

# Representations of the experiences of people with dementia in Irish newspapers

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## Abstract

The aims of the study were to explore what personal narratives in Irish broadsheet and tabloid newspapers reveal about the lived experience of people with dementia. The sample included twenty narratives collected from five Irish newspapers between 2011 and 2017 inclusively. The relative absence of narratives of people with dementia in Irish newspapers is shown as only twelve of the twenty narratives contained the voice of the person with dementia themselves. Inductive analysis and thematic analysis generated four main themes with a total of thirteen subthemes. The main themes are: (1) Dementia as a personal journey, (2) stereotypes and stigma, (3) barriers and (4) awareness. This study highlights the under-representation of personal narratives of people with dementia in Irish newspapers which is seen as a contributing factor in the lack of understanding and awareness of dementia in society in general. Exploring mediated representations of the lived experience of people with dementia through personal narratives provides insight into the naturalised discourses of dementia which impact on people's lived experiences. (172)

## Keywords

dementia, Alzheimer's, lived experience, Irish newspapers, personal narratives

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## Introduction

Expanding knowledge and public awareness of dementia is an established public health priority (World Health Organization [WHO], 2012) with the International Classification of Functioning, Disability and Health [ICF] (WHO, 2001) advocating for a person-centred focus on function for people living with dementia (Hopper, 2007). Worldwide, there are approximately 50 million people living with dementia (WHO, 2020). In Ireland, this figure is estimated to be 55,000 (Health Services Executive (HSE), 2020). Dementia is a syndrome involving a range of symptoms affecting memory, reasoning, perception and communication skills (Brookes, Harvey, Chadborn, & Denning, 2018). A lack of public awareness of and knowledge about dementia have been reported in the literature (Werner et al., 2019; Oleson et al., 2019; Li et al., 2011; McParland et al., 2012).

In the ICF (WHO, 2001), the social and attitudinal contexts in which people live are called Environmental Factors, a component of Contextual Factors (Hopper, 2007). Representations of people with dementia have been explored in a range of such contexts. For example, Behuniak (2011) explored the topic in relation to scholarly and popular literature, while Low and Purwaningrum (2020) examined popular culture (film, television, literature, news, social media and language). Newspapers are also prominent sources of information in relation to health and illness (Young et al. 2011). Furthermore, they are an interesting site for exploration as they are contradictory: controlled and owned by those with power while simultaneously claiming to express and stand for the views of the people (Peel, 2014). Perceptions of dementia are derived partly from portrayals in available discourses, that is, newspaper discourse (Guendouzi & Muller, 2012). Negative societal attitudes can hinder the participation of individuals with dementia, whereas positive attitudes can be facilitative (Howe, 2008). Mass media has the capacity to raise awareness and influence attitudes (Gerritsen et al., 2016). Awareness may be a fundamental precursor for enabling the development of positive attitudes towards people with dementia (Howe, 2008).

### *Representations of people with dementia in mass media*

Several studies have reported on the portrayal of people with dementia in mass media (Lawless & Augoustinos, 2016; Peel, 2014; Clarke, 2006; Kirkman, 2006; Brookes et al., 2018; Werner et al., 2019). Peel's (2014) analysis of UK national newspaper articles and in-depth interviews with carers revealed a pattern of catastrophic representations of 'tsunami' and 'worse than death' in addition to lifestyle recommendations to prevent dementia. Peel (2014:887) made the case that representations of dementia as controllable or preventable in UK newspaper discourse are problematic because such representations are considered an 'extension of broader (western) liberal-humanistic discourses of self-responsibility for health and wellbeing'.

While Clarke (2006) and Kirkman (2006) both highlighted the missing voices of people with dementia in media in New Zealand, Canada and USA contexts, Werner et al. (2019) explored the portrayal of Alzheimer's disease and people with the disease in Hebrew and Arabic online newspapers. The majority of the articles were found to have a neutral tone with experts or researchers as the main sources of information. In contrast to Peel (2014), Clarke (2006), Kirkman (2006) and Werner et al. (2019: 554) found stigmatising elements to be infrequent although none of these three studies included people with dementia. Including the voice of the person with dementia, in media articles, is important. If we are to understand the experience of living with dementia, we need to listen to the lived experience from the individual, as nobody else can provide this insight (Hellström et al., 2007). However, eliciting the person's experience can be challenging as communication is affected by dementia, particularly in later stages when language capabilities are in decline (Hubbard,

Downs, & Tester, 2003; Nygård, 2009; Ennis et al., 2019). Beard and Fox (2008:1511) described dementia as 'an embodied breakdown, with the most severely impaired living in a world that simply *does not appear* meaningfully structured'.

### *Subjective experiences of people with dementia: self and identity*

A substantial literature has explored the subjective experiences of people with dementia reporting at least some evidence for persistence of self across all stages of dementia while simultaneously reporting some deterioration in aspects of self and identity (Critten & Kucirkova, 2019; Gerritsen et al., 2016; von Kutzleben et al., 2012; Caddell & Clare, 2010; Beard, 2004; Kitwood & Bredin, 1992). Bender and Cheston (1997) presented a three stage model of the subjective world of people living with dementia, drawing on ideas from clinical and social psychology: 1) feelings produced by the process of dementia comprised of at least four separate states: anxiety, depression, grief and despair/terror; 2) behaviours triggered by the process of decline and 3) the social nature of emotional behaviour and the concept of a continuum of emotional actions. Furthermore, Beard (2004) revealed the following crucial aspects of subjective experiences of early Alzheimer's disease: how to identify memory deficits, the diagnostic context and ways to manage illness. Additional research has identified subjective experiences ranging from '*not a big deal*' to '*hellish*' (Hulko, 2009), people with dementia consciously working to integrate a 'manageable disability into their existing identities' (Beard et al., 2009:227.) and a cohesive sense of self in dementia across past, present and future contexts (Strikwerda-Brown et al., 2019). A substantial body of research exploring personal narratives of people with dementia exists and is summarised briefly in the next section.

### *Personal narratives of people with dementia*

Caddell and Clare (2010) reviewed research aimed at analysing how well people with dementia can share their narrative and the implications for narrative identity and sense of self. A difficulty with this approach is its restriction to participants who can verbally share their narrative. Caddell and Clare (2010) pointed out that it possible for people to retain a sense of narrative identity while being unable to share it verbally with others. Mills (1997) and Usita et al. (1998) described fragmented narratives characterised by lack of chronological order, omission of significant events and repetition of events while Benbow and Kingston (2016) looked at narrative production and use in people with dementia and their families concluding that the production of written, audiotaped or videotaped narratives would be beneficial both to the person with dementia and their families and for health and social care professionals. More recently, Kannely et al. (2019) used thematic analysis to analyse blog narratives written by people with Alzheimer's disease and related dementia and care partners with a view to increasing understanding of their experiences. The themes reported included: effects on the person and the care partner; seeing positives; feeling out of control; empowerment and advocacy; compensatory strategies and coping mechanisms and, frank descriptions of experiences with Alzheimer's disease and related dementia.

Understanding the lived experiences of people with dementia is important because traditionally, the perspectives and subjective experiences of people with dementia have been excluded from both research and media (Bethell et al., 2018; Peel, 2014). While research has explored how newspapers represent people with dementia and people's subjective experiences and narratives of dementia separately, relatively few studies have investigated how the personal narratives of people with dementia are represented in newspapers. That is, how mediated personal narratives, (narratives published in mass media contexts, newspapers in particular), are represented. The current study aims

to address this gap in the literature in the Irish newspaper context. The research question is: *What do mediated personal narratives of people with dementia in Irish newspapers reveal about their experiences?*

## Methods

### Data collection

This qualitative study utilised purposive sampling, involving the deliberate selection of data by the researchers, based on predefined criteria (Depoy & Gitlin, 2016). Pre-existing publicly available textual data was used for this study (i.e. newspapers). Inclusion criteria were:

- Irish broadsheet and tabloid newspaper articles of personal narratives of people with dementia.
- Articles published between 2011 and 2016 in Irish newspapers and accessible through Lexis-Nexis database. A 5-year time frame was chosen initially as it was anticipated that this would provide greater depth and variability of findings (Clarke, 2006). This time period reflected our interest in contemporary representations of people living with dementia as opposed to historical representations (Peel, 2014). Furthermore, it was presumed that this time frame would provide sufficient articles to reach data saturation. Saturation is reached when most or all perceptions have been uncovered and new data would not provide any additional information (Kumar, 2011). However, saturation was not reached using the 5-year time frame. Therefore, the initial 5-year time frame was extended to 7-years (2011–2017 inclusive) which resulted in a total of twenty articles for analysis ensuring that data saturation was achieved.
- Search terms were ‘Alzheimer’s’ and ‘dementia’ and articles with three or more mentions of the terms were selected for analysis.

These search terms yielded 2221 and 1448 articles, respectively. The headlines of these articles were screened to remove articles not relevant to the research question (such as articles pertaining to health promotion (HP) and narratives from the perspective of the loved ones or family members of people with dementia). Subsequently, 31 articles were considered ‘personal narratives’; a finding indicative of the continued paucity of newspaper coverage including personal narratives of people with dementia. The highest number of articles was retrieved from the ‘Irish Daily Mail’ (I.D.M), which contained four of the twenty articles. The I.D.M. is a tabloid newspaper with a circulation of 88,659 in 2016 and a readership of 217,000 (News Brands Ireland, 2017). The I.D.M is UK owned by Associated Press who then produces specific editions of their British newspapers for the Irish market (McMenamin, Flynn, O’Malley, & Rafter, 2012). According to Sweetman (2008), the I.D.M. is a right-wing newspaper.

### Data management

Each newspaper was downloaded from Lexis-Nexis and coded with an abbreviation of the newspaper title, that is, *Irish Daily Mail* (I.D.M), the *Irish Examiner* (I.EX), *Irish Independent* (I.IN), *Sunday Independent* (S.I) and *Irish Times* (I.T) and the date of publication. The articles were transcribed orthographically to facilitate coding for the thematic analysis.

## Data analysis

Braun and Clarke's (2006) six-step thematic analysis process was employed to analyse the data<sup>1</sup>. Thematic analysis is a method for identifying, analysing and reporting recurring themes within data and can provide a rich, detailed and complex account of data (Braun & Clarke, 2006).

### Rigour

Rigour is an important goal in research (Morse, 2015) and close attention to methodological rigour is required to study and understand individuals' lived experiences, (Ravitch & Carl, 2020). To enhance rigour of the study, the strategies of saturation (described above in Data Collection), reflexivity and peer debriefing were employed and are described below.

### Reflexivity

The presence of research bias is expected in qualitative research and addressed through reflexivity (Depoy & Gitlin, 2016). This involves the researcher's self-examination of their perspectives and attitudes to minimise bias and the impact these will have on the research process (Depoy & Gitlin, 2016). Reflexivity was achieved by the authors identifying their personal perspectives and attitudes to people with dementia and ensuring these had minimum impact on the research process. Inductive analysis was employed whereby themes identified were strongly linked to the data and the data was not made to fit pre-existing coding frames in an attempt to minimise researcher bias (Braun & Clarke, 2006).

### Peer debriefing

Peer debriefing is intended to prevent bias (Morse, 2015). A randomly selected set of data was coded independently by the authors to ensure similar themes were identified, thus strengthening the dependability of the data analysis process. Further discussion between authors supported the trustworthiness of this process.

## Findings

The most prominent finding from this study is the dearth of personal narratives of people living with dementia published in Irish newspapers. Over a 7-year period, twenty articles were published which contained the person's voice and their lived experience of dementia (see Table 1). However, in many of these articles the personal narratives of the person with dementia also included the voice of editor

**Table 1.** Numbers of personal narratives in Irish newspapers 2011–2017.

	2011	2012	2013	2014	2015	2016	2017	Total
Sunday Independent (S.I)	0	0	1	2	0	0	0	3
Irish Examiner (I.EX)	0	0	0	0	2	1	1	4
Irish Times (I.T)	1	0	0	0	0	1	2	4
Irish Independent (I.IN)	0	0	2	0	1	0	1	4
Irish Daily Mail (I.D.M)	0	0	1	2	1	0	1	5

and editor bias, evident in lexical choices, with catastrophic tones, for example, *...dementia sufferer tells of her ordeal....* Editorial authority in newspapers is a relatively under-researched topic and beyond the scope of this paper. Afzal and Harun (2015:243) describe editorials as social and institutional, making them ‘worth probing to know the orientation of a particular media group or organisation’. According to Fowler (1991), editorials are intended to suggest a characteristic voice for the paper in question. Lexical choice is one marker of the orientation of newspapers. The discourse of editorial comments in relation to the personal narratives of people with dementia, is worthy of investigation in its own right as is the heteroglossic nature of media texts which interweave voices from different sources (Martin and Rose, 2007).

Analysis of the data corpus revealed a reliance on the same people to tell their story (see Table 2) and a lack of new stories being published in Irish newspapers.

## Thematic analysis

Figure 1 presents a thematic map of the findings. Adhering to Braun and Clarke’s (2006) framework, eighty-five initial codes were identified. These codes were then consolidated to form thirteen subthemes, which were refined to four main themes. The four main themes were: (1) Dementia as a personal journey, (2) stereotypes and stigma, (3) barriers and (4) awareness. These findings are illustrated below using figures and extracts from the data.

**Table 2.** Authors of personal narratives of people with dementia in Irish newspapers 2011–2017.

Personal narrative of	Occurrence	Newspaper of publication	Year of publication
Brian Hannon	1	I.T	2011
Jennifer Bute	1	I.D.M	2013
Agnes Houston	1	S.I.	2013
Liz Cunningham	1	S.I.	2014
Karen Lewis	1	I.D.M	2014
Martin Murtagh	1	I.T	2016
Valerie Blumenthal	1	I.D.M	2017
Kathy Ryan	2	I.D.M	2014
		I.EX.	2015
Ronan Smith	3	I.D.M	2015
		I.EX	2015
		I.IN	2015
Maureen O’ Hara	3	I.EX	2017
		I.T	2017
		I.IN	2017
Paddy Butler	3	I.EX	2017
		I.T	2017
		I.IN	2017
Helen Rochford Brennan	6	I.IN	2013
		I.IN	2013
		S.I	2014
		I.EX	2015
		I.EX	2016
		I.T	2017

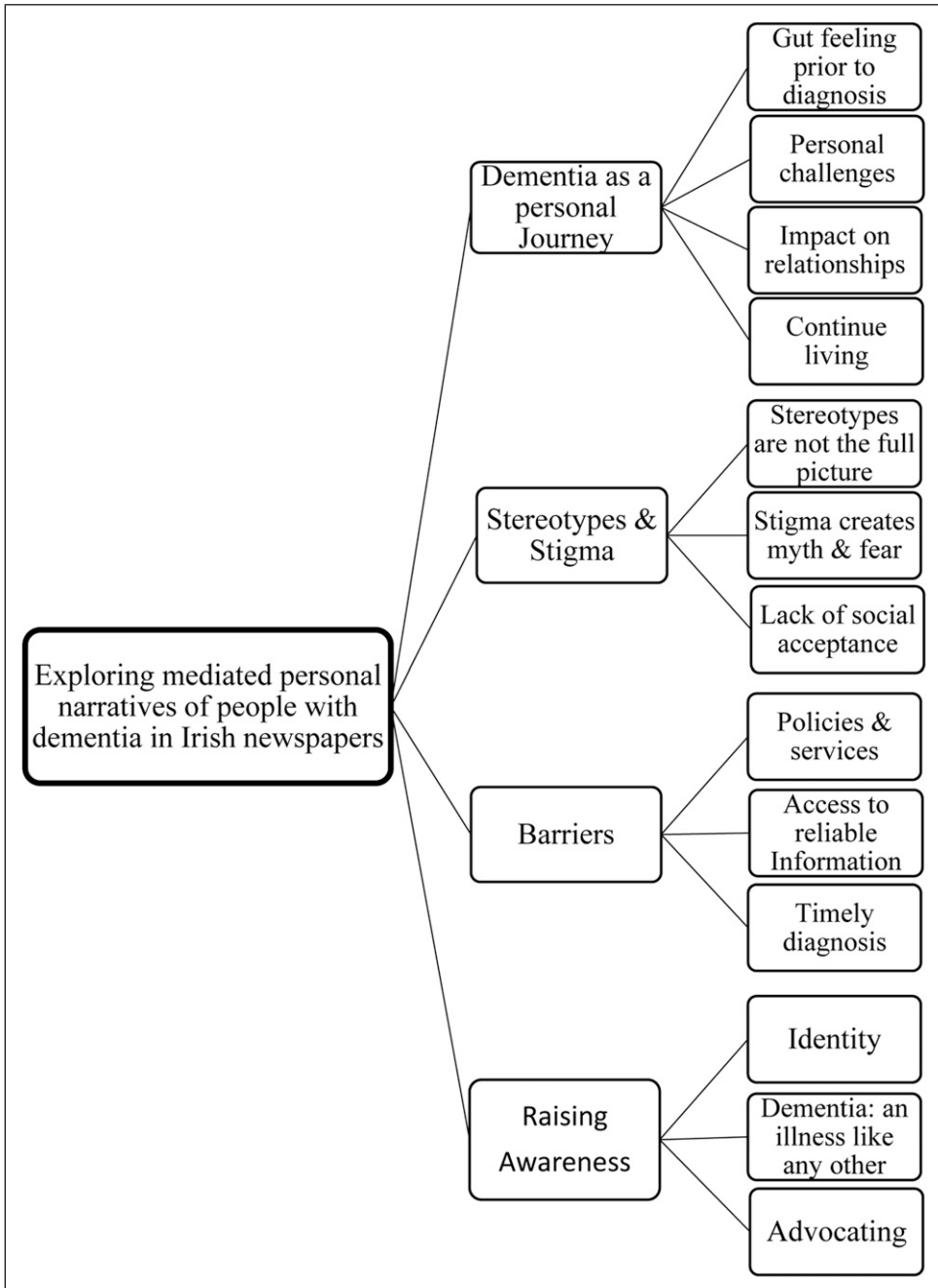


Figure 1. Thematic Map at the end of Phase 4 of data analysis.

## Main theme 1: Dementia as a personal journey

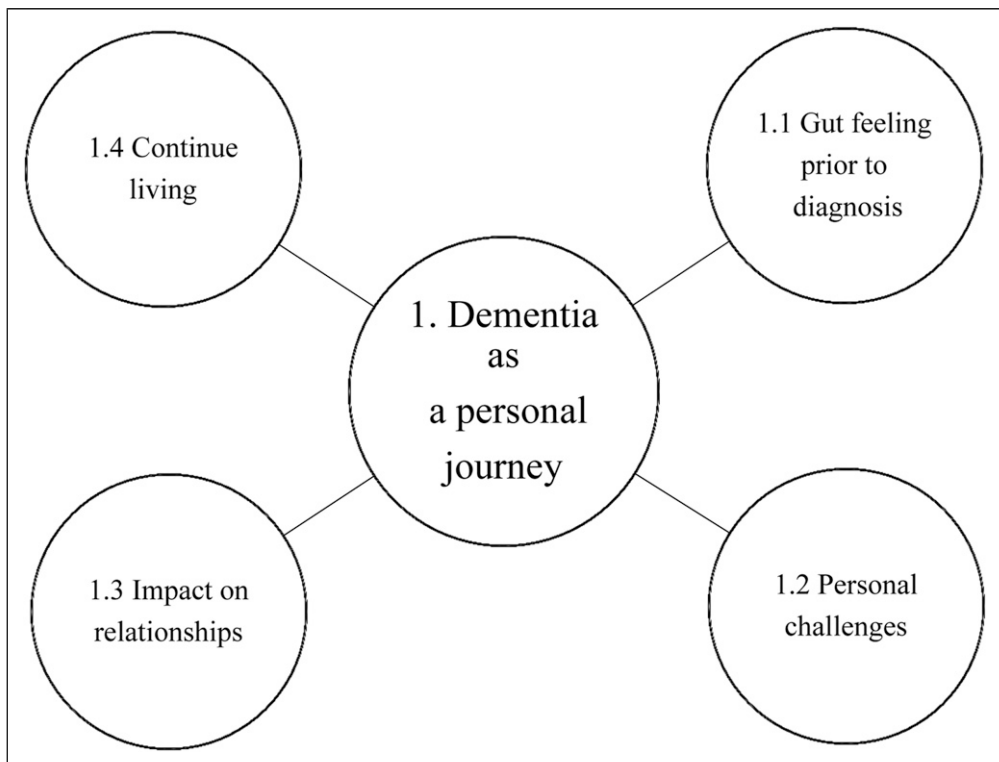
'Dementia as a personal journey' is comprised of four subthemes as illustrated in Figure 2, which relate to the finding that living with dementia is a personal journey, travelled differently by each person.

### Subtheme 1.1: Gut feeling prior to diagnosis

Analysis of the data highlighted a gut feeling that people had prior to diagnosis, a result of signs and symptoms they were experiencing which they knew could not be explained by the typical ageing process. The signs varied for each person with reports of forgetfulness, inability to concentrate, not recognising people and/or objects, having word finding difficulties, dropping things, inability to judge distances and hallucinations (aural, olfactory or visual). For example, *'For me the diagnosis was not a shock as I had been living it. It was nearly a relief to know.* However, the overarching theme is 'Dementia as a personal journey' and not everyone had a gut feeling of dementia prior to diagnosis, for example, *I did not know I had a problem at all.*

### Subtheme 1.2: Personal challenges

The personal trials faced by people living with dementia varied for each individual, further highlighting the personal journey of dementia. Not all people experienced the same issues to the



**Figure 2.** Main Theme 1 'Dementia as a Personal Journey' and associated subthemes.



same degree, for example, *...you go to a meeting and halfway through you forget what happened at the start...forget things that you do every day, like how to make dinner and A flight of stairs becomes Everest.*

### **Subtheme 1.3: Impact on relationships**

In the mediated narratives of the lived experience of people with dementia, it was highlighted that dementia affects relationships with friends, family and colleagues. These relationships were described as becoming strained due to frustration, annoyance and agitation: *Alzheimer's tests friendships to the limits...some friends stick with you... most leave you and He [husband] ...did not feel anything would change between us... that's not to say [dementia] is not a test of any marriage.*

### **Subtheme 1.4: Continue living**

The personal narratives of people with dementia highlighted that acceptance took time but that continuing to live life the best way possible was described as important, following acceptance of the diagnosis. The following extracts illustrate this subtheme: *You have to go out and do what you have to do, do everything as you used to do it before and ...it is not a reason to declare your life over.*

## **Main theme 2: Stereotype and stigma**

A prominent theme in the personal narratives of people with dementia was the stereotyping of people with dementia and the stigma associated with the label, which contributed to a lack of social acceptance. This theme is comprised of three subthemes as illustrated in [Figure 3](#).

### **Subtheme 2.1: Stereotype is not the full picture**

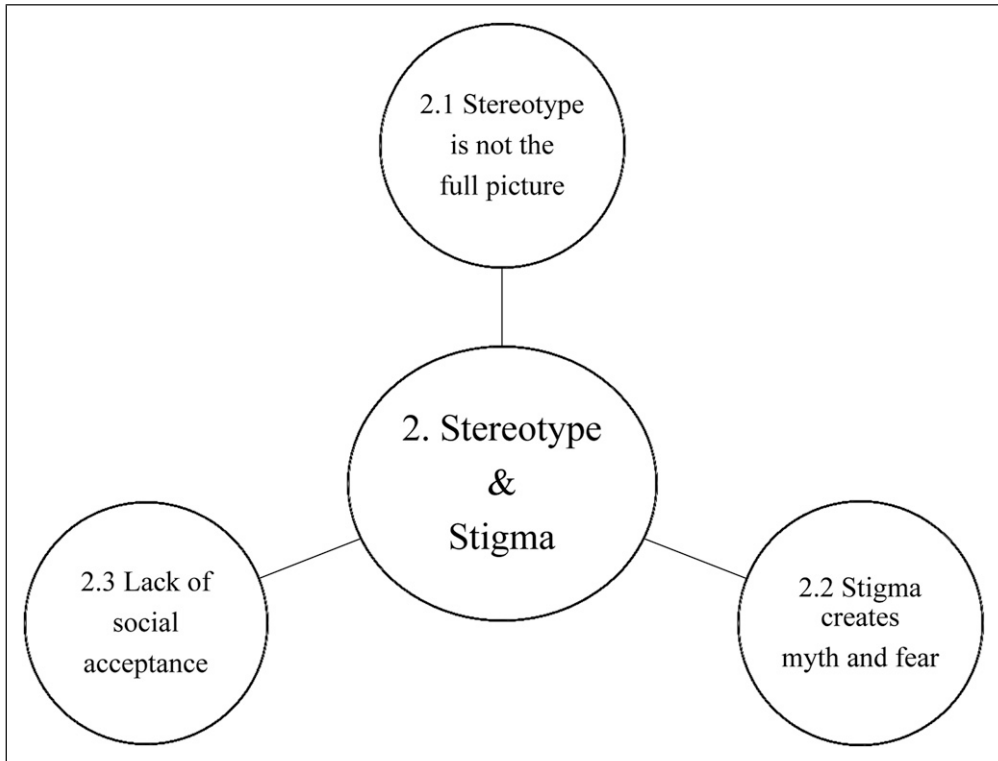
In many of the personal narratives of people with dementia, stereotypes of people with dementia was challenged as seen in statements such as: *...the typical image of the older person languishing in the nursing home sinking into a decline is not the whole picture and ... [people] normally say: 'But you do not look old enough'....I just shrug because I did not think I was old enough either.*

### **Subtheme 2.2: Stigma creates myth and fear**

The narratives of peoples' lived experience of dementia highlight the stigma associated with the label and emphasise the negative impact this stigma has on their experience of living with dementia. For example: *...stigma...shrouds the condition in myth and fear and unnecessarily worsens the burden of carrying it.* People also commented upon the reactions of others, for example, *People are terrified you are going to suddenly dysfunction in front of their eyes.*

### **Subtheme 2.3: Lack of social acceptance**

The narratives further highlight how a lack of social acceptance of dementia impacts on the quality of life of the person living with dementia. These narratives emphasise that the lack of social acceptance results in fear of telling people about the diagnosis and leads to social exclusion and avoidance. For example, it was reported that *...one of the toughest things is people not believing or accepting that*



**Figure 3.** Theme ‘Stereotype and Stigma’ and associated subthemes.

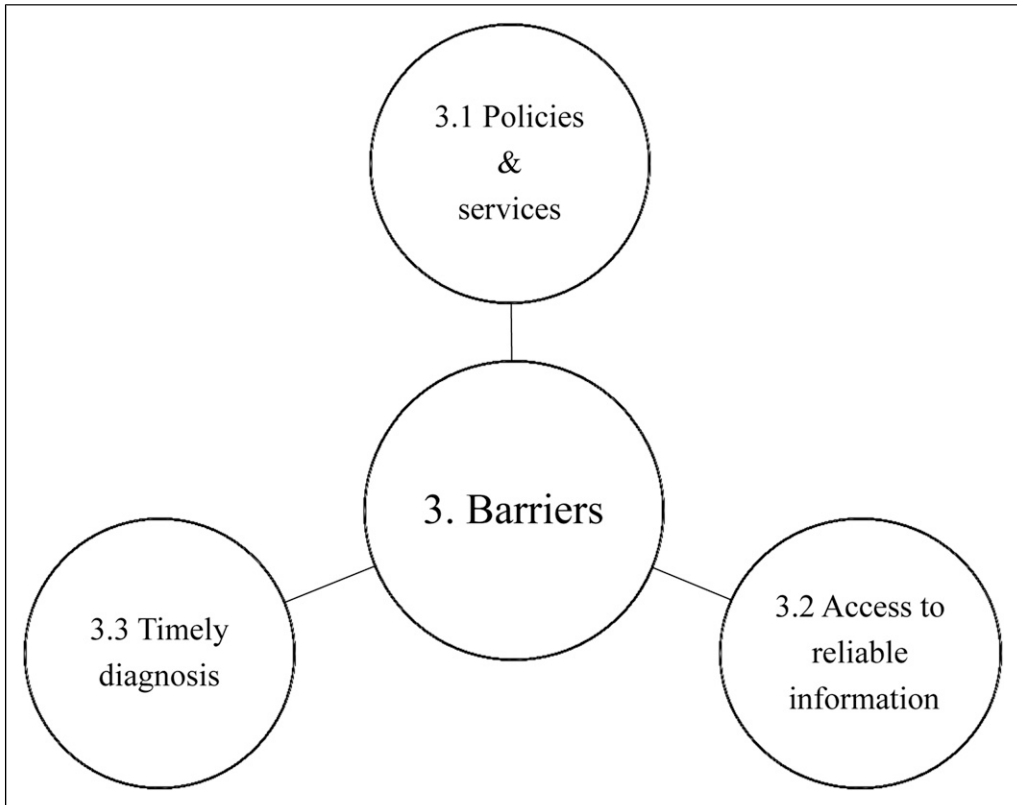
*you have the condition because you don't look any different..* Another person commented on their experience of feeling avoided: *...they say I must come and see Helen but they never come.*

### **Main theme 3: Barriers**

Another core finding is the lack of public policies and services, access to information and timely diagnosis. The main theme ‘Overarching Barriers’ is comprised of three subthemes as illustrated in [Figure 4](#).

#### ***Subtheme 3.1: Policies and services***

A lack of implemented policies and services for people with dementia in Ireland was highlighted in these narratives in addition to a need for political support and leadership: *Political will and leadership are what is needed to ensure there is a strategic approach to dementia care in this country that caters for all age profiles.* The narratives reveal experiences of limited services available for people diagnosed with early onset dementia (people who are under 65 years of age and diagnosed with dementia): *There is nothing there for those people at the moment and we believe that many of them go undiagnosed.*



**Figure 4.** Theme 'Barriers' and associated subthemes.

### ***Subtheme 3.2: Access to reliable information***

Troubles with access to reliable information and the need for ongoing support was discussed in these narratives. Individuals expressed both the need for support from people around them and guidance on where to access reliable information relating to dementia. Lack of knowledge relating to accessing reliable information was commented upon, as was action taken to secure knowledge about dementia by the individuals themselves: *I know now these are symptoms of the disease but only because I looked it up on the internet.*: The importance of support was also expressed by individuals, for example, *You need the support and help . . . You need the people behind you; you need the medical team, the carers, you need everybody behind you.*

### ***Subtheme 3.3: Timely diagnosis***

Challenges with diagnosis, particularly the lack of timely diagnosis were also highlighted in these narratives. Furthermore, they revealed people's experiences of misdiagnosis, especially in the case of early onset dementia, for example, *I was having trouble in my mid-50s, but it was not until I was 62 that I was diagnosed with early onset Alzheimer's* and *So I went to see a psychiatrist, who said: 'You are not stressed or depressed. I do not know why you have been referred to me'.*

## Main theme 4: Awareness

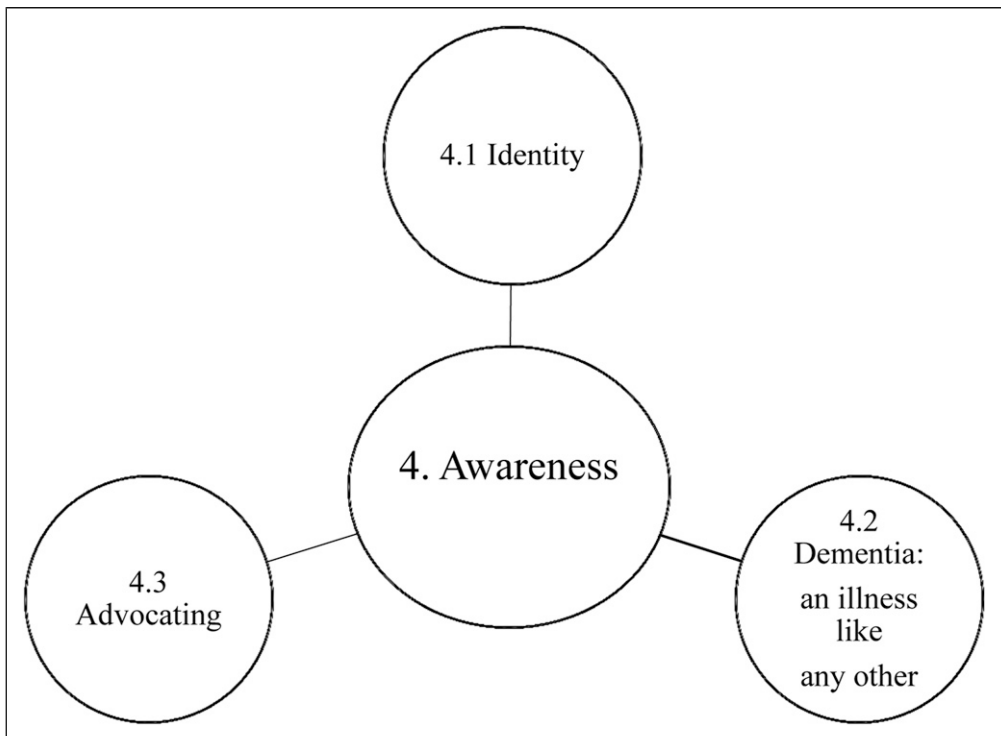
The final main theme identified in the mediated narrative of people with dementia is ‘awareness’. This theme is comprised of three subthemes as illustrated in [Figure 5](#).

### Subtheme 4.1: Identity

Identity was a subtheme identified in the data set, whereby the person living with dementia emphasised that they are still the same person, with the same needs as everybody else and that their label or diagnosis does not define them: *...we are still ourselves*. Another person commented on their experience with acquaintances whose interaction with the person altered as their perception of the person’s identity shifted, for example, *Some of my acquaintances avoid me or have as little interaction as possible until they realise I am the same (person)*.

### Subtheme 4.2: Dementia: an illness like any other

Another subtheme was the need to increase understanding about dementia by making it more relatable and comparable to other illnesses. People commented that *...it is vital for society to be more open about Alzheimer’s, treating it as a normal thing that an awful lot of people have*. One participant likened dementia to disability: *...It is a disability you have acquired, the same way you*



**Figure 5.** Theme ‘Raising Awareness to Normalise Dementia’ and associated subthemes.

would get rheumatoid arthritis and find yourself limping to work. Nobody would expect you to retire over that. In this extract, the person also likens dementia to rheumatoid arthritis, an autoimmune disease leading to physical symptoms; a condition that is framed differently to dementia, (i.e. as a disability by this person) and in relation to being in the workforce in this particular extract. Framing dementia as a disability is of note as the consequences for the person living with dementia would be significant in relation to public perceptions, activities, participation and barriers to participation in society.

### Subtheme 4.3: Advocating

The final subtheme in theme four is advocating. The majority of people were involved in advocating to raise awareness of dementia and emphasised the importance of this activity to benefit everyone who experiences dementia: *I will continue to advocate for dementia awareness for as long as is possible. As advocates, we are creating a better quality of life that, someday, we will all benefit from.* Finally, advocating for a broader framing and understanding of dementia was commented upon: *What I feel very strongly about is advocate for the bigger profile of the illness to be understood.*

## Discussion

The primary aim of this study was to explore what mediated personal narratives published in Irish newspapers reveal about the lived experience of people with dementia. One of the most significant findings in this study was that the voices of people with dementia were missing from Irish newspapers. Irish newspapers, over a 7-year period (2011–2017 inclusively) were searched for personal accounts of the lived experience of dementia. Over this period, only twenty articles containing the person's voice were found. This finding is in keeping with previous literature highlighting that the voice of those living with dementia is missing from print media (Clarke, 2006; Kirkman, 2006).

The dearth of narratives focussing on the lived experience of dementia may be viewed as an environmental barrier for people with dementia participating in society to (WHO, 2001). If the lived experience of people with dementia is invisible in Irish newspapers, societal attitudes may be negatively affected by the publicly under-represented experience of dementia (Lyons, 2000). Furthermore, the absence of these narratives in newspapers may also be viewed as a personal barrier (WHO, 2001), as individual coping styles may be affected by a sense of isolation due to the absence of evidence that other people are having similar experiences (Elman et al., 2000). The presence of editors' unwitting bias was considered during the analysis of the mediated narratives. Newspaper articles have a finite length resulting in choices being made on the part of the editor as to what to include and exclude (Street, 2011). This bias is referred to as unwitting because it is neither conscious nor deliberate but is the product of journalistic culture – what is considered news and what is considered newsworthy (Street, 2011).

Reliance on the same people's stories and the resulting restricted range of voices of people with dementia in Irish newspapers was also found in this study. From the twenty articles gathered, twelve people's stories were published with one person's story occurring six times over a 5-year period. This finding further indicates the under-representation of personal experiences of people with dementia in mass media. The restricted range of voices of people with dementia may be due to perceived challenges of interviewing people with dementia, described by Brooks et al. (2017) in relation to research, as *consent*, *capacity* and *communication*. Concerns relating to informed consent are a significant issue in the inclusion of people with dementia, due to their declining cognitive status

(Brooks et al., 2017). Hellström et al. (2007) suggest that the goal should be to try to ensure maximally informed consent. In relation to communication, an additional issue is eliciting the voice of people with dementia who are unable to adhere to narrative conventions due to the impact of the dementia on language and communication. Brooks et al. (2017) and Hubbard et al. (2003), in relation to research, recommend the use of memory boxes, memorabilia, life story books and tablets with photographs, including support from known and trusted family, friends and professionals to elicit voice. These strategies could also be deployed in mass media contexts in order to ensure inclusion of a diverse range of perspectives.

Basting (2003) highlights that the ways people with Alzheimer's express themselves and share their personal identities changes as the disease progresses. People with Alzheimer's disease share their social identities through their autobiographies which offer a 'glimpse into the embodied experience of the disease' (Basting, 2003:98). Considering the life writing of people who live with dementia with representations, mediated narratives constitute some in-between form. The accounts in this study reveal dementia as being a personal journey, travelled differently by each individual with many of the personal narratives including feelings, signs, challenges, impact on relationships, acceptance and determination varying in each narrative. Dementia as a personal journey is in keeping with Morris (2014), who reported that each individual experience of dementia is unique. The lived experience of people with dementia is impossible for others to comprehend which gives rise to the potential for misunderstanding (Morris, 2014). First person perspectives enhance public awareness which may facilitate more positive attitudes towards people with dementia. Furthermore, understanding a person's strengths, capabilities and their lived experience of dementia may enhance the development of positive outcome measures in person-centred care (Wolverson et al. 2016). Maintaining a person's identity through their journey with dementia is important and requires assistance from family members (Kitwood, 1997).

The negative impact that stereotypes and stigmas associated with dementia has on social acceptance was highlighted in the mediated narratives. Stigma is described as a salient feature of the experience of people living with dementia (Alzheimer's Society, 2008). Stigma has implications in relation to dementia, including a person's willingness to seek diagnosis, support and participation in research (Swaffer, 2014). Health care services can also feel the impact of stigma with the standard of care expressed as being lower for people with dementia (Swaffer, 2014). Reducing stigma is essential to ensure person-centred care and to improve quality of life for people with dementia (Swaffer, 2014). Furthermore, language is a powerful tool and referring to people with dementia as 'sufferers', as seen in these mediated narratives, implies that people living with dementia are helpless, thus reinforcing inaccurate stereotypes and heightening the fear and stigma associated with dementia (Swaffer, 2014). Gilleard and Higgs (201:141) argue that how later life is represented needs to be questioned and that the role of abjection needs to be considered, thus reminding us of 'the universal vulnerability of our bodies and our relationships'.

Barriers identified through the mediated personal narrative of dementia encompass policies and services, access to reliable information and timely diagnosis. Many of the mediated narratives analysed in this study were published at specific times when dementia was topical, both in the government and Health Service Executive (HSE). The national context during the data collection period featured the development and launch of nationwide awareness campaigns, the charter of rights for people with dementia, the national dementia strategy and times of pre-budget submissions making the dearth of personal narratives in the data set even more striking. In recent years, the WHO has had an essential role in the development of health promotion worldwide (Naidoo & Wills, 2016). Health Promotion encompasses principles, including developing personal skills whereby the provision of information is essential (Ferguson & Spence, 2012 Sep-Oct). However, in relation to

dementia, once a diagnosis is received, people with dementia and their family members report difficulty in accessing reliable information (Department of Health, 2014). Therefore, a priority area identified in the Irish National Dementia Strategy is that the HSE will ensure that information is routinely given to people with dementia and their families (Department of Health, 2014).

Timely diagnosis is promoted by clinical guidelines and national strategies (Foley & Swanwick, 2014). While dementia can bring many challenges for an individual and their carer, there is increasing recognition that if there is timely access to assessment and diagnosis, and adequate services and supports are in place, people can live well with dementia for a number of years (Department of Health, 2014). However, there are challenges associated with diagnosing early onset dementia and symptoms are frequently misdiagnosed and confused with other illness, such as depression (Department of Health, 2014). The frequent misdiagnosis of dementia was highlighted in the mediated narratives in this study with individuals being diagnosed with depression, anxiety and stress. Foley and Swanwick (2014), highlighted the need for dementia education in General Practitioners' (GPs) learning needs in areas including diagnosis. Furthermore, Cahill et al. (2011) report that failure by GPs to detect dementia due to lack of education is a critical barrier to early diagnosis.

Dementia service provision is generally tailored to the needs of older people; therefore, people with early onset dementia usually experience greater difficulty fitting into these service provisions (Department of Health, 2014). The development of the National Dementia Strategy addresses the needs of all people with dementia regardless of age (Department of Health, 2014). While this strategy highlights priority actions including (1) better awareness and understanding, (2) timely diagnosis and intervention (3) integrated services, supports and care for people with dementia and their carers (4) training and education and (5) leadership, these are yet to fully materialise. Cahill (2010) states that dementia specific services are sparse in Ireland. Support services for people with dementia are insufficient in quantity, variable in quality and difficult to access (Wilcock et al., 2016).

People with dementia state that they are not defined by the label and they are still the same person. Guendouzi and Muller (2012) found that people with dementia are portrayed in dementia texts as 'an empty shell' and that the individual is reported to no longer be their former self. However, Guendouzi and Muller (2012) argue that this portrayal is inaccurate and an individual with dementia is still the same person despite experiencing cognitive decline. Therefore, people with dementia should be given the same rights and treated with the same dignity and respect as they were pre-dementia (Guendouzi & Muller, 2012). Advocating to raise awareness of dementia by comparing it to illnesses such as diabetes, heart disease and cancer that are more publicly well-known was also identified as a subtheme in the data set. It is not surprising that advocating was identified due to the publication of these narratives occurring at the same time as nationwide campaigns, development of the charter of rights for people with dementia, the development of the national dementia strategy and times of pre-budget submissions. Many of the individuals who told the story of their journey with dementia are involved in these campaigns and developments and therefore have a current role in advocacy. Beard et al., (2009), highlighted the positive role advocacy has on enriching the lives of people living with dementia in their study whereby participants lobbied to be seen as 'more than dementia'.

### *Strengths and limitations of the study*

The utilisation of qualitative analysis to explore the mediated personal narratives of people with dementia is considered a strength, as it allowed for a more detailed account of these experiences. Furthermore, this study is a response to the need for greater understanding of the lived experience of

people with dementia (Steehan et al. 2007), which help to enhance public awareness and knowledge about this experience (Morris 2014). The authors aimed to increase and maintain accuracy and rigour in this study through reflexivity, reaching saturation and the use of peer debriefing as previously discussed.

While this study adds emphasis to the growing interest of exploring lived experiences from the person's perspective, there are limitations to the study. A primary limitation of this study is the limited sample size of data as due to the time constraints of this study extending the time frame of publication of newspaper articles further was not possible (Depoy & Gitlin, 2016). Publication of mediated narratives of people with dementia in Irish newspapers from 2011 to 2017 inclusively, occurred around the time of campaigns, charters and pre-budget submissions and contained the voices of people with dementia who were involved in same. Therefore, the impact of the social and political contexts of the data collection period on the data generated must be taken into consideration.

## Conclusion

Newspapers continue to be a prominent source of information relating to health and illness (Young et al., 2011). Perceptions about conditions such as dementia are derived in part from widely available discourses such as that found in newspapers (Lyons, 2000). Mass media portrayals of people living with illnesses and conditions in newspapers influence societal attitudes (Lyons, 2000; Peel, 2014). Howe (2008) and Hopper (2007) state that negative societal attitudes can hinder the participation of people with conditions such as dementia, whereas positive societal attitudes can be facilitative. Awareness may be an essential precursor for enabling the development of positive attitudes towards people with various conditions, including dementia (Howe, 2008). Without awareness, meagre public support is expected (Elman et al., 2000). Although newspapers continue to disseminate information about health and illness to the general public, as this study shows, personal narratives of people with dementia continue to be marginalised in Irish newspaper discourse. In contrast, a wealth of newspaper articles pertaining to health promotion in relation to dementia was noted during the data collection phase of the study. A reliance on the same restricted range of people to tell their story was identified as was a pattern of perspectives of family and loved ones being published more frequently than the individuals' own lived experiences. The challenges associated with accessing the lived experiences of people in the later stages of dementia could be mitigated using the strategies suggested by Brooks et al. (2017) and Hubbard et al. (2003). The findings highlight the restricted range of representations of people with dementia in Irish newspapers. This study provides valuable insights into naturalised media discourses of people with dementia in Irish newspapers, discourses known to impact on people's lived experiences (Hopper, 2007). The study also supports Gilleard and Higgs' (2011) interrogation of existing representations of people with dementia and advocates for a widening of the range of visible, nuanced representations in order to acknowledge the collective vulnerability of all bodies and relationships.

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## Notes

1. Phase 1: Familiarisation with the data, Phase 2: Generating initial codes, Phase 3: Searching for themes, Phase 4: Review themes, Phase 5: Defining and naming themes, Phase 6: Producing the report (Braun & Clarke, 2006).

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