

Progressive Release of Informational Materials for People Living with Dementia and Their Informal Carers

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Abstract. We describe a process for selecting informational material for people living with dementia that is most appropriate for their stage of dementia. This material provides information on the disease, on ways of living with the disease, and on activities that may delay the progression of the disease, with a view to maintaining an individual's independent living at home. Informational material is suggested according to both an individual's overall clinical disease progression and progression along seven cognitive domain axes that contribute to the overall progression, for example 'working memory' performance or 'attention', with scores for these axes being derived from clinical judgement, from fixed and wearable sensors, or from performance when interacting with devices. Material is rated according to relevance to overall disease progression and relevance to each of the seven axes. For example, the Alzheimer Society of Ireland 'Living Day To Day' document is most relevant to those diagnosed with early dementia onwards, but may also have useful information for those without a dementia diagnosis but are experiencing problems with their working memory or attention.

Keywords. Dementia, People Living with Dementia (PLwD), Personalised information, Document selection

1. Introduction

The number of people living with dementia (PLwD) in Ireland is expected to exceed 150,000 by 2045 [1], increasing pressure on care services. To help address this, CODESIGN (Co-creating Dementia Support for InteGrated care, a Novel platform

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approach) [2] aims to extend an individual's independent living at home for as long as practical. The project brings together a transdisciplinary team and stakeholders including PLwD and carers, to co-design a holistic digital platform for integrated dementia self-management. Receiving a dementia diagnosis is often overwhelming for individuals and their families; providing relevant information at different stages can ease concerns and improve quality of life. Part of the work of CODESIGN is to provide information on living with dementia, using existing publicly available documents, but made available in a structured manner, highlighting documents most relevant for a PLwD's disease stage. While extensive information exists, e.g., in documents from Alzheimer's Society Ireland (ASI) [3], identifying appropriate content to highlight at the appropriate time is challenging. We propose a system for curating and delivering relevant materials based on disease progression and material content, using dementia as an exemplar.

2. Background

2.1. Benefits of information to patients and caregivers

Heesen, et al., [4] and Lode, et al., [5] highlight the importance of providing disease-related information at the time of diagnosis. Such information enables patients to make informed decisions and plan for future care needs effectively. Caregivers also benefit from clear communication, reducing their stress and improving care quality [6].

2.2. Benefits of phased delivery of information

Patients who receive high-quality information at disease onset engage in better coping strategies, with Buzgova, et al., [7] writing that "lack of information about the disease and available support available resulted in a deterioration [of] mutual understanding between the patient, family, and the medical staff; also increased stress for the caregiver, and lowered quality of life for the caring family." There is limited research on the benefits of staged information release, i.e., releasing information relevant to later disease stages at the time of disease progression, although it has been proposed that tailored information interventions can improve disease management and quality of life [8].

3. Methods

To highlight information appropriate to an individual's disease stage, it is necessary to match that individual's disease stage with the disease stages for which the informational material is relevant. This requires knowledge of that individual's disease stage according to overall disease progression and, where possible, progression along the individual cognitive domain axes that contribute to the overall disease progression in dementia, and an assessment of the relevance of informational material to different disease stages.

3.1. Dementia progression scales

Several scales for dementia disease progression exist, including: Alzheimer's Society UK (ASUK) [9]; Global Deterioration Scale (GDS) [10]; and Functional Assessment

Table 1. Comparison of the different dementia progression scales.

ASUK	GDS	FAST	Composite	Composite stage
-	No cognitive decline	No functional cognitive impairment	No impairment	1
-	Very mild cognitive decline	Early functional changes	Mild cognitive impairment	2
-	Mild cognitive decline	Mild functional losses	Early dementia	3
Early dementia	Moderate cognitive decline	Moderate functional losses	Early dementia	3
Middle dementia	Moderately severe cognitive decline	Moderately severe functional losses	Middle dementia	4
Later dementia	Severe cognitive decline	Severely impaired functional abilities	Later dementia	5
Later dementia	Very severe cognitive decline	Total dependence	Later dementia	5

Table 2. Comparison of the cognitive domains that specify the different dementia progression axes.

ASUK	BCRS	Composite
Thinking	Concentration	Attention
Memory	Recent memory	Working memory
Memory	Past memory	Long-term memory
-	Orientation	Orientation
ADLs	Functioning and self-care	ADLs
Problem-solving or language	-	Higher cognitive functions
Emotion, perception or behaviour change	-	Personality

Table 3. Example document data set showing the disease stages to which they are most relevant.

Document name	Overall range	Attention	Working memory	Long-term memory	Orientation	ADLs	Higher cognitive functions	Personality
I have dementia – first steps	3	3	3	2	3	3	3	3
Planning for the future	1-5	2	2	3	2	3-5	4-5	3-5
Living Day-to-Day	3-5	2-3	2-3	4-5	4	3-5	2-3	3-5
Eating well with dementia	4	1-5	1-5	2	4	4-5	3	4

Staging Tool (FAST) [11]. These three scales are summarized in Table 1, which also includes a composite scale developed for our work. This five-point disease progression scale (comprising, in sequence: no impairment; mild cognitive impairment (MCI); early dementia; middle dementia; later dementia) is used for overall disease progression.

3.2. Cognitive domain axes

Dementia affects different cognitive domains, and each of these can progress at different rates (see e.g., [12]). With no agreed set of domains that contribute to overall dementia progression, a composite set of domain axes was used, summarized in Table 2, combining those presented by ASUK [9] and those proposed by Reisberg and Ferris [13].

Progression along these seven axes of cognitive decline is scored using the same composite scale used for overall disease progression shown in Table 1. Overall disease progression for a PLwD is that diagnosed by clinicians; axis scores may be clinician-assigned, or estimated from wearables and other sensors, use of apps, or self-reports. An example of the use of wearables to estimate dementia progression is given in [14].

3.3. Document scoring

Informational literature in the form of 12 documents from ASI [3] was analysed by an Occupational Therapist with experience working with dementia patients in Ireland. Each document was reviewed and considered for its relevance to the stages of dementia, based on the therapist's experience of working with PLwD and their experience of the relevance of each document to the stages of dementia. Similarly, each document was reviewed for its relevance to each of the cognitive domains corresponding to the seven disease axes. Table 3 shows examples from the ASI document set together with scores for their relevance to overall disease progression and their relevance to progression along the individual cognitive domain axes.

3.4. Document selection

For each PLwD, we take their overall disease progression score and assign scores for progression along the cognitive domain axes. If an axis score is unknown we default to the overall progression score for that axis. The disease progression scores are then matched against the scores for individual documents, with those documents that match being highlighted as relevant for that PLwD.

4. Results

Informational material from ASI was analysed and scored for relevance to overall disease progression and to progression along seven disease axes. For example, the document 'I have dementia – first steps' is highlighted as relevant for a patient whose overall disease progression is diagnosed as early dementia (stage 3), since the document was scored as being relevant to that stage. However, should a patient with overall progression of 'no dementia' (stage 1) or 'MCI' (stage 2), be judged as having long-term memory performance equivalent to MCI (stage 2), the document would be highlighted as being relevant to them.

5. Discussion

While research supports providing disease-related information at diagnosis, little research exists on phased information release. More studies are needed on tailoring educational interventions to individual progression rates. This work proposes a method for highlighting informational material in a way tailored to the stage of disease, taking into account the different rates at which the disease axes can progress.

6. Conclusions and Future Work

A process was developed to select appropriate informational material for presentation to PLwD and their carers according to disease progression. This phased information delivery enables PLwD and caregivers to access relevant information at appropriate stages, enhancing autonomy and supporting informed decision-making. Future work will include selecting passages from complete publications that are relevant to particular disease axis progression and automating the scoring of informational material, work which can potentially benefit from the use of Large Language Models, and validating our work with PLwD and their caregivers.

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