



Exposing negative societal perceptions and stigma towards individuals with dementia

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Abstract

Dementia is a progressive neurological disorder, which is often linked to negative connotations and stigmatising views perpetuated by its portrayal in media. Media frequently frames dementia as a catastrophic and inevitable decline, emphasising the loss of cognitive function of the individuals and their personhood. Such representations contribute to public fear, leading to misunderstanding of the disease, social distance and reinforced stereotypes suggesting that individuals with dementia are burdensome and devoid of agency. These narratives in the media foster a culture of stigma, leading to discrimination, isolation and a reduction in the quality of life for those affected. This commentary deliberates on the complex relationship between these representations and their impact on individuals living with dementia and their families, underlining a need for more balanced and compassionate representations that combat stigma and promote a more inclusive and supportive environment for individuals with dementia.

Keywords: Societal perceptions; Stigma; Dementia; Alzheimer's.

Commentary

Dementia is a condition in ageing societies which is of increasing importance because many individuals worldwide are affected by dementia and this figure is rising. It was suggested that approximately 6% of individuals over the age of 65, and 24% of individuals over the age of 85 years suffer from one type of dementia [1]. A more recent report by the Alzheimer's society [2] estimates that one in three people born in the UK will suffer from dementia at some point in their lifetime. Additionally, the number of individuals suffering from a form of dementia in the UK is projected to rise to 1.4 million by 2040 [2]. From a global perspective, there are currently more than 55 million individuals living with dementia, which is expected to rise to 139 million by 2050 [2]. Even though dementia has been extensively explored in the academic literature, there are misrepresentations of the disease in mainstream media channels that distort people's perceptions of the disease. These representations contribute to the misunderstanding of the disease, and this shapes the societal perceptions towards those who suffer from it. In addition, previous literature highlights the issues regarding the

public education on dementia and societal awareness of the disease [3].

Culture is an important variable which has a significant influence on societal perceptions [4]. As such, mental illnesses, behaviors or characteristics might vary in their societal acceptance dependent on the cultural and societal norms. Cultural stigma is defined as the shared prejudices, negative belief systems and structures which can be discriminating within a society [5-7]. Stigma from a cultural perspective towards dementia patients might mean that there will be higher levels of fear of dementia and its sufferers [8,9], the culture will experience therapeutic nihilism [10] and the chances of having locked care units for dementia patients will be more acceptable [11].

From a patient's perspective, dementia stigma might lead to a failure to seek help [8,9], and healthcare professionals' reluctance to diagnose dementia patients [12]. Experiencing stigma due to dementia diagnosis might cause individuals to feel ignored, experience discrimination within the healthcare system, and experience perceived stigma by other individuals due to dementia being closely linked to depression, low self-esteem, lack

It is important to consider the significant influence of mainstream media on shaping attitudes and behaviors towards mental illnesses. The existing literature suggests that the current representations of dementia in the media are closely linked to cultural stigma [15]. Media provides members of the public with a stereotypical representation of dementia, where individuals living with the disease are old, passive, impaired and have no independence and quality of life [16-18]. Even though, dementia is portrayed as an “old people” disease in the media, there are currently more than 70,000 people living with young onset dementia in the UK, where the symptoms of the disease develop before the age of 65 [2]. As such, these negative portrayals of individuals living with dementia reinforces negative stereotypes and leads to more negative societal perceptions by instilling stigmatizing views to the public opinion [18].

Society perceives dementia as a normal part of aging, which hinders individuals from taking actions. This hopeless acceptance of every single individual battling with dementia in old age prevents patients and their family members from having adequate access to support systems and leads to an average delay of 4 years when it comes to getting a diagnosis. As a result, individuals become more vulnerable both financially and legally, and experience stigmatization and social isolation [19].

In their systematic review of dementia in popular culture, Low and Purwaningrum [20] highlight that the media often interchangeably use the term dementia with the term Alzheimer's. Dementia is an umbrella term which incorporates different types such as vascular dementia, Alzheimer's disease, frontotemporal dementia, amongst others. Previous literature highlights that Alzheimer's disease accounts for %50 to %70 of dementia cases [21]. Given that the media does not accurately represent the disease and use related terms interchangeably might contribute to the misinformation amongst the societies and muddy the understanding of different types of dementia. The misinformation on popular media might be considered one of the culprits of the negative societal perceptions towards those living with any type of dementia.

Dementia has been adopted as a convenient plot twist in cinema since early days. Many movies have represented the disease with the aim of building bridges of empathy between sufferers and members of the society. Historically, the representation of dementia was very closely linked to being forgetful in the movie industry. However, more recent depictions of the disease represent it from a more humane perspective, by focusing on different symptoms in more detail. Suffering from any type of dementia is much more than forgetting. There is a complex tapestry of symptoms that dementia weaves which is life changing not only for the individual suffering but also for their loved ones [22]. Some of these symptoms relate to individuals grappling with their changing identities and idea of self, struggling with language and transitioning into a new reality.

Given the recent developments in cinema, there are also stronger representations of the impact of dementia on the caregiver's perspective. Existing literature often highlights the cost of caring for a loved one suffering from dementia [22] and its impact on the carer's own well-being [22]. Research underlines the importance of the shift in family dynamics when a loved one is diagnosed with dementia [23]. As such, accurate representations of the carers' experiences might also contribute to shifting the perspectives surrounding dementia.

A report published in 2022 found that 11.5 million families spend an average of 18 billion hours of care on Alzheimer's and other dementia patients [24]. As can be estimated, the 18 billion hours of care include meeting the patient's basic needs (cleaning, excretion, dressing, movement, etc.), managing doctor and hospital relations for medical treatment follow-up, keeping neuropsychiatric symptoms under control (depression, agitation, apathy, aggression, mania, and psychosis), and managing the patient's economic processes within the framework of legal responsibilities through ‘guardianship’. In addition to the daily duties listed above, carers of dementia patients fail to balance a healthy balance in their own lives when it comes to managing their personal time, socialisation, physical, emotional, and economic needs. This imbalance between being a caregiver and attempting to live a fully functioning life is called ‘caregiving burden’ [25]. Additionally, a decrease in work performance, and experience of chronic illnesses are commonly reported amongst dementia patient carers. Thus, dementia is a costly disease both for the patient and individuals who turn into full-time carers to meet their needs.

Stigmatisation can occur at any given time, as any one individual might consider a specific trait or behaviour offensive or inappropriate [26]. As such, it is not possible to list all the grounds for stigmatisation of individuals and behaviours. Attitudes, perceptions, and beliefs towards behaviours which have been labelled as “deviant” or “different” are complex and multifaceted, and might vary dependent on different factors (law, location, religion) and situations. Individuals who suffer from dementia and its types – and their carers might experience stigma within their families, social groups and the society. The present review article discusses the existing literature surrounding the perceptions towards dementia from a broader perspective and provides a discussion of the anecdotal evidence and media representations of the disease with the aim to raise awareness of this significant topic.

Historically, the term *stigma* has had different conceptualizations, such as cuts or burn marks on criminals, slaves, and traitors, in order to easily identify them as people who are immoral and should be avoided [27]. In more recent times, however, stigma is considered an attribute which results in social disapproval [27]. There are different ways in which stigma can be expressed in society. Depending on the situation, it can present itself in an observable way or manifest itself in subtle ways. Individuals can reject (groups of) people socially, practice avoidance and refuse to interact with one another [28]. Moreover, stigmatisation might occur as nonverbal expressions of discomfort (e.g., avoiding eye contact, keeping distant from certain individuals) which may lead to tense interactions amongst the individuals in the society [29]. Independent of how it is manifested, it is imperative to consider stigma as a concept that is present globally. Indeed, almost any behaviour or characteristic might be perceived as deviating from the norm by any specific observer [26]. Thus, it is possible to stigmatise any kind of deviation amongst individuals.

Moreover, stigma is a complex concept which encompasses individual experience and the interaction between groups [30]. According to Goffman [6] stigma is an attribute which links an individual to undesirable stereotypes, which leads other people to reduce the bearer from a whole and common individual to a discounted one. Individuals who experience stigma are exposed as a consequence to negative attitudes such as fear, blame, hostility, and discrimination (unfair treatment, segregation, exclu-

sion) from other members of society [30]. When focusing on individuals who suffer from dementia, the negative attitudes above might extend to their family members given the negative connotations attached to the dementia patient by the society.

Many groups of individuals suffer from detrimental consequences of experiencing stigma, impacting both their personal and professional lives [31]. Some of these consequences might lead to experience of further mental health conditions such as depression, social isolation, and lack of self-image leading to a decrease in an individual's self-worth [32-35]. Individuals who suffer from dementia or one of its types are already vulnerable due to the consequences of the disease. As such, experiencing stigmatising views might add further weight on their well-being and might lead them to further isolate from the society.

In the context of Dementia, it is imperative, therefore, to enrich the societal understanding surrounding stigma, its impact on individuals and the interaction of different components related to stigma in order to successfully reduce and manage its outcomes. By improving the societal understanding of stigma and the attitudes towards individuals suffering from dementia, it will be possible to achieve more positive outcomes on the quality of life and care of dementia patients which will also subsequently increase the support available to their carers and family members.

In attempts to reduce stigma surrounding Dementia, stigma theories [27,36-38] suggest that conceptions of mental illness and disease are developed during early life due to an individual's family interactions, personal experience, social relationships, and the portrayal of individuals who suffer from mental illnesses in the media [39,40]. Thus, individuals tend to form expectations about whether other members of the society will reject individuals with mental illnesses and whether people suffering from a mental illness will be considered less valuable, less intelligent, and less competent. These beliefs become of importance to individuals who develop a mental illness by leading them to believe that others will reject them and consider a less valuable part of the society [40].

There have been active attempts to reduce stigma towards individuals living with mental health issues in order to improve the lives of these individuals [41]. Some of these attempts include educating the public on specific topics such as mental health to reduce the stigmatising conditions. For instance, the National Alliance of the Mentally Ill, established by the family members and individuals with mental illness, who call themselves "stigmabusters" carry out protests against the media representations of stigma across the U.S. [41]. In Germany, for example, groups of individuals and organisations (i.e., BASTA) who ally for individuals suffering from mental health conditions engage in campaigns using technology (e-mailing lists) and hold extensive education programmes in schools and at government organisations such as the police departments and academies to educate the public on mental health illnesses [41]. Similarly, in Australia and New Zealand, the government leads both regional and national initiatives for individuals with mental health conditions active engagement and participation in the society.

Three main strategies have been utilized to tackle stigma: education, protest and contact [42]. Individuals and organisations have utilised educational programmes to reduce levels of stigma by providing information contradictory to societal beliefs. Individuals being exposed to educational courses on mental health conditions has led to a reduction on stigmatising at-

titudes amongst different groups of individuals [police officers, 43; government employees, 44; high school students, 45]. Even though, psychoeducation has been reported as an effective way to tackle stigma surrounding mental health issues and "deviant" behaviours, the research on the impact of educational campaigns suggests that the behavioural change after participation in these programmes is not accurately measured [41]. Furthermore, educational programmes might be more effective on individuals who had previous understanding of mental health conditions or experienced a firsthand contact with an individual suffering from a mental illness previously [46].

Protest often involves the public's reaction towards stigmatising statements, reports or advertisements involving minority groups [42]. Around 80 percent of discriminating cases that BASTA took action against in Germany were successfully stopped and the media institutions publicly apologized for stigmatising advertisements and inaccurate media representations regarding individuals with mental health illnesses. Similarly, Wahl [47] suggests that protest and similar initiatives have been effective in the U.S. when it comes to reducing negative public attitudes towards mental illness. However, social psychological research suggests that engaging in protest might lead to individuals suppressing their stereotypical thoughts and discriminating behaviour. Individuals who engage in suppression might be less likely to learn new information regarding their stigmatising stereotypes [48] and within time, they might experience more stigmatising thoughts in comparison to before [49]. As such, even though protest might be considered a useful strategy to reduce stigmatising public images, it may not lead to a significant change in discriminating behaviour in the long run [41].

Further, Allport [50] introduced the term contact hypothesis which proposes that acquaintance and knowledge will help reduce the levels of prejudice. The opportunity to get to know an individual or a minority group, makes it possible to break down the stigma and prejudice [51,52]. When a person who has stigma against a particular individual or group encounters a minority group member and have a positive experience with them, an attitude change will take place [50]. Firstly, the negative stereotypes associated with the group will change to a more positive perception of the individual and/or the group. Secondly, these newly developed positive perceptions towards the individual will extend to the individual's group. As such, the integration of individuals who suffer from dementia into the society holds a crucial value when it comes to increasing contact. One of the culprits of low contact with individuals suffering from dementia might be the negative portrayal of the disease in media. Creating more opportunities for dementia patients to be integrated in the society might challenge these negative attitudes towards these individuals and also contribute to bridging empathy between them and members of the society.

There is much empirical research that focuses on defining and explaining stigma and its intertwined components such as prejudice, stereotyping and discrimination rather than exploring and assessing interventions which might lead to the reduction of stigma experienced by individuals [53]. Given that stigma is a universal experience which impacts one's decision to seek care [54], scholars should aim to further explore strategies to reduce the broad and pervasive effects of stigma on individuals and the society [55].

Conclusion

Experiencing any form of Dementia comes with a cost for

the individual and their caregiver. Even though extensively researched by scholars, perceptions and attitudes towards dementia might be influenced by various factors such as personal conditions, cultural and societal norms, and media representations of the disease. Individuals who suffer from dementia and their caregivers might suffer from additional burden due to the stigmatizing views of the public. As such, future directions might consider exploring the lived experiences of dementia patient carers is equally as important when it comes to providing them with the right support network and ease their caregiving journey. Improving our understanding of experiences of individuals living with dementia and lived experiences of their carers will pave the way to more inclusive policies and contribute to designing better media guidelines which might lead to a more positive representation of the disease. Finally, reviewing policies and media guidelines might normalize the perceptions towards those living with dementia, lead to a more compassionate treatment within the society, and spark more evidence-based educational tools and strategies to reduce stigma surrounding this progressive disease.

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