

Driving Change in Complex Social Systems: How to Design Healthcare Pathways

A. Feldman^{1,✉}, F. Patou² and A. Maier^{1,3}

¹ Technical University of Denmark, Denmark, ² Oticon Medical, Denmark,

³ University of Strathclyde, United Kingdom

✉ afeld@dtu.dk

Abstract

How does change occur in healthcare settings? In this paper, we take a design-based approach to healthcare research. From researcher-patient interactions to information sharing between practitioners, we examine how clinical research can mediate a change of routines and illuminate potential new system structures. Using a hospital-based cognitive care clinic as an example, we demonstrate how the inclusion of new actors, tools and resources was able to shed light on the prevalence of hearing loss among mild cognitive impairment (MCI) patients and lay the framework for new care pathways.

Keywords: healthcare design, complex systems, human behaviour, hearing care, cognitive decline

1. Introduction

In any given day, practitioners repeatedly ask the same questions and administer the same tests to a number of patients. While the path for each patient may differ, the underlying procedure remains the same. These recognisable and repetitive patterns are referred to as routines (Feldman and Pentland, 2003). In a healthcare setting, this is also referred to as a protocol, which defines a set of steps used to assess a patient and determine appropriate interventions within a specific disease area (Thomas and Farrell, 2015). Healthcare is an area with high risk and little room for error. Thus, protocols are designed to increase uniformity, reduce uncertainty and maintain efficient patient care through a consistent pattern of action.

Despite the existence of specific and prescribed medical guidelines, these routines are maintained—and changed—by those who take part in these repeated patterns on a regular basis. Hospitals are complex social systems, where routines are "shaped by patterns of interaction among diverse and ever changing agents" (Moore et al., 2019, pp. 27). This includes doctors, nurses and patients—as well as primary caregivers, administrators, researchers and digital systems. These systems are inherently adaptive (Keshavarz et al., 2010). When research projects are conducted, new actors and tools are integrated into a clinical setting and routines are altered. The presence of the researcher in the clinical setting can bring about new perspectives and lead to potential new healthcare pathways.

In this paper, we demonstrate how a design perspective can impact research in clinical practice. Using the example of a research project in a cognitive care clinic in Denmark, we demonstrate how the inclusion of new actors can mediate a change of routines and illuminate new care pathways in within the complex clinic environment. In section one, a care pathway is mapped and in section two, we demonstrate how the introduction of a clinical research project was able to alter extant routines. Section three describes how eligibility screening was able to shed light on unmet system needs and expose the number of patients with significant and unaddressed hearing loss. Using a systems-based design lens provides all researchers with the opportunity to test more than the efficacy of an intervention—we are

also presented with an opportunity to design new patterns of action within the healthcare system (Feldman, Patou and Maier, 2020).

Methodology

This paper demonstrates the benefit of interdisciplinary collaborations that integrate both design and healthcare. Using a case-control study as an entry point, we have combined design thinking with clinical research to explore the complexity of the problem and solution space and envision new pathways towards improving care (Yilmaz and Daly, 2016; Noël, 2017). Just as divergent thinking is needed within a social system to introduce new perspectives and consider new possibilities, convergent thinking is equally necessary to evaluate and synthesise available and existing knowledge (Cropley, 2010). Expanding upon the considerations by Feldman and colleagues (2020) for effective research translation, we demonstrate that taking a design approach to clinical research can reframe relevant clinical endpoints and identify barriers and enablers to healthcare delivery in clinical practice.

This paper uses observational research compiled over 12 months in the clinical setting. During this time, the researcher ran a case-control study, participated in team meetings and consulted regularly with neurologists, neuropsychologists, nurses and other members of a cognitive care clinic in Denmark. In the process of recruitment and testing with the case-control study—the entry point for this paper's findings—the researcher consulted with over 50 patients with cognitive dysfunction about their hearing history. Together with current Danish Health Ministry guidelines, these experiences and encounters resulted in a mapping of system actors within the cognitive care system and the diagnostic care pathway for an individual experiencing cognitive dysfunction (Greenhalgh, 2008; Balogh, Miller and Ball, 2016). The presence of new resources, actors and routines were included to illustrate the structure of networks and routines during the one-year study interval.

2. Healthcare as a complex social system

Healthcare clinics are inherently complex systems. They are formed by set of rules—a protocol—and interconnected components. However, their complexity is defined by their social and adaptive nature. While these individuals have the shared goal of achieving more effective health outcomes, the routes that are taken, and the trade-offs made along the way add to the complexity of these sociotechnical systems (Jones, 2014; Rouse and Serban, 2014). System actors utilise knowledge, experience, feedback, local values and system rules to continuously adapt within the fuzzy boundaries of the rule-based framework (Keshavarz et al., 2010). Here, complexity is a characteristic of the system itself, and not the individual actors.

Moore et al. (2015) describes the complexity of these social systems and their interventions as a continuum that is dependent on time, activity settings and social networks. For example, a referral from a doctor to a specialist, a conversation between a patient and a spouse, or a meeting with a hospital director and a clinician team. Each of these are nested in different sub-systems. Some of these are informal, parallel systems, such as a patient and their interaction with their families. Others are more formalised, such as treatment guidelines from national health authorities. When new actors enter the system, they have the capacity to change these relationships, disrupt existing activities and redistribute resources (Hawe, Shiell and Riley, 2009).

Interventions change the networks of interactions, from the micro system of a doctor-patient interaction to the more macro setting of cross-disciplinary information sharing between practitioners. All of these interactions are dedicated to best practice and improved patient wellbeing. However, their response to change is crucial to establishing best practice within a system. In response to change, the systems self-organise by either embracing change and adopting a new routine or maintaining the status quo by rebounding to original patterns. Working with interventions as events within systems is therefore a fruitful way to examine new patterns, provide in situ evidence and change the dynamics within a complex social system.

2.1. Framing events within systems

Change is rarely a linear process. Large scale intervention projects which fail to consider the context, key actors, roles and social relationships within the system are unlikely to succeed in generating long-

lasting change. Here, systems and design thinking share principles that enable problem solving in complex environments (Jones, 2014). Framing a situation in new and novel ways, depending on the point of entry into a project, is a key component in the design process. This strategic reframing, taking into account the roles and values of the environment, may serve similarly useful when advocating for change within a complex social system (Paton and Dorst, 2011).

The development phase of an intervention, for example, may benefit from considering how the dynamics of the particular system serve to maintain current routines, and how these patterns could be disrupted by new actors. The UK Medical Research Council (MRC) have developed a five-phase strategy for the development, feasibility and pilot testing, implementation and evaluation of complex interventions (Craig *et al.*, 2008). While this framework has had great influence on the design and evaluation of interventions within healthcare, recent work has forwarded the importance of considering the complex nature of the system, and viewing the intervention instead as an event within the structure of the complex and adaptive social system (Hawe, Shiell and Riley, 2009; Moore *et al.*, 2019). Feasibility and pilot testing would benefit from viewing feasibility as fluid, shifting based on the alignment goals and values, and the existence of the right relationships and resources within the system.

2.2. Cognitive care

According to the World Health Organization, dementia is one of the major causes of disability and dependency among older people worldwide. There are approximately 50 million people worldwide currently living with dementia, and number is expected to increase to 75 million by 2030 (World Health Organization, 2021). This growing number places increased burden on both the healthcare system and the caretakers and families who support this growing demographic.

The aim of the cognitive healthcare system is to support the diagnosis, treatment and management of dementia and other neurodegenerative disorders. More recently, an increasing focus has been placed on preventing the onset and progression dementia using current knowledge of potentially modifiable risk factors in early to late stages of life (Livingston *et al.*, 2017). An approach based on emerging knowledge and new technology may help promote prevention and improve health outcomes (Thorpe *et al.*, 2016). Although the underlying cause of dementia is not curable, best-practice care can improve symptoms, slow the progression and help families provide support.

Similar to global statistics, Denmark is experiencing an increase in the prevalence of dementia. In the previous year, 9,600 individuals were referred to a hospital-based dementia care system. Two-thirds of these received a diagnosis of dementia. A further 2,000 patients received a dementia diagnosis through a separate hospital department (Sundhedsdatastyrelsen, 2020). The assessment and treatment of dementia in Denmark is based on guidelines set out by the wider supra-system, the Danish Health Ministry. The implementation of these guidelines is further specified by each region's healthcare system and their associated hospitals. Within each clinic, there are networks of routines which streamline protocol within the sub-system and maintain efficient care patterns between practitioners and patients.

As outlined in the corresponding figures, the actors and care journey are described in this paper are defined in accordance with the Danish Health Ministry's guidelines and the process outlined by discussions with practitioners in the cognitive care clinic in Denmark. This constitutes our research frame. Within this frame, individuals act, react and adapt to one another in ways that are intrinsically related to their broader environments (Moore *et al.*, 2019). The use of specific cognitive and imaging tests, number of patient visits and coordination between practitioners may differ internationally. The use of context-specific guidelines reflects the system's current organisational structure and recommended best-practice.

2.3. Research frame: Dementia care pathway

As the Danish Health Ministry's guidelines note (Sundhedsstyrelsen, 2013, 2018) there is no single test method that can determine dementia with ultimate certainty. Therefore, it is vital that results are evaluated in combination with medical history, symptoms and clinical observations. The pathway focuses on the interaction points between the various actors. After experiencing symptoms, an individual visits their general practitioner and is referred to the cognitive care clinic for two major visits. In the first visit, all medical history is taken into consideration, and a battery of neuropsychological tests and brain imaging scans are administered. After a weekly team conference with the team of

neuropsychologists and neurologists, a diagnosis is provided and the patient comes in for a second visit to receive the diagnosis and discuss treatment. Following a dementia diagnosis, a series of phone and home visit follow-ups occur, both with nurses and municipality-based dementia care coordinators. A series of at least two control visits at the cognitive care clinic also follow, where their function and level of disease progression can be re-assessed. This pathway is illustrated in figure 1, including the referral, eligibility testing and protocol of our case-control study, also described in section 2.2 and at clinicaltrials.gov (Feldman *et al.*, 2020; Feldman *et al.*, 2022).

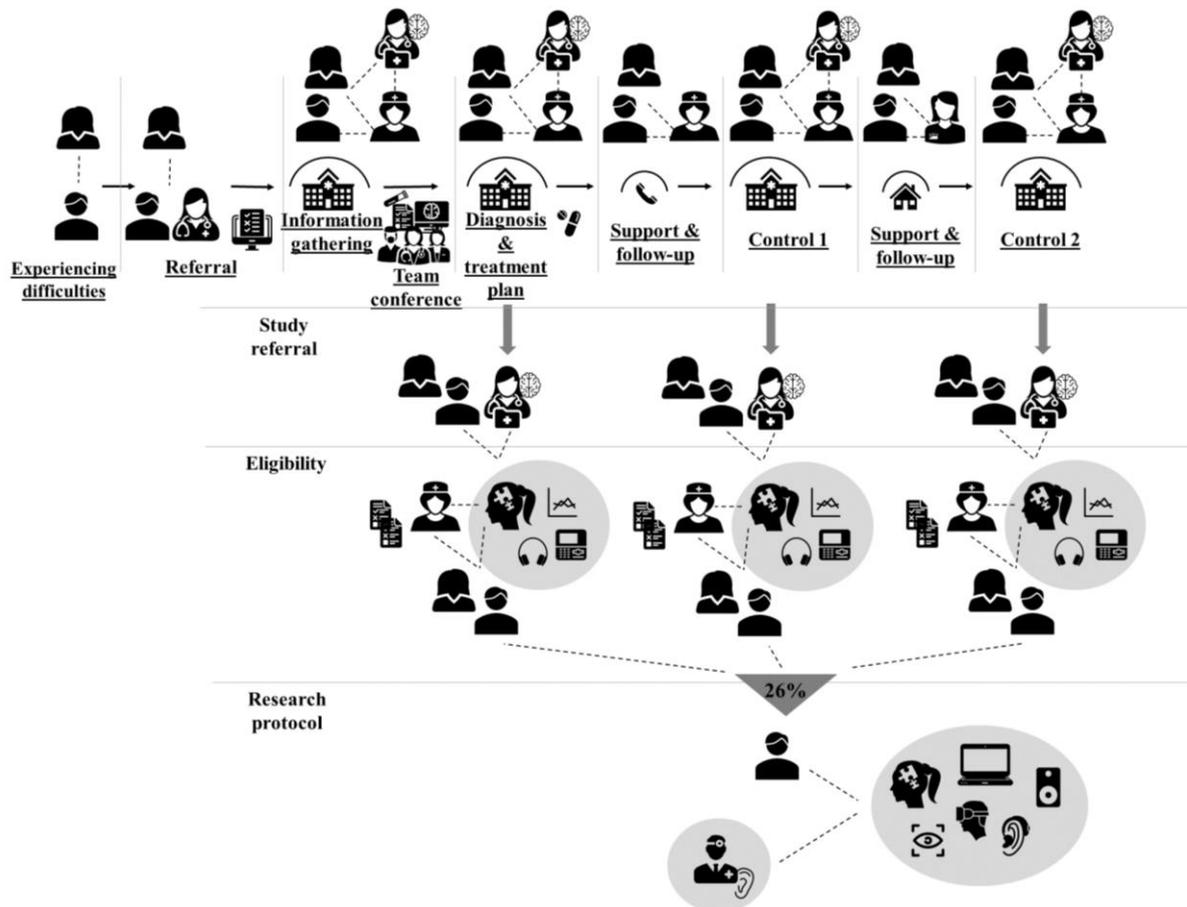


Figure 1. Dementia diagnostic care pathway with research protocol: observational research, Danish Ministry of Health guidelines (Sundhedsstyrelsen, 2013, 2018) Clinicaltrials.gov research protocol (Feldman *et al.*, 2020; Feldman *et al.*, 2022) and (Thorpe, 2018)

3. Introduction of new actors

Every complex social system has its own pattern of diverse actors, defined as either *someone* that acts, or *something* to which activity is granted by others (Doolin and Lowe, 2002). Instead of seeing these artefacts as peripheral to the system's functioning, we take an approach similar to Cresswell *et al.* (2010) and Doolin and Lowe (2002) and consider both human actors and nonhuman technology and tools as actors within the healthcare system. In an approach based in actor-network theory, we view these as key components of the network's relationships and routines. Society, organisations, agents and machines are all generated by patterned networks of diverse materials (Law, 1992). Based on resources, rules and power dynamics, they build networks with particular roles that together constitute a system.

3.1. New actors bring new insights

The care pathway is supported by actors and elements that intersect at pre-defined stages. Roles and responsibilities are pre-defined, and rely increasingly on tools, both physical and digital, to coordinate care and make diagnostic decisions (Greenhalgh, 2008). These actors and tools aid in diagnosis,

communicate health information to fellow practitioners and provide care and information to patients and caregivers. When new actors are introduced, they must be considered within the local and contextual context of the clinic (McLean and Hassard, 2004). Hardly impartial observers, the researcher becomes a key actor in the care practice (Rivard, Lehoux and Hagemester, 2021). They are also responsible for 'giving care', as they direct attention to ways care can be improved, mobilise their skillset to address problems and co-design with 'need knowers', such as caregivers and patients to develop solutions. In this way, the new actor becomes the spokesperson for the new components. They offer new tools, abilities, and beliefs as they test a hypothesis within the system's network of connections. The new and existing actors in our research are illustrated in figure 2.

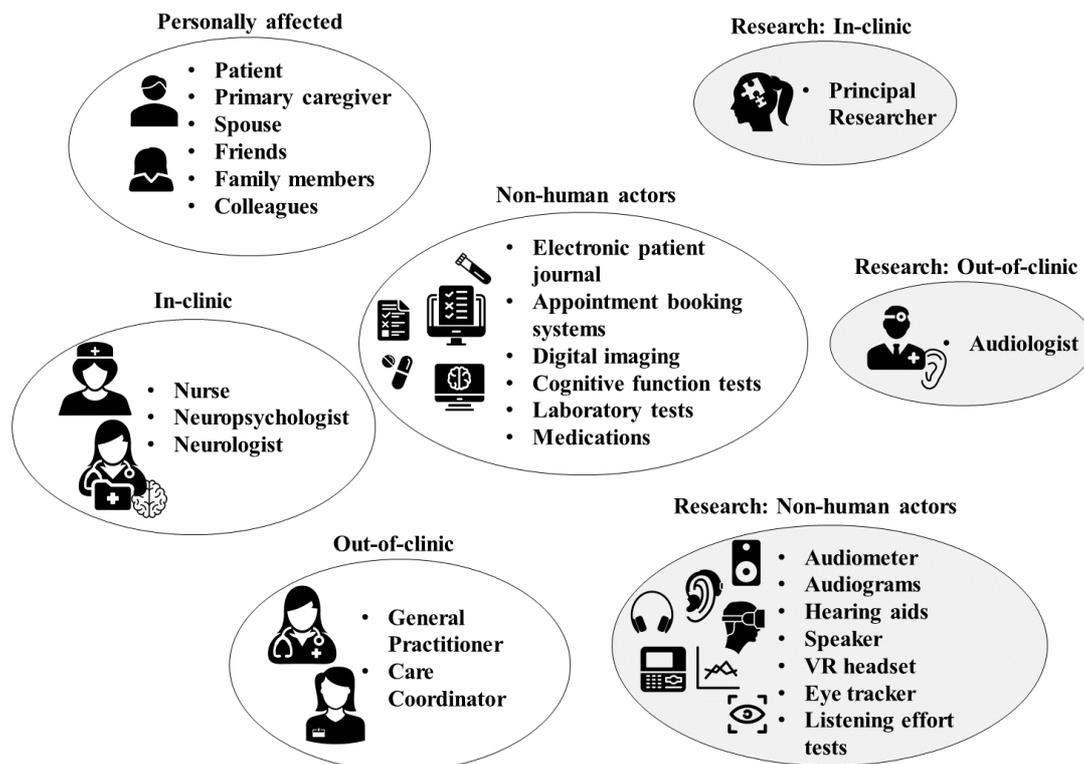


Figure 2. Introducing new system actors through research (shaded ellipses); Clinicaltrials.gov research protocol (Feldman *et al.*, 2020; Feldman *et al.*, 2022)

3.2. Clinical entry point

Currently, hearing and cognitive care are separate sub-systems within the healthcare supra-system. Housed in separate departments, resources are not immediately available for hearing screening during the dementia care process. Conversely, screening for cognitive dysfunction is not usually available during the hearing care process. Lin and Albert (2014) note a lack of interaction between these disciplines, suggesting that this disconnect hinders the advancement of research in this area. For someone with a hearing impairment, the cognitive burden of speech comprehension may result in consistent additional effort, making performance in daily activities and cognitive tasks more difficult.

The current paper considers the impact of our research protocol on the routines within the clinic. By altering routines, resources and relationships, we created new affordances for hearing care in a cognitive care context. The knock-on effects of our *event within the system* provided insights and identified needs that can be used to structure interventions that consider the clinic's current care pathway.

3.3. Study eligibility

Figure 1 outlines the how diagnostic care pathway included new routines, such as pure tone audiometry testing, whereby only 26% of those tested in the clinic were eligible to participate. In the context of the clinical research project, eligibility testing was carried out by both the researcher and a nurse at the

cognitive care clinic, who administered two standardised cognitive tests. We defined normal hearing based on the World Health Organization's hearing impairment grading system, with adapted thresholds above 25 dB at 4 kHz to account for the average hearing levels for men and women in older age groups, as described by ISO-7029 (International Standards Organization, 2017; Humes, 2019; Feldman *et al.*, 2020). Among the 57 patients with cognitive dysfunction who were referred from the clinic, only 26% were eligible to participate, as the rest had hearing loss. Among these patients, 46% were previously unaware of their hearing loss. A 35% considered their hearing as *normal*, despite demonstrating a hearing loss during testing. Of the 23% who were aware of their hearing loss, 77% had hearing aids. However, a majority of these hearing aids were no longer being used or were in need of repair or replacement. Primarily in the high frequencies, hearing loss was common among patients in the cognitive care clinic. These findings are not entirely unexpected, as previous research alludes to the high prevalence of hearing loss in this age group. However, the integration of these tools into the clinic environment was entirely new. In doing so, we were able to shed light on the statistics surrounding the unmet hearing care needs among their own patient group.

4. Shedding light on an unmet need

In this study, eligibility screening revealed an unanticipated number of patients with unaddressed hearing loss. This introduced audiology-based tools and resources into the clinic. While these patients were ineligible for the original study protocol, these eligibility screenings became counselling sessions, as audiograms were shared and reviewed with the patient and the primary caregiver, and next steps and course of action were discussed. Clinic staff became familiar with the presence of audiological equipment in the clinic environment, and patients had their first conversation in a cognitive care clinic pertaining to their hearing health, including results and relevant recommendations.

4.1. Hearing loss as a relevant risk factor

The basic assessment of hearing loss traditionally focuses on pure-tone and speech audiometry to measure speech and sound at standard thresholds. However, speech perception—particularly in noisy environments—also requires inhibitory control, attention and working memory (Pichora-Fuller *et al.*, 2016). This may explain the greater effort and fatigue experienced in complex listening situations, which is a common patient complaint in audiology. Some of these mechanisms may account for some of the cognitive challenges observed in individuals with cognitive impairment.

Evidence suggests that hearing loss, even at mild levels, is associated with the long-term risk of cognitive decline and dementia (Uhlmann *et al.*, 1989; Lin *et al.*, 2013). Cognitive factors such as attention and memory also play an important role in speech understanding (Akeroyd, 2009; Strauss and Francis, 2017; Peelle, 2018) and older adults with hearing loss perform worse on nonverbal tests of spatial working memory, learning and association ability and psychological function (Jayakody *et al.*, 2018).

Global reports, such as the dementia report by the Lancet Commission (Livingston *et al.*, 2017, 2020) focus on the need for dementia prevention and management. They advocate for an approach that considers potentially preventable risk factors at different stages of life. From these life-course risk models, they estimate that one-third of dementia cases could be preventable, given that these risk factors are addressed at the appropriate life stages. The risk factors with the largest population attributable factors are outlined below:

- Hearing loss (midlife, 8%)
- Less education (early life, 7%)
- Smoking (later life, 5%)
- Depression (later life, 4%)
- Social isolation (later life, 4%)

4.2. Providing situational evidence

The first introduction to our study was made at the end of a consultation with a neurologist or neuropsychologist—often during control visits, where no new diagnostic information was likely to be received. Occasionally, these referrals were made during the visit where the diagnosis of mild cognitive

impairment was communicated to the patient. The project is introduced by the specialist, who has been given an information letter by the researcher. This begins a conversation about the patient's hearing and the connection between hearing and cognition.

Patients often under-report their own level of hearing loss, or are unaware of how a loss of hearing is experienced (Halpin, Iezzoni and Rauch, 2009). Patients with cognitive dysfunction experience cognitive difficulties that make them particularly vulnerable against sensory loss, and the presence of an untreated hearing loss may exacerbate attention difficulties and memory issues (Akeroyd, 2009; Jayakody et al., 2018). Over time, compensatory strategies mean that individuals don't notice their hearing difficulties, or experience them instead with other labels, such as fatigue, unclear speakers, or difficulty concentrating.

As Lin and Albert (2014) note, hearing is often considered an afterthought in an older patient population, due to the frequency of other, often more pressing, clinical issues. As discussed in section 3.1, its prevalence and relation as a risk factor with significant predictive power makes hearing loss a relevant consideration for patients with concurrent memory and attention difficulties. In some cases, the study referral began a conversation about a risk factor that otherwise would not have otherwise been discussed during this patient visit. This illuminated a potential entry point for a new care delivery pathway.

Summary and conclusions

We have shown how a design-based approach to clinical research can illuminate the roles, resources and routines within the clinic and illuminate new potential for healthcare delivery. Through mapping the care pathway, we demonstrated how the audiological resources and tools actors became a temporary part of the cognitive care system. Beyond the original objectives of the case-control study, these new routines shed light on the need for hearing care among patients in the clinic. Hearing loss is a significant risk factor for cognitive impairment and dementia—however, many patients were not addressing their hearing impairment while moving along the dementia care pathway. The use of a systems-based design lens provided us with the opportunity to work concurrently with our research protocol, detect an entry point for a new routine, and iterate a future solution for wider, temporary hearing screening within the clinic. In doing so, we began to identify the necessary tools, networks and knowledge needed to integrate hearing care directly into the care pathway. Future research should incorporate audiological screening into the information gathering phase and conduct similar observation and mapping of the hearing care pathway to identify viable synergies within the healthcare supra-system.

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