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Designing healthcare systems for earlier diagnosis and prevention of dementia

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Abstract

Recent clinical trials have successfully slowed Alzheimer's disease dementia progression, but only in early-stage patients. Society must therefore shift to early diagnosis. By framing this is as an engineering design challenge, we argue that a systems approach will identify solutions by providing the means to validate dementia medical technologies from multiple levels and perspectives: society, government, public health, healthcare, and patient ecosystems. We show that new data-enabled design methods can facilitate these different granularities of thinking and outline the need for designers.

Keywords: dementia, engineering design, healthcare design, artificial intelligence (AI), data-driven design

1. Introduction: early dementia disease diagnosis is an engineering design challenge

Dementia is the fifth leading cause of death globally, and prevalence is expected to triple by 2050 with population growth and ageing (Prince, 2015). Alzheimer's disease accounts for 70% of dementia cases, with the pathology developing progressively in the brain up to 10 – 20-years prior to first onset of symptoms such as impaired memory and daily functioning. Because of this protracted 'silent' disease phase, Alzheimer's is diagnosed after the irreversible loss of brain tissue. This has had dire consequences: dementia diseases have a 97% clinical trial failure rate because new therapies have been trialled too late, while rapid disease progression post-diagnosis forces patients and their communities into often ill-fitting end-of-life circumstances that accrue greater care costs than any other disease (Dubois et al., 2015).

The WHO Dementia Action Plan lists earlier diagnosis of dementia diseases as a priority. Earlier diagnosis and intervention holds promise that less brain damage will occur - preserving more cognitive function and quality of life, reducing care costs, and enabling better informed patients and caregivers that can be more actively engaged in society for longer. Dementia interventions are now possible - a Lancet commission showed that 40% of dementia cases could be prevented through physical and social lifestyle improvement (Livingston et al., 2020). Even more pressingly, recent clinical trials have demonstrated stabilised cognitive decline in participants with early-stage Alzheimer's disease, suggesting that a therapeutic treatment may soon be available (Van Dyck et al., 2023).

However, the challenge of enacting early dementia disease diagnosis in healthcare systems is no longer a medical or scientific challenge. Innovative medical technologies that can capture diagnostic signals of early stage dementia diseases up to 25 years before dementia onset have already been developed, including blood tests, digital clinical assessments, and wearable technologies (Mattsson-carlgren et al.,

2023; Newton et al., 2023) - many of which are already undergoing regulation and commercialisation. Public surveys demonstrate a majority demand for early knowledge of dementia risk status (Dementia Attitudes Monitor, Alzheimer's Research UK 2023), and healthcare professionals recognise the value of earlier diagnosis when treatments are available (Wilson et al., 2023). Individual pilot programmes have explored implementation of early detection programmes in localised regions (Schröder et al., 2024), and health economics modelling studies have established the cost-effectiveness of dementia prevention programmes (Mattke et al., 2024). There is unequivocal verification for scientific, medical, and societal acceptance and capability of earlier diagnosis - the challenge remaining is validation and change in practice.

In this positioning paper, we propose that the challenge of early dementia diagnosis is therefore one of engineering design and interdisciplinary systems thinking, with an objective to increase awareness of it among designers in healthcare systems research. Earlier dementia disease detection necessitates not just localised clinical service improvement with a new medical technology product-service solution provider, but, as we argue later, larger cross-sector population-scale transformation: encompassing social care and legal services, public health and education campaigns, political will, workplace environments, and societal stigma of dementia. Designers are well-versed in approaching these problems, but are currently missing in dementia research teams.

Section two aims to make the case for a systems and design-led approach in the early dementia diagnosis challenge, drawing on complexity concepts from the "DesignX" and "wicked" problems literature. We focus on the Engineering Better Care systems framework, which was co-created by systems engineers with clinicians to provide a shared, accessible platform for interdisciplinary health improvement teams. Although founded in system 'improvement' contexts, we suggest that this platform can additionally act as a playbook to facilitate interdisciplinary designer-led teams to address larger-scale, cross-sector healthcare challenges - like that of early dementia diagnosis - where more complex system 'transformation' is warranted.

Section three aims to show that, when addressing such large-scale healthcare challenges, designers need new data-enabled methods that allow for experience mapping at population-level as well as individual-level scales. We illustrate this with an example of our ongoing data-enabled study with the UK Alzheimer's Society online dementia forum, which aims to visualise collective patient/caregiver journey maps through text-mining analysis of over two million lived experience posts.

2. How design and systems thinking can address the early dementia diagnosis challenge in practice

2.1. Systems approaches in healthcare

Although many definitions exist, a systems approach can be broadly thought of as a collection of activities and processes that prompt more reflective thinking around how to understand, analyse and intervene in complex systems (Arnold and Wade, 2015). It aims to establish the individual components making up a system as well as the interactions and dependencies between them. For healthcare contexts, multiple data sources such as quantitative empirical data or qualitative lived experience anecdotes are used to create holistic visualisations of the why, what, how, where and when of a system, according to the different perspectives of who is in the system.

Systems are integral to healthcare at multiple levels, from biological systems or disease models to hospital operational or care pathway management (Uleman et al., 2024). However, a systems approach is often theorised but rarely practiced when enacting healthcare change. For example, when a new workflow or device is implemented to increase care quality (c.f. clinical efficacy, patient satisfaction or cost efficiency), it usually happens through a process of "silent design" (Gorb and Dumas, 1987), and under the banner of healthcare improvement or implementation science disciplines that often lack prompts for thinking about the wider system perspective (Clarkson, 2018).

Part of this issue is that a systems approach is necessarily broad, applied rigorously and technically in engineering disciplines but more conceptually in design disciplines, and consequently lacks a universally defined language or guiding framework that would permit wider uptake among healthcare

professionals. This was addressed within the healthcare context through a program of co-design workshops with patient leaders, clinicians, physicians, pharmacists, systems engineers and improvement professionals that culminated in the Engineering Better Care report (Royal Academy of Engineering, 2017). It describes systems from four key perspectives: the people that make up the system, the emergent properties and behaviour of the system elements, the range of possible designs that may provide creative and appropriate interventions for system improvement, and the risk to system integrity introduced by those interventions. Through the later introduced "Improving Improvement Toolkit", improvement management teams wishing to adopt the Engineering Better Care framework can follow an iterative process of gathering data that answer a series of guiding questions (Figure 1). The questions consider each of the four system perspectives and are wrapped in stage-gated project management practices.
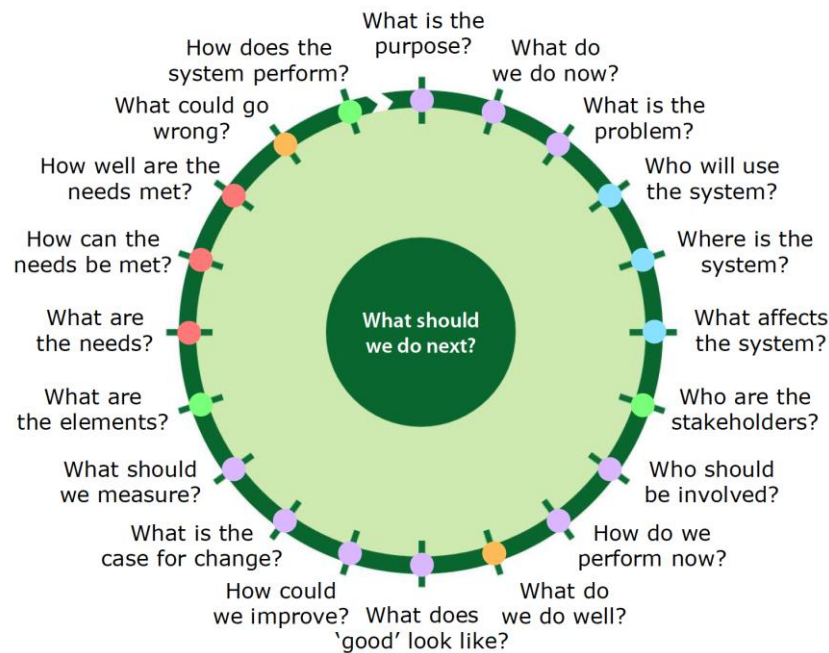

Figure 1. The Engineering Better Care framework for healthcare system improvement

A systems approach in healthcare is conventionally used within improvement projects - namely, to help healthcare teams locally design a system change that provides measurably increased care quality, with less risk and broader oversight. Examples might include in the introduction of a new digital dispensing trolley that aims to solve the problem of manual prescription errors by time-pressed nurses, or the creation of a new triage system to optimise patient flows through hospital wards and minimise waiting times. However, in the next sections, we propose that the systems approach outlined in Engineering Better Care can equally be scaled to much larger, more complex healthcare problems spanning society: those that require not just system improvement, but system transformation.

2.2. The complexity of the early dementia diagnosis challenge

At a most basic level, the system of dementia diagnosis broadly involves the following: an individual with subjective cognitive complaints presents to their primary care doctor, who asks them to complete a short, ten minute 'pen-and-paper' cognitive assessment. Based on population norms of expected scores for a given age and sex, the patient would be deemed either unimpaired or impaired, and if the latter, would be referred onwards for secondary diagnostic investigations into disease biomarkers using brain scans.

One well-established problem that contributes to the late detection of individuals with dementia within this system is the poor sensitivity of the 'pen-and-paper' of the initial cognitive assessment, which was originally designed to detect overt dementia symptoms and not subtle changes in thinking that accompany very early dementia disease stages (Hampel et al., 2022). As a result, many people with

early-stage dementia are deemed unimpaired and will be inappropriately turned away with a request to return for a follow-up the following year.

A solution may therefore be to replace the cognitive assessment with a new medical technology that can detect earlier stage signals of disease presence (Figure 2). However, the question then arises of how early? With increasingly early detection offered by various technology options comes increasingly large system changes in elements such as intended location (in clinic vs at home), user (clinician vs patient), data (digital vs physical), clinician-patient communication (dementia *presence* disclosure vs *increased risk* status for future dementia), and timing of use (on presentation of symptoms vs screening prior to symptoms). The consequences of these differing elements and the dependencies between them will also impact pre- and post-diagnostic pathways, raising labyrinthine questions around screening and the blurred responsibilities of healthcare vs public health sectors in disease prevention (Milne et al., 2021). Such changes can introduce further sources of inequality into an already racially and educational biased diagnostic and care systems, including workplace or driving licence discrimination and vulnerability to increased insurance costs.
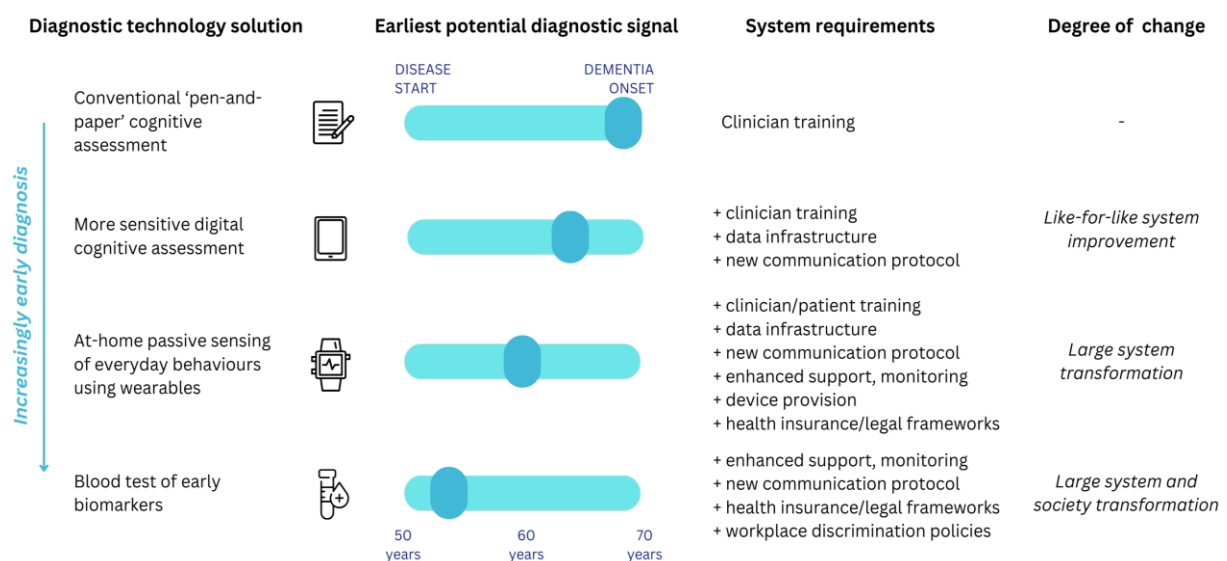

Figure 2. Summary of medical technologies capable of early dementia disease detection

In reality, there is also more than just the problem of cognitive assessment sensitivity that holds dementia diagnosis systems back from earlier detection. A systematic review of 126 qualitative studies worldwide into the lived experiences of the dementia disease diagnosis systems revealed that one of the most common barriers to an early diagnosis is delays in people with dementia actually seeking help - due to either stigma, normalisation of their symptoms or lack of recognition of dementia-related symptoms (Bunn *et al.*, 2012). In most cases, symptoms are noticed by other people first, be it family, friends, neighbours, or clinicians during unplanned hospitalisation. This highlights how the diagnosis system as described above is grossly oversimplified; the system instead reflects a deeply ingrained but highly varied community phenomenon (see Section 3). Solutions directed towards the lack of brain health awareness education or loneliness problems are just as warranted as new medical technology product-services that are more sensitive to early disease stages.

2.3. A playbook for finding the right problems to solve and co-designing solutions

How then to approach these types of complex healthcare challenges, when there are multiple cross-sector problems causing equal levels of system constraint, each with a range of scientifically verified solutions that involve some form of system transformation to implement? The first step must be recognition and acceptance of the need to conceive of individual healthcare challenges in this way. This has only recently begun to gain traction in medical and scientific disciplines; a high-impact dementia journal article described Alzheimer's disease as a problem that "if we try to fix in one bite…we will choke on it" and called for a "system-preparedness framework" among medical, scientific, payer and

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government stakeholders (Ball *et al.*, 2022). With the Davos Alzheimer's Collaborative, a global initiative launched in 2021 that has funded seven pilot programmes for earlier dementia diagnosis (Siva, 2021), significant progress is being made in the conceptualisation of dementia as a systems problem. However, designers are currently not part of this new dementia conversation - despite their rich history of describing and proposing solutions for such complex sociotechincal "DesignX" or "wicked" system problems that are chaotic, hard to define, and span entire societies (Norman and Stappers, 2015; Rittel and Webber, 1973). Norman and Stappers (2015) proposed the need for designers capable of modular thinking across different scales and disciplines, who continuously place humans at the centre, and can incrementally 'muddle through' towards progress. Others have considered how to reconcile the interests of diverse local or international stakeholders (e.g. user, payer, supplier, etc.) when faced with the inherent tension between needing the value gained through technological innovations and the financial struggle of healthcare systems in adopting them (Patou and Maier, 2017). Although design approaches are gaining more widespread outside attention - the UK Medical Research Council recently funded a guide on participatory systems mapping methods for public health, for example (Blake *et al.*, 2024) - this does not circumvent the need for involvement of designers themselves.

We propose that the Engineering Better Care framework and resultant Improving Improvement toolkit holds potential as a playbook for addressing complex healthcare challenges, like early dementia diagnosis, in a way that i) directly involves designers, ii) allows for the flexible integration of these previously established design approaches to complex challenges, and iii) does so in a practical 'hands-on' way that can meet the language and conceptual thinking modes of experts from medical and scientific fields. This does not seek replace any current efforts but can instead wrap-around them in a way that systematises them into a coherent workflow, ensuring a broad as scope as possible and providing a common thread for 'muddling through'.

To illustrate this, we briefly describe our ongoing UK-based study involving the first application of the toolkit to the early dementia detection problem. As argued in the original Rittel and Webber (1973) definition of wicked problems that exploring them requires a solution, the study began with the development of a more sensitive digital cognitive assessment prototype led by a group of neurologists and neuroscientists (Chan *et al.*, 2016). In a National Institute of Health Research funded grant, this group joined forces with systems engineers and designers experienced in healthcare system improvement, and behavioural psychology scientists experienced in patient-public engagement around patient safety in digital health. Representatives of these three groups form the interdisciplinary project leadership team to manage the planning and application of the Improving Improvement toolkit, with progress captured in an 'improvement canvas' (akin to the concept of a business model canvas from entrepreneurship). The project objective is to implement the digital cognitive assessment in NHS primary care through co-designing the service and system changes around it with clinicians and patients. Six NHS trusts are collaborators in the project, providing over 12 pilot UK-wide pilot sites that were selected to maximise diversity of end-users involved in their validation: across socio-economic, racial, cultural, and geographical variables.

The first 'Understand' stage of the Improving Improvement toolkit seeks to explore the dementia diagnosis system through stakeholder engagement and mapping methods. In our study this involves UK primary care and secondary care services, commissioning systems, and patient journeys. Following articulation of the current consensus system view, the 'Co-design' stage is initiated, where creative designer-led workshops and interviews are used to ideate ways in which new digital cognitive assessments add value to the different systems identified. Combining the human-centred perspective with systems metrics and modes of invariant operation help guide the conceptual evaluation of designs. Physical pilots are then carried out in the subsequent 'Deliver' stage to physically evaluate designs in practice using tools such as expert review, patient exclusion audits and environmental life cycle assessments. Outcomes from likely several iterations of stages one-three inform the 'Sustain' stage, where the case for scaling the most value-generating solution is pitched to stakeholders of influence, and ongoing evaluation by local teams seeks to embed the system change.

Although this study may appear to reflect system improvement rather than transformation, we view it as the first step in 'muddling through' a single module of the dementia diagnosis system. As discussed in Section 2.2, we do not anticipate that replacing cognitive assessments with more sensitive digital tools

will solve the problem of early dementia diagnosis - it may transpire not add any value at all. Instead, through this first iteration of muddling through we will gain enhanced understanding of the human-centred system barriers and facilitators, unveiling new system modules with which to replicate this study and incrementally gain traction towards the larger systems at play - those of local policymakers, dementia charities, medical technology or pharmaceutical companies and public health bodies. Only by bringing about collective action with the right stakeholders and interdisciplinary teams can we transform the systems currently failing us.

3. Using data-enabled methods for large scale health systems design

The first critical step in projects like the above seeking human-centred health system transformation is understanding the person perspective. Patient journey mapping is the foremost tool used by designers to address and represent the experiences of people within healthcare systems (McCarthy *et al.*, 2016). Commonly, mapping will involve multiple rounds of focus groups and one-to-one interviewing of people with lived experience. Through synthesis, designers gain the necessary insights to visualise a typical patient progression through a clinical pathway, be it touchpoints with clinical staff or services, particular procedures undergone, the emotions experienced, or the information learnt. However, this process is often criticised for lacking representativeness of the entire population experience. Collecting anecdotes, narratives, and insights from the population of interest is a highly labour-intensive process that is often constrained by project timelines. Providing human-centred healthcare necessitates first capturing the entire range of different patient personas that could possibly use the health system.

Data enabled methods that make use of publicly available patient experience data from online forums may provide a solution to this (Jung *et al.*, 2023). Online patient support forums offer a public community space to exchange experiences, form friendships, share advice and help minimise perceptions of loneliness. They are particularly used by carers and families of patients with chronic diseases such as dementia who are at risk of poor mental health long-term (Attard and Coulson, 2012).

Given the wealth of patient experience data available within these forums, designers are increasing looking to data and machine-learning collaborators to help generate new design insights from them (Bourgeois and Kleinsmann, 2023). Data mined from forums provides the "what", which through participatory analysis with stakeholders helps designers build narratives and create a collective picture of the system and range of different people within it. By mining two online cancer patient support forums with over ten thousand posts and using machine learning (a form of artificial intelligence) to analyse the data, Jung et al. (2023) were able to demonstrate feasibility of the approach and derive novel insights beyond traditional journey mapping techniques - including a quantified frequency of stories, co-occurrences between events, and a generic community-level journey map that could serve as a benchmark to better contextualise unique individual experience.

Although there are several drawbacks to this approach, such as the bias of forum users to digitally literate citizens and the limitations inherent to machine learning algorithmic decision-making processes, careful mitigation with well-informed multidisciplinary teams can rapidly yield large-scale data-sets and novel findings into patient journeys that would enhance a systems approach to solving complex health system challenges. We describe an ongoing application of the Jung et al. (2023) method to the early dementia diagnosis challenge with the UK Alzheimer's Society Dementia Support Forum. The study is approved under the Delft Technical University ethics review board and methods adhere to guidelines for ethical internet mediated research (The British Psychological Society, 2021). The Alzheimer's Society provided permission for the study.

3.1. Data-enabled design in dementia

The UK Alzheimer's Society Dementia Support Forum is one of the largest globally for dementia, with over 1.9 million posts dating from as early as 2003. In October 2023 alone, 9380 messages were sent and over 750 new users joined to reach a total of 85,301. We selected this forum due to the number of messages (permitting machine learning analysis approaches), the authors of messages being the target study audience (citizens living with dementia, carers or family members, or citizens concerned about their risk for future dementia), and the messages being written in English language. The forum is structured as a collection of 11 topic sub-forums, each with separate discussion threads comprising of

individual posts. Topics range from "Memory concerns and seeking a diagnosis" to "I have dementia" or "I have a partner with dementia", but initial manual analysis of messages and threads revealed discussions relating to the diagnosis system across topics.

3.2. Methods

After extraction of text from the individual posts, data scientists will pre-process the text to enhance algorithm performance. This includes removal of digits and hyperlinks, lemmatisation of verbs (grouping different tenses into the dictionary form), and deleting common non-contextual greetings (such as welcomes or greetings).

Two main forms of machine learning techniques can be employed for analysis of large text datasets, which both aim to succinctly summarise the text themes and identify hidden patterns between them. Supervised algorithms search the data and attempt to assign messages to pre-defined topic-labels that are manually created by designers. Conversely, unsupervised algorithms search the data and attempt to self-create clusters of topics based on similarity of concepts or words. Designers must subsequently manually interpret the clusters to assign topic meaning to them. For the purposes of this study, an unsupervised approach will be employed to explore the data in a hypothesis-free manner. Health system designers, design students, neuroscientists, clinicians and people with lived experience of dementia will interpret the resulting clusters by reading individual messages within clusters and extracting high level conceptual themes in the context of seeking, receiving or fearing a dementia diagnosis. The team will seek to achieve consensus on the themes and use them to map out collective journey maps.

3.3. Pilot results

Machine learning analysis is currently ongoing. We therefore present findings from a manual qualitative analysis to demonstrate the utility of patient forum data. Within the 'Memory concerns and seeking a diagnosis' sub-forum, ten discussion threads were randomly selected (every tenth thread dating back from 10 November 2023) with an average of nine posts each. We conducted a realist thematic analysis, extracting non-overlapping coded themes from the surface-level meaning of post messages to better reflect forum user's realities (Braun and Clarke, 2006). This revealed three core and common problems in the pre-diagnosis and diagnosis experiences of citizens that we aim to build on with the machine learning approach.

3.3.1. The patient journey experience is not limited to the patient

Nearly all threads were initiated by a child, grandchild or partner of a person who they suspected was showing early signs of dementia but who was also in denial. One was initiated by a concerned neighbour. These posts were seeking advice on how to begin the patient journey if they are themselves not the patient, with example quotes including:

> "How do I go about getting a diagnosis without my dad knowing? He is due a medication check by his doctor, can I speak to the doctor before he goes to see if he can do any tests while he's at his appointment?" (Thread #4, post #1)

> "If your expectations are that you will be believed and your mum will have thorough testing and Something Will Be Done, then you're going to be disappointed." (Thread #6, post #16)

3.3.2. Extreme patient journey experience variation

The pathway appears typically to involve first presentation to a general practice doctor, who then refers a patient to a memory clinic for more in depth diagnosis. However, some posts mentioned home visits from a nurse or psychiatrist that performed initial diagnostic cognitive tests. The tests themselves varied as well, with some not initially detecting people with dementia. Waiting times for referrals to a memory clinic varied from six weeks to over two years.

> "Mums memory clinic was later to provide the most awful service and I put a complaint in about the way we were treated. By comparison the memory clinic near

me offer a 6 week course for PWD [people with dementia] and their carers about what to expect, where to get support and how to access the local carers centre" (Thread #6, post #5)

"I thought my mum might ace her assessment as she had done with mini mental type assessments in the GPs. However this time the hospital referred to memory clinic" (Thread #6, post #9)

3.3.3. Patients lack information and trust in the system

Many threads involved questions around what to expect during the diagnostic process and criticised the validity of some of the diagnostic tests used. Replies often included links to information sources provided by the Alzheimer's Society but none to sources provided by the National Health Service:

"Im having to chase every one and thing, its almost no -one cares or can be bothered" (Thread #5, post #3)

"I found the testing of my husband unscientific & demeaning" (Thread #6, post #21)

3.4. Discussion

These initial findings from the forum both reflect and extend previous literature. Descriptions of symptom denial by concerned families or friends echoes the meta-analysis of qualitative studies showing a delay to diagnosis is lack of help-seeking by patients (Bunn et al., 2012). However, the concept of neighbours as a stakeholder in the patient journey is novel and warrants inclusion in future interviews. The variation in experiences underscores the need for broader engagement of lived experiences in this particular health system, which traditional interview-only design methods may have missed. Although deriving machine learning insights is ongoing, manual exploration of this large data source promises the ability to map out both collective population-level themes as well as the range of individual experiences.

4. Summary

This positioning paper intended to raise awareness among designers of the need for systems and design engineering thinking in the challenge of transforming healthcare systems for earlier diagnosis of dementia diseases. We contributed two key ideas to the literature. First, the co-designed Engineering Better Care framework as a systems approach provides a playbook to integrate designer thinking into a practical 'hands-on' framework capable of planning health system transformation, chiefly through its ability to cater to interdisciplinary clinical teams. Second, data-enabled design methods such as text-mining of patient online forums provides the scale and speed for designers to approach complex societal level healthcare challenges. Particularly for the latter, initial analysis of an online patient support forum for dementia has revealed key insights that will influence the design of our larger study involving the Engineering Better Care framework, such as the need to think more broadly around the stakeholders in patient journeys. With a parallel publication on this topic targeted for dementia related journals, we hope that this work forges new connections between interdisciplinary teams and designers with a vision to help make dementia preventable.

Acknowledgements

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