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“The Graying of the World”: Medical and Popular Expressions of Dementia

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Abstract
Unlike the biomedical account of illness, cultural/social/literary models investigate the central role of culture in mediating the lived experiences of the sufferers. As such, the meaning of illness is not shaped by biomedical factors alone, cultural artefacts also determine the social meanings of illness and suffering. Put differently, popular cultural media such as films, novels, television, and advertisements among others collectively generate and shape public attitudes toward illness. However, popular cultural media very often promote the prevailing stereotypes and normative concepts of illness and thus negatively contribute to the understanding of illness conditions. Along these lines, existing cultural and literary discourses on Alzheimer’s disease and related dementia (ADRD) trivialize dementia and dehumanize the sufferers of dementia as zombies, empty shells, and non-persons. Taking these cues, the present paper close reads popular representations of dementia in movies, newspapers, novels, and comics in order to demonstrate how such representations of ADRD reinforce dominant stereotypes and even sustain them. Furthermore, the paper also investigates the negative implications of such representations in the context of illness and ADRD on personal and social lives.

Keywords: representation, media, stigma, dementia, Alzheimer’s disease

Illness and Representation

“Pictures or representations of bodies that we conjure up in our minds influences our experience of the real bodies (including our own) that we come upon in life. One of the cornerstones of the humanities is that the study of the body, its processes and illnesses, is pervasively affected by our own cultural presuppositions about bodies.”
— Sander L. Gilman (2014, 171)

While illness is patient’s perspective on his ill-health, the experience of illness is universal depending on various factors as Renee Fox (1968) remarks thus: “particularities and nuances of the emotional meaning of an illness to an individual and the nature of his affective response to his state and symptoms are profoundly influenced by his social and cultural background as well as by his personality traits” (p. 91). As claimed by David Morris (2000), illness is “always created at the crossroads of biology and culture” and hence, should be perceived as “the unique experience of a meaning-making and embodied cultural being” (p. 8). Morris, therefore, observes the role of cultural codes and discourses in mediating the experience of health and illness. By reflecting and (re)shaping the public’s perceptions and attitudes towards illness, cultural representations are
crucial in creating the social significance of illness. At another level, patients usually internalise illness concepts created and disseminated through various cultural and literary discourses. Among representations, the role of popular cultural media such as films, fiction, and TV programmes in shaping collective meanings of illness cannot be neglected. These popular cultural media mould the public perceptions of illness and people’s experience of illness because they are not just “a reflection of the world,” but rather “an active shaper of reality” (Jenkins, McPherson, Shattuc, 2002, p. 39). Popular culture has a long history of misrepresenting diseases such as plague, cancer, AIDS, schizophrenia, bipolar disorder and dementia.

In her seminal works Illness as Metaphor, Susan Sontag demonstrates how popular cultural texts such as novels and films, along with other cultural artefacts, perpetuate demoralising metaphors of illness which affect the afflicted adversely. Sontag (1978) argues, while plagues are “invariably regarded as judgements on society” (p. 13), AIDS and cancer are penalised and considered as results of an unhealthy lifestyle, addiction and self-indulgence (p. 113). Emma Gray Munthe (2020) observes how popular culture has been instrumental in framing the LGBTQ community as the causal agent for AIDS thus: “the early story of AIDS was all about “family values”, homophobia, stereotyping and fear of the other” (n.p.). The recent drama series on the OTT platform (Prime Video), Breathe: Into the Shadows (2020), positions the leading character with split personality as ferocious and murderous. In the same fashion, the most famous superhero, The Dark Knight (2008), projects Joker as a psychopathic illegal mastermind behind mass murdering and an agent of chaos. Again, popular Hollywood films, Psycho (1960), Total Recall (1990), Shutter Island (2010) and The Visit (2015), portray unflattering stereotypes associated with the mentally ill as violent and criminally insane. Such distorted images of the insane “overtly or covertly colour our concept and serve to categorise them upon first glance” (Gilman, 2014, p. iii). In the context of cancer, Sontag (1978) notes the adverse impact of restrictive cultural imaginings of illness thus: “as long as a particular disease is treated as an evil, invincible predator, not just a disease, most people with cancer will indeed be demoralised by learning what disease they have” (p. 7).

Social representations provide a framework showing how socio-cultural and historical forces impact individuals’ health-related thoughts and actions. Social representation is concerned with the explanations and assumptions ordinary people give for their illness experience, which they encounter in the social world. The purpose of social representation, as stated by French social psychologist Serge Moscovici (1984):

“These are the questions then to which we hope to find answers: What goes on in people’s minds when they are faced with life’s great enigmas such as illness...? How do the systems of social representations this imposing heritage that turns us into active participants in society even without our being aware of it, how do these systems being and then evolve?” (p. 941).

People’s commentary on the world and the spontaneous philosophies they articulate are presumed to build up their sense of reality. Again, in The Wounded Storyteller, Arthur Frank (1995) writes of the importance of representations of illness and how these determine the experience of illness:

“The shape of the telling is molded by all the rhetorical expectations that the storyteller has been internalising ever since he first heard some relative describe an illness, or she
saw her first television commercial for a non-prescription remedy, or he was instructed to “tell the doctor what hurts” and had to figure out what counted as the story that the doctor wanted to hear. From their families and friends, from the popular culture that surrounds them, and from the stories of other ill people, storytellers have learned formal structures of narrative, conventional metaphors and imagery, and standards of what is and is not appropriate to tell. Whenever a new story is told, these rhetorical expectations are reinforced in some ways, changed in others, and passed on to affect others’ stories.” (p. 3)

Elsewhere, a study on social representations of health and illness in *Health and Illness* (1973) by Claudine Herzlich demonstrates that people’s accounts of health and illness focus on the genesis of illness primarily assigned to the urban lifestyle. People say that contemporary urban living is unhealthy, city life is unnatural, and people are not built for it. As a result, the decline in health produces vulnerability to illness.

The experience of dementia and its reception is, like all other illnesses, subject to the influence of representations in various genres, media and formats, from the biomedical to the popular. Stereotypes of old age and its related problems are responsible for shaping how dementia is perceived. Metaphor, imagery, and emotive language are three primary devices used in media representations of dementia, including news broadcasting. Moreover, such descriptive features influence the everyday conversation about dementia, perpetuating negative attitudes towards the condition. The study shows that the prevalent, pessimistic attitudes presented in the media perpetuate the stigmatisation of dementia. Jackie Guendouzi and Nicole Muller (2006) present an analysis of dementia in the media that reveals a predominantly negative angle. Similarly, Gillian McColgan (2004) notes that “despite a definitive research focus on finding the social meaning of dementia developed over the last decade, lack of understanding and negative popular representations of dementia persist” (p. 169). As such, existentially threatening dementia is dementia that prevails in journalistic reporting and artistic portrayals, sometimes including misrepresentations of the condition. Significantly, many agree that media depictions are “a greater influence on what people think, believe and do than are the so-called facts” (Johnstone, 2013, p. 23). Investigating the popular cultural representations of dementia foregrounds the role of memory in the way mainstream cultural codes and ideologies inform representations of ill bodies. In this context, an examination of popular cultural representations of dementia reveals how popular texts create and contribute to the cultural derision and stigmatisation of individuals with dementia, causing irreparable social damage.

**Dementia: A Global Stigma?**

Truly we must include all people with dementia when we say ‘ubuntu’ – we are together in our great humanity... Like Mandela we people with dementia can transform a personal tragedy into a triumph. We need no longer be the forgotten ones who have forgotten how to remember.

— Christine Bryden (2005, 80)

People with Alzheimer’s are perceived as zombies, bodies without minds, waiting for valiant researchers to find a cure. For Alice and me, the story was different. Alzheimer’s was a time of healing and magic. Of course, there is loss with dementia, but what matters is how we approach our losses and our gains. Reframing dementia as a different way of
The rise in the global ageing population is bringing a significant surge in the prevalence of dementia. Dementia has become a paramount public health concern acknowledged worldwide, predicting that 152 million people will have dementia by 2050 (WHO). After cancer and heart disease, dementia is the most feared condition in western countries (Pin, Bodard and Richard, 2011). Unlike the West, though less, according to the 2011 census, the prevalence of dementia in India is 2.7% out of the 65 million ageing population (NHP India). From the clinical perspective, dementia is an umbrella term to describe forgetfulness. Originally ‘dementia’ from the Latin de mentis, means “out of the mind” (Zeilig, 2013, p. 259). Hannah Zeilig (2013), a social gerontologist, further remarks that dementia has also been the subject of “changing psychiatric, biomedical, and social/cultural stories” (p. 260). Thus, dementia is a complicated term with various interpretations and, therefore, difficult to discuss as a finite concept. A German psychiatrist in 1910, after Alois Alzheimer, named the most common dementia like Alzheimer’s disease. Alzheimer’s is a terminal illness, and no cure is currently available. One of the causes of dementia is Alzheimer’s disease (hereafter AD), which worsens the condition with time. Dementia leads to deterioration in cognitive faculties, resulting in progressive loss of function and autonomy (WHO 2019).

The biocultural perspective of dementia accentuates the central role of culture in mediating the lived experiences of the sufferers. The most accessible information about dementia for laypeople is embedded with the prevailing cultural attitudes and the rhetoric and imagery associated with the condition. The general sentiment towards dementia is that of fear, dread, and existential threat. As Guendouzi and Muller (2006) state, the “public is very aware, and indeed very fearful, of the growing threat of dementia” (p. 147). Zeilig (2015) observes that because dementia “brings together a heady combination of anxiety about old age and mental illness” (p.17), it induces a compounded fear. Sarah Robinson (2009) describes Alzheimer’s thus: “affliction haunting and stigmatising the late-life years” (p. 91). Elsewhere, Danny George and Peter Whitehouse (2010) claim thus: “rapidly ‘graying’ Western culture that often satirises but mostly laments the ageing process, the benefits conferred by increasing years...are often buried beneath the perceived deficits” (p. 343). Similarly, Anthea Innes (2009) observes that “the conceptualisation of dementia used within Western societies binds dementia to old age, and the fear of ageing, disease and death that is associated with an ageing body” (p. 10). Ageism is a stigma toward the elderly, and Robinson reckons the genesis of the ageing stigma thus:

“After centuries of respecting and caring for the elderly as a part of God’s eternal order, the Age of Reason and the Industrial Revolution inverted Western conceptions so that ageing came to be perceived as a sort of personal failure of the human body as opposed to a mark of God’s favour; it was viewed as a deficiency in self-reliance as opposed to a balanced form of interdependency within a community” (pp. 87-88).

Colin Palfrey and Nancy Harding (1997) implicate that industrialism facilitates ageism in Western societies. Again, Cecil Helman (2007) observes that “loss of productivity (and reproductivity) with age, usually means a steep drop in social status” (p. 10). The elderly are often considered dependent, vulnerable, and “non-contributors to society” (Tataru 2009, p. 18), a judgement
compounded when a person is both elderly and sick. Thus, the notion of stigma is a strong theme within dementia literature, namely in social and cultural studies. Innes (2009) observes the stigmatisation of dementia thus: “Stigma related to mental illness has been found to indiscriminately over-emphasise social losses, leading to social isolation and distress for those with mental illness” (p. 73).

Clinical features of the condition are interpreted in a social and cultural context. Furthermore, several cultural and personal stories, press and medical science are a catalyst to such limited and naive analysis. For instance, Dr Andrew Less, a Professor of Neurology at the National Hospital for Neurology and Neurosurgery, London, in his book Alzheimer's: The Silent Plague (2013), accounts AD as among the greatest medical mysteries (Venkatesan & Kasthuri, 2018, p. 63). In addition, the title of the book resorts to cliched terms such as “silent plague”. Again, microbiologist Charles T. Ambrose calls dementia by analogy “great morbidity” (p. 194). While such medical perspectives of dementia and AD greatly influence lay attitudes, social and cultural studies are agents in perpetuating stigma and the negative views of dementia that come to form the West. Thus, the Western biomedical dimension of dementia was almost hegemonic, strengthened by the elements such as ‘brain’ and ‘cognitive decline’ (Calia et al., 2019). Regarding the social representation of dementia, Canabate et al. (2017) suggest that stigma towards people with dementia and their families negatively affects their quality of life (p. 1103). In evaluating a case, Canabate et al. (2017) manifest ordinary people’s perceptions thus:

“It’s the worst you can go through because it is against every logic. It is a monstrosity, something incomprehensible [...]. Alzheimer is destructive, as it completely impairs the sufferer” (p. 1103).

The authors remark that mentioning the word “Alzheimer’s” itself causes distress:

“I have a really bad image of Alzheimer’s. That’s the reason I got scared? [...]. To me, Alzheimer’s is being dead and alive simultaneously” (Canabate et al., 2017, p. 1103).

As Terry Pratchett (2013) has aptly said thus: “People seem to think of AD as something rather terrible or dreadful, almost as if witchcraft is involved” (n.p.).

Cognitive decline or impaired cognition, often perceived as ‘brain death,’ is assumed to diminish an individual’s self-worth with dementia. As Susan M. Behuniak (2010) in her article “The living dead? The construction of people with Alzheimer’s disease as zombies” contends, the zombie imagery permeates the popular cultural figurations of AD, “constructing them as animated corpses and their disease as a terrifying threat to the social order” (p. 72). The experience of individuals with dementia is described as “the death that leaves the body behind” and “the funeral that never ends” (Downs, Small and Froggatt, 2006, p. 194). A universal sense of relief associated with the death of dementia afflicted is remarked by Steven Zarit and Joseph Gaugler (2006) thus: “The death of the patient is the end of a long journey for the family. When a death occurs in the late stages of dementia, families are often prepared and view it as an end to the patient’s suffering” (p. 191). Murna Downs, Neil Small, and Katherine Froggatt (2006) observe thus: “dementia undermines those qualities which we in the West consider to be distinctly human—coherent communication, memory, being socially orientated, and having behavioural self-control” (p. 194).

However, recent studies critique the traditional perception and representations of an individual
with dementia as ‘demonic’, ‘empty’ or a ‘zombie’ (Aquilina and Hughes, 2006, Behuniak, 2010). Further, the critics posit that such perception has led to an “objectification, marginalisation and silencing of people with dementia within health and social discourses” (Gilmour and Brannelly, 2010, p. 240). Stephen Post (2014) remarks thus: “we ought not to even speak of individuals as demented because the term is so often used in a derogatory manner, and lends itself to dehumanisation and despair.” (p. 5)

Observations on such an antipathetic image of dementia can be attributed to three following findings. The studies firstly focus on the terminal status of the illness. Shortly after diagnosing dementia, the patient is suspended to a state of confusion and disorientation (Gorp & Vercruysse, 2012, p. 1274). Secondly, the person with dementia is rarely allowed to express oneself. That is, people with dementia have lived in silent existence, and their voices are predominantly mediated through others (McColgan, 2000, p. 100). Lastly, the “family stigma” (Werner, Goldstein and Buchbinder, 2010) presents how the illness leads to a vast economic flush out and affects the family members and caregivers economically as well as mentally.

The literary and media (re)presentations of dementia shape the perception of the disease and are decisive in determining the social meanings of the disease and its suffering. The present paper explores how mainstream culture is interpolated by the ideological concepts that evoke frightening images of dementia. An examination of various research studies on the portrayal of ageing reveals that most of the studies have depicted the elderly in a negative light and that elderly people were rarely cast in significant roles. Several dementia discourses—medical, fiction, news reports, TV documentaries and films—have portrayed people with ADRD as dehumanised figures such as zombies, empty shells and non-persons among others. In this context, an examination of popular cultural representations of dementia can reveal how popular texts shape and contribute to the cultural derision and stigmatisation of the elderly, with dementia causing irreparable social damage to the afflicted by treating them as non-persons or someone devoid of personhood.

**Facing the Fear: Dementia in Silver Screen**

The prevalence of dementia is predicted to double every 20 years, with a maximum boom in developing countries, including India, eventually escalating the need for awareness of dementia. With the ability to incorporate visuals, cinema is an effective way to showcase dementia. Films from several countries with dementia as a crucial theme, such as *A Moment To Remember* (South Korea, 2004), *A Separation* (Iran, 2011), and *Still Alice* (USA, 2014), among others, portray diverse factors of dementia and shift the biomedical understanding of the self away from declining cognition. For instance, the character, Alice, in the film adaptation of the fictional narrative *Still Alice* (2014), embodies the contradictions contributing to the contemporary images of dementia. While they reflect the fear of elimination and the tragedy of the erasure of humanity, Alice, remains present as a “moral force, who feel pleasure and pain, who have emotional responses and connections to their social and material worlds. Perhaps the effects of the disease are less of a tragedy than the torment of our own contradictions” (Hillman & Latimar, 2017, p. 2). Again, Richard Eyre’s *Iris* “conforms to and resists the dominant tropes associated with the body and Alzheimer’s” (Wearing, 2013, p. 317).
Predominantly, films from South Asia ranged from forgetfulness, aimless wandering, agitation, combative behaviour and difficulties with mundane tasks. For instance, in *Black* (2005), the character, Debraj, encounters forgetfulness, vacant expressions and prosopagnosia (unable to recognise anyone). In one scene, Debraj forgets who he bought ice cream for and forgets to collect the change from the shop. Moreover, Debraj is shown chained to the hospital bed to prevent him from wandering off. Again, in *Maine Gandhi Ko Nahin Mara* (2005), Uttam, the protagonist forgets that he has retired or his wife has passed away. Uttam, a Hindi professor gradually forgets the lines of his favourite poems and suspects his maid of poisoning his meals. Uttam later finds himself in a state of delusion, where he believes he is the reason for Mahatma Gandhi’s assassination. Elsewhere, the notion of the burden of a dementia caregiver has been portrayed in the Indian Malayalam-language film, *Thanmatra* (2005). Ramesan Nair, a middle-aged government servant, develops symptoms of dementia, such as misplacing his files and toothbrush. Ramesan gets irritated when informed of his forgetfulness by his colleagues or family members. One scene in the movie portrays Ramesan in a state of undress in his office. Gradually, as his disease progresses, he develops speech difficulties, writing difficulties, loss of capability of taking care of himself, and not identifying his family members. The film also highlights how much the disease had affected his family. Being the only breadwinner, Ramesan is forced to take premature retirement from work due to his illness, his family has to relocate from the city to his ancestral home, and the eldest son sets his career ambitions aside to look after his family.

These films neither portray the management of dementia patients adequately nor discover any cure. Instead, films such as *Black*, *Maine Gandhi Ko Nahin Mara* and *Thanmatra* among others, add pessimism and show a gloomy prognosis of the disease. Although cinema is the primary form of entertainment in India, Indian films have long portrayed dementia pessimistically, with themes focusing on the gradual decline in the patient and the caregiver’s burden (Ratnakaran et al., 2018, p. 9). Although recognisable actors of Indian cinema played the characters, the films failed to contribute or raise public awareness of the disease.

*The Telegraph’s* Max Pemberton (2012) has deemed *The Iron Lady* thus:

“It is representative of how society largely views elderly people, particularly those with dementia. They are ignored. They are considered to be dead long before they actually are. Those with dementia experience a loss, not just of their memory and cognition, but of respect and dignity... As people with dementia decline, they are no longer deemed worthy of attention or thought. As far as society is concerned, they are already history. This film gets away with treating Lady Thatcher as though she were already dead because that’s precisely how society behaves towards the old and infirm” (Pemberton, 2012).

whom has dementia—as a murderous duo. The other two horror films similarly portray dementia as an unpleasant turn of events.

Dementia features as a subplot, that is a condition of someone other than a lead character in several shows, for instance, Uncle Junior Soprano in *The Sopranos* (1999-2007), Denny Crane in *Boston Legal* (2004-2008), Maw Maw in *Raising Hope* (2010-2014), and Jimmy in *Orange is the New Black* (2013). Portrayals of dementia on television are more challenging to find, especially with the protagonist as dementia afflicted. Amir Cohen-Shalev and Esther-Lee Marcus (2012) remark that mainstream films are “usually more preoccupied with the selfhood of the figures surrounding the character with dementia, rather than on those suffering from it”, which reinforces the stereotype of those with dementia (p. 74). However, films such as *Cortex* seek to present the person’s inner world with dementia, even as they represent the cognitively impaired as possessing an identity, thus offering a counter-narrative to the dehumanising cliches usually employed with dementia (p. 92).

**Dementia in News**

*Language* is a powerful tool that is often utilised to yield a biased image. While the media plays an imperative role in articulating ideas to the public. In history, people with dementia are subjected to limitless scrutiny and are considered abject bodies barren of recognition and respect in society. Such sensitisation measures might help the print and visual media fill the void in portraying persons with dementia. Instead, journalistic depiction of dementia subscribes to society’s ghoulish interest in the extremities to which dementia can be led. For instance, *The Express* newspaper columned on an event of a husband killing his dementia-afflicted wife by brutally “knifing” her (Twomey, 2012). Another event involving the death of a woman patient with Alzheimer’s disease in ChCh rest-home, whom another patient allegedly suffocated, was covered in the news with the headline “‘Ghoulish’ death in ChCh rest-home” (Rush, 2000, p. 3). Jeremy Hunt (2013) wrote about dementia in the *Telegraph* thus: “It is truly a horrible disease”. Megan-Jane Johnstone (2013) claims the media “can (and does) have a potent influence on public attitudes and opinions” (p. 23). David Salter (2007) remarks that the public believes the news media outlets report as the absolute truth, thus: “it is so easy to deceive. Words printed on a page assume immediate authority when we have no more than our own experience and knowledge as a benchmark” (p. 38). Thus, both Salter and Johnstone admit that reductive representation, such as cliched headlines and snapshots, ultimately leads to the subject’s misinterpretation. Salter (2007) further observes that “[n]ews becomes information snack food,” and images, headlines and bullet points are used to deliver information quickly (p. 237). For instance, among the leading news houses of India, *Zee News* published a report of Nirmal Mehra with the title “Dementia, a ‘silent tsunami’” (ZeeNews, 2012). Salter explains this thus:

“The combined effect of an emotive headline, dramatic picture, stark caption and sensational lead paragraph make a powerful package. Many of us will have neither the time nor the interest to read much further, so that first impression—right or wrong—becomes the whole story” (p. 38).
Dementia is immediately rendered with a threat after its clinical diagnosis. Dementia is further discussed in terms of metaphorical descriptions such as ‘epidemic’ that evoke inevitable disaster, including “millennium demon” and “silent epidemic” (Zeilig, 2014, p. 260). Johnstone (2013) notes that the use of metaphor to sketch dementia is significant thus: “it encompasses much more than the mere use of everyday language” (p. 24). Similarly, Zeilig’s (2013) study observes that watery images such as a flood have long been associated with dementia (p. 260). For instance, a 1982 U.K. report entitled: “The rising tide: Developing services for mental illness in old age” (Arie & Jolley, 1983). Moreover, the U.K. Prime Minister (David Cameron) referred to the need for Britain to change its attitude toward the “rising tide of people suffering with dementia” (May 26, 2012).

Patrick Fox’s (1989) survey of identifying and analysing the contexts in which Alzheimer’s disease is portrayed in the New Zealand print media found that the disease is referred to in a number of ways: as the “disease of the century”, the “mind robber”, the “never-ending funeral”, and a “slow death of the mind” and one of the gravest condition that the elderly people faces (p. 58). Several examples where Alzheimer’s disease is used as a first-person, such as Alzheimer’s disease “steals your forties or your fifties” (Cropp, 2001, p. 58); “names to fall victim to Alzheimer’s include...” (Sunday Star Times, 18); and “it’s the sort of thing that creeps upon you, and any household can be affected” (Walsh, 2001, p. 4). Cowley’s (1998) report on the Sunday Star Times—“My battle against Alzheimer’s” (p. 5)—shows that military metaphors are also used to describe Alzheimer’s disease.

Thus, when trusted sources, such as newspapers, are openly available to the public to base their reporting on the statistics without fully explaining their meaning, overall sentiment is attributed to dementia, which is decidedly negative. Ian Connell (1992) observes thus: “television journalism is made to appear to be a kind of megaphone by which ruling ideas are amplified and generalised across all sectors of the social formation” (p. 139). Thus, stigma often delays seeking help for people with dementia, and in other words, stigma creates barriers for people with dementia and their families to access the care and support they need and ultimately affects their well-being and quality of life (Nolan et al., 2006; Phillipson et al., 2012). Hence, the media remains a powerful transmitter of stereotypes, which is evident in the coverage of Alzheimer’s disease and dementia within the journalistic media.

**Drawing Dementia**

The visual arts are among the highest achievements of humanity: a means of emotional, aesthetic and cultural communication, with continuous production since the Palaeolithic age, where it can be related to the development of full human consciousness (Lewis-Williams, 2002). Often images associated with dementia complement pictorial language used on public platforms. Such images designed to (re)present dementia echo the popular Western cultural views of the condition, including brain death, memory constituting loss of self and the automatic association with ageing. An image search on Google for the words “dementia” or “Alzheimer’s” gives an abundance of images of concerned elderly people, brain scans, slices and drawings. These abstract depictions of dementia reflect Western social constructions of the disease. Some abstract images show the head of a person drawn as a tree losing leaves, heads in silhouette losing cogs or puzzle pieces, erasers rubbing out part of the brain, and rational and colourful shapes arranged and disarranged.
inside the human head, among others. Each of these themes illustrates cognitive decline and constitutes a gradual process of brain decay. Therefore, brain atrophy and loss of self are the main anxieties reflected in the images.

The idea of loss is present in each of these visual interpretations of dementia. Such pictures constitute an indiscriminate eradication of the mind. Such manifestations of dementia contribute to fear and stigmatisation and treat people with dementia in a dehumanised manner. Cohen-Mansfield, Golander, and Arnheim (2000) observe thus: “Sufferers of dementia describe the disease as a frightening shadow which sneaks upon them and steals portions of their memories, dreams and selves” (p. 381). For instance, Fig. 1., clearly demonises dementia and positions the condition as a subject and the individual with Alzheimer’s as a passive object, which resonates with issues of medicalisation and institutionalisation. The black-and-white background with the elderly subject trope further ominously frames the content. Also, the hand in the image is equated with dementia, which is shown to steal the memories of the person. The vacant face of the person implies the confusion and frustration that an individual with dementia undergoes. McColgan (2004) observes thus: “Despite a definitive research focus on finding the social meaning of dementia developed over the last decade, lack of understanding and negative popular representations of dementia persist” (p. 169). Similarly, cognition is equated to thought and social worth, and memory constitutes the self of the individual and their identity. Such assumptions, which appear in language and images, exhibit a brain with dementia as useless, and “living death”.

Figure 1: Dementia robs the sufferer. Source: Loonylabs (2016)
Words can significantly impact cultural constructs, especially when expressions include images, metaphors, and emotive language. The way various medical discourses and research talk about it directly affects how people live with the feeling. Moreover, the words used reflect the behaviour of society towards the illness. Until now, an individual with dementia patient experiences discrimination and denial by the neoliberal society that values independence, prosperity and productivity. Non-fictional, personal accounts of dementia are predominantly written by family members of people with dementia and are a popular medium.

The fictional accounts, such as Margaret Forster’s *Have the Men Had Enough?* (1990) and Michael Ignatieff’s *Scar Tissue* (1993) depicts the struggle and burden of the caregiver to cope with a person with dementia. In contrast, Lisa Appignanesi’s *Losing the Dead: A Family Memoir* (1999) and Linda Grant’s *Remind Me Who I Am, Again* (1998) are partly memoirs and written about someone close to the authors who had dementia. Appignanesi’s novel, *Losing the Dead* (1999), the title itself resorts to the eradication of the self, even though the narrative is about a family member. John Bayley’s *Iris: A Memoir of Iris Murdoch* (1998) and *Iris and the Friends* (1999) are about his wife’s (Iris Murdoch) dementia and “their evolving relationship” (McColgan 2004, p. 171). Sue Pieters-Hawke’s *Hazel’s Journey* (2004) and *Hazel: My Mother’s Story* (2011) are books on his dementia-afflicted mother, Hazel Hawke. These stories are personal and portray an authentic account of the familiar experience of dementia, written by caregivers, who tried to approximate the experience of the individual with dementia. Although written by family members, these accounts of dementia still cannot fully convey the direct dementia experience. Significantly, McColgan (2004) recognises “oddly, these personal accounts, like the fictional ones, also characterise people with dementia and use stereotypical images” (p. 170). The narratives are characterised by loss and decline, positioning the person with dementia as “vulnerable and unable to cope” (McColgan, 2004, p. 170). Furthermore, the titles of books indicate the author’s perspective about dementia. For instance, McGowin (1993) allegorises dementia as a labyrinthine maze in her book, *Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer’s*. Some books also associated dementia with a cliched image of the condition in their title (Innes, 2009), for instance, Robert Woods’s *Alzheimer’s Disease: Coping with a Living Death* (1989), David Shenk’s *The Forgetting: Alzheimer’s: The Portrait of An Epidemic* (2001), John Thordike’s *The Last of His Mind: A Year in the Shadow of Alzheimer’s* (2009) and *The Loss of Self* (Cohen and Eisdorfer, 2001) among others have deliberately or inadvertently contributed to the unconstructive and negative portrayal of dementia. McColgan (2004) claims thus: “titles of personal accounts suggest journeys into dementia, being engulfed and lost, and longing to go home” (p. 170).

**Dementia and TV Documentaries**

TV programs on dementia are usually documentary types. Michelle Heward, James Palfreman-Kay, and Anthea Innes (2015) study how TV and visible media improve cognisance of dementia and deal with gaps within the public’s understanding and reckons that “words, faces, voices and tales of affected humans” is impactful (p. 238). Their study concludes that the media performs a “fundamental role […] in challenging negative stigma and stereotypes associated with dementia” (Heward, Palfreman-Kay, and Innes 2015, p. 239). Zeilig (2014) further remarks thus: ‘the press and television documentaries abound in ‘personal’ stories about dementia and in tales of cures
that are imminent or preventative measures that can be taken to ward it off” (p. 261). Examples of a TV documentary on dementia include Terry Pratchett: Living with Alzheimer’s (2009, UK), Terry Pratchett: Choosing to Die (2011, UK), Louis Theroux’s Extreme Love: Dementia (2012, UK), and Dementiaville (2015, UK). There are several examples of main characters with dementia in fictional television, for instance, Mother and Son (1984–1994, AUS), deals with the mother’s dementia. The Australian sitcom highlights Maggie’s memory loss and, to a greater extent, her son Arthur’s navigation of it. Recently, comics with dementia as an imperative theme are burgeoning. While most of them are careful about preventing falling into the common pattern of catastrophizing dementia and portraying people with dementia as dehumanized victims, some of them also promote the historical stereotypes of dementia. With the inclusion of verbo-visual medium, the positioning of the theme is metaphorical and explicit.

**Dementia in Comics**

While comics have been referred to as a negative form of popular literature, comics have always played a central role in the cultural representation of the risky, disturbing, or even taboo ideas within the anatomical and pathological illustrations. Moreover, as a visual medium, comics have been a significant contributor to healthcare culture, as evidenced by the emergence of graphic medicine. Situated within the field of health humanities, graphic medicine “combines the principles of narrative medicine with an exploration of the visual systems of comic art, interrogating the representation of physical and emotional signs and symptoms within the medium” (Williams, 2015, p. 1). The authors of such illness narratives “create valuable new knowledge, which informs the iconography of illness” (Williams, 2015, p. 133) by depicting their illness conditions and illness experiences. As with other art and media, there has been a surge in the number of dementia narratives within the field of graphic medicine in the last decades. Examples include Spanish-translated Paco Roca’s Wrinkles (2007), Sara Leavitt’s Tangles: A Story About Alzheimer’s: My Mother and Me (2010), Dana Walrath’s Aliceheimer’s: Alzheimer’s Through the Looking Glass (2016) with the recent addition, Valerie Villieu’s Little Josepine: Memory in Pieces (2020) among others. Such dementia narratives counteract the biomedical views on selfhood in dementia and provide a holistic understanding of the self with dementia which is away from declining cognition and “loss of self”. Predominantly, dementia narratives are written from the perspective of family members or caregivers and not someone with dementia themselves, i.e., authors tended to portray the person with dementia as they appeared to them by approximating the experience of the person with dementia. Comic narrative on dementia has surfaced a new outlook towards dementia, deploying an alternative anthropological framework with a more inclusive and humanistic approach towards the disease and the individuals afflicted. However, sometimes, comics also promote the “essentially negative” (Bond, Corner and Graham, 2004, p. 221) representations of people with dementia, reducing dementia afflicted to a simplistic stereotype. For instance, in Afloat: A Memoir about Mum, Dementia, and Trying Not to Drown (2019), Nigel Baines posits his dementia-afflicted mother, Hazel, in a gloomy and pessimistic picture as the narrative progresses along with her progressive dementia.
Afloat by Baines is a recent graphic dementia narrative narrating the tribulations of Hazel, Baines' journey with his ageing parents, geriatric care, and the void created in his life after the demise of his parents. Part memoir and part autobiography, the non-sequential fashion of the chapters swinging present and past inform the reader of Baines' childhood and the sacrifices made by his working-class parents. A couple of weeks before Christmas 2014, the author's mother, Hazel, was diagnosed with mixed dementia (mixed dementia is a condition where brain changes represent more than one cause of dementia occurring simultaneously) after a fall. The memoir accentuates the mental pain and agony of a son whose mother has dementia. Baines describes Hazel as “the engine of the home” (Baines, 2019, p. 14) at the beginning of the narrative. As dementia progresses, due to cognitive impairment, memories of family members start to fade for Hazel. Hazel forgets to send Baines a birthday card; she misses calling him on Sundays, and her list of forgetfulness gets longer (Baines, 2019, p. 123). Metaphorically, Baines bridges his mirror image to that of Hazel's mirror reflection, and in doing so, he deliberately or inadvertently contributed to the unconstructive and negative portrayal of the self with dementia. While Baines imagines himself as “whole”, he declares Hazel's image as “a volatile fracture of self” (Baines, 2019, p. 125) (Fig.2.). Baines describes Hazel's inability to take care of herself as growing “beard” and “wild hair” (Baines, 2019, p. 124). Further, he exaggerates that Hazel's toenails are like “great tree roots” (Baines, 2019, p. 124). Therefore, the manipulative depiction of being dirty and uncleanliness plays into and around cultural stereotypes of dementia as Hazel's complete helplessness and dependency. Baines reconciles both the reflections and is bemused with the internal psyche of Hazel disengaging herself with her physical body, losing her individuality, and can only see an
image of a morbid self—a volatile and fractured Hazel with a “beard”, “wild hair”, and toenails like “great tree roots” (Baines, 2019, p. 124). Baines confessed his bewilderment and mixed feelings when he was nursing his mother, who grew doubly incontinent, intimately and echoed with a perplexity, “I spend a lot of time cleaning things I don’t want to” (Baines, 2019, p. 126). Vaidehi Ramanathan (2009) observes that thus: “The dread of Alzheimer patients and caregivers of the loosening grip on meaning (their sure-signs) suggests that there is a slow erasure of that initial moment of the signification process” (p. 303). Put differently, when an individual with dementia undergoes progressive cognitive impairment, they unlearn the skills they once could perform and become dependent on family members or caregivers.

Institutions and discourses shaping the social construction of ‘self’ are instrumental in encompassing Hazel’s self with dementia. In another instance, Baines depicts the disappearance of Hazel as visual sublimation of her degenerating self. Baines draws jumpers around Hazel’s body to suggest how an individual with dementia is cut off from the terrestrial realities of the world and becomes an ‘other’. A cat is also drawn in the image, who pulls the thread in the jumper and unravels Hazel until there is no jumper left. The thread gyred around Hazel’s body constitutes an existing unit indicative of the person’s cognition, which is uncoiled to nought by the cat, metaphorically dementia. The slow erasure of Hazel’s self is presented as the slow uncoiling of the thread by the chasing cat. The uncoiling of the thread implies the progressiveness of cognitive deterioration due to dementia. Elsewhere, Benjamin Fraser (2018) observes that “cognitive disabilities today enjoy less theoretical, social, and cultural attention than do physical disabilities” (p. 29). However, people with dementia still need to feel secure; they still need to feel successful in a social situation and have a sense of being in control. While biomedicine has rendered “much attention on the need to correct a normative and able-bodied social gaze” (Fraser, 2018, p. 230), the neurodiversity activists critique the medicalisation and objectification of bodies with differences and decentre the ableist and normative assumptions.

CODA

It is essential to understand the importance of cultural and discursive norms in shaping the lived experience of illness, which is decisive in determining the biocultural understanding of health and disease. Popular cultural media such as films, novels, images and television shows carry different perspectives on illness, thus accumulating cultural ideologies about health and illness. Alzheimer’s disease and related dementia (ADRD) are often stereotyped, regressive and misleading. These negative expressions increase cultural stigma, prevent people with dementia and their families from accessing the care and support they need, and ultimately affect their happiness and quality of life. While biomedicine is limited to dysfunction, change or deficit taxonomies, they do, however, feed the cultural views on dementia. The prevailing Western cultural understanding of dementia is founded on medical narratives and is filtered through Western ideals of relationships, social engagement, identity, self and humanity. The Western cultural portrait of dementia demonstrates a particular emphasis on loss of self instead of selfhood. Media representations, thus, echoes and perpetuates Western cultural views on dementia. In this context, popular cultural representations of dementia in popular texts predominantly perpetuate and reaffirm dominant stereotypes, normative perceptions and essentialist perspectives surrounding people with the
forgetful syndrome. At the same time, various philosophical studies on the importance of memory and the subsequent stigmatisation of impaired memory provide historical evidence of the falsely prevalent manifestations of this problem. Contemporary novels testify that pop culture represents people with dementia as zombies, living dead, empty shells, burdensome and non-persons. A striking similarity can be found in the stock images on online platforms of head silhouettes losing cogs or part of their memory or shedding leaves. To make matters worse, movies and reality shows portray people with dementia as sanguinary figures and horror blended figures. These unscientific beliefs reinforce the underlying cultural myths and stereotypes about dementia. Such construction is influenced by the medical narrative, especially about Alzheimer’s disease, the condition most associated with dementia. The first part of this essay briefly describes the clinical manifestations of Alzheimer’s type dementia. The social and cultural research literature suggests that deficit and normative models found in medical literature influence negative social perceptions of dementia, as reflected in descriptions of the illness and its sufferers.

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References


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