs. This analysis will demonstrate that prevalence of needs for people with dementia who are living at home vary depending on who is reporting the needs, and according to age of onset of dementia. Caregivers generally report higher levels of needs, although this may be the result of people with severe dementia being unable to understand questions within the needs assessment (Miranda-Castillo et al. 2013).

Review of the published literature on AT interventions provided to meet the needs of people with dementia living at home who have safety and wandering risks.

AT is most frequently deployed to meet safety needs of people with dementia as safety and wandering are identified by caregivers, and health and social care professionals as being their greatest cause of concern related to the care of people with dementia (Douglas et al. 2011; Collins 2018). In order to explore current understanding of the needs of people with dementia and the impact that these have upon the use of AT, the results of a review of the literature on the needs of people with dementia living at home who have wandering and/ or safety risks, and how particular needs are associated with wandering and safety risks is discussed. The author explores the literature relating to the nature and prevalence of adverse outcomes occurring as a result of wandering and safety incidents, and the links between these adverse outcomes and particular characteristics of people with dementia and their caregivers.

The literature regarding the delivery of AT interventions for people with dementia who are living at home and have safety or wandering risks will also be discussed. This describes the processes involved in the current practice of AT assessment and provision for this population will be examined. In addition to providing a narrative on the identified benefits of AT for people with dementia, there is a focus upon the individual characteristics of people with dementia and their caregivers, and individual circumstances, and the impact of these upon the adoption and use of AT to meet their needs. In order to provide a structure for evaluating the interactions of factors which impact upon the effectiveness of AT for this population, the researcher also provides a description of the model of healthcare utilisation.

How are needs associated with level of safety and wandering risks in people with dementia living at home?

Thereafter, there will be an analysis of data collected during the course of the ATTILA pragmatic RCT. This secondary dataset provides a unique opportunity to explore data relating to the needs assessment of people with dementia, and the AT recommended and installed for them. Secondary data analysis will use ordinal regression to explore the relationships between participants' characteristics and the AT they were recommended and had installed.

Initially, the demographic information of the participants is presented to orientate the reader to the population under examination. In order to reduce the risks experienced by people with dementia an increased understanding of their needs and how these are associated with risks will assist professionals to identify appropriate individualised interventions. Therefore, in order to more accurately describe the relationship between the identified needs of this ATTILA population and their risk of adverse outcomes, the researcher will explore the relationship of individual AT needs to (1) level of risk of wandering, and; (2) level of safety risk, using descriptive statistics and ordinal regression models.

In order to establish the impact of risk assessment upon AT interventions, the relationship between level of risk of wandering, or level of safety risk with categories of recommended and installed AT will also be presented.

Are there distinct groups of people with dementia living at home?

Subsequent analysis of the secondary dataset will focus upon the identification of groups amongst the study participants based upon their population characteristics. AT has been proposed as an intervention which can reduce the risk of adverse outcomes by meeting the needs of people with dementia who have safety and wandering risk. However, the potential of AT is not being fully exploited and previous research has focussed on the examination of single variables and their association with AT (Fleming and Sum 2016). However, AT services provided for people with dementia are influenced by many factors enabling resources and predisposing characteristics in addition to needs (Toseland et al. 2002; Hirt et al. 2019). Hence, there is a need to explore the relationship between multiple variables and AT. Therefore, the researcher will conduct cluster analyses of population characteristics identified from demographic data including safety and wandering risks of people with dementia living at home who participated in the ATTILA RCT. Cluster analysis based upon Partitioning around Medoids (PAM) algorithm, using silhouette width for selection of number of cluster and internal validation, will be used to determine the possibility of creating robust groupings of people with dementia which could be used for further analysis. This method allows exploration of underlying structure within the data. Two clustering solutions are to be developed: one including data relating to the person with dementia's risk of wandering, and one including data relating to the person with dementia's safety risk.

Do these clusters of people with dementia living at home have different Assistive Technology recommended and installed?

Thereafter, the researcher examines categories of AT which were recommended and installed for the ATTILA RCT participants within each of the clusters for both clustering solutions, in order to validate the clustering solution as a basis for investigations within this field. Primarily, this secondary data analysis enables examination of the association of multiple factors with AT provision. Groupings of people with dementia identified through cluster analysis are linked with the (1) recommended AT; and (2) installed AT received by these groups in order to increase understanding of the impact of multiple variables upon AT.

1.5.3 Research Objectives

The aims of this research will be achieved through the following objectives;

STUDY 1

1. Systematic Review and meta-analysis of the literature regarding the needs of people with dementia living at home and the sources of heterogeneity associated with these needs

following PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analysis) Guidelines.

   a. Establish prevalence estimates of needs reported by people with dementia living at home and by their informal caregivers;
   b. Compare the prevalence estimates of needs reported by people with dementia to those reported by informal caregivers of people with dementia;
   c. Quantify and explore the heterogeneity associated with these prevalence estimates.

STUDY 2:

2. Review of the published literature on the wandering and safety risks of people with dementia living at home and the AT interventions provided to mitigate these risks. This review will:
   a. Explore the definition of wandering for people with dementia, wandering prevalence and associated adverse outcomes;
   b. Explore the nature of safety risks for people with dementia, safety risk prevalence and associated adverse outcomes;
   c. Explore the population characteristics of people with dementia and their associations with risk;
   d. Describe the provision of AT for people with dementia who have wandering and safety risks;
   e. Consider the characteristics of people with dementia and their impact upon AT interventions.
3. Describe the relationship between the needs of people with dementia living at home and their level of safety or wandering risk.
   a. Conduct univariate and ordinal regression analysis on secondary data to explore the relationship of assessed needs of people with dementia living at home with their level of safety and wandering risk.
4. In order to explore the impact of multiple population characteristics upon AT interventions the researcher will investigate the possibility of grouping participants using robust statistical methods.

a. Employ partitioning around medoids cluster analysis to group participants according to secondary data describing population characteristics.
b. Examine the relationship of these groupings to recommended and installed AT to understand the association of multiple population characteristics on AT intervention.

It is anticipated that this information will inform the tailoring of AT interventions to meet the needs of people with dementia living at home.

1.5.4 Thesis Structure

The structure of the remainder of this thesis is briefly outlined below.

Chapter 2: In order to establish the prevalence and range of needs experienced by people with dementia, this chapter will examine published quantitative data which describes the needs of people with dementia who are living at home, through systematic review and meta-analysis. Quantitative synthesis of information regarding the needs of people with dementia will contribute to what is known about individual differences in this field, the variation in needs for this population and the characteristics associated with variation. Methods used within the study are described**.** The results of this study are discussed in relation to the published literature.

Chapter 3: This chapter reviews the published literature regarding wandering and safety risks of people with dementia as these are commonly identified for people with dementia. The review focusses on the prevalence of these risks, their associated adverse outcomes, and their relationship with the population characteristics of people with dementia.

Chapter 4: This chapter considers the published literature describing AT provided for people with dementia experiencing wandering and safety risks. Attention is focussed upon the population characteristics of people with dementia and their impact upon AT provision.

Chapter 5: This chapter presents the research methods employed in the analysis of secondary data describing the population characteristics of people with dementia and the AT interventions recommended and installed for them.

Chapter 6: This chapter provides the results of the secondary data analyses described in the previous methods chapter. This includes descriptive statistics which provide an understanding of the dataset, followed by results of univariate and ordinal regression analyses, and partitioning around medoids cluster analysis. Results for each of the secondary data research study questions are presented sequentially.

Chapter 7: This chapter discusses the results of the secondary data analysis in the context of the published literature in order to validate the contribution of this study within the field of AT for people with dementia. Limitations of this analysis are also considered prior to providing a statement regarding the unique contribution of this analysis to the field.

Chapter 8: This chapter briefly presents the conclusions which may be drawn from this research. These are considered in relation to their implications for policy, practice and further research.

Chapter 9: This chapter includes an impact statement together with a proposed plan for the dissemination of this research in academic journals and at conferences where the expected audience will include people with dementia and their unpaid caregivers, in addition to professionals working in the AT industry.

CHAPTER 2. SYSTEMATIC REVIEW AND META-ANALYSIS.

In order to establish the prevalence and range of needs experienced by people with dementia, this chapter will examine published quantitative data which describes the needs of people with dementia who are living at home, through systematic review and meta-analysis. Quantitative synthesis of information regarding the needs of people with dementia will contribute to what is known about individual differences in this field, the variation in needs for this population and the characteristics associated with variation. Methods used within the study are described**.** The results of this study are discussed in relation to the published literature.

2.1 Introduction

It is known that people with dementia experience a wide range of intense care needs (Prince et al. 2015), which vary depending on many factors including the type and severity of cognitive impairment, functional dependencies and neuropsychiatric symptoms. These needs, which can be defined as the capacity to benefit from services (NHS Health Scotland 2019), appear specific to the individual and strongly affect health outcomes. Unmet needs result in adverse consequences such as falls, dehydration, reduced quality of life, caregiver impact, institutionalisation and death (Black et al. 2013; Gaugler et al. 2005). Additionally, almost 95% of people with dementia live with multi-morbidities, with an average of four to six illnesses in addition to dementia (Guthrie et al. 2012). In order to provide appropriate care and support for the increasing number of people with dementia (Prince et al. 2015), consideration of information about individuals' needs can enable clinicians to tailor interventions towards personal goals and priorities (Farmer et al. 2016; Morrisby et al. 2018). This includes the key desire of most people with dementia to remain living at home, recognised by policymakers (Parkin and Baker 2018).

One research study examining the needs of older people with severe mental illness including dementia found that most (70%) people were not receiving the interventions indicated by their assessed needs (Cummings and Kropf 2009). Researchers suggest that this may be due to the assessed needs not being specific enough to link to particular interventions (Schmid et al. 2012), for example, needs related to mobility may require among other things: physiotherapy services, assistance in using public transport, or wheelchair repairs.

In order to reorganize care to account for the needs of people with dementia, further knowledge is required to facilitate understanding of the impact of caring for people with dementia and its co-morbidities, and how this impact relates to interventions. To this end, individual studies have presented data regarding the frequency and range of needs of people with dementia (Morrisby et al. 2018). However, this data has not been synthesized and the universality of these results is unknown. Quantitative synthesis of data enables exploration of any associated heterogeneity (Song et al. 2001). This in turn can provide information on the sources of variation in the needs of people with dementia, and will contribute to understanding of those characteristics that can increase or decrease the frequency of reported needs.

Further research regarding the variation in reported needs will assist in targeting services and resources to where they are most required (Gitlin et al. 2018). Informing the efficient organization and delivery of health and social care to manage the complex and diverse requirements of people with dementia can lead to more integrated and person-centred support, addressing actual needs of people with dementia and their caregivers, thereby reducing adverse outcomes including institutionalisation (Banerjee 2015).

Therefore, in order to enhance understanding regarding the needs of people with dementia, the author conducted a systematic review and meta-analysis of existing studies following Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Liberati et al. 2009).

The objectives of this systematic review and meta-analysis were to (a) establish prevalence estimates of needs reported by people with dementia living at home, and needs of people with dementia reported by their informal caregivers; (b) compare the prevalence estimates of needs reported by people with dementia to those reported by informal caregivers of people with dementia; (c) quantify and explore heterogeneity associated with these prevalence estimates.

2.2 Method

In order to endure transparency in the decision making process and to reduce bias, the review protocol was registered *a priori* and published online in the PROSPERO database of systematic reviews (www.crd.york.ac.uk/Prospero registration number CRD42017074119). Subsequent amendments to the protocol are tracked and publicly available.

2.2.1 Inclusion Criteria

Studies were included if; (a) they reported empirical prevalence data regarding the frequency of needs for people with dementia; (b) participants had a diagnosis of dementia; (c) participants were living at home in the community; (d) needs were measured using a validated assessment instrument; (e) needs were identified as concerning the person with dementia and not their caregiver or other significant person; (f) needs were reported by the person with dementia or by their informal caregiver; and (g) the study was reported in English.

To allow for exploration of factors that may affect needs, all age groups and dementia diagnoses were included, as were all publication dates and all geographical areas.

2.2.2 Exclusion Criteria

Studies that were reviews or conference proceedings were excluded. Articles providing further information on studies selected for inclusion in the analysis were used in the assessment of the quality of the selected studies.

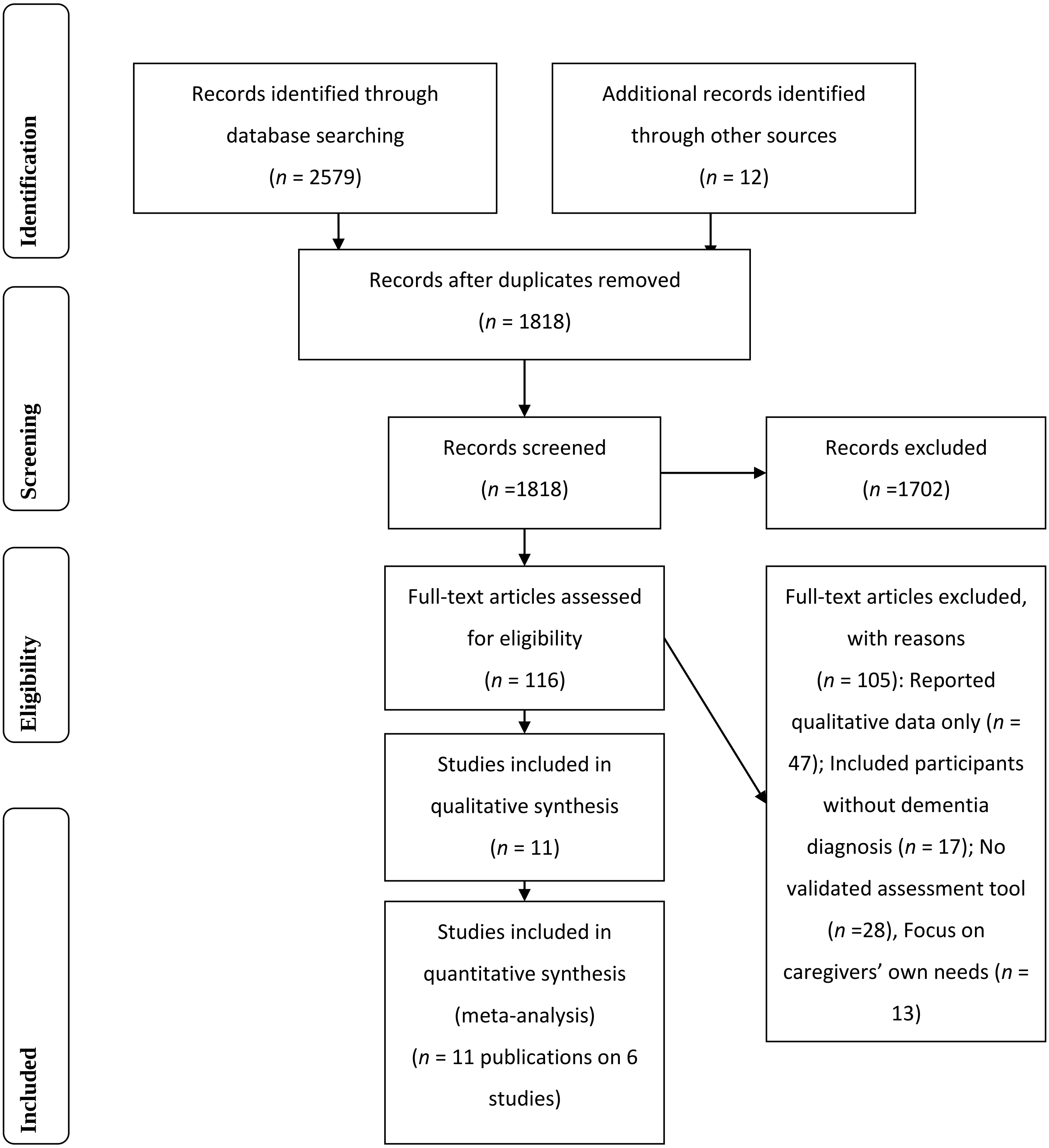
2.2.3 Search Strategy

A systematic search of four databases**,** ASSIA, CINAHL, MEDLINE and PsycINFO was conducted by the author to identify studies in which the needs of people with dementia living at home were quantitatively examined (Appendix A). Further relevant studies were identified through hand searching reference lists by the author. The CINAHL, MEDLINE and PsycINFO databases were searched through EBSCOhost using the following terms as Medical Subject Headings (MESH) and keywords; (1) Dementia OR Frontotemporal Dementia OR Dementia, Vascular OR Delirium, Dementia, Amnestic, Cognitive Disorders OR Dementia, Multi-infarct OR AIDS Dementia Complex OR Dementia, Senile OR Dementia, Presenile OR Lewy Body Disease OR Parkinson Disease OR Alzheimer’s disease, AND (2) Needs Assessment OR Health services needs and demand. The ASSIA database was searched through PROQUEST using the above terms as main subjects.

2.2.4 Study Selection

Following removal of duplicates, titles of the returned articles were examined and irrelevant titles were excluded. Abstracts, then full text of the remaining articles were reviewed to find studies that met the inclusion criteria. The author and one other researcher (SA) selected studies independently to minimize selection bias, results were compared and disagreements were resolved through discussion and with reference to inclusion criteria. If no agreement could be reached it was planned that a member of the supervisory team (DM) would decide, but this was unnecessary. The screening process is described in Figure 1.

Figure 1 PRISMA Flowchart (Adapted from Moher, D.; Liberati, A.; Tetzlaff, J.; Altman, D.G.; The PRISMA Group (2009))



2.2.5 Data Extraction

A data extraction sheet was developed and pilot tested. The author and one other researcher (SA) independently extracted data from included studies. Results were compared and inconsistencies were resolved through discussion, and the inclusion of an additional researcher from the supervisory team (DM) was again unnecessary. Data originating from the same study was included as one study even if reported in more than one paper. Corresponding authors were contacted where required data were not presented in the required format. Three study authors responded to this request and two provided further data.

Information extracted from each study included: (a) characteristics of the study participants including age, diagnosis, living situation; (b) study details including author, title, date of publication; (c) setting; (d) methodological characteristics; (e) outcome measurement tool; (f) outcome data; (g) ethical approval; and (h) data analysis.

2.2.6 Quality Assessment

Studies included in this analysis were assessed for risk of bias using the Prevalence Critical Appraisal Instrument (Munn et al. 2014b). This assessment focused on (a) the instrument used to assess the needs of the person with dementia, and (b) the sampling of the population within the study, as these are issues particularly relevant to prevalence studies. To minimize bias the author and another researcher (SA) completed the tool independently for each study then results were compared and discussed. Disagreements were to be resolved through discussion with a third researcher (DM) but this was unnecessary. All studies were included in the meta-analysis, and leave1out sensitivity analysis was undertaken to explore heterogeneity (Stroup et al., 2000; Higgins et al. 2003; Ryan 2016). Details of information considered in the quality appraisal instrument is included (Appendix B).

2.2.7 Statistical Analyses

The primary measure of prevalence was the proportion of people with dementia reporting a specific need. Needs frequency data presented as percentages were recalculated as proportions. Where needs were reported as unmet and met needs, these data were combined to create total need. Proportions were pooled for meta-analysis, using a double arcsine square root transformation, to normalize the sampling distribution and stabilize variance (Freeman and Tukey 1950; Barendregt et al. 2013; Wang 2017). The double arcsine square root transformation was selected due to the small sample sizes and extreme proportions involved (Wang 2017). Following analysis, the final pooled estimates with 95% confidence intervals (CI) were back-transformed for ease of interpretation (Miller 1978).

Data on each of the 24 needs reported by people with dementia and 24 needs of people with dementia reported by informal caregivers were analysed separately. Random-effects models (DerSimonian and Laird 1986) were used as they are recommended for the meta-analysis of prevalence data to allow for between-study variation and increase the generalizability of conclusions (Munn et al. 2014).

In order to determine if data on the needs of people with dementia reported by the person themselves differed from data on their needs as reported by their caregivers, it was necessary to compare the results of the random-effects meta-analyses for each need type. Fixed-effects models were fitted to allow comparison of the two estimates for each of the 24 need types, as the residual heterogeneity within each subset had already been accounted for through fitting the random-effects model above (Viechtbauer 2010).

2.2.8 Risk of Bias across Studies

Publication bias refers to the number of statistically non-significant studies remaining unpublished. However, studies included in meta-analyses of proportions are observational, non-comparative, and do not calculate significance levels for their results. Therefore, statistical non-significance was unlikely to result in publication bias (Wang 2017).

2.2.9 Additional Analyses

Heterogeneity is expected in prevalence studies and can arise for a number of reasons including: different instruments used to determine the presence of a variable, geographical variation, and differences in the study population (Higgins 2008; Munn et al. 2014a). Whilst meta-analysis is used for pooling effects, another important benefit is the investigation and description of heterogeneity (Thompson 1994; Song et al. 2001; Higgins 2008). Following inspection of the meta-analysis output, heterogeneity was formally tested using I^2 to measure the proportion of the observed variation due to its sensitivity to true heterogeneity (Higgins et al. 2003), and insensitivity to number of studies (Wang 2017). Leave1out sensitivity analyses were performed to identify sources of variation (Higgins et al. 2003; Viechtbauer 2010; Ryan 2016). All analyses were conducted using the Metafor package in R Studio software (Viechtbauer 2010; R Core Team 2017).

2.3 Results

The database search returned 2579 articles. A further 12 papers were identified through hand searching and review of citation lists. Review of title and abstracts resulted in 116 potentially relevant papers being identified for full text review. Of these, 11 papers describing six studies met the inclusion criteria and were retained for review (van der Roest et al. 2008; van der Roest et al. 2009; Freyne at el. 2010; Miranda Castillo, Woods and Orrell 2010; Miranda Castillo, Woods, Galboda et al. 2010; Bakker et al. 2013; Bakker et al. 2014a; Bakker et al. 2014b; Kerpershoek et al. 2018). Included papers were published between 2005 and 2017 (Table 1). The databases were last accessed on 04/06/2019.

Table 1 Study Characteristics

Study	Setting	Sample size: People with dementia (*N*), Caregivers (*N*)	Mean age of people with dementia (years (*SD*))	Assessment of need instrument	Person reporting the needs
Freyne (Freyne et al. 2010)	Republic of Ireland	0, 40	76.9 (6.67)	CANE	Caregivers
Mazurek (Mazurek et al. 2017)	Poland	47, 41	76.6 (13.3)	CANE - Polish version	People with dementia, caregivers
Miranda-Castillo (Miranda-Castillo et al. 2010, 2010b, 2013)	UK	125, 125	79.2 (6.8)	CANE	People with dementia, caregivers, professionals.
Bakker (Bakker et al. 2010, 2013, 2014, 2014b)	The Netherlands	152, 209	61.1 (5.4)	CANE - Dutch version	People with dementia, caregivers
Van der Roest (van der Roest et al. 2008, 2009)	The Netherlands	236, 322	79.8 (7.5)	CANE - Dutch version	People with dementia, caregivers
Kerpershoek (Kerpershoek et al. 2017)	The Netherlands, Germany, UK, Ireland, Sweden, Norway, Portugal, Italy.	451, 451	77.4 (7.9)	CANE	People with dementia, caregivers

Note. *N* = number, *SD* = Standard Deviation, CANE = Camberwell Assessment of Need for the Elderly (Reynolds et al. 2000), CANE – Polish version = Camberwell Assessment of Need for the Elderly (Rymaszewska et al. 2008), CANE – Dutch version = Camberwell Assessment of Need for the Elderly (van der Roest et al. 2008).

Results of the meta-analyses were based on data relating to needs of people with dementia, as reported by 1011 people with dementia and 1188 caregivers. Data was extracted from reports of six studies undertaken in The Netherlands, UK, Ireland, Germany, Sweden, Norway, Portugal, Italy and Poland. Needs prevalence estimates ranged from 0.933 [95% CI 0.881, 0.972] for caregiver reported memory needs (Figure 3), to 0.009 [95% CI 0.001, 0.023] for person with dementia reported alcohol related needs (Figure 4), and varied depending upon need type and the person reporting the needs (Table 2).

Figure 2 Person with Dementia reported Memory Needs

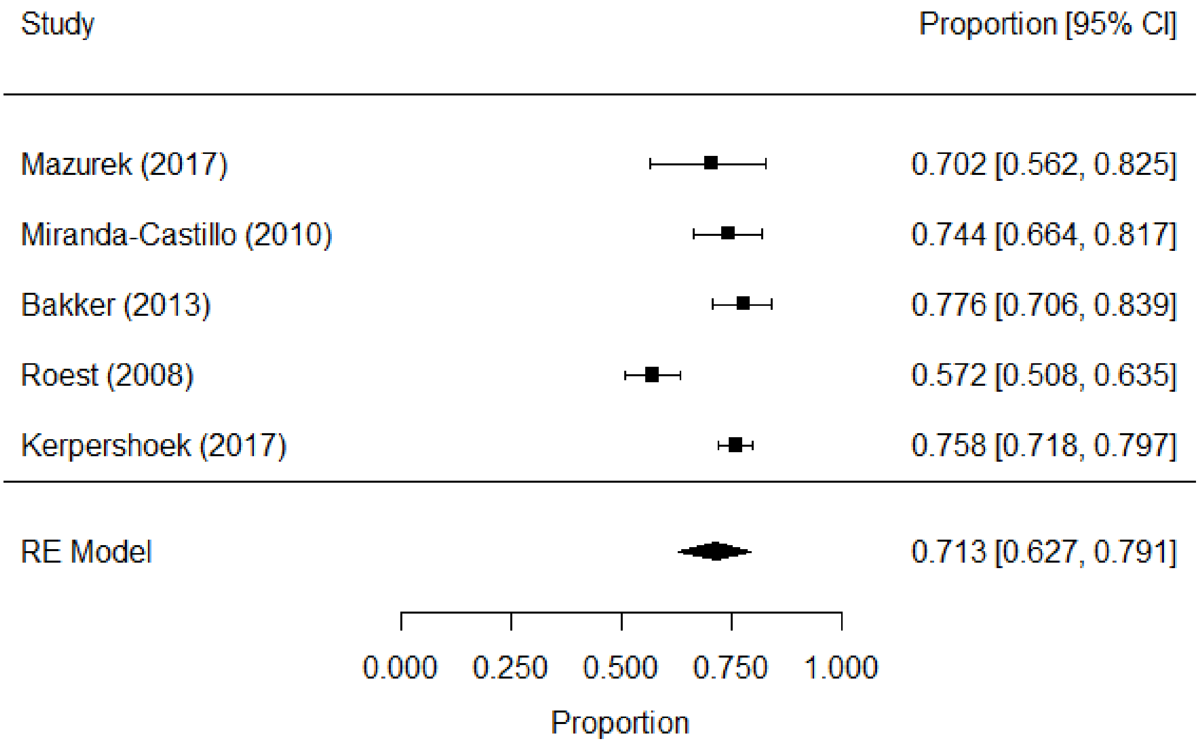


Figure 2. CI = Confidence Interval, RE = Random Effects

Figure 3 Caregiver reported Memory Needs

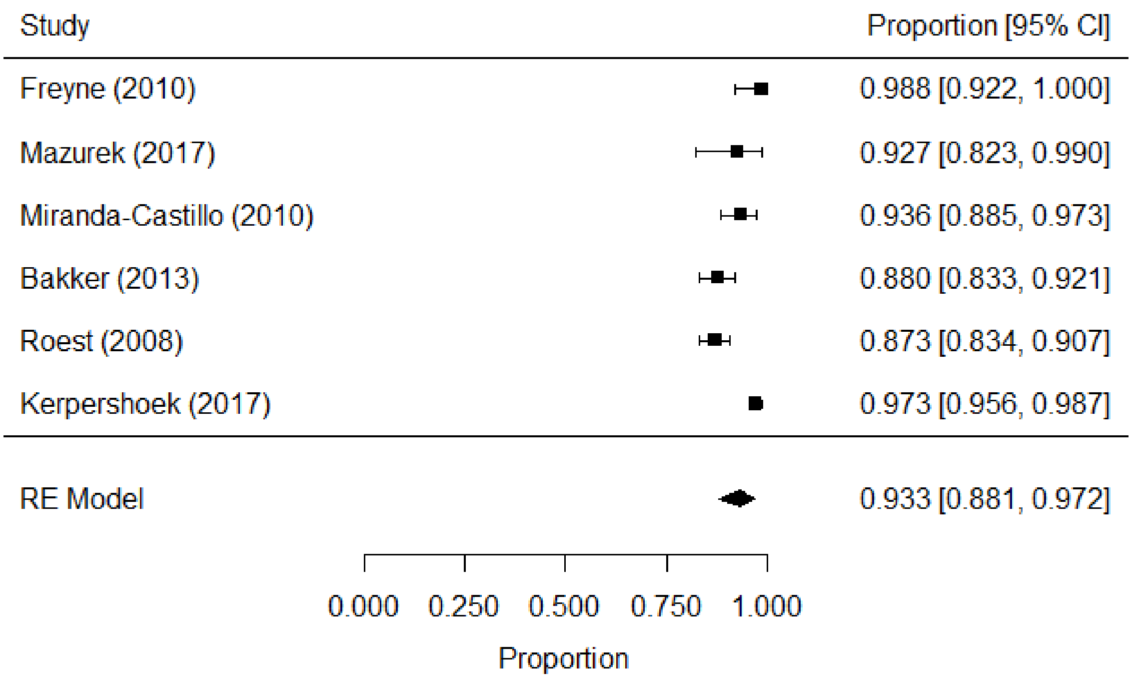


Figure 3. CI = Confidence Interval, RE = Random Effects

Figure 4 Person with Dementia reported Alcohol Needs

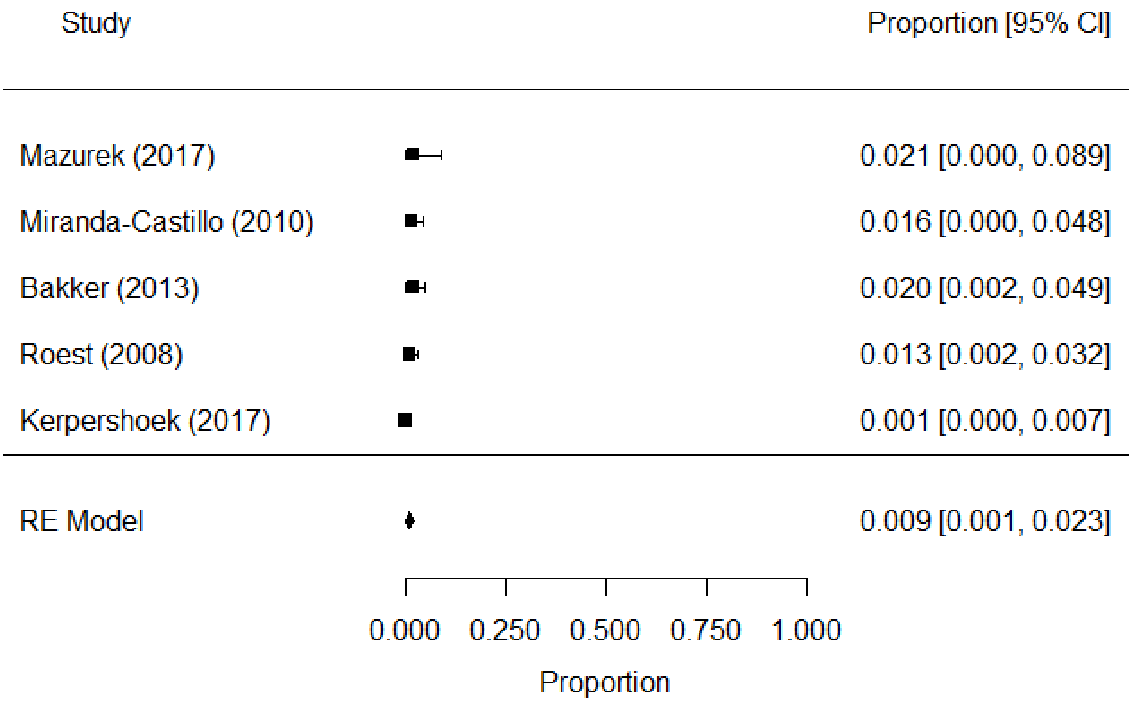


Figure 4. CI = Confidence Interval, RE = Random Effects

Figure 5 Caregiver reported Alcohol Needs

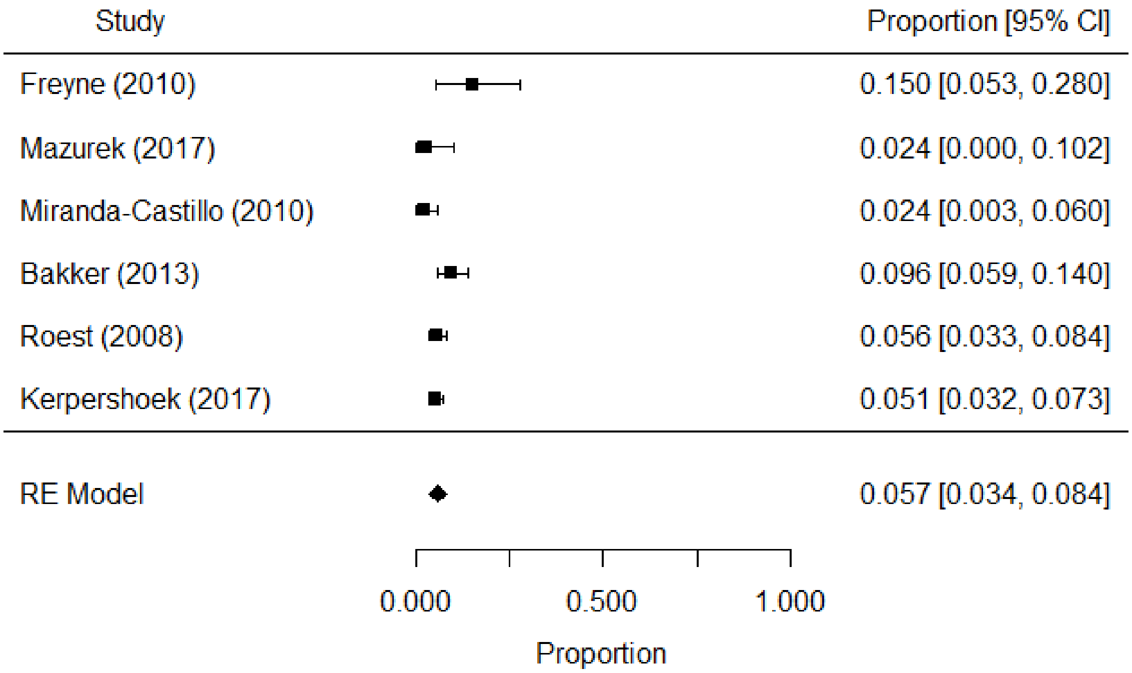


Figure 5. CI = Confidence Interval, RE = Random Effects

Table 2 Prevalence Estimates of Reported Needs

Need	Person with Dementia reported needs				Caregiver reported needs				Difference in Person with dementia and Caregiver needs
	Pooled Prevalence Estimate [95% CI]	I^2 (%) [95% CI]	Major source of variation	Forest Plot	Pooled Prevalence Estimate [95% CI]	I^2 (%) [95% CI]	Major source of variation	Forest Plot	
Memory	0.713 [0.627, 0.791]	86.21 [54.184, 97.812]	Roest	Fig. 2	0.933 [0.881, 0.972]	87.46 [55.249, 97.147]	Kerpershoek	Fig. 3	-0.297, $p < .001$
Food	0.706 [0.547, 0.842]	95.91 [90.034, 99.610]	Roest	Fig. 16	0.839 [0.763, 0.904]	89.11 [72.317, 99.033]	Bakker	Fig. 17	-0.158, $p = .101$
Household Activities	0.677 [0.613, 0.738]	74.13 [21.193, 96.284]	Bakker	Fig. 18	0.866 [0.837, 0.928]	79.28 [31.754, 96.559]	Kerpershoek	Fig. 19	-0.255, $p < .001$
Money	0.566 [0.416, 0.711]	95.1 [92.126, 99.690]	Bakker	Fig. 20	0.855 [0.784, 0.915]	88.16 [85.523, 99.309]	Mazurek	Fig. 21	-0.324, $p < .001$
Physical Health	0.528 [0.453, 0.599]	78.39 [49.007, 98.665]	Roest	Fig. 22	0.707 [0.591, 0.811]	93.32 [91.455, 99.696]	Mazurek	Fig. 23	-0.185, $p = .010$
Mobility	0.400 [0.216, 0.600]	97.29 [94.375, 99.765]	Bakker	Fig. 24	0.511 [0.301, 0.718]	97.92 [95.996, 99.834]	Bakker	Fig. 25	-0.110, $p = .459$
Daytime Activities	0.395 [0.250, 0.551]	95.43 [88.263, 99.501]	Bakker	Fig. 26	0.722 [0.565, 0.856]	96.43 [93.662, 99.614]	Miranda-Castillo	Fig. 27	-0.332, $p = .004$
Eyesight/ Hearing	0.380 [0.310, 0.452]	78.43 [39.715, 97.374]	Bakker	Fig. 28	0.455 [0.296, 0.599]	95.92 [90.421, 99.604]	Bakker	Fig. 29	-0.066, $p = .445$
Drugs	0.371 [0.222, 0.533]	95.87 [93.372, 99.737]	Bakker	Fig. 30	0.531 [0.357, 0.702]	96.92 [96.692, 99.868]	Mazurek	Fig. 31	-0.161, $p = .187$
Company	0.324 [0.182, 0.484]	95.87 [89.249, 99.539]	Bakker	Fig. 32	0.476 [0.269, 0.687]	97.94 [95.443, 99.807]	Bakker	Fig. 33	-0.154, $p = .260$
Psychological Distress	0.293 [0.209, 0.385]	87.8 [68.964, 98.799]	Roest	Fig. 34	0.509 [0.361, 0.657]	95.73 [95.544, 99.734]	Freyne	Fig. 35	-0.220, $p = .015$
Self-care	0.283 [0.217, 0.353]	79.53 [63.769, 99.071]	Mazurek	Fig. 36	0.637 [0.530, 0.738]	91.63 [91.219, 99.542]	Freyne	Fig. 37	-0.361, $p < .001$

Need	Person with Dementia reported needs				Caregiver reported needs				Difference in Person with dementia and Caregiver needs
	Pooled Prevalence Estimate [95% CI]	I^2 (%) [95% CI]	Major source of variation	Forest Plot	Pooled Prevalence Estimate [95% CI]	I^2 (%) [95% CI]	Major source of variation	Forest Plot	
Information	0.226 [0.145, 0.317]	89.34 [73.679, 99.012]	Bakker	Fig. 38	0.256 [0.212, 0.301]	60.51 [0.000, 95.404]	Kerpershoek	Fig. 39	-0.035, $p = .543$
Benefits	0.153 [0.039, 0.321]	97.24 [94.331, 99.762]	Bakker	Fig. 40	0.183 [0.072, 0.329	96.58 [93.779, 99.749]	Bakker	Fig. 41	-0.041, $p = .759$
Continence	0.150 [0.128, 0.173]	0 [0,0]	NA	Fig. 42	0.287 [0.232, 0.345]	73.86 [24.701, 97.368]	Roest	Fig. 43	-0.166, $p < .001$
Accommodation	0.128 [0.050, 0.233]	94.07 [85.868, 99.423]	Bakker	Fig. 44	0.177 [0.047, 0.363]	97.86 [95.261, 99.803]	Bakker	Fig. 45	-0.069, $p = .591$
Accidental Self-harm	0.109 [0.050, 0.186]	90.37 [77.768, 99.164]	Bakker	Fig. 46	0.318 [0.216, 0.429]	92.61 [86.042, 99.491]	Bakker	Fig. 47	-0.259, p = .001
Intimate Relationships	0.108 [0.071, 0.152]	72.56 [25.144, 97.439]	Roest	Fig. 48	0.114 [0.070, 0.168]	82.29 [64.175, 98.304]	Bakker	Fig. 49	-0.011, $p = .827$
Psychotic Symptoms	0.047 [0.025, 0.073]	61.46 [0.000, 95.201]	Miranda-Castillo	Fig. 50	0.175 [0.139, 0.214]	57.93 [0.000, 96.343]	Miranda-Castillo	Fig. 51	-0.210, p < .001
Caring for another	0.045 [0.014, 0.089]	85.13 [63.079, 98.580]	Miranda-Castillo	Fig. 52	0.049 [0.005, 0.126]	94.78 [86.469, 99.432]	Bakker	Fig. 53	-0.012, $p = .887$
Deliberate self-harm	0.036 [0.019, 0.056]	48.63 [0.000, 92.275]	Kerpershoek	Fig. 54	0.034 [0.019, 0.054]	49.98 [0.000, 92.679]	Bakker	Fig. 55	0, $p = .989$
Behaviour	0.024 [0.006, 0.051]	76.87 [28.813, 96.504]	Bakker	Fig. 56	0.125 [0.069, 0.194]	88.45 [70.236, 98.907]	Bakker	Fig. 57	-0.202, $p < .001$
Abuse/neglect	0.015 [0.008, 0.024]	0 [0.000, 82.469]	NA	Fig. 58	0.063 [0.030, 0.105]	81.94 [43.940 98.016]	Kerpershoek	Fig. 59	-0.125, $p = .002$
Alcohol	0.009 [0.001, 0.023]	57.05 [0.000, 93.010]	Kerpershoek	Fig. 4	0.057 [0.034, 0.084]	60.98 [0.000, 96.900]	Bakker	Fig. 5	-0.137, $p < .001$

Note. CI = Confidence Interval, NA = Not applicable, Fig. = Figure, Figures 16-59 are presented in Appendix C.

2.3.1 Study Characteristics

Characteristics of retrieved studies are presented in Table 1. Non-randomized sampling methods were employed in all studies, and two studies used convenience-sampling methods. All retrieved studies collected needs data using validated versions of the Camberwell Assessment of Need for the Elderly (CANE) (Reynolds et al. 2000), although three different language versions; English, Polish and Dutch. The need domains of the original (English language) version of the CANE are presented in Table 3. Other needs assessment instruments were identified in the literature, but studies did not meet the inclusion criteria for this analysis as either reported data was incomplete and authors could not be contacted, or there was no available validation information for the needs assessment tool used within the study.

The quality of the studies included in this meta-analysis was mixed (Appendix B). Importantly, all studies used a validated instrument for the assessment of needs, and used established criteria for the diagnosis of dementia. Two studies recruited small purposive samples which were not compared with the wider population and therefore the representativeness of these samples is unknown (Freyne et al. 2010; Mazurek et al. 2017). Four studies described multiple recruitment approaches (van der Roest et al. 2008; Bakker et al. 2010; Miranda-Castillo et al. 2010; Kerpershoek et al. 2017), of which two reported comparisons of their study population with the wider populations (Bakker et al. 2010; van der Roest et al. 2008).

Table 3 CANE Needs and Key Questions

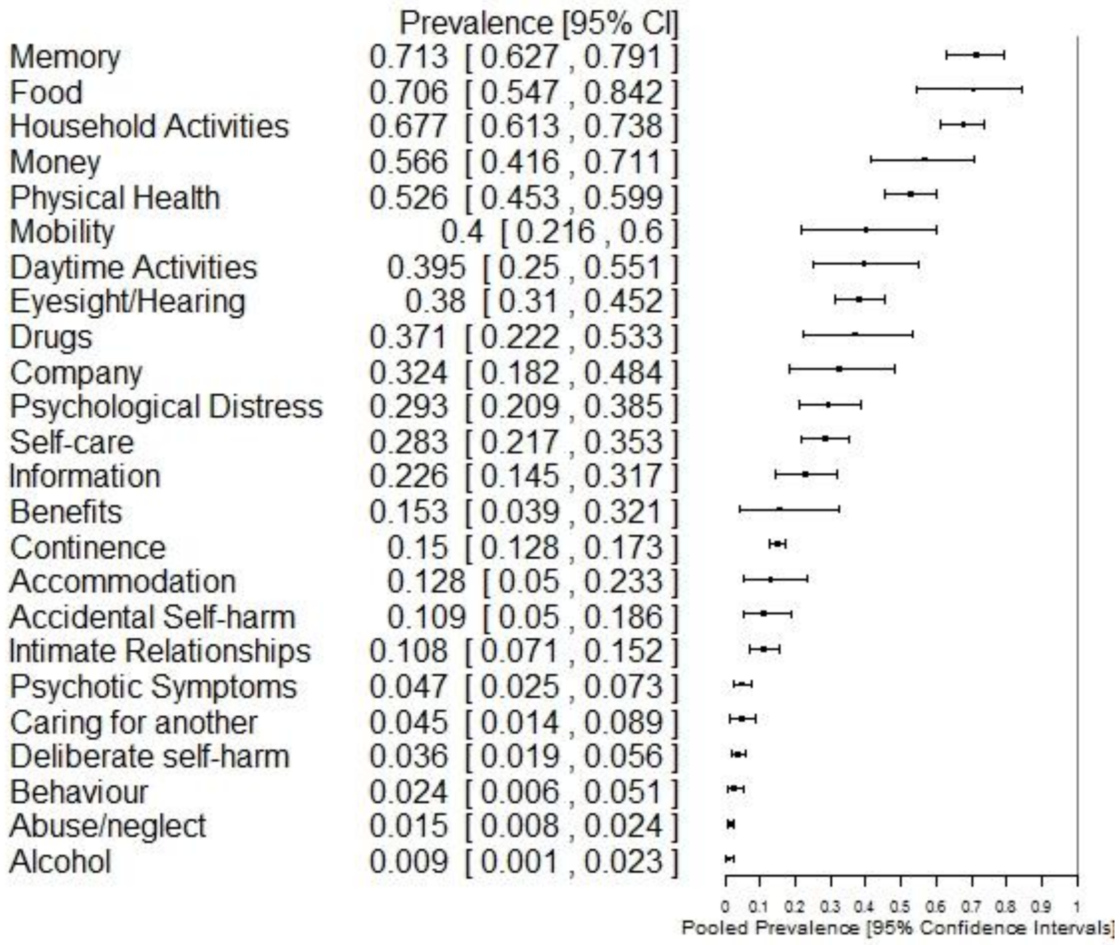
Need	CANE Key Question.
Accommodation	Does the person have an appropriate place to live?
Household Activities	Does the person have difficulty in looking after their home?
Food	Does the person have difficulty in getting enough to eat?
Self-care	Does the person have difficulty with self-care?
Caring for another	Does the person have difficulty caring for another person?
Daytime Activities	Does the person have difficulty with regular, appropriate daytime activities?
Memory	Does the person have a problem with memory?
Communication	Does the person have a problem with sight or hearing?
Mobility/ Falls	Does the person have restricted mobility, falls or any problems using public transport?
Continence	Does the person have incontinence problems?
Physical Health	Does the person have any physical illness?
Drugs	Does the person have problems with medication or drugs?
Psychotic Symptoms	Does the person have symptoms such as delusional beliefs, hallucinations, formal thought disorder or passivity?
Psychological Distress	Does the person suffer from current psychological distress?
Information	Has the person had clear verbal or written information about their condition and treatment?
Deliberate Self-harm	Is the person a danger to themselves?
Accidental Self-harm	Is the person at inadvertent risk to themselves?
Abuse/neglect	Is the person at risk from others?
Behaviour	Is the person’s behaviour dangerous, threatening, interfering or annoying to others?
Alcohol	Does the person drink excessively or have a problem controlling their drinking?
Company	Does the person need help with social contact?
Intimate Relationships	Does the person have a partner, relative or friend with whom that have a close emotional/ physical relationship?
Money	Does the person have problems managing or budgeting their money?
Benefits	Is the person receiving all the benefits that they’re entitled to?

Note: CANE = Camberwell Assessment of Need for the Elderly, (Reynolds et al. 2000)

2.3.2 Prevalence of Needs

Prevalence indicates the number of people in a population with a particular characteristic at a given point in time (Munn et al. 2014). Prevalence estimates for the 24 CANE need domains, reported by people with dementia, and as reported by caregivers of people with dementia, are presented as proportions, together with 95% confidence intervals (CI) (Table 2). Forest plots are included for each prevalence estimate (Figure 2 – 5, Appendix C). Pooled prevalence estimates for person with dementia reported needs and caregiver reported needs are summarised in Figure 6 and Figure 7 respectively.

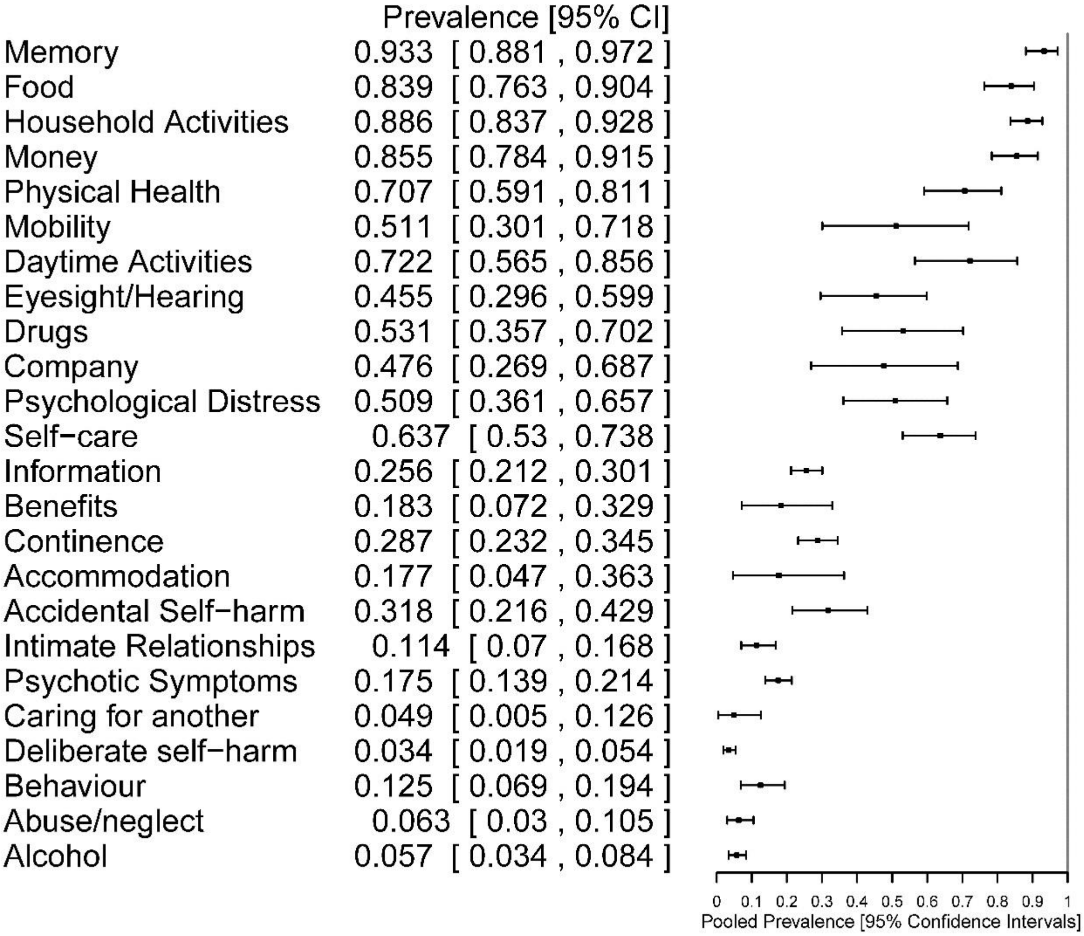
Figure 6 Pooled Prevalence for Person with Dementia reported Needs



	Prevalence [95% CI]
Memory	0.713 [0.627 , 0.791]
Food	0.706 [0.547 , 0.842]
Household Activities	0.677 [0.613 , 0.738]
Money	0.566 [0.416 , 0.711]
Physical Health	0.526 [0.453 , 0.599]
Mobility	0.4 [0.216 , 0.6]
Daytime Activities	0.395 [0.25 , 0.551]
Eyesight/Hearing	0.38 [0.31 , 0.452]
Drugs	0.371 [0.222 , 0.533]
Company	0.324 [0.182 , 0.484]
Psychological Distress	0.293 [0.209 , 0.385]
Self-care	0.283 [0.217 , 0.353]
Information	0.226 [0.145 , 0.317]
Benefits	0.153 [0.039 , 0.321]
Continence	0.15 [0.128 , 0.173]
Accommodation	0.128 [0.05 , 0.233]
Accidental Self-harm	0.109 [0.05 , 0.186]
Intimate Relationships	0.108 [0.071 , 0.152]
Psychotic Symptoms	0.047 [0.025 , 0.073]
Caring for another	0.045 [0.014 , 0.089]
Deliberate self-harm	0.036 [0.019 , 0.056]
Behaviour	0.024 [0.006 , 0.051]
Abuse/neglect	0.015 [0.008 , 0.024]
Alcohol	0.009 [0.001 , 0.023]

Figure 6. CI = Confidence Interval

Figure 7 Pooled Prevalence for Caregiver reported Needs



	Prevalence [95% CI]
Memory	0.933 [0.881 , 0.972]
Food	0.839 [0.763 , 0.904]
Household Activities	0.886 [0.837 , 0.928]
Money	0.855 [0.784 , 0.915]
Physical Health	0.707 [0.591 , 0.811]
Mobility	0.511 [0.301 , 0.718]
Daytime Activities	0.722 [0.565 , 0.856]
Eyesight/Hearing	0.455 [0.296 , 0.599]
Drugs	0.531 [0.357 , 0.702]
Company	0.476 [0.269 , 0.687]
Psychological Distress	0.509 [0.361 , 0.657]
Self−care	0.637 [0.53 , 0.738]
Information	0.256 [0.212 , 0.301]
Benefits	0.183 [0.072 , 0.329]
Continence	0.287 [0.232 , 0.345]
Accommodation	0.177 [0.047 , 0.363]
Accidental Self−harm	0.318 [0.216 , 0.429]
Intimate Relationships	0.114 [0.07 , 0.168]
Psychotic Symptoms	0.175 [0.139 , 0.214]
Caring for another	0.049 [0.005 , 0.126]
Deliberate self−harm	0.034 [0.019 , 0.054]
Behaviour	0.125 [0.069 , 0.194]
Abuse/neglect	0.063 [0.03 , 0.105]
Alcohol	0.057 [0.034 , 0.084]

Figure 7. CI = Confidence Interval

2.3.3 Comparison of Needs reported by People with Dementia and by Caregivers

Caregivers of people with dementia reported higher levels of need for people with dementia in 23 out of 24 needs. These two sets of effects sizes were compared in twenty-four fixed effects models (Table 2). Results were significantly different for Household Activities (-0.255, *p* <.001), Memory (-0.297, *p* <.001), Self-care (-0.361, *p* < .001), Continence (-0.166, *p* <.001), Psychotic Symptoms (-0.210, *p* <.001), Money (-0.324, *p* < .001), Alcohol (-0.137, *p* <.001), Abuse/ Neglect (-0.125, *p* = .002), Accidental Self-harm (-0.259, *p* = .001), Daytime Activities (-0.332, *p* = .004) and Behaviour (-0.202, *p* < .001). Notably, people with dementia and caregivers reported a similar level of need for Deliberate Self-harm (0.0, *p* =.989).

One study reported that 17.8% of their participants with dementia were unable to understand CANE questions, and that this group was significantly more cognitively and functionally impaired than the rest of the sample (Miranda-Castillo et al. 2013). Hence, the needs of this group of people with dementia could only be reported by caregivers, and therefore dementia severity or the inability to comprehend the CANE questions may have contributed to the heterogeneity between the needs reported by people with dementia and by caregivers.

2.3.4 Heterogeneity

Meta-analyses showing very low heterogeneity (I^2 = 0%) (Ryan, 2016) included two needs reported by people with dementia: Continence I^2 = 0% [95% CI 0, 0] and Abuse/ neglect I^2 = 0% [95% CI 0, 82.469]. Notably, these needs had very low prevalence (< 0.05). As prevalence estimates are reported with 95% confidence intervals, the degree of heterogeneity of these results remains uncertain (Wang 2017). Seventeen of the 24 meta-analyses examining the needs reported by people with dementia, exhibited considerable heterogeneity (I^2 > 75%) (Higgins et al. 2003; Alba et al. 2016). Eighteen of the 24 meta-analyses examining the needs of people with dementia reported by caregivers also exhibited high heterogeneity. Heterogeneity (I^2) is reported in Table 2.

As it is important to explore and quantify heterogeneity and bearing in mind that heterogeneity may always be due to chance (Thompson 1994), sensitivity analyses was employed to determine the study that was the major source of heterogeneity for each of the meta-analyses (Higgins 2008). The identified study and residual heterogeneity (I^2) were reported (Table 2). Following sensitivity analysis, 12 of 24 person with dementia reported needs, and nine of 24 caregiver reported needs showed unimportant or moderate heterogeneity ($I^2 \leq 60\%$) (Table 2) (Koletsi et al. 2018).

In 24 of 46 meta-analyses demonstrating heterogeneity, removal of the Bakker study data produced the greatest reduction in variation indicating that a characteristic of this study or its sample population was the source of this variation (Bakker et al. 2013; Bakker et al. 2014a; Bakker et al. 2014b). The Bakker study reported data on the needs of people with young onset dementia, and had a study population with a mean age of 61.1 years, whereas the other studies included in this analysis had populations with mean ages ranging from 76.6 to 79.8 years. Notably, heterogeneity, in Daytime activity and Accommodation needs reported by people with dementia, reduced by 95.43% and 94.07% respectively, to 0% following the removal of Bakker study data from the analysis. Remaining prevalence estimates for Daytime activities and Accommodation for people with later onset dementia were 0.317 [95% CI 0.286, 0.349] and 0.09 [95% CI 0.071, 0.110] respectively. Similarly, variation in caregiver reported need domains of Food; and Deliberate self-harm, reduced by 68.47% and 49.98%, respectively, when this Bakker data was removed from the analysis. Resultant prevalence estimates obtained following removal of each study which was identified as the major source of variation are presented in Table 4.

Visual inspection of the forest plots suggests that there may also be an effect of sample size upon prevalence for some needs but formal testing of this was not possible due to the limited number of studies.

Table 4 Prevalence Estimates following Removal of Major Source of Variation

	Person with dementia reported Needs			Caregiver reported Needs		
Need	*k*	Prevalence estimate following study removal [95% CI]	*I*² following removal of study (%)	*k*	Prevalence estimate following study removal [95% CI]	*I*² following removal of study (%)
Memory	5	0.757[0.726, 0.787]	0	6	0.913[0.873, 0.947]	60.79
Food	5	0.647[0.529, 0.757]	88.58	5	0.810[0.778, 0.839]	20.64
Household Activities	5	0.650[0.601, 0.698]	45.77	5	0.905[0.814, 0.926]	45.90
Money	5	0.495[0.384, 0.606]	88.61	6	0.886[0.834, 0.930]	81.60
Physical Health	5	0.552[0.482, 0.621]	65.85	5	0.635[0.541, 0.724]	89.48
Mobility	5	0.309[0.233, 0.39]	79.91	5	0.410[0.296, 0.529]	90.88
Daytime Activities	5	0.317[0.286, 0.349]	0	6	0.789[0.665, 0.892]	94.23
Eyesight/ Hearing	5	0.347[0.293, 0.403]	56.60	5	0.378[0.314, 0.445]	70.78
Drugs	5	0.303[0.171, 0.454]	94.24	5	0.656[0.525, 0.776]	94.67
Company	5	0.248[0.172, 0.334]	83.72	5	0.384[0.231, 0.550]	95.41
Psychological Distress	5	0.330[0.237, 0.431]	84.61	6	0.417[0.302, 0.538]	93.23
Self-care	5	0.314[0.189, 0.342]	48.06	6	0.586[0.489, 0.680]	89.54
Information	5	0.190[0.122, 0.268]	83.37	5	0.239[0.202, 0.278]	22.13
Benefits	5	0.087[0.038, 0.152]	85.49	5	0.125[0.061, 0.208]	89.19
Continence	5	NA	NA	5	0.268[0.232, 0.305]	18.76
Accommodation	5	0.090[0.071, 0.110]	0	5	0.108[0.035, 0.212]	93.67
Accidental Self-harm	5	0.081[0.043, 0.13]	76.20	5	0.274[0.209, 0.345]	77.03
Intimate Relationships	5	0.123[0.083, 0.170]	61.18	6	0.101[0.058, 0.154]	77.86
Psychotic Symptoms	5	0.038[0.021, 0.059]	42.91	5	0.197[0.173, 0.222]	0
Caring for another	5	0.061[0.027, 0.107]	79.64	5	0.024[0.002, 0.062]	84.32
Deliberate self-harm	5	0.045[0.029, 0.065]	0	6	0.025[0.015, 0.037]	0
Behaviour	5	0.014[0.004, 0.028]	40.17	5	0.101[0.063, 0.146]	70.28
Abuse/neglect	5	NA	NA	5	0.078[0.046, 0.118]	60.48
Alcohol	5	0.015[0.006, 0.028]	0	6	0.048[0.028, 0.073]	47.81

Note: CI = Confidence Interval, NA = Not applicable, *k* = number of studies included in the meta-analysis

2.4 Discussion

Despite global challenges associated with meeting care needs of people with dementia living at home, the author believes that this study is the first to establish the prevalence of needs for this population. This study has produced 48 prevalence estimates which reflect pooled needs experienced by the dementia populations of six research studies and not only needs specifically associated with dementia symptomatology. These outcomes are of interest as needs can lead to someone being put at risk of adverse outcomes including increased multi-morbidity (Seden 2016; Levene et al. 2017). Therefore, greater understanding of these needs and the priority placed upon them by people with dementia and their informal caregivers, can inform the design of services to ensure they meet the needs of people with dementia in a way that is person-centred, rather than disease focused. Accurate, descriptive information regarding the needs of people with dementia and differences in dementia care trajectories, together with details of characteristics which impact upon care needs, will inform service plans (Gitlin et al. 2018). This will result in the needs experienced by people with dementia being more effectively managed (Morrisby et al. 2018). Which, in turn, may reduce the detrimental effects of unmet needs.

As indicated by Munn et al. (2014a) the needs assessment instrument and the sampling of the population within the study are quality issues particularly relevant to prevalence studies. Overall, the quality of the studies included in this meta-analysis was mixed. Importantly, all studies used a validated instrument for the assessment of needs, and used established criteria for dementia diagnosis. Two studies recruited small purposive samples which were not compared with the wider population and therefore the representativeness of these samples is unknown (Freyne et al. 2010; Mazurek et al. 2017). Four studies described multiple recruitment approaches (of which two reported comparisons of their study population with wider populations (Bakker et al. 2010; van der Roest et al. 2008; van der Roest et al. 2009). Comparison indicated that these samples contained mainly people with mild or moderate dementia. The small number of studies restricted subgroup analysis opportunities, but sensitivity analysis did not indicate that study quality influenced the prevalence reported within these studies. These results indicate a requirement for further investigation of the needs of people with dementia particularly in regard to the needs of people with severe dementia and the needs of people with dementia living outside Europe. The representativeness of research samples should be explored and reported.

These resultant prevalence estimates indicate that caregivers believe over 90% of people with dementia experience at least one need. This study also confirms that people with dementia and caregivers identified similar need priorities for the person with dementia. The results of this analysis indicate that the four most prevalent needs for people with dementia and caregivers (Food, Household Activities, Memory and Money) were the same, although they differed in order of presentation. Needs are distinct for different populations, for example; people with dementia living in care homes identified accommodation as their most prevalent need (Orrell et al. 2008).

Due to a limited number of studies within this field, and the different ways in which data is reported, it is difficult to compare these prevalence estimates with other reported needs prevalence estimates. However, in order to add credibility to these results, where possible they will now be examined in the light of other published prevalence data gathered through different methods. As the literature does not consider all the needs examined in this study, the focus will be on self-care, continence, mobility, drugs psychological distress and abuse/ neglect needs.

One study used the CarenapD (McWalter et al. 1998) needs assessment tool, and found that people with dementia reported high levels of self-care needs (Meaney et al. 2005). Meaney et al. (2005) found 80% of people with dementia reported dental care needs, 79% had bathing needs, and 68% identified toileting needs, all of which can be considered self-care needs. Whereas, Chung (2006) reported prevalence estimates of 29.6%, 59% and 76.9% for bathing needs for people who are at the early, middle or late stage of dementia respectively, using CarenapD. This current study estimates a comparatively low overall prevalence for person with dementia reported self-care needs and caregiver reported prevalence for this domain. Hence, the estimates provided in this study for person with dementia reported self-care needs are similar to Chung's estimate for people in the early stages of dementia, whereas the estimates for caregiver reported self-care needs are closer to the estimate provided by Meaney et al. (2005), and Chung's (2006) estimate for people in the middle stages of dementia.

There are no prevalence studies of people with dementia living at home with incontinence (Drennan et al. 2011). However, 31% of home-dwelling people over the age of 75 in the UK have urinary incontinence problems (Rait et al. 2005), and 31% of caregivers of people with dementia in Australia manage incontinence and pads (Drennan et al. 2011). These estimates are slightly higher than in the current study for either person with dementia or for caregiver expressed continence needs. In addition, Chung reported prevalence of continence needs varied from 11.3%

to 46.2%, for people at different stages of dementia. Again, the prevalence estimate for people with dementia reported needs is comparable with the estimate for people who are at an early stage of dementia from the Chung study. It should be noted that the need domains in the CarenapD do not directly overlap with those in the CANE (Reynolds et al. 2000).

It is known that people with dementia have an increased risk for falls (Harlein et al. 2009; Maggio et al. 2010) which can result in injury, increased morbidity, and even mortality (Douglas et al. 2011). In a prospective study of falls in people with dementia Allan et al. (2009) found 65.7% of people with dementia experienced at least one fall, and that a history of falls within the previous 12 months ranged from 51.4% (for people with Alzheimer's disease) to 86.8% (for people with Parkinson's Disease Dementia), as falls prevalence varied according to dementia diagnosis. This suggests that the prevalence estimate for person with dementia reported mobility and falls related needs, or for caregiver reported mobility and fall's needs, appears to be comparable with the lowest estimate provided in Allan's study which was for people with Alzheimer's disease.

The reported prevalence estimate for needs associated with drugs for people with dementia and for caregivers are credible given that 49.02% of people with dementia required assistance with medication administration (Bowen et al. 2014), and polypharmacy is observed in 50% of elderly patients (Leelakanok and D'Cunha 2018).

Prevalence estimates of behavioural and psychological symptoms associated with dementia (BPSD) reported in the literature range from 50 to 100% (Devshi et al. 2015). In this study caregiver reported psychological distress needs prevalence was comparable with the lower end of this range, and this proportion would likely rise when other relevant needs such as accidental self-harm, deliberate self-harm, behaviour, alcohol and psychotic symptoms were taken into account.

Significant abuse occurs in more than a quarter of people with dementia (Cooper et al. 2008). Whereas, overall elder abuse is estimated at 15.7% [95% CI 12.8, 19.3] (Yon et al. 2017), or between 5 and 52% of people with dementia (Cooper et al. 2008), therefore the prevalence estimate for abuse/ neglect reported by people with dementia and from caregiver reports are low. Yon et al. (2017) conducted a meta-analysis of elder abuse prevalence based on published data describing psychological, financial, neglect, physical and sexual abuse and estimated that elder abuse affects one in six older adults worldwide. Furthermore, Cooper et al. (2008) discussed difficulties identifying abuse other than in the most severe cases, and suggest that scales tend to underestimate its prevalence. As CANE attempts to identify care and support needs rather than screening for particular problems it may be that people with dementia and caregivers fail to report incidences of abuse, and Cooper et al. (2008) found that cases of abuse recorded using objective measures are around 5%, which is in line with the prevalence estimated through this meta-analysis.

Overall, the convergence between the results of this study and published data lend the prevalence estimates credibility, although it was not possible to identify comparable prevalence data for all reported needs. Comparisons indicate that generally the needs prevalence estimates produced within this study correspond to the lower end of the range of published prevalence data.

The present study also revealed variations in needs prevalence were associated with who reported the needs, and fixed effects analyses confirmed that caregivers reported higher levels of need for 23 of the 24 needs. This may be explained by the difficulties people, with greater cognitive and functional impairment, being unable to answer questions on the CANE, as described above (Bakker et al. 2014). As discussed above, people with severe cognitive and functional impairment are more likely to be unable to answer the CANE questions and therefore data collected on needs of people with severe dementia may be more frequently reported by caregivers than by people with dementia themselves. Hence, the higher levels of need reported by caregivers may more accurately reflect the needs of a population of people with dementia that includes those with more severe dementia, whereas the person with dementia reported needs are likely to reflect information more focussed on the needs of people with mild or moderate dementia. As the CarenapD does not distinguish between caregiver and person with dementia reported needs, this may also explain the increased needs prevalence estimates provided by studies described above which used this assessment tool.

Additionally, previous research suggests these findings may have arisen, as caregivers experiencing strain are more likely to report unmet service needs (Li 2012). Thus, variation between person with dementia and caregiver reported needs may indicate that caregivers struggle to meet needs and suggests a requirement for additional support. Cummings and Kropf (2009) found that caregivers of older adults with severe mental illness provided the greatest amount of assistance and the most frequent assistance with needs including; food, money management and looking after the home. This indicates that informal caregivers meet the most prevalent needs of older adults, at least in part. Hence, although this research focused upon the needs of people with dementia, caregivers' personal needs and the impact of caring upon caregivers will likely have influenced their responses regarding the needs of the person with dementia. Therefore, better understanding of the relationship between the needs of the person with dementia, and the caregiver's view of their needs, can assist in refining and targeting services to meet those needs (Farmer et al. 2016).

In order to reorganize integrated health and social care services to meet the needs of people living with dementia in a meaningful way, there must be greater understanding of the diversity of needs within this population (Farmer et al. 2016; Commisso et al. 2017). Sensitivity analysis indicated that data from the study examining the needs of people with young onset dementia was the major source of variation for 12 person with dementia reported needs, and 12 caregiver reported needs. When this study data was removed from the analysis, the resultant prevalence estimates were reduced. This indicates that people with young onset dementia and their caregivers both report higher levels of need than do other people with dementia and their caregivers. This may reflect the different life stage, and particular clinical characteristics of this younger population who form 2.2% of people with dementia in the UK (Knapp et al. 2007). People with young onset dementia may be coping with lost self-identity, income and socialisation associated with leaving employment, in addition to the psychological effects of an unexpected diagnosis and role changes associated with becoming a dependent family member (Shuman et al. 2017).

The particular daytime activity needs of people with young onset dementia have previously been noted (Harris and Keady 2004; Millenaar et al. 2016), and there is a recognised requirement for day care which provides stimulating activities for people who may be more active, or at a different life stage (Millenaar et al. 2016). The specific accommodation needs of people with young onset dementia are not widely discussed in the literature, although the lack of age-appropriate residential facilities may also have an impact here (Bakker et al. 2013). Higher rates of benefit related needs reported by both people with young onset dementia and their caregivers perhaps reflect the impact of young-onset dementia on employment for both people with dementia and their caregivers.

These results may indicate the particular impact experienced by younger people and their caregivers who have to cope with the physical and psychological consequences of an early onset dementia diagnosis whilst shouldering responsibilities such as employment, childcare and mortgage repayments. Nicolaou et al. (2010) found that caregivers of people with frontotemporal dementia receive significantly greater amounts of informal support, than do caregivers of people with Alzheimer's disease, but also still require significantly more assistance, even though the level of formal help received by each group was similar. As frontotemporal dementia is associated with specific behaviours, younger age of onset (Nicolaou et al. 2010), and indicates greater impact, particular diagnoses such as this may have contributed towards the differences in reported needs between people with young onset dementia and other people with dementia.

The presented prevalence estimates have particular relevance for service planning. For example, information regarding needs such as Psychotic symptoms, Deliberate self-harm and Psychological distress predict the level of specialist mental health support required by people with dementia and their caregivers as these needs are most likely to be met through formal support services (Cummings and Kropf 2009). Prevalence estimates of needs such as Benefits, Money and Accommodation also have direct implications for social policy and service provision. The prevalence of needs, which perhaps require less specialist interventions such as household activities and food, indicate sources of difficulty and additional impact often shouldered by informal caregivers. However, in some cases CANE domains may be too generic to link to specific interventions (Cummings and Kropf 2009; Schmid et al. 2012). Therefore, there is a requirement for further work that investigates the specific needs referred to within each of these need domains by people with dementia and their caregivers, and linking these with suitable interventions. Further investigation into sources of remaining variation associated with each of these needs will help determine suitable intervention pathways to meet those needs. It may also be useful to explore associations with variation in met and unmet needs to inform understanding in this regard. This in turn will increase the utility of general needs assessment to health and social care professionals as a means to providing meaningful support.

Every effort was made to maximise the quality of this study including *a priori* publication of the study protocol, comprehensive search strategies and peer review revision process which resulted in subsequent publication (Curnow et al. 2019; Appendix H).

2.5 Limitations

Nevertheless, the following limitations apply to presented results. There was a low number of published studies retrieved despite extensive searching. Further, some retrieved studies had small sample sizes and confidence intervals reflect this (Freyne et al. 2010; Mazurek et al. 2017). Further, some studies did not compare their samples with the general population and therefore the generalisability of their findings is unknown (Freyne et al. 2010; Mazurek et al. 2017). All these studies reported needs data which was elicited using versions of CANE, which does not consider educational or vocational needs (Schmid et al. 2012), and which people who are more cognitively and functionally impaired do not understand (Miranda-Castillo et al. 2013). Despite comprehensive search strategies data derived from studies which recruited from nine countries all of which were within Europe. Findings support Morrisby et al. (2018) who claimed that experience is shared across countries and service models. However, data from outside Europe is required to understand the international relevance of results, although a recent publication indicates that caregivers of people with dementia in Chile reported similar need priorities (Muñoz et al. 2019). Furthermore, there was high residual unexplored heterogeneity for a number of analyses (Ryan 2016).

2.6 Summary

This study quantifies prevalence estimates for twenty-four needs of people with dementia living at home, as reported by people with dementia and their caregivers, for the first time. These results suggest people with dementia consistently experience high levels of need across diverse geographical locations, dementia diagnoses, co-morbidities and individual circumstances. Whilst needs data was all obtained using the CANE, Schmid et al. (2012) found that this was the best of the available instruments for the assessment of needs of people with dementia. Overall, analyses confirm that people with dementia and their caregivers prioritize the same needs, however, caregivers of people with dementia report higher levels of need than people with dementia report themselves. Synthesis of results provides evidence of sources of heterogeneity in reported needs including the effects of the person reporting the needs, and age of dementia onset. Understanding prevalence and type of needs experienced by people with dementia, and circumstances in which needs vary can assist in targeting resources to meet the unique range of needs experienced by an individual, hence reducing adverse outcomes for individual patients (Guthrie et al. 2012; Schmid et al. 2012). The author will now consider literature describing the relationship between needs and risks for people with dementia. Then the literature regarding the recommendation and installation of AT in response to these needs will be evaluated.

CHAPTER 3. WANDERING AND SAFETY RISKS FOR PEOPLE WITH DEMENTIA

This chapter reviews the published literature regarding wandering and safety risks of people with dementia as these are commonly identified for people with dementia. The review focusses on the prevalence of these risks, their associated adverse outcomes, and their relationship with the population characteristics of people with dementia.

Initially, this chapter explores the meaning of wandering for people with dementia and examines the literature describing the prevalence of wandering and associated adverse outcomes for people with dementia (section 3.2). Thereafter the nature of safety risks for people with dementia described in the published literature is investigated. Again, the prevalence and adverse outcomes associated with this type of risk are reviewed (section 3.3). Further, the literature describing the population characteristics of people with dementia, their association with wandering and safety risks, and with AT, is discussed. Characteristics discussed include needs, cognition, function, mobility, behavioural and psychological symptoms of dementia (BPSD), social support and caregiver support (section 3.4).

The meta-analysis has estimated the prevalence of needs of people with dementia, and examined the heterogeneity associated with those needs in the previous chapter. Within the published literature particular risks identified as areas of concern for people with dementia and their caregivers include wandering and safety risks (Jarvis et al. 2017; Collins 2018). AT may mitigate safety and wandering related risks for people with dementia and reduce caregiver impact but little is known about which AT are currently used to address safety or wandering issues or which factors should be considered during their selection (Gagnon-Roy et al. 2017; Neubauer et al. 2018). In order to contribute to understanding of the installation of AT to reduce level of risk the researcher firstly intends to explore how population characteristics including needs are associated with wandering and safety risks in this population.

Although there are a wide range of needs associated with people with dementia, many of which are highly prevalent, the focus within the AT literature is firmly placed upon safety and the prevention or reduction of adverse outcomes for people with dementia in order to assist people to remain living at home (Brims and Oliver 2018). It is accepted that unmet needs and risks are strongly associated as they both increase the likelihood of people with dementia experiencing adverse outcomes (Seden 2016; Levene et al. 2017). These risks can occur as a result of cognitive and functional impairment and are identified as a key reason for people with dementia becoming institutionalised (Luppa et al. 2010). Specific risks identified for people with dementia include; falls, hypothermia, inappropriate use of household appliances, flood and fire, ingestion of toxins; and failure to take medication or over-medication due to short term memory problems (Bonner and Idris 2012), and can be directly associated with many of the previously identified needs. As needs facilitate the provision of interventions which reduce the risk of adverse outcomes a clear understanding of the relationship between needs and risks will enhance the provision of effective and acceptable services for people with dementia (Dickins et al. 2018).

This research will focus upon two areas of concern strongly associated with adverse outcomes for people with dementia throughout the literature: safety incidents and wandering incidents (Douglas et al. 2011). These are of particular interest as they are identified as being amenable to interventions including AT which can potentially reduce the likelihood of injury for the people involved (Brims and Oliver 2018).

However, despite this potential development in the field of dementia care, adoption of AT remains lower than expected (Ienca et al. 2017). Possibly because, although AT can be successfully used for supporting people at different stages of dementia there is a requirement that it be individually tailored according to an assessment of their needs (Topo 2009). Unfortunately, there is limited, poor quality research examining the benefits of non-pharmacological interventions for preventing wandering (Robinson et al. 2006), and whilst AT exhibits promise with regard to the reduction of safety issues for people with dementia, further investigation is required to examine its applicability to people with dementia and its flexibility throughout the changes associated with trajectory of dementia (Gagnon-Roy et al. 2017).

Further there is limited research regarding the process used to recommend AT (Wielandt et al. 2006). Assessment is identified as an important element in this process as it identifies those in need of support and at risk of injury (Douglas et al. 2011), and elicits information in order to facilitate the best match between the needs of the person with dementia and the available AT (Wielandt and Scherer 2004). Nevertheless, whilst a comprehensive assessment of need is recommended in dementia care, safety is often insufficiently addressed and the resultant care can be inconsistent and reactive (Amjad et al. 2016). This inconsistency may result from needs assessments failing to direct clinicians towards appropriate interventions for their assessed needs (Cummings and Kropf, 2009), or may be due to the current focus on risk reduction at the expense of responding to individual unmet needs (Seden 2016). Additionally, available validated needs assessment tools may lack the comprehensiveness and reliability required for optimal treatment selection (Schmid et al. 2012). Further, there is a lack of understanding of the appropriateness of AT deployed in response to individual characteristics of people with dementia, and there is no guidance on the prioritisations of these characteristics with regard to the deployment of AT (Lauriks et al. 2007, Topo 2009). In order to describe current understanding of the personal characteristics impacting the wandering and safety risks of people with dementia living at home, this chapter aims to examine the published literature in this regard to;

(1) Explore the definition of wandering for people with dementia, wandering prevalence and associated adverse outcomes (section 3.2).
(2) Explore the nature of safety risks for people with dementia, safety risk prevalence and associated adverse outcomes (section 3.3).
(3) Explore the population characteristics of people with dementia and their associations with risk and AT (section 3.4).

3.1 Risk

Prior to the narrative examining the published literature on safety and wandering it is important to focus on what is meant when discussing risk. Risk is defined as the possibility of something bad happening (Cambridge English Dictionary 2019) and is a concept which is often associated with people with dementia. Due to cognitive changes associated with dementia, people with dementia are often viewed as having diminished responsibility and reduced capacity at every stage of the disease, and are therefore seen as being inherently at risk, whether this is actually the case or not. Further, as risk is concerned with future events which may or may not happen it is a difficult concept to define (Dickins et al. 2018). This means that risk has been defined according to cultural perceptions and individual interpretation of events. Furthermore, despite these complexities, within healthcare, risk is generally viewed as an objective, measurable reality in which healthcare professionals are accepted as the experts in the field, rather than valuing the views of people living with dementia or their caregivers or basing decisions on (Dickins et al. 2018).

Policy drives healthcare professionals to work to reduce injury and to promote safety to support people with dementia to remain living at home for as long as possible (Douglas et al. 2011).

However, whilst there has been a move towards people becoming more responsible for themselves with public resources only being provided as a last resort (Kemshall 2007); safety related problems and cognitive decline are still seen as cause for costly and undesirable nursing home admissions (Thoma-Lürken et al. 2018). Institutionalisation appears to occur because health and social care professionals often aim for the elimination of risk for people with dementia even in the cases where people with dementia prefer to make individual choices regarding their participation in risk-taking behaviours and the benefits they offer. Therefore, quality of life enhancing benefits are often lost to people with dementia as a result of the risk-eliminating stance of healthcare professionals (Dickins et al. 2018).

Views expressed by people with dementia and their informal caregivers throughout the reviewed literature include a focus on the ability to recognise and adjust for risks themselves, the desire to have the freedom of choice regarding which risks they live with, and the benefits of living a full and meaningful life which includes elements of risk-taking. There is therefore a requirement to more fully understand the risks facing people with dementia and to balance them with interventions which provide the benefits of continued activity in providing cognitive stimulation for people with dementia to slow cognitive decline and maintain then at home (Dickins et al. 2018). Ultimately, healthcare professionals and informal caregivers must acknowledge and be guided by the views of people with dementia regarding the levels of risk they wish to accept. In conclusion, needs and risks are interrelated concepts and cannot be viewed independently of each other, as unmet needs result in risk, and conversely meeting care needs can reduce the risk of further harm (Seden 2016).

This review will now focus on two types of risk which particularly cause concern for the professional and unpaid caregivers of people with dementia; wandering and safety risk.

3.2 Risk of Wandering

Wandering is variously defined throughout the literature as elopement (Barnard-Brak et al. 2018), getting lost (Bowen et al. 2011), a tendency to move about, either in a seemingly aimless or disorientated fashion, or in pursuit of an indefinable or unobtainable goal (Brittain et al. 2017), excessive ambulatory behaviour initiated by a cognitively impaired and disoriented individual, possibly to fulfil a particular need (Chung and Lai 2011) and locomotion that is non-direct (Dewing 2005). This variation in the definition of wandering has prevented researchers from understanding this problematic behaviour and in order for this field to move forward one definition should be adopted (Algase at al. 2009). One widely cited definition of wandering in the recent literature is “a syndrome of dementia-related locomotion behaviour having a frequent, repetitive, temporally-disordered, and/or spatially disoriented nature that is manifested in lapping, random, and/or pacing patterns, some of which are associated with eloping, eloping attempts, or getting lost unless accompanied” (Algase et al. 2007; Algase et al. 2009). However, this definition still presents problems as it suggests that people who get lost whilst on a routine walk alone, when there have been no previous atypical locomotion behaviours, are not wandering (Houston et al. 2011).

Further confusion surrounds the distinction between the act of wandering and the adverse outcomes which may result from wandering behaviour. One behaviour associated with wandering is “elopement” or “leaving ones dwelling unescorted” (Chung and Lai 2011). However, Barnard-Brak et al. (2018) provide a more detailed definition of elopement stating that this is “the act of an individual wandering off when that individual should be supervised as a result of disability or declining function” and suggest that this is actually an outcome of wandering, rather than a definition of the act itself (Dewing 2005). Elopement is particularly associated with adverse outcomes (Ali et al. 2016), and therefore should be examined alongside wandering behaviour.

Several possible explanations for wandering have been proposed including cognitive decline, agitation and unmet needs (Dewing 2005). However, an agreed explanation remains elusive (Ali et al. 2016). There appears to be a complex interplay of factors which result in people with dementia exiting their home and becoming lost. For example; Algase et al. (2015) propose that in addition to link with neurocognitive impairments, missing incidents will be preceded by both contextual and situational antecedents. Firstly, missing incidents often occur when the person with dementia is left intentionally alone and has been asked to remain in the same place (Kolanowski et al. 2002; Algase et al. 2015). Secondly, missing incidents commonly occur whilst the person with dementia is undertaking a routine community-based activity (Algase et al. 2015); for example, a walk or drive in a familiar location. Although it has also been found that wandering increased when the environment was unfamiliar (Hong and Song 2009). Further, wandering may be associated with the previous work roles and habits of the person with dementia indicating that walking has personal importance and may impact health and wellbeing (Gu 2015).

Overall, this means that there is no agreed definition of wandering within the literature and therefore this subjective term must be challenged and explored in order to determine to which behaviours the user is referring. The following estimates regarding the prevalence of wandering must be viewed within this context.

3.2.1 Prevalence of Wandering and associated Adverse Outcomes

The reported prevalence of wandering related incidents varies widely within the published literature due to differences in definition of wandering, research methods including different means of data collection, and geographical and population variation. Additionally, some studies report on missing incidents, whereas other studies report other wandering related incidents such as unattended home exits. In order to illustrate these discrepancies a range of studies in this field will now be discussed.

For example; Bantry White and Montgomery (2015) found that people with dementia accounted for 1.4% of all missing person reports within one police authority, although it is unlikely that this method included consideration of incidents which were resolved quickly. Whereas, Rowe et al. (2010) found that 24% of people with dementia had at least one unattended home exit over a 12-month study period. This suggests that wandering is defined as a person leaving home unaccompanied, and the study does not report any associated adverse outcomes. A prospective study identified a prevalence rate of 46% for caregiver reported missing incidents for veterans with dementia over a 12-month period (Bowen et al. 2011), Whereas, Kwok et al. (2009) found that 27.5% of caregivers retrospectively reported losing their person with dementia. The incidence in this second study may be lower as a result of caregivers forgetting and therefore underreporting incidents. Devenand et al. (1997) found 38.7% of people with dementia demonstrated wandering in the initial stages of their study, and this figure increased to 56.9% as their study and the dementia severity experienced by the study participants, progressed. However, Barrett et al. (2018) found that caregivers of only 15% of veterans with mild dementia reported wandering behaviours, although the authors also state that they found caregivers were inconsistent in their reporting of wandering behaviour.

Overall, Bantry White and Montgomery (2015) conclude from incidence rates reported in the literature that between 10 and 35% of people with dementia display wandering behaviour over the course of dementia. However, there is a need for an agreed definition of wandering, as there is obvious inconsistency in reporting of wandering incidents. The impact of research method, severity of dementia and incidence of adverse outcomes associated with wandering, also require further investigation. Further, the views of people with dementia, on wandering, are missing from the literature and should be explored.

Fortunately, most wandering incidents are resolved quickly; one study found that 45.5% of incidents were resolved within one hour, and 96% of missing persons were found within 24 hours (Kwok et al. 2009). It is also notable that a cohort study following 139 community residing people with cognitive impairment prospectively for eighteen months found no incidence of harm as a result of wandering (Tierney et al. 2004). As these events appear rarely, studies require a large sample size in order to detect their presence (Tierney et al. 2004).

However, clearly some cases of wandering result in adverse effects and wandering has been identified as the third biggest cause of accidental injuries in the dementia population (Douglas et al. 2011). Results could not be compared with the general adult population however, as wandering injuries are not reported for that population (Douglas et al. 2011), possibly because wandering is a behaviour attributed only to the dementia population. Wandering has been identified as a risk factor for fall-related fractures (OR 3.6; [95% CI 1.25, 10.4]) (Buchner and Larson 1987). It is also associated with more severe adverse outcomes. From 23668 police reported dementia related missing incidents in one area of Japan, 548 (2.3%) people died, and 357 (1.5%) were yet to be found (Furumiya and Hashimoto 2015). Wandering is therefore associated with a range of adverse outcomes. Further, due to methods of recording adverse outcomes retrospective studies may be unable uncover links with wandering incidents, making it difficult to calculate their relative risk. Studies which obtained information from interviews report higher incidences, perhaps as they include cases where there was no requirement for medical care (Douglas et al. 2011). However, overall low frequency of injury from this cause when compared to falls in larger population studies excludes consideration of wandering as a safety problem (Douglas et al. 2011).

Wandering related anxiety, or the impact upon caregivers is therefore seen as one of the main adverse outcomes associated with wandering for people with dementia (Rowe et al. 2015), alongside the cost of the resources utilised whilst searching for missing persons with dementia (Rowe et al. 2015). For example, 28.4% of caregivers, in one study, believed that the person with dementia had been frightened by their wandering incident and 44.8% of caregivers reported being worried about further missing incidents (Kwok et al. 2009). The results of this study were not verified with people with dementia, There are also examples of more permanent changes following wandering incidents; older adults with cognitive impairment who exhibited wandering behaviour are more likely to be institutionalised sooner than other older adults with cognitive impairment, probably as a result of caregiver anxiety (Strain et al. 2003). Similarly, 17% of people with dementia who experienced an unattended home exit and sustained injuries, were permanently placed in a nursing home as a direct consequence of this event (Rowe et al. 2010).

Although the reported prevalence of wandering incidents and associated adverse outcomes show variation throughout the literature, there is agreement that wandering elicits intense feelings of anxiety amongst the families and caregivers of people with dementia (Brittain et al. 2017). Additionally, a survey of occupational therapists found that elopement was their main safety concern related to clients with dementia (Collins 2018). This intensity of feeling may have triggered the strength of the focus upon this issue within research despite the actual prevalence of wandering related injury being relatively low when compared with other safety issues which affect people with dementia. Similarly, the strong association of wandering incidents with the institutionalisation of people with dementia may be mainly attributed to caregiver anxiety Rowe et al. 2010). Notably, these studies do not consider the views of people with dementia.

Wandering related interventions are further complicated by discussion within the literature regarding the benefits of walking for people with dementia. For example, there are papers stating that walking or wandering provides the person with dementia with physical exercise, promotes regular sleep patterns, enhances quality of life, maintains mobility and physical independence and enables people with dementia to maintain a good appetite (Ali et al. 2016; Robinson et al. 2006). Walking may also permit the person with dementia to participate in familiar patterns of behaviour providing reassurance (Gu 2015). In order to ensure that the positive aspects of walking are not lost for people with dementia, recent literature emphasises the promotion of safe walking for people with dementia rather than the prevention of wandering. These papers also suggest that the term wandering is replaced by the person-centred phrase “people who like to walk” (Graham 2017).

3.3 Safety Risk

In addition to wandering risk this research is also examining the impact of AT on safety risk. Safety risks for people with dementia can occur as the result of a range of concerns including falls, medication management, financial management, cooking, access to firearms, being left alone, inability to respond to crises, driving and abuse or neglect, which in the context of impaired insight and judgment may expose the person with dementia to potential harm (Amjad et al. 2016). Within one observational study of 130 participants Tierney et al. (2007) discriminated safety risks associated with self-neglect from failure to eat and drink, failure to use prescribed assistive devices, failure to report a medical condition, failure to maintain personal hygiene, failure to use medications properly, failure to recognise a familiar environment, failure to turn off electrical appliances and failure to judge fraudulent activity. For the purposes of this review, safety risk is defined as exposure to harm or self-injury including (1) physical injury to self or other, property loss, or property damage; (ii) need of an emergency service intervention. This definition includes a wide range of types of harm associated outcomes such as personal injury, property damage and financial exploitation (Tierney et al. 2004).

3.3.1 Prevalence of Safety Risks and associated Adverse Outcomes

Problems in calculating prevalence of safety risks may result from data which records diverse adverse outcomes such as injury, institutionalisation or emergency service use rather than safety incidents or exposure to risk. Such concepts are harder to define or observe, and therefore have limited understanding of recorded data. Different methodologies, populations and methods of data collection across different studies provide heterogeneous prevalence estimates for adverse events. For example, many studies only include adverse events which have been caused by health care management (Sears et al. 2013). There are a number of activities which are linked with each type of adverse outcome, and prevalence rates for each of these are recorded individually. Similarly, each type of safety risk can be associated with a range of possible adverse outcomes. Further, within the literature, studies often examine risk from the point of view of professionals and family members, however, there may be differences in the views of people with dementia and their caregivers, and this methodology remains troublesome for people with dementia who live alone (Lehmann et al. 2010). People with dementia who live alone may experience safety incidents which are more likely to remain unreported. Douglas et al. (2011) further suggest that data inaccuracies may arise as caregivers and health professionals can be motivated by a desire to prevent injury and may therefore perceive risk to be higher than it is in reality.

Falls are identified as the leading source of both morbidity and mortality in older adults with and without dementia, and are the leading source of in-home injury for people with dementia (Douglas et al. 2011). However, accidental injury and accidental death are reported separately. People with dementia are two to three times more likely to fall than people without dementia, with an annual incidence of falls of about 60-80% (Härlein et al. 2009). Fires were the second highest cause of accidental death at home, but the third highest cause of accidental injury. Injury from self-administered medication errors in people with dementia was found to be the fifth highest source of harm (Douglas et al. 2011).

In a prospective cohort study, 21.6% of persons living alone with cognitive impairment experienced an incident of harm which resulted in physical injury or property damage over their eighteen-month study period (Tierney et al. 2004). There were high incidences of self-neglect including people with dementia who neglected to provide themselves with food, drink and personal hygiene (50%), and 43% of participants required emergency interventions due to lack of communication with their physician or as a result of following instructions inadequately. There were further low incidences of fire damage (3%), and loss of money due to fraud (3%) (Tierney et al. 2004). The study did not compare results with the incidence of harm for people with dementia living with others, or with people without cognitive impairment. Another, Canadian study reported a lower overall incidence rate of 13.2% for adverse events in home care patients, although not specifically people with dementia, of which one-third were considered preventable (Sears et al. 2013).

In hospital admissions data, there was an age-standardised incidence rate for burns in people with dementia of 22.7 per 100 000, whereas the estimated rate for people without dementia was 14.2 per 100 000 population (Harvey et al. 2016). People with dementia were also likely to experience more severe burns than people without dementia. They were 60% more likely to be hospitalised, and increased numbers were admitted to intensive care, experienced complications, they remained longer in hospital and were three time as likely to die as people over 65 years of age without dementia (Harvey et al. 2016). However, following adjustment for a number of factors, dementia did not remain significantly associated with mortality (Harvey et al. 2016). This result suggests that increased adverse outcomes associated with dementia may be at least partly due to other factors such as advanced age, which should be considered and accounted for in future research.

Good medication management is also linked with reduced institutionalisation and improved health outcomes (Gillespie et al. 2013), and Douglas et al. (2011) considered that accidental injury was more likely to result from an error in medication administration than from fire/ burn or wandering. Moreover, Thorpe et al. (2012) found that 33% of people with dementia, and perhaps more surprisingly that 39% of caregivers of people with dementia were taking at least one potentially inappropriate medication indicating that this problem is not specific to people with dementia.

Overall, the literature describing the risks facing people with dementia presents a complex picture of multiple safety hazards. However, there is a need for further research which examines clearly defined safety risks, and accounts for factors such as age and multi-morbidity in order to understand the relationship between dementia and safety risk prevalence, when these other factors are controlled. This will also assist in the identification of factors which indicate people with dementia particularly at risk of adverse outcomes. The literature describing adverse incidents in this population is often limited in its areas of focus exploring discrete adverse outcomes rather than the problem as a whole. Changes in the definition of particular outcomes or incidents restrict comparison of available evidence (Douglas et al. 2011). Further data is required to inform development of standardised assessment instruments which can predict adverse outcomes (Douglas et al. 2011). There is a need for research which explores the extent of this problem using robust statistical analysis to understand the increased risk faced by people with dementia once other characteristics which may impact adverse risk have been considered.

This literature review will now focus on the characteristics of people with dementia which are associated with an increased risk of adverse outcomes.

3.4 Characteristics associated with Risk for People with Dementia

In order to identify people with dementia living at home who are at risk, there is a requirement to identify characteristics which are associated with adverse outcomes for these people. Effective assessment identifies those in need of support and at risk of injury (Douglas et al. 2011). However, safety is often insufficiently addressed within needs assessments and this results in care becoming inconsistent and reactive (Amjad et al. 2016). Improved understanding of these needs and characteristics associated with risk, will provide information regarding targets for intervention which may ameliorate risk. Additionally, the complexity of the AT selection and advice process which must account for the variation in the relationship between the person with dementia and their personal context and environment, is not well researched (Bernd et al. 2009).

3.4.1 Population Characteristics which impact Health Care Use

There are a number of characteristics relating to the person with dementia including their level of wandering and/ or safety risk which may impact upon their use of health care services such as AT. Health care utilisation is the point where patient needs meet the professional system (Babitsch et al. 2012), and is therefore relevant for the examination of the relationship between AT which is recommended and installed in response to participant needs. These factors will be considered here within the context of Andersen's behavioural model of health service use.

3.4.1.1 Andersen's Behavioural Model of Health Service Use

Andersen's behavioural model of health service use is the most cited model in its field (Graham et al. 2017) and has been used to explore healthcare use in many countries including USA, UK and Germany (Babitsch et al. 2012). Studies have included a wide range of variables within the model and it is often used in secondary data analysis due to its flexibility (Babitsch et al. 2012). This model allows examination of health care utilisation in order to provide an explanation of factors which either facilitate or impede service use in different circumstances (Phillips et al. 1998; Toseland et al. 2002; Beeber et al. 2008; Babitsch et al. 2012). Previous studies have explored factors which impact healthcare use within the fields of dementia care (Toseland et al. 2002), and AT (de Klerk et al. 1997) using this model. In addition to environmental factors, the model considers three aspects of population characteristics namely; (i) predisposing factors, (ii) needs factors, and (iii) enabling resources, and their relationship with health behaviours and health related outcomes (Phillips et al. 1998; Babitsch et al. 2012) (Figure 8).

This model of healthcare use has been adopted within this study due to its adaptability, which makes it compatible with exploring the secondary dataset available for analysis in this research (Babitsch et al. 2012). Andersen's model has the advantage over other AT specific models in that it is simple to apply and facilitates consideration of the support network surrounding the person with dementia (Bernd et al. 2009; Sugarhood et al. 2013).As this research aims to investigate the impact of population characteristics upon AT, the Andersen model which attempts to explain variances in health service use is pertinent (de Klerk et al. 1997). Use of this model enables consideration of the relationship of characteristics or factors which facilitate or impede healthcare (AT) use (Gitlow and Rakoski 2009; Babitsch et al. 2012). Previous research found inconsistencies in the categorization of certain variables as predisposing or enabling characteristics indicating a need for further investigation (Babitsch et al. 2012). Resultant information regarding the role of variables in AT use may then be used to inform other AT models and frameworks such as those described in chapter 4.

An adaptation of Andersen's model of healthcare use is presented in Figure 8. This has been populated with factors from the secondary dataset which will be examined in the course of the secondary data analysis study. However, it must be acknowledged that previous studies have identified a number of factors which have an impact upon AT service use. These include personal factors, environmental factors such as healthcare delivery systems and financial and organisational factors, and AT related factors (Rogers and Holm 1992), although the available dataset did not provide an opportunity to include all of these factors within this research. These additional factors are obviously important in understanding the use of AT interventions and will be considered during the following review of the published literature. However, in order to provide context for the forthcoming analysis priority will be given to factors which will be considered during the secondary data analysis study within this research. This research will provide consideration of the relationships between population characteristics of people with dementia and successful AT installation.

Environmental factors include characteristics of the healthcare delivery system, the external environment and community and whilst the importance of these factors is recognized the literature acknowledges that their effect on healthcare utilization is poorly understood (Phillips et al. 1998). The relationship between environmental factors and AT interventions will be discussed later in this study.

Predisposing factors include demographic characteristics such as age and gender; social factors such as occupation, education, ethnicity and social relationships; and health beliefs. These are contextual factors which predispose individuals to the use of health services (Babitsch et al. 2012). Toseland et al. (2002) suggest that predisposing factors including the relationship between the person with dementia and their caregiver are important predictors of health service utilisation, perhaps even more important than need variables.

Within Andersen’s model, need factors are classified as perceived need and assessed need. Perceived needs for health services includes the individual’s view of their own health and functional status and how important they judge their problems to be (de Klerk et al. 1997; Babitsch et al. 2012). Whereas assessed needs (sometimes referred to as evaluated needs) include professional assessments and objective measurements of the patient’s health status and need for medical care. The need variable most commonly linked to health and social care service use is functional status (de Klerk et al. 1997). However, it should be noted that this is not always the case as Roelands et al. (2008) report that the care recipients’ behaviour problems and functional status were not found to be related to service use.

Enabling resources include financial and organisational factors which enable service use (de Klerk et al. 1997). For people with dementia living at home this may include having the income or wealth available to pay for health services. Organisational factors include access to regular care including informal help and services such as transport to appointments, available appointments and services. Weaver and Roberto (2017) explored characteristics of 76 older people at risk of nursing home placement and found that enabling resources were most influential in defining different groups of clients. Further they found that enabling resources were more malleable than predisposing or need variables as available services provided support for family and other informal caregivers.

The literature includes debate regarding the relative importance of each of these factors in respect of their impact upon health service use and suggests that this depends on the population and health care service under scrutiny. Andersen (1995) stated that need factors were the most immediate cause of health service use, and that perceived need indicates the intervention sought by the person with dementia but may also provide information concerning their likelihood to adhere to recommended regimes. Alternatively, it is the assessed needs which indicate the type and amount of intervention that health professionals will provide. Additionally, the health service utilisation literature suggests that need variables explain more of the variation in service use than predisposing or enabling variables (de Klerk et al. 1997; Toseland et al. 2002).

There is therefore a requirement to further understand the relationship of different population characteristics of people with dementia to AT use. This thesis will focus on the professionally assessed needs of people with dementia due to their acknowledged close links with service provision, and the variation in AT interventions recommended to meet those needs. The author will now explore literature on predisposing characteristics, needs and enabling resources, their relationship with adverse outcomes for people with dementia, and their impact on AT use in this population.

Figure 8 Population Characteristics within the Attila dataset which impact Healthcare Utilisation

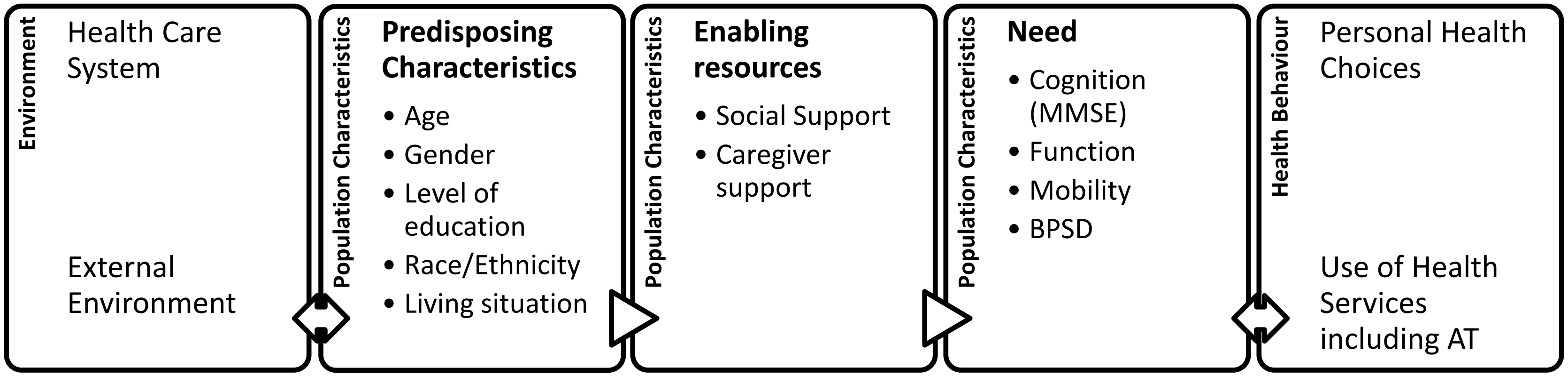


Figure 8: MMSE = Mini Mental State Examination, BPSD = Behavioural and Psychological Symptoms of Dementia, AT = Assistive Technology. Adapted from Phillips et al. (1998)

3.4.2 Predisposing Characteristics

Predisposing characteristics are one of the three groups of factors identified as having an impact upon healthcare utilisation (Figure 8). This category includes sociodemographic characteristics and other variables such as health-related attitudes which may predispose an individual to use healthcare services.

Relationships between the predisposing characteristics of people with dementia to institutionalisation and use of other healthcare services are explored within a number of systematic reviews. For example, there is an increased risk and shorter time to nursing home placement for people with dementia who are of advanced age (Luppa et al. 2008; Cepoiu-Martin et al. 2016), are cared for by caregivers of advanced age, and are unmarried or live alone compared to living with a spouse or caregiver, and when the caregiver is a child or a relative other than spouse (Strain et al. 2003; Cepoiu-Martin et al. 2016). People with Alzheimer's disease living alone have earlier and more frequent institutionalisations, although those living with others die earlier (Strain et al.2003; Soto et al. 2015). Living situation is also associated with marital status, MMSE score, ADL and IADL impairment, number of helpers, agitation and physician recognition of dementia (Lehmann et al. 2010). Further, living alone is a significant predictor of a person with dementia having no community services (Webber et al. 1994).

Females may be more likely to be admitted to nursing homes (Wattmo et al.2011), although another more recent study found no nursing home placement effect for gender (Cepoiu-Martin et al. 2016). However, elderly women are more likely to use AT than their male counterparts (de Klerk et al. 1997). Additionally, there is a decreased risk of nursing home placement and increased time to placement when the person with dementia is African-American or Hispanic rather than white American (Luppa et al. 2008; Cepoiu-Martin et al. 2016). Patients with higher level of education are placed in nursing homes later. Employed caregivers and caregivers with higher levels of education or higher income institutionalise their care recipients sooner. Higher educational level of caregivers is associated with greater service use and may reflect knowledge of services and how to access and use them (Toseland et al. 2002; Zaccarelli et al. 2013).

In addition to demographic characteristics, predisposing factors particularly linked to AT use include the attitude of the person with dementia towards technology, relevant technology experience, perceptions of the benefit of AT, and values and knowledge (Toseland et al. 2002; Wielandt et al. 2006; O'Neill et al. 2013; Boger et al. 2014). Use of AT is strongly influenced by individual awareness of the AT and the belief that it works (Wielandt et al. 2006; Greenhalgh et al. 2013). People with positive perceptions about AT are more likely to use it (Wielandt et al. 2006; Arntzen et al. 2016). Further, people are strongly influenced in their use of AT, by their understanding of what will occur following its use (Greenhalgh et al. 2013). People who believe AT use will result in negative consequences such as the exposure of their failures to strangers are unlikely to activate AT (Greenhalgh et al. 2013).

It is a common perception that older people may be reluctant to engage with new and unfamiliar AT (van den Heuvel et al. 2012; Boger et al. 2014; Sugarhood et al. 2014). However, research has shown that previous use of AT or technical experience, is less important to the adoption of AT than cognitive ability (O’Neill et al. 2013). Additionally, recent evidence demonstrates that people with dementia can engage with digital technologies if support is provided for them and their families (French 2016). Decisions to adopt technology evolve over time and are influenced by members of the wider social network (Sugarhood et al. 2014).

Research specifically examining predisposing characteristics to AT for people with dementia is limited and often compounds characteristics relating to the person with dementia, with those of their caregiver (Toseland et al. 2002). Further research is required to determine the influence of predisposing characteristics of the caregiver and person with dementia respectively.

3.4.3 Needs

Needs refer to the perceived or evaluated health characteristics which can benefit from services (de Klerk et al. 1997; Asadi-Lari et al. 2003; NHS Health Scotland 2019). Traditionally, need factors have been viewed as the driving force behind healthcare utilisation (Toseland et al. 2002), although it is acknowledged that this may vary depending on the type of service under consideration. Cognition, function, mobility and behavioural and psychological symptoms associated with dementia can all be considered to be needs, and the literature evaluating their relationship with adverse outcomes and AT use for people with dementia will now be examined.

3.4.3.1 Cognition

There is a strong relationship between cognitive impairment and adverse outcomes (Tierney et al. 2004) such as self-neglect, wandering, and mobility and gait problems. In a population with moderate cognitive impairment, 50% were found to neglect to provide themselves with essentials such as food and drink, and 43% were unable to follow their doctors’ instructions adequately

(Tierney et al. 2004). Harm resulting from self-neglect or disorientation for participants over the age of 65 with cognitive impairment is predicted by poor performance in the domains of verbal recognition memory, executive function, and conceptualisation, but not by global cognitive functioning as measured by the MMSE (Tierney et al. 2007). People with dementia notice changes in their capacity to complete complex tasks even during the pre-diagnostic phase of dementia (Ali et al. 2016; Chaplin and Davidson 2016), they start making mistakes and become increasingly slow in completing tasks (Andrew et al. 2019).

Cognitive decline is one possible explanation for wandering behaviour (Dewing 2005), and is associated with nursing home admission (Strain et al. 2003; Wattmo et al. 2011; Cepoiu-Martin et al. 2016; Toot et al. 2017). As dementia progresses a significantly greater proportion of individuals are labelled wanderers (Algase 1999), and wandering is associated with faster cognitive decline, poorer neurocognitive abilities particularly impacting spatial skills and perseveration. However, even though cognitive impairment explains a proportion of the variation of random wandering researchers should continue to explore other factors more amenable to interventions such as needs and environmental conditions (Algase et al. 2001).

The association of wandering and wayfinding in people with dementia, is important as issues concerning wayfinding appear early in the progression of dementia (Algase et al. 2004). People with dementia have problems knowing where they are, seek seriously to go elsewhere, or experience a sense of being misplaced. People with dementia may also exhibit visual agnosia (inability to recognise objects or places), even in familiar locations (Algase et al. 2015). This decline in the ability to recognise scenes may contribute to people with dementia becoming lost. There is however, a distinction between wandering and getting lost (Bantry White and Montgomery 2015). Wandering is associated with personality responses to stressors and walking preferences, whilst getting lost is associated with spatial disorientation, reduced topographical memory, and changes in visual-perceptual ability and executive dysfunction (Rowe et al. 2011).

The association of cognitive functioning with mobility and gait related problems means that people with moderate dementia are likely to fall than people with mild dementia (Härlein et al. 2009). Although, motor and process skills generally have a limited relationship to dementia severity (Bouwens et al. 2008).

Additionally, declining cognitive abilities contribute to people with dementia being unable to manage their own medication (While et al. 2012). This may be the result of one further complication of cognitive impairment which is often described in the literature is the impact of dementia upon self-awareness, or awareness of deficits in people with dementia which can result in people with dementia undertaking activities outside their capabilities (Okonkwo et al. 2010).

People with dementia also experience particular difficulties associated with conversation such as confabulation which can impact their ability to communicate effectively (Hydén and Örulv 2009; Kindell et al. 2017). This type of difficulty has important negative implications for the accuracy of assessment, sustaining social interaction and maintaining social identity (Gjernes 2017).

AT can be used successfully to support people at different stage of dementia and their caregivers, but it requires assessment of their needs, to be individually tailored with reliable applications, personal assistance, and adequate social and health care services including follow-up (Topo 2009). The progressive nature of dementia also means that any specific AT device may only be useful for a specific period of time (Lorenz et al. 2019), and the function of AT used by people at different stages of dementia varies. Most AT targets the safety and security of people with moderate or severe dementia living at home in the community. Safety is also important for people with mild cognitive impairment to early stage dementia living at home in the community, although at this stage most AT aims to promote memory function.

Further, in order to benefit from AT, people with dementia require the cognitive and physical capacity to operate the AT (Greenhalgh et al. 2013; Arntzen et al. 2016). Additionally, people with the ability to recall training are more likely to use AT (Wielandt et al. 2006). People in the early stages of dementia can usually learn new things and may adopt AT which requires their active input (Riikonen et al. 2013). Although research has identified that informal and professional caregivers felt most AT too difficult for use by people with dementia themselves (Boger et al. 2013). As cognitive skills and capabilities decline with the progression of dementia, people with dementia may become unable to adopt new AT or may become unable to use the AT they already have (Riikonen et al. 2013).

Acceptance of AT was observed to increase as symptoms start to threaten the independence of the person with dementia (Meiland et al. 2017). However, over time, the use of AT decreased as cognitive impairment became more severe. This may be because the person with dementia's motivation to use AT can also change over time (Collins 2018) and individuals should be motivated to use the device or the intervention will not be successful (Hoppestad 2006). Further, people past the moderate stage of dementia are not able to learn to use new equipment (Riikonen et al. 2013), although people in the early stages of dementia can also experience difficulty managing AT (Arntzen et al. 2016). Even equipment which did not require user input, such as a motion sensitive light, caused confusion for people with dementia who were unable to recall that the light would switch off automatically, and became concerned (Riikonen et al. 2010). Thordardottir et al. (2019) found that disease progression and onset of symptoms negatively affected use of AT and suggest the need for adaptation of AT in response to the changing needs of the person with dementia.

It can therefore be seen that the changes resulting from cognitive impairment are associated with a range of adverse outcomes, and will impact upon the types of interventions which may be suitable to meet these needs. However, despite evidence of AT abandonment for this population, little attention has been given to studying the adoption of technology by older people with cognitive impairments including dementia.

3.4.3.2 Function

Throughout the literature there is a strong association between level of function and adverse outcomes for people with dementia. The ability to conduct complex instrumental activities of daily living (IADL) such as managing finances is significantly associated with wandering related adverse consequences, negative outcomes and eloping behaviour (Ali et al. 2016). People with dementia who have lower baseline scores in performance of daily functions are more likely to wander (Barrett et al. 2018). Further, people with dementia who required assistance in two or more activities of daily living were significantly more likely to suffer adverse consequences including dehydration, falls and injuries (Gaugler et al. 2005). Additionally, preadmission loss of function is associated with caregiver strain (Boltz et al. 2018). However, there is conflicting evidence for the relationship between functional impairment and falls in the literature suggesting that this requires further investigation (Härlein et al. 2009).

Decreased level of functioning is also often associated with hospital admission or institutionalization. A number of studies found greater functional impairment and dependency in activities of daily living such as bathing, dressing, eating and particularly, toileting, was significantly associated with institutionalisation (Andrieu et al. 2002; Strain et al. 2003; Luppa et al. 2008; Wattmo et al. 2011; Risco et al. 2015; Cepoiu-Martin et al. 2016; Toot et al. 2017; Boltz et al. 2018). Dementia is associated with preventable medication related hospital admission, as managing medication is identified as one of the high-level tasks which people with dementia struggle to manage independently at an early stage of the disease (Amjad et al. 2016).

3.4.3.3 Mobility

Cognition is crucial in the control of gait, and adults with executive dysfunction have an altered gait pattern, resultant motor impairments then significantly increase the risk of falling (Härlein et al. 2009; Booth et al. 2015). The progression of dementia is associated with slowing gait speed, shortening stride length and more variable stride lengths (Härlein et al. 2009). Particular dementia diagnoses are associated with decline in mobility and people with Lewy Body Dementia are significantly more likely to fall than people with Alzheimer's disease (Ballard et al. 1999, cited in Härlein et al. 2009; Allan et al. 2009).

Falling is the adverse outcome most strongly linked with mobility throughout the literature for people with dementia who have two to three times increased risk of falls when compared with people without dementia (Härlein et al. 2009; Sadak et al. 2017). The annual incidence of falls for people with dementia is 60 - 80% (Härlein et al. 2009), and people with dementia experience poorer outcomes following falls including an increased risk of institutionalisation and higher mortality rate than people without dementia (Härlein et al. 2009; Cepoiu-Martin 2016). Additionally, people with dementia are three times more likely to fracture a hip, and twice as likely to die as the result of a fall (Sadak et al. 2017). Further, a history of falls within the previous 12 months is a significant predictor of future falls (Allan et al. 2009).

The fear of a fall occurring has also been shown to impact upon caregivers as greater mobility is associated with lower subjective impact upon caregivers for people with mild dementia (Werner et al. 2017). This confirms previous research which found that whilst falls in people with dementia increased caregiver stress, caregiver stress also increased the likelihood of people with dementia falling (Maggio et al. 2010). Reasons for this observation are not clear, but suggest that caregiver training and support could reduce falls for people with dementia.

Whilst it appears logical that wandering and mobility are associated, there is no significant association between mobility and overall wandering rate (Algase et al. 2009). However, better mobility enhances the capacity of people with severe impairment to wander indicating that cognitive impairment and wandering must be considered together. Conversely, persistent walking, and poor gait and balance are two measurable predictors of adverse outcomes associated with wandering (Ali et al. 2016).

Finally, identified modifiable risk factors for falls in people with dementia, include depression scale scores, symptomatic orthostatic hypotension, and autonomic symptom score (Allan et al. 2009). These may therefore be key to reducing the risk of falls in this population.

3.4.3.4 Behavioural and Psychological Symptoms of Dementia

Behavioural and psychological symptoms of dementia (BPSD) affect up to 90% of people with dementia at some point. These hard to manage or changed behaviours can arise as the result of depression, emotional distress, psychosis, aggression, apathy or agitation and can reduce quality of life through exacerbation of sleep deprivation, fatigue and other stress related issues (Wharton and Ford 2014; Trivedi 2018). These behaviours are indicative of problems with routine or the ability of the individual to arrange a balanced, organised and productive routine of daily activities (Parkinson et al. 2004; Forsyth and Dunk 2014) and are associated with wandering (Moore et al. 2009).

Toot et al. (2013) found that behavioural problems in people with dementia slightly increased the risk of hospital admission, although this finding was not statistically significant, BPSD were however, significantly associated with nursing home admissions (Strain et al. 2003; Cepoiu-Martin et al. 2016; Toot et al. 2017). Additionally, sleep disorder is significantly associated with hospital admission for people with dementia (Andrieu et al. 2002), and symptoms including aggression, depression and hallucinations are all associated with institutionalisation (Luppa et al. 2008). Mitchell et al. (2017) also found that dementia is associated with an increased risk of hospitalisations as a result of self-harm. Furthermore, Asada et al. (1996, cited in Härlein et al. 2009) found a significant relationship between resistance to assistance and fall-related injuries.

Reported incidence rates of violent or aggressive behaviour from people with dementia vary greatly within the literature. Wharton and Ford (2014) found prevalence rates ranging from 18-65% of people with dementia displaying these behaviours. One study found over one-third of caregivers reported being abused by the person for which they provided care (Wharton and Ford 2014). This variation may be due to methods of reporting, and different definitions of problematic behaviour. Further, violent or severely aggressive behaviours from a person with dementia results in a fourfold increase in the risk of reciprocal violence from caregivers (Wharton and Ford 2014).

Perhaps unsurprisingly caregiver abuse has been found to be significantly associated with institutionalisation and mortality (Wharton and Ford 2014). Behavioural problems have also been shown to be associated with depression and can be exacerbated by medication (Wharton and Ford 2014).

Other needs that predicted incident harm included diagnoses of COPD and cerebrovascular disease, probably due to their association with delirious patients admitted to emergency departments (Tierney et al. 2004).

3.4.3.5 Summary

Overall, it can be seen that needs, like risks are associated with adverse outcome for people with dementia (Seden 2016). Therefore, needs are strongly related to health service use and explain more variance than predisposing or enabling variables thereby facilitating the individualisation of healthcare interventions (Toseland et al. 2002).

3.4.4 Enabling Resources

Enabling resources facilitate or inhibit the use of healthcare services (de Klerk et al. 1997). Weaver and Roberto (2017) found enabling resources were most influential in defining client groups in relation to their use of healthcare services. The enabling resources encountered most often in the literature describing the use of AT by elderly people include income and informal help (de Klerk et al. 1997). AT related factors which enable their use include ease of use, familiarity, effectiveness, cost, portability, convenience, sense of control (Boger et al. 2014). Literature relating to the impact of these factors on AT will now be explored. Findings are categorised as Cost (including income); Social and Caregiver support; and AT related factors. The subsequent secondary data analysis study will focus upon caregiver support as an enabling resource for people with dementia.

3.4.4.1 Cost

Income affects the type of service used by individuals (de Klerk et al. 1997), and cost is identified as a concern for older people considering the purchase of AT (Yusif et al. 2016). Therefore, the lack of transparency associated with AT service costs and charges across the UK is likely to discourage people from using these services Gibson et al. (2016). Most services (187 out of 331) neglect to provide information on pricing on their website or promotional literature. Furthermore, pricing structures are complex and potentially confusing with additional costs relating to emergency call outs and installation. Reductions or cost exemptions often require the completion of lengthy additional assessment processes. Similar anomalies surround the private purchase of AT, where services direct people with dementia and their caregivers towards expensive telecare solutions rather than cost-effective locally available products which could provide similar benefits (Gibson et al. 2016).

Moreover, there is a lack of studies in this field examining the cost-effectiveness of AT for people with dementia living at home (Meiland et al. 2017), with limited rigorous cost-analysis (Bowes et al. 2013). Importantly, most studies claim a cost benefit due to the delay in admission to nursing home, but often fail to acknowledge the total social cost of care at home including the costs resulting from the informal caregiver being removed from the labour market or other costs associated with providing free care at home in addition to their contribution to the labour market. Care at home may reduce the required level of public funding, and AT may facilitate less expensive care options, however, there must also be further consideration regarding the effectiveness of this method of support (Bowes et al. 2013). Additional focus on the effects on the person with dementia of being cared for through AT rather than human caregivers is also required, as often AT is designed by service providers rather than people with dementia. The reduction in human contact may have negative consequences for the person with dementia. Further, the cost saving associated with AT may merely result from the movement of the costs of care from the healthcare budget to either individual citizens or the social care budget (Bowes et al. 2013).

3.4.4.2 Social and Caregiver Support

Due to obvious overlaps, the influence of social support and caregiver support on risk and AT use, will now be considered together. Social resources and social support are strongly linked to adverse outcomes for people with dementia (Tierney et al. 2004). Caregivers of people with dementia who live alone provide less hands-on assistance and experience less impact, although they are more likely to consider institutionalisation. Spouses caring for people with dementia are more likely than adult children, but less likely than other types of caregiver to place the person with dementia in long-term care. People with a female caregiver have a lower risk of nursing home placement (Cepoiu-Martin et al. 2016).

The largest proportion of dementia care is provided by the families of people with dementia who develop a wide range of skills and knowledge in order to effectively care for their relative (Tudor Car et al. 2017). For example, caregivers may be responsible for managing between one and nineteen prescribed medications within multiple dosage schedules throughout the day (Gillespie et al. 2013). Caregivers are not always present at medical consultations and are therefore not always informed about changes to medication regimes and also may have difficulty understanding dosage and administration instructions. This results in inaccuracies in their management of the medication for the person with dementia (Gillespie et al. 2013).

Responsibility can therefore be associated with particular negative effects for caregivers, due to the length of time for which care is required, and also due to the particularly demanding types of caregiving required (Tudor-Car et al. 2017), such as the need for constant supervision of people with dementia who may wander or be involved in other safety related incidents (Rowe et al. 2010). In such cases, even in the presence of a full-time carer the likelihood of injury or an unattended exit may be high (Rowe et al. 2010). Negative impact of caregiving is associated with the needs of the person with dementia including lower cognitive status (Werner et al. 2012). Caregiver strain has been identified as one of the most consistent factors predicting nursing home admission for people with dementia (Thoma-Lürken et al. 2018). Caregivers reporting many unmet needs tended to institutionalise the person with dementia sooner (Luppa et al. 2008). However, the effect of caregiving hours upon institutionalisation is not known. Further, the caregivers' view of the person with dementia's level of personal care dependency is associated with higher emergency department use (Hunt et al. 2018).

Caregiver impact has been associated with loss of function experienced by people with dementia prior to hospital admission (Boltz et al. 2018). The reason for this observation was not clear, but may be due to the caregiver being unable to provide the necessary care for the person with dementia. This suggests that caregiver training and support could reduce adverse outcomes for people with dementia (Maggio et al. 2010).

Social networks are possibly the most influential factor in the adoption of AT by older people (Toseland et al. 2002; Riikonen et al. 2013; Peek et al. 2015; Liu et al. 2017). However, the role of social support in the AT process is complicated. There is a direct correlation between AT adoption and living arrangement, although there is no correlation between carer involvement and adoption (O'Neill et al. 2014). Older people are considerate of the workload shouldered by their relatives and accept the advice and support of their relatives when evaluating the potential of accepting AT. Caregivers and family members facilitate the integration of AT into daily life through encouragement and guidance. This may be because it is caregivers who often receive the greatest benefit from AT installation, as it maintains the safety of the person with dementia thereby reducing caregiver anxiety (Gibson et al. 2015). Perceived social support by caregivers decreases risk of nursing home placement (Luppa et al. 2008), and the perception of fewer social resources is a significant risk factor for harm (Tierney et al. 2004).

Contrarily, interventions designed to assist in the care and management of people with dementia can negatively affect caregivers. There is recognition within the literature of the additional impact placed upon caregivers by the AT and other interventions designed to increase the safety of people with dementia, as caregivers are required to complete additional tasks such as battery charging, providing instruction on how to use AT (perhaps repeatedly), filling medication boxes and responding to alarms (Tudor-Car et al. 2017). In many cases AT can only assist caregivers in that it alerts the caregiver to a problem (Evans et al. 2015). Often, AT does not independently resolve an issue but may enable a caregiver to continue their role from a distance, or to complete other tasks, whilst maintaining their caregiver role. Services are most likely to be accepted by caregivers when they are seen to reduce the impact of caregiving, suggesting that the positive effect of support on acceptance of AT may partly be the result of self-preservation on the part of the caregiver (Toseland et al. 2002). However, caregivers are also an important factor is assisting people with dementia to accept and use AT (Riikonen et al. 2013; Liu et al. 2017). Integration of AT will only occur if all members of the social network participate in its selection, and view the AT positively (Riikonen et al. 2013; Gibson et al. 2015; Gibson et al. 2018). The adoption of AT is a complex social process (Peek et al 2015).

Enabling resources explain more variation in service use than either needs or predisposing variables (Toseland et al. 2002). Therefore, service providers must account for the wishes and needs of caregivers in order to increase service uptake. However, there is limited exploration regarding the possibility of caregiver needs conflicting with the needs of people with dementia, or how the needs and preferences of people with dementia can be respected whilst accounting for the needs of caregivers.

In addition to population characteristics, the literature indicates that effective use of AT is also impacted by a number of AT related factors which will be discussed below.

3.4.4.3 *Assistive Technology related Factors*

Usability, or the extent to which a product can be used to achieve specified goals with effectiveness, efficiency and satisfaction has not been studied extensively in the field of AT for people with dementia (Meiland et al. 2017). Although, lack of usability is identified as one of the main barriers to AT adoption (Ienca et al. 2017), indicating a need for increased understanding of the human aspects of AT (Wielandt and Scherer 2004). The use of digital technologies is particularly low amongst people with dementia, specific challenges include variability in screen presentation and recalling the meaning of particular icons (French 2016).

AT deployment is more likely to be successful if the AT is already familiar to the user, and clearly meets their needs (Meiland et al. 2017; Ienca et al. 2017). However, familiarity does not guarantee that AT will be adopted, and well-known AT such as alarm clocks and mobile phones, can be difficult to operate (Rosenberg et al. 2009). Passive devices, which don't require active control or activation are more likely to be accepted (Riikonen et al. 2010, Ienca et al. 2017; Meiland et al. 2017).

Modifiability of AT can increase the opportunity for the intervention to suit the specific needs and functional abilities of the person with dementia and their caregiver (Ienca et al. 2017). Therefore, the potential of AT to be adapted to suit individual needs and fit with daily routine increases the usefulness of the device. Methods for increasing adoption of AT include the consideration and inclusion of the user during the design phase of the AT; and ability to modify AT as the disease progresses or to suit the particular needs of the person with dementia or their caregiver. For example, uptake of digital technologies can be increased through the personalisation of interfaces (French 2016). Actively involving people with dementia in the installation of AT and providing them with medium- and long-term follow-up is important in resolving unforeseen problems and increasing device use (Meiland et al. 2017; Thordardottir et al. 2019). Caregivers and family members may be able to support this process. Although caregivers are also often themselves unfamiliar with digital technologies and feel that they have limited time to dedicate to learning new skills (French 2016).

Seeing the benefits of AT was also identified as being important for the adoption of technology into everyday life in a scoping review conducted by Patomella et al. (2018). Liu et al. (2017) examined acceptance of GPS devices by people with dementia and their caregivers, and found that performance expectancy was the most important factor in this regard. Functionality or added value was also identified as important to the adoption of AT (Yusif et al. 2016). Lack of technological issues including power cuts or false alarms were also associated with AT use (Gagnon-Roy et al. 2017; Meiland et al. 2017).

This provides a brief overview of aspects of AT which impact successful use of AT. Factors related to the assessment, recommendation and installation of AT for people with dementia will be further considered in the following chapter.

3.5 Summary

This chapter has explored the literature regarding the definition and prevalence of safety and wandering risks for people with dementia. People with dementia are at greater risk of injury than the general older adult population of wandering, falling, being hospitalised as the results of a burn, ingesting inedible substances, experiencing errors with the self-administration of medication or requiring care due to self-neglect (Tierney et al. 2004; Allan et al. 2009; Härlein et al. 2009; Douglas et al. 2011; Harvey et al. 2016; Yayama et al. 2017). However, the accuracy of prevalence estimates is limited by variation in the definition of wandering and safety risks, and by the classification of adverse outcomes such as reasons for hospitalisation.

In order to mitigate risk for this population there is a requirement for better understanding of the factors which facilitate AT use. These can be categorised according to Andersen's Model of Health Service Use as Predisposing Characteristics, Enabling Resources and Needs. This chapter explored the literature regarding the association of predisposing characteristics, enabling resources and needs, with risk for people with dementia living at home. Need factors contribute to increased risk of harm. However, the literature indicates that injury can be reduced and institutionalisation delayed through appropriate support and other enabling resources (Douglas et al. 2011).

Whilst risk and need are both associated with adverse outcomes there is a requirement for better understanding of the relationship between assessed risk and need. As needs explain more of the variance in AT use this will facilitate the individualisation of interventions (Toseland et al. 2002). Advanced knowledge of the impact of individual context is required, together with information regarding the transferability of this knowledge to other settings (Greenhalgh et al. 2016). This research will therefore explore the relationship between the needs of people with dementia, available support, wandering or safety risk, and recommended and installed AT.

Improved understanding of the interactions of these factors, their impact upon adverse outcomes and upon the acceptance of healthcare services will inform the design of AT services which are both useful and acceptable to people with dementia and their support networks. There is therefore a requirement to investigate intervention options for supporting people with dementia and their caregivers which will enable people with dementia to remain living at home for longer in accordance with their wishes.

Specific gaps identified within the literature include:

- Limited evidence directly reflecting the perspectives of people with dementia. Access to such evidence would assist in identifying the priorities of people with dementia.
- Absence of an agreed definition of wandering. Having such a definition would facilitate calculation of prevalence and incidence estimates for wandering in people with dementia.
- Absence of an agreed definition of safety risk. Access to such a definition would facilitate calculation of prevalence and incidence estimates for people with dementia.
- Lack of clarity regarding the relationship between needs and risks. Increasing clarity would allow interventions to be tailored to reduce risk of adverse outcomes.
- Poor understanding of the relationship between population characteristics and use of AT. Advanced understanding would increase knowledge regarding the adoption of AT.

In order to reduce these identified gaps within the literature, this research will investigate the relationship between identified needs of people with dementia and their level of safety or wandering risks. Information regarding the particular needs of people with dementia who have safety or wandering risks will advance understanding of these risks facing this population and will assist contribute to their definition. The impact of population characteristics on recommended and installed AT will also be explored in order to promote understanding of their relationship.

The next chapter will explore published literature regarding the AT installed for people with dementia living at home and will examine the use of AT to reduce risks associated with safety and wandering, and how this is affected by both the needs of the people with dementia, and other personal factors.

CHAPTER 4. ASSISTIVE TECHNOLOGY FOR PARTICIPANTS WITH SAFETY OR WANDERING RISKS

This chapter considers the published literature describing the processes which support the recommendation and installation of AT for people with dementia experiencing wandering and safety risks. Attention is focussed upon the population characteristics of people with dementia and their impact upon AT provision.

This chapter begins by introducing the purposes of AT for people with dementia together with a very brief overview of the research in this field. An outline of some of the issues surrounding the categorisation of AT follows (section 4.1), together with a brief description of AT used to ameliorate wandering risk and safety risk. The focus then turns to the literature describing the assessment of AT (section 4.2), the recommendation and installation of AT for this population (section 4.3), AT provision (section 4.4), and training and follow-up (section 4.5). This is followed with a review of ethical issues relating to AT (section 4.6), and the need for further research in this field (section 4.7).

This research has confirmed that people with dementia have a wide range of often highly prevalent care needs which differ according to a range of personal characteristics. Unmet needs are similar to risks in that they are associated with adverse outcomes (Seden 2016; Levene et al. 2017). Prevalent risks for this population include wandering and safety (Douglas et al. 2011). AT is often used to reduce the risks associated with wandering and safety for people with dementia, and has been recommended in clinical practice guidelines as a potential intervention to facilitate independence for older people with dementia living in the community (Newton et al. 2016). Research has shown that benefits can be achieved through effective deployment of AT: Steventon et al. (2012) demonstrated that telehealth reduced hospital admissions, and AT may prolong people living at home by as much as eight months (Riikonen et al. 2010). Other potential benefits of AT include a possible reduction in the cost of care (Bharucha et al. 2009), reduced need for social support (Buettner et al. 2010), support with chronic disease management (Khosravi et al. 2016), an increase in safety and independence (LoPresti et al. 2004; Ienca et al. 2017), detection of unusual behaviour (Lotfi et al. 2012); stress reduction for caregivers (de Joode et al. 2010; Gitlin et al. 2010; Gagnon-Roy et al. 2017), improved caregiver quality of life (Woolham 2005); and reduction in the incidence of falls and unattended exits from the home (Jensen and Padilla 2017).

However, AT is not meeting its potential and the World Health Organisation (2017) state that despite the reported benefits of AT there is a global unmet need in this area, and the adoption of AT remains lower than expected (Greenhalgh et al. 2016; Ienca et al. 2017). It has been estimated that 90% of AT is discarded after only brief use (Scherer 2005). This may be due to lack of resources required for the purchase of AT, personnel being limited in their ability to select and install AT, in addition to the failure of service providers to conduct comprehensive assessment (Schere et al. 2005).

Further, there is a lack of high-quality evidence to determine if AT is effective in supporting people with dementia (Robinson et al. 2006; Fleming and Sum 2014; Van der Roest et al. 2017; Neubauer et al. 2018). Studies which indicate potential benefits are based on small sample sizes and lack robustness (Meiland et al. 2017). Additional limitations include; the lack of research studies reporting the number of safety incidents following AT installation (Gagnon-Roy et al. 2017); lack of examination of the cost-effectiveness of AT (Bowes et al. 2013; Meiland et al. 2017); and poor understanding regarding the selection and recommendation of AT for people with dementia (Wielandt et al; Bernd et al. 2009). There is therefore a requirement for further investigation in this field in order to better understand the factors which facilitate and limit current AT provision.

This review will therefore examine the published literature on AT installed for people with dementia who are living at home in order to understand:

(1) What are current practices of AT assessment and recommendations for people with dementia who have wandering and safety risks and what evidence is there to support these?
(2) Which characteristics are associated with the adoption and use of AT for people with dementia living at home who have wandering and safety risks?

Throughout the literature AT is variously defined and due to continuing development of this field it is not possible to provide a definitive list of devices classified as AT. Therefore, for the purposes of this review of the published literature AT search terms included Assistive Technology Devices and Assistive Technology Services under CINAHL subject headings, and Self-help Devices under MESH 2019 on MEDLINE database.

4.1 Assistive Technology used by People with Dementia

Before beginning to describe AT provided for people with dementia it is important to acknowledge the difficulties in categorising AT. In this vast, rapidly developing field, researchers have struggled to develop a coherent widely accepted taxonomy of AT (Greenhalgh et al. 2016). This is particularly challenging as AT are continually updated and replaced due to technological advancements, perform multiple tasks or use different technological innovations to achieve the same goal.

Throughout the literature there are many attempts to categorise the AT used to support people with dementia. Lorenz et al. (2019) categorise AT according to their specific function. However, Ienca et al. (2017) adopted a more comprehensive approach and categorized AT by technology type, application, function assisted, user centred design, primary target-user population and evidence of clinical validation. Alternative, groupings include whether AT are used 'by', 'with' or 'on' the person with dementia (Gibson et al. 2016), or by the type of AT provider (Gibson et al. 2015). Additional complexity arises as the same AT can often be included in a number of categories as they fulfil multiple purposes. Therefore, it can be seen that there is no universally accepted AT taxonomy or categorisation and this makes it difficult to compare conclusions from the literature (Greenhalgh et al. 2016).

In their review of the literature, Ienca et al. (2017) found a varied range of intelligent AT aimed at supporting clinicians and people with dementia in their daily tasks. They identified 539 AT devices with actual or potential application for dementia care. Most AT served a general purpose, followed by AT used to support cognitive functions including memory, communication, orientation, reasoning and decision making. Physical assistance was the third most frequently identified category of AT used by people with dementia which included devices supporting mobility, navigation and motor control. Other AT provided support with emotional and behavioural problems associated with dementia; and in facilitating social interaction.

Gibson et al. (2016) identified five broad categories of AT used by people with dementia; time and place orientation; prompting and reminder devices; communication aids; aids for activities of daily living; and alerts and alarms. They then further grouped AT into devices used with people with dementia; and devices used on people with dementia such as telecare systems and location monitoring services.

Each described method of categorisation has its own limitations due to the complexity, diversity and continual evolution of AT in this field (Greenhalgh et al. 2016), and the author is unable to recommend any method over the others. Although categorisations according to the purpose of the AT or the intended user provide more flexibility for including new developments within this field, high numbers of AT types mean that any taxonomy is unwieldy and difficult to access.

This literature review will now explore types of AT which are used to meet the wandering and safety needs of people with dementia living at home.

4.1.1 Assistive Technology for Wandering Risk

Due to the issues with the categorisation of AT, and with defining wandering, it is also difficult to identify AT used to reduce risk of wandering. This contributes to challenges in researching the benefits associated with particular types of AT. However, AT is identified within the published literature as a suitable intervention for reducing risks associated with wandering (Newton et al. 2016). Non-pharmacological interventions recommended to manage wandering behaviour include motion tracking, behavioural interventions, cognitive rehabilitation, and design or modification of the living environment (Lin et al. 2014). Robinson et al. (2006) expand this list to include specific AT interventions such as enclosed walking pathways, door exit sensors, bed pressure monitors and fall detectors. Overall, Lin et al. (2014) identified 28 different technological systems that can be used for management of wandering in people with dementia.

AT devices often provided to people who are at risk of wandering include GPS location-based technologies and home exit sensors (Neubauer et al. 2018). These can be embedded into a mobile phone, carried or worn in watch style (Dunk et al. 2010), and studies report high acceptance rates of GPS devices amongst people with dementia and their families (Liu et al. 2017; Neubauer et al. 2018).

4.1.2 Assistive Technology for Safety Risk

The majority of AT devices which can be used with people with dementia, aim to promote safety and security for people with mild to moderate dementia living in the community (Evans et al. 2015; Lorenz et al. 2019). AT addressing safety issues associated with dementia has previously been divided into four broad categories based upon their primary purpose, these include; monitoring technologies (including health monitoring and to enhance safety), tracking and tagging technologies, smart home devices and cognitive orthoses (e.g. electronic pill boxes) (Lauriks et al.

2007; Gagnon-Roy et al. 2017; Collins 2018). AT is available to reduce concerns regarding elopement, falls, kitchen safety and medication management (Collins 2018). Three main advantages of using AT to address safety issues include the detection of at-risk behaviour and subsequent caregiver alert; reduced caregiver stress; and improved participation in activities (Gagnon-Roy et al. 2017).

However, despite the promoted benefits for people with dementia uptake of AT is limited (Greenhalgh et al. 2016; Ienca et al. 2017). Possible reasons for this issue include reduced consideration of the context and systems within which AT is provided (Sugarhood et al. 2014; Hansen et al. 2018), and there is a need for greater understanding of their influence upon successful use of AT. This review will now focus on the literature describing the process of assessment and provision of AT for people with dementia living at home.

4.2 Assessment for Assistive Technology

Effective assessment of people with dementia is required to accurately identify those in need of support and at risk of injury (Douglas et al. 2011). AT assessment must include consideration of environmental, personal (including cognitive, physical and sensory capabilities), occupational (Gagnon-Roy et al. 2017), and AT related factors (Scherer 2005; Scherer et al. 2007). Additionally, most useful AT devices are obtained through collaborative assessment involving both health and social care professionals; and the person with dementia with their family suggesting that the inclusion of caregivers in the assessment process is important (Johnston et al.2014). However, professional needs assessment is actually the least likely method for people with dementia to obtain AT (Gibson et al. 2015), indicating problems with this process. The need for careful assessment to determine the possible benefit of AT to an individual is clear (Fleming and Sum 2014), and proper evaluation of needs and functionalities prior to installation of AT will reduce device abandonment (Seok and Dacosta 2014).

Assessment should be tailored towards the identified needs of the individuals. For example; in selecting a GPS device for the prevention of wandering incidents conducting comprehensive assessment should include consideration of the individual’s walking patterns and routines (Dunk et al.2010). Lifestyle monitoring systems may be used as part of the assessment process to confirm details regarding the frequency of incidents and routines of the person with dementia and to confirm details provided by stressed caregiver, or information they are unable to recall. Dunk et al. (2010) emphasised the importance of comprehensive assessment as people with dementia are likely to be receiving other forms of care from other providers. These other forms of care may provide preferred or alternative options for intervention. Regular reviews are required to ensure the continued effectiveness of any agreed solution in view of changes in the person's needs, abilities and support systems (Fleming and Sum 2014).

One suggested method for ensuring that all relevant factors underlying functional performance are considered in the assessment is discussed by Gitlow and Rakoski (2009) who highlight the importance of using a theoretical model or framework to support the relationship of the variables involved in AT outcomes. Despite the identification of seven models that had been applied to the AT field, and fifteen instruments used within the AT selection and advisory process (Bernd et al. 2009), it is notable that only one-third of rehabilitation professionals reported using an instrument within the AT selection process (Friederich et al. 2010). Benefits associated with model use included professionals and caregivers being facilitated to develop more specific goals, involvement of families in the selection process, support of teamwork and improved coordination of care (Bernd et al. 2009).

The identified models were categorised as (1) not AT specific, (2) focus on AT use but not suitable for selection process, and (3) specific and suitable for selection process (Bernd et al. 2009). The three models within this final category were Matching Person and Technology (MPT) (Scherer 1998), Framework for Modelling the Selection of Assistive Technology Devices (Scherer 2005), and the Model of Human Activity Assistive Technology (HAAT) (Cook and Hussey 2002).

These models provide useful consideration of the factors which influence the selection of AT. However, each of these models is limited in its applicability to people with dementia. The MPT was validated for use in persons with disability (aged 15 years and over) not including people with dementia (Bernd et al. 2009). The Framework for Modelling the Selection of Assistive Technology Devices provides a conceptual background of factors influencing AT selection but does not provide any related instruments (Bernd et al. 2009). The HAAT has not been tested for validity and provides no assessment tools (Bernd et al. 2009), although it is holistic and consumer oriented (Friederich et al. 2010). Friederich et al. (2010) found that of these three models only the HAAT was used by rehabilitation professionals to aid AT selection. This may be because practitioners feel they are complicated and not easily applied (Bernd et al. 2009). One unspoken issue with models for the selection of AT is the underlying assumption that there are appropriate AT devices available for selection, which may not be the case (Hansen et al. 2018).

Despite the availability of AT specific models, Friederich et al. (2010) found that professionals were more likely to report using non-AT specific models to guide practice. These models were often conceptual models used with occupational therapy practice; The Occupational Therapy Intervention Process Model (OTIPM) (Fisher 1998); The Model of Human Occupation (MOHO) (Kielhofner 2002); and the Canadian Model of Occupational Performance (CMOP) (Canadian Association of Occupational Therapists 2002). These models are all holistic and support person centred practice but are not intended to support AT selection (Friederich et al. 2010).

Further criticism of current models within the AT field is that they have failed to consider the complexity of the network surrounding the person with dementia including their caregiver and family and their health or social care professional (Sugarhood et al. 2014). Focussing on one aspect of this network, such as the needs of the person with dementia, at the expense of the requirements of others may explain low levels of AT adoption (Sugarhood et al. 2014).

Previous research has been directed towards the initial or short-term adoption of AT (Greenhalgh et al. 2017). This has resulted in limited attention being given to the ongoing assessment and support of the person with dementia and their network. The needs of people with dementia are known to change over time, additionally, the adoption of AT requires sustained support and adaptation (Greenhalgh et al. 2015). Therefore, in order to ensure that AT continues to meet the needs of the person with dementia there must be regular re-assessment and adaptation of the intervention received by the person with dementia (Sugarhood et al. 2014).

Difficulties in adopting models and assessments for AT can also arise due to difficulties in matching the limited range of AT available in most CASSR areas with the diverse, heterogeneous needs of people with dementia. This may be because CASSR areas have failed to provide access to AT suited to the particular priorities and needs of people with dementia (Greenhalgh et al. 2013; Hansen et al. 2018). Greenhalgh et al. (2013) critique the AT services currently available within the UK as focussing on commercial viability whilst failing to account for the lifestyles and heterogeneity of the individuals. This means that consideration of the individual circumstances of each person with dementia during assessment does not result in an individualised intervention. Hence, the adoption of a complex model of intervention or assessment process provides no benefit to the person with dementia. Ideally, the needs of the person with dementia are seen as the starting point of a complex process. AT is then developed or adapted to the requirements of the person with dementia, their social network, home and lifestyle (Sugarhood et al. 2014). This would replace the current system within which a limited range of available AT, often not suited to individual requirements, are being recommended and installed for the person with dementia or their family regardless.

4.3 Recommendation and Installation of Assistive Technology

Problems associated with the assessment process for AT are described above and continue throughout the literature describing the process for recommending and installing AT. Wielandt et al. (2006) found that the process used to recommend AT is not well documented in the literature. Similarly, Bernd et al. (2009) conclude that AT selection process is poorly developed and that there are limited evidence-based procedures within this field. As previously stated, only one-third of neurological rehabilitation professionals reported using a model to guide their selection of AT and the lack of appropriate AT selection instruments has driven professionals in this field to develop their own strategies and checklists (Friederich et al. 2010). Cummings and Kropf (2009) confirm that assessment tools often fail to direct clinicians towards appropriate interventions. Further, one-third of professionals were not satisfied with the AT selection process at their facility (Friederich et al. 2010).

It is advised that AT service providers should have a “toolbox” of options in order to be able to identify the most appropriate AT for an individual (Dunk et al. 2010) as it is important to provide AT that is both desired and needed (Lindqvist et al. 2013). Greenhalgh et al. (2013) promote a system based on bricolage whereby AT are individualised by adapting new and second hand materials, as a solution to meeting the particular needs of individuals. This turns current AT services around and places the person with dementia at the centre of the process.

However, in order for this system to work, there is a requirement for professionals who are knowledgeable and skilled in the adaptation of AT. Currently, occupational therapists are not confident that their AT knowledge is up to date and may never have prescribed AT (Jarvis et al. 2018). GP’s have expressed similar concerns regarding their limited knowledge on accessing AT services making them unlikely to seek AT services for people with dementia (Newton et al. 2016. There is a need for healthcare professionals to become more active in developing expertise in the prescription of AT, and in evaluating the use of AT (Jarvis et al. 2017).

Interventions should be adapted to individual needs and preferences in order to increase uptake (Burgon et al. 2019). However, there is little information describing the individualisation of the

AT service required to support the successful use of the AT devices (Greenhalgh et al. 2013; Gibson et al. 2015; Meiland et al. 2017) and future research should consider individual differences and their association with AT use (Hirani et al. 2016). Currently, the diversity of people with dementia and their circumstances limits our understanding (Greenhalgh et al. 2015). Further insight into the impact of individual context is required, together with information regarding the transferability of particular knowledge to other comparable settings (Greenhalgh et al. 2016).

Gagnon-Roy et al. (2017) identified factors associated with the selection of an appropriate AT device and grouped these as person related, environment related and occupation related. More specifically, occupational therapists noted the requirement to consider the clients' needs, their stage of dementia and cognitive abilities; prior level of function; and previous experience using technology (Collins 2018). Dunk et al. (2010) also highlighted the importance of considering the maintenance of AT such as who will conduct battery checks, and to develop comprehensive agreed response procedures in order to facilitate the successful use of AT. Gramstad et al. (2014) emphasised the diversity of the individual experience and how this necessitates an individualised, client-centred AT service delivery process that includes identification of needs, monitors change and addresses diversity. Further research into AT appropriate for each stage of the dementia process, and how AT can support people with dementia to safely conduct ADL tasks and therefore support them to remain at home is also required (Boger et al. 2014; Czarnuch et al. 2016). Although in this rapidly developing field it is difficult to imagine how this can be kept current. Overall, whilst there is agreement that many aspects of the person with dementia and their environment should be considered during the AT selection process, there is little research on the priority of any one factor over another, or how they relate to the range of available AT (Lauriks et al. 2007).

The recommendation of appropriate AT for people with dementia may also be restricted by the AT service or provision system. Hansen et al. (2018) found limited healthcare service use often indicated a supply led allocation process. This means that assessment, recommendation and installation process is based on a limited range of available AT.

4.4 Assistive Technology Provision

In order to provide a "toolbox of AT options" or to use bricolage to suitably tailor interventions, there is a requirement for professionals to be able to access and implement a range of AT. However, noted problems associated with the deployment of appropriate AT include the limited choice of AT available through local authorities in the UK (Gibson et al. 2016) in addition to complex application and assessment processes (Gibson et al. 2016). This may result in available AT being unsuitable to meet the identified needs of the person with dementia (Hansen et al. 2018).

Currently, within the UK, AT is often delivered in standardised “plug and play” or “walled garden” formats (Greenhalgh et al. 2015; Greenhalgh et al. 2016). This technology focussed service model aims to reduce costs associated with care provision, but offers reduced opportunity for adaptation to meet individual requirements (Greenhalgh et al. 2013; Greenhalgh et al. 2015; Gibson et al. 2015), partly due to the inability of AT products from different suppliers to interact (Greenhalgh et al. 2015). Service providers have in some cases opted to offer only basic AT as a result of their focus on reduced care package expenditure (Sugarhood et al. 2014), and even though there is no evidence supporting the use of AT to reduce costs (Steventon et al. 2013). This means that innovative, specialised AT are often not available for people with dementia due to their initial or ongoing cost (Sugarhood et al. 2014).

Formal AT provision is rarely proactive, health and social care services fail to provide satisfactory support once the AT is installed and people with dementia and their families lack information and guidance on the appropriate use of AT (Gibson et al. 2015). The inexperience of professionals providing AT previously described is one explanation for this state of affairs (Jarvis et al. 2017). Cost efficiencies may also contribute to service providers failing to acknowledge the requirement for initial comprehensive assessment, then ongoing assessment and tailoring of AT following installation due to the intensive work required (Sugarhood et al. 2014). Further issues arise from complexities within provider organisations, where managers may be unaware of the daily realities of AT service provision (Sugarhood et al. 2014), relevant services aren’t well integrated, or AT is poorly planned due to its inability to produce cost reductions (Greenhalgh et al, 2016).

AT innovation is currently focussed upon the development of new products rather than on the support and adaptation of those already available (Greenhalgh et al. 2016). However, non-use of AT by people with dementia may relate to the lack of involvement of the client group during the design phase of the AT (Ienca et al. 2017), prompting the suggestion that AT does not aim to meet the needs of people with dementia but rather the needs of service providers (Greenhalgh et al. 2016; Meiland et al. 2017). AT suppliers claim to have considered the views of AT users but focus on the technical usability of AT rather than the wider context of the person with dementia in which the AT will operate (Sugarhood et al. 2014).Additionally, increasing user involvement may allow

AT to be tailored to the requirements of the individual, but would also increase the costs of developing AT which would in turn make products more expensive for the end consumer (Bowes et al. 2013).

Despite people with dementia and their families viewing AT positively they are finding the AT service offered by health and social care services is not meeting their needs and they are instead purchasing their own AT "off the shelf" (Gibson et al. 2015). Even though, "off the shelf" AT has been found to be more likely to fail as people are unable to integrate them into their lives on their own (Armstrong et al. 2010). People with dementia and their caregivers also report that they find buying AT expensive and, in some cases, this is a barrier to AT use. In some instances, generic household products which serve similar purposes are used instead of formal AT (Gibson et al. 2018).

The literature suggests that we have been misled by the promise of a smart home, where overconfidence results in the belief that AT can effectively meet the care needs of the person with dementia, without technology related issues (Greenhalgh et al. 2016). Rather, due to the heterogeneity of people with dementia and their support networks, any AT which successfully meets the needs of an individual will be as the result of intensive, skilled needs assessment, individualisation of AT and the coordination of formal and informal support services (Gitlin et al. 2003; Greenhalgh et al. 2016).

4.5 Training and Follow-up

AT requires skilled human input and social infrastructure in order to work (Greenhalgh et al. 2015). In addition to ongoing assessment and tailoring, training that includes the person with dementia and their significant others has been shown to have a positive effect on AT use (Wielandt and Scherer 2004; Patomella et al. 2018). Further, AT use is associated with participants being able to recall AT training (Wielandt et al. 2006). Occupational therapists working with people with dementia report that they often concentrate on training caregivers in the use of AT as they will be able to use the AT once the person with dementia is no longer able (Collins 2018). Further, as there is often a need to use repeated demonstrations and opportunities for practice when working with people with dementia, if caregivers are proficient in AT use, they can prompt and train the person with dementia (Collins 2018).

Overall, providing adequate training; adopting a client centred approach to the recommendation process which includes consideration of client opinions, encouraging client choice, and involving significant others in the AT selection and training will promote the use of AT (Wielandt and Scherer 2004; Wielandt et al. 2006).

4.6 Ethics

People with dementia have the right to the highest standard of health. This requires access to affordable AT provided by trained and capable staff (Bennett et al. 2017). Professionals working in this field must consider the balance of privacy and respect for autonomy versus safety and risk minimization (Meiland et al. 2018). However, research indicates that people with dementia are less concerned with ethical issues and more concerned with quality of life (Bächle et al. 2018).

AT often have the capacity to collect and record data, which is required for the device to be able to offer assistance by for example, identifying the location of the person, or recording information on their daily routines. However, when AT is installed, the data it will record is unknown as future events are unpredictable. It is therefore difficult to make a decision regarding access to this future unknown data and this means that consent to share this information may be subject to change and should be reviewed regularly (Dewing 2007).

AT developers and service providers should ensure that data required to operate AT is held securely. There is also a need to define who controls future access to the data. This will increase consumer confidence in AT and enhance acceptability (Zwijsen et al. 2011; Ienca et al. 2017). Uncertain ownership of AT generated data creates concern amongst people with dementia (Guisado-Fernandez et al. 2019). Privacy is identified as the top concern of older people which prevents them from adopting AT (Yusif et al. 2016). Additionally, AT may record data regarding visitors and caregivers of the person with dementia who may be unaware of the AT and may not have given consent for their data to be recorded.

As AT is often provided to ameliorate caregiver concerns or workload, there may be a conflict of interest between the caregiver and the person with dementia which necessitates exploration of the needs of each of these parties (Neubauer et al. 2018). People with dementia may be using AT they are not comfortable with, in response to pressure from their caregiver or family (Zwijsen et al. 2011). In these cases, it must be remembered that caregiver impact is strongly associated with institutionalisation for people with dementia (Luppa et al. 2008). This may explain the acquiescence of people with dementia to the wishes of their caregiver for increased AT provision, as it provides a means for them to remain at home. Guidelines suggest that the needs and wishes of the person with dementia should be the first consideration of professionals installing AT (Alzheimer-Europe 2012), however it would appear that this may be difficult to ensure (Zwijsen et al. 2011). Coercion or incentivising a person with dementia to try AT is rarely justified as they are generally provided as beneficial supplements to conventional caring methods (Nordgren 2018).

Another possible disadvantage of AT is that its use may reduce the amount of human contact received by the person with dementia (Meiland et al. 2017). Replacing human caregivers with AT means that the person with dementia has less caregiver visits. Professionals must consider the need of the person with dementia for human contact and social inclusion, and ensure these are not diminished to a point where the person with dementia is adversely affected through AT installation.

AT use may be associated with stigma for people with dementia who feel that it identifies them as being in need of support, when they may not wish to share this information (Zwijsen et al. 2011). Further, AT may also diminish the autonomy of the person with dementia, for example they may wish the opportunity to cope with a fall or other incident on their own, but AT removes this choice from them (Zwijsen et al. 2011). The literature also identifies concerns that AT may restrict the freedom of people with dementia or increase surveillance mechanisms (Bennett et al. 2017; Guisado-Fernandez et al. 2019). However, it is the way AT is used which may reduce or promote freedom and autonomy rather than the AT itself (Robinson et al. 2009). Professionals must therefore address the views of the person with dementia and their caregiver regarding the impact of AT during their assessment process and thereafter.

Additionally, there may be difficulties in obtaining informed consent from a person with dementia who may not fully understand the technologies and associated ethical issues and whose abilities to fully consider these issues may deteriorate possibly rendering them unaware of the presence of the AT. This again, indicates the need for ongoing consideration of the issue of consent regarding the continued use of AT (Dewing 2007). The complexity and novelty of AT may make it difficult to ensure that the person with dementia is fully aware of the impact of AT and therefore able to give informed consent. However, professionals have a duty to include the person with dementia in decisions regarding their care even if it appears that that they are not able to grant consent (Alzheimer-Europe 2012).

4.7 Need for further Research

Research evidence suggests that AT is not meeting the needs of people with dementia. This may be due to unsatisfactory supply led service delivery models resulting in the limited ability to select or tailor interventions towards individual need. Future research must consider AT in real world situations (Lauriks et al. 2007; Neubauer et al. 2018), and AT delivery systems based upon individual need and clinical validation of AT (Ienca et al. 2017).

The above review of the relevant literature identifies that, in order to develop models which more accurately determine the use of AT for this population there is a need for:

- A taxonomy or categorisation of AT which allows understanding of the type and purpose of the device under discussion;
- Further understanding of factors which facilitate or impede AT use, their malleability, how they interact, and their relevance to particular situations;
- Robust research which examines the effectiveness of AT for people with dementia in real life situations.

This research will therefore examine the AT recommended and installed in relation to wandering and safety risks of people with dementia and other factors including their caregiver support and living situation.

4.8 Summary

AT has been identified as an intervention which can reduce risks associated with safety and wandering for people with dementia who are living at home. However, the potential of AT in this regard is not being fully exploited (World Health Organisation 2016). Further, the processes surrounding the assessment, installation and adoption of AT by this population are not well understood. This research therefore aims to explore the specific needs identified by people with dementia in relation to wandering and safety in order to focus upon specific interventions which may reduce associated risks. Methods implemented to achieve the study objectives are described in the following chapter.

CHAPTER 5. METHOD – SECONDARY DATA ANALYSIS

This chapter presents the research methods employed in the analysis of secondary data describing the population characteristics of people with dementia and the AT interventions recommended and installed for them.

This study aims to explore quantitative secondary data in relation to the following questions previously described in section 1.5;

- How are needs associated with level of safety and wandering risks in people with dementia living at home?
- Are there distinct groups of people with dementia living at home?
- Do these clusters of people with dementia living at home have different AT recommended and installed?

Following an overview of the dataset including treatment of missing data this chapter will describe the method used to answer each of the above research questions in turn.

5.1 Study Design

This is a cross sectional observational study using secondary data analysis of a data set containing information regarding characteristics of people with dementia living at home, and the AT recommended and installed for them collected during the ATTILA RCT (Leroi et al. 2013).

5.2 Secondary Data Analysis

Secondary data analysis is the further analysis of an existing data set with the aim of addressing a research question distinct from that for which the data set was originally collected (Hewson 2006). This research will use information from a dataset containing information on people with dementia living at home within the United Kingdom which was collected as part of an RCT study. This use of existing research data to explore a research question which is different from the original research is called secondary data analysis (Tripathy 2013). This method was selected as it presented the researcher with an opportunity to explore a large professionally collated dataset providing details of the characteristics of this vulnerable population and the AT recommended and installed for them, which would not otherwise have been possible (Johnston 2014; Vartanian 2010; Research Councils UK 2015). This enabled more robust quantitative analysis than would have been possible with a smaller dataset (MacInnes 2017). Collecting additional data would have also caused inconvenience and disruption to the participants and their caregivers on top of the additional time and effort required from the author (Donellan and Lucas 2013). Therefore, secondary data analysis can be a convenient, efficient method of accessing data on vulnerable populations. Additionally, secondary data analysis also required the researcher to develop skills in the management, evaluation, critique, analysis and preparation of data in addition to locating appropriate data and judging how well it fitted the needs of the research (MacInnes 2017). Further, as the data was collected for alternative purposes with regard to this research study, secondary data analysis can also reduce bias related to method of collection.

However, whilst secondary data analysis may provide researchers with a convenient method for obtaining data this method also produces a number of technical and scientific barriers which the researcher must overcome (Lipworth et al. 2017). Issues associated with the use of large datasets in research include the lack of comparability of datasets between settings and over time, difficulties linking individuals across datasets, difficulties analysing and interpreting large amounts of data that are unstructured and contain errors and bias, over-powered analyses and problems with using traditional statistical methods and rules that may produce false-positive results, and variable levels of reproducibility and replicability (Lipworth et al. 2017). Wolpert and Rutter (2018) also highlight issues concerned with the quality of data contained in large datasets such as differences in how the data is recorded, limited information on key subgroups and data items that are proximate for the area under investigation.

In secondary data analysis the sample size is predetermined by the data available (Boo and Froelicher 2013) and therefore a prior power calculation was not conducted. Additional limitations associated with secondary data analysis include the inability of the researcher to collect further data should it be required to enhance the population in order to increase the significance or generalisability of the results (Donnellan and Lucas 2013). Missing data is therefore described within the results chapter (Chapter 6), together with discussion of implications this may have had on the analysis. Further, the researcher must accept the data collection tools, definitions and population adopted during the initial research.

In their discussion regarding large routinely collected quantitative datasets Wolpert and Rutter (2018) conclude that they invariably contain flawed, uncertain, proximate and sparse data. However, rather than citing this as a reason to ignore secondary data they suggest that researchers recognise and embrace these characteristics and use them to understand the complexities of the healthcare system in relation to both research and practice. Whilst the dataset under consideration in this research was collected specifically for a prior RCT study (Leroi et al. 2013), it does include data which was routinely collected by health and social care staff, and the researcher intended to exploit this information to determine the complexities of the process surrounding AT interventions for people with dementia. This author further recognizes that the complex system surrounding AT interventions for people with dementia living at home is not easily understood and that unanswered questions will remain following the analysis (Greenhalgh and Papoutsi 2018).

5.3 Dataset

The dataset used for this secondary data analysis contains anonymised information on participants recruited for the original RCT study from 11 Council with Adult Social Service Responsibilities (CASSR) areas across England including Croydon, Lambeth, Southwark, Cambridge, Oxford, Suffolk, Lancashire, Blackpool, Blackburn, Nottingham and Barnsley between 14th August 2013 and 26th October 2016. Participants were followed up over a two-year period from their date of recruitment. Data was collected from participants during visits at baseline, then 12 weeks, 24 weeks, 52 weeks and 104 weeks. Data collection was therefore completed just prior to commencement of this study which ensures the novelty of this research.

This study included people with a dementia diagnosis, or suspected dementia who were living in the community. Participants were required to have a professionally assessed and documented need for AT, and live in a dwelling suitable for the installation of AT.

Participants were excluded from the original RCT study;

- if they were already in receipt of an AT intervention (excluding non-linked smoke detector or carbon monoxide detector, key safe or pendant alarm) or had previously been provided with AT which they had not used.
- If they were unlikely to comply with follow-up.
- If they were participating in another clinical trial involving an intervention for dementia.
- Where there was an urgent need of a care package due to immediate and severe risks to self or others.

Participants were recruited to the original study from three sources;

1. People who sought help or support from local authorities' social care services in the 11 CASSR areas listed above.
2. People supported by the NHS and referred to social services who met the local eligibility criteria.
3. People recruited from the caseload of NHS services for older adults and referred to local social services who met local eligibility criteria.

Following recruitment to the study and receipt of informed consent each participant was randomised to either (1) an AT needs assessment followed by the provision of an AT package deployed by the host CASSR, or, (2) a control which was the AT needs assessment followed by the provision of AT limited only to non-monitored smoke and carbon monoxide detectors, a key safe and pendant alarms, deployed according to assessed need by the CASSR.

Participants were randomised using telephone-based randomisation and data entry portal. Treatment allocation was via a minimised randomisation procedure stratified by the following criteria:

1. Gender
2. Age
3. Risk of wandering or leaving the home inappropriately (low, moderate, high)
4. Safety risk within the home (low, moderate, high)
5. Level of caregiver support available (live-in caregiver, caregiver visits at least once daily, caregiver visits less often than daily).

Analyses were then conducted on an Intention to Treat basis (ITT). This is where participants are analysed according to the group to which they were randomised regardless of subsequent events (National Institute for Health and Care Excellence (NICE) 2019).

The validity of the dataset was promoted through the use of validated measures for data collection including MMSE, and the training and ongoing support of those responsible for the collection of the data. The original research study protocol document outlined expected procedures and violations of the protocol were recorded. Further, the data was entered into the database following the University of Oxford Standard Operating Procedure (SOP) for data management (Daniels 2014). This procedure insisted that data checks and verifications were built into the database, and a second person verified all data entered. Missing data was accounted for and investigated.

5.3.1 Treatment of Missing Data

Whilst high-quality data is the aim of most researchers it must be accepted that data is often flawed due to missing or erroneously recorded data (Wolpert and Rutter 2018). However, Wolpert and Rutter (2018) argue that this is not reason enough to reject using this data in research and researchers must accept that it may not be possible to access better quality data. Further, in these instances there is an added advantage as data flaws may also highlight or describe real world issues. In order to fully exploit real world data, the researcher must describe its imperfections in order that the possible effects of these flaws may be incorporated into the research design and discussed alongside the results of the research.

Missing data can introduce bias into a research study. To understand the implications and extent of this possible issue, the author will undertake an exploratory data analysis to identify missing data, the variable affected by the missing data, the type of data that is missing (e.g. continuous, normal etc.) and:

I. The amount of missing data - If only a small amount of data is missing say one cell for every 1000, then the researcher need do nothing (McKnight and McKnight 2011). However, a greater amount of missing data can decrease statistical power and introduce bias.

II. The level of the missing data (i.e. **item** - individual questions, **scale** - combination of items, **construct** - all relevant measures of a construct, **person** - an individual participant or **group** - collection of participants). This information is important as it indicates the severity of the missing data. For example, missing data at an item level will have less influence than data missing at group level.

III. the pattern of the missing data; basically, a more random pattern indicates no general cause for the missing data whereas an organised pattern of missing data suggests there may be a systematic or causal process resulting in the missing data.

IV. the mechanism of the missing data (Rubin 1976, Rubin and Little 2002):

- Missing at Random (MAR) – missing values can be predicted by available data
- Missing Completely at Random (MCAR) – no bias or systematic cause for missing data.

- Missing Not at Random (MNAR) – missing values, which cannot be predicted by available data. The likelihood of these variables being missing is directly related to the value of the variable itself (Holmes Finch 2010).

  In order to diagnose the mechanism for the missing data, the researcher must carefully consider if there is information that can account for the missing data.

Once the author was aware of the nature of the missing data this led towards an appropriate method for dealing with the missing data. Treatment methods available for dealing with missing data include:

- Deletion – missing data is essentially ignored. Problems associated with this treatment option include a reduction in sample size, decrease in power and possible increase in bias (Langkamp et al. 2011).

- Weighting - can be used with MAR or MNAR. The researcher applies probabilities to increase the weight of particular populations who are under-represented in the data (Langkamp et al. 2011).

- Adjusting - used for MCAR or MAR data. The researcher adjusts the parameter estimates to fit the expected distribution better. The maximum likelihood estimate of a parameter is the value of the parameter that is most likely to have resulted in the observed data. This is useful only for linear models.

- Imputing - Replaces values. Multiple imputation has the benefit of estimating the impact of missing data on the statistical results (McKnight and McKnight 2011), however methods require that data is MAR or MCAR to avoid introducing potential bias (Agresti 2010).

Researchers are advised where possible to use principled imputation and maximum likelihood techniques, as they are good procedures based on strong statistical traditions (Graham 2009). However, in the case of MNAR data where the pattern of missing data is related to other variables in the dataset this is not always recommended, and there is no easy way to handle this type of missing data (Yang et al. 2008; Field et al. 2012; Harrison 2019). Ultimately, there is no statistical procedure that can overcome data that is missing (Field et al. 2012).

Missing data is described within the results chapter (Chapter 6). Variables with missing data included AT needs assessment variables and MMSE. The reasons behind this missing data are unclear but most likely were MNAR as data may be missing as the result of the practice of the person responsible for undertaking the assessment, or it may be due to the participant being unable or unwilling to provide information. MNAR is defined by Holmes Finch (2010) as when the likelihood of the variable being missing is directly related to the value of the variable itself. This means that data cannot be predicted by available data (Holmes Finch 2010). Therefore, as a result of the extent and nature of this missing categorical data it was not possible to impute missing needs assessment data.

Participants with missing data were excluded from both the regression analyses and the cluster analyses by case wise deletion as these analyses are unable to consider participants with missing data (Field et al. 2012; Christensen 2016; Maechler et al. 2019). However, reasons for data being missing were explored and explained wherever possible (Field et al. 2012).

In health care research it is acknowledged that routinely collected data are often of low quality and may be flawed due it being missing or misreported (Wolpert and Rutter 2018). However, rather than dismiss this data as incomplete or unreliable (Greenhalgh and Papoutsi 2018), Wolpert and Rutter (2018) describe a process which acknowledges the limitations of such data but encourages consideration of the insight they can provide in the absence of alternative better-quality data. Greenhalgh and Papoutsi (2018) argue that such data provides an opportunity for the examination of important issues despite the fact that they do not fully represent the complexities of the healthcare system from which they are drawn. In this study, limitations, missing data, missing data treatments, data analyses and potential implications of missing data are therefore acknowledged and described within this report of the study in order to open up discussion with regard to the findings.

5.4 Data Variables

For this secondary data analysis, the author used data relating to the 451 participants with needs assessment documentation. All participants were resident in England, United Kingdom at time of recruitment to the original study. Participants are described in the results chapter (Chapter 6).

5.4.1 Assistive Technology Needs Assessment

During the original RCT study each participant received an assessment of need for AT according to local routine practice. The documentation resulting from this assessment of need was then subjected to content analysis based on 14 items of the Model of Human Occupation Screening Tool (MOHOST) (Parkinson et al. 2004). The fourteen AT needs assessment items reflected fields within the local needs assessment documentation (Forsyth and Dunk 2014). This content analysis process is described more fully by Forsyth et al. (2019). This framework analysis was intended to establish a cross site practice standard for AT Needs Assessment. This process also facilitated comparison of the content of the AT Needs Assessment for each participant following themes previously agreed across sites within the RCT study.

When information documented within the needs assessment was sufficient, each of the fourteen items was categorised according to level of associated risk on a scale of one to four, where four indicated “no risk”, three indicated “mostly risk free”, two indicated “some risk”, and a score of one indicated “significant multiple risks”. When the original needs assessment documentation did not provide enough information for an item to be rated within the content analysis, these items was recorded as missing.

The fourteen AT needs assessment items are described in Table 5.

Table 5Assistive Technology Needs Assessment Items and Key Questions

AT Needs Assessment Item	Key Question
Appraisal of ability	Does the person's insight put them at risk? No risk indicates that the person accurately assesses their own capacity, recognises strengths and is aware of limitations.
Choices	Does what is important to the person put them at risk? No risk indicates that the person has clear preferences and sense of what is important, is motivated to work towards occupational goals.
Routines	Do the person's routines put them at risk? No risk indicates that the person is able to arrange a balanced, organised and productive routine of daily activities.
Responsibilities	Do the person's responsibilities put them at risk? No risk indicates that the person reliably completes activities and meets the expectations related to role obligations.
Conversation	Does the person's ability to have a conversation put them at risk? No risk indicates that the person appropriately initiates, discloses and sustains conversation.
Vocal Expression	Does the person's ability to express their needs put them at risk? No risk indicates that the person is assertive, articulate, uses appropriate tone, volume and pace.
Knowledge	Does their memory and understanding of how to do things put the person at risk? No risk indicates that the person seeks and retains relevant information, knows how to use tools appropriately.
Problem-solving	Does their ability to problem solve put the person at risk? No risk indicates that the person shows good judgement, anticipates difficulties and generate workable solutions.
Posture and Mobility	Does the person's mobility put them at risk? No risk indicates that the person is stable, upright, independent, flexible, good range of movement (possibly agile).
Strength and effort	Does the person's grip or dexterity put them at risk? No risk indicates that the person grasps, moves and transports objects securely with adequate force/ speed (possibly strong).
Physical Space	Does the person's physical space put them at risk? No risk indicates that the space affords a range of opportunities, supports and stimulates valued occupations.
Physical Resources	Do the person's physical resources put them at risk? No risk indicates that resources enable occupational goals to be achieved with ease, equipment and tools are appropriate.

AT Needs Assessment Item	Key Question
Social Groups	Does the support available put the person at risk? No risk indicates that social groups offer practical support, values and attitudes support optimal functioning.
Occupational Demands	Does the way the person completes an activity put them at risk? No risk indicates that demands of activities match well with abilities, interests, energy and time available.

Note: AT = Assistive Technology, adapted from Forsyth and Dunk, 2014

5.4.2 Cognitive Impairment

Mini Mental State Examination scores of participants were recorded at baseline. The MMSE (Folstein et al. 1975) is the most commonly used assessment tool for cognitive impairment (Carswell et al. 2009). This study used the sMMSE guidance (Molloy and Standish 1997) which incorporates the traditional MMSE measurement tool but imposes guidelines which aim to standardise the use of the tool. MMSE scores are collected on an ordinal scale of 0 -30, and can be categorised according to stage of dementia; a score of 30 indicates no dementia; scores of 26-29 indicate questionable dementia; 21-25 indicate mild dementia; 11-20 suggests moderate dementia and a score 0-10 indicates severe dementia (Perneczky et al. 2006). The assessment tool has satisfactory reliability and construct validity, and measures of criterion validity demonstrate high levels of sensitivity for moderate to severe impairment and lower levels for mild degrees of impairment (Tombaugh and McIntyre 1992). However, the MMSE is criticised by O'Keeffe (2017) who reports that it can fail to identify people with executive cognitive function impairment, which is associated with vascular dementia.

5.4.3 Risk of Wandering

Persons with data gathering responsibilities within the original RCT study rated risk of wandering for each study participants at baseline as low, moderate or high according to advice from the person who completed the needs assessment for that participant. The trial manager for the original study confirmed that advice given to data gatherers regarding the categorisation of risk was: "in general, if there have been no or very few relevant incidents the risk will be rated low, if they have occurred occasionally the risk will be rated moderate; and if there are frequent or very serious incidents, the risk will be high."(Attila Trial Manager email correspondence 2018)

5.4.4 Safety Risk

Similarly, data gatherers within the ATTILA RCT study rated safety risk for each of the study participants at baseline as low, moderate or high according to advice from the person who completed the needs assessment for that participant. Again, advice given to data gatherers by the study trial manager of the ATTILA RCT regarding the categorisation of risk was: “in general, if there have been no or very few relevant incidents the risk will be rated low, if they have occurred occasionally the risk will be rated moderate; and if there are frequent or very serious incidents, the risk will be high” (Attila Trial Manager email correspondence).

5.4.5 Recommended Assistive Technology

During the needs assessment process which was carried out at ATTILA RCT baseline, health and social care professionals and other staff as defined by normal practice within the local area, recorded details of items of AT which they intended to install to meet the needs of the person with dementia. These recommended AT items were subsequently categorised according to their purpose and the type of AT device as detailed in the table below (Table 6). This categorisation was conducted by data gatherers who had experience in this field. It was intended that information was collected on who assessed for the AT, the method of assessment, whether the AT was monitored, and details of who would respond to any device generated alerts, however, most of this data was missing.

Table 6 Assistive Technology Categories

Category relating to purpose	Category relating to AT type
Basic AT	Non-monitored smoke detector Non-monitored carbon monoxide detector Key safe Pendant Alarm Activity monitors for assessment only Other
Safety, comfort and wellbeing	Activity monitors for on-going monitoring Lighting devices Continence management devices Fall detectors Safer walking technologies – to locate the user Safer walking technologies – to alert a responder of movement Gas detectors Monitored smoke detectors Monitored carbon monoxide detectors Monitored extreme temperature detectors Alarm and pager units Flood detectors and water temperature monitors Telehealth technologies Other devices that support safety, comfort or wellbeing.
Reminder or prompting devices	Date and time reminders Voice recorders and memo minders Medication reminders and dispensers Item locator devices Other reminder or prompting devices
Communication	Communication Aids Intercoms Telephones Other communication devices
Supporting meaningful use of leisure time	Electric photo albums/ other reminiscence aids Dementia friendly TV/ radio/ music players Electronic games

Category relating to purpose	Category relating to AT type
	• Computer aids • Other devices that support meaningful use of leisure time.
Any other devices	

Note: AT = Assistive Technology, TV = Television.

5.4.6 Installed Assistive Technology

Following the needs assessment analysis, data regarding the AT provided for the person with dementia was recorded and categorised as with recommended AT (Table 6) by registered occupational therapy practitioners with experience in this field. Only participants randomised to the intervention group of the RCT were eligible to receive AT. The installed AT data used within this research study was collected at baseline, 12- and 24-weeks following randomisation to the RCT study.

5.4.7 Caregiver Support

Within the dataset, the level of support received by the person with dementia at baseline was rated by the data gatherers on the original RCT according to the number of times the caregiver was present; (1) live-in caregiver, (2) Caregiver visits at least once/day, (3) Caregiver visits less than once/ day.

5.4.8 Living Situation

The living situation of the person with dementia at baseline was recorded in the dataset by the data gatherer in the original RCT as (1) living with spouse/ partner, (2) Living alone, (3) Other. All people with dementia categorised as “Other” for this variable were living with another person whom was not classified as a spouse or a partner.

5.4.9 Age

The dataset provided the date of birth of participants. For the purposes of this secondary data analysis study, age was calculated as the time between the participant’s date of birth and their date of randomisation to the RCT.

5.4.10 Gender

All participants within the dataset were categorised as male or female.

5.5 Statistical Analysis

This quantitative study will use statistical analysis to explore and describe the relationship between the needs of participants, their level of safety risk and the AT recommended and installed for them to meet their needs and reduce their level of risk. This section will provide a brief overview of the methods of analysis which will be used.

Initially, this study will use descriptive statistics to report frequencies and explore collinearity between variables within the dataset. Tables are produced using R Studio software (Viechtbauer 2010) and describe the associations between needs variables, participants' demographic information, and risk of wandering and safety risk. Where there are suitable available data associations between variables will be tested using chi-square tests.

5.5.1 Ordinal Regression

In order to understand the relationship between both (1) risk of wandering and participant needs; and (2) safety risk and participant needs, two separate ordinal logistic regression models were developed. Ordinal regression is a special type of multinomial regression which can be advantageous when the response variable takes one value in a number of ordered categories. As the focus of this research was effect of the increasing risk in predictor variables across the range of possible responses in the outcome variable, ordinal regression was selected as the appropriate method (Warner 2008). This type of model generalizes binomial logistic regression to outcome variables that have three or more ordered categories. Additionally, the ordinal logistic regression model has the advantage of more statistical power than binary regression as it runs simultaneous binary regressions resulting in more efficient parameter estimates and reduced unexplained error (Coxe et al. 2013). The model is obtained by considering, for each of the categories, the odds of being in a higher category (Kasza and Wolfe 2014). The estimated parameters may be considered in terms of odds ratios, or cumulative odds, by taking the exponential of the estimated coefficient. This model makes the proportional odds assumption which implies that the odds of being in categories 2,3 or 4 versus being in category 1 is the same as the odds ratio of being in category 3 or 4 versus being in category 1 or 2 (Kasza and Wolfe 2014).

5.5.1.1 Variable Selection

Good model building follows the principle of parsimony, but requires that the model is useful for theoretical purposes and provides good predictive power (Agresti and Finlay 2009). The aim of the ordinal regression models was therefore to identify the parameters which represented the relationship between the predictor variables and the outcome variables: (1) wandering and (2) safety risk. Heinze et al. (2018) conclude that elimination of bias in this context is difficult and that background knowledge is highly important in this process. Following examination of the literature regarding characteristics which have an effect upon risk of wandering, and safety risk, the relationships between the outcome variable and the selected predictor variables were analysed in an iterative process which involved examining correlations between all variables, and also results of univariate ordinal regressions. This was done as any analytical procedure using regression models must be preceded by comparing each covariable with the outcome variable (Abreu et al. 2009). Subsequently, predictor variables that did not achieve a conservative level of significance in their relationship with the outcome variable were removed from the analysis. Variables that were highly correlated with each other were not included in the analysis, but were included individually, then results were compared in order to find which of these variables offered the best representation. Akaike Information Criterion (AIC) was used to compare models, and assist in the selection of the final models (Heinze and Dunkler 2017).

The number of variables which could be included in the models was restricted by the data available as there were high levels of missing data for many of the needs variables and limited data within cells leads to models failing to converge (Christensen 2018). It is therefore possible that the addition of further variables to the described models may have resulted in better fit, or alternative models being developed, but this was not possible. This also meant that backward selection of variables was not possible. Further, Heinze and Dunkler (2017) propose that in variable selection there may be a need for data to provide 50 events per variable for each candidate variable to ensure stable results, which was clearly not possible with the available data. Further, the author was unable to identify appropriate variable selection software for categorical variables with large amounts (<50%) of missing data. It is also known that software variable selection methods have at times resulted in the development of models that did not make sense in terms of the background literature. Therefore, the researcher based the development of the model upon the background information retrieved from the literature to ensure that the models accounted for the variables identified as important within this field. Thereafter the researcher used an iterative selection process adding variables to the analysis according to their importance within the literature for this field in order to test for significantly improved model fit, then removing variables which became less important (Agresti 2010). Likelihood ratio tests were used to ensure that fit was not improved following the removal of any included variable. New models were compared with previous models regarding goodness of fit, and the model demonstrating best fit was retained. Overall, this may have resulted in a smaller, less complex model than would have resulted from a larger set of available data (Heinze and Dunkler 2017).

5.5.1.2 Assessment of Model Convergence

In ordinal regression models, iterative methods may fail to converge when an optimum cannot be found, or parameter estimates are not determined accurately enough. Convergence tests were used to check the accuracy of the parameter estimates of the models. Indicators of an optimum having been found include a small maximum absolute gradient, and a positive condition number of Hessian smaller than 10^4 (Christensen 2016). The number of correct decimals and significant digits also determined the accuracy of the parameters (Christensen 2016).

5.5.1.3 Interpretation of Findings

Odds Ratio (OR) is defined by Valveny and Gilliver (2016) as the odds of an event occurring in the test group divided by the odds of the same event in the reference group. Therefore, OR indicates the relative odds of a higher-level response, for the value of the explanatory variable under consideration, relative to its reference category (Warner 2008). The proportional odds assumption holds that a unit increase in the outcome variable results in a multiplicative unit increase in choosing a higher ordered category versus the lower ordered category for the predictor variable, whilst holding all other variables constant (Coxe et al. 2013).

5.5.1.4 Assumption of Proportional Odds

The ordinal logistic regression model makes a key assumption known as the proportional odds or parallel regressions assumption and this needs to be assessed (Abreu et al. 2009). Violation of this assumption would result in the model being invalid. This assumption states that all equations share the same regression coefficient for the same predictor; the corresponding regression coefficients are constrained to be equal across equations. Constraining the regression coefficients to be equal implies that a predictor variable has the same effect on moving up a category, regardless of the category’s location in the ordered set (Coxe et al. 2013). The assumption of proportional odds was tested using the nominal test which provides likelihood ratio tests of the model (Christensen 2018).

5.5.2 Recommended and Installed Assistive Technology stratified by Level of Risk

In order to demonstrate the influence of the data gatherers' assessment of level of risk on AT intervention, the categories of recommended and installed AT are presented stratified according to the level of wandering risk of participants. Thereafter, recommended and installed AT is presented and stratified according to level of safety risk. Associations between recommended or installed AT and level of wandering or safety risk are investigated by chi-squared tests and significant results are presented.

5.5.3 Cluster Analysis

Research into the effects of multiple variables on the provision of AT is scarce (Fleming and Sum 2014). Previous research has identified conflicting roles of factors which are highly correlated. In particular different aspects of the role of the social support network of the person with dementia are variously categorised as predisposing characteristics, needs and enabling resources. Living arrangements and the caregiver/ care recipient relationship are seen as predisposing characteristics by Toseland et al. (2002) but as enabling resources by Weaver and Roberto (2017). Whilst Phillips et al. (1998) categorised caregiver support as an enabling resource. The literature also indicates that caregiver needs have an impact upon the needs of people with dementia (Li 2012).

Due to the different roles each of these factors can play in the adoption of AT services (Toseland et al. 2002), there is a requirement to examine the relationship of these factors to each other by grouping participants according to a number of these variables at the same time.

In order to determine the robustness of grouping people with dementia by demographic variables of mixed data types, cluster analyses were conducted using partitioning around medoids (PAM) algorithm as it can accept Gower distance. Clustering solutions were selected based upon silhouette width.

As the ultimate validation of clustering solutions is that they are of relevance within their field (Clatworthy et al.2005), the clustering solutions were then related to data describing the AT recommended and installed for the clustered participants. The associations between the AT and the clustering solutions were explored using chi square tests, and reference to frequency data.

The aim of this analysis was to validate findings from the research regarding the associations of population characteristics of people with dementia and the provision of AT interventions.

Therefore, the researcher aimed to investigate the underlying structure of the participant data in relation to their identified level of wandering risk and safety risk, in order to understand whether this was supported by previous research (Clatworthy et al. 2005). If this is the case then such structures could provide a basis for exploring the variation in the pattern of recommended and installed AT devices (Nataraj et al. 2019).

Cluster analysis is an unsupervised, exploratory technique which is essentially about discovering intrinsic, discrete groups within data (Everitt et al. 2001; Hofstetter et al. 2014; Gao and Yang 2018). An unsupervised technique is a type of machine learning used to draw inferences from datasets consisting of input data only and aims to sort a set of observations into groups which are not directly observed (Rupp 2013). Results of cluster analysis can be developed into partial classifications, taxonomies, or the identification of simple rules which subset the data (Reynolds et al. 2006). Partitioning cluster algorithms aim to split the dataset into clusters of objects where objects within clusters are as similar as possible, and objects in different clusters are distinct (Kassambara 2019). Ideally, resultant clusters should have good statistical properties (which reflect that the clusters are compact, well separated, connected and stable) and give results that are relevant to the field (Brock et al. 2011).

Cluster analysis was selected as it is a popular technique used within risk behaviour research to identify subgroups of participants sharing particular characteristics (Hofstetter et al. 2014). This is useful as the focus of this analysis is the identification of groups of participants with wandering and safety risks who may benefit from particular AT interventions (Clatworthy et al. 2005). Reducing a heterogeneous sample of 395 participants into relatively homogenous groups, allows the researcher to organise large quantities of multivariate information (Clatworthy et al. 2005). For mixed data types, as is the case in this analysis which includes nominal, ordinal and discrete data, a robust method for clustering data uses partitioning around medoids (PAM). This clustering method is based upon Gower distance – a measure based upon the dissimilarities between data points; and silhouette width (Martin 2016). Silhouette width is a measure which can be used both to determine which objects lie well within clusters, and can also be used to judge the quality of the clusters (Kaufman and Rousseeuw 1990; Reynolds et al. 2006). The Silhouette index is calculated by comparing the average dissimilarity of the object to all other objects within the cluster, with the average dissimilarity of the object to all other objects in all clusters (Reynold et al. 2006).

PAM has the additional advantage of identifying clusters by medoids which offer robust representations of the cluster centres (van der Laan et al. 2002), and medoids provide useful exemplars of participants within each resultant cluster (Kaufmann and Rousseeuw 1990). Further, PAM is less sensitive to outliers than other clustering algorithms such as k-means clustering as it is not reliant on the means of the data points within the cluster to represent the cluster (Kassambara 2019). PAM is also more robust as it admits the use of other dissimilarities besides Euclidean distance (Brock et al. 2011). Overall, Reynolds et al. (2006) conclude that this demonstrates the overall efficiency of the PAM algorithm which outperforms k-means in most cases and produces better results.

5.5.3.1 Variable Selection

There are multiple factors which impact upon the provision and use of AT for people with dementia. Variables were selected for inclusion in this analysis based upon evidence of their importance in the published literature. In order to facilitate understanding of the impact of multiple participant related variables upon AT this analysis will examine the possibility of grouping participants according to multiple variables including data on their needs, predisposing characteristics and enabling resources.

The selection of variables was restricted to those available within the secondary dataset. Based upon the available data, the researcher selected variables for which the reviewed literature produced evidence regarding their influence on the AT selection and provision process. The selected variables corresponded to the three categories of population characteristics shown to have an impact upon healthcare utilisation namely predisposing, enabling and needs categories (Phillips et al. 1998). This facilitated investigation of each of these categories with regard to AT service utilisation, as previous research has indicated that they are all influential in this area, and all explain some of the variation in service use (Toseland et al. 2002; Scherer et al. 2007). Moreover, Toseland et al. (2002) concluded that enabling resources are more influential on service use than the needs of people with dementia. The selected variables were MMSE (cognition), Caregiver Support, Level of Risk (Safety or Wandering), and Living situation. Cognition and level of risk correspond to needs (Toseland et al. 2002), caregiver support is an enabling factor (de Klerk et al. 1997; Scherer et al. 2007), and living situation is a predisposing characteristic according to the literature (Phillips et al. 1998; Toseland et al. 2002). The importance of social support in the identification of needs, and in the adoption of AT is highlighted within the published literature.

The differences in needs reported by people with dementia and their caregivers was also a key result of the meta-analysis conducted as part of this research.

5.5.3.2 Dissimilarity Measure: Gower Distance

Variables included within this analysis were mixed data types including ordinal, nominal and discrete data. In order to create groups of observations, cluster analysis requires a measure of dissimilarity, which is defined as the measure of how different each pair of data points within the dataset can be. It is therefore a requirement of the analysis to select a dissimilarity measure which can account for the distance between different data types. In this analysis Gower distance was used to measure dissimilarity across participants using the mathematical concept of distance, which in this case was computed as the average of the partial dissimilarities across participants, where partial dissimilarity is the ratio between a) absolute difference of observations, and b) maximum range observed from all participants, and requires the creation of a final distance matrix (Filaire 2018). The metrics used within the calculation of Gower Distance for the different types of data used within this analysis include;

- Quantitative (interval): range- normalised Manhattan distance
- Ordinal: variable is first ranked, then Manhattan distance is used with a special adjustment for ties.
- Nominal: variables of k categories are first converted into k binary columns and then the similarity of the two samples is evaluated (Martin 2016).

Hummel et al. (2017) found that clustering based on Gower distance performed better than other mixed data partitioning algorithms

5.5.3.3 Clustering Algorithm: Partitioning Around Medoids (PAM)

PAM is an algorithm that can handle a custom distance matrix such as the Gower distance, and was therefore selected as an algorithm for clustering. The term medoid refers to an observation within a cluster for which the sum of the distances between it and all the other members of the cluster is a minimum (Department of Statistics University of California, Berkeley 2019). Additionally, medoids serve as exemplars or representatives of each cluster (Kaufman and Rousseeuw 1990; Reynolds et al. 2006). PAM is an iterative clustering procedure that uses the following steps;

- k random entities are selected to become the medoids.

- Every entity is assigned to its closest medoid.
- For each cluster the observation that would yield the lowest average distance if it were to be reassigned as the medoid is identified. If there is an observation for which this is the case, this observation becomes the new medoid.
- If at least one medoid has changed it returns to step 2. The algorithm continues until the medoid is the observation with the overall lowest average distance (Krynska 2018).

5.5.3.4 Determining the Number of Clusters

In the absence of a good *a priori* rationale for selecting a specific number of clusters, the author determined the final number of clusters through examination of the silhouette coefficient. Silhouette width can be used to assist selection of the number of clusters to be extracted in the analysis where larger silhouette width indicates a better clustering solution (Kaufman and Rousseeuw 1990). In this case silhouette width was used to determine the optimal number of clusters (Filaire 2018). After calculating silhouette width for the range of clustering solutions ranging from 2-10 clusters, for the PAM algorithm, the silhouette coefficient contrasted the average distance to elements in the same cluster with the average distance to elements in other clusters. Objects with a high silhouette value are considered well clustered, objects with a low value may be outliers (Filaire 2018). Guidance provided by the Department of Statistics University of California, Berkeley (2019) advises that silhouette width < 0.25 indicates no substantial structure has been found, 0.26-0.50 indicates that the structure is weak and could be artificial, 0.50-0.70 indicates that a reasonable structure has been found, and 0.71-1.0 indicates that a strong structure has been found.

5.5.3.5 Validity of the Clusters

In some cases, cluster analysis can create as well as reveal structure and it is therefore important to demonstrate structure stability, and additionally that the structures are of use within the relevant field (Breckenridge 2000). Internal validation of clusters requires measures that reflect the compactness, connectedness and separation of the cluster (Brock et al. 2011). Connectedness relates to the extent that observations are placed in the same cluster as their nearest neighbours in data space, whereas compactness assesses the heterogeneity of the cluster by examining intra-cluster variance (Brock et al. 2011). Further, separation quantifies the degree of separation of the clusters often by measuring the distance between the centroids of the clusters (Brock et al. 2011).

However, these measures are only useful if there is an alternative cluster solution with which they can be compared.

Previously clustering results were validated through comparisons with results obtained through alternative methods (Gao and Yang 2018). However, the development of internal cluster validation indices has provided researchers with an alternative route to validation. In this case, the internal validation indices developed for numerical data such as the Dunn index or the Calinski-Harabasz index could not be used as they are unsuitable for clustering categorical data (Gao and Yang 2018). Therefore, a clustering solution based upon optimum silhouette width was selected for this analysis. Silhouette width is an aggregated measure of how similar an observation is to its own cluster compared to its closest neighbouring cluster, or the average of each observation's Silhouette value (van der Laan et al. 2002; Wang et al. 2009). Silhouette width can be interpreted as follows; observations with large silhouette width (almost 1) are very well clustered, a small silhouette width (closer to -1) indicates that the observation lies between two clusters, and observations with a negative silhouette width are traditionally seen to have been placed within the wrong cluster although this is not always the case (Kassambara 2019). This method provides a means to validate the clustering solution relative to other possible clustering solutions.

Ultimately, the validation of a clustering solution is obtained through evaluation of the applicability of the solution to the real world (Clatworthy et al. 2005). Hence, following development of the cluster solution the researcher will explore the cluster structure in comparison with published research. This will involve examination of the clustering solution with regard to its relevance within the field of AT for people with dementia. Therefore, the association of the needs of people with dementia and their living situation and caregiver support as described in the literature will provide information regarding the predictive validity of the clustering solutions with regard to AT data variables (Clatworthy et al. 2005).

Thereafter, recommended and installed AT is stratified according to the resultant clusters in order to explore their potential usefulness in explaining the patterns underlying AT provision for people with dementia.

Following development of the clustering solutions, the researcher exported data describing the cluster solution from R Studio to Excel software. The cluster solution provided information which included the participants' unique identifier numbers, together with the number of the cluster to which each participant was allocated. The Excel spreadsheet received from the ATTILA RCT, containing the secondary dataset provided information describing which AT were recommended and installed together with the unique identifier of the receiving participant. Excel spreadsheet functions were then used to combine these two sets of information sorted according to unique participant identifier. This created one unified spreadsheet which included a list of participant unique identifier numbers, the cluster to which they were allocated in the clustering solution, and information on their recommended and installed AT. This enabled the identification of the AT recommended; and installed for each of the participants within the clusters for both of the analyses. The association of the clusters of participants, with the AT recommended and installed for those participants was then examined in both cases and is presented. Where data was available the strength of this association was tested using chi-squared analyses (Campbell 2007; Richardson 2011). Chi square tests are unable to consider cells with missing data or where the cell count is zero. In other cases, data is described and the variation in the frequency of AT recommended or installed is discussed. This analysis also allowed the researcher to assess the validity of this clustering structure within this field in addition to providing further understanding regarding the AT recommended and installed for people with dementia.

5.5.3.6 Interpretation

A summary of each cluster will be provided detailing the characteristics of its participants. A medoid or exemplar for each cluster will also be produced. Clusters are also visualised using t-SNE (t-distribution stochastic neighbourhood embedding) plots (van der Maaten and Hinton 2008). t-SNE should not be used to cluster data directly but can be a useful visualisation tool after cluster analysis has been applied to a raw dataset, as in this case (van der Maaten and Hinton 2008). This dimension reduction technique attempts to preserve local structures in order to make clusters visible in a 2D or 3D visualisation, it also has the ability to handle a custom distance metric such as Gower distance (van der Maaten and Hinton 2008; Martin 2016). Thereafter, the clustering solution will be compared to previous research in this field in order to interpret findings and to understand their relevance (Clatworthy et al. 2005).

5.5.3.7 Software

These analyses were all conducted using R Studio software (Viechtbauer 2010; R Core Team 2017). The Cluster (Maechler et al. 2019) and Ordinal packages (Christensen 2018) were employed during the cluster analysis and ordinal regression analyses respectively.

5.6 Ethics

In accordance with Queen Margaret University Revised Research Ethics Guidelines, Procedures and Regulations (2011), ethical approval for this study was obtained from Queen Margaret University Ethics Committee prior to its commencement (Appendix E). The letter granting ethical approval does not include permission for the systematic review and meta-analysis study as systematic review and meta-analysis activities are exempted from consideration by the Queen Margaret University Research Ethics committee and this is confirmed by them in writing (Appendix F).

The original study received ethical approval from the NHS Health Research Authority National Research Ethics Committee and registered with the International Standard Randomised Controlled Trial Number Registry #ISRCTN86537017. However, in some cases secondary data analysis may involve using data for purposes for which participants have not expressly granted consent, and it is therefore important that all information is anonymised and unidentifiable, and that ethical issues have been considered in order to ensure that the uninformed researched are protected (O'Leary 2014). Ethical approval is also important to ensure that data is being fairly used and that researchers remain aware of their responsibilities.

Hence, in order to ensure that this secondary data research met with required ethical standards the researcher discussed the study with Dr. Helen Newbery, Ethics Scientific Officer, NHS Lothian Research and Development Office; Dr. Gemma Blackledge-Foughali, Convener of the Research Ethics Panel, Queen Margaret University, Edinburgh; and Becky Gathercole, Trial Manager of the RCT study, who all confirmed that as all data within the dataset was anonymised, this study did not raise any ethical issues.

The manager of the original RCT confirmed that this secondary data analysis complied with the conditions regarding the use of data collected during the RCT as described within the study protocol and ethics documentation. Permission to use this anonymised data set was granted by Chief Investigator of the original study (Appendix G).

All data used within this study was anonymised although linked to participant data. The link code was held at another university and this was not available to the researcher. Anonymised research data was stored in accordance with Queen Margaret University Research Data Management Policy in an electronic anonymised format on encrypted, password protected computers in securely partitioned Queen Margaret University servers.

5.7 Summary

This chapter has presented the methods employed within this study including ordinal regression and cluster analysis in order to achieve responses to each of the previously stated research questions. The results of these analyses will be described in the following chapter.

CHAPTER 6. RESULTS

This chapter provides the results of the secondary data analyses described in the previous methods chapter (Chapter 5). This includes descriptive statistics which provide an understanding of the dataset, followed by results of univariate and ordinal regression analyses, and partitioning around medoids cluster analysis. Results for each of the secondary data research questions are presented sequentially.

Firstly, this chapter describes the characteristics of the participants within the data set. This includes information about participants' demographics (section 6.1), including information on the relationship of demographics to level of wandering (section 6.1.1), and safety need (section 6.1.2). Missing data will then be described (section 6.2). Participant needs are stratified according to risk of wandering (section 6.3) and safety risk (section 6.4). Thereafter, results obtained from two ordinal regression analyses examining the relationship between participants' documented needs, and their level of wandering (section 6.5) or level of safety risk (section 6.6) are exhibited. Then, clustering analysis solutions based upon participant characteristic data including risk of wandering (section 6.7) and safety risk (section 6.8) are presented. Data describing recommended and installed AT are then shown (section 6.9). Finally, associations between recommended and installed AT and participants groups are displayed (section 6.10).

6.1 Participants

The analysis included 451 participants with dementia or suspected dementia living at home who were most likely to be female aged 82.22 years (*SD* = 7.18) with low risk of wandering and low safety risk (Table 7). Participants were most likely to live alone, although the most frequent category of caregiver support indicated that most participants receive care from a live-in caregiver.

Table 7 Participant Demographics

Age *M* (*SD*)	82.22 (7.2)
Gender = female *n* (%)	264 (58.5)
Caregiver Support *n* (%)	
Caregiver visits at least once per day	111 (24.6)
Caregiver visits less than once per day	118 (26.2)
Live-in caregiver	222 (49.2)
Living Situation *n* (%)	
Living alone	203 (45.0)
Living with spouse/ partner	181 (40.1)
Other	67 (14.9)
MMSE (*M* (*SD*))	18.16 (6.6)
Safety Risk *n* (%)	
Low	230 (51.0)
Moderate	186 (41.2)
High	35 (7.8)
Risk of Wandering *n* (%)	
Low	328 (72.7)
Moderate	90 (20.0)
High	33 (7.3)

Note. N = 451, M = Mean, SD = Standard Deviation, MMSE = Mini Mental State Examination

There were 496 participants described within the original dataset of which 451 had documented needs assessment (Figure 9). Three hundred and ninety-five participants had documented needs assessment and documented MMSE score. These participants received recommendations for 963 AT, and had 1217 AT installed.

Figure 9 Participants with documented Needs and recommended and installed Assistive Technology.

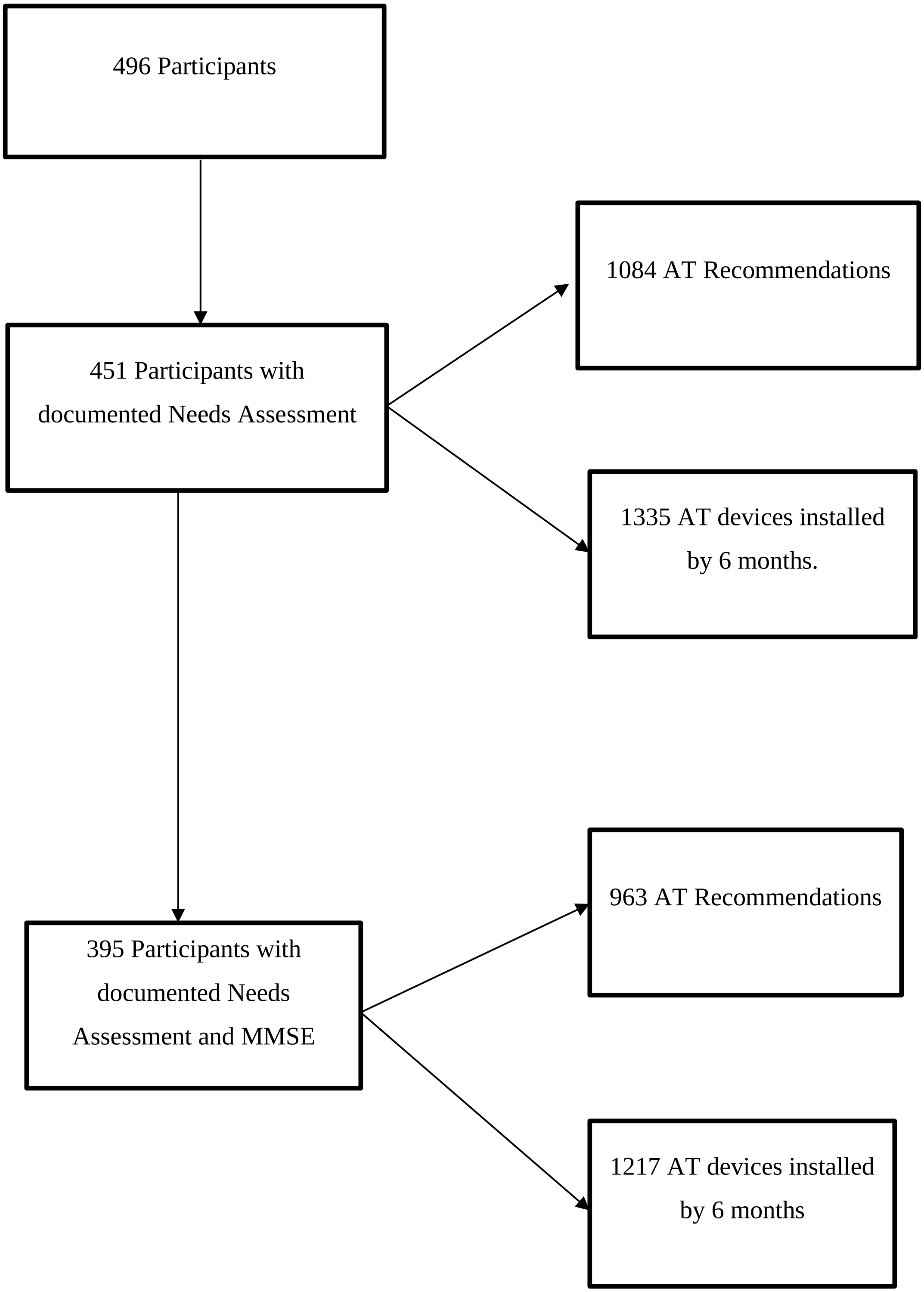


Figure 9: MMSE = Mini Mental State Examination (Folstein et al. 1975), AT = Assistive Technology

6.1.1 Risk of Wandering and Participant Demographics

Participants with moderate risk of wandering were more likely to be male (54.4%), although the population was mostly female (58.5%). Risk of wandering was associated with safety risk (4, χ^2 = 11.29, *p* = .023), although participants with high risk of wandering were most likely to have moderate safety risk (Table 8).

Table 8 Participant Demographics stratified by Risk of Wandering

	Level of Risk of Wandering		
	Low	Moderate	High
n (%)	328 (72.7)	90 (19.9)	33 (7.3)
Age (*M* (*SD*))	82.25 (7.2)	82.53 (6.6)	81.15 (8.4)
Gender = Female	203 (61.9)	41 (45.6)	20 (60.6)
Caregiver Support			
Caregiver visits at least once per day	81 (24.7)	23 (25.6)	7 (21.2)
Caregiver visits less than once per day	91 (27.7)	19 (21.1)	8 (24.2)
Live-in caregiver	156 (47.6)	48 (53.3)	18 (54.5)
Living Situation			
Living alone	152 (46.3)	38 (42.2)	13 (39.4)
Living with spouse/partner	130 (39.6)	39 (43.3)	12 (36.4)
Other	46 (14.0)	13 (14.4)	8 (24.2)
MMSE (*M (SD*))	19.05 (6.1)	16.01 (7.3)	14.35 (7.1)
Safety Risk			
High	28 (8.5)	3 (3.3)	5 (15.2)
Moderate	124 (37.8)	43 (47.8)	18 (54.5)
Low	176 (53.7)	44 (48.9)	10 (30.3)

Note. *N* = 451, *M* = Mean, *SD* = Standard Deviation, MMSE = Mini Mental State Examination (Folstein et al. 1975).

The highest frequency of participants with high risk of wandering lived with “other”, as eight out of 67 (11.94%) participants categorised in the living situation: “other”, had high risk of wandering. Whereas, 13 of the 203 (6.4%) participants living alone, and 12 of the 181 (6.63%) participants living with spouse/ partner had high risk of wandering.

6.1.2 Safety Risk and Participant Demographics

Participant demographics stratified according to level of safety risk are presented in table 9. Chi squared tests showed that safety risk is associated with living situation (4, χ^2 = 16.06, *p* =.003) – participants with high safety risk were most likely to live with spouse/ partner; risk of wandering (4, χ^2 = 11.29, *p* = .023) – people with high safety risk were most likely to have low risk of wandering; and caregiver support (4, χ^2 = 12.46, *p* = .014) – people with high safety risk were most likely to have live-in caregiver. It is also notable that participants with high safety risk have the lowest mean age when compared with participants who have low or moderate safety risk. Participants with a high level of safety risk were younger (*M* = 78.98 (*SD* = 8.73)) years than participants with low (*M* = 82.71 (*SD* = 6.88)), or medium safety risk (*M* = 82.25 (*SD* = 7.09)). Participants with a high level of safety risk receive a higher level of caregiver support (61.1% have live-in caregiver), and are less likely to live alone. Participants with high safety risk had lowest MMSE score (*M* = 16.15 (*SD* = 8.35)).

Table 9 Participant Demographics stratified by Safety Risk

	Level of Safety Risk		
	Low	Moderate	High
n (%)	230(51.00)	185(41.02)	36(7.98)
Age *M* (*SD*)	82.71 (6.88)	82.25 (7.09)	78.98 (8.73)
Gender = Female	130 (56.5)	111 (59.7)	23 (65.7)
Caregiver Support			
Caregiver visits at least once per day	45 (19.6)	55 (29.7)	11 (30.6)
Caregiver visits less than once per day	65 (28.3)	50 (27.0)	3 (8.3)
Live-in caregiver	120 (52.2)	80 (43.2)	22 (61.1)
Living Situation			
Living alone	95 (41.3)	99 (53.5)	9 (25.0)
Living with spouse/partner	105 (45.7)	58 (31.4)	18 (50.0)
Other	30 (13.0)	28 (15.1)	9 (25.0)
MMSE (*M* (*SD*))	18.35 (6.66)	18.23 (6.17)	16.15 (8.35)
Risk of Wandering			
Low	176 (76.5)	124 (67.0)	28 (77.8)
Moderate	44 (19.1)	43 (23.2)	3 (8.3)
High	10 (4.3)	18 (9.7)	5 (13.9)

Note. *N* = 451, *M* = Mean, *SD* = Standard Deviation, MMSE = Mini Mental State Examination (Folstein et al. 1975).

6.2 Missing Data

The secondary dataset contains information on the 496 participants who were recruited to the original study.

This secondary data analysis study excluded data for 45 participants for whom there was no needs assessment documentation as it is focussed upon the needs of people with dementia. This left data describing the needs of 451 participants for analysis (Figure 9). Needs assessment data together with details of missing data for each need are presented in tables 11 and 12 and described in sections 6.3 and 6.4.

There was no missing data for the 451 participants for the variables; Risk of Wandering, Safety Risk, Age, Gender, Living Situation or Caregiver Support. Needs assessment data for all 451 participants was included in the ordinal regression analysis.

Some of the 451 participants did not have a recorded MMSE score (n = 56, (12.42%)). Reasons for this missing data were not documented, however the literature describes reasons given for non-completion of the MMSE as including poor vision and hearing, deficient schooling, consequences of stroke and tremor (Raiha et al. 2001). The demographics of the populations with and without MMSE scores are described in Table10. As it appears that this data was missing for reasons associated with the nature of the assessment (MNAR) it was not possible to impute data for this variable. This left 395 participants for inclusion in cluster analysis.

There is an association between presence of MMSE score and safety risk (2, $\chi^2 = 10.53$, $p = .005$). Participants without an MMSE score recorded in the dataset are more likely to have a moderate or high safety risk than participants who do have a MMSE score. There were no other significant associations identified between the collected demographic variables and presence of MMSE score.

The fifty-six participants without MMSE score were recommended 121 AT devices, and subsequently received installations of 118 AT devices.

Table 10 Populations with and without Mini Mental State Examination Score

	Without MMSE	With MMSE
n (%)	56(12.4)	395(87.6)
Gender = Female	35 (62.5)	229 (57.97)
Age (*M* (*SD*))	80.90 (7.21)	82.41 (7.16)
Living Situation		
Living alone	21 (37.5)	182 (46.1)
Living with spouse/partner	21 (37.5)	160 (40.5)
Other	14 (25.0)	53 (13.4)
Caregiver Support		
Caregiver visits at least once per day	16 (28.6)	95 (24.1)
Caregiver visits less than once per day	11 (19.6)	107 (27.1)
Live-in caregiver	29 (51.8)	193 (48.9)
Risk of Wandering		
Low	35 (62.5)	293 (74.2)
Moderate	14 (25.0)	76 (19.2)
High	7 (12.5)	26 (6.6)
Safety Risk		
Low	19 (33.9)	211 (53.4)
Moderate	28 (50.0)	158 (40.0)
High	9 (16.1)	26 (6.6)

Note. *N* = 451, MMSE = Mini Mental State Examination (Folstein et al. 1975), *M* = Mean, *SD* = Standard Deviation

In summary, comparison of participants with and without MMSE scores indicated that removal of participants without MMSE scores resulted in a study population with lower risk of wandering, lower safety risk, and with fewer participants living with other (Table 10).

6.3 What are the Needs of Participants with different levels of Wandering Risk?

The AT needs of 451 participants stratified by level of wandering risk are presented in Table 11. The frequency of missing data for each need is also presented. Missing data indicates that posture and mobility, social groups, responsibility and knowledge are the most frequently documented needs. The most frequently recorded area of significant risk was responsibility where 40% of responses were in this category, and a further 53% of responses indicated some risk. The need with the lowest frequency of significant risk (1%) and some risk (11%) was strength and effort, whereas vocal expression had the highest frequency of participants with no risk identified (66%).

Table 11 Assistive Technology Needs stratified by Risk of Wandering

AT Need	Risk of Wandering				
	Low	Moderate	High	Total	Missing Data
n (%)	328 (72.73)	90 (19.95)	33 (7.32)		
Appraisal of Abilities					
Significant Risk	37 (21.9)	10 (18.5)	9 (50.0)	56 (23)	210 (46)
Some Risk	60 (35.5)	27 (50.0)	8 (44.4)	95 (39)	
Mostly Risk Free	56 (33.1)	17 (31.5)	1 (5.6)	74 (31)	
No Risk	16 (9.5)	0 (0.0)	0 (0.0)	16 (07)	
Choices					
Significant Risk	28 (16.5)	4 (7.1)	5 (26.3)	37 (15)	206 (46)
Some Risk	37 (21.8)	17 (30.4)	9 (47.4)	63 (26)	
Mostly Risk Free	74 (43.5)	29 (51.8)	4 (21.1)	107 (44)	
No Risk	31 (18.2)	6 (10.7)	1 (5.3)	38 (16)	
Routine					
Significant Risk	27 (15.3)	17 (21.8)	13 (43.3)	57 (20)	167 (37)
Some Risk	93 (52.8)	52 (66.7)	17 (56.7)	162 (57)	
Mostly Risk Free	39 (22.2)	7 (9.0)	0 (0.0)	46 (16)	
No Risk	17 (9.7)	2 (2.6)	0 (0.0)	19 (07)	
Responsibility					
Significant Risk	88 (36.8)	28 (44.4)	13 (68.4)	129 (40)	130 (29)
Some Risk	133 (55.6)	31 (49.2)	5 (26.3)	169 (53)	
Mostly Risk Free	17 (7.1)	3 (4.8)	1 (5.3)	21 (06)	
No Risk	1 (0.4)	1 (1.6)	0 (0.0)	2 (01)	
Conversation					
Significant Risk	12 (7.9)	7 (12.5)	4 (22.2)	23 (10)	225 (50)
Some Risk	47 (30.9)	21 (37.5)	9 (50.0)	77 (34)	
Mostly Risk Free	62 (40.8)	15 (26.8)	3 (16.7)	80 (35)	
No Risk	31 (20.4)	13 (23.2)	2 (11.1)	46 (20)	
Vocal Expression					
Significant Risk	4 (3.3)	0 (0.0)	2 (14.3)	6 (3)	276 (61)
Some Risk	14 (11.7)	2 (4.9)	2 (14.3)	18 (10)	
Mostly Risk Free	26 (21.7)	6 (14.6)	3 (21.4)	35 (20)	
No Risk	76 (63.3)	33 (80.5)	7 (50.0)	116 (66)	
Knowledge					
Significant Risk	77 (32.9)	32 (49.2)	13 (61.9)	122 (38)	131 (29)
Some Risk	126 (53.8)	31 (47.7)	5 (23.8)	162 (51)	
Mostly Risk Free	30 (12.8)	2 (3.1)	3 (14.3)	35 (11)	
No Risk	1 (0.4)	0 (0.0)	0 (0.0)	1 (0)	
Problem Solving					

AT Need	Risk of Wandering				
	Low	Moderate	High	Total	Missing Data
Significant Risk	46 (29.9)	14 (29.2)	7 (43.8)	67 (31)	233 (52)
Some Risk	76 (49.4)	29 (60.4)	9 (56.2)	114 (52)	
Mostly Risk Free	21 (13.6)	5 (10.4)	0 (0.0)	26 (12)	
No Risk	11 (7.1)	0 (0.0)	0 (0.0)	11 (05)	
Posture and Mobility					
Significant Risk	52 (21.1)	7 (10.3)	2 (9.5)	61 (18)	116 (26)
Some Risk	132 (53.7)	26 (38.2)	5 (23.8)	163 (49)	
Mostly Risk Free	32 (13.0)	10 (14.7)	5 (23.8)	47 (14)	
No Risk	30 (12.2)	25 (36.8)	9 (42.9)	64 (19)	
Strength and Effort					
Significant Risk	1 (1.0)	0 (0.0)	1 (10.0)	2 (01)	304 (67)
Some Risk	12 (11.8)	3 (8.6)	1 (10.0)	16 (11)	
Mostly Risk Free	31 (30.4)	12 (34.3)	2 (20.0)	45 (31)	
No Risk	58 (56.9)	20 (57.1)	6 (60.0)	84 (57)	
Physical Space					
Significant Risk	5 (5.3)	2 (5.1)	0 (0.0)	7 (05)	311 (69)
Some Risk	31 (32.6)	9 (23.1)	0 (0.0)	16 (11)	
Mostly Risk Free	23 (24.2)	10 (25.6)	1 (16.7)	45 (31)	
No Risk	36 (37.9)	18 (46.2)	5 (83.3)	84 (57)	
Physical Resources					
Significant Risk	2 (2.3)	1 (3.0)	0 (0.0)	3 (02)	323 (72)
Some Risk	14 (15.9)	8 (24.2)	1 (14.3)	23 (18)	
Mostly Risk Free	32 (36.4)	4 (12.1)	1 (14.3)	37 (29)	
No Risk	40 (45.5)	20 (60.6)	5 (71.4)	65 (51)	
Social Groups					
Significant Risk	9 (3.9)	4 (5.4)	2 (8.7)	15 (05)	126 (28)
Some Risk	117 (51.3)	38 (51.4)	13 (56.5)	168 (52)	
Mostly Risk Free	71 (31.1)	22 (29.7)	7 (30.4)	100 (31)	
No Risk	31 (13.6)	10 (13.5)	1 (4.3)	42 (13)	
Occupational Demands					
Significant Risk	15 (14.9)	10 (23.3)	5 (27.8)	30 (18)	289 (64)
Some Risk	51 (50.5)	24 (55.8)	13 (72.2)	88 (54)	
Mostly Risk Free	22 (21.8)	7 (16.3)	0 (0.0)	29 (18)	
No Risk	13 (12.9)	2 (4.7)	0 (0.0)	15 (09)	

Note. *N* = 451

6.4 What are the Needs of Participants with different levels of Safety Risk?

The needs of participants stratified by level of safety risk are presented in Table 12. The documented AT needs of participants with high safety risk indicated that they were always identified as having significant risk or some risk for the following needs: Knowledge, Responsibility, Problem solving and Occupational demands. Participants with high safety risk were not documented as having no risk or being mostly risk free for any of these four need categories.

Table 12 Assistive Technology Needs stratified by Safety Risk

AT Needs	Safety Risk				
	Low	Moderate	High	Total	Missing Data
n (%)	230 (51.00)	185 (41.02)	36 (7.98)		
Appraisal of Abilities					
Significant Risk	22 (17.5)	26 (27.1)	8 (42.1)	56 (23)	210 (46)
Some Risk	48 (38.1)	40 (41.7)	7 (36.8)	95 (39)	
Mostly Risk Free	44 (34.9)	27 (28.1)	3 (15.8)	74 (31)	
No Risk	12 (9.5)	3 (3.1)	1 (5.3)	16 (07)	
Choices					
Significant Risk	18 (14.8)	14 (14.1)	5 (20.8)	37 (15)	206 (46)
Some Risk	25 (20.5)	30 (30.3)	8 (33.3)	63 (26)	
Mostly Risk Free	58 (47.5)	42 (42.4)	7 (29.2)	107 (44)	
No Risk	21 (17.2)	13 (13.1)	4 (16.7)	38 (16)	
Routine					
Significant Risk	30 (20.0)	21 (18.1)	6 (33.3)	57 (20)	167 (37)
Some Risk	81 (54.0)	73 (62.9)	8 (44.4)	162 (57)	
Mostly Risk Free	25 (16.7)	17 (14.7)	4 (22.2)	46 (16)	
No Risk	14 (9.3)	5 (4.3)	0 (0.0)	19 (07)	
Responsibility					
Significant Risk	53 (32.1)	63 (48.1)	13 (52.0)	129 (40)	130 (29)
Some Risk	100 (60.6)	57 (43.5)	12 (48.0)	169 (53)	
Mostly Risk Free	10 (6.1)	11 (8.4)	0 (0.0)	21 (06)	
No Risk	2 (1.2)	0 (0.0)	0 (0.0)	2 (01)	
Conversation					
Significant Risk	12 (10.6)	6 (6.2)	5 (31.2)	23 (10)	225 (50)
Some Risk	35 (31.0)	39 (40.2)	3 (18.8)	77 (34)	
Mostly Risk Free	35 (31.0)	39 (40.2)	6 (37.5)	80 (35)	
No Risk	31 (27.4)	13 (13.4)	2 (12.5)	46 (20)	
Vocal Expression					
Significant Risk	2 (2.2)	2 (2.8)	2 (18.2)	6 (3)	276 (61)
Some Risk	9 (9.8)	7 (9.7)	2 (18.2)	18 (10)	
Mostly Risk Free	18 (19.6)	15 (20.8)	2 (18.2)	35 (20)	
No Risk	63 (68.5)	48 (66.7)	5 (45.5)	116 (66)	
Knowledge					
Significant Risk	52 (30.6)	57 (43.8)	13 (65.0)	122 (38)	131 (29)
Some Risk	91 (53.5)	64 (49.2)	7 (35.0)	162 (51)	
Mostly Risk Free	26 (15.3)	9 (6.9)	0 (0.0)	35 (11)	
No Risk	1 (0.6)	0 (0.0)	0 (0.0)	1 (0)	

AT Needs	Safety Risk				
	Low	Moderate	High	Total	Missing Data
Problem Solving					
Significant Risk	32 (31.7)	27 (26.0)	8 (61.5)	67 (31)	233 (52)
Some Risk	40 (39.6)	69 (66.3)	5 (38.5)	114 (52)	
Mostly Risk Free	20 (19.8)	6 (5.8)	0 (0.0)	26 (12)	
No Risk	9 (8.9)	2 (1.9)	0 (0.0)	11 (05)	
Posture and Mobility					
Significant Risk	20 (11.9)	26 (18.8)	15 (51.7)	61 (18)	116 (26)
Some Risk	78 (46.4)	74 (53.6)	11 (37.9)	163 (49)	
Mostly Risk Free	27 (16.1)	18 (13.0)	2 (6.9)	47 (14)	
No Risk	43 (25.6)	20 (14.5)	1 (3.4)	64 (19)	
Strength and Effort					
Significant Risk	1 (1.4)	1 (1.5)	0 (0.0)	2 (01)	304 (67)
Some Risk	7 (9.5)	7 (10.6)	2 (28.6)	16 (11)	
Mostly Risk Free	23(31.1)	19 (28.8)	3 (42.9)	45 (31)	
No Risk	43 (58.1)	39 (59.1)	2 (28.6)	84 (57)	
Physical Space					
Significant Risk	2 (2.6)	5 (9.1)	0 (0.0)	7 (05)	311 (69)
Some Risk	20 (26.3)	18 (32.7)	2 (22.2)	16 (11)	
Mostly Risk Free	19 (25.0)	12 (21.8)	3 (33.3)	45 (31)	
No Risk	35 (46.1)	20 (36.4)	4 (44.4)	84 (57)	
Physical Resources					
Significant Risk	2 (3.0)	1 (1.9)	0 (0.0)	3 (02)	323 (72)
Some Risk	11 (16.4)	11 (20.4)	1 (14.3)	23 (18)	
Mostly Risk Free	20 (29.9)	13 (24.1)	4 (57.1)	37 (29)	
No Risk	34 (50.7)	29 (53.7)	2 (28.6)	65 (51)	
Social Groups					
Significant Risk	8 (5.0)	6 (4.3)	1 (3.7)	15 (05)	126 (28)
Some Risk	79 (49.4)	77 (55.8)	12 (44.4)	168 (52)	
Mostly Risk Free	47(29.4)	42 (30.4)	11 (40.7)	100 (31)	
No Risk	26 (16.2)	13 (9.4)	3 (11.1)	42 (13)	
Occupational Demands					
Significant Risk	10 (12.3)	17 (23.9)	3 (30.0)	30 (18)	289 (64)
Some Risk	48 (59.3)	33 (46.5)	7 (70.0)	88 (54)	
Mostly Risk Free	13(16.0)	16 (22.5)	0 (0.0)	29 (18)	
No Risk	10 (12.3)	5 (7.0)	0 (0.0)	15 (09)	

Note. *N* = 451

6.5 Which Needs predict Risk of Wandering?

Prior to building a model to investigate the relationship between risk of wandering and the needs variables, the relationship between risk of wandering and the individual needs was investigated through tests of correlation (Appendix D) and univariate ordinal regression models (Valveny and Gilliver 2016). Univariate tests indicate a significant association between MMSE, Posture and Mobility, Routine, Occupational Demands and Conversation variables and risk of wandering (Table 13).

Table 13Risk of Wandering and Needs - Univariate Ordinal Regression Results

Variable	*OR* [95% CI]	*p* value
MMSE	0.925 [0.894, 0.956]	*p* =.000005
Posture and Mobility	4.073 [2.301, 7.587]	*p* = .000003
Routine	0.145 [0.040, 0.369]	*p* =.0003
Occupational Demands	0.225 [0.059, 0.618]	*p* = .008
Conversation	0.500 [0.250, 0.999]	*p* = .048
Social Groups	0.607 [0.266, 1.422]	*p* = .237
Choices	0.652 [0.299, 1.391]	*p* = .270
Strength and Effort	0.337 [0.033, 3.445]	*p* = .311
Physical Space	1.638 [0.551, 6.322]	*p* = .406
Vocal Expression	0.775 [0.226, 3.172]	*p* = .691
Responsibility	1.334 [0.159, 7.378]	*p* = .744
Physical Resources	0.911 [0.197, 7.269]	*p* = .911

Note. *OR* = Odds Ratio, CI = Confidence Interval, MMSE = Mini Mental State Examination (Folstein et al. 1975)

Univariate ordinal regression analyses did not converge for Appraisal of abilities, Knowledge, or Problem-solving needs indicating that the data for each of these three needs categories are not a good fit with the risk of wandering data. These three needs have missing data for more than one level of risk of wandering (Table 11).

Following an iterative process involving the addition and removal of variables from successive models the following multivariate ordinal regression model was developed indicating an association between risk of wandering and Routine, Posture and Mobility and Cognition needs.

Table 14 Ordinal Regression: Predictors of Risk of Wandering

Model Formula: Risk of Wandering ~ Routine + MMSE + Posture and Mobility		
Variable	*OR* [95% CI]	
Routine	0.11 [0.01, 0.39]	*p* = .004
MMSE	0.95 [0.91, 0.99]	*p* = .017
Posture and Mobility	3.78 [1.82, 8.50]	*p* < .0006

Note. CI = Confidence Interval, *OR* = Odds Ratio, MMSE = Mini Mental State Examination (Folstein et al. 1975)

The model converged successfully with an Akaike Information Criterion (AIC) = 313.06.

Before interpreting the results of this model (Table 14) it is useful to recall that for the AT Needs Assessment variables a score of 1 indicates significant multiple risks whereas a score of 4 indicates no risk. For MMSE higher scores indicate improved cognition. For risk of wandering a low score indicates lower level of risk.

Therefore, for a one-point increase in posture and mobility related risk, where the Routine and MMSE variables are held constant, the odds of the participant having moderate risk of wandering rather than high risk of wandering increase by 3.78. So, as posture and mobility risk increases, risk of wandering decreases. However, as MMSE score increases (indicating improved cognition), and whilst the Posture and Mobility and Routine variables are held constant, the risk of wandering increases by 0.95. As this odds ratio is less than one, this means that the risk of wandering actually decreases when cognition improves. Similarly, when risk associated with Routine increases, and the Posture and mobility; and MMSE variables are held constant, the risk of wandering increases by 0.11. Hence, as this score is again less than one, this means that there is a reduced risk of wandering when the risk associated with Routine is reduced.

6.5.1 Likelihood Ratio Tests of Explanatory Variables

In order to ensure that there is no redundancy within the model likelihood ratio tests were conducted to compare the results of this model with similar models where one of the variables has been removed (Table 15).

Table 15 Single Term Deletions

Model: Risk of Wandering~ Routine + MMSE + Posture and Mobility

Variable	AIC	
None	313.06	
Routine	328.87	*p* = .00007
MMSE	316.86	*p* = .016
Posture and Mobility	321.77	*p* = .002

Note. AIC = Akaike Information Criterion, MMSE = Mini Mental State Examination (Folstein et al. 1975)

Likelihood ratio tests of the explanatory variables while controlling for the remaining variables indicate that inclusion of all of the three selected variables provides the best explanation of risk of wandering (AIC = 313.06) as the model would be significantly different without the inclusion of any of the variables and the AIC would increase.

6.5.2 Test of Nominal Effects

Ordinal regression relies on the proportional odds assumption being met (Christensen 2018). The proportional odds assumption is that the relationship between all pairs of groups within the model is the same i.e. there is a common odds ratio across all levels of each term included in the model. Non-significant results in the test of nominal effects indicate that the proportional odds assumption has not been violated. The Nominal test provided likelihood ratio tests of the proportional odds assumption (Christensen 2018). Results of this test are presented in Table 16.

Table 16 Test of Nominal Effects Results

Model: Risk of Wandering ~ Routine + MMSE + Posture and Mobility

Variable	AIC	
	313.06	
Routine	314.61	*p* = .216
MMSE	314.65	*p* = .522
Posture and Mobility	317.77	*p* = .730

Note. MMSE = Mini Mental State Examination (Folstein et al. 1975), AIC = Akaike Information Criterion.

As no significant *p* values were returned in the test of nominal effects it can be said that the model has not violated the proportional odds assumption (Christensen 2018). Akaike Information Criterion is lowest for the initial model indicating best goodness of fit.

6.6 Which Needs predict Safety Risk?

Prior to building a model indicating the relationship of multiple variables with safety risk, it is advised to explore the individual relationships between safety risk and predictor variables in correlation matrix (Appendix D) and univariate regressions (Valveny and Gilliver 2016). Univariates tests indicated a significant association between Safety Risk and Posture and Mobility, Occupational Demand, Appraisal of Abilities and Problem solving. The results of these analyses are presented in table 17.

Table 17 Safety Risk and Needs - Univariate Ordinal Regression Results

Variable	*OR* [95% CI]	*p* value
MMSE	0.99 [0.96, 1.02]	*p* = .344
Posture and Mobility	0.29 [0.17, 0.49]	*p* = .000002
Routine	0.49 [0.21, 1.03]	*p* = .072
Occupational Demands	0.41 [0.16, 0.95]	*p* = .043
Conversation	0.54 [0.26, 1.10]	*p* = .091
Social Groups	0.82 [0.37, 1.84]	*p* = .624
Choices	0.72 [0.39, 1.32]	*p* = .288
Strength and Effort	0.91 [0.14, 7.97]	*p* = .923
Physical Space	0.54 [0.20, 1.45]	*p* = .215
Vocal Expression	0.33 [0.10, 1.13]	*p* = .080
Appraisal of Abilities	0.33 [0.13, 0.73]	*p* = .009
Physical Resources	1.46 [0.31, 11.69]	*p* = .648
Problem Solving	0.21 [0.06, 0.56]	*p* = .005

Note. *OR* = Odds ratio, CI = Confidence Interval, MMSE = Mini Mental State Examination (Folstein et al. 1975).

The univariate regression analyses did not converge for responsibility or knowledge variables, indicating that the data for these variables was not a good fit with the safety risk data. The relationship between these variables and safety risk will need to be investigated in future research.

Again, after an iterative process involving the addition and removal of variables and comparing the results, the following model was developed exploring the association between safety risk and posture and mobility and problem-solving related risks.

The final ordinal regression model formula was: Safety risk~ Posture and mobility + Problem solving. Results are shown in table 18.

Table 18 Ordinal Regression: Predictors of Safety Risk

Model: Safety Risk ~ Posture and Mobility + Problem Solving

Variable	*OR* [95% CI]	
Problem Solving	0.233 [0.060, 0.676]	*p* = .014
Posture and Mobility	0.294 [0.146, 0.578]	*p* = .0005

Note. CI = Confidence Interval, *OR* = Odds Ratio

The model converged successfully: absolute and relative convergence criteria were met, and parameters were accurately determined. AIC = 329.30.

Bearing in mind that for Problem solving and Posture and Mobility an increased score indicates reduced risk. For these variables a score of 1 indicates significant multiple risks whereas a score of 4 indicates no risk. Whereas for Safety risk a low score indicates low level of risk.

Results can be interpreted as follows: for a one-point increase in posture and mobility related risk where the other variables are held constant, the odds of the participants having a moderate safety risk rather than a low safety risk are 0.294. For a one-point increase in problem solving, where the other variables are held constant, the odds of the participants having a one category increase in level of safety risk are 0.233. As these odds ratios are less than one, these results indicate that there is reduced safety risk when the risk associated with posture and mobility or problem solving is reduced.

6.6.1 Test of Nominal Effects

As previously stated, ordinal regression relies upon the proportional odds assumption being met. The test of nominal effects provides a test of this assumption and non-significant results indicate that the proportional odds assumption has not been violated (Table 19).

Table 19 Results of Test of Nominal Effects for Safety Risk Model

Model: Safety Risk ~ Posture and Mobility + Problem Solving	AIC	
	329.30	
Posture and Mobility	335.12	*p* = .981
Problem Solving	329.52	*p* = .123

Note. AIC = Akaike Information Criterion.

As no significant *p* values were returned from this test of nominal effects, the model has not violated the proportional odds assumption. Additionally, the AIC score for the selected model is the lowest indicating this model is the best fit for the variables considered.

6.6.2 Likelihood Ratio Tests of Explanatory Variables

Table 20 Single Term Deletions

Model: Safety Risk ~ Posture and Mobility + Problem Solving	AIC	
	329.30	
Posture and Mobility	337.73	*p* = .002
Problem Solving	337.39	*p* = .003

Note. AIC = Akaike Information Criterion.

Results of likelihood ratio tests of the explanatory variables while controlling for the remaining variables indicates that the model would be significantly different without the inclusion of the posture and mobility or problem-solving variables (Table 20). AIC indicates that the better model includes both these variables.

6.7 Cluster Analysis of Participants with Risk of Wandering

This section will provide results for two clustering analyses based upon the method described above, where the first analysis included risk of wandering, and the second analysis included safety risk as needs variables for the person with dementia. The other variables included in the analyses, and the clustering algorithm; caregiver support, living situation and MMSE are same in both cases.

Cluster analysis provided a means to examine the occurrence of multiple variables in the study population and to group participants according to these variables. Thereafter this will enable the researcher to explore the impact of these multiple variables upon AT provision in this population.

6.7.1 Participant Data included in Risk of Wandering Analysis

Data included observations for 395 participants on four variables: caregiver support, MMSE, living situation and risk of wandering.

6.7.2 Calculating the Gower Distance

Clustering algorithms require a notion of dissimilarity in order to be able to group observations (Martin 2016). One distance measure which can be used to create a dissimilarity matrix for mixed data sets is Gower Distance. Gower distance uses a different distance metric for each type of data and uses that information to create a distance matrix based upon the number of dissimilarities between the data points, in this case ordinal, integer and nominal data were considered in the solution (Martin 2016).

Participants with the minimum Gower distance are those within the analysis who have the fewest dissimilarities between all data points and are presented in table 21.

Table 21 Minimum Gower Distance

	Caregiver Support	MMSE	Living Situation	Risk of Wandering
1.	Live-in caregiver	27	Other	Low
2.	Live-in Caregiver	26	Other	Low

Note. MMSE = Mini Mental State Examination (Folstein et al. 1975)

Conversely, participants with the maximum Gower distance are those within the analysis who have the most dissimilarities between all data points, and are presented in table 22.

Table 22 Maximum Gower Distance

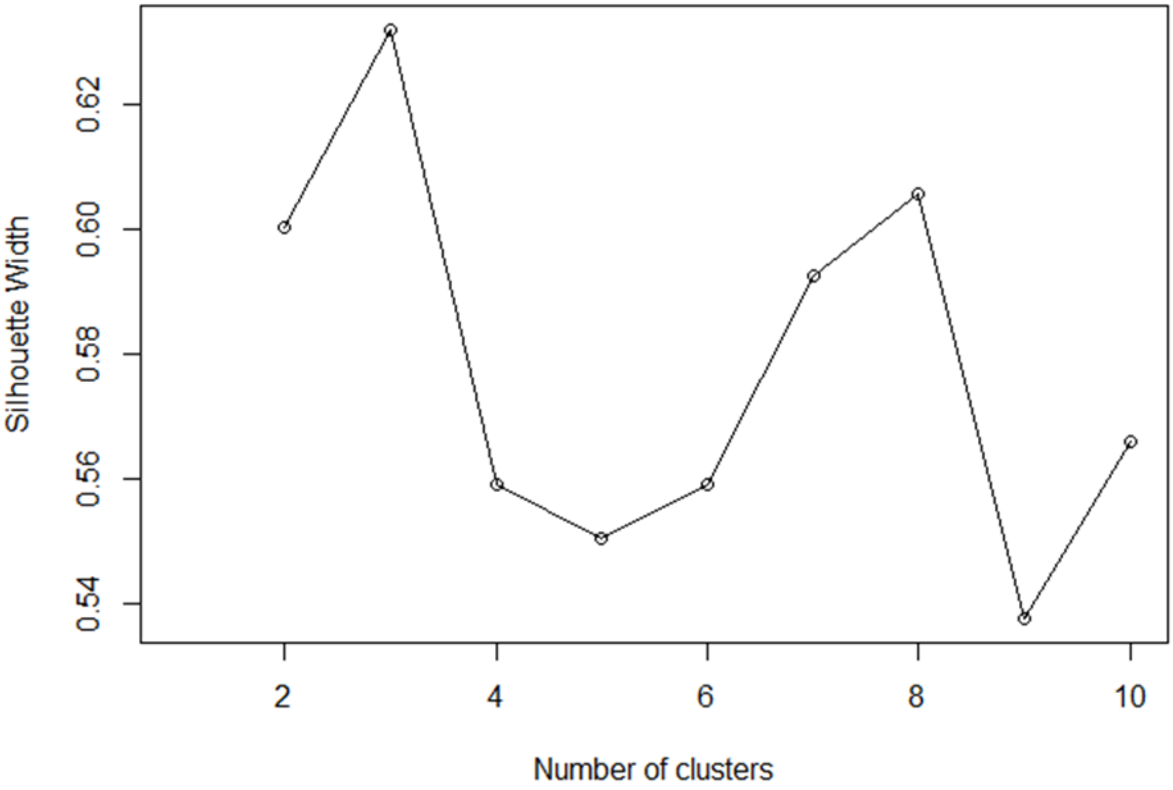
	Caregiver Support	MMSE	Living Situation	Risk of Wandering
1.	Live-in caregiver	1	Living with spouse/ partner	High
2.	Caregiver visits less than once per day	28	Living alone	Low

Note. MMSE = Mini Mental State Examination (Folstein et al. 1975)

6.7.3 Selecting the Number of Wandering Clusters

In this analysis silhouette width was used to determine the number of clusters to be extracted within the cluster analysis, as silhouette width is an internal validation metric which is an aggregated measure of how similar an observation is to its own cluster compared to its closest neighbouring cluster (Martin 2016). By comparing the resultant silhouette width for a range of solutions providing different numbers of clusters, the researcher is able to determine which of the solutions will provide the highest silhouette width and therefore the most robust clustering solution. Figure 10 illustrates the silhouette width of a range of clustering solutions with two to ten clusters, and indicates that robust solutions with a silhouette width of over 0.5 are available (Department of Statistics University of California, Berkeley 2019).

Figure 10 Silhouette Width Plot for Wandering Clusters



Examination of the average silhouette width for the available solutions in figure 10 confirms that the optimal clustering solution in this case includes three clusters as this solution has the highest silhouette width.

6.7.4 Wandering cluster Interpretation via Descriptive Statistics

A summary of the data variables for the participants within each of the three clusters is presented in table 23. Participants in the first cluster all live with spouse/ partner, and participants in the second cluster all live with other. However, none of the participants in the third cluster have a live-in caregiver.

Table 23 Partitioning Around Medoids (PAM) Summary for Wandering Cluster

Cluster	**Caregiver Support: *n* (%)**	**MMSE**	**Living Situation: *n* (%)**	**Risk of Wandering: *n* (%)**
1. (*n* = 156)	Live-in caregiver: 147(94.2) Caregiver visits at least once per day: 8(5.1) Caregiver visits less than once per day: 1(0.6)	Min:0.0 1st Qu.:13.0 Median:19.0 *M*:17.6 3rd Qu.:24.0 Max:28.0	Living alone: 0(0) Living with Spouse/ Partner: 156(100.0) Other: 0(0)	Low:112(71.8) Mod: 34(21.8) High: 10(6.4)
2. (*n* = 51)	Live-in caregiver: 46(90.2) Caregiver visits at least once per day: 4(7.84) Caregiver visits less than once per day: 1(1.78)	Min: 0.0 1st Qu.: 14.5 Median:18.0 *M*: 17.6 3rd Qu.: 24.0 Max: 29.0	Living alone: 0(0) Living with Spouse/ Partner: 0(0) Other: 51(100.0)	Low: 36(70.6) Mod: 10(19.6) High: 5(9.8)
3. (*n* =188)	Live-in caregiver: 0(0) Caregiver visits at least once per day: 83(44.2) Caregiver visits less than once per day: 105(55.8)	Min: 0.0 1st Qu.: 15.0 Median:20.0 *M*: 18.8 3rd Qu.: 23.0 Max: 28.0	Living alone: 182(96.8) Living with Spouse/ Partner: 4(2.1) Other: 2(1.1)	Low:145(77.1) Mod: 32(17.0) High: 11(9.0)

Note. *N* = 395, PAM = Partitioning Around Medoids, MMSE = Mini Mental State Examination (Folstein et al. 1975), Min = Minimum, Qu = Quarter, *M* = Mean, Max = Maximum, Mod = Moderate.

The data included in table 23 indicates that the clustering solution is closely aligned to the living situation and caregiver support of the participants.

An advantage of PAM clustering operation is the production of medoids, and these observations (one per cluster) can be considered to be representative examples of the members of that cluster (Department of Statistics University of California, Berkeley 2019). The medoids for this clustering solution are presented in Table 24.

Table 24 Medoids of Wandering Clusters

Cluster Name	Caregiver Support	MMSE	Living Situation	Risk of Wandering
1. Living with Spouse/ Partner	Live-in caregiver	19	Living with spouse/partner	Low
2. Living with Other	Live-in caregiver	18	Other	Low
3. Living Alone	Caregiver visits less than once per day	20	Living alone	Low

Note. MMSE = Mini Mental State Examination (Folstein et al. 1975)

It is a tradition of cluster analysis that names are assigned to the clusters and that the names often denote a characteristic of the cluster (Hofstetter et al. 2014). These names are included in table 24.

The first cluster, hereafter referred to as “living with spouse/ partner” cluster, included participants who all lived with a spouse or partner, and 94.2% of these participants had a live- in caregiver suggesting that in many cases their spouse or partner may provide care, although this was unspecified. Only one participant in this cluster had a caregiver who visited less than once per day. These participants had a mean MMSE score of 17.6. This cluster had the highest frequency of participants with moderate risk of wandering (21.8%) of the three clusters, although most participants within this cluster had low risk of wandering (71.8%).

In the second cluster, hereafter referred to as the “living with other” cluster, all participants lived with people who were not their spouse or partner, and in most cases, this was reportedly a child or other relative of the participant. These participants mostly had a live –in caregiver (90.2%), although there were four participants in this cluster with a caregiver who visited at least once per day, and one participant with a caregiver who visited less than once per day. These participants also had a mean MMSE score of 17.6, and most of the participants within this cluster had low risk of wandering (70.6%).

The third cluster, hereafter referred to as the “living alone” cluster, included participants who mainly lived alone (96.8%), without a live- in caregiver (100%). This cluster included six participants who did not live alone, but did not have live –in caregivers indicating that the person they lived with did not provide care for them. This cluster of participants had the highest frequency of caregivers who visited less than once per day (55.8%). It would therefore appear that this group received less caregiver support than participants in the other two clusters. Participants within this cluster had the highest mean MMSE score (18.8) indicating that they were slightly less cognitively impaired than participants in the other cluster. Participants within this cluster also had the highest frequency of low risk of wandering (77.1%).

6.7.5 Cluster Interpretation via Visualisation

A silhouette plot provides a means to visualise the silhouette width of the individual participants within each of the clusters (Figure 11). Six of the participants included in cluster three have a negative silhouette width as can be seen in Figure 11. These participants are allocated to this cluster where most participants are living alone, however they are living with spouse/ partner, or living with other. All six of these participants have caregivers who visits less than once per day and they are therefore unusual within this dataset and may be considered outliers. In cluster analysis this situation can sometimes be resolved through moving participants with a negative silhouette width to an alternative cluster. However, in this case moving these participants who have negative silhouette widths to alternative clusters reduces the overall average silhouette width of the solution. This clustering solution has identified these participants as outliers, and they will therefore be examined in relation to the AT which was recommended and installed for them in order to validate their position as distinct from other clustered participants.

Figure 11 Silhouette Plot for Wandering Cluster

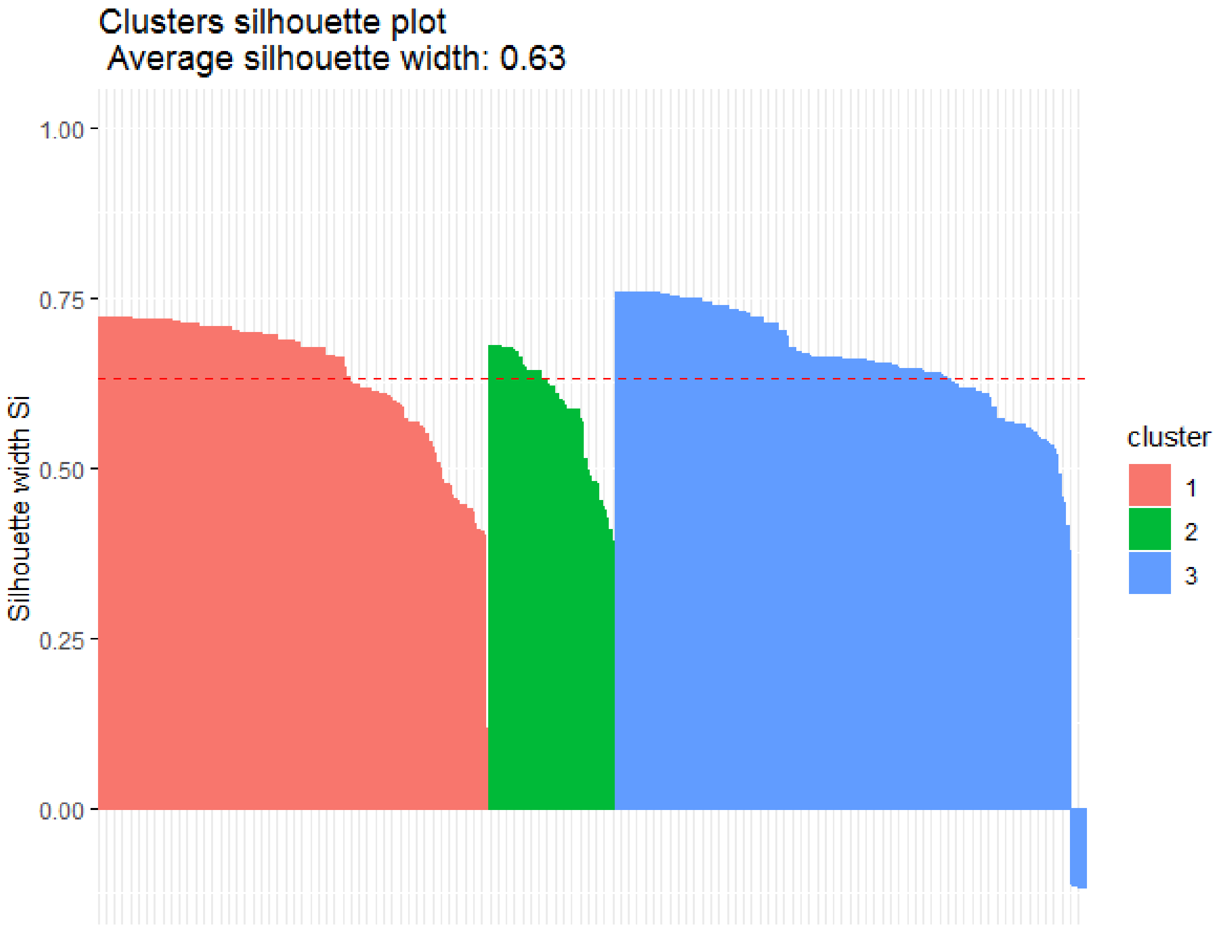


Figure 54: *N* = 395, *Si* = Silhouette Index

An alternative means of visualising the clustering solution is the t-SNE plot pictured in figure 12, and again the outlying participants are clearly visible.

Figure 12 t-SNE Plot for Wandering Clusters

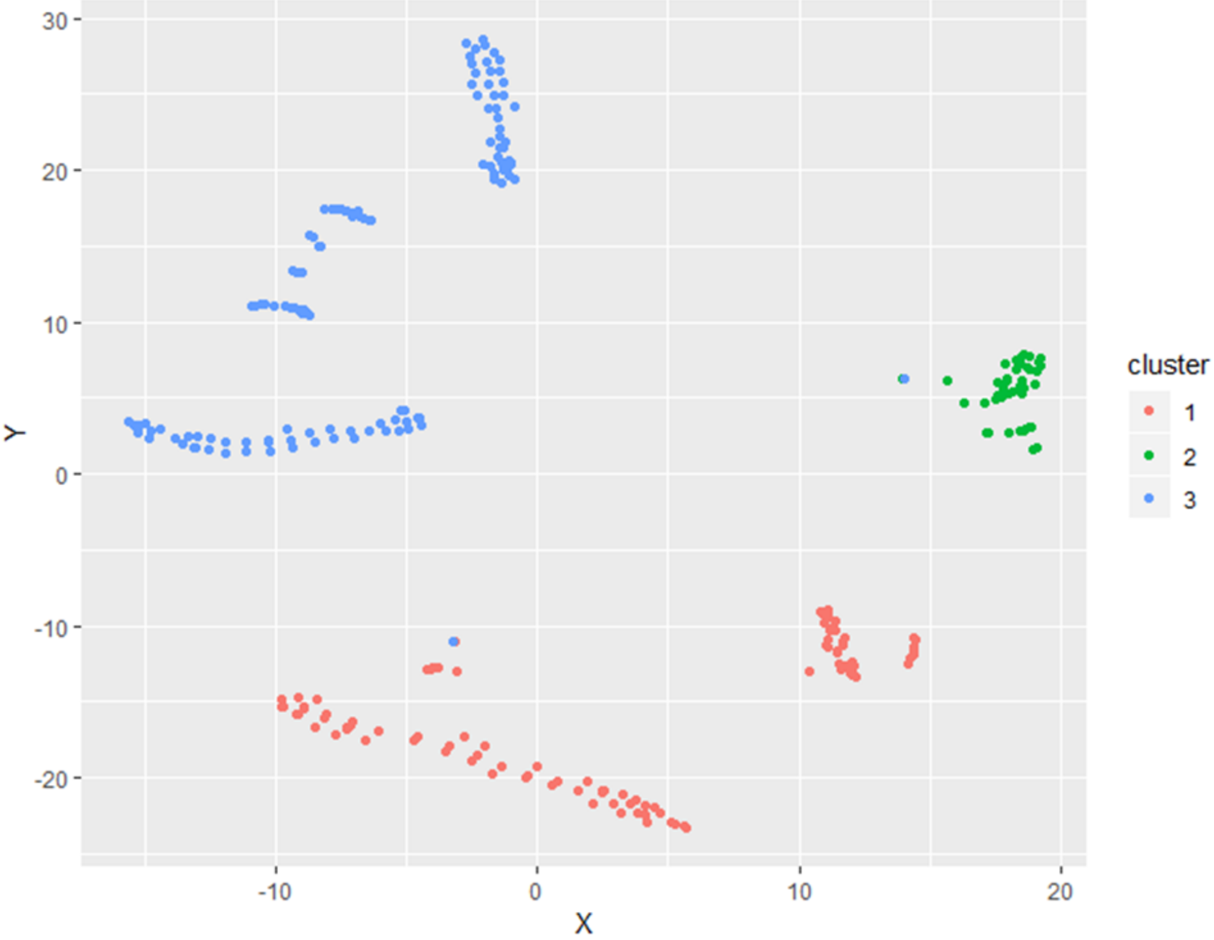


Figure 12: *N* = 395, t-SNE = t-distribution stochastic neighbourhood embedded

6.8 Cluster Analysis of Participants with Safety Risk

Adding data regarding safety risk to the risk of wandering cluster solution decreased the robustness of the solution. Therefore, as safety risk is associated with different adverse outcomes from risk of wandering for people with dementia, a second cluster analysis was conducted to investigate the underlying data structure based upon the characteristics of people with dementia including their level of safety risk.

6.8.1 Participant Data included in Safety Risk Cluster Analysis

Data included observations for 395 participants across four variables: caregiver support, living situation, MMSE and safety risk.

6.8.2 Gower Distance

The Gower Distance was calculated in order to create a dissimilarity matrix based upon ordinal, integer and nominal data describing the variables listed above. The dissimilarity matrix represents the number of differences between all the data points included in the dataset for the cluster analysis.

Table 25 Minimum Gower Distance

	Caregiver Support	MMSE	Living Situation	Safety Risk
1	Live-in caregiver	25	Other	Low
2	Live-in caregiver	24	Other	Low

Note. MMSE = Mini Mental State Examination (Folstein et al. 1975)

Participants with minimum Gower distance have the fewest dissimilarities within the dataset and are shown in table 25.

Table 26 Maximum Gower Distance

	Caregiver Support	MMSE	Living Situation	Safety Risk
1	Live-in caregiver	1	Living with spouse/partner	High
2	Caregiver visits less than once per day	28	Living alone	Low

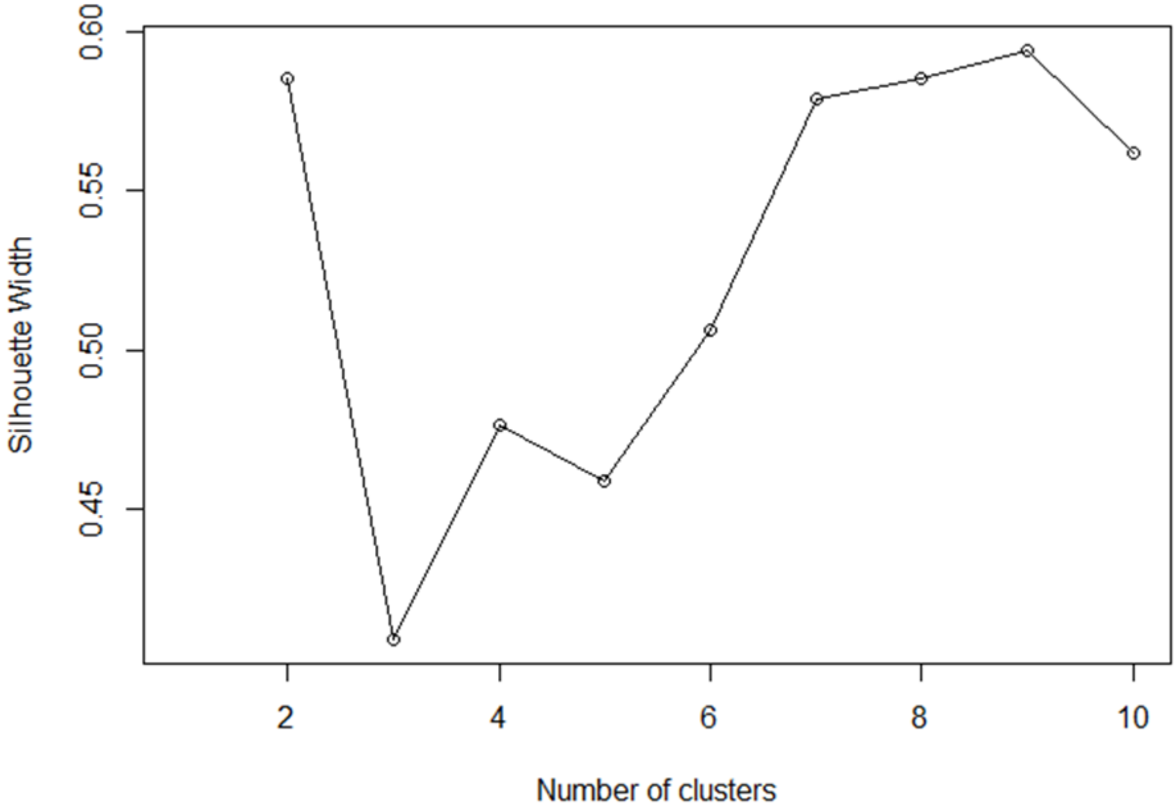
Note. MMSE = Mini Mental State Examination (Folstein et al. 1975)

Participants shown in table 26 with the maximum Gower distance for this dataset have the most dissimilarities within the dataset.

6.8.3 Selecting the Number of Safety Clusters

A silhouette width in the range of 0.51-0.70 indicates that a reasonable structure has been found. Figure 13 shows the silhouette width of cluster solutions with up to ten clusters.

Figure 13 Silhouette Width Plot for Safety Clusters



The silhouette width plot provides a range of possible clustering solutions and their silhouette width. The plot indicates that the optimum number of clusters for the included data is nine, based upon the highest average silhouette width (0.59). However, in the interest of parsimony and as Filaire (2018) suggests that it is difficult to find meaning where the number of clusters is more than eight, the accepted solution which is described below includes two clusters. Moreover, this solution also provides an average silhouette width of 0.59 indicating a similar level of validity as the nine-cluster solution.

6.8.4 Cluster Interpretation via Descriptive Statistics

Data describing the participants within each of the two clusters is presented in table 27. The clustering solution appears to have structured the data around the caregiver support and living situation variables. It can be seen that the first cluster has no participants classed as living alone. Whereas, the second cluster has no participant with a live-in caregiver. Distribution of MMSE score and level of safety risk appear similar across both clusters.

Table 27 Safety Cluster PAM summary

Cluster	Caregiver Support *n* (%)	MMSE	Living Situation *n* (%)	Level of Safety Risk *n* (%)
1. (*n* = 208)	Live-in Caregiver: 193(92.79) Caregiver visits at least once per day: 12(5.77) Caregiver visits less than once per day: 3(1.44)	Min.:0.00 1stQu.:14.00 Median:18.00 *M*: 17.66 3rd Qu.:24.00 Max.:29.00	Living alone: 0(0.0) Living with spouse/ partner: 158(75.96) Other: 50(24.04)	Low: 121(58.17) Moderate:70(33.65) High: 17 (8.17)
2. (*n* = 187)	Live-in Caregiver: 0(0.0) Caregiver visits at least once per day: 83(44.38) Caregiver visits less than once per day: 104(55.61)	Min. 0.00 1st Qu.:15.00 Median:20.00 *M*: 18.72 3rd Qu.:23.00 Max.:28.00	Living alone:182(97.33) Living with spouse/ partner: 2(1.07) Other: 3(1.60)	Low: 90(48.13) Moderate:88(47.06) High: 9(4.81)

Note. *N* = 395, PAM = Partitioning Around Medoids, MMSE = Mini Mental State Examination (Folstein et al. 1975), Min = Minimum, Qu = Quarter, *M* = Mean, Max = Maximum.

As previously stated, an advantage of the PAM method of cluster analysis is the production of medoids or exemplars of each cluster (Department of Statistics University of California, Berkeley 2019). Table 28 displays medoids for each of the safety clusters.

Table 28 Medoids for Safety Cluster

Cluster	Caregiver Support	MMSE	Living Situation	Level of Safety Risk
1. Live with Someone	Live-in Caregiver	18	Living with spouse/ partner	Low
2. Live out Caregiver	Caregiver visits less than once per day	20	Living alone	Moderate

Note. MMSE = Mini Mental State Examination (Folstein et al. 1975)

A characteristic of cluster analysis is that each cluster is given a name which reflects the particular characteristics of the participants included within that cluster (Hofstetter et al. 2014). Therefore, the first cluster is hereafter referred to as “live with someone” cluster to reflect that these participants do not live alone and all live with spouse/ partner (75.96%) or with other (24.04%), and to distinguish them from the clusters which include risk of wandering. The participants in this cluster mostly have low safety risk (58.17%), and live-in caregiver (92.79%). They have a mean MMSE score of 17.66.

The second cluster in this solution will be referred to as the “live out caregiver” cluster as these participants mostly have caregiver who visits less than once per day (55.61%), and no participants in this cluster have live in caregiver (0%). These participants mostly live alone (97.33%), have a mean MMSE score of 18.72, and mostly have moderate (47.06%) or low safety risk (48.13%).

6.8.4.1 Safety Cluster Interpretation via Visualisation

In order to visualise the clustering solution, and the fit of the participants within each of the clusters a silhouette plot can be used.

Figure 14 Silhouette Plot of Safety Cluster

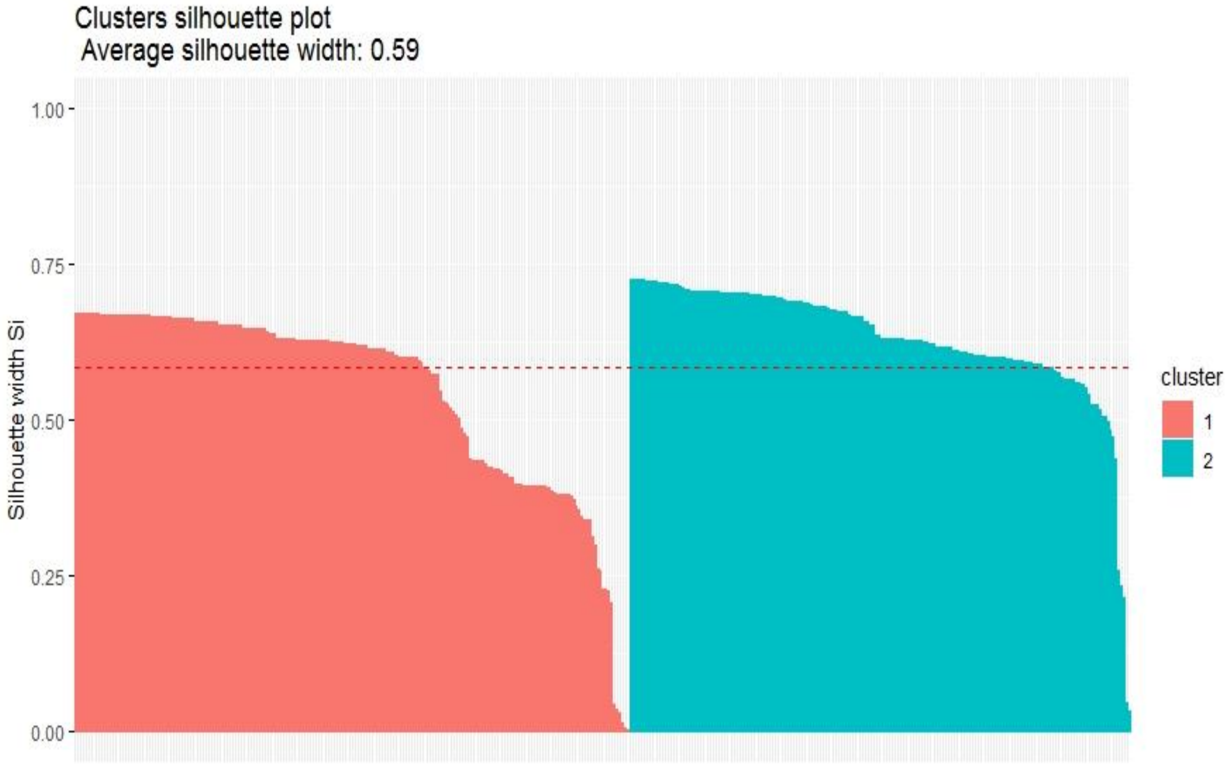


Figure 14: *N* = 395, *Si* = Silhouette Index

Figure 14 illustrates the silhouette width of the two clusters. In this clustering solution there are no participants with negative silhouette width indicating that according to this clustering solution, they are all placed within appropriate clusters.

Another method of visualising the cluster solution is by a low dimensional t-SNE plot (Figure 15).

Figure 15 t-SNE Plot for Safety Clusters

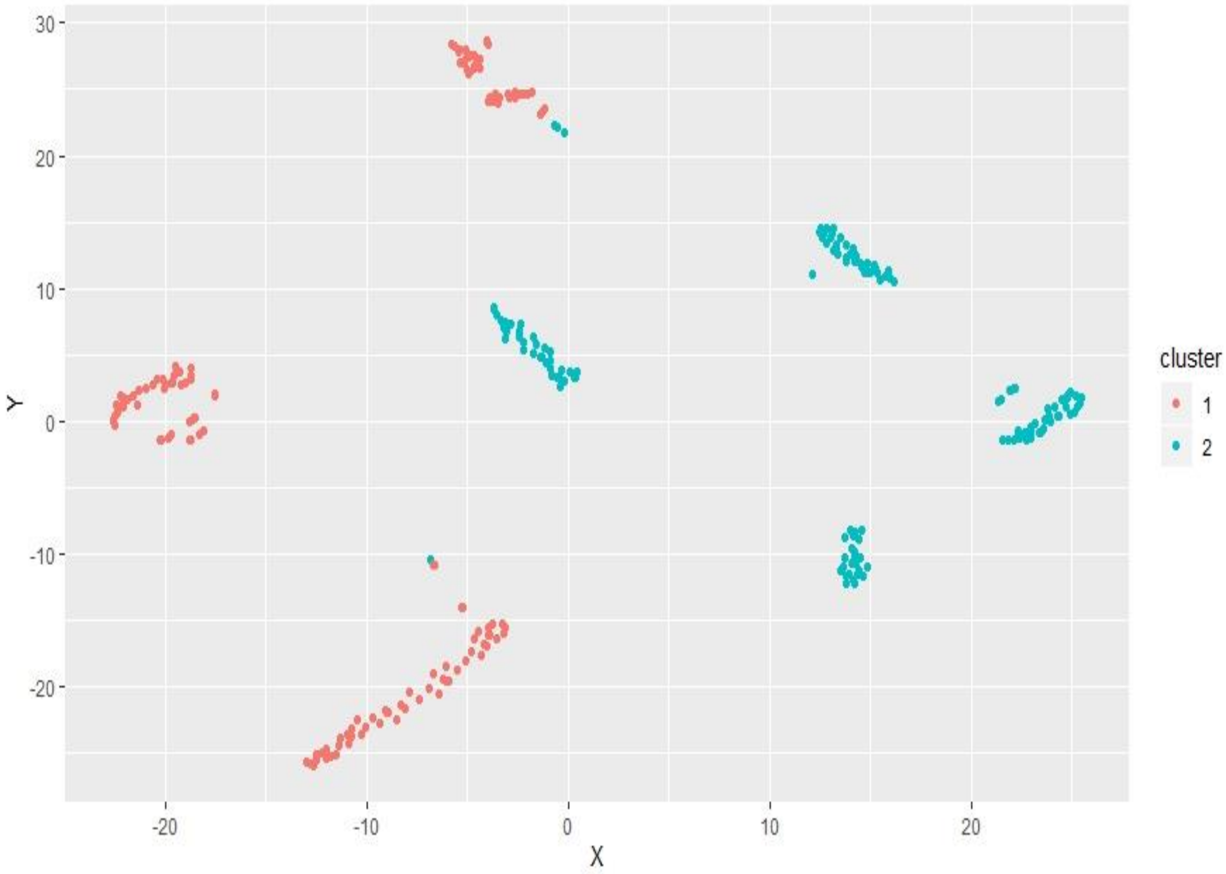


Figure 15: N = 395, t-SNE = t distribution stochastic neighbourhood embedding.

6.8.5 External Validity

The ultimate test of the validity of cluster solutions is that it has applicability within the field. This research will now therefore investigate the relationship between the clustering solutions provided above with the recommendation and installation of AT for these participants.

6.9 What Assistive Technology is recommended and installed for People with Dementia living at Home?

In order to explore the impact of multiple variables upon AT provision for people with dementia living at home clustering solutions based upon a number of variables including caregiver support and living situation, MMSE and risk of wandering or safety risk, were developed. Ultimately, Clatworthy et al. (2005) stipulate that the external validation of clusters is the most important and requires that there is evidence of the value of the clustering solution to the field. Prior to analysis, the variables included in the cluster analysis and their associations to AT for people with dementia were explored in the literature. The following results will now be presented:

(1) Recommended AT (section 6.9.1);

(2) Installed AT (section 6.9.2);

(3) Recommended and installed AT stratified by risk of wandering (section 6.9.3 and section 6.9.4);

(4) Recommended and installed AT stratified by safety risk (section 6.9.5 and section 6.9.6);

(5) Recommended and Installed AT stratified by wandering clustering solution (section 6.9.7 and section 6.9.8);

(6) Recommended and installed AT stratified by safety risk clustering solution (section 6.9.9 and section 6.9.10);

(7) Associations between the recommended and installed AT and risk of wandering or safety risk, (section 6.10.1 and section 6.10.2);

(8) Associations between the wandering and safety risk clustering solutions and recommended and installed AT (section 6.10.3 and section 6.10.4).

6.9.1 Recommended Assistive Technology

The 395 participants had 963 AT devices recommended for them by health and social care staff at the time of their needs assessment. Overall, the most frequently recommended AT across all participants were fall detectors (*n* = 116 (12%)), pendant alarms (*n* = 101 (10.5%)), medication reminders and dispensers (*n* = 98, 10.2%), safer walking technologies to alert a responder of movement (*n* = 91 (9.9%)) and safer walking technologies to locate the user (*n* = 71 (7.4%)).There were no recommendations for AT in the following categories; computer aids; or electronic games.

6.9.2 Installed Assistive Technology

During the six-month period following recruitment to the original RCT, the 395 participants received 1217 AT devices from health and social care services. The most frequently installed AT across all participants were pendant alarms (*n* = 298 (24.5%)), date and time reminders (*n* = 108 (8.9%)), monitored smoke detectors (*n* = 108 (8.9%)) and fall detectors (*n* = 82 (6.7%)). There were no installations for AT in the following categories; communication aids; or dementia friendly TV/ radio/ music players.

6.9.3 Risk of Wandering and Recommended Assistive Technology

The AT recommended for participants stratified by risk of wandering is shown in table 29. Data for participants without MMSE scores were excluded from this table to allow direct comparison with the results of the cluster analysis which will be described later in this document. AT was most frequently recommended for participants with moderate risk of wandering (*M* = 2.49). Participants with low risk of wandering received *M* = 2.45 recommendations for AT whilst participants with high risk of wandering received *M* = 2.15 recommendations for AT. Whilst this result suggests a slight increase in the number of AT recommended for participants with moderate risk of wandering, all received between two and three recommendations for items of AT. Chi-square test also indicated that there is no relationship between level of risk of wandering and number of recommended AT.

Table 29 Recommended Assistive Technology stratified by Risk of Wandering

	Risk of Wandering		
	Low	Moderate	High
n (%)	718 (74.5)	189 (19.6)	56 (5.81)
AT Category			
Activity monitors for assessment only	7 (1.0)	4 (2.1)	1 (1.8)
Activity monitors for on-going monitoring	2 (0.3)	6 (3.2)	0 (0.0)
Additional AT	18 (2.5)	4 (2.1)	1 (1.8)
Alarm and pager units	9 (1.3)	2 (1.1)	0 (0.0)
Any other devices	1 (0.1)	0 (0.0)	0 (0.0)
Communication aids	2 (0.3)	1 (0.5)	0 (0.0)
Continence management devices	0 (0.0)	1 (0.5)	0 (0.0)
Date and time reminders	44 (6.1)	11 (5.8)	4 (7.1)
Dementia friendly TV / radio / music players	1 (0.1)	0 (0.0)	0 (0.0)
Fall detectors	100 (13.9)	14 (17.4)	2 (3.6)
Flood detectors and water temperature monitors	19 (2.6)	2 (1.1)	0 (0.0)
Gas detectors	30 (4.2)	2 (1.1)	1 (1.8)
Intercoms	1 (0.1)	1 (0.5)	0 (0.0)
Item locator devices	14 (1.9)	1 (0.5)	0 (0.0)
Lighting devices	6 (0.8)	2 (1.1)	0 (0.0)
Medication reminders and dispensers	82 (11.4)	10 (5.3)	6 (10.7)
Monitored carbon monoxide detectors	31 (4.3)	6 (3.2)	1 (1.8)
Monitored extreme temperature sensors	34 (4.7)	4 (2.1)	0 (0.0)
Monitored smoke detectors	77 (10.7)	17 (9.0)	1 (1.8)
Other	4 (0.6)	2 (1.1)	0 (0.0)
Other communication devices	3 (0.4)	0 (0.0)	0 (0.0)
Other devices that support meaningful use of leisure time	2 (0.3)	0 (0.0)	0 (0.0)
Other devices that support safety, comfort or wellbeing	16 (2.2)	6 (3.2)	2 (3.6)
Other reminder or prompting devices	4 (0.6)	1 (0.5)	0 (0.0)
Pendant alarm	80 (11.1)	14 (7.4)	7 (12.5)
Safer walking technologies – to alert a responder of movement	45 (6.3)	30 (15.9)	16 (28.6)
Safer walking technologies – to locate the user	27 (3.8)	35 (18.5)	9 (16.1)
Telephones	5 (0.7)	3 (1.6)	0 (0.0)
Voice recorders and memo minders	54 (7.5)	10 (5.3)	5 (8.9)

Note. *N* = 963, AT = Assistive Technology, TV = Television.

6.9.4 Risk of Wandering and Installed Assistive Technology

AT installed during the six-month period following assessment has been stratified by participants' level of risk of wandering in table 30. AT installed for Participants without MMSE scores were excluded from this table. Results indicate that a higher number of AT was installed for participants with high risk of wandering (M = 3.35). People with moderate risk of wandering received M = 3.18 installed AT. People with low risk of wandering received M = 3.03 installed AT. Chi square test indicated that there is no relationship between level of risk of wandering and the number of installed AT. This indicates that level of risk of wandering does not influence the number of AT installed for people with dementia.

Table 30 Installed Assistive Technology stratified by Risk of Wandering

	Risk of Wandering		
	Low	Moderate	High
n (%)	888 (72.97)	242 (19.88)	87 (7.15)
AT Category			
Activity monitors for assessment only	4 (0.5)	3 (1.2)	0 (0.0)
Activity monitors for on-going monitoring	8 (0.9)	11 (4.5)	1 (1.1)
Additional AT	10 (1.1)	3 (1.2)	0 (0.0)
Alarm and pager units	10 (1.1)	3 (1.2)	0 (0.0)
Any other devices	1 (0.1)	0 (0.0)	0 (0.0)
Computer aids	3 (0.3)	0 (0.0)	0 (0.0)
Continence management devices	0 (0.0)	3 (1.2)	0 (0.0)
Date and time reminders	78 (8.8)	23 (9.5)	7 (8.0)
Electronic games	0 (0.0)	0 (0.0)	0 (0.0)
Fall detectors	68 (7.7)	9 (3.7)	5 (5.7)
Flood detectors and water temperature monitors	16 (1.8)	2 (0.8)	0 (0.0)
Gas detectors	30 (3.4)	7 (2.9)	2 (2.3)
Intercoms	4 (0.5)	1 (0.4)	5 (5.7)
Item locator devices	18 (2.0)	1 (0.4)	0 (0.0)
Lighting devices	15 (1.7)	5 (2.1)	3 (3.4)
Medication reminders and dispensers	58 (6.5)	2 (0.8)	3 (3.4)
Monitored carbon monoxide detectors	31 (3.5)	2 (0.8)	0 (0.0)
Monitored extreme temperature sensors	23 (2.6)	3 (1.2)	2 (2.3)
Monitored smoke detectors	82 (9.2)	23 (9.5)	3 (3.4)
Other	38 (4.3)	16 (6.6)	4 (4.6)
Other communication devices	3 (0.3)	0 (0.0)	0 (0.0)
Other devices that support meaningful use of leisure time	1 (0.1)	1 (0.4)	0 (0.0)
Other devices that support safety, comfort or wellbeing	10 (1.1)	10 (4.1)	2 (2.3)
Other reminder or prompting devices	11 (1.2)	0 (0.0)	0 (0.0)
Pendant alarm	236 (26.6)	45 (18.6)	17 (19.5)
Safer walking technologies – to alert a responder of movement	24 (2.7)	21 (8.7)	14 (16.1)
Safer walking technologies – to locate the user	26 (2.9)	31 (12.8)	4 (4.6)
Telephones	22 (2.5)	5 (2.1)	8 (9.2)
Voice recorders and memo minders	57 (6.4)	12 (5.0)	7 (8.0)

Note. N = 1217, AT = Assistive Technology.

6.9.5 Safety Risk and Recommended Assistive Technology

Recommended AT stratified by participant level of safety risk is presented in table 31. Participants without MMSE scores were excluded from this table to allow direct comparison with recommended AT stratified by cluster. Participants with moderate safety risk were recommended the most AT devices (*M* = 2.6), compared with *M* = 2.33 for participants with low safety risk, and *M* = 2.34 for participants with high safety risk. These results indicate that slightly more AT was recommended for participants with moderate safety risk. Chi square test indicated that there is no relationship between level of safety risk and number of recommended AT. This indicates that the number of AT recommended for participants is not impacted by their level of safety risk. Intercoms, other devices that support meaningful use of leisure time, and continence management devices were only recommended for people with moderate safety risk. The only dementia friendly TV/ radio/ music player AT was recommended for a participant with low safety risk.

Table 31 Recommended Assistive Technology stratified by Safety Risk

	Safety Risk		
	Low	Moderate	High
n(%)	491 (50.98)	411 (42.68)	61 (6.33)
AT Category			
Activity monitors for assessment only	3 (0.6)	9 (2.2)	0 (0.0)
Activity monitors for on-going monitoring	5 (1.0)	1 (0.2)	2 (3.3)
Additional AT	9 (1.8)	12 (2.9)	2 (3.3)
Alarm and pager units	9 (1.8)	2 (0.5)	0 (0.0)
Any other devices	1 (0.2)	0 (0.0)	0 (0.0)
Communication aids	2 (0.4)	1 (0.2)	0 (0.0)
Continence management devices	0 (0.0)	1 (0.2)	0 (0.0)
Date and time reminders	35 (7.1)	22 (5.4)	2 (3.3)
Dementia friendly TV / radio / music players	1 (0.2)	0 (0.0)	0 (0.0)
Fall detectors	43 (8.8)	60 (14.6)	13 (21.3))
Flood detectors and water temperature monitors	5 (1.0)	14 (3.4)	2 (3.3)
Gas detectors	15 (3.1)	16 (3.9)	2 (3.3)
Intercoms	0 (0.0)	2 (0.5)	0 (0.0)
Item locator devices	10 (2.0)	4 (1.0)	1 (1.6)
Lighting devices	4 (0.8)	4 (1.0)	0 (0.0)
Medication reminders and dispensers	56 (11.4)	36 (8.8)	6 (9.8)
Monitored carbon monoxide detectors	20 (4.1)	15 (3.6)	3 (4.9)
Monitored extreme temperature sensors	22 (4.5)	13 (3.2)	3 (4.9)
Monitored smoke detectors	41 (8.4)	45 (10.9)	9 (14.8)
Other	1 (0.2)	5 (1.2)	0 (0.0)
Other communication devices	2 (0.4)	1 (0.2)	0 (0.0)
Other devices that support meaningful use of leisure time	0 (0.0)	2 (0.5)	0 (0.0)
Other devices that support safety, comfort or wellbeing	13 (2.6)	10 (2.4)	1 (1.6)
Other reminder or prompting devices	4 (0.8)	1 (0.2)	0 (0.0)
Pendant alarm	52 (10.6)	42 (10.2)	7 (11.5)
Safer walking technologies – to alert a responder of movement	51 (10.4)	36 (8.8)	4 (6.6)
Safer walking technologies – to locate the user	44 (9.0)	26 (6.3)	1 (1.6)
Telephones	5 (1.0)	3 (0.7)	0 (0.0)
Voice recorders and memo minders	38 (7.7)	28 (6.8)	3 (4.9)

Note. *N* =963, AT = Assistive Technology, TV = Television

6.9.6 Safety Risk and Installed Assistive Technology

AT installed during the six-month period following assessment has been stratified by participants' level of safety risk in table 32. Participants with high safety risk received the greatest number of installed AT (*M* = 3.35). The number of installed AT received by participants with moderate (*M* = 3.06) and low (*M* = 3.07) safety risk were similar indicating that three or four AT were installed for participants irrespective of their level of safety risk. Chi square test indicated that there is no relationship between level of safety risk and number of installed AT. Participants with high level safety risk did not receive medication reminders and dispensers despite medication administration errors being an identified safety risk for people with dementia.

Table 32 Installed Assistive Technology stratified by Safety Risk

	Safety Risk		
	Low	Moderate	High
n (%)	645(53.00)	485(39.85)	87(7.15)
AT Category			
Activity monitors for assessment only	1 (0.2)	6 (1.2)	0 (0.0)
Activity monitors for on-going monitoring	7(1.1)	10 (2.1)	3 (3.4)
Additional AT	5 (0.8)	4 (0.8)	4 (4.6)
Alarm and pager units	10 (1.6)	2 (0.4)	1 (1.1)
Any other devices	0 (0.0)	1 (0.2)	0 (0.0)
Computer aids	3 (0.5)	0 (0.0)	0 (0.0)
Continence management devices	0 (0.0)	3 (0.6)	0 (0.0)
Date and time reminders	66 (10.2)	35 (7.2)	7 (8.0)
Electronic games	0 (0.0)	0 (0.0)	1 (1.1)
Fall detectors	27 (4.2)	36 (7.4)	19 (21.8)
Flood detectors and water temperature monitors	8 (1.2)	8 (1.6)	2 (2.3)
Gas detectors	20 (3.1)	18 (3.7)	1 (1.1)
Intercoms	5 (0.8)	5 (1.0)	0 (0.0)
Item locator devices	12 (1.9)	6 (1.2)	1 (1.1)
Lighting devices	10 (1.6)	12 (2.5)	1 (1.1)
Medication reminders and dispensers	45 (7.0)	18 (3.7)	0 (0.0)
Monitored carbon monoxide detectors	15 (2.3)	15 (3.1)	3 (3.4)
Monitored extreme temperature sensors	14 (2.2)	12 (2.5)	2 (2.3)
Monitored smoke detectors	49 (7.6)	51 (10.5)	8 (9.2)
Other	37 (5.7)	19 (3.9)	2 (2.3)
Other communication devices	3 (0.5)	0 (0.0)	0 (0.0)
Other devices that support meaningful use of leisure time	1 (0.2)	1 (0.2)	0 (0.0)
Other devices that support safety, comfort or wellbeing	9 (1.4)	13 (2.7)	0 (0.0)
Other reminder or prompting devices	8 (1.2)	3 (0.6)	0 (0.0)
Pendant alarm	149 (23.1)	127 (26.2)	22 (25.3)
Safer walking technologies – to alert a responder of movement	40 (6.2)	17 (3.5)	2 (2.3)
Safer walking technologies – to locate the user	46 (7.1)	14 (2.9)	1 (1.1)
Telephones	16 (2.5)	18 (3.7)	1 (1.1)
Voice recorders and memo minders	39 (6.0)	31 (6.4)	6 (6.9)

Note. *N* = 1217, AT = Assistive Technology, TV = Television.

6.9.7 Recommended Assistive Technology stratified by Wandering Cluster

Data for recommended AT was stratified according to risk of wandering clusters and the frequency of recommendation for each category of AT is presented in the table 33.

The mean number of AT devices recommended for each participant varied for each cluster. Participants in "living with spouse" cluster were recommended the fewest AT devices (*M* = 1.70). Participants in the "living alone" cluster which received the least caregiver support were recommended the next fewest AT devices (*M* = 2.18). Participants in the "living with other" cluster were recommended most AT devices (*M* = 5.63). Chi square showed that there is a relationship between number of recommended AT and wandering cluster (2, χ^2=400.62, p<.00001).

Table 33 Recommended Assistive Technology stratified by Wandering Cluster

	Living with spouse/ partner (1)	Living with other (2)	Living alone (3)	Total
n (%)	266 (27.6)	287 (29.8)	410 (42.6)	
AT Category				
Activity monitors for assessment only	4 (1.5)	0 (0.0)	8 (2.0)	12 (1.2)
Activity monitors for on-going monitoring	4 (1.5)	2 (0.7)	2 (0.5)	8 (4.9)
Additional AT	8 (3.0)	6 (2.1)	9 (2.2)	23 (2.4)
Alarm and pager units	2 (0.8)	4 (1.4)	5 (1.2)	11 (1.1)
Any other devices	0(0.0)	0 (0.0)	1 (0.2)	1 (0.1)
Communication aids	2 (0.8)	0 (0.0)	1 (0.2)	3 (0.3)
Computer aids	0(0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Continence management devices	1 (0.4)	0 (0.0)	0 (0.0)	1 (0.1)
Date and time reminders	18 (6.8)	17 (5.9)	24 (5.9)	59 (6.1)
Dementia friendly TV / radio / music players	0 (0.0)	0 (0.0)	1 (0.2)	1 (0.1)
Electronic games	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Fall detectors	27 (10.2)	35 (12.2)	54 (13.2)	116 (12.0)
Flood detectors and water temperature monitors	6 (2.3)	4 (1.4)	11 (2.7)	21 (2.2)
Gas detectors	7 (2.6)	10 (3.5)	16 (3.9)	33 (3.4)
Intercoms	0 (0.0)	1 (0.3)	1 (0.2)	2 (0.2)
Item locator devices	2 (0.8)	6 (2.1)	7 (1.7)	15 (1.6)
Lighting devices	2 (0.8)	2 (0.7)	4 (1.0)	8 (4.9)
Medication reminders and dispensers	10 (3.8)	44 (15.3)	44 (10.7)	98 (10.2)
Monitored carbon monoxide detectors	9 (3.4)	12 (4.2)	17 (4.1)	38 (3.9)
Monitored extreme temperature sensors	10 (3.8)	10 (3.5)	18 (4.4)	38 (3.9)
Monitored smoke detectors	29 (10.9)	25 (8.7)	41 (10.0)	95 (9.9)
Other	1 (0.4)	4 (1.4)	1 (0.2)	6 (0.6)
Other communication devices	1 (0.4)	1 (0.3)	1 (0.2)	3 (0.3)
Other devices that support meaningful use of leisure time	1 (0.4)	1 (0.3)	0 (0.0)	2 (0.2)
Other devices that support safety, comfort or wellbeing	4 (1.5)	13 (4.5)	7 (1.7)	24 (2.5)
Other reminder or prompting devices	0 (0.0)	2 (0.7)	3 (0.7)	5 (0.5)
Pendant alarm	32(12.0)	27 (9.4)	42 (10.2)	101 (10.5)
Safer walking technologies – to alert a responder of movement	42 (15.8)	19 (6.6)	30 (7.3)	91 (9.9)
Safer walking technologies – to locate the user	23 (8.6)	18 (6.3)	30 (7.3)	71 (7.4)
Telephones	3 (1.1)	3 (1.0)	2 (0.5)	8 (0.8)
Voice recorders and memo minders	18 (6.8)	21 (7.3)	30 (7.3)	69 (7.2)

Note. *N* = 963, AT = Assistive Technology, TV = Television

6.9.8 Installed Assistive Technology stratified by Wandering Cluster

Data describing the installed AT was also stratified according to the clustering solution including risk of wandering and is presented in table 34. Participants in the “living with other” cluster received the highest frequency of AT (*M* = 7.78), participants in the “living alone” cluster received fewer AT (*M* = 2.75), and participants in the “living with spouse/ partner” cluster received the least installed AT (*M* = 1.94). Chi square test indicated that there is a relationship between wandering cluster and number of installed AT (2, χ^2=360.59, *p*<.00001).

Table 34 Installed Assistive Technology stratified by Wandering Cluster

	Living with Spouse/ Partner	Living with other	Living alone	Total
n (%)	303(24.9)	397 (32.6)	517 (42.5)	
AT category				
Activity monitors for assessment only	3 (1.0)	0 (0.0)	4 (0.8)	7 (0.5)
Activity monitors for on-going monitoring	10 (3.3)	6 (1.5)	4 (0.8)	20 (1.6)
Additional ATT	4 (1.3)	3 (0.8)	6 (1.2)	13 (1.1)
Alarm and pager units	3 (1.0)	6 (1.5)	4 (0.8)	13 (1.1)
Any other devices	0 (0.0)	1 (0.3)	0 (0.0)	1 (0.1)
Communication aids	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Computer aids	0 (0.0)	3 (0.8)	0 (0.0)	3 (0.2)
Continence management devices	3 (1.0)	0 (0.0)	0 (0.0)	3 (0.2)
Date and time reminders	24 (7.9)	40 (10.1)	44 (8.5)	108 (8.9)
Dementia friendly TV / radio / music players	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Electronic games	1 (0.3)	0 (0.0)	0 (0.0)	1 (0.1)
Fall detectors	29 (9.6)	18 (4.5)	35 (6.8)	82 (6.7)
Flood detectors and water temperature monitors	4 (1.3)	3 (0.8)	11 (2.1)	18 (1.5)
Gas detectors	7 (2.3)	7 (1.8)	25 (4.8)	39 (3.2)
Intercoms	1 (0.3)	7 (1.8)	2 (0.4)	10 (0.8)
Item locator devices	2 (0.7)	8 (2.0)	9 (1.7)	19 (1.6)
Lighting devices	8 (2.6)	7 (1.8)	8 (1.5)	23 (1.9)
Medication reminders and dispensers	4 (1.3)	32 (8.1)	27 (5.2)	63 (2.9)
Monitored carbon monoxide detectors	8 (2.6)	11 (2.8)	14 (2.7)	33 (2.7)
Monitored extreme temperature sensors	8 (2.6)	7 (1.8)	13 (2.5)	28 (2.3)
Monitored smoke detectors	28 (9.2)	32 (8.1)	48 (9.3)	108 (8.9)
Other	20 (6.6)	21 (5.3)	17 (3.3)	58 (4.8)
Other communication devices	0 (0.0)	1 (0.3)	2 (0.4)	3 (0.2)
Other devices that support meaningful use of leisure time	1 (0.3)	0 (0.0)	1 (0.2)	2 (0.2)
Other devices that support safety, comfort or wellbeing	7 (2.3)	7 (1.8)	8 (1.5)	22 (1.8)
Other reminder or prompting devices	0 (0.0)	5 (1.3)	6 (1.2)	11 (0.9)
Pendant alarm	78 (25.7)	97 (24.4)	123 (23.8)	298 (24.5)
Safer walking technologies – to alert a responder of movement	20 (6.6)	10 (2.5)	29 (5.6)	59 (4.8)
Safer walking technologies – to locate the user	13 (4.3)	23 (5.8)	25 (4.8)	61 (5.0)
Telephones	1 (0.3)	13 (3.3)	21 (4.1)	35 (2.9)
Voice recorders and memo minders	16 (5.3)	29 (7.3)	31 (6.0)	76 (6.2)

Note. *N* = 1217, AT = Assistive Technology, TV = Television

6.9.9 Recommended Assistive Technology stratified by Safety Cluster

The AT recommended for participants included within each of the clusters generated from the cluster analysis of data including safety risk are presented in table 35. The number of AT recommended for participants for each of these clusters was M = 2.57 (live out caregiver) and M = 2.31 (live with someone), indicating that participants in each cluster received approximately the same number of AT recommendations. Chi square test indicated that there is no relationship between safety cluster and number of recommended AT.

Table 35 Recommended Assistive Technology stratified by Safety Cluster

n (%)	“Live with someone” 481 (49.95)	“Live-out caregiver” 482 (50.05)
AT Category		
Activity monitors for assessment only	0 (0.0)	12 (2.5)
Activity monitors for on-going monitoring	5 (1.0)	3 (0.6)
Additional AT	14 (2.9)	9 (1.9)
Alarm and pager units	9 (1.9)	2 (0.4)
Any other devices	0 (0.0)	1 (0.2)
Communication aids	2 (0.4)	1 (0.2)
Computer aids	0 (0.0)	0 (0.0)
Continence management devices	1 (0.2)	0 (0.0)
Date and time reminders	29 (6.0)	30 (6.2)
Dementia friendly TV / radio / music players	1 (0.2)	0 (0.0)
Electronic games	0 (0.0)	0 (0.0)
Fall detectors	53 (11.0)	63 (13.1)
Flood detectors and water temperature monitors	10 (2.1)	11 (2.3)
Gas detectors	10 (2.1)	23 (4.8)
Intercoms	1 (0.2)	1 (0.2)
Item locator devices	10 (2.1)	5 (1.0)
Lighting devices	6 (1.2)	2 (0.4)
Medication reminders and dispensers	55 (11.4)	43 (8.9)
Monitored carbon monoxide detectors	20 (4.2)	18 (3.7)
Monitored extreme temperature sensors	11 (2.3)	27 (5.6)
Monitored smoke detectors	37 (7.7)	58 (12.0)
Other	2 (0.4)	4 (0.8)
Other communication devices	0 (0.0)	3 (0.6)
Other devices that support meaningful use of leisure time	0 (0.0)	2 (0.4)
Other devices that support safety, comfort or wellbeing	10 (2.1)	14 (2.9)
Other reminder or prompting devices	3 (0.6)	2 (0.4)
Pendant alarm	44 (9.1)	57 (11.8)
Safer walking technologies – to alert a responder of movement	59 (12.3)	32 (6.6)
Safer walking technologies – to locate the user	45 (9.4)	26 (5.4)
Telephones	6 (1.2)	2 (0.4)
Voice recorders and memo minders	38 (7.9)	31 (6.4)

Note. *N* = 963, AT = Assistive Technology, TV = Television.

6.9.10 Installed Assistive Technology stratified by Safety Risk Cluster

AT installed for participants within each of the safety clusters is displayed in table 36. The mean number of types of AT installed per participant varied between the clusters, from *M* = 2.61 for participants in the “live with someone” cluster, and *M* = 3.5 for participants in the “live-out caregiver” cluster indicating that participants who received less caregiver support received more AT. Chi square test indicated that there is a relationship between safety risk cluster and number of installed AT (2, χ^2=69.04, p<.00001).

Table 36 Installed Assistive Technology stratified by Safety Cluster

n (%)	"Live with someone" 489 (40.2)	"Live- out Caregiver" 728 (59.8)
AT Category		
Activity monitors for assessment only	0 (0.0)	7 (1.0)
Activity monitors for on-going monitoring	5 (1.0)	15 (2.1)
Additional AT	9 (1.8)	4 (0.5)
Alarm and pager units	12 (2.5)	1 (0.1)
Any other devices	0 (0.0)	1 (0.1)
Communication aids	0 (0.0)	0 (0.0)
Computer aids	3 (0.6)	0 (0.0)
Continence management devices	3 (0.6)	0 (0.0)
Date and time reminders	44 (9.0)	64 (8.8)
Dementia friendly TV / radio / music players	0 (0.0)	0 (0.0)
Electronic games	1 (0.2)	0 (0.0)
Fall detectors	40 (8.2)	42 (5.8)
Flood detectors and water temperature monitors	9 (1.8)	9 (1.2)
Gas detectors	10 (2.0)	29 (4.0)
Intercoms	4 (0.8)	6 (0.8)
Item locator devices	7 (1.4)	12 (1.6)
Lighting devices	13 (2.7)	10 (1.4)
Medication reminders and dispensers	30 (6.1)	33 (4.5)
Monitored carbon monoxide detectors	6 (1.2)	27 (3.7)
Monitored extreme temperature sensors	6 (1.2)	22 (3.0)
Monitored smoke detectors	30 (6.1)	78 (10.7)
Other	16 (3.3)	42 (5.8)
Other communication devices	1 (0.2)	2 (0.3)
Other devices that support meaningful use of leisure time	0 (0.0)	2 (0.3)
Other devices that support safety, comfort or wellbeing	6 (1.2)	16 (2.2)
Other reminder or prompting devices	6 (1.2)	5 (0.7)
Pendant alarm	96 (19.6)	202 (27.7)
Safer walking technologies – to alert a responder of movement	40 (8.2)	19 (2.6)
Safer walking technologies – to locate the user	42 (8.6)	19 (2.6)
Telephones	13 (2.7)	22 (3.0)
Voice recorders and memo minders	37 (7.6)	39 (5.4)

Note. *N* = 1217, AT = Assistive Technology, TV = Television

6.10 Associations between Recommended and Installed Assistive Technology and Participant Groups

This section will provide a summary of chi squared tests indicating associations between recommended and installed AT and population characteristics of participants. Associations will be presented in the following order:

- AT and Risk of Wandering (Section 6.10.1)
- AT and Safety Risk (Section 6.10.2)
- Wandering Cluster Solution and AT (section 6.10.3)
- Safety Risk Solution and AT (section 6.10.4)

6.10.1 Risk of Wandering and Assistive Technology

Table 37 displays associations between recommended and installed AT and level of wandering risk and indicates the level of risk of wandering of the participants most likely to receive each type of AT.

Table 37 Associations between Assistive Technology and Risk of Wandering

Level of Risk of Wandering	Recommended AT	Installed AT
Low	Medication Reminders and Dispensers (2, $\chi^2 = 6.17$, $p = .04$)	Medication Reminders and Dispensers (2, $\chi^2 = 13.18$, $p = .001$) Pendant Alarms (2, $\chi^2 = 7.79$, $p = .020$)
Moderate	Fall Detectors (2, $\chi^2 = 10.03$, $p = .007$) Safer Walking Technologies to Locate the User (2, $\chi^2 = 54.30$, $p < .00001$)	Activity Monitors for Ongoing Monitoring (2, $\chi^2 = 15.78$, $p = .0003$) Safer Walking Technologies to Locate the User (2, $\chi^2 = 39.04$, $p < .00001$)
High	Safer Walking Technologies to alert a responder of Movement (2, $\chi^2 = 41.54$, $p < .00001$)	Intercoms (2, $\chi^2 = 27.90$, $p < .00001$) Safer Walking Technologies to alert a Responder of Movement (2, $\chi^2 = 40.40$, $p < .00001$) Telephones (2, $\chi^2 = 13.51$, $p = .001$)

Note. AT = Assistive Technology

Similarities can be observed between the patterns of recommended and installed AT stratified by risk of wandering. However, communication devices including pendant alarm, telephones and intercoms are installed but were not previously recommended. Results indicate that the wandering risk of the participant is associated with their recommended and installed AT.

6.10.2 Safety Risk and Assistive Technology

Table 38 shows associations between recommended and installed AT and level of safety risk and indicates the level of safety risk of the participants most likely to receive each type of AT.

Table 38 Associations between Assistive Technology and Safety Risk

Level of Safety Risk	Recommended AT	Installed AT
Low		Safer Walking Technologies to Locate the User (2, χ^2 = 13.41, p = .001)
Moderate	Flood Detectors and Water Temperature Monitors (2, χ^2 = 6.35, p = .041)	
High	Fall Detectors (2, χ^2 = 12.48, p = .002)	Fall Detectors (2, χ^2 = 68.62, p <.00001)

Note. AT = Assistive Technology

Table 38 shows that there were a limited number of associations between recommended and installed AT and safety risk. Fall detectors were the only category of AT which was associated with safety risk for both recommended and installed AT. There were no associations between safety risk and recommended AT where participants with low safety risk were most likely to receive the recommendation. There were also no associations between installed AT and safety risk where participants with moderate level safety risk were most likely to have the AT installed.

6.10.3 Wandering Cluster Solution and Assistive Technology

Table 39 displays associations between recommended and installed AT and the three wandering clusters and indicates which clusters' participants were most likely to receive each type of AT.

Table 39 Associations between Wandering Cluster Solution and Assistive Technology

Wandering Cluster	Recommended AT	Installed AT
Living with Spouse/ Partner	Safer Walking Technologies to alert a Responder of Movement (2, $\chi^2 = 17.35$, $p = .0002$)	Fall Detectors (2, $\chi^2 = 6.94$, $p = .03$) Safer Walking Technologies to alert a responder of movement (2, $\chi^2 = 7.33$, $p = .02$)
Living with Other	Medication Reminders and Dispensers (2, $\chi^2 = 20.46$, $p = .00004$)	Medication Reminders and Dispensers (2, $\chi^2 = 15.91$, $p = .0003$)
Living Alone		

Note. AT = Assistive Technology

The similarities between the recommended and installed AT according to wandering cluster solution are evident in table 39. Installed Fall Detectors were associated with the clustering solution although this was not the case for recommended Fall Detectors. Notably the living alone cluster participants did not receive the highest frequency of any recommended or installed AT associated with the clustering solution.

6.10.4 Safety Cluster Solution and Assistive Technology

Associations between recommended and installed AT and the two safety clusters are presented in table 40 and indicate which group of participants received the highest frequency of each type of AT.

Table 40 Associations between Safety Clustering Solution and Assistive Technology

Safety Cluster	Recommended AT	Installed AT
Live with Someone	Safer Walking Technologies to alert a Responder of Movement (2, $\chi^2 = 8.91$, $p = .003$)	Safer Walking Technologies to alert a Responder of Movement (2, $\chi^2 = 19.67$, $p = .000009$)
	Safer Walking Technologies to Locate the User (2, $\chi^2 = 5.53$, $p = .02$)	Safer Walking Technologies to Locate the User (2, $\chi^2 = 21.96$, $p = .000003$)
Live Out Caregiver	Monitored Smoke Detectors (2, $\chi^2 = 5.10$, $p = .02$)	Monitored Smoke Detectors (2, $\chi^2 = 7.58$, $p = .006$)
		Pendant Alarms (2, $\chi^2 = 10.42$, $p = .001$)

Note. AT = Assistive Technology

The relationship between the recommended and installed AT is clear for both clusters as similar AT features in both recommended and installed categories for each cluster. The associations between installed AT and the clustering solution is stronger than for recommended AT. Installed pendant alarms are associated with the live out caregiver cluster, whereas this was not the case for recommended pendant alarms.

6.11 Summary

A brief summary of the main results of the analysis is presented before proceeding to discuss these results within the context of recent literature.

6.11.1 How are Needs associated with Risks for People with Dementia?

- Missing data indicates that AT needs assessment fidelity to agreed standards is low. Missing data ranged from 26% for posture and mobility needs to 72% for physical resource needs. Information relating to social groups; responsibility and knowledge is most frequently documented.
- Results of univariate regression analysis demonstrated that there is association between risk of wandering and the following AT needs: Posture and Mobility: *OR* = 0.925, 95% CI [0.894, 0.956], *p* = .000003, Routine: *OR* = 0.145, 95% CI [0.040, 0.369], *p* = .0003, Occupational Demands: *OR* = 0.225, 95% CI [0.059, 0.618], *p* = .008, and Conversation: *OR* = 0.500, 95% CI [0.250, 0.999], *p* = .048. MMSE was also associated with risk of wandering *OR* = 0.925, 95% CI [0.894, 0.965], *p* = .000005.
- The relationship between needs and wandering risk was further explored in an ordinal regression model. Results indicated that for a one-point reduction in risk relating to posture and mobility the odds of the person with dementia having a higher level of risk of wandering are *OR* = 3.784, 95% CI [1.820, 8.501] *p* < .0006, when the MMSE and Routine variables are held constant. For a one point reduction in risk relating to Routine, where the other variables are held constant, the odds of the participant having a higher level of risk of wandering increase by *OR* = 0.113, 95% CI [0.015, 0.388], *p* = .004 – a value of less than one indicating reduced odds that the risk of wandering will increase when there is a reduction in level of risk associated with Routine. More simply, as risk associated with Routine reduces risk associated with wandering also reduces. A one-point increase in MMSE score, where the other variables are held constant increases the odds of the participant having an increased risk of wandering, *OR* = 0.947, 95% CI [0.906, 0.990], *p* =.017, – so improved cognition is associated with reduced risk. Therefore, as risk of wandering increases, risk associated with posture and mobility decreases but risk associated with Routine, and MMSE increases.
- Results of univariate analysis demonstrated that there are associations between safety risk and AT needs: Posture and mobility, *OR* = 0.294, 95% CI [0.174, 0.486], *p* = .000002,

Occupational Demands, *OR* = 0.407, 95% CI [0.162, 0.950], *p* = .043, Appraisal of Abilities, *OR* = 0.327, 95% CI [0.130, 0.729], *p* = .009, and Problem solving, *OR* = 0.209, 95% CI [0.056, 0.564], *p* = .005.

- The relationship between needs and safety risk was further explored in ordinal regression model which indicated that a one point in risk relating to posture and mobility, where problem solving variable is held constant, the odds of the participant having an increase in safety risk are *OR* = 0.294, 95% CI [0.146, 0.578], *p* = .0005. Similarly, for a one-point increase in problem solving risk, where the other variables are held constant the odds of the participant having an increase in level of safety risk are 0.233, *OR* = 0.233, 95% CI [0.060, 0.676], *p* = .014. As these odds ratios are less than one, these results indicate that reduced posture and mobility or problem-solving risk are associated with a decrease in level of safety risk.

6.11.2 Are there distinct Groups of People with Dementia living at Home?

- Using a partitioning around medoids (PAM) algorithm, a robust structure of three clusters (silhouette width = 0.63) was found using caregiver support, living situation, MMSE and risk of wandering variables.
- Using a partitioning around medoids (PAM) algorithm, a robust structure of two clusters (silhouette width = 0.59) was found using caregiver support, living situation, MMSE and safety risk variables.
- The solutions uncovered structure within the data relating to level of caregiver support and living situation of the person with dementia. The influence of caregivers and the wider support network of the person with dementia in all aspects of AT service provision is evident across the literature (Gibson et al. 2019), and will be discussed further in section 7.5.

6.11.3 Do these Clusters of People with Dementia have different recommended and installed Assistive Technology?

- 395 participants received recommendations for 963 AT devices. In the six months following assessment 1217 AT devices were installed. This AT data was linked with the clustered participants in order to determine the effects of multiple variables upon recommended and installed AT.

- Clustering structures based on data which included risk of wandering, caregiver support, living situation and MMSE were associated with AT recommendations for people with dementia (2, χ^2=400.62, p<.00001). Specifically, recommendations of safer walking technologies to alert a responder of movement (2, χ^2 = 17.35, p = .00002) which were most likely to be recommended for participants living with spouse/ partner; and medication reminders and dispensers (2, χ^2 = 20.46, p = .00004) which were most likely to be recommended for participants living with other.
- Additionally, AT installations were associated with clustering structures based on variables which included risk of wandering (2, χ^2=360.59, p<.00001), particularly fall detectors (2, χ^2 = 6.94, p = .03), medication reminders and dispensers (2, χ^2 = 15.91, p = .0003), and safer walking technologies to alert a responder of movement (2, χ^2 = 7.33, p = .02).
- Clustering structures based on data which included safety risk, caregiver support, living situation and MMSE were associated with recommendations of the following AT for people with dementia. Specifically, Safer Walking Technologies to alert a Responder of Movement (1, χ^2 = 8.91, p = .003), and Safer Walking Technologies to Locate the User (1, χ^2 = 5.53, p= .02) both of which were most likely to be recommended for participants living with someone. Monitored smoke detectors were also associated with this clustering solution (1, χ^2 = 5.10, p = .02) and were most likely to be recommended for participants with live-out caregiver.
- Installed AT were also associated with clusters which included data on safety risk (1, χ^2=69.04, p<.00001). Safer Walking Technologies to alert a responder of movement (1, χ^2 = 19.67, p = .000009), and Safer Walking Technologies to Locate the User (1, χ^2 =21.96, p = .000003). These were both more likely to be installed for people living with someone. Participants with live out caregiver were more likely to have Monitored smoke detectors (1, χ^2 = 7.58, p = .006), and Pendant Alarms (1, χ^2 = 10.42, p =.001) installed.
- Further, level of risk of wandering was associated with the recommendation of fall detectors (2, χ^2 = 10.03, p = .007), safer walking technologies to alert a responder of movement (2, χ^2 = 41.54, p < .00001), safer walking technologies to locate the user; (χ^2 = 54.30, p < .00001), and medication reminders and dispensers (2, χ^2 = 6.17, p = .040).
- Safety risk was associated with recommendation of fall detectors (2, χ^2 = 12.48, p = .002) and flood detectors and water temperature monitors (2, χ^2 = 6.35, p = .041).

- Level of risk of wandering was associated with the installation of activity monitors for ongoing monitoring (2, $\chi^2 = 15.78$, $p = .0003$); intercoms (2, $\chi^2 = 27.90$, $p < .00001$) ; medication reminders and dispensers (2, $\chi^2 = 13.18$, $p = .001$); other devices that support safety, comfort and wellbeing (2, $\chi^2 = 9.81$, $p = .007$); pendant alarms (2, $\chi^2 = 7.79$, $p = .020$); safer walking technologies to alert a responder of movement (2, $\chi^2 = 40.40$, $p < .00001$); safer walking technologies to locate the user (2, $\chi^2 = 39.04$, $p < .00001$); and telephones (2, $\chi^2 = 13.51$, $p = .001$).
- Level of safety risk was associated with the installation of fall detectors (2, $\chi^2 = 68.62$, $p < .00001$), safer walking technologies to locate the user (2, $\chi^2 = 13.41$, $p = .001$).

Key findings reported in this chapter will now be considered in the context of previous research and relevant subject literature. Limitations of the presented research as well as implications of findings will also be addressed.

CHAPTER 7. DISCUSSION

This chapter discusses the results of the secondary data analysis in the context of the published literature in order to validate the contribution of this research within the field of AT for people with dementia. This chapter also considers the limitations of this analysis prior to providing a statement regarding the unique contribution of the analysis to the field.

This chapter begins by briefly reviewing the context supporting the need for this research (section 7.1). It continues by describing the characteristics of AT needs assessments for people with dementia living at home (section 7.2). Thereafter, the associations between risk of wandering and the needs of people with dementia are examined (section 7.3). Similar examination of the relationship between safety risk and the needs of people with dementia follows (section 7.4). Then, the clustering solutions developed from multiple data variables which were structured around the caregiver support and living situation of the person with dementia, are placed in context (section 7.5). This is followed by discussion regarding AT for people with dementia at risk of wandering (section 7.6), and AT for people with dementia with safety risks (section .7.7). The influence of caregiver support and living situation on AT is then reviewed (section 7.8). Limitations in the use of AT to meet the needs of people with dementia is discussed (section 7.9). Thereafter the implications of these results for AT service improvement are presented (section 7.10). This is followed by discussion of further ethical considerations (section 7.11) and consideration of the limitations of this research (section 7.12). A statement of the unique contribution of this research is presented (section 7.13), before the main points of the chapter are summarised (section 7.14).

7.1 Assistive Technology for People with Dementia

The number of people living with dementia is increasing (Alzheimer's Society 2014; Sriram et al. 2019). The additional cost of providing care to meet the wide range of care needs of this population has created interest in exploring alternative means of care (Powell and Baker 2019). AT has been identified as having the potential to assist in meeting the care needs of people with dementia (Boger et al. 2014), but there is a gap between the required interventions and the services actually provided (World Health Organisation 2017). In order to provide AT which meets the needs of people with dementia there is a requirement to improve our understanding of their AT needs and other characteristics which impact upon their use of AT (Bernd et al. 2009; Schmid et al. 2012). This research therefore aimed to develop understanding of the type of needs experienced by people with dementia, and how variation in needs and other population characteristics impact AT recommended and installed for this population.

Results of the systematic review and meta-analysis examining the prevalence of needs experienced by people with dementia have been discussed in chapter 2. Needs and risks are similar as they are both associated with adverse outcomes (Seden 2016). As wandering and safety are identified in previous research as a major concern of informal and professional caregivers (Douglas et al. 2011; Collins 2018), particular attention was paid to AT needs relating to these risks. This information regarding the needs of people with dementia can facilitate service providers in adopting a client centred approach to service delivery (Rothera et al. 2003; Raivio et al. 2011). Targeting services towards unmet needs allows service providers to tailor interventions for particular people with dementia.

However, needs are only one of the population characteristics which affect healthcare service use (Phillips et al. 1998; Toseland et al. 2002). Previous research has struggled to explain the relationship between different population characteristics of people with dementia including their needs, and the influence which is exerted by each of these characteristics upon AT (Bernd et al. 2009; Boger et al. 2014). As previous research has focussed on the relationship between AT provision and particular population characteristics (Fleming and Sum 2014), this secondary data analysis study aimed to test the possibility of grouping people with dementia according to multiple population characteristics. Identifying groups or categories of people with dementia according to population characteristics can facilitate research regarding effective AT by identifying transferable insights which may apply to others within these groupings (Greenhalgh et al. 2016). This second study grouped people with dementia according to their personal needs, predisposing characteristics and enabling resources. By grouping people with dementia according to a number of different population characteristics researchers can evaluate the impact of multiple factors upon AT. This allowed consideration of multiple factors which may interact with each other or have different effects upon recommended and installed AT. Results of these cluster analyses, their validity within the literature describing people with dementia, and their association with recommended and installed AT will also be discussed.

7.2 Needs Assessment

The data for this second study was drawn from a secondary dataset which included information on the sample population for the ATTILA RCT examining the effects of AT for people with dementia living at home. One aspect of this data was the needs assessment which was conducted by staff on behalf of health and social care agencies, prior to the person with dementia being recommended AT which was analysed and categorised using a MOHOST framework (Forsyth et al. 2019).

In line with previous research, results demonstrate high levels of missing data within the needs assessment documentation, which suggests that there was a limited fidelity between the agreed AT Needs Assessment standard and actual practice (Hansen et al. 2018; Forsyth et al. 2019). In many instances, only one or two needs appear to have been considered during the assessment process (Forsyth et al. 2019). Reasons for this are unknown but may include limited assessment skills, redundancy in the assessment fields or limited availability of AT, and will now be explored further in relation to the literature (Sugarhood et al. 2014; Hansen et al. 2018).

Whilst comprehensive assessment of the person with dementia's AT need is recommended (Newton and Robinson 2013; Lynn et al. 2017), no research has identified the factors which should be considered when recommending appropriate AT to address safety issues in people with dementia (Gagnon-Roy et al. 2017). There is however, an obligation for staff to identify opportunities for the reduction of need and promotion of wellbeing or quality of life, in addition to providing interventions which are most suited to the needs and characteristics of the person with dementia and their caregiver (Mandelstam 2016).

As assessment should be accurate and proportionate (Mandelstam 2016), the low levels of assessment evident in the results may indicate that it is possible to identify and prioritise needs without comprehensive assessment. In straightforward cases self-assessment or telephone assessment may have been considered appropriate (Mandelstam 2016), although it was not possible to gauge the criteria for this brief assessment from the available data. This may mean that health and social care professionals may only require to be involved in more complex cases (Mandelstam 2016). However, data on the background of the assessor was mostly missing from the dataset meaning it was not possible to understand the variation in assessment practices between assessors with different professional backgrounds or levels of experience. Results suggest that fields within the agreed AT needs assessment standards may be redundant, at least in some cases (Forsyth et al. 2019). However, this research supports previous findings indicating that people with more severe dementia actually have less assessment documented that people with more mild cognitive impairment (Hansen et al. 2018). This indicates that reduced level of assessment may not correspond to reduced level of need.

Results indicate increased amounts of missing needs assessment data for people with dementia experiencing high safety risk, suggesting there may be a limited number of practitioners with the appropriate skills, or a lack of validated instruments, for the assessment of people with greater cognitive impairment (van Ooteghem et al. 2019). Documented needs and subsequent service provision may be influenced by perceptions of how challenging the needs are to assess and describe irrespective of the impact of these needs on the lives of people with dementia (Hansen et al. 2018). In general needs that cannot be assessed via interview are less likely to be considered (Malinowsky et al. 2018). Specialist fields identified as important to people with dementia such as visuospatial abilities and sensory impairments, are also less likely to be assessed as a result of the limited availability of validated specialist assessment methods (van Ooteghem et al. 2019). Hence, limited documentation of needs evident in the results of this research may reflect a lack of need on the part of the person with dementia, or alternatively an inability on the part of the assessor due to limited assessment instruments, experience, time or training. In some cases, this may indicate that assessors are obtaining information through only one assessment method, such as interview, rather than employing a variety of assessment methods including practical assessment or observation of the participant conducting particular aspects of their daily living.

Previous research found that health professionals tended to focus on the physical domains (e.g. posture and mobility), and on risks relating to the presenting diagnosis – presumably memory and cognition for people with dementia (Dickins et al. 2018). However, this is contradicted in part by the low reporting of needs relating to physical space and physical resources in the current secondary data analysis study. In the current research, high levels of documented needs in the social group field could indicate assessors' understanding of the relevance of caregiver support to wellbeing of people with dementia, and also the importance of the presence of a caregiver in the acceptance of AT interventions (O'Keeffe 2017; Gibson et al. 2018). Frequency of documented needs, such as social groups, may also reflect the assessment items which are most easily observed (Hansen et al. 2018).

Previous research has confirmed that interviewing people with dementia requires specialist skills and training (van Ooteghem et al. 2019). Particular difficulties with assessment arise when the person with dementia has sensory difficulties, previous stroke, tremor, or low levels of literacy

(Raiha et al. 2001), and people with severe dementia may be unable to understand questions in particular assessments (Miranda-Castillo et al. 2010). These are all factors which may have contributed to the reduced levels of assessment for people with more severe cognitive impairment in this secondary data study population, and can reduce the effectiveness of assessment in this population. This reduced level of understanding of the needs of certain groups can also result in people with particular characteristics such as increased age or increased cognitive impairment being less likely to receive service (Hansen et al. 2018).

In order to improve the quality of assessment there is also a need for further investigation regarding fields for which there are no currently available validated assessment tools (van Ooteghem et al. 2019). Additionally, clinicians with expertise in assessing people with advanced dementia, or dementia and additional impairments should be encouraged to share this expertise through the creation of resources which will support others to develop skills in these fields (Greenhalgh et al. 2015). Research indicates that the right skills and preparation can facilitate good assessment for people with dementia. Assessors must remember the importance of taking time to build relationships with the person with dementia, try to identify underlying meaning in behaviour or what is being said, use prompts such as photographs, and use alternatives to direct questioning such as collecting information through conversation (Moriarty 2005; Handley et al. 2017). There is also a requirement for support from managers with expert knowledge in the field and the provision of opportunities to discuss assessment decisions (Handley et al. 2017).

Professionals within this field acknowledge a lack of awareness regarding available AT (Jarvis et al. 2017). The impact of limited professional knowledge in AT may contribute to reduced assessment as professionals focus on areas which have an easily identified solution. It has been found that purchasers felt that services provided in response to assessed needs were influenced by the ease of formulating administrative decisions relating to the need – in which case physical needs were generally easier to document and could possibly be linked to appropriate interventions more easily (Hansen et al. 2018). In the current secondary data analysis study, this may partly explain the frequency of AT recommended and installed to meet needs associated with falls, safer walking and wandering. It is possible that in many cases these are seen as physical needs which clearly relate to specific interventions. As there are a range of AT devices which are clearly aimed at reducing adverse outcomes associated with these risks (Liu et al. 2017; Lauriks et al. 2018; Jarvis et al. 2017), service providers feel able to offer a potential solution to the participants and their caregiver.

In general, if the assessment process accounts for fewer aspects of the abilities of the person with dementia, and their caregivers, there is reduced material which can be used for the individualisation of the intervention (Greenhalgh et al. 2013). There is also a requirement that the assessment explores these needs sufficiently to inform the assessor regarding the required AT. Therefore, whenever these assessment requirements are unmet any subsequent intervention may be less tailored towards the particular needs of the person with dementia and less likely to be adopted by the person with dementia (Schmid et al. 2012; Gibson et al. 2015).

An alternative explanation for the results, indicating the low number of items considered during assessment, is that there is a limited range of AT available for installation (Woolham et al. 2006; Ward et al. 2017). In a supply led service, the needs of the individual are not the priority (Sugarhood et al. 2014; Hansen et al. 2018). In such a service, assessors provide the only available solution for a particular problem with limited focus on individualisation (Sugarhood et al. 2014; Hansen et al. 2018), and further assessment could not result in any other outcome. However, “off the shelf” AT will often not meet the needs of people with dementia and requires to be tailored for it to meet individual need (Sugarhood et al. 2014; Greenhalgh et al. 2015), suggesting that this type of service will not produce an effective result.

This section has confirmed a requirement to identify the needs of people with dementia in addition to exploring the capacity of the person with dementia and their support network to benefit from AT. Additionally, results indicated that in many cases fidelity to the agreed standard of assessment was low, possible reasons for this were explored with reference to the literature. The following section will focus upon the population characteristics including needs of people with dementia that are associated with risk of wandering.

7.3 Needs of People with Dementia and their association with Risk of Wandering

This section will focus on the needs of people with dementia living at home and their relationship with risk of wandering. As previously discussed, there is debate in the literature regarding the definition of wandering. This research therefore sought to explore the identified needs and other characteristics of people categorised as having wandering risks. Population characteristics have previously been defined within this document and include needs, enabling resources and predisposing characteristics (Phillips et al. 1998). These characteristics are all associated with the use of healthcare services including AT but the relative importance and interaction of different population characteristics is unknown (Toseland et al. 2002). Further understanding of these characteristics and their impact upon the use of AT is required to recommend and install AT which meet the needs of people with dementia and their caregivers. This section will describe and explore the results regarding the population characteristics of people with dementia including their needs, and how these relate to their risk of wandering.

Most participants in the ATTILA RCT dataset had low risk of wandering, and the number of people with dementia categorised as having a high risk of wandering appears low when compared with the literature. The estimated prevalence of wandering for people with dementia living in the community may range from 17 to 63% (MacAndrew et al. 2018). The low numbers of people with dementia rated as having high risk of wandering within this second study may be due to the people with dementia included in the original ATTILA RCT having relatively high levels of cognition (MMSE), whilst wandering is most common in the moderate to severe stages of dementia (Bantry White and Montgomery 2014). Further, the advice given to data gatherers regarding the risk of wandering rating was to base the decision upon previous wandering incidents and did not therefore consider other factors which may predispose a person with dementia to adverse outcomes associated with wandering such as spatial disorientation, or lack of supervision.

Results of this research show that level of risk was related to population characteristics. This research supports previous findings that risk of wandering is associated with gender. However, in this research females were more likely to be categorised as high risk of wandering, whereas previous research found that men were more likely to become lost in the community (Rowe et al. 2004). Results support previous findings regarding the relationship between MMSE and risk of wandering (Song and Algase 2008), and regarding the relationship between MMSE and safety risk (Thoma-Lürken et al. 2018). The association between wandering and safety risk in the results of this research contradicts previous findings, as both are associated with adverse outcomes in the literature (Douglas et al. 2011). This may result from issues relating to the definition of wandering. Further, results support previous research which found that younger age was associated with increased wandering and pacing (Song and Algase 2008).

Whilst, there are limited studies reporting the prevalence of wandering for people with dementia living alone, results supports previous research which identified living alone as a risk factor for people with dementia dying whilst wandering outdoors (Furumiya and Hashimoto 2015). Additionally, low levels of supervision or time spent alone have been associated with missing incidents for people with dementia (Bowen et al. 2011; Rowe et al. 2015; MacAndrew et al. 2018). Conversely, results from the cluster analysis show that participants in the "living with other" cluster had the greatest frequency of participants with high risk of wandering. This contradiction has arisen as a result of the removal of data for participants without recorded MMSE scores prior to cluster analysis resulting in a population with lower risk of wandering, lower safety risk, and with fewer participants living with other. Caregivers of participants in this "living with other" category are likely to be adult children of participants who have other time consuming and stress creating commitments such as employment or childcare which result in the person with dementia spending more time unsupervised (Rowe and Glover 2001). Therefore, participants in this living situation are likely to spend more time alone than participants living with spouse/ partner, supporting previous research that they are more likely to wander (MacAndrew et al. 2018). Notably for a risk often linked with caregiver anxiety and the impact of caregiving throughout the literature, the current research identified no significant associations between wandering and living situation, caregiver support or social group needs variables.

The relationships between predisposing characteristics of people with dementia and risk of wandering have been reviewed. Results of data analysis show that risk of wandering is associated with the following needs: Posture and Mobility (section 7.3.1); Routine (section 7.3.2); Occupational Demand (section 7.3.3); and Conversation (section 7.3.4), in addition to the association with MMSE score (section 7.3.5). The relationship of each of these needs and their relationship with wandering in regard to people with dementia will now be considered in turn.

7.3.1 Posture and Mobility

Notably, the regression analyses indicate that higher risk of wandering is strongly associated with reduced level of posture and mobility risk. This result indicates that people with dementia who have better ability to walk are considered to be at greater risk of wandering perhaps because walking is a characteristic of wandering and people with reduced ability to walk are therefore less able to wander or unable to wander as far (Algase et al. 2009). However, Algase et al. (2009) found that mobility and wandering were only related when cognitive impairment was also considered. This result also indicates that participants who were categorised as having a high risk of wandering were less likely to fall even though this is one of the major adverse outcomes associated with wandering in the literature (Buchner and Larson 1987). This result supports findings that people with dementia who frequently wander are independently mobile, and that wandering is associated with the amount of time spent walking (MacAndrew et al. 2018). Overall, this result indicates that the concerns of the persons categorising the level of risk of wandering related to participant elopement or getting lost rather than to them falling. Caregivers of people with dementia who wander have been found to experience greater caregiver impact than caregivers of people with dementia who are non-ambulatory (Chung and Lai 2011), supporting the view that caregiver anxiety may contribute to the significance of mobility to risk of wandering.

7.3.2 Routine

Further, results also showed that people with dementia who had less risk associated with their daily routine were considered to have a lower risk of wandering. This indicates that people with dementia less likely to wander are more able to arrange a balanced, organised and productive schedule of daily activities (Parkinson et al. 2002). This supports previous understanding that people who exhibited wandering behaviour were more likely to experience reduced capacity for conducting basic activities of daily living (Nygard 2004; Barrett et al. 2018). Low risk of wandering would also therefore indicate an absence of restlessness and agitation, drinking excess alcohol or taking drugs, disorientation, night time disturbances, and lengthy periods spent alone (Parkinson et al. 2004; Forsyth and Dunk 2014). Results are therefore in line with previous research which identified that anxiety and agitation precede wandering incidents (Bowen et al. 2011; Chung and Lai 2011).

7.3.3 Occupational Demand

Univariate analyses indicated an association between level of wandering risk and needs related to occupational demand. Therefore, results indicate that when a participant encounters difficulty completing a task as a result of their changing capacities, they are more likely to wander (Forsyth and Dunk 2014; Ali et al. 2016; Andrew et al. 2019). This finding supports the explanation that as people with dementia may fail to comprehend the severity of their cognitive deficits, they continue to employ previously successful strategies in everyday occupations (Nygard 2004). This may also result in a reduced ability to adapt strategies to cope with the progressive changes they are experiencing. Relevant examples from the literature include that people with dementia experience difficulty in retaining instructions prior to wandering behaviour (Bowen et al. 2011). Further, it has previously been noted that people with dementia experienced wandering incidents as they lacked the insight and awareness that they were lost or not in their usual location (Algase et al. 2003; Song et al. 2008; Bowen et al. 2011), and therefore did not attempt to seek assistance.

7.3.4 Conversation

Further, results indicated an association between level of wandering risk and level of conversation needs. Hence, when a participant experiences difficulty initiating, disclosing or sustaining conversation, they are also more likely to have an increased risk of wandering (Hydén and Örulv 2009; Forsyth and Dunk 2014; Kindell et al. 2017). Engaging in communication is important as it leads to social involvement and participation in organised activities, which provide opportunity to acquire personhood and social identity (Gjernes 2017). Reduction in linguistic capacity is associated with dementia, and with a socially marginal or isolated life (Gjernes 2017), as a person's ability to produce meaningful talk is a function of cognitive ability and interaction (Kindell et al. 2017). Therefore, conversation needs can become intertwined with routine related needs such as spending lengthy periods of time alone. Additionally, these findings support previous research which has associated verbal fluency with people with dementia becoming lost (Pai and Lee 2016).

7.3.5 MMSE

Results of this research support Song et al. (2008) who identified a significant association between MMSE scores and risk of wandering i.e., participants with a high risk of wandering had lower MMSE than participants with moderate or low risk of wandering. This is in line with the findings reported in the literature stating that wandering is associated with cognitive decline (Dewing 2005), and also that risk of wandering increases as dementia progresses (Algase 1999). Previously, Algase et al. (2001) cautioned that although cognitive impairment explains a proportion of the variation in amount of random wandering, this should not distract researchers from exploring other factors which are more amenable to intervention such as human needs and environmental conditions.

This section has explored the relationships identified between risk of wandering and population characteristics of people with dementia particularly needs. The attention of the author will now focus on the relationships between needs and safety risk for this population.

7.4 Needs of People with Dementia and their association with Safety Risk

This section will focus on the needs of people with dementia living at home and their relationship with safety risk. The results regarding the population characteristics of people with dementia including their needs, and how these relate to safety risk will be described and explored.

Safety risks are associated with adverse outcomes for people with dementia (Amjad et al. 2016; Gagnon–Roy et al. 2017; Tudor Car et al. 2017). These adverse outcomes can include falls, medication administration errors; ingestion of toxic substances; burns, malnutrition and other possible events which may lead to a requirement for emergency service intervention (Douglas et al. 2011; Harvey et al. 2016; Yayama et al. 2017). This wide range of safety risks and adverse outcomes for people with dementia mean that it can be difficult to draw conclusions from the literature regarding appropriate interventions.

Predisposing characteristics including MMSE, living situation, caregiver support and age were associated with safety risk in this population. Most participants within the dataset had low safety risk reflecting low incidence of accidental injury identified in the literature (Douglas et al. 2011). Results regarding the relationship between safety risk and MMSE support previous findings that decline in cognitive function is associated with accidental injury (Douglas et al. 2011). Participants with a high safety risk were most likely to live with a spouse or partner and have a live-in caregiver, which contradicts previous findings that people without informal caregivers are less likely to remain living at home (Thoma-Lürken et al. 2018). This may mean that people may remain home for longer as a result of this additional informal support. Results also contradict previous findings that older age is associated with the long-term care placement of people with dementia (Cepoiu-Martin et al. 2016).

Safety risk was shown to be associated with Posture and Mobility (section 7.4.1); Problem Solving (section 7.4.2); Appraisal of Abilities (section 7.4.3) and Occupational Demand (section 7.4.4). The relationship between safety risk and each of these needs will now be discussed briefly in turn.

7.4.1 Posture and Mobility

This research explored the associations of safety risk with needs identified by health and social care practitioners in order to provide information regarding modifiable factors relating to safety risks which can provide a target for interventions aiming to reduce adverse outcomes. Results showed a direct association between posture and mobility risk and safety risk. This supports previous research which demonstrates that falls are one of the major adverse outcomes for people with dementia (Harlein et al. 2009; Goldup 2017; van Ooteghem et al. 2019). Furthermore, people with dementia who fall are more likely to have performed poorly in gait and balance measures, and to have fallen within the previous year (Goldup 2017). However, this results contradicts previous findings from this research which associated higher risk of wandering with reduced posture and mobility risk. Published research associates wandering with increased risk of harm in this population (Tierney et al. 2004), and this research supports a direct association between safety risk and posture and mobility risk. The relationship between posture and mobility risk and adverse outcomes is therefore complicated and requires further investigation.

7.4.2 Problem Solving

Problem solving needs were also associated with safety risk in univariate analysis. This supports findings that the safety of people with dementia is directly affected by symptoms including memory loss, inability to reason and poor judgement (Riikonen et al. 2010; Sandberg et al. 2017), as people with dementia report difficulties resulting from improper use of electronic devices, unsafe behaviours in traffic and improper medication use arising from a lack of safety measures which would prevent dangerous situations (Thoma-Lürken et al. 2018). People with dementia may also experience situations in a fragmented way or be unable to recall the sequence of events resulting in risky situations (Sandberg et al. 2017). People with frontotemporal dementia have been shown to be particularly affected by decline in judgement and problems solving which are associated with reduced functional status (Mayo et al. 2013).

One potential consequence associated with an inability to manage critical incidents is when people with dementia withdraw from activities which they previously enjoyed in order to feel safer (Sandberg et al. 2017). Sandberg et al. (2017) found that this led to participants feeling constrained and that they were losing contact with their life. Hence, adverse outcomes associated with safety needs can results in people with dementia experiencing reduced quality of life.

7.4.3 Appraisal of Abilities

Appraisal of abilities was also associated with safety risk in the results of the secondary data analysis study. There is a lack of literature describing the relationship of appraisal of abilities with issues of safety for people with dementia. However, within the literature the term “insight” is used to describe a similar concept defined as a discrepancy between the subject’s view of reality and that of others (Howorth and Saper 2003). People with dementia report decreased self-reliance as one of the most common problem domains they experience (Thoma-Lürken et al. 2018). Further people with dementia consistently report an inability to judge risk or to make independent decisions, and require to be supported, particularly in the identification of possible risks and to determine a suitable course of action in the event of an emergency (Thoma-Lürken et al. 2018). Additionally, research has found people with dementia living alone were unlikely to recognise their own cognitive impairment and found that this placed them at greater danger of adverse outcomes (Lehmann et al. 2010).

7.4.4 Occupational Demand

Safety risk and occupational demand were also found to be associated. This result supports the literature which states that during the progression of dementia changes in the individual's capacity to complete complex tasks can result in the person with dementia making mistakes (Andrew et al. 2019), and this decline in capacity can directly impact upon the person with dementia's ability to safely perform key tasks (Öhman et al. 2001; Ritchie et al. 2017). This is confirmed by Thoma-Lürken et al. (2018) who found that people with dementia identified a lack of ability to structure the sequence of complex activities resulting in them being unable to manage medications, conduct financial administrative tasks or undertake certain aspects of housekeeping. Additionally, as previously discussed, the onset of dementia or co-morbidities can add to the burden of tasks requiring to be undertaken by the person with dementia (Lorig and Holman 2003; Piven 2015). They may for example be coping with a more complex medication regime or require to manage attendance at multiple clinic appointments. This increase in expectation can also upset the match between the participants' capacity and the requirements of the activities required for occupational demand resulting in additional incidence of adverse outcomes.

7.4.5 Summary

Overall, these results indicate how some of the needs experienced by people with dementia are related to safety and wandering risks. In order to reduce the safety and wandering risks of people with dementia who are living at home health and social care professionals require a greater awareness of the relationship between needs and risk of adverse outcomes in order to effectively target interventions which may reduce the level of risk experienced by people with dementia, thereby reducing adverse outcomes (Allan et al. 2009; Amjad et al. 2016).

Further, identification of variation in unmet needs and their relationship with adverse outcomes provides the professional with an increased understanding regarding the range of factors at which they can target interventions (Gitlin et al. 2018). These sources of variation can also provide insight into protective factors associated with safety and wandering as well as identifying factors which may exacerbate these risks. This is important as previous research has neglected to identify which factors should be considered when selecting AT in dementia care (Gagnon-Roy et al. 2017).

The results of these analyses support recent research which found that professionals prioritised the assessment of the person with dementia's abilities with regard to their stage of dementia as this provides important information with regard to the tailoring of activities to the abilities of the individual, as distinct from the assessment of risk (van Ooteghem et al. 2019). Conversely, risk assessment is seen by professionals as having a deficit focus where the aim is to mitigate adverse outcomes (Dickins et al. 2018). However, lack of specialist assessment tools can restrict professionals from focussing upon particular factors in the care of people with more severe dementia (Miranda-Castillo et al. 2013; van Ooteghem et al. 2019).

Additionally, by identifying the needs of people with dementia through comprehensive assessment processes, or by identifying areas where assessment was not possible, practitioners are collecting evidence which can thereafter be used to enhance service provision through the development of services and assessment procedures where currently no effective intervention exists (Seden 2016).

This section has concentrated on the associations that exist between the needs of people with dementia and wandering or safety risk. However, it is recognised that needs are not the only population characteristics which impacts upon healthcare use (Phillips et al. 1998). The focus of this document will now turn to discuss the examination of multiple population characteristics which might impact AT recommendations and installations.

7.5 Are there distinct groupings of People with Dementia living at Home?

In order to meet the needs of people with dementia living at home there is a requirement to explore the relationship between multiple characteristics which affect service provision. This secondary data analysis therefore investigated the possibility of grouping or clustering people with dementia according to their personal characteristics in order to examine the relationship between these clusters and recommended and installed AT. Identifying clusters of participants with similar characteristics will facilitate personalised interventions, thereby increasing the acceptability and use of AT to reduce adverse outcomes to provide acceptable and effective support (Farmer et al. 2016; Meiland et al. 2017). Additionally, there is a possibility of identifying insights regarding AT for people with dementia possessing particular characteristics (Greenhalgh et al. 2016). Previously AT has been identified as having the potential to assist people with dementia and their caregivers (Boger et al. 2014) but there is a gap between the services currently provided for people with dementia and the interventions they actually need (World Health Organisation 2017). In order for AT to fulfil its potential this research aimed to advance understanding of the relationship between the heterogeneous needs of people with dementia and specific AT interventions which may meet those needs (Fleming and Sum 2014).

Until now, AT research has focussed upon the technical aspects of AT interventions, and has neglected the context within which AT is provided, by failing to consider the use of AT in the real world rather than the laboratory (Bernd et al. 2009; Friederich et al. 2010; Meiland et al. 2017). In order to advance knowledge regarding the fulfilment of the AT requirements of the individual this research explored the possibility of grouping people with dementia according to co-occurring characteristics which impact their use of AT (Bernd et al. 2009). Previous research has identified the importance of enabling resources and predisposing characteristics in addition to needs, in determining the use of healthcare services (de Klerk et al. 1997; Toseland et al. 2002; Scherer et al. 2007). However, the investigation of any single variable and its relationship with AT does not provide results which represent the real world (Greenhalgh et al. 2016; Meiland et al. 2017). Further, the heterogeneity of people with dementia and their individual contexts limits our understanding of AT user requirements (Greenhalgh et al. 2015). Therefore, by creating groups of participants with overlapping requirements this research contributed to understanding the complexity regarding the interaction of these factors and how these impact AT interventions uniquely adapted to meet the needs of the person with dementia (Greenhalgh et al. 2016). Large quantities of multivariate information are difficult to manipulate, therefore this research employed data analysis methods which enabled consideration of the impact of multiple variables upon AT (Fleming and Sum 2014). This facilitated the identification of insights which can be transferred to comparable settings (Greenhalgh et al. 2016), which in turn will inform effective, personalised AT.

Clustering solutions generated within this research demonstrated that robust groupings can be developed from mixed type data describing the needs, predisposing characteristics and enabling variables of people with dementia (Everitt et al. 2001; Clatworthy et al. 2005). These cluster analyses produced intrinsic discrete models where each participant belongs to one and only one cluster (Hofstetter et al. 2014), and provided a means to bridge the gap between nomothetic and idiographic approaches described above (Clatworthy et al. 2005). This is particularly relevant for this field where there is a previously stated dichotomy between the literature which describes real world situations and focusses upon the individual differences of people with dementia and emphasises the need for the individualisation of AT interventions. Yet, the literature describing laboratory-based testing of AT devices provides specific information regarding the relationships between variables and asserts that these findings are applicable to all people with dementia (Greenhalgh et al. 2016).

The importance of the role of needs in determining health service use is acknowledged, although the relationship between needs, predisposing characteristics and enabling variables is unclear (Toseland et al. 2002). The inclusion of safety risk, or risk of wandering together with MMSE, as variables within the cluster analyses ensured that the needs of people with dementia were considered within the analyses in addition to enabling and predisposing characteristics of people with dementia. As policy and legislation drives health and social care staff to focus upon increasing the safety of people with dementia and this is seen as a requirement for the provision of AT, level of risk was an important inclusion (Mandelstam 2016).

7.5.1 Clustering Solutions

This research demonstrated that data can be clustered robustly based upon specific variables associated with people with dementia living at home namely: caregiver support, living situation, MMSE and safety risk or risk of wandering. Previously, research has focussed on the ability of AT to achieve the purpose for which it was intended (Greenhalgh et al. 2016), rather than examining the complexity of the context in which AT is used. This research facilitated the examination of multiple characteristics of the people who are receiving AT, including the need or risk experienced by the participant (Bernd et al. 2009), and thereafter related these groupings to AT interventions.

Clustering solutions indicated that within the data there was structure based upon the living situation and caregiver support of the participant. The resultant clusters, reinforced previous research which indicates the impact of caregiver support and living situation upon interventions. Gibson et al. (2015) found that access to AT was driven by caregivers, and that caregivers derived the greatest benefit from the installation of AT devices. Bantry White et al. (2010) also found that the decision to use AT was based upon the caregiver assessment of safety. The earlier exploration of heterogeneity associated with the reported needs of people with dementia conducted as part of the meta-analysis, confirmed that caregivers of people with dementia report different levels of need from people with dementia report themselves perhaps because available assessment tools are unable to consider the needs of people with severe dementia (Miranda-Castillo et al. 2013). These results indicate that the caregiver can have an impact on each stage of the AT provision process.

Moreover, Gibson et al. (2018) conclude that in order for AT to be usable, assessors need to take account of the support networks available to the person with dementia. Support networks offer a number of added dimensions to the AT needs of the person with dementia in terms both of the caregivers' own needs and the support which the caregiver offers (Riikonen et al. 2013). For example, the caregiver may be required to provide assistance by adapting or maintaining AT, and managing alerts generated by the AT in order for it to be used successfully (Gibson et al. 2018). The importance of the caregiver to AT provision supports the Gibson et al. (2016) categorisation of AT according to whether it was used by, with or on the person with dementia suggesting that in many cases the AT is provided for use by the caregiver rather than the person with dementia. Further an earlier study by Toseland et al. (2002) found that enabling variables such as caregiver support explained more variation in service use than need or predisposing characteristics, and concluded that service providers may wish to consider facilitating caregiver use of resources to increase service uptake. Additionally, the living arrangement of the person with dementia has been shown to be associated with the diversity of service utilisation in dementia care (Roelands et al. 2008). These results suggest that there is a requirement to consider not only the needs of the person with dementia, but also the requirements of the caregiver, and the interaction or conflict between these different sets of needs, in order to understand variation between subjective and objective AT requirements (Scherer et al. 2007).

The role of family or other informal support in the implementation of AT is acknowledged as being important (Gibson et al. 2018). Whilst care is often provided by spouse, family or other informal caregiver predisposing characteristics such as the wider support network or living situation of the person with dementia also appear to be fundamental in facilitating tailored AT interventions (Toseland et al. 2002; Roelands et al. 2008; Greenhalgh et al. 2016; Liu et al. 2017; Gibson et al. 2018). This support network has been shown to assume responsibility for purchasing required items, adapting them to individual circumstances, then maintaining and monitoring the AT (Gibson et al. 2018). Whilst predisposing characteristics can include the caregiver/ care recipient relationship, living arrangement, gender, age and ethnicity (Toseland et al. 2002) they were represented in this cluster analysis by the living arrangement of the person with dementia which in many cases also indicated the relationship between the person with dementia and their informal support. Previous research has concluded that participants living with spouse/ partner or with an adult child often have access to greater resources than people living alone (Roelands et al. 2008; Weaver and Roberto 2017). The benefits of these additional resources are reflected in the differences between recommended and installed AT for people with dementia living alone and those living with others. This variation may occur as previously, Gibson et al. (2018) found that spouses or children of people with dementia often assumed responsibility for the purchase of AT. Configuration of AT was often carried out by male caregivers who were not always co-resident with the person with dementia (Gibson et al. 2018).

In this research, people with dementia who live alone appear to receive different types of AT from people living with someone. People living alone were more likely to receive basic AT items such as monitored smoke detectors and carbon monoxide detectors rather than safer walking technologies or fall detectors. Reasons for this are not clear but possibly there is no-one to adapt and monitor AT on their behalf which indicates a shortfall in available care provision (Gibson et al. 2018). Other reasons have already been discussed such as the requirement for AT to respond to the needs of the caregiver. Alternatively, AT providers may install routine basic AT to enhance the safety of the person with dementia in the absence of specific information regarding their needs. However, living alone is a known predictor of no community service use (Lehmann et al. 2010). Even though Tierney et al. (2004) highlight the particular needs of people with dementia who are living alone due to self-neglect and failure to seek assistance. This group are more likely to be hospitalised than people living with others and have more unmet needs making them vulnerable to adverse outcomes (Soto et al. 2015). Further Lehmann et al. (2010) found signs of cognitive impairment were less likely to be recognised in people living alone. Additionally, the lack of a knowledgeable informant means that people with dementia living alone are often excluded from research, meaning that our understanding of their situation is limited (Lehmann et al. 2010). Resources and assessment methods would appear therefore to be targeted towards people living with their caregiver and additional attention is required to identify the needs of people with dementia living alone and to develop AT which assist these people. Further work is also required to identify service delivery methods which increase the accessibility of AT for people living alone.

Cluster allocation can serve as a predictor of other behaviours not included in the generation of the cluster solution (Clatworthy et al. 2005; Hofstetter et al. 2014). As this research aimed to explore the recommendation and installation of AT for people with dementia and how this was associated with these cluster allocations, the clustering solution was used to stratify recommended and installed AT data.

This section has explored the clustering solutions generated by the partitioning around medoids (PAM) clustering algorithm. The clustering solution suggests that participant data can be structured according to caregiver support and living situation, and the importance of these factors is identified within the literature. The relevance of this data structure to the recommendation and installation of AT in response to wandering and safety risks will now be explored.

7.6 Assistive Technology for People with Dementia at Risk of Wandering

In order to assist people with dementia and their caregivers to reduce risk, there is a requirement to identify appropriate interventions. This research identified associations between particular types of AT and risk of wandering suggesting that practitioners find these AT useful for participants who were experiencing risk of wandering.

In order to understand the impact of risk on recommended and installed AT, the category of recommended and installed AT was stratified according to level of risk of wandering, then level of safety risk and significant associations were identified. This section will review the recommendation and installation of safer walking technologies in relation to the wandering risk of people with dementia (section 7.6.1), before reviewing the recommendation and installation of medication reminders and dispensers in relation to risk of wandering (section 7.6.2).

7.6.1 Wandering and Safer Walking Technologies

Results showed that safer walking technologies to alert a responder of movement were both recommended and installed more frequently as risk of wandering increased meaning that people with higher risk of wandering were more likely to receive this type of AT. This finding supports previous research which indicates that alarm and sensor technologies are amongst the most commonly accepted wander management technologies (Lin et al. 2014; Jarvis et al. 2017; Neubauer et al. 2018). Additionally, there is strong evidence for the effectiveness of monitoring systems in preventing night time unattended exits at home (Rowe et al. 2009; Tchalla et al. 2013; Jensen and Padilla 2017), thereby reducing the incidence of disturbed sleep for caregivers (Rowe et al. 2009; Spring et al. 2009). This type of technology also provides caregivers with an ethical alternative to locking people with dementia in their homes which has the additional benefit of reducing their risk of injury from fire (Bantry White et al. 2010; Dunk et al. 2010).

However, the particular purpose for which this AT is provided remains uncertain as recent research has demonstrated the effectiveness of sensor-based alerts (provided alongside lighting devices) in the reduction of falls for people with dementia (Lauriks et al. 2018). Rowe et al. (2009) also found sensor technologies useful in reducing the incidence of injury in participants. This means that this category of AT may be useful both for the management of elopement and to reduce the incidence of falls for people with dementia, both of which are adverse outcomes associated with wandering (Douglas et al. 2011; Collins 2018).

Analysis indicated an inverse association between risk of wandering and risks associated with posture and mobility supporting the view that the participants who are most likely to wander have less risk associated with walking (Algase et al. 2009). The association between risk of wandering and the recommendation and installation of safer walking technologies to locate the user AT reinforces this finding, although this type of AT were most likely to be recommended and installed for participants with moderate risk of wandering. The literature indicates that UK health and social care services are rarely proactive (Gibson et al. 2015). However, these patterns of AT provision suggest that services are being offered before participants reach a high level of risk of wandering. Alternatively, this type of safer walking technology may be serving a different purpose. Previous research found that caregivers used tracking technology when the risk of harm from the person with dementia getting lost was perceived to be low supporting the findings from the current secondary data analysis study (Bantry White et al. 2010). Generally tracking was used as a back up to caregiver support. However, if the risk of getting lost was perceived by the caregiver to be low then tracking may be used to support the independence of people with dementia to go out alone (Bantry White et al. 2010).

Participants with moderate risk of wandering were also most likely to be recommended fall detectors, although participants with low risk of wandering were most likely to actually receive this type of device. This supports research which found wandering was associated with poor gait and balance (Ali et al. 2016). However, results of this research indicate that risk of wandering and risk associated with posture and mobility are inversely associated. This suggests that fall detectors are actually most likely to be installed when the person with dementia has an increased risk from posture and mobility indicating that the person with dementia is likely to fall.

7.6.2 Risk of Wandering and Medication Reminders and Dispensers

Risk of wandering was associated with both recommended and installed medication reminders and dispensers. People with dementia with low risk of wandering were most likely to be recommended and to receive this type of AT. This result was unexpected and the author is unable to find literature providing discussion of this relationship. It may result from medication previously being used to manage wandering, although non-pharmacological alternatives are now recommended (Neubauer et al. 2018). Alternatively, this finding may have occurred because participants with low risk of wandering have highest MMSE score and are therefore able to use this type of AT (Yusif et al. 2016). Research suggests that 54% of informal caregivers of people with dementia have daily medication management responsibilities and that this rises to 90% in the later stages of dementia (Gillespie et al. 2013). It may be that medication reminder and dispensers are therefore provided to support the caregiver in this task. However, participants with low risk of wandering were also most likely to live alone indicating that they may be required to rely on AT to remind them to take medication rather than being able to depend on their live-in caregiver. Nevertheless, there is evidence that people with dementia who are living alone often fail to follow medical instructions despite the importance of adherence to prescribed medications in achieving improved health outcomes (Gillespie et al. 2013; Soto et al. 2015).

7.7 Assistive Technology for People with Dementia with Safety Risk

This chapter has previously focussed on the recommendations and installations of AT in response to wandering risk of people with dementia and will now turn to examine the recommendation and installation of AT in regard to safety risk. There is overlap between some of the adverse outcomes associated with these two risk categories and therefore results provide validation of some aspects previously discussed. Although this is not the case for all results. Associations between recommended and installed AT and safety risk occurred less frequently than with wandering risk and possible reasons for this will be explored in relation to the literature.

Due to the wide range of activities and needs which give rise to safety risk for people with dementia, there are a number of AT device categories which have been used to reduce risk in this area. Results have demonstrated that level of safety risk was associated with recommendation of fall detectors; and flood detectors and water temperature monitors. Other AT which can be used to reduce the incidence of falls such as lighting devices and safer walking technologies to alert a responder of movement were not recommended more frequently for people with dementia who have a higher safety risk. Level of safety risk was also associated with the installation of fall detectors - where participants with high safety risk received the highest frequency of this type of AT); and safer walking technologies to locate the user although only one participant with high level of safety risk received this type of AT.

The relationships between the safety risk of people with dementia and recommended and installed AT will now be more fully discussed. Specifically, the relationship between safety risk and fall detectors (section 7.7.1), safety monitors (section 7.7.2), and safer walking technologies (section 7.7.3) will be mentioned.

7.7.1 Fall Detectors

Falls are the leading source of morbidity and mortality in older adults and are the major source of in-home injury for people with dementia (Douglas et al. 2011; Amjad et al. 2016). It is therefore unsurprising that results supported previous research and showed that both recommended and installed fall detectors were associated with safety risk (Härlein et al. 2009; Sadak et al. 2017; Brims and Oliver 2018). Participants with high safety risk were most likely to both be recommended and to receive fall detectors. This type of device has been shown to reduce the number of fall incidents particularly when used in conjunction with specialist lighting (Brims and Oliver 2018; Lauriks et al. 2018), although other studies have not found conclusive evidence regarding their effectiveness (Winter et al. 2013).

7.7.2 Safety Monitors

Flood detectors and water temperature monitors were most frequently recommended for participants with moderate safety risk. This supports previous findings that these are risk preventative devices which are generally the most widely accepted type of device (Riikonen et al. 2010). As people with dementia may be less likely to recognise dangerous situations or their own limitations, this type of device does not require activation by the user (Tierney et al. 2004; Lehmann et al. 2010; Riikonen et al. 2010). This type of device may therefore be provided for participants with moderate safety risk supporting previous research which indicates that people with increasing cognitive impairment have difficulty in managing everyday technologies (Hedman et al. 2016). Results did not indicate any association between safety risk and other type of risk preventative device e.g. monitored smoke detectors or carbon monoxide detectors. It may be that as this type of device is now recommended for all homes there is a reduced association with identified safety risk. It may be that many homes were already fitted with this type of AT.

7.7.3 Safer Walking Technologies

Results support previous findings that the installation of safer walking technologies to locate the user was associated with safety risk (Dunk et al. 2010; Wood et al. 2015; Herrera 2017). Safer walking technologies have already been discussed in regard to their relationship with risk of wandering, however, in this case they are associated with safety risk. The main adverse outcome associated with safety risk in people with dementia is falls (Douglas et al. 2011), which suggests that safer walking technologies to locate the user are being implemented in response to identified risk of falls. However, there is little evidence in the published literature linking safer walking technologies to locate the user, with risk of falling. As wandering may also result in accidental injuries (Rowe and Fehrenbach 2004), this may be the reason for this result. This result may indicate that there is a need to provide the caregiver with reassurance regarding the progress of the participant, or alternatively that the person with dementia or their caregivers requires assistance in directing support to the required destination (Herrera 2017). In some cases, safer walking technologies may be used to support the person with dementia to participate in activities outside the home but as previously discussed this is not common (Bantry White et al. 2010; Wood et al. 2015).

It can therefore be seen that recommended and installed AT are influenced by the needs and risk of the person with dementia.

7.8 Influence Of Caregiver Support And Living Situation On Assistive Technology

In addition to being guided by the needs of the person with dementia, results support Liu et al. (2017) who found caregiver support and the living situation of the person with dementia influenced AT provision (Boger et al. 2014; Gibson et al. 2017). This is evident throughout results relating to recommended and installed AT, and for AT for both safety and wandering risks. Therefore, these aspects of the circumstances of the person with dementia should also be considered during assessment of their AT needs in order to individualise interventions. Additionally, Bantry White et al. (2010) found that patterns of care were influenced by the relationship between the caregiver and the person with dementia suggesting that these relationships should also be considered during AT assessment as they provide targets for the tailoring of interventions. The relationship between the person with dementia and their caregiver or wider support network may influence AT provision in a number of ways. These may include (1) that AT is provided to meet the needs of the caregiver; (2) that the caregiver provides a different view of the needs of the person with dementia resulting in a change in AT provision; (3) or that input from the caregiver is required to obtain, maintain or monitor AT. These aspects of the relationship between the caregiver and person with dementia, or between the person with dementia and the people they live with, and their influence on AT will now be discussed.

7.8.1 Impact of Caregiver Needs on AT

Firstly, the results of this research indicated that the needs of the caregiver influence the AT recommended and installed for the person with dementia. In this secondary data study safer walking technologies to alert a responder of movement were most likely to be recommended and installed for participants living with a spouse or partner. This result indicated that the acceptance of this type of AT may be driven by caregiver need, such as the fear of losing the person with dementia described in previous research (Spring et al. 2009; Gibson et al. 2015; Brittain et al.2017). Previous research has found that this fear was strong in caregivers even when the person with dementia was actually unable to leave home and often resulted in limitations being placed upon the independent activity of the participant (Bantry White et al. 2010; Brittain et al. 2017). This suggests that safer walking technologies are not always installed to promote safer walking and the health and wellbeing of the person with dementia but may be required to support the caregiver (Robinson et al. 2006; Robinson et al. 2007). This findings supports previous research indicating that AT is associated with improved quality of life and stress reduction for caregiver (Woolham 2005; Gagnon-Roy et al. 2017). However, the effectiveness of this type of intervention must be challenged as Werner et al. (2012) found that greater impact of caregiving was associated with reduced out of home walking time for the person with dementia.

Additionally, results indicate that participants living alone received different AT from participants living with others. This participant group were least likely to be recommended safer walking technologies which again indicates that the involvement of a caregiver is associated with this type of AT. This again supports previous findings that AT provides reassurance and support for caregivers rather than for people with dementia (Neubauer et al. 2018), rather than directly addressing the needs of people with dementia themselves.

These results support previous investigations which identified one of the major adverse outcomes associated with wandering as the impact upon the caregiver or caregiver anxiety (Rowe et al. 2015). The views or needs of the caregiver may in some cases be driving the recommended AT. This would indicate that safer walking technologies (particularly where it is used to alert a responder) are provided to meet the needs of the caregiver rather than the person with dementia. Indeed, a number of studies reported decreases in caregiver stress following installation of AT (Spring et al. 2009; Gagnon- Roy et al. 2017), indicating benefit for caregivers. As caregiver anxiety is associated with institutionalisation of people with dementia this decrease also has direct benefit for them (Luppa et al. 2008). Results of this secondary data study appear to confirm the influence of caregivers upon the provision of AT. For example, participants within the living with spouse/ partner cluster were most likely to receive safer walking technology devices both to alert the responder of movement and to locate the user suggesting the benefits of this type of technology are most suited to this living situation. The living with spouse/ partner cluster had the highest number of live-in caregivers.

Ultimately, if the impact of caregiving is excessive the caregiver opts for long term care for the person with dementia (Luppa et al. 2008; Rowe et al., 2009). This means that AT providers are required to balance the needs and rights of people with dementia whilst also meeting the needs of the caregiver (O’Keeffe 2017). Results of this research reflect previous investigations which have focussed on the needs of the caregiver and failing to address the needs and opinions of the person with dementia (Neubauer et al. 2018). In order to preserve the rights of the person with dementia, other possible strategies for the reduction of the impact of caregiving upon the caregiver should be considered. Alternative interventions include education, training, guidance, respite; or financial, emotional and physical assistance. Additionally, Bantry White et al. (2010) suggest that professional support and education around the appropriate use of safer walking technologies is required. Although professionals report that they have limited understanding about available AT and do not often use this as an intervention indicating that they may not be in a position where they are able to train others (Jarvis et al. 2017; Collins 2018).

7.8.2 Caregiver View of the needs of the person with dementia

Results of the systematic review and meta-analysis found that caregivers reported higher levels of need than the person with dementia. This may be due to the inclusion of people with more severe dementia, or with communication difficulties resulting in the person with dementia and caregiver populations reporting on different needs. These findings may also reflect differences in the viewpoint of the caregiver from that of the person with dementia. Previously, Bantry White et al. (2010) found that the decision to use tracking technology was informed by the caregivers’ informal assessment of the safety of the person with dementia. Similarly, Wood et al. (2015) found that caregivers justified their use of safer walking technologies claiming their use enhanced the safety of the person with dementia.

Generally, research has identified that GPS technologies are used as a back up to other strategies of support and only in a small number of cases actually allow the person with dementia to go out alone (Bantry White et al. 2010), again suggesting that they are provided to reassure caregivers rather than support participant’ participation. Overall, Wood et al. (2015) found that both elderly people and caregivers felt that safety was the priority for people with dementia even at the expense of autonomy and privacy, suggesting that people with dementia are content with this potential rights violation.

Differences in recommended and installed AT relative to caregiver support and living situation of the person with dementia may also reflect limited understanding of the AT assessor/ provider regarding the needs of participants living alone. People living alone are less likely to be diagnosed with dementia and clinicians often struggle to identify their needs (Lehmann et al. 2010; van Ooteghem et al. 2019). Previous research has also found that people living alone receive fewer community services despite being identified as a high-risk group (Tierney et al. 2004; Lehmann et al. 2010). In this research, people living alone received the greatest number of AT although these tended to be generic risk prevention items such as monitored smoke detectors. When needs were easily identified they were more likely to be met through service provision (Hansen et al. 2018). However, results may indicate that in the absence of a caregiver to identify needs, participants living alone received generic safety AT rather than AT focussed on particular needs.

7.8.3 Impact of Caregiver Response on AT

Results of this secondary data study indicated that AT may be used to alert live-in caregivers to respond to reduce wandering incidents. This supports previous investigation which found that wandering incidents may occur frequently and therefore require a level of caregiver response which people with dementia are unlikely to receive from monitoring centres or dementia response teams (Dunk et al. 2010). Further, monitoring centres would require specific training to be able to deal with such situations particularly as in such a case the responder may be unfamiliar to the person with dementia (Dunk et al. 2010). The practicalities of responding to wandering incidents therefore support the finding that AT is most useful in cases where caregivers who are familiar to the person with dementia are able to respond to the AT generated alerts (Dunk et al. 2010).

Similarly, results showed that participants who live with others were more likely to receive medication reminders and dispensers as medication management often falls to informal caregivers (Gillespie et al. 2013). This finding indicated that these AT may be used to support caregivers look after complex medication regimes for people with dementia rather than being used by people with dementia themselves (Francis et al. 2006).

Conversely, previous research has demonstrated that passive devices are widely accepted (Riikonen et al. 2013, and in this research, participants living alone were more likely to receive installations of monitored smoke detectors and pendant alarms. These are both AT which can be used to summon assistance in an emergency and perhaps reflect needs resulting from the reduced caregiver support available to this participant group.

7.9 Person with dementia needs

The results of this secondary data study support previous research indicating that there is a restricted range of AT being used to support people with dementia living at home meaning that some needs remain unmet (Greenhalgh et al. 2016). There are other ways AT could be used to meet the needs of people with dementia identified in previous research which could offer a reduction in the occurrence of adverse outcomes (Sugarhood et al. 2014; Greenhalgh et al. 2016). Limited knowledge regarding the needs of people with dementia, or regarding the AT to meet those needs may be preventing more creative use of AT (Sugarhood et al. 2014; Jarvis et al. 2017). For example, wandering is associated with agitation and may therefore be reduced through the meaningful occupation of the person with dementia (Gitlin et al. 2008; Gitlin et al. 2010).

Results indicate that risk of wandering was associated with safety focussed AT such as safer walking technologies, activity monitors and fall detectors, rather than AT which would assist the participation of the person with dementia (Evans et al. 2015; Hansen et al. 2018; Lorenz et al. 2019). Additionally, only one dementia friendly TV/ radio/ music players AT device was recommended, and one electronic games device installed during the period of the ATTILA RCT study, suggesting that the benefits of AT in this area are not being fully exploited. Although, previous research has identified the benefits of intuitive tablet devices to reduce isolation and increase personal wellbeing and confidence of people with dementia (French 2016), these were not recommended or installed for ATTILA RCT study participants. Such devices can also facilitate online access to shopping, banking and healthcare professionals thereby reducing the chance of getting lost (French 2016).

Overall, results indicated very limited use of AT to support meaningful use of leisure time. This may also be due to AT recommendations and installations being influenced by available AT or alternatively, that services were overly focussed on risk reduction supporting previous research in this field (Evans et al. 2015; Brims and Oliver 2018; Hansen et al. 2018). This suggests that there may be a supply led AT service which should be enhanced to enable the occupational needs of people with dementia to be met. Hansen et al. (2018) found that whilst assessors expressed a desire to base service allocation upon assessed need, experience taught them to focus their assessment upon needs which could be met by available services.

Results showed the association of recommendation and installation of safer walking technologies to locate the user with both wandering and safety risk. This may indicate intended benefit to the participant by enabling them to continue to participate in activities which they value and which require them to leave the house. However, research indicates that electronic tracking often does not promote independence for the person with dementia, as it is only used to support a small minority to go out alone (Bantry White et al. 2010; Wood et al. 2015). This may be due to the limitations associated with this type of AT including battery life, unreliability of tracking signals, inaccurate location information and reliability on a responsive caregiver (Bantry White et al. 2010; Dunk et al. 2010). However, previous research concludes that this is because of caregiver fear of an adverse outcome which prevents them permitting people with dementia to walk alone (Bantry White et al. 2010; Wood et al. 2015).

In this research safer walking technologies to alert a responder of movement were most likely to be recommended and installed for participants with high risk of wandering supporting previous findings (Gagnon-Roy et al. 2016). As risk of wandering was inversely associated with posture and mobility risk results indicate that this type of AT is used when the participant has been considered to be at risk of elopement or getting lost, rather than falling. Risk of wandering was also associated with MMSE score in regression analyses meaning that people with high risk of wandering have increased risk associated with cognitive impairment. The use of safer walking technologies to alert a responder of movement indicates that the participant may be unaware of their abilities and require a caregiver to remind them not to leave the house alone.

Overall, results indicated the association of the caregiver support and living situation of the person with dementia upon AT intervention. Caregivers and people who live with the person with dementia can influence AT in a number of ways. Firstly, caregivers by definition contribute to the care and upkeep of the person with dementia. AT may then be required to support them to continue to care for the person with dementia, or to maintain their own health, or reduce the impact of caregiving. Secondly, these people can maintain AT through completion of tasks such as battery replacement. Additionally, as they often share a home with the person with dementia, they will also require AT that supports their own lifestyle possibly by attending to the needs of the person with dementia or alternatively to their own needs. In many cases people with dementia will have unpaid and paid caregivers and other people that will be influenced by the installation of AT devices. There is therefore a requirement for models of AT assessment and utilisation to consider the wider social network of people with dementia including the views and needs of all persons that AT will impact rather than focussing on the needs of the person with dementia (Sugarhood et al.

2014; Greenhalgh et al. 2015; Greenhalgh et al. 2016). This move from person-centred care to a wider network focus will require changes in the focus of assessment and require that AT interventions are installed following consideration of the needs and contributions of the social network surrounding the person with dementia.

These results indicate the complexity of individual circumstances of people with dementia and its relationship with AT provision. As discussed earlier, there are many factors which impact on AT for this population which have not been considered within this research. However, the exploration of needs, caregiver support and living situation has indicated how factors interact to create unique individual circumstances. This individuality means that there is no direct link between one person's needs and an AT solution. However, by studying the interdependencies of factors which impact AT services in this large population of people with dementia living at home, this research can contribute to developing insights which will then be transferable to other comparable settings (Greenhalgh et al. 2016).

In order to individualise interventions to match individual needs there is a need for service providers to understand the subtle changes required to adapt AT to suit the complex situations in which people with dementia undertake activities (Greenhalgh et al. 2015; Gibson et al. 2018). Particularly, service providers need to consider the connections between the user care network and AT as human elements may make or break AT solutions (Sugarhood et al. 2014; Greenhalgh et al. 2015). AT service providers require to understand the impact of a wide array of factors upon the requirements of the person with dementia and develop skills in the adaptation of AT to ensure that these specific individual needs can be met (Sugarhood et al. 2014). However, results of this research also indicate that AT providers offer limited assessment and adaptation of AT.

7.10 Service Improvement

The results of this secondary data analysis indicate that limited needs assessment is undertaken with people with dementia. This suggests that staff lack confidence in the assessment of people with dementia, and their understanding of the relationship between personal characteristics and the recommendation and installation of AT (Jarvis et al. 2017). The reasons for these limitations are unclear and require further investigation, but may include organisational policy, time constraints, limited training and support, limited knowledge of available AT, limited access to resources and limited funding allocated for this aspect of AT services (Sugarhood et al. 2014; Handley et al. 2017; Jarvis et al. 2017). Additionally, Handley et al. (2017) found that preoccupation with risk generated interventions restricted patient choice and were more likely to cause distress.

The heterogeneity of people with dementia and their circumstances has been demonstrated through the results of this research and supports the use of person-centred practices for effective, individualised AT in this population. Person centred practice requires organisations to focus on the needs of people with dementia at every level of service and meets their needs and priorities before those of the system or its professionals (Hutchinson 2017). However, the uniqueness of individual contexts can make this field particularly challenging for professionals (Greenhalgh et al. 2015). The literature suggest that in order to enhance assessment in this population, organisations should support staff to learn and increase awareness of the needs of people with dementia in order that they may recognise behaviour as expressions of unmet need (Handley et al. 2017). Undergraduate training of health and social care professionals should facilitate the development of clinical reasoning skills through time spent with people with dementia, considering the problems they face and following narratives describing the experience of people within this population, generating problem lists and considering creative AT solutions to these problems (Neistadt 1996; Sugarhood et al. 2014). The individuality and personhood of the person with dementia and their circumstances, as described in the results of this research, should be emphasised to reduce the acceptability of supply led solutions (Hansen et al. 2018).

Moreover, organisations should ensure that staff have the authority to institute and sustain the changes required to provide a person-centred, dementia friendly AT service. There should also be clinical leaders and managers with sufficient expertise and availability to be a resource for clinical staff (Sugarhood et al. 2014). These experts can act as role models for less experienced staff, offer professional advice in complex situations and validate care priorities (Sugarhood et al. 2014). Senior staff should provide clarity regarding staff priorities and their responsibility to offer patient-centred care rather than supply-led allocation, as this will facilitate the creative problem-solving approach required to tailor AT solutions to individual need (Handley et al. 2017; Hansen et al. 2018). Further, service providers should ensure that there are sufficient AT resources to enable staff to allocate appropriate AT to meet the identified needs of the person with dementia (Hansen et al. 2018). This may require collaboration between multiple stakeholders to ensure the production of AT that meets the needs of the intended user (Greenhalgh et al. 2015).

Effective AT services also require the coordination of multiple stake holding organisations involved in AT provision, and individuals, to provide ongoing support and adaption of installed AT. Closer links between these organisations, people with dementia and people involved in the design and development of AT will ensure that new technologies account for individual need and context (Sugarhood et al. 2014)

In addition to exploring available AT, professionals need to develop expertise on how AT can be adapted to individual need. The reduced amount of assessment indicated by the findings of this research supports previous reports regarding professionals' limited knowledge of AT (Newton et al. 2016; Jarvis et al. 2017) This knowledge can be enhanced by professionals engaging with the wider AT community via online resources and other networking opportunities (Greenhalgh et al. 2015; Ward et al. 2017). These changes must be supported at a managerial and organisational level in order to be effective (Handley et al. 2017). Experts or change agents are required to support these changes and to develop and demonstrate services which individualise care priorities (Handley et al. 2017).

7.11 Ethical Considerations

The literature on ethics surrounding the provision of AT for people with dementia has been discussed earlier in this thesis. However, prior to concluding, consideration must be given to a number of issues concerning the findings of this research. These include ensuring the person with dementia's capacity to consent to both AT interventions, and research participation, as well as balancing the rights of the person with dementia and their caregiver or support network.

Both studies in this research identified that the participant groups included limited numbers of people with more severe dementia. In order to prevent people with dementia becoming a silent and excluded voice (Murphy et al. 2014), there is a requirement to include participants who have increased cognitive impairment in research. Participation in research requires participants to provide their consent (Beattie et al. 2018), in order to protect participant wellbeing and to respect their self-determination (Alzheimer Europe 2011). However, obtaining informed consent in this field is particularly difficult as a result of the complexity regarding the impact of AT and due to the potential impact of dementia upon a person's ability to understand complex information (Gagnon-Roy et al. 2017).

As previously discussed, AT sometimes has the ability to store and transmit personal information which requires the that informed consent is obtained from the person with dementia prior to its use. However, competence to consent is not absolute and people with dementia may be competent in some domains and not others (Murphy et al. 2014). Capacity should therefore be assessed in relation to specific situations, research questions or the requirements of particular interventions. In research, consent may also be dependent on the researcher practitioner participant relationship (Beattie et al. 2018). Further, consent is not absolute and can change at any time depending on individual circumstances (Gagnon-Roy et al. 2017). Even where there are concerns regarding the person with dementia’s understanding of the situation, practitioners should endeavour to explain circumstances as fully as possible. Researchers and service practitioners should check with the person on an ongoing basis that they understand what is being said and that they still give their consent for the research or intervention to continue (Dewing 2007). As people with dementia may experience difficulties in communicating, they may indicate consent or withdrawal of consent through action, behaviour or other means of communication (Handley et al. 2017). If a person with dementia becomes non-compliant this may indicate that they are withdrawing consent.

Practitioners working with people with dementia are responsible for the assessment of mental capacity of their participants, should this be required, and should take time to ensure they understand the individual’s wishes (Social Care Institute for Excellence 2020). Capacity assessment instruments may be used to support decisions particularly where the practitioner has limited clinical background (Beattie et al. 2018). Additionally, professionals should consult with others who know the person with dementia well and where possible should try to make decisions that support their preferences. Decisions should also account for any advanced wishes provided by the person with dementia (Social Care Institute for Excellence 2020).

Ethical decisions become particularly complex when the rights of the person with dementia conflict with the needs or wishes of their caregiver. Many people with dementia living at home rely upon informal caregivers to provide their care and prevent institutionalisation (Tudor Car et al. 2017). It is possible that in some instances AT is provided at the wish of the caregiver rather than the person with dementia or vice versa, therefore balancing the needs, rights and wishes of both the caregiver and the person with dementia can present a challenge to practitioners. AT can provide support to caregivers which enables them to maintain the person with dementia at home. So, it is important to consider the needs of the caregiver, as when the impact of caregiving becomes unbearable many caregivers make the decision for the person with dementia to enter long term care (Rowe et al. 2009). Further, in research the informal caregiver often acts as proxy decision maker for the person with dementia (Alzheimer Europe 2011). The person with dementia may be aware of the workload of the caregiver, or the power of the caregiver to instigate institutionalisation and therefore supports the needs of the caregiver to enable them to remain in their own home (Bächle et al. 2018). This may mean that the person with dementia accepts an intervention that they find undesirable but believe is better than institutionalisation. In such an example the voluntariness of the person with dementia to accept the intervention is challenged (Alzheimer Europe 2011). Such complex decisions require careful consideration and discussion between all involved parties. Researchers and health and social care practitioners should be supported by managers or colleagues with expert knowledge in this field to ensure that they consider the wider implications of their decisions. Again, the person with dementia and people who know them well should be included in these discussions and all decisions should be documented and kept under review (Social Care Institute for Excellence 2020).

Where the researcher is unable to obtain informed consent for participants with dementia, they may wish to explore alternative research methods. Creative use of research methods, such as secondary analysis of anonymised routinely collected data, may provide alternative means of investigating the needs of people with more severe dementia.

7.12 Limitations

Every effort has been made to ensure the robustness of the results obtained during the course of this secondary data study. However, this research was limited by a number of factors which are outlined here.

7.12.1 Data Availability

As this was a secondary data analysis, overall availability of data variables and data was predetermined by the data set (Donnellan and Lucas 2013). Specific limitations related to issues data availability include;

- Results indicate relationships that exist between variables but further research is required to establish the generalisability of results to other sites and settings (Robson 2002; Lipworth et al. 2017).

- Sample size was predetermined by availability of data within the secondary dataset and therefore *a priori* power calculation was not possible (Boo and Froelicher 2013).
- The available sample population contained limited numbers of people with severe dementia, or high-level safety or wandering risk. This restricts the transferability or generalisability of results and further research is required to validate results for these populations (Robson 2002; Lipworth et al. 2017).
- Data on the profession, role or experience of the persons responsible for the completion of the needs assessment, recommendation and installation of AT, or collection of other data was mostly missing from the dataset preventing any meaningful analysis regarding the impact of training or professional differences on recommendation and installation of AT.
- Information regarding the assessment criteria indicating if the person with dementia and/or their caregiver was likely to comply with ATTILA RCT study follow-up, and what constituted an urgent need for a care package, was also unavailable. This information would provide further understanding of the context in which AT is received by the person with dementia and their caregiver.
- Within the dataset there were large amounts of missing data for MMSE and AT Needs Assessment variables. As these data were missing MNAR it was not possible to impute values. Missing AT needs data reflects limited information provided by assessors within their documentation. All missing data is fully described within this document (Wolpert and Rutter 2018). In the case of MMSE data it appears that this was associated with dementia severity and may have reduced the generalisability or transferability of the results of this research to populations including people with more severe dementia.
- All analysis was dependent upon the availability, and form of data within the secondary dataset. Causality could not be determined due to the nature of the data (Nataraj et al. 2019).
- Additional data would have provided an opportunity to replicate regression models and cluster analyses with a comparable population in order to further validate and verify research results (Clark-Carter 2019).

7.12.2 Categorisation of Variables

Some categories of variables and their associated definitions were developed for the original ATTILA RCT study. Particular instances include;

- Risk of wandering and safety risk were defined for the purposes of the primary ATTILA RCT study. This should be considered when comparing the results of this research with other studies (Clark-Carter 2019).
- Due to limited availability of validated instruments in this field some instruments used for data collection were non-validated e.g. AT Checklist – which was used to categorise recommended and installed AT. The reliability and validity of these instruments is therefore uncertain and restricts the comparability of these results with other research (Clark-Carter 2019).
- The range of available AT for the participants within this dataset is unspecified but reflects the AT currently provided within the CASSR areas included in the original ATTILA RCT study. Additionally, recommended and installed AT is examined at a categorical level. AT was categorised by occupational therapists with experience in this field according to the main purpose for which it was intended or used, but the actual AT included within each category is not specified. Further, the purpose of AT was subject to change during the period of the research, resulting in similar AT being categorised differently at subsequent stages of the ATTILA RCT. Therefore, AT devices may be included within different categories if they achieved multiple purposes, achieved different purposes at different times, or achieved different purposes for different participants. Direct comparisons between recommended and installed AT data would therefore not have been meaningful.

7.13 Unique Contribution

This thesis describes new knowledge regarding the heterogeneity of population characteristics of people with dementia living at home and the impact of this variation upon recommended and installed AT. Specifically, this research has for the first-time produced prevalence estimates of twenty-four needs reported by people with dementia and their caregivers. Investigation of associated heterogeneity has provided robust evidence regarding differences in levels of reported needs between groups within this population. Heterogeneity in the reported needs of people with dementia is shown to be associated with the person reporting the needs and the age of dementia onset. Caregivers of people with dementia consistently report higher levels of need than people with dementia, although priority rankings are similar across the two groups. People with young onset dementia report higher levels of need than people with later onset dementia.

Thereafter the dataset provided a unique opportunity to robustly investigate recommendations and installations of AT in relation to population characteristics of people with dementia living at home. Data was collected during ATTILA RCT, from 11 CASSR areas across England. Data derived from usual AT needs assessment practice in each area and therefore provided rich description of real-world situations.

This research advances understanding of the heterogeneity of people with dementia and their wandering and safety risks and how this is associated with recommended and installed AT. Robust analytic methods were employed to explore the relationship between assessed AT needs and the wandering and safety risks of people with dementia living at home. Results demonstrate that wandering risk is associated with MMSE, posture and mobility, routine, occupational demands and conversation needs, and quantify these relationships. As posture and mobility risk reduces the person with dementia is more likely to have a higher risk of wandering. Where there is more risk associated with Routine, Occupational Demands and Conversation the person with dementia is more likely to have high risk of wandering. Safety risk is shown to be directly associated with Posture and Mobility, Occupational Demands, Appraisal of Abilities and Problem-solving needs. As posture and mobility risk reduces the person with dementia is more likely to have a lower level of safety risk. Increase in Occupational Demands, Appraisal of Abilities and Problem-Solving needs indicate an increase in safety risk. Targeting AT towards these identified needs is therefore anticipated to increase opportunities to tailor interventions and reduce risk of adverse outcomes for people with dementia.

This secondary data analysis study identified robust clusters of participants within this population of people with dementia based upon data describing caregiver support and living situation to facilitate examination of the impact of multiple factors upon AT for people with dementia living at home. The relationship between these heterogeneous clusters and recommended or installed AT was explored. Results demonstrate associations between clustering solutions based on participant data describing their living situation, caregiver support and recommended and installed AT. Results indicate that frequency of both recommended and installed AT were associated with the risk of wandering cluster solution, and frequency of installed AT was associated with the safety risk clustering solution. Specifically, people with dementia who live with others were more likely to be recommended safer walking technologies to alert a responder of movement, safer walking technologies to locate the user, fall detectors, medication reminders and dispensers. Whereas people with dementia who live alone were more likely to have monitored smoke detectors or pendant alarms installed. These results indicate the influence that the person with dementia's social support network has upon AT.

Further, this secondary data study produced evidence of the associations between the level of risk attributed to the person with dementia and AT. The level of risk of wandering of the person with dementia was associated with the installation of activity monitors for ongoing monitoring, intercoms, medication reminders and dispensers, pendant alarms, safer walking technologies to alert a responder of movement, safer walking technologies to locate the user and telephones. Safety risk was associated with the installation of fall detectors and safer walking technologies to locate the user.

Inclusion of data on both recommended and installed AT facilitated examination of the patterns of AT recommended by the assessor following AT needs assessment and the actual AT installed for the participant. In most cases there was a similar pattern of associations between recommended and installed AT.

Results demonstrate the impact of multiple factors on both the recommendation and installation of AT. Together, these findings challenge the supply led approach to AT and provide support for developing person-centred and tailored AT services to reduce adverse outcomes for people with dementia living at home and their caregivers.

7.14 Summary

This section has discussed the results of this secondary data study in relation to the relevant published literature in order to place them within the context of current research and knowledge. The limitations of this secondary data study are described. This section has concluded with a statement of the unique contribution of this research, including both the systematic review and secondary data analysis, to the field of AT for people with dementia.

Initially, this research explored published data on the needs reported by people with dementia and the heterogeneity associated with these needs. Thereafter whilst AT may be required in order to reduce unmet need or level of risk on people with dementia, the literature advises that AT must be tailored to meet their individual needs (Dunk et al. 2010). In order to advance understanding of how AT can be tailored to individual circumstances associations between AT needs and risk of wandering or safety risk were then identified.

Cluster allocation can serve as a predictor of other behaviours not included in the generation of the cluster solution (Hofstetter et al. 2014), and this research examined the relationship between cluster allocation and the AT recommended and installed for people with dementia living at home. The examination of this relationship permitted the researcher to explore the impact of multiple factors, specifically caregiver support and living situation, on AT. These results could then be compared with recommended and installed AT stratified by level of risk of wandering and safety risk in order to understand the different impact of various population characteristics.

Examination of published research regarding the views of caregivers and people with dementia on AT placed these findings within context. This also advanced understanding of the roles that caregivers may play in seeking, accepting, maintaining and monitoring AT. The interdependence of people with dementia, their caregivers and others within their network must be considered during assessment and subsequent installation of AT.

CHAPTER 8. CONCLUSIONS

This chapter briefly presents the conclusions which may be drawn from this research. These are considered in relation to their implications for policy, practice and further research.

This research has produced a thesis which describes new knowledge regarding heterogeneity in population characteristics of people with dementia and its impact upon the recommendation and installation of AT for people with dementia who are living at home. This knowledge was developed firstly, through systematic review and meta-analysis of published quantitative data regarding the needs of people with dementia, and thereafter of secondary data analysis a dataset describing the demographic information and AT needs assessments for people with dementia living at home, in addition to information regarding the AT interventions recommended and installed for them.

This research has produced findings regarding:

- The prevalence of needs reported by people with dementia and their caregivers in response to validated needs assessment instruments.
- Heterogeneity of needs prevalence for people with dementia is associated with the reported need, the person reporting the needs and age of onset of dementia.
- The association of level of risk of wandering in people with dementia living at home with needs including; Posture and Mobility, Routine, Occupational Demands, Conversation and MMSE.
- The association of level of safety risk in people with dementia living at home with needs, including; Posture and Mobility; Occupational Demands; Appraisal of Abilities and Problem-Solving.
- The possibility of creating robust clusters based on data describing population characteristics of people with dementia living at home including caregiver support and living situation.
- Heterogeneity of population characteristics of people with dementia living at home, including wandering and safety risk, caregiver support and living situation and its impact upon the recommendation and installation of AT.

The conclusions which can be drawn from this research will now be discussed whilst acknowledging the key questions which were considered.

8.1 What Needs are experienced by People with Dementia living at Home, what is their Prevalence and which Characteristics are associated with Heterogeneity?

For the first time, this research estimated prevalence for twenty-four needs have been identified through the systematic review and meta-analysis of published quantitative data describing the needs of people with dementia living at home. This examined data derived from six studies exploring the needs of people with dementia living at home, using validated needs assessment instruments. Study populations were recruited from The Netherlands, United Kingdom, Poland, Ireland, Germany, Norway, Portugal, Italy and Sweden. Random-effects meta-analyses estimated prevalence for twenty-four needs reported by people with dementia, and their informal caregivers using CANE. Most prevalent needs included memory, food, household activities, money and physical health. Results were compared in fixed effects models which demonstrated that caregivers consistently report higher levels of need than people with dementia.

Sensitivity analysis enabled exploration of heterogeneity associated with prevalence of reported needs. Following sensitivity analysis, 12 out of 24 person with dementia reported needs, and nine of 24 caregiver reported needs showed unimportant or moderate heterogeneity (Koletsi et al. 2018). In addition to type of need, heterogeneity was associated with age of onset. People with early onset dementia report higher levels of need than people with later onset dementia particularly for daytime activity and accommodation needs.

Limited published data on the needs of people with severe dementia may reflect the difficulties this group of participants have understanding the questions in available validated assessment tools (Miranda-Castillo et al. 2013). Resultant prevalence estimates therefore describe the needs of people with mild to moderate dementia.

8.2 How Needs are associated with level of Wandering and Safety Risks in People with Dementia living at Home

This secondary data analysis study advanced understanding within this field of the relationship between AT needs identified in the assessment documentation of people with dementia, and the level of risk of wandering and safety risk of the person with dementia. In identifying the needs of people with dementia associated with particular risks, interventions can be targeted to reduce unmet need thereby reducing the chance of adverse outcomes (Farmer et al. 2016; Morrisby et al. 2018).

This research has quantified the relationship between specific needs experienced by people with dementia and level of safety or wandering risk. The needs of people with dementia that predict their level of wandering risk identified through ordinal regression analyses include MMSE, Routine, Posture and Mobility, Occupational Demand and Conversation needs.

Similarly, the needs of people with dementia that predict their level of safety risk were also identified through ordinal regression analyses. These include Posture and Mobility; Problem solving, Occupational Demands and Appraisal of Abilities needs. Tests of nominal effects confirmed that data conformed to the proportional odds assumption, and likelihood ratio tests ensured there was no redundancy within the regression models.

Results of this analysis were limited by restricted data on the needs of people with dementia contained in needs assessment documentation. Reasons for this data being missing are unclear, but results require verification through application to further data.

8.3 Are there Distinct Groups of People with Dementia living at Home?

The secondary data analysis study demonstrated the possibility of creating robust data-based groupings of people with dementia, which can provide a basis for the exploration of the impact of multiple population-related factors upon AT service provision. Exploratory cluster analysis was conducted using a partitioning around medoids (PAM) algorithm which employed a dissimilarity matrix based on Gower distance. This enabled the creation of clusters based upon mixed data types required for the inclusion of data describing participant needs, living situation and caregiver support. Silhouette width supported selection of robust clustering structures. Two clustering solutions were developed, grouping participants based on data describing risk of wandering, or safety risk. The clustering algorithm, in both cases, structured participant groupings according to caregiver support and living situation. This categorisation was verified through exploration of the literature which confirmed that the needs of people with dementia who live with others are often different from the needs of people with dementia living alone (Toseland et al. 2002).

8.4 Do these Clusters of People with Dementia living at Home have different Assistive Technology recommended and installed?

In this secondary data analysis study, the recommendation and installation of AT is shown to be impacted by variation in the population characteristics of the person with dementia. Data describing recommended and installed AT was stratified according to clustering solutions to facilitate understanding of the relationship between groups of population characteristics and AT. Recommended and installed AT data was also stratified according to level of wandering and safety risk for comparison purposes. Subsequent statistical analysis demonstrated associations between recommended and installed AT, and level of risk or clustering solutions.

Results indicate that overall frequency of recommended or installed AT is not associated with level of risk of wandering or safety risk. Although, there are associations between risks and particular categories of AT. However, there are associations between overall frequency of recommended and installed AT and wandering cluster, and installed AT and safety cluster. Results indicate that AT recommendations and installations are related to the needs of the person with dementia but are also, possibly more strongly, related to the living situation and caregiver support of the person with dementia. This results confirm that it is difficult to distinguish between the needs of people with dementia and the needs of caregivers due to the interdependencies of these two groups (Toseland et al. 2002), and that AT needs assessment should consider the wider impact of AT on the social network of the person with dementia. Further, results indicate that people with dementia living alone receive different, possibly less sophisticated AT.

This needs further investigation, but may be because the needs of people with dementia are not well understood and that staff report that they lack the skills to assess this participant group (Lehmann et al. 2010; Jarvis et al. 2017; Collins 2018). Alternatively, the absence of a caregiver may mean that the needs of the person with dementia living alone are different, or that some AT is less viable for this population due to limited support.

8.5 Implications for Policy

Policy states that people with dementia will have access to an early high-quality specialist assessment (Department of Health 2009). Additionally, the Care Act 2014 gives caregivers the right to assessment and to provisions to meet their assessed needs (Mandelstam 2016). In order to facilitate the tailoring of interventions to meet the needs of people with dementia results indicate there must be assessment of multiple factors which influence interventions required by people with dementia (Gagnon-Roy et al. 2017), including the influence of caregiver support and living situation. Therefore, in recommending and installing AT, consideration must also be given to the needs and views of caregivers of people with dementia, people living with the person with dementia and others who will be affected by the installation of AT (Toseland et al. 2002). Policy should therefore support assessment which considers the needs of both the person with dementia and the needs of significant persons within their social network, including the contribution required of the caregiver towards supporting the AT through maintenance and responses. This will facilitate the recommendation and installation of optimal AT for the situation of the person with dementia.

8.6 Implications for Practice

8.6.1 Assistive Technology Needs Assessment should consider the Needs of the Caregiver in addition to the Needs of People with Dementia.

AT needs assessment should consider factors which influence recommendation and installation of AT. However, results indicate that there are a number of factors which can affect AT selection which are not currently considered in the documented AT needs assessment. This may be because these areas are not included in local assessment guidelines, or alternatively, that they are assessed but not documented. In order to consider the needs of the person with dementia together with the needs of their social network the assessor will require to widen their person-centred stance to consider the person with dementia within the broader dynamics of their care network (Sugarhood et al. 2014). There is therefore a requirement to improve the quality of documentation regarding the assessment of needs for people with dementia and the subsequent consideration of services to meet the identified needs. This should include situations where there was difficulty in assessing particular needs of the person with dementia possibly as a result of limited knowledge within the field, or due to lack of an appropriate validated assessment instrument. Enhanced documentation will improve care for people with dementia through the reduction of repeated assessment processes, and by clearly communicating the needs of the person with dementia to other people involved in their care. This may also identify needs which are difficult to assess and for which there is a requirement to develop specialised methods of assessment. It will also provide information regarding the areas where staff members require additional training. Further, the documentation of needs will provide information for the future development of services which meet the needs of people with dementia.

8.6.2 Expert Assessment of People with Dementia.

This secondary data study informs that people living alone with dementia receive different services from people living with others. This may be due to the absence of caregiver needs or the additional services that informal caregivers provide. Alternatively, it may reflect limited skills and knowledge in the assessment of people with dementia (Collins 2018, van Ooteghem et al. 2019). It is also known that people with moderate to severe dementia have difficulty understanding the questions in validated assessment tools (Miranda-Castillo et al. 2013). In order to account for the AT needs of people at all stages of dementia there is a requirement for the development of skilled assessors, validated assessment tools and alternative methods of assessment (van Ooteghem et al. 2019). This will require work on a number of different levels;

1. There is an initial requirement to identify areas for which there are no available validated assessment tools, such as for people who have advanced dementia and visual impairment, as priority areas for assessment development. There is a need for different methods of assessment which can be used for people with different impairments and multimorbidities, and for assessments to be validated in community languages. Additionally, assessment tools should account for the needs, wishes and contributions of caregivers and other members of the person with dementia’s care network.
2. Professional bodies and other organisations concerned with the provision of AT should facilitate clinicians with expertise in the assessment of people with dementia to develop guidance and other resources which can be shared with other health and social care professionals to enable development of relevant skills.
3. Educators should ensure that trainee professionals spend time with expert clinicians to observe assessment methods and strategies used in the assessment of people with dementia. There should also be facilitation of mentoring relationships which provide the trainee or developing professional to approach an expert clinician to discuss assessment related issues and access support and advice on appropriate techniques and strategies.
4. AT service providers should support the development of professionals ensuring that organisational policies, staffing levels and resources support them to provide dementia-friendly patient centred care. Managers should be aware of the needs of people with

dementia and have the authority to institute and sustain change to support creative problem solving.

8.6.3 Widening Assistive Technology Installations

AT is generally provided to enhance the safety of people with dementia (Lorenz et al. 2019), and safety is identified as a primary concern for professionals working in this field (Collins 2018). However, as people with dementia identify daily activities and socialising as priorities (Dickins et al. 2018), AT should also be installed to meet these needs. Focussing on activities which increase the participation of people with dementia will also increase wellbeing and therefore may reduce anxiety related behaviour such as wandering (Gitlin et al. 2008). Hansen et al. (2018) found that restricted service provision may be due to an allocation process that is supply led rather than needs led. In order to place the person with dementia at the centre of this process, clinicians should provide interventions which meet the needs of the person with dementia identified through a comprehensive assessment process (Greenhalgh et al. 2015; Hansen et al. 2018).

Expert clinicians should also be facilitated to share their expertise in the adaptation of AT to meet the needs of people with dementia. In order to fully exploit the benefits of AT there is a need for a wider range of interventions indicated by the individual needs of people with dementia. Not documenting these needs will decrease the possibility of them being met through AT (Hansen et al. 2018).

Clinicians working in this field should be facilitated to engage with the wider AT community through online resources, professional conferences and other networking opportunities. This will enhance communication between clinicians and the population with which they are working and the people who are developing AT. Clinicians will be able to engage with AT developers regarding areas for which AT is currently insufficient for the needs of people with dementia.

8.7 Implications for Research

This research has identified a number of opportunities for further investigation;

- The studies available for meta-analysis included populations who mostly had mild or moderate dementia. There is a requirement for further research to validate the findings regarding the prevalence of need for people with severe dementia.
- There were few participants included in the secondary dataset available for this study who had high level safety or wandering risk. Further research is required to investigate the

validity of results for a population including more participants who have high level safety and wandering risks.

- Due to limited needs assessment data for some needs categories there is also a requirement for further research into the relationship between needs and wandering or safety risk in a population with more comprehensively documented needs assessments to ensure the validity of the results of this research.
- There is a requirement to examine these results in relation to outcomes associated with AT installation. This will assist in understanding the relationship between the factors examined within this research and successful AT implementation.
- Results indicate that people with dementia living alone receive different recommended and installed AT that participants living with others. Further, research should investigate the reasons for this variation in order to ensure that this group are receiving an equitable service.

8.7.1 Impact of Assistive Technology

Findings of this study indicated the impact of heterogeneity on recommended and installed AT for people with dementia who have wandering and safety risks. However, there remains a requirement to determine the likely benefit of AT for people with dementia (Fleming and Sum 2014; Newton et al. 2016). In order to fully understand the implications of this research the relationship of recommended and installed AT with reduction of adverse outcomes should be investigated. This is required to validate the impact of AT installed following consideration of heterogeneity upon adverse outcomes experienced by people with dementia and their caregivers.

8.8 Summary

Identifying effective interventions which meet the care needs of people with dementia has been identified as a priority (Kenigsberg et al. 2017). In order assist in closing the gap between the care required to meet the needs of people with dementia and current AT provision (World Health Organisation 2017), this research has provided findings which increase knowledge regarding the heterogeneity of population characteristics of people with dementia and the subsequent impact of these upon the recommendation and installation of AT. These results indicate that heterogeneity of needs, enabling resources and predisposing characteristics all have an impact upon AT.

The unique contributions, implications and limitations of this research have all been highlighted. Further research has been indicated to evaluate the benefits of consideration of heterogeneity upon adverse outcomes. It is suggested that the findings of this research provide information regarding the real-world variation of people with dementia and the impact this has upon AT. This information can assist in bridging the gap between laboratory based AT development and the real world needs of people with dementia by identifying heterogeneous groups within this population. Consideration of these groups will facilitate the targeting of AT towards people with dementia who will most benefit. It is anticipated that this research will assist in advancing the development of person centred AT services for people with dementia.

CHAPTER 9. IMPACT STATEMENT

This chapter includes an impact statement together with a proposed plan for the dissemination of this research in academic journals and at conferences where expected audience include people with dementia, their unpaid caregivers, and professionals working in the AT industry

There is an acknowledged gap between the potential and achieved benefit of AT in the care of people with dementia. In order to increase available care options and to reduce associated care costs this research aimed to understand the different needs of people with dementia and how these can be met through AT provision. Research was conducted in two parts. Firstly, a systematic review and meta-analysis of published data was undertaken to determine the prevalence of needs experienced by people with dementia living at home. Subsequent secondary data analysis of data derived from the ATTILA RCT investigated the relationship between the assessed needs of people with dementia, their level of safety and wandering risk, and other participant characteristics on recommended and installed AT. Results indicate that particular needs are associated with wandering and safety risks for people with dementia. Service provision is affected by the needs of people with dementia and by other population characteristics such as caregiver support and living situation. This research has resulted in increased understanding of AT needs which can be used to inform assessment of needs, and to tailor AT interventions to meet identified needs.

Who will benefit and how?

- This research will benefit health and social care professionals working with people with dementia. It is known that the number of people living with dementia and their associated care costs are rising. In order to provide care interventions that offer people with dementia a range of interventions which can be tailored to meet their individual needs there is a requirement to understand the relationship between needs and effective interventions.
- This research will benefit people with dementia and their caregivers and wider social support network through improving understanding of the needs of people with dementia and how these can be met through AT interventions. This in turn will lead to interventions becoming more tailored to meet their individual needs contributing to increased quality of life for this population.
- This research will benefit the AT industries by informing them about the current provision of AT in response to the needs and risks experienced by people with dementia, and the impact

of caregiver support and living situation upon AT provision. Their understanding of the relationship between the population characteristics of people with dementia and AT provision will assist people working within AT industries to develop products and training which can be tailored to meet the needs of particular groups of people with dementia and their support network.

Plan for Maximising Impact

The researcher intends to publish results from this thesis in order to make them available for national and international audiences. Journals have been selected to ensure that this information will reach academic and clinical audiences. These audiences will also be alerted to forthcoming publications via social media.

Published Article:

CURNOW, E., RUSH, R., MACIVER, D., GÓRSKA, S., FORSYTH, K. (2019) Exploring the Needs of People with Dementia Living at Home: A Systematic Review and Meta-analysis. *Aging and Mental Health*. vol.0, no.0, pp. 1-11, doi.org/10.1080/13607863.2019.1695741 Impact factor: 2.956

List of intended Journal Publications

Article Focus	**Journal**	**Impact Factor**
The relationship between needs and safety risks for people with dementia living at home.	Gerontologist	4.078
The role of social support in Assistive Technology provision for people with dementia living at home.	Dementia	2.238
Secondary data analysis of assistive technology to reduce wandering risk of people with dementia living at home	International Journal of Geriatric Psychiatry	3.141

Conferences

1. UK Dementia Congress 2020 dates to be announced
2. CECOPS 1st Assistive Technology Conference UK June 2020

The above conferences provide opportunities to share results with non-academic audiences including people with dementia and their families; and results will also be summarised to facilitate sharing results at a wider range of local conferences and with non-academic audiences.

CHAPTER 10. REFERENCES

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CHAPTER 11. APPENDICES

Appendix A: Full Search Strategy Example

Appendix B: Quality Appraisal for Systematic Review and Meta-analysis

Appendix C: Forest Plots

Appendix D: Correlation Matrix

Appendix E: Ethical Approval

Appendix F: Letter Exempting Systematic Review and Meta-analysis from Ethical Approval

Appendix G: Letter from RCT Chief Investigator granting permission to use study data for secondary data analysis

Appendix H: Publication: Curnow et al. (2019)

Appendix I: Abbreviations and Symbols

Appendix A: Full Search Strategy Example

#	Query	Limiters/Expanders	Last Run Via
S19	S10 AND S18	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S18	S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S17	vascular dementia	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S16	Parkinson’s disease	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S15	Lewy body dementia	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases

			Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S14	cognitive impairment	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S13	Alzheimer’s disease	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S12	dementia	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S11	(MH "Dementia") OR (MH "Frontotemporal Dementia") OR (MH "Delirium, Dementia, Amnestic, Cognitive Disorders") OR (MH "Dementia, Vascular") OR (MH	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text

	"Dementia, Multi-Infarct") OR (MH "AIDS Dementia Complex") OR (MH "Lewy Body Disease") OR (MH "Dementia, Senile") OR (MH "Dementia, Presenile") OR (MH “Alzheimer’s disease”)		
S10	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S9	met need	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S8	unmet need	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text

S7	Johns Hopkins Dementia Care Needs Assessment	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S6	EASYcare	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S5	carenapd	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S4	Camberwell assessment of need for the elderly	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S3	assessment of need	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text

S2	(MH "Needs Assessment")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
S1	needs assessment	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text

Appendix B: Quality Appraisal for Systematic Review and Meta-analysis

		Freyne	Mazurek	Miranda-Castillo	Bakker	van der Roest	Kerpershoek
1.	**Was the sample representative of the target population?**	40 caregivers of people with dementia attending the South Dublin Old Age Psychiatry service. Non-randomized convenience sample. Patient characteristics are not compared with characteristics of wider population.	47 people with mild to moderate dementia and 41 informal caregivers recruited from MeetingDem Project, Wroclaw, Poland. Non-randomized convenience sample. Sample group are not compared with wider population. Exclusion criteria were: (1) MMSE score below 11 points indicating inability to communicate, (2) the presence	152 people with dementia aged 60 years or over, diagnosis of dementia according to DSM-IV-TR, living at home not in institution. Non-randomized sample. Informal caregivers had knowledge of people with dementia and spent a minimum of 4 hours per week in direct contact with them. A sample was recruited similar to those obtained from	215 patient care dyads recruited within Amsterdam and Maastricht. Non-randomized sample. Inclusion criteria were diagnosis of dementia established before age 65, and availability of an informant who had contacted with the patient at least once per week. Participant characteristics are compared with those of participants with later onset dementia taking part in a similar study. The two groups varied	236 people with dementia and 322 informal caregivers. Non-randomized sample. Inclusion criteria were (1) diagnosis of dementia, (2) living at home. Characteristics of the people with dementia recruited to the study (n=322) were compared with characteristics of the people with dementia who were interviewed (n=236). The two groups were significantly different in severity of dementia i.e. the interviewed group of people with	451 dyads of people with dementia and caregivers recruited for cohort study. Inclusion criteria were (1) mild to moderate dementia determined by their specialist according to DSM-IV-TR criteria, (2) an informal caregiver who was in close contact with the person with dementia at least once a week, (3) no use of formal care, defined as home nursing care, day

		Freyne	Mazurek	Miranda-Castillo	Bakker	van der Roest	Kerpershoek
			of a serious mental disorder in participant's medical records	previous community studies of dementia in terms of living situation i.e. 65% participants living with another person and 35% living alone.	significantly in behavioural symptoms, hyperactive symptoms, apathy and mood symptoms.	dementia contained few respondents with severe to very severe dementia.	care services (including help with per, community or long-term medical care, nursing and social care structures.
2.	**Were the study participants recruited in an appropriate way?**	Consecutive referrals of patients aged 65 years or over with a diagnosis fulfilling ICD-10 criteria and who had a caregiver were identified over a 6-month period. Their next-of-kin was asked to participat	Participants were included in the MeetingDem project aimed at implementing and evaluating the innovative Meeting Centers Support Program for people with dementia and their caregivers. Further recruitment procedure	Recruited from health and social care services in north-east London, Cambridgeshire and Liverpool. 84.9% recruited from NHS and the rest were recruited from other organizations. Participants were first approached by professional associated with	Patients were consecutively referred from university medical centres in Maastricht and Amsterdam (n=56), regional hospitals (n=10) or regional community mental health services (n=20), and sampled from specialized day-care facilities	People with dementia and their informal caregivers were approached via public recruitment in 3 Alzheimer's cafes and in the Mantelzorgkrant (magazine for informal caregivers) and through various care providing organizations; CIZ, 2 memory clinics, 10 meeting centres, 3 psychogeria	Participants were recruited from various settings such as general practitioners, memory clinic and community mental health teams. In addition, participants were recruited via advertisements that were placed in local and national

		Freyne	Mazurek	Miranda-Castillo	Bakker	van der Roest	Kerpershoek
		e in the study	s are not described.	service and then followed up by researcher.	(n=115), or participants applied to participate (n=14)	tric day-care centres. Also, through an ongoing study in GP Practices in Noord-Holland.	newspapers.
3.	**Was the sample size adequate?**	40 caregivers of patients with diagnosis of dementia, two caregivers refused to participate.	47 participants with mild or moderate dementia and 41 informal caregivers were included. Six caregivers refused to participate in the study	152 people with dementia and 128 informal caregivers.	215 patient-caregiver dyads	236 people with dementia and 322 informal caregivers.	451 people with dementia and their 451 caregivers.
4.	**Were the study subjects and the setting described in detail?**	Table of demographic details includes age, gender, marital status, living situation, geographical area, education, service contact and previous	Table of characteristics of people with dementia and caregivers includes information on gender, age, marital status, level of education, and for	Details give re age, gender, marital status, social network type, MMSE, functional status, QoL, NPI, caregiver characteristics.	Baseline demographic characteristics of patient and caregiver included.	Large amount of sociodemographic information given. Details of subjects' age, gender, marital status, income, education level, diagnosis and details of the professional	Table of group characteristics are presented including gender, age, diagnosis, marital status, years of education.

		Freyne	Mazurek	Miranda-Castillo	Bakker	van der Roest	Kerpershoek
		admissions.	the person with dementia additionally MMSE, GDS and Qol-AD score.			care received are included in the article.	
5.	**Is the data analysis conducted with sufficient coverage of the identified sample?**	Analysis based on data from 40 caregivers. Two caregivers refused to participate.	47 participants with mild or moderate dementia and 41 informal caregivers.	Data analysis of 152 people with dementia. 27 (17.8%) people with dementia were unable to understand the questions on the CANE, so for these participants only caregiver and professional CANE data are available. Characteristics of this group are described.	209/215 patient/caregiver dyads were included in the study; six caregivers refused to participate due to high levels of subjective burden, 57 patients were unable to complete the CANE interview. 54 dyads were lost to the two-year follow-up assessment; 16 were lost due to the death of the patient; 38 dyads discontinued participation due to	891 patient-caregiver dyads were approached by letter inviting them to participate in the study. 367 were not reached or did not meet the inclusion criteria. Of the remaining 524 dyads, 372 dyads initially agreed to participate with 51 dyads later dropping out due to nursing home admission, illness and time constraints on the informal caregiver. The final	Analysis was based on data collected from 451 people with dementia and their caregivers.

		Freyne	**Mazurek**	**Miranda-Castillo**	**Bakker**	**van der Roest**	**Kerpershoek**
					burden or lack of time due to the caregiving situation. Characteristics of those who dropped out are compared with those remaining in the study.	response was 61.3%.	
6.	**Were objective, standard criteria used for the measurement of the condition?**	CANE. ICD-10 for diagnosis of dementia.	CANE – Polish version. Severity of dementia was established using MMSE and the GDS	CANE. Diagnosis of dementia according to DSM-IV-TR.	CANE – Dutch version. Diagnosis of dementia was made by a clinician according to criteria from the DSM-IV-TR for dementia and the Dutch consensus guidelines.	CANE – Dutch version. Verification of diagnosis of dementia syndrome according to DSM-IV-TR was obtained in writing from GP or specialist.	CANE. DSM-IV-TR for diagnosis of dementia.
7.	**Was the condition measured reliably?**	CANE interviews were conducted by one of the study authors who is a	The needs survey was carried out by a trained physician and physiothe	Researchers were trained by an expert to undertake the interviews using the	Trained researchers and research assistants collected data using structured interviews	CANE – Dutch version conducted by trained interviewers. Verification of diagnosis	CANE conducted by trained researcher. Diagnosis of dementia

		Freyne	**Mazurek**	**Miranda-Castillo**	**Bakker**	**van der Roest**	**Kerpershoek**
		senior social worker. Diagnosis of dementia fulfilled ICD-10 criteria.	rapist who had experience in conducting the CANE – Polish version, and who was not directly related to the medical or social services, which were used, by the participants or their caregivers. People with dementia and their caregivers were interviewed separately.	CANE. Pilot interviews were discussed and agreement in rating criteria was achieved particularly for complex cases.	and questionnaires to collect the data. Diagnosis of dementia was made by a clinician according to criteria from DSM-IV-TR for dementia and Dutch consensus guidelines.	type and severity of dementia was obtained in writing from GP or specialist	made by specialist according to DSM-IV-TR criteria.
8.	**Was there appropriate statistical analysis?**	Results were reported as percentage of no need, met need and unmet need.	Results were reported as number and percentage of met and unmet needs reported	Needs were reported as percentages.	Proportions or means were calculated, chi-square tests for categorical variables and t tests for	Frequency distributions were determined to identify needs on different areas. Level of agreement between	Needs were presented in graphical form. Further information was obtained

		Freyne	Mazurek	Miranda-Castillo	Bakker	van der Roest	Kerpershoek
			by person with dementia, and caregiver.		continuous variables.	needs reported by people with dementia and their informal caregiver was assessed by calculating k coefficients.	from the authors.
9.	**Are all the important confounding factors/ subgroups/ differences identified and accounted for?**	No subgroups were identified.	No subgroups identified.	Living alone v living with others,	Relationship between needs and neuropsychiatric symptoms, agreement between patient and caregiver needs.	The study discussed; the impact of severity of dementia, caregiver gender, caregiver burden, type of caregiver-patient relationship, geographical differences in services on offer on the needs of people with dementia	No subgroups were identified
10.	**Were subpopulations identified using objective criteria?**	NA	NA	PANT– living situation.	NPI	Self-perceived pressure from Informal care (Pot et al. 1995) used to determine	NA

		Freyne	**Mazurek**	**Miranda-Castillo**	**Bakker**	**van der Roest**	**Kerpershoek**
						caregiver burden.	
	Overall Appraisal	Small sample size recruited from one-day hospital. Sample characteristics were not compared with the wider population.	Small sample size recruited from one site. Sample characteristics were not compared with the wider population.	Sample characteristics were not compared with the wider population. People with severe dementia were unable to complete CANE.	Reasonable sample size. Describes characteristics of those who dropped out of the study. Most participants had a moderate disease severity.	Interviewed group contained few people with severe or very severe dementia.	Reasonable sample size. Study only included people with mild or moderate dementia.

Note. MMSE = Mini-mental state examination (Folstein et al. 1975); CANE = Camberwell Assessment of Need for the Elderly (Reynolds et al. 2009); CANE – Dutch version = Camberwell Assessment of Need for the Elderly (Dröes et al. 2004); CANE –Polish version = Camberwell Assessment of Need for the Elderly (Rymaszewska et al. 2008); GDS = Global Deterioration Scale (Reisberg et al. 1982); PANT = Practitioner Assessment of Network Typology (Grant and Wenger 1993), NPI = Neuropsychiatric Inventory (Cummings et al. 1994); NA =Not applicable; QoL = Quality of Life; AD = Alzheimer's disease; DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders 4th edition (American Psychological Association 2000); ICD-10 = International Classification of Diseases and Related Health Problems, 10th Revision (World Health Organisation 1992); GP = General Practitioner.

Appendix C: Forest Plots

Figure 16 Person with Dementia reported Food needs

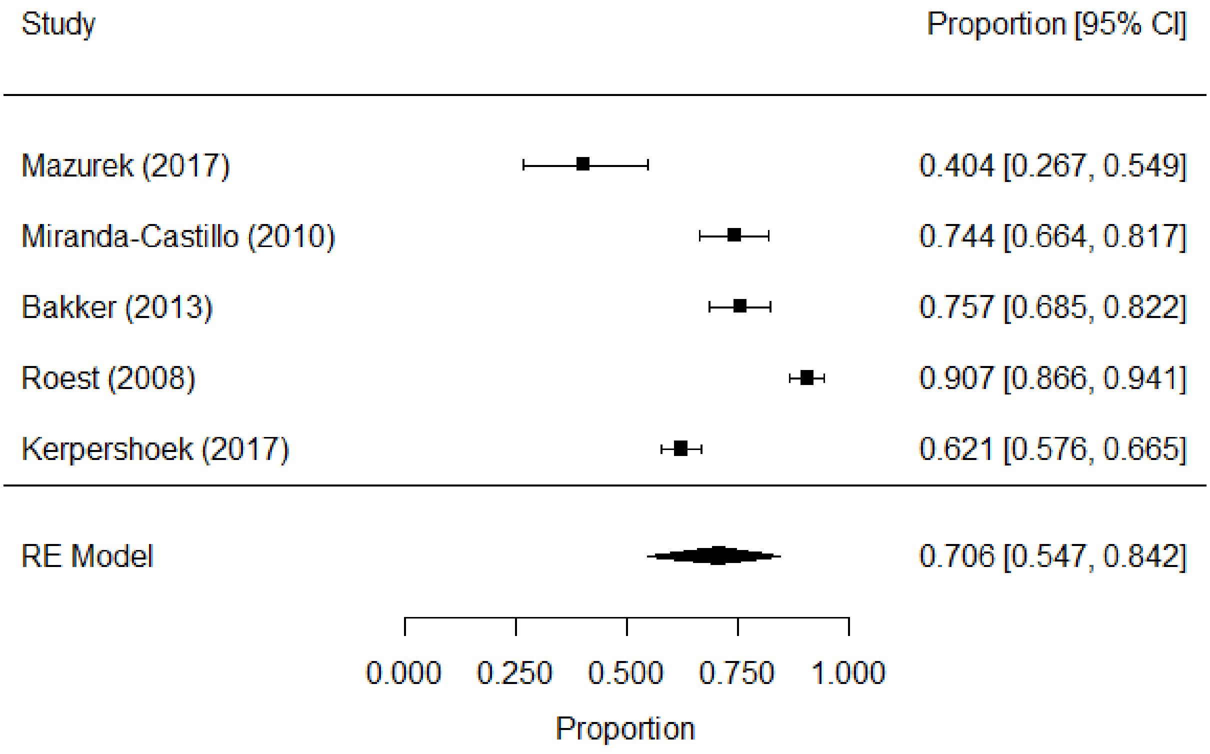


Figure 14. CI = Confidence Interval, RE = Random Effects

Figure 17 Caregiver reported Food needs

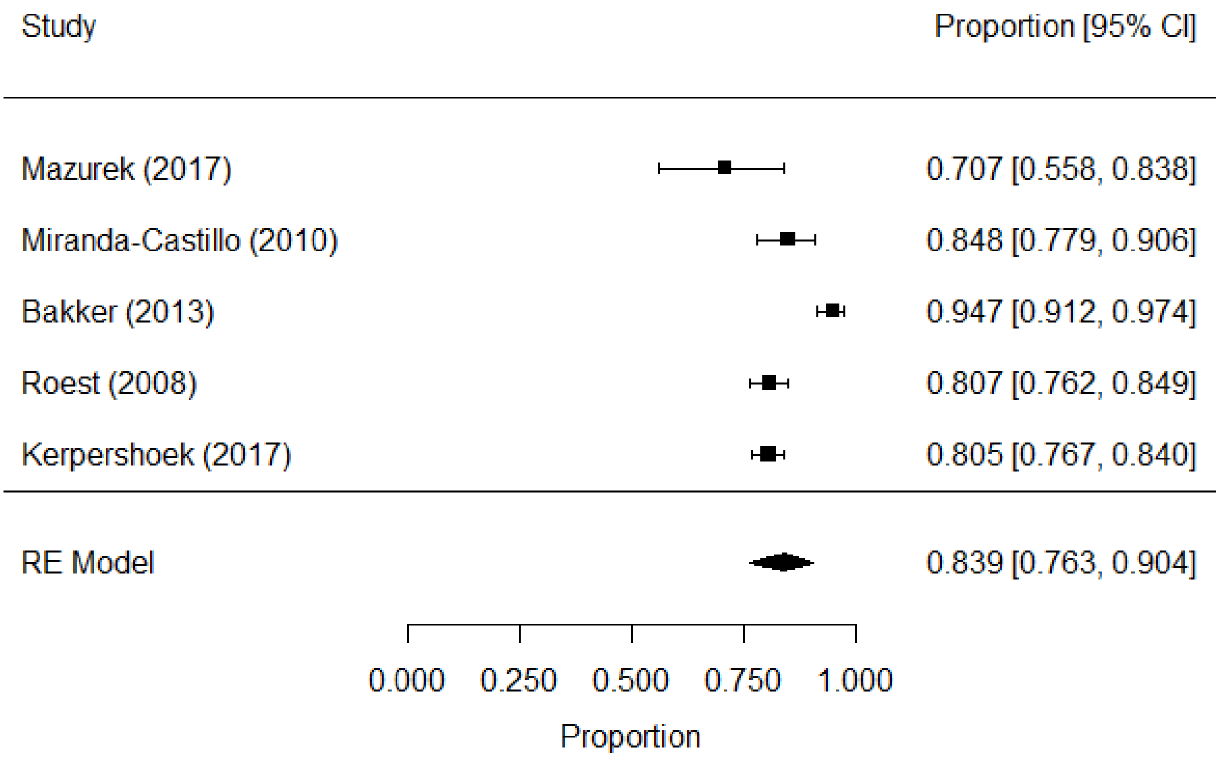


Figure 15. CI = Confidence Interval, RE = Random Effects

Figure 18 Person with Dementia reported Household Activities Needs

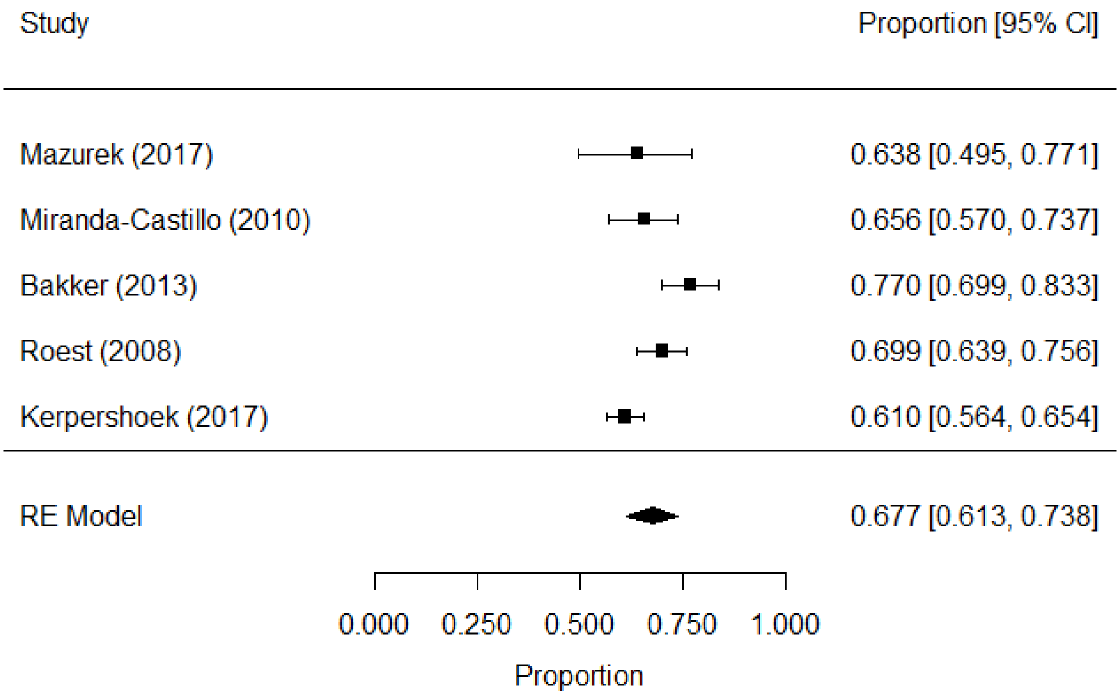


Figure 16. CI = Confidence Interval, RE = Random Effects

Figure 19 Caregiver reported Household Activities Needs

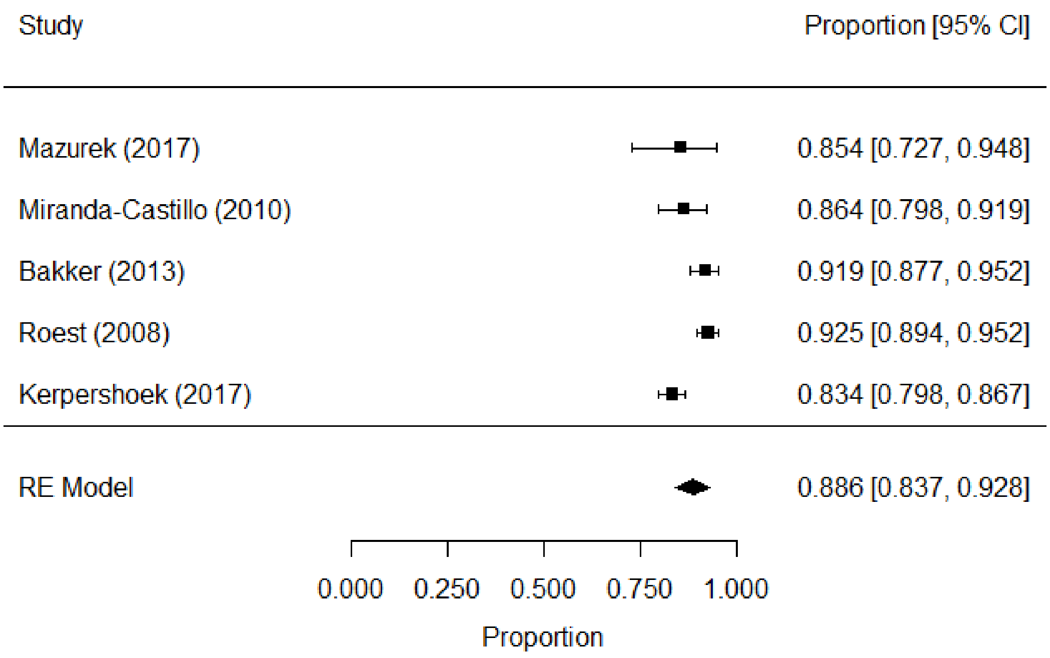


Figure 17. CI = Confidence Interval, RE = Random Effects

Figure 20 Person with Dementia reported Money Needs

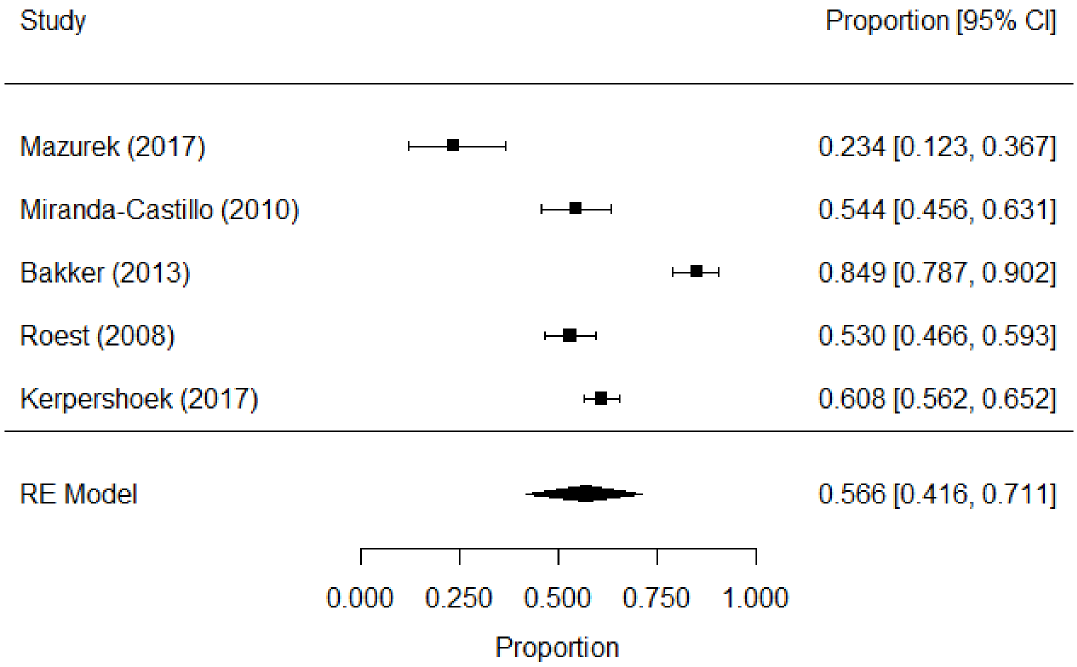


Figure 18. CI = Confidence Interval, RE = Random Effects

Figure 21 Caregiver reported Money Needs

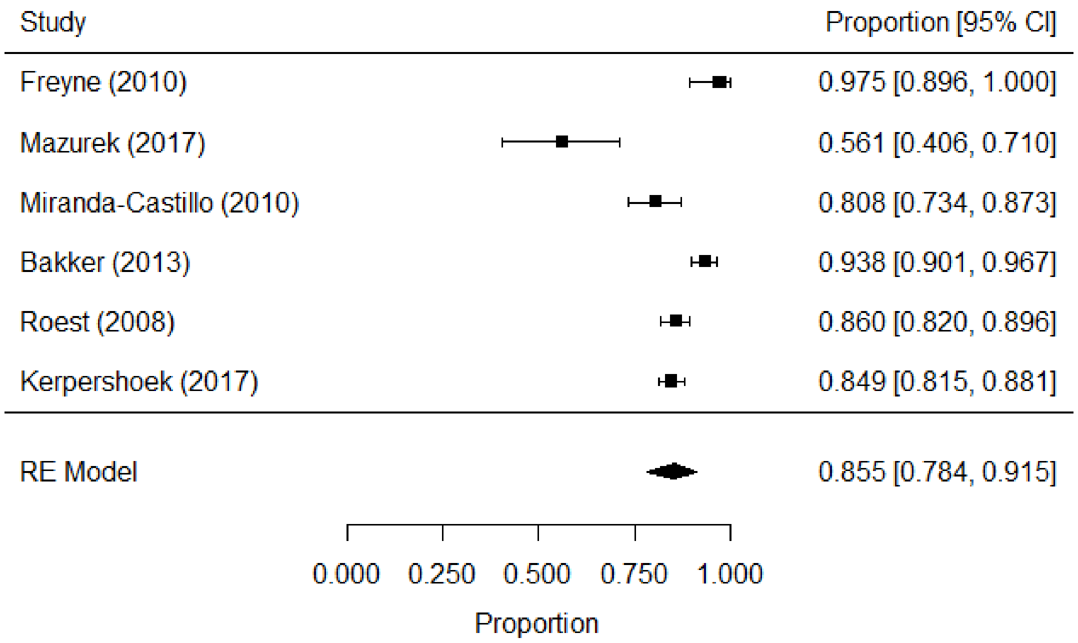


Figure 19. CI = Confidence Interval, RE = Random Effects

Figure 22 Person with Dementia reported Physical Health Needs

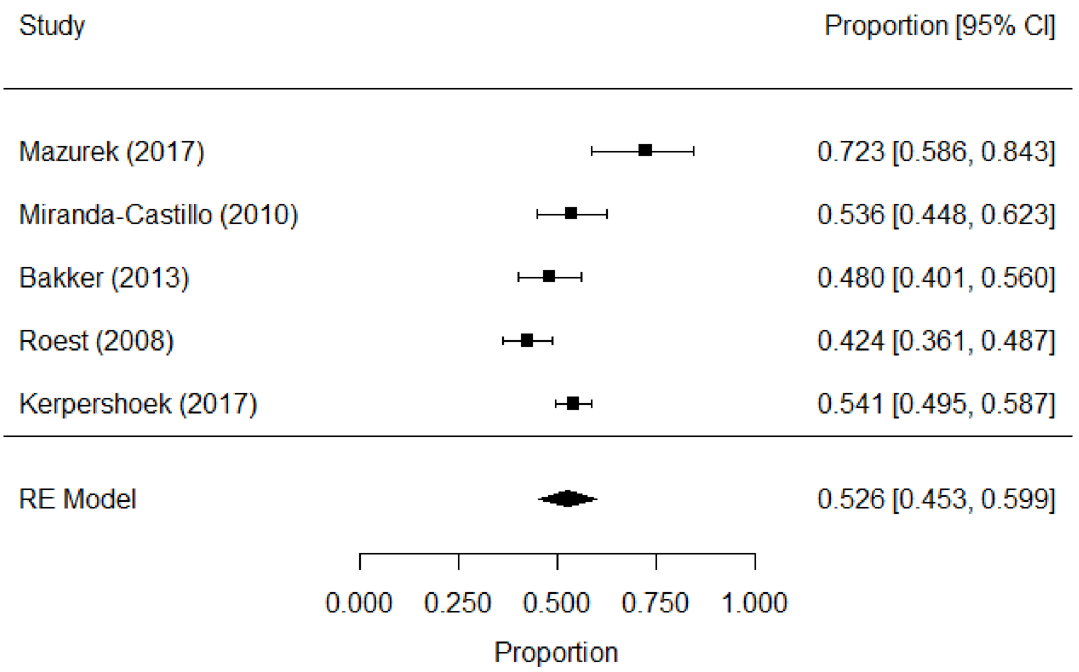


Figure 20. CI = Confidence Interval, RE = Random Effects

Figure 23 Caregiver reported Physical Health Needs

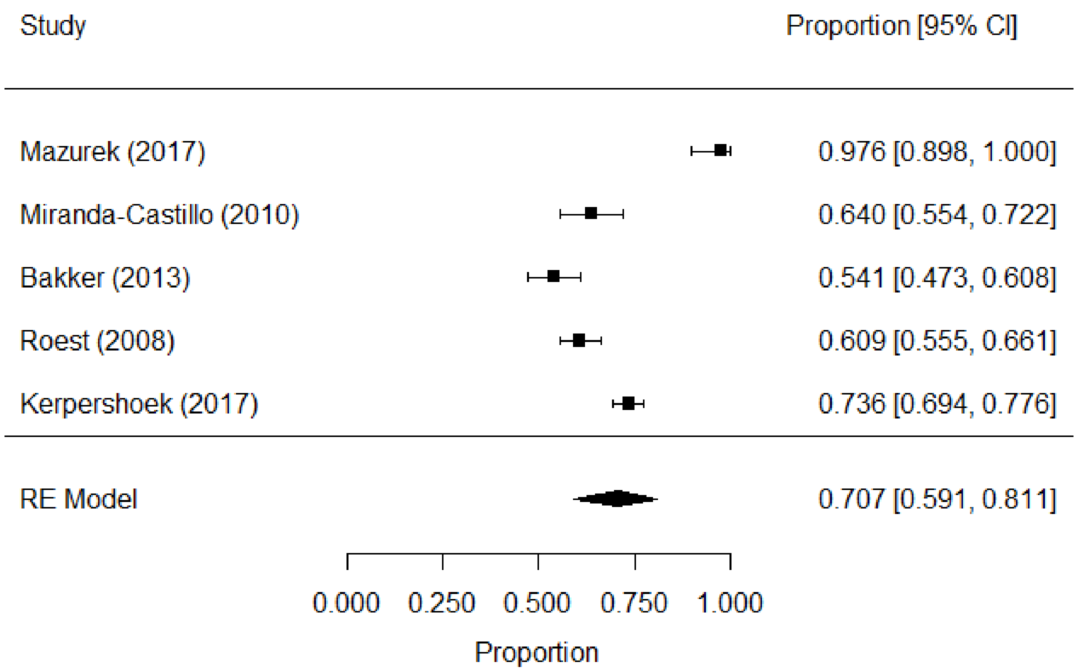


Figure 21. CI = Confidence Interval, RE = Random Effects

Figure 24 Person with Dementia reported Mobility Needs

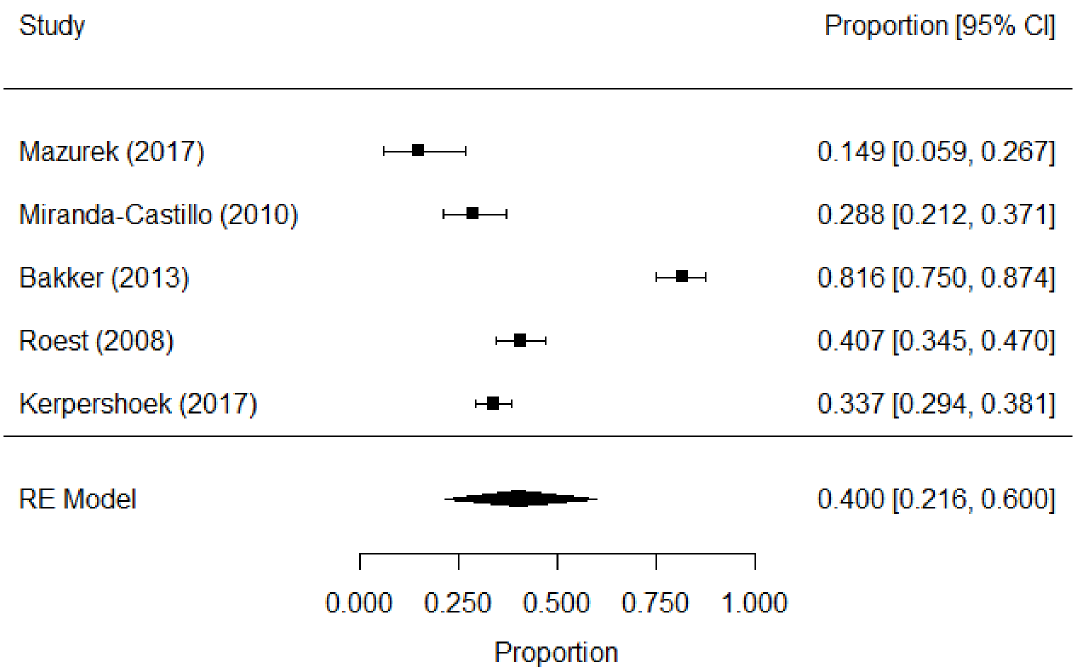


Figure 22. CI = Confidence Interval, RE = Random Effects

Figure 25 Caregiver reported Mobility Needs

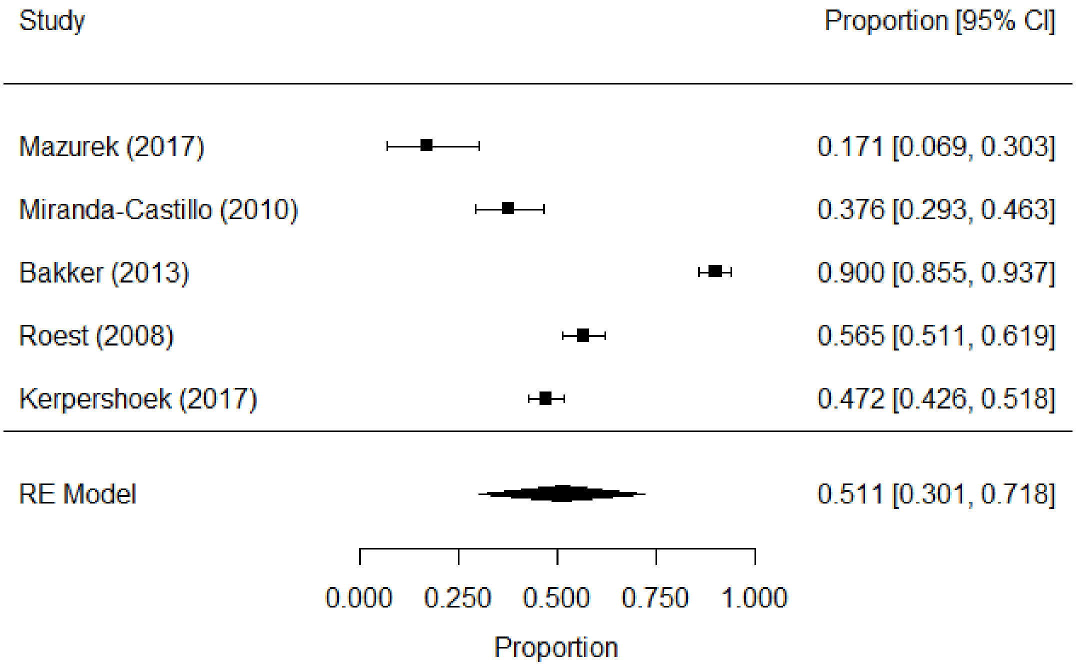


Figure 23. CI = Confidence Interval, RE = Random Effects

Figure 26 Person with Dementia reported daytime activity needs

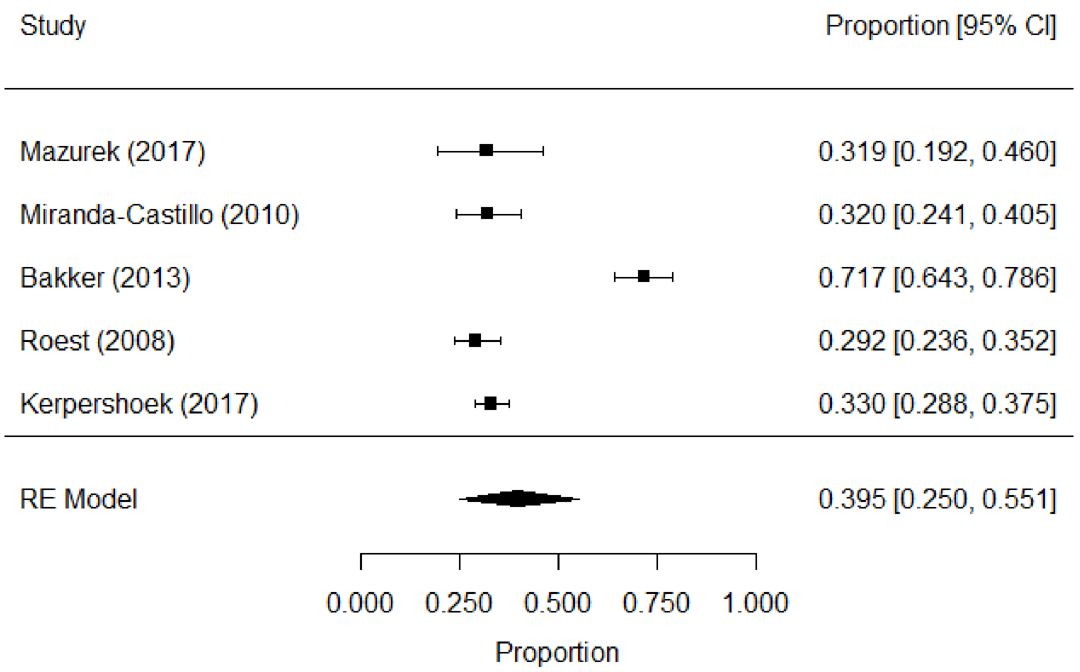


Figure 24. CI = Confidence Interval, RE = Random Effects

Figure 27 Caregiver reported Daytime Activity Needs

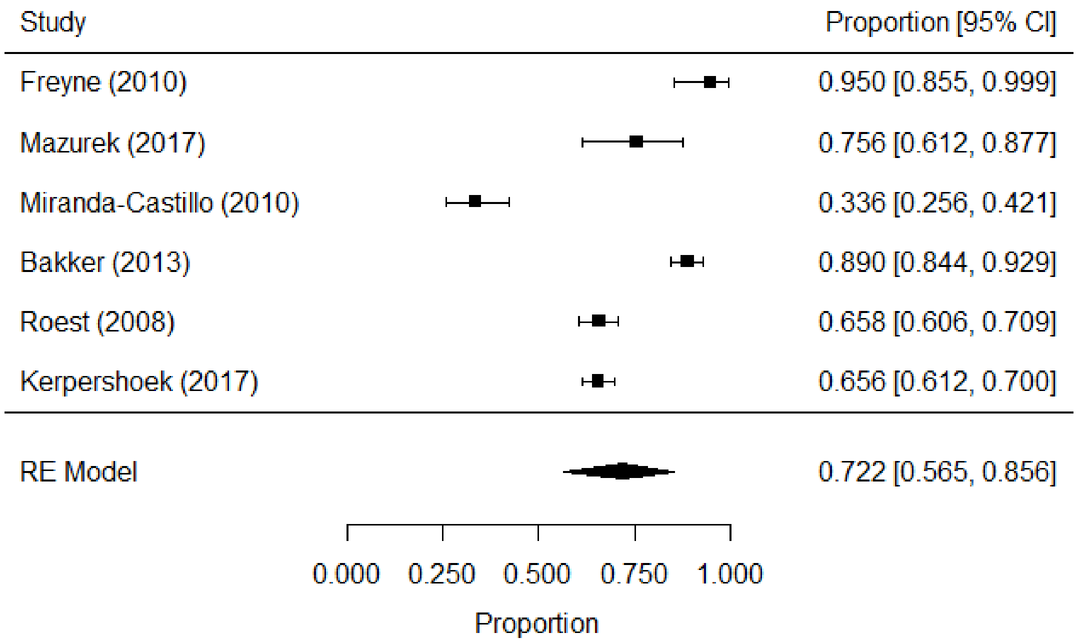


Figure 25. CI = Confidence Interval, RE = Random Effects

Figure 28 Person with Dementia reported Eyesight/ Hearing Needs

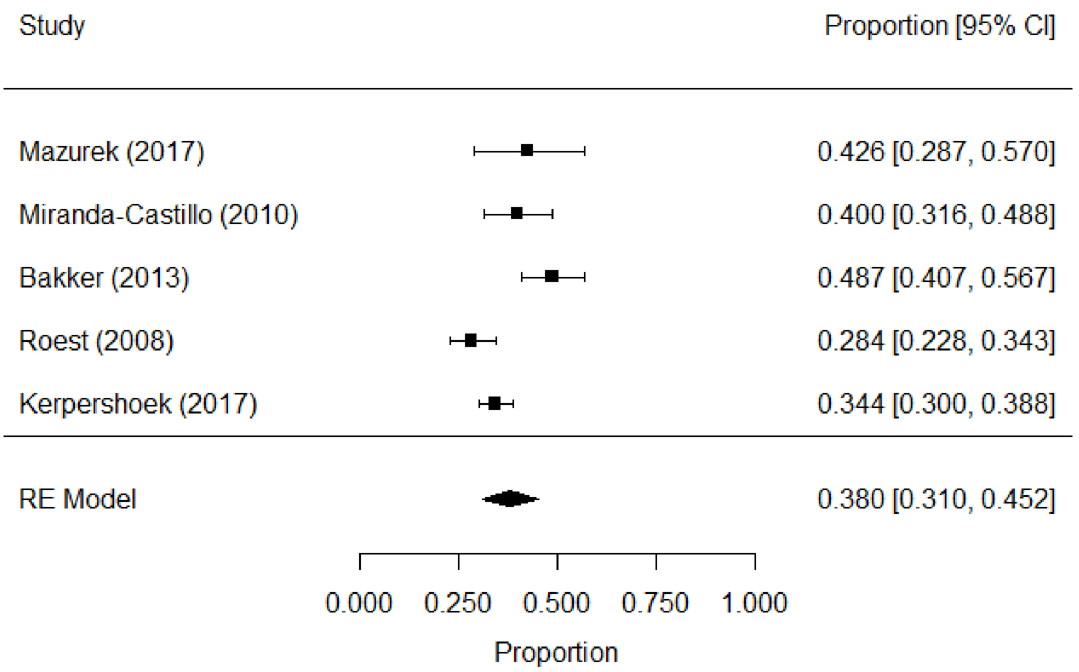


Figure 26. CI = Confidence Interval, RE = Random Effects

Figure 29 Caregiver reported Eyesight/ Hearing Needs

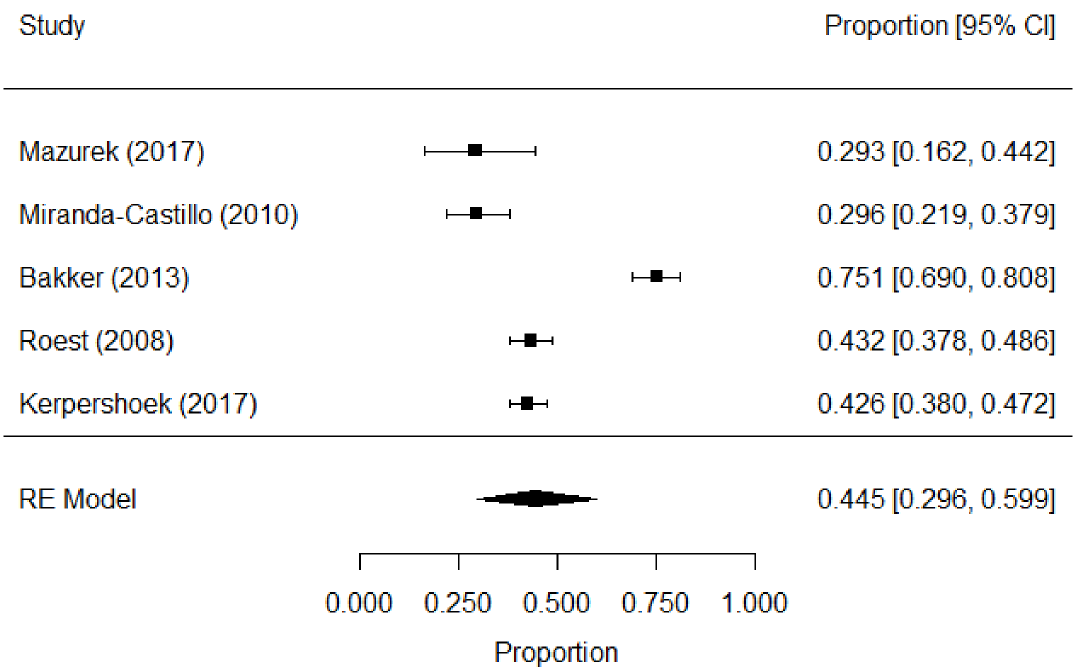


Figure 27. CI = Confidence Interval, RE = Random Effects

Figure 30 Person with Dementia reported Drugs Needs

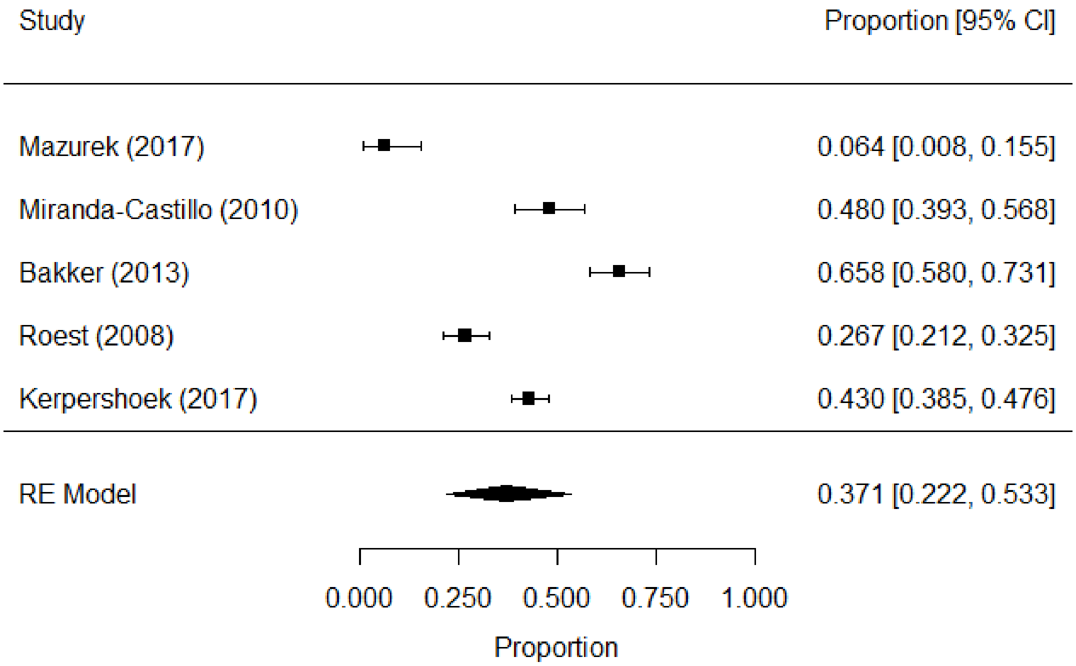


Figure 28. CI = Confidence Interval, RE = Random Effects

Figure 31 Caregiver reported Drugs Needs

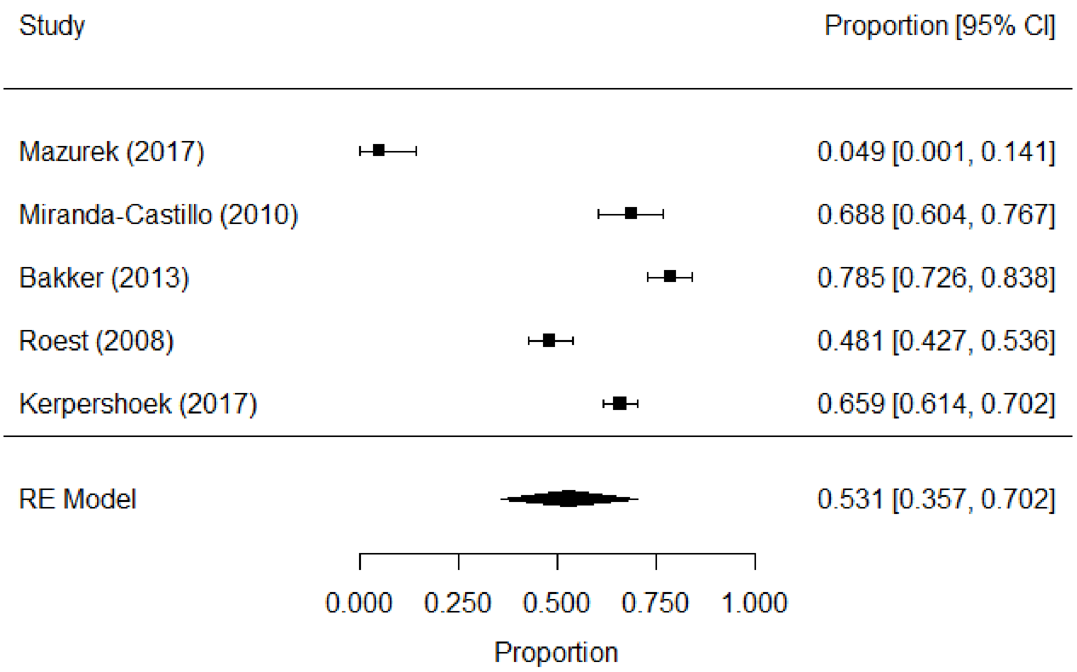


Figure 29. CI = Confidence Interval, RE = Random Effects

Figure 32 Person with Dementia reported Company Needs

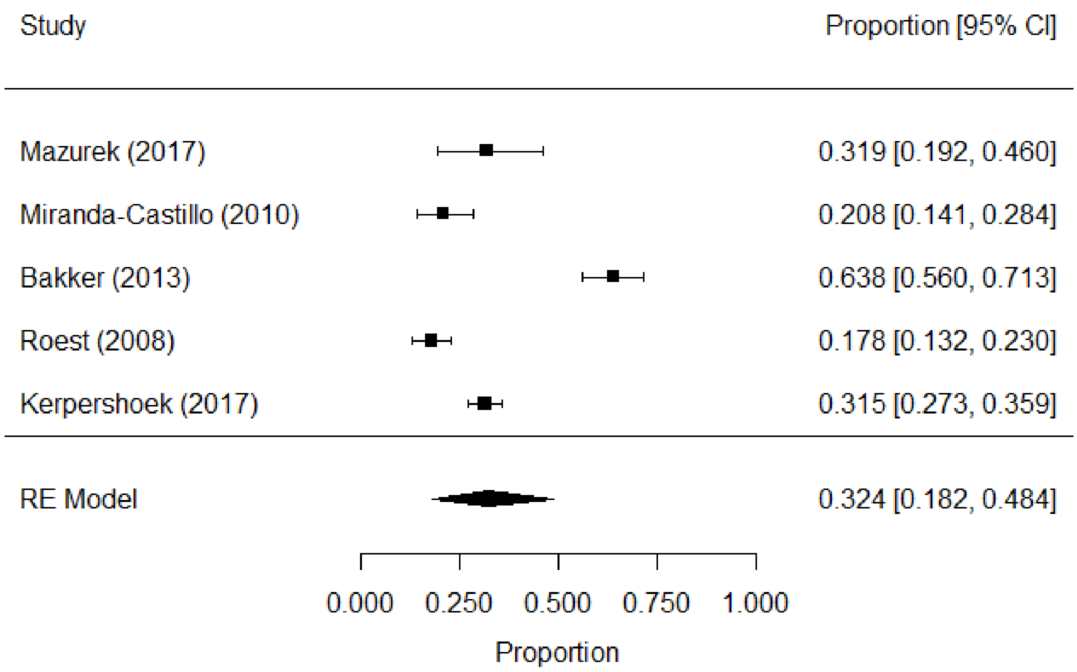


Figure 30. CI = Confidence Interval, RE = Random Effects

Figure 33 Caregiver reported Company Needs

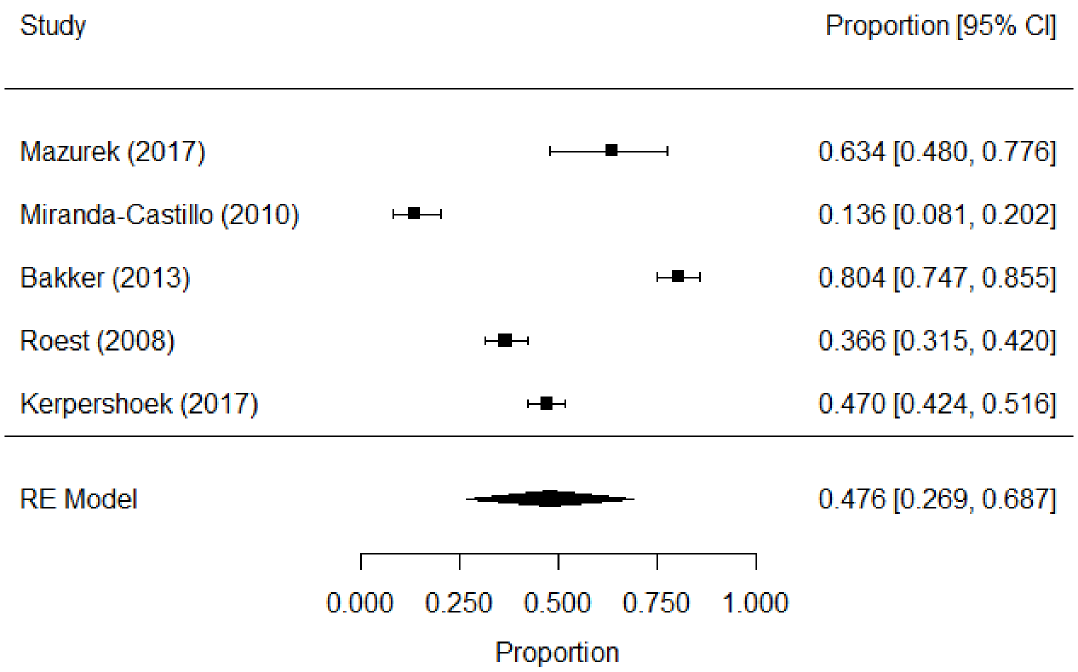


Figure 31. CI = Confidence Interval, RE = Random Effects

Figure 34 Person with Dementia reported Psychological Distress Needs

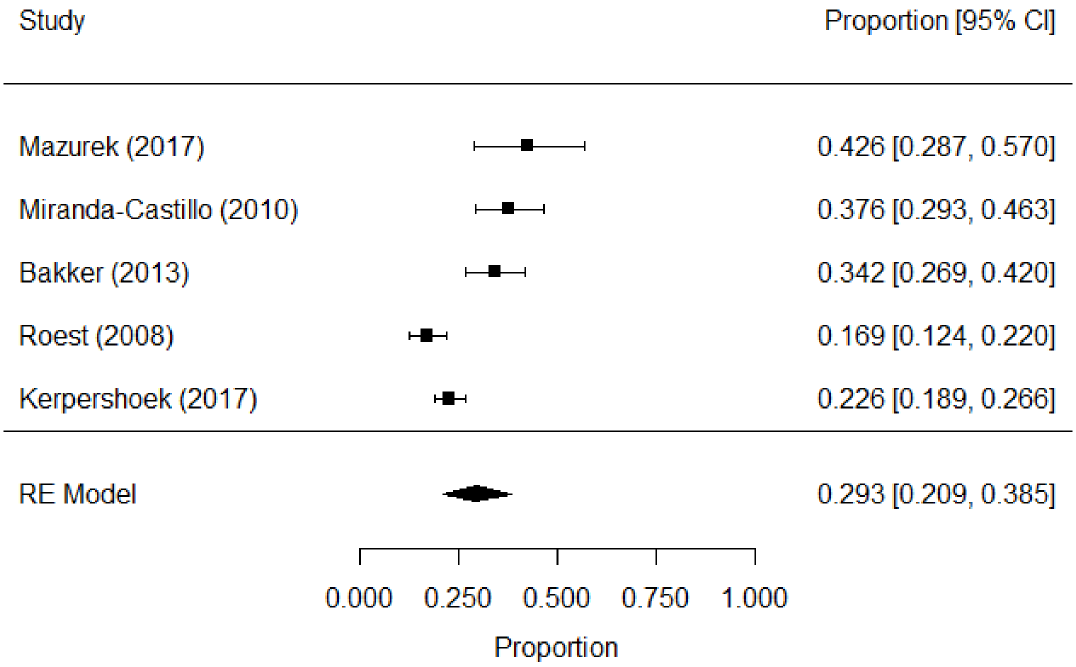


Figure 32. CI = Confidence Interval, RE = Random Effects

Figure 35 Caregiver reported Psychological Distress Needs

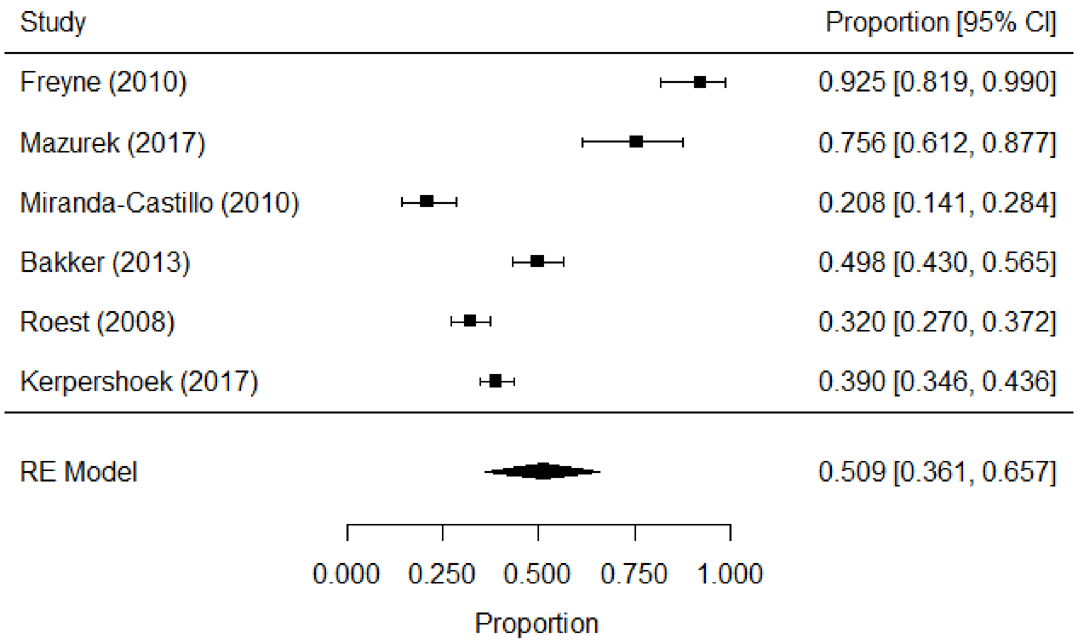


Figure 33. CI = Confidence Interval, RE = Random Effects

Figure 36 Person with Dementia reported Self-care Needs

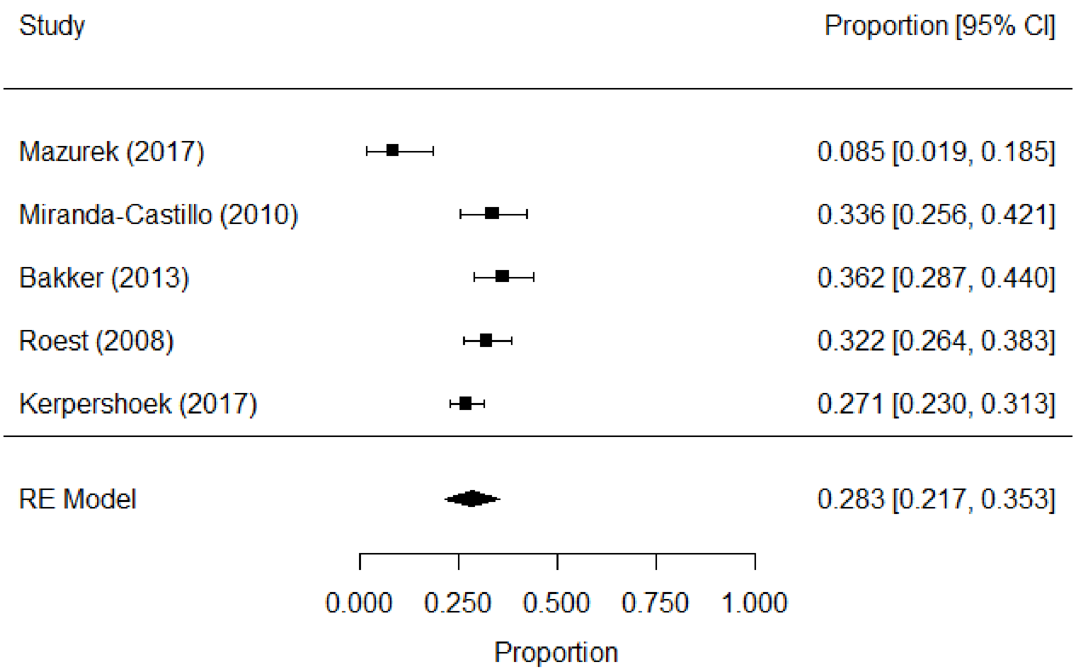


Figure 34. CI = Confidence Interval, RE = Random Effects

Figure 37 Caregiver reported Self-care Needs

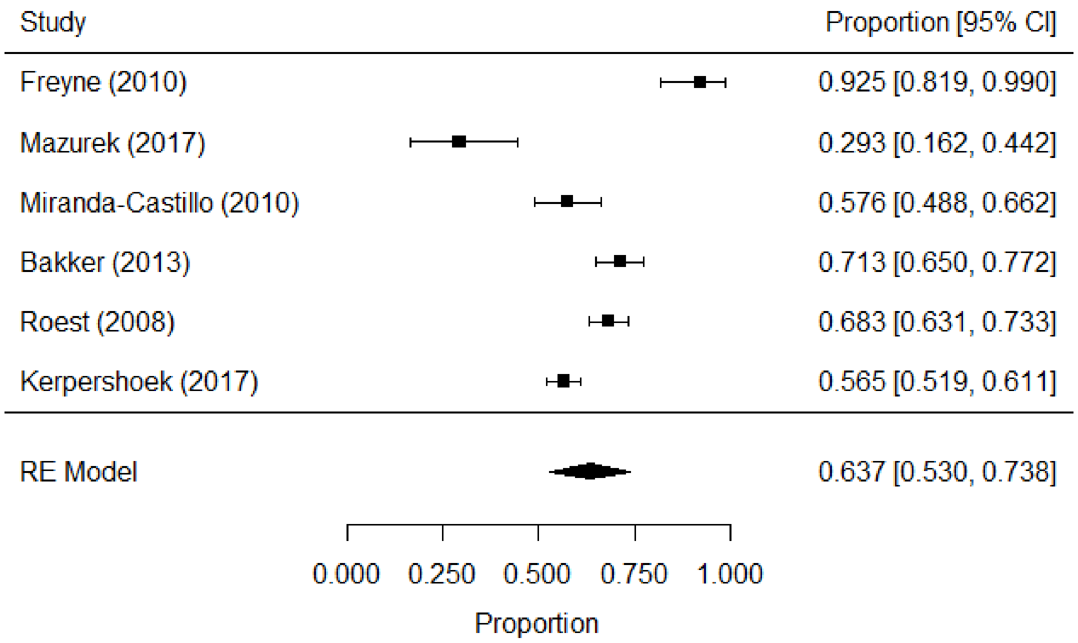


Figure 35. CI = Confidence Interval, RE = Random Effects

Figure 38 Person with Dementia reported Information Needs

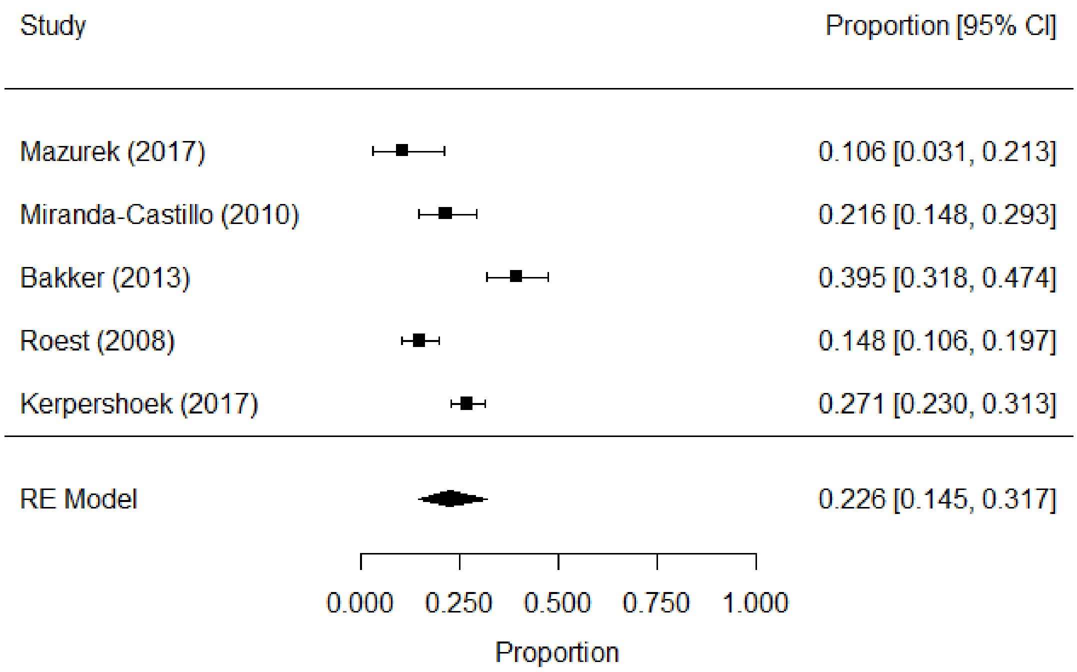


Figure 36. CI = Confidence Interval, RE = Random Effects

Figure 39 Caregiver reported Information Needs

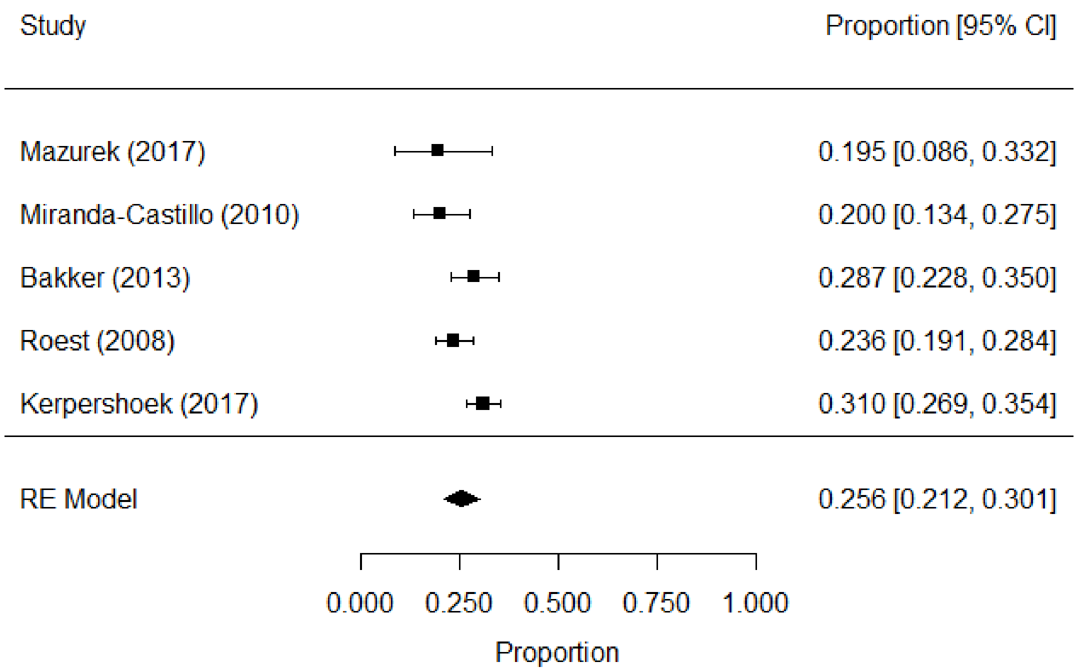


Figure 37. CI = Confidence Interval, RE = Random Effects

Figure 40 Person with Dementia reported Benefits Needs

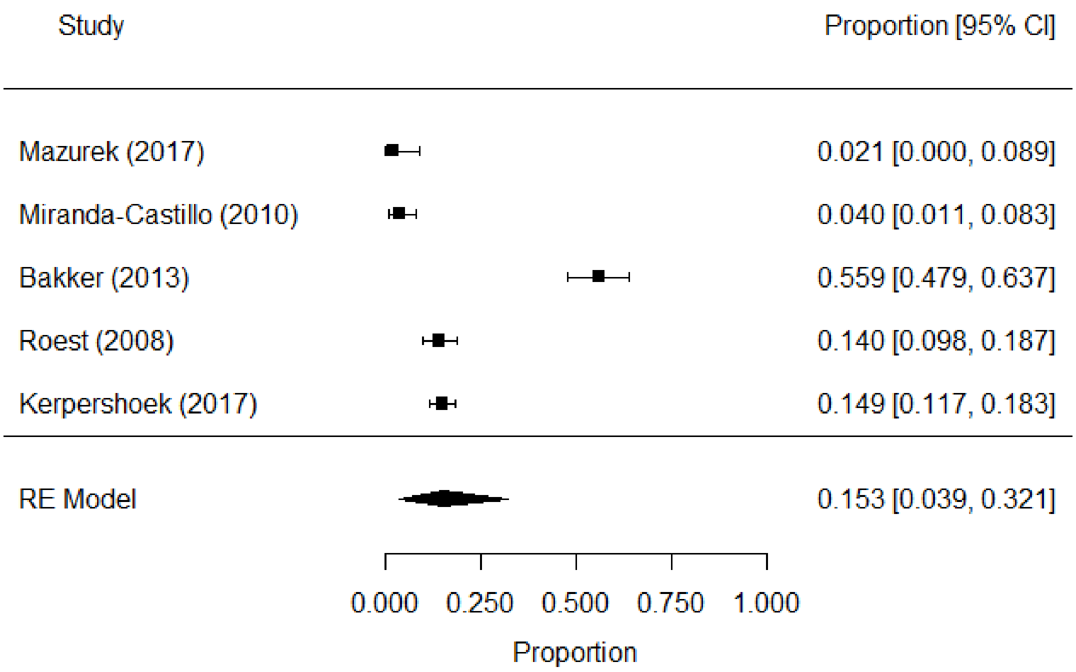


Figure 38. CI = Confidence Interval, RE = Random Effects

Figure 41 Caregiver reported Benefits Needs

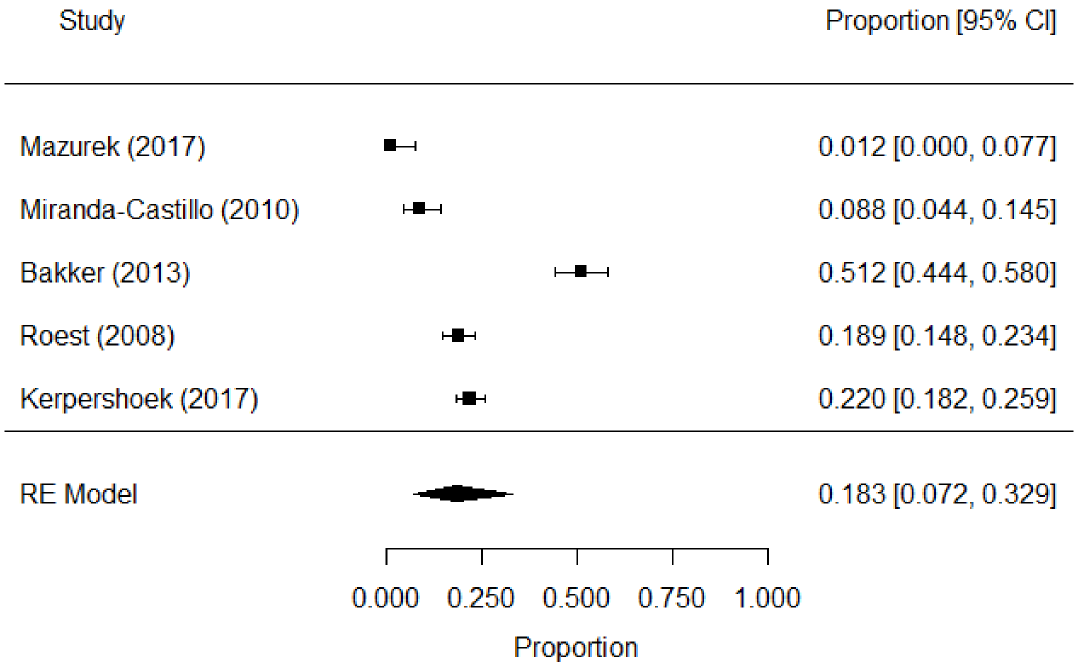


Figure 39. CI = Confidence Interval, RE = Random Effects

Figure 42 Person with Dementia reported continence needs

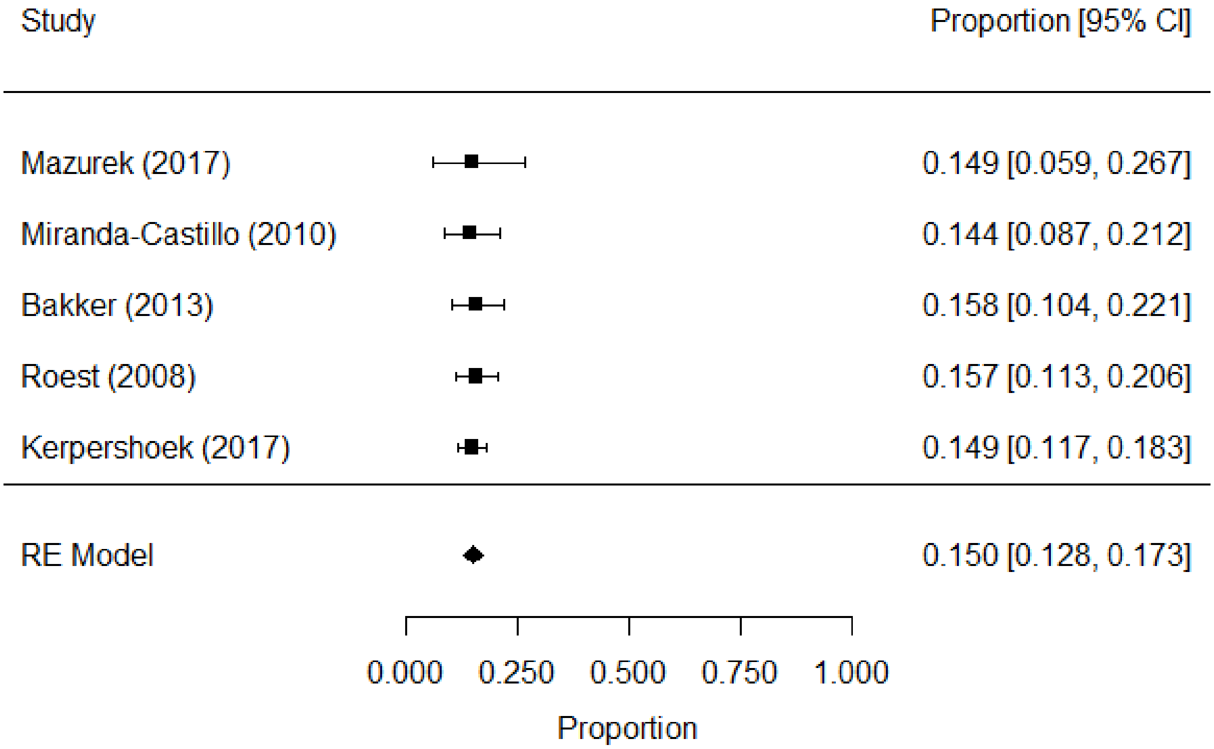


Figure 40. CI = Confidence Interval, RE = Random Effects

Figure 43 Caregiver reported Continence Needs

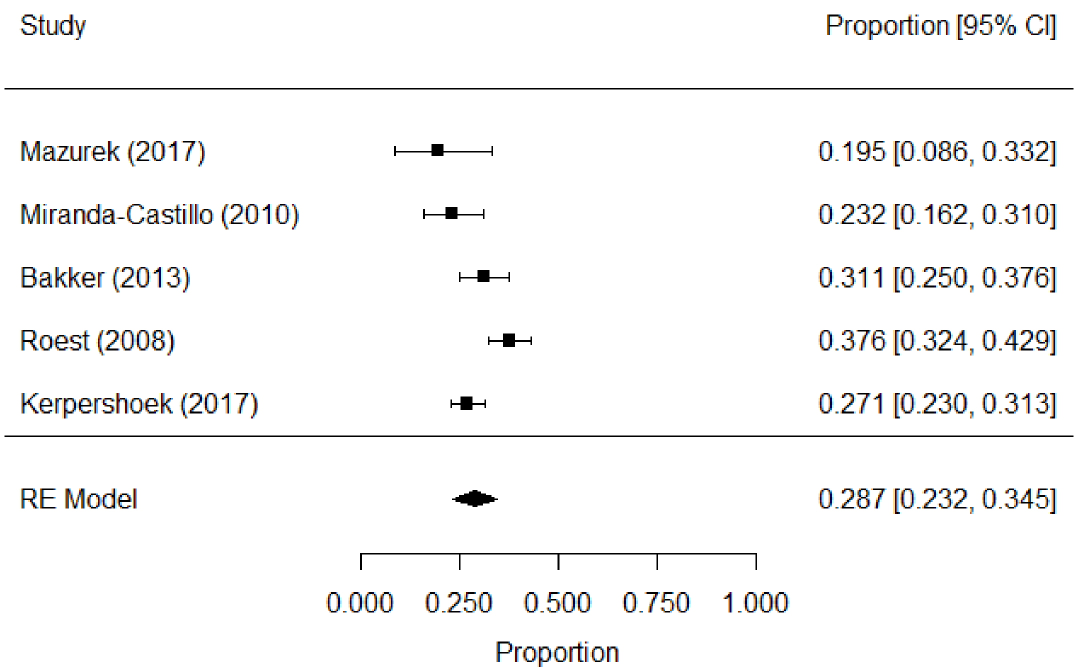


Figure 41. CI = Confidence Interval, RE = Random Effects

Figure 44 Person with Dementia reported Accommodation Needs

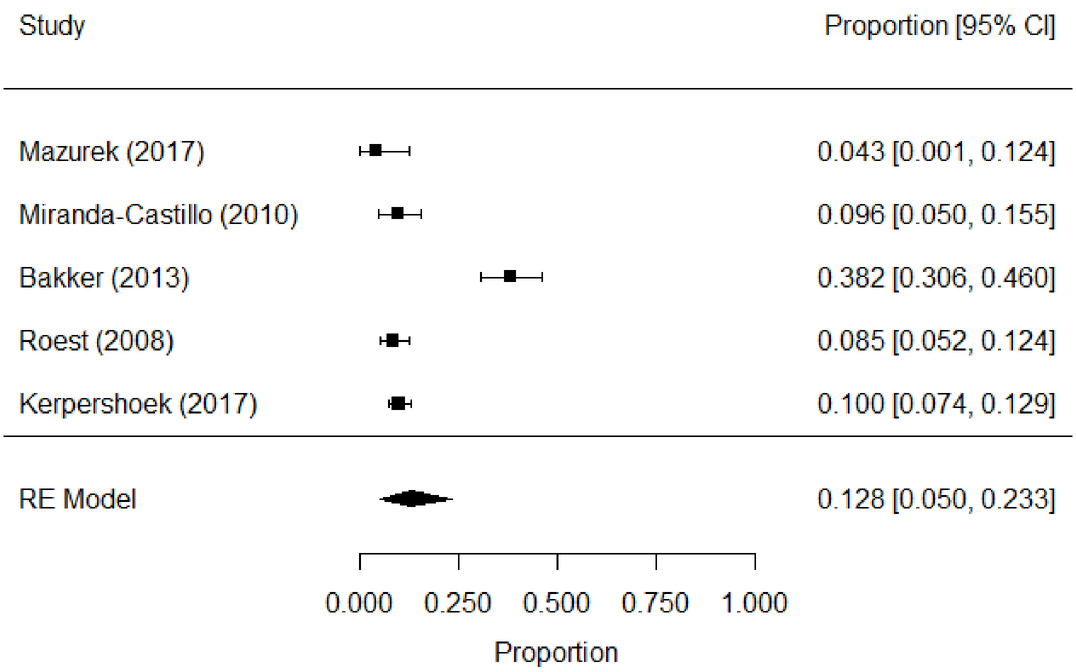


Figure 42. CI = Confidence Interval, RE = Random Effects

Figure 45 Caregiver reported Accommodation Needs

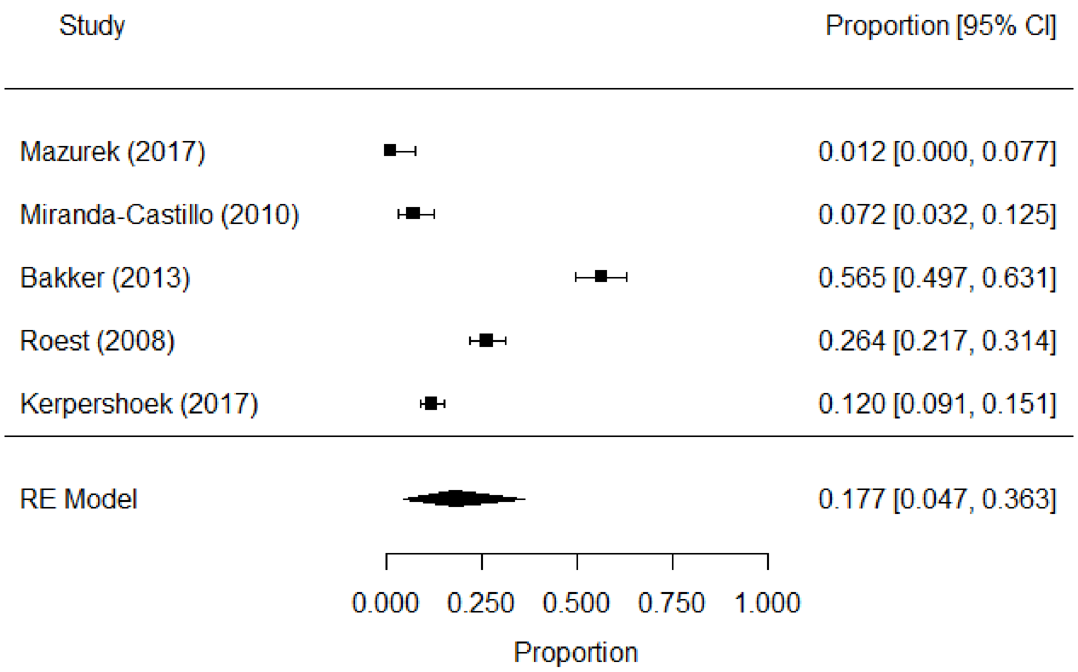


Figure 43. CI = Confidence Interval, RE = Random Effects

Figure 46 Person with Dementia reported Accidental Self-harm Needs

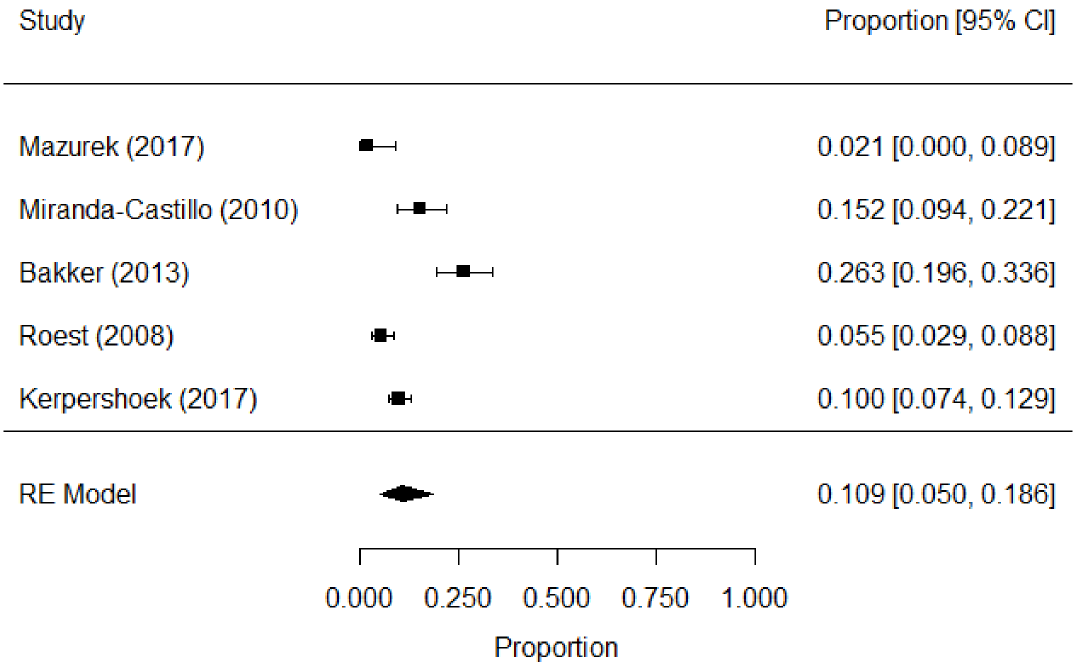


Figure 44. CI= Confidence Interval, RE = Random Effects

Figure 47 Caregiver reported Accidental Self-harm Needs

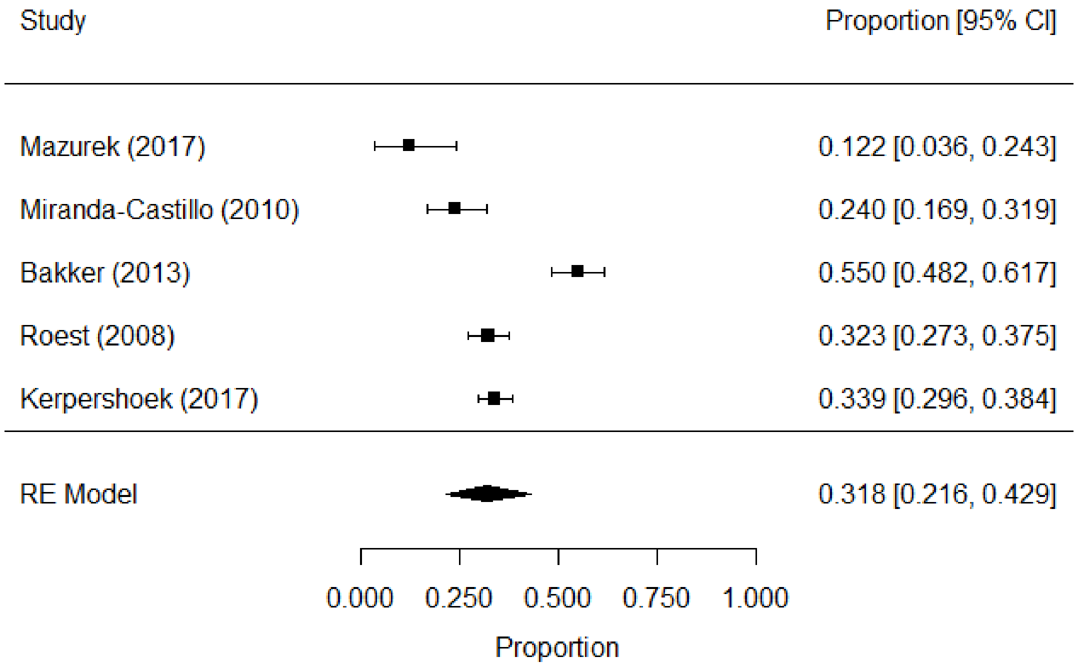


Figure 45. CI = Confidence Interval, RE = Random Effects

Figure 48 Person with Dementia reported Intimate Relationship Needs

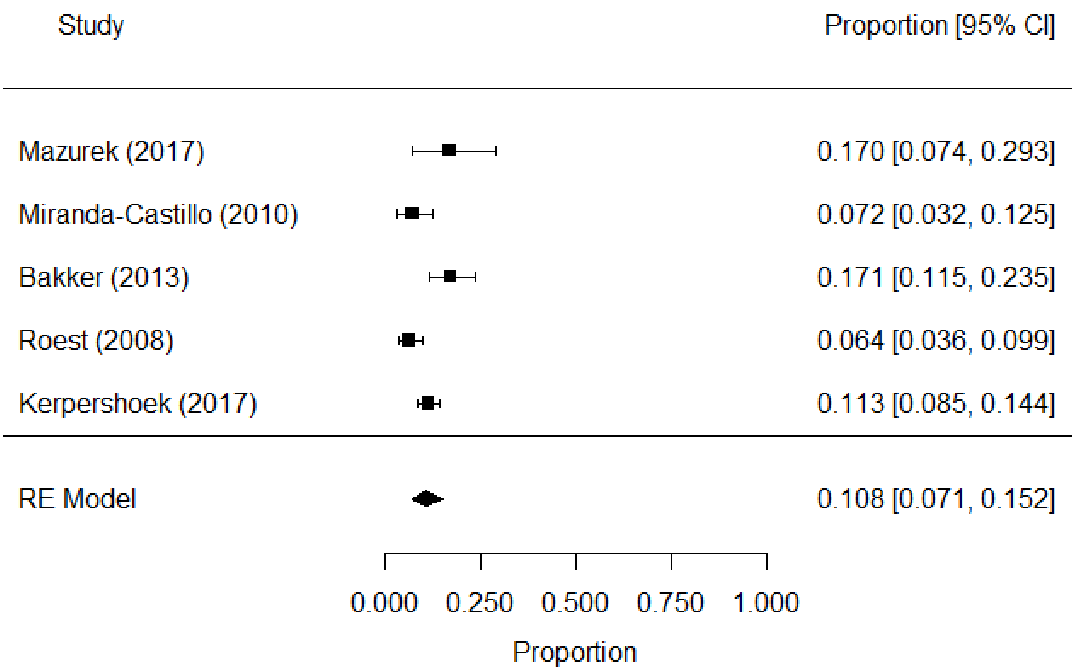


Figure 46. CI = Confidence Interval, RE = Random Effects

Figure 49 Caregiver reported Intimate Relationship Needs

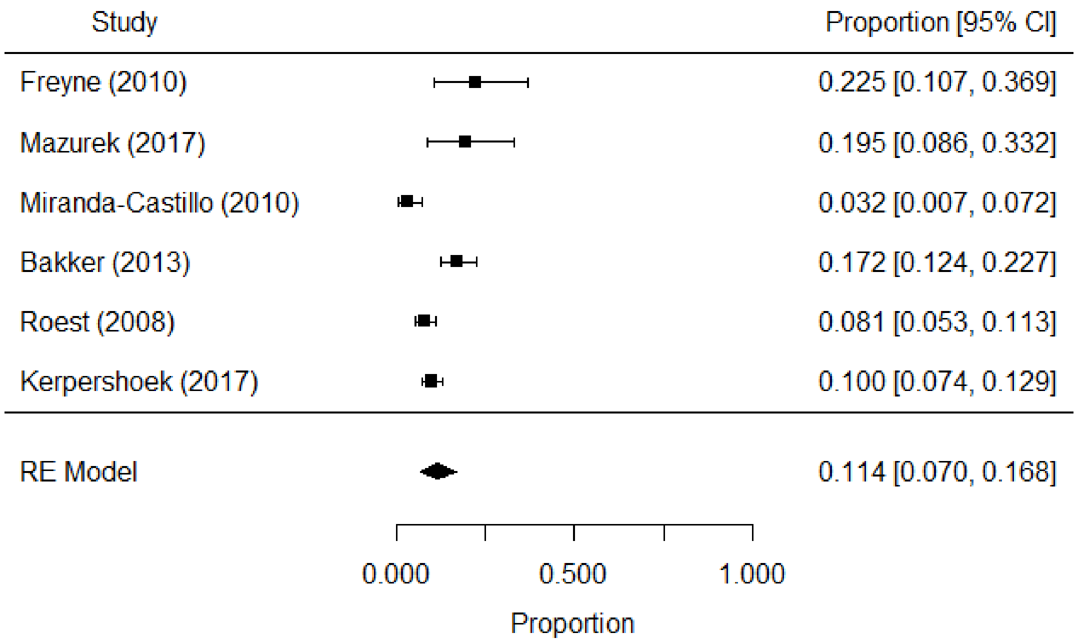


Figure 47. CI = Confidence Interval, RE = Random Effects

Figure 50 Person with Dementia Reported Psychotic Symptom Needs

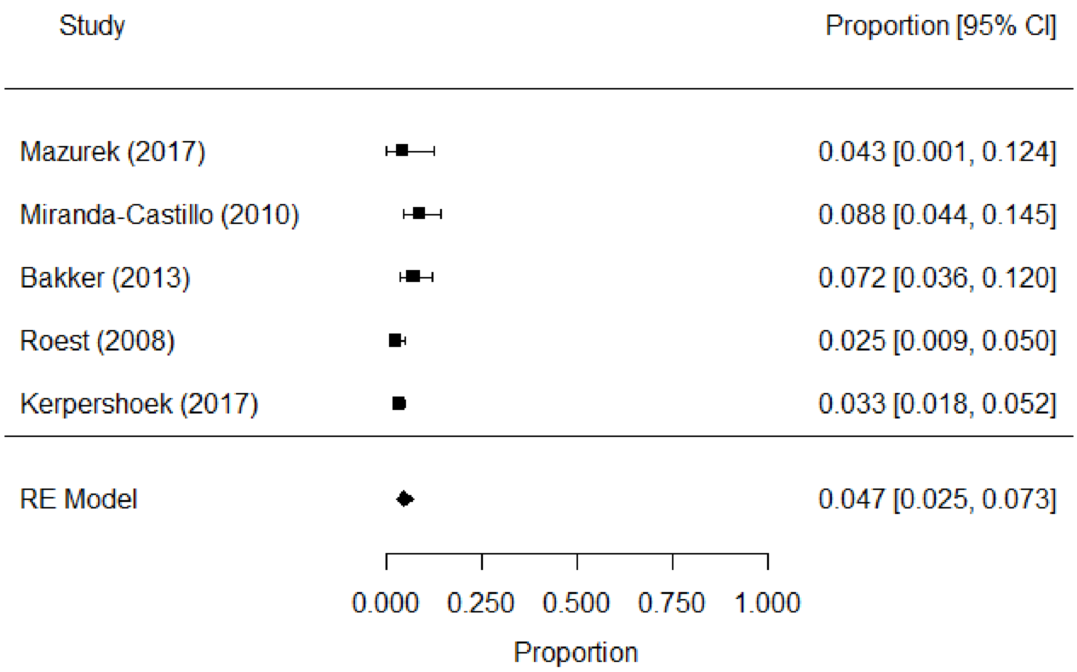


Figure 48. CI = Confidence Interval, RE = Random Effects

Figure 51 Caregiver reported Psychotic Symptom Needs

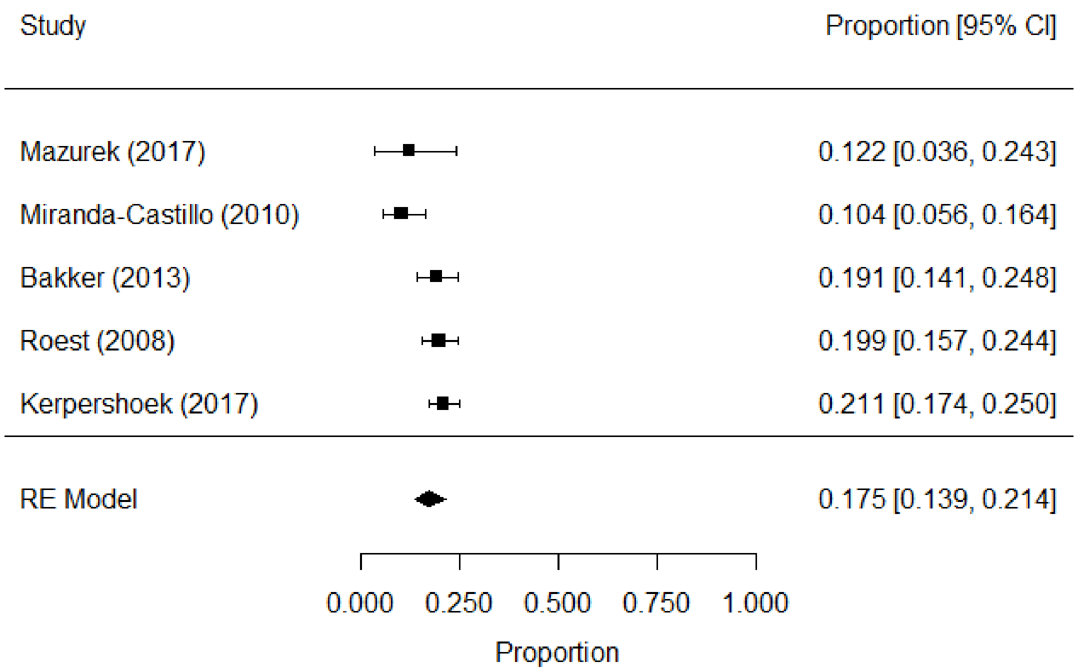


Figure 49. CI = Confidence Interval, RE = Random Effects

Figure 52 Person with Dementia reported Caring for Another Needs

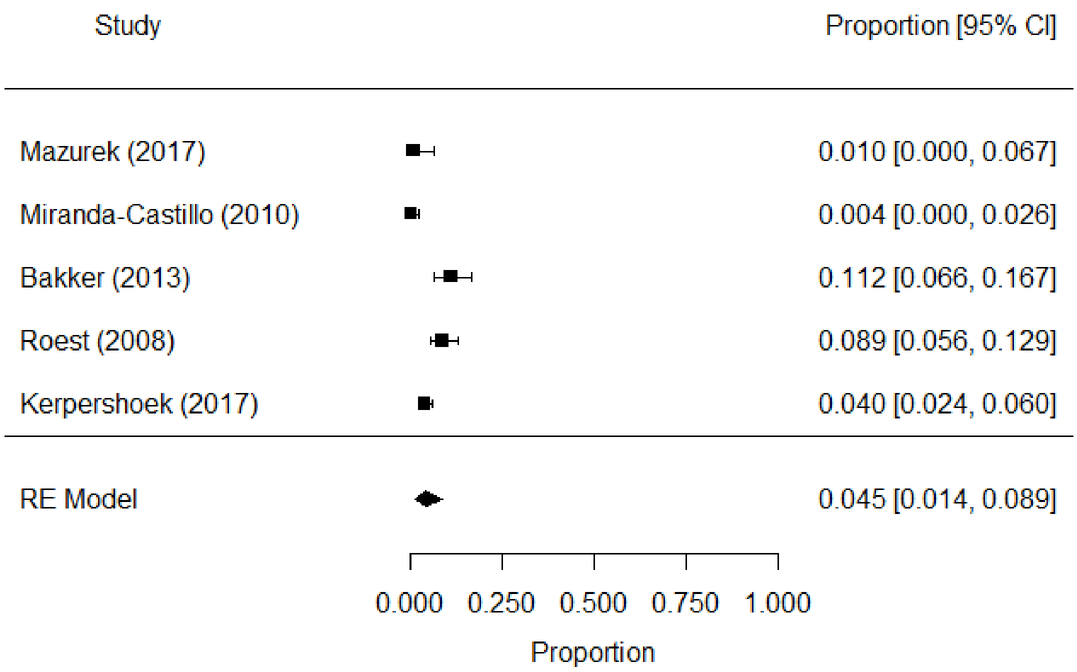


Figure 50. CI = Confidence Interval, RE = Random Effects

Figure 53 Caregiver reported Caring for Another Needs

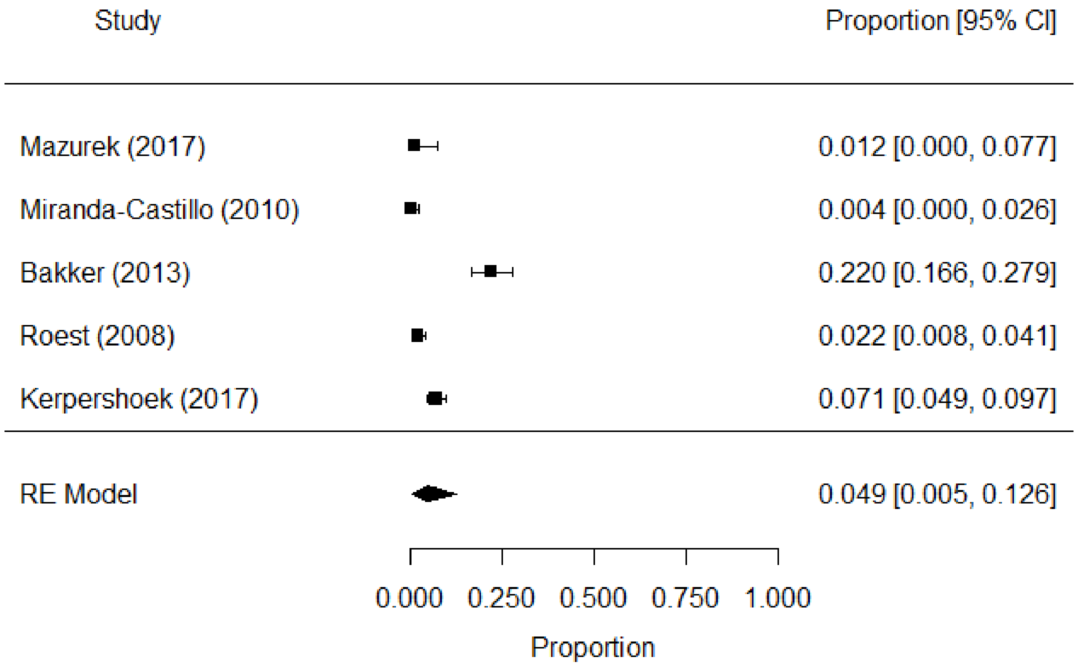


Figure 51. CI = Confidence Interval, RE = Random Effects

Figure 54 Person with Dementia Deliberate Self-Harm Needs

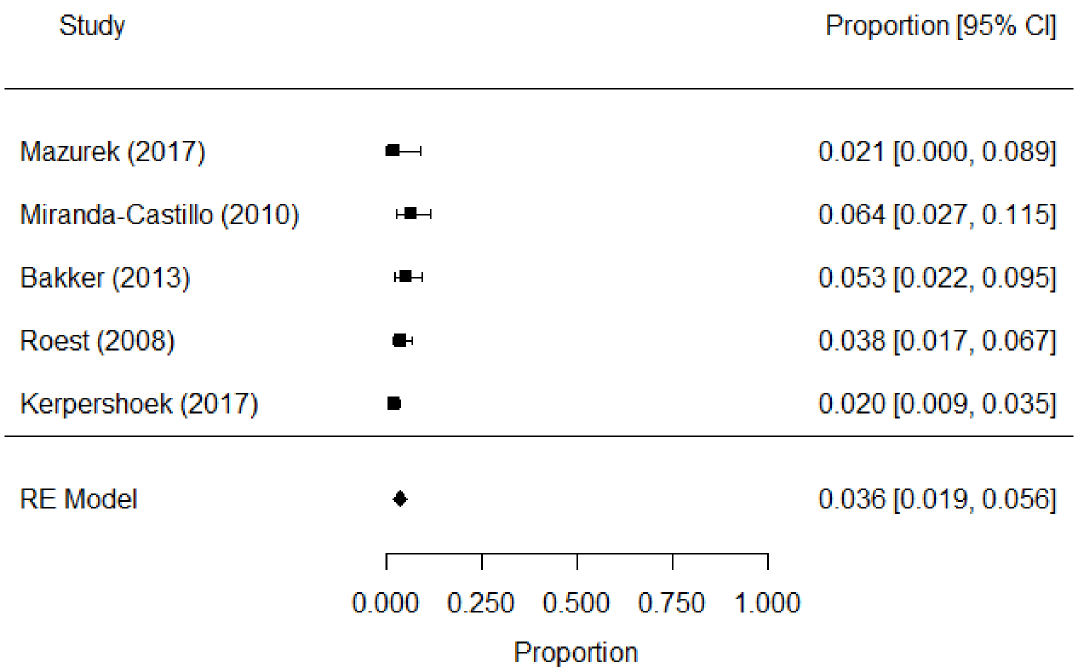


Figure 52. CI = Confidence Interval, RE = Random Effects

Figure 55 Caregiver reported Deliberate Self-harm Needs

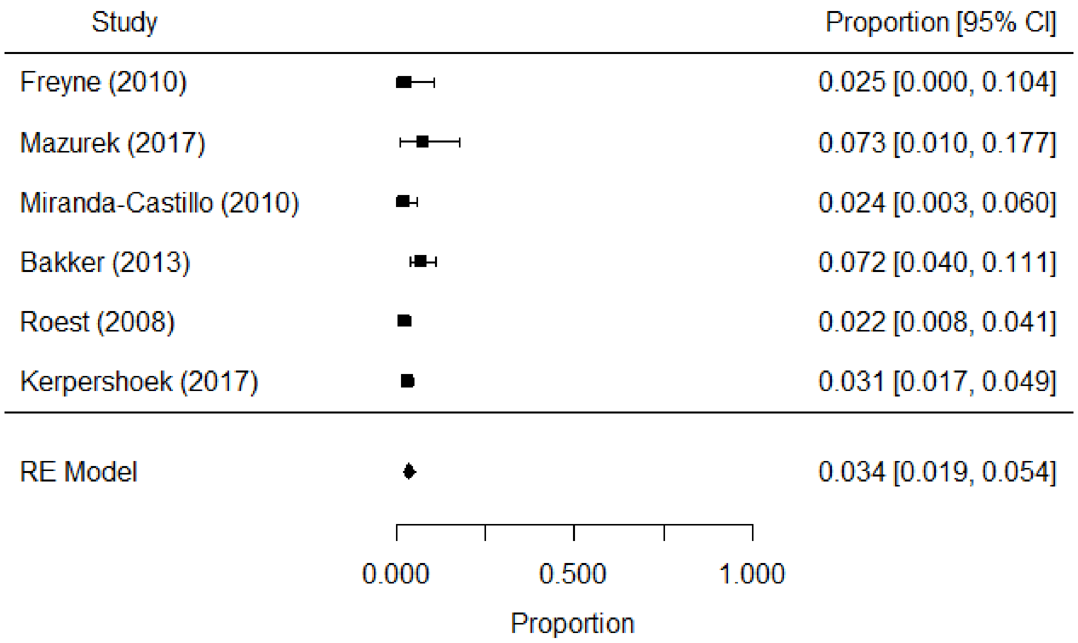


Figure 53. CI = Confidence Interval, RE = Random Effects

Figure 56 Person with Dementia reported Behaviour Needs

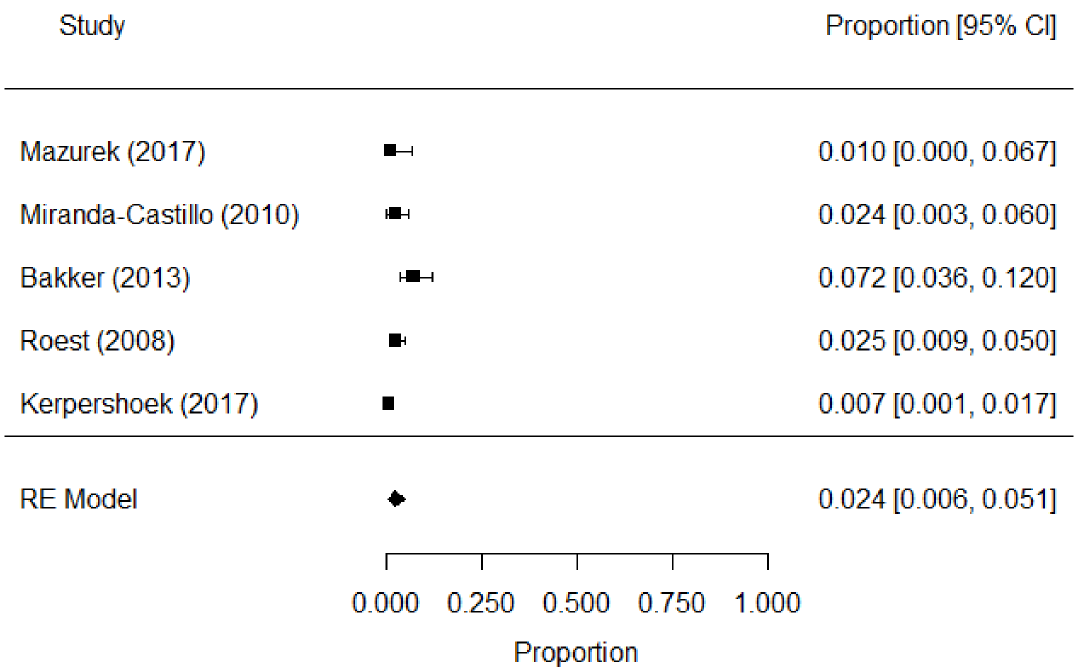


Figure 54. CI = Confidence Interval, RE = Random Effects

Figure 57 Caregiver reported Behaviour Needs

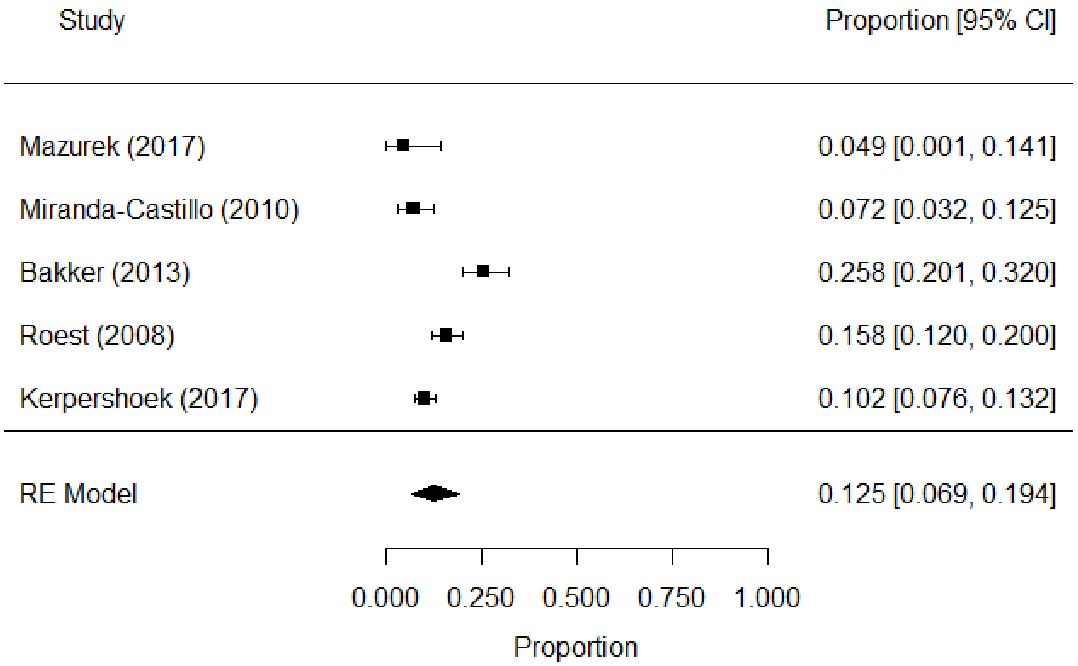


Figure 55. CI = Confidence Interval, RE = Random Effects

Figure 58 Person with Dementia reported abuse/neglect needs

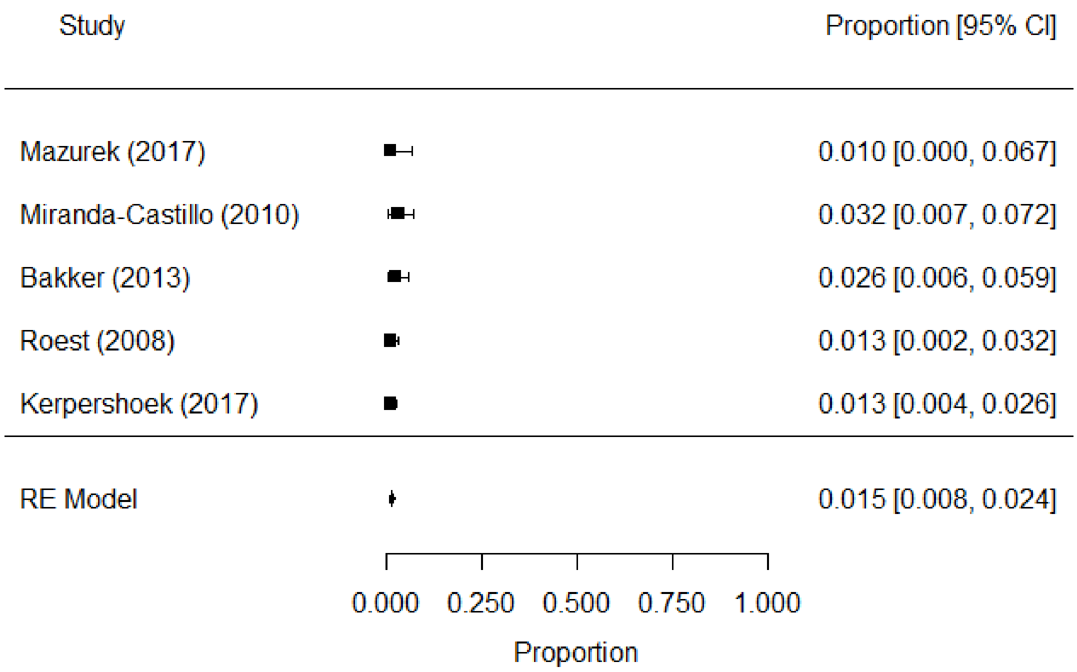


Figure 56. CI = Confidence Interval, RE = Random Effects

Figure 59 Caregiver reported Abuse/ Neglect Needs

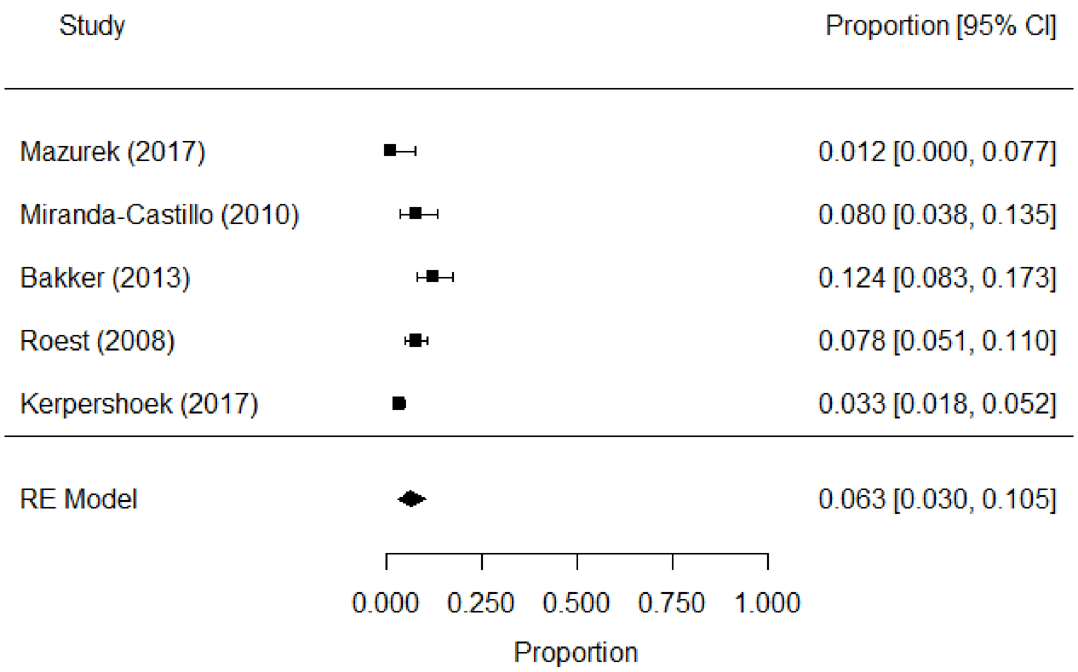


Figure 57. CI = Confidence Interval, RE = Random Effects

Appendix D: Correlation Matrix

Choices	**Routines**	**Responsibilities**	**Conversation**	**Vocal Expression**	**Knowledge**	**Problem-solving**	**Posture and Mobility**	**Strength and Effort**	**Physical Space**	**Physical Resources**	**Social Groups**	**Occupational Demands**	**MMSE**	**Age**	**Risk of Wandering**	**Safety Risk**	**Living situation**	**Caregiver support**	**Gender**	
0.70	0.64	0.49	0.71	0.39	0.61	0.71	0.22	0.10	0.18	0.17	0.29	0.42	0.39	-0.002	-0.29	-0.25	-0.26	-0.13	-0.02	**Appraisal of abilities**
	0.52	0.296	0.55	0.37	0.44	0.55	0.12	.161	0.33	0.23	0.32	0.42	0.32	0.04	-0.15	-0.11	-0.04	-0.01	0.06	**Choices**
		0.15	0.58	0.25	0.59	0.48	0.03	0.33	0.32	0.09	0.34	0.48	0.26	0.10	-0.41	-0.11	-0.20	-0.12	-0.06	**Routines**
			0.56	0.204	0.80	0.58	0.22	0.45	0.22	0.13	0.33	0.46	0.31	-0.04	-0.17	-0.21	-0.04	-0.01	-0.12	**Responsibilities**
				0.58	0.62	0.66	0.16	0.27	0.26	0.06	0.34	0.35	0.45	-0.06	-0.19	-0.17	-0.23	-0.12	-0.19	**Conversation**
					0.24	0.39	0.15	0.25	0.15	0.18	0.22	0.45	0.33	0.26	0.03	-0.17	0.01	-0.13	-0.10	**Vocal Expression**
						0.73	0.14	0.39	0.18	0.16	0.24	0.54	0.36	0.04	-0.25	-0.31	-0.11	-0.04	-0.05	**Knowledge**
							0.08	0.17	0.20	0.18	0.29	0.53	0.48	0.02	-0.20	-0.26	-0.25	-0.17	-0.14	**Problem-solving**
								0.45	0.41	0.04	0.08	0.10	-0.01	-0.001	0.38	-0.34	-0.01	-0.05	0.05	**Posture and Mobility**
									0.29	0.16	0.29	0.52	-0.04	0.22	-0.01	-0.10	-0.20	-0.08	0.06	**Strength and Effort**
										0.62	0.19	0.31	-0.07	0.03	0.24	-0.11	-0.06	-0.09	-0.0003	**Physical Space**
											0.32	0.20	0.07	0.07	0.13	-0.02	0.21	-0.03	-0.14	**Physical Resources**
												0.48	0.02	-0.08	-0.09	-0.05	0.10	0.13	-0.05	**Social Groups**
													0.27	0.26	-0.33	-0.21	-0.15	-0.02	-0.22	**Occupational Demands**
														-0.05	-0.31	-0.07	-0.07	-0.06	-0.05	**MMSE**
															-0.03	-0.13	0.03	-0.07	-0.26	**Age**
																0.13	0.08	0.06	0.14	**Risk of Wandering**
																	-0.03	-0.09	-0.07	**Safety Risk**

Choices	Routines	Responsibilities	Conversation	Vocal Expression	Knowledge	Problem-solving	Posture and Mobility	Strength and Effort	Physical Space	Physic al Resources	Social Groups	Occupational Demands	MMSE	Age	Risk of Wandering	Safety Risk	Living situation	Caregiver support	Gender	
																		0.81	0.09	**Living situation**
																			0.23	**Caregiver support**

Note. MMSE = Mini Mental State Examination (Folstein et al. 1975)

Appendix E: Ethical Approval

Lucy Hinds

Quality Enhancement Officer

Governance and Quality Enhancement

Eleanor Curnow

PhD, Firefly

5th October 2018

Dear Eleanor,

Thank you for contacting us regarding your PhD research which will be using data previously collected within the ATTILA project undertaken within Firefly.

Dr Gemma Blackledge-Foughali, Convener of the Panel, has reviewed the documentation you have provided, and has confirmed that she is happy that no further ethical approval is required from QMU REP as the work you intend to undertake will use existing data from an existing Firefly project with IRAS approval. Within the original agreement for the ATTILA project there is a clause which permits the data to be used for such purposes. Email correspondence provided by you confirms that an IRAS approval is in place and you have consulted with Dr Helen Newbery, Ethics Scientific Officer for East Lothian to ensure that there are no other ethical issues to be considered. We are therefore satisfied that the data you are using is covered by an existing agreement and the permissions granted extend to your PhD.

We would like to wish you well with your project.

Yours sincerely

Lucy Hinds

Secretary to the Research Ethics Panel

DIVISION OF GOVERNANCE AND QUALITY ENHANCEMENT
QUEEN MARGARET UNIVERSITY, EDINBURGH
MUSSELBURGH
EAST LOTHIAN EH21 6UU
TELEPHONE: 0131 474 0000

Appendix F: Letter exempting Systematic Review and Meta-analysis from Ethical Approval.

Lucy Hinds

Quality Enhancement Officer

Queen Margaret University

Queen Margaret University Drive

Musselburgh

East Lothian EH21 6UU

24 January 2019

To Whom it May Concern

Publication Title: Exploring the needs of people with dementia living at home: A Systematic Review and Meta-analysis.

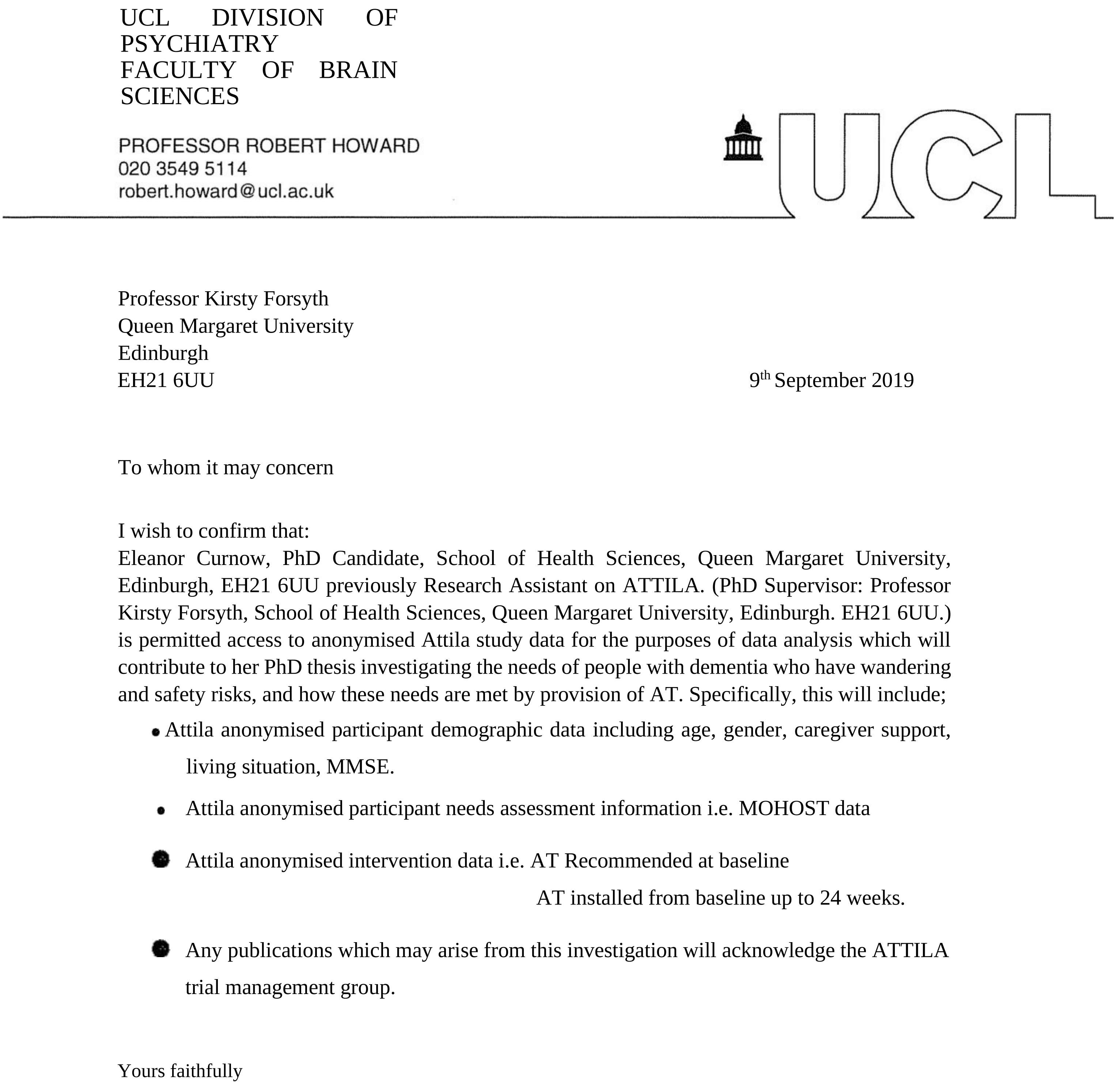
I am writing to confirm that this review is exempt from Queen Margaret University Research Ethics Panel approval. The Panel does not require researchers undertaking a systematic review to apply for ethical approval.

Yours sincerely

Lucy Hinds

DIVISION OF GOVERNANCE AND QUALITY ENHANCEMENT
QUEEN MARGARET UNIVERSITY, EDINBURGH
MUSSELBURGH
EAST LOTHIAN EH21 6UU
TELEPHONE: 0131 474 0000

Appendix G: Letter from RCT Chief Investigator granting permission to use study data for secondary data analysis.



UCL DIVISION OF PSYCHIATRY
FACULTY OF BRAIN SCIENCES

PROFESSOR ROBERT HOWARD
020 3549 5114
robert.howard@ucl.ac.uk

Professor Kirsty Forsyth
Queen Margaret University
Edinburgh
EH21 6UU

9th September 2019

To whom it may concern

I wish to confirm that:
Eleanor Curnow, PhD Candidate, School of Health Sciences, Queen Margaret University, Edinburgh, EH21 6UU previously Research Assistant on ATTILA. (PhD Supervisor: Professor Kirsty Forsyth, School of Health Sciences, Queen Margaret University, Edinburgh. EH21 6UU.) is permitted access to anonymised Attila study data for the purposes of data analysis which will contribute to her PhD thesis investigating the needs of people with dementia who have wandering and safety risks, and how these needs are met by provision of AT. Specifically, this will include;

- Attila anonymised participant demographic data including age, gender, caregiver support, living situation, MMSE.
- Attila anonymised participant needs assessment information i.e. MOHOST data
- Attila anonymised intervention data i.e. AT Recommended at baseline
  AT installed from baseline up to 24 weeks.
- Any publications which may arise from this investigation will acknowledge the ATTILA trial management group.

Yours faithfully

Robert Howard

CI ATTILA Trial

Division of Psychiatry, Faculty of Brain Sciences, University College London, 6th Floor, Maple House, 149 Tottenham Court Road,
London WIT 7NF

http://www.ucl.ac.uk/psychiatry

Appendix H: Publication

Authors’ contributions:

Eleanor Curnow: meta-analysis design; registration of study protocol with Prospero; literature searches; literature review; quality appraisal; data analysis; sensitivity analysis; manuscript write-up; submission and liaison with the editorial office.

Dr Robert Rush: peer debriefing as part of PhD supervision, manuscript review

Dr Donald Maciver: peer debriefing as part of PhD supervision, manuscript review.

Dr Sylwia Górska: peer debriefing as part of PhD supervision, manuscript review

Prof Kirsty Forsyth: peer debriefing as part of PhD supervision, manuscript review.

AGING & MENTAL HEALTH
https://doi.org/10.1080/13607863.2019.1695741

Routledge
Taylor & Francis Group

REVIEW

OPEN ACCESS

Check for updates

Exploring the needs of people with dementia living at home reported by people with dementia and informal caregivers: a systematic review and Meta-analysis

Eleanor Curnow, Robert Rush, Donald Maciver, Sylwia Górska and Kirsty Forsyth

School of Health Sciences, Queen Margaret University, Edinburgh, UK

ABSTRACT

Objectives: To provide prevalence estimates of needs of people with dementia living at home, and to determine sources of variation associated with needs for this population.

Method: A systematic review and meta-analysis was performed searching CINAHL, MEDLINE, PsycINFO and ASSIA databases. Following quality checks, random effects meta-analysis produced prevalence estimates for needs reported by people with dementia and by their informal caregivers. Fixed effects models were undertaken to compare caregiver and person with dementia reported needs. Heterogeneity was explored through sensitivity analysis. The study protocol was registered with Prospero #CRD42017074119

Results: Six retrieved studies published between 2005 and 2017 including 1011 people with dementia and 1188 caregivers were included in the analysis. All data were collected using Camberwell Assessment of Need for the Elderly. Prevalence estimates are provided for 24 needs reported by participants in The Netherlands, United Kingdom, Poland, Ireland, Germany, Norway, Portugal, Italy and Sweden. Most prevalent needs reported by people with dementia were Memory 0.713 [95% CI 0.627, 0.791]; Food 0.706 [95% CI 0.547, 0.842]; Household activities 0.677 [95% CI 0.613, 0.738]; and Money 0.566 [95% CI 0.416, 0.711]. Caregivers reported greater prevalence than people with dementia did for 22 of 24 needs, although the priority ranking of needs was similar. Exploration of heterogeneity revealed that people with young onset dementia were the major source of variation for 24 out of 48 analyses.

Conclusion: Increased understanding of prevalence of needs of people with dementia and associated heterogeneity can assist in planning services to meet those needs.

ARTICLE HISTORY
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Assessment of need; caregivers; dementia; care needs; prevalence

Introduction

It is known that people with dementia experience a wide range of intense care needs (Prince et al., 2015), which vary depending on many factors including the type and severity of cognitive impairment, functional dependencies, multimorbidities and neuropsychiatric symptoms. These needs, which can be defined as capacity to benefit from services (NHS Health Scotland, 2019), are therefore specific to the individual and strongly affect health outcomes. Also, needs are interrelated with risks (Seden, 2016), and unmet needs can result in adverse consequences such as falls, dehydration, lower quality of life, caregiver burden, institutionalisation and death (Black et al., 2013; Gaugler, Kane, Kane, & Newcomer, 2005).

In order to provide appropriate care and support for the increasing number of people with dementia (Prince et al., 2015), consideration of information about the complexity of individuals' needs can enable clinicians to provide services tailored towards their goals and priorities (Farmer, Fenu, O'Flynn, & Guthrie, 2016; Morrisby, Joosten, & Ciccarelli, 2018). However, there is a gap between the required intervention and care, and the services provided for people with dementia (World Health Organization, 2017). One research study examining the needs of older people with severe mental illness including dementia, found that most (70%) people were not receiving the interventions indicated by their assessed needs (Cummings & Kropf, 2009). This may be due to the assessed needs not being specific enough to link to particular interventions (Schmid, Eschen, Rüegger-Frey, & Martin, 2012), for example, mobility needs may require physiotherapy or wheelchair repair services. Alternatively, this may result from a failure to develop services that meet the needs of people with dementia (Knapp et al., 2007).

In order to reorganise care to account for the needs of people with dementia, further knowledge is required to facilitate understanding of the burden of dementia and its co-morbidities, and how this burden relates to intervention. To this end, individual studies have presented data regarding the frequency and range of needs of people with dementia (Morrisby et al., 2018). However, this data have not been synthesised and the universality of these results is unknown. Quantitative synthesis of data enables exploration of any associated heterogeneity (Song, Sheldon, Sutton, Abrams, & Jones, 2001). This can provide information regarding sources of variation in the needs of people with

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dementia, and contribute to understanding of characteristics associated with increased frequency of reported needs.

Further, research regarding variation in reported needs will assist in targeting services and resources to where they are most required (Gitlin, Maslow, & Khillan, 2018). Informing the efficient organization and delivery of health and social care to manage the complex and diverse requirements of people with dementia can lead to more integrated and person-centred support, addressing actual needs of people with dementia and their caregivers, thereby reducing adverse outcomes including institutionalisation (Banerjee, 2015).

Therefore, in order to enhance understanding regarding the needs of people with dementia, the authors conducted a systematic review and meta-analysis of existing studies following Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Electronic Supplementary Material 1) (Liberati et al., 2009).

The objectives of this review and meta-analysis were to (a) establish prevalence estimates of needs reported by people with dementia living at home, and by their informal caregivers; (b) compare the prevalence estimates of needs reported by people with dementia to those reported by informal caregivers of people with dementia; (c) quantify and explore heterogeneity associated with these prevalence estimates.

Methods

The review protocol was registered a priori and published online in the PROSPERO database of systematic reviews (www.crd.york.ac.uk/Prospero. registration number #CRD42017074119).

Inclusion and exclusion criteria

Studies were included if; (a) they reported empirical prevalence data regarding the frequency of needs for people with dementia; (b) participants had a diagnosis of dementia; (c) participants were living at home in the community; (d) needs were measured using a validated assessment instrument; (e) needs were identified as concerning the person with dementia and not their caregiver or other significant person; (f) needs were reported by the person with dementia or by their informal caregiver; and (g) the study was reported in English. All study designs and methodologies were included. To allow for exploration of factors that may affect needs, all age groups and dementia diagnoses were included, as were all publication dates and all geographical areas.

Studies that were reviews or conference proceedings or reported only qualitative data were excluded. Articles providing further information on studies selected for inclusion in the analysis were used in the assessment of the quality of the selected studies.

Search strategy

A systematic search of four databases, ASSIA, CINAHL, MEDLINE and PsycINFO was conducted (EC) to identify studies in which the needs of people with dementia living at home were quantitatively examined. The CINAHL, MEDLINE and PSYCinfo databases were searched through EBSCOhost using the following terms as Medical Subject Headings (MESH) and keywords; (1) Dementia OR Frontotemporal Dementia OR Dementia, Vascular OR Delirium, Dementia, Amnestic, Cognitive Disorders OR Dementia, Multi-infarct OR AIDS Dementia Complex OR Dementia, Senile OR Dementia, Presenile OR Lewy Body Disease OR Parkinson Disease OR Alzheimer's disease, AND (2) Needs Assessment OR Health services needs and demand. The ASSIA database was searched through PROQUEST using the above terms as main subjects. Further relevant studies were identified through hand searching reference lists (EC).

Study selection

Following removal of duplicates, titles of the returned articles were examined and irrelevant titles were excluded. Abstracts, then full text of the remaining articles were reviewed to find studies that met the inclusion criteria. Two researchers (EC, SA) selected studies independently to minimise selection bias, results were compared and disagreements were resolved through discussion and with reference to inclusion criteria. If no agreement could be reached it was planned a third team member (DM) would decide, but this was unnecessary. The screening process is described in Figure 1.

Data extraction

A data extraction sheet was developed and pilot tested. Two research team members independently extracted the following data from included studies; (a) characteristics of the study participants including age, diagnosis, living situation; (b) study details including author, title, date of publication; (c) setting; (d) methodological characteristics; (e) outcome measurement tool; (f) outcome data; (g) ethical approval; and (h) data analysis. (EC, SA). Results were compared and inconsistencies were resolved through discussion between the two research team members, and discussion with a third team member (DM) was again unnecessary. Data originating from the same study was included as one study even if reported in more than one paper, to prevent bias. Corresponding authors were contacted where required data were not present, for example when the paper reported only met or unmet need rather than total need. Three authors responded to this request and two provided further data regarding the frequency of reported needs.

Quality assessment

Studies included in this analysis were assessed for risk of bias using the Prevalence Critical Appraisal Instrument (Munn, Moola, Riitano, & Lisy, 2014). This assessment focused on (a) the instrument used to assess the needs of the person with dementia and (b) the sampling of the population within the study, as these are issues particularly relevant to prevalence studies. To minimise bias two research team members completed the tool independently for each study (EC, SA) then compared and discussed results. Disagreements were to be resolved through discussion with a third team member (DM) but this was

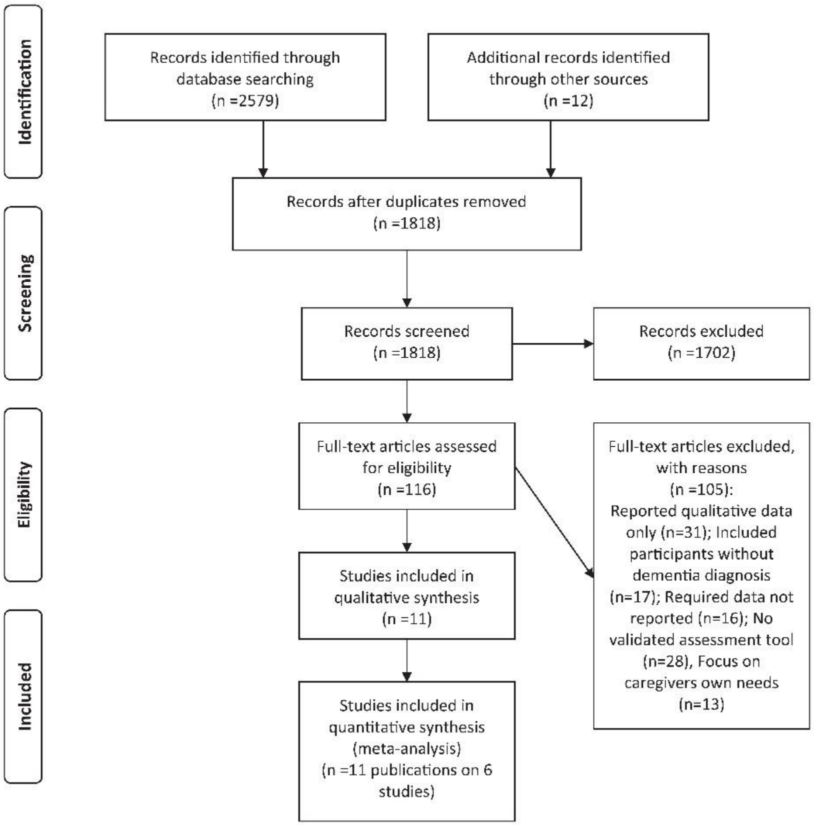


Figure 1. PRISMA flow diagram from Moher, Liberati, Tetzlaff & Altman; The PRISMA Group.

unnecessary. All studies were included in the meta-analysis, and leave1out sensitivity analysis was undertaken to explore heterogeneity (Stroup et al., 2000). Details of information considered in the quality appraisal instrument is included in Electronic Supplementary Material 2.

Statistical analyses

The primary measure of prevalence was proportion of people with dementia reporting a specific need. Needs frequency data presented as percentages were recalculated as proportions. Where needs were reported as unmet and met needs, these data were combined to create total need. Proportions were pooled for meta-analysis, using a double arcsine square root transformation, to normalise the sampling distribution and stabilise variation (Barendregt, Doi, Lee, Norman, & Vos, 2013; Freeman & Tukey, 1950; Wang, 2017). The double arcsine square root transformation was selected due to the small sample sizes and extreme proportions involved (Wang, 2017). Following analysis, the final pooled estimates with 95% confidence intervals (95% CI) were back-transformed for ease of interpretation (Miller, 1978).

Data on each of the 24 needs reported by people with dementia and 24 needs of people with dementia reported by informal caregivers were analysed separately. DerSimonian Laird random-effects models (DerSimonian & Laird, 1986) were performed as they are recommended for the meta-analysis of prevalence data to allow for between-study variation and to increase the generalizability of conclusions (Munn, Moola, Lisy, & Riitano, 2014).

In order to determine if data on the needs of people with dementia reported by the person themselves differed from data on their needs as reported by their caregivers, it was necessary to compare the results of the random-effects meta-analyses for each need type. Fixed-effects models were fitted to allow comparison of the two estimates for each of the 24 need types, as the residual heterogeneity within each subset had already been accounted for through fitting the random-effects model (Viechtbauer, 2010).

Risk of bias across studies

Publication bias refers to the number of statistically non-significant studies remaining unpublished. However, studies included in meta-analysis of proportions are observational, non-comparative, and do not calculate significance levels for their results. Therefore, statistical non-significance was unlikely to result in publication bias (Wang, 2017).

Additional analyses

Heterogeneity is expected in prevalence studies and can arise for a number of reasons including: different instruments used to determine the presence of a variable, geographical variation, and differences in the study population (Higgins, 2008; Munn, Moola, Riitano, et al., 2014). Whilst meta-analysis is used to pool effects, another important benefit is the investigation and description of heterogeneity (Higgins, 2008; Song et al., 2001; Thompson, 1994). Following inspection of the meta-analysis output, heterogeneity was formally tested using the inconsistency index I^2 to measure the proportion of the observed variation due to its sensitivity to true heterogeneity (Higgins, Thompson, Deeks, & Altman, 2003), and insensitivity to number of studies (Wang, 2017). Leave1out sensitivity analyses were performed to identify sources of variation (Higgins, 2008; Ryan & Cochrane Consumers & Communication Review Group, 2016; Viechtbauer, 2010). All analyses were conducted using the Metafor package in R Studio software (R Core Team, 2017; Viechtbauer, 2010).

Results

The database search returned 2579 articles. A further 12 papers were identified through hand searching and review of citation lists. Review of title and abstracts resulted in 116 potentially relevant papers being identified for full text review. Of these, 11 papers describing six studies met the inclusion criteria and were retained for review. Ineligible studies included studies that failed to report the frequency of needs, included participants without a dementia diagnosis, or did not use a validated needs assessment tool. Retrieved papers were published between 2005 and 2017 (Table 1). The databases were last accessed on 04/06/2019.

Results of the meta-analyses were based on data relating to twenty-four needs of people with dementia, as reported by 1011 people with dementia and 1188 informal caregivers. Data were extracted from reports of six studies undertaken in The Netherlands, UK, Poland, Ireland, Germany, Norway, Portugal, Italy and Sweden. The forty-eight needs prevalence estimates ranged from 0.933 [95% CI 0.881, 0.972] for caregiver reported memory needs, to 0.009 [95% CI 0.001, 0.023] for person with dementia reported alcohol related needs, and varied depending upon need type and the person reporting the needs (Table 2).

Study characteristics

Characteristics of retrieved studies are presented in Table 1. Non-randomized sampling methods were employed in all studies, and two studies used convenience sampling methods. All retrieved studies collected needs data using validated versions of the Camberwell Assessment of Need for the Elderly (CANE) (Reynolds et al., 2000), although three different language versions; English, Dutch and Polish. The need domains of the original (English language) version of the CANE are presented in Electronic Supplementary Material 3. Other needs assessment tools were identified in the literature, but studies did not meet the inclusion criteria for this analysis as either reported data were incomplete and authors could not be contacted, or there was no available validation information for the needs assessment tool used within the study.

Prevalence of needs

Prevalence estimates for the 24 CANE need domains, reported by people with dementia, and by caregivers of people with dementia, are presented as proportions, together with 95% confidence intervals (CI) (Table 2). The combined estimated prevalence with 95% confidence intervals are visualised for each need reported by people with dementia (Figure 2), and by caregivers (Figure 3).

Comparison of needs reported by people with dementia and needs reported by caregivers

Caregivers of people with dementia reported higher levels of need for people with dementia in 23 out of 24 needs. These two sets of effects sizes were compared in twenty-four fixed effects models (Table 2). Results were significantly different for Household Activities (−0.255, $p < .001$), Memory (−0.297, $p < .001$), Self-care (−0.361, $p < .001$), Continence (−0.166, $p < .001$)), Psychotic Symptoms (−0.210, $p < .001$), Money (−0.324, $p < .001$), Alcohol (−0.137, $p < .001$), Abuse/neglect (−0.125, $p = .002$), Accidental Self-harm (−0.259, $p = .001$), Daytime activities (−0.332, $p = .004$) and Behaviour (−0.202, $p < .001$). People with dementia and caregivers reported a similar level of need for Deliberate Self-harm (0.0, $p = .989$).

In one study 27.3% of participants with dementia were unable to answer CANE questions (Bakker et al., 2014a). Another study found 17.8% of their participants with dementia were unable to understand CANE questions, and that this group was significantly more cognitively and functionally impaired than the rest of the sample (Miranda-Castillo, Woods, & Orrell, 2013). Hence, the needs of this group of people with dementia could only be reported by caregivers, and therefore dementia severity or the inability to comprehend the CANE questions may have contributed to the heterogeneity between the needs reported by people with dementia and by caregivers.

Heterogeneity

Meta-analyses showing very low heterogeneity ($I^2 = 0\%$) (Ryan & Cochrane Consumers & Communication Review Group, 2016) included two needs reported by people with dementia: Continence $I^2 = 0\%$ [95% CI 0, 0] ; and Abuse/neglect $I^2 = 0\%$ [95% CI 0, 82.469] . Notably, these needs had very low prevalence (< 0.05). As prevalence estimates are reported with 95% confidence intervals, the degree of heterogeneity of these results remains uncertain (Wang, 2017). Seventeen of the 24 meta-analyses examining the needs reported by people with dementia, exhibited considerable heterogeneity ($I^2 > 75\%$) (Alba et al., 2016; Higgins et al., 2003). Eighteen of the 24 meta-analyses examining the needs of people with dementia reported by caregivers

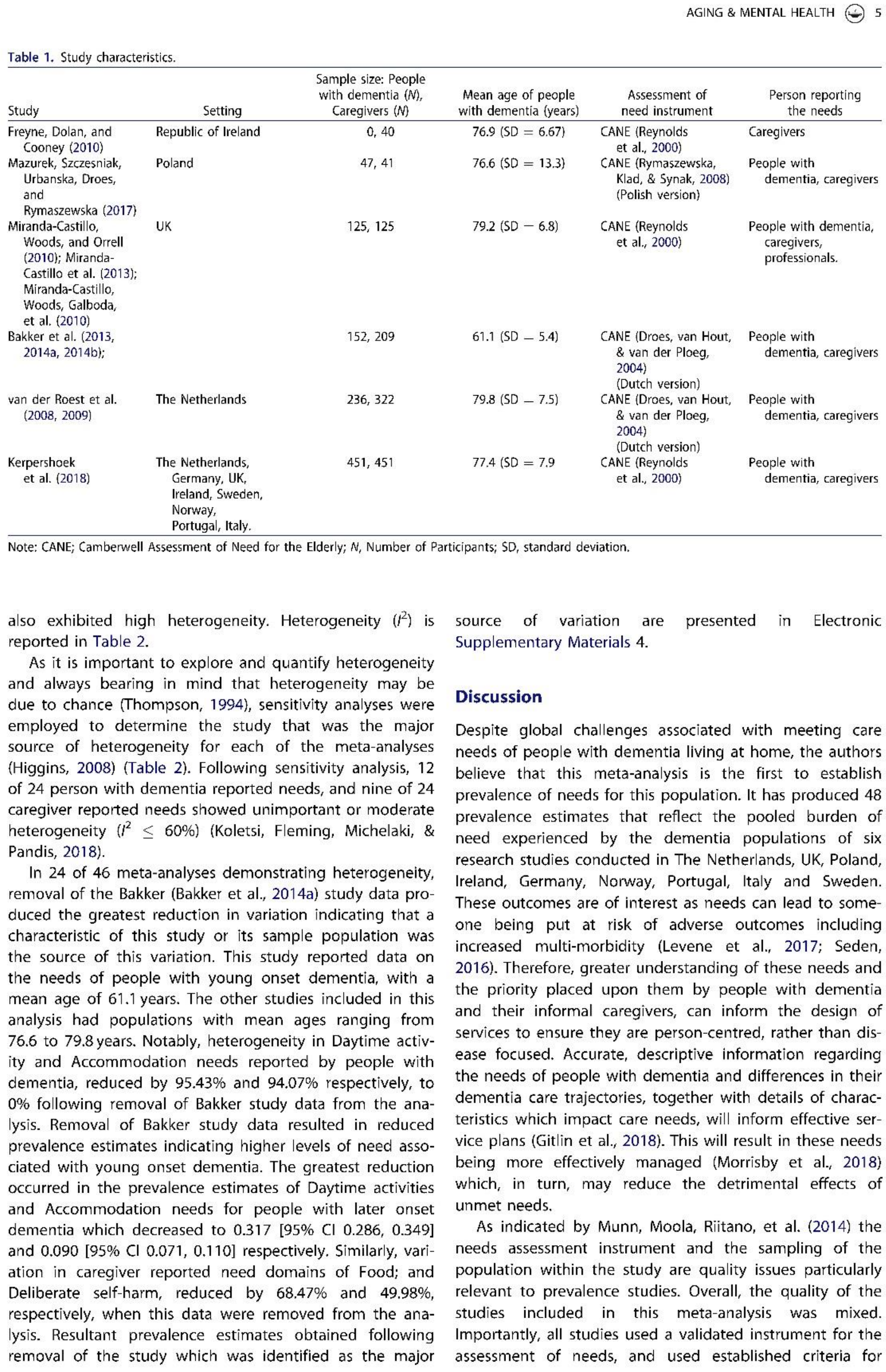


Table 1. Study characteristics.

Study	Setting	Sample size: People with dementia (*N*), Caregivers (*N*)	Mean age of people with dementia (years)	Assessment of need instrument	Person reporting the needs
Freyne, Dolan, and Cooney (2010)	Republic of Ireland	0, 40	76.9 (SD = 6.67)	CANE (Reynolds et al., 2000)	Caregivers
Mazurek, Szczesniak, Urbanska, Droes, and Rymaszewska (2017)	Poland	47, 41	76.6 (SD = 13.3)	CANE (Rymaszewska, Klad, & Synak, 2008) (Polish version)	People with dementia, caregivers
Miranda-Castillo, Woods, and Orrell (2010); Miranda-Castillo et al. (2013); Miranda-Castillo, Woods, Galboda, et al. (2010)	UK	125, 125	79.2 (SD − 6.8)	CANE (Reynolds et al., 2000)	People with dementia, caregivers, professionals.
Bakker et al. (2013, 2014a, 2014b);		152, 209	61.1 (SD – 5.4)	CANE (Droes, van Hout, & van der Ploeg, 2004) (Dutch version)	People with dementia, caregivers
van der Roest et al. (2008, 2009)	The Netherlands	236, 322	79.8 (SD – 7.5)	CANE (Droes, van Hout, & van der Ploeg, 2004) (Dutch version)	People with dementia, caregivers
Kerpershoek et al. (2018)	The Netherlands, Germany, UK, Ireland, Sweden, Norway, Portugal, Italy.	451, 451	77.4 (SD = 7.9	CANE (Reynolds et al., 2000)	People with dementia, caregivers

Note: CANE; Camberwell Assessment of Need for the Elderly; *N*, Number of Participants; SD, standard deviation.

also exhibited high heterogeneity. Heterogeneity (I^2) is reported in Table 2.

As it is important to explore and quantify heterogeneity and always bearing in mind that heterogeneity may be due to chance (Thompson, 1994), sensitivity analyses were employed to determine the study that was the major source of heterogeneity for each of the meta-analyses (Higgins, 2008) (Table 2). Following sensitivity analysis, 12 of 24 person with dementia reported needs, and nine of 24 caregiver reported needs showed unimportant or moderate heterogeneity ($I^2 \leq 60\%$) (Koletsi, Fleming, Michelaki, & Pandis, 2018).

In 24 of 46 meta-analyses demonstrating heterogeneity, removal of the Bakker (Bakker et al., 2014a) study data produced the greatest reduction in variation indicating that a characteristic of this study or its sample population was the source of this variation. This study reported data on the needs of people with young onset dementia, with a mean age of 61.1 years. The other studies included in this analysis had populations with mean ages ranging from 76.6 to 79.8 years. Notably, heterogeneity in Daytime activity and Accommodation needs reported by people with dementia, reduced by 95.43% and 94.07% respectively, to 0% following removal of Bakker study data from the analysis. Removal of Bakker study data resulted in reduced prevalence estimates indicating higher levels of need associated with young onset dementia. The greatest reduction occurred in the prevalence estimates of Daytime activities and Accommodation needs for people with later onset dementia which decreased to 0.317 [95% CI 0.286, 0.349] and 0.090 [95% CI 0.071, 0.110] respectively. Similarly, variation in caregiver reported need domains of Food; and Deliberate self-harm, reduced by 68.47% and 49.98%, respectively, when this data were removed from the analysis. Resultant prevalence estimates obtained following removal of the study which was identified as the major source of variation are presented in Electronic Supplementary Materials 4.

Discussion

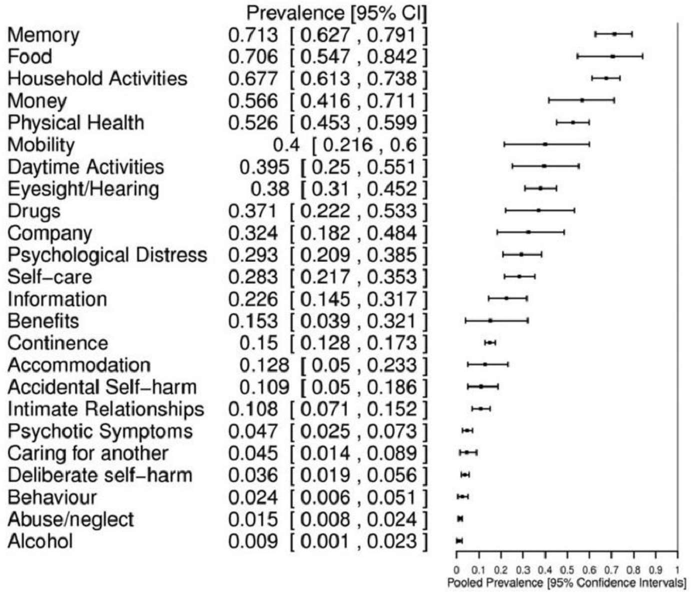
Despite global challenges associated with meeting care needs of people with dementia living at home, the authors believe that this meta-analysis is the first to establish prevalence of needs for this population. It has produced 48 prevalence estimates that reflect the pooled burden of need experienced by the dementia populations of six research studies conducted in The Netherlands, UK, Poland, Ireland, Germany, Norway, Portugal, Italy and Sweden. These outcomes are of interest as needs can lead to someone being put at risk of adverse outcomes including increased multi-morbidity (Levene et al., 2017; Seden, 2016). Therefore, greater understanding of these needs and the priority placed upon them by people with dementia and their informal caregivers, can inform the design of services to ensure they are person-centred, rather than disease focused. Accurate, descriptive information regarding the needs of people with dementia and differences in their dementia care trajectories, together with details of characteristics which impact care needs, will inform effective service plans (Gitlin et al., 2018). This will result in these needs being more effectively managed (Morrisby et al., 2018) which, in turn, may reduce the detrimental effects of unmet needs.

As indicated by Munn, Moola, Riitano, et al. (2014) the needs assessment instrument and the sampling of the population within the study are quality issues particularly relevant to prevalence studies. Overall, the quality of the studies included in this meta-analysis was mixed. Importantly, all studies used a validated instrument for the assessment of needs, and used established criteria for

Table 2. Prevalence estimates of reported needs.

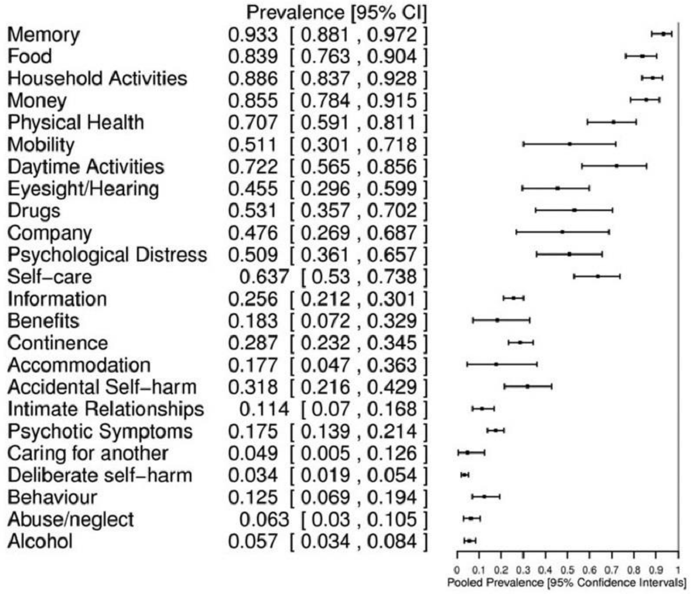
Need	Person with dementia reported needs				Caregiver reported needs				Difference in person with dementia & caregiver needs
	Pooled prevalence estimate [95% CI]	I^2 (%)[95% CI]	Major source of variation	k	Pooled prevalence estimate [95% CI]	I^2 (%)[95% CI]	Major source of variation	k	
Memory	0.713 [0.627, 0.791]	86.21[54.184, 97.812]	Roest	5	0.933 [0.881, 0.972]	87.46[55.249, 97.147]	Kerpershoek	6	−0.297, $p < .001$
Food	0.706 [0.547, 0.842]	95.91[90.034, 99.610]	Roest	5	0.839 [0.763, 0.904]	89.11[72.317 99.033]	Bakker	5	−0.158, $p = .101$
Household Activities	0.677 [0.613, 0.738]	74.13[21.193, 96.284]	Bakker	5	0.886 [0.837, 0.928]	79.28[31.754, 96.559]	Kerpershoek	5	−0.255, $p < .001$
Money	0.566 [0.416, 0.711]	95.10[92.126, 99.690]	Bakker	5	0.855 [0.784, 0.915]	88.16[85.523, 99.309]	Mazurek	6	−0.324, $p < .001$
Physical Health	0.526 [0.453, 0.599]	78.39[49.007, 98.665]	Roest	5	0.707 [0.591, 0.811]	93.32[91.455, 99.696]	Mazurek	5	−0.185, $p = .010$
Mobility	0.400 [0.216, 0.600]	97.29[94.375, 99.765]	Bakker	5	0.511 [0.301, 0.718]	97.92[95.996, 99.834]	Bakker	5	−0.110, $p = .459$
Daytime Activities	0.395 [0.250, 0.551]	95.43[88.263, 99.501]	Bakker	5	0.722 [0.565, 0.856]	96.43[93.662, 99.614]	Miranda-Castillo	6	−0.332, $p = .004$
Eyesight/Hearing	0.380 [0.310, 0.452]	78.43[39.715, 97.374]	Bakker	5	0.455 [0.296, 0.599]	95.92[90.421, 99.604]	Bakker	5	−0.066, $p = .445$
Drugs	0.371 [0.222, 0.533]	95.87[93.372, 99.737]	Bakker	5	0.531 [0.357, 0.702]	96.92[96.692, 99.868]	Mazurek	5	−0.161, $p = .187$
Company	0.324 [0.182, 0.484]	95.87[89.249, 99.539]	Bakker	5	0.476 [0.269, 0.687]	97.94[95.443, 99.807]	Bakker	5	−0.154, $p = .260$
Psychological Distress	0.293 [0.209, 0.385]	87.8 [68.964, 98.799]	Roest	5	0.509 [0.361, 0.657]	95.73[95.544, 99.734]	Freyne	6	−0.220, $p = .015$
Self-Care	0.283 [0.217, 0.353]	79.53[63.769, 99.071]	Mazurek	5	0.637 [0.530, 0.738]	91.63[91.219, 99.542]	Freyne	6	−0.361, $p < .001$
Information	0.226 [0.145, 0.317]	89.34[73.679, 99.012]	Bakker	5	0.256 [0.212, 0.301]	60.51[0.000, 95.404]	Kerpershoek	5	−0.035, $p = .543$
Benefits	0.153 [0.039, 0.321]	97.24[94.331, 99.762]	Bakker	5	0.183 [0.072, 0.329	96.58[93.779, 99.749]	Bakker	5	−0.041, $p = .759$
Continence	0.150 [0.128, 0.173]	0.0[0,0]	NA	5	0.287 [0.232, 0.345]	73.86[24.701 97.368]	Roest	5	−0.166, $p < .001$
Accommodation	0.128 [0.050, 0.233]	94.07[85.868, 99.423]	Bakker	5	0.177 [0.047, 0.363]	97.86[95.261 99.803]	Bakker	5	0.069, $p = .591$
Accidental Self-Harm	0.109 [0.050, 0.186]	90.37[77.768 99.164]	Bakker	5	0.318 [0.216, 0.429]	92.61[86.042, 99.491]	Bakker	5	−0.259, $p = .001$
Intimate Relationships	0.108 [0.071, 0.152]	72.56[25.144, 97.439]	Roest	5	0.114 [0.070, 0.168]	82.29[64.175, 98.304]	Bakker	6	−0.011, $p = .827$
Psychotic Symptoms	0.047 [0.025, 0.073]	61.46[0.000, 95.201]	Miranda-Castillo	5	0.175 [0.139, 0.214]	57.93[0.000, 96.343]	Miranda-Castillo	5	−0.210, $p < .001$
Caring for Another	0.045 [0.014, 0.089]	85.13[63.079, 98.580]	Miranda-Castillo	5	0.049 [0.005, 0.126]	94.78[86.469, 99.432]	Bakker	5	−0.012, $p = .887$
Deliberate Self-Harm	0.036 [0.019, 0.056]	48.63[0.000, 92.275]	Kerpershoek	5	0.034 [0.019, 0.054]	49.98[0.000, 92.679]	Bakker	6	0, $p = .989$
Behaviour	0.024 [0.006, 0.051]	76.87[28.813, 96.504]	Bakker	5	0.125 [0.069, 0.194]	88.45[70.236, 98.907]	Bakker	5	−0.202, $p < .001$
Abuse/Neglect	0.015 [0.008, 0.024]	0[0.000, 82.469]	NA	5	0.063 [0.030, 0.105]	81.94[43.940 98.016]	Kerpershoek	5	−0.125, $p = .002$
Alcohol	0.009 [0.001, 0.023]	57.05[0.000, 93.010]	Kerpershoek	5	0.057 [0.034, 0.084	60.98[0.000, 96.900]	Bakker	6	0.137, $p < .001$

Note: k = number of studies included in the meta-analysis; CI = Confidence Interval; NA = Not Applicable.



	Prevalence [95% CI]
Memory	0.713 [0.627 , 0.791]
Food	0.706 [0.547 , 0.842]
Household Activities	0.677 [0.613 , 0.738]
Money	0.566 [0.416 , 0.711]
Physical Health	0.526 [0.453 , 0.599]
Mobility	0.4 [0.216 , 0.6]
Daytime Activities	0.395 [0.25 , 0.551]
Eyesight/Hearing	0.38 [0.31 , 0.452]
Drugs	0.371 [0.222 , 0.533]
Company	0.324 [0.182 , 0.484]
Psychological Distress	0.293 [0.209 , 0.385]
Self–care	0.283 [0.217 , 0.353]
Information	0.226 [0.145 , 0.317]
Benefits	0.153 [0.039 , 0.321]
Continence	0.15 [0.128 , 0.173]
Accommodation	0.128 [0.05 , 0.233]
Accidental Self–harm	0.109 [0.05 , 0.186]
Intimate Relationships	0.108 [0.071 , 0.152]
Psychotic Symptoms	0.047 [0.025 , 0.073]
Caring for another	0.045 [0.014 , 0.089]
Deliberate self–harm	0.036 [0.019 , 0.056]
Behaviour	0.024 [0.006 , 0.051]
Abuse/neglect	0.015 [0.008 , 0.024]
Alcohol	0.009 [0.001 , 0.023]

Figure 2. Pooled prevalence for person with dementia reported needs, CI = Confidence Interval.



	Prevalence [95% CI]
Memory	0.933 [0.881 , 0.972]
Food	0.839 [0.763 , 0.904]
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Caring for another	0.049 [0.005 , 0.126]
Deliberate self–harm	0.034 [0.019 , 0.054]
Behaviour	0.125 [0.069 , 0.194]
Abuse/neglect	0.063 [0.03 , 0.105]
Alcohol	0.057 [0.034 , 0.084]

Figure 3. Pooled prevalence for caregiver reported needs, CI = Confidence Interval.

dementia diagnosis. Two studies recruited small purposive samples. Four studies described multiple recruitment approaches of which two reported comparisons of their study population with wider populations. Comparison indicated that these samples contained mainly people with mild or moderate dementia. Two further studies recruited small purposive samples, which were not compared with the wider population, and therefore the representativeness of these samples is unknown. The small number of studies restricted subgroup analysis opportunities, but sensitivity analysis did not indicate that study quality influenced the prevalence reported within these studies.

Resultant prevalence estimates indicate that caregivers believe that over 90% of people with dementia experience at least one need. This study also confirms that people with dementia and caregivers identified similar need priorities for the person with dementia living at home. The most prevalent needs for people with dementia and their caregivers (Food, Household activities, Memory and Money) matched, although they differed in order of presentation. Previous research indicates that distinct populations such as people with dementia living in care homes, and elderly people without dementia reported different need priorities (Orrell et al., 2008; Stein, Luppa, König, & Riedel-Heller, 2015)

Due to a limited number of studies reporting prevalence data on the needs of people with dementia, and the different ways in which data are reported, it is difficult to directly relate the results of this meta-analysis with other prevalence estimates. However, in order to enhance their credibility and validity, results are compared with available published prevalence data derived from alternative methods. As the literature does not consider prevalence of all the needs of people with dementia living at home this ‘will focus upon self-care; continence; mobility and falls; drugs; abuse/neglect; and psychological distress needs.

A study, which used CarenapD needs assessment tool found people with dementia, reported high levels of self-care needs (Meaney, Croke, & Kirby, 2005). CarenapD domains do not directly overlap with CANE need domains and Meaney et al. (2005) found 80% of people with dementia reported dental care needs, 79% had bathing needs, and 68% identified toileting needs, all of which can be considered self-care needs. Similarly, people with dementia living in Hong Kong reported prevalence estimated at 29.6%, 59% and 76.9% for bathing needs for people who are at the early, middle or late stage of dementia respectively, using the CarenapD needs assessment instrument (Chung, 2006). Hence, the prevalence estimates for person with dementia reported self-care needs from the current study are similar to Chung's estimate for people in the early stages of dementia, whereas prevalence of the current study's caregiver reported self-care needs is closer to the estimate provided by Meaney et al. (2005), and Chung's estimate for people in the middle stages of dementia.

There are no prevalence studies of people with dementia living at home with incontinence needs (Drennan, Cole, & Iliffe, 2011). However, 31% of home-dwelling people over the age of 75 in the UK have urinary incontinence problems (Rait et al., 2005), and 31% of caregivers of people with dementia in Australia manage incontinence and pads (Drennan et al., 2011). These estimates are higher than the prevalence estimate for continence needs in the current study. In addition, Chung (2006) reports prevalence of continence needs ranged from 11.3% to 46.2% for people at different stages of dementia. Again, the current study's prevalence estimate for people with dementia reported needs is convergent with the estimate for people who are at an early stage of dementia from the Chung study.

The estimated prevalence of mobility and fall related needs from the current study is comparable with data on the number of falls experienced by people with Alzheimer's disease. Allan, Ballard, Rowan, and Kenny (2009) found a history of falls within the previous year for 51.4% of people with Alzheimer's disease.

The prevalence estimate for drug related needs is credible given that 49.02% of people with dementia required assistance with medication administration (Bowen, Gonzalez, Edwards, & Lippa, 2014), and polypharmacy is observed in 50% of elderly patients (Leelakanok & D'Cunha, 2018).

Prevalence estimates of behavioural and psychological symptoms associated with dementia reported in the literature range from 50 to 100% (Devshi et al., 2015). The prevalence estimate for caregiver reported psychological distress needs is comparable with the lower end of this range, and this proportion would likely rise when other relevant needs such as accidental self-harm, deliberate self-harm, behaviour, alcohol, and psychotic symptoms were taken into account.

Significant abuse occurs in more than a quarter of people with dementia (Cooper, Manela, Katona, & Livingston, 2008). Overall elder abuse is estimated at 15.7% [95% CI 12.8, 19.3] (Yon, Mikton, Gassoumis, & Wilber, 2017), therefore the prevalence of abuse/neglect estimate from person with dementia reports and from caregiver reports from the current study are low. This variation may result from the method used to obtain data as rates of abuse detected using objective measures are around 5% (Cooper, Selwood, & Livingston, 2008), which is in line with the estimate from the current study.

Overall, the convergence between the results of this study and published data lend them credibility, although it was not possible to identify data for comparison with all of the reported needs. Generally, the needs prevalence estimates produced within this study are low when compared with other published data possibly because they reflect the needs of people with dementia experiencing mild or moderate cognitive and functional impairment.

The present study also revealed variation in needs prevalence was associated with who reported the needs, and fixed effects analyses confirmed that caregivers reported higher levels of need for 23 of the 24 needs. This may be a result of people with more severe cognitive and functional impairment being unable to answer CANE questions. Hence, higher levels of need reported by caregivers may reflect the needs of a population that includes more people with severe dementia. As the CarenapD does not distinguish between caregiver and person with dementia reported needs, this may explain the increased needs frequencies obtained using this assessment tool. Notably, informal caregivers of people with dementia living in care homes (Orrell et al., 2008; van der Ploeg, Bax, Boorsma, Nijpels, & van Hout, 2013), and of people with dementia attending daycare (van Haeften-van Dijk, Meiland, Hattink, Bakker, & Dröes, 2016) also reported greater needs prevalence than people with dementia.

In order to reorganise integrated health and social care services to meet the needs of people living with dementia in a meaningful way, there must be greater understanding of the diversity of needs within this population (Commisso et al., 2017; Farmer et al., 2016). Sensitivity analysis indicated that data from the study examining the needs of people with young onset dementia was the major source of variation for 12 person with dementia reported needs,

and 12 caregiver reported needs. When this data were removed from the analysis, resultant prevalence estimates were reduced indicating that people with young onset dementia and their caregivers both report higher levels of need than other people with dementia and their caregivers. This may reflect the different life stage, and particular clinical characteristics of this population who received a dementia diagnosis prior to the age of 65 and who form 2.2% of people with dementia in the UK (Knapp et al., 2007). People with young onset dementia may be coping with lost self-identity, income and socialisation associated with leaving employment, in addition to the psychological burden of an unexpected diagnosis and role changes associated with becoming a dependent family member (Shuman, Hughes, Wiener, & Gould, 2017).

People with young onset dementia have particular daytime activity needs which have been previously noted (Harris & Keady, 2004; Millenaar et al., 2016), and there is a recognised requirement for day care which provides stimulating activities for people who may be more active, or at a different life stage (Millenaar et al., 2016). Additionally, a lack of age-appropriate residential facilities may also have an impact upon accommodation needs for this group (Bakker et al., 2013). Higher frequency of benefit related needs were reported by both people with young onset dementia and their caregivers perhaps reflecting the impact of young-onset dementia on employment for both people with dementia and their caregivers.

The presented prevalence estimates have particular relevance for service planning. For example, information regarding psychological needs including Psychotic symptoms, Deliberate self-harm and Psychological distress indicate the level of specialist mental health support required by people with dementia as these needs are most likely to be met through formal support services (Cummings & Kropf, 2009). Prevalence estimates of environmental needs such as Benefits, Money and Accommodation also have direct implications for social policy and service provision. For other needs, which perhaps require less specialist interventions such as household activities and food, prevalence estimates can indicate sources of difficulty and additional burden often shouldered by informal caregivers. In some cases, CANE domains may be too generic to link to specific interventions or services (Cummings & Kropf, 2009; Schmid et al., 2012). Therefore, there is a requirement for further work investigating how these needs link with suitable interventions. Exploration of the heterogeneity associated with needs has determined subgroups of people with dementia experiencing specific needs prevalence. It may also be useful to explore associations with variation in met and unmet needs to inform understanding in this regard. This in turn will increase knowledge regarding the provision of interventions that meet the needs of people with dementia.

Limitations

Limitations of this study include the low number of published studies retrieved despite extensive searching. Further, some retrieved studies had small sample sizes and confidence intervals reflect this. All needs data were elicited using CANE, which does not consider educational or vocational needs, however Schmid et al. (2012) found it was the best of the available needs assessment instruments for people with dementia. Results indicate that participants mostly had mild or moderate dementia, and few had severe dementia in part because they were unable to understand CANE questions. Study data were collected from nine European countries. Findings support Morrisby et al. (2018) who claimed that experience is shared across countries and service models. However, data from outside Europe is required to understand the international relevance of results. There was high residual unexplored heterogeneity for a number of the analyses (Ryan & Cochrane Consumers & Communication Review Group, 2016).

Conclusion

This study quantifies prevalence estimates of twenty-four needs of people with dementia living at home, as reported by people with dementia and their caregivers, for the first time. Overall, analyses confirm that people with dementia and their caregivers prioritise the same needs, however, caregivers of people with dementia report higher levels of need than people with dementia report themselves, although this may be due to people with severe dementia being unable to complete the needs assessment. Synthesis of results provides evidence of sources of heterogeneity in reported needs including the effects of the person reporting the needs, and age of dementia onset. Understanding prevalence and type of needs experienced by people with dementia, and circumstances in which needs vary can assist in targeting resources to meet the unique range of needs experienced by an individual, hence reducing adverse outcomes for individual patients (Guthrie, Payne, Alderson, McMurdo, & Mercer, 2012; Schmid et al., 2012).

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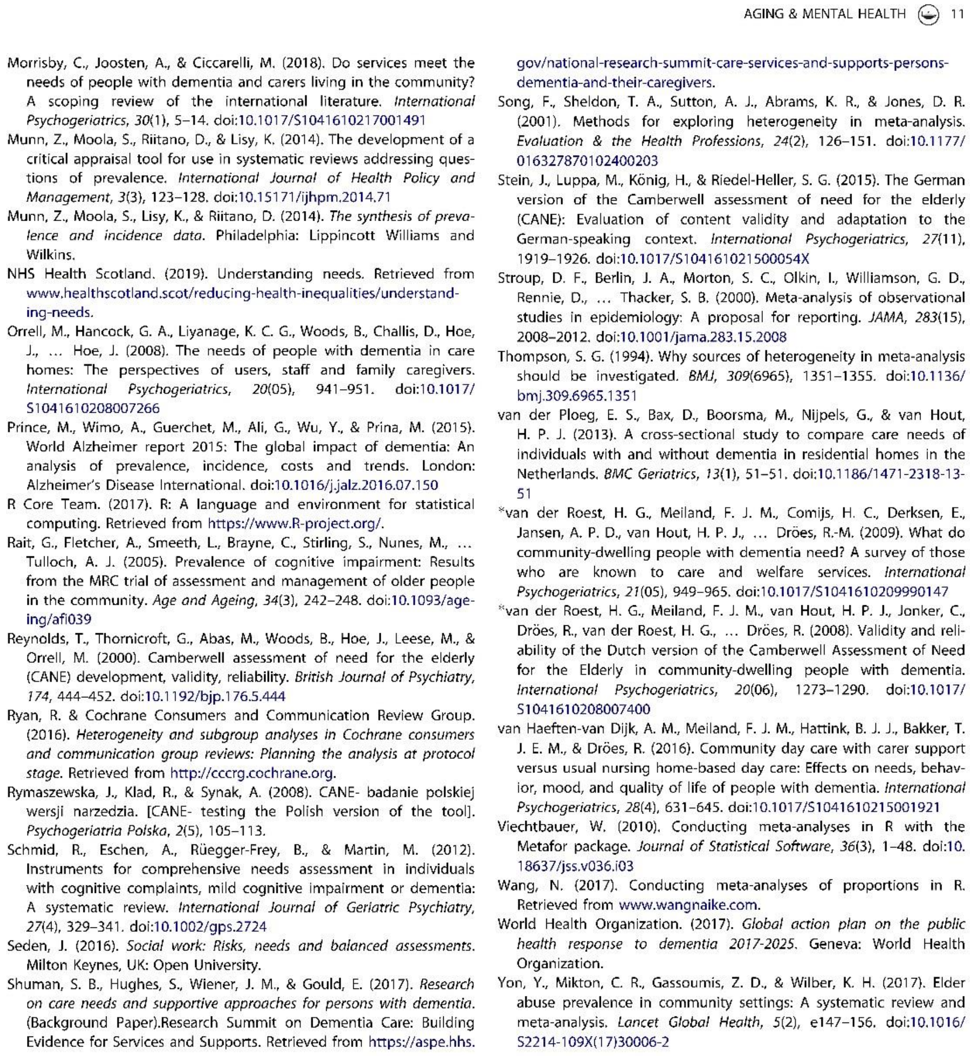

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Appendix I: Abbreviations and symbols

AD	Alzheimer’s disease
ADL	Activities/Activity of Daily Living
AT	Assistive Technology/ Assistive Technologies
ATT	Assistive Technology and Telehealth
ATTILA	Assistive Technology and Telecare to maintain Independent Living At home for people with dementia.
BPSD	Behavioural and Psychological Symptom(s) of Dementia
CANE	Camberwell Assessment of Needs for the Elderly
CarenapD	Care Needs Assessment for People with Dementia
CASSR	Council with Adult Social Service Responsibilities
CI	Confidence Interval
CLM	Cumulative Link Model
COPD	Chronic Obstructive Pulmonary Disease
CTSU	Clinical Trials Service Unit
DSM	Diagnostic and Statistical Manual
GP	General Practitioner(s)
GPS	Global Positioning System
IADL	Independent Activity/ Activities of Daily Living
ICD	International Classification of Diseases
ICT	Information and Communication Technology
ISRCTN	International Standard Randomised Controlled Trial Number
ITT	Intention To Treat
LRT	Likelihood Ratio Test
M	Mean
MAR	Missing At Random
MCAR	Missing Completely At Random
MMSE	Mini Mental State Examination
MNAR	Missing Not At Random
MOHOST	Model of Human Occupation Screening Tool
N	Total number of Participants/ Total number of AT devices
n	Number of participants/ Number of AT devices

NA	Not Available/ Not Applicable
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NPI	Neuropsychiatric Inventory
OR	Odds Ratio
PAM	Partitioning Around Medoids
PDA	Personal Digital Assistant
POLR	Proportional Odds Logistic Regression
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-analysis
QoL	Quality of Life
RCT	Randomised Controlled Trial
RE	Random Effects
RFID	Radio Frequency Identification
SD	Standard Deviation
SE	Standard Error
SOP	Standard Operating Procedure
t-SNE	t-distribution Stochastic Neighbourhood Embedding
UK	United Kingdom
WHO	World Health Organisation
I^2	Measure of the proportion of heterogeneity of the observed variation which is due to its sensitivity to true heterogeneity and insensitivity to number of studies (Higgins et al. 2003; Wang 2017).
χ^2	The chi-square distribution; a statistical test based on the chi-square distribution; the sample value of the chi-square test statistic.
%	Percent