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The components of personal passports for people living with dementia in an acute healthcare setting: An integrative review

(ii) Short running title

Personal passports for people living with dementia

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Abstract

Aim: To explore the components of personal passports for people living with dementia in an acute healthcare setting

Background: Globally, supporting people with dementia poses a prominent health and social care challenge. Importance for people with dementia in an acute healthcare setting includes social relationships and communication with healthcare staff. A personal passport is an international initiative designed to support the personhood of the person living with dementia.

Methods: This integrative review is based on the methodology of Whittmore and Knafl (2005). The Preferred Reporting for Systematic Reviews and Meta- Analyses (PRISMA) guidelines and checklist were adhered to. A database search of PubMed, MEDLINE, CINHALL, Scopus and EBSCO databases were systematically searched.

Results: This integrative review identified nine research studies on the components of personal passports that met the inclusion and exclusion criteria. A constant comparative method of data analysis identified five key pivotal themes: person-centredness, communication, family/carer involvement, education and leadership.

Conclusion: The use of personal passports supports the provision of person-centred care for people living with dementia through enhancing the wellbeing of both the person and their families/caregivers.

Relevance to clinical practice: Personal passports are an important document and should be determined by the person with dementia, their care needs and the caregiver's role in meeting these needs.

KEYWORDS Alzheimer disease; communication; communication passport; dementia; healthcare passport; passport; patient passport; personal passport; personal profile; 'This is me', acute healthcare setting.

1 INTRODUCTION

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Dementia is a progressive neurodegenerative disease characterised by a loss of cognitive abilities, functional abilities and social skills. These losses can impact on the quality of life for the person living with dementia (O'Shea & Monaghan, 2016). In Ireland, supporting people living with dementia poses a prominent health and social care challenge as the prevalence of people living with dementia is increasing exponentially. Increasing life expectancy correlates with an increased incidence of older-age related comorbidities; this includes dementia. International statistics state that 50 million people are living with dementia and this trend is predicted to continue in the coming decades, and by 2050, it is predicted that there will be 152 million people world-wide living with dementia (Alzheimer's Disease International (ADI), 2019).

Dementia is a key health policy priority for many countries in terms of the burden of the disease and significant economic cost (OECD, 2015). The Irish Department of Health (DoH) (2014) estimate that one quarter of people accessing acute hospital services are likely to experience dementia. Connolly & O'Shea (2015) report that people diagnosed with dementia have a greater length of acute hospital admissions than people without a recorded diagnosis of dementia. This results in costing the Irish economy over €199 million per annum.

Currently, there is no cure to alter the progressive course of dementia or offset the clinical manifestations of the disease processes (World Health Organisation (WHO), 2020). The overarching philosophy of dementia care is person-centred care that promotes an approach which highlights individual's unique values, personal history and personality through interpersonal relationships (Fazio et al., 2018). Person-centred care was pioneered in the 1980s by Kitwood and currently is a well-established universally embraced approach to care for people with dementia. Patient-centred care putting the person first is its defining feature (Kitwood, 1997). The concept of person-centred care continues to evolve and marks a distinct move away from traditional medical models of care towards a more holistic, person-centred culture of care (O'Shea et al., 2017). Within an acute healthcare setting, Dewing (2016) contends that a lack of understanding and knowledge of person-centred care results in poorer experiences and outcomes for the person (Suarez & Farrington-Douglas, 2010; DoH, 2014). Limited understanding of dementia care among acute healthcare practitioners, combined with organisational constraints, task orientated approaches and staff motivation can provide challenges in delivering person-centred care and personal passports (Lloyd et al. 2018; Peart et al., 2019).

2 BACKGROUND

People aged sixty-five plus living with dementia have on average four comorbidities, this may increase acute hospital admissions rates for this patient population. In contrast people without dementia have on average two chronic conditions (Poblador-Plou et al., 2014). The detrimental impacts of hospitalisation for a person with dementia has an extensive pool of research including the works of Butcher (2018), Pinkert et al. (2018), Digby et al. (2017) and (DoH, 2020). Their research purports that acute healthcare settings can exacerbate the effects of dementia and increase risks for a person with dementia in this environment. The acute healthcare setting can be perceived as a disorientating and stressful place, by and for, people with dementia. The negative effects of acute hospitalisation are associated with cognitive and functional decline (Suarez & Farrington-Douglas, 2010; Hung et al. 2017, DoH, 2020). The reasons for this are multifactorial and include: the rapid pace of activity within an acute health care setting, and a predominant task-illness orientation that can be challenging for people with dementia (Moyle et al., 2016). In addition, Daly et al. (2013) highlight the negative impacts of poor understanding of the needs of people with dementia, insufficiencies in communication, and disconnects within the acute healthcare setting.

De Suin & Manning (2010) contend that limitations in dementia specific training and education impact negatively on quality care provision people with dementia. It is further reported by Skaalvik et al. (2010) that nurses' interactions are often limited to meeting physical needs and there is a failure to collaborate patient histories (Allwood et al, 2017). Nolan (2006) suggests that it can be difficult for nurses to establish a bond with the person and this can cause distress for the individual person with dementia (Andrews, 2013). Internationally, effective communication during admission is recognised as crucial to ensuring patient safety and quality care provision (WHO, 2017; Braaf et al. 2015). The main emphasis of many of these concerns relates to effective transfer of information between healthcare professionals. However, patients and their carers also play a key role in the information sharing processes on admission and throughout the person's acute hospital stay.

Globally, healthcare systems and organisations are focusing on enhancing health systems performances through the application of a person-centred care model (Santana et al., 2018). A key global initiative designed to support the personhood of the person with dementia is a 'personal passport' (Baillie & Thomas, 2020; Leavey et al., 2017; O' Reilly, 2016; Brooker et al., 2013 Upton et al., 2012). In addition, The Irish National Audit of Dementia Care in

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Acute Hospitals (2020) has recommended addressing the needs of people living with dementia in a more responsive and person-centred manner by using relevant information documents such as a personal passport. A personal passport is a tool designed to address the personhood of the person with dementia and enhance dementia care provision. There are a variety of terminology used within nursing literature to describe the personal passport concept. These including 'personal passport', 'healthcare passport', 'communication passport', 'patient passport', 'personal profile' and 'This is me'. These terms are interchangeable and have broadly similar meanings. Throughout this integrative review the preferred term used will be personal passport.

A personal passport is a written documentation that supports professionals to know the person and better understand the person's abilities and the supports they require in an acute unfamiliar environment. The Alzheimer Society UK (2010) outlines that the 'This is me' document provides a 'snapshot' of the person with dementia. It captures information pertinent to caring for the person living with dementia including routines, preferences, likes and dislikes (O' Reilly, 2016). It is important to note it is not a medical document. The aim is to facilitate individualised communication, enhance the provision of quality person-centred care and family involvement (Upton et al 2012, Brooker et al 2013). International evidence-based empirical data illustrates the effective use of personal passports through strategies such as 'Getting to know me', Scottish Care, (2013); 'All about me' Upton et al. (2012); 'Knowing me' NHS, West Sussex, (2012) and 'This is me' Alzheimer Society UK, (2010). Awareness of the biography of the person with dementia enhances person-centred care and promotes personalised communication; this enables a more positive outcome for the person living with dementia (Brady et al. 2018).

3 METHODS

Whittemore and Knalf's (2005) modified framework for research reviews underpins this integrative review. Their Integrated Review stages were used throughout from question development to data analysis. This stages approach enhances rigour in this review by allowing for the analysis of a combination of eclectic methodologies. The guidelines of Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) are applied (Moher et al. 2009) (Supplemental File 1).

3.1 Aim

The review purpose is to evaluate the key components of personal passports for people living with dementia in an acute healthcare setting.

3.2 Research question

The problem identification stage enabled development of the research question: What are the key components of personal passports for people living with dementia in an acute healthcare setting?

3.3 Search Strategy

In the literature search stage, the electronic databases CINAHL, PubMed, MEDLINE, Scopus and EBSCO were searched with the key words: Alzheimer disease; communication; communication passport; acute healthcare; dementia; healthcare passport; passport; patient passport; personal passport; personal profile; 'This is me'. The uses of Boolean Operators, specifically 'AND' and 'OR' were used. The term dementia was searched in tandem with each of the key terms.

3.4 Inclusion and exclusion criteria

Inclusion criteria included research studies with a clear focus on personal passports for people living with dementia in an acute healthcare setting. Published in the English language in peer reviewed journals between 2010 – 2020; seminal literature outside of this date range was permitted. This 10-year period was selected to ensure the research data had clinical currency and clinical relevance and the English language was applied to enable constant comparative analysis. The exclusion criteria included literature in non-peer reviewed journals and when the focus was not for inpatients with dementia in an acute setting. 486 papers were excluded due to potential innate bias and subjective impartiality resulting from non-peer review; subjective opinions; and/or subjective experiences. This process is summarised in the PRISMA chart (Figure 1).

3.5 Data extraction and data synthesis

The data evaluation stage was undertaken, the extraction of specific methodological features from the initial search returned a combined total of 1158 academic studies. 486 studies were identified as duplicates, resulting in 672 unique investigations that potentially could inform this integrative review. The unique records were screened and a total of 587 records were subsequently excluded, predominately due to their focus on patients without a diagnosis of dementia and non-acute care settings. Of the 85 remaining studies, eligibility criteria were

identified, and a critical examination of each study was conducted. Full papers obtained ($n=85$), of which 9 met the inclusion and exclusion criteria (Figure 1).

The first author extracted data from each study: aim; methodology; population and sampling; data collection; data analysis; results and discussion. A supervisory review panel of three academic and clinical advisors [LK, JL, DC] verified the accuracy of the data extracted, and any discrepancies were resolved (Table 1). The Grading of Recommendations, Assessment, Development and Evaluation (GRADE) system and checklist was utilised to critically appraise the nine studies (Guyatt et al. 2011, Ryan et al., 2016). Grading focuses on key areas of the studies: the type of research; population size and sampling processes; methodology/designs used for the studies; appropriateness of designs to the study aims and research question; validity and reliability of study findings; strengths, limitations, biases and recommendations of the studies. A beneficial component of the GRADE system for clinically focused research is that it provides extensive guidance on assessing the quality of evidence (Ryan et al., 2016). It was further reviewed by a panel of three academic supervisors [LK, JL, DC].

The overall evidence of selected articles was systematically graded into one of four categories: high, moderate, low and very low. The allocated grade was based on their overall quality of the evidence in each of the nine studies (Table 1). Three articles by Leavey et al., 2017; Luxford et al., 2015; Sampson et al., 2016 were graded as High; Baillie & Thomas, 2020; Department of Health, 2019; O'Reilly 2016; Bray et al., 2015; Brooker et al. 2013 and Upton et al. 2012 research were graded as Moderate.

4 RESULTS

The data analysis stage employed constant comparative analysis to order, code, categorise and summarise the data. Studies were conducted in Australia (Luxford et al. 2015), the UK (Baillie & Thomas 2020; Leavey et al. 2017; Sampson et al., 2016; Bray et al., 2015; Brooker et al. 2013; Upton et al. 2012) and Ireland (Department of Health (DoH), 2019; O'Reilly, 2016). Qualitative data collection methods included in-depth interviews (Leavey et al., 2017), semi-structured interviews (Baillie & Thomas, 2020; O'Reilly, 2016) and case studies (Bray et al. 2015; Brooker, 2013). Quantitative data collection methods included a pilot study (DoH, 2019), mixed methods included questionnaires and observations (Sampson et al., 2016), clinical indicators surveys and narrative text (Luxford et al., 2015, Upton et al., 2012).

The number of participants in the individual qualitative studies ranged from 3-58, with a total of 104, these included people living with dementia ($n=28$), family member supporting a person with dementia ($n=6$) and healthcare staff ($n=67$). Three cases studies were included and one pilot studies ($n=62$). The quantitative study recruited 1,277 clinical staff and mixed methods study enlisted 2,020 clinical staff. In order to enhance rigour, a constant comparative analysis approach was applied to the extracted data (Table 2). This enabled analysis of the broad array of designs in this integrative review and facilitated iterative data comparison, conclusion and verification across the nine primary data sources (Miles and Huberman 1994).

Following data reduction, data display and data comparison stages, five key themes emerged from the data: (1) person-centredness, (2) communication, (3) family/carer involvement, (4) education and (5) leadership.

Theme 1 Person-centredness

All nine studies identified person-centredness as a central component of personal passports for people living with dementia (Baillie & Thomas 2020; Department of Health, 2019; Leavey et al., 2017; O'Reilly, 2016; Sampson et al., 2016; Luxford et al., 2015; Bray et al., 2015; Brooker et al., 2013; Upton et al., 2012). Analysis of the data revealed that personal passports are a simple and useful communication tool in an acute healthcare setting when used appropriately.

Luxford et al.'s (2015) large quantitative study with 1059 respondents identified that personal passports are a simple and useful communication tool, utilised to support clinicians in delivering person-centred care and engaging with carers. This was further affirmed by Upton et al.'s (2012) stakeholder two-point prevalence survey and Sampson et al.'s (2016) findings that personal passports are a communication management tool that supports acute care clinicians. Brooker et al. (2013), DoH (2019), O' Reilly, (2016), and Upton et al. (2012) identify that personal passports aided in the implementation of person-centred care by providing staff with readily available clinical and non-clinical information. By engaging with carers identification of early indicators of potential impacts on patient safety and quality of care can be recognised and acted on.

In contrast, Bray et al. (2015) and Brooker et al. (2013) UK based research employed case study methodological approaches, these revealed positive experiential effects for acute inpatients with dementia when person centred care is provided. Their findings affirm that when person centredness is promoted improved care outcomes are realised. These studies

findings resulted from a range of empirical methodologies including quantitative, qualitative and mixed methods. It is apparent that the eclectic methods used across the nine studies demonstrate the importance of a person-centred approach. A key component of personal passports in the provision of quality and effective dementia care is through the promotion of communication.

Theme 2 Communication

All nine studies identified that personal passports promote communication for all stakeholders in an acute care setting. An approach to addressing and aiding the implementation of person-centred care is identified through the gathering of personalised information in the form of a personal passport (DoH, 2019; O' Reilly, 2016; Brooker et al. 2013; Upton et al. 2012). A personal passport provides staff with information important to the person and enables tailored interventions to be more personalised, a fundamental component to the effective use of personal passports (Baillie & Thomas 2020; Department of Health, 2019; Leavey et al., 2017; O'Reilly, 2016; Sampson et al., 2016; Luxford et al., 2015; Bray et al., 2015; Brooker et al., 2013; Upton et al., 2012).

Baillie & Thomas (2020) add that the collection of basic information and small details including, for example, 'if the person likes sugar in their tea' is central to the provision of good person-centred care and getting to know the person. The utilisation of personal passports in acute care subsequently leads to enhancing communication management by supporting staff to realise what is fundamentally important to their individual patients (Leavey et al. 2017; Upton et al. 2012).

Theme 3 Family/Carer involvement

Eight studies identified family/carers participation is an essential component in developing personal passports for people living with dementia (Baillie & Thomas 2020; Department of Health, 2019; Leavey et al., 2017; O'Reilly, 2016; Luxford et al., 2015; Bray et al., 2015; Brooker et al., 2013; Upton et al., 2012). These studies concur that family involvement is vital as the content of personal passports includes information privy to and gleaned from family/carers regarding: a person's culture; family background; important events, people and places from their lives; personal preferences and routines. Furthermore, Upton et al. (2012) observed that for staff to implement person-centred care, personal communication tools such

as the Alzheimer Society's 'This is me' document, is completed with the person and their family to maximise effective communication.

Leavey et al. (2017) proposes that the use of personal passports should be determined by the extent of the person with dementia care needs and the caregiver's role in meeting these needs. Within this context, Upton et al. (2012) agrees that identifying key information is critical for patients who are unable to provide the information themselves. This is further supported by the Irish Department of Health (DoH, 2019) study on an Enhanced Care Model for patients who have altered behaviour and cognition including a dementia diagnosis. This pilot study finding acknowledge the importance of family/carer involvement as a key component in the provision of effective inpatient care. An important finding, during their spot audit on the use of personal passports, was that only 46% of passports had evidence of family engagement during its development. A decision was made to add family signature to the form to note 'their involvement in the development of the passport' (DoH, 2019, p.31-32), an 'increase in use and awareness of the bespoke documents demonstrates an early sign of the model of care becoming embedded within the organisation's practices.' An initial positive outcome of this pilot is increased involvement of family in Enhanced Care; O'Reilly (2016) concurs and refers to familial input as 'guardianship' and 'advocacy' roles.

Theme 4 Education

Education is identified in eight studies as a prominent theme (Baillie & Thomas 2020; Department of Health, 2019; Leavey et al., 2017; O'Reilly, 2016; Sampson et al., 2016; Luxford et al., 2015; Brooker et al., 2013; Upton et al., 2012). Brooker et al.'s (2013) research was conducted through four reflective phases over a two-year period investigated the use of a Dementia Care Bundle for improving the quality and safety of hospital care for patients with dementia with acute physical illness. They identified that staff who were trained in all aspects of dementia care practiced person-centred care and education was central to enabling staff to understand the principles of the care bundles approach, and the practice of information gathering. The results concluded that staff noted significant improvements in care delivery. This was affirmed by Baillie and Thomas (2020).

Baillie and Thomas's (2020) social constructionist qualitative study analysed healthcare professionals' perceptions and experiences of using personal information documents. They used a longitudinal design to conduct twelve focus group interviews over two years; purposive sampling was used with eighty healthcare professionals' participants from a

National Health System Trust in London, England taking part. Education on dementia, using ‘Barbara’s Story’, was seen to embed the use of personal information documents across care settings. Sampson et al. (2016) evaluated the impact of a system-wide training programme in dementia care for acute hospital staff. A ‘train the trainer’ model was implemented across eight English acute care hospitals via a large academic health and social network. It is acknowledged throughout the literature that education plays a key role in promotion, engagement and use of personal passports in the acute healthcare setting.

Theme 5 Leadership

Eight studies identify that effective leadership is required for implementation of personal passports in an acute care setting (Baillie & Thomas 2020; Department of Health, 2019; Leavey et al., 2017; O’Reilly, 2016; Luxford et al., 2015; Bray et al., 2015; Brooker et al., 2013; Upton et al., 2012). Luxford et al. (2015) identified that strong leadership is required to allow additional time and education to further engage, and obtain buy-in, from various stakeholders. Leavey et al. (2017) research finds that further considerations are required regarding responsibility for the dissemination and oversight of the personal passport. In addition, Upton et al. (2017) argue cultural change is required. The key to the successful adoption of personal passport documentation, they suggest was through purposeful leadership across the management spectrum.

Organisation readiness and staff motivation were areas considered in several studies including DoH (2018) and Bray et al. (2015). Bray et al. (2015) case study research was conducted across three hospital trusts in England found that working closely with care teams to ensure the benefits of making personal passports part of the care management increased the communication tool’s usage.

5 DISCUSSION

The following in-depth discussion of the five key themes draws on contemporary comparative literature to support or challenge the findings.

5.1 Effective promotion of person-centred care

It is clear from this integrative review thematic analysis that admission to an acute healthcare setting can be stressful and disorientating for a person living with dementia and results in a decline in their cognitive ability and levels of functioning (DoH, 2020). The WHO (2010) identified person-centredness as a vital competency of health care workers and a key

component of health care quality. Despite the research supporting person-centred care in the acute setting, its implementation has challenged most healthcare systems in its delivery (Santana et al., 2018). Furthermore, nurses indicate the delivery of person-centred care can be challenging for older people with cognitive impairment (Grealish et al., 2019).

A component of person-centred care is to see the person behind the dementia, knowing the person, their history, their interests and understanding how dementia is impacting on their lives (Manthorpe & Samsi, 2016). The personal passport is designed to support the personhood of the individual with dementia, all nine studies reviewed identified person-centredness as a key component of personal passports. However, in order to attain personalised information, healthcare staff need to partner with the person with dementia and their families/carers to co-design and deliver personalised dementia care. (Santana et al. 2018). This will further facilitate the meeting of a variety of challenges posed by the complexity of dementia and thus, lead to higher quality care (Santana et al. 2018; Sampson et al. 2016).

One of the key challenges raised throughout the literature is at what stage is the personal passport introduction to the person living with dementia. Baillie & Thomas (2020) highlight the need for the personal passport documents to be completed at an early stage following diagnosis of dementia. However, Leavey et al. (2017) offer an insightful argument in opposition to this and highlight that a person living with dementia rarely engage with the personal passport themselves and suggest that the passport should not be issued to families soon after diagnosis. Foley et al. (2019) concurs and further outlines there is a risk of overloading of specialist services especially soon after diagnosis. This is further exemplified as a diagnosis of dementia can be associated with stigma (Keogh et al. 2020). Further corroborating the view presented by Leavey et al. (2017) that following a diagnosis of dementia there are adjustments to be made, a great deal of information to be synthesised and the grieving process maybe ongoing for the individual (Alzheimer Society of Ireland, 2020). Person-centredness should acknowledge an individual's right to self-determination along with shared respect and understanding (McCormack & McCance, 2017). These factors are relevant to any consideration of the introduction of the personal passport.

5.2 Use of personal passports to promote effective communication

Improving patient provider's communication and safety is crucial for people with people living with dementia as they are more likely to encounter support from health systems (DoH, 2014). Allwood et al. (2017) acknowledge communication symptoms vary for people living with dementia but can include word finding difficulties, impaired comprehension of spoken or written language and difficulties maintaining topic of conversation. Within the acute setting, communication difficulty can be further intensified by other elements, including an acute healthcare environment, acute illness, and possible delirium (Whittermore et al., 2014). Nursing staff often report communication difficulties result in an urgent need for interventions to improve communication (Keogh et al. 2020). Despite the evidence which suggest effective communication is the corner stone to providing person-centred care (Machiels et al. 2017), communication can be often seen as a low priority due to workloads and nursing staff lacking awareness regarding the importance of communication (Stans et al. 2013).

Addressing this dimension, the introduction of personal passport demonstrates a holistic approach to person-centred care through promoting communication. Vasse et al. (2010) concur that interventions aimed at enhancing communication during the daily nursing care activities have been shown to be more productive than set-time interventions. Person-centred care is influenced and shaped by knowing the person, the personal passport document aims to facilitate a consistent approach to care within the acute hospital setting.

However, a major factor underpinning the success of the passport, is the importance of the document being correct to support the person with dementia as key information is evolving as the condition progresses (Baillie & Thomas, 2020; Leavey et al., 2017). Inaccurate information contained in the passport can adversely affect clinical decisions and quality outcomes for the person, resulting in unmet needs and increased length of stay in hospital (DOH, 2014). Leavey et al. (2017) focuses on the fact that the passport does not conform to a standard template. Bray et al. (2015) and Luxford et al. (2015) identify that the passport is not to supplement medical notes but provides information to enable staff to deliver personalised care for each patient and value patients as individuals. However, it is essential that individuals, carers and acute care hospital staff have a clear pathway in place and identify clarity about ownership and data entry, ensuring the personal passport reaches its potential and promotes communication.

5.3 Frameworks to support family/carers involvement using personal passports

Informally, often family carers play a crucial role in supporting people living with dementia (Greenwood & Smith, 2019). Informal carers are often directly involved for a longer time period in the care for the person with dementia than professionals (Zwaaswijk et al., 2013). An Irish survey of 270 carers of people with dementia identified that the average number of hours per day spent caring as the dementia progressed rise from 7.18 hours in the early stage to 13.15 hours during the late stages (Trepel, 2011). Thus, leaving family/carers ideally placed to provide critical information when the person living with dementia is admitted to the acute setting. However, given the potential of the family carer, this role is largely primitive in developing a quality care service for people with dementia and remains a key priority (Moyle et al. 2016). The literature reveals concerns regarding families frequently reporting negative experience in the acute setting (Burgstaller et al. 2018; DoH, 2014; Calnan et al. 2013) and expressed their dissatisfaction that staff often did not recognise the importance of the family/carer's role of information gathering (Moyle et al. 2016).

This review highlights the importance of family/carer involvement in providing pivotal information in developing a personal passport. (Baillie & Thomas 2020; Department of Health, 2019; Leavey et al., 2017; O'Reilly, 2016; Luxford et al., 2015; Bray et al., 2015; Brooker et al., 2013; Upton et al., 2012). Their ability to provide key information is crucial to enhance the experience of the person with dementia in acute care (Houghton et al., 2016). Baillie & Thomas (2020) espouses the significance of completing the document correctly and many staff considered that the families and/or close friends who know the individual are ideally placed to complete the personal passport. Therefore, family/carer can inform staff about potential triggers that exacerbate and, in some situation, prevent manifestation of the condition (Moyle et al. 2016). Luxford et al. (2015) note that clinical staff engage in a structured process with carers on admission and record up to five important non-clinical tips and management strategies to aid communication and support personalised care.

The literature reveals several areas for concern regarding the correct completion of the personal passport as key information will continue to evolve due to the progressive nature of the condition. Bray et al. (2015) advocates that carers would complete the personal passport with or on behalf of their relative although noted information was not always correct, leading to inconsistency in care. It must be acknowledged older people with dementia are most likely to be cared for by older people, predominantly their spouses (Moyle et al. 2016). In addition, hours per day spent caring for the person living with dementia as the condition progresses can

lead to one of the principal limitations identified by carers as it was an additional task to be undertaken (Leavey et al., 2017).

Alternatively, O' Reilly (2016) outlines that a family member when asked to complete the personal passport for her father identified that she felt 'her father's wellbeing, both physical and emotional, would be supported as a result of the document'. Furthermore, Upton et al. (2012) observed that for staff to implement the care bundle in a person-centred way, the personal passport is completed with the patient's family to maximise communication. This ultimately endorses the holistic person-centred model of care that underpins the personal passport by enhancing the quality of care received by the patient. In order to provide this, it is essential that individuals, carers and acute hospital staff have clear communication models in place and that each entity is aware of their role in ensuring that the personal passport itself reaches its fullest potential.

5.4 Continuous education for essential skills development in person-centred care

Surr et al. (2020) acknowledge that it has long been recognised that the attitudes, skills and knowledge of staff working with people with dementia have the potential to influence the person's well-being, quality of life and care practices. The Irish National Dementia Strategy (DoH, 2020) recommends ongoing specific education is vital to ensure hospital staff have essential skills, knowledge and awareness to deliver person-centred care for people living with dementia. Care is influenced and shaped by staff and research indicates staff who have a good knowledge of dementia care have more positive attitudes towards people living with dementia, thus providing a better quality of care (Keogh et al. 2020). Therefore, framing these issues the importance of providing education to staff and family carer's is vital to the success and completion of the personal passport. Such an approach needs to be specific to all interested parties and the type of education needs to be tailored to each cohort, for example carers need different training about the personal passport (ie in filling it out) to staff (who need training on how to incorporate it into patient care).

As previously discussed, accurate information within the personal passport is essential to deliver quality outcomes for the person living with dementia. Education initiatives increase awareness and knowledge improving quality of dementia care in the acute setting (Keogh et al. 2020). Family/carer's suggest all staff should have a general understanding of dementia resulting in more confidence in the expertise of health professionals and promoting a collaborative relationship (Moyle et al. 2016). The DoH (2019) outlined the benefits of a pilot

study prior to implementation and further emphasised that staff required additional training to complete personal passports. When provided, training results in a rise from 31.5% to 100% and compliance with the personal passport showed an increase from 46% to 93% further indicating as a result of education, personal passports is becoming embedded in practice (DoH, 2019). As outlined families are pivotal and need to be included for in-depth consultation and education around the personal passport (Leavey et al., 2017). Sampson et al. (2017) identified that dementia training programmes, such as ‘This is me’ substantially increase the success of the personal passport use within external organisations.

However, the provision and uptake of education programmes is reported to be poor and challenges such as staffing levels, time restraints and conflicting care priorities may be a barrier (Timmons et al. 2016). O’Reilly (2016) identified challenges inhibiting the use of personal passports was a lack of awareness of dementia and education. Ballie & Thomas, (2020), identified education on dementia, using ‘Barbara’s story’, was reported to embed the use of personal passports across care settings. Education and training are of prime importance and must go past the education of individuals to facilitate organisational change (Moyle et al. 2016). Continued education for all stakeholders including people living with dementia, their families or carers, and the healthcare staff they interact with, is a very important aspect to promote person-centred care for people with dementia (O’Shea et al. 2017). In discussing the theme of education, some limitations from these studies did emerge. For example, the DOH (2019) study was only a pilot investigation and no specific sample was provided by Upton et al. (2012) which ultimately compromises his findings and recommendations. Despite this, education was a strong theme emerging from the review.

5.5 Best practice in the provision of dementia care through effective leadership

Critique relationship between transformational leadership and change, successful change implementation can be attributed to the actions of a specific leaders (Barry et al., 2018). Change needs to focus on best practice initiatives championed at organisational level for policy development (Moyle et al. 2016). Personal passports are a relatively new concept within dementia care in Ireland and require effective leadership to become embedded within services. This study identified the Chief Executive was on board and a dementia outreach nurse and dementia trainer were part of the team to guide the dementia care bundle to become embedded in practice. Luxford et al. (2015) further espouses that the key to successful implementation was executive and clinical leadership including local liaison staff

as a central ‘driver’, clinical champions within the wards, and multi-disciplinary advocates involved in the process. A number of authors endorse a key dementia liaison nurse as central to the implementation of the personal passport (DoH, 2019; O’ Reilly, 2016; Bray et al., 2015).

As a result, the information obtained through the personal passports and the delivery of care Brooker et al. (2013), indicated there was a reduction in complaints, an increase in staff satisfaction and reduced agency staff as mirrored by DoH (2019) as a result. The practical difficulties were highlighted regarding the location for personal information and how this information is transferred between acute healthcare settings, ultimately suggesting that the document could be scanned onto a system. (Ballie & Thomas 2020; Leavey et al., 2017; Bray et al., 2015). It is suggested to promote recognition and acceptance that the personal passport could be called a ‘health passport’ rather than a ‘dementia passport’ for people living with dementia (Leavey et al., 2017). People with dementia need to know that passports are widely used by all patients, so they don’t feel stigmatised. Eight studies outlined the importance of strong leadership during the development and implementation of the personal passport. Central to the success of their implementation include an organisational culture, leadership and education that can sustain a person-centred approach (Leavey et al., 2017).

Without effective leadership in dementia care, the implementation and subsequent success of the personal passport will be diminutive. It is, therefore, vital that systems, policies and key stakeholders work in collaboration and are underpinned by a robust strategy for ensuring implementation of the personal passport. This integrative review clearly proves that the personal passport for people living with dementia holds a significant relevance to nursing practice. Its primary benefit is the focus it places on the person living with dementia. The person living with dementia is the pivot around which a successful person-centred care can be implemented and ultimately, a document such as the personal passport is fundamental to ensuring that this care can be provided. It gives the person living with dementia a voice and facilitates the provision of the familiar in an unfamiliar acute hospital setting. However, while the benefits of a document such as a personal passport are abundant, some problems in its adoption persist.

5.6 Limitations

A dearth of literature pertaining to personal passports in dementia care is acknowledged as a limitation in this integrative review. For further research it may be pertinent to address this by examining personal passports in parallel with those utilised in other areas of patient care for example, personal passports for people living with diabetes or people living with asthma.

6 CONCLUSION

This integrative review has presented the key components of personal passports for people living with dementia in an acute healthcare setting. Constant comparative analysis of the nine research studies by Baillie & Thomas 2020; Department of Health, 2019; Leavey et al., 2017; O'Reilly, 2016; Sampson et al., 2016; Luxford et al., 2015; Bray et al., 2015; Brooker et al., 2013; and Upton et al., 2012 identified five key themes. These were: person-centredness, communication; family/carer involvement; education; and leadership. The discussion explored the benefits in utilising personal passports in the care of a person living with dementia. Undoubtedly, this integrative review highlighted that there are, and will continue to be, some challenges in successfully implementing the personal passport across the broad spectrum of acute healthcare services. The lack of a uniform template, the level of information required on the document and indeed the attitudes of various stakeholders to the passport are challenges that require addressing in order to ensure the effective adoption of personal health passports in an acute healthcare setting for people living with dementia.

7 RELEVANCE TO CLINICAL PRACTICE

Person-centred care is widely accepted as best practice in dementia care and personal passports support the provision of person-centred care for people living with dementia (WHO, 2017; DoH, 2014). Personal passports enhance the wellbeing of both the person living with dementia, their families, while enabling healthcare staff in an acute healthcare setting to understand the person's needs. The implementation of personal passports programme for people living with dementia requires significant investment in education, as well as clinical leadership, to ensure its implementation.

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CONFLICT OF INTERESTS

The authors declare that they have no conflict of interest.


AUTHOR CONTRIBUTIONS

The first author conceived and designed the study and completed the initial search. The first author and a panel of three academic [LK, JL, DC] contributed and worked closely on the extraction of data, analysis and writing the paper.

ETHICAL APPROVAL

No ethical approval was required for this integrative review.

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What does this paper contribute to the wider global clinical community?

- Personal passports support the provision of person-centred care for the person living with dementia through enhancing communication and the well-being of both the person and their carer.
- Personal passports are useful communication tools and should be determined by the person with dementia, their care needs and the care givers' role in meeting identified needs.
- Global recognition of the components of personal passports for people living with dementia in an acute healthcare setting requires further clinically based nursing research.

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TABLE 1 Overview of Integrative Review Research Studies

Author, Year, Country	Aim	Data collection Data analysis Participants	Results	Discussion
Baillie and Thomas, 2020, UK	To analyse healthcare professional's perceptions and experiences of using personal information documents	Purposive sampling, focus groups and one interview <ul style="list-style-type: none"> Healthcare staff / clinical and non-clinical $n = 58$ 	Five themes emerged <ul style="list-style-type: none"> Getting to know the person with dementia is a central feature of person-centred care Supports communication and integrated care Family were best placed to complete passport Education on dementia through- 'Barbara story' Embedding their use across care settings 	The need to complete personal information documents at an early stage following diagnosis of dementia. Location for personal information documents and transfer between settings. GRADE: Moderate
Bray et al., 2015, UK	To illustrates how three NHS trusts addresses the issues of poor experiences for people with dementia in acute hospital	Data Collection <ul style="list-style-type: none"> 3 case studies 	Four themes emerged <ul style="list-style-type: none"> Positive effects on the patient experience Promoting communication and person centeredness Carers complete the personal passport with or on behalf of their relative Project lead dementia nurse 	Engaged with care homes allowing passports to travel with the patient. Adapted from a previous medical version to a more person-focused template ensuring that the passport was 'fit' for purpose and made it a more person-centred. GRADE: Moderate
Brooker et al. 2013, UK	The overall aim is to outline the Dementia Care implemented and how it has improved patient safety	<ul style="list-style-type: none"> Case study outlining the implementation of a dementia care bundle in an acute setting 	Five themes emerged <ul style="list-style-type: none"> Aided implementation of person-centred care Readily available information both clinical and non-clinical enhanced communication Completed by family carers before or on admission Lead by dementia outreach team and training Education important for use of 'This is me' 	Improved staff satisfaction. Personal passport needs to be utilised in conjunction with other dementia friendly initiatives. GRADE: Moderate
Department of Health, 2019, Ireland	The overall aim was to develop, validate and implement the Enhanced Care Model in a test site to provide safe staffing levels and appropriate skill mix	Pilot study <ul style="list-style-type: none"> $n=30$ 	Five themes emerged <ul style="list-style-type: none"> Aided implementation of person-centred care Enhanced communication Family signature required to note family involvement Education required to have sufficient training Dementia liaison nurse central 	It provided staff with ready access to clinical and non-clinical information important to the patient. Personal passport needs to be utilised in conjunction with other dementia friendly initiatives. The staff supporting the patient use information to tailor interventions. GRADE: Moderate

Author, Year, Country	Aim	Data collection Data analysis Participants	Results	Discussion
Leavey et al., 2017, UK	To evaluate the acceptability and use of healthcare passports as an intervention for people living with dementia	In-dept semi structure interviews People living with dementia <ul style="list-style-type: none"> Wave 1 – n=28 Wave 2 – n=21 Wave 3 – n=17 	Five themes emerged <ul style="list-style-type: none"> Communication tool for people living with dementia Determined by the extent of the person with dementia care needs Relies on the commitment and capacity of family and other informal caregivers Implementation will require a concerted policy drive Improve quality of life for the patient and carer alike 	Should not be issued to families soon after diagnosis or at an early stage. Patient themselves rarely engaged with the HP directly but rather through their family caregiver. Clear it is a ‘health passport’ rather than a ‘dementia passport’ It is not a stand-alone solution to current problems in dementia care. GRADE: High
Luxford et al. 2015, Australia	To examine the impact of implementing a clinician–carer communication tool for hospitalised patients with dementia	Surveys <ul style="list-style-type: none"> n=798 clinicians n=240 carers n=21 local liaison staff 	Five themes emerged <ul style="list-style-type: none"> Personal passports are a simple and useful communication tool, utilised to support clinicians in delivering person-centred Clinical staff engage in a structured process with carers on admission and record up to five important non-clinical tips Management strategy to aid communication and support personalised care. Enablers for implementation was leadership, clinical drivers and education 	Initial barriers to uptake included staff resistance to change/time constraints, carer related issues and staff confidence. Carers reported high level of acceptance, high satisfaction (97%), benefitted to patient (85%). GRADE: High
O'Reilly, 2016, Ireland	To explore the experience of staff and family members where personal passports are used to support the care of people with dementia in the acute setting	Semi structured interviews and focus group, purposive sampling <ul style="list-style-type: none"> n=6 family members n=9 staff members 	Five themes emerged <ul style="list-style-type: none"> Enhances the provision of quality person-centred dementia care Families and staff acknowledge personal passports are different to clinical care. Challenges, such as acute care environment and lack of dementia awareness and education, inhibit using personal passports in acute hospital settings Project lead dementia nurse 	Personal passport is only a tool and needs to be in conjunction with other dementia friendly initiatives. Non-medical document. staff members outlined difficulties in relation to the views of the family member may not always mirror the view of the person with dementia. GRADE: Moderate

Author, Year, Country	Aim	Data collection Data analysis Participants	Results	Discussion
Sampson et al. 2016, UK	To evaluate the impact of a system wide training programme in dementia care for acute hospital staff	Questionnaires and Observations n= 2,020 staff trained n=1,688 – baseline questionnaire n=456 three month follow up questionnaire	Four themes emerged: <ul style="list-style-type: none"> • Lead to a person-centred approach • Increased interaction and communication • The gathering of personal information through ‘This Is Me’ documentation improved from 40% to 80% following training. • Hospitals adopted person-centred tools and pathways 	Requires to be utilised in conjunction with other dementia friendly initiatives. GRADE: High
Upton et al. 2012, UK	To improve the outcomes for people with dementia and their families	Interviews with key stakeholders at two-point prevalence surveys	Five themes emerged: <ul style="list-style-type: none"> • For staff to implement the care bundle in a person-centred way ‘This is Me’ is completed with the patient’s family • Guided implementation of person-centred care • Implementation required strong leadership • Readily available information both clinical and non-clinical enhanced communication • Education important for use of ‘This is me’ 	Development and implementation of the dementia care bundles. Provided staff with readily available clinical and non-clinical information that is important to the person. Personal passport needs to be utilised in conjunction with other dementia friendly initiatives. Culture change was required and a key to this success was the leadership leads at different levels. GRADE: Moderate

Table 2 Constant Comparison thematic analysis: themes, subthemes and supporting studies

Themes	Supporting research studies
<p>(1) Person-centredness (9 studies) getting to know the person positive quality effects on patients' experience passport aided implementation of person-centred care implementation of care bundle improved quality of life</p>	<p>Baillie & Thomas 2020; O'Reilly, 2016; Bray et al., 2015; Luxford et al., 2015 Department of Health, 2019; Brooker et al., 2013; Sampson et al., 2016 Upton et al., 2012 Leavey et al., 2017</p>
<p>(2) Communication (9 studies) Positive promotion of communication Clinical and non-clinical enhanced communication Communication tool</p>	<p>Baillie & Thomas 2020; Bray et al., 2015; Department of Health, 2019; Sampson et al., 2016; Brooker et al., 2013; Leavey et al., 2017; Luxford et al., 2015; O'Reilly, 2016; Upton et al., 2012</p>
<p>(3) Family/carer involvement (8 studies) Family/carers are best placed to complete passport Family signature required to note family involvement Improves quality of life of patient and carer Carer related issues- relies on commitment and capacity of family – difference in views Carers reported High level of satisfaction</p>	<p>Baillie & Thomas 2020; Bray et al., 2015; Brooker et al., 2013; Upton et al., 2012 Department of Health, 2019; Leavey et al., 2017; O'Reilly, 2016; Luxford et al., 2015</p>
<p>(4) Education (8 studies) Enabler education on dementia – use across care setting, 'this is me' Sufficient passport training requirements Implementation requires policy drive Challenges in lack of education in acute setting</p>	<p>Baillie & Thomas 2020; Luxford et al., 2015; Brooker et al., 2013; Upton et al., 2012 Department of Health, 2019; Leavey et al., 2017; Sampson et al., 2016; O'Reilly, 2016</p>
<p>(5) Leadership (8 studies) Importance of Project lead dementia liaison nurse role Enabler for implementation is leadership Lead by dementia outreach nurse Implementation requires hospital/policy drive</p>	<p>Bray et al., 2015; Department of Health, 2019; O'Reilly, 2016; Luxford et al., 2015; Brooker et al., 2013; Upton et al., 2012 Leavey et al., 2017; Sampson et al., 2016</p>

Figure 1

PRISMA 2009 Flow Diagram

