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ARTICLE

The Alzheimer case: perceptions, knowledge and the acquisition of information about Alzheimer's disease by middle-aged and older adults in Flanders

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Abstract

Alzheimer's disease (AD) is a major health concern as the world population ages. Yet, few studies have examined what the public over the age of 50 knows about AD. This qualitative study, based on 40 in-depth interviews, examines the knowledge of AD by Flemish people between 50 and 80 years old and their cross-source engagement with information sources. Building on AD media representations and theories on media complementarity and health information behaviour, we find that respondents mostly encounter AD information non-purposively via traditional mass media and interpersonal communication, while the internet is occasionally used to purposefully seek information. Novels, personal experiences/social proximity, public figures and particularly film stand out as channels and sources of AD information, suggesting that fictional narratives, personal experiences and being able to identify with others leave lasting impressions and help to communicate and disperse AD information. However, common misconceptions and gaps in knowledge persist, including AD being considered part of the normal ageing process and old age as well as confusing AD with Parkinson's disease. The biomedical perspective and the tragedy discourse prevail among the majority of respondents, who describe AD in terms of decline, loss and death and as 'the beginning of the end'. Only a few, typically female respondents, appear aware of the role of individual health behaviour and lifestyle choices to prevent dementia or delay its onset. The misconceptions of AD and gaps in knowledge, as well as the fact that a third of all cases of dementia might be delayed or prevented by managing lifestyle and other risk factors, stress the importance of public educational programmes and the need to emphasise and raise awareness of preventative behaviour. Overall, the findings from this study can be of help to public health communicators and dementia-awareness campaigns, as well as AD training programmes for health-care professionals and family care-givers.

Keywords: Alzheimer's disease; media representations; knowledge; health information; media complementarity; middle-aged; older adults; Flanders

Introduction

Deemed one of the biggest contemporary health concerns (Johnstone, 2013; Kenigsberg *et al.*, 2016; Livingston *et al.*, 2017; World Health Organization (WHO), 2019), Alzheimer's disease (AD) is said to strike fear in the hearts and minds of the public (Clarke, 2006; Kessler and Schwender, 2012; Van Gorp and Vercruysse, 2012; Johnstone, 2013; Zeilig, 2013; Cahill *et al.*, 2015). Accounting for 60–80 per cent of all cases of dementia (Johnstone, 2013; WHO, 2019), AD is a chronic, progressive and non-curable neurodegenerative condition which starts mildly and develops gradually. The condition affects various functions of the brain, leading to degradation, the loss of cognitive faculties and ultimately death (Johnstone, 2013; Livingston *et al.*, 2017; WHO, 2019). The number of individuals living with AD is expected to rise as the world population ages (Johnstone, 2013; Livingston *et al.*, 2017; WHO, 2019), which has led to alarmist news stories heralding an imminent AD 'crisis', 'epidemic', 'flood', 'plague' or 'tsunami' (Behuniak, 2011; Johnstone, 2013; Zeilig, 2013; Peel, 2014; Medina, 2018). In parallel to the growing emphasis on AD as a global health priority (Cations *et al.*, 2018; WHO, 2019), a growing body of empirical work has examined the general public's understanding of the condition (Cahill *et al.*, 2015). The overwhelming majority of these studies are quantitative in nature (Cahill *et al.*, 2015; Cations *et al.*, 2018), while qualitative studies are limited in number and somewhat dated (*see* Cahill *et al.*, 2015). In their literature review, Cahill *et al.* (2015) therefore call for more qualitative research to examine in depth the public's knowledge and understanding of AD.

The present qualitative study seeks to improve our understanding of the perceptions and knowledge of AD in middle-aged and older adults between 50 and 80 years of age, as well as where they obtain their information on AD from. Our study is thus guided by the following research question:

- What do Flemish adults aged 50 and over know about AD, and where do they obtain their information from?

The data from our study come from Flanders, the Dutch-speaking part of Belgium. The novelty of this contribution is fivefold. First, as mentioned above, we contribute to the few qualitative studies which have examined public perceptions and knowledge of AD. Second, few studies around this topic have been carried out specifically with adults over the age of 50, despite age being the biggest risk factor for developing dementia (Livingston *et al.*, 2017; WHO, 2019). Third, to our knowledge, no studies have been undertaken in Belgium that have examined public perceptions and understanding of AD. Fourth, we go beyond a mere evaluation of AD perceptions and knowledge (what is known) to also understand where study participants get their information from (how do they know). Fifth, by employing the theoretical concepts of media complementarity (Dutta-Bergman, 2004) and information behaviour (Johnson and Case, 2012; Case and Given, 2016), we approach the topic from a media and communications perspective. To that end, we review the literature regarding public perceptions and media depictions of AD, media complementarity and health information acquisition.

Literature review

Public perceptions of AD

Over the past few decades, studies have consistently found that the general public has limited and poor knowledge of AD (Cahill *et al.*, 2015; Cations *et al.*, 2018), although it has been suggested that knowledge levels are increasing and improving over time (Cations *et al.*, 2018). Nonetheless, there are various public misconceptions about AD which seem to persist over time. The most common one is that AD is a normal, non-preventable and unavoidable occurrence in old age (Cahill *et al.*, 2015; McParland *et al.*, 2017; Cations *et al.*, 2018). In reality, AD and related conditions differ from and can be distinguished from the natural ageing process (Kenigsberg *et al.*, 2016; Livingston *et al.*, 2017; WHO, 2019). Basting (2009) argues that public perceptions and misconceptions of dementia largely come from popular culture, that is, traditional mass media and the internet. Indeed, 'The stories we tell about dementia in the mainstream media create the backdrop against which we forge our understandings of and attitudes toward it' (Basting, 2009: 31). The ageing world population, coupled with a growing number of individuals living with dementia, has led to AD increasingly featuring as a newsworthy topic in information-focused media and as a theme in entertainment-oriented media (Segers, 2007; Van Gorp and Vercruysse, 2012; Medina, 2018). Communication and media scholars have not only examined how AD is represented in traditional mass media programmes and publications, but also how the media provide information about AD and shape public perceptions of and attitudes towards dementia (Basting, 2009; Johnstone, 2013). This latter research focus is important as media users are likely to, both consciously and unconsciously, derive their perceptions, knowledge and understanding of AD from traditional mass media (Clarke, 2006; Rains, 2007; Basting, 2009; Tian and Robinson, 2009; Kline, 2011; Kessler and Schwender, 2012; Van Gorp and Vercruysse, 2012; Peel, 2014; Bailey *et al.*, 2021), with film particularly contributing to the public visibility of AD (Segers, 2007; Gerritsen *et al.*, 2014; Capstick *et al.*, 2015; Medina, 2018).

Media depictions of AD

Prior studies have exposed two dominant AD media narratives, which are in turn related to public discourses on dementia. From a biomedical perspective, AD stems from the malfunctioning of the individual body (Clarke, 2006; Peel, 2014) and is detached from the natural ageing process (Johnstone, 2013; WHO, 2019). The biomedical perspective emphasises pharmaceutical intervention as the first and foremost or even only solution (Clarke, 2006; Bailey *et al.*, 2021), while largely ignoring the social aspects including the environment of the person living with AD, as well as non-pharmaceutical treatments, including assistive technologies, coping strategies and self-management (McParland *et al.*, 2017; Bailey *et al.*, 2021). Furthermore, as McParland *et al.* (2017: 258) explain, because of its 'explicit focus on loss of function, decline and death', the biomedical perspective is also known as the 'tragedy discourse'. From a lifestyle perspective, which is grounded in a broader context of healthy ageing (McParland *et al.*, 2017), AD is viewed as stemming from individual health behaviour and lifestyle choices (*e.g.* unhealthy diet, lack of exercise, smoking, consumption of alcohol) (Clarke, 2006; Peel, 2014; McParland *et al.*, 2017). In other words, the lifestyle perspective emphasises individual responsibility to prevent or delay the onset of dementia by living healthily and actively (Peel, 2014; Bailey *et al.*, 2021). By extension, the related 'living well discourse' attempts to counter and nuance the biomedical perspective on AD and the tragedy discourse by shifting the focus from decline and loss to living well with dementia, that is, emphasising social inclusion rather than exclusion and supporting individuals' remaining strengths and abilities (McParland *et al.*, 2017). In short, the living well discourse emphasises living with dementia rather than dying with dementia.

Previous work has demonstrated that the biomedical perspective and the tragedy discourse not only dominate media narratives and representations of dementia (Kessler and Schwender, 2012; Van Gorp and Vercruysse, 2012), including the news (Clarke, 2006; Bailey *et al.*, 2021), but also the general public's understanding of dementia (McParland *et al.*, 2017). Media narratives of AD and dementia generally focus on the decline and deficits caused by these conditions (Kessler and Schwender, 2012; Van Gorp and Vercruysse, 2012). The 'horror' of dementia is emphasised (Peel, 2014), with AD described as an aggressive and stealthy invader and parasite (Clarke, 2006; Van Gorp and Vercruysse, 2012; Bailey *et al.*, 2021), a predatory thief (Johnstone, 2013) or as a relentless monster which steals people from themselves (Behuniak, 2011; Van Gorp and Vercruysse, 2012; Johnstone, 2013; Zeilig, 2013). The use of metaphors and stereotypes in describing AD has been extensively studied (Basting, 2009; Behuniak, 2011; Johnstone, 2013; Zeilig, 2013), as metaphors work to structure 'what people think, perceive, experience, and how they behave and relate to other people living with or talking about Alzheimer's disease' (Johnstone, 2013: 24). These studies find that people living with AD are often negatively stereotyped, stigmatised and ultimately 'dehumanised', as 'losing oneself' – *i.e.* the loss of memory, orientation and ability to communicate – becomes equal to the loss of humanity and personhood (Behuniak, 2011; Johnstone, 2013; McParland *et al.*, 2017; Medina, 2018). In the latter stages of AD, the individual might be deemed a 'non-person' whose body is still present, but whose brain has been destroyed, leaving only an 'empty shell' (Behuniak, 2011) without identity (Van Gorp and Vercruysse, 2012) who might be likened to a zombie (Behuniak, 2011; Zeilig, 2013).

Media narratives tend to portray and emphasise the rapid development of AD and its symptoms, focusing on the latter, terminal end-stages in which severe memory loss and aggressive, irregular and unsocial behaviour occurs, such as delusions, hallucinations and wandering (Clarke, 2006; Van Gorp and Vercruysse, 2012; Medina, 2018). However, besides dementia being a complex condition (Livingston *et al.*, 2017; McParland *et al.*, 2017), cognitive health comes in variations, from functioning normally to mild impairment and severe dementia (Johnstone, 2013). By ignoring the slow development of AD and its early stages, which consist of only minor symptoms, disturbing narratives and images of the latter stages tend to become representative of the entire condition and its degenerative process (Clarke, 2006; Van Gorp and Vercruysse, 2012; Capstick *et al.*, 2015). Medina (2018) notes in this regard that forgetfulness and disorientation have been firmly implanted in the public's perception of AD by Western social and cultural imagery.

Adults in France, Germany, Italy, Poland, Spain and the United Kingdom were, for instance, found to be 'aware of only the debilitating symptoms characteristic of the late stages of the condition and have little knowledge about the early-stage symptoms' (Rimmer *et al*., 2005: 23). As a result, anxiety, fear and the idea that AD equates with death in the short term have crept into the public consciousness (Johnstone, 2013; Bailey *et al*., 2021). Indeed, 'the sense of horror associated with dementia that has been introduced to the public through a variety of cultural texts has alarmed and increased anxiety about it in public opinion' (Medina, 2018: 3).

In short, the traditional mass media disseminate information and perpetuate stereotypes about AD through narratives and depictions, often in line with the bio-medical perspective and the tragedy discourse. They do so in conjunction with other sources of health information, such as the internet and interpersonal communication. The theoretical concepts of media complementarity (Dutta-Bergman, 2004) and information behaviour (Johnson and Case, 2012; Case and Given, 2016) help to examine and understand what people know about AD and where they get their understanding from.

Media complementarity

The 'information-media environment' (Rains, 2007) has greatly expanded in the 21st century, with people able to obtain health information from numerous traditional mass (*e.g.* magazines, newspapers, film, radio, television) and digital (*e.g.* websites, forums, social network sites, blogs, vlogs) media sources. Arguing for media compatibility rather than competition and displacement, Dutta-Bergman (2004) proposes that people use different media in complementarity within specific content domains such as health. As part of his media complementarity theory, Dutta-Bergman (2004) suggests that people who are interested and/or invested in a certain topic (such as AD) are likely to seek information actively from multiple media sources. The media complementarity model is underpinned by the audience-centred uses and gratifications theory, which proposes that individuals have communication and information needs which can be met in various ways (*i.e.* by traditional mass media as well as digital channels) (Rubin, 2009; Tian and Robinson, 2009). Emphasising purposive media choice and use, the uses and gratifications theory assumes that people have the motivation, awareness and ability to select and use certain channels of information to satisfy their needs and wants (Rubin, 2009). Thus, someone who wants to know about AD might choose from a range of different health information sources (Dutta-Bergman, 2004; Rains, 2007; Tian and Robinson, 2008*b*). As different sources provide different types and quantity and quality of information, they might complement and augment each other. For instance, a newspaper article reporting on the latest AD news might prompt readers to visit the website of a patient association to find a more detailed explanation.

Moreover, health information might be obtained from medical sources (*e.g.* health-care professionals) and everyday interpersonal social interactions with, for instance, relatives, friends, neighbours and colleagues (Dutta-Bergman, 2004; Cline, 2011; Johnson and Case, 2012). Social proximity and experiential exposure (*e.g.* observing, interacting with someone living with AD) have been recognised as predictors of condition awareness, knowledge and concern (Rimmer *et al.*, 2005; Cahill *et al.*, 2015) and being more attuned to news and narratives about AD in traditional mass media (Kline, 2011). Following Tian and Robinson (2008*b*, 2009), who extend Dutta-Bergman's media complementarity theory to include interpersonal communication, we expect that complementarity between traditional mass media and digital media as sources of AD knowledge extends to interpersonal interactions.

Health information acquisition

Dutta-Bergman's (2004) media complementarity theory has been employed to examine how information channels complement each other when people actively and intentionally seek health information (Tian and Robinson, 2008*b*; Ruppel and Rains, 2012; Rains and Ruppel, 2016). Importantly, Tian and Robinson (2008*a*, 2009) extend the media complementarity theory towards incidental and non-purposive health information acquisition. Labelled in the literature as information encountering and exposure (Johnson and Case, 2012; Case and Given, 2016) or scanning (Hornik *et al.*, 2013), this type of information engagement refers to the unintentional acquiring of information through exposure to routinely and habitually used sources of information, both mediated and interpersonal (Hornik *et al.*, 2013; Case and Given, 2016). Information about AD might, for example, be unintentionally acquired when reading a lifestyle magazine or seeing an item about drug treatment development on the news. In these situations, health information is not actively sought after but rather encountered accidentally. The unintentional acquiring of information through exposure plays an important and dominant role in how people engage with information, as it requires less or minimal effort compared to deliberately seeking information and because it takes place much more frequently than active information seeking (Hornik *et al.*, 2013).

In sum, the extant literature suggests that people obtain health information actively and purposively (seeking) as well as unintentionally and non-purposively (encountering) from a variety of mediated and interpersonal channels and sources. This 'expanded media complementarity theory', which includes, besides traditional mass media and digital media, interpersonal channels of information and the notion of purposive and non-purposive information acquisition, serves as the theoretical starting point for this study.

Study design

Sample and data collection

Between April and September 2015, we conducted 40 qualitative, semi-structured interviews with Flemish adults between the age of 50 and 80. With the help of local service centres and OKRA, the largest Flemish association for older people, a heterogeneous group of respondents was recruited in terms of age, gender and educational background (*see* Table 1).

The youngest and oldest participants were 51 and 80 years old, respectively, with an average respondent age of 64.9 years. There was a slight tendency towards higher education (HE: university or postgraduate degree) and middle education (ME: higher secondary) compared to lower education (LE: primary and lower secondary)

Table 1. Participant characteristics

	N	%
Gender:		
Female	22	55.0
Male	18	45.0
Age:		
50–60	12	30.0
61–70	20	50.0
71–80	8	20.0
Highest educational level:		
Primary/lower secondary	11	27.5
Higher secondary	15	37.5
University or postgraduate degree	14	35.0
Employment:		
Employed	14	35.0
Unemployed	1	2.5
Retired	25	62.5

levels (HE: 35%, ME: 37.5%, LE: 27.5%). None of the study participants had a dementia diagnosis and none were primary care-givers for someone living with dementia at the time of the interview, although several respondents had relatives who lived with AD or who had the condition in the past.

The interviews were conducted using a predefined topic list (Mortelmans, 2013), keeping the questioning as open as possible to immerse in and understand health attitudes and information needs and behaviours fully. Being part of a larger audience research about health communication and information in relation to ageing, the interviews broadly covered health information behaviours and experiences (Case and Given, 2016). Respondents were asked about their definitions of health, illness and health information, as well as their sources and use of health information. Three specific cases of health knowledge and information behaviour were brought up, namely AD, diabetes and sleeping disorders, with respondents relating what they knew about AD and where they had obtained their knowledge from.

Analysis

The interviews were recorded and transcribed verbatim to be analysed qualitatively. After a meticulous first reading of the transcripts, we employed semi-open coding in NVivo 12 to identify and code relevant parts of the transcripts by simultaneously employing inductive categories (from the data) and deductive coding categories (derived from an exhaustive literature review) (Mortelmans, 2013). By carrying out a thematic analysis of the data (Boyatzis, 1998), we made ongoing comparisons between the empirical data and its place within conceptual frameworks and the literature. A subsequent round of coding was carried out to narrow down and group the observations and descriptions, thus allowing for coherent interpretation and translation into concepts. The final stage of the analysis further reduced the data in order to focus on the relevant findings. The following sections present our findings pertaining to the perceptions, knowledge and acquisition of information about AD. The first part explores respondents' perceptions and knowledge of AD, the second part zooms in on AD information sources. All respondent quotes have been extracted from the transcripts, anonymised and translated from Dutch into English by the authors.

Results

Perception and knowledge

Respondents generally described AD as a decaying of the individual, which starts with forgetting things and being confused and ends with completely forgetting everything and returning to a child or baby-like state. More specifically, AD was talked about as brain decline, degeneration or damage, as well as the 'drying out' and dying off of the brain:

> I think it is primarily your mind that has lost its way. Not recognising people anymore, not knowing where you are, what you have to do. (Female, 65, ME)

Forgetfulness and loss of memory and orientation were by far the most frequently mentioned symptoms. AD was also related to strange behaviour and being confused, loss of decorum and manners, no longer recognising others, repeating the same things over and over, loss of mobility, inability to carry out daily tasks, tremors, black-outs, mood swings and aggressiveness:

> My grandfather was absentminded and sometimes began to shout. In the end he was nothing more than a foetus. That was awful. The few moments he was a bit better and realised that something was wrong, he became aggressive. (Female, 52, ME)

The cause of AD was primarily thought to be old age, followed by hereditary factors. A few respondents talked about alternative causes such as stress and (noise) pollution. Although some informants indicated that AD can manifest itself in younger people, the condition was characterised by almost all as typical among older people. A substantial number of respondents, though certainly not all, believed AD to be inevitable and inherent to the normal ageing process. This respondent believed that eventually everyone would come to live with dementia:

> They say that it is a normal phenomenon. Everyone will get it, but with one it goes faster and with the other it develops very slowly. (Male, 64, LE)

Fear

Dementia in general and AD specifically evoked considerable dread in respondents. They strongly associated AD with losing oneself (identity) as well as losing one's dignity and control over life. Some respondents talked about AD as a condition which makes people die twice: first when the individual 'loses' him- or herself, and a second time when the body dies physically:

> I think it means to say farewell twice. When you reach the stage that there is no more contact, you have said farewell to others. And again when you die. (Male, 79, LE)

Respondents commonly described AD as a frightening health threat, both for themselves (older participants) as well as for their parents, other relatives and friends (younger participants):

> It is the beginning of the end. (Male, 67, ME)

> It must be a terrible thing. I hope I never have to experience it with my mother. (Male, 51, ME)

Echoing the notion of the 'beginning of the end', some respondents thought of living with dementia as the worst possible thing that could happen to them. These informants spontaneously talked about their preference for a painless and/or quick death over having to live their final years with AD:

> I hope wholeheartedly that when it happens to me, it is over and done very quickly. (Female, 65, ME)

> They can give me a suicide pill if I ever get it. (Female, 71, LE)

Confusion with other conditions

Despite common fears and concerns, many respondents were not able to distinguish clearly between AD and dementia, instead using them interchangeably. More surprisingly, AD was quite often confused with Parkinson's disease, with respondents wondering aloud about memory loss and tremors being symptoms of both conditions:

> Parkinson's is when they start to tremble? But Alzheimer's is that they slowly become demented? That they forget things, that they do not recognise you anymore. Because Alzheimer's and dementia are the same, or…? (Female, 80, ME)

> Alzheimer's, for me, is dementia, uh … I always confuse Alzheimer's and Parkinson's. Parkinson's is that shaky feeling. (Male, 68, HE)

Treatment and prevention

The vast majority of respondents knew that there is no cure for AD. Precisely this awareness seemed to lie at the root of respondents' AD-related anxiety:

> When I see that they cannot do anything about it currently, I get a bit of a nervous stomach. (Female, 55, LE)

Although informants could not come up with any details, they remembered having seen, heard or read news regarding the development of AD drug treatment:

> I heard on the news one time that there was a small breakthrough around Alzheimer's disease, with a tone of voice like 'hip hurray'. (Female, 55, LE)

A large proportion of respondents thought that it was possible to retain the quality of life of people living with AD with drug treatment, but that it was not possible to slow down or stabilise the progress of the condition and the overall decline:

> I do not think it can be cured. They are probably able to maintain your quality of life with medication. But usually these people are in decline, as far as I know. (Male, 58, LE)

Typically, some female respondents mentioned that dementia might be avoided or delayed through lifestyle factors, such as living healthily, physical exercise, and activating and training the brain. However, these informants appeared to not be entirely sure and in fact be in doubt whether dementia can truly be avoided or delayed by managing lifestyle factors. During the interviews, these respondents were wary of not appearing gullible, that is, of appearing to believe just about anything they heard and read. Instead, these study participants emphasised their common sense and an attitude of 'no harm, no foul' with regards to the link between lifestyle factors and dementia:

> They say that keeping your brain busy and using the computer might prevent it, but I … it doesn't hurt to try. No harm, no foul. (Female, 70, HE)

> Living healthily being of influence on your brain is sometimes rejected, because we all know people who live unhealthily and who do not get Alzheimer's or dementia. It is also said that solving puzzles is good for your brain, but there are also people who contradict that. I take everything in perspective and with common sense, although I do think that living healthily can have an influence. (Female, 68, ME)

On the whole, quite a lot of respondents seemed to have encountered conflicting narratives and opinions about AD. As a result, it was often difficult for them to establish what was fact and what was fiction, what was beneficial and what was deleterious. Some respondents took to the view that staying active and healthy was always a good thing, regardless of whether these lifestyle efforts were able to delay or avoid the onset of dementia:

> Is it true, is it not true? I don't know. Of course, rest leads to rust. (Female, 71, LE)

Sources of AD information

Respondents had difficulties recalling the sources from which they had obtained their knowledge and understanding of AD. The traditional mass media and the internet were mentioned by most in a general and nondescript way. Others did not remember at all how they had learned about AD:

> I have read about it here and there, but I haven't looked up anything. It might have been in the newspaper, but I cannot directly say from which particular source. (Male, 60, HE)

> Gosh. Where did I hear that … Good question. I have to think about it for a while. Maybe I saw it on television. (Male, 67, ME)

The majority of study participants did not seem to remember their sources of AD knowledge as they had obtained most information in accidental, non-purposive ways:

> Sometimes I hear something coincidentally, find it interesting, and remember and save it, but sometimes I no longer know from which source it came, from a magazine, or the internet, or television, I don't remember. (Female, 62, LE)

By extension, the following respondent explained how a lack of immediate personal relevance led to her not really saving any information about AD:

> If you don't actually come into contact with the condition, you don't really store the information. If you can't really do much with the information or have use for it in daily life, it might linger somewhere in your head. (Female, 56, ME)

While most informants could not remember specific sources of information, they did indicate that their knowledge came not only from digital and traditional mass media, but also from everyday interpersonal interactions, particularly from hearing dementia stories and the experiences of others:

> You read about it or hear about it from other people. When the television is on, or on the news you hear the same. About forgetting and other things. (Male, 51, ME)

> My friend tells me regularly about what she encounters with her mum. The deterioration process, she sometimes tells me about that. (Female, 59, HE)

Despite respondents having difficulties recalling the origins of their understanding of AD, four distinctive information sources were remembered with surprising clarity and vividness, namely novels, films, personal experiences/social proximity and public figures.

Novels

Respondents mentioned the novels *De Zaak Alzheimer* (*The Alzheimer Case*, 1985) by Flemish writer Jef Geeraerts and *Hersenschimmen* (*Out of Mind*, 1984) by Dutch novelist J. Bernlef as having formed their understanding of AD. Many years after reading the book, this respondent recalled how her image of AD had been shaped by Bernlef's work:

> When I think about Alzheimer's, I think about that book *Hersenschimmen*. It has been 27 years since I read it, but it is a book that sticks with you. (Female, 70, HE)

Film

Both novels mentioned above were turned into namesake feature films, *Hersenschimmen* in 1988 and *De Zaak Alzheimer* (*The Alzheimer Case*, internationally also known as *Memory of a Killer*) in 2003. The latter was released to critical and commercial acclaim and seems to have made a lasting impression on Flemish audiences, as *The Alzheimer Case* was explicitly mentioned by study participants as having introduced them to the topic of AD:

> It's a psychic thing, isn't it? And that people become forgetful. I have seen the film *Alzheimer*. That was the first time I came across that word. (Male, 76, LE)

> That Flemish film … *De Alzheimer Zaak*, that is what gave us a bit of an impression. (Male, 58, LE)

The Alzheimer Case uses AD and the progression of symptoms to attract the attention of the viewer and enhance the story's suspense (Medina, 2018). Memory loss and disorientation rapidly develop in the main character, who attempts to cope with his mental degeneration by using experimental medication and writing information on his forearm. This depiction of AD is problematic as the rapid progression of the condition and its symptoms and the use of experimental medication during episodes of confusion to get a boost is unrealistic (Segers, 2007). However, none of the study participants indicated in any way that the representation of AD in *The Alzheimer Case* might not be true to reality or be exaggerated for entertainment purposes. In fact, respondents seemed to think that films in general offer sincere and true-to-nature depictions of what it is like to live with dementia:

> Of course, it is a film, but in broad terms it shows a fair image of what occurs in daily life. You become more familiar with it. (Female, 61, ME)

Besides introducing viewers to AD, fictional narratives such as *The Alzheimer Case* also triggered respondents to seek out more information. The following participant explained that watching *The Alzheimer Case* led him to seek out information to understand the film's title and story. Moreover, he recognised that watching the film and getting an image of what it is like to live with AD had in effect led him to encounter medical information about AD:

> I wondered why the film was called like that and why the actor forgot things. I looked up what it is about. That is medical information which comes to you

> unconsciously. Because you immediately have an image of someone who has that disease, so you can make that connection. It is recognisable. (Male, 53, HE)

In addition to *The Alzheimer Case*, respondents mentioned having seen other feature films about dementia. Aside from the American drama film *Still Alice* (2014), informants were, however, mostly unable to recall any film titles.

Personal experiences and social proximity

Besides fictional narratives, personal experiences and social proximity contributed to respondents' knowledge of AD. About half of the study participants had experience with AD in their family or in their extended social network (*e.g.* friends, neighbours, colleagues). Some informants had previously, though not during the time of the interviews, taken care of people living with AD as care-givers or volunteers. Drawing on their past experiences as care-givers and/or their social proximity to people living with AD, these informants were generally able to describe AD more accurately and more extensively than respondents without personal experience and social proximity to people living with AD:

> I have known several people with Alzheimer's and yes … that stays with you. It sticks. (Male, 79, LE)

Other informants (had) worked in health care and knew about AD from their medical training and contacts with people living with dementia. These experiences had made lasting impressions, contributing to a heightened awareness and knowledge of the condition:

> I still see this lady in front of me. She was completely disoriented. A serious case of Alzheimer's. She was still walking around but had no idea where she was. No sense of norm or decorum. That woman is for me the image of Alzheimer's. (Female, 67, ME)

Public figures

Public figures and neurology specialists with a degree of recognition and fame because of their work and/or media appearances also contributed to respondents' knowledge of AD. One person stood out, namely molecular biologist Christine Van Broeckhoven, a prominent and distinguished Flemish researcher in the field of neurodegenerative brain conditions. She was described by many interviewees not only as the face of Belgian efforts to understand, treat and cure AD, but also as an inspiration and relevant source of news and information, among others via her Facebook page:

> She has done a lot of work and is appreciated for that. She sometimes appears in the news, because she is one of the world's leading personalities and researchers in that field. (Male, 63, HE)

Purposive information seeking

While the majority of respondents encountered information and news about AD accidentally as part of their routine media use, some respondents actively sought out information about the condition. The main reason to do so was concern and fear of personally developing dementia:

> My mum had Alzheimer's, so I have a bit of fear. I hope I don't get it either. I am alert for that. Of course, I have already Googled what the symptoms are. (Female, 55, LE)

Proximity to people living with AD was another reason to actively search for information. Specifically, respondents searched for AD information to satisfy their curiosity and/or to understand what someone else was going through and how to support that person:

> If someone I know would have a partner with Alzheimer, I would look up information. To understand and to be able to support that friend, I would look up what it is and what can be done. (Female, 52, ME)

> Because we knew three or four people with Alzheimer, we looked up information. (Male, 79, LE)

Conversely, when there was no personal relevance and/or social proximity to someone living with AD, this translated to the absence of an information need or want. As a result, these respondents obtained information about AD almost solely from unintentional and non-purposive information encounters:

> I would look up information on the computer about Alzheimer, or if necessary go to the library, but there is no one in my surroundings with it. (Female, 71, LE)

Having presented our empirical results regarding the perception and knowledge of AD and sources of AD information, we proceed to discuss the findings and their place within the literature. We also consider the implications of the findings in light of public health and dementia-awareness campaigns, as well as AD education.

Discussion

This study set out to understand what Flemish middle-aged and older adults between the ages of 50 and 80 know about AD and from which sources of information they obtain their perceptions and understanding. Our study shows that respondents compiled their knowledge of AD from various channels and sources, both traditional mass media and digital media, as well as everyday interpersonal interactions. While information about AD was sometimes actively sought on the internet in response to an information need or want, the majority of information was obtained accidently during routine exposure to traditional mass media sources, *e.g.* when watching television or reading a newspaper. Taken together, these findings not only confirm the relevance of the media complementarity theory by

Dutta-Bergman (2004), but also illustrate the usefulness of expanding the theory to include interpersonal channels of information as well as different modes of obtaining health information (*i.e.* purposive seeking, non-purposive encountering).

While acknowledging implicitly and explicitly that their knowledge of AD came from multiple sources (*i.e.* media complementarity), most respondents could not recall or could only vaguely remember from which channels or sources exactly. We found four distinctive exceptions, namely novels, films, personal experiences/social proximity and public figures. The first two suggest that literary and cinematic fictional narratives, through their vividness and potential for readers/viewers to engage with the story and identify with the characters, are able to offer representations of AD which leave lasting impressions. It would thus seem that being able to empathise with characters living with AD, even though they are fictional, helps to make AD information stick. Personal experiences and social proximity to people living with AD offered respondents first-hand impressions and knowledge, while public figures (*e.g.* specialists, celebrities) gave AD a recognisable face. This latter finding echoes earlier work which found that the AD diagnosis of former US President Ronald Reagan in 1994 led to mass news coverage and AD being brought into the consciousness of many Americans (Basting, 2009). It thus appears that when AD is given a face, either because of personal experiences/social proximity or through the proxy of a public figure, respondents are better able to remember and recall AD information. These insights about which information sources and types enable AD information to be firmly embedded might be of particular help to dementia-awareness campaigns and AD training programmes for health-care professionals and family care-givers.

One of the most remarkable findings is the prominence of the film *The Alzheimer Case* in exposing study participants to AD and, in some instances, triggering them to seek out more information. As previously noted, both the big (cinema) and small (television) screen propagate images of health and illness, thus contributing to the public's perception, knowledge and attitudes towards AD (Segers, 2007; Gerritsen *et al.*, 2014; Capstick *et al.*, 2015; Medina, 2018). Fiction film is particularly influential in popularising dementia and influencing public perceptions, as health information wrapped under the guise of entertainment is likely viewed and processed unintentionally and unconsciously (Segers, 2007; Gerritsen *et al.*, 2014; Capstick *et al.*, 2015). For instance, the Hollywood blockbuster *Rain Man* (1988), with Dustin Hoffman and Tom Cruise, is credited with having established the persistent stereotype of people with autism possessing savant skills (Segers, 2007). Likewise, *The Alzheimer Case* contributed to respondents' understanding of AD, and perhaps by extension a sizeable part of the Flemish population, given the film's commercial and critical success.

While these dramatised depictions offer engaging and vivid narratives of illness (Kline, 2011), thereby communicating health information and messages, they are first and foremost cinematic entertainment (Segers, 2007; Medina, 2018). Kline (2011) finds that health messages in popular media are often obfuscated by factual inaccuracies, misrepresentations and omissions, as entertainment values rank higher than factual and medical accuracy. Capstick *et al.* (2015: 234) argue in addition that authenticity in representing dementia in film is subordinate to 'melodramatic, sensationalist, or emotionally manipulative representations'. Capstick *et al.*

(2015: 229) thus conclude that cinematic depictions of dementia are 'rarely innocent or unproblematic' and need to be approached carefully as popularised representations of dementia. Inaccurate cinematic portrayals of AD might perpetuate stereotypes and lead to misunderstandings and unrealistic expectations as the audience is left to distinguish between fact and fiction (Gerritsen *et al.*, 2014; Capstick *et al.*, 2015). In *The Alzheimer Case*, the rapid development of the condition and its symptoms as well as the use of experimental drug treatment to get a temporary boost might give rise to such misperceptions and misunderstandings.

The perpetuation of stereotypes, misperceptions and unrealistic expectations brings us full circle to the first part of our study, namely what respondents know about AD. Like previous studies (Cahill *et al.*, 2015), we found certain common misunderstandings, predominantly AD being seen as inherent to the normal ageing process and old age, as well as AD and dementia being used interchangeably. In addition, we found that respondents often were not sure what AD exactly is and what it is not. Most notably, AD was confused by quite a lot of respondents with Parkinson's disease. With regards to treatment, respondents correctly identified that there is no cure for AD, but that drug treatment might be able to maintain individuals' quality of life. This is consistent with the literature, although drug treatment as well as good dementia care can in fact alter the course of the condition and manage many of its manifestations (Livingston *et al.*, 2017; Cations *et al.*, 2018).

Of particular interest and relevance is the impact of, respectively, the biomedical and lifestyle perspective on respondents' perceptions and knowledge of AD. The biomedical perspective and its attendant tragedy discourse clearly prevailed amongst the majority of respondents, who described AD in dark and negative terms of decline, loss and death (*i.e.* 'the beginning of the end'). Informants pointed to pharmaceutical interventions and the absence of a cure, while largely lacking knowledge about non-pharmaceutical interventions and/or lifestyle and dementia risk factors. Only a few female informants stated that individual health behaviour and lifestyle choices might help to prevent dementia or delay its onset. However, even among these respondents there appeared to be considerable uncertainty as to what is true and helpful and what is not with regards to preventing or delaying dementia via social, mental and physical activities, and exercise. Considering the fact that a third of all cases of dementia can be delayed or prevented by managing lifestyle and other dementia risk factors (Livingston *et al.*, 2017), this suggests that there is still a lot of ground to cover in terms of raising public awareness of dementia risk factors and preventative behaviour.

Further, the findings of this study underwrite the notion by McParland *et al.* (2017: 263) that the living well discourse is 'yet to have a significant impact on public discourse'. The biomedical perspective and tragedy discourse appear to dominate and shape media narratives and representations, as well as the understanding of dementia by the public, including the Flemish middle-aged and older adults in this study. Although the living well discourse can present new challenges for people living with dementia by placing social expectations on them (McParland *et al.*, 2017), more emphasis on the living well discourse in health campaigns and media accounts might help to counter stereotypes and alarmist and negative narratives, thus bringing more balance to how dementia and AD are represented, perceived and, ultimately, understood by the public. To that end, dementia awareness and public health campaigns might draw from and highlight the lifestyle perspective and living well discourse to disseminate information to increase public knowledge, redirect misunderstandings of AD and stimulate preventative behaviour. As the world population ages and the number of individuals living with AD is expected to rise (Livingston *et al.*, 2017; WHO, 2019), this might help health-care systems and governments to cope and save costs.

Lastly, raising public awareness of dementia has become one of the key elements of public health policies (Cahill *et al.*, 2015), of which the 2017 WHO Global Action Plan on Dementia is a main example (Cations *et al.*, 2018; WHO, 2019). As Cahill *et al.* (2015: 256) note, 'health educational programmes and national awareness campaigns need to be based on the evidence of what people know, rather than on what policy experts and educators think people know'. This study has not only pointed out public knowledge gaps and misconceptions of AD, as well as the dominance of the biomedical perspective and tragedy discourse, but it has also exposed sources of information from which respondents derive their understanding of AD. Together, these findings and insights can be of help to public health communicators and health campaigns aimed at raising awareness of and educating the public about AD, as well as education and training programmes for care-givers and health-care professionals.

Conclusion

This study examined the perceptions and knowledge of Flemish adults between the ages of 50 and 80 with regards to AD and their cross-source engagement with information channels and sources. Underwriting past studies, respondents' knowledge of AD was limited and often characterised by misconceptions and uncertainty. On the whole, our findings suggest that media narratives about AD, particularly those depicting the rapid development of the condition and its symptoms as well as disturbing stories about the latter and terminal stages of the condition, considerably shaped respondents' perceptions of AD. As a result, the biomedical perspective and the attendant tragedy discourse prevailed amongst the majority of respondents, who described AD in terms of decline, loss and death as 'the beginning of the end'. Only a few, typically female respondents were aware of the potential of individual health behaviour and lifestyle choices to prevent dementia or delay its onset. As such, this study demonstrates and stresses the importance of public educational programmes and the need to emphasise and raise awareness of the role of lifestyle factors and other dementia risk factors and how preventative behaviour fits in.

In terms of sources of AD knowledge, respondents mostly gathered bits and pieces of information unconsciously (non-purposively) from traditional mass media as part of their routine media use and from interpersonal sources. For some respondents with personal concerns or concerns about others, the internet served to facilitate the occasional active and purposive seeking of AD information. Typically, novels, films, personal experience/social proximity to people living with AD as well as public figures stood out as sources of AD information because of their vivid, compelling narratives and/or because they gave a recognisable face to AD. Overall, our study confirms as well as expands Dutta-Bergman's (2004) media complementarity theory to include purposive and non-purposive AD information engagements with traditional mass media, digital channels and interpersonal interactions.

With the world population ageing and the number of individuals living with AD expected to rise significantly, the findings of this study emphasise the importance of public educational programmes on dementia and the need to increase the public's knowledge about AD. Further, the findings of this study, particularly with regards to respondents' sources of AD information, can be of help and interest to public health and dementia-awareness campaigns, as well as AD training programmes for health-care professionals and family care-givers.

Study limitations

The findings and results of the present study should be considered in light of the limitations of qualitative research. First and foremost, as the qualitative data pertain to a unique sample of Flemish middle-aged and older adults, the results cannot and should not be generalised. Future research might attempt to replicate our findings in other geographies and see, for example, if the same types of AD information sources are prominent. Second, our respondents were spread out over a considerable age range. Besides reflecting a larger health communication audience research, this did not inhibit the study but rather helped to find differences and nuances between younger and older respondents. Lastly, our interviews did not discuss in depth how films like *The Alzheimer Case* exactly shape and influence viewers' knowledge. While representations of dementia in cinema have been studied, more work is needed to understand the reception of these films by the audience and their impact on the public's understanding of AD. More broadly speaking, research which combines an analysis of media representations of AD, on the one hand, and public perceptions, on the other hand, as well as their mutual relationship, is welcome. Thus, while we have shed more light on it with this study, the Alzheimer's case remains open.

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Ethical standards. Standard ethical and legal guidelines were followed in setting up and carrying out the interviews with the respondents. For this study, as well as the larger audience research about health communication and information in relation to ageing that it is part of, approval was requested and given by Ghent University Hospital. Prior to participating in the study, all interviewees signed an informed consent in which the research project was explained, confidentiality was guaranteed and in which respondents consented to the interview being recorded. Participants were informed that they could withdraw from participation at any time, for any reason, without negative consequences, as well as request to have their data deleted.

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