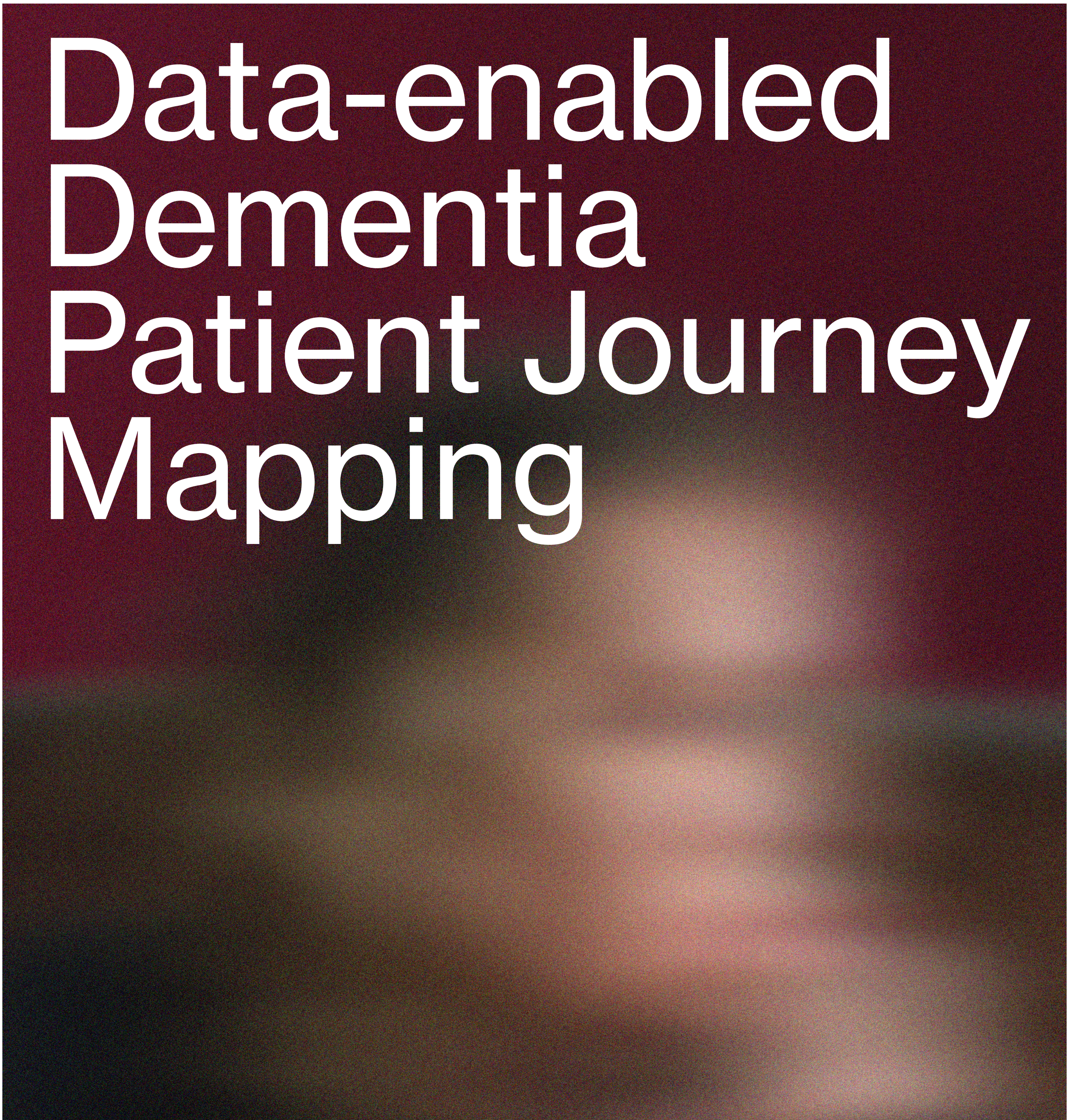
Data-enabled Dementia Patient Journey Mapping



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Finally, I would like to dedicate this project to all those affected by dementia, especially caregivers, who tirelessly provide support to those in need with endless love and compassion.

“It is a strange, sad irony that in the territory of a disease that robs individuals of their memory, it is often the caregivers who are forgotten.”

- Karen Wilder

Summary

The aim of this master's thesis is to lay the foundations for enhancing early dementia detection strategies across the UK, by gaining a comprehensive understanding of the current diagnostic journey from the perspectives of people living with dementia (PLWDs) and their caregivers (CGs). The project consists of a literature review establishing foundational knowledge and identifying existing research gaps, followed by a three-phase mixed-method approach to analysis of online patient stories. Inspired by Online Community Journey Mapping by Jung et al., 2023, initially, a thematic analysis of a representative sample of online patient stories is conducted, followed by LDA topic modeling to validate the thematic insights across the wider dataset of the UK Alzheimer's Society Dementia Support forum. The synthesis of these two methods results in detailed journey maps of the PLWD and CG experiences. The findings reveal nuanced insights into the barriers and facilitators of early dementia diagnosis and caregiving, particularly from the perspective of familial CGs. These journey maps serve as essential tools for policymakers, NHS workers, designers, and academics to inform strategic improvements, ultimately aiming to enhance early diagnosis rates and provide support for PLWDs and their CGs.

Contents

Abbreviations

AD – Alzheimer’s Disease
CG – Caregiver
CT – Computed Tomography
EBC – Engineering Better Care
FDA – Food and Drug Administration
GP – General Practitioner
LDA – Latent Dirichlet Allocation
LPA – Lasting Power of Attorney
MCI – Mild Cognitive Impairment
ML – Machine Learning
MRI – Magnetic Resonance Imaging
NHS – National Health Service
PET – Positron Emission Tomography
PLWD – Person Living with Dementia
TA – Thematic Analysis
TM – Topic Modeling
UK – United Kingdom

1

Introduction

The first chapter aims to provide a foundational understanding of dementia, emphasizing the critical importance of early diagnosis and exploring the multi-faceted challenges associated with achieving timely identification of the disease. To address these challenges, the chapter discusses the necessity of a systemic approach, advocating for the use of the Engineering Better Care (EBC) framework to tackle this issue. Additionally, the chapter introduces the concept of patient journey mapping, specifically data-enabled patient journey mapping, as a method to gain deeper insights into patient experiences and improve the diagnostic process – serving as the first step within the EBC framework.

Chapter Content Overview

1.1 Definition of Dementia and Importance of Early Diagnosis

As of March 2023, more than 55 million people had dementia worldwide, with nearly 10 million new cases identified each year. Dementia, being the umbrella term for several diseases that negatively affect memory, thinking, and the ability to perform daily activities, is in 60-70% cases caused by Alzheimer's disease. (World Health Organization, 2023) Despite the high prevalence of dementia among people aged over 65, dementia is not a part of normal ageing and is a condition that requires significant support from caregivers (CGs) and affects the wider environment of the person living with dementia (PLWD). (Centers for Disease Control and Prevention, 2019) Additionally, caring for a PLWD is a highly demanding task that can lead to the CG themselves needing support. (Chen & Lin, 2022)

The symptoms and severity of dementia vary considerably from person to person, making it challenging to detect the disease. Those closest to the PLWD often suspect dementia based on distinctive symptoms, such as becoming lost in familiar surroundings, suspecting immediate family members of theft, or being unable to complete tasks independently. (Chen & Lin, 2022) In the case of General Practitioners (GPs) who serve as gatekeepers to obtaining a diagnosis, identification of dementia in patients is somewhat more difficult. Symptoms may not be apparent during routine office visits causing the diagnosis to often be only made on the basis of concerns presented by the CGs or PLWDs themselves. (Fernandes et al., 2021)

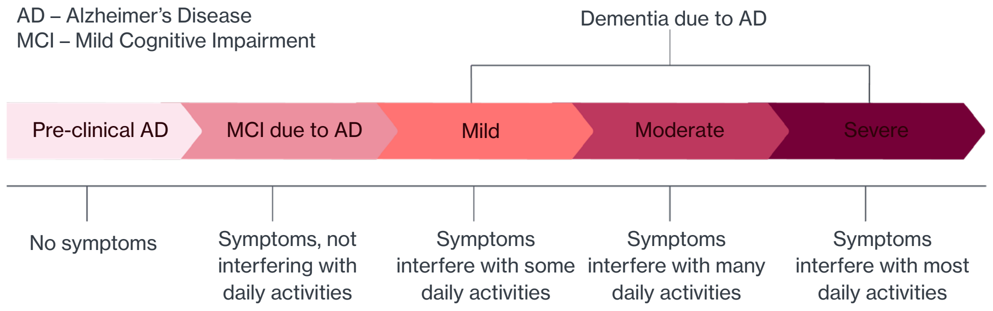


Fig. 1 – Alzheimer's Disease Continuum. Adapted from European Federation of Pharmaceutical Industries and Associations (2023)

According to the UK Alzheimer's Society, there are currently an estimated 982,000 people living with dementia in the UK, with projections suggesting this number will rise to 1.4 million by 2040. (Alzheimer's Society, 2024) In the United Kingdom (UK), receiving a dementia diagnosis involves GP performing blood tests, to help rule out other causes of concerning symptoms, coupled with cognitive pen-and-paper assessments. The most commonly used forms of dementia diagnostic assessment include the Mini-cog, Mini-Mental State Examination (MMSE) and the General Practitioner Assessment of Cognition (GPCOG). (Borson, 2000), (Folstein et al., 1975), (Brodaty et al., 2002). All of these tests consist of an assessment on memory abilities, attention and orientation to detect dementia with differences in methodology and scoring criteria. (Ionova et al., 2023) If these tests indicate probable dementia, the patient is referred to a Memory Clinic or Medical Specialists (such as neurologists, geriatric psychiatrists or neuropsychologists) for further testing, including additional cognitive tests and biomarkers such as MRI, CT and PET brain scans. (National Institute on Aging, 2022), (National Health

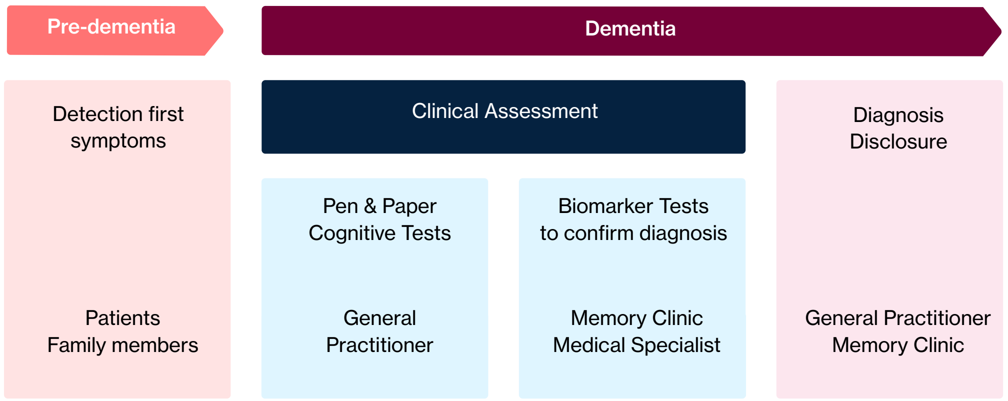


Fig. 2: Current Detection and Diagnosis Pathway in the Uk region. Adapted from European Federation of Pharmaceutical Industries and Associations (2023)

Service, 2023)

For comparison with the Netherlands, where this research is taking place, the dementia diagnostic process is very similar to the UK. In the Netherlands GPs also serve the role of a gatekeeper, referring patients to specialised Memory Clinics for comprehensive diagnostics. The diagnostics process then similarly includes blood tests, neuropsychological assessments, and neuroimaging in order to confirm or refute the presence of dementia in patient. (Prins et al., 2016), (Gruters et al., 2019)

At the European level, although current healthcare systems are not yet equipped for early dementia diagnosis, there is an international consensus favoring early diagnosis to ensure timely treatment. (Waldemar et al., 2006) As a result, efforts are underway to translate this common goal into practice by standardising procedures for dementia diagnosis using biomarkers for detection of dementia in early phases. (Waldemar et al., 2006) A recent example of such an initiative is the recent multidisciplinary effort of experts from 11 European scientific societies that developed a patient-centred diagnostic workflow that prioritises biomarker testing in Memory Clinics. (Frisoni et al., 2024) However, despite strong research supporting timely diagnosis, access to the necessary diagnostic tools and associated costs vary widely across regions and healthcare systems, making their widespread application more difficult. (Waldemar et al., 2006)

Regardless of these challenges, increasing the rate of early dementia diagnosis is essential for several reasons. Primarily, early diagnosis enables timely intervention with therapies that have a better chance of success when introduced in the early stages of the disease, which can be 10-20 years before observable symptoms appear. These therapies cannot reverse the condition but can slow down or halt its progression. (Dubois et al., 2015) This has become increasingly important with the recent emergence of new treatment options. Specifically, three clinical trials from 2022/2023 have demonstrated the slowing of disease progression with the drugs lecanemab and donanemab, of which lecanemab has already been approved by the FDA and Japanese/Chinese equivalents in late 2023/2024. (Eisai Co., Ltd., 2022), (Mattke et al., 2024) With these Alzheimer's treatments now available, concerns arise regarding the ability of healthcare systems to capture a sufficient number of patients in the early stages of the disease to administer the medication in time.

Consequently, systemic improvements are required to enable early detection of dementia allowing individuals to access effective treatment. (The Guardian, 2024), (Mattke et al., 2024) However, early detection of dementia would allow more than just timely medication. It would also enable individuals with dementia to proactively make informed decisions regarding their future care needs, as well as manage financial and legal matters, while they are still capable of doing so independently. (Watson et al., 2018) Last but not least, higher rates of early diagnoses would facilitate the enrollment of individuals in clinical trials for drugs suitable for the early stages of dementia, thereby contributing to the much needed advancement of treatment options. (Dubois et al., 2015), (Isaacson & Saif, 2020).

1.2 Factors Contributing to Delayed Diagnosis of Dementia

Nevertheless, despite the urgent need for early diagnosis, the current process of identifying dementia in patients is often lengthy and burdensome. The journey to a diagnosis entails a series of steps and referrals characterized by long waiting times and potentially incorrect diagnoses.

This problem is further heightened by the short times available for patients' routine GP visits, who usually serve as the first point of contact for people when seeking a diagnosis of dementia. (Sideman et al., 2022) This is particularly problematic for elderly patients, where the GP is required to assess a range of symptoms and health problems in a short timeframe causing dementia testing to be omitted. (Bradford et al., 2009) Consequently, while pen-and-paper tests offer a cost-effective means of assessment, many GPs do not perform them during routine visits as they consider them to be time-consuming and/or low in sensitivity. This lack of early detection during GP consultations prolongs the process and delays referrals to specialists capable of providing a definitive diagnosis. (Borson et al., 2003) Moreover, despite being developed, innovative medical technologies like specialised blood tests, digital assessments, and wearables capable of detecting dementia up to 25 years before symptoms remain underutilized in practice. (Mattsson-Carlgren et al., 2023) This inability to integrate state-of-the-art testing methodologies underscores that the issue is rather systemic than a limitation of available technological capabilities.

However, the problem is not only on the part of of the GP and clinical system, but is also caused by a lack of initiative among PLWDs and CGs in seeking a diagnosis. Traditionally, the main reasons why PLWDs and their CGs hesitated to acknowledge dementia symptoms and seek medical care, and why GPs have been reluctant to make a diagnosis, have centered on the lack of effective treatment options. (Bradford et al., 2009) However, this argument is increasingly outdated. With the development of new treatments effective in the early stages of the disease, there is now the potential to slow or halt disease progression, making early diagnosis all the more crucial.

1.3 Need for a Systems Approach for Early Diagnosis Enhancement

While there are a number of benefits to early diagnosis of dementia, implementing it in practice still remains a complex challenge resembling a 'wicked problem'. (Newton et al., 2024) This term, coined by Horst Rittel and Melvin Webber in the journal Management Science in 1973, refers to an ill-formulated problem that has no clear solution due to its interconnected nature, conflicting values of the involved stakeholders and uncertain consequences. (Churchman, 1967)

To effectively tackle these challenges, a systemic approach is essential. Early dementia diagnosis is part of a broader healthcare issue rooted in a traditionally reactive, rather than preventive, approach to care (Badimon et al., 2023) Shifting towards a preventive healthcare model requires collaborative and systemic efforts to overcome barriers such as educational deficits, lack of collaboration, and outdated healthcare funding models. (Mattke et al., 2024), (Duda-Sikuła & Kurpas, 2023) Moreover, the prevailing reductionist and linear perspectives among policymakers further hinder the adoption of holistic approaches needed to address such systemic challenges. (Petrie & Peters, 2020)

Finally, systemic improvements are also being called for by the UK Alzheimer's Society, a leading dementia charity, which argues that the current UK dementia strategy does not serve the needs of people in the system and requires a review to prioritize early detection and increased support for PLWDs and their CGs. (Alzheimer's Society, 2023)

1.3.1 Engineering Better Care Framework

To effectively address the "wicked" problem of integrating early dementia diagnosis into clinical practice, Newton et al., 2024 proposes employing Engineering Better Care (EBC) framework, developed by Cambridge Professor John Clarkson. This framework, co-designed with clinicians, draws inspiration from Systems Engineering and provides a practical workflow for designing, proposing, implementing, and managing targeted improvements, specifically within complex healthcare systems (Clarkson, 2018).

According to Systems Engineering, an approach pioneered by NASA, systems are defined as a combination of elements producing qualities not present in constituent elements individually, primarily formed by their relationships. This integrative discipline blends various fields to design balanced systems amidst oftentimes conflicting interests and constraints. To succeed in this challenging task, the Systems Engineer must adeptly optimize the overall design without showing bias towards any specific component, requiring a keen ability to assess the system's big picture and strategically probe when necessary. (NASA, 2016) This makes Systems Engineering particularly useful for addressing complex healthcare challenges, such as integrating early dementia diagnosis into clinical practice, due to its holistic approach, multidisciplinary integration, and emphasis on risk management and life cycle perspective. (Clarkson, 2017)

Other methods traditionally employed to tackle systemic problems include Project Management, Agile Methodologies, Lean Engineering, and Design Thinking.

While these methods prove to be useful within specific problem solving stages,they have limitations that make them less suitable for tackling complex healthcare issues:

- **Project Management:** focuses on managing scope, time, cost, and quality but lacks the technical depth and systems perspective needed to design and integrate complex diagnostic systems (Oosthuizen & Benade, 2021).
  Agile Methodologies: offer high adaptability and iterative processes but may not suit the rigid regulatory and procedural requirements of clinical practice (Agile Manifesto, 2001), (Hutter et al., 2023)

- **Lean Engineering:** emphasizes process optimization and waste reduction, useful for improving existing processes but not for designing and implementing entirely new complex systems. (Rhodes & Ross, 2004)
- **Design Thinking:** excellent for ideation and prototyping with a focus on empathy and creativity but may lack the technical and systems rigor needed for detailed and structured implementation in healthcare (Ackermann, 2023)

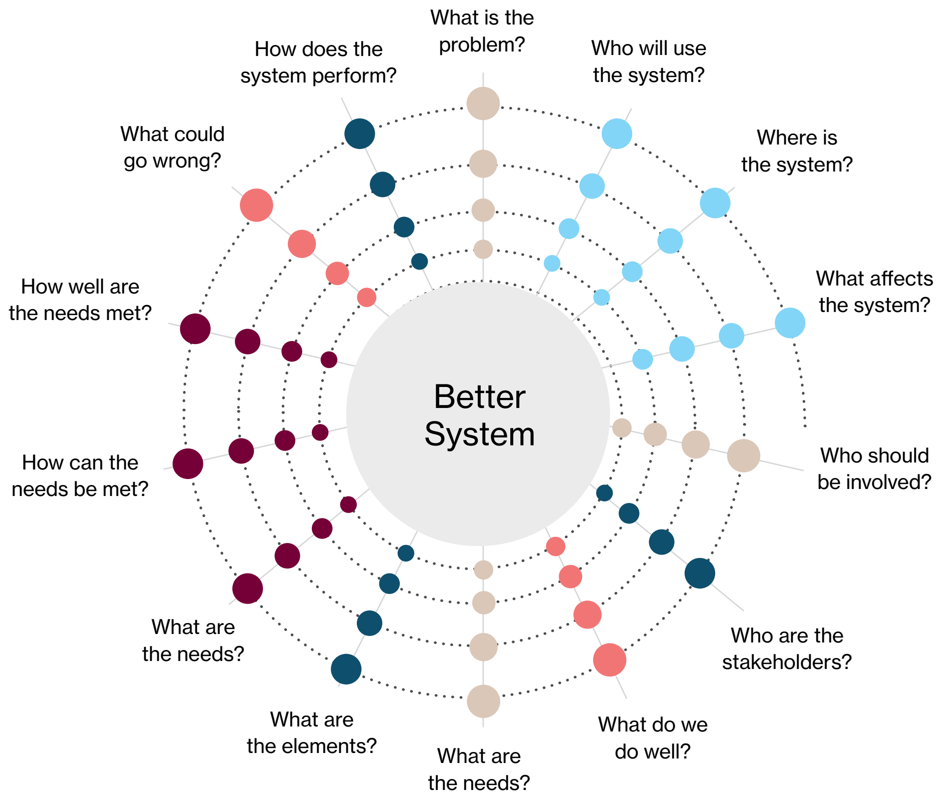
Recognizing the benefits of the alternative methods, the EBC framework aims to incorporate their strengths, seeks to complement their shortcomings and make them directly applicable to the healthcare industry. (Clarkson et al., 2017)

Futhermore, the framework is enriched with a design lens which contributes the capacity to navigate uncertainty inherent in complex problems, employing the double-diamond approach for analysis and synthesis. In addition, the framework includes a risk perspective to ensure that identified threats are mitigated alongside a central people perspective, which is crucial to achieving the human-centred focus that is essential to the revision of the UK's Dementia Strategy. (Clarkson, 2018)

Fig. 3: Systems perspectives of the EBC framework. Adapted from Clarkson (2018)

The EBC framework is characterized by the interconnectedness of these four perspectives: **systems**, **design**, **risk** and **people**, and only if all of these areas are addressed and thoroughly explored can system improvement be successful. To ensure coverage of all the four perspectives, the EBC framework contains 14 structured questions that allow focused exploration of the problem – a capability that matches that of a systems engineer. In addition, the questions are depicted on a spiral model that suggests that the set of questions can be iteratively repeated to gain a deeper understanding of the problem and further reduce uncertainty and

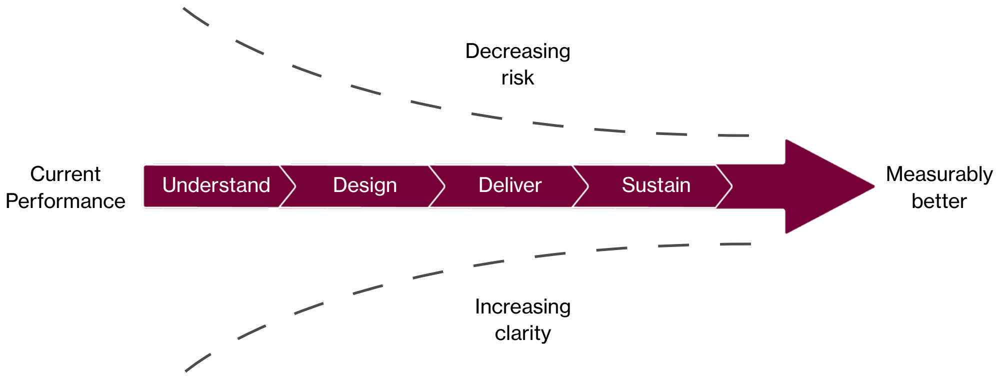
Fig. 4: Spiral model of EBC fraework questions. Adapted from Clarkson (2018)



risk with each round of questioning. (Clarkson, 2018)

At the same time, repeatedly asking the same set of questions allows users to move along the accompanying linear model of the 4 Improvement stages of

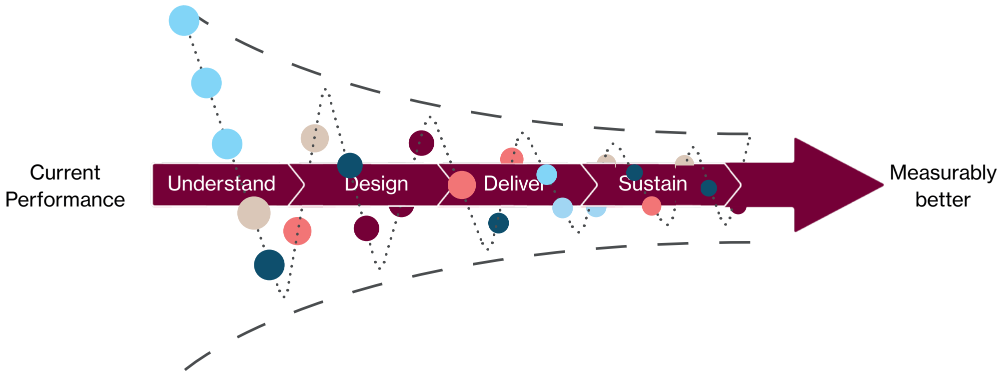
Fig. 5: Linear model of improvement stages. Adapted from Clarkson (2018)



Understand, **Design**, **Deliver** and **Sustain**. (Clarkson, 2018)

The initial **Understand** phase consists of describing the current system, gaining a shared understanding of the problem and reaching consensus on what an improved system could look like. The emergent **Design** phase evolves through iterations to produce a detailed depiction of the envisioned system. Moving to the **Deliver** phase, the focus is on the successful implementation of the new system, supported by appropriate measures of success and user acceptance. Ultimately **Sustain** is all about ensuring the continued operational success of the system, with consideration given to possible enhancements or wider deployment. (Clarkson, 2018) Probing questions are what allows movement within these phases. The goal is to achieve a new system that integrates the four key perspectives - **systems**, **design**, **risk** and **people** - and is also measurably better.

Fig. 6: Combined linear and spiral model of the EBC framework



[2] – https://www.iitoolkit.com/, accessed on 2024, 7 July

In addition to its theoretical form, the EBC framework is complemented by its practical form via the Improving Improvement Toolkit, which is a set of methods that can be used to navigate the different phases of the EBC model. [2]

To conclude, following the study by Coco Newton et al. (2024), there is a critical need to prioritize early diagnosis of dementia, as recent developments in disease-modifying drugs have proven to be effective in early-stage patients. The introduction of early diagnosis is a complex, multifaceted challenge spanning societal, governmental, public health, healthcare, and patient ecosystems. Therefore a framework capable of holistic system improvement is essential. Building directly on the work of Coco Newton et al. (2024), this research employs the EBC framework, specifically its first phase, **Understand**, through data-enabled patient journey mapping. This method aims to capture the experiences of PLWDs and their CGs, thereby supporting policymakers, healthcare professionals, designers, and academics in making more informed decisions regarding dementia diagnosis system improvement.

1.4 Exploring System Context Through Patient Journey Maps

[3] – https://www.iitoolkit.com/stage/understand.html, accessed on 2024, 11 July

In the initial phase of the EBC framework, the Improving Improvement Toolkit suggests using Patient Journey Mapping as one method for gaining an understanding of the system context. [3]

1.4.1 Patient Journey Mapping

Journey maps are a visualization method originating from the field of service design and marketing, where they serve the role of visually capturing the user's experience of using a product or service over time. (Howard, 2014) More recently, journey maps have also found their applications in the context of healthcare systems under the name Patient Journey Maps, where they function as an effective tool to help manage the complexity inherent in these systems. (Joseph et al., 2020)

Unlike static methods such as Personas, Journey Maps dynamically depict patients' evolving experiences (both physical and emotional) and provide a nuanced view of their interactions with healthcare services at different touchpoints and over extended periods of time. (Davies et al., 2022) Moreover, patient journey maps prove to be valuable thanks to their ability to distill research into a concise, visually compelling story of the patient's experience. This not only reduces complexity but also provides stakeholders with a more holistic perspective, fostering understanding of present interdependencies. Last but not least, the use of a patient journey map increases empathy towards patient groups by placing them at the center of the process. (McCarthy et al., 2016), (Joseph et al., 2020)

1.4.2 Data-enabled Patient Journey Mapping

Patient journey maps are traditionally based on qualitative research methods involving patient interviews, focus groups or ethnographic studies, which are later on synthesized into a visual output. Although these data collection methods provide a deep and nuanced insight into individual patient experiences, their relatively smaller sample sizes make it challenging to quantify and generalize their findings to broader patient populations. (Jung et al., 2023)

One approach that attempts to overcome the limitations of traditional patient journey mapping is the Online Community Journey Mapping method developed by Jung et al. (2023). It is a data-driven approach focusing on the use of machine learning (ML) to analyze online patient stories, offering insight into the experiences of a wide patient population who engage with online communities. Online communities are large groups of people with shared interests who interact within web environments, supported by technology and guided by norms and policies. Within the healthcare context, these communities are often used as sources of support to patients or CGs coping with diseases or health concerns. Additionally, they provide people with answers to their questions or simply offer a space to share their experiences. In practice, these communities can take the form of social media, chat rooms, online forums or blogs. (Preece, 2003), (Preece et al., 2004), (Jung et al., 2023)

Data from these online environments, referred to as online patient stories, are then scraped, cleaned and subjected to topic modeling analysis using ML to create topics. These topics describe patient experiences within their longer-term interactions with a particular part of the healthcare system. The approach can be described as hybrid-intelligent as it leverages the complementary strengths of ML to analyse a large scale user dataset in collaboration with human competences to interpret the analysis outcome. (Jung et al., 2023)

1.4.3 Strengths and Limitations of Data-enabled Patient Journey Mapping

While recognizing its limitations, the approach of combining ML and human capabilities to analyze large datasets of online patient stories offers several advantages that address the shortcomings of traditional journey mapping methods.

The main advantage of using online forums as a data source for patient journey mapping lies in the ability to collect large amounts of data from a diverse sample of users over an extended period of time. Unlike traditional journey mapping methods, leveraging such a large data source, together with the involvement of ML for data collection and analysis, allows for greater, but not complete, representativeness and quantification of findings. (Jung et al 2023) Additionally, this approach proves to be a relatively labor and cost-efficient data source, by eliminating the need for large-scale studies involving recruitment of respondents and data collection. However, it's essential to acknowledge that achieving a significant number of forum contributions may take years, making data collection effective for researchers only once the forum is sufficiently populated with posts. (Jung et al., 2023)

In addition to the large number of patient stories, online forums bring with them additional advantages in terms of the quality of the data itself. Primarily, online forums contain PLWD/CG-driven data, meaning users voluntarily contribute their narratives to the forum, independent of researchers' prompts. This allows for the collection of authentic, ecological experience data that reflects their priorities while reducing the risks of providing desirable answers in formal studies. (Jung et al., 2023) Moreover, the online forum environment may help reduce the stigma barrier by allowing respondents to anonymously share stories they might otherwise withhold during interviews. (Marshall et al., 2024) In addition, the longitudinal nature of the data collection allows us to capture trends over time, including recent developments in the PLWD/CG experience.

However, the limitations in data quality of using online forums as a data source must also be considered. Firstly, they may be significantly influenced by self-selection bias, wherein only users who choose to participate contribute to the forum. This can lead to a notable difference in experiences between forum users and non-users, making it challenging to ensure the data's representativeness of the entire population. (Nikolopoulou, 2023) Additionally, forum users may be heavily influenced by previous content on the forum, potentially introducing bias into their contributions. (Jung et al., 2023) Furthermore, the degree of disclosure remains questionable due to the non-removable nature of contributions in the online environment, which may inhibit respondents from openly sharing sensitive information. (Jung et al., 2023) Finally, posts often lack contextual cues and provide only a snippet of the whole context. Without additional information about the respondent or the ability to prompt them for context, objective interpretation may become more challenging.

In addition to limitations in data sourcing, there are constraints associated with the methods used to analyse online patient stories. Although ML helps to streamline the analysis, it cannot fully eliminate human researcher bias given that researchers largely influence the design of ML algorithms, the interpretation of themes generated by topic modeling, and the choice of approach to selecting and visualizing findings. These factors may hinder achieving full representativeness of the data and introduce subjective elements into the analysis process.

Given these strengths and limitations, it should be stressed that the outputs of this method serve only as inspirational material rather than as fully representative evidence of patient experience. (Jung et al., 2023) ■

2

Project Aims & Objectives

This chapter outlines the project's aims and objectives, focusing on establishing a systemic improvement to integrate early detection of dementia into clinical practice. Aligned with the EBC framework, particularly the 'Understand' phase, the study aims to capture the complexities of the current system from the perspectives of its key stakeholders. By mapping the diagnostic journeys of PLWDs and their CGs using ML to analyze online patient stories, the research seeks to gain comprehensive and nuanced insights into the diagnostic process. This approach aims to address the existing gap in understanding and visualizing the diagnostic journey, thereby informing subsequent strategies for system improvement

Chapter Content Overview

The aim of the project is to lay the foundations for systemic change to integrate early detection of dementia into clinical practice across the UK. Through the lens of the EBC framework, specifically focusing on the initial ‘Understanding the Context’ phase, the study seeks to capture the complexities of the system in need of improvement from the perspective of its key stakeholders. To this end, it specifically looks at mapping the journey of PLWD and CG experiencing the dementia diagnosis process, with the aim of gaining a deeper and broader understanding of the current system through online patient stories. The research will specifically use the UK healthcare system as a case study, recognising that this approach may lead to slightly different maps in other contexts.

2.1 Research Gap

The current research in this area is primarily concerned with comprehensively mapping themes related to the experience of key stakeholders (primarily PLWDs, CGs and GPs) throughout the process of dementia diagnosis. This includes understanding their needs, barriers and facilitators to the early diagnosis of dementia. However, in most cases, existing studies are only concerned with mapping individual episodes on the pathway to diagnosis, rather than providing a holistic view of the entire journey to diagnosis, as exemplified by the patient journey maps. Even when researchers attempt to map the journey in its entirety, it is often done from an impersonal point of view, with descriptions of individual phases supplemented by simplified diagrams. (Chen & Lin, 2022), (Campbell et al., 2016)

In terms of the research methods used, the majority of studies primarily employ systematic literature reviews and interview studies with 15 participants on average. While these approaches offer detailed and nuanced insights into individual experiences, they pose challenges in terms of generalizing the findings to broader populations. At the same time, it is important to highlight the minimal contribution of designers within this research, despite their skills potentially being of great benefit. More specifically, the ability of designers to describe and design solutions to wicked problems, while continually putting the human at the center, and being skilled at mapping systems and reconciling tensions between stakeholders, could become useful within the research. Furthermore, their visualization skills could enable effective communication of findings, facilitating a simplified understanding of the complexities present within systems. (van der Bijl-Brouwer & Dorst, 2017), (Segelström, 2012)

To summarize, there exist notable research gaps in:

- Comprehensively mapping the diagnostic journey of PLWDs and CGs while maintaining nuanced findings.
- Generalizing findings to larger populations due to smaller sample sizes in traditional qualitative methods.
- Presenting journeys from a personal viewpoint to enhance empathy in journey representations.
- Incorporating designer input to address complex problems through human-centered approaches.
- Utilizing advanced visualization techniques to effectively communicate research findings on diagnostic journeys.

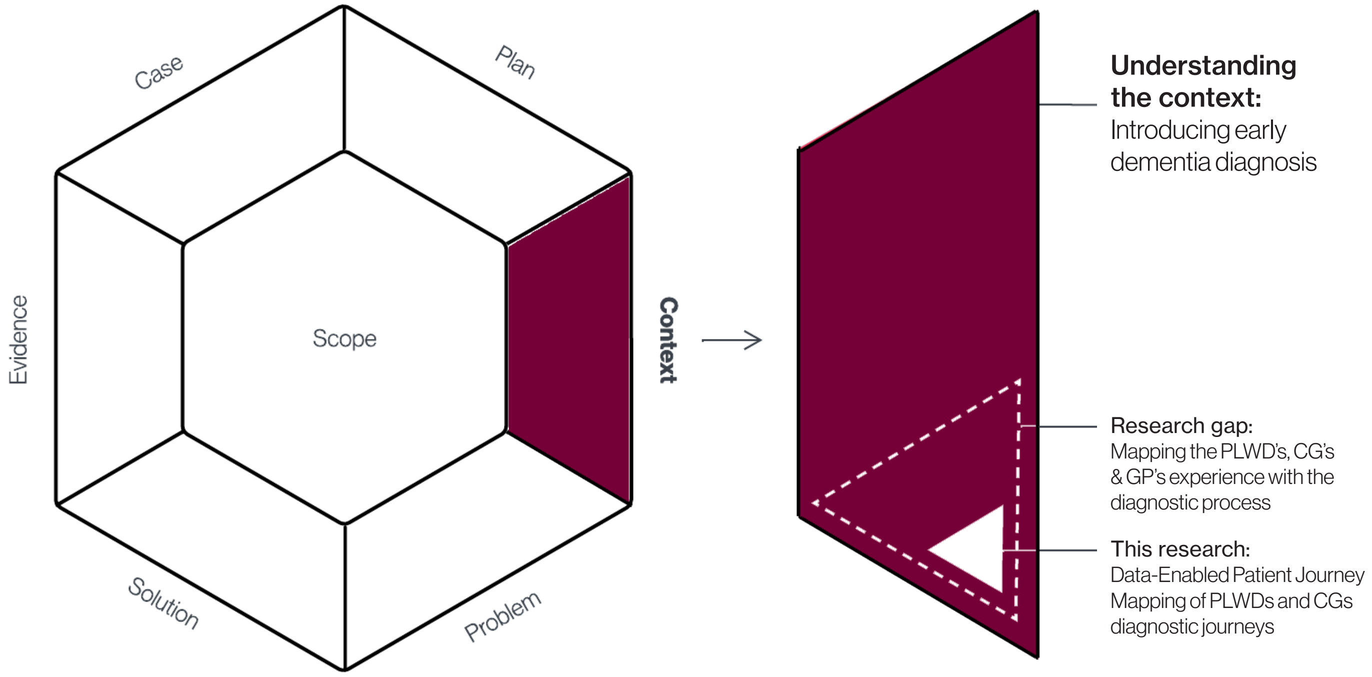


Fig. 7: Integrating this research within the EBC framework – Research Aims & Objectives

2.2 Research Aims and Objectives

To address the identified research gaps, the project aims to answer the following main research question:

RQ1: What nuanced insights can be gained from mapping the experiences of PLWDs and their CGs to inform the enhancement of early dementia diagnosis strategies?

Additionally, two supplementary research questions will be investigated:

- **RQ2:** Given the limitations of traditional journey mapping methods, how can the use of data-enabled design research improve the creation of these journey maps?
- **RQ3:** What is the role of design in advancing dementia research, and what benefits does their involvement offer?

The objective of this research is to produce comprehensive PLWD and CG journey maps as communication tools to assist policymakers, healthcare professionals, designers and academics in making more informed decisions regarding system improvements to increase early dementia diagnosis rates. In addition, the maps could become useful for GPs in primary care to alleviate uncertainty in patients and their carers during the diagnostic process. (Poyser & Tickle, 2018), (Manthorpe, 2013) Maps may also be used in follow-up co-creation sessions or interview studies as tangible visual representations facilitating discussions about the diagnostic experience.

To address these research aims and objectives a three-phase mixed-method approach will be employed:

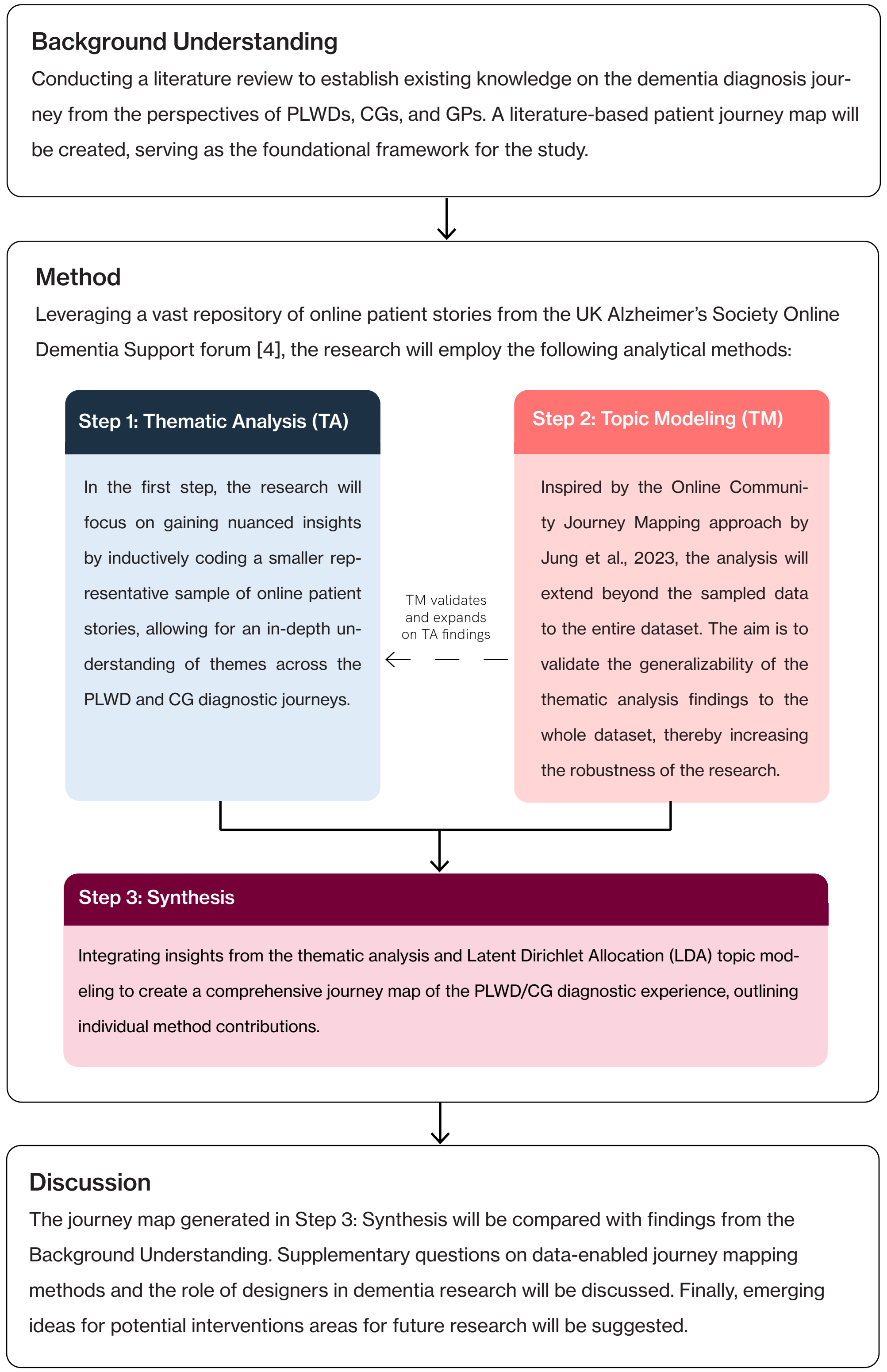


Fig. 8: Integrating this research within the EBC framework – Research Aims & Objectives

Background Understanding

Conducting a literature review to establish existing knowledge on the dementia diagnosis journey from the perspectives of PLWDs, CGs, and GPs. A literature-based patient journey map will be created, serving as the foundational framework for the study.

Method

Leveraging a vast repository of online patient stories from the UK Alzheimer's Society Online Dementia Support forum [4], the research will employ the following analytical methods:

Step 1: Thematic Analysis (TA)

In the first step, the research will focus on gaining nuanced insights by inductively coding a smaller representative sample of online patient stories, allowing for an in-depth understanding of themes across the PLWD and CG diagnostic journeys.

Step 2: Topic Modeling (TM)

Inspired by the Online Community Journey Mapping approach by Jung et al., 2023, the analysis will extend beyond the sampled data to the entire dataset. The aim is to validate the generalizability of the thematic analysis findings to the whole dataset, thereby increasing the robustness of the research.

Step 3: Synthesis

Integrating insights from the thematic analysis and Latent Dirichlet Allocation (LDA) topic modeling to create a comprehensive journey map of the PLWD/CG diagnostic experience, outlining individual method contributions.

Discussion

The journey map generated in Step 3: Synthesis will be compared with findings from the Background Understanding. Supplementary questions on data-enabled journey mapping methods and the role of designers in dementia research will be discussed. Finally, emerging ideas for potential interventions areas for future research will be suggested.

By pioneering this interdisciplinary approach combining clinical research, data science, and design knowledge, we anticipate gaining a deeper understanding of the complexities of a dementia diagnosis, facilitating the development of more effective interventions and support strategies in future work by the wider academic team. ■

[4] – https://www.alzheimers.org.uk/get-support/dementia-support-forum. Accessed on 2024, 20 July.

3

Background Understanding

This chapter presents the background understanding necessary for this study, focusing on mapping the state-of-the-art knowledge regarding the dementia diagnosis journey. Through a literature review at the intersection of medicine, design, and psychology, the chapter identifies key phases and themes related to the experiences of PLWDs, their CGs, and GPs in the diagnostic process. By synthesizing this information into literature-based stakeholder and journey maps, the chapter aims to reveal research gaps and set the stage for subsequent data-enabled analysis, ultimately contributing to a more comprehensive and

Chapter Content Overview

3.1 Literature Review Method

A literature review was conducted, combining articles from the fields of medicine, design, and psychology to map the current knowledge concerning the journey to receiving a dementia diagnosis. The document search process used a query with the keywords “dementia”, “diagnosis”, “design” and “experience” in the title and abstract, identifying a total of 1422 documents via PubMed, Google Scholar, and NHS websites. Due to time constraints (1 month), convenience sampling was employed to screen 60 articles from the 1422 records identified. Additionally, 26 articles underwent full-text assessment for eligibility.

The criteria for convenience sampling and full-text eligibility assessment included:

- **Full text accessibility:** Articles that are readily accessible without subscription barriers.
- **Publication date:** Preference is given to more recent articles, typically those published within the last 10 years, to ensure the information is current. However, studies that do not meet this criterion are not strictly excluded.
- **Language:** Articles published in English to avoid translation issues.
- **Research type:** Preference for systematic reviews or meta-analyses that provide comprehensive insights into the diagnostic journey.
- **Study population:** Focus on studies involving PLWDs, CGs, and GPs.
- **Geographical focus:** Preference is given to studies studies conducted in the UK to ensure relevance to the local healthcare system. However, studies that do not meet this criterion are not strictly excluded.

Based on full-text eligibility assessment., 14 articles were deemed suitable for inclusion in the qualitative synthesis. The inclusion criteria for these articles required that they identify:

- **Stages of the diagnostic journey:** The distinct phases through which PLWD, CGs, and GPs progress from observing initial symptoms to managing the disease post-diagnosis.
- **Temporal steps:** The sequence of events and actions taken during the diagnostic journey.
- **Needs, barriers, and facilitators:** The specific needs of PLWD, CGs, and GPs, as well as the obstacles they face and the factors that aid in reaching a formal diagnosis.

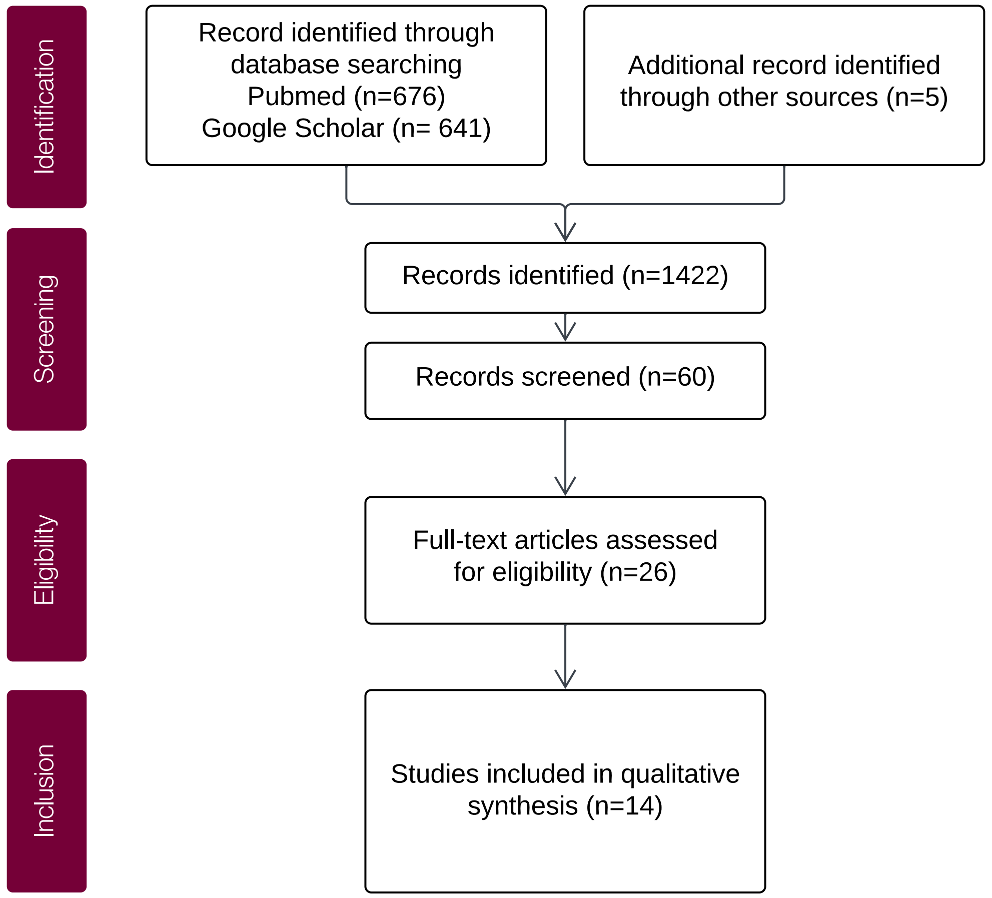


Fig. 9: PRISMA Flow Diagram

The output of the literature review includes a **Stakeholder Map of the dementia diagnosis system** and an overview of existing knowledge captured in a **Literature-based Journey Map**. Within the literature-based journey map, two perspectives are included: 1) the perspective of PLWDs and CGs, and 2) the perspective of GPs. These two perspectives were chosen since they were the most frequently discussed in the reviewed studies. In addition to outlining the state-of-the-art knowledge in this area, the maps offer a visual representation that enhances clarity and helps contextualize the insights gained from subsequent data-enabled analysis. Finally, the maps facilitate the identification of research gaps within the current understanding of diagnostic journeys, which will be addressed within the scope of this thesis.

3.2 Stakeholder Map

The stakeholder map was created based on the synthesis of insights from a literature review and findings from Coco Newton, who began focusing on system mapping prior to this study. The stakeholders identified during the mapping process were categorized into two main areas: 1) Stakeholders who come into direct contact with PLWD and 2) Indirect stakeholders providing system support. The stakeholders who come into direct contact with PLWD are further divided into three groups based on their role in the diagnostic journey: Symptom Awareness, Point of Advice, and Clinical/Social Support.

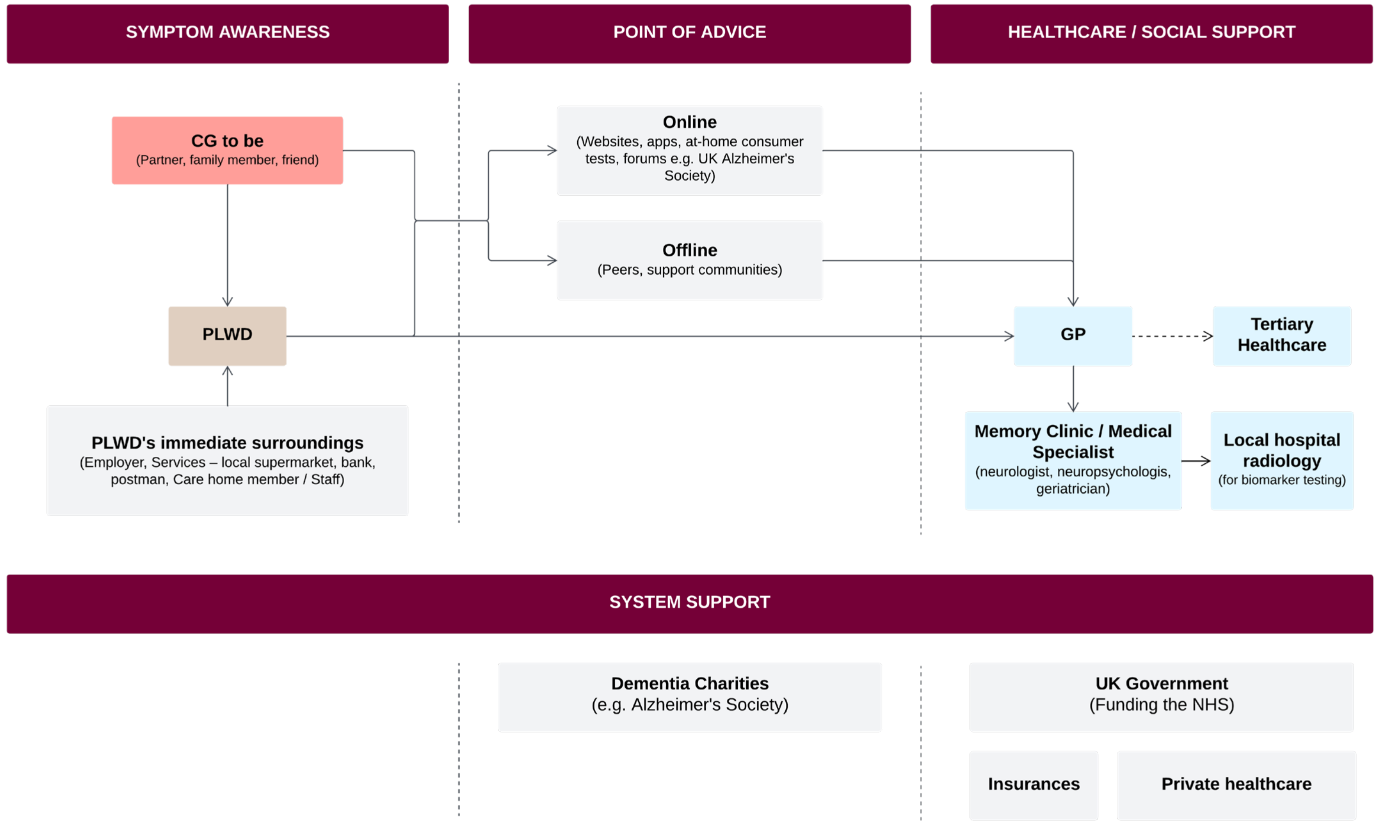


Fig. 10: Literature-based Stakeholder map

Symptom Awareness

As cognitive changes manifest in PLWD, various stakeholders become key in identifying these changes. Stakeholders who notice changes in PLWD include people who are regularly in their immediate surroundings, including employers, service providers and members/staff of carehomes. (Newton, 2024) In addition, those in close relationships with PLWD, including partners, family members, and friends, often serve as the primary observers of cognitive changes, with one (or several) of them typically taking on the role of the primary CG. (Bradford et al., 2009), (Xanthopoulou & McCabe, 2019), (Prorok et al., 2013), (Sideman et al., 2022)

Point of Advice

Once PLWDs and CGs become aware of the presence of cognitive changes, they use multiple offline and online resources to find out what to attribute symptoms to and how to effectively manage them. Online platforms such as websites, apps and forums, including the UK Alzheimer's Society Dementia Support Forum, offer accessible routes to information and advice. Outside the internet, peer support communities and advice networks play a vital role. (Lian et al., 2017), (Campbell et al., 2016), (Prorok et al., 2013)

Clinical/Social Support

Upon recognizing the need for clinical intervention, PLWDs and their CGs initiate contact with GPs for an initial diagnostic assessment of dementia. (Lian et al., 2017), (Vinay & Biller-Andorno, 2023) Subsequently, they may then be referred to memory clinics involving specialists such as neurologists, geriatric psychiatrists, neuropsychologists and geriatricians for a comprehensive dementia assessment. Biomarker tests, including MRI, CT and PET brain scans, may be performed at local hospitals or neuroradiology departments to assist in making a diagnosis. , (Campbell et al., 2016) Once a diagnosis is made, GPs can then refer the PLWD to tertiary health services for specialised treatment and support. (Bradford et al., 2009)

Indirect stakeholders – System Support

In addition to direct interactions of PLWDs and CGs with healthcare and dementia support communities, stakeholders additionally benefit from system support mechanisms. Since the majority of NHS healthcare model funding in the UK comes from the state, insurance companies play a minor role in providing financial coverage for diagnostic procedures and treatments. (The King's Fund, 2024) In contrast, the US system is heavily dependent on insurance. (Bradford et al., 2009)

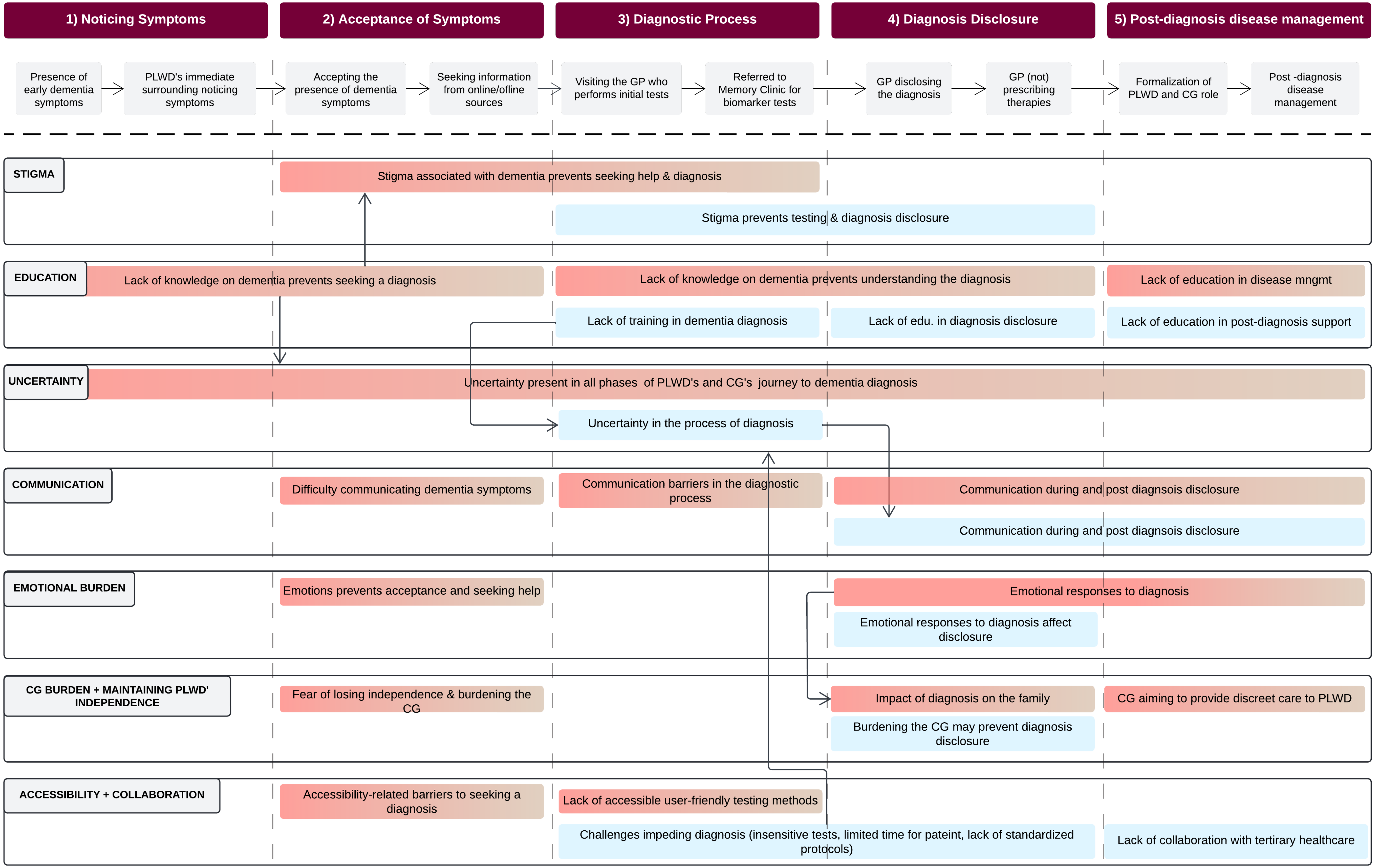
Moreover, due to the NHS's recent inability to provide high-quality care promptly, an increasing number of people in the UK who can afford it are turning to private healthcare to avoid long waiting times, with varying degrees of success. Meanwhile, in contrast, China has a very low reliance on private care. (Lian et al., 2017)

In addition to providing direct medical care, UK government initiatives offer PLWDs and their CGs broader support that includes policy interventions, research funding and community support. (GOV.UK, 2022) These initiatives in the form of national dementia plans can be observed in most European countries. (Vinay, 2023), (Alzheimer's Disease International (ADI), 2024) Additionally, other initiatives in this area include non-governmental charities which provide a lot of system support through offering advice that system fails to provide. Examples include UK charities like Alzheimer's Society and Dementia UK [6]. Similarly, a large contribution from non-governmental charities can be observed in the US or Canada, such as the Alzheimer's Society of Canada [7]. (Prorok et al., 2013), (Wollney et al., 2022)

[6] – www.dementiauk.org/about-us/, accessed on 2024, 20 July

[7] – alzheimer.ca/en, accessed on 2024, 20 July

Literature-based Journey Map



1) Noticing Symptoms

2) Acceptance of Symptoms

3) Diagnostic Process

4) Diagnosis Disclosure

5) Post-diagnosis disease management

Presence of early dementia symptoms → PLWD's immediate surrounding noticing symptoms → Accepting the presence of dementia symptoms → Seeking information from online/ofline sources → Visiting the GP who performs initial tests → Referred to Memory Clinic for biomarker tests → GP disclosing the diagnosis → GP (not) prescribing therapies → Formalization of PLWD and CG role → Post -diagnosis disease management

STIGMA

Stigma associated with dementia prevents seeking help & diagnosis

Stigma prevents testing & diagnosis disclosure

EDUCATION

Lack of knowledge on dementia prevents seeking a diagnosis

Lack of knowledge on dementia prevents understanding the diagnosis

Lack of education in disease mngmt

Lack of training in dementia diagnosis

Lack of edu. in diagnosis disclosure

Lack of education in post-diagnosis support

UNCERTAINTY

Uncertainty present in all phases of PLWD's and CG's journey to dementia diagnosis

Uncertainty in the process of diagnosis

COMMUNICATION

Difficulty communicating dementia symptoms

Communication barriers in the diagnostic process

Communication during and post diagnsois disclosure

Communication during and post diagnsois disclosure

EMOTIONAL BURDEN

Emotions prevents acceptance and seeking help

Emotional responses to diagnosis

Emotional responses to diagnosis affect disclosure

CG BURDEN + MAINTAINING PLWD' INDEPENDENCE

Fear of losing independence & burdening the CG

Impact of diagnosis on the family

CG aiming to provide discreet care to PLWD

Burdening the CG may prevent diagnosis disclosure

ACCESSIBILITY + COLLABORATION

Accessibility-related barriers to seeking a diagnosis

Lack of accessible user-friendly testing methods

Challenges impeding diagnosis (insensitive tests, limited time for pateint, lack of standardized protocols)

Lack of collaboration with tertirary healthcare

Fig. 11 – Literature-based journey map.

☐ Journey theme	▢ Temporal step	▢ GP experience
■ Journey phase	▨ PLWD/CG experience	

3.3 Journey Map Phases and Temporal Steps

The findings from the literature were synthesised into an initial journey map, which served as a "springboard" for subsequent research into mapping the journey of PLWDs and CGs in receiving a dementia diagnosis. Based on the literature, the journey to a diagnosis consists of five key phases:

- Phase 1: Noticing Symptoms
- Phase 2: Acceptance of Symptoms
- Phase 3: Diagnostic Process
- Phase 4: Diagnosis Disclosure
- Phase 5: Post-diagnosis Disease Management

The initial journey map, depicted in Fig. 11, presents the dementia diagnosis process from the perspective of PLWD and CG, while also including key interactions with clinical stakeholders, particularly the GP. Each phase includes several temporal steps that capture the key points on the journey to reaching a dementia diagnosis.

Phase 1: Noticing Symptoms

In the first stage, the early signs of cognitive or behavioral changes emerge in the PLWD, which, in addition to forgetting, may include becoming disoriented in a familiar environment, having reduced ability to perform previously mastered tasks and experiencing suspicions, such as accusing family members of theft. (Lian et al., 2017), (Chen & Lin, 2022) While PLWDs in some cases may recognize these changes themselves, in most cases they are noticed by individuals who are in regular contact with the PLWD, such as family members, friends or service providers, e.g. the postman or supermarket staff. (Campbell et al., 2016), (Lian et al., 2017)

Seldom are the initial symptoms of dementia noticed by the GPs. This is due to the short amount of time available for routine visits. In these short appointments, GPs must address a wide range of health concerns for elderly patients, leaving insufficient time to thoroughly assess for dementia. (Bradford et al., 2009), (Xanthopoulou & McCabe, 2019), (Bradford et al., 2009)

Phase 2: Acceptance of Symptoms

Following the recognition of cognitive and/or behavioral changes in the PLWD, different attitudes towards these symptoms arise. The acceptance of these cognitive and behavioural changes depends on several factors including family relationships, communication dynamics and prioritisation in regards to health concerns. (Campbell et al., 2016) The adjustment period of accepting the presence of dementia symptoms in PLWD may vary significantly among individuals.

Upon acknowledging the presence of dementia symptoms, many PLWDs and CGs initially begin to seek information, help and advice either from their peers in real life or on online communities, such as the UK's Alzheimer's Society before reaching out to clinicians for help. (Campbell et al., 2016), (Lian et al., 2017), (Prorok et al., 2013)

Phase 3: Diagnostic process

The subsequent diagnostic process length can vary substantially, ranging from 6 months up to 10 years. (Lian et al., 2017) It starts with a decision to seek medical help, followed by a consultation with the GP, who serves as the gatekeeper to a diagnosis. (Lian et al., 2017), (Vinay & Biller-Andorno, 2023) During this consultation, prompted by either the PLWD or their CG, the GP conducts initial neuropsychological assessments and blood tests aimed at eliminating alternative causes of symptoms. (Ionova et al., 2023) In the event of the neuropsychological assessments being positive, the GP refers the PLWD to a specialist or memory clinic, where more extensive neuropsychological examinations and biomarker assessments are conducted. (Campbell et al., 2016) Conversely, if the initial assessments yield negative results, the patient is recommended to be re-evaluated after a year. This cycle continues until the assessments become positive. However, it is important to note that the low sensitivity of tests used by GPs can often contribute to a negative result, thereby postponing the diagnosis. (Borson et al., 2003)

Phase 4: Diagnosis disclosure

After receiving a positive diagnosis from specialists or a memory clinic, the GP discloses the diagnosis to the PLWD and CG. The emotional burden of this information often presents several barriers that may prevent immediate disclosure of the diagnosis by the GP. (Chen & Lin, 2022), (Poyser & Tickle, 2018) In some cases the GP opts to initially inform the CG, allowing for a gradual and supportive approach towards sharing the information with the PLWD. (Chen & Lin, 2022), (Poyser & Tickle, 2018) Following the diagnosis disclosure, the GP may proceed to prescribe adequate therapies. (Campbell et al., 2016)

Phase 5: Life post-diagnosis

Based on the diagnosis disclosure, the roles of PLWD and CG become formalized and a stage focusing on post-diagnosis disease management and caregiving journey is reached. (Chen & Lin, 2022), (Prorok et al., 2013)

3.4 Journey Map Themes

In addition to outlining the temporal steps leading to a dementia diagnosis, the literature describes the needs, barriers and facilitators that are characteristic of this journey. The identified aspects of the journey have been captured in themes that span across the individual phases and together offer insight into the current knowledge in obtaining a diagnosis of dementia from the perspective of the PLWD, CG and the GP.

Stigma

Stigma presents a significant challenge throughout the dementia diagnosis process. In the context of dementia, stigma refers to the negative perceptions, attitudes, and stereotypes associated with the condition, often leading to discrimination and marginalization of affected individuals including PLWD and CG. (Alzheimer Society of Canada, 2024)

Within the journey, it features strongly in the process of accepting the presence of dementia symptoms, as the fear of stigmatization prevents acceptance of cognitive changes in PLWD and discourage seeking a formal diagnosis. (Lian et al., 2017), (Bradford et al., 2009), (Xanthopoulou & McCabe, 2019)

As far as GPs are concerned, stigma surrounding dementia is particularly impactful at the stage of diagnosis and subsequent disclosure, where it can prevent GPs from openly discussing dementia, performing tests and disclosing dementia presence to the PLWD and/or CG. (Bradford et al., 2009), (Wollney et al., 2022)

Education

Education spans all phases and encompasses multiple layers, making it a crucial theme influencing the journey to diagnosis.

Early in the journey, limited understanding of dementia among PLWDs and CGs leads to misattributing symptoms to normal aging (Bradford et al., 2009; Wollney et al., 2022). Additionally, lacking information about choosing the appropriate healthcare provider hinders the search for a diagnosis (Bradford et al., 2009). Raising awareness about the importance of early diagnosis for timely therapies is essential as lack of knowledge about early-stage treatments fosters the perception of dementia as incurable, discouraging early diagnosis-seeking behavior among PLWDs and CGs (Manthorpe et al., 2013; Lian et al., 2017; Bradford et al., 2009).

Mass education campaigns highlighting the benefits of early diagnosis encourage greater patient activity in seeking clinical support (Lian et al., 2017; Bradford et al., 2009). Providing free educational materials about dementia through resources like the Alzheimer's Society equips individuals with basic knowledge, reducing uncertainty for those potentially facing the disease (Lian et al., 2017; Prorok et al., 2013; Xanthopoulou & McCabe, 2019).

During the diagnosis and subsequent disclosure process, a lack of education on dementia causes underestimation of cognitive changes' impact, making it less likely to be discussed with a GP. This can prevent the initiation of the diagnostic process since GPs often rely on PLWDs or CGs to bring up suspected symptoms. (Bradford et al., 2009) Additionally, insufficient knowledge of dementia is a barrier for understanding the diagnosis. (Wollney et al., 2022)

Lastly, a lack of education in post-diagnosis management affects the final phase of the journey, where both PLWDs and their CGs require a significant amount of practical advice on how to manage the practical aspect of living with dementia. (Patel et al., 2021), (Prorok et al., 2013)

However, limited knowledge about dementia also affects GPs. A lack of education and experience in diagnosing dementia reduces healthcare professionals' confidence in recognizing cognitive problems. (Lian et al., 2017; Bradford et al., 2009; Wollney et al., 2022) Limited awareness of the importance of early diagnosis and the latest advances in diagnostics and treatment causes GPs to perceive the disease as untreatable, hindering timely diagnosis. (Bradford et al., 2009) Many GPs also struggle with communicating the diagnosis due to a lack of education in dementia disclosure strategies. (Wollney et al., 2022) Finally, in the post-diagnosis phase, GPs need more education on supporting PLWDs, CGs, and their families post-diagnosis. (Patel et al., 2021)

Uncertainty

Uncertainty as a theme permeates the entire diagnostic journey of the PLWDs and CGs. More specifically, it occurs in the struggle to understand cognitive and behavioural changes, find the right healthcare provider, undergo testing, understand the disease, and plan ahead to manage the unpredictable course of the disease. (Campbell et al., 2016), (Xanthopoulou & McCabe, 2019), (Prorok et al., 2013), (Sideman et al., 2022)

Uncertainty is also present among GPs, who struggle with the lack of high-sensitivity assessment methods and the limited time available for patient visits, leading to insufficient information gathered from PLWDs and CGs (Borson et al., 2003). This diagnostic uncertainty subsequently complicates the process of disclosing the diagnosis to PLWDs and their CGs.

Communication

Communication emerges as a critical theme, particularly in the initial phases of the journey, where difficulties in communicating self-noticed symptoms of dementia between PLWDs and CGs can hinder early diagnosis efforts (Prorok et al., 2013). In the diagnosis phase, communication barriers include language difficulties and instances where PLWDs forget to mention cognitive symptoms.(Bradford et al., 2009). Additionally, there is often a reliance on GPs to initiate discussions about cognitive symptoms, which can be hindered by patients' reluctance to challenge GP authority. Triadic communication problems (involving the GP, PLWD, and CG) also arise when the PLWD/CG avoids addressing the problems in the presence of others. (Bradford et al., 2009)

In the disclosure and post-diagnosis phases, poor communication coupled with lack of empathy and negative attitudes may hinder obtaining tailored treatment (Prorok et al., 2013; Sideman et al., 2022). Effective, empathetic communication during diagnosis disclosure is crucial, allowing PLWDs and CGs to ask questions without being overwhelmed (Manthorpe, 2013; Prorok et al., 2013). PLWDs and CGs value GPs who respect their perspectives and provide hope (Prorok et al., 2013; Poyser & Tickle, 2018; Sideman et al., 2022). Focusing communication solely on CGs in triadic appointments can leave PLWDs feeling disempowered.

For GPs, balancing honesty, hope, and optimism while using language appropriate to the knowledge levels of PLWDs and CGs is essential (Poyser & Tickle, 2018; Wollney et al., 2022). However, effective communication is often hindered by inadequate training, language barriers, and the challenges of conveying difficult messages and uncertainties (Wollney et al., 2022; Bradford et al., 2009). Triadic communication further complicates matters, requiring careful handling of conflicting goals and preferences regarding sensitive information (Bradford et al., 2009; Wollney et al., 2022).

As suggested by literature, educating GPs on empathetic communication strategies can significantly improve the diagnostic experience for PLWDs and CGs. Tailored communication that considers knowledge levels and family dynamics can prevent negative reactions (Lian et al., 2017). Moreover, providing GPs with skills and visual tools to explain dementia causes and progression, while addressing questions, can reduce post-diagnosis uncertainty (Poyser & Tickle, 2018). Finally, effective follow-ups and relationship-building further support PLWDs and CGs in managing their condition (Wollney et al., 2022; Prorok et al., 2013; Poyser & Tickle, 2018).

Emotional Burden

The emotional toll of a dementia diagnosis significantly influences the journey of PLWDs and CGs. This is particularly important in the initial phases, where emotional burdens prevent acceptance of symptoms and delay help-seeking (Bradford et al., 2009). In the disclosure and post-diagnosis phases, emotional responses vary: some PLWDs and CGs are mentally prepared and accepting, while others experience distress and denial (Chen & Lin, 2022; Wollney et al., 2022; Xanthopoulou & McCabe, 2019; Prorok et al., 2013; Sideman et al., 2022). Managing these emotions, adapting to the new situation, and maintaining a positive outlook are essential for preserving the agency and self-worth of both PLWDs and CGs (Xanthopoulou & McCabe, 2019).

CG Burden and Maintaining PLWD's Independence

The journey towards a diagnosis is influenced by the burden imposed on the CG, a theme that holds particular significance in the second phase of accepting the presence of dementia symptoms. Here, the weight of caregiving responsibilities, coupled with fear of loss of independence for PLWD prevents the search for a dementia diagnosis. (Bradford et al., 2009), (Wollney et al., 2022) In addition, disclosure of a diagnosis also affects the family, particularly familial CGs, who may feel helpless and fearful about care responsibilities (Chen & Lin, 2022) Such concerns regarding the potential burden on both PLWD and CG may prevent the GP from disclosing the diagnosis. (Bradford et al., 2009)

In the final phase, following diagnosis disclosure, CGs face significant challenges during the caregiving process, which raises the need for support services to help maintain PLWD independence. (Lian et al., 2017), (Jais et al., 2018), (Patel et al., 2021) In addition, after diagnosis, CGs seek assistance in facilitating independent decision-making by PLWDs in matters related to care, finances, and legal matters. (Chen & Lin, 2022), (Patel et al., 2021)

Accessibility and Collaboration

The theme of accessibility emerges prominently in the early phases of the journey, where accessibility-related barriers prevent seeking a diagnosis. These barriers include rural locations, transportation limitations, the perceived scarcity of physicians capable of making a diagnosis, financial concerns, perceived time-intensive nature of the diagnostic process and a lack of social or community support. (Bradford et al., 2009), (Wollney et al., 2022) During the diagnostic phase, PLWDs and CGs face long referral delays, low access to support services, and prolonged waits for test results, necessitating faster and more user-friendly diagnostic methods (Prorok et al., 2013; Sideman et al., 2022; Lian et al., 2017; Manthorpe et al., 2013).

Practitioners also struggle with insufficient, user-friendly, fast, and sensitive assessment tools, compounded by a lack of standardized testing protocols and support services, leading to long wait times (Bradford et al., 2009; Wollney et al., 2022; Prorok et al., 2013). In addition, limited time for pateint consultation impacts the accuracy of diagnoses and the quality of diagnosis disclosure, leaving little opportunity to address the emotional impact of dementia (Bradford et al., 2009; Wollney et al., 2022; Xanthopoulou & McCabe, 2019).

In response to this problem, the literature suggests prioritizing the development of user-friendly and flexible screening methods, characterized by speed and high sensitivity. (Lian et al., 2017) In addition, encouraging greater collaboration within multidisciplinary teams would allow health professionals to more effectively assess the needs and symptoms of diagnosed individuals. (Vinay & Biller-Andorno, 2023)

In the post-diagnosis phase, GPs often lack knowledge of or contact with local dementia support resources due to inadequate collaboration with tertiary healthcare. (Bradford et al., 2009; Lian et al., 2017) Enhancing GP-tertiary health service collaboration is essential for optimizing the post-diagnosis journey for PLWDs and CGs as dementia communities offering psychoeducation for CGs also play a pivotal role in alleviating caregiver burden and depression. (Campbell et al., 2016), (Lian et al., 2017), (Prorok et al., 2013).

3.5 Background Understanding Summary

A literature review at the intersection of medical, design, and psychological research aimed to map the current knowledge on the journeys to dementia diagnosis. The output was twofold: a Stakeholder Map of the dementia diagnosis system and a synthesis of knowledge captured in a Literature-based Journey Map of PLWDs, CGs, and GPs diagnostic experience.

The stakeholder map delineated direct and indirect stakeholders, providing insights into their roles in the diagnostic journey. Direct stakeholders included those in Symptom Awareness, Point of Advice, and Clinical/Social Support roles, while indirect stakeholders provided systemic support.

The literature-based journey map revealed five key phases in the journey to a dementia diagnosis:

- 1) Noticing symptoms
- 2) Acceptance of symptoms
- 3) Diagnostic process
- 4) Diagnosis disclosure
- 5) Life post-diagnosis

Each phase highlighted temporal steps and interactions involving PLWDs, CGs, and GPs. Themes concerning the needs, barriers, and facilitators for PLWDs, CGs, and GPs during the diagnostic process included Stigma, Education, Uncertainty, Communication, Emotional Reaction, Caregiver Burden, Maintaining Independence, Accessibility, and Collaboration.

The map primarily served to highlight areas where knowledge is already robust, while revealing areas where notable research gaps exist. The visual aspect of journey maps also contributed to revealing the presence of research gaps. While the themes of education, uncertainty, and communication are well-covered, research gaps are evident in the early phases of the journey.

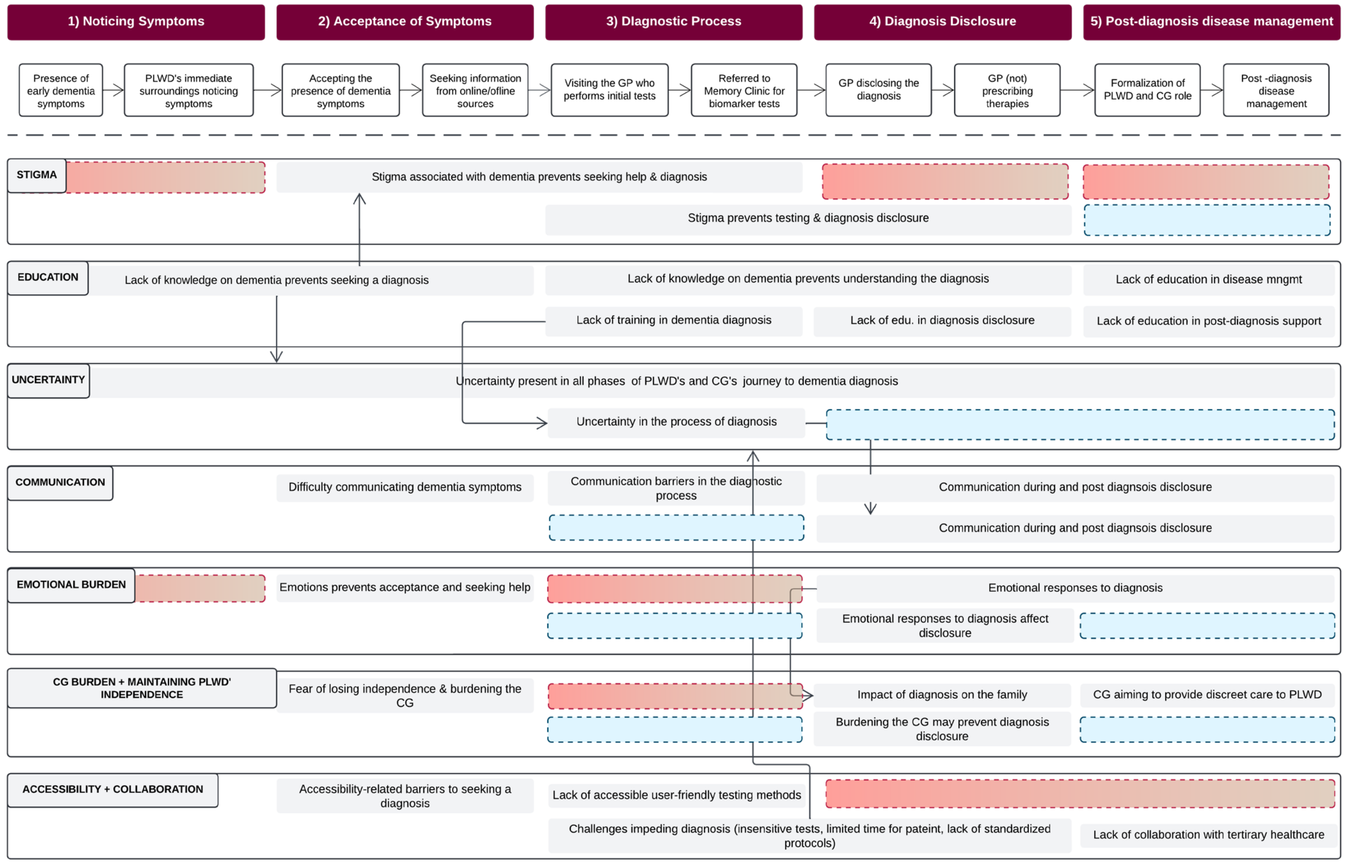


Fig. 12 – Highlighted research gaps within literature-based journey map

🟥 PLWD/CG experience research gap
🟦 GP experience research gap

In terms of the research methods identified in the background understanding research gaps lie in the lack of direct input from respondents and smaller sample sizes, which prevents generalisation of findings to broader populations.

More specifically, majority of assessed studies employ systematic literature reviews or qualitative interviews as their primary approach. Systematic literature reviews synthesize findings from various studies, providing a broad overview of existing knowledge but lack the depth of first-hand respondent experience. On the other hand, qualitative interviews, typically involving around 15 participants, capture nuanced insights, however their small sample sizes, limit the generalizability of the findings to wider populations.

Furthermore, there is minimal input from designers in dementia research, despite early dementia diagnosis being a “wicked” problem where designers’ skills in addressing complex, chaotic, and socio-technical issues would be highly valuable. (Newton et al., 2024)

More specifically, designers can contribute to dementia research in a variety of ways, including:

Mapping

- Journey mapping: Designers can facilitate the creation of detailed journey maps and service blueprints that illustrate the diagnostic process, highlighting pain points and areas for improvement. (Jung et al., 2023), (Mintrom & Luetjens, 2016)
- Stakeholder mapping: Designers can help identify and understand the various stakeholders involved, their roles, and their interactions within the dementia care system. (Geissdoerfer et al., 2016)

Visualising

- Designers can develop effective visualizations that make complex data more accessible and comprehensible to diverse stakeholders, including policymakers, healthcare providers, and the general public. (Jung et al., 2023), (Moere & Purchase, 2011)

Co-designing solutions

- Designers can contribute to the co-creation of solutions with PLWDs and CGs, ensuring that the perspectives and needs of these groups are directly integrated into the development of interventions and support systems. This form of contribution is currently the most common, with designers inviting PLWDs into the design process to jointly develop tailored tools and aids. (Wang et al., 2019)

Employing human-centred principles

- By employing human-centered design principles, designers can help create more empathetic and effective healthcare experiences tailored to the real-life contexts of those affected by dementia. (Geissdoerfer et al., 2016)

Reconciling value tensions

- Designers can help reconcile the tensions in interests of diverse stakeholders present in the dementia care system. (Patou & Maier, 2017), (Geissdoerfer et al., 2016)

Ideating and prototyping

- Designers can employ design thinking principles to propose new solutions through ideation and prototyping, allowing practical innovative ideas to emerge. (Geissdoerfer et al., 2016)

Aligned with Newton et al. (2024), this research aims to integrate designerly skills into dementia research through the EBC framework, addressing the under-representation of designers in this field. The potential contributions of designers to dementia research, as well as the validation of the points already mentioned, will be further explored in the discussion section informed by the findings gained from this study.

To conclude, the Background Understanding section facilitated the identification of research gaps and served as a foundation for subsequent analysis phases. The following Method section aims to build upon this foundation, leveraging data-enabled approaches to fill the identified research gaps and improve the understanding of the PLWD/CGs’ journeys to a dementia diagnosis. ■

4

Method

This chapter outlines the method used in this study, addressing the research gaps identified in the Background Understanding chapter. It provides an overview and rationale for the three-step mixed-method approach employed to analyze data collected from the UK Alzheimer's Society Dementia Support online forum. The method includes thematic analysis, LDA topic modeling, and synthesis, each detailed in subsequent sections. By integrating qualitative and quantitative methods, the study aims to produce journey map of the diagnostic journey, offering comprehensive and nuanced insights for designing more effective diagnostic strategies.

Chapter Content Overview

After gaining a foundational understanding of themes related to the journeys of PLWDs, CGs and GPs within the Background Understanding, a three-step approach was employed to analyse the data collected from the UK Alzheimer's Society Dementia Support online forum. The objective was to create a comprehensive journey map of of PLWDs and CGs, addressing identified research gaps and answering the following main research question:

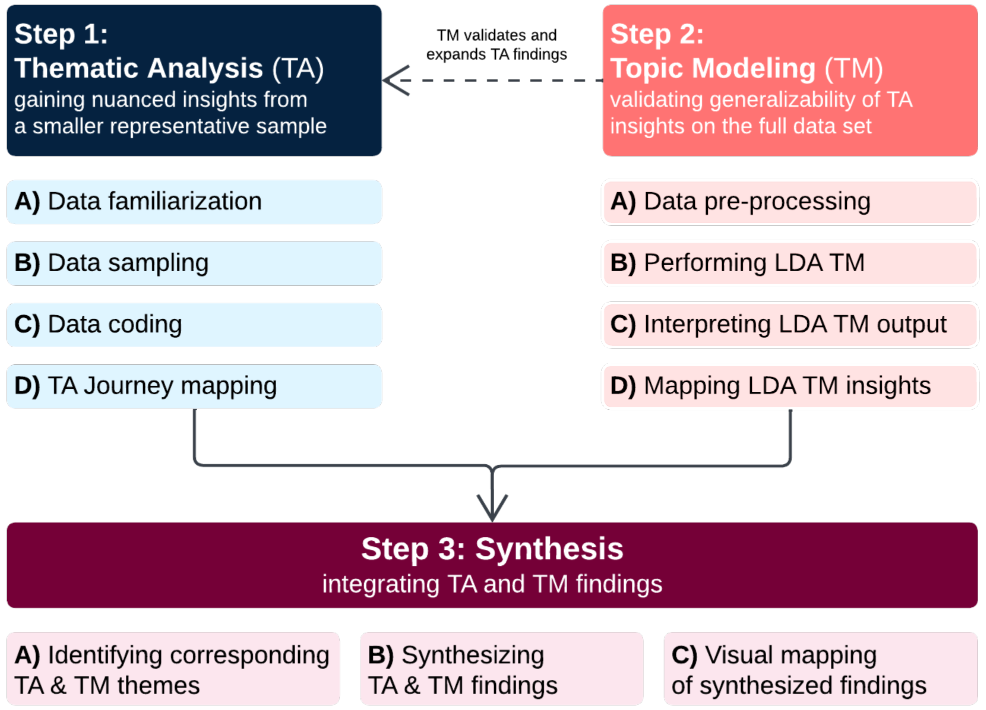
RQ1: What nuanced insights can be gained from mapping the experiences of PLWDs and their CGs to inform the enhancement of early dementia diagnosis strategies?

GPs' perspectives were no longer included, as they do not directly engage with the UK Alzheimer's Society Dementia Support online forum, hence it was not possible to capture their perspective on the journey.

Inspired by Online Community Journey Mapping by Jung et al. (2023), the analysis involved three main steps:

- **Step 1: Thematic Analysis:** A smaller data sample was analyzed using manual coding to capture nuanced themes within the experiences of PLWDs and CGs with the diagnostic process.
- **Step 2: LDA Topic Modeling:** A larger dataset was examined using ML, specifically LDA topic modeling, to test the generalizability of the findings from the thematic analysis on the wider forum.
- **Step 3: Synthesis:** Insights from the thematic analysis and LDA topic modeling were combined to create comprehensive journey maps.

Fig. 13: Process overview diagram



4.1 Method Rationale

Analyzing online stories from the Alzheimers Society Dementia Support forum using thematic analysis followed by LDA topic modeling, addresses the idenfitied research gap of lack of comprehensive mapping of the diagnostic journeys of PLWDs and their CGs.

- **Step 1: Thematic Analysis:** Thematic analysis of a smaller sample of forum posts provides in-depth and nuanced insights into the experiences of PLWDs and CGs, forming the foundational understanding of the dementia diagnostic journey.
- **Step 2: LDA Topic Modeling:** LDA topic modeling validates the generalizability of the insights gained from thematic analysis by processing a larger dataset. This method identifies overarching themes and trends on the larger forum and uncovers patterns not apparent in the smaller sample, expanding on the initial findings. Additionally, the detailed insights from thematic analysis also help interpret the outputs of LDA topic modeling, providing context to the broader trends identified.

By integrating these methods, the study effectively addresses the methodological gaps commonly found in dementia research. Systematic literature reviews often lack first-hand experiences, and surveys frequently fail to capture authentic respondent-driven data. Additionally, qualitative methods such as interviews, focus groups, and ethnographies typically involve smaller sample sizes, limiting their ability to capture the breadth of experiences. Conversely, purely quantitative studies that focus on forum statistics lack the qualitative insights necessary to understand the experiences of PLWDs and CGs in the diagnostic journey. Due to these limitations, these traditional methods were not employed in this study.

Instead, this mixed-method approach integrating thematic analysis and LDA topic modeling provided a comprehensive understanding of the diagnostic journeys of PLWDs and CGs, capturing both the depth and scope of their experiences.

It was anticipated that this integrated approach would produce a holistic map of the diagnostic journey of PLWDs and their CGs that would inform the design of more effective strategies for early diagnosis of dementia.

4.2 Positionality Statement

In an effort to guarantee maximum rigor of the study, emphasis was placed on the reflexivity of the researcher. This was achieved through an awareness of personal biases, including received education or previous experiences related to the topic, which may have influenced the researcher's analytical judgement.

The researcher is a designer by training interested in researching user experiences with an emphasis on the emotional aspects. This background informed researcher's choice of method and interpretation of results, emphasizing qualitative, user-centred approaches and empathy.

Additionally, the researcher was supervised by a postdoctoral researcher with background in cognitive neuroscience and an Assistant Professor of Human-Centered AI with expertise at the intersection of Human-Computer Interaction (HCI) and Social Cognition. The research interests of the supervisors may have influenced the study towards a greater emphasis on an interdisciplinary approach, combining medical, computer science, and psychological fields. Additionally, the scientific background of the supervisors could have led to a greater focus on quantification of research findings.

Moreover, on the topic of dementia, the researcher has personal experience with some relatives who are either living with dementia or performing caregiving duties. These relationships provided the researcher with direct insight into the complexities and emotional challenges associated with dementia and caregiving. Specific experiences that have influenced researcher's perspective include:

- **PLWD's behavior:** Witnessing relatives with dementia exhibit suspicions, aggression, and childlike behavior, creating significant stress for both the PLWD and their CGs.
- **CG's burden:** Observing CGs experience significant burden from caregiving duties at the expense of their health and emotional well-being resulting in the need for support.
- **Challenges in seeking care facilities:** Noticing relatives struggling to find care homes with the capacity to accept PLWDs, especially in rural areas where such facilities are scarce or less financially accessible to CGs.
- **Emotional toll of placement:** Seeing the guilt and fear of judgment that CGs face when placing a PLWD in a care home. The stigma associated with not being able to provide home care and thus "betraying" the PLWD can be deeply distressing for CGs.
- **Family dynamics:** Experiencing caregiving becoming a collective family affair, with differing opinions and, sometimes even denial about the PLWD's condition. Witnessing these dynamics significantly complicating caregiving decision-making processes.

In order to account for bias, these assumptions were documented prior to performing the analysis, increasing awareness of potential influences and helping to mitigate their impact.

4.3 Data Collection

4.3.1 Data Source

The data for this study was collected from UK Alzheimer's Society Dementia Support Forum, a free, publicly available online community for sharing experiences with other people affected by dementia. This particular forum was chosen as it is the largest of dementia-specific forum in the UK (the focus region of this study) and one of the largest of its kind globally. According to a list compiled by the Alzheimer Society of Canada (2024), other English-language forums that could have potentially been used for this research include:

- Alzheimer Society of Alberta and Northwest Territories [8]
- Alzheimer Association US [9]

[8] – www.asantcafe.ca, accessed on 2024, 8 July

[9] – www.alzconnected.org, accessed on 2024, 8 July

- Virtual Hospice [10] (not dementia-specific)
- Mayo Clinic Connect [11] (not dementia-specific)

UK Alzheimer's Society asks members to share helpful information, offload concerns about dementia, read other people's stories and ask for advice. (Alzheimer's Society, n.d.) As of 20.5.2024 the forum has 91,531 members, 139,798 threads and 2,010,548 messages. The forum is run by a small team of staff and volunteers who have personal experience of caring for people with dementia. Volunteers are not professional advisers therefore they cannot give medical or legal advice. Instead, their role is to help provide forum users with support and useful resources. (Alzheimer's Society, 2024)

Forum altogether contains 25 sub-forums including:

- Say hello and introduce yourself
- How to use dementia support forum
- I have dementia
- I have a partner with dementia
- I care for a person with dementia
- Younger people with dementia and their carers
- LGBT+ people with dementia and carers
- Memory concerns and seeking a diagnosis
- Recently diagnosed and early stages of dementia
- Middle – later stages of dementia
- End of life care
- After dementia – dealing with loss
- Dementia related news and campaigns
- Legal and financial issues
- Helpful websites
- Health and wellbeing
- Books, film and music
- Equipment and technology
- Fundraising for Alzheimer's Society Researchers, students and professionals
- Expert Q&As
- Alzheimer's Society notices
- Alzheimer's Society videos and podcasts
- ARCHIVE FORUM: Support discussions
- ARCHIVE FORUM: Resources

4.3.2 Ethical Considerations

Given the sensitive nature of the dementia topic, it was very important to ensure research complied with ethical considerations. To address this, a detailed data management plan was developed, outlining the strategies for mitigating risks associated with data scraping, analysis, and storage. The application titled: "Data-Enabled Patient Journey Mapping for Early Dementia Diagnosis in the UK" (application number 3969) received approval from the Human Research Ethics Committee (HREC) of Delft University of Technology. The application included a data management plan and an HREC checklist, available in Appendix 2. Additionally, Informed Consent (Appendix 3) was obtained from the UK Alzheimer's Society, granting permission for scraping and analyzing data from the Dementia Support Forum. This consent ensured that the research was conducted in alignment with ethical guidelines and respected the rights and privacy of forum participants.

[10] – www.virtualhospice.ca, accessed on 2024, 8 July

[11] – connect.mayoclinic.org, accessed on 2024, 8 July

4.3.3 Data Scraping

Data scraping was performed externally using the BeautifulSoup Python library [14] to extract data from the forum website. The website structure was identified through browsing and inspecting the HTML elements in a browser. By determining the structure (including categories, forums, subforums, threads, and messages) and relevant HTML elements, the website was scraped using BeautifulSoup Python libraries. (The full script available in Appendix 4) The extracted data was then parsed and stored in a structured format in CSV files.

Out of all the 25 sub-forums, 6 of those that are most relevant to the research question were selected for data scraping, including:

- Say hello and introduce yourself (42,678)
- I have dementia (19,970)
- I have a partner with dementia (13,295)
- I care for a person with dementia (294,078)
- Memory concerns and seeking a diagnosis (16,425)
- Recently diagnosed and early stages of dementia (13,295)

A total of 399,741 posts from six sub-forums were scraped on April 4, 2024. The data was saved as a csv. file with the following structure:

- **Category:** Grouping of sub-forums under a broader topic.
- **Forum:** Title of the sub-forum indicating the main topic.
- **Thread_title:** Title of the thread indicating the main topic.
- **Thread_url:** The URL of the thread, a direct link to the online discussion.
- **Post_author_title:** The author's role in the forum; Titles were assigned by the forum and included: New Member, Registered User, Staff Member, Volunteer Host, and Volunteer Moderator.
- **Username:** Author's username on the forum
- **Post_id:** Unique identifier for each post.
- **Quotes:** The post_id of previous posts that this post is quoting, linkage to earlier discussions.

In the following three sections, Step 1: Thematic Analysis, Step 2: Topic Modeling, and Step 3: Synthesis, the data will be sequentially analyzed both in depth within the thematic analysis and at a broader level through topic modeling. The insights from the two steps will finally be integrated in Step 3: Synthesis, providing a comprehensive overview of the PLWD and CG journey to a dementia diagnosis. ■

[12] – https://pypi.org/project/beautifulsoup4/, accessed on 2024, 7 July

5

Step 1: Thematic Analysis

This chapter details the first step of the research method, focusing on thematic analysis (TA) to gain in-depth insights from online patient stories. The goal was to understand the diagnostic journey of PLWDs and their CGs by examining a smaller representative sample of online patients stories from the UK Alzheimer's Society Dementia Support forum. Using an inductive approach, themes emerged organically from the data and were visualized in a journey map. This step captured the nuances within individual themes, laying the groundwork for further analysis to provide a comprehensive understanding of the diagnostic experiences of PLWDs and CGs.

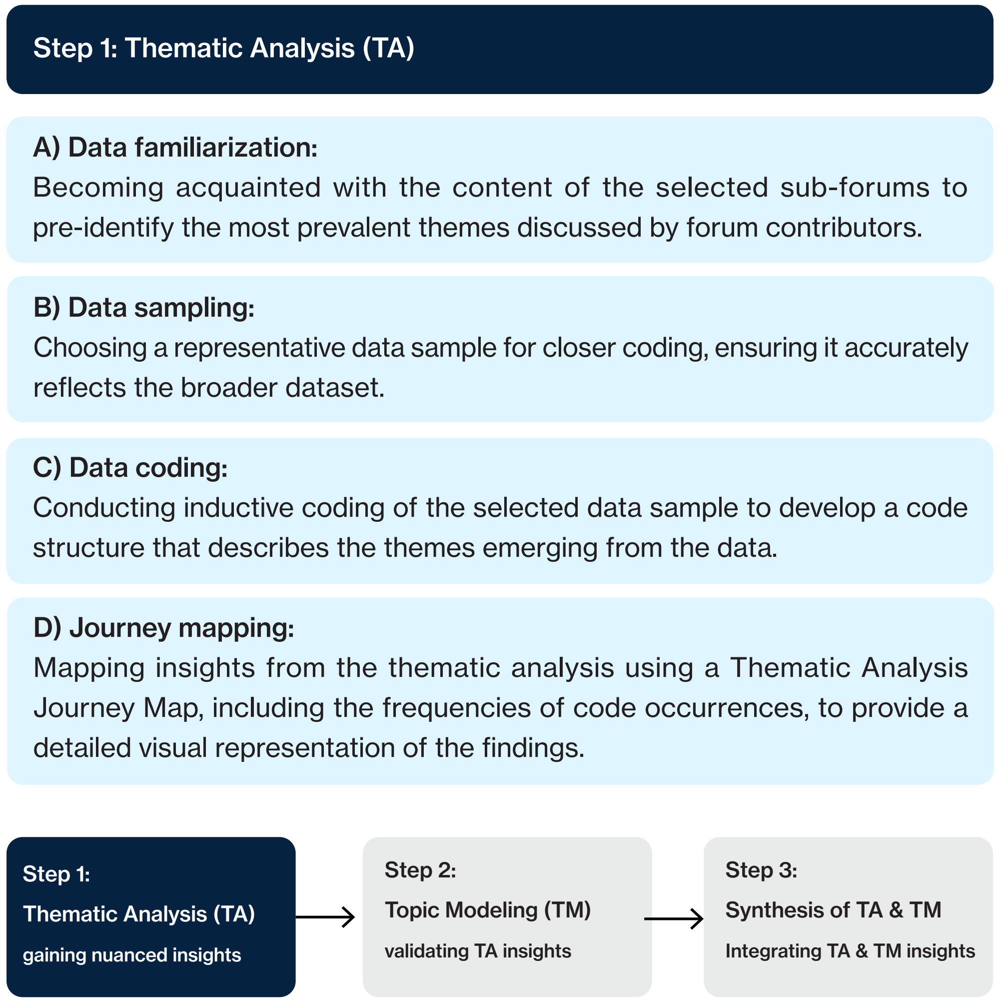
Chapter Content Overview

5.1 Objective

The initial step of the analysis involved gathering in-depth insights from online patient stories by examining a smaller, representative sample using thematic analysis.The goal was to thoroughly understand the themes within the diagnostic journey, focusing on capturing the nuances within the experiences of PLWDs and CGs. Thematic analysis followed an inductive approach, as described by Braun & Clarke (2014), allowing themes to emerge from the data itself rather than being shaped by pre-existing theories. Although the identified themes were not shaped by pre-existing theories, the qualitative analysis is inevitably influenced by the researcher's attitude, disciplinary knowledge, and epistemology. (Braun & Clarke, 2014) Therefore, great emphasis was placed on achieving the researcher's reflexivity, involving an awareness of one's own standpoints that might influence the outcome of the analysis. After performing the thematic analysis, the identified themes, including their sequencing, interdependencies and frequencies of occurrence were visualised using the **Thematic Analysis Journey Map**.

5.2 Process Overview

The thematic analysis drew inspiration from the method for inductive thematic analysis by Braun & Clarke (2014). The process involved several sub-steps:



Step 1: Thematic Analysis (TA)

A) Data familiarization:
Becoming acquainted with the content of the selected sub-forums to pre-identify the most prevalent themes discussed by forum contributors.

B) Data sampling:
Choosing a representative data sample for closer coding, ensuring it accurately reflects the broader dataset.

C) Data coding:
Conducting inductive coding of the selected data sample to develop a code structure that describes the themes emerging from the data.

D) Journey mapping:
Mapping insights from the thematic analysis using a Thematic Analysis Journey Map, including the frequencies of code occurrences, to provide a detailed visual representation of the findings.

Fig. 14: Thematic Analysis (TA) Process overview diagram

5.2.1 A) Data Familiarization

The aim of this sub-step was to become familiar with the online forum and identify any themes that might be relevant to the research question. (Braun & Clarke, 2014) The process involved freely recording findings relevant to the experience of PLWDs and CGs with the diagnostic process. These observations were then organized into clusters and visually represented using a journey map, providing a comprehensive visual overview of the findings. The outcomes of data familiarisation not only facilitated a deeper understanding of the forum content but also provided a foundational framework for subsequent inductive coding.

Since the outsourced data scraping was not yet completed, the researcher familiarized themselves with the general content of the selected sub-forums rather than the specific data sample for later coding. In total, the 240 most recent threads from the selected sub-forums were reviewed, including:

- Say Hello and Introduce Yourself
  (reviewed 40 most recent threads, 2/295 pages)
- I Have Dementia
  (reviewed 40 most recent threads, 2/95 pages)
- (I Have a Partner With Dementia
  (reviewed 40 most recent threads, 2/482 pages)
- I Care For A Person With Dementia
  (reviewed 40 most recent threads, 2/1251 pages)
- Memory concerns and seeking a diagnosis
  (reviewed 40 most recent threads, 2/94 pages)
- Recently diagnosed and early stages of dementia
  (reviewed 40 most recent threads, 2/78 pages)

5.2.2 B) Data Sampling

The following sub-step involved identifying a manageable, yet sufficiently representative, sample of data from the scraped dataset. The data familiarization phase revealed that the first posts within a thread (first-thread posts) contain the densest information content. Via these initial posts, contributors provide comprehensive details about their personal situations and the narrative leading up to their current circumstances, typically concluding by seeking advice. Subsequent replies from other forum members or hosts primarily offer reassurance, guidance or support. Given the research focus on mapping the experiences of PLWDs and their CGs, the first-thread posts were identified as the most relevant and information-dense data source.

From the total dataset of 399,751 posts across 6 selected sub-forums, the sample for the thematic analysis was chosen specifically from the first-thread posts. Using R, a random sample function was employed to select 500 first-thread posts from the total of 45,927 first-thread posts, corresponding to roughly 1% of all first-thread posts within the forum. (Code for random data sampling accessible in Appendix 6).

Sub-forum distribution

Based on data in Fig. 15, the proportions of posts sampled to total posts in each sub-forum are fairly close, ranging from approximately 0.0096 to 0.0115. This minor variation suggests that the distribution of posts sampled is proportional to the number of total posts in each sub-forum.

Fig. 15: Proportion of sampled first-thread posts per sub-forums to total first thread posts

Selected sub-forum	First-thread posts sampled	Total first-thread posts in sub-forum	Proportion sampled
Say Hello and Introduce Yourself	57	5930	0.009612
I Have Dementia	19	1898	0.010011
I Have A Partner With Dementia	103	9667	0.010655
I Care For A Person With Dementia	287	25015	0.011473
Memory Concerns and Seeking a Diagnosis	19	1866	0.010182
Recently Diagnosed and Early Stages of Dementia	15	1551	0.009671
Total	**500**	**45,927**	**0.010887**

This sampling method ensured that the sample was manageable to be manually coded while being informationally dense. Additionally, use of the random sampling function ensured highest likelihood the sample would be representative of the broader dataset.

5.2.3 C) Data Coding

Subsequently, the data sample of 500 first-thread posts was analyzed using Atlas.ti, a tool used for effective qualitative data analysis and visualization. Each post was imported to Atlas.ti as a separate document and automatically grouped by forum and post_author_title categories. The sample included:

Total posts in data sample: 500

Post_author_title distribution:
- New member: 109
- Registered user: 386
- Staff member: 1
- Volunteer host: 3
- Volunteer Moderator: 1

As for the coding itself, the complete coding method was used. That is, instead of selecting a specific set of cases, all data relevant to the research question were coded and only later in the analytical process were relevant data selected. Inductive coding was applied, with codes generated directly from the data without predetermined categories, allowing themes and patterns to emerge naturally.

Coding involved the following steps:

- **Initial coding:** The first 50 posts were coded inductively to generate initial codes.
- **Developing an initial code structure:** These codes from initial coding were organized into a primary code structure.
- **Continuing coding:** Coding continued with the initial structure, adding new codes as necessary.
- **Reaching saturation:** Coding was concluded at 100 posts when new themes stopped emerging. 100 first thread posts accounted for ~0.22% out of all first thread posts (45 927 first-thread posts)
- **Organizing codes into a final code structure:** The final code structure was developed, forming the basis for the thematic analysis journey map.

Fig. 16: Final condensed code structure; codes ordered alphabetically

	Code Structure	Code Frequency
Actors:		
	CG's relation to PLWD	68
Stages:		
	Dementia Stage	26
Steps:		
	Diagnostic Steps	65
Phases:		
	Denial vs. Acceptance & Seeking a Diagnosis	32
	Diagnosis Disclosure	11
	Diagnostic Process	31
Themes:		
	Care Home	35
	CG Burden	121
	Experience with NHS and Social Services	9
	Impact of Covid	3
	Interacting with the Forum	87
	Maintaining PLWD's independence and safety	79
	PLWD Symptoms + Ways of Coping	139
	Seeking a Diagnosis	14
	Uncertainty	4

The complete thematic analysis code structure, is available in Appendix 9.

5.2.4 D) Journey Mapping

To conclude the thematic analysis, identified codes were analyzed to uncover patterns appearing across the data. This process involved organizing the individual codes into thematic clusters.

In the upper part of the journey map, a suggestion of time progression was illustrated using an arrow. Below, the journey map was divided into 5 key phases, derived from the Background Understanding and supported by findings from data familiarization and coding. Similar to the literature-based journey map, the 5 key phases included:

- **Phase 1:** Noticing Symptoms
- **Phase 2:** Acceptance of Symptoms
- **Phase 3:** Diagnostic process
- **Phase 4:** Diagnosis disclosure
- **Phase 5:** Post-diagnosis Disease Management

Codes related to the diagnostic journey steps were displayed at the top of the map as temporal steps, with overarching themes depicted below as thematic clusters. Themes concerning PLWDs and CGs were color-coded for distinction.

Additionally, the map included a dimension of the frequency of occurrence of individual codes. However, it is important to note that, given the qualitative nature of the analysis, the frequency of a code occurrence does not directly correlate with its importance (Braun & Clarke, 2014). Instead, frequencies of occurrence became useful for quantifying the online forum demographics, including roles of forum contributors, the diagnostic stage, or the caregiving location of PLWDs.

5.3 Results

The thematic analysis results offer insights into forum demographics and detailed descriptions of the journey phases, including temporal steps and themes. These findings are presented both in text and visually through a journey map.

5.3.1 Forum Demographics

Based on 100 coded posts from individual users, the online forum primarily comprises CG users, with a ratio of 76 CGs to 3 PLWDs. Most CGs are relatives of PLWDs, mainly children (39%) or partners (23%). Among the 76 CGs, 51 are at an undefined stage of seeking a diagnosis, 38 are managing post-diagnosis, and 11 have not yet received a diagnosis. Regarding dementia stages, 55 CGs care for PLWDs at an undefined stage, 16 at the early stage, 21 at the mid stage, and 8 at the late stage. Most caregiving occurs at home (75%), with fewer in care homes (12%). Across the 100 users, there is only one care assistant by profession and no GPs contributing to the forum.

5.3.2 Journey map phases and temporal steps

Phase 1: Noticing Symptoms

The journey begins with PLWD developing early signs of dementia. In the initial stages, early cognitive or behavioral changes in PLWD may be subtle and/or easily mistaken for emotional problems or arrogance. Therefore, recognition of these symptoms as signs of dementia may often take up to a year. During this time, relatives and friends play a key role in noticing these changes. However, there may be differences in awareness with only some people close to the PLWD noticing the symptoms. This emphasizes the importance of communication of observations to ensure everyone is equally informed.

Phase 2: Acceptance of Symptoms

In the second stage, the decision of PLWD/CG to seek a diagnosis by visiting a GP may take considerable time. This is often due to denial of dementia symptoms, fear of diagnostic tests, or not recognizing the value of receiving a diagnosis.

Phase 3: Diagnostic Process

Once the PLWD/CG decides to seek medical help, the GP performs initial testing to rule out other causes of the diagnosis and possibly confirm the suspected presence of dementia. If suspected, the PLWD is then referred to Memory clinic for further testing to confirm or exclude the presence of dementia. The diagnostic process is often characterised by long waiting times and lack of support, which causes CG to often feel like giving up seeking a diagnosis for the PLWD.

Phase 4: Diagnosis Disclosure

After receiving the results of the additional confirmatory tests, the Memory Clinic or the GP will disclose the diagnosis to the CG and PLWD. In most cases, the diagnosis is first communicated to the CG who then informs the PLWD. In some cases the PLWD or CG receive a diagnosis which they suspect is not sufficiently precise (i.e. diagnosed with Mild Cognitive Impairment instead of Vascular Dementia). Upon the diagnosis disclosure, the doctor may prescribe medication. Reactions to medications vary across patients from positive to negative. In many cases, the response is indeterminate due to medication being prescribed too late to be effective.

Phase 5: Life post-diagnosis

In the final phase of the journey map, the focus of the CG and PLWD shifts to adapting to the life after dementia diagnosis. CGs may also seek a Lasting Power of Attorney (LPA) for managing PLWD's legal affairs. Depending on the level of CG's burden and severity of PLWD's symptoms, CGs may consider placing PLWD in a care facility.

5.3.3 Journey map themes

Themes in a journey are identified by a title and a number indicating the frequency of relevant codes in the data sample. Individual insights within a theme are marked by a specific code from the detailed code structure, along with a number showing the frequency of that code in the sample.

Theme 1: PLWD Symptoms and Ways of Coping – 143

Dementia causes PLWDs to experience a progressively worsening range of cognitive, behavioral, and physical symptoms. Cognitive and behavioral symptoms are often the most prominent, with memory problems being the primary concern, including short-term memory loss and difficulty recognizing relatives (PLWD Memory Problems – 14). These memory concerns coupled with reduced ability to perform previously mastered tasks, childlike behavior and reluctance to be alone cause PLWD over time to lose the ability to be independent (Losing ability to be independent – 20).

Full quoted post messages available in Appendix 11.

> "Since then, in the past three years she has gone from being a University lecturer, to not being able to get ready for bed on her own. She has delusions, rarely knows who my father is (even though he's her primary carer), can't really dress or bathe without help, and only makes sense (verbally) about 30% of the time. Her decline has been SO fast." (Post ID: 1651174)

Furthermore, PLWD may experience aggressive behavior which can manifest through aggression towards CGs, destruction of objects and self-harm (Agressive behavior – 17). Disorientation is also frequent, with individuals experiencing difficulty navigating familiar spaces and heightened confusion (Disorientation – 16). Last but not least, PLWDs can experience overwhelm, especially in social interactions with too many people (Overwhelmed by too many people – 16)

Less frequent but notable symptoms include accusatory or suspicious behavior, especially towards CG and relatives (Accusations or suspicions – 3). Emotional changes are also present primarily in the form of mood swings, anxiety, and overly apologetic or timid actions (Emotional changes – 7). Finally, PLWD may also develop fixations on certain tasks (Fixations – 6) and struggle with communication by either ceasing to talk or repeatedly asking questions (Changes in communication – 4).

PLWDs may also experience decline in appetite (Food consumption – 4) and disruptions in sleep pattern, with individuals either sleeping excessively or not at all (Sleep pattern – 3). Physical symptoms are also significant, including decreased mobility manifested by physical weakness and frequent falls (Mobility – 10). Finally, eyesight problems are very common (Eyesight problems – 16). It is important to note, that despite these challenges, many PLWDs remain physically fit but struggle mentally (PLWD struggling - 3), often feeling bored, apathetic, lonely, or emotional (PLWD emotional experience – 9).

Effective coping mechanisms for PLWD include engaging in creative or manual work, listening to music or writing, which provide mental stimulation and enjoyment. Maintaining a positive outlook and being part of a community also contribute positively to their well-being. Moreover, some PLWD find relief in recording their experiences and changes, potentially by posting on online forums, which helps them process their symptoms and feel connected to others sharing similar experiences. (PLWD ways of coping – 8)

> "I find it extremely cathartic to write things down and also an enjoyable hobby. I am not really bothered whether it is good writing as recording

> what I am thinking. I don't think I will be a best seller writer, although one can hope! I am trying to record any changes I see in myself which I add to my Wordpress blog." (Post ID: 893616)

Theme 2: Seeking a diagnosis (19)

Following the acknowledgment of potential presence of dementia symptoms by either the PLWD or their CG, the theme of seeking a diagnosis becomes prominent. The active pursuit of a diagnosis largely depends on the perceived value of the diagnosis by both PLWD and CG. In many instances, CGs recognize the importance of a formal diagnosis, viewing it as a gateway to future assistance and support in caregiving. Conversely, if the CG does not perceive a diagnosis as valuable, they often consider the process of seeking a diagnosis a waste of time, causing them not to engage in the pursuit. (Perception of value in receiving a diagnosis – 6)

> "What will a diagnosis mean or do.?...Once an official diagnosis what happens...if anything. I have read on TP it really changes very little but after three years of tests.....more tests etc...need it officially!)" (Post ID: 1634330)

Meanwhile, PLWDs most of the time avoid seeking a diagnosis. This reluctance to become diagnosed is manifested by their fear of the diagnostic test itself (PLWD afraid of taking the diagnostic test – 3) or a tendency to downplay or deny symptoms during medical visits (PLWD pretends to not experience any symptoms when visiting the doctor – 1). The underlying reason for this behavior may often be the PLWD's fear of losing independence as a result of being diagnosed. In some cases, this leads to CGs resorting to telling PLWD white lies to get them to attend medical appointments (Telling PLWD a white lie – 1).

Regarding the diagnostic process itself, CGs often face uncertainty as a result of not being familiar with the diagnostic process (CG not familiar with the process of diagnosis – 1), which can lead to CGs being unsure of how proactive they should be when seeking help (CG debating how proactive they should be when seeking help – 1). Moreover, some CGs have negative experience with doctors, stating doctors often seemed rushed and unhelpful. Some CGs attribute this lack of helpful attitude from doctors to the perceived untreatability of dementia. (Negative experience with doctor during diagnosis – 6); (Percieved disease untreatability – 1)

Theme 3: Experience with NHS & social services (9)

During the search for a diagnosis a number of CGs voice complaints about NHS services, primarily complaining about long waiting times between appointments. They also highlight inconsistent communication with social service providers and their inability to effectively arrange social support and CG benefits. (CG dissatisfied with social services and NHS – 3); (Problems with receiving CG benefits – 1)

> "I have really struggled to come to terms with the way in which this has obliterated our lives. We have no other family, and have found social services and the NHS very unhelpful- they have offered us almost no support." (Post ID: 1651174)

Theme 4: CG maintaining PLWD's independence while ensuring their safety (73)

As dementia progresses, PLWDs lose the ability to maintain their independence, making them increasingly vulnerable and in need of protection (Losing ability to be independent – 20). This requires CGs to step in to ensure the safety and well-being of PLWD. In situations where PLWD lives alone or with a partner who is also unable to provide care due to their own dementia (CG's partner cannot provide care (also has dementia) – 2), CGs may choose to move in with the PLWD. Alternatively, they may hire caregiving staff if they themselves cannot or do not wish to move in. Moreover it includes managing financial and legal matters such as obtaining a Lasting Power of Attorney (LPA), overseeing PLWD's finances, or hiring caregiving staff.

It is common among CGs that they are aware of PLWDs' fear of losing independence. This awareness motivates CGs to provide care in a discrete and respectful manner, allowing PLWD to enjoy as much independence as possible. To achieve this delicate balance between independence and active protection, some CGs opt for security technologies that allow them to protect PLWD without overtly interfering with their autonomy. (CG wanting to protect PLWD without taking away their independence – 37)

> "I appreciate I need to give him space and let him have independance but I am really worried that something may happen and I will not be there!" (Post ID: 839980)

However, these protective measures are often perceived as restrictive by PLWD, recognizing them as a threat to their independence. This resistance can manifest itself in different ways, for example, by PLWD hesitating to give CG an LPA or by refusing to accept care from care assistants. Additionally, PLWD may start to feel resentment towards CG and hold them responsible for their loss of independence. However, this resentment is not one-sided and also occurs from the part of CG as a result of CG burnout (described in more detail in the CG Burden theme). This tension highlights the complex dynamic CGs face when trying to maintain PLWD's safety while respecting their need for independence. (PLWD does not want to lose independence – 12)

> "The DVLA has taken her driving licence away due to the dementia diagnosis, but also because we mentioned on the medical form that she has falls and has double vision. She blames me for her having to stop driving, and refuses to sell her car." (Post ID: 1622533)

Theme 5: CG Burden (110)

During caregiving, CGs experience significant emotional burden, which, combined with lack of support and neglect of self-care, often leads to CG burnout.

The emotional burden primarily involves the struggle of watching the PLWD's mental and physical health deteriorate (Difficult to watch PLWD deteriorate – 2; Worry about PLWD's health – 5). This deterioration causes CGs to feel increasingly alienated from the PLWD, leading to resentment, as they no longer recognize the person they once knew (CG 'losing' PLWD due to dementia – 7; CG feeling resentment towards PLWD – 4). Additionally, worries about financial aspect of caregiving further stress the CG (CG worried about the financial aspect of caregiving – 1).

The situation is often intensified by a feeling of loneliness in the caregiving journey, caused by inadequate support (CG lonely in the caregiving journey - 11). Particularly, if CG is the child of a PLWD, it is common for them to experience a lack of support from siblings in caregiving, which causes resentment and negatively affects family relationships (Caregiving affecting CG's relationship with siblings - 11).

> "at heart it is about how lonely and difficult it becomes when dementia means that one's partner is no longer able to understand, empathise or support." (Post ID: 1575321)

Finally, a significant factor contributing to CG burnout is the prioritization of caregiving over personal time, leading CGs to neglect their own needs (CG Prioritizing Caregiving – 11). These combined factors result in CG burnout, where the CG becomes so exhausted that they can no longer provide care effectively (CG Burden leading to burnout – 52). In such situations, the CG's outlook on the future is often negative, highlighting a need for hope and strength (CG being negative – needing hope and strength – 5).

> "Why does no one care for the carer? Why does no.one believe me? Why doesn't my sibling.care for her mother? Why does.the PWD portray the perfect life? Why do I feel guilty for not caring.and then neglect my own family due to.caring too much? I didn't sign up.to the **** I've been dealt, but no other family.care Sorry.just feel miserable today " (Post ID: 2047532)

As a result of their inability to continue caregiving, CGs frequently experience intense guilt. This guilt manifests not only during the burnout phase but also throughout the caregiving process, as CGs feel guilty for taking any personal time (CG guilty of taking self-care time + not having capacity for caregiving – 3). Additionally, guilt arises from not providing care earlier (CG feeling guilty for not providing care earlier – 1) and from hoping the PLWD would not suffer any longer (CG feeling guilty for hoping PLWD would not suffer any longer – 3).

Theme 6: Carehome (35)

In many cases, due to CG burnout or the increasing difficulty of caregiving in the later stages of dementia, CGs decide to place PLWD in a care home (CG deciding to put PLWD in a care home – 6). This decision is often challenging for CGs, as many perceive placing PLWD in a care home as betrayal towards the PLWD (CG consequences of joining a care home – 12).

> "Feeling so very sad, still feel like we've let mum down as we promised we wouldn't do this but we never imagined she would end up how she is." (Post ID: 1147132)

Additionally, the process of finding a suitable care home can be laborious and time-consuming. CGs often struggle with the unfamiliarity of the process and the difficulty of finding a home that will accept the patient, especially if the CG needs to place a couple in cases when both partners have dementia. (Struggling to find a care home – 5).

Once a suitable home is found, CGs struggle with communicating the move to PLWD. (How to communicate to PLWD they are going to care home – 1). This is particularly difficult as most PLWDs refuse to join a care home (PLWD consequences of joining a care home – 11). This refusal leads to PLWD being dissatisfied with the care home which may lead to a rapid worsening of dementia symptoms (PLWD consequences of joining a care home – 11).

> "After looking after o/h till I was ready to drop got a care home to come an assess which they did on thursday, -and much to y relief we took her thursday afternoon they said leave it a couple of days so I went on Sunday. She was standing in the hall screaming at the top her voice she calmed down a bitbut accused me of dumping her!h" (Post ID: 1340338)

From the CG's perspective, there is often a deep sense of guilt and betrayal associated with placing PLWD in a care home. Additionally, CGs frequently debate the extent to which they should be involved in caregiving after the patient has been placed in a care home (CG consequences of joining a care home – 12).

Theme 7: Uncertainty (4)

As part of the process of seeking a diagnosis and follow-up care, CG experiences a sense of uncertainty, especially given the uncertain progression of the disease and the difficulty in predicting how long caregiving will continue/how long PLWD will live with the symptoms of the disease. (Uncertain disease progression – 4)

> "im trying so hard to even take in the news of his dementia without having to deal with this as well.... feel so overwhelmed i cnt even think... i know im waffling but really am unsure of everything" (Post ID: 1085969)

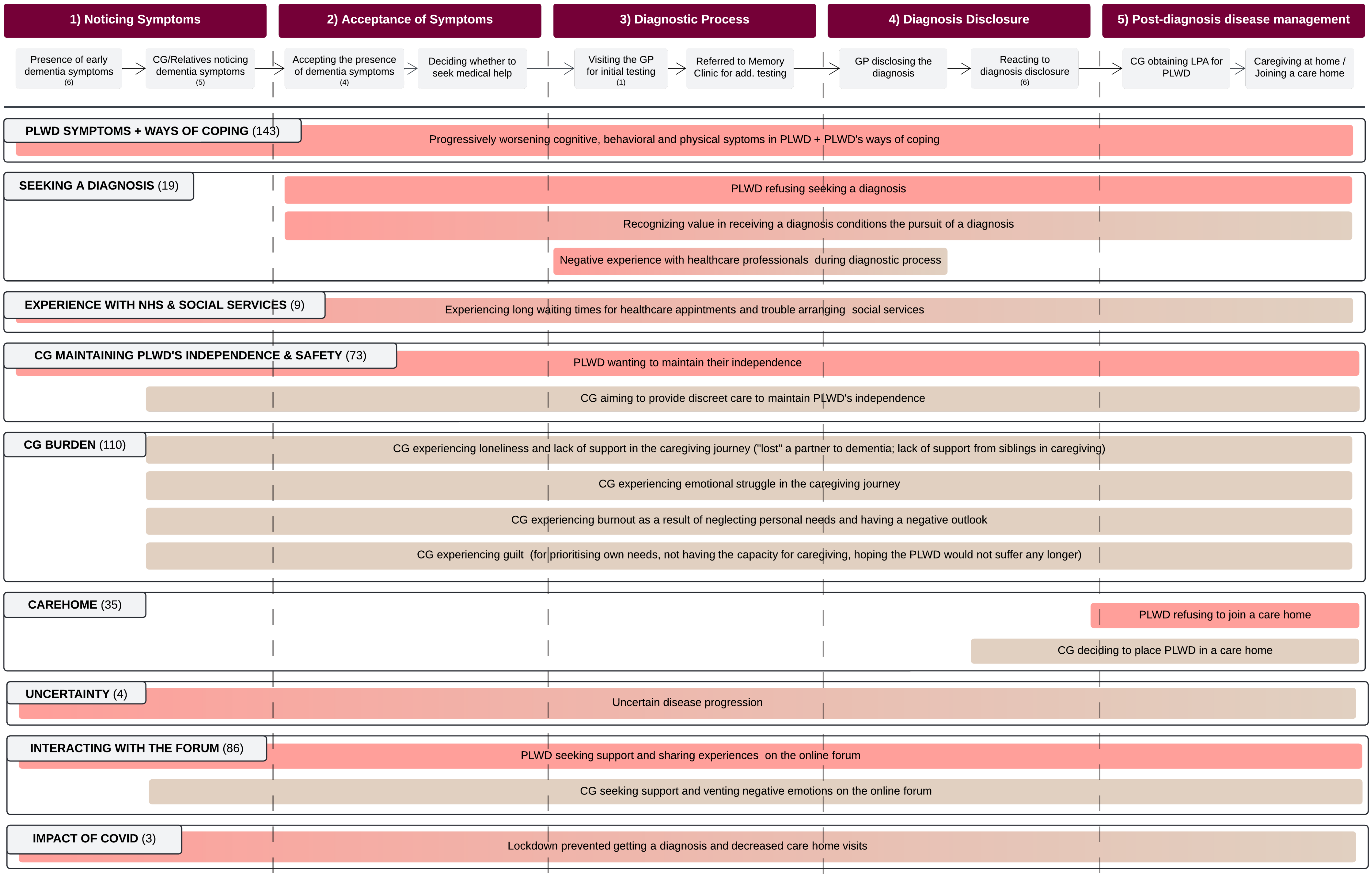
Theme 8: Interacting with the forum (86)

Both PLWDs and CGs turn to an online forum both during the process of diagnosis and subsequent life post-diagnosis. In several cases, the use of the forum is directly recommended by the memory clinic (memory clinic recommended using the forum - 1). For both PLWDs and CGs, the main intention is to seek support from people who share similar experiences (PLWD interacting with the forum - 3); (CG interacting with the forum - 73). Amongst PLWDs, however, there is also a desire to use the forum as a platform for sharing things, whether experiences, recording symptom progression or showing creative creations. CGs, on the other hand, mainly use the forum for advice on symptoms, legal and financial issues and ways of dealing with PLWD's changes in behaviour. In many cases, CGs also turn to the forum because they need to vent their frustrations related to care provision. An online forum is ideal for this purpose, as it enables CGs to anonymously share their frustrations with an understanding community, free from judgment (CG interacting with the forum - 73).

> “I am already feeling exhausted and don’t know how I will be able to do this. I hope I can find some good advice and support here. Thanks for listening.” (Post ID: 1652429)

Theme 9: Impact of Covid (3)
Lastly, caregivers report the significant impact of COVID-19 on both seeking a dementia diagnosis and living post-diagnosis. The pandemic worsened dementia symptoms due to lockdown isolation, hindered the ability to obtain a diagnosis and reduced the number of visits in care homes. (Covid worsened dementia symptoms – 1; Lockdown preventing getting a diagnosis – 1; no visits in care home due to COVID – 1) These challenges have added to the already substantial emotional burden of caregiving.

Thematic Analysis Journey Map



1) Noticing Symptoms

- Presence of early dementia symptoms (6) → CG/Relatives noticing dementia symptoms (5) →

2) Acceptance of Symptoms

- Accepting the presence of dementia symptoms (4) → Deciding whether to seek medical help →

3) Diagnostic Process

- Visiting the GP for initial testing (1) → Referred to Memory Clinic for add. testing →

4) Diagnosis Disclosure

- GP disclosing the diagnosis → Reacting to diagnosis disclosure (6) →

5) Post-diagnosis disease management

- CG obtaining LPA for PLWD → Caregiving at home / Joining a care home

PLWD SYMPTOMS + WAYS OF COPING (143)

- Progressively worsening cognitive, behavioral and physical syptoms in PLWD + PLWD's ways of coping

SEEKING A DIAGNOSIS (19)

- PLWD refusing seeking a diagnosis
- Recognizing value in receiving a diagnosis conditions the pursuit of a diagnosis
- Negative experience with healthcare professionals during diagnostic process

EXPERIENCE WITH NHS & SOCIAL SERVICES (9)

- Experiencing long waiting times for healthcare appintments and trouble arranging social services

CG MAINTAINING PLWD'S INDEPENDENCE & SAFETY (73)

- PLWD wanting to maintain their independence
- CG aiming to provide discreet care to maintain PLWD's independence

CG BURDEN (110)

- CG experiencing loneliness and lack of support in the caregiving journey ("lost" a partner to dementia; lack of support from siblings in caregiving)
- CG experiencing emotional struggle in the caregiving journey
- CG experiencing burnout as a result of neglecting personal needs and having a negative outlook
- CG experiencing guilt (for prioritising own needs, not having the capacity for caregiving, hoping the PLWD would not suffer any longer)

CAREHOME (35)

- PLWD refusing to join a care home
- CG deciding to place PLWD in a care home

UNCERTAINTY (4)

- Uncertain disease progression

INTERACTING WITH THE FORUM (86)

- PLWD seeking support and sharing experiences on the online forum
- CG seeking support and venting negative emotions on the online forum

IMPACT OF COVID (3)

- Lockdown prevented getting a diagnosis and decreased care home visits

Fig. 17 – Thematic analysis journey map

☐ Journey theme
▨ Temporal step
▨ CG experience
■ Journey phase
▨ PLWD experience
▨ PLWD/CG exp.

5.4 Thematic Analysis Summary

The initial step of the method focused on gathering detailed insights into PLWD and CG experiences by examining a smaller representative sample of online patient stories using thematic analysis. The thematic analysis followed an inductive approach, allowing themes to emerge organically from the data. Ultimately, it has revealed several journey phases, temporal steps, and themes capturing the nuances in the dementia diagnosis journey.

5.4.1 Forum Demographics

The findings from the thematic analysis align with and expand upon insights from the Background Understanding. However, in contrast to the Background Understanding, the thematic analysis captured themes solely relevant to PLWDs and CGs, as no posts from GPs were identified in the analyzed data sample. This absence suggests that GPs may not participate in these forums due to confidentiality concerns or preference for professional platforms. Additionally, the findings primarily reflect the perspectives of caregivers, who constitute the majority of forum users, with most being family members rather than professionals.

5.4.2 Journey Phases and Temporal Steps

In general, the identified themes primarily address the perspectives of CGs, reflecting their high prevalence on the forum. At the same time, the themes relate predominantly to the emotional aspects of the caregiving journey, corresponding with the tendency of CGs to use the forum as an outlet to share their feelings, doubts or negative emotions online. Consistent with this finding, the majority of posts relate to internal/interpersonal issues rather than external matters such as interacting with the NHS or social services or arranging legal and financial matters.

The journey phases and temporal steps identified in the thematic analysis corresponded with those revealed in the Background Understanding. These included:

Phase 1: Noticing Symptoms
- Early dementia symptoms in PLWD
- CG/Relatives noticing dementia symptoms in PLWD

Phase 2: Acceptance of Symptoms
- Denying vs. Accepting the presence of dementia symptoms (by PLWD/CG/Relatives)
- PLWD/CG deciding to seek medical help

Phase 3: Diagnostic process
- PLWD/CG Visiting the GP for initial testing
- PLWD referred to a Memory Clinic for additional testing

Phase 4: Diagnosis disclosure
- Diagnosis disclosure
- PLWD/CG Reaction to diagnosis
- (Not) Being prescribed medication

Phase 5: Post-diagnosis Disease Management
- Caregiving journey post diagnosis (at home / joining a care home)
- CG obtaining LPA for PLWD

5.4.3 Journey Themes

Most themes from thematic analysis match those previously identified in the Background Understanding. However, the thematic analysis explores them in more detail. Meanwhile, the Background Understanding includes additional GPs' perspectives and offers direct recommendations for systemic improvements. The themes identified in the thematic analysis include:

PLWD Symptoms and Ways of Coping (143)

Thematic analysis identified a range of cognitive, behavioral, and physical symptoms in PLWDs, making it the most frequent theme. Cognitive and behavioral symptoms include memory problems, disorientation, accusations, and emotional changes. Physical symptoms include changes in food consumption, sundowning, mobility issues, and eyesight problems. This variability complicates dementia recognition, aligning with the theme of Uncertainty from Campbell et al. (2016). Additionally, the difficulty in recognizing dementia symptoms is consistent with the Background Understanding – Education theme, showing that limited dementia knowledge among PLWDs and CGs leads to misattribution of symptoms to normal aging, as outlined by Bradford et al. (2009) and Wollney et al. (2022).

Seeking a Diagnosis (19)

Thematic analysis shows that PLWDs avoid seeking a diagnosis due to the fear of losing independence, leading them to downplay or deny symptoms during medical visits. This aligns with insights from Xanthopoulou & McCabe (2019), linking reluctance to seek a diagnosis to fear of stigmatization, a theme not explicitly found in the thematic analysis. A new insight is the importance of perceived value in a diagnosis, which influences whether CGs and PLWDs pursue a diagnosis when suspecting dementia. Additionally, the need to raise awareness about the benefits of diagnosis to increase early diagnosis rates is emphasized under the Education theme by Manthorpe et al. (2013).

Experience with NHS & Social Services (9)

CGs express dissatisfaction with the NHS and social services due to long waiting times, inconsistent communication, and difficulty arranging social support and benefits. This aligns with the accessibility issues identified in the Background Understanding. Studies by Prorok et al. (2013) and Sideman et al. (2022) highlight how dissatisfaction with healthcare services deters PLWDs and caregivers from seeking a diagnosis.

Maintaining Independence and Ensuring Safety (73)

Both the thematic analysis and the Background Understanding indicate that caregivers strive to balance maintaining PLWDs' independence with ensuring their safety. The Background Understanding highlights how caregiving responsibilities and the fear of losing independence can prevent seeking a diagnosis, as noted by Bradford et al. (2009) and Wollney et al. (2022). The thematic analysis provides additional insights into the nuances of this theme, including the decision-making process regarding moving in with the PLWD to ensure their safety, using security technologies, or hiring caregiving staff to preserve PLWD's independence.

Moreover, the thematic analysis highlighted a new insight, namely the resentment felt by PLWDs toward CGs, as PLWDs often blame CGs for taking away their independence.

CG Burden (110)

Another frequently occurring theme in the thematic analysis is caregiver burden. Present in both the thematic analysis and the Background Understanding, this theme captures the emotional and physical toll of caregiving, often leading to caregiver burnout as outlined by Bradford et al. (2009) and Wollney et al. (2022). The thematic analysis provides additional details, highlighting intense feelings of loneliness and emotional strain experienced by caregivers, contributing to burnout. Inadequate support is particularly reported by child CGs, often due to the lack of involvement from their siblings in caregiving responsibilities. Additionally, the thematic analysis revealed a new insight: the resentment CGs feel toward PLWDs due to significant behavioral changes in PLWDs and the constant demands of caregiving. Another new finding is the prioritization of caregiving over personal time, leading to the neglect of personal needs, ultimately resulting in CG burnout.

Care Homes (35)

Since the literature review primarily focused on articles related to the diagnostic process, the topic of care homes was not covered in the Background Understanding. The thematic analysis, therefore, introduced new insights on this issue. It addresses the emotional aspects of deciding on care home placement and coping with placing PLWDs in full-time care. The thematic analysis captures the challenges CGs face, including feelings of betrayal and guilt when deciding on care home placement. CGs also struggle with communicating the move to PLWDs, who often resist joining the facility. Additionally, CGs frequently debate the extent of their involvement in caregiving after the placement.

Uncertainty (4)

Although the theme of uncertainty does not frequently appear explicitly in forum discussions, it is implicitly present in a large number of posts. According to the thematic analysis, CGs experience a great deal of uncertainty both during the diagnostic process and in relation to the unpredictable progression of the disease. These findings correlate with Background Understanding, more specifically a study by Campbell et al. (2016), which emphasizes uncertainty as a theme that is present at all stages of the PLWD and CG journey.

Interacting with the Forum (9)

As identified in both the Background Understanding by Sideman et al. (2022) and thematic analysis, both PLWDs and CGs turn to online forums for support, advice, and sharing experiences. In addition, the thematic analysis provided direct observations of forum interactions, including the need for reassurance, seeking out people with similar experiences and frequently using the forum to vent negative emotions in a safe and judgment-free space.

Impact of COVID-19 (3)

As outlined by Sideman et al. (2022), the pandemic has significantly hindered access to diagnosis and professional care from medical and social services. The thematic analysis further elaborated on this theme, revealing that isolation has worsened dementia symptoms in PLWDs and increased both the burden and feeling of loneliness experienced by CGs.

5.4.4 Method Strengths and Limitations

The thematic analysis provided an in-depth overview of journey phases and detailed nuances in the experiences of PLWDs and CGs. By analyzing a smaller sample, it captured complexities of the diagnostic journey often overlooked in larger quantitative studies. The alignment of most themes with the Background Understanding demonstrates the method's depth and comprehensiveness, forming a foundation for interpreting subsequent topic modeling analysis.

The use of representative sampling ensured that the analysed data reflected the broader data set, thereby increasing the comprehensiveness and generalisability of the analysis findings. Moreover, an inductive coding approach allowed themes to emerge organically from the data, ensuring that the findings were grounded in the actual experiences of forum participants, free from preconceived theories. In addition, the researcher placed great emphasis on reflexivity to mitigate bias resulting from personal preconceptions about the topic.

Finally, visualizing the results using a journey map not only effectively summarized the findings, but also highlighted the interdependencies and sequencing of themes. This visual representation made complex information more accessible and easy to comprehend and aided in subsequent comparison with literature and integration with topic modeling.

One limitation of the method was the limited diversity of forum participants. While the goal was to map the journey of both PLWDs and CGs, the vast majority of users were CGs, resulting in second-hand insights about PLWDs. Additionally, self-selection bias meant that individuals who chose to participate in online forums might have different characteristics or experiences compared to those who do not, making it challenging to generalize the findings to a broader population.

Another limitation was the lack of context for interpretation. Variations in post length and level of detail sometimes left the researcher lacking context, affecting interpretation depth.

Furthermore, despite efforts to ensure reflexivity, the analysis remains subject to the researcher's biases and perspectives, influencing data interpretation. Additionally, the reliability of the coded data heavily depends on the researcher's diligence and consistency throughout the coding process.

The main limitation of the method, however, lied in its smaller sample size of 500 first-thread posts, which accounted for only 1% of all first-thread posts. (A total of 100 posts were coded, as saturation was achieved at this point; accounts for 0.22% of all first thread posts) While beneficial for capturing detailed insights, this significantly limited the generalizability of the findings. As a result the experiences of the selected participants might not fully represent the wider population of forum users. To address this limitation, the following step of the method employs topic modeling to validate and further extend on the findings gained from the thematic analysis.

In conclusion, thematic analysis provided an in-depth understanding of the diagnostic journeys of PLWDs and CGs, revealing important insights and nuances. Despite its limitations, this analysis served as a foundational step, informing subsequent research phases and contributing to a holistic understanding of the dementia diagnosis journey. ■

6

Step 2: Topic Modeling

This chapter details the second step of the research method, focusing on topic modeling (TM) to test the generalizability of thematic analysis (TA) findings on a larger dataset. Inspired by Jung et al.'s (2023) Online Community Journey Mapping method, TM was employed to analyze data from the UK Alzheimer's Society Dementia Support online forum. The goal was to extend the insights gained from TA (approx. 0.22% of the dataset) by examining the entire dataset of 45,927 first-thread posts. Using Latent Dirichlet Allocation (LDA), the chapter aims to uncover hidden semantic structures within the data, validating and potentially expanding the themes identified in TA. This step provides broader insights into the diagnostic experiences of PLWDs and their CGs, setting the stage for synthesis of TA and TM findings in the subsequent chapter.

Chapter Content Overview

6.1 Objective

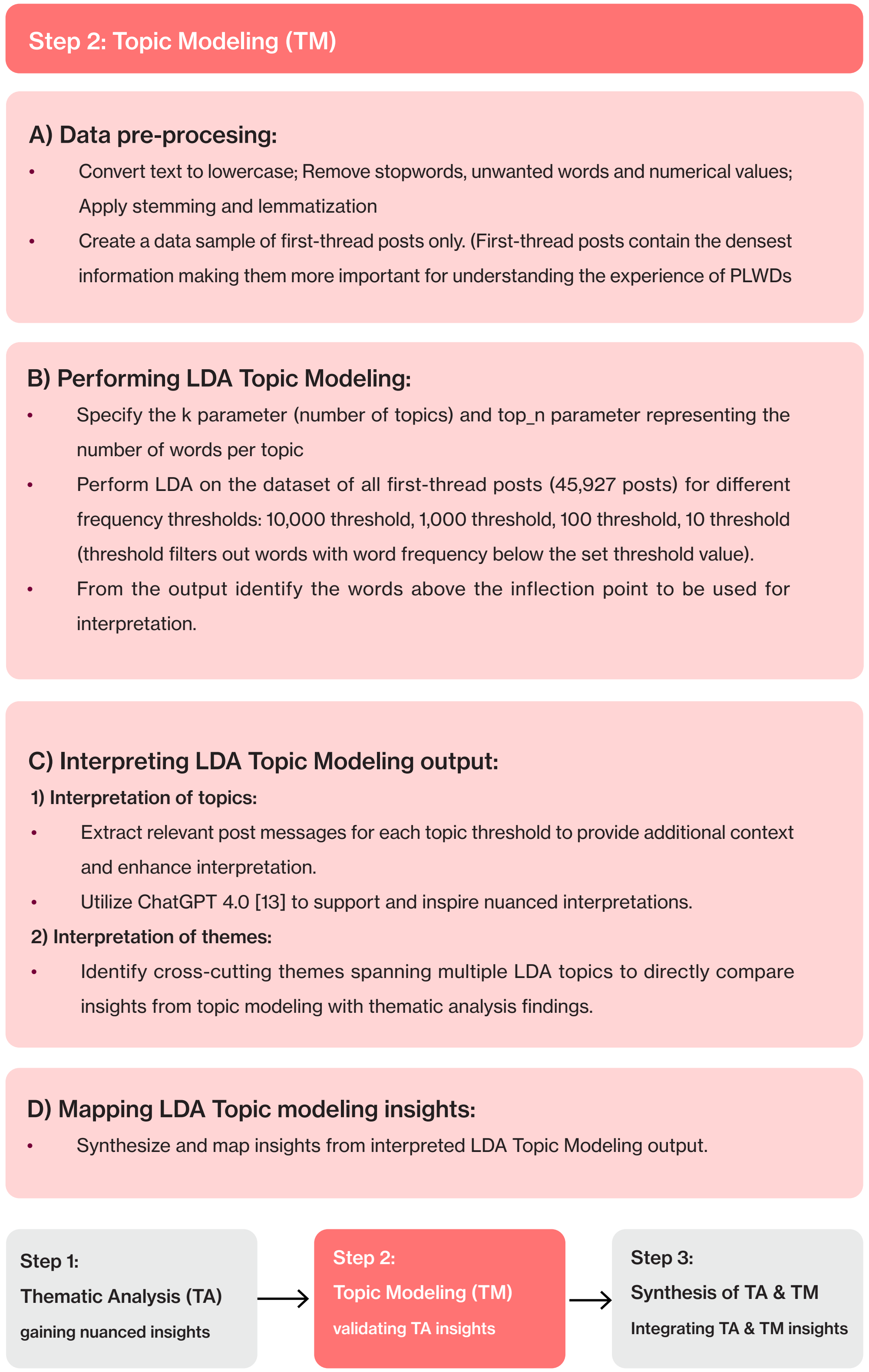
Inspired by Jung et al.'s (2023) method of Online Community Journey Mapping, topic modeling was employed in the second step to validate the generalizability of thematic analysis findings and capture insights from the larger dataset. While the thematic analysis provided valuable insights, despite reaching saturation, it covered only about 1% of all first-thread posts in the forum. Analyzing the entire dataset of 45,927 first-thread posts manually would be unmanageable. Therefore, topic modeling was used to efficiently analyze the larger dataset and determine how its results reinforce, contradict, or extend the thematic analysis findings.

Topic modeling, a widely used technique in natural language processing, serves this purpose by uncovering hidden semantic structures (topics) within gigantic datasets. (Jelodar et al., 2018), (Blei et al., 2003) In current research, this method finds its application for analyzing social media, facilitating an understanding of a vast number of human interactions within online communities. (Jelodar et al., 2018) The most popular method of topic modeling is Latent Dirichlet Allocation (LDA), first introduced by Blei, Ng, and Jordan in 2003. LDA is an unsupervised generative probabilistic model used for modeling a corpus (a collection of authentic texts or audio organized into datasets), where the corpus is treated using a bag-of-words approach. (Subex, 2023) The term "unsupervised learning" refers to a type of machine learning algorithm that automatically groups unlabeled text data into clusters and searches for patterns without the need for pre-labeled results or instructions from the researcher. (Google Cloud, 2024) The "bag-of-words" approach refers to a method in which the algorithm disregards word order and context and focuses solely on the frequency and co-occurrence of words in individual documents. This approach considers each document as a set of words producing a matrix of document terms. The matrix contains documents as rows and words as columns, with values indicating the frequency of each word. This matrix forms the basis for creating a vector space model where documents with similar word usage are placed closer together, indicating similar content. The topic models, however, go beyond the bag-of-words approach. While the bag-of-words method only counts word occurrences, topic models group frequently co-occurring words into topics. (IBM, 2024)

In practical terms, the output of LDA is several topics (k; a parameter set by researcher) represented using words with associated probabilities. Topics are arranged in descending order of significance and words within each topic are listed in descending order of their probability (beta values). Words with the highest probabilities in each topic typically provide a good indication of what the topic is about. Due to the unsupervised nature of LDA, researchers are required to interpret the words of the LDA output, necessitating the researcher to have sufficient knowledge about the context of the data to be able to draw meaningful insights. (Jung et al., 2023)

6.2 Process Overview

Fig. 18: Topic Modeling (TM) Process overview diagram



Step 2: Topic Modeling (TM)

A) Data pre-procesing:

- Convert text to lowercase; Remove stopwords, unwanted words and numerical values; Apply stemming and lemmatization
- Create a data sample of first-thread posts only. (First-thread posts contain the densest information making them more important for understanding the experience of PLWDs

B) Performing LDA Topic Modeling:

- Specify the k parameter (number of topics) and top_n parameter representing the number of words per topic
- Perform LDA on the dataset of all first-thread posts (45,927 posts) for different frequency thresholds: 10,000 threshold, 1,000 threshold, 100 threshold, 10 threshold (threshold filters out words with word frequency below the set threshold value).
- From the output identify the words above the inflection point to be used for interpretation.

C) Interpreting LDA Topic Modeling output:

1) Interpretation of topics:

- Extract relevant post messages for each topic threshold to provide additional context and enhance interpretation.
- Utilize ChatGPT 4.0 [13] to support and inspire nuanced interpretations.

2) Interpretation of themes:

- Identify cross-cutting themes spanning multiple LDA topics to directly compare insights from topic modeling with thematic analysis findings.

D) Mapping LDA Topic modeling insights:

- Synthesize and map insights from interpreted LDA Topic Modeling output.

Data analysis was performed in R and inspired by the tutorial on LDA (Topic Modeling) by Muhammad Usman (https://rpubs.com/asmi2990/988736). The complete code used for the data analysis, including A) Data-preprocessing and B) Performing LDA, can be found in Appendix 7.

[13] – https://chatgpt.com/, accessed on 2024, 7 July.

6.2.1 A) Data pre-processing

In the first step of the analysis, libraries were loaded to enable efficient data-pre-processing, data wrangling, LDA topic modeling and generating visualizations. (Full list of libraries accessible in Appendix 5).

Subsequently, individual sub-forums were retrieved and merged into one large dataset, referred to as forum_data_union, comprising a total of 558,419 posts. From forum_data_union a subset (subset_data) was extracted, containing only the first-thread posts, with a total of 45,927 posts.

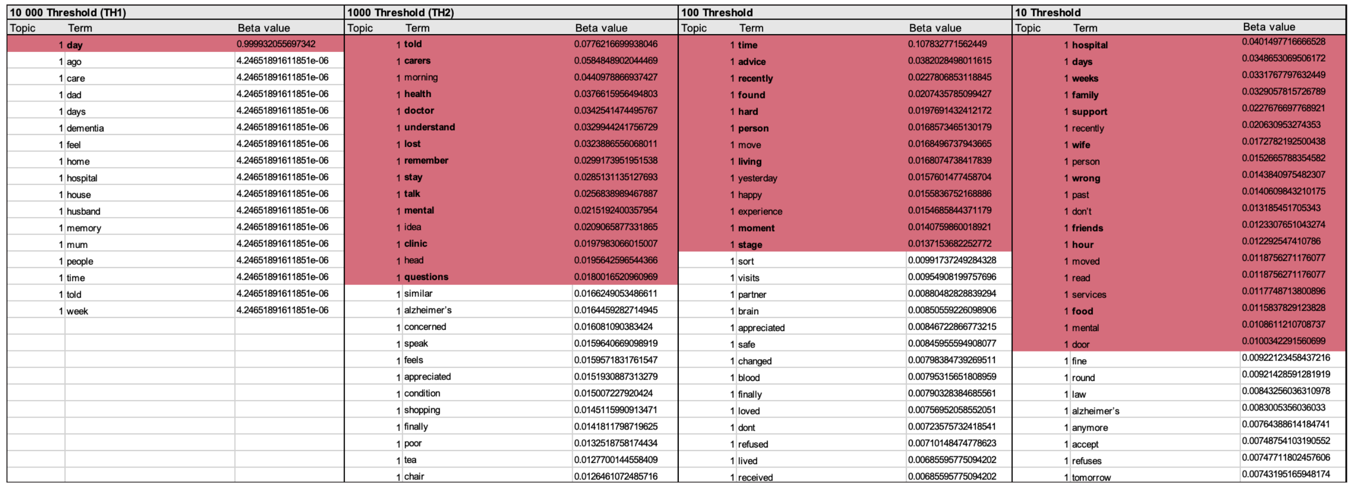
In the next step, subset_data needed to be pre-processed to ensure usability and interpretability of data, thereby laying the groundwork for accurate LDA topic modeling. Initially, the text was converted to lowercase to preserve text uniformity and avoid redundancy, given that the algorithm treats uppercase and lowercase variants in words as separate tokens. Next, stopwords, numerical values and `unwanted words` were removed to eliminate noise and ensure relevance of extracted topics. `Unwanted words`, characterized by high frequency but low contribution to topic meaning, were detected by the researcher in the initial LDA outputs. The algorithm was subsequently refined to exclude these words and ensure that all words in the topic modeling output contributed meaningfully to the final interpretation of the topic.

Finally, stemming and lemmatization were applied to reduce words to their root form and dictionary form, helping in minimizing word variations.

To check the effectiveness of these pre-processing steps, the most frequent words in the pre-processed dataset were displayed, ensuring the dataset was prepared for LDA topic modeling.

6.2.2 B) Performing LDA Topic Modeling

Before proceeding to the LDA analysis itself, a threshold for the minimum word frequency was set. This threshold was used to filter out words occurring below a certain frequency, thus producing LDA outputs at different levels of granularity. A higher threshold meant that the words in each topic were more frequent and therefore more generic. Conversely, a lower threshold allowed more unique words to be included, providing a more nuanced view of the extracted topics.



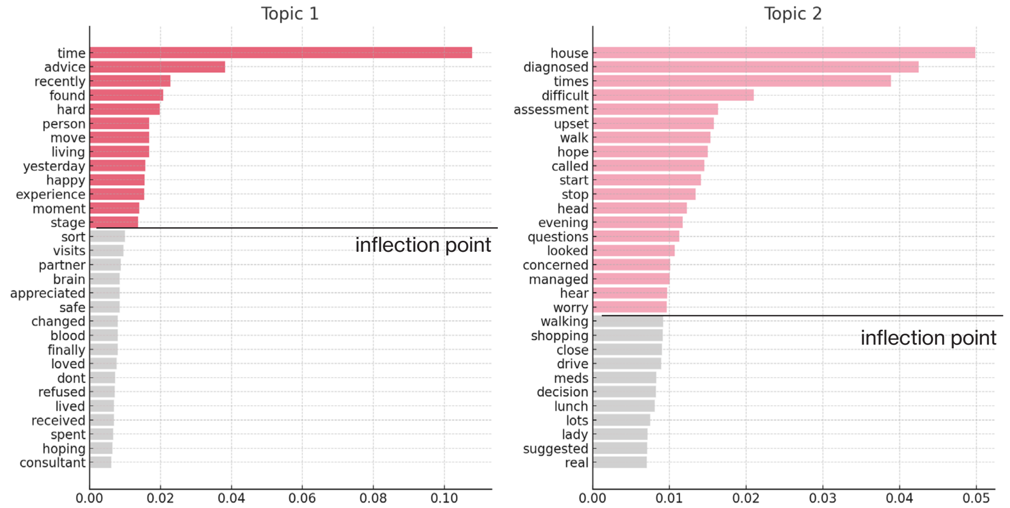
10 000 Threshold (TH1)			1000 Threshold (TH2)			100 Threshold			10 Threshold		
Topic	Term	Beta value	Topic	Term	Beta value	Topic	Term	Beta value	Topic	Term	Beta value
1	**day**	0.999932055697342	1	**told**	0.0776216699938046	1	**time**	0.107832771562449	1	**hospital**	0.0401497716666528
1	ago	4.2465189161l851e-06	1	**carers**	0.0584848902044469	1	**advice**	0.0382028498011615	1	**days**	0.0348653069506172
1	care	4.24651891611851e-06	1	morning	0.0440978866937427	1	**recently**	0.0227806853118845	1	**weeks**	0.0331767797632449
1	dad	4.24651891611851e-06	1	**health**	0.0376615956494803	1	**found**	0.0207435785099427	1	**family**	0.0329057815726789
1	days	4.24651891611851e-06	1	**doctor**	0.0342541474495767	1	**hard**	0.0197691432412172	1	**support**	0.0227676697768921
1	dementia	4.24651891611851e-06	1	**understand**	0.0329944241756729	1	**person**	0.0168573465130179	1	recently	0.020630953274353
1	feel	4.24651891611851e-06	1	**lost**	0.0323886556068011	1	move	0.0168496737943665	1	**wife**	0.0172782192500438
1	home	4.24651891611851e-06	1	**remember**	0.0299173951951538	1	**living**	0.0168074738417839	1	person	0.0152665788354582
1	hospital	4.24651891611851e-06	1	**stay**	0.0285131135127693	1	yesterday	0.0157601477458704	1	**wrong**	0.0143840975482307
1	house	4.24651891611851e-06	1	**talk**	0.0256838989467887	1	happy	0.0155836752168886	1	past	0.0140609843210175
1	husband	4.24651891611851e-06	1	**mental**	0.0215192400357954	1	experience	0.0154685844371179	1	don’t	0.013185451705343
1	memory	4.24651891611851e-06	1	idea	0.0209065877331865	1	**moment**	0.0140759860018921	1	**friends**	0.0123307651043274
1	mum	4.24651891611851e-06	1	**clinic**	0.0197983066015007	1	**stage**	0.0137153682252772	1	**hour**	0.012292547410786
1	people	4.24651891611851e-06	1	head	0.0195642596544366	1	sort	0.00991737249284328	1	moved	0.0118756271176077
1	time	4.24651891611851e-06	1	**questions**	0.0180016520960969	1	visits	0.00954908199757696	1	read	0.0118756271176077
1	told	4.24651891611851e-06	1	similar	0.0166249053486611	1	partner	0.00880482828839294	1	services	0.0117748713800896
1	week	4.24651891611851e-06	1	alzheimer's	0.0164459282714945	1	brain	0.00850559226098906	1	**food**	0.0115837829123828
			1	concerned	0.016081090383424	1	appreciated	0.00846722866773215	1	mental	0.0108611210708737
			1	speak	0.0159640669098919	1	safe	0.00845955594908077	1	door	0.0100342291560699
			1	feels	0.0159571831761547	1	changed	0.00798384739269511	1	fine	0.00922123458437216
			1	appreciated	0.0151930887313279	1	blood	0.00795315651808959	1	round	0.00921428591281919
			1	condition	0.015007227920424	1	finally	0.00790328384685561	1	law	0.00843256036310978
			1	shopping	0.0145115990913471	1	loved	0.00756952058552051	1	alzheimer’s	0.0083005356036033
			1	finally	0.0141811798719625	1	dont	0.00723575732418541	1	anymore	0.00764388614184741
			1	poor	0.0132518758174434	1	refused	0.00710148474778623	1	accept	0.00748754103190552
			1	tea	0.0127700144558409	1	lived	0.00685595775094202	1	refuses	0.00747711802457606
			1	chair	0.0126461072485716	1	received	0.00685595775094202	1	tomorrow	0.00743195165948174

Fig. 19: Comparison of outputs from multiple thresholds

After setting the threshold, LDA topic modeling was performed. In this step, the dataset was first converted into a matrix. Subsequently, the LDA algorithm was applied with the parameter k, representing the number of topics, set to 9. This value was chosen to align with the number of themes identified in the thematic analysis. Initially, during the iterative process of algorithm optimization, an alternative parameter of k = 17 was tested to match the total number of sub-themes from the thematic analysis. However, this higher parameter value resulted in suboptimal performance, with notable issues such as variability in the number of words per topic and a words not ordered by their probabilities, (k = 17 output available in Appendix 8). Consequently, k = 9 was chosen as the optimal parameter, as it produced coherent and stable topic distributions.

Additionally, the parameter top_n(30, beta), representing the number of words per topic, was set to 30. This number was chosen to be sufficiently large, with the actual number of words selected for interpretation for each topic determined up to an inflection point - the point at which the probabilities of words within a topic began to level off.

Fig. 20: inflection point



Finally, the extracted topics were visualized using ggplot2 graphs, with each topic distinguished by different colors for better differentiation. The LDA topic modeling was repeated with varying frequency thresholds: 10,000, 1,000, 100, and 10, to obtain inputs for topic interpretation at different levels of granularity.

6.2.3 C) Interpreting LDA Topic Modeling Outputs

The interpretation of each topic followed a systematic pipeline, progressing from higher to lower thresholds, corresponding to the granularity of the topic modeling outputs. Higher threshold outputs (containing more frequently used words) offered a general understanding of the topic, while lower thresholds revealed more detailed findings. This approach enabled a comprehensive interpretation of the data, starting with a broad overview to identify major themes and then narrowing down to uncover specific details and nuanced insights.

To effectively interpret the LDA analysis outputs, the results were imported into Excel sheets (available in Appendix 14), facilitating a side-by-side comparison of topics across different thresholds. For each topic output within each threshold, cut-off points were established to include words up to the inflection point. Additionally, these words were highlighted in colors corresponding to their topic numbers for easier identification (see Fig. 19).

Interpreting groups of words within topics without any context proved challenging as the researcher could only rely on their prior knowledge from thematic analysis. To ensure a more evidence-based interpretation, post messages from subset_ data that closely matched the word probabilities in each topic threshold were extracted. For each topic within each threshhold (10000; 1000; 100; 10), 10 matching post messages were extracted, making a total of 360 post messages that were analyzed for a more evidence-based interpretation of individual topics. This approach allowed the researcher to test hypotheses about word interpretation by locating specific words within relevant posts and understanding their contextual meanings.

The process of extracting post messages for each topic was performed in Python by an external data analyst. The process involved converting post messages into numerical vectors that reflect the importance of each word based on its probability of occurrence within a topic. By comparing these vectors using cosine similarity, the data analyst identified which posts were most relevant to each topic. This method ensures that posts closely matching the characteristics of a topic are extracted, providing meaningful insights into the data. The full script used for extraction is available in the Appendix 10.

In addition, the interpretation of topic modeling outputs was supported by the use of ChatGPT 4.0, which generated an interpretation of each topic based on the provided words and their probabilities within the topic. (The prompt used for Chat GPT 4.0 interpretation available in appendix 12). This procedure was repeated for all 9 topics. The individual outputs are recorded in the Excel model in the appendix. These outputs served as useful inspirational material, however, in the process of utilising this information, the researcher had to engage her knowledge from the thematic analysis and analysis of the extracted posts for each theme to assess which insights were relevant. Additionally, the captured nuance in the ChatGPT 4.0 interpretations was often insufficient. The researcher had to supplement this nuance based on her familiarity with the context derived from the thematic analysis and the extracted post messages.

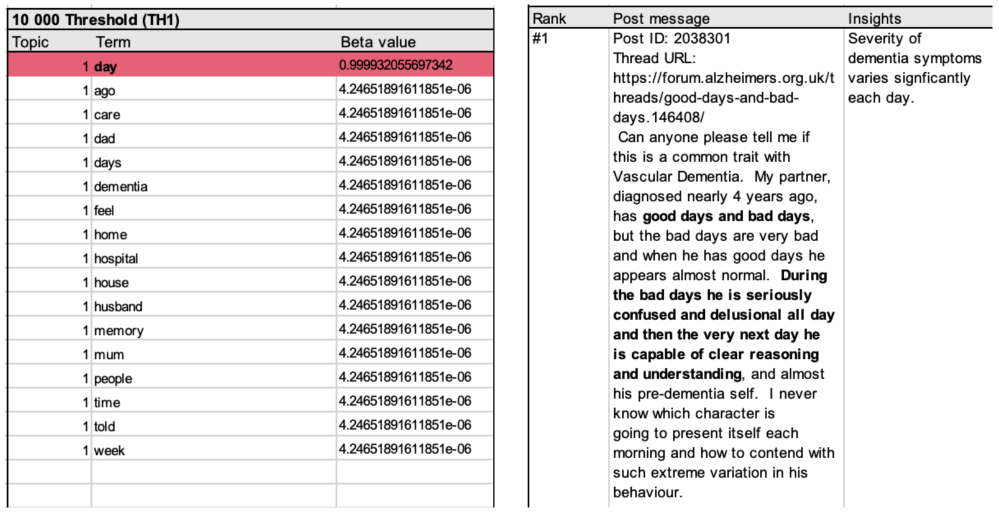
To summarize, the interpretation pipeline involved the following steps:

Fig. 21: Interpretation pipeline diagram

C.1) Analyzing Extracted Posts:

- For each topic at each threshold, the extracted post messages were analyzed by identifying the words from the LDA topic modeling output and interpreting them within the context of the posts.
- E.g., in T1_TH10,000, the word “day” was found in Post ID: 2038301: “My partner..., has good days and bad days, but the bad days are very bad and when he has good days he appears almost normal.” Interpreted as: “The severity of dementia symptoms varies significantly each day.” (See Appendix 14 for more details on the process.)

Fig. 22: Example of extracted post analysis



10 000 Threshold (TH1)		
Topic	Term	Beta value
1	**day**	0.999932055697342
1	ago	4.24651891611851e-06
1	care	4.24651891611851e-06
1	dad	4.24651891611851e-06
1	days	4.24651891611851e-06
1	dementia	4.24651891611851e-06
1	feel	4.24651891611851e-06
1	home	4.24651891611851e-06
1	hospital	4.24651891611851e-06
1	house	4.24651891611851e-06
1	husband	4.24651891611851e-06
1	memory	4.24651891611851e-06
1	mum	4.24651891611851e-06
1	people	4.24651891611851e-06
1	time	4.24651891611851e-06
1	told	4.24651891611851e-06
1	week	4.24651891611851e-06

Rank	Post message	Insights
#1	Post ID: 2038301 Thread URL: https://forum.alzheimers.org.uk/threads/good-days-and-bad-days.146408/ Can anyone please tell me if this is a common trait with Vascular Dementia. My partner, diagnosed nearly 4 years ago, has **good days and bad days**, but the bad days are very bad and when he has good days he appears almost normal. **During the bad days he is seriously confused and delusional all day and then the very next day he is capable of clear reasoning and understanding**, and almost his pre-dementia self. I never know which character is going to present itself each morning and how to contend with such extreme variation in his behaviour.	Severity of dementia symptoms varies signficantly each day.

C.2) Prioritizing Findings by Thresholds:

- Focus on word interpretations from higher thresholds to identify broad themes and use lower thresholds to uncover more detailed insights.

C.3) Enhancing interpretations with ChatGPT 4.0:

- Use ChatGPT 4.0 to generate interpretations for each topic based on word probabilities, then refine and supplement these interpretations with insights from thematic analysis and extracted posts. (Treating the output from ChatGPT 4.0 only as inspiration).

C.4) Synthesize Interpretations:

- Synthesizing interpretation insights from individual interpretation pipeline steps into a topic title and description of relevant primary and secondary sub-themes.

6.2.4 D) Mapping LDA Topic Modeling

In the final phase of the topic modeling step, the topics were mapped to synthesise the findings and provide a structured overview of online forum content. Additionally, they facilitated effective comparison with the results of the thematic analysis. The outputs of topic mapping are discussed in more detail in the Results section below.

6.3 Results

6.3.1 LDA Output

Based on the parameters specified by the researcher, LDA topic modeling step resulted in the generation of 9 individual topics, each containing 30 words across 4 minimum word frequency thresholds: 10,000, 1,000, 100, and 10. For interpretation, only words until the the inflection point (where probabilities of individual words leveled off) were used. Words below the inflection point are grayed out.

Threshold 10,000; 9k; 30 beta:

Fig. 23: LDA Output: Threshold 10,000; 9k; 30 beta

Threshold 1,000; 9k; 30 beta:

Fig. 24: LDA Output: Threshold 1,000; 9k; 30 beta

Threshold 100; 9k; 30 beta:

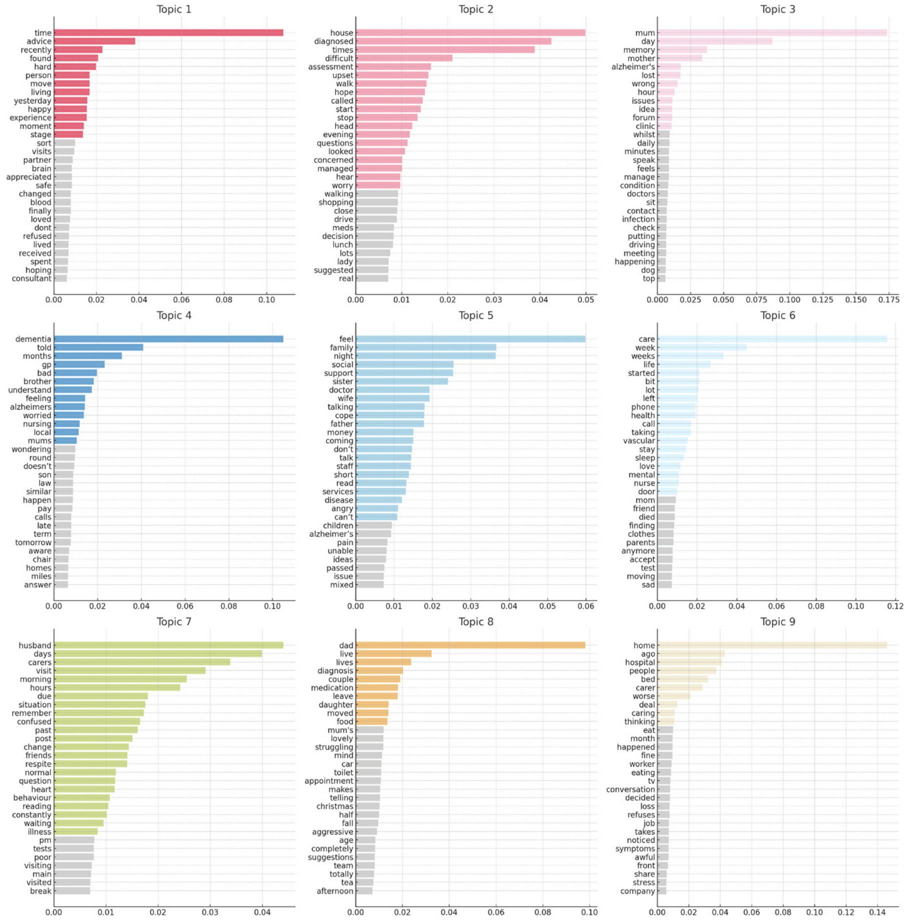


Fig. 25: LDA Output: Threshold 100; 9k; 30 beta

Threshold 10; 9k; 30 beta:

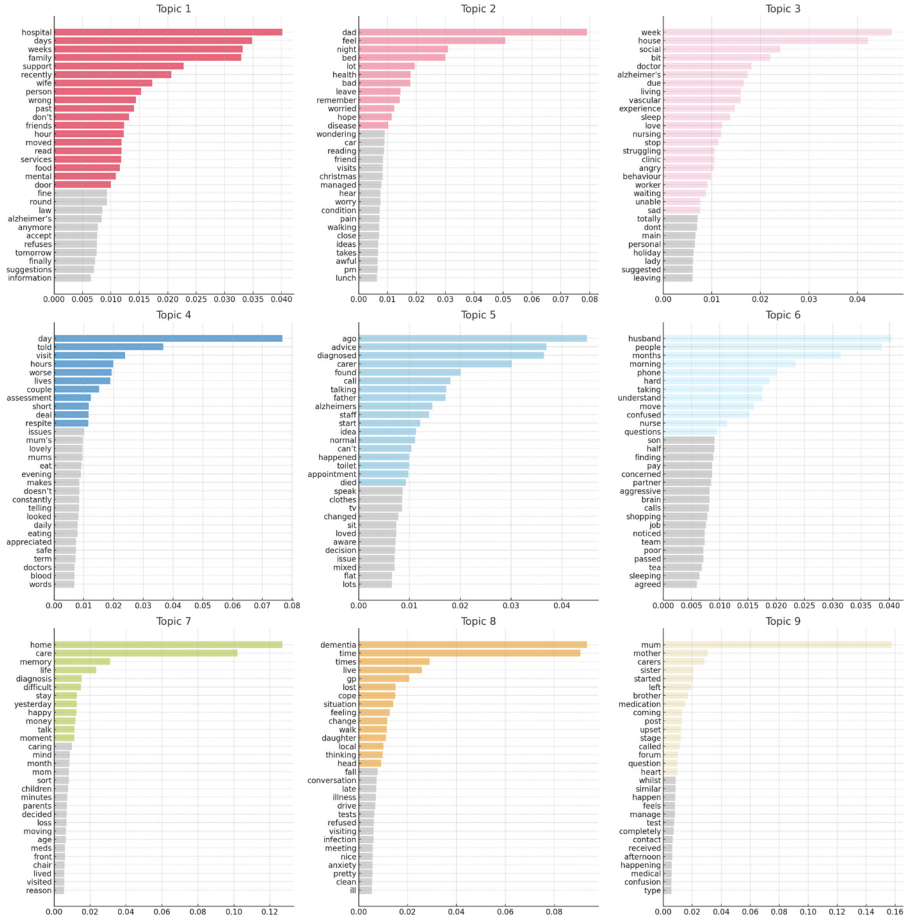


Fig. 26: LDA Output: Threshold 10; 9k; 30 beta

6.3.2 Interpretation of Topics

Topic modeling step resulted in identification of 9 individual topics:

- **Topic 1:** Daily Caregiving Routines
- **Topic 2:** Recently Diagnosed
- **Topic 3:** Emotional Aspect of Caregiving
- **Topic 4:** Dementia diagnosis, symptoms & coping
- **Topic 5:** Care home
- **Topic 6:** Spousal Caregiving (Taking Care of a Male PLWD)
- **Topic 7:** Hospital respite
- **Topic 8:** Caregiving Roles and Challenges
- **Topic 9:** Child Caregiving

Topics were then categorised into 4 main thematic areas, identified by the researcher, according to their prevalent themes: **Dementia diagnosis**; **CG roles**; **Caregiving** and **Coping strategies**. Within these categories, the topics are recorded on the matrix below (Fig. 27). The columns of the matrix indicates which thematic area the topic belongs to (based on main theme within each topic from researcher interpretation). The row orders denotes the probability of that topic occurring across the subset_data dataset (based on the LDA output).

Fig. 27: LDA topics grouped and ordered from most to least prevalent on the forum

Diagnosis	CG Roles	Caregiving	Coping strategies
		Topic 1: Daily Caregiving; Coping Strategies	
Topic 2: Recently Diagnosed; Symptoms; Coping			
		Topic 3: Emotional Aspect of Caregivig	
Topic 4: Diagnosis; Symptoms; Coping			
			Topic 5: CG Burden; Care Home
	Topic 6: Spousal Caregiving		
		Topic 7: CG burden; Hospital Respite	
		Topic 8: CG burden, Care at Home	
	Topic 9: Child Caregiving		

The following pages contain interpretations of each topic, including the main theme, secondary themes, and assigned words with their probabilities from various thresholds.

Topic 1: Daily Caregiving

Main theme: PLWD Symptoms / Daily caregiving

- **Symptom variability:** PLWDs experience significant day-to-day symptom variability highlighitng the unpredictable nature of dementia, and the inherent lack of routine that makes each day a new “endless” challenge. Symptoms may include memory problems, struggling to navigate familiar spaces, constantly asking the same questions, refusing to eat or moving things around the home.
- **Daily tracking of developments:** CGs monitor dementia symptoms on a daily basis to better understand patterns and manage care.

[day (TH1; 0.9999); lost (TH2; 0.0323); remember (TH2; 0.0299); talk (TH2; 0.0256); questions (TH2; 0.0180); time (TH3; 0.1078); living (TH3; 0.0168); stage (TH3; 0.0137); days (TH4; 0.0348); wrong (TH4; 0.0143); hour (TH4; 0.0122); food (TH4; 0.0115)]

> “My partner, diagnosed nearly 4 years ago, has good days and bad days, but the bad days are very bad and when he has good days he appears almost normal. During the bad days he is seriously confused and delusional all day and then the very next day he is capable of clear reasoning and understanding, and almost his pre-dementia self. I never know which character is going to present itself each morning and how to contend with such extreme variation in his behaviour.” (Post ID: 2038301; Symptom variability; Daily tracking of developments)

Secondary theme: Dementia diagnosis

- **Diagnosis disclosure:** Learning about the diagnosis from healthcare providers leads to initial shock and confusion for CGs, who may feel lost and unprepared, taking on the role of a carer without prior training.

[told (TH2; 0.0776); clinic (TH2; 0.0197); recently (TH3; 0.0227); found (TH3; 0.0207); moment (TH3; 0.0140); wife (TH4; 0.0172)]

Secondary theme: CG role

- **Relatives as CGs:** In most cases, caregiving is undertaken by relatives of PLWDs. Many CGs have full-time jobs, which prevents them from fully committing to caregiving and therefore leads them to use help of professional CGs. (T1; 100TH; #1)

[carers (TH2; 0.0584); stay (TH2; 0.0285); hard (TH3; 0.0197); person (TH3; 0.0168)]

Secondary theme: Support from family & friends

- **Lack of support from family and friends:** CGs often lack support from friends and family, making them feel invisible once diagnosed with dementia. (T1; 10TH; #3).

[family (TH4; 0.0329); support (TH4; 0.0227); friends (TH4; 0.0123)]

> “Since my wife developed dementia most of our family and friends avoid visiting or phoning so there is little support from there, some close members of family now might visit once or twice a year, to a certain extent we have become invisable people, not only to family, friends, neighbours, social services and the health services, this is our reality.” (Post ID: 1988862; Lack of support from family & friends)

Secondary theme: Support from healthcare providers & social services

- **Seeking advice:** CGs interact with healthcare professionals to learn more about managing dementia and obtaining social support.
- **Lack of support from social services:** Many CGs lack access to support from social services.

[mental (TH2; 0.0215); understand (TH2; 0.0329); health (TH2; 0.0376); doctor (TH2; 0.0342); advice (TH3; 0.0382); hospital (TH4; 0.0401); weeks (TH4;

Topic 2: Recently Diagnosed

Main theme: Dementia diagnosis

- **Time of diagnosis:** CG’s often join the forum shortly after being disclosed the diagnosis. Regardless of when the diagnosis was made, they frequently emphasize this moment in their posts, viewing it as a pivotal moment in their caregiving journey.

[ago (TH1; 0.5177); told (TH1; 0.4821); diagnosed (TH3; 0.0424); assessment (TH3; 0.0163)]

> “My wife has just been told she has Alzheimer’s and vascular dementia I am at a loss at the moment as what to do next” (Post ID: 2050979; Time of diagnosis)

- **Retrospective realization:** Based on receiving a diagnosis, carers often confide that they should have arranged social services or installed care equipment earlier, highlighting the common problem of a lack of proactive care planning.

Secondary theme: Dementia diagnosis

- **Diagnosis disclosure:** Learning about the diagnosis from healthcare providers leads to initial shock and confusion for CGs, who may feel lost and unprepared, taking on the role of a carer without prior training.

Secondary theme: CG role

- **Spousal caregiving:** Majority of posts by caregivers are wives taking care of their husbands who are PLWDs, with some cases of husbands taking care of their wives.

[husband (TH2; 0.0802)]

Secondary theme: Caregiving – PLWD Symptoms / Daily caregiving

- **Impact of caregiving on daily life:** Caregiving often takes over the lives of CGs, who face numerous challenges related to PLWD’s symptoms. These include PLWD struggling to navigate their own home, mistaking CGs for strangers, experiencing sleep issues and nighttime wandering, as well as interpersonal conflicts with CG over household matters.
- **Health and safety concerns:** CGs are constantly worried about PLWD’s health and safety, with many showing interest in security technologies to monitor and protect PLWD.

[bad (TH2; 0.0393); medication (TH2; 0.0321); living (TH2; 0.0317); wrong (TH2; 0.0300); money (TH2; 0.0281); worry (TH2; 0.0161); safe (TH2; 0.0159); house (TH3; 0.0498); times (TH3; 0.0388); difficult (TH3; 0.0209); upset (TH3; 0.0158); walk (TH3; 0.0153); hope (TH3; 0.0150); evening (TH3; 0.0117); questions (TH3; 0.0113); night (TH4; 0.0309); bed (TH4; 0.0299); health (TH4; 0.0179); bad (TH4; 0.0178); leave (TH4; 0.0144); remember (TH4; 0.0142)]

> “He has sneaked out of the house a couple of times and I worry the day will come when he won’t know his way back, he can’t remember our address…Are there any sorts of sensors that people have tried that would alert me if he leaves the house.” (Post ID: 2018520; Health and safety concerns)

- **Uncertainty about the future:** CGs express fear and uncertainty about how to cope as the disease progresses leading to an increase in caregiving demands.

Secondary theme: Support from family & friends

- **Children’s concerns:** Adult children, though not primary CGs, are deeply worried about their parent’s condition. Primary CGs being spouses of PLWD also care about their children’s perceptions and feelings towards their parent PLWD.
- **Lack of support from social services:** Many CGs lack access to support from social services.

[daughter (TH2; 0.0250); friend (TH2; 0.0183); parents (TH2; 0.0162); concerned (TH3; 0.0100); worry (TH3; 0.0096); dad (TH4; 0.0790)]

Secondary theme: Support from healthcare providers & social services:

- **CG seeking advice from GPs:** CG frequently calls the GP for advice on symptom management

[phone (TH2; 0.0400); called (TH3; 0.0145)]

Secondary theme: Support in online forums

- **CG seeking advice on online forums:** Many CGs turn to online forums for support and advice, actively seeking and applying advice from peer support networks.

[advice (TH2; 0.0721)]

Secondary theme: Hospitalization / Care home

- **CG seeking respite:** CGs frequently seek temporary relief through respite care. Additionally CGs
- **CG Considering moving PLWD to a care home:** Some CGs consider moving PLWD to full-time care homes due to the overwhelming nature of caregiving. After placement, CGs maintain contact with care homes primarily through phone calls

[week (TH2; 0.0933); found (TH2; 0.0392); move (TH2; 0.0318); respite (TH2; 0.0256); feel (TH4; 0.0507)]

Topic 3: Emotional Aspect of Caregiving

Main theme: CG burden & need for respite

- **CG’s emotional experience:** As a result of changes in PLWD’s behaviour, CGs experience complex emotions and changes in their feelings towards PLWD. They often feel a sense of distance, as if they have lost a partner. The intensity of these emotions grows as CGs suppress them, feeling guilty when expressing negative emotions related to caregiving.

[feel (TH1; 0.2474); hope (TH2; 0.0218); caring (TH2; 0.0197); behaviour (TH2; 0.0169); day (TH3; 0.0869); memory (TH3; 0.0374); lost (TH3; 0.0173); wrong (TH3; 0.0152); issues (TH3; 0.0112); house (TH4; 0.0421); love (TH4; 0.0121); struggling (TH4; 0.0105); angry (TH4; 0.0103); behaviour (TH4; 0.0098)]

> “My husbands personality is slowly changing. My feelings towards him are changing. It’s changing our marriage. I feel guilty. My husband doesn’t recognise these changes I don’t think. How does a marriage survive Alzheimer’s? How do I even know what is Alzheimer’s and what is my husband lacking empathy? Being difficult? Being selfish? I’m trying so hard to support him on this journey but I’m a human too and my marriage no longer gives me what I need - I hate saying that out loud but I don’t feel the connection I once did, I feel so confused. If I feel like this in the beginning, how am I going to feel further down the rd? I ask my husband if he’s ok, if I’m supporting him enough etc, his reply is “I feel the closest I’ve ever felt to you”. Why do I not feel the same? I love him but we’ve changed and we can’t discuss it because he doesn’t see anything’s different“ (Post ID: 2021649; CG’s emotional experience)

Secondary theme: Dementia diagnosis

- **Emotional reaction to diagnosis disclosure:** The moment of dementia diagnosis disclosure has a significant emotional impact on both PLWD and CG. The moment also formalises the role of the CG.

[feel (TH2; 0.0973); diagnosed (TH2; 0.0618); carer (TH2; 0.0511); vascular (TH2; 0.0274); alzheimer’s (TH3; 0.0175); clinic (TH3; 0.0106)]

> “My partner was referred to a Mental Health Clinic, Who diagnosed Alzheimer’s, now they want to discharge to GP. Feel like we are being abandoned, I have no training as a carer. Or able to cope with 24-7 its driving my mental health and general health down, i feel like i am on a ever increasing downwards spiral.“ (Post ID: 1998093; Emotional reaction to diagnosis disclosure)

Secondary theme: CG role

- **Role of a mother:** The mother either as PLWD or often in the role of a CG caring for her spouse who is living with dementia.

[mum (TH1; 0.7524); mum (TH3; 0.1735); mother (TH3; 0.0338)]

Secondary: Support from family & friends

- **CG lacking support from family and friends:** CGs frequently feel unsupported by family, friends, and even the PLWD, whom they they have “lost” to dementia. They miss their pre-caregiving social life and connections.
- **Child’s concern for their mother:** Children worry about their mother who is a CG, often posting on forums on their behalf to seek advice and find support.

[support (TH2; 0.0412); friends (TH2; 0.0223)]

Secondary theme: Support from healthcare providers & social services

- **Social services:** CGs are interested in Adult Social Care for PLWD, highlighting the need for external support to manage caregiving responsibilities. Additionally, they seek comprehensive support, including individual social workers for both the PLWD and themselves.

[support (TH2; 0.0412); friends (TH2; 0.0223)]

Secondary theme: Support in online forums

- **CG seeking advice on online forums:** CGs interact with online communities to find out if others feel the same way, reflecting the need for shared experiences, reassurance and understanding among peers.

[forum (TH2; 0.0188); idea (TH3; 0.0112); forum (TH3; 0.0110)]

Topic 4: Dementia diagnosis, symptoms & coping

Main theme: Dementia diagnosis

- **Cnticipation and fear:** CGs and PLWDs face anxiety and uncertainty when awaiting a formal diagnosis, especially if they have a family history of the disease
- **PLWD hiding symptoms:** PLWD may try to hide their symptoms during doctor’s visits, complicating the diagnostic process.
- **Recent diagnosis:** Diagnosis marks a significant moment in PLWD and CG’s dementia journey.

[dementia (TH1; 0.9999); moment (TH2; 0.0221); told (TH3; 0.0409); gp (TH3; 0.0232); feeling (TH3; 0.0143); alzheimers (TH3; 0.0141); assessment (TH4; 0.0123); deal (TH4; 0.0115)]

Secondary theme: PLWD Symptoms / Daily caregiving

- **Good and bad days:** Dementia symptoms signficantly vary from day to day, causing caregiving not to be of a routine nature.
- **Nighttime symptoms:** Sleep disturbances and incontinence are common nighttime issues among PLWDs.
- **Communication difficulties:** CG struggles to communicate with PLWD.

[day (TH2; 0.1418); night (TH2; 0.0568); difficult (TH2; 0.0292); food (TH2; 0.0200); bad (TH3; 0.0197); understand (TH3; 0.0173); worried (TH3; 0.0136); day (TH3; 0.0767); worse (TH4; 0.0193)]

Secondary theme: Hospitalization / Care home

- **CG deciding on care home placement:** Transitioning PLWD to a care home is emotionally challenging for caregivers, who may struggle with feelings of guilt and anxiety. There is a preference for care homes in CG’s proximity when choosing a care facility.

[visit (TH2; 0.0440); hard (TH2; 0.0310); staff (TH2; 0.0224); nursing (TH3; 0.0118); local (TH3; 0.0113); told (TH4; 0.0367); visit (TH4; 0.0238); respite (TH4; 0.0115)]

- **Appreciation for care home staff:** CGs express gratitude and recognition for the care provided by care home staff.

[dementia (TH3; 0.1049)]

Secondary theme: other

- **Personification of dementia:** CGs may personify dementia to distinguish the disease from the person, helping them manage difficult behaviors, e.g.: "It's hard to separate it and say it's not him, it's the dementia that's being thoughtless and unreasonable."

> " I get cross with the dementia. It's s hard to separate it and say its not him it's the dementia that's being thoughtless and unreasonable... And it never says sorry. When dementia kicks in he doesn't care and it hurts. People keep saying dont take it personally but thats easy when its not you thats being told you did stuff, said things that you didn't say. I wish I could open his head and pull the dementia out and have my lovely, kind man back." (Post ID: 1977933; Personification of dementia)

Topic 5: Care Home

Main theme: Hospitalization/ Care home

- **CG deciding to place PLWD in a care home:** CGs struggle with the decision to place PLWD in a care home due to varying symptom severity. ("First he has good days where he will have a walk in the garden. During these times I feel awful even thinking of a nursing home. Other times when I'm struggling to wash and dress him I feel a nursing home is right for both of us.") Finding a care home in close proximity is important for CGs to allow for frequent visits. Some CGs start choosing a care home in advance to plan ahead for future needs.
- **PLWD's desire to return home:** PLWD often express a strong desire to return home and may blame CGs for their placement. Extreme distress can lead to threats of suicide from the PLWD.

[care (TH1; 0.4554); time (TH1; 0.3860); house (TH1; 0.1584); home (TH2; 0.2236); ago (TH2; 0.0655); thinking (TH2; 0.0164); struggling (TH2; 0.0156); feel (TH3; 0.0598); staff (TH3; 0.0144); ago (TH4; 0.0449); toilet (TH4; 0.0098)]

> "He is very defensive. He also thinks its me that doesn't want him home and I am keeping him in the home against his will." (Post ID: 1996376; PLWD's desire to return home)

- **CG doubting the care home decision:** CGs often seek reassurance that placing PLWD in a care home was the right choice. Many CGs are upset about "betraying" the PLWD or dissatisfied with care home services leading them to feel conflicted about whether to keep PLWD there or bring them back home.
- **Care home returning the PLWD home:** Some care homes may find PLWD too difficult to manage, leading to pressure on CGs to take them back home.

Secondary theme: CG burden & need for respite

- **CG's exhaustion & inability to provide full-time care:** CGs often reach a point where they can no longer provide required care due to work commitments, exhaustion, or emotional strain, leading them to consider full-time care homes.
- **CG's resentment towards PLWD:** Behavioral changes in PLWD can cause CGs to feel resentment towards them. CGs often feel guilty about these emotions, leading them to share these feelings anonymously in online forums to avoid judgment and burdening family members.

[memory (TH2; 0.0549); days (TH2; 0.0543); alzheimer's (TH2; 0.0257); sleep (TH2; 0.0205); change (TH2; 0.0196); deal (TH2; 0.0192); night (TH3; 0.0365); wife (TH3; 0.0192); cope (TH3; 0.0178); angry (TH3; 0.0109)]

Secondary theme: Support from family & friends

- **Loss of a partner: CGs feel lonely due to "losing" their partner to dementia.**

[family (TH3; 0.0366); sister (TH3; 0.0240); talking (TH3; 0.0179)]

Secondary theme: Support from healthcare providers & social services

- **Lack of support from healthcare providers and social services:** CGs often feel abandoned by healthcare providers and social services.

[social (TH2; 0.03568); services (TH2; 0.0183); social (TH3; 0.0254); support (TH3; 0.0253); doctor (TH3; 0.0192); staff (TH4; 0.0138);

> "Our GP. Is aware of my wife's dementia but I cannot say they support us in any way regarding her dementia, unfortunately since Covid seeing GP's has become extremely difficult and trying to get appointments is a nightmare. Following her initial diagnosis from the memory clinic we have had no other contact from them, that seems to be most people's experience." (Post ID: 1988862; Lack of support from healthcare providers and social services)

Secondary theme: Support in online forums

- **Seeking support in online forums:** CGs often turn to online forums for advice and support, seeking shared experiences and practical guidance. In addition, they use the forum to anonymously vent their negative emotions related to caregiving.

[advice (TH4; 0.0369)]

Topic 6: Spousal Caregiving

Main theme: CG role

- **Wives as CGs: Wives frequently take on the role of caring for their husbands with dementia.**

[husband (TH1; 0.5245); wife (TH2; 0.0302)]

Secondary theme: CG burden & need for respite

- **Impact of caregiving on marriage:** CG may feel distant from PLWD due to behavioural change in PLWD, leading to feelings of isolation and sadness for the CG.
- **Caregiving for a male PLWD:** Caregiving for a male PLWD is highly demanding, as male PLWDs may often become aggressive, physically abusive, and physically more difficult for women to manage.

[days (TH1; 0.4753); started (TH2; 0.0368); diagnosis (TH2; 0.0302); talking (TH2; 0.0292); confused (TH2; 0.0252); happy (TH2; 0.0246); feeling (TH2; 0.0239); upset (TH2; 0.0222); life (TH3; 0.0267); sleep (TH3; 0.0132); love (TH3;

> "it's so hard to watch my husband who was such an independent, kind, caring husband and father become such a angry, insensitive, unhappy person. Any advice?" (Post ID: 2050456; Caregiving for a male PLWD)

Secondary theme: Hospitalization / Care home

- **Considering hospitalization or care home:** As a result of caregiving being too challenging, women often consider hospitalizing PLWD for respite or placing them full time in care homes. by care home staff.

[hospital (TH2; 0.0701); weeks (TH2; 0.0579); sister (TH2; 0.0377); care; (TH3; 0.1157); week (TH3; 0.0449); weeks (TH3; 0.0333); phone (TH3; 0.0192); call (TH3; 0.0169); nurse (TH3; 0.0107)]

> "Hi, my husband was taken into hospital where he stayed for four weeks then came home for another four weeks when I found I just couldn't cope anymore. We had two carers coming in four times a day and I still couldn't cope." (Post ID: 1995606; Considering hospitalization or care home)

Secondary theme: Dementia perception & stigma

- **Dementia perception & stigma: CGs may be concerned about how others perceive PLWD's health condition, reflecting the social stigma associated with dementia**

[husband (TH4; 0.0404); people (TH4; 0.0386); understand (TH4; 0.0174)]

Topic 7: Hospital respite

Main theme: Hospitalization/ Care home

- **CGs seeking respite:** PLWDs are often placed in hospitals for several weeks on respite, allowing CGs to take a necessary break from caregiving.
- **Transitions to long-term care:** Many caregivers hope this will lead to a transition directly to care homes as they cannot cope with providing care any longer
- **PLWD's desire to return home:** PLWDs are often placed in hospital respites or care homes by their CGs. However, PLWDs may refuse care and express dissatisfaction with the care home environment, leading CGs to face tough decisions about whether to bring PLWD back home.

[week (TH1; 0.5269); hospital (TH1; 0.4729); visit (TH3; 0.0290); confued (TH3; 0.0165); home (TH4; 0.1269); care (TH4; 0.1019); difficult (TH4; 0.01493)]

> "...what I need is for my husband to have some respite time in a care home, with a view to a permanent placement later in the year" (Post ID: 2021909; CG seeking respite; Transitions to long-term care)

Secondary theme: CG role

- **Children as CGs:** Children often step in as primary CGs for their parents, particularly their mothers living with dementia. This may be due to a tendency for male partners to be less likely to assume the CG role.
- **Spouses as CGs:** Primarily wives take on the role of CGs for their husbands.

[mum (TH2; 0.2498); husband (TH3; 0.0440); carers (TH3; 0.0337)]

Secondary theme: CG burden & need for respite

- **Impact on marriage and need for respite:** Wives often feel confused about their feelings toward PLWD due to the behavioral changes in their spouses. CGs frequently voice the need for respite from their husbands to get a break from the intense caregiving duties.

[time (TH2; 0.1493); cope (TH2; 0.0245); days (TH3; 0.0398); change (TH3; 0.0143); respite (TH3; 0.0140); behaviour (TH3; 0.0107)]

Secondary theme: Support from family & friends

- **Children's concern:** Even when not the primary CGs, children actively seek advice on forums to support their caregiving mothers.

[mum (TH2; 0.2498)]

Topic 8: CG roles and challenges

Main theme: CG role

[mother (TH2; 0.0481); dad (TH3; 0.0981)]

- **Females as primary CGs: The primary CGs are often the wives of male PLWDs. Daughters often step in as primary CGs of their parents, especially in cases of female PLWDs when the male partner is unable to fulfill this role.**

- **Spouses as CGs:** Primarily wives take on the role of CGs for their husbands.

[family (TH3; 0.0366); sister (TH3; 0.0240); talking (TH3; 0.0179)]

Secondary theme: PLWD Symptoms / Daily caregiving

- **Not recognizing relatives and delusions:** PLWDs may mistake family members for their parents or believe deceased parents are alive.
- **Bedridden, agressive and refusing care:** PLWDs may be bedridden, or refuse care, especially personal care, increasing the strain on CGs
- **Accusations:** PLWDs may accuse family members of stealing.

> "He is bedridden in a care home . He is aggressive to me and our family, wants me dead . And the family including our baby grandson in prison for stealing his money. He refuses care most days and has terrible symptoms stage 4 ulcers which gives him MRSA so hospital treatment is then necessary. He hates his care home and is very rude to his carers . He has started a court case stating he has the right to go home to die." (Post ID: 2029125; Bedridden, agressive and refusing care, accusations)

Secondary theme: CG burden & need for respite

- **CGs overwhelmed by caregiving:** Despite trying to be patient, CGs often feel overwhelmed and unable to cope with the continuous demands of caregiving.
- **Financial strain:** CGs may stop working to provide full-time care for PLWD, which can be financially unsustainable.

[lost (TH4; 0.01518); cope (TH4; 0.0149); feeling (TH4; 0.0127)]

Secondary theme: Support from family & friends

- **Children support:** children show significant concern and seek advice, even if not primary CGs.
- Involvement in decision making: Family members, including children, are actively involved in decisions regarding care home placement.

[family (TH2; 0.0498); daughter (TH4; 0.0111)]

Secondary theme: Hospitalization/ Care home

- **Placement in a nursing home:** CGs choose to place PLWDs in nursing homes due unbearable demands of caregiving. CGs often feel guilt for not being able to continue caregiving at home, especially as they witness PLWDs dissatisfaction with carehomes and their strong desire to return home. This leads CGs to struggle with the decision of whether to keep PLWD in the nursing home or bring them back home.

[home (TH1; 0.8028); care (TH2; 0.1744); moved (TH3; 0.0139)]

Secondary theme: Other coping strategies

- **Personifying Dementia:** CGs may personify dementia to separate the disease from their loved one, helping them to process emotions.

[dementia (TH4; 0.0934)]

Topic 9: Child Caregiving

Main theme: CG role

- **Children as CGs:** Children often step in as primary CGs for their parents, particularly their mothers living with dementia. This may be due to a tendency for male partners to be less

[dad (TH1; 0.6943); father (TH2; 0.0289); mum (TH4; 0.1575); mother (TH4; 0.0306)] likely to assume the CG role. Even when not the primary CGs, children actively seek advice on forums to support their caregiving mothers.

- **Spouses as CGs:** Primarily wives take on the role of CGs for their husbands. the male partner is unable to fulfill this role.

> “Hi all, I’m posting on behalf of my mother who isn’t on the forum, Dad, 76, FTD, late stages now due to infections last year.” (Post ID: 2041880; Children as CGs; Spouses as CGs)

Secondary theme: PLWD Symptoms / Daily caregiving

- **Falls and safety:** Need to ensure safety for PLWD, including preventing falls, is a significant concern for CGs.
- **Aggressive behavior:** PLWDs may exhibit aggressive behavior, adding to the caregiving burden.
- **Not recognizing relatives and delusions:** PLWDs may mistake family members for their parents or believe deceased parents are alive.

[bed (TH3; 0.0323); carer (TH3; 0.0287); deal (TH3; 0.0125)]

Secondary theme: Support from family & friends

- **Children support:** children show significant concern and seek advice, even if not primary CGs.
- **Lack of visits and recognition:** CGs may feel unsupported due to infrequent visits from family members. Additionally CGs feel unrecognized by family members and friends for their efforts.

[sister (TH4; 0.0284); brother (TH4; 0.0168); forum (TH4; 0.0100)

Secondary theme: Hospitalization/ Care home

- **Placement in full-time care:** CGs place PLWDs on respite care due to the demanding nature of caregiving. CGs often decide whether to directly move PLWD from respite care to nursing home. CGs struggle with guilt and doubt when deciding on nursing home placement.
- **Desire to retun home:** PLWDs often express a strong desire to return home upon being placed in a nursing home.
- **Capacity issues:** Care homes sometimes lack capacity, forcing caregivers to bring PLWDs back home.

[nursing (TH2; 0.0204); angry (TH2; 0.0178); toilet (TH2; 0.0167); home (TH3; 0.1461); ago (TH3; 0.0428); hospital (TH3;

> “Care is good, nice room which I’ve personalised, purpose built but not as well designed as my 1st choice food good and lots of activities and a few residents who he can have a conversation with. Sounds ideal but I visit at least every other day and always leave almost in tears. He just wants me and to be at home with me. I can give him both but know that in a week or two I’ll be tired and desperate again... I’m totally torn - can’t bear to see him so sad but know I can’t cope with him at home.” (Post ID: 1988524; Placement in full-time care; Desire to return home)

Secondary theme: Dementia perception & stigma

- **Dementia perception & stigma:** CGs may be concerned about how others perceive PLWD’s health condition, reflecting the social stigma associated with dementia

[people (TH1; 0.3055); dementia (TH2; 0.1820); people (TH2; 0.0666); people (TH3; 0.0374)]

6.3.3 Interpretation of Themes

In Section 6.3.2, themes identified in the topic interpretations often repeated across different topics. To address this, the researcher grouped these recurring themes into broader thematic interpretations, combining similar themes from multiple topics.

These broader thematic interpretations were derived from the LDA topic modeling output and were independent of the themes identified in the thematic analysis. The themes were then categorized by the researcher into the following groups:

Diagnosis:
- Dementia diagnosis

CG role:
- CG role

Caregiving:
- PLWD Symptoms / Daily caregiving
- CG burden & need for respite

Coping strategies:
- Support from family & friends
- Support from healthcare providers & social services
- Support in online forums
- Hospitalization / Care home
- Other coping strategies

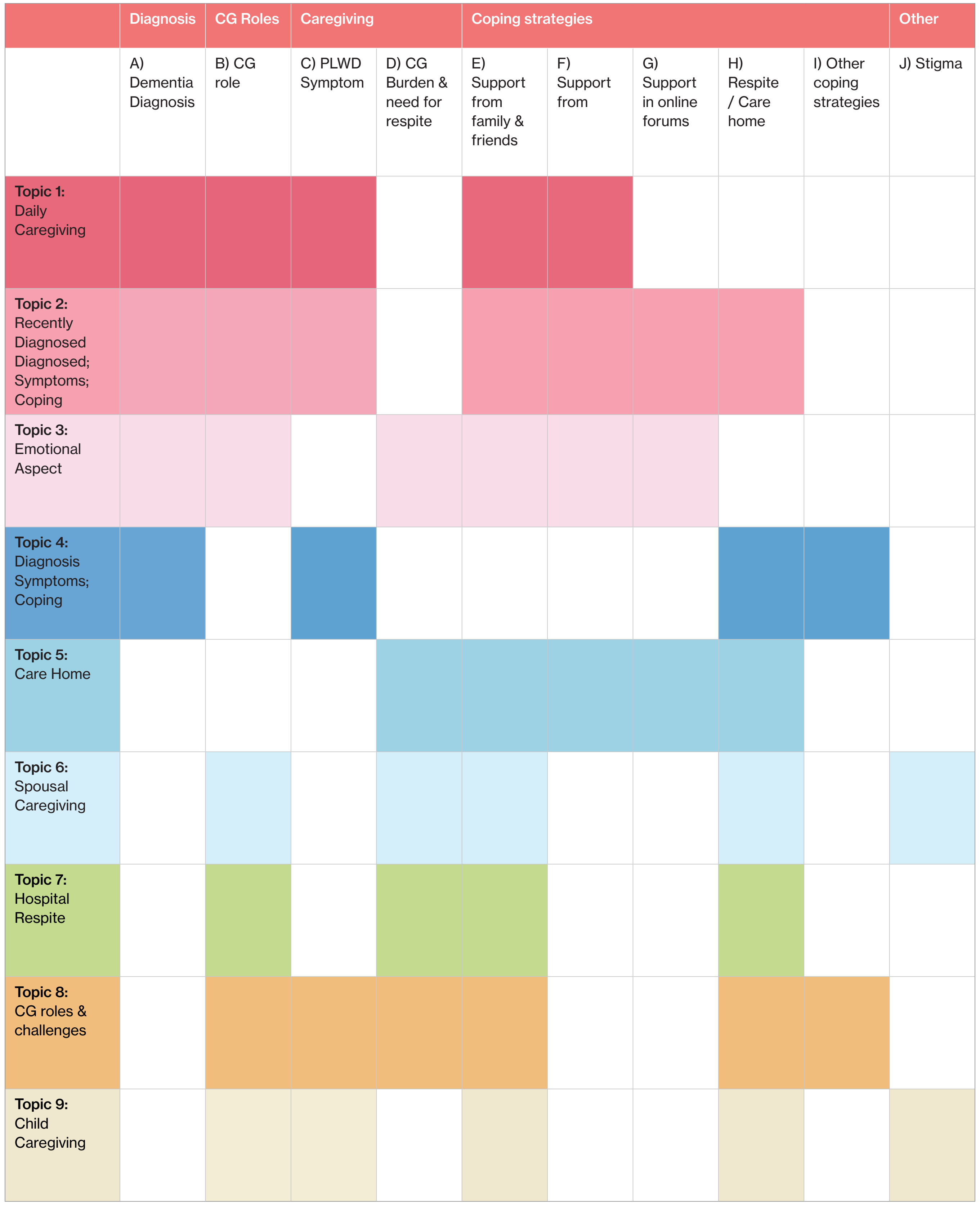
Other:
- Dementia perception & stigma

The presence of each theme within the LDA-generated topics is shown in Fig. 28. In this matrix:

- Columns display the identified themes.
- Rows list the individual LDA-generated topics in order of likelihood.
- Blank fields indicate that the theme did not appear in the LDA topic.

A detailed description of each topic’s contribution to TM themes is available in Appendix 15.

This innovative approach, proposed by the researcher, enabled a direct comparison between thematic analysis and topic modeling findings, facilitating the synthesis of insights from different parts of the methodology.



	Diagnosis	CG Roles	Caregiving		Coping strategies					Other
	A) Dementia Diagnosis	B) CG role	C) PLWD Symptom	D) CG Burden & need for respite	E) Support from family & friends	F) Support from	G) Support in online forums	H) Respite / Care home	I) Other coping strategies	J) Stigma
Topic 1: Daily Caregiving	■	■	■		■	■				
Topic 2: Recently Diagnosed Diagnosed; Symptoms; Coping	■	■	■		■	■	■	■		
Topic 3: Emotional Aspect	■	■		■	■	■	■			
Topic 4: Diagnosis Symptoms; Coping	■		■					■	■	
Topic 5: Care Home				■	■	■	■	■		
Topic 6: Spousal Caregiving		■		■	■			■		■
Topic 7: Hospital Respite		■		■	■			■		
Topic 8: CG roles & challenges		■	■	■	■			■	■	
Topic 9: Child Caregiving		■	■		■			■		■

Fig. 28: Presence of identified themes within LDA-generated topics

The following paragraphs provide a synthesized description of the themes identified across the individual topics.

TopX = Topic number X

Theme A: Dementia Diagnosis

(Thematic category: Diagnosis)

PLWDs often hide symptoms during doctor's visits, which complicates and prolongs the diagnostic process (Top4). Both CGs and PLWDs experience significant emotional reactions both during the diagnostic process and following the diagnosis disclosure (Top3). During the diagnostic process they face anxiety and uncertainty while awaiting a formal diagnosis, especially with a family history of the disease (Top4). The diagnosis disclosure formalizes the role of the CG, often leading to shock and feelings of unpreparedness (Top3, Top1). Shortly after receiving the diagnosis (Top2), CGs often join online forums, where they emphasize the diagnosis as a starting point of their caregiving journey (Top2). Finally, post-diagnosis, CGs often regret not arranging dementia-related matters sooner. (Top2)

Theme B: CG role

(Thematic category: CG role)

In most cases, relatives are expected to become CGs for PLWDs. (Top1) However, many CGs have full-time jobs, causing them to need assistance from professional CGs. (Top1) The majority of CGs on forums are females, often wives of male PLWDs or daughters caring for their parents (Top8). Spouses, primarily wives, are often the CGs for their husbands (Top2, Top6, Top7, Top9). Children, particularly daughters, commonly step in as CGs for mothers with dementia, possibly due to a lower likelihood of husbands taking on the caregiver role (Top7, Top9). Mothers frequently appear in the roles of either PLWDs or CGs caring for their husbands with dementia (Top3).

Theme C: PLWD Symptoms / Daily caregiving

(Thematic category: Caregiving)

Caregiving often takes over the lives of CGs, who face numerous challenges related to PLWD's symptoms (Top2). PLWDs experience significant symptom variability, having good and bad days, making routine difficult, causing each day to feel as a new challenge to the CG (Top1, Top4). CGs monitor dementia symptoms on daily basis to manage care effectively (Top1). Additionally, the demanding nature of caregiving causes each day to feel very long and exhausting (Top1).

PLWDs experience a variety of symptoms including very common nighttime issues, such as sleep disturbances, nighttime wandering (Top2) and incontinence (Top4). During the whole day they may often struggle with navigating their home space (Top2), communicating (Top4), not recognizing relatives, believing deceased relatives are still alive (Top8, Top9) and frequently falling (Top9). These symptoms lead to CGs being constantly worried about PLWD's health and safety, with many showing interest in security technologies to monitor and protect PLWD. (Top2)

Moreover, PLWDs can exhibit behavioural changes, such as aggression, refusal of care (Top8, T9) and accusing family members of theft (Top8). In later stages many PLWDs become bedridden (Top8). CGs often express fear and uncertainty about how to cope as the disease progresses leading to an increase in caregiving demands. (Top2)

Theme D: CG burden & need for respite
(Thematic category: Caregiving)
CGs experience complex emotions and changes in their feelings towards PLWD due behavioral changes in PLWD (Top3). These changes often lead to resentment (Top5) and a sense of distance, as if they've lost a partner, causing a feeling of isolation and sadness (Top3, Top6). This dynamic in particular negatively impacts marriages, with CGs feeling resentment towards their spouses living with dementia (Top7).

The intensity of these feelings grows as CGs suppress them out of guilt for expressing negative emotions towards PLWD (Top3). To avoid judgment and burdening family members, CGs often share their negative feelings towards PLWD anonymously on online forums (Top5).

As a result of longstanding caregiving burden, many CGs find themselves unable to cope with the demands of caregiving (Top8). Exhaustion from caregiving can lead to the inability to continue providing care (Top5), causing CGs to often seek respite from caregiving tasks (Top7). Caregiving can be especially demanding for male PLWDs, as they may have a tendency for becoming aggressive, and thus physically challenging for female CGs to handle (Top6).
Additionally, caregiving can cause financial strain, particularly if CGs have to stop working to commit to providing full-time care (Top8).

Theme E: Support from family & friends
(Thematic category: Coping strategies)
CGs often miss their pre-caregiving social life and connections (Top3). They frequently lack support from friends and family, feeling invisible to them after the PLWD is diagnosed with dementia (Top1). CGs consider visits from family members to be rare (Top9), plus they feel unrecognized for their caregiving efforts by their family and friends (Top9). They also feel a lack of support from the PLWD, whom they feel they have "lost" to dementia (Top3, Top5).

Despite many CGs feeling unsupported by their family and friends, children play a significant role in the caregiving dynamic. Even when they are not the primary CGs, children show concern for both the PLWD and the CG, actively seeking advice and support online (Top2, Top6, Top8, Top9). Children are especially concerned for their mother who are CGs (Top3, Top7). Additionally, children are often involved in decision-making regarding care home placement for the PLWD (Top8).

Theme F: Support from healthcare providers & social services
(Thematic category: Coping strategies)
CGs frequently interact with healthcare professionals to seek advice on managing dementia (Top1), often by the means of calling the GP's office for guidance on dementia symptom management (Top2). Additionally, CGs show a keen interest in receiving support from social services (Top3), in some cases seeking comprehensive assistance, including individual social workers for both PLWD and

themselves (Top3).However, CGs often complain about a lack of support from social services (Top1) and healthcare professionals (Top5).

Theme G: Support in online forums
(Thematic category: Coping strategies)
CGs actively seek advice, support, and reassurance on online forums, often applying advice from peer support networks (Top2). Due to fear of being judged by family and friends, they interact with online communities to vent their negative emotions towards caregiving and connect with others who have similar experiences (Top3, Top5).

Theme H: Hospitalization/ Care home
(Thematic category: Coping strategies)
While some CGs star planning ahead for future needs by choosing a care home in advance (Top5), most CGs only seek care support options once feeling exhausted from caregiving duties. Majority of CGs initially seek temporary relief through respite care (hospitalization of PLWD for a couple of weeks), allowing CG to take a much needed break from caregiving duties. (Top2, Top6, Top7, Top9) While PLWD is placed on hospital respite, CGs often start considering transferring PLWD directly to a care home, as they cannot cope with caregiving duties any longer. (Top2, Top7, Top8, Top9)

For CG, making the decision of placing PLWD in a full-time care home is extremely challenging, as they fight the feeling of guilt and betrayal (Top4, Top9, Top8). Moreover, the varying symptom severity, with PLWD having better and worse days, makes it increasingly more difficult to make a choice. (Top5) When deciding to place PLWD in a care home, CG's prefer facilities in their proximity, which would allowed them for frequent visits. (Top4, Top5)

In most cases CGs appreciate the care provided by care home staff (Top4), however there are still instances of CG being dissatisfied with the care provided by the care home (Top5). Meanwhile, PLWD majority of the time expresses a strong desire to return home, blaming CG for carehome placement. (Top5, Top7, Top9). As a result, CG doubts the decision of full-time care home placement due to feeling of guilt and betrayal towards PLWD, often turning to the online forum to seek reassurance they made the right decision moving PLWD to a care home. CGs often struggle with their decision so much that they even consider taking PLWD back into home care. (Top5, Top8) In other cases the care home may put pressure on CG to take PLWD back home due to lack of capacity or PLWD being too difficult to manage. (Top5, Top9) During the process of coming to terms with their decision, CG often communicates with the care home only by phone and does not visit PLWD in person. (Top2)

Theme I: Other coping strategies
(Thematic category: Coping strategies)
Another coping strategy that many CGs adopt is the personification of dementia with the aim of separating it from PLWD and thus maintaing the perception of PLWD as the person they knew before. This technique helps CGs to manage the

resentment they may feel towards PLWD as a result ot their behaviour change (Top4, Top8).

Theme J: Dementia perception & stigma
(Thematic category: Other)
CGs may be concerned about how others perceive PLWD's health condition, reflecting the social stigma associated with dementia. They may question whether others will understand the abrupt and often unexplainable changes in PLWD's behaviour. (Top6, Top9)

6.4 Topic Modeling Summary

The aim of this step of the method was to effectively test the generalisability of findings from thematic analysis to a wider online forum and to capture insights from a larger dataset that could not be manually obtained from a smaller sample. The outputs of this section include:

- 1) Interpreted topics from LDA Topic Modeling
- 2) Interpreted themes identified across the topics.

This summary presents findings from the topic modeling and compares them solely with the Background Understanding. An in-depth comparison with thematic analysis will follow in the next section: Step 3: Synthesis.

6.4.1 Forum Demographics

Most topics reflect the experiences of CGs, suggesting that the vast majority of forum users are CGs rather than PLWDs. Moreover the CGs on the forum are primarily relatives of PLWD, with the majority being women, typically the wives or daughters of PLWDs. It is unclear if this prevalence of women reflects a broader societal trend where women are more likely to provide care. On the one hand, current research suggests that women are indeed more likely to be CGs in a variety of contexts, not just dementia. (Pacheco Barzallo et al., 2024) On the other hand, studies also show that compared to men, women are more likely to seek help on online forums, indicating a self-selection bias (Hausner et al., 2008) Understanding gender dynamics is crucial to address gender-specific needs and provide tailored support to CGs (Bartlett et al., 2016) However, the Background Understanding does not address the theme of gender and caregiving.

6.4.2 Interpreted topics from LDA Topic Modeling

The LDA Topic Modeling resulted in 9 topics, each encompassing individual sub-themes which are discussed in the next section, "Interpreted Themes Identified Across Topics from LDA Topic Modeling." The identified topics include:

- **Topic 1:** Daily Caregiving Routines
- **Topic 2:** Recently Diagnosed
- **Topic 3:** Emotional Aspect of Caregiving
- **Topic 4:** Dementia Diagnosis, Symptoms & Coping

- **Topic 5:** Care Home
- **Topic 6:** Spousal Caregiving
- **Topic 7:** Hospital Respite
- **Topic 8:** Caregiving Roles and Challenges
- **Topic 9:** Child Caregiving

Topic 1: Daily Caregiving Routines is the most frequent, suggesting that users often share their daily caregiving tasks on the forum. Additionally, it highlights the significant day-to-day variability in PLWD symptoms, preventing routine in caregiving. This insight not covered in the Background Understanding.

The second most common – Topic 2: Recently Diagnosed focuses on the initial stages after receiving a dementia diagnosis. CGs often highlight this point as pivotal in their caregiving journey consistent with studies by Chen & Lin (2022) and Prorok et al. (2013), who refer to the diagnosis disclosure as a key moment of PLWD and CG role formalization. Topic 4: Dementia Diagnosis, Symptoms & Coping covers accepting a dementia diagnosis and coping with the fear and uncertainty of awaiting a formal diagnosis, supported by Campbell et al. (2016) and corresponding with the theme of Emotional Burden and Uncertainty in the Background Understanding.

Topic 3: Emotional Aspect of Caregiving highlights the emotional aspects of caregiving and the considerable burden on CGs. This aligns with the Emotional Burden theme explored by Bradford et al. (2009) and Xanthopoulou & McCabe (2019) in the Background Understanding. The relatively significant prevalence of this topic within the forum corresponds to the importance of the emotional side of dementia journeys.

Topics 5: Care Home and 7: Hospital Respite and explore the high burden on CGs needing respite or placing PLWDs in full-time care facilities. Topic 7 focuses on temporary relief for CGs through hospital respite care, while Topic 5 addresses the decision-making and emotional challenges of placing PLWDs in full-time care, not paralleled in the Background Understanding.

Topics 6: Spousal Caregiving, 8: Caregiving Roles and Challenges, and 9: Child Caregiving examine the roles and challenges faced by different types of CGs. They highlight the challenges faced by spousal CGs, particularly wives, and child CGs, particularly daughters, in caring for parents with dementia. These themes do not have direct parallels in the Background Understanding

6.4.3 Interpreted Themes identified across Topics from LDA Topic Modeling

The researcher identified several cross-cutting themes spanning multiple topics, grouped into thematic categories, including:

Thematic category: Diagnosis
- Theme A: Dementia Diagnosis

Thematic category: CG role:
- Theme B: CG role

Thematic category: Caregiving
- Theme C: PLWD Symptoms / Daily caregiving
- Theme D: CG burden & need for respite

Thematic category: Coping strategies
- Theme E: Support from family & friends
- Theme F: Support from healthcare providers & social services
- Theme G: Support in online forums
- Theme H: Hospitalization/Care home
- Theme I: Other coping strategies

Other:
- Theme J: Dementia perception & stigma

The themes identified in the topic modelling are closely compared and integrated with the results of the thematic analysis in the following part of step 3: synthesis.

6.4.4 Method Strengths and Limitations

LDA Topic Modeling provided a broad overview of forum topics by efficiently analyzing a large dataset of 45,927 first-thread posts, a task impractical to perform manually. This data-enabled approach provided a structured overview of the data, represented by topics and their associated words with probabilities, offering a clear indication of the predominant topics in the forum.Its unsupervised learning approach allowed for clustering of unlabeled textual data and pattern identification without prior assumptions, thereby reducing researcher bias. This method validated and augmented thematic analysis findings with new insights from a larger dataset, resulting in a comprehensive understanding of online forum themes at scale.

Regarding data quality, online forum posts provided authentic testimonies of forum users independent of researchers prompts, reducing the risk of desirable answers (Jung et al., 2023). The anonymity of the forum further reduced stigma and encouraged more open sharing. Additionally, the longitudinal nature of data collection within the forum captured trends and recent developments, contributing to a deeper understanding of the experiences of PLWDs and CGs.

However, the method has its limitations. LDA results are highly sensitive to parameters like the number of topics (k) and the number of words per topic (top_n). Choosing optimal parameters requires extensive trial and error to achieve coherent and stable topic distributions. More topics (higher k parameter values) can result in overlapping themes and less distinct topics, while fewer topics may oversimplify the data, missing important nuances. In this method, the parameter k (number of topics) was aligned with the number of themes identified in the thematic analysis. Initially, a variation of k=17 (matching the number of subthemes in the thematic analysis) was tested but produced errors in the output. Consequently, k=9 (corresponding to the primary themes in the thematic analysis) was utilized.

Another limitation is the interpretation of LDA outputs, which are sets of words requiring contextual understanding to avoid misinterpretation. To address this shortcoming, an interpretation pipeline was used, employing multiple minimum word frequency thresholds and analyzing extracted matching posts for context. Finally, ChatGPT 4.0 was used to inspire the interpretation. This comprehensive interpretive approach allowed to reduce limitations imposed by the lack of context for interpretation, thereby reducing researcher bias.

In terms of the data quality, limitations included self-selection bias, wherein only voluntary participants contribute to the forum, leading to a difference in experiences between forum users and non-users. This discrepancy makes it challenging to ensure the data's representativeness. (Nikolopoulou, 2023) Moreover, users' contributions might be influenced by previous content. (Jung et al., 2023) Additionally, the permanent nature of online contributions may inhibit users from sharing sensitive information openly on the forum. (Jung et al., 2023)

In conclusion, while LDA Topic Modeling is effective at identifying prevalent topics within a broader forum, it falls short in capturing the depth of understanding and contextual nuances of the identified topics. Given this limitation, combining LDA topic modeling with thematic analysis proves to be a suitable approach that leverages the strengths of both techniques for a more nuanced and comprehensive understanding of online forum themes. An integration of the findings from these two methods will be further explored in the following Step 3: Synthesis. ■

7

Step 3: Synthesis

This chapter details the final step of the research method, focusing on the synthesis of findings from thematic analysis (TA) and topic modeling (TM) to create a comprehensive journey map. By identifying how TM findings reinforce, contradict, or extend TA insights, this step aimed to achieve a robust understanding of the dementia journey. The resulting method journey map captured the forum demographics, journey phases, temporal steps, and themes, visually distinguishing

Chapter Content Overview

7.1 Objective

The final step of the method involved synthesizing findings from thematic analysis (TA) and topic modeling (TM) to create a comprehensive journey map illustrating the experiences of PLWDs and their CGs throughout the dementia journey.

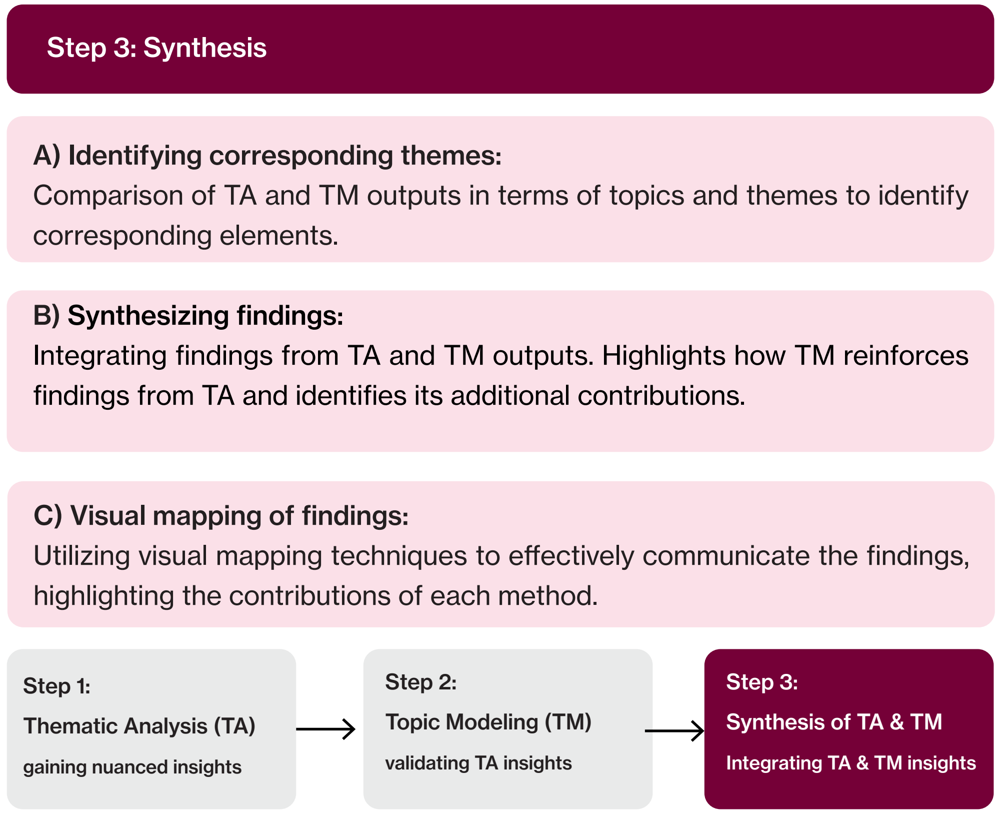
The goal of this synthesis step was to determine how insights from topic modeling reinforce, contradict, or expand upon the findings from TA. This approach aimed to provide a comprehensive understanding of the dementia journey, capturing its depth through the nuances of TA and its breadth by verifying which themes are applicable to the entire forum population via TM.

The output of the synthesis step was captured using a method journey map, which included two main components:

- An overview of the forum's demographics to understand the profile of forum contributors
- A journey map outlining journey phases, temporal steps, and journey themes grouped into thematic categories.

The resulting Method Journey Map used visual techniques to showcase the contributions of each method, aiding in drawing method-related conclusions discussed in the Discussion chapter.

7.2 Process Overview



Step 3: Synthesis

A) Identifying corresponding themes:
Comparison of TA and TM outputs in terms of topics and themes to identify corresponding elements.

B) Synthesizing findings:
Integrating findings from TA and TM outputs. Highlights how TM reinforces findings from TA and identifies its additional contributions.

C) Visual mapping of findings:
Utilizing visual mapping techniques to effectively communicate the findings, highlighting the contributions of each method.

Fig. 29: Synthesis process overview diagram

7.2.1 A) Identifying corresponding themes

First of all, it was necessary to establish a common platform for comparing the findings from the individual steps of the method. To this end, the TA themes from were compared with:

- 1) Interpretations of TM topics
- 2) Interpretations of TM themes

1) Topic Correspondence with TM topics

TM_TopX = Topic Modeling Topic num. X

The majority of TM topics correspond well with the two most frequently occurring themes from thematic analysis: PLWD Symptoms + Ways of Coping (143) linked to TM_Top1, TM_Top2, TM_Top4 and CG Burden (110) linked to TM_Top3, TM_Top5, TM_Top7, TM_Top8. This correspondence supports the notion that the most frequent codes in TA align with the prevalent topics identified in TM. Moreover, the theme Carehome (35) to a great extent aligns with TM_Top5, and Seeking a Diagnosis (19) matches well with TM_Top2 and TM_Top4. The theme CG Maintaining PLWD's Independence While Ensuring Their Safety (73) aligns to a smaller degree with TM_Top2. The themes of Interacting with the forum (86), Experience with NHS & Social Services (9), Uncertainty (4) and Impact of Covid (3) do not have a corresponding topics in the TM output.

Topic Modeling (TM) topics: (Topics ordered based on probability of topic occurence within dataset)
Topic 1: Daily Caregiving
Topic 2: Recently Diagnosed
Topic 3: Emotional Aspect
Topic 4: Diagnosis
Topic 5: Care Home
Topic 6: Spousal Caregiving
Topic 7: Hospital Respite
Topic 8: CG roles
Topic 9: Child Caregiving

Thematic Analysis (TA) themes: (Topics ordered based on code occurence frequencies)	**Alignment of topics from TM with TA themes:**			
PLWD Symptoms + Ways of Coping (143)	TM_T1	TM_T2	TM_T4	
CG Burden (110)	TM_T3	TM_T5	TM_T7	TM_T8
Interacting with the forum (86)				
CG Maintaining PLWD's independence and safety (73)	TM_T2			
Care home (35)	TM_T5			
Seeking a diagnosis (19)	TM_T2	TM_T4		
Experience with NHS and social services (9)				
Uncertainty (4)				
Impact of Covid (3)				

Fig. 30: Overview of topic comparison: TM topics vs. TA themes

2) Thematic Interpretations Correspondance

At a thematic level, the alignment is substantially greater, with 7 of the 9 themes from TA finding counterparts in the TM themes. Only the themes with minimal occurrences – Uncertainty (4) and Impact of Covid (3) – do not find counterparts in TM themes. In addition, there are four other themes within the TA themes (B) CG Role, E) Support from Family & Friends, I) Other Coping Strategies, J) Dementia Perception & Stigma,, and), which do not have a direct thematic counterpart from the TM themes.

Fig. 31: Overview of topic comparison: TM topics vs. TA themes

Thematic Analysis (TA) themes: (Topics ordered based on code occurence frequencies)	**Topic Modeling (TM) Themes:** (Topics ordered based on probability of topic occurence within dataset)	Correspondance
PLWD Symptoms + Ways of Coping (143)	C) PLWD Symptoms / Daily Caregiving	yes
CG Burden (110)	D) CG Burden & need for respite E) Support from family & friends (corresponds with CG loneliness / lack of support sub-theme)	yes
Interacting with the forum (86)	G) Support in online forums	yes
CG Maintaining PLWD's independence and safety (73)	C) PLWD Symptoms / Daily Caregiving	yes
Care home (35)	H) Hospitalization / Care home	yes
Seeking a diagnosis (19)	A) Dementia Diagnosis	yes
Experience with NHS and social services (9)	F) Support from Healthcare Providers & Social Services	yes
Uncertainty (4)	(HL insight)	partial
Impact of Covid (3)		no
(demographics)	B) CG role	non-direct
	I) Other Coping Strategies	no

Both comparisons show significant overlap, highlighting the robust thematic similarity between the two analytical approaches. This supports the usefulness of the method innovation consisting of converting TM topics to TA themes for direct comparison. To establish a basis for comparison, the following steps compared the themes identified in TA with the TM thematic interpretations, given their considerable correspondence.

7.2.1 B) Synthesizing Findings

Findings from the thematic analysis were synthesized with the topic modeling thematic interpretations. The aim was first to classify the findings from each method into three categories:

- **[TA + TM]:** Themes that appear in the thematic analysis and are also reinforced by topic modeling, indicating their generalizability to the wider forum population.
- **[TA]:** Themes that appear only in the thematic analysis, adding a deeper understanding of the theme's nuances
- **[TM]:** Themes that appear only in topic modeling, pointing to another dimension of the forum that was not identified in the thematic analysis.

In addition, insights from TM theme B) CG roles were used in a synthesis of insights on forum demographics.

7.2.1 C) Visual mapping of findings

In the final step, the synthesis process used visual mapping techniques to group findings into related units, effectively communicating the analysis results.Color coding was employed to differentiate the contributions of each method within the synthesis categories. Lucid Chart software was used for this purpose. The visual map facilitated the extraction of general insights, providing an overarching view of the findings

7.3 Results

7.3.1 Forum Demographics

Both methods reveal a significant prevalence of CGs on the forum, primarily relatives of PLWDs, mostly spouses or children. Professional CGs are minimally represented. Majority of the CGs are female.

Regarding the stage of diagnosis, both TA and TM indicate that most forum users are already diagnosed, supported by TM's Topic 2 – Recently Diagnosed, Symptoms & Coping. TA suggests most PLWDs discussed are in the mid or late stages of dementia. Early-stage dementia is more frequently mentioned in TA but rarely in TM. TM topics focus on caregiving burden, coping strategies, and care home placement, implying later-stage dementia. Despite the prevalence of advanced stage of dementia in the PLWDs discussed on the forum, both methods indicate that the majority still receive home care.

7.3.2 Journey Map Phases and Temporal Steps

Journey of PLWD and CG spans across 5 main phases, each including two temporal steps:

Phase 1: Noticing symptoms
- PLWD experiencing early dementia symptoms
- Noticing dementia symptoms in PLWD

Phase 2: Acceptance of Symptoms
- Accepting the presence of dementia symptoms
- Deciding to seek medical help

Phase 3: Diagnostic Process
- GP performing initial testing
- Memory Clinic performing testing

Phase 4: Diagnosis Disclosure
- GP or Memory Clinic disclosing the diagnosis
- PLWD and CG reacting to diagnosis

Phase 5: Post-diagnosis Disease Management
- CG considering placing PLWD in care facilities
- CG visiting PLWD at care facilities

While according to the TA, Phase 1: Noticing symptoms has been identified as the start of the journey, TM identifies Phase 4: Diagnosis Disclosure as the journey beginning. This is due to the strong prevalence of the CG perspective within the TM findings, whereby from the CGs perspective the journey often only begins with the formalisation of the CG role in response to the diagnosis disclosure.

7.3.3 Journey Map Themes

When combining TA and TM findings, there are a total of 11 themes across the different journey stages, grouped into 4 thematic categories. The themes are clusters of individual findings from TA and TM. Of the 39 findings across all 11 themes, 13 appear only in TA, 6 appear only in TM, and 20 appear in both TA and TM. Each finding illustrates the relevance of a given theme in the context of the PLWDs and CGs journeys. The themes include:

Thematic category 1: Diagnosis

Theme 1.a) Seeking a Diagnosis

Shared TA + TM findings:
The pursuit of a dementia diagnosis is an emotionally complex process, as revealed by the combined insights from TA and TM. Both PLWDs and CGs face significant emotional challenges, including anxiety, unfamiliarity with the diagnostic process, and a stressful wait for test results. PLWDs often avoid seeking a diagnosis due to fear of losing independence and facing stigmatization, complicating the diagnostic process as they downplay symptoms during medical appointments. (According to TA, CGs sometimes resort to using white lies to ensure PLWDs attend diagnostic

assessments.) The disclosure of a dementia diagnosis formalizes the roles of CGs and PLWDs, leading to feelings of shock, uncertainty, and unpreparedness.

Exclusively TA findings:
TA offers deeper insights into the motivations and experiences involved in seeking a diagnosis. The pursuit depends on the extent to which CG and PLWD recognize the value of a diagnosis as a gateway to medical help, future assistance, financial support, and legal management. Without awareness of these benefits, the process can seem like a waste of time. Additionally, during the diagnostic process CGs often find healthcare professionals to be rushed and unhelpful, which they attribute to the perceived untreatability of dementia among GPs. Long waiting times and a lack of support further discourage CGs and PLWDs from pursuing a diagnosis.
Following a diagnosis, CGs frequently regret not arranging dementia-related matters earlier, reflecting missed opportunities for better planning. In cases of Mild Cognitive Impairment diagnoses, CGs and PLWDs may seek re-diagnosis due to doubts about accuracy.

Exclusively TM findings:
Within this theme, no findings were identified exclusively by TM.

Thematic category 2: Caregiving

Theme 2.a) Dementia Symptoms

Shared TA + TM findings:
Both TA and TM identify considerable symptom variability in PLWD, complicating dementia identification and care approaches. Most common cognitive symptoms include memory loss, not recognizing relatives, reduced ability to perform tasks, disorientation in familiar places, and delusions. Behavioral symptoms often include aggression, mood swings, anxiety, accusations towards relatives, and nighttime wanderings. In addition to cognitive and behavioral changes, dementia also leads to physical symptoms such as mobility issues (including frequent falls), refusing to eat, eyesight problems, and incontinence. In the later stages, PLWDs may become bedridden significantly intensifying the demands of caregiving. This symptom range adds to the complexity of diagnosing and managing dementia.

Exclusively TA findings:
According to TA, relatives and friends play a crucial role in noticing changes in PLWDs. However, early signs of dementia are often subtle and can be easily mistaken for emotional problems. TA emphasizes the importance of observation sharing among relatives to ensure everyone is aware of observed changes, facilitating early detection and timely intervention.

Exclusively TM findings:
TM findings additionally highlight the significant variability in symptoms within the same individual over time, even in matter of days. More specifically, PLWDs may experience good and bad days, which makes routine hard to achieve and adds to the unpredictability of caregiving.

Theme 2.b) Providing Care

Shared TA + TM findings:
CGs often try to provide discreet care to maintain PLWD's sense of independence. This leads them to be interested in the use of security technologies. However, protective measures may be perceived as restrictive by PLWDs, leading to resistance, including hesitancy to grant Lasting Power of Attorney (LPA) or refusal of care from assistants. In addition, PLWDs may feel significant resetnment towards the CG and express aggression towards them.

Exclusively TA findings:
As dementia progresses, PLWDs lose the ability to maintain independence, requiring CGs to step in to ensure their safety and well-being. This often means CGs have to move in with the PLWD or hire caregiving staff, especially when the PLWD lives alone or with a partner who also has dementia.

Exclusively TM findings:
Within this theme, no findings were identified exclusively by TM.

Theme 2.c) CG Burden

Shared TA + TM findings:
According to both methods, the progressively worsening health of the PLWD leads to increased caregiving demands. This ongoing increase in responsibilities and tasks places a significant burden on CGs, contributing to feelings of exhaustion and burnout.
Moreover, CGs often experience shifts in their feelings towards PLWDs due to the behavioral changes and intense caregiving demands. This frequently leads to feelings of resentment, even when the PLWD is a spouse or parent. The intensity of these feelings grows as CGs suppress them out of guilt for feeling negative emotions towards caregiving.
As a result of the longstanding caregiving burden including both demanding physical tasks and emotional toll, many CGs find themselves exhausted and unable to cope with the demands of caregiving, often seeking respite through temporary or full-time placement in care facilities. This emotional and physical exhaustion is particularly challenging for female CGs handling male PLWDs, who may exhibit aggressive behavior.

Exclusively TA findings:
According to TA, CGs have a tendency to prioritize caregiving over personal time, driven by guilt for taking time off caregiving. This prioritization causes them to neglect their own needs, thereby contributing to CG burnout.

Exclusively TM findings:
Full-time caregiving often causes financial strain, particularly if CGs have to stop working to provide care.

Thematic category 3: Coping Strategies

Theme 3.a) Support from Family & Friends

Shared TA + TM findings:
As identified in both methods, CGs, particularly spouses of PLWD often feel a profound sense of loss and lack of support from their PLWD partner, whom they feel they have “lost” to dementia. This emotional disconnection caused by PLWD’s change in behaviour, significantly impacts the CG’s well-being and underscores the need for external support systems.

Exclusively TA findings:
According to TA, child CGs frequently feel isolated and burdened in the caregiving journey due to inadequate support from their siblings in caregiving. This leads to feelings of resentment and strained family relationships, worsening the emotional burden on the primary CG.

Exclusively TM findings:
TM has identified a prominent topic of child’s involvement in caregiving. Even if not primary caregivers, children of PLWDs frequently show concern for both the PLWD and the primary CG. They actively seek advice and support online on behalf of their parents, particularly expressing concern for their mothers who are the primary caregivers. Additionally, children are often involved in decision-making regarding care home placement, reflecting their active engagement in the caregiving process.

Theme 3.b) Support from Healthcare & Social Services

Shared TA + TM findings:
CGs express interest in receiving comprehensive support from social services, including individual social workers for both the PLWD and in rare cases also themselves. Despite actively seeking help, CGs frequently complain about a lack of adequate support from social and healthcare professionals, highlighting a significant gap in the support system.

Exclusively TA findings:
According to TA, some CGs feel lack of support from doctors, describing them as rushed and unhelpful.

Exclusively TM findings:
Based on findings from TM, CGs frequently interact with healthcare professionals, often calling the GP’s office to seek advice on managing dementia symptoms. This interaction underscores the need for accessible and responsive healthcare guidance for CGs.

Theme 3.c) Support from Online Forums

Shared TA + TM findings:
CGs actively interact with online forums to seek advice, support, and reassurance from people with shared experiences. The primary topics of concern include managing dementia symptoms, addressing legal and financial matters, and coping with PLWD’s behavioral changes. According to the highly prevalent Topic 2: Recently diagnosed, Symptoms & Coping most CGs join these forums following the disclosure of a dementia diagnosis, indicating a critical need for support and information during this period.

Apart from seeking practical guidance on dementia management, online forums serve as a space for CGs to anonymously vent their frustrations and share their emotional burdens in a judgment-free space. The ability to share and receive empathy from others in similar situations helps CGs manage the emotional stress of caregiving.

Exclusively TA findings:
TA reveals the ways in which PLWDs interact with online forums. It identifies that PLWDs use these forums to seek support from people with similar experiences, share their own experiences, record their symptom progression, and showcase their creative works. Similar to CGs, the majority of PLWDs join the forum immediately after receiving their diagnosis, highlighting the forum’s role as an important support system during the post-diagnosis phase.

Exclusively TM findings:
Within this theme, no findings were identified exclusively by TM.

Theme 3.d) Other Strategies

Shared TA + TM findings:
No shared findings were identified for this theme.

Exclusively TA findings:
TA reveals that PLWDs employ various effective coping strategies to manage their condition including engaging in creative activities such as music, writing, and recording their experiences online. Additionally, maintaining a positive outlook and being part of a supportive community

prove to be effective in helping PLWDs cope with their dementia symptoms and emotional challenges.

Exclusively TM findings:
TM identifies a unique coping strategy that CGs use to manage their frustration and resentment towards PLWDs as a result of changes in their behaviour. The strategy involves personifying dementia in order to separate it from PLWD, helping them to perceive the PLWD as the person they once knew.

Theme 3.e) Care Home

Shared TA + TM findings:
Most CGs consider care home options when they become exhausted from caregiving duties or face increasing difficulties associated with late-stage dementia care. Many CGs initially seek temporary relief through respite care, which provides them a break from their caregiving responsibilities. During this respite period, they often contemplate transitioning the PLWD to a care home permanently.

However, despite urgently needing respite, deciding on care home placement is a highly emotionally challenging process for CGs, who often struggle with feelings of guilt and betrayal towards the PLWD. They frequently seek reassurance in online forums to cope with these emotions. Additionally, finding a suitable care home is time-consuming, with CGs preferring facilities nearby to allow for frequent visits.

After deciding on a care facility, CGs face significant challenges in informing PLWD about the move to a care home. After placement, PLWDs often express a strong desire to return home, leading to distress and worsening of symptoms. This reaction reinforces CGs' feelings of guilt and betrayal.

Exclusively TA findings:
Within this theme, no findings were identified exclusively by TA.

Exclusively TM findings:
As identified in the TM, majority of CGs remain actively involved after the placement of PLWD in a care home, frequently visiting or calling the care facilities. In some cases CGs even consider bringing the PLWD back home, or they face pressure from care homes due to capacity issues or severe symptom management challenges.

Thematic category 4: External Factors

Theme 4.a) Stigma

Shared TA + TM findings:
No shared findings were identified for this theme.

Exclusively TA findings:
Within this theme, no findings were identified exclusively by TA.

Exclusively TM findings:
Although the topic of stigma is present implicitly also in TA, within the broader forum the TM findings directly reveal that CGs are often concerned about how others perceive the health condition of PLWDs. This concern reflects the social stigma associated with dementia. More specifically, CGs may question whether others will understand the abrupt and often unexplainable changes in PLWD's behavior, which can lead to feelings of isolation and additional emotional burden for CGs.

Theme 4.b) Impact of Covid

Shared TA + TM findings:
No shared findings were identified for this theme.

Exclusively TA findings:
TA findings highlight how the COVID-19 pandemic worsened dementia symptoms due to lockdown-induced isolation. Moreover, lockdowns hindered the process of obtaining diagnoses and reduced the frequency of care home visits. The isolation not only affected the well-being of PLWDs but also intensified the challenges faced by CGs, as they struggled to provide adequate care and support under restricted conditions.

Exclusively TM findings:
Within this theme, no findings were identified exclusively by TM.

Method Synthesis Journey Map

1: THEMATIC ANALYSIS (TA)

Gaining nuanced insights from a smaller representative sample

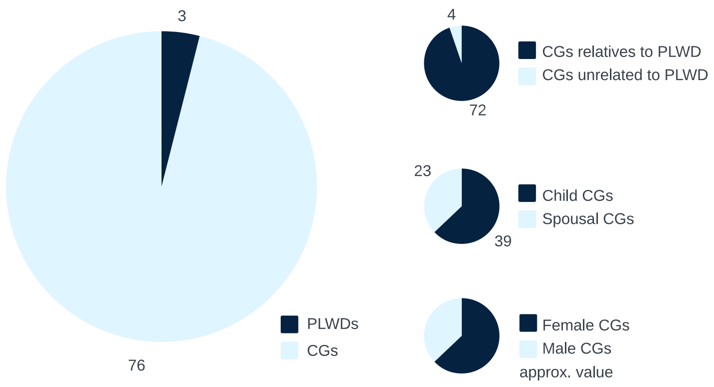
2. LDA TOPIC MODELING (TM)

Validating generalizability of TM findings across the larger dataset

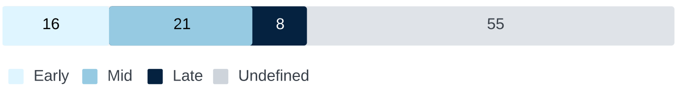
3. SYNTHESIS

Integrating TA and TM insights to draw comprehensive insights

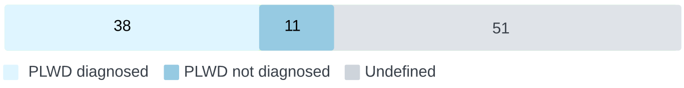
Forum Demographics



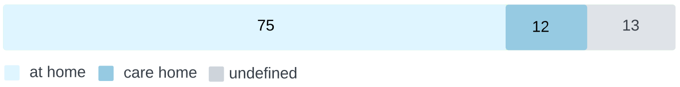
PLWD'S DIAGNOSIS STAGE



DIAGNOSIS STAGE



CAREGIVING TYPE



All values are drawn from TA categorisation
of a sample of 100 coded posts

Legend

⌛ Significant waiting time

⬚ Thematic category

▭ Theme

■ Thematic analysis (TA) insight

▨ Topic modeling (TM) insight

▩ Combined TA + TM insight

1) Noticing Symptoms → **2) Acceptance & Seeking Help** → **3) Diagnostic Process** → **4) Diagnosis Disclosure** → **5) Post-diagnosis Disease Management**

Presence of early dementia symptoms in PLWD → ⌛ PLWD's immediate surroundings noticing symptoms → ⌛ Accepting the presence of symptoms → ⌛ Deciding to seek medical help → GP performing initial testing → ⌛ Memory Clinic performing additional testing → ⌛ GP or Memory Clinic Disclosing the Diagnosis → PLWD and CG reacting to the diagnosis → CG considering placing PLWD in care facilities → CG visiting PLWD at care facilities

DIAGNOSIS

SEEKING A DIAGNOSIS

- Perceived value of a diagnosis determines pursuit
- PLWD's fear of stigma and loss of independence prevents pursuit
- PLWD/CG roles feeling shocked & unprepared post disclosure
- Process uncertainty and anxiety about test results
- Long waiting times, rushed and unhelpful doctors
- Regretting not arranging dementia-related matters sooner

CAREGIVING

DEMENTIA SYMPTOMS

- Symptoms vary greatly from person-to-person
- Cognitive symptoms: memory loss, task difficulty, disorientation, and delusions
- Physical symptoms: mobility issues, refusal to eat, eyesight problems, incontinence, bedridden.
- Symptoms vary greatly day-to-day preventing routine
- Behavioral symptoms: aggression, mood swings, anxiety, accusations, sundowning
- Sharing early symptom observations among relatives to keep everyone equally informed

PROVIDING CARE

- PLWDs lose ability to be independent requiring CGs to ensure their safety
- CG aiming to provide discrete care (e.g. using security technologies)
- CG moving in with PLWD/hiring staff: to provide 24h care
- PLWD feels restricted by CG's protective measures leading to resentment

CG BURDEN

- PLWD's worsening health leads to higher caregiving demands
- Intense caregiving causes shifts in feelings towards PLWD, leading to resentment and guilt for negative emotions.
- Longstanding caregiving and neglecting personal needs leads to CG burnout.
- Financial strain from stopping work for full-time caregiving

COPING STRATEGIES

SUPPORT FROM FAMILY & FRIENDS

- CGs feel lonely, missing pre-caregiving social life
- Children actively seek advice and support for the PLWD and CG
- Child CGs lack of sibling involvement causing strained relationships
- Spouse CGs feel lonely, having "lost" their partner to dementia.

SUPPORT FROM HEALTHCARE PROVIDERS & SOCIAL SERVICES

- CGs frequently consult GPs, for dementia management guidance
- Gs report doctors being rushed and unhelpful (due to perceived dementia untreatability)
- CGs struggle to arrange social services support

SUPPORT FROM ONLINE FORUMS

- CGs seek advice on symptoms, legal, and financial issues in online forums, joining mostly after diagnosis
- CGs share negative feelings anonymously online to avoid judgment and find understanding communities.
- PLWDs use forums to seek support, share experiences, record symptoms, and showcase creative works, joining mostly after diagnosis.

OTHER STRATEGIES

- PLWDs enjoy creative work, music, writing, and being part of a community for effective coping
- CGs combat frustration by personifying dementia, separating it from the PLWD to remember them as they were before.

CARE HOME

- CGs seek care homes for relief from caregiving duties
- CGs seek reassurance online to cope with feeling of guilt and betrayal
- Post-placement, PLWD often wants to return home, increasing CG guilt.
- CGs stay involved after placement, visiting and calling

EXTERNAL FACTORS

STIGMA

- CGs worry about how others perceive PLWD's condition due to dementia stigma

IMPACT OF COVID

- Lockdowns worsened dementia symptoms, hindered diagnoses and reduced care home visits

7.4 Synthesis Summary

The aim of method Step 3: Synthesis was to integrate findings from TA and TM into a visual output depicting the forum's demographics and the journey of PLWDs and CGs. This visualization emphasized effective communication of insights while clearly indicating which method contributed to each finding. Capturing method contributions helped evaluate the types of insights provided by each theme, which can be useful for further research in further developing the data-enabled patient journey mapping methodologies. This map subsequently served as a foundation for creating a simplified design output intended to facilitate co-creation sessions or interview studies, further described in the following section 8: Design Output.

7.4.1 Forum Demographics

The synthesis suggests that vast majority of forum users are familial CGs with the majority being female - either spouses or daughters of PLWD. At the same time, the majority of PLWDs being discussed on the forum are already diagnosed. Regarding the form of care, although most patients are in an advanced stage of the disease, they are mostly cared for at home, with a large number of CGs on the forum discussing the placement of PLWD in full time care facilities.

These findings describe the forum's dynamics, but their generalizability to a broader population is questionable due to self-selection bias. While research suggests that women are more likely to be caregivers in various contexts, not just dementia, studies also indicate that women are generally more likely to seek help on online forums compared to men. Therefore, the overrepresentation of female caregivers on the forum may reflect this tendency rather than a true demographic distribution. (Pacheco Barzallo et al., 2024), (Hausner et al., 2008)

On the other hand, the findings on forum demographics are supported by a recent study by Gilsenan et al. (2022), which analyzed a sample of 530 informal caregivers of persons with dementia in the UK. The study revealed that 86.6% of CGs were female, primarily caring for a parent (50.5%) or spouse/partner (23.7%) with dementia. The study also found that the average age of the caregivers was 54 years and they had been providing care for one to three years, which are findings that were not obtained in this research.

7.4.2 Journey Phases and Temporal Steps

According to synthesis, journey of PLWD and CG spans across 5 main phases, each including two temporal steps:

Phase 1: Noticing symptoms
- PLWD experiencing early dementia symptoms
- Noticing dementia symptoms in PLWD

Phase 2: Acceptance of Symptoms
- Accepting the presence of dementia symptoms
- Deciding to seek medical help

Phase 3: Diagnostic Process
- GP performing initial testing
- Memory Clinic performing testing

Phase 4: Diagnosis Disclosure
- GP or Memory Clinic disclosing the diagnosis
- PLWD and CG reacting to diagnosis

Phase 5: Post-diagnosis Disease Management
- CG considering placing PLWD in care facilities
- CG visiting PLWD at care facilities

The phases identified in this research align with Background Understanding findings, although no single study maps the entire journey this comprehensively. The closest approximation is the study by Campbell et al. (2016), which focuses on mapping the process of uncertainty throughout the diagnostic journey and Chen & Lin (2022), which focuses on the process of seeking medical help and disclosing the diagnosis. Additionally, the Background Understanding primarily reviewed literature related to the diagnostic process, thereby lacking detail on Phase 5 (Post-diagnosis Disease Management).

7.4.3 Journey Themes

The integration of insights from TA and TM involved finding a platform enabling for direct comparison of journey themes. This was achieved by translating TM topic interpretations into thematic interpretations, which to a large extent corresponded with the themes identified in TA. This allowed the themes from the two different methods to be directly compared and synthesized. The themes identified in step 3: Synthesis are listed below with links to relevant studies within Background Understanding.

Thematic Category 1: Diagnosis

Theme a) Seeking a diagnosis
- The pursuit of a diagnosis is motivated by recognizing its value as access to medical help, future assistance, financial support, and legal management. However, it is often hindered by a lack of support from healthcare professionals. Manthorpe et al. (2013) similarly emphasizes the need for education about the benefits of obtaining a diagnosis to promote proactive seeking.
- The process of seeking a diagnosis is emotionally complex, marked by anxiety, uncertainty, fear of stigmatization, and a stressful wait, aligning with findings from Campbell et al. (2016). Bradford et al. (2009) who further discusses the stigma associated with dementia, which can delay seeking a diagnosis.

Thematic Category 2: Caregiving

Theme a) Dementia Symptoms
- Significant symptom variability, both from person-to-person and day-to-day, complicates diagnosis and care, and prevents achieving routine in both diagnostic procedures and caregiving. This variability among individuals with dementia is also noted by Lian et al. (2017) and

Chen & Lin (2022), while day-to-day variability is a new insight from this research. Relatives are often the first to notice symptoms, highlighting the importance of observation sharing to ensure everyone is equally aware. Similarly, Bradford et al. (2009), Xanthopoulou & McCabe (2019), Prorok et al. (2013), and Sideman et al. (2022) observe family members to typically be the first to detect symptoms in PLWD.

Theme b) Providing Care

- PLWD losing ability to be independent requires CGs to step in, often by moving in or hiring caregiving staff. CGs aim to provide discreet care to maintain PLWD's independence.
- However, PLWDs might see this as restrictive, causing resentment toward CGs. The desire of PLWDs to retain independence aligns with findings from Bradford et al. (2009) and Wollney et al. (2022), while the feeling of resentment is a new insight.

Theme c) CG Burden

- The research provides a detailed understanding of the increasing physical and emotional demands of caregiving and the neglect of personal needs ultimately leading to CG burnout. On a broader level, this is also captured in background studies by Chen & Lin (2022) and Patel et al. (2021).
- A new insight is the profound negative shift in the relationship between CGs and PLWD due to behavioral changes in PLWD, resulting in mutual resentment. Additionally, CGs often feel guilty for experiencing negative emotions towards PLWD and the caregiving tasks in general.

Thematic Category 3: Coping Strategies

Theme a) Support from Family & Friends

- A prominent finding of the research is the loneliness CGs experience during their caregiving journey, missing their pre-caregiving social life. This loneliness is particularly acute among spousal CGs who feel the "loss" of a partner due to dementia.
- Children who are heavily involved in caregiving often feel they lack support from siblings – an insight that has no direct parallel in the Background Understanding.

Theme b) Support from Healthcare Providers & Social Services

- Some CGs report negative experiences with healthcare professionals and social services, whom they frequently seek for advice and support. Prorok et al. (2013) and Sideman et al. (2022) emphasize that these negative experiences can deter PLWDs and CGs from seeking a diagnosis.

Theme c) Support from Online Forums

- A significant new insight from this study is the form of interaction of CGs and PLWDs with online forums. CGs and PLWDs mostly join the forum post-diagnosis. CGs use forums for advice, support, reassurance and anonymously venting negative emotions. Meanwhile, PLWDs use the forum for advice, support, recording disease progress and sharing creative works.

Theme d) Other Strategies

PLWDs engage in creative activities and maintain a positive outlook. Additionally, CGs personify dementia to separate it from the PLWD, helping to combat feelings of resentment. Both insights are not covered in the Background Understanding.

Theme e) Care Home

- CGs often consider temporary or full-time care facilities when they can no longer provide adequate care themselves. Deciding on care home placement is emotionally challenging, accompanied by feelings of guilt and betrayal toward PLWD. Post-placement, PLWDs frequently wish to return home, causing distress and reinforcing CGs' guilt. CGs remain involved even after the placement, visiting/calling and even considering bringing PLWDs back home due to pressures from the care facility lacking capacity. Since the Background Understanding focused primarily on the diagnostic process, these findings do not have a direct parallel in the reviewed literature.

Thematic Category 4: External Factors

Theme a) Stigma

- CGs worry about social stigma and perceptions of PLWDs condition, as confirmed by findings from Bradford et al. (2009).

Theme b) Impact of Covid

- COVID-19 induced lockdown worsened symptoms and hindered diagnoses. This insight has no parallel within Background Understanding.

To summarize, this research introduced new insights into the form of interaction with online forums for CGs and PLWDs. Moreover it revealed how symptom variability prevents routine in caregiving and highlighted specific CG burdens like spousal loneliness, lack of sibling support, and mutual resentment. Additionally, it detailed the decision-making process for care home placement and CG involvement after PLWDs move to full-time care facilities. These insights complemented the findings in literature which already covered symptom variability among individuals with dementia, diagnosis-seeking motivations, broader caregiving burdens, negative healthcare experiences, and stigma's impact on diagnosis-seeking behaviors.

7.4.4 Method Strengths and Limitations

The main strength of the Synthesis step of the method lies in integrating insights from TA and TM, providing both deeper and broader insights for a gaining a comprehensive understanding of the experiences of PLWDs and their CGs.

Use of the innovative approach of transposing TM topic interpretations into thematic interpretations allowsed for a more direct comparison and integration of findings from both TA and TM, extending on the original Online Community Journey Mapping method outlined by Jung et al. (2023). The ability to directly compare findings from both methods could potentially facilitate the automation of this approach in future research. Furthermore, unlike the original method by Jung et al. (2023), which treated identified TM topics as discrete points, this approach captures themes spanning longer sections of the journey.

The use of visualization techniques enabled effective communication of the results of the qualitative analysis. Current research in this area, presents qualitative findings only in text or very simplified schematic diagrams. This research has enabled the creation of a comprehensive visual overview, highlighting the relationships between themes and the contributions of each methodological step to the final findings.

However, the method has limitations, particularly in executing the visual output. Balancing detail and readability in a 2D map is challenging, often requiring simplification that can lose valuable detail. An interactive interface with toggleable layers could offer more nuance and better illustrate relationships between themes.

Moreover, the method failed to capture the temporal dimension of the journey due to significant variability in patient experiences. Additionally, while the primary goal was to map the diagnostic process, the map covers a broader scope, reflecting the nature of the data sources and extending beyond the initial research focus.

To summarize, the final step of the method – Step 3: Synthesis – enabled the integration of insights from previous steps, creating a comprehensive visual representation of the PLWD and CG journey that also captures individual method contributions. In the subsequent Design Output phase, the map was simplified for use in co-creation sessions and follow-up interview studies. This simplification aimed to support the next phase of the EBC framework design, focusing on ideating interventions to improve the current dementia diagnosis system. ■

8

Design Output

This chapter presents the research output designed for use in co-creation sessions and follow-up interview studies. It includes condensed and simplified findings to facilitate understanding and engagement. These outputs take the form of Personas and a Journey Map that illustrates the experiences of PLWDs and their CGs as they seek a dementia diagnosis.

Chapter Content Overview

8.1 Design Objective

Within the EBC framework, the initial “Understand” phase is followed by the “Design” phase, which focuses on ideating and crafting strategies for systemic improvements. This chapter presents design outputs derived from the synthesized insights of the research method section. These outputs serve as tangible visual aids to facilitate discussions on potential system interventions during co-creation sessions. More specifcially, they may enhance communication among interdisciplinary teams by providing a common reference point that illustrates the nuanced experiences of key stakeholders. They may also prove valuable in follow-up studies with general practitioners (GPs) to gain their perspectives on the diagnostic journey.

The design output includes:

- **Journey Map:** of PLWDs and CGs seeking a dementia diagnosis
- **Personas:** two PLWD personas (male and female) and two CG personas (spousal and child CG)
- **Thematic Cards:** providing detailed explanations of themes

8.1.1 Journey Map

The journey map provides a comprehensive yet nuanced depiction of the dementia journey for PLWDs and CGs, from noticing early symptoms to post-diagnosis disease management. The map is structured into five main phases, temporal steps, and overarching themes. Additionally, it includes a graph showing forum demographics to contextualize the journey map findings. Colors are used to clearly distinguish themes relevant to PLWDs and CGs, enhancing clarity and readability.

8.1.2 Personas

The personas are designed to enhance empathy with key system stakeholders – including PLWDs (male and female) and CGs (spousal and child). Each persona includes a blurred photograph of a person to ensure greater anonymity, allowing participants in co-creation sessions to better identify with the persona. Additionally, each persona includes a brief description of their situation, reflecting the typical experiences of PLWDs or CGs on the forum based on research findings. These personas are given voice through a short quote from the forum, adding a sense of authenticity and providing context.

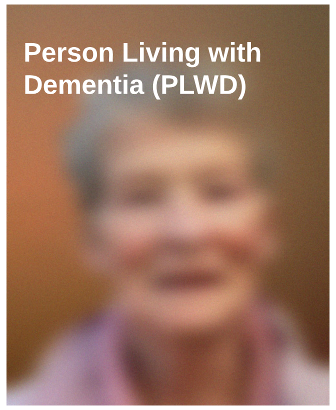
8.1.3 Thematic Cards

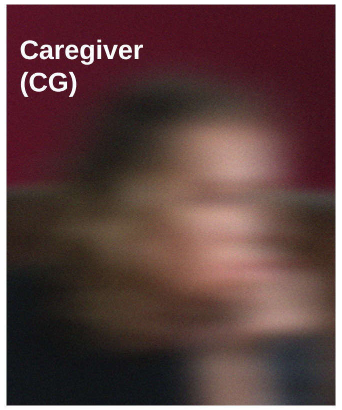
Thematic cards feature the title and a brief description of each theme from the journey map, providing additional detail. During co-creation sessions, participants can distribute and discuss these cards to facilitate deeper understanding and engagement with the journey map.

8.2 Design Output

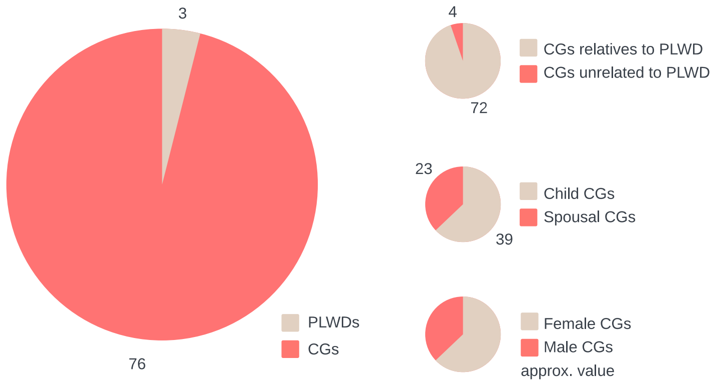
The following pages contain the individual parts of the design output.

Journey Map of PLWDs and CGs Seeking a Dementia Diagnosis



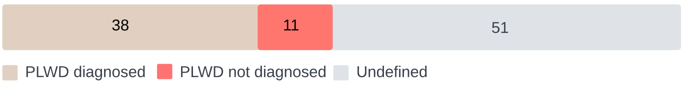


Forum Demographics



PLWD'S DIAGNOSIS STAGE

DIAGNOSIS STAGE

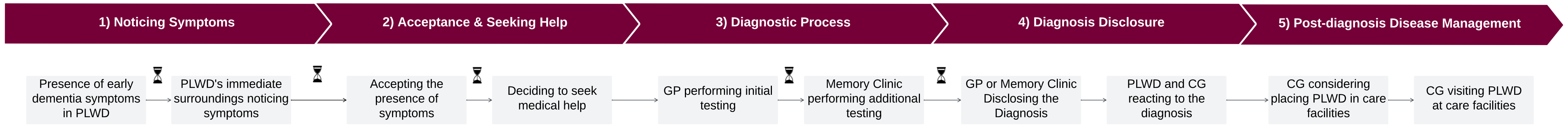


CAREGIVING TYPE

All values are drawn from TA categorisation of a sample of 100 coded posts

Legend

⌛	Significant waiting time
▭ (dashed)	Thematic category
☐	Theme
🟥	PLWD-related sub-theme
🟫	CG-related sub-theme
▨	PLWD and CG related sub-theme



DIAGNOSIS

SEEKING A DIAGNOSIS

Motivation for pursuit: Diagnosis recognized as a gateway to medical help and support.

Barriers for pursuit: Fear of stigma and loss of independence

Diagnostic process: Anxiety, unfamiliarity, stressful waits, and unhelpful professionals

Post-Diagnosis: Shock, unpreparedness regret for not arranging dementia-related matters sooner

CAREGIVING

DEMENTIA SYMPTOMS

Symptom variability from person-to-person: Cognitive (memory loss, disorientation, delusions), behavioral (aggression, mood swings, anxiety), and physical symptoms (mobility issues, incontinence).

Symptom fluctuation from day-to-day: Significant variability within the same individual hinders routine and predictability in caregiving.

Observation and early detection: In most cases relatives and friends notice changes; early signs often mistaken for emotional problems; sharing observations is crucial to ensure everyone is equally informed.

PROVIDING CARE

Loss of independence: With progressing dementia PLWDs lose ability to be independent, requiring CGs to move in or hire caregiving staff.

Discreet Care Approach: CGs try to maintain PLWD's sense of independence; interested in use of security technologies.

Resistance and Aggression: PLWDs may resist care and resent CGs, perceiving them as taking away their independence.

CG BURDEN

Increasing burden: Worsening condition of PLWD causes increasing physical and emotional burden on CGs, leading them to feel resentment toward PLWD due to behavioral changes and intense caregiving demands.

CG burnout: CGs prioritize caregiving over personal time, neglecting their own needs, ultimately leading to CG burnout and need for respite through placement of PLWD in temporary or full-time care facilities.

COPING STRATEGIES

SUPPORT FROM FAMILY & FRIENDS

CG loneliness: CGs feel isolated, lacking pre-caregiving social connections. Spousal CGs experience a profound sense of loss due to PLWD behavior changes. Child CGs report inadequate sibling involvement, leading to resentment and strained family relationships.

SUPPORT FROM HEALTHCARE & SOCIAL SERVICES

Lack of adequate support: CGs seek comprehensive support from healthcare professionals (seeking advice on managing caregiving for a PLWD) and social services but frequently find it inadequate.

SUPPORT FROM ONLINE FORUMS

PLWD forum interaction: PLWDs use forums to seek support, share experiences, record symptom progression, and showcase creative works.

Seeking support and advice: CGs use online forums for advice on managing symptoms, legal and financial matters, and coping with behavioral changes. Majority joins the forum post-diagnosis.

Emotional outlet: Online forums offer a judgment-free space for CGs to vent, share burdens, and receive empathy, helping in stress management.

OTHER STRATEGIES

PLWD coping strategies: PLWDs engage in creative activities, a positive outlook, and supportive communities to manage their condition.

CG Coping Strategies: CGs personify dementia to separate it from PLWD, reducing frustration and resentment.

CARE HOME

Care home placement: Consider care homes due to inability to provide care; the decision involves guilt and betrayal, seeking reassurance in online forums.

Refusal to join care home: PLWDs experience distress and worsening symptoms after moving to a care home, with a strong desire to return home.

EXTERNAL FACTORS

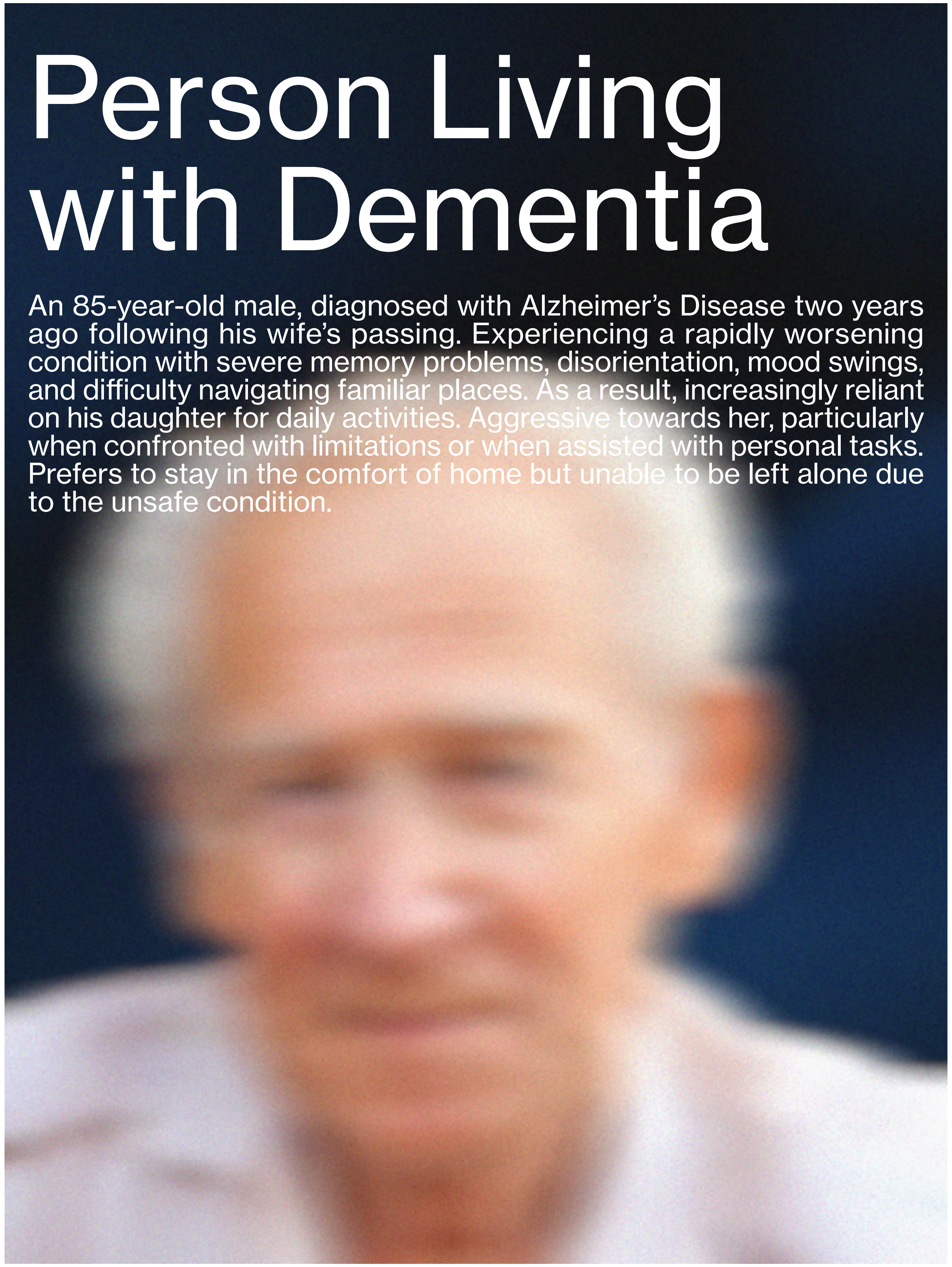
STIGMA

Dementia Perception & Stigma: CGs worry about others' perceptions of PLWDs. Fear of stigmatization also prevents PLWDs from accepting symptoms and seeking a diagnosis.

IMPACT OF COVID

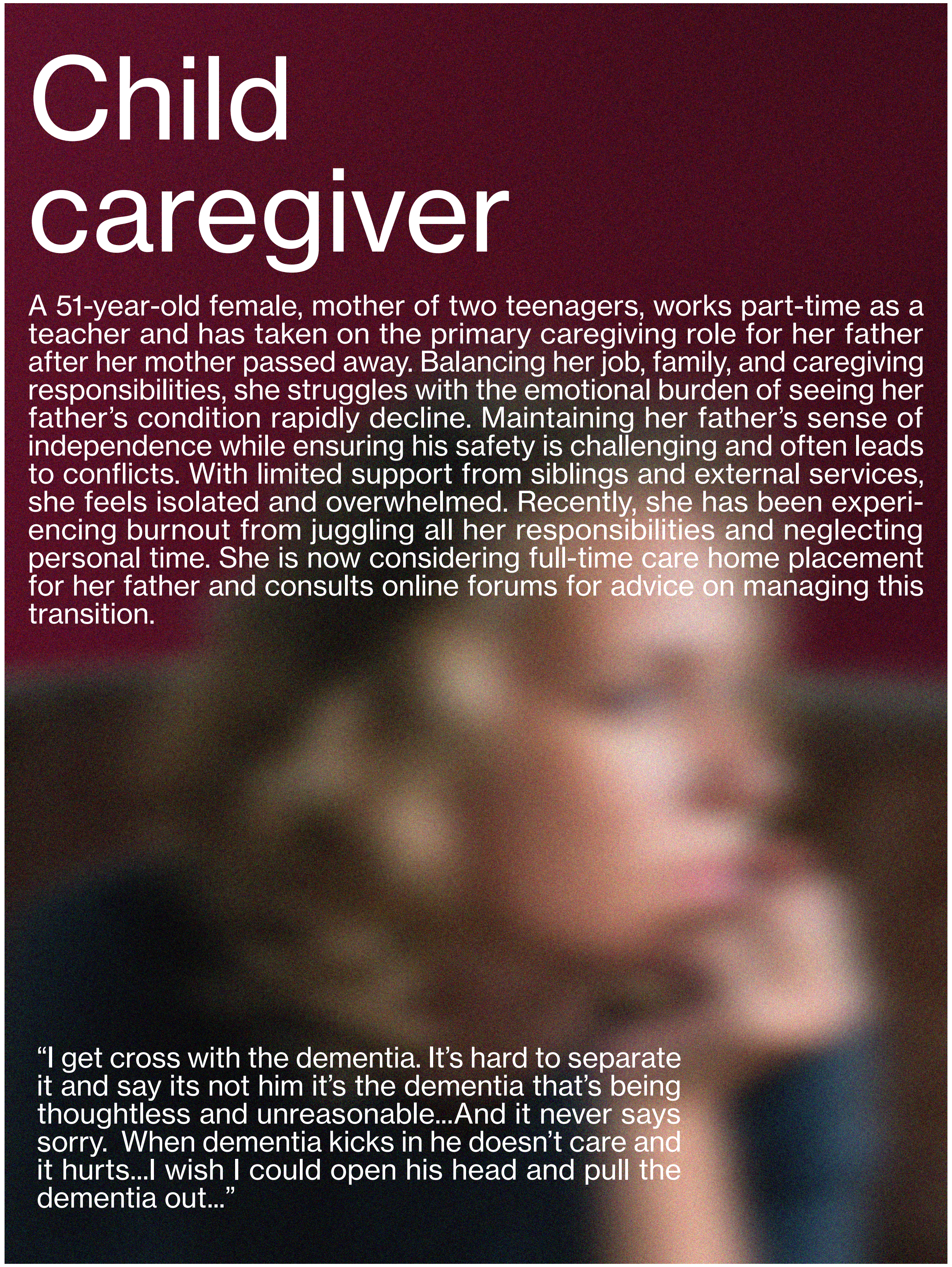
Lockdown isolation: Worsened dementia symptoms in PLWD, hindered obtaining diagnoses, and reduced care home visits.

Personas



Person Living with Dementia

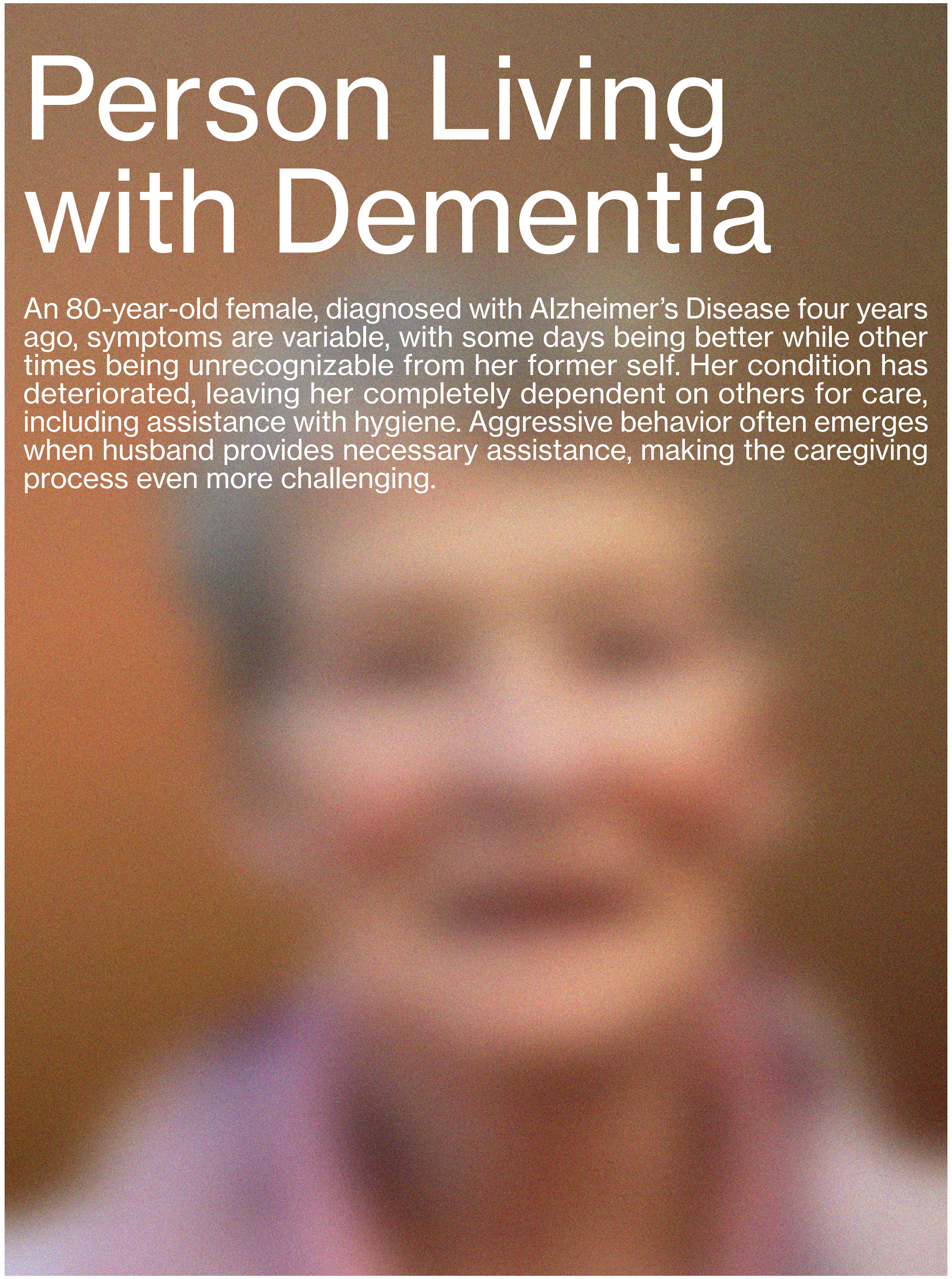
An 85-year-old male, diagnosed with Alzheimer's Disease two years ago following his wife's passing. Experiencing a rapidly worsening condition with severe memory problems, disorientation, mood swings, and difficulty navigating familiar places. As a result, increasingly reliant on his daughter for daily activities. Aggressive towards her, particularly when confronted with limitations or when assisted with personal tasks. Prefers to stay in the comfort of home but unable to be left alone due to the unsafe condition.



Child caregiver

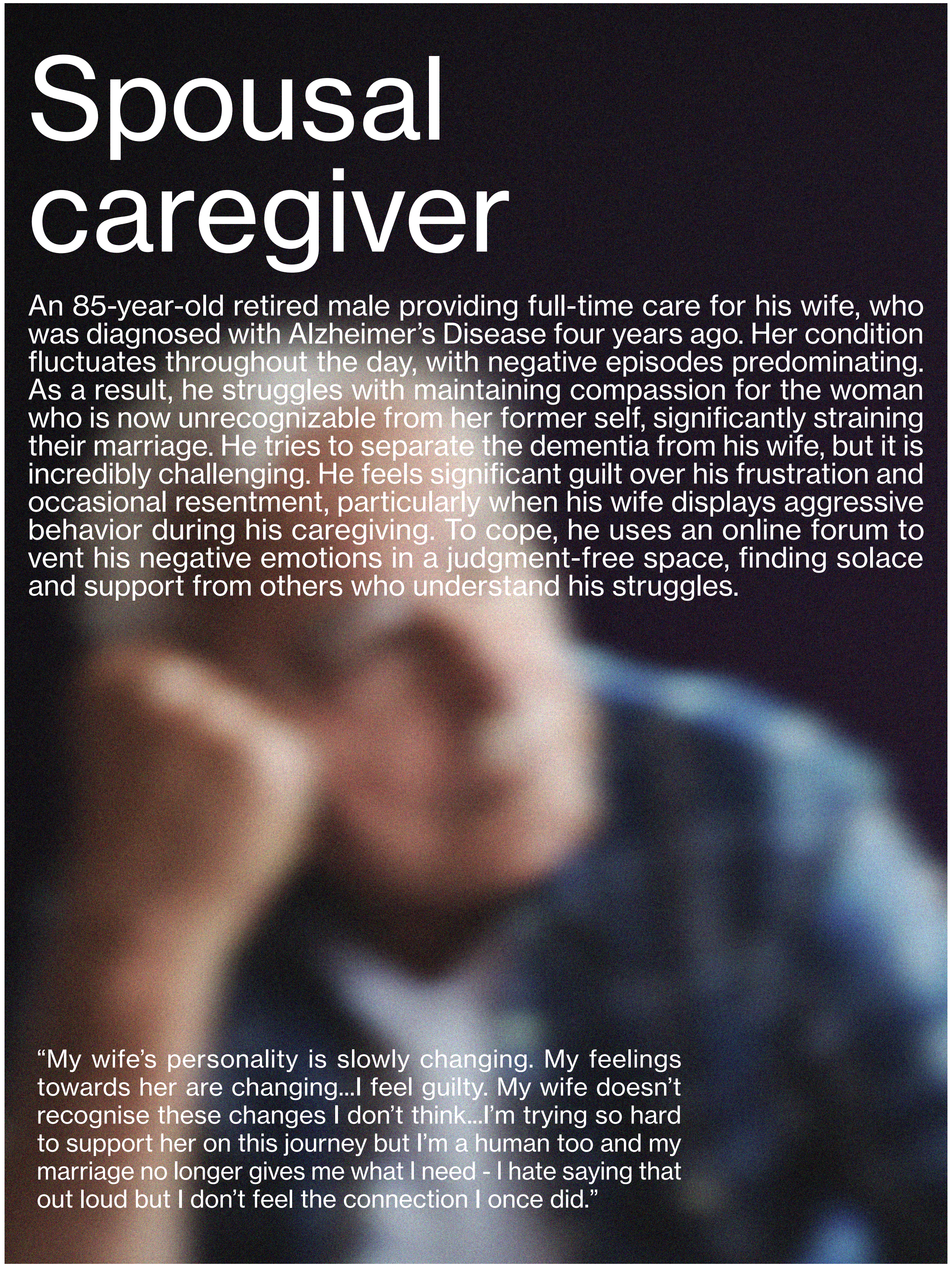
A 51-year-old female, mother of two teenagers, works part-time as a teacher and has taken on the primary caregiving role for her father after her mother passed away. Balancing her job, family, and caregiving responsibilities, she struggles with the emotional burden of seeing her father's condition rapidly decline. Maintaining her father's sense of independence while ensuring his safety is challenging and often leads to conflicts. With limited support from siblings and external services, she feels isolated and overwhelmed. Recently, she has been experiencing burnout from juggling all her responsibilities and neglecting personal time. She is now considering full-time care home placement for her father and consults online forums for advice on managing this transition.

"I get cross with the dementia. It's hard to separate it and say its not him it's the dementia that's being thoughtless and unreasonable...And it never says sorry. When dementia kicks in he doesn't care and it hurts...I wish I could open his head and pull the dementia out..."



Person Living with Dementia

An 80-year-old female, diagnosed with Alzheimer's Disease four years ago, symptoms are variable, with some days being better while other times being unrecognizable from her former self. Her condition has deteriorated, leaving her completely dependent on others for care, including assistance with hygiene. Aggressive behavior often emerges when husband provides necessary assistance, making the caregiving process even more challenging.



Spousal caregiver

An 85-year-old retired male providing full-time care for his wife, who was diagnosed with Alzheimer's Disease four years ago. Her condition fluctuates throughout the day, with negative episodes predominating. As a result, he struggles with maintaining compassion for the woman who is now unrecognizable from her former self, significantly straining their marriage. He tries to separate the dementia from his wife, but it is incredibly challenging. He feels significant guilt over his frustration and occasional resentment, particularly when his wife displays aggressive behavior during his caregiving. To cope, he uses an online forum to vent his negative emotions in a judgment-free space, finding solace and support from others who understand his struggles.

"My wife's personality is slowly changing. My feelings towards her are changing...I feel guilty. My wife doesn't recognise these changes I don't think...I'm trying so hard to support her on this journey but I'm a human too and my marriage no longer gives me what I need - I hate saying that out loud but I don't feel the connection I once did."

Thematic Cards

Seeking a Diagnosis

Diagnosis

The pursuit of a dementia diagnosis is emotionally complex, marked by anxiety, fear, and uncertainty for both PLWDs and CGs. Fear of losing independence and stigmatization causes PLWDs to avoid seeking a diagnosis and downplaying symptoms during diagnostic appointments. Diagnosis officially formalizes the roles of CGs and PLWDs, leading to feelings of shock and unpreparedness. Morevoer, CGs often regret not planning for dementia-related matters sooner.

Dementia Symptoms

Caregiving

Dementia symptoms vary among PLWDs, hindering standardization in diagnostic and care practices. Cognitive symptoms include memory loss, disorientation, and delusions, while behavioral symptoms include aggression, mood swings, accussations and anxiety. Physical symptoms such as mobility issues, incontinence and eyesight problems also arise. The variety of these symptoms adds to the unpredictability of caregiving, as PLWDs experience good and bad days.

Providing Care

Caregiving

CGs strive to provide discreet care to maintain PLWD's sense of independence, leading them to be interested in the use of security technologies. However, PLWDs may resist care and show aggression towards CGs, perceiving these measures as restrictive.As dementia progresses, CGs must take on more responsibilities, usually moving in with PLWD or hiring staff, particularly when PLWDs live alone or with a partner who also has dementia.

CG Burden

Caregiving

The progressive nature of dementia, combined with CGs neglecting their personal needs out of guilt ultimately leading to exhaustion and burnout. Particularly in spousal caregiving, this is further compounded by the emotional burden, including shifts in feelings towards PLWDs, resulting in resentment toward PLWD due to behavioral changes and high caregiving demands. As a result many CGs seek respite through temporary or full-time placement of PLWD in care facilities.

Support from family & friends

Coping Strategies

CGs often feel very isolated, missing their pre-caregiving social connections. Spousal CGs, in particular, experience a profound sense of loss and a lack of support from their PLWD partner, due to their significant shift in behaviour. Meanwhile, child CGs frequently feel lonely and excessively burdened due to inadequate support from siblings, leading to feelings of resentment and strained family relationships.

Support from healthcare & social services

Coping Strategies

CGs frequently seek help, whether it be advice on managing symptoms from healthcare professionals or practical caregiving assistance from social services. Unfortunately, they often find the support inadequate – social services are difficult to arrange, and healthcare professionals are often rushed and unhelpful.

Support from Online Forums

Coping Strategies

Dementia-related online forums offer caregivers (CGs) and people living with dementia (PLWDs) a platform to seek advice, support, and reassurance from those with shared experiences. Both CGs and PLWDs typically join these forums post-diagnosis. In addition to seeking advice, CGs primarily use the forums to vent their negative emotions about caregiving in a judgment-free space. Meanwhile, PLWDs use the forums to document changes in their condition and share their creative works.

Other Strategies

Coping Strategies

PLWDs use creative activities, maintain a positive outlook, and engage with supportive communities to cope with their symptoms. Caregivers (CGs) manage their frustration and resentment towards PLWDs by personifying dementia, which helps them separate the condition from the person.

Care Home

Coping Strategies

CGs consider care homes when they are exhausted from caregiving or face late-stage dementia care challenges. The decision is significantly emotionally difficult, filled with guilt and a sense of betrayal towards the PLWD. As a result they seek reassurance online and prefer nearby care homes allowing for frequent visits. Post-placement, PLWDs often refuse to join a care home, increasing CGs' guilt. After placement of PLWD in a care hme, CGs remain actively involved, sometimes even considering bringing PLWDs back home.

Stigma

External Factors

CGs worry about societal perceptions of PLWDs' behavior, reflecting the stigma associated with dementia. Fear of stigmatization may also prevent PLWDs and CGs from accepting presence of dementia symptoms and seeking a diagnosis.

Impact of Covid

External Factors

The COVID-19 pandemic worsened dementia symptoms in PLWDs due to isolation. Moreover it hindered the process of obtianing a diagnosis. Lockdowns additionally reduced care home visits, affecting PLWDs' well-being and intensifying caregiving challenges for CGs.

9

Discussion

This chapter provides a high-level discussion of the research, addressing three main questions: mapping the journeys of PLWDs and their CGs, exploring how data-enabled journey mapping overcomes traditional method limitations, and examining how designers can contribute to dementia research.

Chapter Content Overview

In light of the recent approval of therapies effective only in the early stages of Alzheimer's disease, the need to enhance early diagnosis strategies is more pressing than ever. Consequently, this project sought to lay the groundwork for systemic change of integrating early detection of dementia into clinical practice across the UK. Aligned with the EBC framework, focusing on its first phase – 'Understand', the study sought to capture the complexities of the dementia diagnostic journey from the perspectives of its key stakeholders – PLWDs and their CGs. This study aimed to address identified research gaps and answer the following research question:

RQ1: What nuanced insights can be gained from mapping the experiences of PLWDs and their CGs to inform the enhancement of early dementia diagnosis strategies?

Based on the findings from addressing **RQ1**, the project also explored two supplementary research questions:

RQ2: Given the limitations of traditional journey mapping methods, how can the use of data-enabled design research improve the creation of these journey maps?

RQ3: What is the role of design in advancing dementia research, and what benefits does their involvement offer?

9.1 RQ1: Mapping the Experiences of PLWDs and CGs

The findings from the Background Understanding revealed significant gaps in current research on the diagnostic journey of PLWDs and their CGs. These gaps include the lack of a holistic perspective and difficulty generalizing findings.

- **Lack of holistic perspective:** Existing studies often focus on individual episodes of the diagnostic process, missing the broader context and continuity of the entire journey. Even when capturing the whole journey, they typically explore a single theme, such as the theme of uncertainty during the diagnostic process explored by Campbell et al. (2016).
- **Difficulty generalizing findings:** Most studies employ traditional qualitative methods, which are laborious and thus tend to analyse smaller samples, preventing generalisation of findings. Conversely, larger quantitative studies often lack the nuance needed to detail the experiences of PLWDs and their CGs.

To address these gaps, this research aimed to provide a comprehensive overview of the diagnostic journey, maintaining both nuance and generalizability of the findings. Inspired by Jung et al. (2023), the project leveraged a combination of thematic analysis and topic modeling to create a detailed journey map of PLWDs' and CGs' diagnostic experiences. The findings from these maps were captured at three levels: 1) Forum demographics, 2) Journey phases and temporal steps, and 3) Journey themes.

9.1.1 Forum demographics

The data analysis revealed that majority of the forum users are CGs, vastly outnumbering PLWDs and other stakeholders, such as professional CGs or GPs. Consequently, the research predominantly captured the perspectives of CGs and only yielded second-hand insights from PLWDs, despite the original intent to primarily map the patients' journeys Future research should therefore explore more ways to directly obtain PLWDs' perspectives.

Consistent with Gilsenan et al. (2022), the majority of these CGs are female, predominantly spouses or daughters of PLWDs. However, predominance of female CGs may be influenced by self-selection bias, as research shows women are more likely to seek help on online forums (Hausner et al., 2008). Understanding gender dynamics further is crucial to address gender-specific needs and provide tailored support to CGs. (Bartlett et al., 2016)

Furthermore, most CGs on the forum care for already diagnosed PLWDs, primarily in advanced stages of the disease. These PLWDs are mainly cared for at home, while CGs often consider transitioning them to full-time care facilities, as also noted by Gilsenan et al. (2022). The predominance of already diagnosed patients made it challenging to capture the nuances of the early diagnostic process, an area insufficiently covered in existing research. This suggests a need to explore other sources to understand why early diagnosis is often missed and gain further insights into the experiences of undiagnosed individuals.

9.1.2 Journey phases and temporal steps

The research identified an overview of five main phases of the journey with corresponding temporal steps, including: Phase 1: Noticing symptoms, Phase 2: Acceptance of Symptoms, Phase 3: Diagnostic Process, Phase 4: Diagnosis Disclosure and finally Phase 5: Post-diagnosis Disease Management. These phases correlate with those identified by Campbell et al. (2016) and Chen & Lin (2022). However, this research further develops these phases with concrete temporal steps and nuanced themes visualized using a journey map, providing a more holistic depiction of the PLWD and CG experience.

9.1.3 Journey themes

In terms of journey themes, this research aimed to capture a comprehensive overview of themes spanning all identified phases, unlike existing literature, which typically delves deeply into themes within a single phase or focuses on one theme exclusively. Mapping a broader range of themes longitudinally, rather than as individual snapshots, provides a more comprehensive understanding illustrating the evolution of topics over time. As a result, this allows for suggesting more sustainable and long-term solutions for system improvement.

The journey map identified themes spanning across five different phases, grouped into 4 thematic categories. Below are the main findings from each category related to the literature findings. At the same time, the findings are complemented by any resulting systemic improvements that can be validated in future research on assessing the feasibility and impact of these proposed solutions.

Thematic Category 1: Diagnosis

The research identified motivations for seeking a diagnosis, including the awareness of its importance for obtaining medical, financial, and legal support. It also highlighted significant barriers, such as a lack of knowledge about early treatment options and insufficient support from healthcare professionals. Emotional barriers like anxiety and fear of stigma were also identified, reflecting findings from Manthorpe et al. (2013) and Campbell et al. (2016). Based on these findings, and in line with the aforementioned studies, it is recommended to enhance educational campaigns to raise awareness of the benefits of early diagnosis, encouraging more proactive behavior from PLWDs and CGs. Additionally, providing clear information about the diagnostic process can help alleviate uncertainty.

Thematic Category 2: Providing Care

Regarding dementia symptoms, the research confirmed the significant role of relatives in detecting initial symptoms, a finding supported by multiple studies including Bradford et al. (2009), Xanthopoulou & McCabe (2019), Prorok et al. (2013), and Sideman et al. (2022). Additionally, the research highlighted significant symptom variability among patients, as noted by Lian et al. (2017) and Chen & Lin (2022). Contribution of this research lies in the revelations of signfiicant day-to-day variability in symptoms, which prevents the establishment of routines in diagnostic procedures and caregiving. Based on these findings, we recommend exploring the application of the latest personalization technologies, including the use of AI and GPTs, to help detect specific symptoms and provide tailored care tips allowing to manage the variability in dementia symptoms.

Another significant contribution of the research is the identification of nuances in the context of care provision. As PLWDs lose their ability to be independent, CGs often step in, striving to provide discreet care to maintain the PLWD's sense of independence. However, PLWDs may see this as restrictive, leading to resentment toward CGs. The desire of PLWDs to retain independence aligns with findings from Bradford et al. (2009) and Wollney et al. (2022), while the feeling of resentment is a new insight from this research.

Due to an increase in physical and emotional demands increase, coupled with the neglect of personal needs, CGs ultimately experience burnout. This broader level of caregiver burden is also documented in studies by Chen & Lin (2022) and Patel et al. (2021). A new insight from this research is the profound negative shift in the relationship between CGs and PLWDs due to behavioral changes in PLWDs, resulting in mutual resentment. As a result of the significant burden placed on CGs, it is essential to provide comprehensive support not only for PLWDs but also for CGs to help them manage these complex emotional challenges.

Thematic Category 3: Coping Strategies

A significant contribution of the research is the identification of strategies that help CGs to cope with the disease. These include support from family and friends, healthcare providers and social services, and online forums. Finally, in the later stages once CGs can no longer provide care, placing PLWDs in care facilities becomes the ultimate strategy. While these strategies are individually mentioned across various studies, this research offers their comprehensive overview, capturing nuances enabled by analyzing online forums as a data source.

In terms of support from family & friends, the research highlights the loneliness CGs experience, particularly spousal CGs who feel the "loss" of a partner, and child CGs who often lack support from siblings in caregiving, an insight not paralleled in the the reviewed literature.

Regarding support from healthcare and social services, the research captured CGs reporting negative experiences with healthcare professionals and social services, deterring PLWDs and CGs from seeking a diagnosis, as emphasized by Prorok et al. (2013) and Sideman et al. (2022). Improving these services and further training healthcare providers in empathic communication is vital to prevent discouraging PLWDs and CGs from seeking a diagnosis, as outlined by Wollneyet al. (2022), Prorok et al. (2013) and Poyser (2018).

A significant new insight is how CGs and PLWDs interact with online forums post-diagnosis. CGs use forums for advice, support, reassurance, and anonymously venting negative emotions, while PLWDs use them for advice, support, recording disease progress, and sharing creative works. Based on this research further exploration and targeted use of these forums for providing practical support and emotional relief would be recommended. Given that most CGs or PLWDs join the forum only after receiving a diagnosis, encouraging a more early engagement with these forums could help users identify symptoms sooner, and hence seek diagnosis more proactively.

Additionally, the research identified the strategy of personifying dementia, which helps CGs separate the disease from the PLWD, thereby helping to combat resentment. This strategy is not covered in the existing literature. Promoting these strategies could help others manage similar challenges.

Finally, the research delves deeply into the strategy of considering temporary or full-time care facilities when CGs can no longer provide care themselves. Due to feelings of guilt and betrayal associated with relocating PLWDs to care facilities, CGs often seek reassurance and understanding from others with shared experiences on the forum, allowing to capture nuances in this theme including emotional complexities due to PLWD's refusal and post-placement involvement of CGs. These insights do not have a direct parallel in the reviewed literature, which focused primarily on the diagnostic process.

Thematic Category 4: External Factors

Finally, research highlighted several external factors affecting the dementia journeys. Firstly, research reveled CGs experiencing worry about social stigma and perceptions of PLWDs' conditions, as confirmed by Bradford et al. (2009). Efforts to reduce stigma through education and support are needed. Furthermore, posts on the forum from the time of the Covid-19 pandemic highlighted how lockdowns worsened symptoms and hindered obtaining diagnoses. This insight has no parallel within the reviewed literature.

To summarize, this research introduced new insights into the CG experience throughout the dementia journey, from noticing symptoms in PLWD to managing the disease post-diagnosis. It highlighted the significant role of online forums as a coping mechanism, revealed how day-to-day symptom variability complicates caregiving routines, and identified specific burdens such as spousal loneliness, lack of sibling support, and mutual resentment among PLWDs and CGs. Additionally, it detailed the decision-making process for care home placement and ongoing CG involvement after PLWDs move to full-time care facilities. These insights complemented existing literature on motivations for seeking a diagnosis, symptom variability, caregiving burdens, inadequate support from healthcare professionals, and the impact of stigma.

9.1.4 Strengths and Limitations

The research provided valuable, nuanced insights into CGs caregiving experiences and coping strategies. The TM analysis of over 45,000 online patient stories further validated these insights enhancing their generalizability. These findings can inform the design of effective system interventions to improve the well-being of both CGs and PLWDs post-diagnosis.

The primary limitation, in terms of answering RQ1, was the second-hand nature of PLWDs' perspectives and the lack of insight into pre-diagnosis stages, as most forum users were CGs of already diagnosed PLWDs. While the aim was to understand barriers and facilitators from PLWDs' perspectives, most identified themes instead related to CGs' experiences with post-diagnosis care management. In contrast, traditional qualitative interview studies, such as those by Lian et al. (2017), Xanthopoulou & McCabe (2019), and Prorok et al. (2013), allow for obtaining more direct information from PLWDs.

9.1.5 Future research

Future research should explore other sources to gain direct insights from PLWDs, professional CGs and GPs. Examining forums focused on the pre-diagnostic process or engaging individuals who do not yet have a diagnosis can help further understand barriers to diagnosis pursuit. Considering more general platforms like Reddit [16] or Quora [17], might provide more insights into the experiences of those still seeking a diagnosis, who are not yet aware of specialized Alzheimer's Disease forums.

Morevoer, in the next phase of the EBC framework – `Design`, interdisciplinary teams should evaluate the feasibility and impact of suggested interventions. Finally, continued interaction with the journey map and personas through co-creation sessions would help generate and refine new ideas on system interventions.

9.2 RQ2: Data-Enabled Journey Mapping

The literature review identified several limitations associated with current methods of mapping themes related to dementia diagnosis journeys. Traditional journey mapping methods typically rely on qualitative techniques using relatively smaller samples, providing nuanced insights but lacking representativeness and comprehensive coverage of the full range of journey themes, as seen in studies by Lian et al. (2017), Campbell et al. (2016), and Xanthopoulou & McCabe (2019). Alternatively, systematic literature reviews provide comprehensive overviews but

[16] – https://www.reddit.com/, accessed on 2024, July 28

[17] – https://www.quora.com/, accessed on 2024, July 28

lack direct responses from system stakeholders.
To address these gaps, this research employed a data-enabled design research method inspired by Online Community Journey Mapping by Jung et al. (2023). This method was applied to analyze online patient stories on the UK Alzheimer's Society dementia support forum, one of the largest of its kind globally.

The method combined three steps integrating human design researcher and ML capabilities:

- **Thematic Analysis:** Conducted on a smaller representative sample to capture nuances and gain a deep understanding of journey dynamics, facilitating subsequent interpretation of topics.
- **Topic Modeling:** Validated the generalizability of insights from thematic analysis on a broader forum and augmented them with insights obtainable from the larger dataset.
- **Synthesis:** Integrated insights from thematic analysis and topic modeling to provide comprehensive yet nuanced understandings of PLWDs' and CGs' journeys.

9.2.1 Method Innovations

The method was enhanced with two key innovations beyond the original Online Community Journey Mapping approach by Jung et al. (2023):

- 1) Enhancing interpretation of LDA Topic Models using frequency thresholds and extraction of relevant posts per topic.
- 2) Transposing LDA topics into themes allowing to directly compare them with thematic analysis themes.

1) Frequency thresholds and Extraction of relevant posts

LDA topic modeling outputs are sets of words without context, making interpretation challenging. To address this an interpretation pipeline with thresholds at different levels of granularity was proposed, allowing interpretations to progress from general to highly nuanced insights. Moreover, extracting post messages containing words with similar probabilities within the topic modeling outputs at various thresholds provided more context and a more evidence-based approach to interpretation. This enhanced the robustness of topic interpretations by better contextualizing the words from the topic modeling output.

Future research could benefit from quantifying this approach to validate the method further:

- Within-topic threshold variability: Assess robustness by minimizing variance among extracted posts for various thresholds within a single topic.
- Between-topic variability: Ensure uniqueness by maximizing variance among extracted posts between all topics.

Additionally, these innovations can contribute to automating the method as feeding the interpretation pipeline and extracted posts to ChatGPT 4.0, could generate more accurate topic interpretations.

2) Transposing LDA topics into themes

After interpreting the topics from TM, they were compared with the themes from TA. Recurring themes across different TM topics were identified by the researcher and transposed into cross-cutting themes. This innovative approach revealed that insights from the thematic analysis were largely aligned with those from topic modeling, allowing for direct comparison of findings between the two methods Unlike presenting TM topics as isolated snapshots in time, as in the current Online Community Journey Mapping method by Jung et al. (2023), this transposition allowed to capture insights from TM in themes spanning across the entire journey. The direct comparison of insights from TA and TM, could potentially enhance collaboration between human researchers and ML, and has potential for future method automation.

9.2.2 Strengths and Limitations

The method demonstrated several strengths in terms of addressing RQ2. Primarily, the integration of TA and TM allowed to capture both nuanced insights and comprehensive coverage, which is a unique strength of this method. The use of TM further enabled the effective analysis of an extensive sample of online patient stories, enhancing the generalizability of the findings.

Additionally, the online patient stories captured authentic expressions independent of researchers' prompts, with the anonymity of forum posts helping to reduce stigma. Contrary to initial expectations, participants were very open in their disclosures despite the permanent nature of the online forums.

Finally, translating findings into a visual journey map proved to be a significant research contribution, as it allowed for a more effective visualization of findings compared to purely textual research.

However, there were notable limitations, including the self-selection bias, which prevented the generalizability of forum insights to populations outside the forum. Additionally, the variability in post length and content among forum messages further impeded the generalizability of findings, as a large sample of posts did not guarantee uniform quality. To mitigate this, only first thread posts were analyzed for their consistency in density and content quality.

Furthermore, both online patient stories and LDA topic modeling outputs lacked context, complicating interpretation. This issue was addressed by including frequency thresholds in the interpretation pipeline and extracting relevant posts to more accurately interpret the text.

Finally, the visual mapping itself was challenging, particularly in balancing comprehensiveness with detail in a 2D format. A digital map with toggleable layers allowing to show various levels of depth might offer a better solution depending on the intended use.

9.2.3 Future Research

Future research should focus on automating the approach to enhance its effectiveness and applicability across various parts of the system, different stakeholders, or other diseases. Integrating innovations from the interpretation pipeline and extracted posts could facilitate this automation using tools like ChatGPT 4.0.

Additionally, further quantifying thematic insights to identify the most critical points in the journey could guide design teams, helping to focus their interventions on the most crucial aspects of the journey.

Morevoer, given the EBC framework's goal of achieving a measurably better system, comparing and further quantifying the initial journey map before and after implementing solutions could allow to track increased satisfaction or barrier removal providing evidence for system improvement. Finally, developing digital maps with toggleable layers could balance nuance with readability.

9.3 RQ3: Role of Design in Dementia Research

The literature review found minimal designer involvement in dementia research. Newton et al. (2024) supports this, highlighting that despite their skills in tackling complex problems, designers are not well integrated into this field. Currently, designers primarily co-design tailored dementia tools and aids with PLWDs and CGs, incorporating their needs and perspectives (Wang et al., 2019), however they are very rarely involved in designing interventions for systemic improvements.

To address this gap, the researcher, with a background in design, aimed to demonstrate the value of designerly capabilities in dementia research to advocate for their inclusion. These capabilities proved useful at various stages of the research, particularly in mapping and visualizing themes related to PLWD and CG journeys.

Consistent with findings by Jung et al. (2023), the designers' ability to deeply empathize was invaluable for interpreting forum user's experiences and identifying trends. Additionally, this profound understanding, coupled with designerly intuition, was essential for interpreting the LDA topic modeling outputs.

Furthermore, designers' skills in navigating complex systems and seeking simplification opportunities proved valuable for system mapping and subsequent effective visualization. Given the complexity of the dementia journey, which involves multiple concurrent themes, this capability was indispensable.

Last but not least, designers' ability to craft visualizations effectively communicating the delicate balance between journey comprehensiveness and nuance made complex research data more accessible and comprehensible to diverse stakeholders. (Jung et al., 2023; Moere & Purchase, 2011).

Conversely, participating in dementia research and employing data-enabled design research methods helped expand designers' capabilities. Based on the researcher's experience, it was identified that this participation can enhance skills in quantifying and generalizing nuanced thematic findings. This can suport more evidence-based design outcomes, crucial for advocating and implementing ideas, especially in healthcare transformations. (Morales Ornelas et al., 2023)

9.3.1 Future research

Future research should focus on further integrating designers into dementia research, specifically through the use of frameworks like EBC, which inherently integrate design into their processes. Additionally, in line with Morales Ornelas et al. (2023), designers should emphasize evidence-based design development, which is particularly crucial for driving innovation in fields like medicine that heavily rely on empirical evidence. Finally, in line with findings from Jung et al., the researcher recommends more intensive collaboration with machine learning experts to enhance the efficiency of the research process and further quantify findings and validate methodologies leading to potential method automation. ■

10

Conclusion

This chapter provides a summary of the research, including a brief overview of the main findings, limitations of the study and suggestions for future research.

In light of the recent approval of Alzheimer's Disease therapies, effective only in the early stages of the disease, this study aimed to integrate early detection of dementia into clinical practice across the UK by examining the initial 'Understand' phase of the EBC framework. The research focused on capturing the complexities of the dementia diagnostic journey from the perspectives of PLWDs and their CGs by analyzing a large sample of online patient stories from the UK Alzheimer's Society using a data-enabled design research method inspired by Online Community Journey Mapping by Jung et al. (2023).

The literature review highlighted significant gaps in current research on the diagnostic journey of PLWDs and their CGs, such as the lack of a holistic perspective and challenges in generalizing findings. Existing studies often focus on individual episodes without providing a comprehensive view of the entire diagnostic journey. Traditional qualitative methods, while detailed, analyze smaller samples, limiting their generalizability. This study leveraged a data-enabled design research method combining thematic analysis and LDA topic modeling to create a detailed journey map, capturing both comprehensive and nuanced insights across five main journey phases including: noticing symptoms, acceptance of symptoms, the diagnostic process, diagnosis disclosure, and post-diagnosis disease management.

The research introduced several new insights into the current knowledge on dementia diagnostic journey, including significant day-to-day symptom variability and nuances captured in terms of the emotional burden on CGs and their coping strategies. These findings suggest the need for improved educational campaigns to raise awareness of early diagnosis benefits, enhanced support for CGs, and the use of personalization technologies to provide tailored support. Additionally, the study advanced the data-enabled journey mapping methodology by introducing innovations in the interpretation process of topic modeling, contributing to a more evidence-based and potentially automated research process. Furthermore, the study underscored the importance of including designers in dementia research to map complex systems and craft effective visualizations.

The primary limitation of the research was the second-hand nature of PLWDs' perspectives, as most forum users were CGs of already diagnosed PLWDs. This limited the study's ability to capture insights into the pre-diagnosis stages. Additionally, the self-selection bias of online forum users and variability in the quality of online patient stories impacted the generalizability of findings.

Future research should primarily focus on directly engaging PLWDs and GPs to better understand barriers to early diagnosis. Additionally, the EBC framework's 'Design' phase should evaluate the feasibility and impact of suggested interventions. Automating the data-enabled design research method could enhance its effectiveness and applicability across different stakeholders or diseases. Finally, designers should be increasingly more involved in dementia research, specifically through the use of frameworks like EBC, which inherently integrate design into their processes.

This research provides a comprehensive, yet nuanced overview of the dementia journey. By integrating design expertise and leveraging data-enabled research methods, the study lays the groundwork for systemic changes in dementia care. Continued interdisciplinary collaboration and further methodological innovation are essential for advancing dementia research and enhancing the well-being of PLWDs and their CGs. ■

11

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Appendix

This chapter includes appendices. Access the digital versions of Appendix 14 and Appendix 15 using the following link: https://drive.google.com/drive/folders/11KYqP5SLeEQhsxWBx8uFzeJ-V9XN_Yck?usp=sharing

Plan Overview

A Data Management Plan created using DMPonline

Title: Data-Enabled Patient Journey Mapping for Early Dementia Diagnosis in the UK

Creator: Natalia Bodnarova

Affiliation: Delft University of Technology

Template: TU Delft Data Management Plan template (2021)

Project abstract:

My research aims to gain a deeper understanding of patients/caregivers experiencing dementia diagnosis to integrate early diagnosis of dementia into UK clinical practice. Their perspectives would be collected primarily by analysing Alzheimer’s Society’s publicly available online forum and a literature review of qualitative studies with stakeholders and policy/charity reports. Potentially I would also organize a co-creation session to validate the created journey maps and personas. Co-creation session would involve participants from the UK, but all analysis would be performed at TU Delft.

ID: 144506

Start date: 19-02-2024

End date: 17-07-2024

Last modified: 28-02-2024

Data-Enabled Patient Journey Mapping for Early Dementia Diagnosis in the UK

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0. Administrative questions

1. Name of data management support staff consulted during the preparation of this plan.

My faculty data steward, Jeff Love, has reviewed this DMP on 28.2.2024.

2. Date of consultation with support staff.

2024-02-28

I. Data description and collection or re-use of existing data

3. Provide a general description of the type of data you will be working with, including any re-used data:

Type of data	File format(s)	How will data be collected (for re-used data: source and terms of use)?	Purpose of processing	Storage location	Who will have access to the data
Text forum posts on platform	json files	Re-use of public posts scraped from external company (Alzheimer's Society forum) that has signed informed consent	Understanding patient context when dealing with dementia diagnosis	SURF Research Cloud	The direct researchers from the project team
Username, reason for joining, location (from front user profile) – all this data will be anonymized	json files	Scraped from public website from external company (Alzheimer's Society) that has signed informed consent	Balancing the collected data	SURF Research Cloud	The direct researchers from the project team
Audio recording from a co-creation session	mp3	Audio recording based on a signed informed consent from the participants	Validating the outputs of Alzheimer's Society's forum posts study	Project storage drive	The direct researchers from the project team
Co-creation session transcript	docx.	Transcript of the audio recording from a co-creation session based ona signed informed consent from the participants.	Validating the outputs of Alzheimer's Society's forum posts study	Project storage drive	The direct researchers from the project team

4. How much data storage will you require during the project lifetime?

- < 250 GB

In theory will be less than 5 GB.

II. Documentation and data quality

5. What documentation will accompany data?

- Methodology of data collection
- README file or other documentation explaining how data is organised

- A small readme file will be in the repository about how the data is collected and the structure of the json files.

III. Storage and backup during research process

6. Where will the data (and code, if applicable) be stored and backed-up during the project lifetime?

- SURFdrive
- Project Storage at TU Delft

- The data will be stored and processed on the SURF Research Cloud, the code will possibly be stored on a private TU Delft hosted Gitlab server.
- Audio and transcript data will be stored on Project Storage at TU Delft.

IV. Legal and ethical requirements, codes of conduct

7. Does your research involve human subjects or 3rd party datasets collected from human participants?

- Yes

8A. Will you work with personal data? (information about an identified or identifiable natural person)

If you are not sure which option to select, first ask your Faculty Data Steward for advice. You can also check with the privacy website . If you would like to contact the privacy team: privacy-tud@tudelft.nl, please bring your DMP.

- Yes

10. Which personal data will you process? Tick all that apply

- Other types of personal data - please explain below
- Signed consent forms

Other types of personal data:

- Alzheimer's Society forum posts, user names, user location, reason for joining – all data will be anonymized
- Working titles of co-creation session participants

11. Please list the categories of data subjects

- Alzheimer Society's forum: people experiencing symptoms of dementia and their caregivers – no direct contact, only passive
- Co-creations session: UK National Health System workers, policymakers

12. Will you be sharing personal data with individuals/organisations outside of the EEA (European Economic Area)?

- No

15. What is the legal ground for personal data processing?

- Informed consent

16. Please describe the informed consent procedure you will follow:

- Alzheimer's Society will be asked for their written consent for taking part in the study and for the data processing. This will be done before the start of the data collection from their platform.
- All co-creation session participants will be asked for their written consent for taking part in the study and for data processing before the start of the session.

17. Where will you store the signed consent forms?

- Same storage solutions as explained in question 6

18. Does the processing of the personal data result in a high risk to the data subjects?

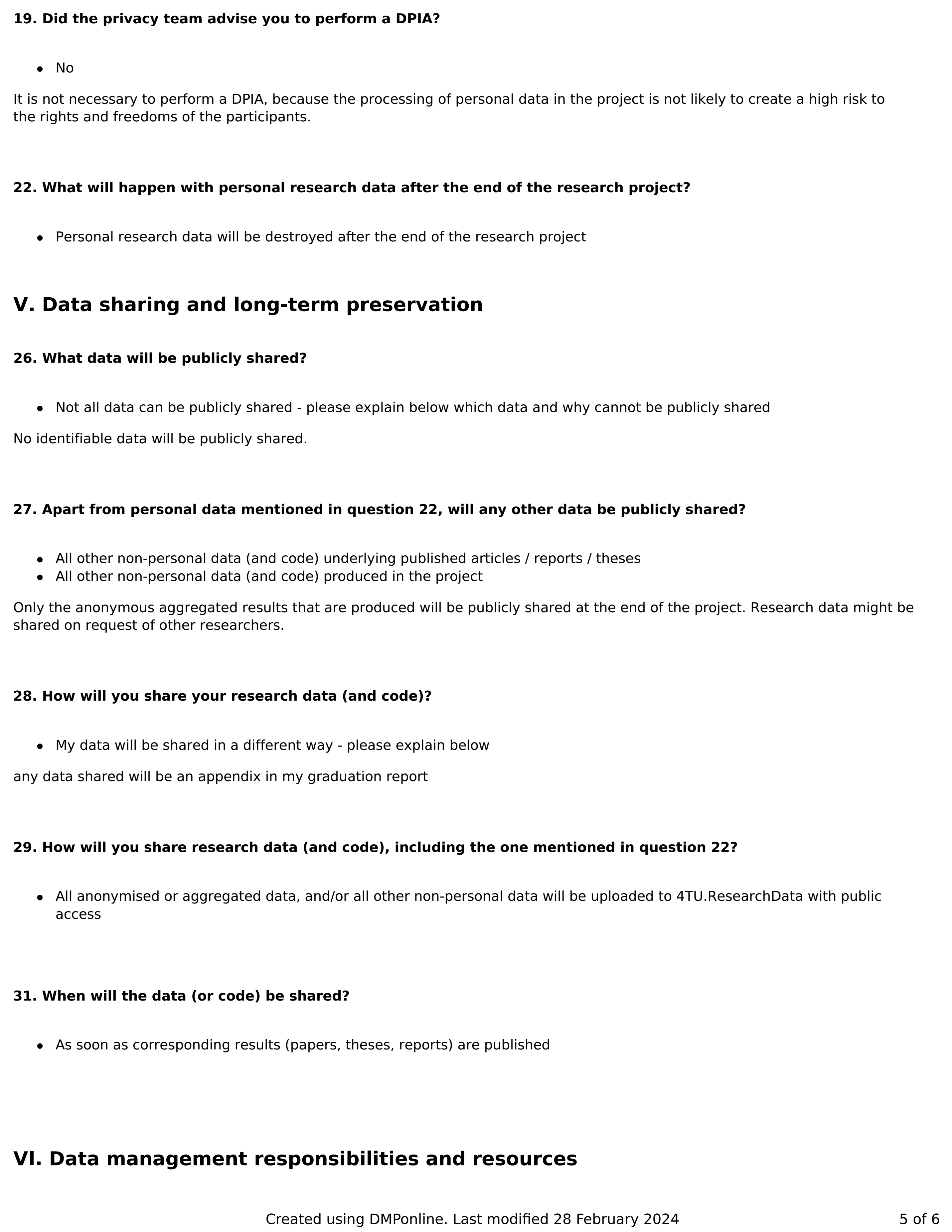
If the processing of the personal data results in a high risk to the data subjects, it is required to perform a Data Protection Impact Assessment (DPIA). In order to determine if there is a high risk for the data subjects, please check if any of the options below that are applicable to the processing of the personal data during your research (check all that apply).

If two or more of the options listed below apply, you will have to complete the DPIA. Please get in touch with the privacy team: privacy-tud@tudelft.nl to receive support with DPIA.
If only one of the options listed below applies, your project might need a DPIA. Please get in touch with the privacy team: privacy-tud@tudelft.nl to get advice as to whether DPIA is necessary.

If you have any additional comments, please add them in the box below.

- Data concerning vulnerable data subjects

For more information on risk mitigation of using data concerning vulnerable data subjects check: Issue C.7. in the HREC Checklist



19. Did the privacy team advise you to perform a DPIA?

- No

It is not necessary to perform a DPIA, because the processing of personal data in the project is not likely to create a high risk to the rights and freedoms of the participants.

22. What will happen with personal research data after the end of the research project?

- Personal research data will be destroyed after the end of the research project

V. Data sharing and long-term preservation

26. What data will be publicly shared?

- Not all data can be publicly shared - please explain below which data and why cannot be publicly shared

No identifiable data will be publicly shared.

27. Apart from personal data mentioned in question 22, will any other data be publicly shared?

- All other non-personal data (and code) underlying published articles / reports / theses
- All other non-personal data (and code) produced in the project

Only the anonymous aggregated results that are produced will be publicly shared at the end of the project. Research data might be shared on request of other researchers.

28. How will you share your research data (and code)?

- My data will be shared in a different way - please explain below

any data shared will be an appendix in my graduation report

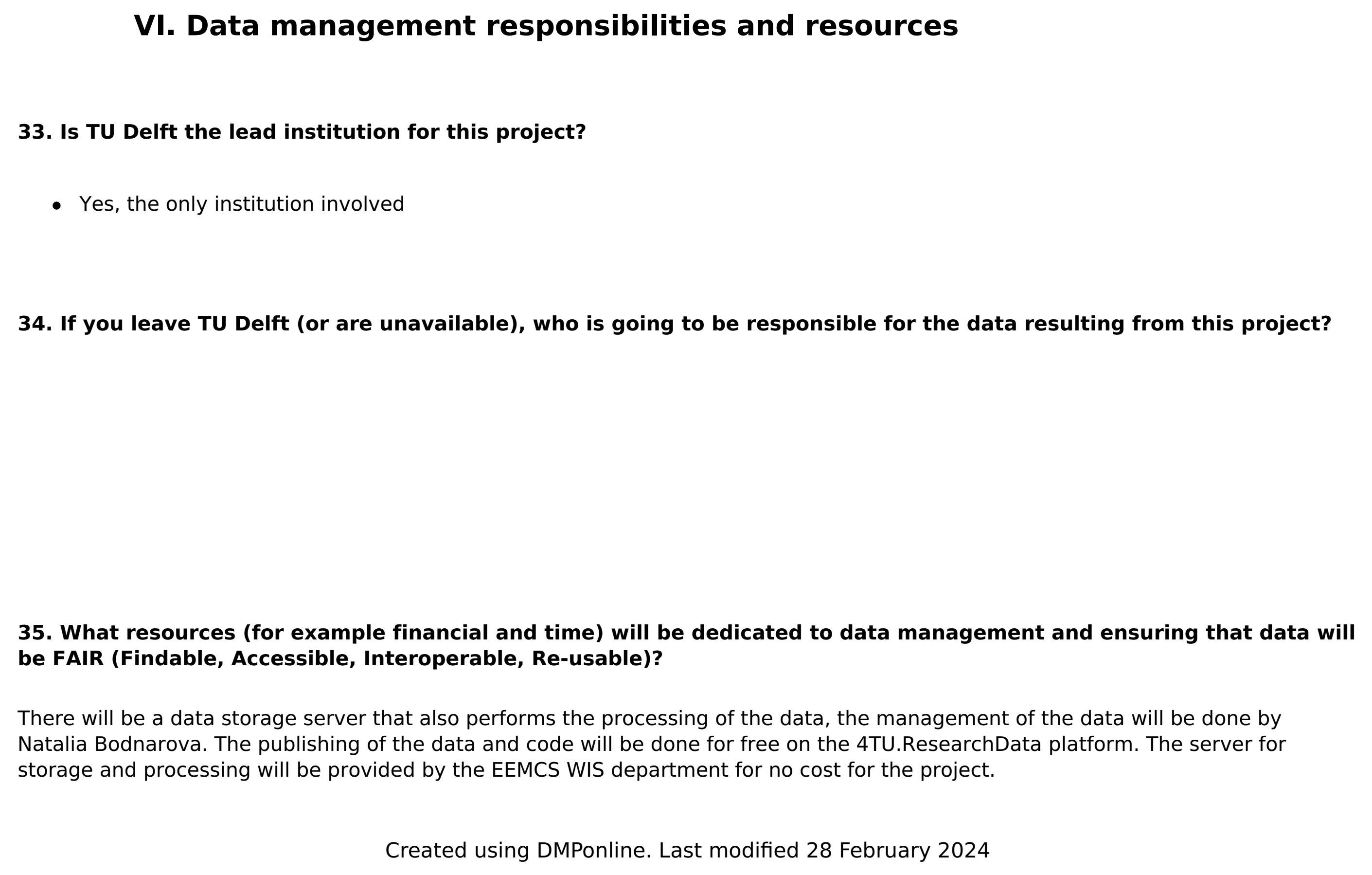
29. How will you share research data (and code), including the one mentioned in question 22?

- All anonymised or aggregated data, and/or all other non-personal data will be uploaded to 4TU.ResearchData with public access

31. When will the data (or code) be shared?

- As soon as corresponding results (papers, theses, reports) are published

VI. Data management responsibilities and resources



VI. Data management responsibilities and resources

33. Is TU Delft the lead institution for this project?

- Yes, the only institution involved

34. If you leave TU Delft (or are unavailable), who is going to be responsible for the data resulting from this project?

35. What resources (for example financial and time) will be dedicated to data management and ensuring that data will be FAIR (Findable, Accessible, Interoperable, Re-usable)?

There will be a data storage server that also performs the processing of the data, the management of the data will be done by Natalia Bodnarova. The publishing of the data and code will be done for free on the 4TU.ResearchData platform. The server for storage and processing will be provided by the EEMCS WIS department for no cost for the project.

Appendix 2: Human Research Ethics Checklist (HREC) for Human Research

I. Applicant Information

PROJECT TITLE:	Data-Enabled Patient Journey Mapping for Early Dementia Diagnosis in the UK
Research period: *Over what period of time will this specific part of the research take place*	Graduation Project: Feb 2024 – July 2024
Faculty:	Industrial Design Engineering
Department:	DOS
Type of the research project: *(Bachelor's, Master's, DreamTeam, PhD, PostDoc, Senior Researcher, Organisational etc.)*	Master's graduation project
Funder of research: *(EU, NWO, TUD, other – in which case please elaborate)*	TUD
Name of Corresponding Researcher: *(If different from the Responsible Researcher)*	Natalia Bodnarova
E-mail Corresponding Researcher: *(If different from the Responsible Researcher)*	n.bodnarova@tudelft.nl
Position of Corresponding Researcher: *(Masters, DreamTeam, PhD, PostDoc, Assistant/ Associate/ Full Professor)*	Master's student of Strategic Product Design
Name of Responsible Researcher: ***Note:** all student work must have a named Responsible Researcher to approve, sign and submit this application*	Coco Newton, Himanshu Verma
E-mail of Responsible Researcher: *Please ensure that an institutional email address (**no Gmail, Yahoo, etc.**) is used for all project documentation/ communications including Informed Consent materials*	c.c.newton@tudelft.nl, h.verma@tudelft.nl
Position of Responsible Researcher : *(PhD, PostDoc, Associate/ Assistant/ Full Professor)*	Coco Newton: PostDoc at TUD, Himanshu Verma Assistant Professor at TUD

II. Research Overview

***NOTE:** You can find more guidance on completing this checklist here*

a) Please summarise your research very briefly (100-200 words)
What are you looking into, who is involved, how many participants there will be, how they will be recruited and what are they expected to do?

Add your text here – (please avoid jargon and abbrevations)
My research aims to gain a deeper understanding of patients/caregivers experiencing dementia diagnosis to integrate early diagnosis of dementia into UK clinical practice. Patient/caregiver perspective would be collected primarily by analysing Alzheimer's Society's publicly available online forum and a literature review of qualitative studies with stakeholders and policy/charity reports. Potentially I would also organize a co-creation session to validate the created journey maps and personas. Co-creation session would involve participants from the UK, but all analysis would be performed at TU Delft.

b) **If your application is an additional project** related to an existing approved HREC submission, please provide a brief explanation including the existing relevant HREC submission number/s.

Add your text here – (please avoid jargon and abbrevations)

III. Risk Assessment and Mitigation Plan

***NOTE:** You can find more guidance on completing this checklist here*

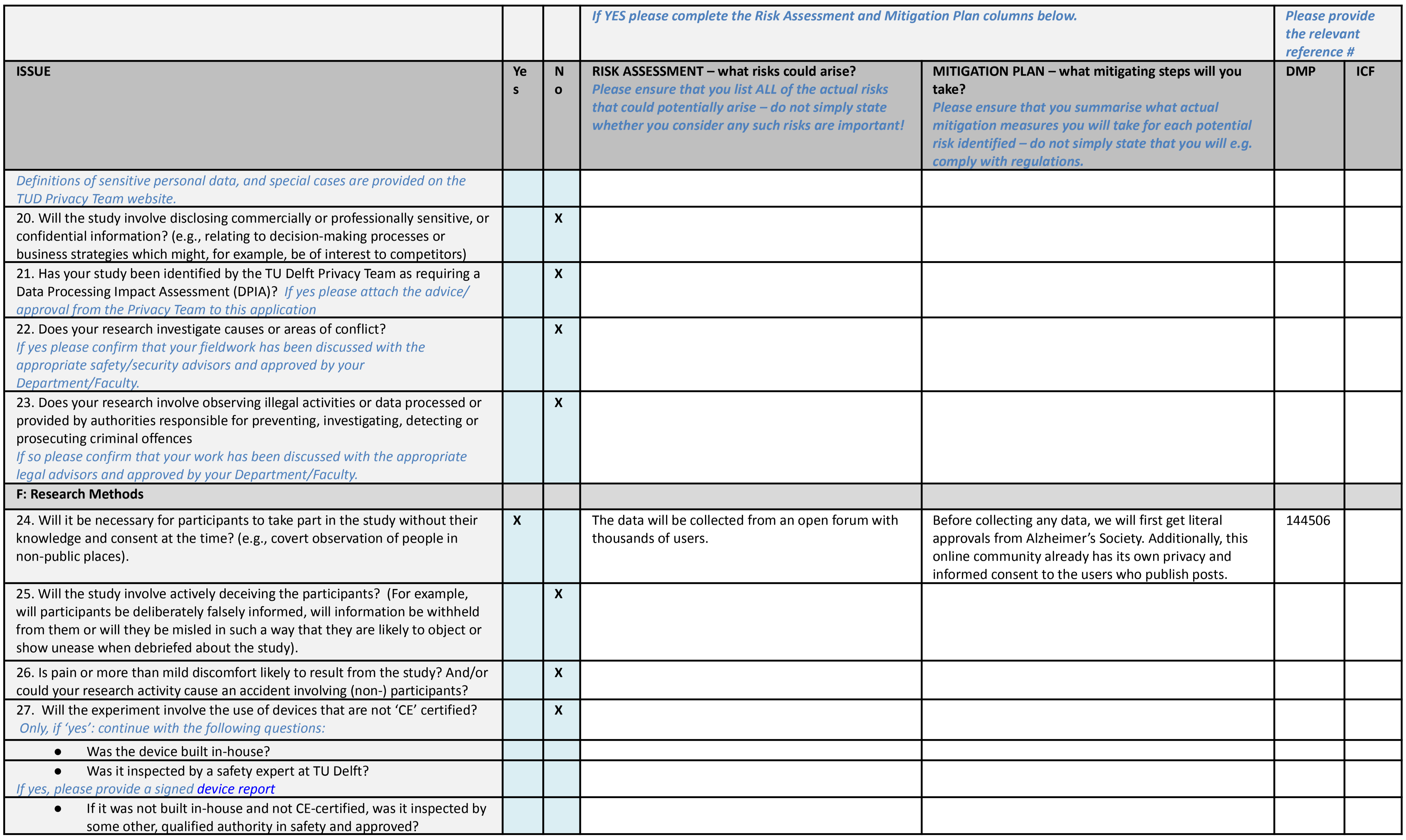
Please complete the following table in full for all points to which your answer is "yes". Bear in mind that the vast majority of projects involving human participants as Research Subjects also involve the collection of **Personally Identifiable Information (PII)** and/or **Personally Identifiable Research Data (PIRD)** which may pose potential risks to participants as detailed in Section G: Data Processing and Privacy below.

To ensure alighment between your risk assessment, data management and what you agree with your Research Subjects you can use the last two columns in the table below to refer to specific points in your Data Management Plan (DMP) and Informed Consent Form (ICF) – **but this is not compulsory**.

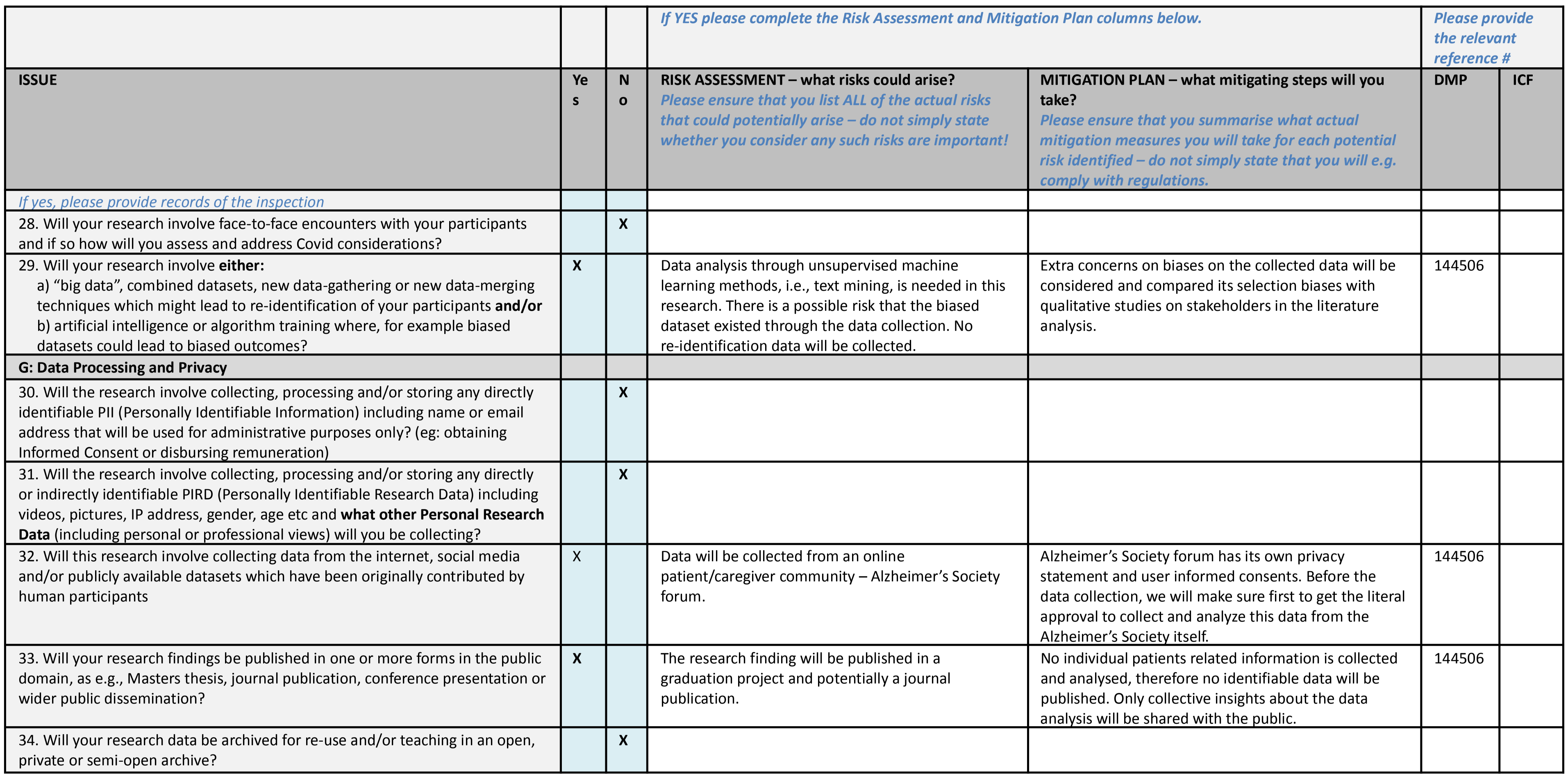
It's worth noting that **you're much more likely to need to resubmit your application if you neglect to identify potential risks**, than if you identify a potential risk and demonstrate how you will mitigate it. If necessary, the HREC will always work with you and colleagues in the Privacy Team and Data Management Services to see how, if at all possible, your research can be conducted.

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		*Please provide the relevant reference #*	
ISSUE	**Yes**	**No**	**RISK ASSESSMENT – what risks could arise?** *Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!*	**MITIGATION PLAN – what mitigating steps will you take?** *Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.*	**DMP**	**ICF**
A: Partners and collaboration						
1. Will the research be carried out in collaboration with additional organisational partners such as: • One or more collaborating research and/or commercial organisations • Either a research, or a work experience internship provider[1] *[1] If yes, please include the graduation agreement in this application*		X				
2. Is this research dependent on a Data Transfer or Processing Agreement with a collaborating partner or third party supplier? *If yes please provide a copy of the signed DTA/DPA*		X				
3. Has this research been approved by another (external) research ethics committee (e.g.: HREC and/or MREC/METC)? *If yes, please provide a copy of the approval (if possible) and summarise any key points in your Risk Management section below*		X				
B: Location						

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		*Please provide the relevant reference #*	
ISSUE	**Yes**	**No**	**RISK ASSESSMENT – what risks could arise?** *Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!*	**MITIGATION PLAN – what mitigating steps will you take?** *Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.*	**DMP**	**ICF**
4. Will the research take place in a country or countries, other than the Netherlands, within the EU?		X				
5. Will the research take place in a country or countries outside the EU?		X				
6. Will the research take place in a place/region or of higher risk – including known dangerous locations (in any country) or locations with non-democratic regimes?		X				
C: Participants						
7. Will the study involve participants who **may** be vulnerable and possibly (legally) unable to give informed consent? (e.g., children below the legal age for giving consent, people with learning difficulties, people living in care or nursing homes,).	X		Data on the Alzheimer's Society forum might include posts from patients living with dementia, who may be vulnerable due to their decline in cognitive abilities.	Alzheimer's Society forum has its own privacy and informed consent to the users who publish posts. Additionally, we will first get literal approval from the Alzheimer's Society itself before collecting and analyzing any data, and no identifiable data from the users will be collected.	14 4506	
8. Will the study involve participants who **may** be vulnerable under specific circumstances and in specific contexts, such as victims and witnesses of violence, including domestic violence; sex workers; members of minority groups, refugees, irregular migrants or dissidents?		X				
9. Are the participants, outside the context of the research, in a dependent or subordinate position to the investigator (such as own children, own students or employees of either TU Delft and/or a collaborating partner organisation)? *It is essential that you safeguard against possible adverse consequences of this situation (such as allowing a student's failure to participate to your satisfaction to affect your evaluation of their coursework).*		X				
10. Is there a high possibility of re-identification for your participants? (e.g., do they have a very specialist job of which there are only a small number in a given country, are they members of a small community, or employees from a partner company collaborating in the research? Or are they one of only a handful of (expert) participants in the study?		X				
D: Recruiting Participants						
11. Will your participants be recruited through your own, professional, channels such as conference attendance lists, or through specific network/s such as self-help groups	X		There is no recruitment needed for analysis of Alzheimer's Society's online forum, however participants for potential co-creation session would be recruited through the network of Coco Newton.	Participants in a potential co-creation session would be asked to sign an informed consent form which will state that participation is voluntary and that participants can withdraw at any point without adverse consequence. Additionally, no individual patients related information is collected and analysed, therefore no identifiable data will be published.	144506	
12. Will the participants be recruited or accessed in the longer term by a (legal or customary) gatekeeper? (e.g., an adult professional working with children; a community leader or family member who has this customary role – within or outside the EU; the data producer of a long-term cohort study)		X				
13. Will you be recruiting your participants through a crowd-sourcing service and/or involve a third party data-gathering service, such as a survey platform?	X		Data will be sourced from Alzheimer's Society's online forum.	We will first get literal approval from the Alzheimer's Society itself before collecting and analyzing any data, and no identifiable data from the users will be collected.	144506	
14. Will you be offering any financial, or other, remuneration to participants, and might this induce or bias participation?		X				
E: Subject Matter *Research related to medical questions/health may require special attention. See also the website of the CCMO before contacting the HREC.*						
15. Will your research involve any of the following: • Medical research and/or clinical trials • Invasive sampling and/or medical imaging • Medical and *In Vitro Diagnostic Medical* Devices Research	X		Research is related to the medical question of receiving a dementia diagnosis.	Research focuses solely on the experience of patients and caregivers with the process of receiving a dementia diagnosis. The research will not involve any clinical trials, invasive sampling, medical imaging or medical and in-vitro diagnostic medical device research.	14 4506	
16. Will drugs, placebos, or other substances (e.g., drinks, foods, food or drink constituents, dietary supplements) be administered to the study participants? *If yes see here to determine whether medical ethical approval is required*		X				
17. Will blood or tissue samples be obtained from participants? *If yes see here to determine whether medical ethical approval is required*		X				
18. Does the study risk causing psychological stress or anxiety beyond that normally encountered by the participants in their life outside research?		X				
19. Will the study involve discussion of personal sensitive data which could put participants at increased legal, financial, reputational, security or other risk? (e.g., financial data, location data, data relating to children or other vulnerable groups)		X				



			If YES please complete the Risk Assessment and Mitigation Plan columns below.		*Please provide the relevant reference #*	
ISSUE	**Yes**	**No**	**RISK ASSESSMENT – what risks could arise?** *Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!*	**MITIGATION PLAN – what mitigating steps will you take?** *Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.*	**DMP**	**ICF**
Definitions of sensitive personal data, and special cases are provided on the TUD Privacy Team website.						
20. Will the study involve disclosing commercially or professionally sensitive, or confidential information? (e.g., relating to decision-making processes or business strategies which might, for example, be of interest to competitors)		**X**				
21. Has your study been identified by the TU Delft Privacy Team as requiring a Data Processing Impact Assessment (DPIA)? *If yes please attach the advice/ approval from the Privacy Team to this application*		**X**				
22. Does your research investigate causes or areas of conflict? *If yes please confirm that your fieldwork has been discussed with the appropriate safety/security advisors and approved by your Department/Faculty.*		**X**				
23. Does your research involve observing illegal activities or data processed or provided by authorities responsible for preventing, investigating, detecting or prosecuting criminal offences *If so please confirm that your work has been discussed with the appropriate legal advisors and approved by your Department/Faculty.*		**X**				
F: Research Methods						
24. Will it be necessary for participants to take part in the study without their knowledge and consent at the time? (e.g., covert observation of people in non-public places).	**X**		The data will be collected from an open forum with thousands of users.	Before collecting any data, we will first get literal approvals from Alzheimer's Society. Additionally, this online community already has its own privacy and informed consent to the users who publish posts.	144506	
25. Will the study involve actively deceiving the participants? (For example, will participants be deliberately falsely informed, will information be withheld from them or will they be misled in such a way that they are likely to object or show unease when debriefed about the study).		**X**				
26. Is pain or more than mild discomfort likely to result from the study? And/or could your research activity cause an accident involving (non-) participants?		**X**				
27. Will the experiment involve the use of devices that are not 'CE' certified? *Only, if 'yes': continue with the following questions:*		**X**				
• Was the device built in-house?						
• Was it inspected by a safety expert at TU Delft? *If yes, please provide a signed device report*						
• If it was not built in-house and not CE-certified, was it inspected by some other, qualified authority in safety and approved?						



			If YES please complete the Risk Assessment and Mitigation Plan columns below.		*Please provide the relevant reference #*	
ISSUE	**Yes**	**No**	**RISK ASSESSMENT – what risks could arise?** *Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!*	**MITIGATION PLAN – what mitigating steps will you take?** *Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.*	**DMP**	**ICF**
If yes, please provide records of the inspection						
28. Will your research involve face-to-face encounters with your participants and if so how will you assess and address Covid considerations?		**X**				
29. Will your research involve **either:** a) "big data", combined datasets, new data-gathering or new data-merging techniques which might lead to re-identification of your participants **and/or** b) artificial intelligence or algorithm training where, for example biased datasets could lead to biased outcomes?	**X**		Data analysis through unsupervised machine learning methods, i.e., text mining, is needed in this research. There is a possible risk that the biased dataset existed through the data collection. No re-identification data will be collected.	Extra concerns on biases on the collected data will be considered and compared its selection biases with qualitative studies on stakeholders in the literature analysis.	144506	
G: Data Processing and Privacy						
30. Will the research involve collecting, processing and/or storing any directly identifiable PII (Personally Identifiable Information) including name or email address that will be used for administrative purposes only? (eg: obtaining Informed Consent or disbursing remuneration)		**X**				
31. Will the research involve collecting, processing and/or storing any directly or indirectly identifiable PIRD (Personally Identifiable Research Data) including videos, pictures, IP address, gender, age etc and **what other Personal Research Data** (including personal or professional views) will you be collecting?		**X**				
32. Will this research involve collecting data from the internet, social media and/or publicly available datasets which have been originally contributed by human participants	X		Data will be collected from an online patient/caregiver community – Alzheimer's Society forum.	Alzheimer's Society forum has its own privacy statement and user informed consents. Before the data collection, we will make sure first to get the literal approval to collect and analyze this data from the Alzheimer's Society itself.	144506	
33. Will your research findings be published in one or more forms in the public domain, as e.g., Masters thesis, journal publication, conference presentation or wider public dissemination?	**X**		The research finding will be published in a graduation project and potentially a journal publication.	No individual patients related information is collected and analysed, therefore no identifiable data will be published. Only collective insights about the data analysis will be shared with the public.	144506	
34. Will your research data be archived for re-use and/or teaching in an open, private or semi-open archive?		**X**				

H: More on Informed Consent and Data Management

NOTE: You can find guidance and templates for preparing your Informed Consent materials) here

Your research involves human participants as Research Subjects if you are recruiting them or actively involving or influencing, manipulating or directing them in any way in your research activities. This means you must seek informed consent and agree/ implement appropriate safeguards regardless of whether you are collecting any PIRD.

Where you are also collecting PIRD, and using Informed Consent as the legal basis for your research, you need to also make sure that your IC materials are clear on any related risks and the mitigating measures you will take – including through responsible data management.

Got a comment on this checklist or the HREC process? You can leave your comments here

IV. Signature/s

Please note that by signing this checklist list as the sole, or Responsible, researcher you are providing approval of the completeness and quality of the submission, as well as confirming alignment between GDPR, Data Management and Informed Consent requirements.

Name of Corresponding Researcher (if different from the Responsible Researcher) (print):

NATALIA BODNAROVA

Signature of Corresponding Researcher:

Date: 2024/2/28

Name of Responsible Researcher (print):

HIMANSHU VERMA

Himanshu

Signature (or upload consent by mail) Responsible Researcher:

Date: 2024/2/28

V. Completing your HREC application

Please use the following list to check that you have provided all relevant documentation

Required:

- **Always:** This completed HREC checklist
- **Always:** A data management plan (reviewed, where necessary, by a data-steward)

- **Usually:** A complete Informed Consent form (including Participant Information) and/or Opening Statement (for online consent)

Please also attach any of the following, if relevant to your research:

Document or approval	Contact/s
Full Research Ethics Application	After the assessment of your initial application **HREC will let you know if and when you need to submit additional information**
Signed, valid Device Report	Your Faculty HSE advisor
Ethics approval from an external Medical Committee	TU Delft Policy Advisor, Medical (Devices) Research
Ethics approval from an external Research Ethics Committee	Please append, if possible, with your submission
Approved Data Transfer or Data Processing Agreement	Your Faculty Data Steward and/or TU Delft Privacy Team
Approved Graduation Agreement	Your Master's thesis supervisor
Data Processing Impact Assessment (DPIA)	TU Delft Privacy Team
Other specific requirement	Please reference/explain in your checklist and append with your submission

Appendix 3: Informed Consent Alzheimers Society

Information about the research study of "Data-Enabled Patient Journey Mapping for Early Dementia Diagnosis in the UK"

Purpose

This study is part of a master thesis project 'Data-Enabled Patient Journey Mapping for Early Dementia Diagnosis in the UK' by Natália Bodnárová at Delft University of Technology (TU Delft).

The research aims to develop journey maps detailing the experiences of patients and caregivers when seeking a dementia diagnosis. This map will serve to facilitate the integration of early dementia diagnosis into clinical practice within the UK. To achieve this goal, anonymized textual data from posts on the Alzheimer's Society's online forum will be collected and analyzed. Only aggregated analysis results will be shared publicly in the form of a research paper upon the project's completion. All data will be promptly removed from our records following the project's finalisation. We kindly ask for your authorization to scrape and analyze non-identifiable data from the Alzheimer's Society Dementia Support Forum.

Your participation in this research is invaluable, as it will provide insights crucial for policymakers to better understand and enhance the experiences of patients and caregivers. Additionally, we are happy to share the research findings with you once they are published.

Contact Details

In case you want to see the final outcome of this research or you have any questions, you can always contact me. Below you can find the contacts of me and my supervisor:

Master student: Natalia Bodnarova
Email: n.bodnarova@student.tudelft.nl
Mobile Number: +420 724 619 619

Supervisor: Coco Newton
Email: C.C.Newton@tudelft.nl

Consent Form for "Data-Enabled Patient Journey Mapping for Early Dementia Diagnosis in the UK"

Taking part in the study:

PLEASE TICK THE APPROPRIATE BOXES	YES	NO
1. I have read and understood the study information. I have been able to ask questions about the study and my questions have been answered to my satisfaction.	☒	☐
2. I understand that personal information collected about the users, such as name, locations, and contacts, will not be collected or shared.	☒	☐
3. I understand that taking part in the study involves giving authorization to the research team to scrape, collect and interpret the non-identifiable textual data of the online forums.	☒	☐

Signatures

Will Jacobs — W Jacobs — 04/07/2024
Name of the organization owner — Signature — Date

__________ — __________ — __________
Name of the Research — Signature — Date

Appendix 4: Script for Data Scraping

```
# https://forum.alzheimers.org.uk/
from bs4 import BeautifulSoup
import requests
import csv
import pandas as pd
from datetime import datetime

URL = "https://forum.alzheimers.org.uk/"
page = requests.get(URL)
# print(page.text)
soup = BeautifulSoup(page.text, 'html.parser')

base_url = "https://forum.alzheimers.org.uk"


# get forum categories
def get_category_blocks(soup_html):
    blocks = soup.find_all("div", {"class": "block--category"})
    return blocks

def get_category_name_from_block(block):
    category_name = block.find(class_='uix_categoryTitle').text
    # block_header = blocks.find_all("div", {"class": "block--header"})
    return category_name

def get_forums_from_block(block, category_name):
    forums_list = []
    forums = block.find_all(class_='node-title')
    for forum in forums:
        forum_name = forum.a.string
        forum_url = base_url + forum.a['href']
        forum_entry = [category_name, forum_name, forum_url]
        forums_list.append(forum_entry)
    # get forum name, url
    return forums_list

def get_all_forums(soup):
    blocks = get_category_blocks(soup)
    all_forums = []
    for block in blocks:
        category_name = get_category_name_from_block(block)
        forum_list = get_forums_from_block(block, category_name)
        all_forums = all_forums + forum_list
    return all_forums

def load_thread_from_soup(thread_page_soup):
    posts_info = []
    posts = thread_page_soup.find_all(class_=['message', 'message--post'])
    for post in posts:
        post_author = post.find(class_='username').text
        post_author_title = post.find(class_='message-userTitle').text
        post_id = int(post['data-content'].replace('post-', ''))
        timestamp = post.find("time")['datetime']
        post_nr = post.find(class_='message-attribution-opposite').find_all("li")[-1].text
        post_nr = str(post_nr).replace('\n', "").replace('\t', "").replace('#', "").replace(',','')
        post_nr = int(post_nr)
        # replace with `soup.findAll` if you are using BeautifulSoup3
        quotes = []
        for div in post.find_all("blockquote", {'class':'bbCodeBlock--quote'}):
            quotes.append(div['data-source'].replace('post: ', ''))

        for div in post.find_all("blockquote", {'class':'bbCodeBlock--quote'}):
            div.decompose()
        post_message =  post.find(class_='message-body').text
        post_info = [post_author, post_author_title, post_id, timestamp, post_nr, post_message,
quotes]
        posts_info.append(post_info)
    return posts_info

def load_thread_posts(thread_page_url):
    page = requests.get(thread_page_url)
    soup = BeautifulSoup(page.text, 'html.parser')
    posts_info = load_thread_from_soup(soup)
    return posts_info

def load_thread(thread_url):
    page = requests.get(thread_url)
    soup = BeautifulSoup(page.text, 'html.parser')

    # get number of pages
    page_numbers_nav = soup.find_all(class_='pageNav-page')
    page_numbers = 1
    if len(page_numbers_nav) == 0:
        page_numbers = 1
    else:
        page_numbers = page_numbers_nav[-1].a.string

    post_list = load_thread_from_soup(soup)

    if int(page_numbers) == 1:
        return post_list
    elif int(page_numbers) == 2:
        return post_list + load_thread_posts(thread_url + 'page-2')
```

```
    # enumerate over the pages
    for i in range(2, int(page_numbers)+1):
        # print(thread_url + 'page-' + str(i))
        post_list = post_list + load_thread_posts(thread_url + 'page-' + str(i))
    # per page get the thread name and url
    result = post_list
    # print(result)
    return result

def get_thread_info_from_soup(forum_page_soup):
    threads_list = []
    threads = forum_page_soup.find_all(class_='structItem-title')
    for thread in threads:
        thread_name = thread.a.string
        thread_url = thread.a['href']
        threads_list.append([thread_name, base_url + thread_url])
    return threads_list

def get_threads_info(forum_page_url):
    page = requests.get(forum_page_url)
    soup = BeautifulSoup(page.text, 'html.parser')
    threads_list = get_thread_info_from_soup(soup)
    return threads_list

def load_forum(forum_category, forum_name, forum_url):
    page = requests.get(forum_url)
    soup = BeautifulSoup(page.text, 'html.parser')

    # get number of pages
    page_numbers_nav = soup.find_all(class_='pageNav-page')
    page_numbers = 1
    if len(page_numbers_nav) == 0:
        page_numbers = 1
    else:
        page_numbers = page_numbers_nav[-1].a.string

    threads_list = get_thread_info_from_soup(soup)

    if int(page_numbers) == 1:
        result = []
        for thread in threads_list:
            thread_with_info = [forum_category, forum_name] + thread
            result.append(thread_with_info)
        return result
    elif int(page_numbers) == 2:
        threads_list = threads_list + get_threads_info(forum_url + 'page-2')
        for thread in threads_list:
            thread_with_info = [forum_category, forum_name] + thread
            result.append(thread_with_info)
        return result
    # enumerate over the pages
    for i in range(2, int(page_numbers)+1):
        # print(forum_url + 'page-' + str(i))
        threads_list = threads_list + get_threads_info(forum_url + 'page-' + str(i))
    # per page get the thread name and url
    result = []
    for thread in threads_list:
        thread_with_info = [forum_category, forum_name] + thread
        result.append(thread_with_info)
    # print(result)
    return result

def get_entire_forum_tocsv(soup):
    begin_ts = datetime.now()
    # temp = load_forum("Support from other members", "I have dementia",
"https://forum.alzheimers.org.uk/forums/i-have-dementia.56/")
    # spamWriter = csv.writer(open('results.csv', 'a', newline=''))
    # spamWriter.writerow(['category', 'forum', 'thread_title',
'thread_url','username','timestamp', 'message_nr' , 'post_message'])
    forums = get_all_forums(soup)
    all_posts = []
    for forum in forums:
        print(forum[2])
        threads = load_forum(forum[0], forum[1], forum[2])
        forum_name = str(forum[1]) + '.csv'
        spamWriter = csv.writer(open(forum_name, 'a', newline=''))
        spamWriter.writerow(['category', 'forum', 'thread_title', 'thread_url','username',
'post_author_title', 'post_id','timestamp', 'message_nr' , 'post_message', 'quotes'])
        for thread in threads:
            print(thread[3])
            posts = load_thread(thread[3])
            for post in posts:
                # category, forum, thread, thread_url, username, timestamp, post_nr, post_message
                results_post = [thread[0], thread[1], thread[2], thread[3]] + post
                spamWriter = csv.writer(open(forum_name, 'a', newline=''))
                spamWriter.writerow(results_post)
    print('Time info:', begin_ts, ', ', datetime.now())

def get_subforum_tocsv(category, forum, forum_url):
    begin_ts = datetime.now()
    print(datetime.now(), ': start', forum)
    spamWriter = csv.writer(open(forum + '.csv', 'a', newline=''))
```

```
    spamWriter.writerow(['category', 'forum', 'thread_title', 'thread_url','username',
'post_author_title', 'post_id','timestamp', 'message_nr' , 'post_message', 'quotes'])
    threads = load_forum(category, forum, forum_url)
    for thread in threads:
        # print(thread[3])
        posts = load_thread(thread[3])
        for post in posts:
            # category, forum, thread, thread_url, username, timestamp, post_nr, post_message
            results_post = [thread[0], thread[1], thread[2], thread[3]] + post
            spamWriter = csv.writer(open(forum + '.csv', 'a', newline=''))
            spamWriter.writerow(results_post)
    print('Time info:', forum , '-> ', begin_ts, ', ', datetime.now())

subforums = [
    ["Support from other members", "Memory concerns and seeking a diagnosis",
"https://forum.alzheimers.org.uk/forums/memory-concerns-and-seeking-a-diagnosis.26/"],
    ["Welcome and how to use Dementia Support Forum", "Say hello and introduce yourself ",
"https://forum.alzheimers.org.uk/forums/say-hello-and-introduce-yourself.32/"],
    ["Support from other members", "I have dementia", "https://forum.alzheimers.org.uk/forums/i-
have-dementia.56/"],
    ["Support from other members", "I have a partner with dementia",
"https://forum.alzheimers.org.uk/forums/i-have-a-partner-with-dementia.69/"],
    ["Support from other members", "I care for a person with dementia",
"https://forum.alzheimers.org.uk/forums/i-care-for-a-person-with-dementia.70/"],
    ["Support from other members", "Recently diagnosed and early stages of dementia",
"https://forum.alzheimers.org.uk/forums/recently-diagnosed-and-early-stages-of-dementia.71/"]
]

for subforum in subforums:
    get_subforum_tocsv(subforum[0], subforum[1], subforum[2])

# # "Support from other members", "Memory concerns and seeking a diagnosis",
"https://forum.alzheimers.org.uk/forums/memory-concerns-and-seeking-a-diagnosis.26/"
# get_subforum_tocsv("Support from other members", "Memory concerns and seeking a diagnosis",
"https://forum.alzheimers.org.uk/forums/memory-concerns-and-seeking-a-diagnosis.26/")

# # Say hello and introduce yourself
# get_subforum_tocsv("Welcome and how to use Dementia Support Forum", "Say hello and introduce
yourself ", "https://forum.alzheimers.org.uk/forums/say-hello-and-introduce-yourself.32/")

# # I have dementia
# get_subforum_tocsv("Support from other members", "I have dementia",
"https://forum.alzheimers.org.uk/forums/i-have-dementia.56/")

# # I have a partner with dementia
# get_subforum_tocsv("Support from other members", "I have a partner with dementia",
"https://forum.alzheimers.org.uk/forums/i-have-a-partner-with-dementia.69/")

# # I care for a person with dementia
# get_subforum_tocsv("Support from other members", "I care for a person with dementia",
"https://forum.alzheimers.org.uk/forums/i-care-for-a-person-with-dementia.70/")

# # Recently diagnosed and early stages of dementia
# get_subforum_tocsv("Support from other members", "Recently diagnosed and early stages of
dementia", "https://forum.alzheimers.org.uk/forums/recently-diagnosed-and-early-stages-of-
dementia.71/")

# print(load_thread_posts('https://forum.alzheimers.org.uk/threads/worried-about-my-elderly-
aunt.120402/'))
```

Appendix 5: Libraries

```
# LIBRARIES
library(topicmodels)
library(tm)
library(SnowballC)
library(wordcloud)
library(RColorBrewer)
library(syuzhet)
library(ggplot2)
library(dplyr)
library(tidytext)
library(forcats)
library(stringr)
```

Appendix 6: Script for Data Sampling

```
# Load subforums
data_say_hello <- read.csv("Say hello and introduce yourself.csv")
data_recently_diagnosed <- read.csv("Recently diagnosed and early stages of dementia.csv")
data_memory_concerns <- read.csv("Memory concerns and seeking a diagnosis.csv")
data_i_have_dementia <- read.csv("I have dementia.csv")
data_i_have_partner <- read.csv("I have a partner with dementia.csv")
data_i_care <- read.csv("I care for a person with dementia.csv")

forum_data_union <- rbind(data_say_hello, data_recently_diagnosed, data_memory_concerns,
data_i_have_dementia, data_i_have_partner, data_i_care)

# Sample from forum_data_union - first thread posts only
print("sample data first post")
subset_data <- data_i_care[data_i_care$message_nr == 1, ]

sample_size <- 500

sample_data_first_thread_post_only <- subset_data[sample(nrow(subset_data), sample_size),, drop =
FALSE]

write.csv(sample_data_first_thread_post_only, "sample_data_first_thread_post_only.csv", row.names =
FALSE)
```

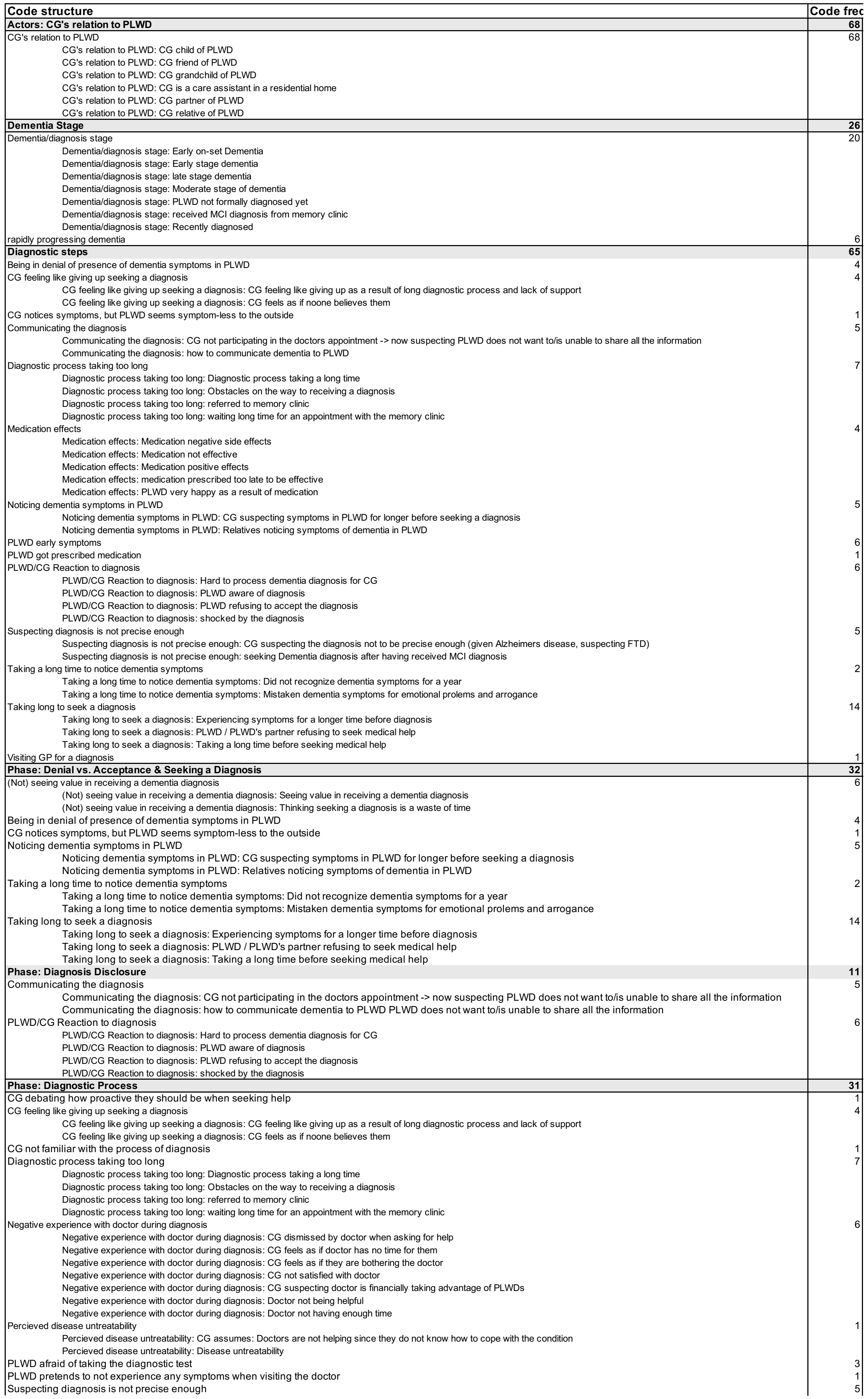
Appendix 7: LDA Topic Modeling Script

```
# DATA PRE-PROCESSING
glimpse(subset_data)

# List of unwanted words
unwanted_words <- c("im", "mil", "i'm", "i’m", "xx", "ss", "it's", "it’s", "ch", "mil", "she's",
"she’s", "he's", "he’s", "i've", "i’ve")

# Convert to lowercase to ensure case insensitivity
subset_data$post_message <- tolower(subset_data$post_message)

# Remove numerical values from post_message before tokenizing
subset_data$post_message <- gsub("[0-9]+", "", subset_data$post_message)

# Tokenize text and remove custom stopwords
custom_stop_words <- tibble(word = c(stop_words$word, unwanted_words))

data_review <- subset_data %>%
  unnest_tokens(word, post_message) %>%
  anti_join(custom_stop_words, by = "word")

# Verify that unwanted words are removed
head(data_review)
dim(data_review)

# Counting words and arranging them in descending order to see which words occur more frequently
data_review %>%
  count(word) %>%
  arrange(desc(n)) %>%
  head()

# THRESHOLD

# See frequency of every word
word_freq <- data_review %>%
  count(word, sort = TRUE)

# Set a threshold for the minimum frequency to keep a word
threshold <- 10  # You can adjust this value as needed

# Filter out words with frequency below the threshold
data_review_filtered <- data_review %>%
  semi_join(filter(word_freq, n >= threshold), by = "word")


# TOPIC MODELING

# Using as.matrix()
dtm_review <- data_review_filtered %>%
  count(word, word) %>%  # count each word used in each identified review
  cast_dtm(word, word, n) %>%  # use the word counts by reviews to create a DTM
  as.matrix()
```

```
# LDA topics

lda_topics2 <- LDA(
  dtm_review,
  k = 9,
  method = "Gibbs",
  control = list(seed = 42)
) %>%
  tidy(matrix = "beta")

word_probs2 <- lda_topics2 %>%
  group_by(topic) %>%
  top_n(30, beta) %>%
  ungroup() %>%
  mutate(term2 = fct_reorder(term, beta))

ggplot(
  word_probs2,
  aes(term2, beta, fill = as.factor(topic))
) +
  geom_col(show.legend = FALSE) +
  facet_wrap(~ topic, scales = "free") +
  coord_flip()
```

Appendix 8: LDA Output Threshold 1,000; 17k; 30beta

Appendix 9: Thematic Analysis Complete Code Structure



Code structure	**Code frec**
Actors: CG's relation to PLWD	**68**
CG's relation to PLWD	68
CG's relation to PLWD: CG child of PLWD	
CG's relation to PLWD: CG friend of PLWD	
CG's relation to PLWD: CG grandchild of PLWD	
CG's relation to PLWD: CG is a care assistant in a residential home	
CG's relation to PLWD: CG partner of PLWD	
CG's relation to PLWD: CG relative of PLWD	
Dementia Stage	**26**
Dementia/diagnosis stage	20
Dementia/diagnosis stage: Early on-set Dementia	
Dementia/diagnosis stage: Early stage dementia	
Dementia/diagnosis stage: late stage dementia	
Dementia/diagnosis stage: Moderate stage of dementia	
Dementia/diagnosis stage: PLWD not formally diagnosed yet	
Dementia/diagnosis stage: received MCI diagnosis from memory clinic	
Dementia/diagnosis stage: Recently diagnosed	
rapidly progressing dementia	6
Diagnostic steps	**65**
Being in denial of presence of dementia symptoms in PLWD	4
CG feeling like giving up seeking a diagnosis	4
CG feeling like giving up seeking a diagnosis: CG feeling like giving up as a result of long diagnostic process and lack of support	
CG feeling like giving up seeking a diagnosis: CG feels as if noone believes them	
CG notices symptoms, but PLWD seems symptom-less to the outside	1
Communicating the diagnosis	5
Communicating the diagnosis: CG not participating in the doctors appointment -> now suspecting PLWD does not want to/is unable to share all the information	
Communicating the diagnosis: how to communicate dementia to PLWD	
Diagnostic process taking too long	7
Diagnostic process taking too long: Diagnostic process taking a long time	
Diagnostic process taking too long: Obstacles on the way to receiving a diagnosis	
Diagnostic process taking too long: referred to memory clinic	
Diagnostic process taking too long: waiting long time for an appointment with the memory clinic	
Medication effects	4
Medication effects: Medication negative side effects	
Medication effects: Medication not effective	
Medication effects: Medication positive effects	
Medication effects: medication prescribed too late to be effective	
Medication effects: PLWD very happy as a result of medication	
Noticing dementia symptoms in PLWD	5
Noticing dementia symptoms in PLWD: CG suspecting symptoms in PLWD for longer before seeking a diagnosis	
Noticing dementia symptoms in PLWD: Relatives noticing symptoms of dementia in PLWD	
PLWD early symptoms	6
PLWD got prescribed medication	1
PLWD/CG Reaction to diagnosis	6
PLWD/CG Reaction to diagnosis: Hard to process dementia diagnosis for CG	
PLWD/CG Reaction to diagnosis: PLWD aware of diagnosis	
PLWD/CG Reaction to diagnosis: PLWD refusing to accept the diagnosis	
PLWD/CG Reaction to diagnosis: shocked by the diagnosis	
Suspecting diagnosis is not precise enough	5
Suspecting diagnosis is not precise enough: CG suspecting the diagnosis not to be precise enough (given Alzheimers disease, suspecting FTD)	
Suspecting diagnosis is not precise enough: seeking Dementia diagnosis after having received MCI diagnosis	
Taking a long time to notice dementia symptoms	2
Taking a long time to notice dementia symptoms: Did not recognize dementia symptoms for a year	
Taking a long time to notice dementia symptoms: Mistaken dementia symptoms for emotional prolems and arrogance	
Taking long to seek a diagnosis	14
Taking long to seek a diagnosis: Experiencing symptoms for a longer time before diagnosis	
Taking long to seek a diagnosis: PLWD / PLWD's partner refusing to seek medical help	
Taking long to seek a diagnosis: Taking a long time before seeking medical help	
Visiting GP for a diagnosis	1
Phase: Denial vs. Acceptance & Seeking a Diagnosis	**32**
(Not) seeing value in receiving a dementia diagnosis	6
(Not) seeing value in receiving a dementia diagnosis: Seeing value in receiving a dementia diagnosis	
(Not) seeing value in receiving a dementia diagnosis: Thinking seeking a diagnosis is a waste of time	
Being in denial of presence of dementia symptoms in PLWD	4
CG notices symptoms, but PLWD seems symptom-less to the outside	1
Noticing dementia symptoms in PLWD	5
Noticing dementia symptoms in PLWD: CG suspecting symptoms in PLWD for longer before seeking a diagnosis	
Noticing dementia symptoms in PLWD: Relatives noticing symptoms of dementia in PLWD	
Taking a long time to notice dementia symptoms	2
Taking a long time to notice dementia symptoms: Did not recognize dementia symptoms for a year	
Taking a long time to notice dementia symptoms: Mistaken dementia symptoms for emotional prolems and arrogance	
Taking long to seek a diagnosis	14
Taking long to seek a diagnosis: Experiencing symptoms for a longer time before diagnosis	
Taking long to seek a diagnosis: PLWD / PLWD's partner refusing to seek medical help	
Taking long to seek a diagnosis: Taking a long time before seeking medical help	
Phase: Diagnosis Disclosure	**11**
Communicating the diagnosis	5
Communicating the diagnosis: CG not participating in the doctors appointment -> now suspecting PLWD does not want to/is unable to share all the information	
Communicating the diagnosis: how to communicate dementia to PLWD PLWD does not want to/is unable to share all the information	
PLWD/CG Reaction to diagnosis	6
PLWD/CG Reaction to diagnosis: Hard to process dementia diagnosis for CG	
PLWD/CG Reaction to diagnosis: PLWD aware of diagnosis	
PLWD/CG Reaction to diagnosis: PLWD refusing to accept the diagnosis	
PLWD/CG Reaction to diagnosis: shocked by the diagnosis	
Phase: Diagnostic Process	**31**
CG debating how proactive they should be when seeking help	1
CG feeling like giving up seeking a diagnosis	4
CG feeling like giving up seeking a diagnosis: CG feeling like giving up as a result of long diagnostic process and lack of support	
CG feeling like giving up seeking a diagnosis: CG feels as if noone believes them	
CG not familiar with the process of diagnosis	1
Diagnostic process taking too long	7
Diagnostic process taking too long: Diagnostic process taking a long time	
Diagnostic process taking too long: Obstacles on the way to receiving a diagnosis	
Diagnostic process taking too long: referred to memory clinic	
Diagnostic process taking too long: waiting long time for an appointment with the memory clinic	
Negative experience with doctor during diagnosis	6
Negative experience with doctor during diagnosis: CG dismissed by doctor when asking for help	
Negative experience with doctor during diagnosis: CG feels as if doctor has no time for them	
Negative experience with doctor during diagnosis: CG feels as if they are bothering the doctor	
Negative experience with doctor during diagnosis: CG not satisfied with doctor	
Negative experience with doctor during diagnosis: CG suspecting doctor is financially taking advantage of PLWDs	
Negative experience with doctor during diagnosis: Doctor not being helpful	
Negative experience with doctor during diagnosis: Doctor not having enough time	
Percieved disease untreatability	1
Percieved disease untreatability: CG assumes: Doctors are not helping since they do not know how to cope with the condition	
Percieved disease untreatability: Disease untreatability	
PLWD afraid of taking the diagnostic test	3
PLWD pretends to not experience any symptoms when visiting the doctor	1
Suspecting diagnosis is not precise enough	5

Suspecting diagnosis is not precise enough: CG suspecting the diagnosis not to be precise enough (given Alzheimers disease, suspecting FTD)	
Suspecting diagnosis is not precise enough: seeking Dementia diagnosis after having received MCI diagnosis	
Telling PLWD a white lie	1
Visiting GP for a diagnosis	1
Theme: Care Home	**35**
CG consequences joining a care home	12
CG consequences joining a care home: CG debating how much to stay involved once PLWD is put in a care home	
CG consequences joining a care home: CG feels guilt and betrayal towards PWDs after placing them in a care home	
CG consequences joining a care home: CG not satisfied with care home service	
CG consequences joining a care home: relatives not wanting to visit PLWD in a care home	
CG deciding to put PLWD in a care home	6
CG deciding to put PLWD in a care home: CG debating whether to put PLWD in a care home	
CG deciding to put PLWD in a care home: CG wanting to put PLWD in a care home (cannot cope anymore)	
CG deciding to put PLWD in a care home: PLWD joined care home since they refused carers	
CG deciding to put PLWD in a care home: Putting PLWD in a care home for their safety	
How to communicate to PLWD they are going to care home	1
PLWD consequences of joining a care home	11
PLWD consequences of joining a care home: PLWD about to join a care home	
PLWD consequences of joining a care home: PLWD hesitant to join care home	
PLWD consequences of joining a care home: PLWD wants to go home from a care home	
PLWD consequences of joining a care home: PLWD wants to see family	
PLWD consequences of joining a care home: Rapidly progressing dementia as a result of joining care home	
Struggling to find a care home	5
Struggling to find a care home: Care home search is time intensive	
Struggling to find a care home: CG not familiar with the process of finding a care home	
Struggling to find a care home: CG struggling to find a care home that would accept the PLWD	
Struggling to find a care home: PLWD cannot be provided carehome due to lack of diagnosis	
Struggling to find a care home: Wanting to keep the pair of PLWDs together when putting them in a care home	
Theme: CG Burden	**121**
Caregiving affecting CG's relationship with siblings	11
Caregiving affecting CG's relationship with siblings: CG accusing siblings of taking advantage of the PLWD (financially)	
Caregiving affecting CG's relationship with siblings: CG angry at other relatives (siblings) for not helping with caregiving	
Caregiving affecting CG's relationship with siblings: CG appreciating if siblings contribute to caregiving	
Caregiving affecting CG's relationship with siblings: CG experiencing worsened relations with siblings as a result of dementia	
Caregiving affecting CG's relationship with siblings: CG feels being a caregiver is unjust	
Caregiving affecting CG's relationship with siblings: CG lacking support from siblings in caregiving journey	
Caregiving affecting CG's relationship with siblings: Dementia has a significant impact on the family	
CG "losing" PLWD to dementia	7
CG "losing" PLWD to dementia: CG "lost" their partner due to dementia	
CG "losing" PLWD to dementia: CG missing the "old" PLWD	
CG "losing" PLWD to dementia: PLWD lacking empathy towards CG	
CG burden leading to burnout	52
CG burden leading to burnout: Caregiving negatively affecting CG's mental health	
CG burden leading to burnout: CG exhausted from caregiving	
CG burden leading to burnout: CG feeling miserable	
CG burden leading to burnout: CG not being able to provide care for longer	
CG burden leading to burnout: CG overwhelmed by caregiving	
CG burden leading to burnout: CG struggling	
CG burden leading to burnout: CG themselves needing rest and care	
CG burden leading to burnout: CG trying to keep calm / struggling to be patient	
CG feeling guilty	6
CG feeling guilty: CG feeling guilty for hoping PLWD would not suffer any longer	
CG feeling guilty: CG feeling guilty for not having capacity for caregiving	
CG feeling guilty: CG feeling guilty for not providing care earlier	
CG feeling guilty: CG guilty of taking self-care time	
CG feeling resentment towards PLWD	4
CG lonely in the caregiving journey	11
CG lonely in the caregiving journey: CG does not have access to a support group of people sharing the same caregiving experience	
CG lonely in the caregiving journey: CG feeling alone in this battle	
CG lonely in the caregiving journey: CG lacking empathy from PLWD	
CG lonely in the caregiving journey: CG needing support	
CG outlook on future	8
CG outlook on future: CG being negative – needing hope and strength	
CG outlook on future: CG not giving up – trying to see the positive in the negative	
CG Prioritizing Caregiving	11
CG Prioritizing Caregiving: Caregiving taking over CG's life	
CG Prioritizing Caregiving: CG feeling selfish for prioritizing own needs	
CG Prioritizing Caregiving: CG needing to prioritize own needs	
CG Prioritizing Caregiving: CG neglecting own family as a result of prioritising PLWD	
CG Prioritizing Caregiving: CG not taking breaks from caregiving	
CG Prioritizing Caregiving: CG prioritising caregiving	
CG ways of coping	3
CG ways of coping: CG enjoying self-care time	
CG ways of coping: CG enjoying walks	
CG worried about financial aspect of caregiving	1
CG worried they might also get dementia, not wanting to put this burden on their children	1
Difficult to watch PLWD deteriorate	1
Difficult to watch PLWD deteriorate: It is difficult for CG to watch PLWD deteriorate	
Worry about PLWD's health and emotional state	5
Worry about PLWD's health and emotional state: CG worried about PLWD's emotional state	
Worry about PLWD's health and emotional state: CG worried about PLWD's health	
Worry about PLWD's health and emotional state: CG worried if PLWD's state is harming PLWD's partner	
Theme: Experience with NHS and social services	**9**
CG dissatisfied with social services and NHS	4
Long waiting times	4
Long waiting times: burreaucracy taking long	
Long waiting times: Long wait for appointments	
Long waiting times: PIP assessment taking a long time	
Long waiting times: Social services taking long to arrange	
Problems with receiving CG benefits	1
Theme: Impact of Covid	**3**
Covid worsened dementia symptoms	1
lockdown preventing getting a diagnosis	1
no visits in care home due to covid	1
Theme: Interacting with the forum	**87**
Care assisstant not able to share much information on the forum due to legal agreements	1
CG interacting with the forum	74
CG interacting with the forum: CG apologizing for complaining	
CG interacting with the forum: CG asking for financial & legal advice	
CG interacting with the forum: CG feeling misunderstood regarding caregiving journey	
CG interacting with the forum: CG looking for people with similar experiences	
CG interacting with the forum: CG seeking advice on forum	
CG interacting with the forum: CG wanting to vent on the forum	
CG reaction to forum	6
CG reaction to forum: CG finding forum posts sad	
CG reaction to forum: CG finding the forum useful	
CG reaction to forum: Finding comfort on forum	
CG reaction to forum: Forum has given CG confidence	
Lack of education on dementia	2
memory clinic recommended using the forum	1
PLWD interacting with the forum	3
PLWD interacting with the forum: PLWD seeking support on forum	
PLWD interacting with the forum: PLWD wanting to share things on forum	
Theme: Maintaining PLWD's independence while keeping them safe	**79**
CG wanting to protect PLWD without taking away their independence	37
CG wanting to protect PLWD without taking away their independence: Agression towards PLWD	
CG wanting to protect PLWD without taking away their independence: CG apologizing for PLWD's behaviour	
CG wanting to protect PLWD without taking away their independence: CG debating to what extent they should obey PLWD's wishes or act on the actual needs of PLWD	
CG wanting to protect PLWD without taking away their independence: CG hired caregiving staff	
CG wanting to protect PLWD without taking away their independence: CG looking for ways to persuade PLWD to get LPA	
CG wanting to protect PLWD without taking away their independence: CG managing PLWD's finances	
CG wanting to protect PLWD without taking away their independence: CG moved in with PLWD to take care of them	
CG wanting to protect PLWD without taking away their independence: CG not wanting to cause anxiety in PLWD	
CG wanting to protect PLWD without taking away their independence: CG not wanting to make PLWD suspicious about money	
CG wanting to protect PLWD without taking away their independence: CG wanting LPA for PLWD	
CG wanting to protect PLWD without taking away their independence: CG wanting to keep PLWD safe	
CG wanting to protect PLWD without taking away their independence: CG wanting to maintain PLWD's independence	
CG wanting to protect PLWD without taking away their independence: People taking advantage of PLWD's cognitive defficiency	
CG wanting to protect PLWD without taking away their independence: Using security technology to maintain PLWD's independence & safety	
CG's partner cannot provide care (also has dementia)	2
CG's partner cannot provide care (also has dementia): both CG's parents have dementia	
CG's partner cannot provide care (also has dementia): PLWD's partner cannot provide care	
Losing ability to be independent	20
Losing ability to be independent: PLWD cannot perform personal hygiene	
Losing ability to be independent: PLWD cant perform tasks they used to be previously skilled in	
Losing ability to be independent: PLWD childlike behaviour	
Losing ability to be independent: PLWD does not want to be alone	
Losing ability to be independent: PLWD losing ability to be independent	
PLWD does not want to lose independence	12
PLWD does not want to lose independence: PLWD blaming CG for their loss of independence	
PLWD does not want to lose independence: PLWD does not let care assistants take care of him	
PLWD does not want to lose independence: PLWD hesitant to register a Power of Attorney	
PLWD does not want to lose independence: PLWD resenting the CG	
PLWD does not want to lose independence: PLWD wanting to stay independent	
PLWD still independent – living alone	8
Theme: PLWD Symptoms + Ways of coping	**139**
Agressive behavior	17
Agressive behavior: PLWD agressive behaviour	
Agressive behavior: PLWD agressive behaviour towards CG	
Agressive behavior: PLWD dangerous behaviour	
Agressive behavior: PLWD destroying things	
Agressive behavior: PLWD hurting themselves	
Agressive behavior: PLWD intentionally bothering the CG	
Changes in communication	4
Changes in communication: PLWD keeps asking questions	
Changes in communication: PLWD stopped talking	
Disorientation	16
Disorientation: PLWD being confused	
Disorientation: PLWD getting lost in familiar places	
Emotional changes	7
Emotional changes: PLWD anxious behaviour	
Emotional changes: PLWD apologetic and timid	
Emotional changes: PLWD mood swings	
Eyesight problems	1
Fixations	6
Fixations: PLWD being fixated on something	
Fixations: PLWD cannot stand change	
Fixations: PLWD repeating tasks	
Food consumption	4
Food consumption: PLWD not wanting to eat	
Losing ability to be independent	20
Losing ability to be independent: PLWD cannot perform personal hygiene	
Losing ability to be independent: PLWD cant perform tasks they used to be previously skilled in	
Losing ability to be independent: PLWD childlike behaviour	
Losing ability to be independent: PLWD does not want to be alone	
Losing ability to be independent: PLWD losing ability to be independent	
Mobility	10
Mobility: PLWD decreased mobility	
Mobility: PLWD falling	
Mobility: PLWD physical weakness symptom	
Overwhelmed by too many people	1
PLWD accusations / suspicions	3
PLWD Behaviour Change	11
PLWD Behaviour Change: PLWD change in behaviour	
PLWD Behaviour Change: PLWD scary behaviour	
PLWD Behaviour Change: PLWD unexplainable behaviour	
PLWD emotional experience	9
PLWD emotional experience: PLWD being bored/apathic	
PLWD emotional experience: PLWD being emotional	
PLWD emotional experience: PLWD emotional trauma	
PLWD emotional experience: PLWD feeling lonely	
PLWD emotional experience: PLWD struggling	
PLWD Memory Problems	14
PLWD Memory Problems: PLWD not recognizing relatives	
PLWD Memory Problems: PLWD short term memory problems	
PLWD ways of coping	8
PLWD ways of coping: PLWD enjoying creative/manual work	
PLWD ways of coping: PLWD enjoys talking to people	
PLWD ways of coping: PLWD recording changes they are experiencing	
PLWD ways of coping: PLWD trying to keep a positive outlook	
Refusal	4
Refusal: PLWD does not leave the house	
Refusal: PLWD refuses everything	
Sleep pattern	3
Sleep pattern: PLWD not sleeping	
Sleep pattern: PLWD sleeping all the time	
UTI	1
Theme: Seeking a diagnosis	**14**
(Not) seeing value in receiving a dementia diagnosis	6
(Not) seeing value in receiving a dementia diagnosis: not seeing value in receiving a diagnosis	
(Not) seeing value in receiving a dementia diagnosis: Seeing value in receiving a dementia diagnosis	
(Not) seeing value in receiving a dementia diagnosis: Thinking seeking a diagnosis is a waste of time	
CG debating how proactive they should be when seeking help	1
CG not familiar with the process of diagnosis	1
Negative experience with doctor during diagnosis	6
Negative experience with doctor during diagnosis: PLWD afraid of taking the diagnostic test	
Negative experience with doctor during diagnosis: PLWD pretends to not experience any symptoms when visiting the doctor	
Negative experience with doctor during diagnosis: Telling PLWD a white lie	
Theme: Uncertainty	**4**
Uncertain disease progression	4
Uncertain disease progression: CG uncertain about how long PLWD will live	
Uncertain disease progression: CG uncertain about the progression of the disease	

Appendix 10: Script for Extracting Relevant Forum Post Messages

```python
from utils.configs import setup_configs
from utils.data_readout import load_csv_data
import pathlib
from sklearn.feature_extraction.text import TfidfVectorizer
from sklearn.metrics.pairwise import cosine_similarity
import nltk
import ssl
from nltk.corpus import stopwords
from nltk.tokenize import word_tokenize
from nltk.stem import WordNetLemmatizer
import logging
import numpy as np
import os
import textwrap
ssl._create_default_https_context = ssl._create_unverified_context
def preprocess(text):
    stop_words = set(stopwords.words('english'))
    lemmatizer = WordNetLemmatizer()
    tokens = word_tokenize(text.lower())
    tokens = [lemmatizer.lemmatize(word) for word in tokens if word.isalpha() and word not in
stop_words]
    return ' '.join(tokens)

def wrap_text(text, width=150):
    return textwrap.fill(text, width=width)

def save_post_thread_txt(output_dir,similar_posts)-> None:
    os.makedirs(output_dir, exist_ok=True)
    for idx, row in enumerate(similar_posts.itertuples()):
        filename = f"RANK{idx + 1}.txt"
        filepath = os.path.join(output_dir, filename)
        with open(filepath, 'w', encoding='utf-8') as file:
            header = f"Post ID: {row.post_id}\nThread URL: {row.thread_url}\n"
            wrapped_message = wrap_text(row.original_post_message)
            file.write(header + wrapped_message)
            file.write("\n")  # Ensure there's a newline at the end for better readability

def compute_similarity(df,tfidf_matrix,feature_names, topic_words,
log_path,n_top_posts,n_threshold) -> None:
    logging.info(f'Calculating cosine similarity between topic words and thread posts for threshold
{n_threshold} !')
    threshold = topic_words[f'threshold_{n_threshold}']
    topic_vector = np.zeros(len(feature_names))
    for word, prob in threshold.items():
        if word in feature_names:
            index = feature_names.tolist().index(word)
            topic_vector[index] = prob
    topic_vector = topic_vector / np.linalg.norm(topic_vector)
    cosine_similarities = cosine_similarity(topic_vector.reshape(1, -1), tfidf_matrix).flatten()
    df['similarity_score'] = cosine_similarities
    similar_posts = df.nlargest(n_top_posts, 'similarity_score')
    wrapped_results = "\n\n".join([
        f"RANK{idx + 1}:\nPost ID: {row.post_id}\nThread URL:
{row.thread_url}\n{wrap_text(row.original_post_message)}"
        for idx, row in enumerate(similar_posts.itertuples())
    ])
    logging.info(f"Saving the top {n_top_posts} similar posts:\n{wrapped_results}")
    threshold_output_path = log_path / f'threshold_{n_threshold}'
    save_post_thread_txt(threshold_output_path, similar_posts)


def main(read_configs:dict, log_path) -> None:
    df = load_csv_data(data_file_path=pathlib.Path(read_configs['data_folder']))
    nltk.download('stopwords')
    nltk.download('punkt')
    nltk.download('wordnet')
    topic_words = read_configs['topic_words']
    logging.info('Applying preprocessing to the text (This takes a while ...)')
    df = df[:1000]
    df['original_post_message'] = df['post_message']
    df['post_message'] = df['post_message'].apply(preprocess)
    vectorizer = TfidfVectorizer()
    tfidf_matrix = vectorizer.fit_transform(df['post_message'])
    feature_names = vectorizer.get_feature_names_out()
    for N_threshold in [10,100,1000,10000]:
        compute_similarity(df,tfidf_matrix,
feature_names,topic_words,log_path,n_top_posts=read_configs['number_of_best_topics'],n_threshold=N_
threshold)
    logging.info('Analysis completed :)')


if __name__ == '__main__':
    read_configs, log_path = setup_configs()
    logging.info('Running ...')
    main(read_configs, log_path)
```

Appendix 11: List of selected Post Message Quotes

Page	Sub-forum	Thread	Post ID	Post message
67	I care for a person with dementia	I'm 27, my mum has rapidly progressing dementia	1651174	Hi everyone, I have never met or spoke to anyone like me, so it would mean a lot to hear from others who are/ have been in a similar situation! To give you some background, my mum started becoming forgetful, and socially inappropriate in my early-20s. By the time I was 25, to be brutally honest, she had gotten so unemphatic that I started to hate her, until it got so bad that I realised something must be wrong. This was confirmed shortly after by my father, and then our GP. Since then, in the past three years she has gone from being a University lecturer, to not being able to get ready for bed on her own. She has delusions, rarely knows who my father is (even though he's her primary carer), can't really dress or bathe without help, and only makes sense (verbally) about 30% of the time. Her decline has been SO fast. I have really struggled to come to terms with the way in which this has obliterated our lives. We have no other family, and have found social services and the NHS very unhelpful- they have offered us almost no support. She has been given a general diagnosis of 'Alzheimers', but we think it might be FTD, as she has retained a lot of long term-memory until recently, and her decline was initially mostly organisational/functional. However, brain scans have shown no localised shrinkage at the front (just all over), so who knows. I really struggle with not knowing what it is, especially having no idea of how long she is going to live. It is torture seeing how much emotional pain she and my father are in, and like many carers, I would rather this did not drag out for her sake. I have a million things i'd love to talk about with someone like me, like how it affects: relationships, career, the health of your surviving parent/aunt/uncle/family member, your own health.... I could go on, but this post is already so long!! Lots of love.
67	I have dementia	Has anyone started their own Life Story/This is me book?	893616	The mental health nurse suggested I start a 'This is me' information booklet to record my dietary intolerance's and other relevant information. However, having initially started to write things down I am now up to 70,000 words and realise I am writing an account of my life and my daily life today!!! I find it extremely cathartic to write things down and also an enjoyable hobby. I am not really bothered whether it is good writing as recording what I am thinking. I don't think I will be a best seller writer, although one can hope! I am trying to record any changes I see in myself which I add to my Wordpress blog. More recently my mental health nurse gave me a template to base a 'brief' information pack on to record things such as medication, dietary problems, likes and dislikes etc. As I am in the very early stages with only minor cognitive difficulties (memory and loss of attention etc) I have not yet started to fill it out. Has anyone else created their own This is me info booklet yet? How easy did you find it? How many find it a benefit to write a daily 'blog' to record any changes or difficulties they notice?
68	I have a partner with dementia	Crunch time!	1634330	Friday is D day!!! I hope, wonder, and I am not sure what to expect.....A follow up appointment with Dr at memory clinic....hopefully to confirm the memory nurses diagnosis of mixed dementia! So much has happened in the four months since seen by Nurse(OH been catheterised, total loss of mobility, Three hospital stays........BUT. What will a diagnosis mean or do.? He is insistent he wAnts to purchase a power wheelchair..... I have been advised unofficial he doesn’t have the cognitive ability for such!) .I fully understand why, he has lost all independence.......so the crunch will be on Fridays diagnosis . A question to others on TP......Once an official diagnosis what happens...if anything. I have read on TP it really changes very little but after three years of tests.....more tests etc...need it officially!) (PS.....DN attends for insulin.. and catheter care .....Carers attend 4x daily....) Any suggestion as to what I should be asking or seeking. Thanks in advance!
68	I care for a person with dementia	I'm 27, my mum has rapidly progressing dementia	1651174	Hi everyone, I have never met or spoke to anyone like me, so it would mean a lot to hear from others who are/ have been in a similar situation! To give you some background, my mum started becoming forgetful, and socially inappropriate in my early-20s. By the time I was 25, to be brutally honest, she had gotten so unemphatic that I started to hate her, until it got so bad that I realised something must be wrong. This was confirmed shortly after by my father, and then our GP. Since then, in the past three years she has gone from being a University lecturer, to not being able to get ready for bed on her own. She has delusions, rarely knows who my father is (even though he's her primary carer), can't really dress or bathe without help, and only makes sense (verbally) about 30% of the time. Her decline has been SO fast. I have really struggled to come to terms with the way in which this has obliterated our lives. We have no other family, and have found social services and the NHS very unhelpful- they have offered us almost no support. She has been given a general diagnosis of 'Alzheimers', but we think it might be FTD, as she has retained a lot of long term-memory until recently, and her decline was initially mostly organisational/functional. However, brain scans have shown no localised shrinkage at the front (just all over), so who knows. I really struggle with not knowing what it is, especially having no idea of how long she is going to live. It is torture seeing how much emotional pain she and my father are in, and like many carers, I would rather this did not drag out for her sake. I have a million things i'd love to talk about with someone like me, like how it affects: relationships, career, the health of your surviving parent/aunt/uncle/family member, your own health.... I could go on, but this post is already so long!! Lots of love.
69	Recently diagnosed and early stages	help and advice please	839980	My dad has just be diagnoised with early stages of Alzheimers, he is only 65. My problem is that we are a very small family with just myself and my uncle able to look out for him. he lives 200 miles away from me and my uncle lives 1 hours drive away from him. Neither my uncle or my father want him to move closer to me so that I can start to keep an eye on things, he wants to stay where he is, but I cant keep an eye on such things as his condition, his heigeine, bills etc. I appreciate I need to give him space and let him have independance but I am really worried that something may happen and I will not be there!. He does travel to me by train several times a year but other than that we communicate by phone. The other issue I have which I can not get my head around is the power of attourny - I am struggling to talk to him about it as I really dont want him to think I am only trying to get my hands on his money! Has anyone else had this problem and what did you do.
69	I care for a person with dementia	Newly diagnosed but determined to still drive....	1622533	I care for a dear elderly friend who is like a Mum to me. She is 87 years old and can be very temperamental in her moods which has got worse due to the dementia. The DVLA has taken her driving licence away due to the dementia diagnosis, but also because we mentioned on the medical form that she has falls and has double vision. She blames me for her having to stop driving, and refuses to sell her car. As I am 'only' a friend I have no way of hiding her car keys or removing her car at all, and the problem is that she gets very hostile towards me if I mention the subject of her driving at all. She knows that she no longer has a licence, and is no longer insured, but doesn't care, and when I have tried to ask her how she would feel if she had an accident and hurt or even killed someone she becomes very aggressive towards me and says I'm nagging her and to leave her alone. I have strong suspicions that she is driving the car every morning as she always has, as the car has moved from where I park it in the garage, the seat has been moved forward and the car is parked very badly at an awful angle in the garage. She is refusing to sell the car because she wants me to drive her in it instead of using my car, which I have explained I need to use my car as I use a wheelchair, but she is adamant that she is keeping her car. Does anyone have any advice please?
70	I have a partner with dementia	Oh what a Knight	1575321	It is shortly after noon and I’ve just finished the breakfast dishes after finally getting some sleep after a long night. Knight our greyhound was very excited when visitors called the day before yesterday, even going so far as to bark, a very rare occurrence. I suspected at the time that he might have banged into something. He seemed alright that night but the next morning came downstairs quite slowly (ie not jumping the last 3 stairs) and seemed to be limping slightly. After I got back from a day's cycling the carer (and my wife) told me that he was definitely limping and had turned for home when they were out with him. I checked his paws and then up his left leg and he gave a squeal. He seemed increasingly uncomfortable when walking about and even getting settled down seemed to give him some distress. My wife kept repeating that we should get ‘the doctor’ to do a house call, which did nothing for my anxiety so I decided to phone the out of hours vet (at our normal practice). We were advised to take him for a checkup straightaway rather than to wait for an appointment the next day. I had to help him climb into the car and out again at the vets. During the 15 minute journey my wife must have asked at least 15 times where we were going.The vet soon confirmed that the dog has a sore elbow on his left foreleg, but with no swelling evident she felt that it was unlikely to be a fracture. She gave him a syringe worth of an opiate to help with his pain and a course of painkillers for the next 7 days. My wife remembers none of this. The vet advised that Knight should avoid walks and going up or down stairs so, after his final toilet break last night, I tried to get him settled down in the kitchen. From upstairs I could hear what appeared to be a locomotive as Knight developed a reaction to his medication that left him standing panting. As it was not stopping I rang the vet for advice. On hearing the panting she said that this was something that sometimes happened, would do him no harm, and should subside approximately 8 hours after the time the medication was administered. I did not want to leave him until it subsided so sat in the kitchen whilst he stood in the corridor, his tongue a mile long and his ribs going in and out with each rapid pant. My wife was upstairs ready for bed but came down after about 40 minutes, having put on additional clothes, and refused to go to bed again or to sit down. Her commentary about the ‘doctor’ coming back, my lack of attention to the dog, her love for him, and wanting to say goodbye (as he was dying) and so on did nothing for my own mood. She was at the same time surprised to hear that there was anything wrong. The dog stopped panting about 4am and we went to bed. Not for long though as he started to whimper and howl at the injustice of being left alone in the kitchen. I went to calm him down and eventually got to bed about 5, only to be woken by my wife getting dressed before 8. Knight had by then made his way upstairs so we caught up on our sleep until about 10:30, whilst she did whatever she does (involving lots of kitchen roll and the grate in the living room this time).Knight now looks back to his normal self, though still limping a bit. As he can stand for hours on end this suggests that nothing is broken. I have a course of pain killers to give him and he had one with his breakfast this morning. Trying to get my wife to take any of this in is a lost cause. We now need to take the dog out for a toilet break before going to the shops but before that I want my wife to change out of her nightwear, over which she has added tops, jumpers and coats, and the pair of non-matching shoes (one black, one blue) that she is wearing. She claims that they are a pair and that she has no others. A very long post about a dog, you may think but at heart it is about how lonely and difficult it becomes when dementia means that one's partner is no longer able to understand, empathise or support. Hence the things that they say and do just add to the stress one is already feeling and the whole situation just seems so much worse. Not unfamiliar to others I guess.
70	I care for a person with dementia	2 minutes of personal selfishness	2047532	Why does no one care for the carer? Why does no.one believe me? Why doesn't my sibling.care for her mother? Why does.the PWD portray the perfect life? Why do I feel guilty for not caring.and then neglect my own family due to.caring too much? I didn't sign up.to the **** I've been dealt, but no other family.care Sorry.just feel miserable today 😪

70	I care for a person with dementia	Care Home is iminant - Any Advice Very Sad	1147132	Hi, Mum is definitely doing the respite then will be admitted to the CH after the respite period. She's not functioning on her own anymore with any day to day tasks and she had a fall last week and ended up in A & E and it's now blaringly obvious she needs 24/7 care. We are so upset that when she leaves for respite she won't be coming back to her home, but it's going to be for the best. We I can't imagine not being with her as much as me and my sisters are now, but don't know if it's healthy. Do we need to step back when she's in the care home or should we just carry on as normal. We have her assessment this afternoon and then we go from there. Feeling so very sad, still feel like we've let mum down as we promised we wouldn't do this but we never imagined she would end up how she is.
71	I care for a person with dementia	I thought it could not get worse but it has	1340338	After looking after o/h till I was ready to drop got a care home to come an assess which they did on thursday, -and much to y relief we took her thursday afternoon they said leave it a couple of days so I went on Sunday. She was standing in the hall screaming at the top her voice she calmed down a bitbut accused me of dumping her!h At lunch she threw a glass of water at me then had a tantrum. I was advised to leave later that day they rang to say they wanted her out Just when when you think it cannot get worse-it does so see what tomorrow brings as I ring around to find a place
71	I have a partner with dementia	benefit minefield	1085969	where di i begin.... before my husbands diagnosis of frontotemporal dementia he was in reciept of contribution based esa... failed his work assesment with 0 points... appealed this and thannkfully had everythinng in place before the tribunal took place...we have now recieved a letter stating that he his entitled to esa with the support component... now for the next bit on the same day we recieved a letter stating that his esa is to finish on the 31st may because he has had it for 365days... we get no other benefits.. what the hell do we do now...im trying so hard to even take in the news of his dementia without having to deal with this as well.... feel so overwhelmed i cnt even think... i know im waffling but really am unsure of everything
72	I have a partner with dementia	Just starting out on this journey	1652429	i don't even know what to say! My dear husband, brilliant architect, my rock, has had memory problems and finally we got him to a neurologist to hear last week he is Early on-set Alzheimers. We were both in shock. And the MD wasn't very helpful, rushing us out of his office. We've had a rough year that should have been wonderful. His mood swings and rages made me withdraw and resent him and I never guessed he had some major problem because he could always be difficult and sometimes My way is the right way. Now I see he just needed love and reassurance. I feel so bad I didn t get it. Now I'm feeling overwhelmed with caring for him even he is capable of a lot but he won t fix his own food, like maybe it is too hard to organize himself even if I put it in the refrigerator for him. He gets very weak and anxious if he dosen t eat. He is 74 this week and I am 65. I am already feeling exhausted and don't know how I will be able to do this. I hope I can find some good advice and support here. Thanks for listening. I live in the US.
96	I have a partner with dementia	Dementia and marriage	2021649	My husband is 3 yrs into a diagnosis of MCI following the pattern of Alzheimer's. I'm not exactly sure how to express my thoughts and questions but I'll try. My husbands personality is slowly changing. My feelings towards him are changing. It's changing our marriage. I feel guilty. My husband doesn't recognise these changes I don't think. How does a marriage survive Alzheimer's? How do I even know what is Alzheimer's and what is my husband lacking empathy? Being difficult? Being selfish? I'm trying so hard to support him on this journey but I'm a human too and my marriage no longer gives me what I need - I hate saying that out loud 😔 but I don't feel the connection I once did, I feel so confused. If I feel like this in the beginning, how am I going to feel further down the rd? I ask my husband if he's ok, if I'm supporting him enough etc, his reply is "I feel the closest I've ever felt to you". Why do I not feel the same? I love him but we've changed and we can't discuss it because he doesn't see anything's different
96	I have a partner with dementia	Why Do NHS Mental Clinic just want to Get us off their list	1998093	My partner was referred to a Mental Health Clinic, Who diagnosed Alzheimer's, now they want to discharge to GP. Feel like we are being abandoned, I have no training as a carer. Or able to cope with 24-7 its driving my mental health and general health down, i feel like i am on a ever increasing downwards spiral. Days i feel like walking off. Why does NHS expect us to be full time carers
98	I have a partner with dementia	Can i just rant here?	1977933	I hate nights like these. He's locked in the downstairs loo saying I've told him he's got to go to Oxford. He then says its his money and he's got to go to pay for the volume and I should ring the woman off the telly and she'll explain. I'm worrying because I keep hearing him run water in sink and fiddling with things......No 50 minutes into this episode, he's now washed and dressed.(02:50hr) There's no reasoning with him, he's humming and whistling and pottering round. Do I get dressed too? Or just try to sleep? I've got the keys to house by me so he can't get out. I get cross with the dementia. It's s hard to separate it and say its not him it's the dementia that's being thoughtless and unreasonable. I've explained to him what time of night it is and dementia doesn't care. It's reasonable to the dementia to put all the lights on and search for that thing in the middle of the night and whitsle . It doesn't matter that anyone else might like to sleep. And it never says sorry. When dementia kicks in he doesn't care and it hurts. People keep saying dont take it personally but thats easy when its not you thats being told you did stuff, said things that you didn't say. I wish I could open his head and pull the dementia out and have my lovely, kind man back.
99	I have a partner with dementia	Becoming invisable and no support	1988862	I read with interest the results of your survey, my wife has mixed dementia we do not get any support from social services, I wasn't aware they did provide any support If you live in your own home. Our GP. Is aware of my wife's dementia but I cannot say they support us in any way regarding her dementia, unfortunately since Covid seeing GP's has become extremely difficult and trying to get appointments is a nightmare. Following her initial diagnosis from the memory clinic we have had no other contact from them, that seems to be most people's experience. We have found some areas of the NHS do not seem to understand dementia and how to deal with patients or their carers, the worst examples we have experienced is with physiotherapist who have expected patients with dementia experiencing short term memory problems to understand their treatment and remember to do exercises on their own, but do not like their carer to answer and be present. This is our own personal experience. I have also experienced problems with some staff when you explain the person you are looking after has memory problems so can you speak for them they want to speak to them first, if this a phone call they have no way of knowing that they are actually speaking to. In one instance a receptionist insisted on speaking to my wife and arranged an appointment, unfortunately she then ended the call, my wife had forgotten the details of the appointment or even if an appointment had been made. It could be that some dementia patients from initial appearance do not seem to have any problems, they can conduct a good conversation, the fact that they will forget the conversation and the person a short time later is not seen or understood by some individual. We both arranged lasting powers of attorney, unfortunately some staff do not understand these or choose not to, and on the phone I accept it is difficult to prove you have one in place, based on my experience it is difficult to see the point in them. My wife's short term memory can be very bad and she can be confused in unfamiliar places, she also has severe problems with arthritis, I have a blue badge for driving, very occasionally my wife is taken out by one of our family, it would be extremely useful if she had a blue badge for these occasions, I mentioned that to get into and out of the car she needs to open the car door very wide. The assessor appeared to ignore her dementia and dismissed the need to open car doors wide, making disabled parking bays essential, her arthritis requires a need to park close to the destination. The request was refused, the assessor again ignoring or not understanding dementia wanted to know how many pain killers my wife took daily for her arthritis they didn't understand that a dementia patient would not necessarily take medication, if she complains of pain I will get her to take some pain killers. I think this illustrates the lack of understanding of dementia. A blue badge is sometimes looked at as way to avoid parking fees by some people without disabilities, in most instances most of my parking is at free supermarket car parks. I did appeal but this was ignored. Since my wife developed dementia most of our family and friends avoid visiting or phoning so there is little support from there, some close members of family now might visit once or twice a year, to a certain extent we have become invisable people, not only to family, friends, neighbours, social services and the health services, this is our reality. Dementia is a terrible disease and can be a hidden disease with sufferers avoiding contact, not always by choice but unable to mix socially unless carers, family or friends help them to mix.
99	I have a partner with dementia	Should he be told of his diagnosis…..	2050456	Hello all,My OH has been diagnosed with Alzheimer's and FTD. We are trying to decide as a family whether we should tell him about his diagnosis, so that he stops asking to drive his car or will he just not understand or continue asking and He is also becoming more upset and angry as we are taking his independence away from him. He already accuses me and my sons for rnot letting him do things, it's so hard to watch my husband who was such an independent, kind, caring husband and father become such a angry, insensitive, unhappy person. Any advice ?
99	I have a partner with dementia	Guilt and loss feelings	1995606	Hi, my husband was taken into hospital where he stayed for four weeks then came home for another four weeks when I found I just couldn't cope any more. We had two carers coming in four times a day and I still couldn't cope. I'd looked after him for thirty years, he is 76 and I am 74. He is confused and has several co morbidities, muscular dystrophy, Bi-polar, Atrial fibrillation, Parkinson's, incontinent both ways, Bowel polyps, skin cancer, bladder cancer and now has lost the use of his legs so he's in a wheelchair. He thinks he can walk so tries to at times and inevitably falls over. I keep thinking I'll be okay if I have him home again but I know I can't, but he keeps asking, " when will I be coming home", although he doesn't know where home is. I am almost grieving and full of guilt. Have I done the right thing by moving him to a nursing home?
100	I have a partner with dementia	What are the key things to say?	2021909	My husband is in the late stages of Alzheimer's and we have a visit from a Social Worker from Adult Social Care later this week. I need to know the key points I should tell her to make it clear that what I need is for my husband to have some respite time in a care home, with a view to a permanent placement later in the year. I don't want to be fobbed off with talk of carers in the home (I have already researched this), Day Centres (he refuses to go) or continued visits from representatives from ASC, the Alzheimer's Society, DISS and the Memory Clinic. They have all visited and they have been really good and helpful but he is beyond that now.I have researched the care homes in our area, asked locally for personal recommendations and have two of them in mind. I have emailed a report to the Social Worker , saying exactly what my husband is like at this time. I believe she has also received a very desperate message I sent to the representative from the Alzheimer's Society just before Christmas. I would really appreciate suggestions from people on here who have done this already - I am desperate for help and respite from my husband, who is driving me mad. Thank you in advance for any suggestions
101	I have a partner with dementia	Send him home to die.	2029125	My 90 year old husband has frontal lobe dementia with paranoid delusions. He is bedridden in a care home . He is aggressive to me and our family, wants me dead . And the family including our baby grandson in prison for stealing his money .He refuses care most days and has terrible symptoms stage 4 ulcers which gives him MRSA so hospital treatment is then necessary. He hates his care home and is very rude to his carers . He has started a court case stating he has the right to go home to die. He has delusions about rats in his room cats on his bed woman having sex under his bed . And he says I have many lovers and after he kills me he will kill them . He is an ex police man and regulary phones the police to find out about the man that tried to kill him .He is being supported by the mental health professionals with vigour . They are on a mission to get him home to me.i have had a breakdown over all of this , it's been going on for years. He is coercive and I am only just beginning to get a bit of life back. Not a lot but a bit. If he comes home again I really don't no what I would do. My health just won't cope with it all.He was sectioned by the police and treated in a mental hospital. We were told he needed 24/7 care in a care home. So how can the social services say differently. I have lost my CHC funding and only get the nursing eliment . I feel as though I am being treated like a bad person for trying to get the best outcome for my husband who is very unwell. Any advice would help. THANKYOU .
102	I have a partner with dementia	Advice needed	2041880	Hi all, I'm posting on behalf of my mother who isn't on the forum, Dad, 76, FTD, late stages now due to infections last year. He now needs full time care, day to day he is "okay" but the issue with have is he is a fall risk due to losing the ability to safely walk in hospital. He can get around with our help, and furniture walks a lot. He has a bed downstairs with rails (due to him thrashing about in his sleep pre dementia anyway) Dad can't be left on his own due to his compete inability to sit still, he can no longer lay in bed or sit in a chair because he constantly wants to get up and walk around, which is usually okay if either my mother or I am in the room with him as we watch him, and assist when we need to - If this makes sense? So whilst he's not "bed bound" he has to be put on the bed with the sides up when he gets too tired as he then begins tripping up on his feet etc when he's tired When he is in bed, he gets frustrated being "trapped" (he has said this to us during his cognitive moments) and so he tries to climb out of bed (leg over the rails and using elbows to push himself up) - but the problem is we can't leave the sides down all the time as he gets moments when he forgets he can't walk properly and will try get out of bed like a regular person (legs over the side of the bed and standing up) - which unless we are they sometimes he can't get the moment to stand unaided and then falls So the huge dilemma is he can't be left alone, he isn't bed bound, but needs to be put on the bed to rest in between walking around - when he's on the bed he can't sit still and will try and climb out ! It's such weird position to be in, at night time he will sit in his bed and move about and "thread" and sometimes just wiggle about, but won't try and climb as he sort of "knows" it's night time if that makes sense? We have tried chairs and he just wants to stand up and walk around or he gets restless and shuffles off them onto the floor which is no good for us lifting him let me tell you! Now the context behind my post is this - My mother is younger than him, 60, and until last July was a part time nurse (3 days a week) which she loved and enabled her to be with him more (he was still independent until he had an huge infection which sent him over to the end stages from middle stages literally in the space of a week) Since this she has become a full time carer - As I live with her I also share the care when I come home from work (i'll sit in the living room with him whilst she goes out with the dog or cooks tea etc) so we are coping with the daily care fairly well (we have carers 4 x a day for changing and cleaning as Mum didn't want to do that) Mum wants to go back to work / they have offered her 2 days a week, local to her (10 mins drive) and have said she can go home for a 90 mins lunch break) Originally my sister in law was going to come and sit with Dad for them 2 days a week - It would have been 10-4 (I get home from work At 4 every day) and with Mum popping back from 11:30-1pm, she would be with Dad on her own from 10am-11:30, then 1-4 - She was happy to do that Until Dad started to become more mobile and this "climbing" routine started (when this was proposed he was still bed bound) Now it's obvious she doesn't want to do it, as she is scared he will fall with her, and hurt himself. Mum was due to go back in 2 weeks but has now had to extend her sick leave as our "carer" for the 2 days has effectively cancelled the arrangement. Mum doesn't want him in a home, as he isn't ready for that yet / he can still hold a conversation, still has his humour at times, and enjoys being with us both (he's said it when he's been cognitive) and Mum doesn't mind the caring at all, it's just she wants to go back to work for 2 days for a few reasons. It will allow her some of her "life" back (which is ironic that she is a nurse!)Financial stability - house is mortgage free but still has running costs (which i contribute to). Gives her sometimes to do Now that our carer has cancelled mum is stuck - She doesn't want him in a home, but he can't be left alone due to fall risk just 2 days a week for 6 hours is all we'd need, to give mum her life back a little Has anybody got any advice ? Mum is worried about money, if we can't organise this, she is going to have to resign (currently on long term sick) but when she resigns, she will have no money coming in at all, Does anybody know any benefits she'd be entitled to? She was told to apply for ESA, she did it, and then got told she had to do work interviews and job trials to be paid! She didn't even claim the first
102	I have a partner with dementia	Coping with going into care	1988524	My partner is coming to the end of his respite and I have to decide whether to bring him home or keep him in. It's a sister care home to the one I wanted which has a waiting list. I was at the end of my tether through lack of sleep and the sheer hard work of 24/7 care so agreed to try this second choice. Care is good, nice room which I've personalised, purpose built but not as well designed as my 1st choice food good and lots of activities and a few residents who he can have a conversation with. Sounds ideal but I visit at least every other day and always leave almost in tears. He just wants me and to be at home with me. I can give him both but know that in a week or two I'll be tired and desperate again. He could come home and wait for a place at the preferred home or stay put till till there's a space but both would be so disruptive. I'm totally torn - can't bear to see him so sad but know I can't cope with him at home. I wonder if any of you have been in this situation and have any wise words to offer?

Appendix 12: ChatGPT 4.0 LDA Topic Modeling Output Interpretation Prompt

The output of the LDA topic modeling is categorized into four thresholds, each offering a different level of granularity for the identified topics. The thresholds are set at 10000, 1000, 100, and 10, where higher thresholds provide a broader overview and lower thresholds offer more detailed insights. Each threshold includes words and their respective probabilities.

Interpretation Steps:

Start with the 10000 Threshold:
Identify the core themes represented by the high-probability words.
Summarize the general idea of the topic based on these words.

Move to the 1000 Threshold:
Observe how the additional words refine the understanding of the topic.
Note any emerging sub-themes or additional relevant aspects.

Examine the 100 Threshold:
Focus on the specific aspects and sub-themes.
Identify detailed elements and their relationships to the core theme.

Conclude with the 10 Threshold:
Analyze the fine-grained details provided by the high-probability words.
Understand how these details contribute to the overall topic and its nuances.

Next, I will provide the thresholds along with the respective words and their probabilities.

Appendix 13: Graduation Project Brief

Personal Project Brief – IDE Master Graduation Project

Name student Natalia Bodnarova **Student number** [redacted]

PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT
Complete all fields, keep information clear, specific and concise

Project title Data-Enabled Patient Journey Mapping for Early Dementia Diagnosis in the UK

Please state the title of your graduation project (above). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

Introduction

Describe the context of your project here; What is the domain in which your project takes place? Who are the main stakeholders and what interests are at stake? Describe the opportunities (and limitations) in this domain to better serve the stakeholder interests. (max 250 words)

Dementia is often diagnosed only after irreversible brain damage has occurred, causing treatments to become ineffective. Despite new methods capable of earlier detection being developed, their implementation is hindered by the complexity of the disease's diagnostic system. Recognising this complexity, a consortium between TU Delft, University of Cambridge and UCL seeks to integrate early diagnosis into UK clinical practice by employing a systems design approach. It is essential to note that research will be conducted exclusively at TU Delft, within the framework of this larger collaborative effort.

The project is underpinned by the Engineering Better Care (EBC) framework, which provides a usable workflow for designing, devising, implementing and managing improvements to healthcare systems. [1] My graduation project will focus on the initial phase of EBC – understanding the system. Collaborating with a data science colleague we will employ a blend of machine learning and designerly skills to analyse the publicly available online dementia support forum of the UK Alzheimer's Society – a leading dementia charity). Inspired by the novel approach of Jung et al. [2] our goal will involve creating data-enabled community patient journey maps that provide valuable insights for more effective interventions in the next stages of the EBC framework.

The project's key stakeholders will include the system improvement team (Cambridge/UCL), the data science and design team (TU Delft), the UK NHS healthcare system and the UK Alzheimer's Society, a major source of patient stories used for data analysis. Engaging patients, carers and families, along with NHS policymakers and clinicians will enable the design of a feasible intervention that is aligned with the needs of the system.

Opportunities in this domain involve introducing new technologies for early detection of dementia which facilitates effective therapies, timely prevention, and allows diagnosed patients or members of the public to understand and engage with their risk for future dementia. Limitations may arise from the complexity and resistance to change within the current healthcare system together with a lack of patient initiative. Addressing these limitations is essential to successfully integrate advancements in the early detection of dementia in UK's clinical practice.

[1] Newton, C. 2023. Designing healthcare systems for earlier diagnosis and prevention of dementia [Unpublished].
[2] Jung, J., Kim, K., Peters, T., Snelders, D., & Kleinsmann, M. 2023 Aug 30. Advancing Design Approaches through Data-Driven Techniques:
Patient Community Journey Mapping Using Online Stories and Machine Learning. International Journal of Design [Online] 17:2. Available: https://www.ijdesign.org/index.php/IJDesign/article/view/4671/1031

→ *space available for images / figures on next page*

Problem Definition

What problem do you want to solve in the context described in the introduction, and within the available time frame of 100 working days? (= Master Graduation Project of 30 EC). What opportunities do you see to create added value for the described stakeholders? Substantiate your choice.
(max 200 words)

In the given context the central challene lies in the need for integration of early dementia diagnosis into UK clinical practice. To effectively navigate the complexity of the UK healthcare system and bring about succsesful change, the project se relies on the structured approach provided by the EBC framework. The framework's initial phase emphasizes the importance of first gaining a deep understanding of the system. However using traditional research methods for such an intricate system would be both time and resource-intensive. Therefore, my project instead aims for the application of the Online Community Journey Mapping method by Jung et al. 2023. This involves analyzing a large publicly available dataset of patient/caregiver experiences with the process of receiving a dementia diagnosis. By employing this approach a more comprehensive understanding of the system can be attained, complemented by the effective communication of these insights via journey maps. This in turn which would aid policymakers in designing better informed and targeted system improvements.

Assignment

This is the most important part of the project brief because it will give a clear direction of what you are heading for. Formulate an assignment to yourself regarding what you expect to deliver as result at the end of your project. (1 sentence) As you graduate as an industrial design engineer, your assignment will start with a verb (Design/Investigate/Validate/Create), and you may use the green text format:

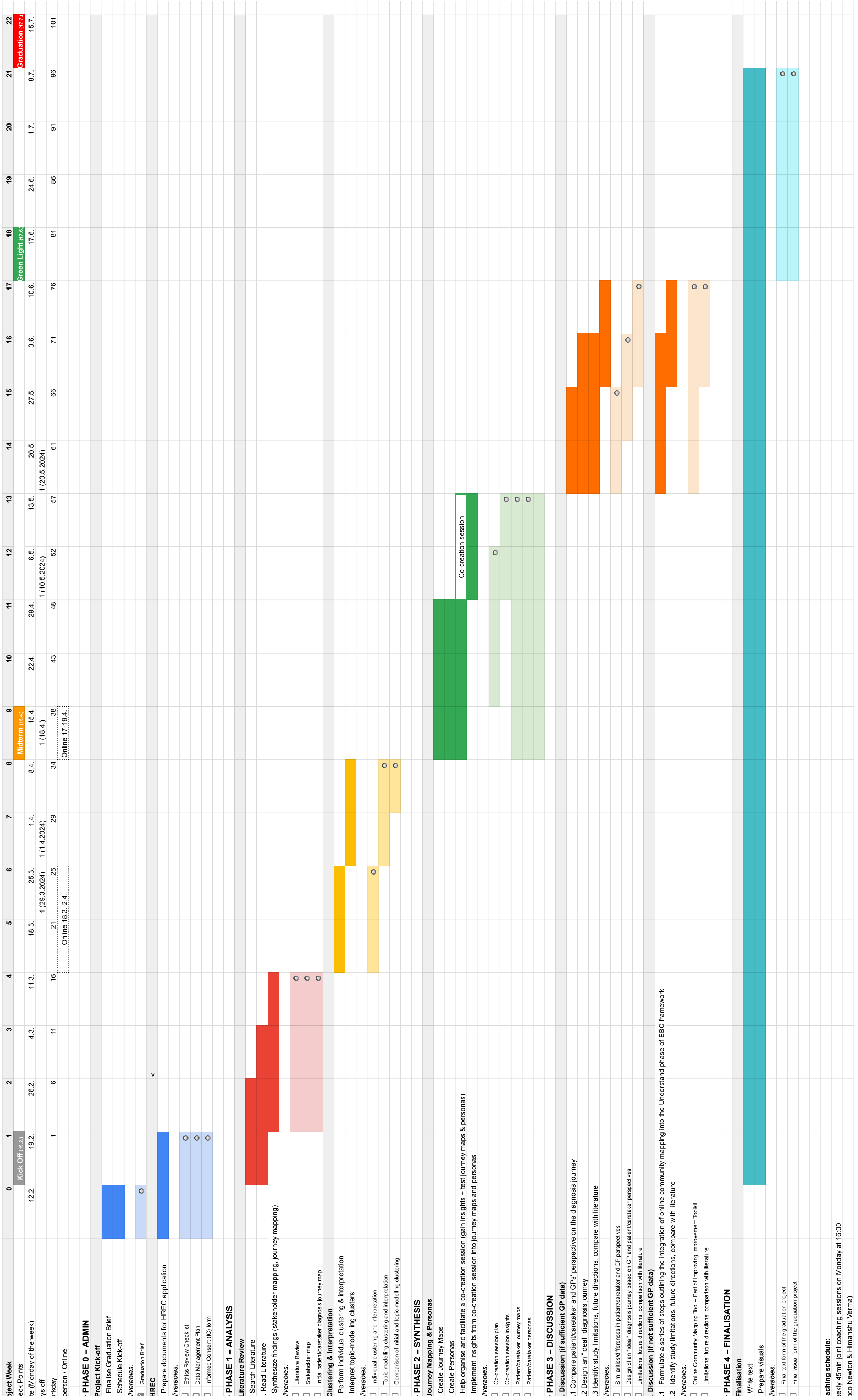
Create journey maps and personas of patients (and their caregivers or relatives) living with dementia to enhance the understanding of their needs and pathways to receiving a dementia diagnosis. This effort aims to contribute to gaining a comprehensive understanding of the current system of dementia diagnosis in the UK and to lay the foundations for its improvement.

Then explain your project approach to carrying out your graduation project and what research and design methods you plan to use to generate your design solution (max 150 words)

My project approach involves 4 key phases (detailed project plan and project structure can be found in the attachments):

1. Analysis will consist of a literature review (focusing mostly on qualitative studies with stakeholders and policy/ charity reports) helping me to identify existing research gaps, individual clustering and interpretation of a sample of forum posts, and subsequently interpretation of the clusters obtained from topic modelling.
2. Synthesis will involve the creation of journey maps and personas based on the findings in the analysis phase, followed by facilitation of co-creation session with stakeholders to validate these outputs.
3. Refinement depends on data from a parallel study of GPs and aims to triangulate patient/carregiver journey maps with GP perspectives. Alternatively (in case of insufficient GP data), this section would address the integration of the online journey mapping method within the Improving Improvement Toolkit.
4. Finalisation deals with completing the text and visuals into the final form of the graduation project.

The whole project is underpinned by the Engineering Better Care framework developed by Professor John Clarkson, which provides a usable workflow for designing, devising, implementing and managing improvements



Digital Appendices:
available on the following link: https://drive.google.com/drive/folders/11KYqP5SLeEQhsxWBx8uFzeJ-V9XN_Yck?usp=sharing
(Tip: download the file for improved readability)

Appendix 14: TM Topics Interpretation
Appendix 15: TM Themes Interpretation