Journey of People Living with Dementia (PLWD) and their Caregivers (CG) Seeking a Dementia Diagnosis

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

- **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.

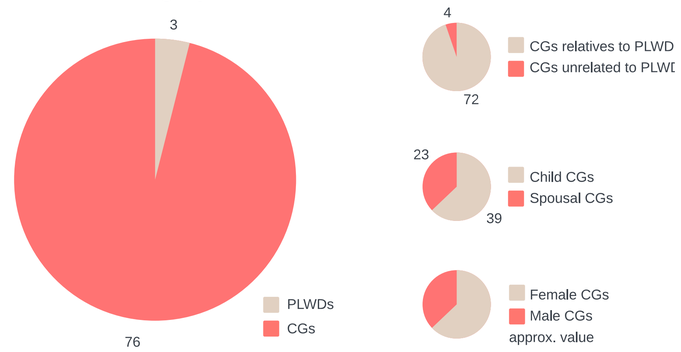
IMPACT OF COVID

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

Project Summary

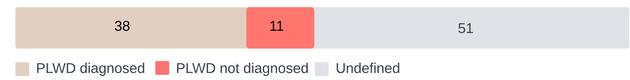
This master's thesis aims to improve early dementia detection in the UK by understanding the diagnostic journey from the perspectives of people living with dementia (PLWDs) and their caregivers (CGs). The project includes a literature review to identify knowledge gaps, followed by a three-phase analysis of online patient stories. Inspired by Online Community Journey Map by Jung et al. (2023), it involves thematic analysis and LDA topic modeling of the UK Alzheimer's Society Dementia Support forum. The resulting journey maps highlight barriers and facilitators in early diagnosis and caregiving. These maps are crucial for policymakers, NHS workers, designers, and academics to enhance early diagnosis rates and support for PLWDs and their CGs.

Forum Demographics

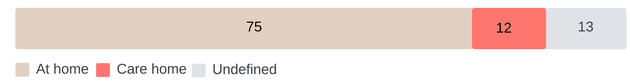


PLWD'S DIAGNOSIS STAGE

DIAGNOSIS STAGE



CAREGIVING TYPE



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

⏳ Significant waiting time

Thematic category | Theme | PLWD-related sub-theme | CG-related sub-theme | PLWD and CG related sub-theme

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