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More of a hindrance than a help?

Staff perspectives on the usability of Electronic Patient Records for planning and delivering dementia care in nursing homes: a multiple case study

Doctoral thesis

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Mandatory formal declaration.

Declaration

Hereby I declare that I have written this doctoral thesis by myself, using solely the references and data cited and presented in this thesis. I declare that I have not been awarded other degree or diploma for thesis or its substantial part. I give approval to make this thesis accessible by Charles University libraries and the electronic Thesis Repository of Charles University, to be utilized for study purposes in accordance with the copyrights.

Bristol, UK. **26.02.2020**   Kate Shiells

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Pomoc nebo překážka?

Pohledy zaměstnance na použitelnosti elektronických záznamů (EPR) pro plánování péče o lidi s demencí v pečovatelských domech:

komparativní případová studie

Background to the thesis

This thesis for the Ph.D. in *Studie Dlouhověkosti* or Longevity Studies has been undertaken as part of the Marie Skłodowska-Curie International Training Network entitled Interdisciplinary Network for Dementia using Current Technology (INDUCT) and funded accordingly under H2020-MSCA-ITN-2015, grant agreement number 676265. The overall aim of the project has been to develop a multi-disciplinary, inter-sectorial educational research framework for Europe to improve technology and care for people with dementia, and to provide the evidence to show how technology can improve the lives of people with dementia. The research presented in this thesis falls under Work Package 5: Healthcare Technology.

The thesis itself is composed of four papers. At the time of submission of the thesis, three have been published (Papers 1-3) and one (Paper 4) is currently under review. The thesis also begins and ends with introductory and conclusion chapters, the latter of which contains *Best Practice Guidance for Human Interaction with Technology in Dementia.* These guidelines have been developed as a culmination of the results presented in the articles within this thesis and correspond to the INDUCT objectives around usability and implementation of technology. Due to the requirements of the project, the thesis has been written in English.

Contents

Introduction

Dementia: a policy priority

There are an estimated 50 million people currently living with dementia worldwide (ADI, 2019), with a prevalence rate of 7.1% in EU members states (Bacigalupo et al., 2018). Consequently, dementia is now at the forefront of the policy agenda in many countries, particularly in Europe (OECD, 2004). National dementia plans laying out policy priorities have been implemented in a number of countries. Common priorities include risk reduction, dementia friendliness, and coordination of care (ADI, 2018). In 2017, the World Health Organisation (WHO) also introduced its first dementia plan, representing an initial step towards global action. As part of the plan, the WHO identifies a number of priorities, including 'Dementia diagnosis, treatment, care and support' (action area 4), which states that care for people with dementia should move away from a hospital setting towards integrated, person centred health and social care in a community setting. In this plan, the WHO also sets out its goal for member states to develop a national response to dementia by 2025.

As part of this project, research has been carried out in nursing homes in Belgium, Czech Republic and Spain. Therefore, the following sub-section provides background information on the prevalence of dementia in these three countries as well as an overview of their dementia plans, with a focus on those policies related to care planning and provision.

Belgium

Both Flanders and Wallonia have their own regional dementia plans. In this section, the dementia plan in Flanders will be described; the region where data collection took place in this study. The number of people with dementia in Flanders stands at approximately 122,000, with around 70 % living at home (Vlaamse Regering, 2016). In the dementia plan, which will run until 2019, the Flemish government states that they have adopted the World Health Organisation's 'Conceptual framework for people-centred and integrated health and care services' (2015) as a model of care.

They state that their dementia policy 'starts from the needs of people living with dementia'. The plan places an emphasis on adopting a broader approach than the medical model, whereby 'care diagnostics' should be taken into account alongside medical diagnosis. They also highlight the need to promote 'person-centred', 'integrated' and 'customised' care, with a drive to enable people with dementia to stay in their own home for as long as possible. Similarly, they also note that people with dementia should have 'control over their own care and maximum retention of their individual autonomy' in order to ensure quality of life. They outline the following requirements needed to achieve this goal: people with dementia should be part of society wherever they live; and people with dementia should have an integrated care and support plan, which is shaped by their individual needs. The document also emphasises the importance of early care planning, with an emphasis on end of life care.

Czech Republic

In the Czech Republic, there are an estimated 150,000 people living with dementia (Holmerová et al., 2016), approximately 19% of which reside in nursing homes (Ministerstvo zdravotnictví České republiky, 2016). The 'National action plan for Alzheimer's disease and

other similar diseases' was implemented in 2016, covering the period up until 2019. Key elements of the plan include: improving early diagnosis; standardizing treatment methods, including preventing the use of antipsychotics; implementing epidemiological surveillance; and improving access to care (Chow et al., 2018).

Under 'improving access to care' (section 3.3) there is a particular emphasis on the coordination of care. The plan describes how individuals may not receive appropriate care due to a poor interconnection of the health and social services in the Czech Republic. The plan states that the aim is to support the emergence of specialised interdisciplinary centres, which will focus on rare and complex forms of dementia. There is no specific reference to care planning in the document, however.

Spain
In Spain, there are estimated to be more than 800,000 people with dementia (Alzheimer Europe, 2013). The first national dementia plan in Spain was adopted in October 2019. However, at the time of writing this is not accessible. Prior to this plan, the Ministry for Health, Social Services and Equality implemented the country's first National Health System Strategy for Neurodegenerative Diseases (Ministerio de Sanidad, Servicios Sociales e Igualidad, 2016), which included Alzheimer's disease and other dementias. Objectives of this plan include prevention and early detection; training of professionals; and coordination of care across departments. There is also a focus on provision of comprehensive care (objective 3), which states that individuals should be provided with an individualised health and social plan of care from diagnosis, which is updated throughout the trajectory of the disease

The continuing role of nursing homes in dementia care
Following an increasing awareness about the importance of the 'physical environment as a component of care' (Calkins, 2009) and a subsequent paradigm shift towards deinstitutionalisation as a result of national dementia plans and the WHO global plan, there has been an increasing focus on enabling people with dementia to remain in their homes for as long as possible (Dawson et al, 2015; OECD, 2004). There is evidence to show that there are increased positive outcomes for people with dementia in smaller homelike settings (Kane et al., 2007; Pekkarinen et al., 2004; Reimer et al., 2004). However, due to the progressive nature of dementia and its associated neuropsychiatric symptoms, worsening of co-morbidities, carer-breakdown, and the lack of advancement as regards to pharmacological treatments, people with dementia often spend time in institutions as they pass through the continuum of care (OECD, 2004). For instance, in the United Kingdom, approximately two thirds of people with late onset dementia live in the community, whilst approximately one third live in care homes (Knapp & Prince, 2007).

Introduced partly as a result of 'public policy designed to minimize the use of acute hospitals' (Fahey, 2003), nursing homes are able to provide personal care, as well as addressing more complex medical needs (ADI, 2013). Due to a general lack of dementia-specific care facilities across many countries, nursing homes often cater for people with and without dementia (OECD, 2004). For example, in the United Kingdom, 69 per cent of older people living in care homes have a diagnosis of dementia (Prince et al, 2014). People with dementia living in nursing homes may have more complex needs than those who do not have dementia. This

could include the need for 1:1 support, as well as greater needs relating to personal care (ADI, 2016).

Current issues in nursing homes

In addition to the challenges accompanied with caring for individuals with a wide range of needs, nursing homes face a multitude of issues. Firstly, they have long been characterised by a 'workforce crisis', which has come about from high staff turnover and low employee morale (Gibson & Barside, 2003). Difficulties in recruiting staff can be attributed to a range of factors, such as low pay, lack of formal training and job prospects, as well as the emotional and physical challenges associated with working in the nursing home environment (Geiger-Brown et al., 2004). A lack of staff has resulted in a number of consequences for residents, mainly the degree to which their needs are met on a daily basis. In particular, staff may only have time to fulfil basic personal care, meaning often residents' social needs may not be met. This can have profound effects on people with dementia. For example, boredom has been shown to be associated with agitation amongst people with dementia (Cohen-Mansfield et al., 2010).

Nursing homes may also face challenges in lack of funding (Bartlett et al., 1998), as well as monopolies in profit-making care providers, commonplace in the UK (Carey, 2014). Dementia care in the community is also fragmented (Minkman, Ligthart & Huijsman, 2000), and nursing homes in particular experience varying relationships with General Practitioners and physical and mental health teams (Fossey, 2008). For instance, nursing homes in the UK have been found to be lacking access to GP services, such as home visits or regular medication reviews (Glendinning et al., 2002). This highlights the importance of case management[1] and the need for integrated care through multidisciplinary collaboration across services in order to plan and deliver optimal care for people with dementia living in nursing homes (Fossey, 2008; Minkman, Ligthart & Huijsman, 2000). An important factor prohibiting the coordination of care across is the lack of ability to share and access information across service providers (ADI, 2016). A combination of these factors is likely to have led to poor standards of care for people with dementia in nursing homes (Ballard et al., 2001).

However, this research focuses specifically on the challenge faced by nursing homes in the form of documentation, a task frequently described as a burden by those working in the sector (Bartlett et al., 1998; Fournier, Gosselin & Rioux, 2006). This can be attributed to an increase in the demands for documentation, which have come about from 'increasing regulatory scrutiny and soaring public awareness' (Fournier, Gosselin & Rioux, 2006). Furthermore, nursing home staff have expressed resistance towards documentation because they do not see its value (Edelstein, 1990), or as a result of its complexity (Ron & Bar-Tal, 1993). In particular, staff may experience difficulties in 'articulating the nature of nursing practice' in written format (Hanesbo, Kihlgren & Ljunggren, 1999; Howse & Bailey, 1992).

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[1] Case management is defined as a: *collaborative process of assessment, planning, facilitation, care coordination, evaluation and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote patient safety, quality of care, and cost effective outcomes* (Case Management Society of America, 2008).

Nursing home documentation

Documentation used in nursing homes will usually reflect the different stages of the nursing process (Forster, 2003a). Documentation plays an important role in the care of people living in nursing homes, particularly for those with dementia, as emphasised by Alzheimer's Disease International (2013) who describe the four main 'apparatus' of long-term care, the first of which being the 'assessment and evaluation of social and health care status, resulting in an explicit care plan'.

The first stage in the nursing process, assessment, involves collecting information relating to a person's 'physical, psychological, and social status' (Forster, 2003b). Assessment may take place in a direct or proxy manner, such as through observations or discussions with relatives. Various tools may be used in the assessment process, for example, the Resident Assessment Instrument-Minimum Data Set (Hutchinson et al., 2010). However, assessment is often a time-consuming process for staff, and in addition can be a potentially stressful activity for the person with dementia (Forster, 2003b).

Information gathered during the assessment process is then used to formulate a care plan (Dellefield, 2006). Care plans have been described as 'prescriptions for nursing care' (Forster, 2003c) and act as a reference for nurses to facilitate continuity of care, as well as record care provided (Wang et al., 2015; Ballantyne, 2016). This is an important function of the care plan, which may protect staff in case of complaints (Ballantyne, 2016). The care plan will include information relating to the maintenance of physical health, as well details about the most appropriate physical and social environment for each individual (Nasso & Celia, 2007). Plans should include goals which maximise individuals' current abilities and minimise their deterioration (Nasso & Celia, 2007). Care plans are also 'dynamic documents' that should be updated regularly as part of the evaluation process (Forster, 2003c).

An essential characteristic of the care plan is that it should be fully personalised to reflect the individual (Jeon et al., 2013). This approach has been influenced by the work of Carl Rogers (1958), and later Tom Kitwood (Brooker, 2003). Kitwood challenged the medical model of care focused on treatment of disease, which had led to care plans purely concerned with routines and organisational needs (Fazio et al., 2018). Instead, he emphasised the importance of maintaining selfhood and respecting each person's needs, whilst trying to view the world through their perspective (Fazio et al., 2018). In this way, as far as possible, care planning should also be participatory (Forster, 2003c), although cognitive decline accompanied by communication difficulties may sometimes pose difficulties in developing a care plan alongside an individual with dementia, which may then require the involvement of close relatives or friends. However, the individual's need should always be at the heart of the plan (Nasso & Celia, 2007).

An area of care planning that has been found to be poor for people with dementia is the recording of neuropsychiatric symptoms (Hansebo, Kihlgren & Ljunggren, 1999; Jeon et al., 2013). This is important as systematic documentation can provide an insight into what triggers certain behaviour and thus indicate ways to avoid similar scenarios from recurring (Omelan, 2006). In particular, person-centred care planning has been shown to reduce neuropsychiatric symptoms of dementia whilst also leading to a reduction in psychotropic medication use in nursing homes (Li & Porock, 2014). However, whilst the importance of assessment and care

planning as part of the nursing process is apparent, the most effective way of doing so electronically remains unclear.

History of the Electronic Patient Record (EPR)

One of the earliest forms of the patient record dates back to the nineteenth century, which saw the advent of the 'lab notebook': a personalised notebook used by clinicians to record patient observations and treatment plans (Shortliffe & Blois, 2001). The paper record then became commonplace throughout much of the twentieth century, until the development of the computer in the 1960s and a new horizon for patient records (Evans, 2016). However, it was not until 1991 when the Institute of Medicine in the United States called for the shift from paper to computerised patient records (Hanson & Lubotsky Levin, 2013), which coincided with a turning point in time when computers were more 'affordable, powerful and compact' (Evans, 2016). The initial electronic patient records were described as simply an electronic version of the paper record and were widely considered to be more time-consuming than filling out the paper version (Evans, 2016).

The EPR was predicted to improve the safety, quality and efficiency of healthcare through the incorporation of a number of functionalities (IOM, 2001). Shortliffe and Blois (2001) summarise the key functionalities of a 'useful' record system required for healthcare today: easy access and display of data; possibility to share data among colleagues and secondary users; and the analysis of data. Widerhold & Shortiffe (2001) describe similar functions that an EPR should fulfil, such as record keeping and access at the point of care; communication and integration of information; and surveillance and decision support. However, incorporating these components into the EPR successfully has been challenging. The consistent issues associated with the EPR are summarised by Shortliffe and Blois (2001): '(1) the need for standards in the area of clinical terminology'; (2) concerns regarding data privacy, confidentiality, and security; (3) challenges of data entry by physicians; and (4) difficulties associated with the integration of record systems with other information resources in the healthcare setting'.

From the initial development of computing technology, the role of computers in assisting doctors with diagnosis was envisaged (Musen, Shahar & Shortliffe, 2001). Information management now plays an important role in optimal decision making (Shortliffe & Perreault, 2001). Often introduced into the EPR, the clinical decision support system (CDSS) is marketed as one its key features (Evans, 2016), and has the potential to analyse data in order to carry out diagnoses, alert staff to problems and indicate treatment or appropriate pathways of care (Shortliffe & Barnett, 2001; Shortliffe & Bois, 2001). However, a lack of common standards when implementing CDSS into the EPR has meant that clinical care is often provided without the use of a decision support system (Kawamoto et al., 2014). For instance, a lack of consistent terminology across medicine and healthcare has been problematic for the development of CDSS (Kawamoto et al., 2014).

Efforts to code data and reduce free text entry have been made to remedy this problem (Evans, 2016), and in the field of nursing, there has been a call for Standardised Nursing Language (SNL) to be integrated into the CDSS (Müller-Staub, de Graaf-Waar & Paans, 2016). The integration of common terminology or coded entry into the EPR is increasingly important in the field of epidemiology, where data need to be aggregated to measure trends such as

prevalence and incidence of disease (Ponojan et al., 2019). Researchers have also recently used longitudinal data from GP electronic patient records to develop machine learning models for the early diagnosis of dementia (Ford et al., 2019).

A further challenging aspect associated with the EPR has been the sharing of data amongst secondary users, also known as interoperability. As individual healthcare providers have implemented their own EPR systems, there have been calls for patient information to be shared in order to provide more integrated, seamless care. In addition to ethical aspects such as consent, data privacy, and security all hindering interoperability, the nature of information management across various providers has also caused problems. For instance, the type of EPR used by providers of mental health services will often need to be adapted from the EPR used by hospital doctors, as traditional medical notes are more commonly comprised of numeric data from test results, whilst mental health data often takes the form of handwritten notes (Hanson & Lubotsky Levin, 2013: 95).

The challenge faced by EPR designers is thus designing a system that responds to the needs of the environment in which it is situated, whilst meeting both the needs of the user and the client group for whom the care is planned. The EPR should facilitate effective record keeping, access and display, as well as incorporate a CDSS which meets common standards, whilst enabling information to be shared securely and effectively across healthcare providers. At the same time, the system should be cost-effective to implement (Hanson & Lubotsky Levin, 2013). Moreover, technology should not reduce the human side of care delivery (Bailey, 2011)

Theoretical Framework

The penultimate section discusses the theoretical framework underpinning the research: Human Factors Engineering.

The EPR has been described as 'underused and failed' across multiple health systems and countries (Obstfelder & Moen, 2006). These issues have been linked to a failure to consider the socio-technical issues associated with Health Information Technology (HIT) implementation, which includes technical, social but also environmental components (Obstfelder & Moen, 2006; Rogers et al., 2013; Sockolow et al., 2012). Human Factors Engineering (HFE), also known as usability engineering or ergonomics (Rubin, 1994), has emerged from the various evaluation methods used in the field of Human Computer Interaction (HCI) (Kushniruk & Patel, 2004). However, HFE is largely un-established in healthcare environments. HFE is distinct from traditional 'outcome-based evaluations' which have historically taken an objectivist approach, frequently using the randomised controlled trial to explore aspects such as the safety, accuracy and reliability of technology (Kushniruk & Patel., 2004). Issues with quantitative methods such as the RCT arise when results show a negative outcome, as it is normally not possible to know the reasons behind this outcome (Kushniruk & Patel, 2004). Another common quantitative method frequently used to evaluate HIT is the questionnaire. However, questionnaires require participants to answer pre-defined questions, thus providing 'limited value in identifying new or emergent issues' (Kushniruk & Patel., 2004). Moreover, questionnaires are commonly retrospective, and so require the participant to recall their experiences using the system, which may be subject to recall bias (Kushniruk & Patel., 2004).

HFE may provide a more appropriate theoretical and methodical underpinning to address socio-technical issues (Rogers et al., 2013). Firstly, this approach emphasises the importance of iteration: the cyclical nature of designing, modifying and testing products and incorporating feedback from end users at each step (Rubin, 1994; Kushniruk & Patel, 2004). Therefore, a human factors approach is also participatory, highlighting the need for joint development (Rubin, 1994). For instance, in practice, a HFE approach to evaluation usually involves representative users performing representative tasks whilst collecting information about their experiences of using the system in real-life conditions (Kushniruk & Patel., 2004). Issues have previously occurred with the EPR when companies purchase the system as an 'off-the-shelf product', demonstrating the importance of joint development (Shortliffe & Bois, 2001). These finding have been echoed in numerous studies, such as Cherry et al.'s (2011) qualitative study, which found that nursing home staff consistently expressed the need for regular meetings with system developers in order to provide feedback and discuss improvements with the EPR system. Likewise, Wiederhold and Shortliffe (2001) found that the development of a successful EPR system is dependent on the relationship between developer and user.

An HFE approach also takes into account three 'domains of system design': physical, cognitive, and organisational (WHO, 2016). For example, the physical domain of EPR would include an exploration of the ideal type of device, such as the size or shape. The cognitive domain would be concerned with factors such as software design and how these impact on user interaction. The third domain, organisational, may include an exploration of the ways in which information is shared across the organisation, amongst other factors (WHO, 2016). Therefore, HFE allows for an understanding not only of the device and software, but also the user, the task and the environment (Hanson & Lubotsky Levin, 2013). The importance of an HFE approach has also been translated into policy action. For instance, the WHO (2016) recommend that member states prioritise end user research when designing HIT, so that technology addresses information needs and matches with the preferences of healthcare providers and patients, as well as the context of use.

Research Questions

This final section describes the overarching research questions that are used to guide the study, and the corresponding papers that address each question. Please note, Paper 2 is the study protocol.

(1) How do EPR systems currently facilitate and/or hinder care provision in nursing homes, as stated in the literature? What methods have researchers used previously to explore EPR usability in nursing homes? *(Paper 1)*

(2) Which type of device and software are used by nursing homes for assessment and care planning in Belgium, Czech Republic and Spain? Which types of information do the systems capture? *(Paper 4)*

(3) What are the usability issues associated with the electronic patient record system for assessment and care planning for people with dementia in nursing homes? What are the potential modifications? *(Paper 1, Paper 4)*

(4) What are the contextual conditions of the nursing home in which the electronic patient record system has been introduced? What is the impact of these contextual conditions on usability? *(Paper 4)*

(5) What are the barriers and facilitators to implementation of the EPR in nursing homes? *(Paper 4)*

(6) What is the opinion of residents and their family members on the EPR? Is the EPR dehumanising dementia care in nursing homes and to what extent? *(Paper 4)*

(7) What are the best practice guidelines for care planning for people with dementia that should be captured by the care plan? To what extent are the electronic patient records used by nursing homes capturing this information? *(Paper 3)*

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Literature Review

Abstract

Objective: The electronic patient record (EPR) has been introduced into nursing homes with the aim of reducing time spent on documentation, improving documentation quality and increasing transferability of information, all of which should facilitate care provision. However, previous research has shown that EPR may be creating new burdens for staff. The purpose of this literature review is to explore how the EPR is facilitating or hindering care provision in nursing homes.

Methods: An integrative literature review was carried out using four electronic databases to search for relevant articles. After screening, 22 articles were included for thematic synthesis.

Results: Thematic synthesis resulted in six analytical themes linked to care provision: time for direct care; accountability; assessment and care planning; exchange of information; risk awareness; and person-centred care.

Conclusion: For EPR to facilitate care provision in nursing homes, consideration should be given to the type of device used for documentation, as well as the types of applications, the functionality, content, and structure of EPR. Further research exploring the experiences of end users is required to identify the optimal characteristics of an EPR system specifically for use in nursing homes.

Introduction

In recent decades, a change in demographic trends in Europe has led to an increasingly ageing population [1]. Consequently, there has been a rise in the number of people being diagnosed with non-communicable diseases, such as dementia, which has placed new demands on the long-term care sector [2]. An effective response to the challenge of delivering healthcare to an ageing population may incorporate the introduction and utilisation of appropriate technology [3, 4, 5] and the electronic patient record (EPR) is one technological solution that has been identified as potentially beneficial for facilitating the provision of care in a nursing home environment [6, 7, 8].

Healthcare today has been described as 'information-intensive' [9]. Consequently, completing documentation has become one of the most time-consuming activities for staff, meaning that they spend less time on delivering direct-care [10]. Furthermore, traditional, paper-based documentation is often inconsistent, incomplete and illegible [11], as well as out-of-date and difficult to update [12]. As a result, there is an increase in the possibility for errors and a reduction in the quality of care [13].

In nursing homes, EPR systems may be used to record various nursing processes, such as assessment and care planning, and to write daily progress notes and handover forms [14]. Potential benefits associated with using EPR include the effective management of chronic conditions [15]; the collection of longitudinal information [8]; and the ability to rapidly access information securely [8]. Consequently, EPR may assist staff to deliver a more person-centred approach to care [16]. Furthermore, the increased legibility and accuracy associated with electronic documentation should result in a reduction in data errors and improve standards of care [17]. EPR also has the potential to lead to greater transferability of information across multiple stakeholders [17], allowing for a more integrated approach to care provision [18]. Finally, EPR has also been associated with raising the 'social standing of care work' [16].

Despite the potential benefits, the uptake of EPR in nursing homes has varied considerably across countries, with much of the literature referring to a 'technology lag' [16, 19, 20]. Furthermore, a previous systematic review of six studies exploring staff experiences with IT implementation in nursing homes found that the introduction of IT for documentation purposes may bring both benefits and burdens [21]. Consequently, there have been calls to expand research to further examine the impact that electronic documentation systems have on working practices in nursing homes [9, 15, 22]. Therefore, this literature review aims to add to existing knowledge in the field by exploring the impact of electronic documentation systems on the provision of care in nursing homes.

Method

Study design

The following literature review takes an integrative approach, synthesising evidence from both quantitative and qualitative studies. Although integrative reviews allow for the 'inclusion of diverse methodologies', they have been criticised for their lack of methodological rigour and bias [23]. Therefore, Whittemore and Knafl suggest a specific framework for carrying out integrative reviews, influenced by the model developed by Cooper [24] for conducting systematic reviews and meta-analyses. This framework is used below to describe the process of data collection, analysis and synthesis.

Search strategy

Various terms can be found in the literature to refer to technology used to record patient data digitally, which are often used interchangeably [25]. For example, in their systematic review, Häyrinen et al. [26] found the following common terms: electronic health records (EHR), electronic patient records (EPR), and electronic medical records (EMR). The terms EPR and EMR have the same meaning, with EPR more commonly seen in the United Kingdom, and EMR used in the USA. An EPR or EMR is defined as an application which is 'composed of the clinical data repository, clinical decision support, controlled medical vocabulary, order entry, computerized provider order entry, pharmacy, and clinical documentation applications', and refers to information collected from one organisation [25]. Whereas an EHR refers to a broader application, which brings together longitudinal data from an individual's various EPRs from different healthcare organisations [25].

Likewise, the terms nursing home and long-term care are often considered synonymous. In the United Kingdom, introduced in response to 'public policy designed to minimise the use of acute hospitals' [27], nursing homes address the more complex medical needs of individuals, including personal care needs [2]. The World Health Organisation defines long-term care as 'the system of activities undertaken by informal caregivers and/or professionals to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life' [28]. One 'apparatus' of long-term care is 'care in an institutional setting', such as a nursing home [2].

In order to obtain as many relevant results as possible, the terms 'electronic medical records', 'electronic patient records', 'electronic health records', as well as the more general term 'electronic documentation', have been combined with the terms 'nursing home' and 'long-term care'. Four databases were used to search for articles. Table 1 shows the exact search string used for each database, along with the number of articles that resulted from the searches.

The following criteria were subsequently used to select appropriate articles:
Inclusion criteria
- Published between 2000 and 2017.
- Published in English or French.
- Original qualitative or quantitative research.
- Conducted in a nursing home or long-term care setting.
- Research into any type of electronic documentation system used for the purposes of care planning, assessment, records or reports and forms.

Exclusion criteria
- Articles published before 2000.
- Articles not in English or French.
- Systematic reviews, meta-analyses or integrative reviews.
- Studies carried out in residential homes, hospitals or in the community. (Some studies compared the use of electronic documentation across a range of nursing environments, such as hospitals and nursing homes. If data from nursing homes could not be extracted, these studies were also rejected.)

- Studies which looked only at electronic documentation for medication administration.
- Duplicated articles.

Table 1. Search strings employed to identify articles

Database	Search terms	Number of records identified through searching
PubMed	("long-term care"[All Fields] OR "nursing home*"[All Fields]) AND ((("electronic medical records"[Title] OR "electronic patient records"[Title]) OR "electronic health records"[Title]) OR "electronic documentation"[Title])	24
Scopus	(TITLE-ABS-KEY ("long-term care") OR TITLE-ABS-KEY ("nursing home*") AND TITLE ("electronic medical records") OR TITLE ("electronic patient records") OR TITLE ("electronic health records") OR TITLE ("electronic documentation"))	76
CINAHL	("long-term care" OR "nursing home*") AND (TI "electronic patient records" OR TI "electronic health records" OR TI "electronic medical records" OR TI "electronic documentation")	14
ScienceDirect	TITLE("electronic medical records" OR "electronic patient records" OR "electronic health records" OR "electronic documentation") and TITLE-ABSTR-KEY("long-term care" OR "nursing home*")	11
Total number of records identified		125

The primary search was conducted manually by the first author. A second author conducted a subsequent search of the databases and found no new additional articles. Full texts were then screened using the PRISMA guidelines [29] as shown in Figure 1.

Figure 1. PRISMA flowchart showing search strategy
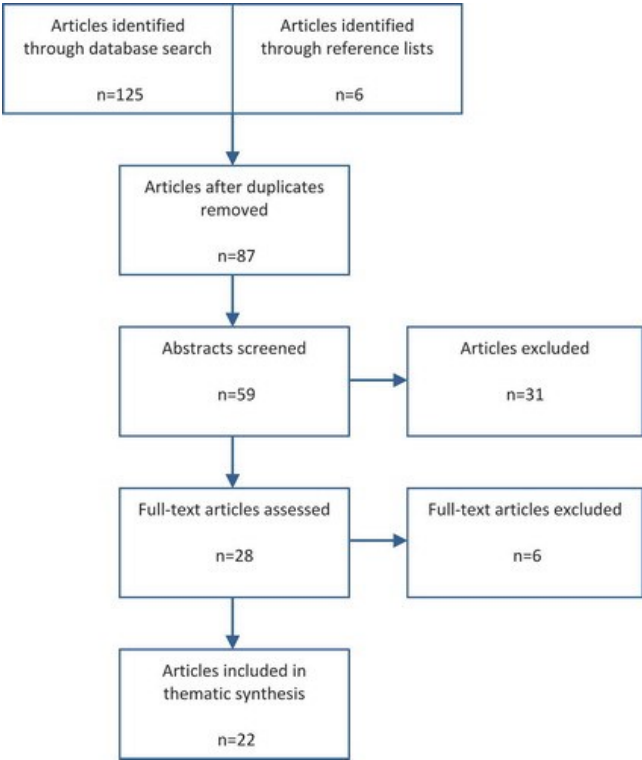
Data analysis

Thematic synthesis was used as a method of data analysis [30]. Both the results and discussion sections of the 22 articles were coded inductively by hand line by line which presented emerging themes across the literature. This process was carried out until saturation of themes was reached. Similarities across themes were then searched for and several were merged and re-named leaving ten. The final stage of thematic synthesis, 'generating analytical themes' [30] involved synthesising these ten existing themes in order to address the research question directly, leaving the following six analytical themes: time for direct care; accountability; assessment and care planning; exchange of information; risk awareness; and person-centred care. Table 2 summarises the articles used for thematic synthesis.

Table 2. Summary of articles used for thematic synthesis

Authors, date, country	Aims	Study design and methods	Sample size	Results
Alexander (2007) United States	To assess the frequency of active alerts in two nursing homes implementing an EHR with CDSS, and to explore the documented clinical responses of care staff when alerts are active and not active.	Comparative study. Collection of de-identified data from residents' EHRs.	Analysis of 118 alerts from two nursing homes.	Active alerts did not lead to significant changes in the documentation of clinical responses in most categories of documentation, with the exception of turning charts.
Cherry et al. (2008) United States	To gain information about long-term care leaders' general understanding about EHRs, and identify factors that facilitate and hinder implementation of EHRs in long-term care facilities.	Exploratory study. Focus groups.	34 participants from 24 different organizations.	Aspects of resident care affected by EHR use: increased accessibility to information; more time to spend on care; increased retention of staff; supervisors more able to monitor care provision and care needs. Not relevant for this review: barriers to EHR implementation, and factors promoting EHR adoption.
Cherry et al. (2011) United States	To explore early users' experiences with EHR in long-term care facilities.	Exploratory study. Semi-structured interviews and observations with staff, residents and family members.	Interviews (n = 70) and observations (n = 10) across 10 nursing homes.	Largely positive experiences were described by participants from each role and divided into two themes: "care quality implication" and "cost implications."
Cherry and Carpenter (2011) United States	To determine the effect of the electronic medical record system on work process efficiencies in a long-term care facility.	Pre–post intervention study. Process flow analysis measured through observation of five working processes.	Observations (n = 20) from one long-term care facility.	The number of steps required to complete four out of the five working processes decreased post-implementation of the EMR. However, there was an increase in the number of steps for the resident admission process.
Faxvaag et al. (2011) Norway	To examine experiences of healthcare professionals when using access control mechanisms as part of EHR systems in nursing homes and hospitals.	Exploratory study. Questionnaire administered to healthcare staff in nursing homes and hospitals.	29 nursing homes with a response rate of 43% (n = 239). Not relevant for this study: 21 hospitals with a response rate of 15% (n = 206).	60% of respondents believed that it took too long to log-in. Subsequently, staff do not regularly access records before delivering care, and frequently communicate information verbally.

Authors, date, country	Aims	Study design and methods	Sample size	Results
Filipova (2013) United States	To determine the levels of automation for 21 clinical functions, and the benefits and barriers to electronic health records use in skilled nursing facilities.	Evaluation study. Cross-sectional survey.	Response rate was 39% ($n = 156$).	Top three benefits of EHR use: improved quality patient care monitoring; improved management control of performance; anywhere/anytime access to charts and clinical data. Not relevant for this study: levels of clinical function automation; automated clinical decision support; automated systems for summary reports; barriers to HIT use.
Florczak et al. (2012) United States	To rate the ease of use and wound management effectiveness of an electronic point-of-care wound documentation system.	Prospective study. User satisfaction surveys administered to nurses at the start and end of the 2-month study. Observations of residents with pressure sores over two months.	Observations ($n = 38$) in one nursing home. Survey response rate ($n = 9$).	Documentation was found to be complete, consistent and legible. Internal and external communication improved, and physicians could easily review wound healing. Managing changes and treatment of wounds was more effective. Little change was seen in the prevention of avoidable wounds.
Fossum et al. (2013) Norway	To investigate the effects of a computerized decision support system and an educational program on care planning for pressure ulcers and malnutrition.	Comparative study. The first intervention group was trained in using the CDSS and took part in an educational program. The second intervention group only took part in the program. The third group was a control group.	150 resident records from 15 nursing homes were audited before, and 141 audited 8 months after the intervention was introduced.	The documentation from the first intervention group was more complete in recording the risk and prevalence of pressure ulcers and malnutrition.
Jiang et al. (2016) Australia	To examine the influence of EHR in managing risks and meeting the accreditation standard for information systems in Australian residential aged care homes.	Content analysis of aged care accreditation reports.	2754 reports.	One home using EHR and 12 using paper-based records failed to meet one or more accreditation outcomes. 9 out of these 12 homes failed the accreditation outcome for information systems.

Authors, date, country	Aims	Study design and methods	Sample size	Results
Lindner et al. (2007) United States	To develop and test an electronic medical records intervention to improve documentation of patient preferences about life-sustaining care, detail of resuscitation and treatment-limiting orders.	Prospective before–after intervention trial.	224 admissions to one nursing home.	The intervention with computerized clinician order entry and reminders increased the rate of completion of advanced directive discussion notes from 4% to 63%. Treatment-limiting orders were often more detailed and 98% in accordance with patient preferences.
Marier et al. (2016) United States	To investigate whether data from EMR can improve predictive power for falls in comparison to more common models using only the minimum data set.	Comparative study. Application of a repeated events survival model to analyze MDS and EMR data.	Data from 5129 residents in 13 nursing homes were analyzed.	Incorporating EMR data improves the ability to identify those at highest risk for falls relative to prediction using minimum data set data alone.
Meehan (2015) United States	To examine the end user's perspective of an EHR in a LTC setting, and to understand how this technology is being used.	Descriptive qualitative study. Interviews with care staff.	Interviews ($n = 20$) in one LTC facility.	Three themes emerged from the interviews: EHR has a positive impact on quality of care; staff members have innovative ideas on how to improve EHR for current and future use; ongoing staff training for EHR is crucial.
Michel-Verkerke and Hoogeboom (2012) Netherlands	To measure the adoption and the suitability of an EPR for the nursing home environment.	Evaluation study. Questionnaires to evaluate the implementation of the EPR, and semi-structured interviews with end users one year after implementation of the EPR (phase I) and 4 years after (phase II).	Response rate for questionnaires was 38% ($n = 130$).	In phase I, the greatest advantages reported were: availability of information at any time, by all care providers; and readability. Nurses did not think that EPR gave them more time for direct care. Physicians were the least satisfied with EPR. In phase II, nurses were positive about the EPR and reported that they spent less time using it. Disadvantages remained, such as lack of EPR access in residents' rooms.

Authors, date, country	Aims	Study design and methods	Sample size	Results
Munyisia et al. (2011) Australia	To explore care staff's perceptions about the quality of information and benefits when using an electronic system for documentation.	Comparative study. Questionnaires administered 3 months before and 6, 18, and 31 months after the introduction of an electronic documentation system in one nursing home. Structured interviews with staff conducted at 20 months.	Response rates: 64% (n = 32) at 3 months; 50% (n = 25) at 6 and 18 months; 50% (n = 15) at 31 months. Structured interviews (n = 17).	Participants perceived electronic documentation to be more accurate, legible and complete, but not more reliable or relevant than paper-based documentation. Managers reported that the electronic system had led to improved access to records and made it easier to identify care needs and outcomes.
Munyisia et al. (2014) Australia	To examine the effect of an EHR system on registered nursing and care staff's time.	Comparative study. Observations of staff two months before and at 3, 6, 12, and 23 months following the introduction of an EHR system.	Observations (n = 242) in one nursing home.	Time that registered nursing staff spent on documentation increased significantly, whilst time spent on verbal communication decreased. There was no change in the time spent on direct care. For care staff, there was no significant change in the time spent on documentation, verbal communication and direct care.
Rantz et al. (2010) United States	To explore the impact of a bedside EMR and onsite clinical consultation on cost, staffing, and quality of care in nursing homes.	Comparative study. Group 1: implemented bedside EMR and onsite consultation. Group 2: implemented bedside EMR only. Group 3: implemented onsite consultation only. Group 4: did not implement either intervention.	Group 1: 4 facilities, 2066 residents. Group 2: 4 facilities, 3643 residents. Group 3: 5 facilities, 1040 residents. Group 4: 5 facilities, 1417 residents.	Impact on staff retention: no change in any group. Impact on resident outcomes: improvement trends were found solely in group 2 for decline in late loss activities of daily living (ADLs), and decline in range of motion. Larger and more sustained improvements in pressure sores seen in groups 1 and 2 compared to groups 3 and 4. Not relevant for this study: impact on costs.
Rantz et al. (2011) United States	To evaluate if and how the use of a bedside EMR improves the quality of care provision and the reliability and accuracy of nursing home quality measures.	Evaluation study. Interviews, focus groups, and collection of observational data at 6, and 12–18 months after implementation of the EMR. Additional interviews at 24 months.	Focus groups (n = 22) and interviews (n = 120) in four nursing homes.	Benefits: increased accuracy; faster access to information; improved communication; ability to see trends; alerts which direct staff to appropriate care; increased accountability; some staff reported documentation time decreased. Disadvantages: some staff reported the EMR limited time spent with residents; documentation not always taking place at point of care; assessment documentation too lengthy or limited; iButtons inconvenient.

Authors, date, country	Aims	Study design and methods	Sample size	Results
Wang et al. (2013) Australia	To describe assessment documentation practices in residential aged care homes, and to compare the quality of electronic and paper-based assessment forms.	Comparative audit study. Paper and electronic assessment forms were audited and evaluated for their quality and content.	Paper assessment forms (n = 2299) and electronic assessment forms (n = 6997) from three residential aged care homes.	All electronic resident records contained assessment forms; 9% of paper records did not contain any assessment forms. There was no significant difference in the completeness or timeliness of admission assessment forms. Ongoing paper assessment forms were found to be more complete, but less comprehensive.
Wang et al. (2015) Australia	To describe care plan documentation practice in residential aged care homes and to compare the quality and quantity of electronic and paper care plans.	Comparative audit study. Paper and electronic care plans were audited for quantity and quality.	Paper care plans (n = 111) and electronic care plans (n = 194) from seven residential aged care homes.	The electronic care plans were found to have a lower quality score than the paper care plans. Electronic care plans were found to document more information about signs and symptoms of residents' problems, but less information in relation to problem/diagnosis statements, contributing factors, resident outcomes and interventions.
Yu et al. (2008) Australia	To examine caregivers' experiences of using electronic documentation systems.	Comparative study. Semi-structured interviews and questionnaires administered to caregivers in one home using an electronic system, and one home using paper-based records.	Interviews (n = 12). Response rate of questionnaires: 82% (n = 14) at the electronic site; 43% (n = 10) at the paper-based site.	Participants using the electronic system were happy with the design, legibility, accessibility, and documentation speed, but unhappy about the time it took to log-in and -off and for synchronization. Participants using the paper records were unhappy with illegible handwriting and double data entry, and found it difficult to retrieve information.
Yu et al. (2013) Australia	To explore the unintended adverse consequences following the introduction of EHR in residential aged care homes, and to investigate the causes of these adverse consequences.	Exploratory study. Semi-structured interviews with staff at two data points after the introduction of the EHR system.	Interviews (n = 110) at nine residential aged care facilities.	Eight categories of adverse consequences were identified. These were linked to the nature of the EHR system, the way in which EHR had been implemented and used by staff, and the initial conditions.
Zhang et al. (2012) Australia	To explore the benefits of EHR in residential aged care homes and to investigate how these benefits have been achieved.	Exploratory study. Semi-structured interviews with staff at two data points after the introduction of the EHR system.	Interviews (n = 110) at nine residential aged care facilities.	Care staff identified three categories of benefits: for care staff, residents, and residential aged care facilities.

Results

Time for direct care

A number of studies reported that the introduction of an electronic documentation system allowed staff to spend less time on documentation, meaning that they had more time for direct care [5, 19, 31-33]. Staff find using a computer for documentation faster than filling out forms by hand. Furthermore, staff can quickly move from one resident's record to another, and multiple staff members are able to access records at the same time [32]. The processes of data distribution, storage and retrieval were also described as more efficient [5, 19, 31, 32, 34-36], and the presence of a spellcheck saves time on proofreading [37]. Moreover, increased legibility has meant that staff are no longer forced to call doctors to clarify information that was previously handwritten, often causing time delays [35].

Florczak et al. [33] found that portable, handheld devices increased efficiency, as they enabled staff to access and record data at the point of care. However, in a separate study, some staff felt that bedside technology was time-consuming and as a result, they were found to be documenting at the end of their shift, and some documenting before care had been provided [38]. In several other studies, it was also suggested that electronic documentation systems do not necessarily save staff time [19, 22, 36, 38], for reasons such as slow log-in processes [9, 14]; difficulties with updating passwords [35]; and having to access each resident's record individually to chart information as opposed to using one paper chart for all residents [37]. In one home, the reporting of incidents required staff to document information into the electronic record and into a separate software system, increasing overall time spent on incident reporting [35].

Accountability

Documented evidence of care is essential for managers to 'assess whether care […] was professional, safe and competent' [13]. In four studies, senior staff highlighted that they are more able to monitor the quality of care provision with an electronic documentation system [5, 19, 31, 34]. Electronic documentation also enables managers to identify 'patterns and trends in care needs and evaluate outcomes of care' [13], increasing their knowledge about the current health status of residents in their homes [5, 19]. However, in a study by Yu et al. [37], participants stated that they were not able to easily generate trends from data, and require an application that could automatically produce graphs and generate reports. As regards to external audits, staff found that they were able to record the minimum data set (MDS) more accurately with EHR [38]. Furthermore, electronic records make it easier to extract relevant information from documentation, allowing inspectors to carry out the audit process with 'greater consistency and regularity' [19].

One study described the use of iButtons, a device designed to increase accountability, which the staff found 'inconvenient and bothersome' [38]. iButtons should be worn by residents and staff, and allow for the 'verification of caregiver activities' at the point of care [38]. However, in the home in this study, residents were often found not to be wearing iButtons and staff had to search for them, causing delays in the documentation, and showing the incorrect time for care delivery. Furthermore, when residents were wearing the iButtons, staff felt that touching the buttons disturbed them. Participants from this study also expressed concern that the increased monitoring of care delivery was making them feel 'watched'. Although others believed that monitoring would lead to their work being 'recognised' [38].

Assessment and care planning

Across several studies, caregivers' perceptions of using electronic documentation for assessment and care planning were positive [5, 19, 33]. Staff believe that some electronic assessment templates are more thorough as they provide prompts to identify potential problems [19], whilst also guiding nurses 'through body systems' [19]. Participants in the study by Zhang et al. [5] noted that the interface for assessments popped up as soon as a staff member logged in, which enabled them to start with the task as quickly as possible. As regards to advance directives, an electronic intervention implemented into an EHR, designed to encourage documentation of patient wishes regarding life-sustaining care, increased the rate of advance directive discussion notes significantly [39]. This was linked with improved accessibility to this section of the care plan, as the link was 'uniformly placed' within notes, appearing at the top of the patient order list and labelled 'code status' [39].

Staff from one study also felt that electronic documentation facilitated the writing of care plans because they are more able to access assessment forms and other relevant information and 'think more critically' when developing a care plan [5]. In particular, staff appreciate being able to switch between documents and copy and paste information [5]. Using laptop computers that contain resident information during care planning meetings is also beneficial [32]. Furthermore, participants widely reported that electronic systems generate more accurate, complete, consistent and legible information than paper records [5, 13, 14, 19, 31, 33-36, 38], and highlighted that their quality does not deteriorate over time like paper records [5].

However, several studies indicated that electronic documentation systems may not necessarily facilitate care planning and assessment [13, 37, 38, 40-42]. For example, Wang et al. [42] carried out an audit study with results suggesting that electronic care plans provided less information about resident diagnosis and outcomes than paper-based records. However, this lack of information was linked with a possible issue with the wording of the data fields, which did not encourage nurses to 'formulate diagnosis statements' [42].

Other sources of frustration included having to enter unnecessary information, but not having space in data fields for free text [35, 37, 38]. Furthermore, staff found that necessary forms were missing from the system [37, 38]. In one study, frustrations with unsuitable electronic forms led staff to using shortcuts; in this case, documenting data in free text as opposed to using the forms. However, this meant that information was not standardised, and prevented the automatic population of data into reports for trending purposes [38]. Suggestions for improvements to systems included a function where staff could enter a keyword and jump to the right section in a resident's notes, and care plans that could be automatically generated from assessment data [5, 36, 37].

Exchange of information

There were mixed results as to whether electronic documentation facilitated an exchange of information. Issues with external communication were described in one home where staff were restricted from accessing the electronic hospital records of patients who were about to be discharged from the hospital to their nursing home. This meant that hospital staff would

fax or send printed hardcopies of electronic records, which were often incomplete, causing time to be lost in contacting the hospital to clarify information [35].

Munyisia et al. [13] also found that staff did not believe that the introduction of an electronic documentation system had improved communication within the home. This could be linked to slow log in processes, which in a separate study, led staff to avoid recording information electronically [9]. However, staff may also be reluctant to change their established means of communication. In two studies, participants reported that they preferred to communicate information about residents verbally within the home [5, 37]. Moreover, in one study where there had been a reduction in face to face communication, staff were concerned about losing 'a sense of belonging' [37].

Positive ways in which electronic documentation facilitates an exchange of information within the nursing home include the instant availability of records [5, 36], which is particularly helpful for staff who have been on leave and need to catch up on notes quickly [5]. Furthermore, it allows for immediate access to initial resident assessments so that 'correct care' can start straight away [5]. Electronic documentation systems may also facilitate an exchange of information outside of the home. In one study, it was described how a camera built into the electronic device allowed staff to take photos of wounds [33]. These photos could be uploaded to residents' records and accessed by external healthcare providers who could then make a remote diagnosis or clinical decision. Staff also found that they could communicate better with physicians [38], and provide more detailed information to families due to the immediate accessibility of records through an electronic system [19, 32].

Risk awareness
The comprehensive and standardised nature of electronic records are reported to increase the 'visibility' of changes in health [35, 38], allowing senior staff to 'more quickly identify resident care needs' [31]. Particularly valuable are applications that can trend clinical problems and produce alerts about new resident events, which direct staff to provide appropriate care [19]. For example, in one study, improvements were seen in both the decline of range of motion and in high-risk pressure sores following the implementation of a bedside EMR, which prompted required care [43].

An electronic wound documentation system as investigated by Florczak et al. [33] was also found to more effectively manage treatment of wounds, promote healing, and enable staff to better recognise changes in wounds. However, nurses did not feel that the system had significant influence on preventing avoidable wounds from initially occurring, although the authors note that this may be linked to staff not fully implementing the 'risk functionality' element [33]. Likewise, in another study, alerts were not always utilised, and furthermore, the importance of updating alerts with 'best practice information' was highlighted [38].

Two studies specifically described the effect of a computer decision support system (CDSS) embedded in an electronic system. Fossum et al. [44] found that documentation completed by staff in the intervention group using a CDSS was significantly more complete and comprehensive in recording 'the risk and prevalence of [pressure ulcers] and malnutrition'. However, it should be noted that this group were exposed to two simultaneous interventions. In a separate study, Alexander [15] found that alerts produced by a CDSS to warn staff about

'potential skin breakdown' did not lead to a significant increase in the recording of clinical responses in most types of documentation, except for turning and repositioning charts for residents.

Data from electronic records may also increase the prediction of fall risk in comparison to data from the MDS alone, linked with the 'increased frequency with which EMR data are updated' in comparison to MDS data [45]. Another possible benefit of an electronic documentation system is the ability to manage behaviour more effectively [5]. In one study, staff described how due to the improved accessibility of information, they were more able to 'analyse common occurrences of certain undesirable behaviours', and understand why they may have occurred [5]. This allowed staff to avoid potential triggers when interacting with residents, reducing incidents of undesirable behaviour [5].

Person-centred care

In the study by Zhang et al., staff reported that electronic documentation facilitated person-centred care, as they were more able to access information about an individual's past, as well as their current needs, which gives a 'broader and more holistic view' of an individual [5]. The electronic records system also allowed for the storage of photos of residents, which new staff found to be a helpful tool for learning residents' names, and access to additional information provided new staff with a topic of conversation for when they met with residents for the first time [5].

Meehan [35] reported that staff in one home found it difficult to share discharge plans and care instructions with those patients and their families who were only in the home for rehabilitation purposes. They suggested that the introduction of a portable device would act as a tool to take into resident's rooms and visually show the patient their care plan, as well as web tutorials relating to relevant aspects of care provision [35]. Participants from the same study also believed that mobile devices would allow them to have improved access to vital information about a resident's needs, for example allergies, which is particularly important for those individuals who are only staying in the home for a short time, or for staff who work infrequently in the home.

Discussion

This integrative review has explored the ways in which EPR is facilitating or hindering care provision in nursing homes. The results of this review suggest that EPR may have the potential to assist staff in the provision of care in nursing homes. However, results have also highlighted that in order for this to occur, there are certain requirements that should be considered as regards to the type of device and applications used for electronic documentation, as well as the functionality, structure and content of EPR. These are summarised in Table 3 and subsequently described.

Table 3. EPR facilitators for care provisions

Device	Applications	Structure and content	Functionality
Portable device or device that is accessible at the point of care Camera embedded into portable device Devices should not disrupt residents or invade their privacy	Spellcheck Copy and paste function Keyword search button Rapid, secure log-in	Use of standardized nursing language Include the necessary forms Space for free text Structured templates that guide staff through body systems Accessible links to important documents Space to collect detailed resident history Space to upload photos	Interoperable Alert staff to create or update a new document Alert staff to changes in resident's conditions and prompt correct care (CDSS) Automated generation of care plans from assessment data Automated generation of graphs to show trends in data

Device and applications

A number of studies in this review highlighted the importance of technology that can be accessed at the point-of-care [22, 33, 36, 37]. This echoes results from a study by Chau and Turner [46] who explored nursing home staff's experiences with using mobile, handheld technology. They found that the quantity and quality of documentation improved with the use of a mobile device, and that documenting information at the point-of-care was less time-consuming. Furthermore, in this review, portable devices were described as particularly useful for providing person-centred care [5, 35]. However, as found by Rantz et al. [38], introducing devices for bedside documentation has the potential to create burdensome expectations for staff and as a result, they may be reluctant to record documentation. Another device considered burdensome by staff was iButtons [38]. Although this device promoted accountability, developers should also take into account that devices do not disturb or invade residents' privacy, nor make staff feel watched.

Florczak et al. [33] highlighted the benefits of portable devices with cameras that enable staff to take photos of wounds, which can easily be shared with relevant external healthcare providers, who can then suggest appropriate care. As regards to applications for EPR systems, a spell check, a copy and paste function, as well as a function to enter a keyword to search for specified information within records were all identified as saving staff time [5, 36, 37]. Secure login processes should also allow for quick access to records so that staff are not prevented from accessing information prior to care delivery [9].

Functionality

Munyisia et al. [22] argue that electronic documentation systems should act as more than 'a repository of information' and prompt staff about changes in residents' condition. A CDSS embedded into a system may be useful in alerting staff to potential risk factors and enable them to provide the correct care accordingly. However, the two studies used in this review that explored CDSS did not conclusively support such an application for increased documentation of clinical responses [15], or improved documentation of ulcer and malnutrition-related assessments and interventions [44]. Furthermore, it is important that alerts are consistently updated in line with good clinical practice in order to support evidence based practice in nursing homes [44], and that the CDSS is user-friendly [47]. Participants also

thought that alerts which prompt staff to create or update a document would be useful, and highlighted the need for the EPR to generate care plans from assessment data, as well to create graphs from data to produce trending reports [37].

Another common requirement identified across the studies was the need to be able to share and access information externally [33, 35, 38]. The transferability of information is particularly important in the long-term care sector as patients are frequently transferred from hospitals to nursing homes and effective transitions of care are required [48]. The lack of ability to share information across care providers has been described as 'the largest limitation factor' of electronic records [49]. Widely introduced in Canada, interoperable EHRs (iEHRs) are 'a secure consolidated record of an individual's health history and care, designed to facilitate authorised information across the care continuum' [50]. Ensuring interoperability of future EPR systems is particularly important as information gaps in long-term care have been shown to have consequences for patients, clinicians and the healthcare system [48].

Structure and content

One of the principal reasons for the introduction of electronic records was to improve the quality of documentation, specifically assessments and care plans [13, 42]. However, Wang et al. [42] found that staff were documenting less information relating to the nursing problem and resident outcomes. This was linked to possible flaws in the language used to prompt staff to record information. Furthermore, a lack of appropriate forms meant that staff in one study were found to be adding notes in free text, preventing the automatic population of data into reports [38]. Therefore, as well as including the appropriate forms for the environment, developers should ensure systems allow for a structured form of data entry with 'formalised nursing language' [42], which will also mean that decision making tools can be successfully integrated into EPRs [26].

Nurses also identified the importance of structured templates for assessment purposes [19], and links to important documents that should be accessible and 'uniformly placed' [39]. In addition, the EPR should allow for the detailed collection of information about a resident's background. Such information was highlighted as being particularly important for new staff whilst they are becoming acquainted with residents [5], but may also act as a useful source of information for staff who work infrequently in the home. Furthermore, person-centred care is an integral part of dementia care [51], and access to a detailed history may improve staff's understanding of a resident's behaviour and how to respond appropriately [5].

Limitations

Limitations of this study include the nature of integrative reviews, which are complex due to the way in which they combine studies with diverse methodologies, potentially leading to bias [23]. This study has used the PRISMA guidelines [29] in order to increase transparency and reduce bias. However, the synthesis of qualitative and quantitative research is a developing area and currently lacks explicit guidance [52]. Restrictions to articles in either English or French may have meant some studies were not included, and as google scholar was not used in the search, additional grey literature may have been missed, which could have provided a wider insight into the topic. Finally, a number of issues relating to implementation of EPR were raised in many of the articles used in this research. However, this review has not focussed on these issues as they have been described in detail in numerous other studies [21, 53, 54].

Conclusion

One of the principal reasons for the introduction of EPR into nursing homes was to assist staff to provide care [6, 7, 41]. However, findings of this review have shown that several aspects relating to the EPR system are hindering care provision in nursing homes, and that consideration should be given to numerous factors linked to the device, applications, structure, content, and functionality. Within the literature used for this review, there were some references to the technology that staff are currently using to document information electronically, as well as suggestions for modifications to existing technology that would increase usability. However, more research is required to identify the optimal characteristics of an EPR system for use in a nursing home environment, and in particular, research which focuses on the end user's experience of EPR.

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Methods

Abstract

Nursing homes are more frequently turning to the electronic patient record (EPR) to manage documentation. Potential benefits associated with EPR include the storage of longitudinal information, interoperability, and improved documentation quality. However, the uptake of EPR in nursing homes has varied considerably across countries, which has been associated with the incompatibility of some EPR systems with this environment. Furthermore, the suitability of EPR for planning dementia care is largely unknown. This study aims to produce recommendations for the future development of EPR systems for use in the assessment and care planning for people with dementia in nursing homes. Case studies of four nursing homes using EPR in Belgium, Czech Republic, Spain and the UK will be conducted. There are two elements to the study: (i) the contextual inquiry method will be employed to explore usability issues with different types of end users. Data will be analysed using qualitative content analysis; (ii) the electronic care plan used in each of the homes will be compared with best practice guide-lines for dementia care planning in order to explore the extent to which they include aspects of care that are relevant for people with dementia. Primary data col-lection will be ongoing throughout 2018, and results will form the basis of recommendations for future EPR development. It is expected that results will lead to improved design of EPR for use in nursing homes, specifically in the assessment and care planning for people with dementia.

Keywords: dementia care, electronic patient record, nursing home.

Background

It is estimated that there are currently 47 million people living with dementia world-wide [1]. Despite a growing awareness of the 'physical environment as a component of care'[2], the progressive nature of dementia, worsening of co-morbidities, and carer-breakdown [3] have meant that people with dementia are still likely to spend time in a nursing home as they pass through the continuum of care [4].

Alzheimer's Disease International describe four main 'apparatus' of long-term care, the first of which being the, 'assessment and evaluation of social and health care status, resulting in explicit care plans' [5]. However, although documentation plays an important role in the care of people with dementia in nursing homes [6], increased regulatory pressures [7] have meant completing documentation has become one of the most time-consuming activities for staff [8]. As a result, nursing homes are more frequently turning to electronic solutions, such as the electronic patient record (EPR), to manage the process of documentation.

Despite the envisaged benefits of EPR as a health information technology (HIT), several systematic reviews exploring the impact of electronic documentation systems have found numerous incompatibilities with the nursing home environment [9, 10, 11]. These incompatibilities have been linked with a lack of research investigating the usability of electronic documentation systems from the end-user's perspective [12], with clinicians reporting a lack of involvement in the design of systems [13]. An understanding of the ways in which EPR systems facilitate or create barriers for end users to carry out their work in nursing homes is thus crucial in order for developers to modify and improve EPR technology for this specific environment [14].

This paper describes the protocol for a study exploring usability issues associated with EPR systems for use in the assessment and care planning for people with dementia in nursing homes. The study is part of a broader European project entitled 'Interdisciplinary Network for Dementia using Current Technology' (INDUCT). We begin by introducing the research objective and research questions, and subsequently suggest a methodology for addressing these questions.

Research Objectives

The overarching aim of this study is to produce recommendations for the future de-velopment of electronic documentation systems for use in the assessment and care planning of people with dementia living in nursing homes.

The following research questions will be addressed as part of this study:

(1) Which type of device and software are used by nursing homes for assessment and care planning in Belgium, Czech Republic, Spain and the United Kingdom? Which types of information do the systems capture?

(2) What are the usability issues associated with the electronic patient record system for assessment and care planning for people with dementia in nursing homes? What are the potential modifications?

(3) What are the contextual conditions of the nursing home in which the electronic patient record system has been introduced? What is the impact of these contextual conditions on usability?

(4) What are the best practice guidelines for care planning for people with dementia that should be captured by the care plan? To what extent are the electronic patient records used by nursing homes capturing this information?

Study Design and Methods of Data Collection and Analysis

Study design
This study uses an exploratory, qualitative research design with a case study approach in order to examine usability issues associated with EPR from the staff perspective, as well as the contextual conditions of the nursing home in which the EPR has been implemented.

Data collection
For the purposes of this study, the contextual inquiry (CI) method will be employed. CI is based on the premise that understanding exactly who users are and how they work is implicit in effective design [15]. Therefore, the CI method frequently involves combining interviews and observations of users within their natural environments [16].

An initial interview will be carried out in order for the researcher to grasp an un-derstanding of contextual factors, such as number of hours of training with the EPR system, and availability of technology. This will be followed by an observational interview with a defined task, and a follow-up interview to allow the participant to expand on any issues discussed during the task. During observations, each participant will be observed recording assessment and care planning documentation for one resident with dementia and asked to use the 'think aloud' method to describe components of the EPR system that are facilitating or hindering the task.

A list of problem statements developed prior to data collection will be referred to during the observations and follow-up interviews [17]. These problem statements have been developed from evidence collated from an earlier literature review carried out by the lead researcher exploring the ways in which EPR systems are facilitating or hindering assessment and care planning in nursing homes, and from a scoping review of the literature on best practice for care planning for dementia. An example of a problem statement is: 'do forms use standardised nursing terminology?'. Each problem statement also corresponds to a 'structural quality component' (organizational support, hardware, software, functionality) as listed in the Health Information Technology Research-based Evaluation Framework (HITREF) [18].

Sampling and inclusion criteria
According to research carried out by Nielsen and Landauer [19], the testing of 8-10 participants will identify at least 80% of usability issues. However, they recommend that with distinct groups of users, 3-4 participants from each group is sufficient. There are three foreseen groups of participants within the nursing home (managers, nurses and care assistants). Therefore, observations and interviews will be carried out with a minimum of 9-

12 staff members from the nursing home. Transcripts will also be analysed for data saturation (i.e. until new codes are no longer emerging), and if not reached, the sample size will be increased and additional interviews will be conducted.

Individuals will be selected if they: (i) are a permanent member of staff who man-ages or provides care to residents; (ii) are involved in completing assessment and care planning documentation; (iii) have worked in the nursing home for at least 6 months; (iv) have been trained in how to use the electronic documentation system, and; (v) have been using the electronic documentation system for at least 6 months.

Data analysis

Recorded interviews will be transcribed and translated by an external transcriber and translator. Transcripts will be de-identified and coded by the lead researcher using NVivo. Contextual data (e.g. length of time working with the system) will be grouped into categories and displayed quantitatively.

Qualitative content analysis will be employed to analyse qualitative data. More specifically, empirical post hoc coding will be used. This refers to the creation of codes that are not predefined, and rather 'emerge through the exploration of data' [20]. Commonalities across the data will be explored, and codes will then be grouped into overarching, a priori themes, which correspond to the structural quality components specified by the HITREF [18].

Ethical Issues

Assessment and management of risk

Any risks of harm involved in participation for this group are low. However, before data collection begins, participants will be informed that they can withdraw from the study at any time. There are ethical considerations in relation to ensuring anonymity of participants who could potentially be identified due to the small sample size. This may mean some participants may be reluctant to discuss any negative aspects during the interviews. In order to reduce this risk, demographic data will not be collected, except for in relation to: (i) role (ii) length of time using the electronic documentation system.

Furthermore, there are ethical considerations in relation to patient confidentiality of documentation. As a result, no data will be collected that could lead to the identifi-cation of residents. Ethical approval will be obtained in all four countries before data collection commences. At the time of writing, ethical approval has already been re-ceived in the Czech Republic and Belgium.

Data confidentiality will be maintained through the following measures: (i) all par-ticipant data will be de-identified and participants will be assigned pseudonyms; (ii) no identifying information (such as role) will be assigned to any quotes in the write-up; (iii) the number of individuals accessing data (for reasons of transcription, translation, and analysis) will be limited; (iv) interview recordings will be destroyed following transcription; (v) field notes from observations will be immediately written up and stored electronically in NVivo, with password

protection. Original notes will be destroyed; (vi) transcripts will be uploaded to NVivo for data analysis, which will be password protected.

Consent
After initially expressing interest in participating, the staff member will be provided with an information sheet describing the purpose of the study and their involvement. They will then have the opportunity to ask questions about the study, as well as be provided with a written consent form and asked to confirm that they have: (i) read the information sheet; (ii) received sufficient information about the project and the implications of participating; (iii) had the opportunity to ask further questions about the research; (iv) understood that they are able to withdraw from the study at any time, without giving a reason; (v) agreed to their anonymised data being used in the write-up.

Impact of Results
Data collection will be ongoing throughout 2018. It is anticipated that the results of the study will lead to a reduction in usability issues associated with EPR for assessment and care planning for dementia, and subsequently, increased adoption and more successful implementation of EPR, as well as improved care for people with dementia in nursing homes. Results will also form part of the broader European project 'Interdisciplinary Network for Dementia using Current Technology' (INDUCT), which aims to produce guidelines on human interaction with technology and dementia.

Compliance with Ethical Standards
Funding

Conflicts of interest
The authors declare that they have no conflict of interest.

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Results (1)

Abstract

Objectives: With rates of dementia continuing to rise, the impetus on improving care for people with dementia is growing. Unmet needs of people with dementia living in nursing homes have been linked with worsening neuropsychiatric symptoms, higher levels of depression, and reduced quality of life. Furthermore, proxy accounts exploring the needs of people with dementia have frequently been shown to be unreliable. Therefore, this literature review aims to explore the self-reported needs and experiences of people with dementia in nursing homes.

Method: A scoping review of the literature was carried out using the databases PubMed and PsycINFO to search for relevant articles according to PRISMA guidelines. Search terms were designed to include both quantitative and qualitative study designs. Thematic synthesis was used to categorise findings into themes related to self-reported needs and experiences.

Results: A total of 41 articles met the eligibility criteria. An analysis of study characteristics revealed more than half of studies used a qualitative design. Thematic synthesis resulted in eight themes: activities, maintaining previous roles, reminiscence, freedom and choice, appropriate environment, meaningful relationships, support with grief and loss, end-of-life care.

Conclusion: Whilst the voice of people with dementia has previously been neglected in research, this review has shown that people with dementia in nursing homes are able to describe their experiences and communicate their needs. The findings in this review have provided a contribution towards guiding evidence-based practice that is tailored to the needs of nursing home residents with dementia.

Keywords: Dementia; experiences; long-term care; nursing home; subjective needs

Introduction

Historically, people with dementia, and specifically those living in nursing homes, have been excluded from participation in research (Davies et al., 2014). Exclusion from research can be linked with the dominance of the biomedical model and an emphasis on developing pharmacological treatments for dementia. Consequently, researchers have frequently pursued a positivist-based paradigm of research, with participants playing a passive role in clinical trials (Bond & Corner, 2001). Furthermore, involving people with dementia in qualitative research has commonly been disregarded because of the association of dementia with 'dwindling personhood' (Moore & Hollett, 2003), and the view that associated communication and memory problems may affect an individual's ability to share their experiences (Nygård, 2006).

In recent years, research into the needs and experiences of people with dementia living in nursing homes has been recognised as an increasingly valuable field (Milne, 2011). In the United Kingdom, approximately 70% of people living in nursing homes have dementia, which is often in the moderate to severe stages (Prince et al., 2014). Unmet needs of people with dementia living in nursing homes have been linked with worsening neuropsychiatric symptoms of dementia (Cohen-Mansfield et al., 2015), higher levels of depression (Hancock et al., 2006), and reduced quality of life (Hoe et al., 2006). However, research in this field has frequently relied on reports from family members and staff, despite evidence to suggest that proxy accounts are not always reliable (Crespo et al., 2012; Orrell et al., 2008). Therefore, eliciting the voice of people with dementia in research aimed at exploring their needs is essential for the production of evidence-based guidelines for care delivery in nursing homes, paving the way for improved quality of life amongst people with dementia (Sabat, 2003).

Although literature reviews exploring the self-reported needs of people with dementia have been carried out, these have focused on those living in the community (Van der Roest et al., 2007; Von Kutzleben et al., 2012). One review by Cadieux et al. (2013) looked at the needs of people with dementia in long-term care, using both proxy and subjective accounts. Their search included quantitative and qualitative studies published between 2000 and 2010. However, their search string did not include specific terms to identify subjective accounts, and consequently, some articles exploring subjective needs and experiences may have been overlooked. The aim of this scoping review therefore, is to explore the self-reported needs and experiences of people with dementia in nursing homes.

Method

Scoping review methodology

Due to the broad nature of the research question and the lack of current research in this area, the scoping review was selected as the appropriate methodology for this study (Peters et al., 2015). A scoping review has been described as a form of 'knowledge synthesis' and involves examining the nature and extent of research activity, which is important for determining gaps in the literature and directing future research (Colquhoun et al., 2014). For the purposes of this review, the six-stage framework as described by Arksey and O'Malley (2005) and adapted by Levac et al. (2010) has been used to guide the process.

Search strategy

Search strings were discussed amongst the authors (K.S & L.P) and with a librarian. They were then organised according to the PICOS model for constructing search strings for mixed-methods reviews (Methley et al., 2014). The databases PubMed and PsycINFO were used in the search, which took place during February and March 2018. The search was initially narrowed to include articles published between January 2000 and February 2018 in English, French or Czech, which resulted in a total of 1158 articles. Table 1 shows the exact search string used for each database and the number of articles found.

Table 1. Exact search strings used for each database and number of articles found

Database	Search terms	Records identified
PubMed	("Nursing Homes"[Mesh] OR "Residential Facilities"[Mesh] OR "Long-Term Care"[Mesh] OR "Nursing Home*"[Title/Abstract] OR "Residential Facilities"[Title/Abstract] OR "Long-Term Care"[Title/Abstract]) AND ("Dementia"[Mesh] OR "Dementia"[Title/Abstract] OR "People with Dementia"[Title/Abstract]) AND ("Self Report"[Mesh] OR "Self Report*"[All Fields] OR "Subjective"[All Fields] OR "Surveys and Questionnaires"[Mesh] OR "Survey*" OR "Questionnaire*"[All Fields] OR "Trial" [All Fields] OR "Interviews"[All Fields] OR "Phenomenological"[All Fields] OR "Qualitative Research"[Mesh]) AND ("Experience*"[All Fields] OR "Health Services Needs and Demand"[Mesh] OR "Quality of Life"[Mesh] OR "Quality of Life"[All Fields] OR "Care Needs"[All Fields] OR "Wellbeing"[All Fields])	750
PsycINFO	(MJMAINSUBJECT.EXACT("Nursing Homes") OR MJMAINSUBJECT.EXACT("Residential Care Institutions") OR MJMAINSUBJECT.EXACT("Long Term Care") OR ab("Nursing Home*") OR ab("Residential Facility") OR ab("Long Term Care")) AND (MAINSUBJECT.EXACT.EXPLODE("Dementia") OR ab("Dementia") OR ab("People with Dementia")) AND (MAINSUBJECT.EXACT.EXPLODE("Self-Report") OR "Self Report*" OR "Subjective" OR MJMAINSUBJECT.EXACT("Surveys") OR MAINSUBJECT.EXACT("Questionnaires") OR "Survey*" OR "Questionnaire*" OR MJMAINSUBJECT.EXACT("Interviews") OR "Interview*" OR "Trial" OR "Phenomenological" OR MAINSUBJECT.EXACT.EXPLODE("Qualitative Research")) AND (MJMAINSUBJECT.EXACT("Experiences (Events)") OR MJMAINSUBJECT.EXACT("Health Service Needs") OR "Care Need*" OR MAINSUBJECT.EXACT.EXPLODE("Quality of Life") OR "Quality of Life" OR MAINSUBJECT.EXACT.EXPLODE("Well Being") OR "Well Being")	408
Total number of records		1158

Inclusion and exclusion criteria

The inclusion and exclusion criteria were initially decided upon by the authors (K.S & L.P) and reviewed during the search process by all authors. Articles of both quantitative and qualitative study designs exploring the self-reported needs and/or experiences of people with a diagnosis of any type of dementia living in a long-term care facility, such as a nursing home or residential home, were included. Those only involving participants with dementia living at home or in hospital were rejected, as well as studies involving only participants with mild cognitive impairment (MCI) or probable dementia. Studies where participants already had a confirmed diagnosis of dementia were included, as well as those where researchers assessed cognitive impairment using an appropriate test. Those studies using only proxy accounts or observational methods were not included, as these did not seek to obtain views of people with dementia themselves. Finally, conference reports, editorials, books, protocols and dissertations were rejected. The screening process was carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Liberati et al., 2009), as shown in figure 1.

Figure 1. Search flowchart in accordance with PRISMA guidelines
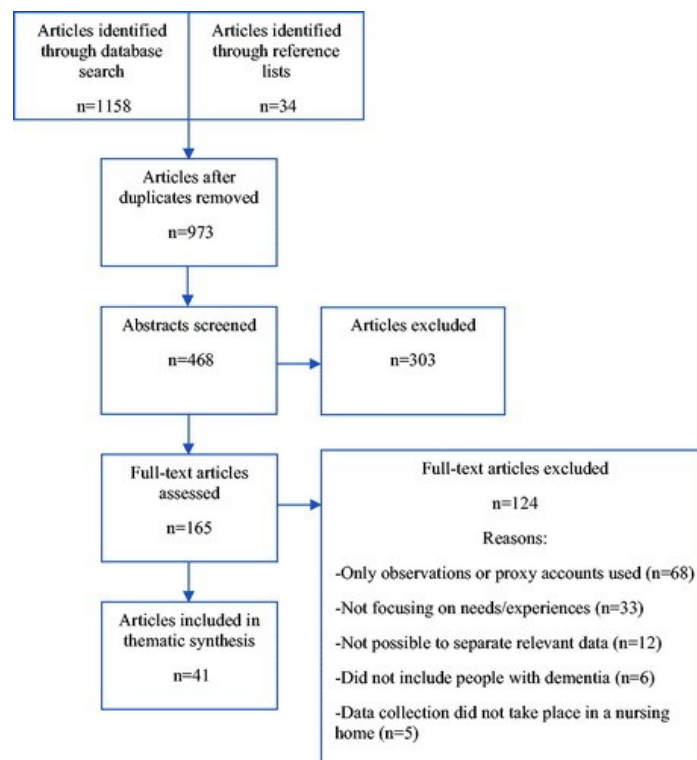
Critical appraisal

Critical appraisal in mixed methods reviews is currently a developing area. The Mixed Methods Appraisal Tool (MMAT) (Pace et al., 2012) was used as a general guide to assess the quality of articles of all study designs and to exclude any articles with fatal flaws. No studies were considered to warrant exclusion on this basis alone.

Data analysis

A convergent qualitative synthesis was carried out, enabling the transformation of both quantitative and qualitative data into qualitative findings (Pluye & Hong, 2014). In order to transform data, thematic synthesis as described by Thomas and Harden (2008) was used. This involved firstly coding data inductively, according to both the category of needs and the category of experiences. For instance, a number of participants made reference to being bored and to repetitive days, and these topics formed initial codes under the category of experiences. In the second step, similar codes were merged into sub-themes wherever possible. In this case, codes were categorised into the sub-theme 'boredom and monotony'. The same process was undertaken according to the category of needs.

The final stage of thematic synthesis requires the development of 'analytical themes', which address the research question directly. In this example, two authors (K.S & L.P) discussed, developed and sorted sub-themes to form the overarching analytical theme 'activities'. Wherever possible, direct quotes from participants were used for data analysis, rather than the authors' interpretation of what participants had said (Van Leeuwen et al., 2019).

Results

Study characteristics

A total of 41 studies were included in the final synthesis. The most commonly stated aims were to explore participants': experiences (n=14); quality of life (n=10); perspectives (n=5); perceptions (n=4); preferences (n=3); needs (n=3); views (n=3); self-report (n=2); wellbeing (n=1); priorities (n=1); requirements (n=1); and feelings (n=1). 28 studies used a qualitative design, eight studies used a quantitative design, and five studies used mixed methods. Of the qualitative studies, the majority used interviews (n=27), including semi-structured and unstructured or conversational interviews, and one study used focus groups. Of the quantitative studies, five were randomised controlled trials. A number of studies used various methods to collect additional data, including: proxy interviews or focus groups with family or staff (n=15); observations (n=12); proxy scale ratings or questionnaires completed by family or staff (n=5); and data from medical notes (n=7). A small number of studies (n=4) used stimulus materials, such as photos, symbols or Talking Mats to aid participants' communication during interviews. Finally, details about participants' type of dementia were only described in a small number of studies (n=10), whilst severity of dementia was more commonly described (n= 33), with approximately half of studies specifying that they included people with severe dementia (n=20). In Table 2, we provide a summary of the individual studies.

Table 2. Summary of articles used in thematic synthesis

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Aggarwal et al. (2003) UK	To explore how people with dementia and their relatives experience dementia and to find out how they perceive and receive care provision.	Qualitative	Residential care settings (number unknown).	Exploratory study with semi-structured interviews using stimulus materials such as photos and expression cards.	17 residents at various stages of Alzheimer's disease.	-Activities -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss
Bartlett (2007) UK	To explore how men with dementia experience, and deal with, nursing home life.	Qualitative	Specialist dementia care wing of a nursing home.	Phenomenological case study with an unstructured interview.	'Mr Brown'-a resident with Alzheimer's Disease.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships
Bauer et al. (2013) Australia	To explore residents' perceptions of the needs and barriers to the expression of sexuality in long-term care.	Qualitative	Six long-term care facilities, including high, low and mixed care facilities.	Naturalistic inquiry with semi-structured interviews.	Five residents with a diagnosis of dementia in its early stages.	-Meaningful relationships
Cahill and Diaz-Ponce (2011) Ireland	To ascertain if similarities or differences exist in perceptions of quality of life amongst nursing home residents with different levels of cognitive impairment.	Qualitative	Three nursing homes.	Exploratory/descriptive study using in-depth, semi-structured interviews.	61 residents with a mean MMSE score of 12.6.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Casey et al. (2016) Australia	To describe nursing home residents' perceptions of their friendship networks using social network analysis, and to contribute to theory regarding resident friendship schema, network structure, and connections between network ties and social support.	Mixed methods	Dementia Specific Unit in one nursing home.	Social network analysis (SNA) methods: (i) resident self-report structured interviews with open questions where researchers also showed participants photos of co-residents to identify friends; (ii) self-reports on nonfamily objective social support using the Lubben Social Network Scale-6 (LSNS-6) Friendships Sub-scale; (iii) subjective reports of social isolation measured with The Friendship Scale.	30 residents with mild to severe dementia, according to the Global Deterioration Scale (GDS).	-Meaningful relationships
Chung et al. (2016) USA	To explore dementia patients' experiences of a media presentation including images of nature.	Mixed methods	One long-term nursing facility.	Exploratory study with semi-structured interviews exploring participants' views on a DVD set of nature scenes.	23 participants with a diagnosis of mild-severe dementia based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).	-Activities -Reminiscence
Clare et al. (2008) UK	To explore the subjective experience of life with dementia in residential care from the perspective of the person with dementia, and to understand the psychological impact of being in this situation.	Qualitative	Ten care homes, specialised for people with dementia or mixed needs.	Exploratory study with interpretative phenomenological analysis of 283 unstructured conversations between researchers and people with dementia.	Data from 71 residents with a mean MMSE of 10.54 was included in analysis.	-Activities -Reminiscence -Maintaining previous roles -Freedom and choice -Meaningful relationships -Support with grief and loss
Cohen-Mansfield et al. (2000) Israel	To explore the role-identity of residents with dementia, and the potential for utilising their enduring sense of self-identity for enhancing their quality of life.	Quantitative	Two nursing homes.	Exploratory study using close-ended questionnaires.	26 residents with various types of dementia at the mild-severe stage.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Conradsson et al. (2010) Sweden	To evaluate the effects of a high-intensity functional exercise programme on depressive symptoms and psychological wellbeing among older people dependent in activities of daily living and living in residential care facilities.	Quantitative	Nine residential care facilities, four of which had units for people with dementia.	Cluster-randomised controlled trial where participants either received the intervention in the form of a high-intensity functional weight-bearing exercise programme (n = 47), or a programme of activities performed whilst sitting in the control group (n = 53). Outcome measures: depressive symptoms, measured by the Geriatric Depression Scale 15-item version (GDS-15), and psychological wellbeing, measured by the Philadelphia Geriatric Center Morale Scale (PGCMS).	100 residents with mild-moderate dementia according to the MMSE.	-Activities
Cooke et al. (2010) Australia	To investigate the effect of live music on quality of life and depression amongst older people with dementia.	Quantitative	Two aged care facilities providing high and low care.	Randomised controlled cross-over trial. Participants received the live music intervention (n = 23; at cross-over n = 16) or attended a reading group if in the control group (n = 21; at cross-over n = 15). Outcome measures: self-reported quality of life, measured by the Dementia Quality of Life (DQOL) questionnaire, and depression, measured with the Geriatric Depression Scale (GDS).	47 residents with a diagnosis of early-mid stage dementia or probable dementia according to the MMSE or DSM-IV, and a documented history of agitation or aggression within the last month. Mean MMSE score was 16.51.	-Activities

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Cooney et al. (2014) Ireland	To understand people with dementia, staff and relatives' perspectives on reminiscence, its impact on their lives and experience of care and care giving.	Qualitative	Four long-term care settings.	Grounded theory study using unstructured conversations with residents.	Eleven residents with a mean MMSE score of 14.9.	-Reminiscence -Meaningful relationships
De Boer et al. (2017) Netherlands	To compare quality of care, quality of life and related outcomes in green care farms, regular small-scale living facilities and traditional nursing homes for people with dementia.	Quantitative	Three types of nursing homes: green care farms (n = 5); regular small-scale living facilities (n = 9); traditional nursing homes (n = 4).	Cross-sectional design with data collected on self-reported quality of life using the Quality of Life-Alzheimer's Disease Scale (QoL-AD).	115 residents with a formal diagnosis of dementia and a mean S-MMSE score of 8.4.	-Appropriate environment
Doyle et al. (2015) USA	To explore the notion of generativity among elders with dementia living in long-term care settings	Qualitative	One long-term care dementia residence.	Ethnographic study using formal interviews with residents.	Three residents: -Daniel- diagnosis of Lewy Bodies dementia, MMSE 11. -Samantha- diagnosis of moderate, non-specific dementia, MMSE 9. -Donna- diagnosis of severe early onset dementia, MMSE 18.	-Maintaining previous roles -Meaningful relationships
Dröes et al. (2006) Netherlands	To explore to what degree does what people with dementia in nursing homes and meeting centres consider important to their quality of life correspond with how their carers feel about what is important for the quality of life of the people with dementia they take care of.	Qualitative	Four wards in three nursing homes.	Exploratory study with interviews with residents.	37 residents with mild to moderately severe dementia, according to the GDS.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
George and Houser (2014) USA	To explore the subjective experience of residents and staff of a skilled-nursing dementia special care unit who participated in TimeSlips.	Qualitative	One skilled-nursing dementia special care unit in a continuing care retirement community.	Exploratory study with semi-structured interviews with residents during the final week of the TimeSlips intervention.	Ten residents with a diagnosis of dementia at the moderate-severe stage and a mean MMSE score of 6.1.	-Activities
Godwin and Poland (2015) UK	To examine the self-experience of people with moderate to advanced dementia.	Qualitative	Three long-term residential or nursing care homes.	Interpretative phenomenological analysis approach using semi-structured empathetic interviews.	Ten residents with varying diagnoses of dementia, all at moderate to early stages of advanced dementia.	-Activities -Maintaining previous roles -Support with grief & loss
Goodman et al. (2013) UK	To explore how older people with dementia discuss their priorities and preferences for end-of-life care.	Qualitative	Six care homes.	Exploratory study using semi-structured, conversational interviews.	18 residents with dementia, as recorded in their care notes.	-Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss -End-of-life care
Graneheim and Jansson (2006) Sweden	To illuminate the meaning of living with dementia and disturbing behaviour, as narrated by three persons admitted to a residential home.	Qualitative	Residential home for people with dementia and complications that mainly take the form of disturbing behaviour.	Interpretative hermeneutic and phenomenological analysis approach with conversational interviews with each resident.	Three residents: -John-diagnosis of vascular dementia, MMSE 20. -Annie-diagnosis of Alzheimer's disease, MMSE 16. -Philip-diagnosis of Alzheimer's disease, MMSE 20. All three also experienced disturbing behaviour.	-Activities -Maintaining previous roles -Freedom and choice -Meaningful relationships -Support with grief and loss

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Guzmán-García et al. (2013) UK	To investigate the effect of introducing a dance-based psychomotor intervention using Danzón (Latin ballroom) for people with dementia in care homes.	Qualitative	Two care homes.	Pilot study using grounded theory methodology. Interviews were carried out twice with residents after six weeks of attending the Danzón Intervention	Seven residents diagnosed with varying types of mild-severe dementia, with a mean MMSE score of 11.71	-Activities
Harmer and Orrell (2008) UK	To explore concepts of meaningful activity, as defined by older people with dementia living in care homes, staff and family carers.	Qualitative	Two homes providing traditional residential care and one home providing dementia residential care.	Exploratory study with three focus groups with participants with dementia using pictures of different activities to facilitate discussion.	17 individuals with a mild-severe diagnosis of dementia as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM), and with a mean MMSE score of 12.	-Activities -Maintaining previous roles -Reminiscence -Meaningful relationships
Haslam et al. (2010) UK	To investigate the impact of group reminiscence (GR) and individual reminiscence (IR) activities on older adults living in care settings.	Quantitative	Specialised units for people with dementia in 9 residential care homes.	Randomised controlled trial where participants were assigned to one of three interventions: group reminiscence, individual reminiscence, or a group control activity (skittles). Outcome measures: Hospital Anxiety and Depression scale (HADS), Quality of Life in Alzheimer's Disease scale (QoL-AD), Life Improvement scale, and Quality of Life Change scale.	40 residents from specialised units with a general medical diagnosis of dementia.	-Reminiscence

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Heggestad et al. (2013) Norway	To investigate how life in Norwegian nursing homes may affect experiences of dignity among persons with dementia.	Qualitative	A special care unit for people with dementia in one nursing home, and a general unit in a second nursing home.	Interpretative hermeneutical and phenomenological approach using formal interviews.	Five residents with a diagnosis of dementia at various stages.	-Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss
Jonas-Simpson and Mitchell (2005) Canada	To give voice to expressions of quality of life for persons who live with dementia and who reside in long-term care, primarily on locked cognitive support units.	Qualitative	Locked cognitive support units and one physical support unit in a long-term care facility.	Descriptive study using semi-structured interviews conducted alongside a music or art therapist. Music and art was offered to participants as mediums to further describe their quality of life.	16 participants from the locked support units, and one participant from the physical support unit, all diagnosed with varying types of dementia with mild-severe impairment.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss
Kaufmann and Engel (2016) Germany	To examine Tom Kitwood's model of psychological needs and well-being in dementia based on the self-report of individuals with moderate or severe dementia, and to differentiate and elaborate this model in the light of the empirical qualitative data.	Qualitative	Long-term care unit for people with moderate or severe dementia.	Deductive-inductive design using semi-structured interviews with questions based on Tom Kitwood's model of needs.	19 residents with mild-severe dementia and an average MMSE score of 9.41.	-Activities -Reminiscence -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss
Milte et al. (2016) Australia	To describe the meaning of quality residential care from the perspective of people with cognitive impairment and their family members.	Qualitative	3 residential aged care facilities.	Descriptive study with in-depth, semi-structured interviews.	12 residents with mild-severe cognitive impairment. The mean number of errors on the Short Portable Mental Status Questionnaire (SPMSQ) for participants was 7.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Mjørud et al. (2017) Norway	To investigate the personal experience of living in a nursing home over time from the perspective of the person with dementia and to learn what makes life better or worse in the nursing home.	Qualitative	Two special care units for people with dementia and 2 regular units across 3 nursing homes.	Interpretative phenomenological hermeneutic approach with unstructured interviews.	12 residents with mild to severe dementia according to the clinical dementia rating scale (CDR).	-Activities -Reminiscence -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss
Monroe et al. (2014) USA	To determine if a diagnosis of dementia influenced pain self-reports and pain medication use in a group of verbally communicative nursing home residents.	Quantitative	Long-stay beds in one nursing home.	Comparative study using the seven question structured pain interview derived from the Geriatric Pain Measure comparing outcomes in residents with and without dementia.	45 participants completed the interview. 19 with a diagnosis of mild-moderate dementia, and 26 without dementia. All participants had a minimum of one pain-related diagnosis.	-End-of-life care
Moyle et al. (2011) Australia	To understand the factors that influence quality of life for people living with dementia in long-term care, including an understanding of how they perceived they were valued.	Qualitative	Four long-term care facilities providing low and high care, as well as dementia-specific care.	Pragmatic, exploratory approach with semi-structured interviews.	32 residents with a dementia diagnosis according to the MMSE and DSM.	-Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships
Moyle et al. (2015) Australia	To describe quality of life as reported by people living with dementia in long-term care in terms of influencers of, as well as the strategies needed, to improve quality of life.	Qualitative	Four aged care facilities.	Descriptive, exploratory design with a case study approach and structured interviews.	12 residents with a diagnosis of varying types of dementia, with MMSE scores in the range of 16-24 indicating mild to moderate dementia.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships -Support with grief and loss

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Mulqueen and Coffey (2017) Ireland	To explore the preferences of residents with dementia for their end of life care, and nurses' perceptions of these preferences.	Mixed methods	One residential care facility.	Nominal group technique with group discussion and ranking of preferences.	Nominal group of six residents with mild dementia and an MMSE score of 18 or over.	-End-of-life-care
Murphy et al. (2005) UK	To obtain the views of frail older people with communication impairments using an innovative interviewing methods, Talking Mats™.	Qualitative	Care homes (number unknown)	Exploratory study with semi-structured interviews using the Talking Mats visual framework.	Seven older people with communication difficulties and a diagnosis of dementia.	-Activities -Reminiscence -Freedom and choice -Appropriate environment -Meaningful relationships
Olsen et al. (2015) Norway	To explore the positive and negative experiences of a high-intensity functional exercise program in nursing home residents with dementia, from the perspective of the residents.	Qualitative	One nursing home.	Exploratory study with semi-structured interviews.	Eight residents with mild to moderate dementia, according to the CDR.	-Activities -Freedom and choice
Popham and Orrell (2012) UK	To determine to what extent the care home environment met the requirements of residents with dementia in the context of the views of managers, family carers and staff, and a standard environmental assessment.	Mixed methods	One large care home with residential, nursing and specialised dementia care; three nursing homes, two of which had specialised dementia beds; and one residential home with no specialised provision.	Exploratory, evaluative study with five focus groups with residents using open-ended questions.	Twenty-five participants with a diagnosis of dementia at the mild-severe stage and a mean MMSE score of 8.8.	-Activities -Maintaining previous roles -Freedom and choice -Appropriate environment -Meaningful relationships

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Powers and Watson (2011) USA	To obtain an understanding of residents' spiritual orientations, practices and preferences; to examine family member and NH staff perceptions of spiritual nurturance and support for residents; and to analyse institutional resources for and approaches to assessing and meeting residents' spiritual needs.	Mixed methods	Three nursing homes providing care for people of all religious faiths, but with mainly the following faith-based affiliations: Catholic, Jewish, and Protestant.	Concurrent nested strategy in which the predominant method was qualitative semi-structured interviews.	47 residents with mild-severe dementia according to the Cognitive Performance Scale (CPS).	-Activities -Support with grief and loss
Serrani Azcurra (2012) Argentina	To investigate whether a specific reminiscence programme is associated with higher levels of quality of life in nursing home residents with dementia.	Quantitative	Two nursing homes.	Single-blinded, parallel-groups randomised controlled trial where participants in the intervention group received the reminiscence therapy; an active control group where participants received counselling and informal social contact; and a passive control group where participants received unstructured social contact. Outcome measures: Quality of life measured by the Self Reported Quality of Life Scale (SRQoL).	135 residents diagnosed with Alzheimer's Disease according to the DSM-IV, with a mean MMSE score of 13.9.	-Reminiscence
Tak et al. (2015) USA	To describe types of current activity involvement and barriers to activities reported by nursing home residents with dementia.	Qualitative	Nursing homes (number unknown)	Ethnographic study with semi-structured interviews.	37 residents with a range of mild-moderate dementia and a mean MMSE score of 16.4.	-Activities -Maintaining previous roles -Appropriate environment -Meaningful relationships

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Tan et al. (2013) Australia	To explore the perceptions and experiences of aged care residents with mild dementia on the deaths of co-residents.	Qualitative	Three aged care facilities, two of which providing low care, and one providing both high and low care.	Exploratory study with two rounds of semi-structured interviews.	23 residents with mild dementia according to the Psychogeriatric Assessment Scale (PAS) and the CDR, and with a mean MMSE score of 22.	-Support with grief and loss
Thein et al. (2011) UK	To explore the personal experience of people with dementia of moving into a care home.	Qualitative	Ordinary or specialist dementia residential and nursing homes (number unknown).	Exploratory study with semi-structured interviews with participants before and five weeks after their move into the care home.	18 individuals with a diagnosis of dementia in the moderate stages.	-Freedom and choice -Meaningful relationships -Support with grief and loss
Travers et al. (2013) Australia	To conduct a randomised controlled trial of dog-assisted therapy for people with dementia living in aged care facilities using validated instruments of mood, quality of life, and psychosocial functioning.	Quantitative	Three residential aged care facilities, all caring for residents with high and low care needs.	A multicenter randomised controlled trial where participants were randomly assigned to either the dog-assisted therapy group (n = 27) or human-therapist (control) group (n = 28). Outcome measures: Quality of Life-Alzheimer's Disease questionnaire (QOL-AD); the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36); and the Geriatric Depression Scale Short Form (GDS-SF).	55 residents with a diagnosis of mild-moderate dementia, according to the Modified Mini-Mental State Exam (MSE-3MS), with a mean MSE-3MS score of 58.1 in the dog-assisted therapy group, and 59.8 in the control group.	-Activities
Van Zadelhoff et al. (2011) Netherlands	To investigate experiences of residents, their family caregivers and nursing staff in group living homes for older people with dementia and their perception of the care process.	Qualitative	Two group living units located on the grounds of a large-scale nursing home.	Naturalistic inquiry with semi-structured, in-depth interviews.	Five residents with a diagnosis of dementia ranging from moderate to severe and a mean MMSE score of 10.	-Maintaining previous roles -Appropriate environment

Author/Year/Country	Aim	Research type	Number & type of facility	Study design & methods	Study population	Themes
Wiersma and Pedlar (2008) Canada	To examine the experiences of older adults with dementia while they were in long-term care and while they were in in a summer-camp setting.	Qualitative	Locked cognitive support units in one long-term care facility and one summer camp setting with cabins for 4-6 residents and 2-3 staff.	Exploratory study with conversational interviews at three different phases: (i) during the 3 months prior to going to camp; (ii) during the 4 days of camp; (iii) during the month after the camp.	Ten residents with dementia, mostly World War II veterans, seven of which participated in all three phases, and three of which participated in phase one only.	-Freedom and choice -Appropriate environment -Meaningful relationships

Themes

Eight themes resulted from thematic synthesis: activities, maintaining previous roles, reminiscence, freedom and choice, appropriate environment, meaningful relationships, support with grief and loss, end-of-life care. Table 3 shows the sub-themes according to both experiences and needs for each of the eight analytical themes.

Table 3. Specific experiences and needs according to each theme

Analytical Theme	Experiences Sub-themes	Needs Sub-themes
Activities	Boredom & monotony Isolation & loneliness Belonging Wellbeing Mobility & independence Quality of life Exclusion	Unstructured activities e.g. crosswords, playing instruments, jigsaws, reading and knitting. Facilitated activities in group settings e.g. music sessions, bingo, dancing, group storytelling, pet therapy, reading group, regular exercise classes. Opportunities to attend religious ceremonies. Activities tailored to individual preferences and abilities.
Maintaining previous roles	Boredom & monotony Loss of identity Comfort Coping Feeling appreciated Purpose	Opportunity to contribute to domestic tasks around the home. Opportunity to engage in altruistic activities within the home and in the wider society. Involvement in sharing ideas and knowledge.
Reminiscence	Boredom & monotony Quality of life Wellbeing	Opportunities to share memories with others through photographs or newspaper clippings. Reminiscence sessions involving staff. Watching clips of familiar places.

Analytical Theme	Experiences Sub-themes	Needs Sub-themes
	Improved staff relationships Comfort Hope Empowerment Loss of identity	
Freedom & choice	Restriction Quality of life Frustration Disempowerment Lack of choice Loss of identity	Listening to or playing music. Going home and attending family events. Support and freedom to access the garden. Control over daily routines. Choice over what to eat. Choice over which room to sit in. Facilities to prepare a drink/snack when hungry. Respect for individual preferences.
Appropriate environment	Isolation & loneliness Mobility & independence Confusion Ownership Privacy	Living near family or in a familiar area. Good relationships with staff. Internal environment that does not increase risk of falls. Internal environment that is not confusing. Access to personal space. Key to room. Family photos in room. Opportunity to bring larger familiar items from home. Spaces encouraging interaction. Accessible external spaces & gardens.
Meaningful relationships	Comfort Isolation & loneliness Exclusion Restriction Frustration Abuse Loss of identity Anxiety Confusion	Routines conducive to forming friendships. Positive relationships with staff. Spending time with family. Assistance to maintain relationships outside of the home. Reassurance of family visits. Staff acceptance of sexuality & intimacy.
Support with grief & loss	Coping Loss of identity Confusion Fear Loss of hope Isolation & loneliness Loss of purpose Mobility & independence Comfort	Informed about the death of a fellow resident. Opportunity to attend funerals. Afternoon tea in memory of residents. Pre-move visit. Known person in the home to talk to. Religious or spiritual support.
End-of-life care	Comfort Pain	Peaceful surroundings. Appropriate pain relief. Presence of family. Surrounded by familiar possessions. Effective communication. Familiar staff providing care. Appropriate environment according to wishes (hospital/home). Religious or spiritual support.

Activities

One of the most commonly occurring experiences of residents with dementia was boredom, with synonymous expressions such as 'monotonous' days (Harmer & Orrell, 2008) and 'lack of stimulation' (Aggarwal et al., 2003) also conveyed. The effects of boredom were spoken about

by one resident who said: 'I get bored here […] I feel like throwing something at them' (Clare et al., 2008). Participants discussed a number of unstructured activities they enjoyed, such as crosswords, playing instruments, jigsaws, reading and knitting (Harmer & Orrell, 2008; Jonas-Simpson & Mitchell, 2005; Murphy et al., 2005). However, many participants wished for 'more social interaction' (Popham & Orrell, 2012), and said that they take part in activities as a way of socialising with others (Tak et al., 2015).

Preferred facilitated activities occurring in group settings included: music sessions (Mjørud et al., 2017), dancing (Guzmán-García et al., 2012; Tak et al., 2015), bingo (Cahill & Diaz-Ponce, 2011); pet therapy (Travers et al., 2013), and group storytelling (George & osHouser, 2014). A reading group was shown to increase feelings of belonging (Cooke et al., 2010), and residents experienced improvements in wellbeing (Conradsson et al., 2010) and increased mobility, independence and self-esteem from regular exercise classes (Olsen et al., 2015). Practicing of religion was also linked with improved quality of life (Dröes et al., 2006; Powers & Watson, 2011), with residents wishing to attend church services (Mjørud et al., 2017; Moyle et al., 2015), and take part in 'life-long religious practices' within the home (Tak et al., 2015).

Activities should also be tailored to the individual (Moyle et al., 2015). Specific barriers to partaking in activities included deterioration in hearing and sight, arthritis, and lack of staff, transport and space in the home (Moyle et al., 2015; Tak et al., 2015). For those residents at a more advanced stage of dementia, engaging in 'simple pleasures', such as having an ice cream and a chat were described as enjoyable activities (Cahill & Diaz-Ponce, 2011).

Maintaining previous roles
A number of participants from various studies described feeling sad about the loss of roles, as portrayed by the following example: 'I used to be a famous teacher, a psychologist, now I am nothing' (Cohen-Mansfield, Golander & Arnheim, 2000). Participants described feeling of 'little value' (Moyle et al., 2011), and many still had a desire to contribute to the home or society (Godwin & Poland, 2015; Jonas-Simpson & Mitchell, 2005). This could be achieved through engagement in domestic tasks such as tidying their rooms (Kaufmann & Engel, 2016). However, some participants were happy to be relieved of the responsibility of domestic tasks (Godwin & Poland, 2015; Van Zadelhoff et al., 2011).

Altruism was also important for some residents, providing occupation, as well as comfort (Doyle, Rubinstein & de Medeiros, 2015; Kaufmann & Engel, 2016). This may take place within the home, as explained by one participant, who said the best thing about her day was 'chatting with other people, hearing their complaints and their worries and trying to give them a little advice' (Moyle et al., 2015). This was echoed by other participants who said they cope better with their own situation by helping others (Clare et al., 2008). Residents also feel appreciated when staff asked for their knowledge about a subject (Graneheim & Jansson 2006). Finally, one participant reported how being involved in altruistic activities benefitting the wider society, in this case crocheting baby clothes for hospitals, gave her 'purpose in life' (Tak et al., 2015).

Reminiscence
Reminiscence was described as a meaningful activity (Harmer & Orrell, 2008) and led to a sustained improvement in quality of life amongst participants in one trial (Serrani Azcurra,

2012), although these results were not replicated in a trial investigating reminiscence therapy and wellbeing (Haslam et al., 2010). Residents enjoy reminiscence sessions that involve staff, as they feel they are taking more of an interest in them, which in one study led to increased interaction during activities of daily living (Cooney et al., 2014). Residents also gain consolation from reflecting on things they have done in the past, which provides hope that life may be like that again (Kaufmann & Engel, 2016). Furthermore, reminiscence provides a means to reflect on things they can still do (Clare et al., 2008).

Tools for reminiscence included 'photographs, recordings and newspaper clippings' and subsequent group discussion (Serrani Azcurra, 2012). Films showing familiar places were enjoyed by some participants (Chung, Choi & Kim, 2014). However, such reminders could bring back both happy and sad memories (Mjørud et al., 2017). In particular, photographs may remind individuals of what they have lost (Murphy et al., 2005).

Freedom and choice

As with boredom, an experience of a restriction was common. Residents described staff as 'controlling' (Moyle et al., 2011), and said that their quality of life would improve if they could do more of what they pleased (Dröes et al., 2006). When asked what they would like to do but were not allowed to, participants answered: music, going home, and attending family events (Cohen-Mansfield, Golander & Arnheim, 2000). Lack of freedom to leave the home was noted as a source of frustration across a number of articles (Cahill & Diaz-Ponce, 2011; Goodman et al., 2013; Milte et al., 2016; Popham & Orrell, 2012), and being prevented from simply going for a walk in the garden was associated with lower ratings of quality of life (Dröes et al., 2006). World War II veterans living in locked cognitive support units in one nursing home described them as prison camps (Wiersma & Pedlar, 2008); an experience echoed by a number of others residing in general nursing homes (Moyle et al., 2015; Olsen et al., 2015). However, in a home where the doors were not locked, one resident still felt restricted because staff did not have time to assist him to go outside (Heggestad, Nortvedt & Slettebø, 2013).

Several participants experienced a sense of disempowerment (Moyle et al., 2011), and a lack of choice (Aggarwal et al., 2003) in other areas of their lives. Residents stated that they should have control over their daily routines and not have to fit in with 'the status quo' (Milte et al., 2016). This included choosing: what to eat (Aggarwal et al., 2003); whether to have a bath or shower (Murphy et al., 2005); which room to sit in (Popham & Orrell, 2012); and what time to go to bed (Jonas-Simpson & Mitchell, 2005). Residents would also like to prepare a drink or snack when they are hungry (Heggestad, Nortvedt & Slettebø, 2013), with one participant suggesting that there should be a small kitchen in the home for their use (Popham & Orrell, 2012). Participants also wished to be respected as a person with individual preferences (Milte et al., 2016). For instance, in one study, although staff addressed almost all residents by their first name, only 70% of participants who expressed an opinion were happy with this (Cohen-Mansfield, Golander and Arnheim, 2000).

Appropriate environment

There were varied reports as to whether nursing homes were a homely environment. Reasons for feeling 'at home' included living near family or near where they used to live, and good relationships with staff. Those with mild dementia were more inclined to consider a nursing

home homely compared to those at a more advanced stage (Cahill & Diaz-Ponce, 2011). Participants discussed several needs in relation to their built environment, including the need to navigate areas without risk of falls (Dröes et al., 2006) or confusion, particularly for those at advanced stages of dementia (Bartlett, 2007). Participants also appreciated access to 'personal space' (Popham & Orrell, 2012), which promotes a sense of ownership (Moyle et al., 2015), and fulfils the need for time alone (Kaufmann & Engel, 2016). However, some residents lacked privacy and disliked that strangers could enter without permission (Dröes et al., 2006). As a result, some said they should be provided with a key (Milte et al., 2016; Heggestad, Nortvedt & Slettebø, 2013). Within their rooms, family photos were important for combatting loneliness (Mjørud et al., 2017). When asked about other objects they would have liked to bring, participants mentioned: furniture, carpet, and plants (Cohen-Mansfield, Golander & Arnheim, 2000).

The type of home may also play an important role in meeting individuals' needs, such as group living homes, which were found to encourage interaction (Van Zadelhoff et al., 2011). As regards to the outdoor environment, participants wished for accessible external spaces (Moyle et al., 2011) and gardens (Bartlett, 2007), which were found to be important in maintaining independence and ownership (Moyle et al., 2015). Green care farms were also explored. However, no statistically different quality of life scores were found when green care farms were compared with traditional nursing homes or small-scale living facilities (De Boer et al., 2017).

Meaningful relationships

A number of participants spoke about the importance of relationships, and gaining comfort through human contact (Kaufmann & Engel, 2016). Fear of loneliness was discussed, specifically amongst those residents with advanced dementia (Cahill & Diaz-Ponce, 2011; Mjørud et al., 2017). In one study, a male participant highlighted how as a man it was harder to make friends, partly because there were a lot more women in the home (Moyle et al., 2011). Furthermore, in one dementia specific unit, no residents reported having a friendship within their unit, compared with non-dementia specific units (Casey et al., 2016). Participants frequently described frustrations with fellow residents, disliking how they shout or hurt others (Bartlett, 2007; Murphy et al., 2005; Wiersma & Pedlar, 2008). Some residents felt that routines kept in the home were not conducive to forming friendships, as most went to bed early (Moyle et al., 2011).

As regards to relationships with staff, Cahill and Diaz-Ponce (2011) found that they are especially important for those with mild-moderate dementia. Some residents described positive relationships with staff (Mjørud et al., 2017). However, others described their relationships as 'economic' (Bartlett, 2007), and said that staff could be difficult to find, manhandled them, and treated them like patients (Goodman et al., 2013; Milte et al., 2016). Relationships with family also continue to be significant (Dröes et al., 2006; Harmer & Orrell, 2008; Tak et al., 2015). Spending time with family provided opportunities for 'meaningful conversations', as well as reminding individuals about their existence outside of the care setting (Moyle et al., 2011). Losing contact with family was mentioned as a 'key source of anxiety' for residents, particularly when first moving into the home, and they may require staff to assist them to maintain contact (Milte et al., 2016), including through the use of Skype

(Moyle et al., 2015). Participants felt that their families were not visiting them enough, which was particularly common amongst those at an advanced stage of dementia, who often wrongly believed family had not visited them when they had (Cahill & Diaz-Ponce, 2011).

Finally, a small number of participants talked about how they missed intimacy (Bauer et al., 2013; Dröes et al., 2006). In one study, nursing homes were not considered to be conducive to expressions of sexuality, with residents fearing negative reactions from staff and gossip. Residents found talking to staff about sexual needs too personal, and viewed staff as 'strangers' (Bauer et al., 2013).

Support with grief and loss
Individuals residing in a nursing home are likely to experience the loss of fellow residents. However, Tan et al. (2013) found that 70% of residents with mild dementia in their study were not concerned about being around people dying. Instead, they were unhappy about not being told about the death of a resident, and felt that all residents should be informed together. As regards to funerals, 40% of participants in this study indicated that they would have liked to have attended a funeral of a resident they were close to. Furthermore, participants appreciated the idea of an afternoon tea in memory of residents who had died.

Residents may also experience loss in regards to their former lives and identities (Cahill & Diaz-Ponce, 2011; Mjørud et al., 2017). A number of participants expressed confusion and fear about why they were in the nursing home (Clare et al., 2008). Others wished to go home, with one participant describing how she had taken to walking down corridors so she would become strong enough to live with her daughter (Goodman et al., 2013). Other residents disliked living in the home so much that they felt they had no future, with three residents in one study saying that they wished for their lives to end. Notably, two of these residents said that they had not been able to talk this way with anyone except the researcher (Goodman et al., 2013). However, Thein, D'Souza & Sheehan (2011) found that most of the 18 participants they interviewed after their move liked their new homes, which was in part linked with having undertaken a pre-move visit, as well as having a 'known person in the home'

Participants also described a 'loss of function', leading to a 'loss of purpose'. For instance, a decline in physical independence led one resident to express: 'I can't help anybody else in here, what's the point of it all' (Goodman et al., 2013). Support for residents may be provided in the form of a pastor (Powers & Watson, 2011) or other 'spiritual rituals' (Kaufmann & Engel, 2016), which were identified as providing comfort during difficult times.

End-of-life care
Needs at the end of life were explored in two studies. Mulqueen and Coffey (2017) found that, amongst six participants with mild dementia, comfort and peace were ranked most important at this stage. Participants wished to be 'pain free, worry free' at the end of their lives, with 'quiet and peaceful surroundings'. This included not being moved to hospital. Presence of family was ranked second in importance, followed by 'my own things', where participants said being in their own room surrounded by familiar items, such as family photos, would provide comfort. Fourthly, residents highlighted the need for effective communication, hoping that

staff would not withdraw from them. In particular, residents would like familiar staff to care for them.

Goodman et al. (2013) qualitatively explored the preferences of 18 residents with dementia for end-of-life care. There were mixed feelings regarding place of death, with one resident expressing preference for the nursing home. However, another said that she would prefer to go to hospital as she felt that there people 'especially take an interest in your feelings'. As regards to religious needs, one resident said he would like to see a priest. Another participant emphasised that she would prefer to talk to a particular staff member about any concerns she may have, more so than her children, who she worried about upsetting.

Residents with dementia may also have varying needs as regards to pain relief. Although it was not specified whether participants were receiving end-of-life care, Monroe et al. (2014) found that nursing home residents with dementia reported more intense levels of pain than those without dementia. However, participants were less likely to tell staff about pain, and less likely to report that nursing home staff asked about their pain.

Discussion

This scoping review provides new evidence concerning the needs and experiences of people with dementia in nursing homes, a previously underrepresented population in research. One of the most commonly occurring needs in the literature was the need for activities. However, participants emphasised the need for activities that are tailored to their abilities and interests. This is a challenge for nursing homes where often 'personal preferences are constrained by the needs of others' (Bruce & Schweitzer, 2008). Obtaining a life history when an individual first moves into the home has been suggested to ensure all aspects of care are personalised. This should be followed by a thoughtful approach to replicating activities, in a way that evokes 'the "feel" of an activity enjoyed in the past, without engendering any anxiety about performance' (Bruce & Schweitzer, 2008).

One particular activity explored in the literature was reminiscence. There was conflicting evidence regarding the impact of this activity on quality of life and wellbeing. Schweitzer and Bruce (2008) propose a 'creative communication-based approach' to reminiscence, underpinned by a person-centred philosophy. For instance, this approach involves listening to individuals tell their stories in a respectful manner, and avoiding questioning information that may seem factually incorrect.

The need for freedom was another common theme amongst participants in this review. In particular, low quality of life ratings were linked with a lack of access to the outdoor environment. Although restricting access to the outdoor environment reduces risk from a staff perspective, it limits activities and prevents the 'possibility of building relationships which might enhance the person's life' (Fossey, 2008). Furthermore, access to the outdoor environment has been shown to have a number of health benefits for people with dementia, including reducing neuropsychiatric symptoms (Heyn, Abreu & Ottenbacher, 2004), restoring circadian rhythm, and increasing levels of vitamin D (Pollock & McMair, 2012), linked with a reduction in falls (Bischoff-Ferrari et al., 2009). One potential solution to this dilemma is to introduce 'dementia-friendly outdoor environments' (Mitchell & Burton, 2006). Preliminary

recommendations for which include environments that are 'familiar, legible, distinctive, accessible, comfortable and safe' (Mitchell & Burton, 2006). For example, flat paving and regular seating intervals.

Under the theme of 'meaningful relationships', frustrations with fellow residents, and staff were described, as well as a loss of contact with communities and families. These findings may suggest the need for a movement towards 'relationship-centred care', as explored by Nolan et al. (2001), who argue that relationships play an important role in determining quality of life, in particular by maintaining 'identity and personhood' (Davies & Nolan, 2008). Participants also described feeling unable to talk to staff about sexual needs. In their study exploring the attitudes of nursing home staff, Ward et al. (2005) found that staff commonly avoid this topic during the assessment process as they find it 'problematic'. The authors suggest that staff should be trained in how to broach this topic, and develop an understanding of the way in which sexuality forms an important part of personhood.

As regards to end-of-life care, only two studies in this review specifically addressed this area of need, and in both studies, there were mixed opinions amongst participants about the preferred place of death. This stresses the requirement for future wishes to be discussed, which may take the form of advance care planning (ACP), a process where patients determine their preferences for future care (Robinson et al., 2012). ACP has been shown to reduce inappropriate hospitalisations for people with dementia. However, the ACP process should be commenced in the early stages of dementia before loss of capacity (Robinson et al., 2012).

Implications

This study has shown that people with dementia in nursing homes, including those at a more advanced stage, are able to voice their experiences and needs, which has implications for education, practice and policy in the domain of dementia care planning, provision and evaluation in this setting. Firstly, wherever possible, nursing homes should involve people with dementia in the planning of their care at all stages, including for end of life. Furthermore, the themes and sub-themes presented in this paper have provided a possible evidence-based framework to guide nursing homes in the process of person-centred assessment and care planning for people with dementia. Thirdly, people with dementia should be given the opportunity to contribute to the evaluation of their care.

Future research

This study has also provided a means to identify gaps in the literature and future research priorities. More research addressing the needs of this population in relation to reminiscence, sexuality and intimacy, and end-of-life care is required. Furthermore, only one study specifically exploring the spiritual needs of people with dementia was identified. Spiritual needs have been found to be neglected in research, despite the role that spirituality has been shown to play in providing a source of comfort for people with dementia, and the way in which spiritual needs determine a range of other needs, such as end-of-life care (Higgins, 2013).

Secondly, due to the broad nature of dementia, needs of individuals according to various types, as well as stages of the condition should be explored. Finally, as regards to methods

used in the studies, observations and proxy accounts were commonly used to complement self-reports. Although it has been said that triangulation increases confidence in drawing conclusions from data in dementia research (Black & Rabins, 2006), the researcher should consider that different sources of data may actually introduce 'different perspectives' (Nygård, 2006). Table 2 provides a brief description of methods and additional tools used to collect data. However, a review exploring methods used to elicit the experiences and needs of people with dementia in more detail could provide a valuable source of information for researchers developing their own studies in this area.

Limitations
Only two databases were used to search for articles, hence some articles may have been missed, including grey literature. Restriction to articles in English, French and Czech may also mean that results are more representative of a European or Western perspective.

Conclusion
With rates of dementia continuing to rise, the impetus on improving care for this population is growing. Whilst the voice of people with dementia has previously been neglected in research, this review has shown that people with dementia in nursing homes are able to describe their experiences and communicate their needs. A total of eight themes were identified across the articles used in this scoping review, providing evidence that people with dementia have a wide variety of needs which, as developed by Kitwoood (1997), span significantly further than physical needs alone, to include psychosocial and environmental needs. However, this review is only a starting point towards guiding evidence-based practice, and has highlighted a number of gaps in the literature. In particular, further research is required to investigate needs according to the type and stage of dementia, as well as needs in relation to reminiscence, sexuality, spirituality, and end-of-life care for people with dementia in nursing homes.

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Results (2)

Abstract

Background: The Electronic Patient Record (EPR) has been introduced into nursing homes in order to facilitate documentation practices such as assessment and care planning, which play an integral role in dementia care. However, little is known about how the EPR facilitates or hinders assessment and care planning from the staff perspective, or the usability of the EPR specifically for dementia care. Therefore, the objective of this qualitative study was to explore the usability issues associated with the EPR for planning and delivering dementia care in nursing homes from a staff perspective.

Methods: An exploratory, qualitative research design with a multiple case study approach was used. Observations and interviews (n=21) with a variety of staff members who use the EPR were carried out in three nursing homes situated in Belgium, Czech Republic and Spain. Thematic analysis was used to code interview data, with codes then sorted into a priori components of the Health Information Technology Evaluation Framework: device, software functionality, organisational support. An additional theme, structure and content, was also added.

Results: Staff provided numerous examples of the ways in which EPR systems are facilitating and hindering dementia care under each theme. All three EPR systems lacked specific characteristics needed to effectively plan and deliver care for people with dementia, who may have more complex needs in comparison to other residents. Furthermore, the way in which EPR systems were not customisable was a common issue across all three homes.

Conclusions: EPR systems introduced into the nursing home environment should be customisable and reflect best practice guidelines for dementia care, which may lead to improved outcomes and quality of life for people with dementia living in nursing homes. All levels of nursing home staff should be consulted during the development, implementation and evaluation of EPR systems as part of an iterative, user-centred design process.

Keywords: Assessment; dementia; care plan; electronic health records; electronic patient records; nursing home

Introduction

Nursing homes currently face a multitude of pressures, such as difficulties in recruiting staff, high employee turnover and low staff morale [1]. Added to these pressures is a growing demand for documentation, which has come about from 'increasing regulatory scrutiny' [2]. Two of the principal nursing processes which are required to be documented and regularly updated are assessment and care planning. Assessment involves 'the gathering of data relating to a person's physical, psychological, and social status' [3] and may take place in a direct or proxy manner. For example, by gathering information from family members or observing individuals. Assessment is often a time-consuming process for staff and can be a potentially stressful activity for the individual, particularly for those with dementia [3]. However, it is an important first step in the nursing process, providing a core set of information from which to develop care plans [4].

Care plans have been described as 'prescriptions for nursing care' [5] and act as a reference for nurses to facilitate continuity of care [6]. Furthermore, care plans are often used to provide evidence of the quality of care which has been delivered [7], in this way, protecting staff in case of complaints [6]. An essential element of the care plan is that it should be personalised to reflect the individual [8]. Care planning plays a particularly important role in the provision of care for people with dementia [9], specifically in nursing homes, where approximately 70% of residents will have a diagnosis of dementia [10].

Defined as an application incorporating 'the clinical data repository, clinical decision support, controlled medical vocabulary, order entry, computerized provider order entry, pharmacy, and clinical documentation applications' [11], the electronic patient record (EPR), was introduced to assist with documentation processes such as assessment and care planning. For nursing homes, the EPR has the potential to reduce administrative burdens [12], improve the quality of documentation [13], as well as allowing for the identification of care needs [13] and management of long-term conditions more effectively [14]. If EPR systems are interoperable, data can also be shared across healthcare providers [15]. With demands for documentation alleviated, staff potentially have more time to spend with residents providing direct care [16]. The EPR may play a particularly important role in the delivery of care to people with dementia, by allowing access to detailed background information at the point of care when, for instance, staff may require more information about the cause of an individual's behaviour [17].

Despite the benefits associated with this technology, there are numerous examples where the EPR has been described as a burden by nursing home staff [18]. This emphasises how, in order for Health Information Technologies (HIT) such as EPR to effectively meet the needs of end users, it is imperative that the HIT design and evaluation process is participatory, so that end-users' feedback is gathered as part of an iterative process [19, 20]. However, in a recent review exploring the use of EPR in nursing homes [21], all four studies investigating EPR for assessment or care planning used audit methods to examine the quality and completeness of electronic care plans [7, 22, 23, 24]. Moreover, despite the high prevalence of dementia amongst those residing in nursing homes, little is known about how the EPR is enabling staff to carry out assessment and care planning for this population [21]. Therefore, through a qualitative lens, this study aims to address the following question: what are the usability issues associated with the EPR for planning and delivering dementia care in nursing homes?

Methods

Study design
Principles of human factors engineering state that during the development of technology, the device should not be considered in isolation from the organisational context [25]. Therefore, a qualitative, multiple case study design was used, allowing for the 'exploration of a phenomenon within its context' [26].

Data collection method
In this study, the ISO definition of usability as 'the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use' [27] was adopted. The contextual inquiry (CI) method was used as a means to explore usability issues associated with the EPR. CI involves asking users to perform relevant tasks whilst the researcher simultaneously 'asks questions about what is happening and why' and 'how tasks could be improved', with observations allowing the researcher to understand contextual issues [28].

For the purposes of this study, participants were asked to show the researcher how they would enter assessment data and create a care plan for an individual with dementia whilst using the 'think aloud' method, which allows for a 'running commentary of [the participant's] thought process' [20]. This was followed by a semi-structured interview with open-ended questions to elaborate on any areas of interest raised during the task.

In Belgium, interviews were carried out in French or English by the first author (KS). In Spain, interviews were carried out by a co-author (ADB) who is a native speaker with the first author present. In the Czech Republic, interviews were conducted either in English by the first author, or in Czech with the assistance of an interpreter who had prior knowledge of the study.

Interview guide
The interview guide was designed according to the components of the 'structural quality concept' of the Health Information Technology Framework (HITREF) [29]. The HITREF was developed in response to a lack of consistent approaches to evaluating HIT, with previous frameworks also commonly omitting contextual evaluation [29]. The components explored here included: device, software functionality, and organisational support. A fourth component 'structure and content' was added by the authors in order to elicit opinions on the language and structure of the EPR forms. Under each component, specific questions were developed from evidence collated from the authors' prior research [21] and designed to elicit responses about the usability of the EPR for the task.

Setting
Data collection took place in three nursing homes in Belgium, Czech Republic and Spain between March 2018 and January 2019. In order to be eligible for this study, the nursing home had to have been using an EPR system for at least six months and provide care to people with dementia. Basic characteristics of the nursing homes are provided in Table 1.

Table 1. Characteristics of nursing homes participating in the study

Date of interviews	Country	Region	Type of nursing home	Total number of beds	Time using the current EPR
March 2018	Belgium	Flanders	Public	316	8 years
June 2018	Spain	Castilla y León	Private	150	8 years
January 2019	Czech Republic	Praha	Public	260.	9 months

In Belgium, the EPR system was introduced in 2010. The occupational therapist completes the initial assessment template on the EPR system, as well as a separate document on paper created by the nursing home more suitable for their needs. Trained nurses complete the care plan using a template in the EPR. Nurses use either a desktop computer or a laptop, which contain the full EPR. The auxiliary nurses use a tablet they carry with them, which contains a more simplified version of the care plan.

In Spain, they have been using the EPR system since 2010, however auxiliary nurses do not have access to the system and fill out documentation in notebooks. Currently, when a resident moves into the nursing home, all trained staff have one month to fill out their own version of a 'Programa de Atención Individualizado' (PAI) on paper, which is a needs assessment and an individualised plan of action according to their field. The PAI is not incorporated into the EPR. Staff who have access to the EPR all use a desktop device.

In the Czech Republic, they had transitioned to a new EPR programme in March 2018 as the previous software was unsuitable for the nursing home environment. Due to data protection laws, the nursing home is split into two fields: 'health' and 'social care' and a dual approach to assessment and care planning takes place. Staff members can only view documents in the field in which they work. They mostly use a desktop computer but had introduced tablets for auxiliary nurses six weeks prior to the interviews.

Participants and recruitment
According to research carried out by Nielsen and Landauer [30], carrying out usability testing with 8-10 participants should identify 80% of usability problems, which was the goal sample size. Eight participants were recruited in Czech Republic (female n=8), but only seven in Spain (female n=5; male n=2) and six in Belgium (female n=6) due to staff shortages. In usability testing, there is also a need to involve a range of users [25] and maximum variation sampling as characterised by job role was used.

The following inclusion/exclusion criteria for participation was applied:

Inclusion criteria
- Permanent staff member who manages or provides care to residents with dementia.
- Is involved in assessment and care planning.
- Has worked in the nursing home for at least 6 months.
- Has been trained in how to use the electronic documentation system.
- Has been using the electronic documentation system for at least 6 months.

Exclusion criteria
- Temporary staff member.

In each of the homes, management were asked to suggest staff who met the inclusion criteria to participate. These staff were provided with an information sheet and consent form. A brief background questionnaire was first given to consenting participants, which was designed to provide an insight into their performance from a historical perspective [20]. For instance, number of years in their role, and number of years using the EPR. Sample characteristics expressed as means are provided in Table 2.

Table 2. Basic sample characteristics expressed as means

Country	Number of participants	Years of experience in nursing home (mean)	Length of time using the current EPR system (mean)	Self-rated expertise with Information Technology (1-5) (mean)
Belgium	6	12.8	5 years	3.4
Spain	7	4.9	4.5 years	4.1
Czech Republic	8	2	8.3 months	3.6

Ethical approval
Ethical approval was provided by the Ethics Committee at the Centre of Gerontology, Prague, and from the Medical Ethics Committee of the Vrije Universiteit Brussel [2017/410]. Ethical approval was not required in Spain for a study of this nature.

Data analysis
Interviews from Belgium were transcribed by the first author (KS). Interviews from Spain and Czech Republic were transcribed by a professional transcription company then translated into English by two authors (KS, ADB). Theoretical thematic data analysis was carried out, which allows data to be coded for a specific research question and according to a theoretical pre-conception [31]. Data was coded post hoc into sub-themes according to each of the a priori, overarching components from the Structural Quality of the HITREF Framework [29]. The first

author (KS) carried out data analysis and transcripts were checked by a co-author (ADB) for any additional sub-themes. Data analysis was carried out using ATLAS.ti software.

Results

The overarching components from the adapted HITREF framework and corresponding sub-themes are described below. Table 3 summarises results by component.

Table 3. Summary of themes arising from the data

HITREF component	Sub-theme	Considerations
Device	Type of device	Portable device allows staff to access care plans and record assessments at point of care.
		Desktop device may be preferable for writing longer documents.
		Portable device should be discrete and not invade residents' privacy during care delivery.
	Number of devices	Appropriate number of devices is important for staff to access care plans before care delivery and record important information at the point of care.
Software functionality	Automatic log-out	Automatic log-out after period of inactivity may ensure system runs faster.
	Drop-down menus	Incorporation of drop down menus that can be customised by the nursing home may save time.
		Space for free data entry may still be required.
	Customisable terminology	Nursing home should be able to customise terminology used in assessment and care plan templates that is appropriate for staff level.
	Alerts about changes in a resident's condition	EPR should alert staff on entering the programme to any significant changes in a resident's condition, such as admission to hospital.
	Alerts to update care plans	EPR should alert staff when care plan requires updating.
		Nursing home should be able to choose whether old care plan is automatically deleted or not.
	Interoperability	Interoperable system would mean less time is spent entering information from hospital discharge forms into the EPR and clarifying unclear information.
		Interoperable system would allow nursing home staff to remain up to date about a resident's condition whilst in hospital and plan for their return.
Structure & content	Information about people with dementia	EPR should alert staff to any specific changes in physical health that could impact on a resident's behaviour, such as: -Changes in eating or drinking habits. -Changes in bowel habits. -Changes in body temperature.

HITREF component	Sub-theme	Considerations
		Care plan template should be customisable, but may need to prompt staff to include the following: -Type of dementia. -Key contact person such as family member or friend. -Life history of resident. -Information about routines. -Information about hobbies, -Past profession and whether this was enjoyed by the individual or not.
	Assessments for dementia	EPR should include assessment scales relevant to dementia care, for instance: -QUALID Scale -Mini-mental State Examination -Barthel Index
		EPR may need to incorporate assessment templates based on observations of individuals for those at advanced stages of dementia.
		Various assessment templates should be incorporated for all relevant staff, including assessment of social needs.
		Assessments should be customisable for client group and not force staff to enter irrelevant information.
	Improvements in structure	Staff require a table in the EPR where they can record all observations (e.g. blood pressure, temperature, oxygen saturation, heart rate) in the same place.
		EPR should allow staff to easily access assessments and care plans of other staff, for instance, by incorporating tabs according to each profession (e.g. physiotherapist, occupational therapist) that appear on the screen.
		EPR may need to include space to record how long each task of the care plan takes to complete.
Organisational support	Access	EPR may need to offer customisable access to assessments and care plans for staff according to their level of training. For instance, access to dementia diagnosis may need to be restricted.
	Training	Training 'on the job' should be offered as an alternative to classroom-based teaching.
		Training should be customised according to previous experience with technology.
		Training should be offered at appropriate times.
	System support	Ongoing communication with EPR developers is crucial for appropriate updates to be made to the programme.
		A named person within the nursing home who maintains contact with the developer and to whom problems can be addressed may be appropriate.

Device

Type of device

A tablet device was preferred by many participants as it can be transported in the nurses' trolley for easy access to care plans:

When you are with a resident who needs care, I do not have to go downstairs to see the treatment. (Nurse)

In two homes, staff are currently carrying out the initial assessment with residents in their rooms on paper, then entering information into the EPR. Several staff members said it would be faster if they had a tablet device to record the assessment. However, when writing care plans, nurses preferred to use a desktop computer as they found the keyboard easier to use for long documents. Staff were also concerned about tablets becoming broken or lost.

Staff had mixed opinions on whether devices should be used in residents' rooms. In one home, this was no longer the case as staff felt it made their rooms 'like a convenience store' (Care quality manager). In the home where they were using devices in rooms, the noise of the device made one participant uncomfortable:

It's horrible. There is a human being, and you come and beep, beep like a robot. What is this, science fiction? (Auxiliary nurse)

Number of devices

Several staff complained about having to share devices and having to wait until they became available. Typically, staff need to use the device at the same time:

It's terrible during lunchbreak because the clients are eating and sleeping so everybody is on the computer. (Art therapist)

There were concerns that by sharing devices, staff were prevented from viewing updated care plans before delivering care. One participant highlighted how often she did not know someone was in hospital until she visited their room and found that they were not there.

Software functionality

Automatic log out

In two homes, the speed at which the EPR system operated was too slow, linked with the number of people logged in at the same time:

It takes too long to open a document. It's because we're all connected to it and the network is underpowered. (Manger of Social Department)

This was problematic when staff needed to rapidly access care plans. The system did automatically log users out, but only after ten minutes of inactivity, which participants suggested should be sooner.

Drop down menus

Participants across all three homes noted that it takes time to type free text into the EPR. As a result, despite having a portable device for data entry at the point of care, staff often carried out administrative work after delivering personal care to all residents, in order to prioritise time spent with individuals. This is even more crucial when caring for people with dementia:

The tablet is extra work, and for people with dementia, it's very important for me to give them extra time. (Auxiliary nurse)

It was suggested that users would benefit from writing less if the software incorporated drop down menus. In particular, nurses found a body chart with drop-down menus to record wound care intuitive:

You don't have to think what you have to do. You can select "clean at 7am with Betadine". (Nurse)

However, staff noted that drop down menus should be customisable, and that space for free text may still be required.

Customisable terminology

There were complaints that the terminology used in some EPRs was complex for staff with less training in the field:

There are a lot of terms, which often a basic caregiver doesn't understand. (Care Quality Manager)

However, in the Czech home where they had recently introduced a new programme, there was a functionality that addressed this issue:

It has an advantage, that you can adjust the phrases as you please so that everyone can understand. (Care Quality Manager)

Alerts about changes in a resident's condition

Staff in all homes currently use an internal messaging application within the EPR to communicate changes in a resident's condition and how to adjust care. However, there is no functionality to alert staff based on data entered into the EPR:

The program does not alert us at all. We have a multidisciplinary meeting every day. (Supervisor)

In order to increase awareness of a resident's condition, staff would like an alert system:

If there will be any alarm when I open [the EPR] and it tells me the most important stuff it will be brilliant [...] if it shows that this person died or this person fell down. (Art therapist)

Alerts to update care plans

In the Czech home, staff are warned that the care plan needs updating when a red circle appears next to a resident's name. In the two other homes, the EPR does not provide alerts and staff keep a record on paper. Staff in one home are required to evaluate the care plan every three months. At this time, the previous care plan is automatically deleted and they should rewrite it, which causes frustration. However, not everyone agreed that this was a negative functionality of the EPR:

I personally don't mind, because at least the staff are forced to think about the current care plan. (Nurse)

In Belgium, the auxiliary nurses are required to tick off each section of the care plan on the tablet which has been completed, but this can sometimes be forgotten during a busy shift, leading to repercussions:

What happens is if inspection comes, they will say "you have not washed this woman today", you say "no I forgot [to enter it on the care plan]", but on the computer it shows that she hasn't been washed. (Auxiliary nurse)

In the home in Belgium where they have two types of devices, there is no alert to remind staff to sync the updated care plan with the tablets so that auxiliary nurses provide correct care:

Sometimes people change the care plan […] and they don't always change it here in the tablet. (Auxiliary nurse)

Interoperability

In all three homes, the EPR was not interoperable. When residents move to the home, they bring a paper report with details of medical history, which has to be manually entered into the EPR. Nurses find this frustrating and they often need to call the hospital to clarify unclear information:

We get no information from hospitals, only on paper, the old-fashioned way. (Nurse)

Structure & content

Information about people with dementia

When asked about the most important information in a care plan that staff needed to know about a resident with dementia, a common answer was the need to be alerted to any deterioration in physical health. For example, changes in eating, drinking or bowel habits, and changes in temperature, all of which could indicate possible infection and explain recent behavioural changes. It was emphasised that such information is particularly valuable for those residents with difficulties communicating verbally that they are unwell. Furthermore, staff require contact information of a family member or friend who may have greater insight into reasons linked to any changes in a resident's behaviour. Information about the type of dementia is also important:

You have several sorts of dementia and sometimes you have dementia without forgetting things, so the kind of dementia is important (Occupational therapist)

In addition to information about physical health, a number of staff highlighted the importance of obtaining a life history in order to obtain a holistic picture of an individual:

I want to put the stories in [the EPR] to remind people that this person who is lying on the bed was really a hero in his life. (Art therapist)

In order to create the most natural environment for the resident, knowledge about hobbies and past routines and professions are needed:

What routines did this person have before coming to the home, for example, if he loves to walk in the park, if he needs a coffee at two o clock in the afternoon so I don't interrupt his routines. (Art therapist)

It was emphasised that creating a care plan template for people with dementia was not always possible, and staff would prefer to personalise care plans on the EPR:

For every person, dementia is different. I have to make my own plan […] the development of the disease is also different. (Art therapist).

Assessments for dementia

Often core assessment scales were missing from the EPR, which is frustrating for staff as they need to complete these scales on paper. Scales that staff said they require for assessing people with dementia are the Quality of Life in Late-Stage Dementia Scale (QUALID) [32], the Mini Mental State Examination (MMSE) [33], and the Barthel Index [34, 35]. Furthermore, it was highlighted how staff also require access to assessment templates based on observations, which may be more appropriate for assessing people with advanced dementia with communication problems or those who become anxious during a typical assessment:

A lot of people like it that you come and speak about the past and the future, and just have a talk. Others are scared and think that you are asking questions about something bad. (Occupational therapist)

In the Czech nursing home, many of the areas in the electronic assessment forms were said to be inappropriate for the client group, where questions were aimed at the assessment of patients with mental health problems. However, for people with dementia:

there are no options that we might like to have clicked, that the clients are, for example, chronically or acutely confused. (Nurse)

Staff were also frustrated that they could not add assessment templates themselves:

The program does not offer flexibility, they give you the formats, they are the ones that exist and you cannot adapt them. The program is standardised for all nursing homes, but each nursing home has its own characteristics. (Home manager)

Improvements in structure

There were examples across all three homes where the amount of information staff were required to fill in was more than necessary, and other instances where there was not enough space to record what was needed:

This one for falls, it does not reflect everything that our [paper] fall sheet reflects. (Supervisor)

Specific improvements in structure included a table where all observations can be entered and viewed together. Trained staff also need to be able to access information recorded by each staff member. In one EPR there are tabs for each profession where they can easily access each professional's assessment and care plan, which is important, as explained by one participant:

Families always come to ask the nurse. They ask you about the physio, the therapist, the doctor and everyone. You have to know everything. (Nurse).

One auxiliary nurse wanted to be able to enter next to each step of the care plan how long it takes them:

This system does not show how much time you put in to caring for each person. It can be that you take more time with someone because they are slower, or they don't understand.
(Auxiliary nurse)

Organisational Support

Access
In Spain, auxiliary nurses could not access the EPR and were required to write notes by hand, and in Belgium where auxiliary nurses had basic access to care plans via the tablet, they were frustrated with the limited amount of information they could access:

[The tablet] shows what you have to do, but not how the person is. So, it doesn't show if the person has behavioural issues. (Auxiliary nurse)

Some trained staff felt that due to the complexity of the system, access should be restricted so that documentation is not accidentally deleted. They also believed axillary nurses should not have access to dementia diagnosis, as they may treat the individual differently:

We have always tried not to work with that person on the basis of his diagnosis, but on the basis of the personality. (Nurse)

Others believed auxiliary nurses should have access to the full EPR, including dementia diagnosis, in order to provide the most person-centered care.

Training
When asked about training, the majority of participants said that learning 'on the job' was more useful than attending a course, as they found the EPR intuitive:

In the beginning it was just pure information [...] but I'm the type, I just need to see it. (Social Worker)

This may be linked with age and prior experience with technology:

I basically grew up with these kinds of technology It really didn't cause me a problem. (Nurse)

One participant with limited experience of technology would have liked more basic training in the home, and the option of booking extra training when required. Another nurse felt overwhelmed when starting her role, and would have liked more time to learn to use the EPR:

When you start as a new staff member, then there's a lot you have to learn, and you have to learn it very quickly. There's no time to practice. (Nurse)

System support
The importance of contact with developers on an ongoing basis was highlighted. In one home, staff could write notes and feedback any problems directly to the developer, who also had remote access. However, this was not the case in another home, and staff complained about a lack of updates:

We use equipment that is not sufficiently agile. (Supervisor)

In all homes, there were allocated staff who were in charge of reporting issues to the developer, a system which worked well:

I tell my boss if there is a problem with the EPR because I am not the relevant person who can call. There is a structure. It would be a mess if anyone can call. (Art therapist).

Discussion
A common issue associated with the EPRs across all three homes was the way in they were not customisable. Participants spoke about how they wished to adjust various elements of the EPR to meet the specific needs of the nursing home and the individuals who live there. This highlights how a close relationship between the developer and the end user as part of a user-centred design (UCD) process is important [36].

As regards to devices, portable devices accessible at the point of care were often preferable. However, some nursing staff said they preferred working on a desktop device due to ease of use. This stresses the need for all levels of nursing home staff to be consulted and individual requirements according to role and experience with technology to be taken into account during system design [37]. There were also concerns amongst several staff that the use of technology in the proximity of residents was intrusive and had led to a reduction in the personal aspect of delivering care, which is in line with previous research showing that HIT may be dehumanising care [38]. The need for unobtrusive devices is of particular importance when taken in the context of dementia-friendly nursing homes, one principle of which states that personalised environments encouraging ownership are crucial [39].

Developers should ensure that software facilitates the assessment and care planning process, for instance, through customisable drop-down menus, which may reduce time spent on entering information. A number of participants also described the benefit of a system that provides alerts in a resident's condition and directs them to the appropriate care, which could be achieved through the incorporation of a clinical decision support system (CDSS). CDSS is

defined as software that assists 'clinical decision-making in which characteristics of individual patients are matched to a computerized knowledge base for the purpose of generating patient-specific assessments or recommendations' [40]. However, in order for CDSS to function effectively, information entered into the EPR should be accurate, for which Standardised Nursing Language (SNL) that follows the Advanced Nursing Process may be appropriate [41].

A lack of interoperability was described by staff in all three nursing homes, which is a common shortcoming of EPR systems [42]. A review of the literature on the management of dementia in primary care found that in order for the effective coordination of dementia care to take place, it is critical for information to be shared across healthcare providers [43]. Access and sharing of care plans across those services previously supporting an individual in the community through the means of an interoperable EPR system would allow continuity of care as the individual moves into the nursing home [44, 45]. However, interoperability is also reliant upon the consistent use of terminology across EPR systems, as well as common standards in data quality and a common architectural model [46].

Consideration of the nursing home population during the design process is also necessary. This was evident in one of the nursing homes, where the EPR was designed for patients of mental health services and inappropriate for planning dementia care. Moreover, in one home, there was no specific place to record dementia diagnosis. Staff also reported that they require a large and varied amount of information in order to plan and deliver care for an individual with dementia. Prior research has shown that staff access to a life history of an individual with dementia is linked with increased understanding and empathy towards individuals displaying neuropsychological symptoms of dementia [47]. Furthermore, due to the range of dementias and their different associated needs, which will also vary according to each individual, staff need space to create personalised care plans with individualised goals, in addition to entering standard information required by local and national best practice guidelines for care planning [45].

Although this research has primarily focused on the usability of the EPR system for dementia care, a consideration of organisational issues has revealed the importance of certain factors implicit in the successful implementation of an EPR system. Evidence from a number of studies have shown that training is crucial if effective implementation of EPR is to take place in nursing homes [22, 48]. In this study, training 'on the job' was more widely-preferred over classroom-based teaching and should be tailored to the individual's level of experience with IT. Secondly, system support, which may take the form of a specific individual onsite was specified as crucial. This is in line with prior research, which found that onsite support was one of five key elements of successful implementation of EPR in nursing homes [49, 50]. The question of who should have access to the EPR also raised issues associated with staff level of training, particularly auxiliary nurses. Unfortunately, it was not possible to interview auxiliary nurses in two of the homes, although there is previous research to suggest that, although using EPR reduced time spent with residents, it increased their accountability [49].

Limitations

Recruitment within each nursing homes was challenging due to lack of available staff and time. Furthermore, although this project aimed to compare similar nursing homes across three

countries, this was problematic due to the different systems of care across Europe. In particular, the fact that one nursing home was privately funded whereas two were public could have meant results were not comparable. Finally, translation of transcripts from their original language into English may have caused some nuances to be lost, and as interviews took place in the nursing home often surrounded by other staff, it may have meant some participants were reluctant to discuss negative issues.

Future research
Future research should consider including auxiliary nurses in data collection as they are key staff members often at the frontline in regards to care delivery. In addition, more research into the particular guidelines for dementia assessment and care planning in each of the countries is required to develop country-specific guidelines for EPR systems.

Conclusions
This qualitative exploration of staff perspectives of EPR in three nursing homes has revealed that the three EPR systems are both helping and hindering staff in assessment and care planning. All homes highlighted the importance of customisable systems, and the lack of specific characteristics needed to effectively plan and deliver care for people with dementia. People with dementia in nursing homes may have more complex needs in comparison to other residents. Therefore, EPR systems introduced into the nursing home environment should reflect best practice guidelines for dementia care, which should lead to improved outcomes and quality of life for people with dementia. Furthermore, all levels of nursing home staff should be consulted during the development, implementation and evaluation of EPR systems as part of an iterative, user-centred design process.

List of abbreviations
CDSS: Computerised Decision Support System
CI: Contextual Inquiry
EPR: Electronic Patient Record
HIT: Health Information Technology
HITREF: Health Information Technology Evaluation Framework
MMSE: Mini Mental State Examination
QUALID: Quality of Life in Late-Stage Dementia Scale
SNL: Standardised Nursing Language

Declarations

Ethical approval and consent to participate
All participants gave written informed consent prior to participation. The study was approved by the Ethics Committee at the Centre of Gerontology, Prague, Czech Republic, and by the Medical Ethics Committee of the Vrije Universiteit Brussel, Belgium [2017/410]. Ethical approval was not required in Spain for a study of this nature.

Consent for publication
Not applicable.

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Conclusions

This final chapter provides an overview of the implications of the research presented in this thesis by first discussing the best practice guidelines that were developed as a culmination of the results from all articles. Limitations of the project are then discussed, as well as some final remarks regarding avenues for future research in the field.

INDUCT Best Practice Guidance

As stated in the overview, the end goal of the INDUCT project was to produce three publications for high-impact journals, leading to best practice guidance for human interaction with technology in dementia. These recommendations are also likely to be of importance for both developers designing EPR systems for nursing homes, and nursing homes looking to implement an EPR system that is suitable for planning and delivering dementia care.

The full list of recommendations have been published online at: https://www.dementiainduct.eu/guidance/. There are five recommendations which relate to the usability of technology for people with dementia, and one which relates to the facilitators and barriers associated with the implementation of technology in dementia care.

Practical, cognitive & social factors to improve the usability of technology

1. *Portable and unobtrusive devices for electronic records are optimal for staff and residents [3.1.3.1]*

Guidance: Nursing homes providing care for people with dementia should consider introducing portable devices in addition to desktop devices for electronic patient records (EPR). Devices should not disrupt or invade residents' privacy.

Explanation & Examples: Portable devices have been shown to increase efficiency in some instances as they allow staff to record data into the EPR at the point of care instead of at the end of the shift. This enables staff to spend more time providing care to residents, particularly for residents with dementia and complex needs. Portable devices can support person-centred care by allowing immediate access to care plans with vital information about residents, such as dementia diagnosis. Rapid access to care plans is important for staff retrieving information about individuals who are at the nursing home temporarily on respite; for those residents who may be unable to recall personal information; and for those staff who work infrequently in the home and are unfamiliar with residents. However, it should be taken into consideration that some staff may prefer desktop devices based on ease of use when completing substantial documents. During the development of portable devices for nursing homes, the impact that such devices could have on residents should be taken into account and staff should explain the purpose of EPR devices to residents and family members who may be unfamiliar with the technology.

Keywords: Device; electronic patient record; nursing home; portability.

Target group: Developers of EPR, Nursing homes

Type of evidence
Integrative literature review
Qualitative study

2. Applications promoting the effective use of electronic records are required [3.1.3.2]

Guidance: Applications that should be incorporated into EPR systems used in nursing homes providing care for people with dementia include a spell-check, a copy and paste function and a keyword search function. Log-in processes should be rapid and secure.

Explanation & Examples: The presence of a spell-check has been described as saving time on proofreading, as well as increasing legibility and comprehension of documentation. This allows for more time to be spent with residents with dementia in direct care, and for correct care to be provided. A copy and paste function also saves time by allowing staff to easily transfer information across sections of the EPR where information is often required to be replicated. A keyword function allows staff to enter a keyword and jump to the relevant section in a resident's notes, allowing for more efficient retrieval of information, important in situations when a resident is unable to recall personal information. Rapid log-in processes should reduce barriers to using the EPR, as slow log-in processes have been found to prevent staff from accessing information about residents before delivering care, and have meant staff have been forced to pass on information about residents verbally instead of entering it into the EPR. This may mean important information regarding any sudden changes in an individual's condition might be missed.

Keywords: Applications; electronic patient record; nursing home; software

Target group: Developers of EPR, Nursing homes

Type of evidence

Integrative literature review

Qualitative study

3. Functionalities of electronic records should be tailored to the nursing home environment [3.1.3.3]

Guidance: Developers of EPR systems for dementia care should consider including a function allowing for the automated generation of graphs to show trends in data, and an accompanying function to prompt staff about changes in a resident's condition. In addition, functions allowing for the automated generation of care plans from assessment data, and alerts to prompt staff to create or update a new document in the EPR may be of value to nursing homes. Interoperability should be a goal for the future.

Explanation & Examples: Automatic generation of graphs displaying trends in a resident's condition increases visibility of changes, allowing staff to more rapidly identify and respond to changing care needs. For example, graphs showing changes in weight, which can commonly affect individuals with dementia. Furthermore, through the incorporation of artificial intelligence (AI), some EPR systems are able to analyse resident data and provide alerts to staff about potential risk factors. For instance, alerts to warn staff about potential skin breakdown, important for those residents with dementia receiving end-of-life care, who may be spending considerable amounts of time in bed and have reduced fluid intake. Automatic generation of care plans from assessment data could save staff time in administration, as well as automatic alerts incorporated into the EPR that prompt staff to update care plans, meaning optimal care can be planned and provided to individuals with dementia. Finally, EPR systems should be interoperable, so that staff can access and communicate relevant information securely over the internet with external healthcare providers, instead of using paper records.

4. *Electronic care documentation should meet the needs of nursing home staff caring for people with dementia [3.1.3.4]*

Guidance: EPR systems should include the necessary assessment templates for use in the care of people with dementia, as well as space for entry of free text and to upload photos of residents. Electronic assessment forms and care plans for dementia care should use formalised nursing language to prompt the entry of correct information, and structured templates that guide staff through body systems, leading to comprehensive care plans.

Explanation & Examples: EPR systems in nursing homes have been found to omit the appropriate scales and assessments required by nursing staff caring for people with dementia. For instance, staff stated that they require the MMSE assessment, the QUALID scale, and the Barthel Index of Activities of Daily Living incorporated into the EPR. Furthermore, staff have identified incorrect nursing language in electronic forms, meaning important information is not recorded. For example, the omission of the term 'dementia diagnosis' from assessment forms meant that nurses were not entering this information about residents. By including the appropriate structured forms for data entry with formalised nursing language, AI tools can be more successfully integrated into the EPR. Space for photos of residents is important for new staff when learning residents' names and for confirming identities of residents when required, and structured body templates included into the EPR have been identified as a useful visual prompt for completing assessments. Staff also require space to enter life stories, and space for free data entry for additional notes and observations. For example, changes in the behaviour of a resident with dementia.

5. *Electronic care documentation should meet the needs of people with dementia in nursing homes [3.1.3.5]*

Guidance: Electronic assessment forms and care plans used for planning dementia care in nursing homes should prompt staff to consider the following needs of residents: activities, maintaining previous roles, reminiscence, freedom and choice, appropriate environment, meaningful relationships, support with grief and loss, and end-of-life care.

Target group: Developers of EPR, Nursing homes

Explanation & Examples: The themes above have been described by people with dementia in various studies exploring their self-reported needs and experiences in nursing homes. Developers should therefore consider including these themes into electronic assessment and care plan templates as prompts for nursing home staff to explore with residents.

Keywords: Assessment; care plan; electronic patient record; needs; nursing home; self-report

Target group: Developers of EPR, Nursing homes

Type of evidence

Scoping literature review

Implementation of technology in dementia care: faciliators & barriers

   1. *Nursing home managers should ensure the appropriate conditions for implementation of EPR systems*

Guidance: Issues such as access to the EPR system, appropriate training and system development and support should all be considered by nursing homes before and during the implementation of EPR systems.

Explanation & Examples: Access or non-access to various parts of the EPR system should be discussed and put in place. For instance, management should consider whether auxiliary staff should be allowed to access medical information, such as dementia diagnosis, and whether this would consequently entail training in the field of dementia. Appropriate training in the EPR system according to individual staff needs is also required, as some staff may be more experienced in the use of technology than others. Training 'on the job' was found to be preferred by many over classroom-based teaching. Finally, nursing homes should consider working alongside software developers during the design of EPR systems in order to ensure software is appropriate for their needs. Developers should continue to be involved in improving the EPR following implementation, as part of an iterative cycle.

Keywords: electronic patient record; implementation; nursing home; software development; training

Target group: Developers of EPR, Nursing home management

Type of evidence
Qualitative study

Limitations
This sub-section will provide a brief resumé of the limitations of the overall project. Limitations of each separate study can be found in the discussion section of each of the papers.

Firstly, the project has been conducted from a European or Western perspective. In both literature reviews (papers 1 & 3), synthesised studies were written in English, and predominantly carried out in Europe, USA or Australia. In other areas of the world, there is often more importance placed on dementia care at home, and therefore individuals with dementia and their family carers are likely to require access to the EPR on their phone or

another personal device. EPR software may also need to be adapted for informal carers, for instance, adopting vocabulary which is suitable for persons without a healthcare background. Moreover, the design of care plan templates should take into consideration that the needs and experiences of people with dementia may also vary considerably according to not only their living environment, but also different societies, cultures and religious beliefs.

Secondly, the qualitative usability study (paper 4) was carried out in three European countries, each with different health services. For instance, in the Czech Republic, there is a clear distinction between the health service and social care service, with data protection laws preventing staff from accessing a patient's notes if they do not work for the service. Therefore, the topic of interoperability may have been even more significant for the participants in the nursing home in Prague than for participants in Spain and Belgium, and therefore this topic may have been discussed to a greater extent during the interviews. A further limitation could have been associated with the way in which two of the nursing homes were public, whilst the Spanish nursing home was private. For instance, this home may have had additional funds to spend on a superior EPR system, with more devices for staff. This may have limited the generalisability of results.

Finally, qualitative methods were chosen as they allowed for an in-depth exploration of the user, task and environment as part of a Human Factors approach, the theoretical framework underpinning this research. However, there may have been limitations associated with the methods used. For instance, the presence of one, and sometimes two researchers, as well as fellow staff members who were sometimes in and out of the offices, could have meant participants were reluctant to discuss certain topics, particularly those perceived as negative. Participants may have felt they were being 'tested', which could have also had an impact on their behaviour.

The incorporation of quantitative methods could have produced a larger number of usability issues (Georgsson & Staggers, 2016). For instance, the System Usability Scale (SUS) (Brooke, 1986) was considered for use alongside qualitative data collection. However, the SUS has not yet been translated into Flemish or Czech, and the timeframe of this project did not allow for the professional translation of the questionnaire into new languages or its pilot testing. The use of eye tracking may have also provided a valuable way in which to gather objective information on how individuals interact with EPR software (Cooke, 2006).

Future research

This project has provided initial evidence towards the development of guidelines for the design of EPR systems for use in dementia care planning and delivery in nursing homes, which to the author's knowledge, is the first piece of research to do so. EPR systems that meet the needs of nursing home staff may lead to improved care, and consequently bring about enhanced quality of life for residents with dementia. Moreover, consistent recording of patient data in an electronic record can provide a valuable resource for secondary uses of data, for instance in epidemiological monitoring, and the development of machine learning for identifying optimal care pathways.

Future research should consider engaging people with dementia in the design of electronic templates for care planning so that their full range of needs are assessed and planned for. An evaluation of the impact of various EPR systems on outcomes for residents specifically with dementia may also provide new evidence as to the optimal design of EPR for dementia care. Furthermore, EPR usability research should be conducted with auxiliary staff, who are often at the front line of care delivery in nursing homes, and therefore require rapid access to a range of information about an individual with dementia. Successful design of the EPR system is thus particularly crucial for their role. Researchers should also consider exploring in more detail the ways in which decision support systems can be developed that are specific to nursing practice decisions in the field of dementia, and finally, explore the standards for the development of a common nursing terminology used in EPR templates, in order to support successful interoperability across healthcare providers, ensuring joined-up care for people with dementia.

References

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Cooke, L. (2006). Is Eye Tracking the Next Step in Usability Testing? 2006 IEEE International Professional Communication Conference.

Georgsson, M., & Staggers, N. (2016). An evaluation of patients' experienced usability of a diabetes mHealth system using a multi-method approach. *Journal of Biomedical Informatics,* 59, 115–129.

Appendices

Appendix A- Research Materials

Appendix A1. Information Sheet

Participant Information Sheet

Title: Care programmes and ICT support in different countries

Who am I?

My name is Kate Shiells and I am from the United Kingdom. I am currently working as a trainee researcher at the VUB on a European Commission-funded project called INDUCT (Interdisciplinary network for dementia using current technology). The objective of this project is to improve technology and care for people with dementia. Before joining the project, I worked for over ten years in care homes with people with dementia in the United Kingdom, and also for the Alzheimer's Society.

What is the purpose of the study?

I would like to find out which aspects of the electronic documentation system help or hinder you to fill out assessment forms and care plans for people with dementia. For example, I would like to know:

-how easy the device (e.g. computer or tablet) is to use

-whether there are enough devices in the nursing home

-what you think about the layout and wording of the assessment and care plan forms.

-whether the forms let you enter enough information about residents with dementia.

-the changes you would like to be made to the system so it is easier to use.

After collecting this information, I will produce guidelines for the development of electronic documentation systems for use in nursing homes.

Why have you been chosen?

You have been chosen because you are a member of staff at [name of nursing home] who uses electronic documentation.

What will happen if you take part?

I would like to observe you using the electronic documentation system completing an assessment form and a care plan. Whilst you are completing this task, I would like you to tell me all the things you like or dislike about the system. For example, you may dislike that it takes too long to open a document, or you may like the layout of a particular form.

This is not a test of any sort and you should feel free to give your opinion on everything you like and don't like.

I will record what is said and also take notes during this task. I will ask you some brief questions before the observation about your professional background, and may also ask some questions during and after the observation in order to understand more about the things you have said.

The whole process should take no longer than one hour.

Please note

- All recordings and notes will be used for data analysis and then destroyed afterwards.
- The study will be anonymous so that that neither your name, the name of the nursing home where you work, nor any other identifying information relating to you or the nursing home will appear in the study.

Do you have to take part?

Not at all. If you decide to take part, you should feel free to answer as many questions as you are happy to and you are free to stop the observation or interview process at any time without stating reasons for doing so.

Additional information

-The results will be treated confidentially, in accordance with the Belgian legislation on the protection of privacy and the law on patient rights. Any incorrect information can be corrected at your request. Reports in which you are identified will not be publicly available. If the results of the study are published, your identity will remain confidential information.

-"Every study entails a risk, however small this may be, even if it is limited to insufficient protection of the confidentiality of the participant's personal data. In accordance with the Belgian law of 7 May 2014 on experiments on the human person (Article 29), the client is, even faultlessly, liable for the damage incurred by the participant or his beneficiaries directly or indirectly related to the experiments carried out. The researchers have taken out an insurance for this.

-You will not be reimbursed for your participation in this research.

-The study was approved by the Medical Ethics Committee of the UZ Brussel and the VU

Consent Form

Title of Study: Care programmes and ICT support in different countries

If you have read the information sheet and you are happy to take part, please read the statements, tick the boxes and complete and sign the sections at the bottom of the page.

I confirm that I have read and understood the information sheet for the study ☐

I confirm that I have had the opportunity to ask questions about my involvement ☐

I confirm that I have received enough information about the study and that my questions have been answered fully ☐

I understand that my participation is voluntary, and that I am free to withdraw From the study at any point, without stating a reason ☐

I agree to take part in the study ☐

I consent to the interview being audio-taped ☐

I agree for my anonymised quotes to be used in the reporting of the study ☐

_____   _____   _____

Name of Participant   **Signature**   **Date**

_____   _____   _____

Name of researcher taking consent   **Signature**   **Date**

Background Questionnaire

Participant (Number of interview)
…………………………………………………..

Date, time of day, and place of observation
……………………………………………………

Job Role
 ……………………………………………………

How long have you been working in this role?
……………………………………………………

How long have you been using the electronic documentation system?
……………………………………………………

How would you rate your experience in IT in general?
1-None
2-Minimal
3-Moderate
4- Good
5-Excellent

Interview Guide

1. Device

What do you think about the type of device you use?
What is your opinion on the amount of devices in the home?
Do the residents or family members/ visitors ever express an opinion on the device?
Do you think that devices ever invade residents' privacy? Or are annoying for residents?

2. Applications

Which changes to the system would help you to complete assessment and care planning forms more easily? Are there any applications that could help you with assessment and care planning?
Which changes to the system would help you to access assessment forms and care plans more easily?

3. Structure and Content

How do you feel about the amount of information you collect about residents for assessment and care planning?
What is your opinion on the language used in the forms? Is standardised nursing terminology used?
Do forms reflect best practice in dementia care?
What is your opinion on the layout of forms? Are there sections missing?
How easily can you access care plans?
How easily can you access information about dementia diagnosis etc.?
What is most important for you to know about the residents with dementia you care for?

4. Functionality

How easy do you find filling out assessments?
How easy is it to create a care plan from assessment data?
How easily can you access resident information from other care providers? E.g. hospitals?
How easily can you create trends from data?
Are you reminded to create or update assessments and care plans?
How do you receive alerts about changes in a resident's condition?

5. Organisational support

How much training did you receive? Can you describe the training? Was it sufficient? Is it ongoing?
If there is a problem with the EPR, how do you access help? Is this sufficient?

Appendix B- Presentations

Appendix B1. List of presentations delivered 2016-2019

-Shiells, K. Britské inspirace pro život s demencí (British Inspiration for living with dementia). Oral presentation at the Czech Alzheimer's Society Conference (Prague, September 2016).

-Shiells, K. Holmerova, I. Steffl, M., Stepankova, O. Electronic patient records as a tool to facilitate care provision in nursing homes. Poster presentation at Alzheimer Europe Conference (Berlin, October 2017).

-Shiells, K. Update on my research-Mid Term Review. Oral presentation at the 3rd INDUCT School (Witten, February 2018).

-Shiells, K., Holmerova, I., Stepankova, O. Usability of Electronic Patient Records for Care Planning in Nursing Homes: Protocol. Poster presentation at World Congress on Medical Physics and Biomedical Engineering (Prague, June 2018).

-Shiells, K., Holmerova, I., Stepankova, O. Usability of Electronic Patient Records for Care Planning for People with Dementia in Nursing Homes: Preliminary Results. Poster presentation at Alzheimer's Disease International Conference (Chicago, July 2018).

-Shiells, K. Update on my research. Oral presentation at the 4th INDUCT School (Prague, September 2018).

-Shiells, K., Stepankova, O., Holmerova, I. Usability of Electronic Patient Records (EPR) for Care Planning for People with Dementia in Nursing Homes: A Multiple Case Study. Oral presentation at the Czech Alzheimer's Society Conference (Prague, September 2018).

-Shiells, K. Update on my research. Oral presentation at the 5th INDUCT School (London, May 2019).

-Shiells, K., Pivodic, L., Holmerova, I., Van den Block, L. Self-reported needs of people with dementia in nursing homes: a scoping review. Poster presentation at the Alzheimer's Society Conference (London, May 2019).

Appendix C- List of co-author publications

-Steffl, M., Bohannon, R.W., Sontakova, L., Tufano, J.J., Shiells, K., Holmerova, I. (2017). Relationship between sarcopenia and physical activity in older people: a systematic review and meta-analysis. *Clinical Interventions in Aging,* 12, 835-845.

-Steffl, M., Sima, J., Shiells, K., Holmerova, I. (2017). The increase in health care costs associated with muscle weakness in older people without long-term illness in the Czech Republic: Results from the Survey of Health, Ageing and and Retirement in Europe (SHARE). *Clinical Interventions in Aging,* 12, 2003-2007.

-Vanova, M., Irazoki, E., García-Casal, J.A., Martínez Abad, F., Botella, C., Shiells, K., Franco-Martín, M.A. (2018). The effectiveness of ICT-based neurocognitive and psychosocial rehabilitation programmes in people with mild dementia and mild cognitive impairment using GRADIOR and ehcoBUTLER: Study protocol for a randomised controlled trial. *Trials,* 19:1.