



Evaluation of a Healthcare Passport to improve Quality of Care and Communication for People with Dementia (EQuIP)

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Evidence Brief

Why did we start?

How to better support people living with dementia and multiple comorbidities is a major challenge to the individual and their families. It is also an increasing problem for health and social services, particularly so when demand is high and resources are shrinking. There is a need for interventions that assist people living with dementia to navigate treatment and support in ways that are 'joined-up' and enhance their autonomy and dignity. Healthcare passports are available for different patient groups but their acceptability and usefulness in dementia care has not been assessed.

What did we do?

As a component of a feasibility assessment of a dementia healthcare passport, we undertook a realist review of the evidence. This approach seeks to provide a more explanatory analysis of the evidence on what works, for whom, in what circumstances and why. We then undertook a qualitative longitudinal study to examine the experiences of a purposive sample of people living with dementia and their family carers and their use of the healthcare passport at different time points. We explored barriers and facilitators of the use of the passport with other service user groups and with healthcare professionals. We also examined General Practitioners' views on the passport.

What answer did we get?

The passport, at a very general level is considered as potentially worthwhile. However, there are various barriers that deter more effective and widespread usage. Thus, the passport requires more clarity about 'ownership' – we found that it is predominantly held and used by the family caregivers. Passport use is often determined by how recently a diagnosis of dementia was provided and/or the severity of the symptom. At early stages, the passport is deemed unnecessary, at later stages where the carer assumes greater control, it is sometimes regarded as an additional burden. The negative or 'lukewarm' response by clinicians dampened or quashed further use by families.

What should be done now?

While it does not constitute a stand-alone solution to current problems in dementia care, with some alterations, and with health and social care professionals' knowledge and understanding of the passport and its purpose, it has the potential to improve quality of life for the patients and carers. Retaining personhood, improving communication and promoting self-management require the commitment and dedication of all health and social care professionals, in collaboration with family carers and patients.

Background

Increasing numbers of people across the world will experience dementia. How to better support people living with dementia is a major health and social care challenge. In the UK alone it is estimated that dementia care and treatments incur an annual cost of £17billion [1], more than cancer, stroke and heart disease combined [2]. Over the next 40 years, as our society ages, dementia will become more common in Northern Ireland. Approximately 19,000 people currently live with dementia, a number projected to rise to almost 60,000 by 2051, the fastest expected rate of increase in the UK [3]. As our society ages, health and social care expenditure on services for PLWD could be expected to double within 20 years. In 2013/14, the cost of acute care (in-patient and day case only) for PLWD in Northern Ireland was £913,091 [4]. The Northern Ireland government's *'Improving Dementia Services in Northern Ireland: A Regional Strategy'* [3] underlines the importance of proactive, seamless and accessible services, that adopt person-centred care (PCC) principles, where families and carers are 'well informed and supported' [3].

We require new and imaginative ways of living with and managing dementia care so that people living with dementia ('PLWD') can lead full and meaningful lives and receive high quality, coordinated, and person-centred care. Ideally, PLWD and their families should play an essential role in determining the kinds of services that are needed and also, when and how these are provided. Currently, this may not be the case for many people [7].

When dementia is accompanied by multiple and complex health problems, care and treatment can often be experienced as disjointed, with people being moved between services in a somewhat compartmentalised and fragmented process and with limited consultation with patient and their carers [8]. This may become more distressing during episodes of illness and injuries, or where there is accelerated cognitive and functional challenges, adverse events and hospitalisation [9, 10]. Almost by definition, contact with multiple medical services reduces the likelihood of receiving holistic care and diminishes personhood, defined by Kitwood [11] as "a standing or status that is bestowed upon one human being by others, in the context of relationship and social being". It has been argued that what it is to be a person is central to our understanding of person-centred care. Kitwood suggests that even the best services may be unintentionally complicit in the disablement and marginalisation that is often associated with dementia [12]. In this context, modern medical care is increasingly regarded as mechanistic and lacking compassion [13]. The Alzheimer's Society states that a person-centred approach should "see the person with dementia as an individual, rather than focusing on their illness or on abilities they may have lost. Instead of treating the person as a collection of symptoms and behaviours to be controlled, person-centred care considers the whole person, taking

into account each individual's unique qualities, abilities, interests, preferences and needs". Families may play a key role in ensuring that these aspects are acknowledged and upheld.

Families

Maintaining the autonomy and independence of PLWD is of central importance. However, in most instances of help-seeking for healthcare needs, people tend to obtain support from other family members [14]. Unfortunately, navigation through the different layers and agencies of health and social care is often difficult and stressful, especially so in the midst of complex and changing health needs. Thus, supporting families in caring for relatives with dementia must be a pivotal element of any national strategy [15-17]. While family and friends are generally willing to provide an extraordinary range of informal caring which would otherwise be carried by public and charitable services, [17, 18] their support can be taken for granted by professionals. However, while many family caregivers derive satisfaction from doing so, they are likely to experience disruption to their own working and family lives in order to attend meetings with doctors and care staff. Evidence from our consultation with carers and supported by research evidence reveals a weary resignation of having to explain and negotiate care with an ever-changing cast of professionals. Families of PLWD are known to face greater emotional and physical strain than do those caring for people with other illnesses. Where there is strain, this is likely to be compounded by challenges to knowledge and help-seeking in dementia care, difficulties of communicating need and decision-making. A recent European report highlighted the need for person-centred care, communication and shared decision-making, continuity of care and family care and involvement [19].

In the UK, recent evidence from primary care revealed that family members (not professionals) were the main care coordinators, and that transitions between services -for example from specialist care to general practice were challenging [20]. It is acknowledged that families of PLWD require support to help them in their role as proxy decision-makers. However, families of patients with complex needs are often daunted and distressed by a health and social care system perceived as poorly integrated. A recent national report by the Royal College of Psychiatrists indicated a lack of advice, information and support on legal matters such as power of attorney, welfare benefits, advance directives and managing finances [21]. Poor provision of information by services to family carers is recognized as a major determinant of low satisfaction [22, 23]. However, when and how to provide information is unclear [24]. Our own study indicated the difficulties that family carers face related to various aspects of organizing care and areas of decision-making for relatives with dementia [25]. The challenges included, contradicting the demands of the family member, gaining permission to receive confidential information, negotiating referral to specialist services, and obtaining professionals'

agreement. Family carers sometimes describe frustration with services and the person for whom they are caring, increasing isolation and diminishing self-esteem [25] some of which can be attributed to lack of information and service contact. Thus, family carers may feel that they lack the knowledge and competence to deal with their family member's needs or how to seek appropriate help [26, 27]).

There have been attempts to address service barriers through care planning strategies but their use is generally confined to hospital and hospice settings [28]. Thus, they are likely to neglect the full range of possible contacts between PLWD, families and healthcare agencies at different stages of illness. Moreover, interventions designed to improve communication between PLWD, family carers and clinicians may be overly focused on clinical decisions and pathways, to the neglect of person-centred approaches, which encompass the personhood of the individual (e.g. personal history, habits, social, spiritual and emotional) [29] [20] [23]. With a growing population of PLWD we need better-integrated health and social care, which purposefully facilitates the involvement of families. In addition, there is a need to develop interventions that improve care planning and support for PLWD and family carers. Evidence supports the use of well-designed psycho-educational or multi-component interventions for caregivers of PLWD [30]. The factors that appear to positively contribute to effective interventions are those which: provide opportunities within the intervention for the person with dementia as well as the caregiver to be involved; encourage active participation by caregivers; offer individualised programs and provide information on an ongoing basis, with specific information about services and coaching regarding their new role [31].

Communication

The quality of life for people living with dementia (PLWD) may be improved by communication of the individual's needs, their strengths and their life situation to the various health and social care services. However, research has increasingly identified that communication with, and between health, and social care professionals is increasingly experienced as poor. Attempts to address service barriers to communication by improved care planning strategies are generally confined to hospital and hospice settings [28], and thus are likely to neglect the full range of possible contacts between people with dementia, families and healthcare agencies at different stages of illness. Where interventions are designed to improve communication between people with dementia, family carers and clinicians have been developed, many tend to be overly focused on clinical decisions and pathways with less focus on person-centred approaches encompassing the personhood of the individual (e.g. personal history, habits, social, spiritual and emotional)[29].

More effective care of people with dementia requires better-integrated health and social care, which purposefully facilitates the involvement of families. In addition, there is a need to develop interventions that improve care planning and support for people with dementia and family carers. Evidence supports the use of well-designed psycho-educational or multi-component interventions for caregivers of people with dementia [30].

A Healthcare Passport for Dementia

The Northern Ireland Public Health Agency (PHA), in collaboration with the Royal College of General Practitioners (RCGP) and the voluntary sector in dementia care, has developed a 'Healthcare Passport' ('HP'); held by patients and family carers. The HP is designed to provide essential knowledge and information between PLWD, their families, and the full range of services with which they are in contact. A key function of the HP is to support those who are living with dementia and their carers in the work of self-management ([32, 33]. In the context of an illness such as dementia, it includes the core involvement of family and carers [34] and potentially of wider communities in managing the adaptive challenge of maximising an individual's daily wellbeing while living with evolving illness.

The HP has been designed to facilitate this process by acting as a conduit of the evolving key information, which is needed by an individual with dementia and their support network at differing stages of their illness journey. Crucially, the HP aims to stimulate among health-, and care professionals a sense of the personhood of the individual with dementia. In its current design, it is constructed to allow a compendium of information about the person with dementia such as their close family members and friends, activities, interests, and beliefs. It will also provide brief but key information about dementia. Other sections are available to encourage the entry of information from health and social care professionals; these include information on co-morbid diagnoses, medication, and other treatments. It is designed to allow continuous updating by family and health-, and care professionals, and is therefore, intended as a 'live' synchronized record of changing need, service contact and information provision. While the content of the healthcare passport has been thoroughly discussed by professionals, PLWD and caregiver stakeholders, its implementation and use require evaluation.

The HP is intended to carry significant aspects of the individual's life and provide meaningful information between people living with dementia and the health and care services with which they are in contact. The key purposes of such a document are: (1) To help people living with dementia clearly communicate their social, health, and spiritual needs to a range of health and social support services in a way that enhances quality and continuity of care; (2) to allow people living with

dementia the opportunity (if wished) to consider in some detail the challenges which their illness may bring, and to articulate preferences about how these challenges might be managed. The HP aims to embed these views and choices into the patient's documentation, so that it can be accessed and reviewed by them and by their healthcare team, as the course of their illness unfolds. While the concept and the content of the HP have been praised by various stakeholders, such tools need to be grounded in the everyday realities of the experience of dementia so that we can develop a deeper understanding of how integrated care can be negotiated across health and social care boundaries.

Aims and objectives

Our aims in this study were two-fold. First, the findings hope to make an important contribution to the evidence base on the use of services, communication needs and decision-making processes of PLWD and their family caregivers as these unfold over time. Secondly, the study findings should help us understand better the true practical potential of a HP and how it may be improved. The study also provided a highly grained understanding of the implementation issues for a full evaluation trial from multiple perspectives. It provided robust evidence of proof-of-concept for the HP. Adopting a realist review approach, we sought to examine the theoretical underpinnings of the healthcare passport in dementia care and to consider research findings from other clinical areas on patient-held records.

1. Is a HP acceptable and useable for people with dementia, their family caregivers and health professionals?
2. Is a sense of 'personhood' in the midst of dementia conveyed by the use of HP?
3. Will the use of a HP help overcome problems of communication between people with dementia and health and care services?
4. Will a HP empower and support the autonomy and decision-making of people with dementia and family carers?
5. What is the level and quality of engagement with such a HP by health and social care professionals?
6. How do the needs of people with dementia and their family carers, with regard to service contacts and communication, evolve over time?

Methods

In the first part of the evaluation, we undertook a realist review of communication and integrated health and social care for PLWD and family caregivers. Realist reviews seek to unpack the relationships between context (C), mechanism (M) and outcomes (O) of interventions i.e. how particular contexts have triggered (or interfered with) mechanisms to generate the observed

outcomes (Pawson, 2006). Thus, the realist review is an analysis of the evidence seeking to understand what works for whom, in what circumstances, and how. The core tasks required in such reviews are: thinking, reflecting; and interpreting (Pawson et al. 2005; Greenhalgh et al 2005). **N.B. The findings of the review are reported in the main report.** We then undertook a qualitative longitudinal approach to examine the use of the healthcare passport by a sample of people living with dementia over time. Importantly, we explored the passport use in the context of their lives and family situation in the midst of changes to health and social care needs. Qualitative Longitudinal Research (QLR) methods are relatively new. QLR uses mainly in-depth interviews and is invaluable when there is a need to record and explore change over time, and the processes associated with such changes [35]. We examined the actual usage of the HP by the participants through content analysis. Additionally, we carried out discussions with stakeholder groups comprised of people with dementia and their family caregivers in order to elicit their views on the HP. We also interviewed general practitioners involved in the care of some of the participants in order to seek their views and experiences of using the HP.

Data Analysis

Data analysis was informed by the findings from the realist review which were incorporated into a Framework approach [36, 37]. We coded and indexed the data, using spreadsheets in order to generate matrices into which the data were 'charted'. This involved summarising the data by category from each transcript, building themes with the support of memos and data display (matrices and diagrams). Transcripts were coded and analysed independently by the researcher. Some specific areas that we covered: **(a)** a retrospective examination of the experience of PLWD, family carers, help-seeking and communication needs – prior to using the HP; **(b)** practical use of the HP, differentiated by different care characteristics and contexts (e.g. dementia stage, social class and social support networks, gender and care-relationship); and **(c)** change in use of the HP over time in response to need; **(d)** care planning and advance directives for end of life care; **(e)** joint decision making (family and patient); **(f)** comprehension and ease of use by stakeholders (professionals and family); **(g)** reasons for discontinuation. Additionally, we sought to examine the socio-demographic and contextual factors of people in the use and maintenance of this type of intervention and how it can be more effective. From our realist systematic review, we sought to develop specific questions on contextual and intervening conditions that may additionally help guide analysis

Patient and Public Involvement

The healthcare passport was developed with the support of many community and voluntary sector agencies involved in promoting the health, wellbeing, rights and welfare of people with a range of

long-term and life-limiting conditions, many of whom were directly involved in the development of the 'passport'. We have engaged with people who live with dementia and their carers from the conception of the current evaluation through to the recommendations for improvement in design and roll-out. Thus, at the beginning of the project, we consulted with people with dementia and the people who are important to them about the challenges within the health and social care systems and of dementia, more widely. The very rich, sometimes painful, sometimes humbling, views and experiences of people living with dementia as participants have been recorded throughout the project. The Alzheimer's Society also helped us establish workshops with people with dementia and their family caregivers and these groups contributed substantially to an understanding of the passport and potential improvements.

Findings

Participant recruitment and attrition

The Memory Clinic identified and assisted in the recruitment of 28 patients with dementia and their families (15 males, 13 females) who were contacted prior to the first wave of interviews by the researcher. Following some attrition after wave 1 (N=11; 6 males, 5 females), four additional participants (1 male, 3 female) were engaged, which meant that 21 participants in total took part in wave 2 (10 males, 11 females). After wave 2, five further participants opted to discontinue with the study (1 male, 4 females), leaving 16 families to take part in the 3rd wave of interviews (9 males, 7 females) (see flow chart – Figure 6) providing us with a range of individual situations and experiences. We made no assumptions about participants' prior use of health and social care services. Having recruited 28 patient-carer dyads for the first wave of interviews with the help of the Memory Clinic at the Western Health and Social Care Trust, two declined when contacted by us, and interviews were conducted with 26 patients and carers. Five females and six males opted to withdraw following 1st interview, leaving 17 participating families. Following recruitment of six further families by the Memory Clinic to counteract attrition, two declined when contacted by us, but we were able to add four patients and carers to our participants, resulting in 21 interviews at wave 2. Following wave 2, one male and three female patients withdrew, which left us with a total of 16 patients for the final wave, nine of whom were male, and seven were female.

Reasons for attrition ranged from declining when contacted about the study, to not returning calls, low mood, patients not coping well, carers not coping well, carer having health problems, the HP being regarded as an extra chore and of no benefit, high carer distress and patient going into care-home, bereavements and serious illness, dying of spouse, worries about breach of data protection, patient moving to England, HP causing arguments and stress, high carer stress and house move, GP

not knowing about HP. An understanding of the use of the healthcare passport is meaningful only in the context of the lives and experiences of the people with dementia and their family members. Thus, in our interviews we aimed to build a picture of how their world has been altered by dementia, how they manage their dementia in the midst of other health and social challenges and how the uptake and usage of the healthcare passport might be influenced by these factors. What stands out is the central role and responsibility of the carer.

Healthcare Passport

In the main report, we provided a considerable level of contextual information about the lived experience of people living with dementia, their experience of services and how the varying degrees to which they managed the dementia-related challenges, medical and social. In doing so, we were able to confirm the fragmentation of services for people with dementia and complex co-morbidities; the associated health-, and social care communication problems barriers that highlight the urgent need for interventions such as the healthcare passport. In some of the previous sections we also briefly referred to some of the challenges to rolling out the healthcare passport. In the following section, we more directly address the use of the passport and offer a more nuanced account of its use – the barriers and facilitators to its acceptability and use. Thus, we examined the passport's suitability for this particular population, participants' attitude to the passport and how it was used over the duration of the evaluation. We also investigated participants' views of the different passport sections and contents, with feedback from participants, user engagement groups, and GPs.

Attitude to and use of the HP

Having had the HP and its purpose explained to them, many participants said they could see the potential benefit in terms of sharing information, ensuring that everyone has the correct information thus avoiding mistakes, as well as unnecessary appointments, and patients having to repeatedly explaining their situation. Participants who had health and social care service experience (e.g., C1, C13) were quick to recognise the potential value of the passport in terms of improving communication between different HSCPs involved in someone's care, and thereby improving their care, avoiding mistakes, saving time and avoiding frustration.

“No I think it will, I work in the caring environment myself and I just heard about this last week. They were telling us at work that this HP was coming out, and I think it will be very helpful, because we have patients admitted to the ward, sure I know their name but I don't know nothing about them. So, this would be available for us as carers I'm sure, to

flick through and say "please don't mention...likes or dislikes or whatever", so I think it will be very helpful." (C1)

Generally, participants decided to “give it a go”, despite not being entirely sure how much time and effort it would involve on their part exactly. It was not completely clear to them whether and how the passport would benefit them, but they wanted to be helpful, but also wanted to see how it might “work out”. “Definitely, if it's a benefit to us and to yourselves that would be all right.” (C11) Others saw the benefit at the outset and had the best intentions of using it, but due to their particular circumstances did, in fact, not make entries into the passport sections. For example, one patient-carer dyad (P3/C3) were too much in shock, too overwhelmed by the impact of the dementia diagnosis, depressed, and barely able to cope with day-to-day life. They did try, however, taking the passport to various health appointments but reported that no-one was prepared to engage with it. They returned the HP without entries.

C10 experienced considerable distress, her father had further deteriorated prior to wave 2, and C10 opted to withdraw from the study as her father had to move into residential care.

"I don't think so. It would really be... I think we should try it anyway, and especially with a view to us travelling, it mightn't be a bad thing to have that with me as well. He will not understand what you have told him today. His intake of information doesn't work, and the outflow can be the same sometimes." (C10)

Some people were reluctant to engage with the HP. “We'll have to sort of digest a wee bit of it first before we can decide.” (C11). P11/C11 were overwhelmed and decided to withdraw from the study post 1st interview. C17 expressed a degree of scepticism about its usefulness, that is – what is in it for them? Others had already been using other means of keeping note of the patient’s medical journey (e.g., diary) and thought that this would be enough, rather than starting something similar. There was the belief that there would be no point in the HP because doctors will not have the time to engage with its contents.

"It's not so much reservations but will it actually really make any difference to (husband's name) or myself, really? Will it actually make any difference? [] Well, I've only glanced at it but really I don't know." (C17)

“Sometimes they don’t appear to have time to talk to you, and somebody with dementia, as I say, you have to give Daddy time to answer, and they don’t have time to talk to us so I can’t imagine them reading it.” (C20a)

Crucially, the HP also served as a reminder of their illness and was not popular for that reason with some. *“How much did [memory clinic] tell you about the HP?” “Nothing really. We haven’t taken a lot in yet. We don’t want to know, really, we just want to live our life the way we want to” (C2).* Some people were simply too busy and were not inclined to prioritise the completion of the HP which they regarded as a chore, or as “intimidating” (e.g., C19a). It is interesting to note the extent that people felt that the passport represented a transfer of management responsibilities to the patient and their families. As one person perceived it – “doing the homework”.

“We weren’t good at doing the homework, I have to say. Some of it’s done and some of it hasn’t been updated. I have it sitting there beside you there; there’s bits of it done Dagmar. It was busy, we were...you know there’s periods when you don’t get time to...” (C32)

Some were anxious to take the HP to their GP, pointing out that there would be no time in the obligatory 10-minute consultation slot to cover health concerns, and ask the GP to read, and make entries in, the passport. This appears to be a reasonable and important point which needs to be considered if the HP is to fulfil its function. First, a review of the length of individual patient contact time may be required in order to make the passport a feasible intervention. Alternatively (or additionally), a more practical format of the passport may be considered.

“Taking it to your GP, that’s where I would find the difficulty, asking the doctor to take the time to fill that out for me there. [] You’re telling me that I have to take this here to every appointment, is that what your telling me, to take this book? [] Two different ailments and you were only allowed 10 minutes, like, and if your time is up and then you produce this book...” (C18)

Others were concerned that the passport may be an imposition on healthcare professionals and that they had no right to demand this. Thus, one man (C18) was apprehensive about bringing “the book” to GPs, consultants, or the hospital. He believed that he would be asking the impossible, and

imposing on HSCPs, and he was not prepared to do that. The passport was referred to as “the book” by other participants, too (e.g., P3/C3). This may be interpreted either as a shorthand term for the passport or, more worryingly, expressing a negative view on its size.

“You'd be taking your life in your hands when you hand them the book and say 'can you fill that in?' They would just tell you that they don't have time and that would be the way like, and I wouldn't go back and ask a second time.” (C18)

There was also some uncertainty about what entries to make or how to fill it in and some who believed that “It's more for the future, for other people, isn't it?” (C33, referring to P33 who was 89). That is, the passport was regarded as something similar to advanced directives for people in the later stages of dementia. Commonly, participants did not consider themselves to be either sufficiently old or sufficiently progressed with dementia as to be eligible for the HP.

“I wonder about this, the sense of it. I'll go over it very, very quickly, don't worry now I'll not keep you hours and hours. There are lots of things. For example, what I would have filled in, or what has been filled in, "All about me"...that's the 7th May, oh whether it is relevant. For instance, "All about me", I'm such and such a height, my weight is such and such...?” (P8)

Importantly, ownership and authorship of the passport posed difficulties for participants, with a residual uncertainty about who ‘owned’ it and who was eligible to make entries in it. One participant (P21), who had slight learning difficulties, and lived alone, wanted to know whether the carers could write into the book (as she was not able to). It was eventually her social worker who made the initial entries. Some pointed out that, as they have no need to see a doctor any time soon, the passport would, for the time being, be redundant and they'd have nothing to write into it (e.g., P30, who was new at wave 2 but withdrew prior to wave 3). Those who were in the early stages of dementia would not have as much contact with HSCPs, and not as many appointments with different strands of the health-, and social care system. There was a belief that there is no need for the HP early on, but that it may be useful in the later stages (e.g., C12, C15, C17).

“It’ll be some time before I’m going back to see my GP, and I’ll have to wait until F. comes back, so there’s really nothing I’ll be doing immediately, and it’ll be some time before I would get to use it.” (P30)

Because most participants were recruited for the study by the Memory Clinic they believed the passport related solely to their dementia, rather than being a passport that covered all their healthcare needs. Thus, many who were in the early stages of dementia did not see the need for the passport and did not recognise its value. In terms of its usefulness it was candidly stated that “It can’t do any harm.” (C25). This highlighted the importance of timing the intervention so that people feel they derive immediate benefit from it.

“That would be my... particularly if anything happens to me in the next couple of years and the Alzheimer’s progressed, that it might be important. But again, I think we would have someone anyway to help along.” (P9)

HP Use and Contents

At the 2nd wave of interviews it became apparent that use of the HP had been very limited. Consequently, we explained the HP again to the participants, and in addition, engaged Dementia Support Workers from the Alzheimer’s Society to call the families and offer help with the HP. The response to this offer was poor and none of the participants opted to take it up, insisting that they were happy to, and able to deal with the HP themselves. Following an investigative phone-call from the researcher eight weeks prior to the scheduled final interview, at wave 3, 12 out of the final 16 participants had made entries into the HP, and five had taken it to health appointments.

Use of HP between 1st and 2nd interview

At 2nd interview two things transpired; first, participants were still unclear on how to use the passport or if they were using it ‘properly’; secondly, they commonly reported lacking time to do so. Something that we had not anticipated was that some participants worried about not being able to write or spell. Importantly, most carers took complete responsibility for the passport to the exclusion of the patients. It is possible that the label “carer” by default places the burden of responsibility on the person, who assumes that particular role identity and all it entails, which cascades through every task or effort in relation to the patient. The passport was described by one

carer as “my book”, indicating ownership (C16). C20a’s comment (funny as it is) highlights that it would be better if, where possible, the patient themselves is involved in putting together their personal narrative to ensure authenticity.

“If I go and get my book and you explain to me again what things I have to fill in? That was puzzling me a wee bit, that was one of the reasons why I didn't fill it in.” (C16)

“Daddy is horrified that I wrote in that that he likes sausages!” (C20a)

“Why do you think you might not have wanted to use it?” “To be honest about it, I'd be more lazy than anything else.” (C14) “I can't spell properly, that's why I don't write.” (P14)

There was a belief that the patient is not yet at a stage where they would need the HP, indicating that the HP was associated with illness progression and patient deterioration. Few patients or carers saw themselves at a point where dementia had progressed sufficiently to warrant use of the HP. Most participants had been recruited to the study within a relatively short period of time following their diagnosis. This had two consequences: 1) People were still coming to terms with the diagnosis and what this means to them and their families; 2) People did often not have a need to attend doctors and hospitals over the duration of the study.

“No, I just filled in the basic information and that's it. That was all, really. I haven't really used it, because I didn't feel...because she hasn't been to any appointments so at this stage...I would say maybe in the future it will be more relevant but, at the minute, no.”
(C1)

Those who saw the value of the HP and were coping reasonably well (e.g., C17, C20a, P27, P32) made entries, including a narrative.

“Yes, M. liked gardening so I have put in some photographs of the garden when it used to be... I have sort of kind of tried to look after the plants now but...” (C17)

Use of HP since 2nd interview

At 3rd interview, entries had been made within 12 passports, the nature and extent of which varied

greatly from person to person. The most detailed entries came from C17, C32, and C12, who incidentally were the carers of the patients who had deteriorated the most, along with C20a. C17 provided a lot of information about P17's life, likes and dislikes, hobbies, food preferences, daily routine, and disease progression. This was mirrored by C32, with a little less detail from C12. In contrast, P8 who completed his own HP, provided no narrative but simply a few medical details and some contacts. Other carers (C1, C15, C16) similarly provided basic information, i.e., details referring to the patient's condition and medication, and some contacts. One family (C3/P3) who had been overwhelmed since P3 had received his diagnosis, did not make entries into the HP.

"So you haven't actually written anything in the passport yourselves?" "No. It's empty now just with one letter from (GP name), she put a wee note in it." (C3)

One person (P21), who has a learning disability and was not able to complete the HP, had engaged her social worker to do so, but had not used it otherwise.

"So then what about the infamous passport, have you used it?" "God love her, she wouldn't have a clue." (C21) "Do you still have it?" "I wouldn't have a clue. I was saying there was a book in there but it's not even getting touched." (P21)

Another carer who did not use the passport was C13, a former psychiatric nurse who told us that her mother had not really had any health appointments recently. Additionally, she felt that the passport was "cumbersome" and should be smaller.

"No, we haven't used it because we haven't really got anybody else that we're going to for help, or taking her to the GP, because we really haven't been to (Doctor's name) since you got diagnosed. She gets a chest infection, she's always ?? with that, but really there's been no reason really to involve other professionals, because she's been keeping so well. And secondly, and this is only to help towards your research, I have found it cumbersome, there's far too many expectations of the HP. People think, 'I won't bother with it because it is so intense and there's so much to...' If it was made smaller and more generalised people would probably fill it in more, I think. Mammy the passport thing, you didn't start filling it in, didn't you not?" (C13).

At wave two some participants were still unsure as to how to use the passport. One person (C17's daughter), however, had made extensive and detailed entries. She described that C17 was exhausted and exasperated from the day-to-day challenge of caring for her husband who had significantly deteriorated. As with C3, it was clear that once demands on carers' time and substance became too great, and/or if carers did not cope well mentally, they did not find the time or energy to deal with the HP, which was essentially another responsibility.

"Yeah. We think, my daughter and I, that maybe the doctors and things could have been a wee bit more... when I asked they just sort of jotted down a few things on a sheet and put it in. I don't know; they don't really give you much information." "Let's have a quick look. So, you have tried to take it to the various appointments?" "No, we didn't take it, no. We just asked. Should we have taken it to the various appointments? I didn't realise that." Well, Tricia has written in the notes anyway when she updated it. That came from the GP." (C17)

The timing of the passport use related to severity and complexity of health care needs was an important factor. As noted above, as health care becomes more complex, some carers feel too burdened to complete the passport. However, one participant's experience (C12) highlighted that the passport may be valued as the patient's condition progresses, more HSCPs become involved, and care becomes yet more demanding. It allows the carer to record everything that happens on a daily basis at a time when patient health and behaviour can change rapidly, and the capacity and ability of the carer are significantly challenged. This record can then help to provide a complete picture to the health professional at the next appointment.

"The HP, at the moment, I think the HP will only be coming into usefulness now, because we are getting more people involved. Before there was nobody much except the social worker and the nurse practitioner and the GP involved, so there wasn't much to fill in, and he very rarely went to the GP, which didn't help either. I can see that it would be useful if there's more going on, so you can keep track of it all. It would also, I think, be very useful for somebody who doesn't have anyone to look after them." (C12)

Healthcare Passport content analysis

During the 3rd round of interviews we made copies of the passport entries with the permission of the participants. We found that, with one exception (P8), carers had filled in the passport, rather than the participants with dementia. It may be that family caregivers soon after diagnosis begin incrementally to assume control of various responsibilities in the patient's life. Sometimes family intervention is a response to cognitive changes and the diminishing capacity of the person, for others it appears to be a pre-emptive and prematurely unnecessary intervention, prompted by anxiety about risks. In return, the family member with dementia assumes a new identity role which undermined their sense of agency and initiated an erosion of abilities and skills. Additionally, some of the participants with dementia had various co-morbid conditions and/or learning difficulties, which made writing problematic. Each of the passports was completed in a distinctly idiosyncratic style. While this demonstrates the different individuals' personhood, it may also present challenges for health and social care professionals. In other words, our evidence suggests that the passports may not conform to a standard information collection. For example, in terms medication and side effects, as well as comorbidities and their impact, and self-care, the level of detail varies considerably between patients, and some do not mention these at all, even when these are a significant aspect of their needs and difficulties. So, HSCPs may be concerned that vital information is not recorded and may consider that the passport in its current form is unreliable.

To be expected, perhaps, the personal narratives, hobbies, and activities also varied considerably in content and magnitude between participants. Of concern, we found that information was also recorded unsystematically. Thus, carers included details about dementia progression and patient deterioration, along with details on religion, likes, and dislikes, and activities. As there is no set format or prescribed detail, every HP is indeed a personal story, and this may make them difficult to work with for HSCPs. Of the 12 completed HPs, four contained only undated entries, two contained partially dated entries only, all but two (P8 self-completed; P21: social worker completed) were completed by the carer. Those who were overwhelmed (e.g., C13), or coping very well (e.g., C13) did not complete the HP.

Taking HP to appointments

Ultimately, only five patients took the HP to a health appointment (P8, P12, P20, P21, P27). They found that doctors were not familiar with the HP and did not have time to engage with it. This made participants feel uncomfortable and led them to abandon the HP in terms of HSCP engagement.

*“We’ve tried to use it.” (C20) “When we saw the reaction to it, we don’t take it anymore.”
(C20a) “They just look at you as if-“ (C20)*

Patients and carers were concerned about the time constraints of HSCPs and believed that usage of the HP in its current format is unrealistic and incompatible with usual consultation times. In contrast to GPs and hospital doctors, professionals who came to the house (e.g. social workers, and OTs), were better able to make entries into the passport. It may be that such individuals had more generous patient contact time and or that the power dynamic between patient and professional is considerably altered by these transactions taking place within the patient’s home.

“But what happened was, we went to Casualty and the doctor in Casualty was just like “I don’t have time. [] You see, they are very busy. You can understand that. [] We had to go to A&E, and it was in the middle of the night. It was a foreign doctor, and it wasn’t that he didn’t want to, he just didn’t know, and he had spent enough time too, explaining. I think in reality it’s not realistic, []

GPs’ feedback

The general consensus among the GPs was that “... the fundamental idea is very good, actually.” (CB) Some GPs had patients with maternity notes which they thought “... work well if the patients bring them” (CB) but said that often they did not. This resonates with the belief of some patients and carers that it is likely they would forget the notes when going for an appointment. Some doubt about the potential efficacy of the HP was expressed by one carer (C17) as to whether the HP will make a difference to her and her husband. This is a fair point, of course, particularly in light of the fact that the HP is regarded as requiring a lot of time and effort and regular input and updates from carers, GPs, and other HSCPs. While the benefits were clear to some, this was not the case for others and highlights that the benefits need to be made crystal clear to ensure buy-in and commitment from all involved.

“Another form! Will it improve lives of patients and carers? The others rarely do!” (Dr Mc)

In this study, few patients took the passport to their GP, and those who did, reported that the GP appeared to be unfamiliar with it or unenthusiastic about its use, which deterred them from taking it

again. Many other patients / carers did not take the HP to appointments at all. This could potentially be remedied by having GPs directly distribute the passports to their patients. The practicality of, and reasoning behind, offering the passport in paper format was questioned in the context of ubiquitous digital technology within the healthcare system. That GPs mostly use technology-based communication now, and that the future of patient care may become increasingly paper-less, along with the obvious advantages an electronic platform would bring, and the suggestion that the latter is the best way forward.

“Clearly all the basic demographic and carer information and social work contacts info is great to have but “paper” is so last century that the concept that a booklet like this is envisaged as an advance of patient care is beyond me.” (Dr O)

Discussion and practice and policy recommendations

Despite the challenges to its widespread use, the health care passport for people living with dementia was still considered favourably by many participants, including formal and informal caregivers. Its potential for enabling effective and timely communication between agencies and carers is endorsed by most. However, in its current format, it will not suit the needs of all people living with dementia. In our evaluation, patients themselves rarely engaged with the HP directly but rather, through their proxy, the family caregiver, who often expressed concern about taking on additional tasks. The use of the passport is therefore determined by the extent of the person with dementia’s care needs and the caregiver’s role in meeting these. While the research team anticipated this, and consulted the patient and carer together, it may be that future work in this area more explicitly covers the pivotal role of the carer.

1. Associated with the previous issue, some families will require much more in-depth consultation on the use of the passport and over a longer period of time than the resources permitted in the current evaluation. Thus, the passport should not be issued to families soon after diagnosis or at the early stages of dementia. Indeed, it may be that the criterion for issuing a healthcare passport is the presence of complex or multiple needs alongside a dementia diagnosis. It must be made clear that it is a “health passport” rather than a “dementia passport”. People living with dementia need to know that it is widely used by all patients, so that they do not feel stigmatised by its use.
2. Implementation will require a concerted policy drive to have the passports more widely

recognised and accepted by health and social care professionals and this will necessitate time and resources to explain its purpose and level and type of professional contribution. Nevertheless, family use of the passport is strongly predicated on the passport's acceptance by professionals. Moreover, families need to know that the passport is in common use.

3. Widespread implementation will require a publicity campaign, perhaps using leaflets and posters in GP surgeries and other clinical settings. GPs may take the lead in introducing and explaining the passport to patients and carers in the first instance to avoid negative associations. Importantly too, it must be made explicit that the passport belongs to, and is for the benefit of, the person with dementia and their family.
4. The degree and exact nature of GP resistance may require further understanding about how, if at all, it may be overcome. Alternatively, future design and implementation may have to consider which service should take responsibility for the dissemination and oversight of the passport. While it is important that GPs' are committed to the aims of the passport, sustainability will be underpinned by HSCP's and long-term engagement with families.
5. Successful use of the passport relies on the commitment and capacity of family and other informal caregivers, including the use of the passport, and communication with all HSCPs. This commitment and capacity is determined to a large extent by the perceived quality of life, including their own health, but also by the extent to which they believe that the passport will actually help them. The implementation of the passport must accommodate the needs and values of families and the involvement of carers could be made more explicit.
6. Contextual factors such as organisational culture, the learning environment and the care environment itself, are acknowledged as posing the most significant challenges to person centred care and the development of cultures that can sustain person centred care (McCormack et al., 2011). The implementation and effectiveness of the passport is more likely to succeed when these wider determinants are also appreciated.

Passport structure and contents

1. An electronic version (on an internet platform or as a smart phone app) may assist communication as it could facilitate instant access to information by HSCPs, while being password protected and therefore not in breach of data protection (access could be provided or restricted as required). Entries could be dated automatically, improving effectiveness and accuracy; there would be no problems due to illegibility of handwriting; and there would be no concern about people forgetting to bring their passport to appointments. In the initial stages, and for those patients and carers who are uncomfortable with electronic platforms, it ought to

be possible to hold a slimmer, simplified paper version of the passport with a “personal” section which could be scanned into their electronic HP, and conversely, patients would have the option of obtaining regular print-outs of their updated medical information to add to their paper version.

2. To ensure accuracy and consistency, any entries pertaining to medical treatment and therapies or interventions should be made and updated by the relevant HSCPs in their respective section/s. The “medical” sections of the passport ought to be standardised in order to ensure that all relevant details are provided for all patients.
3. Personal narratives also varied considerably in terms of detail, so perhaps some guidance would be helpful to ensure that basic information will be provided. There should be room for detailing progression, deterioration, comorbidities, and side-effects from medication within the “about my health” section. The “about me” section should allow for personal narrative, hobbies, activities, likes, dislikes, etc.
4. A space for name and photograph of the patient should be on the front cover of their HP. The section “About me” can provide HSCPs with an accurate account of who the patient is and was, what they like and dislike. Importantly, this section should also offer space for carer notes and reflections (“Carers’ log”).

Conclusion

While it does not constitute a stand-alone solution to current problems in dementia care, with some alterations as suggested by key stakeholders, it has the potential to help facilitate and improve quality of life for the patients and carers alike. The introduction of the passport in itself cannot bring about positive change. Our findings related to the challenges of families living with dementia suggest systemic changes necessary to retain personhood, improve communication, and facilitate self-management. They include, but go considerably beyond, changes to the current version of the healthcare passport. This evaluation has provided rich, in-depth information about the uptake and use of a healthcare passport for people living with dementia. For example, recruitment to studies such as this may be relatively easy but meaningful participation is more difficult to achieve. Thus, a future trial will need to set much stricter parameters for participation including true informed consent rather than a willingness to please clinicians, complexity of care, disease progression and passport ‘ownership’. As a result of the evaluation, we understand more fully, the complex multi-level factors that must be addressed prior to widespread roll-out of the healthcare passport and a large-scale trial of its effectiveness.

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