Knowledge, attitudes, and stigma relating to rarer dementias among members of the general public in an international cohort

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Part one presents a conceptual introduction reviewing the literature on dementia related knowledge, attitudes, and stigma among the general public, and discusses the implications for the less common forms of dementia.

This thesis is a study within the studies of the Rare Dementia Support (RDS) Impact study: a 5-year programme of research exploring the impact of multicomponent support groups for those living with rare dementias. It is a collaboration between University College London (UCL), Bangor University and Nipissing University in Canada (http://www.raredementiasupport.org/research/) and is joint funded by the Economic & Social Research Council (ESRC) and National Institute for Health Research (NIHR) and ethical approval for the study was granted by UCL Ethics Committee (Reference: Project ID: 8545/004). The presented thesis is my own work, supervised by Dr. Joshua Scott Yes. I was involved in the design of the study, completed the data collection and analysis independently with exception for the following contributors:

- Emilie Brotherhood involved in the ethical approval amendment and applications for this thesis.
- Joanna Stroud (Head of Online Learning at UCL) who set the study' surveys up on Future Learn the open education platform which houses The Many Faces of Dementia Massive Open Online Course. Joanna also linked the Surveys to Qualtrics.

Impact statement

This study has some potential implications for both clinical practice and directions for future research.

Regarding the clinical implications this thesis is part of a five-year international research programme aimed at developing and evaluating multicomponent support groups for people living with rare forms of dementia that is accessible anywhere. The study, led by a team from University College London's Dementia Research Centre in collaboration with local and international partners such as Rare Dementia Support members and researchers at Bangor University and Nipissing University, is the first major study of its kind. Results from this study will contribute to the overall wider study's findings which will be used to meaningfully impact the lives of people living with rarer dementias, their carers, and health care providers.

Academically, this study presents an important contribution to the limited literature on stigma, attitudes, and knowledge in the context of the less common forms of dementia. This study starts to address the gap in the literature by not only looking at baseline dementia related knowledge, attitudes, and stigma but by also looking at changes in these pre and post participating in the MOOC in an international cohort of participants. Further studies evaluating learning effects surrounding rare dementia MOOCs using robust methodologies are warranted. Additionally, the study' findings highlight the need for measures specifically designed to measure rare dementia knowledge.

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I dedicate this thesis to my parents Joy and Kenneth Kankinza whom I sadly lost during my training journey. Although they are not physically with me, their values and love which I internalised is still with me and continues to carry me through life.

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Part One: Conceptual Introduction

Public general dementia knowledge, attitudes, and stigma and their implications for rarer dementias

Conceptual introduction overview

Less common forms of dementia are under-recognised when compared to more common ones, particularly Alzheimer's disease. In this conceptual introduction, I will present the clinical features of rare dementias and briefly discuss their implications for dementia care and support. The main focus of this review will be on knowledge, attitudes and stigma associated with rare dementias among members of the general public. Since there is very little evidence directly relating to this, in the following I will draw on the literature relating to knowledge, attitudes and stigma associated with dementia in general and discuss implications for rarer dementias.

A narrative literature review was conducted aimed to get a broad perspective on public knowledge, attitudes, and stigma in relation to the less common forms of dementia. An initial brief search of the literature identified that most research covered dementia of the Alzheimer's type and focused more on caregivers as a study population. This led to redefining the topic and conduct the literature view on public knowledge, attitudes, and stigma in relation dementia in general. Highlighting implications for the less common forms of dementia followed as there seemingly was not enough data in the literature to meet the need to conduct the review specifically on the public's rare dementia related knowledge, attitudes, and stigma. Despite redefining the topic, evidence on public knowledge, attitudes, and stigma in relation to dementia in general were few and even fewer in relation to the less common forms of dementia. This finding supported the choice to conduct a review aimed to provide an overview of the concepts, evidence and research gaps surrounding public dementia knowledge, attitudes, and stigma in general then highlighting implications for the less common forms of dementia thus a narrative review was deemed most appropriate.

Multiple sources were used to search for the relevant literature. These included using a range of databases, conferences proceedings, and abstracts and organisational websites such as the Alzheimer's Disease International, Rare Dementia Support and World Health Organisation. The online databases searched for primary, peer-reviewed resources was conducted using PubMed, PsycINFO (psychology, mental health, and behavioural sciences), CINAHL PLUS (nurse and allied health professionals), and EMBASE (biomedical and pharmacological), and was structured using a PICO framework:

- (Population→ members of the general public,
- Intervention→ dementia interventions,
- Comparison→ comparison was not necessary in this case,
- Outcomes→ efficacy of intervention/improved knowledge, attitudes and reduced stigma).

The key search terms used were included population terms (public OR general-public OR community OR layperson*), dementia terms (Dementia, rare-dementia OR atypical-dementia OR uncommon-dementia OR young-onset-dementia OR early-onset-dementia) and (knowledge OR understating OR literacy, attitude, stigma). Further searches included gray literature search using Google Scholar, UCL's thesis depository and hand checking through the reference lists of review papers and other relevant reports not otherwise retrieved through online sources.

The inclusion criteria restricted the focus on only dementia related knowledge, attitudes, and stigma among members of the general public globally as the population. Articles which were not published in English were excluded. The review was structured to set the scene by introducing the rare dementias before

subdividing the main body to explore the global perspective public dementia knowledge, attitudes, and stigma and illustrate research gaps using the existing dearth of articles found.

Dementia is a global public health challenge with huge human and financial costs that are predicted to increase further. While there is no cure for dementia, there are several pharmacological and non-pharmacological interventions that can delay symptoms or disease progression and manage the impact of living with dementia. Furthermore, it may also be possible to prevent the disease by addressing known modifiable risk factors associated with developing dementia. To access interventions and address modifiable risk factors, awareness of early signs and symptoms is fundamental as it may affect health seeking behaviours, earlier diagnosis, planning for future symptom management and access to support. Therefore, raising awareness around dementia among the general public is critical. Addressing negative attitudes and stigma surrounding dementia is equally important as these are additional known barriers to dementia care and support.

Currently, there is more literature on dementia in relation to theoretical approaches to reducing public stigma, increasing positive attitudes and knowledge than actual active interventions are taken or evaluated. It is not clear whether existing efforts to raise dementia awareness, knowledge, positive attitudes and reduce stigma among the general public are in fact having the intended effect. Furthermore, evidence in relations to the less common forms of dementia is limited and yet knowledge of dementia subtypes is essential for dementia care given differences in management, disease course, and outcomes for different dementias. Existing studies have predominantly focused on the common forms of dementias and to our knowledge no study has evaluated the utility of attempts to increase knowledge, positive attitudes and reduce stigma around the less common forms of dementia.

Review of the literature

Clinical features of rarer dementias

Dementia is an umbrella term referring to several progressive diseases affecting the brain. This heterogeneous syndrome results in multiple and complex changes in social behaviour, memory, communication, thinking patterns or perception, which significantly impair day-to-day functioning. These changes are not due to the normal ageing process (World Health Organisation, 2017). Alzheimer's is the most common cause of dementia followed by vascular then lewy body dementia. There are a number of less common causes referred to as "rare dementias" (**www.raredementiasupport.org**). These rare dementias have particular features that differ from more common dementias and often occur before the ages of 65 (younger onset) (Brotherhood et al., 2020). For instance, symptoms of progressive difficulties with cognitive functioning rather than memory are a common feature. Consequently, rare dementias are associated with different challenges from diagnosis as a result of being poorly recognised due to unusual symptom profiles to management given that services are focussed on typical dementias and older adults (Brotherhood et al., 2020). These rare dementias, which are the focus of this review, include posterior cortical atrophy (PCA), familial Alzheimer's disease (FAD), frontotemporal dementia (FTD) of the Behavioural variant FTD (bvFTD), Primary progressive aphasia (PPA) and familial frontotemporal dementia (fFTD) types.

Posterior cortical atrophy (PCA)

It is estimated that 5% of the 65,000 people in the UK with early onset dementia are living with posterior cortical atrophy (PCA) (Harding et al., 2018). PCA, which is also known as Benson's syndrome or the visual variant of Alzheimer's disease, is usually caused by Alzheimer's disease or Lewy body disease but presents differently compared to the more common forms of these diseases. It is

associated with the degeneration of the posterior parietal and occipital cortices regions of the brain, primarily resulting in complex visual impairments despite relatively preserved memory and insight (Crutch et al., 2013; Suárez-González et al., 2015).

Impairments include deficits in recognising visually presented objects, impairments in spatial awareness, inability to coordinate between visual inputs and hand movements and thus inability to reach and grab objects and difficulties understanding written words as well as simple mathematical tasks (Crutch et al., 2013; Suárez-González at al., 2015). Moreover, the anterior region may be affected resulting in difficulties with left-right orientation, language skills, and space perception deficits. Disturbance of balance, bodily orientation, chronic pain syndrome, and dysfunctional motor patterns are additional unusual symptoms that may arise due to visual vestibular and pontomedullary reticular formation interactions in the brain (Crutch et al., 2013; Suárez-González at al., 2015). PCA symptoms vary from person to person and in later stages progress to a multicognitive presentation in a similar manner to typical Alzheimer's (AD), or Lewy body dementia (Harding et al., 2018).

PCA diagnosis is often delayed (Crutch et al., 2012). Crutch and Colleagues (2012) explain that the atypical dementia presentation leads to poor early recognition of the symptoms by health-care professionals and the patient due to limited awareness and understanding of PCA signs, symptoms, risk factors and its pathophysiology. Typically, adults in their mid-50s or early 60s initially present to Opticians with visual difficulties followed by a prolonged search for ocular causes of visual symptoms. Once referred to the appropriate service which includes specialist neurologist, psychiatrist or neuro-ophthalmologist, it can take about one to three years to get a formal diagnosis. A combination of medical history, brain scans

physical and cognitive tests are used to diagnose PCA (Crutch at al., 2012; Olds et al., 2020).

Living with PCA is disabling and can have negative impact on well-being: identity, confidence, changes in mood including frustration, anxiety, and depression. It also limits the ability to be active and independent (Crutch et al., 2012; Suárez-González et al., 2015).

Limited symptom management and disease modifying therapies are available to support and enhance the quality of life for people with PCA at the various stages of the disease progression (Olds et al., 2020). Cholinesterase inhibitors drug therapy used to slow down disease progression in Alzheimer's disease might be given to people with mild to moderate PCA as no specific drug for this condition exists (Olds et al., 2020). Medications can also be used for anxiety and depression associated with the condition (Olds et al., 2020). Symptom management includes a combination of various strategies tailored to the specific needs and stages of the disease progression (Harding et al., 2018; Olds et al., 2020). Physiotherapy or occupational therapy is used for difficulties with visuospatial tasks, writing, and motor control. Reasonable adjustments and modifications of the environment minimise difficulties related to depth perception deficits. Support groups target psychological wellbeing by reducing loneliness, promoting camaraderie and enhancing a sense of belonging. Additionally, visual aids such as talking clocks and watches and various resources such as audio books, devices with simple displays, voice recognition software and walking aids are used when needed (Harding et al., 2018).

Familial Alzheimer's disease

An estimated one to five percent of people with AD have familial Alzheimer's disease (FAD), also known as autosomal dominant Alzheimer's disease (ADAD)

(O'Connor et al., 2020). FAD is mostly caused by inherited faulty presenilin 1 (PSEN1), presenilin 2 (PSEN2) and amyloid precursor protein (APP) genes, with the mutated PSEN1 gene as the most common cause (O'Connor et al., 2020). These genes are known to influence the production of amyloid beta proteins, which are the hallmarks of AD(O'Connor et al., 2020). FAD is usually hereditary, with a high probability of developing the condition among those who carry the genetic predisposition of this condition (Bateman et al., 2011). A parent with FAD has a 50 percent chance of passing on the faulty gene. A first-time appearance of FAD through a new genetic mutation is rare. Sporadic forms of FAD unrelated to the faulty genes exist and are not well researched or understood (Bateman et al., 2011). Genetic counselling to determine faulty genes is available, although not widely offered partly due to the unavailability of effective interventions (Steinbart et al., 2001).

FAD typically, presents in the late 30s, 40s and 50s with primarily difficulties with memory, particularly problems with learning and remembering recent information (Mendez, 2019). FAD Symptoms are like typical AD symptoms which include cognitive, neurological and psychiatric symptoms. Cognitive symptoms can present as difficulties with language (speech production, comprehension and coordinating movement in writing), problem-solving, and orientation. Accompanying behavioural and personality changes, such as emotional lability, general lack of awareness, confusion, agitation, restlessness and apathy, can easily be mistaken for depression (Mendez, 2019). Psychiatric symptoms can present as delusions, hallucinations in combination with anxiety, agitation, depression, apathy or disturbances in the sleep-wake cycle (mostly awake at night and sleepy during the day). Neurological symptoms can present as difficulties with physical movement, coordination, seizures, and jerky contraction of muscles often leading to difficulties

walking. These neurological symptoms are a striking difference from AD (Mendez, 2019).

Similarly, to other dementias, the symptoms exists on a continuum, progress over time and vary among individuals. Although unusual symptoms typically develop in the later stages of the condition, they can also develop in early stages (Dubois et al., 2016).

Living with FAD can be challenging in many ways. The impact of living with FAD may not only negatively affect the individual but creates a high burden on the immediate family. An early onset diagnosis implies that individuals are often at a life stage when they are employed and have responsibilities of looking after young children. Financial stability surrounding securing a mortgage, life insurance or employment may also be a worry.

FAD treatment options are aimed to manage symptoms and improve the quality of life for the person living with FAD. Psychological therapy during the mild stage of the condition is helpful. Some have used therapy to address difficulties associated with being diagnosed at an often-prime stage of life. Medications are available for involuntary jerking movements, seizures or leg stiffness, behavioural difficulties, mood changes and to stabilise or improve memory difficulties similar to typical AD. No treatments currently exist to slow down FAD progression. Literature attributes this to the lack of advocacy, funding, visibility, and research on FAD. People with FAD have been excluded from clinical or drug clinical trials as most people younger than 65 are typically not enrolled in Alzheimer's clinical trials (Alzheimer's forum, 2020)

Routine physical health examination is also highly important. FAD is also known as a life shortening condition as it is usual to get affected by other conditions. Pneumonia is a common comorbid condition and causes death in about two thirds of

this population (Manabe et al., 2019). Individualized social and practical support is equally an essential aspect of FAD treatment (Rare Dementia Support, 2020). This could include supporting immediate family members, such as the children involved through psychoeducation on FAD and raising their awareness about the possibility of inheriting the genetic predisposition of this condition. Support can also be provided with respect to helping the person with FAD learn new ways of working and contributing to society, which are realistic considering the impact of the condition on functioning. Lastly, assisting the person with FAD with the planning for the future and life in the later stages of the disease may involve providing practical support with regards to legal issues, such as arranging a lasting power of attorney.

Frontotemporal dementia

Frontotemporal dementia (FTD) is the umbrella term of various disorders characterised by damage and atrophy in frontal and temporal cortex of the brain, which govern personality, behaviour, language and speech, resulting in problems in these areas (Kurz et al., 2014; Onyike & Diehl-Schmid, 2013). FTD disorders vary depending on affected brain regions. Approximately 30-40% of cases of FTD have a strong genetic predisposition linked to mutations in specific genes, while 50-70% of the cases are sporadic (Onyike & Diehl-Schmid, 2013).

Causes of damage and atrophy in frontal and temporal brain regions involve a build-up of various proteins within nerve cells, neurites, axons and other brain cells such as astrocytes and oligodendrocytes (Bang et al., 2015; Kurz et al., 2014). It is assumed that these proteins namely tau and TDP-43 might either be the cause, or a symptom of the disorders. Details of how or why this occurs is not well understood. Further causal explanations include mutations in genes that encode tau and TDP-43 proteins, as well as other proteins called progranulin, and C9ORF7. In addition to the complex, varied and poorly understood causes, FTD can overlap and share

comorbid symptoms with movement disorders such as motor neurone disease (MND), progressive supranuclear palsy (PSP), and corticobasal syndrome (CBS) (Onyike & Diehl-Schmid, 2013). Onyike and Diehl-Schmid (2013) report that about 15% of people with motor neuron disease may develop FTD, and a small proportion of people with FTD may develop motor neuron disease.

Comparable to other rare dementias, the rare and complex nature of FTD often results in long and frustrating journeys to diagnosis, given that even some of the most experienced medical professionals tend to be ill-informed and equipped to recognise the symptoms (McIntyre at al., 2019). There are equal male and female incidences of FTD with an onset commonly occurring between 45 and 65 years. An earlier or older presentation can occur. Overall, FTD management is challenging, and its symptomatology and rate of progression vary from person to person, further compounding the complexity of the condition (Rare dementia, 2020). The FTDs covered in this review are behavioural variant FTD (bvFTD), primary progressive aphasia (PPA) and familial frontotemporal dementia (fFTD).

Behavioural variant FTD (bvFTD)

This FTD subtype is due to atrophy in the frontal regions of the brain and is mainly characterised by behaviour and personality changes and relatively few memory problems (Kurtz et al., 2014). Symptoms as described by Kurtz and colleagues (2014) include a pronounced decline in social conduct marked by inappropriate or offensive behaviour, which could include unsuitable sexual comments, impulsivity, disinhibition, inflated comicality and emotional display, personal neglect, withdrawal from usual social activities and poor risk assessment. Anxiety, a general disregard for others' feelings, reduced empathy, apathy, aggression, impatience, and lack of emotional insight may present. Additionally, changes in eating habits (overeating, gluttony, selectivity of food), repetitive or

compulsive behaviours e.g. clock-watching, superstitious behaviours like not standing on cracks in pavements, obsessing over things and routines, and deficits in executive functioning such as planning and judgement are common while memory and visuospatial functions are relatively spared. Movement disorder symptoms can develop. These symptoms are insidious and progressively become worse, leading to challenging social situations (Kurtz et al., 2014).

Diagnosis of bvFTD involves a thorough history examination heavily reliant on others to give an account of the family history, profound behavioural and character changes, comprehensive cognitive and behavioural assessments as well as brain scans (Fluorodeoxyglucose PET, functional MRI, and single-photon-emission CT) (Bang et al., 2015; Vieira et al., 2013). Other physical examinations such as blood tests or a lumbar puncture aid in ruling out other possible medical conditions (Bang et al., 2015). BvFTD can be misdiagnosed for psychiatric such as obsessive-compulsive disorder, bipolar disorder or depression and other dementias such as Alzheimer's disease and vascular dementia (Vieira et al., 2013). Symptoms of bvFTD can be very challenging causing significant impairment in activities of daily living with significant negatively impacting other people around the person living with bvFTD. Rare Dementia Support (2020) reports that some carer and family members have described some of these behavioural symptoms as awkward and embarrassing and often struggle with managing the impact of the various symptoms. For example, it can be difficult to know what to do when individual with bvFTD is having trouble concentrating on meals, recognising food, feeding themselves or coordinating chewing and swallowing.

To date, there are no specific medications to treat or slow the progression of bvFTD. Selective serotonin reuptake inhibitors (SSRIs), such as sertraline or citalopram, potentially and Neuroleptic drugs treat behavioural symptoms and mood changes especially as the condition progresses (Vieira et al., 2013). However,

medications should be used with caution by weighting the benefits and risks and require motioning, as they can cause side effects (Bang et al., 2015). For example, the development of Parkinsonism or deterioration in thinking could be a side effects of neuroleptic drugs (Rare Dementia Support, 2020). A combination of approaches is used to provide support and manage symptoms. Behavioural strategies help address behavioural difficulties that are harmful to oneself and that have a negative impact on others, by removing potential challenging behaviours triggers, modifying the environment, implementing other practical problem-solving solutions, and using safe eating strategies (Rare Dementia Support, 2020). The involvement of the carer in implementing these behavioural strategies is critical as most lack insight into their challenging behaviours or their impact on other. Mental health support for symptoms of depression or anxiety experienced as well as speech and language therapy for difficulties with eating are good treatment options.

Primary Progressive Aphasia (PPA)

Primary progressive aphasia (PPA), sometimes referred to as language-led dementias is a syndrome of dementias that come about due to the degeneration of inferior frontal and anterior temporal brain regions involved in language control (Bang et al., 2015). Consequently, speech and language are affected in about three cases per 100,000 persons (Marshall et al., 2018). The most common PPA are progressive non-fluent aphasia (PNFA) Semantic dementia (SD) and Logopenic aphasia (LPA).

In SD, semantic memory is affected, and typical features include difficulties with language production and comprehension (Marshall et al., 2018). Language production difficulties may include fluent but indirect and circular speech and naming or word finding difficulties, while comprehension difficulties may encompass deficits in word and object meaning and understanding (Bang et al., 2015). Reading and

Spelling may be affected too. Common behavioural and personality changes include a preoccupation with the self and rigid daily routines (Bang et al., 205). In the later stages, difficulties with the recognition of previously known people and environments as well as impaired planning and problem solving may progress significantly impairing daily life.

In PNFA, speech production is mostly affected and includes symptoms such difficulties producing words (require lots of effort to speak, may stutter, speak slowly or hesitantly) and when they speak, the word order or speech sound might be incorrect (Marshall et al., 2018) and could include inconsistently inserting, deleting, substituting, or distorting words and thus demonstrating difficulties with sentence construction (Bang et al., 2015). Long and complex sentences may equally be difficult to understand and gradually, grammar, reading, writing and spelling difficulties may develop (Bang et al, 2015). Non language specific symptoms that may also develop include difficulties with hearing, swallowing, making plans or decisions and changes in behaviour. Some of the symptoms such as shaking, unsteady balance or “having trouble using the hand” are comparable to Parkinson’s disease (Band et al., 2015). Additionally, frustration and mood disorders are also common.

In LPA, language production and comprehension are generally preserved, and difficulties are related to word finding leading to long pauses or speech with muddled up words (Marshall et al., 2018), for example, “aminal” instead of “animal” (**www.raredementiasupport.org**) (Rare Dementia Support, 2020). As the condition progresses, challenges with memory and cognition may develop. It is usual to show symptoms of more than one type of PPA at the same time and as condition progresses, experiences of living with PPA can become increasingly disabling resulting in a greater need for care and support due to the limited autonomy or ability to move (Rare Dementia Support, 2020).

Diagnosis procedure is like the one for bvFTD, with an emphasis on other medical examinations to rule out causes by other conditions such as cerebrovascular disease as well as endocrine or metabolic disorders (Bang et al., 2015). Living with PPA can be isolating with devastating implications affecting all areas of life for the person living with PPA and those around them. Therefore, a multidisciplinary approach and integration of carers in the treatment is critical (Kurz et al., 2015; Rare Dementia Support, 2020). Currently, no pharmacological treatments are available to treat or slow down the progression of PPA, but cholinesterase inhibitors, normally used in AD in some cases of PPA like LPA, can be prescribed (Kurz et al., 2014). Research on medications for PPA is ongoing (Vieira et al., 2013). Non-pharmacological management of PPA includes a combination of various interventions providing individualised support for managing symptoms, as no one experience of PPA is the same (Rare Dementia Support, 2020). These include behavioural strategies for any behavioural problems, speech therapy and engaging in activities that require less language such as watching TV, listening to music or audiobooks, walking, and doing yoga. Reports indicate that some people with SD find non-verbal puzzles, such as Sudoku and jigsaw puzzles, as enjoyable challenges, and people with the non-fluent variant of PPA (PNFA) may be better at singing than talking (Rare Dementia Support, 2020). Speech and language therapy is used to assess swallowing, manage communication difficulties, and possibly explore the use of electrical gadgets and strategies to compensate for communication problems (Kurz at al., 2014). Other available treatment options include group support and psychological support to treat symptoms of anxiety and depression as well as difficulties due but not limited to speech and language problems (Kurz et al., 2014).

Familial frontotemporal dementia (fFTD)

Familial frontotemporal dementia (fFTD) is an inherited form of FTD caused by an inherited faulty gene and is diagnosed in about 30-40% of people diagnosed with FTD (Onyike & Diehl-Schmid, 2013). Like FAD, a parent with fFTD has a 50% chance of passing on the faulty gene and genetic counselling to determine faulty genes is available (Steinbart et al., 2001). Conversely, a small minority do inherit faulty gene and live without developing fFTD (Onyike & Diehl-Schmid, 2013). fFTD symptoms are like other FTDs with variable onset presentation. For instance, there are reports of individuals who developed fFTD around the same age that their parent developed it, while others showed an age discrepancy of 20 years for the onset of this condition. Lastly, challenges related to fFTD are like those related to FTD and the same treatment and management are applied for both conditions (Rare Dementia Support, 2020).

Dementia knowledge

Major strides have been made in raising the profile of dementia as a public health concern and priority globally across a wide variety of platforms such as radio, television, newspapers, magazines, community events and online platforms such as Twitter, YouTube or Facebook (Alzheimer's Society, 2019). Consequently, information on dementia is currently available and accessible more than ever before. Despite this proliferation of information, gaps in public dementia knowledge remain (Cahill et al, 2015; Cations et al., 2018; Chung, 2000), thus showing the need for interventions.

Several population studies have reported an overall limited dementia knowledge and a reoccurring lack of in-depth understanding of dementia coupled with several misconceptions on a global scale, suggesting that this issue is

widespread (Alzheimer's Disease International, 2019). A systematic review by Cations and colleagues (2018) identified 26 studies of population surveys assessing dementia prevention in Europe, Eastern Asia, Israel, Australia, and the United States (US) and reported poor knowledge of dementia prevention and treatment. Respondents in these studies were knowledgeable about some dementia risks, but unsure about the protective factors (e.g. education), specific biological mechanisms (e.g. midlife cardiometabolic health links to dementia or interactions between modifiable and non-modifiable risk), and health promoting factors (e.g. good dietary habits, not smoking and physical activity). A recent study found similar findings of reduced dementia risk and prevention knowledge among a UK population (Swindells & Gomersall, 2020) and the Netherlands (Heger et al., 2019). Information on dementia risk or prevention knowledge among the public in developing countries, who tend to have the highest burden and risk of dementia, is unavailable (Cation et al., 2018; Ekoh et al., 2020; Stephan et al., 2015).

Findings from a systematic review by Cahill and colleagues' (2015) on public knowledge and understanding of Alzheimer's disease and dementia reveal that the public have some awareness of dementia symptomology but are ill-informed about dementia characteristics such as onset and progression of symptoms. Several other studies have reported similar poor knowledge of dementia symptoms in Cuba (Broche-Pérez at al., 2018), Brazil (Farina et al., 2020), Ireland (Glynn et al., 2017), a Bangladeshi community in England (Hossain & Khan, 2019), and the UK (Olsen et al., 2019).

Population studies on public knowledge of treatment reported a lack of awareness about the specific needs of PLWD in an international cohort (McInerney et al., 2018) or about how to interact with PLWD among a Chinese community (Wang et al., 2018). An Australian study found that respondents were unfamiliar

about available dementia treatments and showed a limited knowledge of the benefits of evidence- based dementia treatments (Rahja at al., 2018).

All population-based studies examining dementia knowledge reported in this review consistently report misconceptions about dementia. The most common existing misconceptions were the attribution of dementia to age, as unpreventable, a normal aging process, and curable (Cations et al., 2018). A prior review by Cahill and colleagues (2015), which examined public dementia knowledge over a 20-year period reported the same misconceptions, suggesting limited improvement in public dementia knowledge. Additionally, these misconceptions have been consistent cross-culturally (Cahill et al, 2015; Cations et al., 2018; Chung, 2000).

Sociodemographic factors affecting knowledge

Factors affecting dementia knowledge of participants was examined in several studies. Findings report higher levels of dementia knowledge correlated with higher levels of education, being female and exposure to dementia through informal caregiving, knowing someone or health care education (Cahill et al, 2015; Cations et al., 2018; Eccleston et al., 2019). Moreover, studies have also evaluated knowledge of dementia across cultures. A review of studies on differences in the public's understanding of dementia across Chinese American immigrants, African Americans, Anglo-European Americans South Asians and Chinese cultures found that South Asians and Chinese communities based their understanding of causes and symptoms of dementia on individual wrong-doing actions as opposed to the biomedical views among the Chinese American immigrants, African Americans and Anglo-European Americans communities (Ekoh et al., 2020). Ekoh and colleagues (2020) also reported that the Xhosa and Afrikaner communities of South Africa based their understanding of the causes and symptoms of dementia on religion and spirituality.

Findings from reported studies should be interpreted with caution as they have limitations. Limitations include variability methods used for assessing dementia knowledge, which limits the validity of comparisons across studies. Some studies used both unvalidated and validated standardised questionnaires, while others used case vignettes to assess lay knowledge. Additionally, the use of cross-sectional studies, small sample sizes and convenient sampling limit the generalizability of the findings and the ability to draw conclusions.

Implications for the less common forms of dementia

Numerous domains of dementia knowledge ranging from basis epidemiology, aetiology, and symptomatology were assessed in the reviewed studies using questions developed by the researchers and valid and reliable instruments. The reported instruments used to measure dementia knowledge in these reviewed studies include the Alzheimer Disease and Ageing Perception Scale (ADAPS) (Bettens et al., 2014), the Knowledge of Memory Ageing Questionnaire (KMAQ) (Cherry et al., 2000), the Alzheimer's Disease Knowledge Scale (ADKS) (Carpenter et al., 2009). Non-AD specific measures include Dementia Knowledge Questionnaire (DKQ) (Graham et al., 1997), and Dementia Knowledge Assessment Scale (DKAS) (Annear et al., 2015; Annear et al., 2016). The extent to which the assessment of dementia knowledge in these reviewed studies covers the assessment of the less common forms of dementia is not clear. For example, the items on the Dementia Knowledge Assessment Scale (DKAS) (Annear et al., 2015; Annear et al., 2016) measures mostly cover a range of domains relevant to common forms of dementia such a "Dementia is a normal part of the ageing process", dementia of the AD type such as "Alzheimer's disease is the most common form of dementia" or relevant to all types of dementia such as "most forms of dementia reduce the length of a person's life ". Typical rare dementia specific knowledge domains including symptoms such as predominant visual, language, or motor

dysfunction are either limited or lacking. Moreover, the focus is more on AD indicated in the title, abstract, or in the omission of mentioning rare dementias and common dementia knowledge domains and thus unlikely to be suitable for assessing rare dementias.

Consequently, the extent of the public's knowledge on the less common forms of dementia is unclear. The lack of information or enquiry on dementia knowledge of the non-AD subtypes potentially maintains the knowledge gap and barriers to dementia care and support. Public dementia knowledge influences how the public behaves toward PLWD (Kim et al., 2018). About 15% of all dementia cases present with symptoms that do not fit with societal perceptions of dementia (Suárez-González at al., 2020) such as language difficulties in PPA (Bang et al., 2015). Some dementias have early age of onset and present before the ages of 65 (Crutch at al., 2012; Rare dementia, 2020), suggesting that dementia is not only a concern for older adults. Additionally, factors that influence the development of dementia may vary. In some rare dementia such as fFTD and FAD, genetic mutations play a significant role in the developing dementia, but less so in the dementia of the AD type (Farlow & Foroud, 2013). Knowledge about symptoms correlates with help-seeking behaviours. Accurate knowledge of disease symptoms positively correlates with early detection and potentially enhances treatment benefits (Werner et al., 2003). People who are unable to detect or recognize the symptoms of dementia are unlikely to seek treatment, resulting in under-diagnosis and risks of under-treatment due to late diagnosis (Werner et al., 2003).

Dementia stigma

Dementia stigma has been widely discussed in the literature. Yet, there is a lack of consensus regarding the operational definition of this construct. On one hand Goffman (1963) defined stigma as a discrediting characteristic resulting in difficulties

with social acceptance for the individual who has it. On the other hand, Link and Phelan (2001) referred to stigma as a social process, which occurs in a relationship of power, in which the targeted individuals or the associated group are labelled with undesirable characteristics, stereotypes and placed in a distinct category (separating), which can then result in emotional distancing, a loss of status and/or discrimination. Additionally, while Link and Phelan's (2001) conceptualisation included the occurrence of social, economic, and political power as a requirement, Corrigan and Watson's (2002) conceptualisation placed a greater emphasis on the characteristics of stereotypes (negative beliefs), the mental and emotional responses to stereotypes (prejudice) as well as discrimination (behaviours that usually follow this prejudice). It is important to note that stigma is more than just an attitude which is conceptualised as a conscious or unconscious mental state, belief, feeling or value and predisposition to action or behaviour (Altmann, 2008). Rüsch and colleagues (2005) more recently combined Link and Phelan's (2001) as well as Corrigan and Watson's (2002) definitions to develop the integrated social cognitive model of stigma, which include various forms of stigma:

- Structural stigma: imbalances and injustices in social structures such as discrimination in health services
- Self-stigma: internalised or felt stigma
- Courtesy or affiliate stigma: stigma extended towards individuals without a stigmatised mark and is due to the association with individuals with a stigmatised mark.
- Public stigma: negative reactions in the form of stereotyping, prejudice or discrimination from the general population towards those with a stigmatised mark or other individuals without the stigmatised mark but are associated with them such as carers.

There are several explanations on how stigma towards people with dementia is created. One explanation is through the stereotype content model's classification of social groups such as older adults or those living with a disability as having warmth and perceived as non-competitive and benevolent or having competence and perceived as capable and of a high-status (Cuddy et al., 2009 as cited in O'Connor &McFadden, 2012). According to this model, positive stereotypes of warmth in groups such as the elderly or those with a living disability maybe enhanced when the negative stereotype of incompetence is confirmed (Cuddy et al., 2005 as cited in O'Connor &McFadden, 2012). Moreover, O'Connor and McFadden (2012) add that mixed patterns of prejudice and emotions such as being liked yet disrespected are referred to as paternalistic prejudice and may also be elicited among these groups. This is illustrated in Fiske and colleagues' (2002) findings of older adults who were rated high on pity but little on contempt and envy (Fiske et al., 2002 as cited in O'Connor &McFadden, 2012).

Other explanations on how stigma towards people with dementia is created include Tajifel and Turner's 1979 social identity theory which suggest that there is a tendency for people to define groups they belong to as positive and opposing groups as negative (Tajifel &Turner, 1979 as cited in Newton et al., 2021). This theory when applied to dementia explains how PLWD can often be viewed as possessing a socially undesired trait that can lead to discrimination, social isolation, and disenfranchisement. The Greenberg and colleagues' (1986) terror management theory states that people avoid situations that trigger death related thoughts (Greenberg at al., 1986 as cited in Newton et al., 2021). This theory when applied to dementia potentially explains stigma towards PLWD as a strategy to psychologically distance oneself from the perception of dementia as an inescapable decline or loss of the self and personhood.

This conceptualisation of stigma has widely been adopted in dementia stigma research (Guyen & Li, 2020). In the context of dementia stigma, the social process is characterised by excluding, rejecting, blaming, or devaluating based on an enduring feature of identity, conferred by dementia symptomology, such as cognitive deficits (e.g., memory) or behavioural and psychological symptoms of dementia (BPSD), which include unusual psychotic symptoms, aggressiveness, repetitive behaviours, wandering, and apathy (Herrmann et al., 2018). This literature review focuses on public stigma and adopts Corrigan and Watson's (2002)'s conceptual framework as shown in table 1.

Table 1. Definition of public stigma

Public stigma and its different aspects	
Stereotype (belief)	Negative belief about a group (e.g., dangerousness, incompetence)
Prejudice (emotion)	Agreement with the belief and or negative emotional reaction (e.g., anger, fear)
Discrimination (Behaviour)	Behavioural manifestation of prejudice (e.g., avoidance, withholding of help)

***Note**. Data from "understanding public stigma and self-stigma in the context of dementia: A systematic review of the global literature" by Ngyuyen, T, and Li, X., 2020, Dementia, 19(2), p. 150*

Public stigma among the general public

Evidence on stigma in dementia when compared to stigma research in other health conditions generally remains limited (Blay, 2019). Global public responses towards dementia are generally negative, with a view of dementia as a stigmatizing condition (Alzheimer Disease International, 2019). The world's largest survey on attitudes to dementia surveyed almost 70,000 individuals across 155 countries and reported prejudice about dementia views (fears of developing dementia) and

stereotypes (thoughts that nothing can be done to prevent dementia) among the general public (Alzheimer Disease International, 2019). A prior survey on personal experiences of stigma with PLWD and carers was conducted and reported that over 2,500 respondents from 54 countries including 157 people with dementia felt marginalised by society and wanted to be treated like normal people (Alzheimer Disease International, 2012). These findings suggest that the general public hold stigmatised views, as affiliate and self-stigma results from the process of absorbing public stigma (Corrigan & Watson, 2002).

Further evidence from systematic reviews conducted on dementia-related stigma from across the globe raises interesting insights and suggests public stigma has been persistent over time. A recent systematic review assessing public stigma towards PLWD, and their family members recommended a more positive shift in public attitudes following a review of eight qualitative and fifteen quantitative studies (Guyen & Li, 2020). In this review, the reported aspects of public stigma included views of PLWD as dangerous, lacking self-esteem, and incompetent as well as mixed emotions that ranged from fear, anxiety disgust to pity, sympathy, and empathy, resulting in social distancing and avoidance. Similarly, a prior review by Herrmann and colleagues (2018), which examined stigma over a past decade (January 2004 to December 2015), indicated that the public reacted with fear, had views of persons with AD as less competent, and engaged with behavioural discrimination. In an earlier review of published studies between 1990 and 2012 by Werner's (2014), moderate levels of public stigma towards individuals with dementia of the Alzheimer's subtype were reported. Comparable to findings from the most recent systematic review (Guyen & Li, 2020), feelings of shame and fear as well as thoughts that people with AD were unpredictable, difficult to communicate with and should be institutionalised were common public responses (Werner, 2014).

Other population studies have examined different aspects of public stigma and reported varying results ranging from positive to negative and mixed responses. Positive public inclusive responses include accepting attitudes towards euthanasia (Terkamo-Moisio et al., 2019), acknowledging the basic human rights of people living with AD (Bourkel at al., 2012). Most evidence report negative public responses. These include negative stereotypes from studies in Germany (Ludecke et al. 2016), Ireland (McManus and Devine 2011), and South Korea (Seo et al. 2015). Prejudices and negative emotions of fear and shame have been reported by populations in Singapore (Tan et al., 2012), Belgium (Huisman et al., 2020), Lebanon (Hamieh et al., 2019), Japan (Aihara et al., 2020; Umegaki et al., 2009), China (Li et al., 2011), and the United Kingdom (Martin et al., 2015). Studies found public responses of avoiding or socially distancing from PLWD in the US (Lee at al., 2020), due to erroneous beliefs such as dismissive language such as “demented” resulting in negative connotations about dementia in both UK and Brasil (Pelegrini et al., 2020) use of disparaging names such as 'madman' in Nigeria (Adebiyi et al., 2016) PLWD perceived as witches in South Africa (Mkhonto & Hanssen, 2018).

Several studies have reported mixed public responses towards PLWD. A Japanese study by Aihara and colleagues (2020) analysing public attitudes reported a generally supportive attitude coupled with participants wanting to help and share happiness with PLWD. However, nearly half of these 594 participants also reported they would be ashamed of a family member with a dementia diagnosis and more than 70% thought PLWD often cause trouble for others (Aihara et al, 2020). Similarly, findings of empathic attitudes about wanting to help from 150 Jewish Israeli adults presented with a hypothetical situation describing a person with AD, found this population tended to react more positively than negatively (Werner and Davidson, 2004). Empathetic attitudes (such as pity coupled with stereotypes of incompetence) toward PLWD should be viewed with caution as perceptions of

PLWD as helpless and dependent may lead to stereotypes about incompetence or discrimination through coercive options and perhaps perpetuate stigma (Kane et al, 2018). For example, a study by Werner (2006) argued that perceptions of the competence of a person with AD predicts social distance from this person. An experimental vignette methodology was used for participants to rate competence based on the performance on some activities of daily living and areas of driving, health-decision making, and financial decisions. Participants who perceived the person with AD as less competent tended to perceive them as more dangerous and more likely to endorse coercive options.

Majority of existing evidence on public stigma are from western countries including Israel, US, UK and Australia (Ngugen & Li, 2020). Evidence from the world bank's classified low- and middle-income countries (Central Asia, eastern Europe, southern Latin America, eastern and southern sub-Saharan Africa) are few despite reports that 58% of PLWD live in these regions (Prince at al., 2015). The higher prevalence in these regions could suggest higher stigma experiences.

A systematic review exploring perceptions of dementia in Latin America found that a significant minority had negative or stigmatising attitudes (Farina et al., 2020). These findings mirror the negative perception of dementia reported in a systematic review exploring view on Dementia in sub-Saharan Africa (Brooke & Ojo, 2020). Additionally, there have been reports of violence towards and sometimes murders of PLWD in these regions (Alzheimer's Disease International, 2019). A recent study by Owokuhaisa and colleagues (2020) assessed public perceptions of PLWD and caregivers among lay 26 men and 33 women from three villages within separate districts in Southwestern Uganda. In this study using interviews lasting approximately 30–70 min in free and flowing discussions, several aspects of stigma came up. Views about dementia being negatively attributed to satanic powers,

witchcraft and life stress as well as concerns about the burden of caregiving on the family considering the unavailability of formal dementia services were reported.

Findings, matched closely with available stigma evidence reporting fear, discrimination, and social isolation of PLWD is related to negative stereotypes and beliefs about spiritual beliefs such as possession by the devils (Kehoua et al., 2019) retributions for misdeeds (Mukadam et al., 2011), punishment from God or ancestors (Brooke & Ojo, 2020) or to witchcraft (Mkhonto & Hanssen, 2018) among populations in Tanzania (Mushi et al., 2014), Nigeria (Adebiyi et al., 2016). Other reports of stigma on the African continent include rejection and psychological abuse (Ndamba-Bandzouzi et al., 2014).

Sociodemographic factors affecting public stigma

Mixed results were reported regarding the socio-demographic correlates of public stigma across several population studies. These include age, gender, educational level, exposure to dementia or prior contact with someone living with dementia and knowledge about dementia. A Brazilian sample found no significant association between public stigma and any socio demographic variable apart from education: lower educational levels predicted stigma towards a person with AD (Blay & Peluso, 2009). These findings were consistent with the findings of the systematic reviews by Werner (2014) and Guyen and Li (2020).

A study in France found an association of higher levels of public stigma with younger participant (Piver et al. 2013) as did the systematic review by Herrmann and colleagues (2018). Conversely, several other studies in the systematic review by Guyen and colleagues (2020) and Werner (2014) found lower levels of public stigma were associated with younger participants. Similar findings were reported among populations in UK (Cheston et al., 2016), Northern Ireland (McParland et al., 2012), Korean Americans (Lee et al., 2020) China (Cheng et al., 2011) and Australia

(Phillipson et al., 2014). It is important to note that the association between age and attitudes is more complex than reported in this review.

Some evidence showed a significant association between gender and public stigma, such as women tended to show more positive reactions than men (Werner & Davidson, 2004; Guyen & Li, 2020; McParland et al., 2012). However, Blay and Peluso (2010) and Jang and colleagues (2010) found that gender has no effect on stigma among Brazilian and American Korean populations respectively.

With respect to the level of dementia knowledge, findings from a pilot study by Lane (2020) among Singaporean respondents showed greater knowledge of dementia symptoms was associated with help giving intentions and not stigma characterised by avoiding contact with PLWD and feelings of shame about dementia.

Conflicting evidence has also been reported between the association of public stigma and exposure to dementia. All three systematic reviews reported that prior contact with someone living with dementia was associated with lower levels of public stigma (Guyen & Li, 2020; Herrmann et al., 2018; Werner, 2014). Conversely, experience with dementia or personal contact with someone with dementia was unrelated to public stigma in Korean Americans (Jang et al., 2010), UK (Cheston et al., 2016), Brazil (Blay & Peluso, 2009), and Northern Ireland (McParland et al., 2012), Additionally. ethnicity seemed to affect public stigma. In the UK study by Chelston and colleagues (2016), white participants held more positive attitudes than their non-white counterparts. Similar findings were reported in a systematic review by Guyen & Li (2020). In the US, older Korean Americans (Jang et al., 2010) and Chinese- American (Woo and Chung, 2017; Woo & Mehta, 2017) were reported to present with more stigmatic attitudes. Given the variability of evidence, the

sociodemographic correlates of public stigma are still unclear. Further investigations are needed.

Findings from this review should be viewed with caution as there are several limitations with the studies making it difficult to draw clear conclusions. The limitations include (a) stigma definition and (b) study designs. First, with respect to stigma definition, some studies did not use any theoretical framework to define public stigma. Additionally, stigma was not the main focus of some of the studies. Second, regarding the study designs, some samples used were not representative. For example, the views and responses of younger members of the public are not represented in these findings as the vast majority of participants are aged 18 and over with the exception of the study by Cheston and colleagues (2016) with 16% of the participants in the sample aged 16–24. Moreover, there was a lack of consistency in the measurement of public stigma. Some studies used structures questionnaires, standardised measures while others used measures originally developed by other health conditions. No stigma measure has been specifically developed and validated for the general public.

Stigma variation across cultures

A growing body of empirical work has examined cultural variations of public stigma among populations globally and found variability in stigma experiences. Most reported studies on dementia are based on western societies and little is known about how dementias are experienced or understood elsewhere (Cipriani & Borin, 2015).

Cipriani and Borin's (2015) study about an indigenous Australian population characterised by poor health and high mortality rate reports that dementia among this population is perceived as a luxury for people fortunate to live long enough. This contrasts with Huisman and colleagues' (2020) study about a Flemish community

who perceived dementia as the time to when life starts to end. This view was shaped by media narratives depicting disturbing stories about dementia related to the terminal stages of dementia. Several communities generally do not consider dementia as a medical problem and have different explanations that contribute to stigma. In the UK, some Black African and Caribbean communities attribute dementia to possession by evil spirits or associate changes in behaviour during the more advanced stages of the disease with mental illness (Berwald et al., 2016; Mkhonto & Hanssen, 2018). Attributions of dementia to having been a victim of an evil spell or to one's fate as a result of earlier wrongdoing are some other common explanations in Pakistan, India and Bangladesh communities in the UK (Blakemore et al., 2018). The implications of these beliefs place blame on PLWD for their condition and compromise the marriage prospects of relatives as the family is perceived to have a biological defect. Reports of some communities across the world whose views of dementia are not shaped by the medical model include the elderly Turkish population (Shain et al., 2006), Chinese Americans (Woo & Chung, 2018), some Congolese communities (Kehoua et al., 2019), some Tanzanian communities (Hindley et al., 2017), and most African cultures in Africa (Ndamba-Bandzouzi et al., 2014).

Other cultural factors influencing stigma include religion and history. Dementia stigma has been associated with religious beliefs. For example, in some contexts, PLWD are perceived by fellow religious believers as bad or evil or not strong enough to keep dementia away through prayers (Mukadam et al., 2011). Stigma in relation to seeking help from services is present in cultural contexts where family-based caregiving of PLWD is perceived as a duty and hence accessing help from health care professionals is frowned upon such as in some Asian communities in the UK (Mukadam et al., 2011). Accounts of stigma and history indicate historical experiences of war and persecution in eastern Europe has been reported to

contribute towards some communities' tendency to keep their identity and family affairs secretive (Mackenzie, 2006). Mackenzie (2006) explained that this secretive tendency has influenced the stigma associated with dementia among eastern Europeans.

Lastly, findings from studies that made direct comparisons between distinct cultural groups have also been conducted. Werner and colleagues (2019) assessed stigmatising beliefs between 450 Greek and 213 Israeli students and found low levels of stigma. These authors were surprised to find significantly higher levels of stigmatising beliefs among Israeli students whose culture they characterised by individualistic cultures predicted to show higher stigmatising beliefs. In another comparison of cultural population study conducted by Werner and colleagues (2015), Israeli Jewish participants had higher levels of stigmatising beliefs toward persons with AD compared to Israeli Arab population.

Implications for the less common forms of dementia

Alzheimer's Disease International (2019) recommend using educational strategies that include brief videos, using art, and advocacy by PLWD to raise dementia knowledge, improve attitudes and reduce stigma among the general public but have provided limited evidence for the effectiveness of these strategies nor impact on PLWD and their carers.

Several global initiatives to reduce stigma, improve attitudes and knowledge publicly include educational short dementia videos disseminated via YouTube (Woo, 2018), Television (Woo, 2017) and WhatsApp (Shu & Woo, 2020), community awareness meetings in Australia (Alzheimer's Australia, 2015), dementia awareness resource packages for primary and secondary school children in UK (Alzheimers' Scotland, n.d.), dementia-friendly communities (Alzheimer's Society , 2020b), global dementia friends (Alzheimer's Society , 2020a) and various other public awareness

campaigns as national dementia strategies in over 30 countries (World Health Organisation, 2017).

Despite existing initiatives, evidence of whether initiatives to raise dementia awareness and reduce stigma achieve their intended purpose is limited. Few studies have reported initiatives that yielded positive results. In the US, a study by Harris and Caporella (2014) used an arts-based intervention aimed to reduce AD stigma among college students. In this study, 12 college students who were part of an intergenerational choir which included six people living with early-stage AD and their seven family members showed an increased understanding about lived experience of AD following participant following 8 weeks of rehearsing for a performance together. Additionally, Investigators reported a change in attitudes and behaviour towards the person living with AD and referred to them as friends. Similarly, a Canadian study evaluated a one-hour dramatic production aimed to shift negative perceptions about PLWD (Kontos et al., 2020). A sample of 602 members drawn from a diverse general population completed questionnaires following the performance and reported lower levels of stigma, suggesting the production to be an effective public health strategy in tackling dementia stigma. In Australia, Phillipson and Colleagues (2019) designed educational activities using various channels including media, face-to-face and website interventions with the aid of PLWD and their carers with the hopes to increase public dementia knowledge. Over 1000 Australian community members engaged with the material and completed a survey which showed a significant improvement in their awareness of dementia and the availability of dementia information.

Fewer studies have pre/post designs to evaluate effectiveness of public interventions. In a UK study aimed to raise awareness and challenge negative perceptions of dementia, 109 participants watched three public orchestra performances of performers that included of PLWD and their carers, and were

asked to report their expectations about PLWD (Reynold et al., 2017). These researchers reported a significant improvement in the perception of dementia, as 108 audience members reported that the orchestra had either met or exceeded their expectations following the performance compared to 53% of audience members who reported low or no expectation of the performance prior to the performance. Similarly, 51 respondents in Puerto Rico completed the pre/post education surveys following conversations with health professionals working in dementia care which took place at coffee shop and demonstrated an overall improvement in AD knowledge (Friedman at al., 2016).

A study evaluating a free online Dutch course on Alzheimer's reported a significant increase in the knowledge of dementia and informal caregiving among the 220 caregivers who completed the pre and post questionnaires (Prins et al., 2020). Eccleston and colleagues (2019) examined changes to dementia related knowledge among informal carers, health care workers and the general public from 180 countries following completion of the Understanding Dementia Massive Open Online Course (UDMOOC) and found a significant increase in dementia knowledge. This increase in knowledge was regardless of the diverse participants' age, experience of dementia and levels of education.

Findings in these reviewed studies have various limitations including the lack of a control group, small sample sizes and the use of non-validated measures. Limitations limit the ability to draw conclusions, track changes over time, or make meaningful comparisons across settings and populations. Other limitations include the predominate focus on common forms.

Conclusions

This review has summarised atypical causes of dementia and detailed their possible causes, clinical presentation, treatment approaches and highlighted the

complexity and variation of how dementia affects people living with this subtype. Consideration of these differences in experiences is fundamental to the planning and delivery of appropriate care and support.

The review also covered dementia related knowledge, attitudes and stigma among the public. It demonstrated existing gaps in knowledge mostly correlated with lower education and no experience of dementia either through education or caring for someone with dementia. In addition to this, dementia continues to be publicly viewed as a stigmatising condition with inconsistent reports of social demographic factors associated with this. Specific information on how these factors present in rarer dementias is limited.

Lastly, there are limited evidence-based interventions and explanations for tackling dementia related stigma and improve attitudes and knowledge for the general public. Existing studies show promising results about current initiatives, however aspects of the study design such as no group control, small sample sizes, use of unvalidated measurement tools are problematic and limit the generalisability of these findings. Additionally, a focus on common forms of dementia are among current limitations with the findings. More carefully designed studies addressing less common forms of dementia are warranted.

Part two is a quantitative, empirical study into whether an educational tool is an effective strategy in improving knowledge, attitudes, and stigma in the context of dementia. It investigates the effect of an online intervention on the less common forms of dementia ('The Many Faces of Dementia' MOOC) in an international cohort by examining changes to dementia related stigma, knowledge, and attitudes in a pre-post design over three runs of the free online course using validated scales.

Part three is a critical appraisal of the process of doing this research. It begins with an outline of my journey about starting the project, reflects on

methodological challenges that arose, my response and what I could have done differently. It also includes a discussion on the process of reviewing the literature and ends with a personal reflection.

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Part Two: Empirical Paper

Evaluation of the effect of “The Many Faces of Dementia” massive open online course (MOOC) in an international sample

Abstract

Background: Various interventions using education and direct or indirect contact with people living with dementia (PLWD) have been developed to mitigate the lack of knowledge, misunderstanding, negative attitudes, and stigma surrounding dementia and to improve dementia care and support. The effectiveness of these interventions remains unclear. Fewer studies have reported interventions specifically to raise knowledge, change attitudes and reduce stigma around dementia. Moreover, existing studies have predominantly focused on the common forms of dementia and to our knowledge no study has evaluated the utility for the less common forms of dementia.

Aims: To start addressing this gap by exploring public knowledge, attitudes, and stigma in the context of the less common forms of dementia and looking at changes in dementia related knowledge, attitudes, and stigma associated with completing *The Many Faces of Dementia Massive Open Online Course* (TMFD-MOOC). A further aim included preliminarily validating a brief rare dementia measure to explore its suitability to measure public knowledge of rare dementia.

Methods: An international cohort of participants (who included healthcare professionals, members of the general public and carers) undertaking TMFD-MOOC were recruited into the study. The Dementia Knowledge Assessment Scale (DKAS), Rare Dementia Knowledge Questions (RDKQ), Approaches to Dementia Questionnaire (ADQ) and STIG-MA Survey were used to assess their knowledge, attitude, and stigma related to dementia. These measures were completed at baseline, immediately and two months after completion of the TMFD-MOOC. Demographic data was also collected prior to administering the measures.

Results: In the baseline sample (N=568), internal reliability for the four rare dementia items was poor, with Cronbach's alpha of 0.35. Overall mean scores indicated poor rare and general dementia knowledge, positive attitudes, and moderate levels of stigma. Following TMFD-MOOC, participants who completed the MOOC and provided follow-up data (n=70) showed increased general and rare dementia knowledge but no changes in attitudes nor reduced stigma.

Conclusion: To the author's knowledge, this study is the first to explore public knowledge, attitudes, and stigma in the context of the less common forms of dementia. While findings suggest the usefulness of the intervention for improving dementia related knowledge and not dementia related stigma or attitudes further robust research is needed to measure whether interventions are effective.

Introduction

Dementia and rare dementia

Dementia is the umbrella term used to refer to a group of neurodegenerative conditions affecting the brain and negatively impacting on a person's ability to think, communicate, understand, or remember, that also interfere with activities of daily life (National Institute for Clinical Excellence, 2018). Dementia is among the world's leading cause of disability in the elderly, contributing to a high burden and care costs on carers, families, and societies (World Health Organisation, 2021). Currently, the World Health Organisation's (2021) reports estimate that dementia affects 55 million people worldwide, and cases are on the rise at an estimated rate of 10 million new cases per year. Furthermore, figures are predicted to rise to about 78 million in 2030 and139 million cases by 2050. The increasing cases, growing disease burden and death rate due to dementia as well as limited dementia awareness and understanding has prompted the World Health Organisation (WHO) and Alzheimer's Disease International (ADI) to declare dementia as a critical global public health challenge (Wortmann, 2012).

There are over 100 types of dementia with Alzheimer's disease (AD) and vascular dementia as the most prevalent subtypes. Reports indicate that AD accounts for over 60 % of all dementia cases while non-AD or vascular dementias account for about 25 % (Brotherhood et al., 2020). Non-AD or vascular dementias are rarer forms of dementia frequently presenting progressive atypical features including an onset of possible behavioural symptoms such as impairment of emotional sensitivity personal conduct rather than typical AD cognitive symptom of memory impairment and occurring before the age of 65 although they can also occur after the mentioned age group (Brotherhood et al., 2020, Collins et al., 2020).

Rarer forms of dementia summarised in systematic review by Collins and colleagues (2020) include a logopenic variant of primary progressive aphasia (lv-PPA) characterised by progressive language impairment like word-finding difficulties alongside impaired sentence comprehension; posterior cortical atrophy (PCA) marked by vision difficulties; familial AD (FAD) caused by mutated inherited presenilin 1 (*PSEN1*) gene, presenilin 2 (*PSEN2*) gene, or amyloid precursor protein (*APP*) resulting in progressive loss of episodic memory before the ages of 65 as its trademark symptom. Frontotemporal dementia (FTD) also falls within the 'rare dementia category' and is an umbrella term for a number of syndromes that have in common changes in personality, behaviour, and language as hallmark symptoms due to the affected frontal and temporal brain lobes. The FTD syndromes comprise non-fluent variant PPA (nfv-PPA), behavioural variant frontotemporal dementia and semantic variant PPA (sv-PPA) with hallmark symptoms of progressive languages impairment like agrammatism and effortful, non-fluent speech, changes in personality and social behaviour and progressive languages impairment of word and object comprehension. Additionally, there is an inherited FTD occurring because of mutated progranulin (*GRN*), microtubule-associated protein tau (*MAPT*), or chromosome 9 open reading frame (*C9ORF72*) genes is known as familial FTD (fFTD).

Knowledge and stigma

The lack of knowledge, misunderstanding, negative attitudes, and stigma surrounding dementia among people affected with dementia, healthcare practitioners and the general public continue to be significant barriers to dementia care and support (Alzheimer's Disease International, 2019). Participation of the general public in addressing these barriers is critical as community support is an essential component in dementia care (World Health Organisation, 2017; Woo & Chung, 2013). An inclusive society potentially leads to earlier access to care,

greater support, understanding, acceptance, engagement and eventually a higher quality of life for people affected with dementia (Bradford et al., 2009; Herrmann et al., 2018; Werner, 2014; World Health Organisation, 2017). Education and direct or indirect contact with people affected by dementia are well known, widely accepted and recommended strategies to address these barriers (Kim et al., 2019; Herrmann et al., 2018). In terms of mechanisms of effect, Kim and colleagues (2019) summarisethat through education, erroneous stereotypes and beliefs influencing stigmatising attitudes could be replaced with accurate information and potentially improve affirming attitudes. Several interventions using these strategies aim to address the barriers to dementia care and support, and have been developed for people living with dementia (PLWD), carers, healthcare professionals (HCP), and the general public.

Interventions in dementia as a whole (including rare and general dementia)

Existing global initiatives to reduce stigma, improve attitudes and knowledge publicly include educational short dementia videos disseminated via YouTube (Woo, 2018), Television (Woo, 2017) and WhatsApp (Shu & Woo, 2020), community awareness meetings in Australia (Alzheimer's Australia, 2015), dementia awareness resource packages for primary and secondary school children in the UK (Alzheimers' Scotland, 2017), dementia-friendly communities (Alzheimer's Society , 2020), global dementia friends (Alzheimer's Society , 2020) and various other public awareness campaigns as part of national dementia strategies in over 30 countries (World Health Organisation, 2017).

Evidence of whether existing initiatives to raise dementia awareness and reduce stigma achieve their intended purpose is limited. Few studies have reported initiatives that yielded positive results. In the United States of America, a study by Harris and Caporella (2014) used an arts-based intervention aimed to reduce AD

stigma among college students. In this study, 12 college students who were part of an intergenerational choir which included six people living with early-stage AD and their seven family members showed an increased understanding of the lived experience of AD following the eight weeks of rehearsing for a performance together. Additionally, Investigators reported a change in attitudes and behaviour towards the person living with AD and referred to the people living with AD as friends. Similarly, a Canadian study evaluated a one-hour dramatic production aimed at shifting negative perceptions about PLWD (Kontos et al., 2020). A sample of 602 members drawn from the general public that completed questionnaires before and after the performance reported lower levels of stigma, suggesting that the production was an effective public health strategy in tackling dementia stigma. In Australia, Phillipson and colleagues (2019) designed educational activities using various channels including media, face-to-face, and website interventions with the aid of PLWD and their carers with the hope of increasing public dementia knowledge. Over 1000 Australian community members engaged with the material and completed a survey which showed a significant improvement in their awareness of dementia and the availability of dementia information.

Fewer studies have pre/post designs to evaluate effectiveness of public interventions. In a UK study aimed to raise awareness and challenge negative perceptions of dementia, 109 participants watched three public orchestra performances of performers that included PLWD and their carers and were asked to report their expectations about PLWD (Reynold et al., 2017). These researchers reported a significant improvement in the perception of dementia, as 108 audience members reported that the orchestra had either met or exceeded their expectations following the performance. This was compared to 53% of audience members who described low or no expectations of the performance prior to the performance. Similarly, 51 respondents in Puerto Rico completed pre/post education surveys

following conversations with health professionals working in dementia care. These took place at coffee shop and demonstrated an overall improvement in AD knowledge (Friedman at al., 2016).

More recently, a pre-post study design by Zhang and Cheng (2020) aimed to investigate whether exposure to information about dementia changes stigma. They randomly assigned 200 adults aged 18–83 years in Hong Kong to three of the following experimental groups: 1. completing a stigma questionnaire after reading fictional vignettes about older adults experiencing memory loss, 2. completing a stigma questionnaire after reading fictional vignettes about older adults experiencing memory loss and BPSD symptoms of dementia. After reading the vignettes, both groups answered questions about stigma and 3. no exposure to experimental manipulation and being offered the questionnaire without reading any vignette. The Researchers found a moderate level of dementia related stigma at post-test comparable in all three groups suggesting that exposure to information did not change participants dementia related stigma levels. To the author's knowledge there are no other public dementia related stigma intervention studies besides an evaluation of the short-term efficacy of the Dementia Risk Reduction (DESeRvE) study. The DESeRvE study hopes to assess whether education, contact, and the combination of education and contact can reduce public dementia stigma reduction using a randomized controlled trial (RCT), and is currently underway in Australia (Kim et al., 2019).

Online interventions

In addition to face to face or mixed media interventions there is an increasing emphasis on online interventions. These are easily accessible and scalable educational platforms, with low costs that can help to overcome the logistical and resource boundaries of in-person interventions (Blom et al., 2015).

For example, a study evaluating a free online Dutch course on AD reported a significant increase in the knowledge of dementia and informal caregiving among the 220 caregivers who completed pre- and post-questionnaires (Prins et al., 2020). Eccleston and colleagues (2019) examined changes to dementia related knowledge among carers, HCP and the general public from 180 countries following completion of the Understanding Dementia Massive Open Online Course (UDMOOC) and found a significant increase in dementia knowledge. This increase in knowledge was regardless of the diversity in participants' age, experience of dementia, and levels of education.

Online interventions in rarer dementias

Existing studies have predominantly focused on the common forms of dementia, and to our knowledge no study has evaluated the utility of attempts to increase knowledge and reduce stigma around the less common forms of dementia. This is despite the fact that there is likely to be less knowledge of these conditions and more stigma around them compared with the common forms of dementia (Werner et al., 2009). Furthermore, less common forms of dementia are more likely to be unrecognised by individuals showing symptoms by those around them or HCP (Suárez-González et al., 2020).

These dementias are also frequently misdiagnosed and characterised by a difficult and lengthy diagnosis process (O'Malley et al, 2019; Stamou et al., 2021). For example, a recent systematic review summarising data on best practice in young-onset dementia diagnosis by O'Malley and colleagues (2019) indicate that on average it can take four years to get a diagnosis, and that the diagnosis process is further compounded by the characteristic complexities of dementia such as its rarity and the heterogeneous presentation of progressive symptoms.

Post diagnostic care pathways are inadequate as some existing services are inappropriate for the needs of those diagnosed with the less common forms of dementia and their carers, and specialist services that can adequately address their need are few (Stamou et al., 2021). Additionally, there are further psychosocial issues experienced by people living with the less common forms of dementia and their carers. These include financial difficulties since these dementias typically occur before the age of 65 when most adults are at a working stage in life, or the prevalence of depression, anxiety, apathy and other specific needs which remain poorly understood in comparison to more typical forms of dementia (Collin et al., 2020). Ongoing effective care management for people living with these rarer dementias and their carers require HCP involved in their care to have a solid knowledge base surrounding the specific pathophysiology, psychology, drug treatment and caregiving aspects of these rarer dementias (Stamou et al., 2021).

To address some of these issues, the UCL dementia Research Centre in collaboration with experts by experience, scientists, and clinicians developed a course in attempts to address gap identified *The Many Faces of Dementia* MOOC (TMFD-MOOC) https://www.futurelearn.com/courses/faces-of-dementia , a four-week Massive Open Online Course about the rare forms of Dementia (familial Alzheimer's disease, behavioural variant frontotemporal dementia, dementia with Lewy bodies and posterior cortical atrophy). In an analytical paper by Davies and Hopwood (2017) assessing whether TMFD-MOOC is beneficial to general practitioners (GPs) in the UK, the authors reported that TMFD-MOOC was useful as it provided useful clinical information to aid with screening, and diagnosing, understanding rare dementia specific medical and social challenges, and signposting people affected with rare dementias to appropriate services.

Measuring rare dementia knowledge

Accurate measurement of rare dementia across a spectrum of cohorts is essential to developing tailor made rare dementia educational interventions and evaluating their efficacy. It is also essential to improving rare dementia awareness and education, care and support. These cohorts include HCPs, Carers, members of the general public or policymaker and other key professionals involved in the implementation of national government plans and initiatives for an inclusive society. However, the extent of these cohort's understanding of rarer dementias is unclear. To establish these cohorts' baseline knowledge of rare dementia or changes to their knowledge, valid and reliable scales measuring a range of rare dementia knowledge domains is needed. To the author's knowledge, there are no instruments to measure rare dementia knowledge with the exception of Wynn and Carpenter's (2020) Frontotemporal Dementia Knowledge Scale (FTDKS). The FTDKS has 18 true or false questions measuring general knowledge relating to risk factors, symptoms, care and treatment was confirmed as a reliable and valid measure following administered to health care professions and carers (Wynn & Carpenter, 2020).

Current study

This study aims to start to address this gap by looking at changes in dementia related knowledge, attitudes, and stigma around rarer dementias pre and post participating in the MOOC in an international cohort of participants who included HCP, members of the general public (MGP), and carers undertaking TMFD-MOOC. Since there is no measure of rare dementia knowledge and little knowledge about the impact of rare dementia knowledge even in the absence of interventions, secondary aims will be to preliminarily validate a brief measure of this and to look at factors associated with baseline knowledge in this cohort.

Research Aims

The study posed the following research questions and hypotheses:

Secondary aims

1. Preliminarily validation of the rare dementia knowledge questions (RDKQ)

    a. What is the internal consistency and convergent validity of RDKQ?

    b. Is the RDKQ suitable to measure rare dementia knowledge among the general public?

2. Evaluation of baseline rare and general dementia knowledge, dementia related attitudes, and stigma

    a. What do participants know about the general and rare forms of dementia and what factors may be associated with their knowledge?

    b. What are participants' dementia related attitudes and stigma and what factors may be associated with their attitudes and stigma?

    c. What is the relationship between demographic characteristics (gender, age, religion, educational level, previous dementia experience or exposure contact with PLWD and rare and general dementia knowledge, dementia related attitudes, and stigma?

Considering the limitations in literature about public knowledge of rare dementias, an exploratory approach to this secondary aim and research question was adopted and no specific hypothesis was made.

Primary aim

3. Is there change in dementia related knowledge, attitudes, and stigma outcome post vs pre participating in the TMFD-MOOC?

In relation to this aim, I hypothesise that following the intervention, participants' post intervention scores will be higher when compared to pre intervention scores, thus suggesting participants' increased knowledge, increased positive attitudes, and reduced stigma post intervention.

Method

Participants

Setting

This was an online study with participants accessing the survey through a link on the intervention's home page. A longitudinal quantitative method to evaluate changes in quantitative measures completed at baseline, immediately after the intervention and two months post the intervention was employed. This study is part of the Rare Dementia Support (RDS) Impact study: a collaboration between University College London (UCL), Bangor University and Nipissing University in Canada (http://www.raredementiasupport.org/research/). The study is joint funded by the Economic & Social Research Council (ESRC) and National Institute for Health Research (NIHR) and ethical approval for the study was granted by UCL Ethics Committee (Reference: Project ID: 8545/004).

Intervention

The intervention studied was The Many Faces of Dementia Massive Open Online Course (MOOC), about the less common forms of dementia hosted on the Future Learn platform (https://www.futurelearn.com/courses/faces-of-dementia). It

covers four lesser-known forms of dementia namely familial Alzheimer's disease, frontotemporal dementia, dementia with Lewy bodies, and posterior cortical atrophy. It provides an insight into the clinical, scientific, and personal aspects of these dementias. Aspects of caring and supporting people to live well with dementia are also covered to provide insight into the experiences and challenges facing many people who live with dementia and their carers. The MOOC was designed by UCL experts in consultation with key stakeholders (people affected by dementia, healthcare professionals, carers registered with the RDS support group and various stakeholders including online support experts, Alzheimer's Society, and the ageing well in Wales society). It was developed for health care workers, people in early stages of dementia, students or anyone interested in dementia and its effects on people and the brain.

The MOOC is free, accessible to anyone with internet access across the globe and delivered in an interactive and flexible manner. Learners can self-pace through approximately two hours of the weekly learning material designed to explore and discusses real case studies, symptoms, personal experiences and science on the particular dementia subtype. The four less common forms of dementia are covered over four weeks with each week exploring a different form of dementia.

- Week one is about familial Alzheimer's disease. It is introduced by brief interviews about familial Alzheimer's disease with an experts and world-renowned scientists before exploring the challenges faced by families affected by the condition. Other topics covered include diagnosis, genetic factors, treatment trials and support for those affected by the condition.

- Week two: Focuses on behavioural variant frontotemporal dementia. It covers the different symptoms and syndromes of this dementia type and the pathology underling the symptoms. It also investigates particular challenges related

to the diagnosis and care, available support and includes research related to exploring innovative methods of detecting symptoms early on.

- Week three: Covers dementia with Lewy bodies. It details the symptoms, causes and diagnosis of this form of dementia. Research on the relationship between a diagnosis of dementia and mental health for those affected by the condition is also covered.

- Week four: Looks at posterior cortical atrophy. It details the symptoms and diagnosis before exploring the experience of living with posterior cortical atrophy and the support available. The Research features investigations of potential techniques for supporting independence in the home of people with this dementia type.

This is realised through video interviews, end of module quizzes, articles and informal discussions in the chat forums moderated by a dementia expert. The course runs over 4 weeks with the opportunity to access the online course material for a further two weeks. Additionally, Learners can, at a fee, access the Course for as long as it is on Future Learn. The course has been running since March 2016.

Participants

All participants registered for TMFD-MOOC on Future Learn platform were invited to participate in the study. A total of 4356 learners registered for the MOOC in February, March and May 2020 and a sample of 568 participants (13%) consented to participating in the study. Inclusion criteria were that participants were able to understand, communicate, read, and write in English and could access the internet via computer, tablet, or a mobile phone, that they were over 18 years old and did not self-report a diagnosis of dementia.

Power calculation

There are no comparable rare dementia studies in the literature on which to base the sample size calculation, we therefore used work from the general dementia literature which suggests a small to medium effect on dementia knowledge (Bousfield & Scott, 2019). Based on this, G*Power 3.1.8 was used to complete a priori power analyses (Faul, Erdfelder, Lang & Buchner, 2007). A sample size of 67 was required when estimating a medium to small effect size of Cohen's *d* at 0.35 (Faul, Erdfelder, Buchner & Lang, 2009) at a power of 0.8 and alpha of 0.05 when using a matched samples t-test.

Procedure

Registered learners for TMFD-MOOC on the Future Learn platform were invited to participate in the study. Notification about the study and invitation to participate were sent along with the TMFD-MOOC registration confirmatory email. Interested participants clicked on link in the email which directed them to the survey company that was used for this study (Qualtrics, www.qualtrics.com). On this website, participants had the opportunity to read and download the RDS Impact study information sheet followed by an invitation to complete the online consent form.

Consented participants were then asked to complete the demographic questionnaire followed by the dementia related knowledge, stigma, and attitudes questionnaires (baseline survey) within the survey's two weeks open period.

At the end of the course after four weeks', registered TMFD-MOOC learners are routinely sent an email to thank them for their participation. For this study, an invitation requesting participants to complete the post intervention measures was included in this email. Like the procedure at baseline, participants had to click on the link which directed them to the study's Qualtrics survey platform to complete the post intervention survey. The TMFD-MOOC normally ends in four weeks.

Thereafter TMFD-MOOC allows registered TMFD-MOOC learners an extra two-week access to the course once the official four weeks course duration ends. In the study, participants were notified and invited to complete the post intervention survey during this extra two-week access to the course time period only.

After two months, another email using agreed text from the initial invite was sent by the TMFD-MOOC inviting participants to complete the follow-up survey. Similarly, to the other surveys, participants had a period of two weeks to complete the survey.

All data collected was securely stored using Data Haven as per RDS Impact study protocol. See appendices 1, 2, 3, and 4 for more details on recruitment flow, Impact study's participant information sheet, this study's information sheet, and email notifications that was sent to participants.

Once rare dementia knowledge definition was outlined, the question development process began. An initial pool of 18 questions was collected from the TMFD-MOOC which has 4-5 quiz questions at the end of each of the four chapters of the MOOC designed to help learners recap on some of the main learning points covered in each chapter.

Validating the measure

The 18 questions were reviewed by experts, scientists and clinicians involved in the development of the TMFD-MOOC and work for the UCL Dementia Research Centre. Based on these staff's expert review, a total of four questions assessing symptoms of the rare forms of dementia related to familial AD (fAD), prominent and early symptoms in behavioural variant frontotemporal dementia (Bvft), dementia with Lewy bodies (DLB) and posterior cortical atrophy (PCA) were used to create the scale. As an unvalidated scale, provisional measurement

properties (cronbach's alpha and correlation of scores with the DKAS) of this instrument was examined in the baseline dataset.

Measures

Prior to administering the measures, demographic data were collected via a Socio-*demographic questionnaire:* This included information about participants age, gender, ethnicity, religion and or beliefs, whether English was their first language, level of education, occupation, nationality, current geographical location, dementia experience, type of dementia experience and duration of dementia experience. See appendix 5 for the precise questions used to collect the demographic data)

To assess knowledge, attitudes and stigma related to dementia the following self-administered measures were used:

Knowledge

Dementia Knowledge Assessment Scale (DKAS) (Annear et al., 2015; Annear et al., 2016): is a 25 item Likert scale with factually correct or incorrect dementia statements from false, probably false, probably true, true to don't know. Total DKAS scores were obtained by summing the score for each of the 25 items providing a total score of 50 with higher scores representing more knowledge. The DKAS scale also has four subscales designed to measure dementia pathology and terminal course, how a person with a common form of dementia engages with the world, dementia symptoms relevant to the provision of care and finally risk and health promotion. Please see appendix 6 for the full measure. Previous research using a dementia related online course found good reliability ($\alpha = .85$; $\omega h = .87$; overall scale), with acceptable subscale internal consistency ($\alpha \geq .65$; subscales) thus confirming the scale as a reliable and valid measure for diverse international population including health care professionals, students, and members of the general public (Annear et al., 2017). Kim and Colleagues (2019) have also used this

scale to measure dementia knowledge in their randomized controlled trial of an online intervention program to reduce dementia-related public stigma.

Rare dementia knowledge Questions (RDKQ): The dementia knowledge assessment scale is not specific to rare dementias and no scales to measure knowledge specific to these forms of dementia exist. Consequently, a secondary measure of knowledge was constructed using four questions assessing symptoms of the rare forms of dementia related to familial AD (fAD), prominent and early symptoms in behavioural variant frontotemporal dementia (Bvft), dementia with Lewy bodies (DLB) and posterior cortical atrophy (PCA). Respondents received a point for each question answered correctly for a possible maximum score of 4. Total scores were obtained by adding up all items, thus a higher score indicates greater knowledge of aforementioned rare dementia. Please see appendix 7 for the RDKQ. Preliminary validation for this RDKQ scale was assessed and reported in the results.

Attitudes

Approaches to Dementia Questionnaire (ADQ; Lintern, Woods & Phair, 2000) is a validated 19 item Likert measure from 1 strongly disagrees to 5 strongly agrees with a total score ranging 19-25. The higher the score, the more positive the attitude. The measure has eight questions targeting hope for people with dementia and 11 questions about the recognition of personhood. Please see Appendix 8 for the full measure. Schepers and colleagues (2012) reported good internal consistency (Cronbach's $\alpha = 0.78$ overall; $\alpha = 0.73$ for hope and $\alpha = 0.74$ for personhood subscales). The measure has been used in a Dutch study evaluating an online media production to raise public awareness and enhance knowledge and understanding of dementia (Prins et al., 2019). The first survey of public attitudes towards people affected by dementia in Bristol and South Gloucestershire also used this measure (Cheston et al., 2016). The words “dementia sufferers” was replaced

with “living with dementia” in the measure as this language was deemed more inclusive.

Stigma

STIG-MA Survey (Piver et al, 2013) is a 10-item measure with the options of yes, maybe, do not know and no in response to statements that explore what respondents feeling would be if they had a diagnosis of AD. The internal validity reported is Cronbach’s alpha 0.83. This measure was adapted from Weiss and colleagues’ (1992) explanatory model interview catalogue (EMIC) which includes disease knowledge, perceived causes, perceived stigma, and the use of resources. The measure was originally developed for mental health and leprosy related stigma in India and due to its design has been adapted and used for epilepsy in Benin (Rafael et al., 2010) and dementia in Congo DRC (Faure-Delage et al., 2012). For this study, the word AD was replaced with dementia in the measure for the purposes of including all forms of dementia for this study. Please see Appendix 9 for the full measures described.

MOOC usage data

To understand the amount of time using the MOOC, four questions adopted from Hollands and Tirthali (2014) report looking at the expectations and reality in relation to MOOCs were included in the questionnaire immediately post MOOC. These multiple-choice style questions assess overall amount of time spent on the course per week, quantity of lecture videos watched, quizzes completed, participation in discussion forums and extent to which learners revisited the course materials. Please see Appendix 10 for the questions.

Data analyses

Initial process involved assessing all study variables for normality. Multiple approaches were used to assess all study variables for normality. This included calculating Shapiro-Wilk Test of normality for each level of the independent variable, skewness, and kurtosis statistics, identifying outliers as well as visually inspecting histograms and normal Q-Q plots (Field, 2013).

Byrne's (2001) three stage missing data framework was adopted for this study when determining how to handle missing data. It included the following steps:

1. An exploration of the amount of missing data. Missing data may have been due to user missing values (Participants skipping the questions) or system missing value (something may have gone wrong with the equipment when recording participant's responses). To inspect the missing values among the categorical variables, frequency distributions were used.

2. Examination of the pattern of incomplete data using Little's MCAR test.

Analyses for the main findings using SPSS version 27, (SPSS Inc., 2020) included Cronbach's alpha, Spearman's one-tailed test, Kruskal-Wallis, Mann-Whitney U tests Wilcoxon signed rank tests and paired t- tests.

Results

This section is presented in three parts. The initial section presents the descriptive analysis of the demographic and key variables in the study. The second section details baseline data results including preliminary validation of a brief rare dementia measure and exploring participants' knowledge, attitudes, and stigma and their associated social demographic characteristics in the context of rare dementias. The third section outlines changes in dementia related knowledge, attitudes, and

stigma associated with completing *The Many Faces of Dementia Massive Open Online Course* (TMFD-MOOC) are presented.

Missing data

The data contained some missing responses. An examination of the pattern of incomplete data in the databases (baseline, post and follow-up samples) using Little's MCAR test confirmed that some data was missing completely at random (MCAR) suggesting that the missing values are unrelated to the observed values. The test also confirmed that some of the data were not missing completely at random (See appendix 11 for Little' MCAR test results). Handling missing data involved several approaches depending on the method of data analysis used. The listwise deletion method which involves excluding from the analysis any participant's entire record with one or more missing values was used in handling the missing data for the cross-sectional analyses of baseline data.

For the matched post intervention and follow up missing data, the last observation carried forward (LOCF) single imputation method was used. This method replaced all missing values in the post intervention with the last observed value from the pre-intervention scores in the baseline database for each individual subject. The matched post intervention and follow up missing data was used as a conservative method for assessing intervention effect (i.e., assuming no effect). Some data was still missing following the handling of missing data as some participants had skipped some items. Consequently, there was no data to carry forward for three participants. This left a final analytic n=70 for the pre-post analysis.

Normality testing

Normality test results indicated that baseline ADQ, DKAS, RDKQ and STIG-MA variables as well as pre- post DKAS and RDKQ variables were not normally

distributed and thus nonparametric tests were used in analysing these. The exceptions were STIG-MA and ADQ variables in the final sample for the pre-post analysis which were normally distributed, thus parametric tests were used to analyse these variables in that analysis.

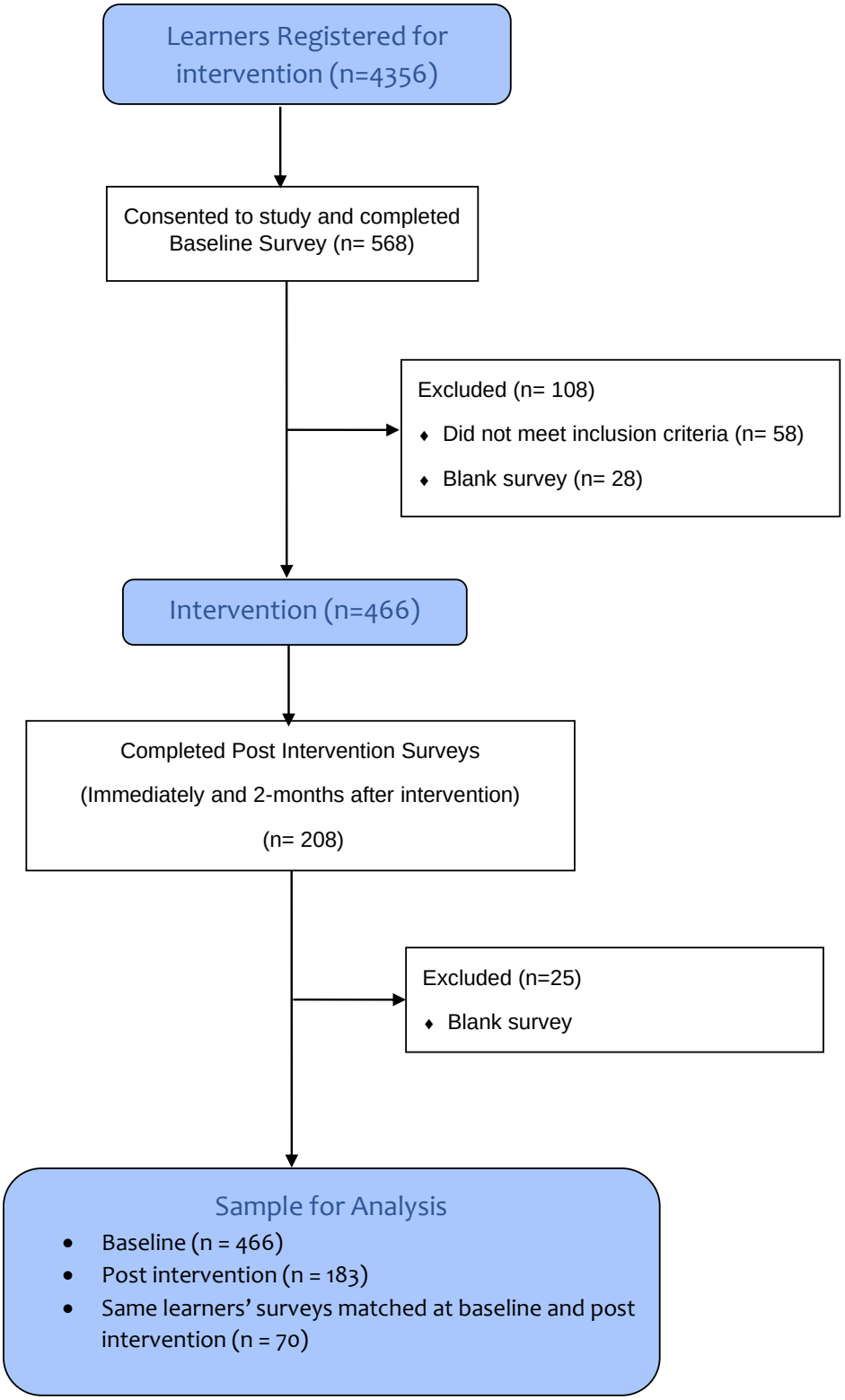
Participants

A total of 4356 learners registered for the MOOC in February, March, and May 2020 and a sample of 568 participants (13% of participants) consented to participating in the study. Baseline data revealed 58 participants, eight of whom self-reported as living with dementia and 50 as younger than 18 years old, did not meet the study's eligibility criteria. Consequently, their responses were not included in the analysis. There were 28 participants who did not answer any survey questions, 14 participants who completed only the demographic section of the survey and two participants who completed less than five questions on the 58 items of the outcome measures of the survey. These were all excluded from the analysis. Subsequently, the final sample included in the analysis were 466 of the initial 568.

A total of 208 participants (37% of participants) completed the surveys: one immediately after the intervention and two months post the intervention. 25 surveys responses in this dataset were blank and therefore omitted from the post intervention analysis. Due to a glitch in the way that the Future Learn platform assigned unique identifiers across the different time points, participants' post intervention surveys could only be identified by matching geographical location numbers, IP address of computers and completion dates across pre and post intervention surveys. There were also some malfunctions in survey administration as participants were in some cases mistakenly invited to complete the two months follow- up survey instead of the survey designed to be completed immediately after the intervention. Consequently, for the longitudinal element of the study excluded

cases of participants who had no matching geographical location numbers or IP addresses. Additionally, participants who had the same IP addresses and completion dates were excluded as their individual surveys could not be matched. This resulted in 70 participants' data for the analysis of the pre-post intervention survey. Moreover, the surveys for the post intervention and two months follow up were amalgamated due to low post intervention response rates and described difficulties in identifying participants post survey responses. Figure 1 shows a flow chart of participants at each stage of the study.

Figure 1. Flow Chart of participants at each stage of the study



Participant characteristics

As shown in Table 1, The MOOC was accessed from Africa, Americas, Asia, Europe Australia and Oceania. Most of the participants in both completer and baseline samples were female (86%, n = 464: 84%, n = 69), of white ethnicity (80.3%, n = 461: 85.5%, n = 69) from the general public (43.3%, n = 466: 42.9%, n = 70) with exposure to dementia prior to the MOOC (87.3%, n = 466: 85.7%, n = 70). The majority also had experience of personally caring for someone with dementia (65.35%, n = 404: 75%, n = 60). The mean age of participants was 44 years (SD = 16.16 [18 – 91]) for the baseline sample and 45.94 years (SD = 15.30 [21 – 91]) for the matched completers sample.

Table 2. Participants' demographic characteristics

	Baseline			Completers		
Sample Characteristic	**Total**	**N***	**%**	**Total**	**N***	**%**
Gender	464			**69**		
Male		57	12.3		10	14.5
Female		403	86.9		58	84.1
Non-binary		4	0.9		1	1.4
Participant type	466			**70**		
Member of the general public		202	43.3		30	42.9
Caregiver		81	17.4		14	20
Healthcare professional		183	39.3		26	37.1
Ethnicity	**461**			**69**		
Arab		5	1.1		0	0
Asian		47	10.2		6	8.7
Black (African or Caribbean)		28	6.1		1	1.4
Mixed/Multiple ethnic		11	2.4		3	4.3
White		370	80.3		59	85.5
Religion or Belief	**462**			**69**		
Yes		233	50.4		39	56.5
No		229	49.6		30	43.5
Educational level	**464**			**70**		
Primary and secondary		75	16.1		8	11.4
Higher education		351	75.7		58	82.8
Vocational training or apprenticeship		38	8.2		4	5.7
Prior dementia Exposure	**466**			**70**		
Yes		407	87.3		60	85.7
No		59	12.7		10	14.3
Prior dementia exposure	**404**			60		
Part of studies		126	31.19		6	10
Part of work		109	26.98		5	8.3
Voluntary work		61	15.1		1	1.7
Neighbour, friend, or family had dementia		46	11.39		3	5
Personal caring		264	65.35		45	75
Care Relationship	**260**			**46**		
Spouse /Partner		10	3.8		2	4.35
Parent		73	28.1		12	26.09
In law		17	6.5		4	8.70
Other family		81	31.2		13	28.26

Friend		13	5		2	4.35
Client at work		66	25.4		13	28.26
Prior MOOC experience	**464**			**70**		
Yes		12	2.6		1	1.4
No		452	97.4		69	98.6
Personal dementia care duration	N=237, M =44, SD = 51.18, [min = 1 – max = 360]			N=43, M =60.95, SD =68.17, [min =1, max = 360]		
Age	N= 459, M = 44, SD = 16.16, [min=18, max=91]			N= 69, M = 45.94, SD =15.30, [min=21, max=91]		
Religion or Belief Type	N = 230: Christian, Islam, Buddhism Hinduism Spiritualism, Interfaith Jewish, Sikh, Wicca/Paganism, Quaker, Bogomils			N = 28: Christian, Islam, Spiritualism, Sikh, Quaker, Bogomils		
Current Location	N = 463: Africa, Americas, Asia Australia and Oceania, Europe			N = 70: Africa, Americas, Asia, Australia and Oceania, Europe		
Nationality	British, Australian, Canadian, American (USA), Irish, Multinational: Bangladeshi-Canadian, British-German, British-Luxembourgish, British-Nigerian, Sri Lankan-British, Irish-German-Polish-Norwegian, Trinidadian-US citizen, Azerbaijani, Bangladeshi, Barbadian, Cameroonian, Chinese, Colombian, Croatian, Danish, Dominican, Dutch, Egyptian, Estonian, Filipino, French, German, Ghanaian, Greek, Hong Kong, Hungarian, Indian, Indonesian, Italian, Jordanian, Korean, Malaysian, Nepali, New Zealander, Nigerian, Norwegian, Pakistani, Polish, Portuguese, Singaporean, Slovakian, South African, Spanish, Sri Lankan, Sudanese, Swedish, Turkish, Ukrainian, Venezuelan, Vietnamese, Zambian, Zimbabwean			British, Australian, Irish, American, Canadian, Colombian, Estonian, Filipino, Indian, Italian, Malaysian, New Zealander, Nigerian, Pakistani, polish and Venezuelan		

**Differences in n are due to missing data. Abbreviations: M, mean; SD, standard deviation; Min, the minimum score; Max, the maximum score.*

Baseline data results

Preliminary validation of the RDKQ scale

What is the internal consistency of the RDKQ?

A reliability analysis based upon the baseline sample (N = 466) carried out on the RDKQ demonstrated poor internal consistency. The overall value of the Cronbach's alpha for the 4 items (N = 466) was α = 0.35 which is considered to not be an acceptable reliability (Field, 2005) and suggests a poor internal consistency.

The item RDKQ 1 assessing “similarity between familial (fAD) and sporadic Alzheimer’s disease” symptoms showed a higher average score (M = 0.39, SD = 0.49) than the other items: RDKQ 2 - prominent and early symptoms in behavioural variant frontotemporal dementia (Bvft) (M = 0.09, SD = 0.28), RDKQ 3 - Key features of dementia with Lewy bodies (DLB) (M = 0.03, SD = 0.17) and RDKQ 4 - Unusual symptoms of posterior cortical atrophy (PCA) (M = 0.11, SD = 0.32).

The extent to which each question on the RDKQ taps into the less common forms of dementia knowledge being measured was examined. Items did not correlate well with the total questionnaire. They were relatively weak, unsatisfactory and all under r = 0.3. Table 2 displays the inter-item correlation matrix.

Table 3. Inter-item correlation matrix

Inter-Item Correlation Matrix				
	RDKQ1 FAD	RDKQ2 Bvft	RDKQ3 DLB	RDKQ4 PCA
RDKQ1 FAD	-			
RDKQ2-Bvft	.121	-		
RDKQ3- DLB	.068	.203	-	
RDKQ4- PCA	.218	.051	.163	-

It was found that deleting any of the scale items would not increase the Cronbach's alpha score as can be observed in Table 3. The deletion of an item would therefore not increase the level of reliability to recommended acceptable levels of 0.5 for a questionnaire with less than four items based on criteria outlined by Pallant (2013).

Table 4. Corrected item-total correlations and Cronbach´s alpha if item is excluded

Items	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
RDKQ1 FAD	.23	.27
RDKQ2-Bvft	.16	.31
RDKQ3- DLB	.20	.31
RDKQ4- PCA	.23	.23

What is the relationship between RDKQ and other measures?

A Spearman's one-tailed test was run to determine the correlation between scores on RDKQ and the other measures (ADQ, DKAS and STIG-MA scores). A weak, positive, and statistically significant correlation was observed between both RDKQ and DKAS scores ($r(408) = 0.32$, $p < 0.01$) and RDKQ and ADQ scores ($r(407) = 0.11$, $p = 0.02$) indicating that participants with more positive general dementia knowledge and attitudes were also more likely to have increased knowledge about the less common forms of dementia.

Further significant positive associations were demonstrated between RDKQ and ADQ subscale scores of personhood ($r(417) = 0.12$, $p < 0.01$) and hope ($r(412) =$, $p = 0.03$) as well as RDKQ and DKAS subscales scores: causes and characteristics ($r(417) = 0.32$, $p < 0.000$); Communication and behaviour ($r(417) = 0.28$, $p < 0.000$); care considerations ($r(417) = 0.19$, $p < 0.000$); and risk and health promotion ($r(416) = 0.29$, $p < 0.000$). The association between the RDKQ and

STIG-MA scores were non-significant (r = 0.04, p = 0.43). Correlations between scores on the RDKQ and ADQ, DKAS and STIG-MA scores are available in appendix 12.

Given the poor internal consistency of this measure these results should be interpreted with caution.

Secondary aim of this study

Baseline rare dementia knowledge: What do participants know about rare forms of dementia and what factors may be associated with knowledge?

The majority of participants' responses to the RDKQ were incorrect. The frequency distribution of participants' responses are presented in table 4. Only 3 % of participants correctly identified Dementia with Lewy bodies (DLB) symptoms while 8% correctly identified behavioural variant frontotemporal dementia (Bvft) symptoms. The best performance was observed on the 39.2% of participants who correctly differentiated between familial and sporadic Alzheimer's disease symptoms followed by 11.1% of participants who correctly identified Posterior cortical atrophy (PCA) symptoms.

Table 5. Frequency distribution of participants' RDKQ responses

Questions	N*	Correct		Incorrect	
		N	%	n	%
Familial and sporadic Alzheimer's disease symptoms	429	168	39.2	261	60.8
Behavioural variant frontotemporal dementia (Bvft) symptoms	431	35	8.4	395	91.6
Dementia with Lewy bodies (DLB) symptoms	433	14	2.8	421	97.2
Posterior cortical atrophy (PCA) symptoms	431	48	11.1	383	88.9

**Differences in n are due to missing data*

Kruskal-Wallis test results indicated that rare dementia knowledge varied across participant type and educational levels. HCP had a mean rank score of 245.60 and scored significantly higher than those caring for PLWD who had a mean rank score of 87.1 ($\chi^2(2) = - 58.49$, $p < .001$) and members of the general public with mean rank score of 190.02 ($\chi^2(2) = 55.57$, $p < .001$). Participants who completed vocational training or apprenticeship significantly scored lower (mean rank = 168.05) than those who completed college or university (mean rank of 222.48) ($\chi^2(2) = -54.427$, $p = 0.013$). These college/university completers also significantly scored higher than those who completed secondary or high school (mean rank of 183.37) ($\chi^2(2) = - 39.108$, $p = 0.024$). No other variations across sociodemographic characteristics were found.

General dementia knowledge, attitudes, and stigma baseline scores

DKAS scores

The mean score on the DKAS was 18.02 (SD = 8.05) (45% of responses articulated as correct). Results demonstrated knowledge gaps with the least accurate responses relating to dementia risk and health promotion (M= 4, SD = 2.29), seconded by communication and behaviour (M = 4.52, SD = 2.84) and then causes and characteristics (M = 4.75, SD = 2.95) subscales. The most accurate responses were observed on the care considerations subscale (4.78, SD = 2.43). Kruskal-Wallis test indicated significant differences in DKAS scores across educational levels, ethnicity, and participant type. Health care professionals scored higher than members of the general public ($\chi^2(2) = 66.85$, $p < .001$). Participants that completed college or university scored higher than secondary and high school completers ($\chi^2(2) = -59.940$, $p = 0.001$). Participants who identified themselves as Black African or Caribbean participants scored lower than those who identified as White participants($\chi^2(4) = - 88.456$, $p = 0.003$). Further analysis indicated care

duration and DKAS scores were both positively correlated r (208) = .16, p = .01, at the 0.05 level (two-tailed). Lastly, Mann-Whitney U test revealed that participants who reported exposure to dementia prior to the MOOC participation significantly scored higher than participants with no dementia exposure (U = 6187.000, p < .001).

ADQ scores

The overall mean ADQ scores were (M = 75.62, SD = 7.53) suggesting positive attitudes towards dementia with scores on the subscale reflecting more person-centred (M = 48.71, SD = 4.42) than hopeful (M = 26.92 (SD = 4.77) attitudes towards dementia. Increased ADQ scores were associated with being a health care professional ($\chi^2(2) = 29.48$, p < .001), being white ($\chi^2(4) = - 82.647$, *p < .001*), higher levels of education ($\chi^2(2) = - 41.416$, *p* = 0.037), having a religion or faith (U = 28018.500, p = .006). Moreover, dementia exposure prior to participating in the MOOC was also related to higher ADQ scores (U = 6739.000, p < .001). Further analysis indicated care duration and ADQ scores were both positively correlated, r (222) = .15, p = .02 at the 0.05 level (two-tailed).

STIG-MA scores

The overall mean score on the STIG-MA (M = 10.30, SD = 4.41) was which according to the measure implies moderate levels of dementia related stigma. The different mean scores on the STIG-MA subscales showed preliminarily suggested that participants held more stigmatised views in relation to the emotional impact (M = 3.95, SD = 1.72) and fear of exclusion (M = 3.64, SD = 2.07) than the reluctance to disclose (M = 1.16, SD = 1.21) and courtesy stigma (M = 0.76, SD = 0.88). Loss of family support (M = 0.79, SD = 1. 22) scored the lowest scores across all subscales thus demonstrating the least perceived levels of stigma. All Kruskal - Wallis and Mann-Whitney U tests were not significant and therefore indicating stigma scores did not vary due to social-demographic differences.

Relationship between the DKAS scores, RDKQ scores, ADQ scores and STIG-MA scores

The study results demonstrated relationships between general dementia knowledge, rare dementia knowledge, and attitudes. Spearman's correlation found significant positive associations between RDKQ and ADQ scores ($r(407) = .11$, $p = .02$), at the 0.05 level (two-tailed); RDKQ and DKAS scores $r(408) = .32$, $p < .01$, at the 0.01 level (two-tailed); ADQ and DKAS scores $r(402) = .40$, $p < .00$, at the 0.01 level (two-tailed).

The frequency distribution of participants' responses to overall baseline measures are available in appendix 13.

Primary aim of this study

Changes in pre-post intervention scores: Is there change in dementia knowledge, attitudes, and stigma outcome pre and post The Many Faces of Dementia MOOC?

Hypothesis one predicted that compared to pre intervention, participants would show increased knowledge, increased positive attitudes and reduced stigma post intervention. A summary of the mean scores is presented in Table 6.

Table 6. Mean pre, post and change in scores for completers sample

Measures	Pre-score			Post-score			Change score	Effect size (r)
	n	Mean	SD	n	Mean	SD	%	
DKAS	64	17.95	8.94	70	20.99	7.52	17	0.37
▪ **Causes and characteristics**	68	4.94	3.04	70	6.09	2.83	23	0.43
▪ **Communication and behaviour**	69	4.84	3.07	70	4.91	2.42	2	-
▪ **Care considerations**	68	4.44	2.50	70	5.44	2.34	23	0.33
▪ **Risks and health promotion**	67	4.11	2.49	70	4.54	2.34	11	-
RDKQ	69	0.68	0.92	70	2.04	1.23	200	0.51
▪ **fAD**	70	0.41	0.61	70	0.50	0.49	22	0.21
▪ **Bvft**	70	0.10	0.26	70	0.30	0.44	200	0.22
▪ **DLB**	70	0.06	0.43	70	0.23	0.50	283	0.41
▪ **PCA**	69	0.10	0.74	70	0.34	0.44	240	0.56
ADQ	68	78.57	7.23	70	77.59	6.75	-1	-
▪ **Hope**	68	28.49	4.40	70	28.07	4.16	-2	-
▪ **Personhood**	70	49.97	4.55	70	49.57	3.95	-1	-
STIG-MA	68	9.63	3.49	69	10.09	3.71	5	-
▪ **Reluctance to disclose**	70	1.04	1.10	70	1.23	1.13	18	-
▪ **Emotional impact**	70	3.74	1.88	70	3.64	1.70	-3	-
▪ **Fear of exclusion**	70	3.47	1.87	70	3.83	1.90	10	-
▪ **Courtesy stigma**	69	0.65	0.80	69	0.72	0.91	11	-
▪ **Loss of family support**	68	1.03	1.08	69	0.62	1.11	-40	-

**Differences in n are due to missing data*

Wilcoxon signed rank tests was used to assess the differences between pre and post RDKQ scores whose data was not normally distributed while t- tests were used for DKAS, ADQ and STIG-MA scores.

Dementia knowledge

Rare dementia knowledge: Wilcoxon signed rank test results showed RDKQ scores were significantly higher post intervention (Md = 2, n = 70) when compared to pre- intervention scores (Md = 0, n = 69), z = -6.03, p = 0.000, with a strong effect

size of r =0.51. The 4 RDKQ items also showed a significant difference in scores. For the RDKQ1-FAD and RDKQ4- PCA items, scores significantly increased from Md = 0 to Md = 1 for both items respectively: z = -2.48, p = 0.000, r = 0.21; z = -6.63, p = 0.000, r = 0.56. The results for the other two questions were RDKQ2-Bvft z = -2.57, p = 0.008, r = 0.22 and RDKQ3- DLB z = -4.91, p = 0.000, r = 0.41 with the median score of 0.00 remaining the same before and after the intervention.

*General dementia knowledge***:** DKAS scores on the paired samples T- test revealed that the overall DKAS scores following intervention (M = 17.97, SD = 8.94) when compared to before intervention (M = 21.06, SD = 7.32) were significantly higher t (63) = -2.96, p = 0.004 with a moderate effect size of 0.37. For the DKAS subscales, the scores prior to the intervention were Causes and characteristics (M = 4.94, SD = 3.04), Communication and behaviour (M = 4.84, SD = 3.08), Care considerations (M = 4.44, SD = 2.51) Risks and health promotion (M = 4.10, SD = 2.49) and increased to Causes and characteristics (M = 6.15, SD = 2.85) Communication and behaviour (M = 4.96, SD = 2.41), Care considerations (M = 5.40, SD = 2.33), and Risks and health promotion (M = 4.59, SD = 2.36). These differences were according to the results with Bonferroni adjustments which were significant for Causes and characteristics (t (67) = - 3.55, p = 0.001, r =0.43) and Care considerations (t (67) = -2.75, p = 0.008, r = 0.33) but not significant for Communication and behaviour (t (68) = -0.35, p = 0.72) or Risks and health promotion (t (66) = -1.42, p = 0.16) scores on the DKAS subscales.

Attitudes

The paired sample T- test conducted to compare differences between ADQ scores before (M = 78.57, SD = 7.23) and after the intervention (M = 77.72, SD = 6.80) yielded a non-significant result was not significant (t (67) = -1.065, p =0.291). Moreover, differences in the ADQ subscales before (M = 28.49, SD = 4.40 for Hope

and M = 49.97, SD = 4.56 for Personhood) and after (M = 28.07, SD = 4.19 for Hope and M = 49.57, SD = 3.95 for Personhood) the intervention were also not significant (t (67) = 0.84, p =0.40 for Hope and t (69) = 0.72, p =0.47 for Personhood).

Stigma

Similarly, paired samples T- test results were not significant for the overall change in STIG-MA scores (t (67) = -0.95, p = 0.35) and its subscales of Reluctant to disclose (t (69) = -1.02, p=0.31), Fear of exclusion (t (69) = -1.37, p = 0.176), Emotional impact (t (69) = 0.38, p = 0.71), and Courtesy stigma (t (68) = - 0.60, p = 0.55). The results for the Loss of family subscale were significant without Bonferroni adjustment (t (67) = 2.39, p = 0.2).

These findings offer support for the hypothesis that both rare and general dementia knowledge improved over the course of the intervention. However, contrary to the hypothesis stigma and attitudes did not improve.

Discussion

The study sought to explore public knowledge, attitudes, and stigma in the context of the less common forms of dementia and to examine changes to dementia knowledge, attitudes, and stigma associated with completing TMFD-MOOC. The hypothesis was that participants would show increased knowledge, increased positive attitudes and reduced stigma post intervention compared to before TMFD-MOOC participation. Public rare dementia related knowledge, attitudes, and stigma have formerly not been examined and no specific rare dementia knowledge, scales exist. Consequently, this study also conducted an exploration of the internal consistency and convergent validity of a rare dementia knowledge questionnaire (RDKQ), designed by the authors to measure rare dementia knowledge among the general public and associations of this scale with demographic indices. No specific hypothesis were offered for these aims as these aspects of the study were largely exploratory.

Is the RDKQ a suitable measure for public rare dementia knowledge?

The Cronbach alpha score did not indicate a good internal consistency for the baseline sample (RDKQ $\alpha = 0.35$) suggesting the scale may not reliably measure rare dementia knowledge. One possible reason for this is that rare dementia knowledge does not represent a unidimensional construct. Less common forms of dementia measured using the RDKQ, are a complex set of syndromes with each dementia type varying in terms of symptoms, mechanism, and outcomes. Because of this complexity, and further knowledge domain specifics about those various rarer dementia syndromes, the RDKQ may not be a suitable measure. Perhaps different measures to measure a unidimensional construct knowledge of each of the less common forms of dementia would be more appropriate. Unfortunately, no empirical study results were available for comparison as previous

research about public knowledge and on scales measuring the less common forms of dementia among the general, is scarce. Only one study on the development of a scale to measure frontotemporal dementia knowledge was found. It was tailored for health care professionals (HCPs) and carers, and contrary to this study's findings, Wynn & Carpenter (2020) reported good internal consistency and split-half reliability for its 18-item Frontotemporal Dementia Knowledge Scale (FTDKS). Future evaluations of TMFD-MOOC might wish to use this scale for comparison, analysis of convergent validity and further development of other dementia scales.

Although internal consistency was poor, convergent validity was tentatively investigated, with results in support of the hypothesis that there would be positive correlations between rare and common dementia knowledge. Specifically, the results regarding the relationship between RDKQ and other measures demonstrated weak positive correlations between the knowledge scales as well as the knowledge and attitudes scales but not the stigma scales. These findings are similar to Wynn and Carpenter's (2020) who reported a modest overlap between the FTDKS and the DKAS scales but not crystallised intelligence, measured using the Shipley Institute of Living Scale. The researchers hypothesised that their reported lack of convergent validity between the frontotemporal dementia knowledge and crystallised intelligence may have been because the measures constructs were less related. Possible explanations for the lack of association between the RDKQ and STIG-MA scales could be due to either the scale's lack of internal consistency, a general lack of relationship between dementia knowledge and stigma or a lack of relationship between rare dementia knowledge and common dementia stigma. These explanations reflect the complex nature of interpreting construct validity with reasons which could include a combination of various factors relating to the internal validity of the scale or study's weaknesses as described by Schepers and colleagues (2012).

Public dementia related knowledge, attitudes, and stigma

Secondly, this study examined what an international public sample knows about general and rare dementia as well as their attitudes and stigma related to dementia. The evidence in this study suggests that rare dementia knowledge was poor among the public represented in this international sample, although results must be treated with caution given the poor internal consistency of the measure. Most of the respondents clearly showed considerable gaps in their knowledge. The mean rare dementia scores were 0.62 (SD = 0.78). However, perhaps individual item findings are more meaningful given the lack of internal consistency of the full measure. Only 39.2% of 429 participants correctly distinguished familial Alzheimer's disease symptoms from Alzheimer's disease 8.4 % of 431 participants correctly identified the symptoms of Behavioural variant frontotemporal dementia (Bvft), 2.8 % of the 433 participants correctly identified the symptoms of Dementia with Lewy bodies (DLB) symptoms and 11. 1 % of 431 participants identified Posterior cortical atrophy (PCA) symptoms correctly. HCPs scored significantly higher than caregivers and the general members of the population. No previous studies on the public's knowledge about rare forms of dementia were found in the literature search and therefore comparison could not be made. Additional research is required to establish what the public know about the less common forms of dementia, particularly given the present findings about the measurement properties of the RDKQ. A potential explanation for this study's findings is that they reflect the existing poor to moderate levels of general dementia knowledge within the public. This would also be consistent with the persistent nature of these misconceptions which has been reported in the literature (Cations et al., 2019).

The overall knowledge about general dementia was low, although relatively higher than the rare dementia knowledge. Findings of this study are in line with previous population studies reporting insufficient levels of dementia knowledge in

Lebanon (Hamieh et al., 2019), Japan (Arai et al., 2018), Ireland (McManus and Devine, 2011), Denmark (Nielsen and Waldemar, 2016), South Korea (Seo et al., 2015), and Singapore (Tan et al., 2012). In the present study, respondents were most knowledgeable about care considerations, followed secondly by causes and characteristics and then by communication and behaviour. Interestingly, knowledge about risk and health promotion had the lowest score. These findings are replicated across other prior population studies that found relatively good knowledge of dementia in general but a lack of knowledge about risk factors in dementia as found in research samples across Ireland (Rosato et al., 2019), Germany (Lüdecke et al., 2016), China (Zheng et al., 2020), Australia (Smith eta al., 2014), and Cuba (Broche-Pérez et al., 2021). In the present study, better dementia knowledge was related to education, being a HCP and of a white ethnicity. This is in line with previous studies, which have found that previous dementia exposure either through training, personal or professional care or contact with PLWD, higher social class, higher education, being younger, residing in an urban area are all factors related to higher dementia knowledge (Glynn et al., 2017; Rosato et al., 2019)

This study found that this sample generally have positive dementia attitudes despite the low levels of both general and rare dementia knowledge. Baseline attitudes relating to the development of more person-centred attitudes towards dementia personhood were higher than those related to sense of hope for people living with dementia. Moreover, higher attitude scores were found to be related to being a HCP, higher level of education, being white, having a religion or belief and exposure to dementia prior to the MOOC participation through personal caring experiences at work or home environment. Similar findings are reported in previous studies (Wang et al., 2018; Phillipson et al., 2014) except for sex and age which were found to be unrelated to the attitude scores in this study.

Dementia related stigma in this international sample is in the moderate range, as indicated by the STIG-MA scale guidelines (M = 10.30, SD = 4. 41). Examination of mean scores suggest that participants' self-reported stigma had the strongest relationship to the emotional impact of dementia subscale, then fears surrounding exclusion followed by a reluctance to disclose a diagnosis, courtesy stigma and finally, loss of family support. It is possible that limited dementia knowledge including misconceptions about dementia may influence stigma. For example, the misconception that all PLWD become aggressive could be the information used to decide to avoid social interactions with them. This could reduce their connection with others, leaving them isolated and thus negatively impacting the quality of their lives. For some and not all PLWD depending on numerous factors and related to the stage of the condition might have challenges making sense of the world around them or verbally communicating their needs and as a consequence the frustration of the experience, they might understandably respond in an angrily manner (Müller-Spahn, 2003). Understanding that the PLWD's behaviour is linked to experiences of distress might elicit empathy and general positive response to the PLWD. A systematic review by Herrmann and colleagues (2018) reported that being younger in age, limited contact with PLWD and limited knowledge of dementia were all are related to higher levels of stigma. Contrarily to this systematic review, no associations between stigma and the demographic factors were identified in the present study

Changes in dementia related knowledge, attitudes and stigma following TMFOD MOOC

Changes in dementia related knowledge, attitudes and stigma following TMFD MOOC revealed that the mean scores for general and rarer dementia knowledge as well as rare dementia items specifically related to FAD and PCA were significantly higher post intervention. Mean scores for BvFTD or DLB did increase

though this was not statistically significant. It is possible that the TMFDMOOC was more effective at educating the sample about FAD and PCA dementia than DLB and PCA dementia. Another possible explanation might be the reliability of the RDKQ. Whatever the reasons, more research is needed. These results generally support findings from previous studies (Eccleston et al., 2019; Prins et al., 2019) which have demonstrated similar results with regards to increased knowledge when evaluating the learning outcomes of an educational interventions about general dementia.

There was no significant difference between the average ADQ score before the TMFOD MOOC than after the TMFOD MOOC. A further non-significant change in dementia related attitudes was observed on the ADQ subscales related to sense of hope for people living with dementia and development of more person-centred attitudes towards dementia personhood. These results were unable to show positive trends which may support existing research but not significant enough to confidently conclude this. Prins and Colleagues (2019) in the Netherlands found improved attitudes following completion of the free online media production aimed for raising public awareness and enhancing dementia knowledge and understanding. No other previous studies have explored changes in attitudes following online dementia learning among the general population.

Similar to the findings of changes in attitudes, no significant difference was found between the average STIG-MA score before the TMFOD MOOC than after the TMFOD MOOC. No statistically significant improvements in stigma leaves room for the idea that extraneous variable relating to study design may be responsible.

Overall, the results demonstrate that TMFOD MOOC was effective in improving both general and rare dementia knowledge with no significant change in attitudes nor stigma related to dementia found. These mixed results are in line with

Cheston and colleagues' (2019) views about the lack of clarity surrounding the formation of attitudes towards PLWD and questions about whether indeed education impacts attitudes or stigma. This lack of correspondence between knowledge attitudes and stigma is also supported by a study by Chang and Hsu (2021) where they examined the relationship between knowledge and attitudes and found that dementia knowledge among a Taiwanese public were related to feelings of shame. This highlights that knowledge about the dementia may relate to feelings and attitudes towards dementia in a less tangible or predictable way. It is also possible that the most effective element of the TMFOD MOOC is its educational component, whereas changing attitudes or stigma was not targeted in the same way. However, increased contact with PLWD, either through work or personal experience has been reported to positively change attitudes (Cheston et al., 2019).

Lastly, the study design means it is not possible to infer causality between variables and it should be noted that the reported improvements in knowledge may not only be due to exposure to the TMFOD MOOC, but that perhaps other extraneous variables may have impacted the observed increased knowledge found in this study.

Strengths and limitations

To the best of author's knowledge, this is one of the first studies to evaluate the impact of education about the less common forms of dementia on knowledge, attitudes, and stigma. While positive links were made, it is important to note that there are some limitations to this study, which are outlined below.

Participants consisted of those who self-selected to learn about rare dementias and consented to the study. As such, they may be part of the population already concerned about rarer dementias. Additionally, participants were established internet users with internet connectivity and these factors may mean

that the sample was not necessarily representative of the general population. Moreover, the majority of participants self-reported previous exposure to dementia prior to the course as part of work, training or by knowing of a family member or friend with dementia. It is possible that these active information seeking participants hold more baseline knowledge about dementia compared to a purely random sample. Moreover, the overrepresentation of females and white participants mostly from Europe (69.5% of the 462 participants) is not representative of the heterogeneity of an international population. Only 10.6 % of 463 participants represented the lower- and middle-income countries and yet nearly 60% of 10 million people reported to develop dementia each year reside in these countries (Alzheimer's Disease International, 2019). Prince and colleagues (2015) report increasing dementia cases in LMICs are the reasons for the projected tripling of dementia cases globally. The convenience sampling method used, coupled with the small sample size and missing data may further limit the generalisation of results globally.

The inclusion of a valid and standardised rare dementia scale would have been advantageous for the probable accuracy and comparison of results with future study findings over time which according to Morgado and colleagues (2017) are benefits of standardised scales. The selected questions used to assess rare dementia knowledge were exploratory and given the poor internal consistency of the measure, further research, and development around this is needed.

The study design did not allow for the inference of any causal relationships between variables. It is possible that the changes in knowledge, scores observed may have been due to uncontrolled extraneous variables and learning unrelated to the MOOC and within participants' environment which may have affected the observed outcome. For example, some patients may have been interested in rare dementias prior to the study and therefore could have completed personal research

for more information. Furthermore, issues in carrying out the research meant that although intended, the current study could not allow for the examination of possible changes at three points in time (baseline, following intervention and two months follow up) and may have introduced bias into the results. The limited duration of the study was not sufficient to detect any longitudinal changes in stigma and attitude scores.

Lastly, the study did not assess any sociodemographic factors associated with changes to dementia knowledge, attitudes, and stigma and is therefore unable to examine how the MOOC might perform in a diverse cohort. Eccleston and colleagues' (2019) evaluation of the effectiveness of the Understanding Dementia MOOC to educate an international cohort reported a comprehensive increase in dementia knowledge independent of participants' sociodemographic differences following the Understanding Dementia MOOC. In this study, the magnitude of the differences in participants' dementia knowledge, attitudes, and stigma in relation to social demographic factors following the MOOC remain unknown and were not possible to assess due to sample size considerations. Future studies could include the analysis of associated demographic factors.

Future Research

These findings have implications for the development of training and education which are important in addressing barriers to dementia diagnosis, treatment, and support.

Existing dementia measures seem to have broad items measuring general forms of dementia rather than knowledge specific to the less common forms of dementia. There is a shortage of dementia scales measuring public dementia knowledge, attitudes, and stigma in general and even greater need for reliable and valid measures specific to the less common forms of dementia. This study highlights

the importance of specific and appropriate rarer dementias related knowledge and attitude tools for the general population. There is a need for ongoing scale refinement of the RDKQ as well as the development of other scales. RDKQ is not an exhaustive measure of the rare dementias. The scale only covers the rare dementias namely familial Alzheimer's disease, behavioural variant frontotemporal dementia, dementia with Lewy bodies and posterior cortical atrophy. Moreover, the complex nature of these dementias in relation to their different pathologies, symptoms, biological progression, and outcomes cannot adequately be summarised into a 4-item general rare dementia knowledge scale. Future research could investigate the scale's content coverage. As noted by Boateng and colleagues (2018), domain identification, item generation and consideration of content validity are essential to the scale development process. Therefore, future refinement of the RDKQ could involve a closer scrutiny of the RDKQ item development process guided by expert and general public opinion combined with a thorough literature review of the development of the RDKQ. The use of deductive and inductive approach such as this in the item development of any scale is considered best practice (Boateng, 2018). Lastly, a pilot study of the RDKQ with the general public as its target population would enable early identification of challenges with the scale prior to applying it at large. Future research could also develop a variety of rare dementia knowledge scales with subscales covering a range of domains such as prevalence, symptoms, progression of the condition, treatments, and support. The scales could be designed for clinical or research purposes and tailored to diverse groups with varying experiences of rare dementia. These groups include HCPs, carers, or general members of the public

Moreover, future studies could explore what aspects of the less common forms of dementia need to be covered in the educational components. Appropriate

tools with good psychometric properties are crucial for evaluating interventions and exploring these aspects of dementia further (Wynn & Carpenter, 2020).

Finally, as stated earlier, an inclusive and accepting society potentially leads to earlier access to care, greater support, understanding, acceptance, engagement and eventually a higher quality of life for people affected with dementia (Bradford et al., 2009; Herrmann et al., 2018; Werner, 2014; World Health Organisation, 2017). Therefore, improving the public's levels of knowledge, attitudes and stigma is critical to enhancing dementia diagnosis, treatment, and support. It is important to hold in mind that, as might be suggested by the findings of the current study, that the relationship between knowledge and its outcomes in relation to behavioural change is complex. It cannot be assumed that an increase in knowledge will translate into the improved attitude and stigma levels that is hoped will contribute to better early dementia diagnosis, treatment, or support. More research is needed to explore and understand this complexity and even more so for the rarer dementias, which are frequently misdiagnosed and unrecognised.

Conclusion

This study reported on the impact of online learning about the less common forms of dementia, on public dementia related knowledge, attitudes, and stigma, using a pre- post study design. The study identified poor general dementia knowledge attitudes and at baseline. It also identified increased general and rare dementia knowledge but no significant improvement in attitudes nor reduced stigma following the intervention. While these findings should be interpreted with caution, they suggest the potential usefulness of the MOOC in improving dementia knowledge and raise awareness for the need for greater education for all.

Additionally, the study also explored the internal consistency and convergent validity of the RDKQ for use with the general population and found that the measure

was not acceptable for the current sample. The findings highlight an existing issue about the scarcity of appropriate dementia tools and the need for measures that do not only contain broad items measuring general forms of dementia but the less common forms too.

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Part Three: Critical Appraisal

Introduction

This reflective account will summarise aspects of my research journey. I begin by briefly outlining the genesis to this project and process of reviewing of a body of literature relevant to rarer dementias. I then discuss some of the main challenges and limitations that arose in relation to the methodology, data collection and data analysis. I also highlight the ways in which I responded to the stated challenges and limitations. Finally, I conclude this critical appraisal with some personal reflections.

The genesis of this research project

I was introduced to the concept of rarer dementias when the opportunity to work on this project availed itself. I was introduced to the concept of rarer dementias when the opportunity to work on this project availed itself. I still have vivid exciting memories of the initial meetings with my supervisor, which I went into thinking I had a fairly good understanding of dementia. Despite not having any known clinical experience working with someone living with dementia or with their carer prior to training and throughout my clinical placements, dementia was a topic that had been mentioned at various points throughout my psychology education. Moreover, we had teaching on dementia on the DClinpsych Course. However, very quickly into the conversation about the potential research project, I realised that what I knew about

dementia was not all there was. Most of my dementia knowledge was in relation Alzheimer's and not the less common forms of dementia. For example, although I was familiar with the Alzheimer's disease which most commonly occurs in persons over the age of 65, I was not knowledgeable about the Alzheimer's diseases as described by Brotherhood and colleagues (2020) occurring in persons under the age of 65. My limited knowledge mirrored literature reports of insufficient dementia knowledge among health care professionals (Foley eta al., 2017; Annear, 2020) or general public (Cahill et al., 2015; Cations et al., 2018) as well as reports highlighting the often under recognition of rarer dementias and the consequences of living with these dementia types for the people diagnosed with them and their carers (Crutch et al., 2018). This made me consider the implications of this lack of knowledge in my position as reported in the literature can result in difficulties in detecting early signs of dementia which may influence the diagnosis and possibly management of dementia that is reported globally (World Health Organisation, 2006). I believe it can be so easy to distance oneself from the literature and statistics however in my role as a general member of the public or psychologist, myself, or someone I know, could develop dementia, or I may have contact with people living with dementia in health, social care, or community settings from the point of diagnosis to end-of-life care. How I respond to dementia based on my knowledge and attitudes towards dementia can have a positive or negative effect on dementia care and support. These levels of insufficient dementia knowledge and their implications on dementia care and support are even worse for the less common forms of dementia.

Based on the above and upon reflection, I may have had interactions with undiagnosed people living with dementia or their families prior to my training through my clinical and research work in Zambia and South Africa. Interestingly, some of my research work in Zambia was about the development of the Bilingual Aphasia Test (BAT): a widely used clinical and research measure used to investigate language

difficulties in people who are bilingual (Paradis, 2011). The measure as highlighted by Paradis (2011), can be used in relation to any condition resulting in language difficulties including developmental language disorders, multiple sclerosis, mild cognitive impairment, and various dementias such as Alzheimer's, Parkinson's, and vascular dementia. My role in this research project involved administering this measure to the research participants. Some of the symptoms I observed included word finding problems, difficulties with repeating words or sentences and using made up words that are not real words which are symptoms of progressive aphasia (PPA) (Gupta et al., 2009). It is possible that some of these participants on this project may have had PPA. I reflect on this with caution as it is important to make the distinction between primary progressive aphasia (PPA) the neurodegenerative condition (Gupta et al., 2009) rather than aphasia as a result of brain injury or a stroke (Paradis., 2011). I will never know for sure who had or did not have dementia; however, I think the possibilities are high as the literature indicates that the majority of people living with dementia live in low- and middle-income countries (Salcher-Konrad et al., 2019) and account for 60% of the estimated 50 million people with dementia globally, and that by 2050 this will rise to 71% (Alzheimer Disease International, 2020).

It is against this backdrop that I found myself interested in learning more. My limited understanding of rarer dementias sparked a curiosity that led me to want to investigate this topic further. Moreover, I found that working on this piece of work (to evaluate the effects of a rare dementia online course) as part of the bigger study of Rare Dementia Support (RDS) Impact study. The impact study aims to investigate multicomponent support for rare dementias consisting of health economic analyses, development of theories, innovative measures, and support interventions methods (Brotherhood et al., 2020). One of the biggest perks was that the study's ethical approval had already been granted. I would simply apply for an amendment to conduct the study which I believe most researchers can agree is much easier than

an initial application for ethical approval. In addition to this, I enjoy and value working with a multidisciplinary team. So, the opportunity to be a part of the Impact project left me feeling grateful and excited.

Process of reviewing a body of literature relevant to rarer dementias

My review of the literature originally sought to understand what the public knew about rarer dementia as well as the status of rarer dementia related attitudes and stigma. To investigate this, I initially wanted to conduct a systematic review mainly because I had never conducted one and thought this would be a great opportunity to learn how to do it. I also had the preconceived notion that because literature indicates that systematic reviews provided a more unbiased review of the literatures compared to conceptual introduction review (Collins, & Fauser, 2005), they would always be better than conceptual introductions and therefore always the best option. Through supervision and initial searches of the topic, I began to understand that a systematic review may not have been the most suitable approach to understand the public's rare dementia related knowledge, attitudes, and stigma and that a conceptual introduction review might be more useful in this circumstance.

Firstly, data about public rare dementia knowledge, attitudes and stigma was lacking. It has been suggested that when conducting a conceptual introduction review to adopt a funnel shaped approach to the review of the literature by starting general, then becoming more specific to hone in on the research questions and hypothesis (Collins, & Fauser, 2005). I broadened my review by researching on the knowledge, attitudes, and stigma in relation to dementia in general before focusing on public dementia related knowledge, attitudes, and stigma before finally researching the topic in the context of rarer dementias. The conceptual introduction review approach also enabled me to condense some of the high-quality existing evidence from systematic reviews. I was also able to include evidence that was not only limited to academic databases hosting formal peer-reviewed articles. For

example, the World Alzheimer's reports and WHO publications found on their respective websites were useful as they provided me with the information about the descriptive nature of dementia and really explore dementia related knowledge, attitudes, and stigma. These reports were among the main articles that informed my research as they highlighted the gaps in the field. The 2019 World Alzheimer's report focused on attitudes towards dementia and highlighted the need for a strong dementia baseline which could be used to measure the efficacy of interventions as numerous initiatives but there is not enough evidence-based information on whether improvements and differences are being made (Alzheimer's Disease international, 2019). Another advantage of using the conceptual introduction approach was that it reduced the language bias which often occurs when conducting systematic reviews as most of the indexed articles are in English (Henry et al., 2018).

Overall, this experience taught me that the choice of a systematic review and conceptual introduction are not interchangeable and as Henry and colleagues (2018) so eloquently put it, "the chosen approach is based on what works best for the specific topic".

Reflection on some of the methodology

In this section, I explore my reflections concerning the design of the survey and will focus on the length, order, and difficulty of the items.

To measure knowledge, attitudes, and stigma, I had the Dementia Knowledge scale (DKAS) with 25 items, Rare Dementia Knowledge questions (RDKQ) with 4 items, Attitudes towards Dementia Questionnaire (ADQ) with 19 items and STIG-MA with 10 items resulting in a minimum of 58 items for participants to think about and complete each time 1(Baseline), 2 (immediately post intervention) and 3 (two months follow up) surveys. In hindsight I think the survey may have been lengthy. For example, survey 1, had 71 questions (58 measure items plus the 13 demographic questions). The length of the surveys might have negatively impacted participants' engagement. Additionally, The DKAS, ADQ and STIG-MA measures

each had items that made up 4, 2, and 5 subscales respectively. The subscales impacted my data analysis experience. It was tricky keeping track of these subscales and research questions when analysing the data. This called for the utmost focus on the task at hand and any distractions left me double checking my work to ensure I had not left out any items or made any errors.

Besides the quantity of the surveys, I also wondered about the order of the measures in the survey and its impact on a participant's engagement. The order was ADQ, DKAS, RDKQ and then STIG-MA measure and the data collected revealed that the majority of the missing data came from the STIG-MA questionnaire then RDKQ. In the raw baseline data captured on an Excel spreadsheet, there was a clear view of a drop in engagement as participants approached the last questionnaire. The ADQ was the most answered questionnaire. On reflection, ADQ as the first measure may have been appropriate when considering item difficulty as it has no right or wrong answer. On the other hand, RDKQ uses multiple choice questions requiring participants to choose the correct answer. The literature suggests that reliability and validity of any data collection and analysis procedure can be enhanced using well-drafted surveys (Regmi et al., 2016). Some participants can therefore be put off by an assessment and therefore disengage. Such reflections related to measures should be considered when designing the study. If I could go back in time, I would have preferred to focus the study on one domain: knowledge, attitudes, or stigma as standalone topics. This would have also afforded me the chance to investigate these topics, their measures and strategies surrounding survey designs in more depth.

Challenges that arose

I will now discuss some background information to provide context before highlighting the challenges that arose during the study and my response.

Firstly, it is important to mention that the study design was a longitudinal pre-, post- and two months follow up study over three runs which despite the disadvantage of no control group was meaningful as indicated in a systematic review by Herrmann and colleagues (2018) most dementia studies have been critiqued for not using this method. The study's surveys (baseline, immediately and two months follow up post intervention) were hosted on the Future Learn platform which would also use its software to create linkages that would enable me to identify any participant's completed baseline survey to their immediate and two months post intervention surveys. All surveys had the knowledge, attitudes, and stigma questionnaires. The differences were the demographic question in the baseline survey and MOOC usage questions in the immediate post intervention survey. The completed surveys were stored on the Qualtrics platform to which I accessed and periodically monitored to get a sense of participants' engagement with the study.

During one of my checks on the data collected during run 1, I noticed that some participants had completed survey 3 (two months follow up post intervention) rather than survey 2 (immediate post intervention). The challenge with completing the wrong survey would result in data from surveys 1 and 2 being captured incorrectly and MOOC usage missing data (the MOOC usage questions were only found in survey 2). Looking back, I cannot think of anything I could have done to avoid this challenge as I had no control over how the surveys were set up on Future Learn. This experience taught me that the research process is not always smooth, and we are reliant on third parties. Perhaps creating contingency plans could be a solution to this challenge. In my case, perhaps having an alternative source of gathering data would have been helpful.

The second challenge I faced occurred after all the data had been collected, exported from Qualtrics and was ready for analysis. A technical glitch with the platform that hosted the surveys meant that there was no way of linking participants answers from survey 1 to survey 2 or survey 3 completed questionnaires. This

discovery was distressing as I was deeply concerned that I had no valid data to analyse. Moral behind this: create linkages within the surveys as a backup rather than solely relying on a computer system. To address this unexpected challenge with the data, IP addresses and location from surveys 2 and 3 were matched against survey 1. The disadvantage with this solution was that some participants may have used different devices in different locations to access the survey resulting in possible multiple IP addresses and locations which could not be matched. However, the worldwide restriction on movement due to COVID-19 may have forced some participants to use the same device to access the survey. The matching process was tedious and unpleasant, but I was able to match 73 participants. A key insight gleaned from this was that the majority of participants were European and from the United Kingdom in particular. The UK was under strict lockdown during the data collection period. It is possible that other countries may have had less restrictions on movements when compared to the UK, which would have allowed them to access the survey on different devices and thus impact on my ability to accurately geo-track match them.

Attrition was another challenge. The rate of completion between baseline and post (immediately post and 2 months follow up) intervention was 36.7%. While I am unable to make conclusions on the reasons for this observation, attrition as indicated in the literature is not an uncommon experience when using online surveys during research (Young et al., 2006). A similar study evaluating the effects of a general dementia online course among an international cohort reported a completion rate of 42. 01 % (Eccleston at al., 2019). There is need to know more about ways to improve data completeness as the impact of missing data can invalidate study results (Young et al., 2006).

Due to the above-mentioned challenges, Survey 2 and 3 data were combined with the acknowledgement of this decision's impact on results which should be viewed with caution. I also acknowledged the reduced sample size

implications on this study's results. Moreover, the MOOC usage data was not considered for analysis, which was disappointing. I had hoped that data would have helped me investigate whether any changes in the knowledge, attitudes and stigma outcomes were characteristic of the intervention or participants' associated change in stigma, knowledge, and attitudes. I was particularly interested in the aspect of the MOOC usage relating to the amount of time spent assessing the intervention and whether that would positively be correlated with a reduction in stigma, increased knowledge or increased positive attitudes. There was missing information in the rest of data set two which was resolved following multiple discussions with my supervisor, consultation with an expert in statistics and extra reading and studying of the concept to gain a better understanding. During these challenging experiences, it was helpful and important to discuss, and solve these challenges as they arose with my supervisor.

Some other reflections on the data

I will discuss some of the study's data and their implications for future research. I was struck by the fifty participants below the ages of 18 whose data was excluded as they did not meet the eligibility criteria. I wondered about their interest in learning about rarer dementias and their decision to participate in the study. I wondered whether they had a friend, relative or parent living with a less common form of dementia or whether any of them were young carers. The consequence of living with a rarer dementia that occurred during midlife (below the age of 65), is that it not only impacts on work and finances but on family too (Collins et al., 2020; Giebel et al., 2021). Family might include young children. The participation of this under 18 population highlights implications for future researchers to explore this population's knowledge, attitudes, and stigma in relation to the less common forms of dementia.

Personal reflection

I undoubtedly experienced a roller coaster of emotions throughout this project. Some of my low points included late nights, working in isolation with no peers, and failed meetings. Joining and starting the project, working out an analysis on SPSS and completing part of the thesis were some of my high points and would not have been possible without the support from friends and family. My work was also severely impacted by the COVID-19 pandemic, and other personal matters. I really struggled with my cognition: mostly focus and retaining information. I can identify with Becker and colleagues' (2021) description of brain fog, and inattention that was experienced by many during the COVID-19 pandemic.

This research experience has modified my preconceptions about various aspects of research. My preconceived notions about literature reviews, data collection and analysis and conducting research in general have changed. I am a lot more open to critically thinking about various research approaches and how they suit the topic. These include lessons about the choice of a literature review which is driven by the topic rather than desire or popular method; that data can be messy rather than the neat complete datasets used during teaching, and that unexpected results are still useful results. I also now have a different perspective on statistics. I disliked statistics and just studied the bare minimum to pass my modules during my undergraduate degree. At doctorate level, I was forced to learn and apply my learning beyond passing a module or reading academic papers. My overall statistical skills have improved and the process of applying my learning has changed my mind. I no longer find statistics to be painstaking, although I am not in love with it either, I have a newfound appreciation for it. Other lessons learnt are that I not only have a more in-depth understanding of dementia but gained valuable insight into the rarer dementias too. I have truly gained a deeper understanding of the scientific process: an important aspect of my role as a clinician and researcher. Consequently, this motivates me to keep learning.

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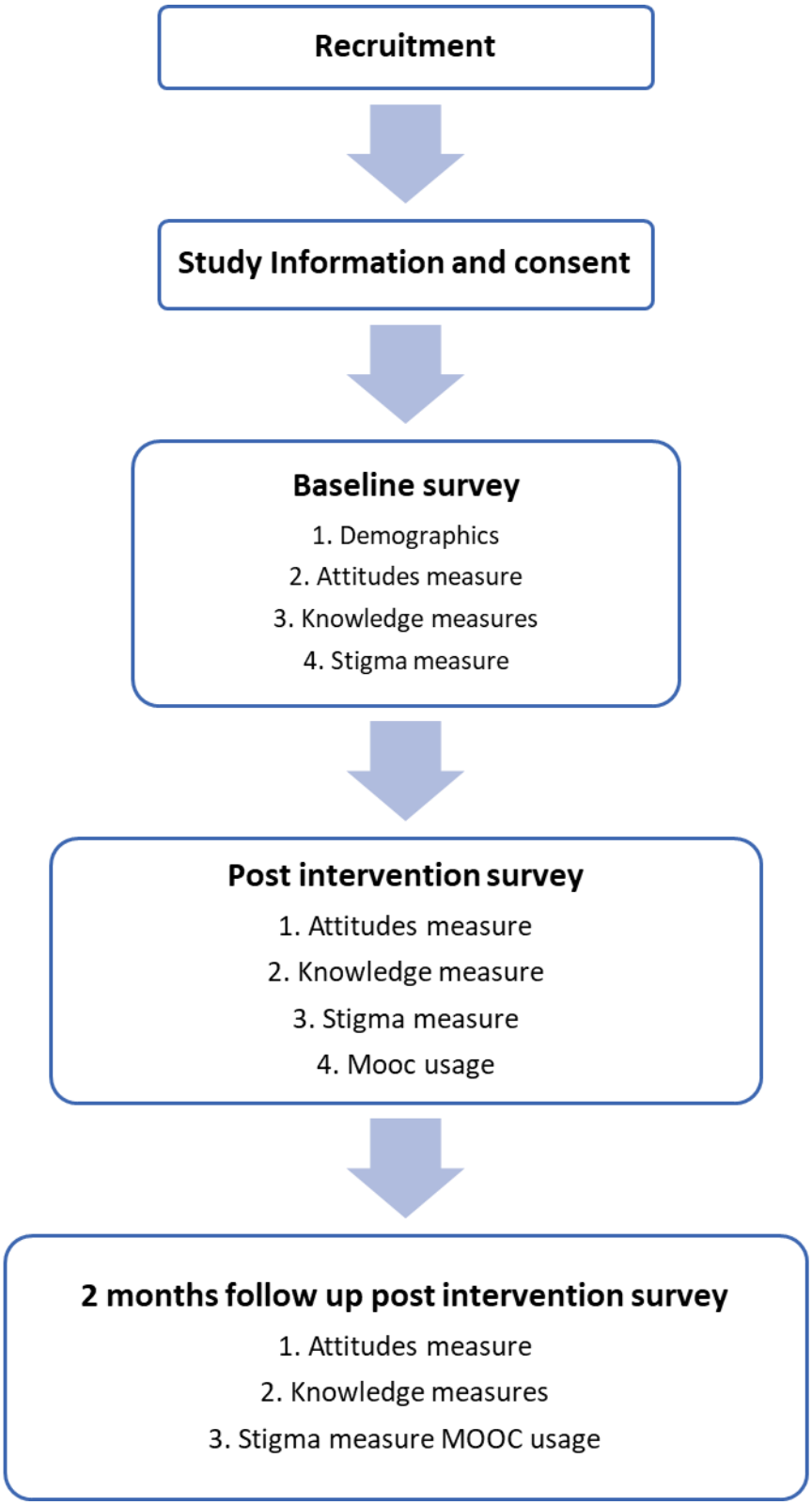
Appendices

Appendix 1: Recruitment flow chart



Appendix 2: Impact study's participant information sheet

APPENDIX I - PARTICIPANT INFORMATION SHEET

Participant Information Sheet
UCL Research Ethics Committee Approval ID Number: _____

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Rare Dementia Support Impact Study

Department: Department of Neurodegeneration, Institute of Neurology

You are being invited to take part in a research study which is running from 2019-2024, and aims to investigate the impact of rare dementia support groups. This study is funded by the Economic and Social Research Council and the National Institute for Health Research, with involvement from researchers based at University College London, Bangor University (Wales) and Nipissing University (Canada).

Before you decide it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

1. What is the project's purpose?
This is the first major study of the value of support groups for people living with or supporting someone with a rare form of dementia. With your help we are aiming to:

- Generate the world's first evidence base showing the critical role and significant added value of support groups in providing support for people affected by rare dementias throughout and beyond the course of their dementia;
- Develop an understanding of support group membership, social aspects, coping skills and understanding of a given diagnostic condition;
- Improve access to such support through innovative online services;
- Show that multicomponent support groups provide a valuable, continuous and cost-effective means of support which can be adopted in different locations and with different dementia communities.
- Generate new research tools and methods that can help us understand the impact of rare dementia support groups and online provisions

2. Why have I been chosen to participate in this study?
You have been chosen as you are either a person living with a diagnosis of a rare dementia, supporting someone living with a rare dementia, or working with people with rare dementias.

3. Do I have to take part?
It is entirely up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form or verbally indicate your consent. If you decide to take part you are free to withdraw at any time without giving a reason.

A decision to withdraw at any time, or a decision not to take part, will not affect your ability to continue to access the support groups or your clinical care. If you do decide to withdraw from the study, we will keep the data we have collected from you up until that point.

1

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4. What will be involved if I decide to take part?

This study is running from 2019-2024. As it is a large study, there are multiple parts to it, to help us achieve our aims.

The study parts include: 6-monthly interviews, filling out questionnaires and scales, helping us to develop our website, and designing measures. You do not have to participate in all aspects of the study, you can choose to take part in multiple parts of the study or just one if you would prefer. You can also change your mind at any time and opt out of any part of the study if you no longer wish to be involved.

If you would like to be involved in the interviews, you will be invited to have a conversation with one of our research team every 6 months between 2019 and 2024 (either face-to-face, over the telephone or on the computer). The research team will ask you questions about your lived experience with a rare dementia, and about the support you have or would like to experience.

If you decide to take part in other aspects of the study, you will be invited to complete feedback questionnaires about new areas we will be developing as part of this study; for example, our legal advice service or our new website.

You may also be invited to take part in creative activities where we will ask you to represent your responses by drawing, rather than by writing the answer down or telling us verbally.

Example Study Schedule:

- *1 Month*: contact by a member of the research team to arrange a time to have a two-hour interview (either face-to-face, over the telephone or on the computer according to your wishes). You will also receive some questionnaires (either online or in the post) to fill out before the interview takes place.
- *3 Months: (example)* fill out feedback questionnaire about legal advice service
- *6 Months:* follow-up interview
- *1 Year:* follow-up interview
- *1.3 Years: (example)* invited to respond to a questionnaire about the design of a new measure
- *1.5 Years:* follow-up interview
- *2 Years:* follow-up interview
- *2.5 Years:* follow-up interview
- *3 Years:* follow-up interview
- *3.5 Years:* follow-up interview
- *4 Years:* follow-up interview
- *4.5 Years:* follow-up interview
- *5 Years:* follow-up interview

Different parts of the research project will be taking place at different times over five years. For this reason, you may not be contacted immediately about all areas of the study that you have selected to take part in. Instead, if the researcher feels that it is appropriate, you will be contacted at the time that part of the project is taking place. If you no longer wish to take part in that area of the study, you are free to decline to participate or to withdraw at any point.

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We will make every effort to ensure that you are consistently contacted by the same researcher wherever possible, however as this is such a large study over a long period of time, there may be times when you are contacted by a different researcher from the team. If this occurs, the researcher will always explain where they are calling from, and what their affiliation with the research project is. Additionally, this study involves collaboration from three different universities (University College London, Bangor University in Wales and Nipissing University in Canada). Wherever possible, we will try to ensure that you are contacted by someone from the university located in your country of residence. However, there may be times when that is not possible and a researcher from one of the collaborating universities might make contact with you instead. They will always explain that they are calling on behalf of the research project and will make sure that you are happy to speak to them before proceeding.

5. Will I be recorded and how will the recorded media be used?

The audio and/or video recordings of your activities made during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission. We will not show anybody these recordings unless we are required to do so under instruction from a regulatory body during a research data audit.

If you are being interviewed over the phone or via video conference we will be using a system called GoToMeeting (https://www.gotomeeting.com/en-gb). You will be given a phone number to dial-in or sent a unique link to join the meeting, which will then be locked so no other users are able to attend. GoToMeeting uses end-to-end encryption, meaning that the only people that are able to watch and listen in on the meetings are those that have joined directly, which will be you and the researcher. Any personal information you provide during these interviews will subsequently be anonymised by the researcher when the interview is written up word-for-word, so that you cannot be identified by this information.

6. What are the possible disadvantages and risks of taking part?

There are no immediate risks involved if you choose to take part in this study. As we will be asking questions about your lived experience of a rare dementia, there may be some questions or topics that you find sensitive. You are free to not answer any questions that you feel are not appropriate or are too distressing. Additionally, if at any point during the study you feel distressed, you can take a break or stop taking part in the study completely.

7. What are the possible benefits of taking part?

Whilst there are no immediate benefits to you for participating in this study, it is hoped that this work will help you maximise your use and understanding of the types of support Rare Dementia Support can offer to people living with or supporting someone with a diagnosis of a rare dementia. It is also hoped that the knowledge gained from this research project will help to inform potential adaptations and interventions that will be beneficial to other people affected by dementia.

8. What if something goes wrong?

If you or your relatives have any concerns about the research study, in the first instance please raise a complaint to the Principal Researcher, Prof. Sebastian Crutch (email: s.crutch@ucl.ac.uk, telephone: 020 3448 3113). However if you feel your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk

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9. Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential in compliance with General Data Protection Regulation (GDPR) and other relevant legislation. You will not be able to be identified in any ensuing reports or publications.

For confidentiality during interviews, we ask that you try to avoid using names where possible (e.g. saying 'my husband' instead of using the person's name), however we do understand that this may not always be possible. The interview will be automatically transcribed (converted to text), the researcher will then manually go through the transcription to ensure that any identifiable information, such as names, are anonymised. Additionally, if you are sent an online questionnaire, you may be given the opportunity to write long answers in response to certain questions. We request that you kindly do not provide us with any personal information in these comments. If you do wish to refer to a particular person, e.g. a loved one, please refer to them in an anonymous form (e.g. Mr X).

10. Limits to confidentiality

Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached, such as any concerns about your safety or the safety of someone else. If this was the case we would inform you of any decisions that might limit your confidentiality. The only exception to this would be if there were a significant concern such that the researcher felt that the emergency services should be contacted.

11. What will happen to the results of the research project?

We hope to disseminate the results through appropriate research platforms, such as conferences, and publish the results in a peer-reviewed journal. You will not be identified in any reports or publications, however we may include quotes from the data collected in publications to justify the inclusion/exclusion of specific measures. If we include your comments, these will be presented in a way that would not include information which could identify you.

We will contact you to inform you about the results from the research. The data collected during the course of this project might be used for additional or subsequent research as the Rare Dementia Support group study develops.

12. Who is organising and funding the research?

This research is funded by the Economic and Social Research Council and the National Institute of Health Research. This research is being organised by UCL and project collaborators are based across UCL, Bangor University, Wales and Nipissing University in Canada.

13. Who has reviewed this study?

This study has been reviewed by the UCL Research Ethics Committee.

14. Data Protection Privacy Notice

Notice:

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The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk *(contact: Lee Shailer: Data Protection & Freedom of Information Officer)*
Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be 'public task'. The legal basis for holding and processing 'special category' data about you (which is any data about your or a loved one's health, and other sensitive information) is for 'scientific or historical research purposes'. Processing your personal and special category data would take place for specific research, training, quality control, and auditing purposes. You can provide your consent for this use of your data in this project by completing the consent form that has been provided to you.

Your data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

For the purposes of this study, data will be uploaded to UCL Data Safe Haven, a very secure system which may be accessed by RDS Impact study team members from: UCL, Bangor and Nipissing University (Canada) as part of this research collaboration. All researchers from collaborating institutions will have been appropriately trained and will have agreed to manage the research data in a secure way in accordance with UCL guidance and regulatory requirements.

After the study has ended in 2024, we will store the data on the UCL Data Safe Haven in line with UCL's Data Retention Schedule (20 years). Our funding body also requires us to anonymise the data and make it available to other researchers from different institutions. Please be assured that no personal details will be revealed as part of this process.

UK data protection law is regulated by the Information Commissioner's Office (ICO). If you are concerned about how your personal data is being processed you may wish to submit a complaint to them. Contact details, and details of data subject rights are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

14. Contact for further information

Name and Contact Details of Researcher:

Name: Claire Waddington
Email: c.waddington@ucl.ac.uk

Name and Contact Details of the Principal Researcher:
Name: Prof, Sebastian Crutch
Email: s.crutch@ucl.ac.uk

Telephone: 020 3448 3113

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Please keep a copy of this information sheet for your records.

Thank you for reading this information sheet and for considering to take part in this research study.

Appendix 3: Study Information

Evaluation of "The Many Faces of Dementia" massive open online course (MOOC) study

We are inviting everyone working through this course to complete an online questionnaire. The questionnaire forms part of a research study examining the effects of the Many Faces of Dementia online course on dementia knowledge and attitudes. Increasing knowledge and changing attitudes to dementia has been identified by Alzheimer's Disease International as very important in improving dementia care globally. Your feedback will help us to find out whether this course increases knowledge and changes attitudes to rarer dementias and can thus contribute to global dementia care.

The study will last for four months. We will ask you to complete confidential online questionnaires at three time points; before you begin the course, in the week or so after you complete the course and two months after course completion. Each of these three questionnaires will take approximately 15 minute to complete. You can complete each of the questionnaires one sitting, but if for any reason you need to stop, you can return to complete it within two week. However, it is important that you complete the first survey before you start the course. **Please note that as this survey is meant to be completed before the course the survey will close after XXXX date.**

This research study is part of the Rare Dementia Support Impact project. (http://www.raredementiasupport.org/research/) Information about this project including more detail about procedures, how we will keep your information secure and who to contact if you have questions can be found in this hyperlink to the document on the RDS digital platform: HERE.

Please tick this box to tell us you have read and understood the information provided to you about this study, and you are happy to complete this online questionnaire".

once they have ticked this box they can then automatically be directed to a page that says – thank you for agreeing to complete this online.

Appendix 4: Email Notifications sent to participants

A. Pre study notification about the study attached and sent in confirmatory email: 'for the first time we are evaluating whether this course has important effects on dementia knowledge and attitudes, we will be sending confidential online questionnaires to all course participants at the start of the course '
B. Invitation to participate in the study notification attached and sent in the welcome to week one email: 'We want to invite you (and all other course participants) to take part in an online questionnaire study examining the effects of the Many Faces of Dementia online course on dementia knowledge and attitudes. Increasing knowledge and changing attitudes to dementia has been identified by Alzheimer's Disease International as very important in improving dementia care globally. This study will help us to find out whether this course increases knowledge and changes attitudes to rarer dementias and can thus contribute to global dementia care".

C. Post intervention incitation to complete survey notification: you may remember that at the start of this course we asked you to fill in a survey we now want to invite you to fill in the post-course survey for this online questionnaire study"……. [we will use text from initial invite]

Baseline: Thank you for completing the survey. We will contact you once you complete the course.

Post Survey: Thank you for completing the survey, we will contact you two months after course completion.

Two months follow up: Thank you for completing the survey.

Appendix 5: Demographic questions

Instructions: Please read each question carefully, choose the most appropriate response and try to answer all questions to the best of your ability.

Question 1

Target group: Please select the option that best reflects your situation:

- Person living with dementia
- Caregiver for a person living with dementia
- Health care professional
- General public/no particular role

If health care professional: What type of health or care provider are you?

- Specialist doctor
- General/family doctor/physician
- Psychologist
- Pharmacist
- Nurse
- Community health worker/health educator
- Care home/residential or nursing home care assistant
- Other

If other: Please specify what type of health or care provider you are:

_____

How long have you been working as a healthcare practitioner or in social work? An approximate time (years and months) is fine:

_____

Question 2

Gender: Please select your gender

- Male
- Female
- Prefer not to say

Question 3

Age: How old are you? _____

Question 4

What is your ethnic group?

- Arab
- Asian
- Black / African / Caribbean
- Mixed / Multiple ethnic groups
- White
- Other ethnic group

If other, please specify ethic group: _____

Question 5

Do you have a religion or belief?

- Yes
- No

If yes, what religion, religious denomination or body do you belong to?

- Christian
- Islamic
- Jewish
- Buddhist
- Sikh
- Hindu
- Other (please specify in the next field)

If other please specify the church, denomination, or a religious community you belong to: __

Question 6

Country: In which country do you currently live?

_____

Question 7

Nationality: What is your country of legal nationality?

Question 8

Is English your first language?

- Yes
- No

If no, what is your first language? _____

Question 9

Education: What is the highest level of education you have completed?

- Less than primary/elementary school
- Primary/elementary school completed
- Secondary school completed
- High school (or equivalent) completed
- Vocational training or apprenticeship
- College/pre-university/university completed
- Post graduate degree completed

Question 10

Employment: What is your current employment situation (tick all that apply)?

- Full time paid employment

- Part time paid employment
- Self-employed
- Unpaid / voluntary work
- Looking for paid work, unemployed
- Unpaid care partner / carer / caregiver
- Retired
- Homemaker
- Student
- Illness/sick leave
- Other (please specify in the next field)

If other, please specify your current employment situation

_____

Question 11

Do you have any personal experience of caring for someone with dementia?

- Yes
- No

If yes, how long have you cared for someone living with dementia? An approximate time (years and months) is fine: _____

If yes, what is your relationship with the person that you care for?

- Spouse/partner
- Parent
- Sibling
- In-law
- Other family
- Friend
- Other (please specify in next field)

Question 12

Do you have any prior experience of dementia? (Tick all that apply)?

- None
- Part of studies
- Voluntary work
- Other (please specify in the next field)
- If other, please specify your prior experience of dementia: _____

Question 13

Have you ever completed The Many Faces of Dementia course?

- Yes
- No

Appendix 6: Dementia Knowledge Assessment scale (DKAS)

Instructions: The following questions will ask you about what you know about dementia. Please try and answer all questions to the best of your ability.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Most forms of dementia do not generally shorten a person's life.					
Blood vessel disease (vascular dementia) is the most common form of dementia.					
People can recover from the most common forms of dementia.					
Dementia is a normal part of the ageing process.					
Dementia does not result from physical changes to the brain.					
Planning for end-of-life care is generally not necessary following a diagnosis of dementia					
Alzheimer's disease is the most common form of dementia					
It is impossible to communicate with a person who has advanced dementia.					
A person experiencing advanced dementia will not generally respond to changes in their physical environment					
It is important to correct a person with dementia when they are confused					
People experiencing advanced dementia often communicate through body language					
Uncharacteristic behaviours in a person experiencing dementia are generally a response to unmet needs					
Medications are the most effective way of treating behavioural symptoms of dementia					
People experiencing dementia do not generally have problems making decisions					
Movement is generally affected in the later stages of dementia					
Difficulty eating and drinking generally occurs in the later stages of dementia					
People with advanced dementia may have difficulty speaking					
People experiencing dementia often have difficulty learning new skills					
Daily care for a person with advanced dementia is effective when it focuses on providing comfort					

Having high blood pressure increases a person's risk of developing dementia					
Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia					
Symptoms of depression can be mistaken for symptoms of dementia					
The sudden onset of cognitive problems is characteristic of common forms of dementia					
Exercise is generally beneficial for people experiencing dementia					
Early diagnosis of dementia does not generally improve quality of life for people experiencing the condition					

Appendix 7: Rare Dementia Knowledge Questions (RDKQ)

Questions
Q1: similarity between familial and sporadic Alzheimer's disease
They both typically start with symptoms of impaired recent episodic memory
They both often start before the age of 65
Don't know
Q2 Behavioural variant frontotemporal dementia (Bvft) symptoms
Loss of empathy
Difficulty finding the right word to say
Impairment in executive function (e.g. planning, decision making)
Develop
Hallucination
Do not know
Q3: Dementia with Lewy bodies (DLB) symptoms
Fluctuations
Depression
Hallucinations
Parkinsonism
Anxiety
Memory loss
Don't know
Q4 Posterior cortical atrophy (PCA) symptoms
Prolonged colour afterimages
Upside-down vision
Better reading of small than large text
Better vision for moving things than still things
Don't know

Appendix 8: Approaches to Dementia Questionnaire (ADQ)

Instructions: The following questions will ask you about your beliefs and attitudes about with people living with dementia. Please try to answer as honestly and accurately as you can. Press next when you are ready to continue.

	Strongly Agree	**Agree**	**Neither Agree nor Disagree**	**Disagree**	**Strongly Disagree**
It is important to have a very strict routine when working with people living with dementia					
People with dementia are very much like children					
There is no hope for people with dementia.					
People with dementia are unable to make decisions for them.					
It is important for people with dementia to have stimulating and enjoyable activities to occupy their time.					
People living with dementia are sick and need to be looked after.					
It is important for people with dementia to be given as much choice as possible in their daily lives.					
Nothing can be done for people with dementia, except for keeping them clean and comfortable					
People with dementia are more likely to be contented when treated with understanding and reassurance.					
Once dementia develops in a person, it is inevitable that they will go downhill.					
People with dementia need to feel respected, just like anybody else.					
Good dementia care involves caring for a person's psychological needs as well as their physical					
It is important not to become too attached to residents.					
It doesn't matter what you say to people with dementia because they forget it anyway.					
People with dementia often have good reasons for behaving as they do.					
Spending time with people with dementia can be very enjoyable.					

It is important to respond to people with dementia with empathy and understanding.					
There are a lot of things that people with dementia can do.					
People with dementia are just ordinary people who need special understanding to fulfil their needs					

Appendix 9: STIG-MA Questionnaire

Instructions: The following questions will ask you about what you think about dementia. Please try and answer all questions to the best of your ability.

If you were suffering from dementia:

	Yes	**Maybe**	**Do not know**	**No**
Would you rather people did not know about your disease?				
Would you tell the person you are closest to?				
Would you lose self-esteem because of the disease?				
Would this disease cause you shame or embarrassment?				
Would your neighbours, your colleagues have less respect for you?				
Do you think others would avoid you because of the disease?				
Would your neighbours, your colleagues have less esteem for your family?				
Do you think your wife/husband would stay with you and support you?				
Do you think people you know at work or friends would ask you to stay away, even if you were taking medication for the disease?				
Would your family give you their support right from the start?				

Appendix 10: Little MCAR Test Results

Variables	***Little' MCAR test results***
Baseline ADQ	$\chi 2(279\ N = 466) = 272.98,\ p = 0.59$
Baseline DKAS	$\chi 2(282\ N = 466) = 321.13,\ p = 0.05$
Baseline RDKQ	$\chi 2(43\ N = 466) = 41.785,\ p = 0.52$
Baseline STIG-MA	$\chi 2(13\ N = 466) = 9.40,\ p = 0.74$

Post intervention ADQ	$\chi 2(176\ N = 183) = 196.65,\ p = 0.14$
Post intervention DKAS	$\chi 2(72\ N = 183) = 95.644,\ p = 0.03$
Post intervention STIG-MA	$\chi 2(24\ N = 183) = 17.75,\ p = 0.82$
Post intervention RDKQ	$\chi 2(6\ N = 183) = 6.07,\ p = 0.42$
matched completers pre-intervention ADQ	$\chi 2(36\ N = 70) = 54.07,\ p = 0.027$
matched completers pre- intervention DKAS	$\chi 2(135\ N = 70) = 132.23,\ p = 0.147,$
matched completers pre- intervention RDKQ	$\chi 2(3\ N = 70) = 0.79,\ p = 0.85$
matched completers pre- intervention STIG-MA	$\chi 2(16\ N = 70) = 17.88,\ p = 0.33$
Post intervention had no missing data apart of the stigma variable $\chi 2(7\ N = 70) = 5.39,\ p = 0.61$	

**Differences in n are due to missing data*

Appendix 11: Correlation matrix comparing RDKQ scores to ADQ, DKAS and STIG-MA scores

Spearman's rho (1-tailed) Correlation matrix comparing RDKQ to ADQ, DKAS and STIG-MA subscales													
		1	2	3	4	5	6	7	8	9	10	11	12
1.Baseline RDKQ Total	Correlation Coefficient	1.000	-.069	.070	.043	-.006	-.004	.091*	.117**	.279**	.233**	.191**	.289**
	Sig. (1-tailed)	.	.081	.078	.190	.452	.469	.033	.008	.000	.000	.000	.000
	N	423	416	415	415	415	408	412	417	417	417	417	416
2.Baseline Reluctance to Disclose	Correlation Coefficient	-.069	1.000	.192**	.162**	.117**	.156**	-.030	-.075	-.031	-.006	-.067	.068
	Sig. (1-tailed)	.081	.	.000	.000	.008	.001	.274	.063	.260	.451	.084	.081
	N	416	427	426	426	426	419	415	420	421	421	421	420
3. Baseline Emotional Impact	Correlation Coefficient	.070	.192**	1.000	.289**	.171**	.063	-.030	-.010	.105*	.131**	.151**	.113*
	Sig. (1-tailed)	.078	.000	.	.000	.000	.099	.272	.422	.016	.004	.001	.010
	N	415	426	426	425	425	418	414	419	420	420	420	419
4. Baseline Fear of Exclusion	Correlation Coefficient	.043	.162**	.289**	1.000	.523**	.155**	-.055	-.079	.001	.133**	.052	.131**
	Sig. (1-tailed)	.190	.000	.000	.	.000	.001	.133	.052	.492	.003	.145	.004
	N	415	426	425	426	425	418	414	419	420	420	420	419
5. Baseline Courtesy Stigma	Correlation Coefficient	-.006	.117**	.171**	.523**	1.000	.179**	-.070	-.086*	-.142**	.021	-.021	-.006
	Sig. (1-tailed)	.452	.008	.000	.000	.	.000	.079	.039	.002	.333	.333	.448

	N	415	426	425	425	426	419	414	419	420	420	420	419
6. Baseline Loss of Family Support	Correlation Coefficient	-.004	.156**	.063	.155**	.179**	1.000	-.048	-.102*	-.110*	-.039	-.115**	-.012
	Sig. (1-tailed)	.469	.001	.099	.001	.000	.	.167	.019	.012	.211	.009	.403
	N	408	419	418	418	419	419	408	413	414	414	414	413
7. Baseline ADQ-Hope	Correlation Coefficient	.091*	-.030	-.030	-.055	-.070	-.048	1.000	.407**	.258**	.426**	-.132**	.225**
	Sig. (1-tailed)	.033	.274	.272	.133	.079	.167	.	.000	.000	.000	.004	.000
	N	412	415	414	414	414	408	452	445	416	416	416	415
8. Baseline ADQ-Personhood	Correlation Coefficient	.117**	-.075	-.010	-.079	-.086*	-.102*	.407**	1.000	.377**	.484**	.229**	.304**
	Sig. (1-tailed)	.008	.063	.422	.052	.039	.019	.000	.	.000	.000	.000	.000
	N	417	420	419	419	419	413	445	457	422	422	422	421
9. Baseline DKAS-Causes and Characteristics	Correlation Coefficient	.279**	-.031	.105*	.001	-.142**	-.110*	.258**	.377**	1.000	.489**	.429**	.518**
	Sig. (1-tailed)	.000	.260	.016	.492	.002	.012	.000	.000	.	.000	.000	.000
	N	417	421	420	420	420	414	416	422	428	425	424	424
10. Baseline DKAS-Communication and Behaviour	Correlation Coefficient	.233**	-.006	.131**	.133**	.021	-.039	.426**	.484**	.489**	1.000	.334**	.463**
	Sig. (1-tailed)	.000	.451	.004	.003	.333	.211	.000	.000	.000	.	.000	.000

	N	417	421	420	420	420	414	416	422	425	428	425	425
11. Baseline DKAS-Care considerations	Correlation Coefficient	.191**	-.067	.151**	.052	-.021	-.115**	-.132**	.229**	.429**	.334**	1.000	.353**
	Sig. (1-tailed)	.000	.084	.001	.145	.333	.009	.004	.000	.000	.000	.	.000
	N	417	421	420	420	420	414	416	422	424	425	428	424
12. Baseline DKAS-Risk and Health Promotion	Correlation Coefficient	.289**	.068	.113*	.131**	-.006	-.012	.225**	.304**	.518**	.463**	.353**	1.000
	Sig. (1-tailed)	.000	.081	.010	.004	.448	.403	.000	.000	.000	.000	.000	.
	N	416	420	419	419	419	413	415	421	424	425	424	427
*. Correlation is significant at the 0.05 level (1-tailed).													
**. Correlation is significant at the 0.01 level (1-tailed).													

Appendix 12: Frequency distribution of participants' responses

Appendix 12 a.: Frequency distribution of participants' RDKQ responses

Questions	N*	n	%	Responses
Q1: similarity between familial and sporadic Alzheimer's disease	**429**			
They both typically start with symptoms of impaired recent episodic memory		168	39.2	correct
They both often start before the age of 65		42	9.8	incorrect
Don't know		219	51	incorrect

Q2 Behavioural variant frontotemporal dementia (Bvft) symptoms	431			
Loss of empathy		162	15.6	correct
Difficulty finding the right word to say		188	18.1	incorrect
Impairment in executive function (e.g. planning, decision making)		227	21.8	correct
Develop		243	23.4	correct
Hallucination		86	8.3	incorrect
Do not know		134	12.9	incorrect
Q3: Dementia with Lewy bodies (DLB) symptoms	433			
Fluctuations		140	12.9	Correct
Depression		123	11.3	Incorrect
Hallucinations		200	18.4	Correct
Parkinsonism		154	14.2	Correct
Anxiety		131	12.1	Incorrect
Memory loss		182	16.7	Incorrect
Don't know		157	14.4	Incorrect
Q4 Posterior cortical atrophy (PCA) symptoms	431			
Prolonged colour afterimages		30	7.0	correct
Upside-down vision		24	5.6	incorrect
Better reading of small than large text		18	4.2	Correct
Better vision for moving things than still things		40	9.3	incorrect
Don't know		319	74	correct

**Differences in n are due to missing data*

Appendix 12 b.: Frequency distribution of for participant's DKAS responses

Statements about dementia	Response scale						
	N*	Incorrect		Partly correct		Correct	
		n	%	n	%	n	%
1.Most forms of dementia do not generally shorten a person's life. (False)	433	299	69.1	117	27	17	3.9
2. Blood vessel disease (vascular dementia) is the most common form of dementia. (False)	432	282	65.3	105	24.3	45	10.4
3. People can recover from the most common forms of dementia. (False)	432	118	27.3	204	47.2	110	25.5
4.Dementia is a normal part of the ageing process. (False)	432	121	28	179	41.4	132	30.6
5. Dementia does not result from physical changes to the brain. (True)	433	412	95	20	4.6	1	0.2
6. Planning for end-of-life care is generally not necessary following a diagnosis of dementia. (False)	430	153	35.6	161	37.4	116	27

7. Alzheimer's disease is the most common form of dementia. (True)	431	140	32.5	160	37.1	131	30.4
8. It is impossible to communicate with a person who has advanced dementia. (False)	431	132	30.6	218	50.6	81	18.8
9. A person experiencing advanced dementia will not generally respond to changes in their physical environment. (False)	432	171	39.6	187	43.3	74	17.1
10. It is important to correct a person with dementia when they are confused. (False)	431	170	39.4	152	35.3	109	25.3
11. People experiencing advanced dementia often communicate through body language. (True)	432	158	36.6	205	47.5	69	16
12. Uncharacteristic behaviours in a person experiencing dementia are generally a response to unmet needs. (True)	430	191	44.4	177	41.2	62	14.4
13. Medications are the most effective way of treating behavioural symptoms of dementia. (False)	432	258	59.7	127	29.4	47	10.9
14. People experiencing dementia do not generally have problems making decisions. (True)	431	411	95.4	18	4.2	2	0.5
15. Movement is generally affected in the later stages of dementia. (True)	431	158	36.7	218	50.6	55	12.8
16. Difficulty eating and drinking generally occurs in the later stages of dementia. (True)	432	115	26.7	241	56	74	17.2
17. People with advanced dementia may have difficulty speaking. (True)	432	73	16.9	261	60.4	98	22.7
18. People experiencing dementia often have difficulty learning new skills. (True)	431	118	27.4	226	52.4	87	20.2
19. Daily care for a person with advanced dementia is effective when it focuses on providing comfort. (True)	431	75	17.4	248	57.5	108	25.1
20. Having high blood pressure increases a person's risk of developing dementia. (True)	430	244	56.7	132	30.7	54	12.6
21. Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia. (False)	430	231	53.7	148	34.4	51	11.9
22. Symptoms of depression can be mistaken for symptoms of dementia. (True)	431	143	33.2	239	55.5	49	11.4
23. The sudden onset of cognitive problems is characteristic of common forms of dementia. (False)	431	354	82.1	66	15.3	11	2.6
24. Exercise is generally beneficial for people experiencing dementia. (True)	431	52	12.1	288	66.8	91	21.1
25. Early diagnosis of dementia does not generally improve quality of life for people experiencing the condition. (False)	431	154	35.7	211	49	66	15.3

**Differences in n are due to missing data*

Appendix 12 c.: Frequency distribution of for participant's ADQ responses

Statements	N*	Strongly Agree		Agree		Neither Agree nor Disagree		Disagree		Strongly Disagree	
		n	%	n	%	n	%	n	%	n	%
1. It is important to have a very strict routine when working with people living with dementia	465	59	12.7	176	37.8	120	25.8	87	18.7	23	4.9
2. People with dementia are very much like children	464	34	7.3	116	25	82	17.7	158	34.1	74	15.9
3. There is no hope for people with dementia.	464	4	0.9	20	4.3	58	12.5	163	35.1	219	47.2
4. People with dementia are unable to make decisions for them.	463	9	1.9	62	13.4	129	27.9	172	37.1	91	19.7
5. It is important for people with dementia to have stimulating and enjoyable activities to occupy their time.	464	301	64.9	140	30.2	10	2.2	3	0.6	10	2.2
6. People living with dementia are sick and need to be looked after.	464	40	8.6	144	31	171	36.9	78	16.8	31	6.7
7. It is important for people with dementia to be given as much choice as possible in their daily lives.	465	207	44.5	168	36.1	45	9.7	36	7.7	9	1.9
8. Nothing can be done for people with dementia, except for keeping them clean and comfortable	463	5	1.1	14	3	29	6.3	204	44.1	211	45.6
9. People with dementia are more likely to be contented when treated with understanding and reassurance.	466	252	54.1	177	38	24	5.2	5	1.1	8	1.7

10. Once dementia develops in a person, it is inevitable that they will go downhill.	464	30	6.5	160	34.5	162	34.9	96	20.7	16	3.4
11. People with dementia need to feel respected, just like anybody else.	466	373	80	83	17.8	1	0.2	0	0	9	1.9
12. Good dementia care involves caring for a person's psychological needs as well as their physical	464	382	82.1	75	16.2	0	0	2	0.4	6	1.3
13. It is important not to become too attached to residents.	464	14	3	88	18.9	178	38.2	141	30.3	43	9.2
14. It doesn't matter what you say to people with dementia because they forget it anyway.	464	9	1.9	6	1.3	21	4.5	176	37.9	252	54.3
15. People with dementia often have good reasons for behaving as they do.	465	112	24.1	212	45.6	112	24.1	22	4.7	7	1.5
16. Spending time with people with dementia can be very enjoyable.	465	204	43.9	188	40.4	65	14	6	1.3	2	0.4
17. It is important to respond to people with dementia with empathy and understanding.	464	352	75.9	106	22.8	3	0.6	0	0	3	0.6
18. There are a lot of things that people with dementia can do.	464	235	50.6	198	42.7	26	5.6	3	0.6	2	0.4
19. People with dementia are just ordinary people who need special understanding to fulfil their needs	466	239	51.3	180	38.6	29	6.2	16	3.4	2	0.4

**Differences in n are due to missing data*

Appendix 12d.: Frequency distribution of participants' STIG-MA responses

Questions about stigma	N*	Yes		Maybe		Do not know		No	
		n	%	n	%	n	%	n	%

1.Would you rather people did not know about your disease?	427	55	12.9	132	30.4	45	10.5	195	45.7
2. Would you tell the person you are closest to?	427	26	6.1	5	1.2	2	0.5	394	92.3
3. Would you lose self-esteem because of the disease?	427	28	6.6	173	40.5	195	45.7	31	7.3
4. Would this disease cause you shame or embarrassment?	426	58	13.6	166	39	112	26.3	90	21.1
5. Would your neighbours, your colleagues have less respect for you?	427	144	30.4	116	27.2	37	8.7	13	30.4
6. Do you think others would avoid you because of the disease?	426	64	14.8	208	48.8	91	21.4	63	14.8
7. Would your neighbours, your colleagues have less esteem for your family?	426	108	25.4	88	20.7	13	3.1	217	50.9
8. Do you think your wife/husband would stay with you and support you?	420	48	11.4	67	16	16	3.8	289	68.8
9. Do you think people you know at work or friends would ask you to stay away, even if you were taking medication for the disease?	427	104	24.4	76	17.8	18	4.2	229	53.6
10. Would your family give you their support right from the start?	425	44	10.4	22	5.2	6	1.4	353	83.1

**Differences in n are due to missing data*