Depicting Dementia: An analysis of the affirmative contribution made by mainstream film and television representations of dementia in improving understanding of the condition in the broader community and the residential aged care workforce.

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Thesis

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DECLARATION

I certify that this thesis:

does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and

to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

ROSE CAPP

DEDICATION

To my teachers - the many generous people living with dementia that I have had the privilege to work alongside over more than three decades - you continue to teach me so much. As Allen Power so memorably observed – you are the 'True Experts'.

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Thesis Summary

Dementia is an urgent global health imperative but a condition that continues to attract stigma and misunderstanding, including within the health profession. There is a clear need to educate the broader community and health professionals about the complexities of the condition and how best to support someone to live well with dementia.

Popular culture can play a critical role in shaping opinion and knowledge about health-related issues in the public domain. This thesis argues that affirmative depictions of dementia in contemporary mainstream film and television texts can make a significant contribution to informing general audiences about the complexity of dementia and its consequences. Equally, these texts can be employed as valuable resources in educating the residential aged care workforce in relation to key principles of best practice dementia care.

A thematic, discursive analysis of selected mainstream films and television series from 1990 – 2018 developed three typologies. The analysis differed from extant scholarship by differentiating how each typology could contribute to improving dementia literacy in different ways. The analysis draws on a diverse range of texts from the feature films *Billy Elliot*, *Friends with Benefits*, *Robot and Frank* and *Head Full of Honey* to the TV series *Mother and Son*, *Absolutely Fabulous*, *The West Wing* and *Exile*.

Particular emphasis was given to the influence of first person accounts and depictions of the lived experience of dementia in educating aged staff about the importance of a person-centred approach to care.

In arguing for the clear and compelling educative worth of these texts, this thesis points to the potential synergies of the proposed typologies with extant and emerging educational resources including virtual technologies and experiential approaches to dementia care training. The analysis undertaken in this thesis also makes recommendations for collaborative partnerships between the health sector, individuals living with dementia, dementia

advocacy organizations and film and television industries in Australia and internationally. This kind of approach could work towards future productions of affirmative portrayals of people living with dementia that, as with the impact of the texts that have been the focus of this analysis, could contribute to improved knowledge and understanding of the condition.

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Preface

This thesis – as many invariably do - had a lengthy gestation period. After more than three decades of working in different roles in two discrete domains – as a clinician in residential aged care and teaching and writing on film – I eventually came to the realization that bringing these two areas of expertise together made for an original research premise.

Other than the requisite graduate year in an acute care setting, as a registered nurse I have spent my entire professional life working in the residential aged care sector. For me, there was simply no other choice. Looking back, a much loved summer job as an 18 year-old 'tea lady' at a small and supportive coastal age care facility was perhaps portentous. During my nursing training, compulsory rotations in specialist areas interested me but nothing came close to the passionate commitment I felt when working with older people. This was where I belonged and where I could hopefully make a contribution.

Over the course of many years in the sector, my interest in dementia and best practice dementia care developed, accompanied by a growing conviction that residential aged care was not providing the best possible care for people living with the condition. The escalating incidence of dementia in the community, the concomitant need for specialist dementia care knowledge in the residential sector and the changing demographics of the Australian aged care workforce (an increasingly multicultural, casualized and under-educated cohort) firmed my belief that an innovative approach to dementia care training and education was required.

Over the same period of time, my equally passionate interest in film led to teaching and writing in cinema studies and regular work as a film critic. My admiration for the Australian TV series *Mother and Son* (Atherden, 1984 – 1994) – a comedy focused on the exploits of an older woman living with dementia – and the enduring popular acclaim of the series suggested to me that despite the challenging central premise, there was an appetite for mainstream popular culture that dealt with the subject of dementia. This in turn piqued my interest in exploring other examples of contemporary mainstream film and television that tackled the topic of dementia and thinking about the ways in which these screen representations might influence a viewer's awareness of and attitudes to the condition.

The research process revealed an increasing number of detailed and considered depictions of dementia, particularly over the last two decades, a finding that strengthened my focus on the *affirmative* role these texts might play in informing and educating the general public. My experience as part of the Australian Government funded Flinders University team that developed and disseminated the Dementia Dynamics Toolkit, a dementia e-learning resource for Australian residential aged care staff, informed my belief that popular culture texts could also play a valuable educative role in this context.

My objective in writing this thesis is therefore two-fold: to suggest ways in which affirmative examples from mainstream film and television can enhance understanding about dementia in the broader community and equally significantly, contribute to tangible practice change in the residential aged care sector.

INTRODUCTION

Dementia: an overview

Dementia – in all its variant forms - represents a significant global health issue. This thesis acknowledges the most recent Diagnostic and Statistical Manual of Mental Disorders (DSM-5) classifications of dementia as a Neurocognitive Disorder (NCD) (APA, 2013). However, given that the vast majority of the primary sources, both audio-visual and academic texts, on which this thesis draws use dementia in the broad understanding of the term, dementia will be used in this context. Dementia is thus a broad descriptor that encompasses symptoms of a range of conditions that cause progressive neurological and functional decline.

Australian and international estimates of dementia diagnosis rates predict escalating numbers over the next three decades. Alzheimer's Disease International (ADI) puts the number of people living with dementia worldwide in 2017 at nearly 50 million (ADI, 2015). This is equivalent to one new case diagnosed every 3 seconds. These figures are predicted to almost double every 20 years, reaching 75 million in 2030 and 131.5 million in 2050 (ADI, 2015). The current and future geographical shifts in the incidence of dementia diagnosis rates are equally significant, with an increasing proportion of new cases occurring in Asia (49% of the total), the Americas (18%) and Africa (8%) respectively (ADI, 2015). Global analyses have also looked at the dementia prevalence rates in terms of income base with lower to middle income countries (including East and Northern Asia, Africa, South America and parts of Eastern Europe) currently comprising 58% of all people living with dementia. This is predicted to increase to 63% by 2030 and 68% by 2050 with clear socio-economic implications. These countries have been identified as less well resourced, in both economic and health professional terms, to provide support for the ageing population, including those living with dementia (ADI, 2015).

In Australia, more than 459,000 people are currently living with dementia **(**Dementia Australia, 2018**).** This number is projected to increase to 590,000 in the next decade and almost 1.1 million by 2058 (Dementia Australia, 2018). Women account for 60% of all those diagnosed with dementia and the condition is now the leading cause of death for women in Australia (Dementia Australia, 2018). There are equally compelling statistics for those involved in caring for people living with dementia. It is estimated that there are currently almost 1.6 million caregivers (formal and informal) in Australia (Dementia Australia, 2020). The demand for formal caregivers (individuals paid to provide care) in the aged care workforce is predicted to increase two-three fold by 2050 (National Institute of Labour Studies, 2017).

A small number of recent studies have suggested that in some countries, dementia incidence rates are falling (Schrijvers, et al (2012); Larson, Yaffe and Langa, 2013; Sposato, Kapral, Fang J, et al. 2015). There are multiple factors arguably influencing this recent downward trend, primarily the protective effect of better education and improvements in cardiovascular health and stroke incidence (Sullivan et al, 2019). While important to acknowledge, these findings are limited in number, have focussed exclusively on higher income countries and have been described as 'too inconsistent to reach firm and generalisable conclusions regarding underlying trends' (ADI, 2015). The World Health Organization predicts that despite trends in reducing incidence in some countries, global dementia prevalence will continue to increase as the population ages (World Health Organization, 2012). Global increases in dementia prevalence and diagnosis rates have clear implications in terms of the social, economic and other costs associated with the treatment and care of people with dementia.

Research in focus

In recent decades, there has been a concerted, multidisciplinary approach to dementia research. Alzheimer's disease remains the most commonly diagnosed type of dementia and a significant focus for research efforts. From the 1970s onwards, refinements in the understanding of the pathological basis of Alzheimer's disease have resulted in the dominance of the biomedical model of dementia and a corresponding emphasis on developing a 'cure' or pharmacological treatment for the condition. For some, the hegemony of the biomedical model has come at the expense of developing more nuanced models focussed on understanding the psychosocial consequences of the condition and the importance of caregiving interventions (Holstein, 2000; Ballenger 2006; Sabat, 2019). In the ongoing absence of a disease modifying treatment for any form of dementia, there has been an increasing research focus on risk reduction including lifestyle factors and concomitant advances in the field of non-pharmacological approaches to support people living with dementia.

The latter have been led by amongst others Tom Kitwood, Steven Sabat, Allen Power and Dawn Brooker and have collectively asserted the importance of psychosocial and other supportive approaches. Rather than treatment, these approaches have introduced ideas around personhood and identity into the dementia care field and emphasized the impact of the social and physical environment on the emotional well-being of people living with dementia (Kitwood, 1993, 1995, 1997, 1998; Sabat 1992, 2001, 2002, 2012, 2019; Power 2010, 2014 and Brooker, 2007; Brooker and Latham, 2016).

(Mis)understanding dementia: global attitudes and perceptions

Despite these multidisciplinary advances and a raised profile for various forms of dementia, global ignorance and misapprehension about dementia remains widespread in the 21st century. As Hannah Zeilig and others have argued, the word dementia provokes a 'profound dread' and for many, the disorder has supplanted cancer as the 'scourge of modern times' (Zeilig, 2014, p 260). The fear of dementia, known as anticipatory dementia or dementia worry, has emerged as a specific and increasingly prominent phenomenon in Western societies (Kessler et al., 2012). The 2019 World Alzheimer's Report, surveying global attitudes to dementia, found that 95% of the public believed they will develop dementia in their lifetime and nearly 80% are concerned about developing dementia at some point (ADI, 2019a). Significantly, 25% of people believe that ' …there is nothing you can do about dementia' (ADI, 2019b, p. 9).

Research over the last decade on Australian attitudes and beliefs about dementia is equally revealing. Of 1500 Australian adult participants surveyed in 2018, 80% had heard of dementia and of those, nearly 60% had some direct experience of the condition, primarily through a family member or close friend living with dementia (Dementia Australia, 2018). Despite the increasing diagnosis rates and personal contact with someone living with the dementia, the impacts on quality of life and the attendant psychosocial and emotional consequences are still poorly understood. Two thirds of participants could nominate one symptom of dementia (memory loss) but only 6% understood that dementia is a progressive and ultimately fatal disorder (DA, 2018). The report found that despite increased awareness and empathy (compared with a 2012 survey), there was still significant community and individual unease around interacting with people with dementia (Dementia Australia, 2018).

The 2019 World Alzheimer's Report noted that the significant barriers to improving health care and supportive services for people living with dementia were at least in part because of the persistent stigma and the lack of knowledge associated with the disorder *within the ranks of health professionals* (italics added) (ADI, 2019b). The report found that 62% of healthcare practitioners believe that ' … dementia is part of normal ageing' (ADI, 2019b,

p. 9). One third of people believed that they would not be listened to by health professionals if they had dementia and this appeared to be confirmed by the statistic that over 50% of healthcare practitioners agreed that their own colleagues ignore people living with dementia (ADI, 2019a).

Describing the latter finding as ‘staggering’, the report goes on to make a series of recommendations including ‘specialised education about dementia-related stigma and person-centred care practice for healthcare practitioners’ (ADI, 2019b, p. 11). Another key recommendation emphasized the importance of increased public advocacy of people living with dementia and ‘amplifying the voice of lived experience’ (ADI, 2019b, p. 11). The report underlines the clear and urgent need for the global community, including health care professionals, to be better informed about dementia to reduce stigma and misinformation and to improve health care and support services for those living with the condition.

This thesis contends that representations of dementia in contemporary film and television can play a significant role in mitigating stigma and improving awareness around dementia in the broader community. As one expert contribution to the 2019 ADI report noted, well researched and produced ‘ … popular entertainment programmes ... powerfully yet subtly convey to their several million viewers various stigma-busting messages’ (Kelly, 2019, p. 96). Equally importantly, in conjunction with other training and education resources, popular culture texts can make a contribution to the kind of specialised education about dementia-related stigma and person-centred care practice identified in the 2019 ADI report and encourage lasting practice change in the residential aged care sector.

This thesis specifically addresses the potentially positive impacts of contemporary representations of dementia in film and television on Australian audiences and the application of popular culture as an educational resource for the Australian residential aged care workforce. However, given the findings from international studies and surveys cited above, this analysis has clear implications in relation to the educative potential of contemporary representations of dementia in popular culture in a global context.

Depicting dementia on the screen

' … entertainment media may be even more important to deal with than news media. It is not merely the credibility of the source that influences public perceptions, but the sheer pervasiveness, repetition and homogeneity of images.' (Wahl, 2001, p. 530)

' … artistic portrayals of people with dementia such as in movies, art, fiction and contemporary music, will provide a more comprehensive view of the public portrayal of dementia messages' (Doyle et al, 2012, p. 100).

The influence of film and television in shaping individual and collective beliefs and attitudes on issues relating to health and ageing has been well documented in a range of studies over the last three decades (Cohen-Shalev, 1992; Bell 1992; Cole, Van Tassel and Kastenbaum 1992; Zoglin, 1994; Cuenca, 2001; Wedding, Boyd & Neimic; Segers 2007; Basting, 2009; Chivers, 2011; Doyle et al, 2012, Mukadam and Livingston, 2012; Gravagne, 2013, Peel 2014 and Dionigi, 2015; Shary and McVittie, 2016). As one of the defining disorders associated with older age in the 21st century, dementia has become more prominent on the small and large screen over the same period. Attesting to this increasing prominence is the notion of a burgeoning contemporary sub-genre of 'Alzheimer's movies'. A recent review of *What They Had* (Chomko, 2018) described the film as ' … not the best Alzheimer's movie ever made (thus far, that is *Away From Her*), but it's a fine addition to the sub-genre …' (Bertaut, 2019, para. 8).

There has been, and continues to be, a wide-ranging response from producers of film and television to the subject of dementia. The history of screen representations of dementia range from coded and oblique mid 20th century references to misrepresentative or frankly alarmist depictions of the condition in the 21st century. Other examples from the small and large screen offer clinically better-informed, more nuanced delineations of the disorder and its consequences.

The increase in screen depictions of dementia in the last three decades can be explained at least in part as a result of the multidisciplinary research efforts outlined above, the raised profile for dementia (particularly Alzheimer's disease) and the corresponding increase in community awareness. Given the increasing incidence of dementia, it could also be argued that writers, directors, producers and other key creative figures in film and television are increasingly coming into contact with people living with dementia. This immediate, more personal experience has had a modest but tangible effect in generating more projects dealing with dementia in some form on the small and large screen.

Learning from the screen

'… the image that many people currently have of dementia does come via some indirect experience gleaned from TV, novels or the Internet' (Van Gorp, 2012, p. 1275).

Understanding dementia and its consequences through popular culture, and fiction films in particular, has been described as 'rarely innocent or unproblematic' (Capstick, Chatwin and Ludwin, 2015, p. 229). The merits of 'cinemeducation' and 'edutainment' - drawing on mainstream film to educate health professionals – has also attracted considerable debate in recent years (Alarcon and Aguirre, 2007, Moyer-Gusé, 2008; Morris, 2014; Karasik, Hamon, Writz & Reddy, 2014; Capstick, Chatwin and Ludwin, 2015; Hoffman, Shensa, Wessel, Hoffman and Primack, 2017).

Chivers has argued that our broader societal fears around the impacts of ageing – particularly the loss of autonomy and identity - are collapsed on to dementia and these are played out on the mainstream screen in unhelpful and alarmist ways (Chivers, 2011). Others have argued that the 'unconscious' effect of cinema means that viewers might process and absorb negative depictions of dementia 'unintentionally or unconsciously' (Gerritsen, Kuin & Nijboer, 2013, p. 1). Anne Basting notes the particular potency of negative stereotypes of older people including those with dementia (Basting, 2009).

Where Basting and others have suggested that negative screen depictions of dementia can exert a powerful influence and encourage discrimination and stigma, it could equally be argued that nuanced and complex depictions of people living with dementia, and the empathetic and compassionate responses of carers and family members could make a potentially *positive* impact. An analysis of representations of mental illness in film has made a similar argument suggesting that if viewers are encouraged to identify with the person with mental illness and issues are not oversimplified, mainstream film can counter historically negative depictions and be a positive influence (Doyle et al, 2012). Advocates of cinemeducation argue that using popular culture texts offer opportunities for 'perspective taking,' 'concept acquisition' and the exploration of wide ranging and expansive health-related themes, all ideas that are central to the way in which texts will be discussed in this analysis (Karasik et al, 2014, p.96).

Acknowledging that the image many people have of dementia is mediated by popular culture, and the potentially problematic nature of these mediated images and representations, the central premise of this thesis is that contemporary film and television can play a constructive role in addressing the gaps in knowledge and understanding about dementia in both the broader community and the residential aged care work force.

Time frames, texts and typologies

This analysis will focus on a selection of contemporary film and television texts from the period of 1990 – 2018. This encapsulates the most significant period in the development of contemporary representations of dementia in film and television. This significance is both quantitative in terms of the relative numbers of texts identified in this period, but equally importantly, qualitatively in terms of the increasingly detailed, more clinically accurate and considered way in which the subject of dementia is addressed. The term 'text' will be used throughout this thesis to refer to the feature films and TV series that form the focus of the discussion. This in keeping with contemporary film scholarship that understands films as texts that, as with conventional literary texts, are open to different ways of being viewed or 'read' and interpreted (Gillard, 2009).

A thematic, discursive analysis of the selected examples will address key questions, the first of which is: what is the extent and nature of the portrayal of dementia in mainstream film and television in this period? Secondly, how might the selected texts influence knowledge and attitudes about dementia in the broader Australian community? And finally, how might representations of dementia on screen be useful in educating Australian health care professionals, in particular, individuals working to support people living with dementia in the residential aged care sector?

A series of inter-related issues emerged from these broader questions. These cohere around the following themes: Is the depiction of the illness clinically accurate or otherwise? How is dementia positioned or deployed in the overall narrative trajectory? Whose perspective on dementia takes precedence? If the carer, spouse or family member's point of view predominates, are there issues or themes common to these particular narratives? Do these differ from narratives where the dominant perspective is that of the person living with dementia? If so, what is the nature and significance of these differences? And critically, is the depiction of dementia instructive or potentially detrimental in educating the viewer about the disorder? In addressing these questions, depictions of dementia ranging from the simplistic to the clinically well-informed will be analysed in arguing for the potentially valuable contribution mainstream film and TV series can make to improving knowledge and understanding of the condition.

This analysis is distinguished from extant scholarship in specifically focussing on how accurate and well-informed depictions of dementia can exert a *positive* influence on viewers in the general community and health care professionals in the residential aged care sector. These selected examples will be referred to throughout as *affirmative,* indicating that the narrative trajectory, characters, themes or other key aspects of the screen depiction offer important insights and contribute to improving knowledge and awareness of the complexities and consequences of dementia.

In this thesis I have developed a tripartite typology as a framework for analysing how the selected texts depict dementia on screen (see Appendix One). Each typology represents a different perspective and can be differentiated in relation to how each speaks to or informs audiences about the complexities of dementia. Identifying differences in genre, narrative structure, theme, perspective and audience appeal will suggest the way in which examples in each typology can be utilized as resources in educating residential aged care staff. Individual texts, narratives, scenes and characters can be used as a basis for discussions, concept acquisition and experiential exercises to address a range of issues. The analysis will suggest that these texts are valuable for encouraging insight and empathy and exploring and consolidating key concepts in person-centred dementia care.

The framework consists of three broad but not mutually exclusive typologies, each designation indicative of the role and function of dementia in the storyline: Dementia at the Margins, Dementia as Dramatic Device and Dementia Takes the Lead. The category of Dementia at the Margins consists of films and TV series that reference dementia *briefly or peripherally*. This recognizes that minor characters or references to dementia in globally successful mainstream texts can potentially influence attitudes and beliefs in an equally powerful way as an ‘arthouse’ or independent film with a more narrowly defined audience focussed specifically on the subject. Examples of films in this typology include *Friends with Benefits* (Gluck, 2011) and *Gone Girl* (Fincher, 2014). This typology also represents a critical distinction from previous scholarship in the area that has overwhelmingly focussed on texts with a central or substantive focus on the disorder (*Iris* [Eyre, 2001], *Away*

From Her [Polley, 2006]*, The Savages* [Jenkins, 2007] and *Still Alice* [Glatzer and Westmoreland, 2014]).

In terms of absolute numbers, Dementia as Dramatic Device is the most substantive of the three and comprises film and TV texts that employ dementia in what I characterize as primarily a catalyst or *dramatic device*. As the designation suggests, drama dominates, with most feature film and TV examples falling into this generic category. Dementia is frequently explored in considerable detail, and a wide range of issues and themes are addressed including symptomatology, treatment and care options. Examples in this typology typically explore dementia-related issues and concerns *from the point of view of a spouse, family member or informal caregiver*. Prominent examples include the feature films *Hanging Up* (Keaton, 2000)*, The Savages, Happy Tears* (Lichenstein, 2009)*, Still Mine (*McGowan, 2012*), What They Had, Head Full of Honey* (Schweiger, 2018), the telemovie *A Time to Remember* (Putch, 2003) and the TV Mini-Series *After the Deluge* (Maher, 2003) and *Exile* (Abbott, 2011).

Dementia Takes the Lead is the smallest of the three typologies and comprises films and TV series where dementia features overtly as the central theme or concern. While relatively modest in size, this category has grown rapidly in the last decade. The rise of the dementia advocacy movement - and the increasing prominence of people with lived experience speaking out – is arguably at least in part responsible for this more recent screen emphasis. Examples in this category include the feature films *Still Alice, The Iron Lady* (Lloyd, 2011) and *Robot and Frank* (Schreier, 2012) and significant storylines in TV series including *Packed to the Rafters* (Lee, 2008 – 2013), *Neighbours* (Watson, 1985 -) and *Boston Legal* (Kelley, 2004 – 2008). As with Dementia at the Margins, film and TV dramas dominate but in this category, *the perspective of the person with dementia occupies either a significant amount of screen time or the story is told entirely from their point of view*. This concerted focus on the lived or felt experience or dementia distinguishes this category from the preceding two.

Where Sabat meets the screen

The increasing focus on presenting the perspective of the person with dementia on screen is a significant development and one that constitutes a substantive focus in this thesis. In arguing that examples from popular culture – and specifically those addressing the lived experience of dementia in feature films and television series – can improve knowledge and awareness about the illness, I will be drawing on the work of prominent neuropsychologist Steven Sabat. Sabat's influential contribution to reframing our thinking about and understanding of dementia has been critical to the field (Sabat and Harre, 1992; Sabat, 2001; Sabat, 2002, Hughes, Louw and Sabat, 2005; Sabat to cite just a few publications). His 2012 study is of particular relevance in this context. The depictions of dementia in film and television that form the basis of my analysis – particularly those from the perspective of the person with the illness - provide a form of qualitative knowledge about and insight into the experience of living with dementia that conforms in many respects to Sabat's proposed Bio-Psycho-Social model of knowledge translation (Sabat, 2012).

Sabat's small but influential 2012 case study outlined how an undergraduate cohort's exposure to qualitative information, in the form of direct accounts from people living with dementia, could positively influence their attitudes about Alzheimer's disease. The study found that these first person accounts, emphasizing how people with dementia feel about their diagnosis, cognitive capacities and treatment by others, promoted understanding and empathy (Sabat, 2012, p 107). Learning about the *personal* experiences of people living with dementia 'dramatically enhanced students' appreciation of persons with AD' and generated increased levels of sympathy and empathy 'in ways that cannot be achieved by learning about the biomedical aspects of the disease' (Sabat, 2012, p. 107).

The participants in Sabat's study were exposed to a range of first hand written accounts of the lived experience of dementia. Exposure to feature films and television series that address dementia from a first person perspective, and repeated viewing via streaming services, YouTube and shared content through social media exchanges, is arguably commensurate with Sabat's form of qualitative knowledge and could have an equivalent and equally persuasive impact. As noted in the most directly pertinent study for this thesis:

> Whilst research articles and text books expound upon many facets of the dementia experience, it can sometimes be difficult to fully appreciate the emotional component or the contextual issues of actually living with this condition. When considering the felt experience of dementia, it becomes more clearly understood when placed in context and personalised through biographical narratives. (Morris, 2014, p 437?)

Methodological considerations

A number of considerations informed the selection criteria for the texts included in this analysis. Selections were made on the basis that texts must either include specific reference to a character's dementia, or the symptomatology and context on screen makes it clear that a character has some form of dementia. Feature films and television series featuring characters with cognitive decline or memory loss unrelated to dementia were excluded. Many of the selected texts refer only to dementia in the broad understanding of the term and do not specify a dementia type. Any form of dementia was included regardless of its type but as with the preponderance of Alzheimer's disease (AD) in real world statistics, AD is the most commonly identified type on the small and large screen.

Films that form the focus of the proposed typologies are primarily English language texts. Box office figures for Australian cinema attendance for 2010 – 2015 reveal that the top 50 films each year are English language films, indicating that most films seen by contemporary Australian audiences have English language dialogue (Australian Box Office, 2015). In order to explore the potential influence of specific film and television texts on the predominantly English-speaking audiences in Australia, English language films form the focus of this discussion. A further rationale for focussing on English language texts is their suitability as a resource in the Australian health care education and training context. While acknowledging the multicultural composition of contemporary Australian society and the residential aged care workforce, English is the dominant language in both contexts and therefore justifies the choice of English language texts.

Film and television texts have been selected regardless of the conditions of their initial or subsequent distribution and exhibition. Feature films that received a wide or limited theatrical first release, screened solely at film festivals or released on streaming or other services are included, as with television series that screened on free-to-air or other platforms. While the analysis takes account of box office takings, youtube viewings and other considerations, the focus is on the potential impact of an individual text on a general audience and its application as an educational resource in the residential aged care sector.

A number of non-English language films from a diverse range of countries representing national cinemas from most of the major continents were viewed in the data collection process. Many of these assisted in identifying dominant narratives and key concerns and themes but only one is included in the discussion. The Spanish animation *Wrinkles* (Ferreras, 2011) forms a central part of the discussion in Chapter Ten. The singular and original way that it presents the lived experience of dementia has no English language counterpart.

The Preview

In the course of this introduction, the focus of each chapter has been addressed but the following gives a brief overview of the structure and content of each individual chapter. Given the centrality of dementia to this thesis, the current state of evidence-based knowledge about dementia will be outlined in the first chapter. This will include an acknowledgement of recent changes to dementia terminology and classifications, and a brief summary of the most prominent dementia sub-types. In order to consider how *contemporary* representations of dementia on screen might influence awareness of and knowledge about the disorder, it is important to understand how Western medico-scientific knowledge and socio-cultural beliefs about the disorder have changed over time. Chapter One will describe historical conceptions of dementia from the earliest period of documented medical knowledge and trace significant shifts in Western beliefs and attitudes to the disorder.

Cultural gerontology, a relatively recent development from the broader discipline of gerontology, has been described as having recast the field of ageing studies in widening its theoretical, intellectual and political remit (Twigg and Martin, 2015). Loosely defined as the exploration of the way in which cultural meanings are associated with old age, cultural gerontology encompasses amongst other forms, film and television. This will provide the broad theoretical framework for understanding the shifts in historical thinking about dementia outlined in Chapter One, the literature review that comprises Chapter Four and the proposed screen typologies discussed in subsequent chapters. The discussion in Chapter Two explores the way in which mainstream media coverage of dementia over the last three decades has influenced knowledge and perceptions about the condition in the public domain. Identifying shifts in language, theme and tone in newspaper coverage contextualizes analogous changes in the nature of representations of dementia on screen over the same period.

Methodological criteria and other considerations form the basis for Chapter Three, setting out research methods, key selection criteria and a detailed rationale for the proposed typologies. The literature review examines earlier, clinically informed assessments of representations of dementia on screen

(Dastoor, 1991; Segers 2007, Cohen-Shalev, 2007). The significance of recent studies in cultural gerontology investigating depictions of the disorder across a range of popular culture forms is explored (Basting, 2009; Chivers, 2011; Gravagne, 2013, Swinnen and Schweda, 2015). Debates around the merits or otherwise of cinemeducation constitutes the final section of the literature review Alarcon and Aguirre, 2007, Moyer-Gusé, 2008; Morris, 2014; Capstick, Chatwin and Ludwin, 2015; Hoffman et al 2017).

A chapter is devoted to each of the three proposed typologies: Dementia at the Margins, Dementia as Dramatic Device and Dementia Takes the Lead (Chapters Six, Seven, Eight and Nine respectively). Each chapter will discuss the differences in genre, narrative structure, perspective and audience address that distinguish each category. A detailed discussion of a range of prominent examples in support of each category will suggest how different texts might speak to or inform general audiences about the complexities of dementia and the specific application of the typological framework as a resource for training and education of the residential aged care workforce.

A concluding chapter will point to the potential synergies of the proposed typologies with extant and emerging education resources including virtual technologies and experiential approaches to dementia care training in the residential aged care sector. Finally, the conclusion will outline the way in which the analysis undertaken in this thesis has implications for collaborative partnerships between the health sector, individuals living with dementia, dementia advocacy organizations and film and television industries in Australia and internationally.

CHAPTER ONE: A CULTURAL HISTORY OF DEMENTIA

Introduction

If illness is a 'varied historical and cultural concept', changes in knowledge about and attitudes towards dementia exemplify this claim (Mercadé, 2005, p. 77). In order to consider how contemporary representations of dementia on screen might influence awareness and knowledge about the disease in the late stages of the 20th and early decades of the 21st century, it is important to outline historical conceptions of dementia and the way in which Western medico-scientific knowledge and socio-cultural attitudes and beliefs about the condition have changed over time. Tracing these intellectual and conceptual shifts - from the unambiguous Pythagorean conflation of 'senium' with cognitive decline in the Greco-Roman period to 21st century Western notions of 'anticipatory dementia'– will provide a framework for contextualizing how representations of dementia in contemporary popular culture can both reflect current beliefs and attitudes and in turn shape opinion and influence in an affirmative direction.

This chapter will outline the key moments in the understanding and classification of dementia and the broader attitudinal shifts that have accompanied these changes. A broad historical overview will preface a more detailed focus from the beginning of the 20th century onwards. This period saw significant developments in the medical and psychosocial understanding of dementia, the former driven by the breakthrough developments defining Alzheimer's disease by German psychiatrist Alois Alzheimer in 1906. Alzheimer's work offers a logical theoretical starting point from which to examine modern knowledge and attitudes about the disease.

Given the comprehensive analyses of shifts in American ideas and understanding of dementia over the course of the 20th century do not appear to have an Australian equivalent, I have chosen to draw primarily on these accounts in setting out a contemporary context for conceptualizing and understanding dementia. This rationale is further supported by the observation that while my analysis focuses on the use of popular culture texts as educational resources in Australian residential aged care settings, the majority of the texts are American in origin. The findings of my analysis and their application in a residential aged care context are germane to both.

The 20th century also charts the history of cinema, a useful parallel context through which to trace attitudinal shifts to dementia. Early 20th century depictions of dementia on the mainstream screen will be discussed in Chapter Five in order to chart the subsequent representational shifts in the late 20th century and beyond.

Dementia Redefined

Dementia is a general descriptor that encompasses a range of neurocognitive changes and their associated symptoms that in turn characterize a number of variable conditions. In the most recent edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5, 2013), dementia was redefined in a number of ways; most significantly, dementia is now described as a *major* neurocognitive disorder (NCD). The DSM-5 also identifies earlier stages of cognitive decline in the new diagnostic category of *mild* neurocognitive disorder. These new classifications acknowledge that the etymology of dementia – from the Latin connoting insanity - being literally 'out of one's mind' - is both inaccurate and unpalatable in the current context. The new terminology aims to both refine understanding about different NCD subtypes and mitigate the stigma associated with the word and the disorder itself. Importantly, the DSM–5 also acknowledges that the term dementia is still in common usage (including by leading international dementia advocacy organizations such as the Alzheimer's Association and Dementia Australia) and therefore remains appropriate for describing the various etiological subtypes of dementia.

The most prominent and identifiable dementia subtypes are Alzheimer's disease, vascular dementia, dementia with Lewy bodies, and frontal lobe dementia, Pick's disease and alcohol-related dementia (Stephan and Brayne, 2014). In the most recent DSM-5 classification, mild and major forms of all subtypes have been assigned diagnostic criteria. While varying in pathology and presentation as outlined above, all of these subtypes, in both mild and major form, are characterized by impacts on six key cognitive domains. These domains are defined as complex attention (including sustained/divided attention/selective attention and information processing speed), executive function (planning, decision making, working memory, responding to feedback, inhibition and mental flexibility), learning and memory (free recall/cued recall, recognition memory, semantic and autobiographical long term memory, and implicit learning), language (object naming, word finding, fluency, grammar and syntax, and receptive language), perceptual-motor function (visual perception, visuoconstructional reasoning and perceptual-motor coordination) and social cognition (includes recognition of emotions, theory of mind and insight). Diagnosis of mild or major NCD or dementia is predicated on evidence of modest or significant cognitive decline from a previous level of performance in one or more of the cognitive domains respectively (DSM-5, 2013).

Significantly, the diagnostic criteria for different dementia subtypes have been revised in a key aspect. Previous DSM criteria were developed using Alzheimer's disease as the predominant dementia type, with memory impairment regarded as a definitive feature of all dementia variants. Given the new, expansive reclassification and associated pathologies and symptomatologies, impairment in *any* of the cognitive domains, including learning and memory, is now regarded as diagnostically significant. Which cognitive domains are affected and to what degree depends on the etiological subtype of the dementia involved (DSM-5, 2013).

Alzheimer's disease accounts for between 60 – 80% of all cases of dementia currently diagnosed (Alzheimer's Association, 2020). Public health debates, awareness in the general community and representations in film and television, unsurprisingly, also focus almost exclusively on this form of the disorder. As noted above, while acknowledging the specificity of the numerous subtypes that come under the general descriptor of dementia, given the prevalence of AD both on and off screen, it forms the principal focus of this historical overview and textual analyses in subsequent chapters.

There are two main types of Alzheimer's disease: sporadic and familial AD. The former accounts for more than 90% of all cases of AD, typically occurs after the age of 65 and definitive causation is still unknown. Younger or early onset Alzheimer's disease is typically manifested at between the ages of 40 – 60 but can occur at an even younger age; this younger form can be of the sporadic or the familial type, where the latter is a much rarer, genetic variant of the disease. As with real world statistics, the preponderance of mainstream film and TV texts identified in the course of researching this thesis deal with the sporadic or late onset form of the condition. The critical analysis in the following chapters therefore overwhelmingly addresses scenarios and issues pertaining to individuals in older age.

It is important however to acknowledge the early onset form of AD and the particular issues that younger people with dementia may encounter that are distinct from those living with the condition in older age. Some researchers have argued that this younger cohort and the issues they face have been significantly under researched compared with their older counterparts (Harris and Keady, 2008). There is nevertheless a burgeoning body of research over recent decades exploring the complexities of the younger onset experience of dementia (Keady and Nolan, 1994; Svanberg, Spector and Stott, 2011; Lockeridge and Simpson, 2013; Roach, Keady, Bee, & Williams, 2014; Cabote, Bramble & McCann, 2015;

Hutchinson, Roberts, Kurrle and Daly, 2016 and Spreadbury & Kipps, 2017).

Researchers have identified a range of issues unique for this cohort from workplace concerns in relation to performance, stigma associated with a dementia diagnosis and financial consequences, to the changing roles and responsibilities and the impacts on self-identity for the person with dementia raising young children. These kinds of issues are explored in the feature film *Still Alice*, a significant touchstone for this thesis and the only text included in this discussion that deals with younger onset dementia. The film focuses on a fifty-year old female academic and the repercussions of her diagnosis of the FAD variant of Alzheimer's disease and will be discussed in detail in Chapter Eight.

Classical conceptions of dementia

Dementia – variously defined and described in terms of pathology, symptomology and consequences – has been documented in some form from the very earliest periods of Western civilization. Some of the first references include observations from the 7th C BC Greek philosopher and mathematician Pythagoras, who described 'senium' or old age as characterized by both physical decline and a 'regression' of mental capacities (Berchtold and Cotman, 1998, p. 173). Subsequent descriptions by Aristotle in the 3rd century BC are no less equivocal in making the association between old age and cognitive decline:

'…there is not much left of the acumen of the mind which helped them in their youth, nor of the faculties which served the intellect, judgment, power of reasoning and memory.' (Berchtold and Cotman, 1997, p. 174).

In contrast, Roman orator and politician Cicero argued that cognitive decline was not in fact inevitable (Boller and Forbes, 1998). He argued that what was described in first century BC as senile debility or dotage was a sign of individual weakness and not a general consequence of older age (Berchtold and Cotman, 1997). Cicero's exhortation to remain intellectually active and engaged in order to maintain cognitive function into later years was profoundly prescient, though unhappily, not influential at the time. His observations remain relevant for our current understanding of the condition and are worth quoting in full here:

> Much greater care is due to the mind and soul; for they, too, like lamps, grow dim with time, unless we keep them supplied with oil. . . . Intellectual activity gives buoyancy to the mind . . . Old men retain their mental faculties, provided their interest and application continue. (Berchtold and Cotman, 1997, p. 174).

Roman physician Galen (150 – 200 AD) employed the term 'morosis' to describe the general condition of dementia, and noted that old age was a strong predisposing factor in the disease. In older people with morosis, intellectual capacity and knowledge appeared 'totally obliterated' to the extent that they were unable to remember their own names (Berchtold and Cotman, 1997, p. 174). At the end of the second century AD, Aretheus of Cappadocia is thought to have been the first to distinguish between acute and chronic neurological and psychiatric disorders. Chronic disorders (such as dementia) were associated with irreversible impairment of higher cognitive functions (Boller and Forbes, 1998).

It has been argued that in the Greco-Roman period, linking old age ineluctably with cognitive decline signaled a formative shift in regarding the process of aging itself as a disease, or as Galen describes it, 'an inevitable infection of the body' (Berchtold and Cotman, 1997, p. 175). This in turn foreshadowed a change in the meaning of the word senile. From the Greco-Roman period onwards, senility was subject to a gradual but inexorable lexical transformation, moving from denoting advanced age to taking on a meaning specifically related to the condition of dementia itself (Haber, 1983; Covey, 1988).

The Western medieval period has been broadly characterized as devoid of significant developments in knowledge and research in medicine, given the dominance of the church and religious doctrine and the attendant stifling of intellectual and philosophic endeavour (Bernal, 1965; Berrios, 1994 and Berchtold and Cotman, 1998; Boller and Forbes, 1998). This included notable developments in the mental health area including dementia, with the singular exception of the efforts of 13th Franciscan English friar and philosopher, Roger Bacon. Bacon's *Methods of Preventing the Appearance of Senility,* contained some remarkably astute and original observations about the relationship between brain structure and cognitive processes. Where previous medico-scientific and philosophic thinking located intellectual functioning in the heart rather than the brain, Bacon's radical conceptual shift identified specific parts of the brain with different cognitive functions. He then theorized that injury to discrete areas resulted in specific symptoms. 'An injury to the reasoning faculty happens in the middle part of the brain . . . An injury to the imagination occurs in the anterior part of the brain' (Berchtold and Cotman, 1998, p. 175).

Regarded as heretical rather than enlightened, Bacon's treatise on neuro-cognition resulted in his incarceration. The aforementioned stifling of significant medico-scientific developments by the church in the ensuing three centuries ensured that the conventional belief that cognitive function resided in the heart persisted into the 16th century.

Throughout the 16th and 17th centuries, medical textbooks including those published by the physicians Barrough (1563) and Thomas Willis (*Practice of the Physick*, 1684), outlined various mental illnesses, including those associated with memory loss. Willis employed 'morosis' or equivalent terms to make detailed distinctions between different forms of dementia and their causes – the latter including age, head injury, alcohol abuse and disease – and in the process, considerably advanced knowledge in the area. In pathologist William Cullen's 1776 reclassification of mental and physical illnesses, 'senile dementia' is identified for the first time as a discrete disease (Berchtold and Cotman, 1998). Catalogued under Neuroses, Cullen describes senile dementia as ' … decay of perception and memory, in old age - Amentia senilis …' (Berchtold and Cotman, 1998, p. 177).

Social historians have argued that while there was some progress in describing and defining types of dementia, there were no significant developments in the overall conceptualization of 'senile dementia' from that earlier Greco-Roman period to the beginning of the 19th century or refinement of the idea of dementia associated with older age (Berthold and Cotman, 1998; Ballenger, 2000). There were individual efforts to link the various types of dementia with brain pathology, but there was no consensus on the specifics of that pathology.

Several developments in the late 18th century and early 19th century indicated a shift in thinking that was formative in both the classification of dementia, and the treatment and care of people diagnosed with the illness. Described as the founder of modern psychiatry, Philippe Pinel was instrumental in advocating for an improved, more compassionate understanding of mental illness, insisting on moving people with mental health issues including those with dementia, from prisons to health facilities where they could receive appropriate treatment and care (Boller and Forbes, 1998). This shift in turn encouraged a clinical approach based on more objective observations of symptomology and pathology and resulted in an improved system of classification of psychiatric conditions.

Pinel's student and colleague Jean-Étienne Dominique Esquirol was responsible for instituting a more systematic way of describing and classifying mental illness, including some useful, further distinctions dealing with different dementia types (Boller and Forbes, 1998). Crucially, he distinguished between congential cognitive impairment ('Amentia') and the 'loss of mental faculties consequent on disease ('Dementia'). Esquirol's subsequent description of the latter – including reference to the 'feebleness of memory, particularly recent memory' - established the framework for what in the 20th century became known as senile dementia (Berchtold and Cotman, 1998, p. 178).

Alzheimer's disease

Significant medico-scientific advances in the late 18th and early 19th century linking changes in brain pathology - including cerebrovascular changes, a reduction of brain volume and the presence of protein plaques and neurofibrillary tangles in affected brains on post-mortem - led to the decisive early 20th century breakthrough in the classification of a specific type of dementia, Alzheimer's disease. As outlined in the introduction, Alzheimer's landmark 1906 case study described the symptomology of a 51-year-old woman, Auguste D (Maurer, Folk and Gerbaldo, 1997). The most prominent clinical features in this case were memory loss, disordered thinking, hallucinations and delusions and the progressive loss of execution function and language skills. The younger onset and rapid progression of the disease (Auguste D died four and a half years after symptom onset), in addition to post mortem pathological results describing the presence of unusual protein plaques and neurofibrillary tangles, led Alzheimer to postulate a 'distinctive disease process'. This, he suggested, was different to other dementias, including what was then referred to as 'senile' dementia or dementia associated with older age (Berchtold and Cotman, 1997, p. 179).

Subsequent cases reported in younger patients by other practitioners appeared to support Alzheimer's findings, while his colleague, pre-eminent German psychiatrist Emil Kraepelin gave considerable weight to this new dementia category by acknowledging 'pre-senile dementia' in his formative *Textbook of Psychiatry*. Published in 1910, the eighth edition specifically referred to the new dementia subtype as 'Alzheimer's disease' while also acknowledging there was ongoing uncertainty as to the exact etiology of this 'pre-senile dementia' (Berchtold and Cotman, 1998; Maurer, Volk and Gerbaldo, 1997). Kraepelin's support was central to the designation and recognition of Alzheimer's disease as a new condition in this period. Equally, his descriptions of the behavioural and other clinical features associated with the senile form were influential at the time and remain germane today. These included a marked reduction in 'receptivity', 'mental resilience' and the ability to sustain emotional relationships, and the parallel development of 'obstinate unmanageability' (Berchtold and Cotman, 1998, p. 181).

Kraepelin's notes on memory impairment were particularly detailed and accurate, specifically highlighting the retention of long-term recall but the pronounced loss of short-term memory. These descriptions made a significant contribution to documenting what has subsequently become the symptom, above all others, most commonly associated with the disorder. This emphasis on memory loss associated with dementia will be addressed in subsequent chapters in relation to the way in which it has become a commonplace in films and TV series depicting dementia. As a standard dramatic device and a defining trope of dementia on screen, memory loss is problematic in offering an at times unhelpfully reductive depiction of a complex illness and its consequences.

The decades following Alois Alzheimer's breakthrough were characterized by ongoing debates around the diagnostic significance of protein plaques and neurofibrillary tangles as definitively associated with a diagnosis of AD, and more significantly, whether AD could in fact be regarded as distinct from the 'senile' form of dementia. From the mid twentieth century onwards, Roth, Blessed and Tomlinson made a significant contribution to refining diagnostic criteria (Roth, Blessed and Tomlinson, 1966; 1967; 1970). It was not until the late 1970s that a form of medico-scientific consensus was achieved. It was acknowledged that the features that had previously been thought to distinguish the two – age of onset, differences in behavioural and other symptoms, severity of symptomatology and pathological changes – were in fact not significant enough to justify a distinction between senile dementia and Alzheimer's disease. The two were therefore were combined under the single classification of Senile Dementia Alzheimer's Type (SDAT) or what is now recognized as the most common form of dementia and simply referred to as AD.

The hegemony of the biomedical model

The clarification of the key features and diagnostic parameters of AD played a significant role in the shift to a biomedical model of understanding dementia that took hold from the 1970s onwards. In this reconceptualization of the disease, distinctions were now made between the processes of 'normal aging' and disease in older age, including AD. This shift away from an assumed correlation between ageing and dementia acknowledged that while AD was more common in older age, age-related changes were not the 'cause' of the disease. In this biomedical model, the 'data of disease' was prioritized and as a consequence, research efforts increasingly focused on identifying different types of dementia and their respective etiologies, accompanied by an emphasis on treatment rather than care (Holstein, 2000, p.170).

In this historical interpretation, the consequent focus on cure rather than caregiving resulted in misapprehension, stigmatization and hostility in relation to the disease, attitudes that arguably persist today (Ballenger, 2000). What one analyst calls the ' "diseasing" of AD …' has therefore produced decidedly mixed outcomes (Holstein, 2000, p. 172). On the one hand, in the intervening five decades, there has been an undisputed contribution to the mapping of different forms of dementia - more than 100 types of dementia with varying symptoms have been identified and categorized under the general syndrome of dementia. Conversely, since the biomedical model of the disease gained primacy in the 1970s, the medico-scientific and broader community have regarded dementia with increasing unease. The fearfulness and fatalism that have characterized Western attitudes to dementia in the late 20th century and beyond has been traced to the increasing emphasis on the condition as a separate disease entity (Ballenger, 2000; Post, 2000; Holstein, 2000). In order to fully understand the attitudinal (and in subsequent chapters, representational) shifts in understanding and beliefs about dementia over time, it is important to take account of the broader historical considerations at work.

The definition of the condition as a disease, progressive refinement of categories and broader understanding of dementia, is not simply a result of bio-medical research developments, but is equally the product of cultural, intellectual and technological forces of the period (Fox, Kelly and Tobin, 1999; Holstein, 2000; Ballenger, 2006; Zeilig, 2014). Dementia, as with the history of other diseases, can be understood as a socially constructed entity (Kitwood, 1997; Holstein, 2000; Mercade, 2005; Basting 2009). A brief survey of attitudes around aging and disease - and as a corollary dementia - over the last two centuries of American history illustrate how significant shifts in thinking and beliefs have occurred even in this relatively short period.

Conceptions of dementia in modern America – a short social history

In his account of historical perspectives on Alzheimer's disease in Modern America, Jesse Ballenger notes that the current fear and anxiety around dementia and its consequences is a relatively new phenomenon, one that he traces back to the late 19th century (Ballenger, 2000, p. 3). In contrast, attitudes towards dementia in 17th and 18th century America were underpinned by the religious beliefs and affiliations of the period and fundamentally benign. Piety and devotion to God gave meaning to lives, and this remained so, even for the frail and elderly, including those with cognitive impairment. This unwavering religiosity effectively provided a protective effect, so despite an individual's physical and mental deterioration and their inability to make a productive contribution in other ways, religious devotion obviated 'imbecility of body and mind' and allowed them to remain 'fully human' and part of their community (Ballenger, 2000, pp. 5-6).

By the late 19th century, broader changes in American society produced different attitudes to ageing more generally, and to dementia specifically. The dual impact of the declining influence of organised religion and the advent of democratising imperatives in this period - with the attendant loss of binding ideals around piety and community – meant the most vulnerable individuals, including those with dementia, lost the protective effect conferred by religion. In this increasingly secularized socio-cultural context, the emphasis was increasingly on *individual* rather than collective moral responsibility. This shift in turn brought with it a more uncompromising attitude towards old age and infirmity. Decline in older age – both physical and mental – came to be regarded as a sign of individual 'moral failure' (Ballenger, 2000, p. 14).

Broader changes in 20th century American society – an increasing emphasis on notions of individualism, selfhood and autonomy, in tandem with industrialization and associated changes in what constituted useful work and productiveness into middle and older age - exacerbated this anxiety around the ageing process. This manifested in an increasingly hostile collective attitude to the elderly. Those seen as incapable of fulfilling the new, modern aspirations around independence, selfhood and meaningful engagement in society - namely the aged and infirm - were increasingly marginalized (Ballenger, 2000).

In his 1905 valedictory address at the Johns Hopkins University School of Medicine, pre-eminent Canadian physician and 'Father of Modern Medicine', Sir William Osler stated that ' … men over the age of 40 were comparatively useless while men over 60 were absolutely useless' (Holstein, 2000, pp. 161-2). Setting aside the considerable irony that Osler himself was in his mid-fifties when he delivered this speech, his comments starkly illustrate the prevailing attitudes of the medical profession in the early 20th century. These attitudes in turn shaped those of the broader community in this period, encouraging a view of older age as an essentially enfeebled and superannuated state.

The tendency to characterize 'normal' ageing in negative terms, and as a process involving inevitable physical and mental deterioration, persisted well beyond the mid-20th century (Holstein, 2000, p. 162). The ineluctable socio-cultural corollary of this attitudinal shift was an escalating disregard for those with cognitive impairment (Ballenger, 2000; Zeilig, 2014). A diagnosis of dementia and the associated inability to 'independently sustain a coherent self-narrative' thus became by the late 19th and early 20th century, the worst of all imaginable futures (Ballenger, 2000, p. 9). For these gerontological historians, the catastrophizing around dementia and its correlation with 'social death' became entrenched in this period and persists today in the fear and anxiety that continues to accompany a dementia diagnosis (Ballenger, 2000; Lamb, 2015).

For Ballenger and others, these broader changes in attitudes toward ageing generally, and dementia specifically, are neatly symbolized in the changing meaning attached to the word senility. The lexical transformation that began in Greco-Roman times is thus complete by the end of the 19th century. Rather than simply signifying older age, in the late 19th century, senility is firmly co-opted by the medico-scientific profession to connote the decline, particularly cognitive, associated with ageing. From the late 19th onwards, senility takes on an unmistakably pejorative import, and one that that unhappily, is still deployed in both clinical and broader contexts today.

Ageism is alive and well

The consistently negative sentiments are arguably informed by a broader, entrenched socio-cultural and economic narrative about the ageing of our local and global population and the associated 'burdens' imposed by the needs of older people. A recent Australian study specifically linked two cohorts – the young and the 'baby boomer' generations - to negative and condemnatory attitudes about the elderly, and the associated costs of caring for them. In this survey, older people were seen as 'not making a contribution', being 'fragile' and a 'burden on society' (McCabe, Mellor, McNamara and Hill, 2010).

This disparaging characterisation of older people is neither new nor uncommon, as identified by Simone de Beaviour in her seminal 1970 treatise *Old Age* (1970). Noting censorious attitudes towards older people were alive and well in Roman times, she cites Pompeian banker Lucus Caecilius (20–62

AD), who lamented that the most regrettable thing about growing older is that 'one feels like one is now repulsive to the young'. (De Beauvoir, p. 134). Australian attitudes towards ageing and older people have not changed significantly in recent decades. In the forward to her anthology *Coming of Age*, Anne Deveson remarks on the contrast in our reverence for things of advanced age or antiquity in the built environment, the arts and the natural world compared with our repugnance for older people (Deveson, 1994, p. 1). Patricia Edgar's more recent analysis of ageing noted the profoundly pejorative connotations of 'old' in the Australian lexicon, and the ingrained, and insidious but equally often overt ageism consistently on display in every aspect of our way of life in this country. (Edgar, 2013, p. 7)

Equally, it has been argued that Western culture's enduring socio-cultural reticence around older age and death, and the atomisation of the traditional family, accounts at least in part for the pronounced fearfulness and anxiety that continues to define attitudes to dementia in the West (Van Gorp and Vercruysse, 2012). Western culture's collective failure to engage with the consequences of the ageing process, including the possibility of cognitive impairment, insistence on living rigorously independent lives into oldest age, and attenuation of traditional family ties and obligations, mitigates against an understanding of - and willingness to engage with - the complexities of living with a dementia diagnosis.

In contextualizing attitudes to dementia in order to interpret recent representations of the disease in dominant forms of Western popular culture, it is worth noting that the kind of 'terror' that often accompanies a diagnosis of dementia in the West - and is reflected on the mainstream screen - is notably absent in other cultures (Holstein, 2000). Throughout Asia, Africa and Latin America, rather than a Western insistence on the congruence of 'successful ageing' with individual autonomy and independence, strongly embedded notions around intergenerational reciprocity and filial piety ensure that families and communities provide care for older family members. In

India, living alone in older age has been described as 'not part of human nature' and 'unthinkable' (Lamb, 2015, pp. 37 - 44).

Similarly, cultural difference has historically shaped beliefs about dementia in these countries in ways that contrast sharply with the kinds of increasingly fearful Western attitudes outlined above. In countries including China and India, the 'diseasing' of dementia has not been the dominant lens through which to view the condition; rather, the understanding of ageing comfortably admits the possibility of cognitive impairment and dementia, interdependence of family members is assumed and the care consequences of dementia are routinely accommodated within a familial, non-institutional setting (Lamb, 2015).

If Western attitudes to dementia in the healthcare and broader public domains have been defined since the late 20th by a biomedical model, this has also had implications in terms of the prioritizing treatment and care options. The emphasis on dementia as a disease and the attendant focus on finding a 'cure', has inadvertently but perhaps inevitably produced what has been described as a pervasive 'therapeutic nihilism' (Bryden and Friedell, 2001). This has been characterized as a belief, still widespread today within the health profession, that there is little on offer in terms genuinely therapeutic treatment or care for those diagnosed with dementia (Iliffe, Wilcock and Haworth, 2005).

Numerous studies have shown that for primary health care clinicians, the perceived lack of therapeutic treatment or care options is a significant factor in either delaying or withholding a diagnosis of dementia (Woods, Moniz-Cook, & Iliffe, 2003; Downs et al, 2005; Iliffe et al., 2005; Bradford, Kunik, Schulz, Williams and Singh, 2009; De Vries and Brooker, 2010). This clinically-based therapeutic nihilism has arguably both informed the broader fatalism that remains typical of attitudes to dementia in the public domain and in turn, continues to influence depictions of diagnostic processes, symptomatology, treatment and care options in relation to dementia on the small and large screen.

In The Absence Of A 'Cure': The Biopsychosocial Model of Dementia

The dominant shifts in Western knowledge and thinking around dementia over the last century – and the continued emphasis on disease, treatment and cure – are reflected in the ongoing disparity in funds allocated for research into pharmacological treatments for dementia compared with non-pharmacological interventions. As Steven Sabat has noted, expenditure on the latter has ' … been minuscule relative to expenditures on pharmacological interventions' (Sabat, 2019, p. 164). Likewise, American health insurance companies will pay for medications prescribed for AD but not for day centre programs offering supportive psychosocial interventions (Sabat, 2019).

Despite this funding inequity, over the five decades since the biomedical model of dementia has taken hold, there has been a corresponding interest in and focus on alternative perspectives on dementia that prioritize the importance of psychosocial and other supportive interventions. The biopsychosocial (BPS) perspective is the most prominent of these. Described as a model that attempts to both challenge and expand on the traditional biomedical model across a number of different health domains, it has not been without criticism but it has made and continues to make a significant contribution to current thinking about dementia and approaches to dementia care (Farre and Rapley, 2017).

This thesis argues for cultural constructions of dementia on the mainstream screen as a potentially affirmative and instructive influence. Many of the texts discussed depict dementia from the perspective of the caregiver, family member and most significantly, the person living with dementia, and foreground the importance of psychosocial interventions. A brief overview of the BPS approach and related principles of person-centred care is important here in order to contextualize how these screen representations might make a positive contribution to an audience’s understanding of dementia and how to best support someone living with the condition.

Engel’s original conception of the BPS model argued for health professionals to assess a patient’s presenting illness not simply from a biomedical perspective but to consider the broader context including psychological and social factors. In this rethinking of the way in which medical assessment was conducted, decision-making about treatment and care should take into account and integrate information from all three of these domains (Farre and Rapley, 2017). This approach has been valuable in reframing our understanding of dementia and supportive interventions for the person living with dementia, and in the specific context of residential aged care, what constitutes best practice dementia care.

Rather than viewing the condition and its symptomatology as straightforward manifestations of the neuropathology associated with the disease, proponents of the BPS approach argue that other factors need to be considered (Kitwood 1997; Killick and Allan, 2001; Sabat 2001 and Wilkinson, 2002). Tom Kitwood’s seminal contribution to this field is well established, particularly in relation to his ideas around the influence of physical and social environmental factors on the illbeing and wellbeing of the person living with dementia (Kitwood, 1992, 1993, 1997 and 1998). Calling for a shift away from the influence of the biomedical model and associated notions of treatment and intervention, Kitwood advocated for a ‘positive transformation of care practice’ (Kitwood, 1997, p. 144). This transformation prioritized respectful communication and the centrality of relationships in all interactions between people living with dementia and those supporting them (Kitwood, 1997).

Reframing previously prescriptive ideas about ‘behaviours’ associated with dementia, Kitwood argued that the ‘problem’ of dementia did not lie with the individual but rather with their ‘interpersonal milieu’ (Kitwood, 1993, p. 543).

The actions of *other* people could have a significant impact on the illbeing and wellbeing of the person with dementia. Kitwood argued that Malignant Social Psychology (MSP) - actions including ignoring, infantalizing, disempowering, disparaging or intimidating the person with dementia - while rarely intentionally malicious, could have a significant and deleterious effect on wellbeing (Kitwood, 1998).

Over the long term, in a formal or informal care setting, an environment shaped by MSP could lead to feelings of helplessness, social isolation and de-personalization (Kitwood, 1998). In contrast, what Kitwood called 'Positive Person Work', an approach that demonstrates amongst other features warmth, acknowledgement, validation and respect, could actively support wellbeing (Kitwood, 1998). Kitwood's concepts of 'personhood', 'person-centredness' and a 'person-centred' approach to the care and support of people living with dementia were underpinned by belief that the individual, rather than the health professionals and others gathered around them, was the 'expert' and should be central to determining their own care needs.

Over the last three decades, the impact of the BPS approach is clear in the growing body of literature in support of this more inclusive way of thinking about dementia. Steven Sabat's interventions in the field have been critical. While acknowledging the biomedical approach has 'certain assets' but equally clear limitations, Sabat argues for the prioritization of 'qualitative psychosocial approaches' in the endeavor to understand people living with dementia and those who care for and support them (Sabat, 2019, p. 171). Expanding on some of Kitwood's key propositions, Sabat has suggested that the social and relational context - the way in which the person with dementia reacts to the effects of their condition, how 'healthy others' treat the person and their own responses to this treatment – are crucial considerations (Sabat, 2014, p.108). Distinguishing between a genuine symptom of neuropathology and an apposite emotional or behavioral response to an adverse physical or social environment therefore becomes central to understanding how best to support a person in that environment (Sabat, 2014).

Related studies have explored the educational potential of the BPS approach for health care professionals in residential aged care settings (Spector and Orrell, 2010; Revolta, Orrell and Spector, 2016). Drawing on the biopsychosocial model as a tool for clinical practice, the authors of a 2016 study claimed that the " … BPS model of dementia may contribute to improvement in one's ability to incorporate information from biological, psychological, and social domains, in the development of treatment plans' (Revolta, Orrell and Spector, 2016, p. 1086). Recent refinements to the BPS model have included the addition of a physical domain, comprising the five components of physical well-being, physical health and examination, physical care, physical treatment and physical environment (Keady et al, 2012). Arguing for the importance of the physical dimensions of care and the ' … opportunities for engagement and evaluation …' that these offer, the authors suggest that the original BPS approach could benefit from an expanded and more expansive understanding as a bio-psycho-social-physical model (Keady et al, 2012, p. 2769).

Promulgating Person-centred Care

The continued influence of the BPS model can also be seen in the subsequent iterations of Kitwood's profoundly influential ideas around 'person-centredness' and a person-centred approach to dementia care (Edvardsson, Windblad and Sandman, 2008; Fazio, 2008; Power, 2008; Power, 2014; Loveday, 2013; Higgs and Gilleard, 2016; Fazio, Pace, Flinner and Källmyer, 2018). Dawn Brooker and Allen Power, amongst others, have been prominent in subsequent efforts to refine and clarify what is meant by these terms and how best to embed them in workplaces cultures in residential aged care and other settings (Brooker, 2007;Brooker and Latham, 2016; Power, 2010; 2014). Both have been important influences for this thesis in thinking about the impact of representations of dementia and dementia care on the mainstream screen, particularly in a pedagogical context.

Brooker's formative definition of a person-centred approach to care for people living with dementia identifies four key elements: valuing people regardless of their cognitive ability; individualizing care and support and recognizing the uniqueness of every individual; adopting the perspective of the person with dementia and emphasizing the importance of relationships and the social environment (Brooker, 2007, p. 12 -13). Neatly summarized under the accessible VIPS acronym, these guiding principles have subsequently been influential in an international context in shaping a culture of person-centredness and changing the way in which support for people living with dementia is planned and delivered in residential aged care settings (Baker, 2015; Brooker and Latham, 2016).

As with Kitwood's notion of the person with dementia as the expert in their own care, Power casts himself and other health professionals as professional students of dementia in contradistinction to the 'True Experts' - people living with the condition (Power, 2014, p. 12). As with Kitwood, Sabat and others, Power interrogates the narrowness and inadequacy of the biomedical view of dementia and the way in which dementia is characterized in terms of the deficits and losses experienced with dementia rather than abilities and capacities retained or developed. Importantly for this thesis, Power notes that this positioning '*discounts the subjective experience of people living with dementia*' (Power, 2014, p. 15).

Power argues for a fundamental reframing of how we think about dementia, one that privileges rather marginalizes that subjective experience. His redefinition of dementia is thus ' a shift in the way the person experiences the world around her/him …', a definition that focuses on the person rather than the pathology and encourages an associated change in approach that he argues can produce improved outcomes for people living with dementia

(Power, 2014, p. 20). Power's reframing of dementia is valuable for considering the way in which key texts discussed in this thesis assert the centrality of the subjective experience of dementia and the impact this could have on a broad audience and the residential aged care workforce.

Conclusion

Screen depictions over the last three decades have dealt with the subject of dementia with varying degrees of clinical accuracy, insight and empathy, with many reflecting the kinds of historical shifts in thinking outlined above. Cultural constructions of dementia on the film and television screen can foreground affirmative, positive and complex depictions of the condition and this includes a prominent focus on the importance of psychosocial interventions and the efficacy of caregiving. The BPS model of dementia and the guiding principles of person-centred care offer a framework for considering issues in relation to representations of dementia and dementia care in the film and television texts in this analysis. In the following chapter, tracing shifts in public sentiment and reportage in contemporary mainstream media coverage of dementia over the last three decades provides further contextualization for understanding the representations of dementia on the mainstream screen over the same period.

CHAPTER TWO: DEMENTIA AND THE MAINSTREAM MEDIA – THE MESSAGE AND THE MEDIUM

‘Accounts of dementia, particularly from politicians and in the press, tend to evoke frightening images, presenting it as a kind of living death for its sufferers—the body remains but the person is lost.’ (Hillman and Latimer, 2017,p. 2)

‘Positive language and terminology in communications about dementia can strengthen community awareness and eliminate fear and stigma associated with the disease’ (Doyle et al, 2012, p.100)

Introduction

The role that the mainstream media – defined here in the traditional sense of broadcast news, newspapers, radio and television - can play in public health debates has been well established (Brodie et al, 2001; Kline, 2006; Moyer-Guse, 2008; Bryant and Oliver, 2009; Brown and Bobkowski, 2011). The influence that the mainstream media can exert specifically in relation to mental health issues has also been the focus of sustained research, particularly over the period this thesis encompasses (Rosen and Walter, 2000; Pirkis, Blood, Francis and McCallum, 2006; Doyle et al, 2012, Peel, 2014).

‘The credibility that society grants to the media makes them ideal instruments to spread public interest messages that are aimed at modifying attitudes and behaviours regarding specific topics, such as mental health issues …’ (Cuenca, 2001, p.527). The 2005 WHO Mental Health Report noted that ‘people with stigmatized illnesses do not usually announce themselves’, rather, mainstream media and popular culture are potent sources of global influence in shaping attitudes and knowledge about mental health issues (WHO Mental Health Report, 2005, p. 44).

Mainstream media commentary on dementia offers an instructive example in this context and will be the focus of this chapter. A prominent study of mainstream media discussions of Alzheimer's disease noted, '…the media is frequently cited as the main source of publicly available information about Alzheimer's disease' (Kirkman, 2006, p 74). Media commentary over the last three decades reflects shifts in knowledge and awareness about the disorder and equally as suggested above, has contributed to 'shaping attitudes and behaviours' about dementia. Analysis of the language, tone and dominant themes in mainstream media commentary in this chapter will provide a framework for the subsequent discussion of representations of dementia in film and TV over the same period. As with the latter, this chapter will focus on studies of Western, English language, mainstream media sources over the last three decades.

Mainstream media descriptions of dementia vary considerably. Dementia is often associated, if not conflated with, older age (Kirkman, 2006; Zeilig, 2014). The disease is typically referred to as a homogenous entity or reductively collapsed into the Alzheimer's disease category. Dementia subtypes are rarely distinguished, ignoring the complexities of the symptoms and consequences associated with each type of disorder. The dominance of the biomedical model of dementia, outlined in the previous chapter, is reflected in the coverage (Kirkman, 2006, p 74). Over the last three decades, research initiatives and the search for a pharmacological 'cure' have emerged as key themes reflecting the hegemony of this disease-focussed model (Kirkman, 2006, Basting, 2009, Doyle et al, 2012 and Peel, 2014, Manthorpe and Iliffe, 2016). Causation, symptoms, preventative strategies and to a lesser extent, personal accounts from informal carers and people living with dementia also feature in mainstream media accounts (Kirkman, 2006, Doyle et al, 2012; Peel, 2014). The details of treatment options and care interventions are often dealt with summarily, if at all and the complex, psychosocial impacts of the disease on the person, their family members and the broader community are rarely explored (Kirkman 2006; Doyle et al, 2012).

Where the thematic focus has varied, the *tone* of media coverage has been consistently negative and pessimistic (Bond, Corner and Graham, 2004; Basting, 2009; Chivers, 2011; Van Gorp and Vercruysse, 2012; Zeilig, 2014; Peel, 2014; Manthorpe and Iliffe, 2016). It has been suggested that the 'language of loss and determinism' pervades Western mainstream media accounts of dementia (Hillman and Latimer, 2017 p 2). This echoes what Anne Basting has described as the 'tragic narrative' that dominates recent mainstream media commentary and cultural representations of dementia (Basting, 2009, p 32).

Read All About It

Given the influential role newspapers have played in information dissemination and shaping public debates around dementia over the last three decades, analysis of the language and rhetoric associated with dementia in newspaper reportage will be discussed as illustrative of the tenor of mainstream media coverage more broadly. Newspaper coverage in the medico-scientific domain, including stories about conditions such as dementia, is prompted by the specific interests of its readership and equally, has the potential to influence knowledge and opinion of this readership. If 'newspaper articles about diseases provide windows on their social histories and barometers of their contemporary social impact', the coverage of dementia is exemplary in this context (Adelman and Verbrugge, 2000, p 363).

The global medico-scientific discourse about dementia regularly describes the rising incidence of the disorder as an 'epidemic' (WHO and ADI reports, Dharmarajan and Srinivas, 2009; Basting, 2009 and Larson, Yaffe and Langa, 2013 and Zeilig, 2014). In the context of academic and grey literature, the choice of terminology is justifiable in epidemiological terms as indicative of increasing incidence and prevalence whereas in the mainstream media, 'epidemic' is frequently used in a broader, more hyperbolic sense and can take on distinctly alarmist overtones. It is a semantic distinction with potentially serious consequences, where the mainstream media deployment of the term can feed into a popular discourse about the disease that frightens the general public and contributes to misinformation and stigma.

A 2016 UK study of newspaper coverage of dementia noted the 'preponderance of headlines emphasizing the catastrophic nature of dementia in various ways' (Peel, 2014, p. 890). In addition to regularly invoking dementia as an 'epidemic', other alarmist metaphors include dementia as a 'bomb ready to explode' and headlines warning of the imminent medical and fiscal threat to the community posed by the condition (Peel, 2014, p. 890). Other UK analyses of the tone and content of the national press identified a clear set of messages the most prominent of which insisted that 'Dementia is an impending and inevitable apocalypse' (Butler, 2014, para. 2).

Australian newspaper accounts have included equally hyperbolic descriptions, portraying the Australian population as being at risk of being 'overwhelmed' by a 'tidal wave' or 'surge' of people living with dementia (Jay, 2015). News stories invoking metaphors related to the 'danger of flooding', 'waves' and the 'rising tide' have a long history of association with the healthcare needs of older people and dementia in particular (Zeilig, 2014, p. 260). Comparable studies of mainstream English language media accounts have noted that the urgency of the public health issue has been regularly described in the mainstream media as a 'crisis' and likened to a 'plague' and an 'unstoppable force' (Mandell and Green, 2011; Zeilig, 2014 and Hillman and Latimer, 2017 p. 2 respectively). In this more populist context, 'epidemic' and 'plague' carry the additional semantic weight of contagion, feeding into an overarching media narrative of medical and even moral panic. It has also been argued that the use of terms such as epidemic, plague and contagion is an unhelpful oversimplification that seemingly equates dementia with a virus, with the attendant implication that the condition is easily treated by medical science (Rahman, 2013; Gordon, 2014).

The contemporary West has been characterized as a ‘hypercognitive culture and society’ that venerates autonomy, intellectual engagement and economic self-sufficiency above all else (Post, 2000, p. 245). This forms a crucial backdrop for the ‘profound dread’ associated with dementia in Western societies that, as noted in the introduction, is not a feature of non-Western community counterparts. In this Western interpretation, a disease that fundamentally compromises the key indicators of individual fulfilment therefore represents the worst of all possible diagnoses (Post, 2000). The corollary of this profound fear of dementia is the relatively new construct of ‘anticipatory dementia’ or ‘dementia worry’ (Kinzer and Suhr, 2016). Defined as ‘an emotional response to the perceived threat of developing dementia’, anticipatory dementia has been posited as a specifically Western phenomenon (Kessler et al, 2012, p. 275). Heightened awareness of and experience with dementia, widespread misapprehension about the risks and consequences of the condition and a perceived lack of support services and resources have been identified as contributing factors to the high prevalence of anticipatory dementia in middle-age and older adults in Western populations (Kessler et al, 2012, p. 275**)**. Anticipatory dementia has arguably been shaped in significant part by the catastrophizing tone and content of newspaper reportage about the disorder over the last three decades (Clarke, 2006; Kirkman, 2006, Doyle et al, 2012).

Economic (ir)rationalists

The alarmist mainstream media discourse detailed above is underpinned by the unsubtle implication that the needs of older people with dementia threaten to ‘swamp’ or ‘infect’ the general population, monopolizing valuable economic and other resources and unfairly depleting other sectors of the community. These sentiments are arguably informed by a broader, entrenched socio-cultural and economic narrative about the ageing of our global population and the associated ‘burdens’ imposed by the needs of older people. In recent decades, debates around funding for dementia – including research initiatives, treatment and care resources - have been framed in similar terms, with an increasing emphasis on the financial burden imposed by dementia and dementia care (Kirkman, 2006; Manthorpe and Iliffe, 2016). As with broader media commentary on the topic, economic reportage on escalating aged care, and in particular dementia care costs, is often characterized by a sense of impending fiscal panic. The title of a recent UK *Financial Times* profile – 'Financial Burden is Set to Grow' - exemplifies the tone (Eley, 2018). The costs of dementia care are described as 'wildly expensive, both for the individuals directly affected and for wider society' and the related costs of social care associated with dementia as 'potentially crippling' (Eley, 2018).

Similar arguments have been advanced in other Western economies. Dementia's 'mounting toll' on the U.S. economy has been described as 'devastating', with the 'market' costs for dementia already exceeding those of cancer and heart disease (Hurd et al, 2013). These sentiments are equally prevalent in an Australian context. A typical recent example included headlines highlighting the 'brutal dementia statistics' and warning of Australia's 'budget time bomb' followed by content emphasizing the 'dramatic and disturbing growth' of dementia rates and the 'startling financial burden of dementia care' typical (McCabe, 2017). As noted in the introduction, the economic implications of service provision for people living with dementia in coming decades is a significant global health issue and the urgency of the imperative to address this is not in question. What *is* questionable is the emphasis on the economic 'burden', the characteristic tone of fiscal alarmism and the contribution this arguably makes to the broader 'catastrophizing' discourse about dementia in the mainstream media.

Dementia as Social Death

If newspaper accounts cohere around the collective threat to the community represented by the dementia 'epidemic', the fate of the individual living with dementia is equally typically inflected with a thoroughgoing fatalism. 'Dementia is a terrible disease. It strips away any sense of dignity and pride, and in the worst cases, any semblance of humanity' (Campbell, 2016). This recent Australian broadsheet account of dementia is representative of newspaper coverage that depicts the disease trajectory as a uniformly ghastly and undignified decline, with little if any emphasis on the capacity of the person living with the illness to maintain relationships, social engagement and quality of life (Kirkman, 2006; Doyle et al, 2012).

Canadian media stories were found to consistently depict dementia as 'fearsome, relentless and aggressive' (Doyle et al, 2012, p 96). Analyses of British newspaper accounts found dementia was typically characterized as 'a terrible affliction' and a 'crippling brain-wasting disease' (Peel, 2014, p 890). Coverage reinforced collective perceptions that there were numerous, unavoidable risk factors associated with the condition and that dementia was the worst of all possible diagnoses. 'Just about anything can increase your chance of succumbing to dementia … [and] … dignified suicide is a blissful and necessary release …' (Butler, 2014, para. 2). Euro-American newspaper depictions of dementia follow a similar thematic pattern. 'Accounts of dementia, particularly from politicians and in the press, tend to evoke frightening images, presenting it as a kind of living death for its sufferers—the body remains but the person is lost' (Hillman and Latimer, 2017,p 2). ' How do you fight a ghost – a pitiless, relentless, insidious ghost?' (Campbell, 2016).

The related and unsubtle social construction of people with Alzheimer's disease as the 'living dead' and akin to 'zombies' – a commonly occurring trope in mainstream media commentary around dementia - reinforces a perception the condition is overwhelming and marginalizes those living with dementia from the rest of the population (Behuniak, 2011, p 70). Recent examples from mainstream film and TV make explicit the zombie or living dead analogy including *The Taking of Deborah Logan* (Robitel, 2014) and *The Visi*t (Shyamalan, 2015). While these texts are not within the remit of this thesis, it is telling that the taglines, testimonials and imagery associated with these examples are explicit and at times hyperbolic in their representation of the 'horror' of ageing and dementia. 'What *Jaws* did for sharks and *Psycho* did for showers, *The Visit* will do for grandparents' (Walkuski, 2015).

Inflammatory newspaper articles asserting 'Geriatric attacks terrorise staff' and 'Violent old people have sparked calls for rest home workers to be trained in self-defence' amplify the depiction of dementia as somehow monstrous (Kirkman 2006, p. 77). A recent article in the Australian Financial Review offers a particularly egregious example. Purporting to detail Australian Government initiatives around the management of 'severe behaviours', the alarmist headline ('Dementia troublemakers in retirement homes ') and associated content depicts the residential aged care population as under threat from 'Feral dementia patients' (Jay, 2015). The latter were described as ' … mad, bad and dangerous to know, a menace to themselves and … other inmates (sic)' (Jay, 2015). Clearly situated at the more extreme end of a spectrum of ill-informed and irresponsible commentary, the characterisation of dementia is unambiguously horrific; the lack of accurate information about the condition is potentially equally damaging.

What is Missing from this Picture?

Australian analyses of newspaper coverage note that many people sourced information about dementia support services and treatment and care options from the print media. Recent findings from analysis of newspaper coverage noted that the absence of detailed and accurate information had a potentially negative effect on awareness about dementia and specifically, on help seeking behaviour following a diagnosis (Kirkman, 2006; Doyle et al, 2012). As noted above, the mainstream media emphasis on the search for a dementia 'cure', and associated pharmacological treatments, has intentionally or otherwise, minimized the importance of non-pharmacological approaches to care, and available support services. Australian mainstream print and television coverage outlining a recent pharmacological development 'to treat behavioural issues' offers a typical example of well-intentioned but unhelpful reportage. With its emphasis on medication for treating 'behaviours' and failure to acknowledge the complex psychosocial factors and needs of people living with dementia, the coverage was described by Australian academics, practitioners and advocates working in the dementia care field as a damaging misrepresentation of 'the facts and the real-world experiences of people living with dementia' (Bisiani et al, 2018).

Newspaper accounts of dementia are also notable for the absence of personal accounts *from the perspective of the person living with the condition*. Other than the occasional activist voice embedded within representations from charitable and advocate organizations, a UK study noted that the voices of people living with dementia are largely missing from mainstream newspaper coverage (Peel, 2014, p.897). If personal stories about dementia are featured in newspapers, they tend to be written from the perspective of the carer, spouse or family member (Clarke 2006; Kirkman, 2006; Doyle et al, 2012; Peel, 2014, Hillman and Latimer, 2017). This aligns with the typologies of film and TV texts central to this thesis, where the dominant category similarly comprises stories told from the point of view of a person caring for or related to the person living with dementia (Dementia as Dramatic Device). The implications of this narrative predominance will be explored in detail in Chapter 7.

As with the smallest film and TV category (Dementia Takes the Lead), newspaper column space is rarely devoted to first person accounts of people living with the condition. Even when the lived experience of dementia is featured, the 'focus is on … the extremes of the disease, making dementia freakish, something that happens to "them" rather than "us" '(Hillman and Latimer, 2017, p. 2). The duality of popular accounts of dementia has also been noted, where dementia is framed as both a massive or monstrous force that must be defeated (by medical science) and a specific condition that affects individuals in extraordinary ways (Zeilig, 2014, p. 261).

Personal stories that detail the complexities of living with dementia, including treatment and care options, are rare (Clarke, 2006). As an increasingly prominent group of dementia advocates, including those living with the condition have suggested, while the perspective of family members and carers is important, accounts of the lived experience of dementia play a critical role in increasing understanding about dementia in the community (Bryden, 2016; Swaffer, 2014 and 2015). Hearing the voices of those with dementia offers a vital corrective to the dominant, 'tragic' narrative, a corrective that both acknowledges the challenges of dementia and affirms the possibility of achieving a good quality of life with the condition. This in turn potentially mitigates some of the erroneous fears and assumptions underlying the increasingly widespread phenomenon of anticipatory dementia (Bryden, 2016; Swaffer, 2014 and 2015).

Language Matters

If the mainstream media discourse about the collective threat posed by dementia has been consistently negative and frequently alarmist, the seemingly benign but nevertheless dehumanizing labels deployed in relation to people living with the disorder are equally unhelpful. As advocates for people living well with dementia have pointed out, being branded as 'demented' or 'afflicted' and 'sufferers' or 'victims' of dementia imposes demeaning labels and connotes passivity (Bryden and Friedell, 2001; Bryden, 2016; Swaffer, 2014 and 2015). These descriptors are frequently deployed in mainstream media coverage and as dementia advocates have argued, even if used unwittingly, imply a lack of autonomy and identity that compounds the complexities of an individual's lived experience of dementia (Bryden, 2016; Swaffer, 2014 and 2015).

A recent Australian broadsheet article offered a typical example including 'fades to grey', 'happily demented' and 'dementia sufferers' (multiple references) in the space of one short, and otherwise considered opinion piece on the topic of advanced care directives (Brandi, 2017). Others have acknowledged that while we must be alert for the 'potentially homogenising and patronising' use of 'sufferer' in mainstream media and health discourses, the term has legitimacy in specific contexts including the domain of palliative care for those living with dementia (McInerney, 2017, p. 410).

The use of emotive phrases such as the 'long goodbye' and the 'never ending funeral', are also typical and potentially harmful (Van Gorp and Vercruysse, 2012). This characterisation of dementia perpetuates the fatalistic language outlined above and reinforces the 'tragic narrative' that Basting and others have argued must be countermanded by alternative accounts and depictions in the mainstream media if we are to collectively develop a more informed understanding of the complexity of dementia and its ramifications (Basting, 2009, p 32).

Not All Bad News

If the defeatist tenor of newspaper reportage is pervasive, encouragingly, it is not the complete story. Australian and British studies have noted an increasingly prominent, affirmative discourse in newspaper coverage in the last decade focussed on preventative strategies including lifestyle modifications and *living well* with dementia (Kirkman, 2006; Peel, 2014). This alternative discourse has the 'potential to influence public perception of risk reduction and early intervention' in a positive direction (Doyle et al, 2012, p.96). The focus on general health promotion and living well with dementia is a welcome counterpart to the fatalism of the tragic narratives outlined above, it is also however, potentially problematic. With an emphasis on the biomedical model of dementia and onus on the individual to prevent dementia by taking personal responsibility for health and wellbeing, this alternative discourse could imply that a dementia diagnosis somehow signals a personal failure to be preventatively proactive (Peel, 2014; Leibing, 2015; Manthorpe and Iliffe, 2016). A shift in the broader Western biopolitical discourse, where governments have increasingly moved away from responsibility for health and well-being shifting this toward individual citizens, has been linked with the emergence of this 'victim-blaming' message or 'blame discourse' (Peel, 2014, pp. 896 - 897).

More encouragingly, comparative studies looking at the changes in Australian newspaper coverage across a decade have showed some positive shifts in language, thematic emphases and understanding of key issues in relation to dementia (Doyle et al, 2012). Comparing newspaper, radio and television coverage in 2000/2001 with 2006/2007, significant improvements in the quality of reporting in relation to 'sensationalism, language and provision of information about help services' were identified (Doyle et al, 2012, p.99). The authors were unable to establish a clear causal link between the dissemination of information, including efforts by dementia advocacy organisations to educate the wider public, and the improved dementia reportage. It was however argued that there was a probable connection that warranted further exploration (Doyle et al, 2012).

A contemporaneous European study supports this contention. Positive 'counterframes' about dementia deployed in a campaign advertisement showed that beliefs about the disorder could be influenced in a positive direction (Van Gorp and Vercruysse, 2012). Participants were exposed to a series of alternative frames about dementia that included affirming the preservation of personhood, identity and humanity, and the possibility of a rich emotional life. The study findings revealed that three quarters of all participants exposed to the advertisement agreed that individuals with dementia could maintain relationships and should be assisted to live a full life (Van Gorp and Vercruysse, 2012). The study's broader findings are particularly pertinent to this thesis. The change in participant attitudes depended on the belief that advertising campaigns and *mainstream media sources were valid sources of information and that these needed to be part of a wider campaign to inform the general public about dementia* (italics added). Crucially, personal testimonials delivered *in the voice of the person living with dementia* were found to be central to the positive impact of the advertisement (italics added) (Van Gorp and Vercruysse, 2012). Other studies have similarly advocated for the provision of 'realistic and credible images of people with dementia to the general public' via social marketing and other forums as part of a wider strategy to educate the community and reduce the stigma and fear associated with the condition (Manthorpe and Illiffe, 2016, p. 15).

Accuracy and affirmation

As the findings outlined above suggest, while a persistently pessimistic tenor has characterized newspaper coverage of dementia in recent decades, modest but demonstrable shifts in the language, themes and accuracy of the information provided have been identified. These shifts are potentially significant in ameliorating what has been described as the 'panic-blame' discourse that has characterized mainstream media accounts of dementia (Peel, 2014, p.885). This change in the tone and content of newspaper coverage could in turn make a significant contribution to changing attitudes and awareness about dementia and as a corollary, reduce the exclusively Western phenomenon of 'dementia worry'. These changes in language, content and emphasis identified in mainstream media coverage of dementia are instructive in providing a broader context for analysing the corresponding representational shifts on the mainstream screen in the twentieth century and beyond that are explored in Chapter Five. Mainstream media coverage and mainstream film and television depictions differ in one significant respect. Where the perspectives of people living with dementia were notably absent from newspaper coverage, the emergence of stories told from the point of view of the person with dementia signal a significant development in the expanding screen depictions of the condition. The analysis in Chapter Eight and Nine will suggest that first person screen depictions are critical to the endeavour to improve knowledge and attitudes about dementia in the broader community and residential aged care workforce.

CHAPTER 3: METHODOLOGICAL CONSIDERATIONS

Introduction

Given the cross-disciplinary nature of this thesis, this chapter will set out the methodological approach that draws on theoretical frameworks from both the ageing and film studies disciplines. This thesis was inspired in large part by a growing awareness of the increasing number of mainstream films and TV series tackling dementia in a detailed and considered way. Two notable feature films, *Away From Her* and *The Iron Lady*, were the catalyst for speculating about how many English language films and TV series dealing with dementia in some form had been produced over the last three decades. This in turn lead to thinking about what kind of positive influence these texts might have had on a general audience and could have as teaching resources in the residential aged care sector.

My initial research focus encompassed a wide range of film and TV texts including English language and non-English language fiction films and English language TV series spanning the period of 1990 - 2018. Relevant film and television search engines, databases and film and television review sites including IMDb, Yahoo! Movies, Film Comment, film.com, MRQE (Movie Review Query Engine), Roger Ebert, Rotten Tomatoes and Metacritic, were searched on a monthly basis over the data collection period. Key word search terms including ageing, aging, age, old age, memory, memory loss, Alzheimer's disease, AD, cognitive impairment, dementia, senile dementia, neurodegeneration, loss of personality and dependence were employed to find potentially relevant texts.

A similar process using plot outline and summary searches (old age, ageing, memory loss, dementia) was followed. Limited searches under character type were also conducted (old man/woman/person) in certain databases. Given that most of the selected feature films were categorized as drama, genre search terms were also used in conjunction with key words to identify potential feature films. Other databases including Informit Humanities & Social Sciences Collection and Informit EduTV were helpful in identifying texts suitable for inclusion. The literature review process, outlined in the following chapter, also yielded a number of relevant texts.

Selection Criteria and Rationale

A long list of more than 100 feature films and TV series was compiled comprising English language, feature length fiction films (n = 59), non-English language, feature length fiction films (n = 35) and English language TV series (n = 18). All texts in the long list were viewed at least once to ascertain relevance and suitability for inclusion. The initial, broad selection criteria simply required that the film or TV episode dealt with dementia in some form. Texts were selected on the basis that they must either include a specific reference to a character's dementia or the symptomatology and context on screen makes it clear that a character has a diagnosis of some form of dementia. The reference to, and characterisation of, dementia could be brief or sustained.

Films and television series featuring characters with cognitive decline or memory loss unrelated to dementia were excluded. Many of the selected texts refer only to dementia in the broad understanding of the term and do not specify a dementia type while others feature less well-known forms of dementia from Binswanger's disease (*Happy Tears*) and Wernicke's encephalopathy (*Choke,* [Gregg, 2008]) to familial Alzheimer's disease (*Still Alice*). Texts referencing any form of dementia were included regardless of the type but as with the preponderance of Alzheimer's disease in real world statistics, AD is the most commonly identified and analysed dementia type on the small and large screen.

The 102 texts were then reduced to a shortlist of 47 on the basis that the representation of dementia in the shortlisted texts had to make a contribution in some way to improving understanding or insight into the condition. All shortlisted texts were then viewed again, accompanied by detailed note taking in relation to clinical accuracy of the depiction of symptomatology, treatment and care.

For the purposes of this thesis, clinical accuracy is defined as an accurate depiction of the symptoms, disease trajectory and the treatment and care options in relation to the particular type of dementia depicted (if a type is identified) and importantly, *in the context of the period in which the film or TV text was produced*. As noted in Chapter One, significant research developments and advances in knowledge about dementia have occurred over the time frame this thesis encompasses. This evolving knowledge about dementia is reflected in various ways in the texts that are the focus of this discussion. My emphasis on clinical accuracy is therefore not a prescriptive requirement that each text must include the full array of symptoms, treatment and care options but rather that the features and concerns associated with the form of dementia depicted are correct within the narrative, generic and temporal constraints of the text.

Contrasting texts from the same time frame are a useful illustration of this. The 2003 telemovie *A Time to Remember* deals directly with the older character's AD, delineates a range of symptoms accurately and explores the emotional responses of family members and related caregiving issues with considerable insight. Released the following year, *The Notebook* (Cassavetes, 2004) details the central female character's fluctuating cognition in misleading fashion, includes alarmist scenes of heavy-handed medical intervention and concludes with an emotionally gratifying but clinically preposterous scenario. As with *The Notebook*, *Aurora Borealis* (2005) features a youthful romance at its center and an older character with dementia, specifically identified as AD. The disease trajectory and symptomology are inconsistently and unrealistically portrayed. A year later, the Canadian film *Away From Her* (2006) measures the impact of a dementia diagnosis on a longstanding marriage, exploring with the principal female character's changing symptomatology and progressive decline within a residential aged facility with considerable sensitivity.

Note taking also focused on which perspective dominated the film and the kinds of issues addressed including impacts on family members and carers, the approach to supporting the person living with dementia and the depiction of the lived experience of dementia (See Appendix Two for a sample of the note-taking table). The data collection is discussed in more detail in a later section of this chapter.

Three broad themes emerged in the course of the data collection and viewing phase: dementia appeared surprisingly frequently as a minor character or plot point in a diverse range of genre films aimed squarely at a broad audience. Dementia was frequently a catalyst for action in dramas, primarily functioning as a device to explore familial relationships or other issues relating to characters *other* than the person with dementia. Finally, a small but increasingly prominent group of films positioned dementia as the central focus of the narrative with a small subset specifically privileging the perspective of the person with dementia. These categories, while not mutually exclusive, firmed over the data collection phase, with each of the shortlisted films conforming to at least one these three typologies.

Repeated viewings of the shortlisted texts reduced the final list to 16 texts, with 12 feature films (including one non-English language film) and four TV series or mini-series. Each was selected for the constructive contribution the text made to enhancing the understanding of some aspect of dementia and its suitability as a teaching resource in residential aged care setting. The latter included that the film or TV episode provided relevant scenarios that raised key issues and concepts that aged care staff could apply to their own practice supporting residents with dementia. This ranged from the brief but instructive learning curve the central character undergoes in understanding his father's experience with dementia in *Friends with Benefits* to the powerful and comprehensive depiction of the lived experience of dementia in a residential aged care setting in *Wrinkles*.

Thematic considerations

A number of inter-related questions and issues emerged from analysis of the selected texts and these cohered around the following central themes:

- Where and how is dementia positioned in the narrative trajectory?
- Whose perspective on dementia dominates the story?
- If the carer, spouse or family member's point of view predominates, what are the central issues in these narratives?
- Do these differ from depictions where the central character and perspective is that of the person living with dementia?
- Is the depiction of the illness clinically accurate or otherwise?
- Are the psychosocial consequences of dementia addressed and if so how?
- Finally and critically, how is the depiction of dementia instructive in educating the viewing audience about the realities and complexities of the condition?

In addition to the considerations above, and employing a broadly thematic approach to the data analysis, the following questions were posed in relation to each selected text:

- What are the key messages or themes about dementia that are identifiable from these films or television series?
- How do these affirmative representations of dementia encourage an improved understanding of the condition and its consequences?
- In terms of their pedagogical application, how could these texts be useful in educating residential aged care staff about dementia and best practice, person-centred dementia care?

In the process of data collection and analysis, two central concerns emerged. Each film or TV series was viewed in relation to the *way in which the theme or* *treatment of dementia functioned in the overall narrative* and *which perspective – or perspectives - the viewer was encouraged to identify with*. Each text was assessed and subsequently categorized in terms of the following questions:

- How was dementia treated within the storyline?
- Was it a minor reference or did it constitute the central focus of the text?
- If the reference to dementia was brief, how did this relate to the central themes or focus of the film or television series?

The Emerging Story of Dementia on Screen

The selected texts are drawn from feature film and television series from 1990 to 2018. This encapsulates the most significant period in the development of representations of dementia in film and television. The exponential increase in the number of texts dealing with dementia is notable. In acknowledging that the feature films and TV series included in this analysis and those identified in the pre-1990s period do not represent a complete account, my estimations suggest that between 1990 - 2018 there has been a three-fold increase in film and television texts addressing dementia in some form.

This time frame is significant in relation to the relative number of texts identified in this period, but equally importantly, qualitatively in terms of the increasingly detailed, more clinically accurate and considered way in which the subject of dementia is addressed. Simplistic, inaccurate and even alarmist depictions of dementia on the small and large screen are also a feature of this period, and this analysis will make reference to these as an important counterpoint in arguing for the potentially affirmative influence of popular culture in shaping public opinion on the condition.

There have been a small number of films, and to a lesser extent television series, over the course of the first seven decades of the 20th century that have dealt with dementia in some form. An overview of the significance of these texts will be given in Chapter Five to provide an historical framework for analysis of the more recent examples that follow. The quantitative and qualitative increase in texts addressing dementia in the 1990s and beyond can be accounted for in a number of inter-connected ways. From the 1970s onwards, there was an increasing consensus in medico-scientific circles that dementia, and specifically AD, should be understood in a biomedical context and this in turn drove a concomitant emphasis on the search for a 'cure'.

Refinements in understanding of the pathological basis of the dementia were seen as research breakthroughs during this period and funding flowed accordingly and with it, an elevated profile for the condition. At the same time, a loose alliance of various vested interests including researchers, policy makers, advocacy groups, clinicians, groups of family members and caregivers formed what Patrick Fox has described as the 'Alzheimer's disease movement' (Ballenger, 2006, p. 115). These two interrelated developments generated improved awareness in the public domain around the condition and its consequences. As with the impact on the broader community, interest in and knowledge about dementia gradually penetrated into the mainstream media, including film and television production offices.

In addition to increased awareness about dementia as a result of research developments and the 'Alzheimer's disease movement', writers, directors, producers and other key creative figures in film and television were also increasingly coming into contact with people living with dementia. These personal experiences contributed to the production of more projects dealing with dementia in some form. This discussion deals exclusively with fiction films and television series but it is notable that a number of non-fiction films released in the last few decades have been inspired by the filmmakers' personal experiences with the condition. Recent examples include *Me and My Mum* (Robinson, 2006), *Mum and Me* (Bourne, 2008), *Everyday is Alzheimer's* (Sekiguchi, 2012), *Once My Mother* (Turkiewicz, 2013) and *Istoria* (Ockenden, 2015). Examples from the fiction genre include the feature films *Away From*

Her, (Polley, 2006) *Angel's Perch* (Haine, 2013) and *What They Had* all of which were inspired by the directors' personal experiences of close family members living with dementia. The Spanish animation feature, the only non-English language text included in this thesis, was inspired by the writer's observations of a close family friend and mentor living with dementia. Australian screenwriter Andrew Knight drew on his father's experience living with dementia as the basis for his script for the TV movie *After the Deluge* (Maher, 2003). A number of these examples are central to the discussion in subsequent chapters.

From 1990 onwards, dementia is addressed in an increasingly detailed fashion, including depictions of diagnostic testing, symptomatology, treatment and care. The subject is explored from the perspective of a family member, spouse, carer, health professional and importantly, from the point of view of the person living with the condition. Examples drawn from 1990 – 2018 demonstrate that while there continue to be simplistic or inaccurate depictions, the on screen treatment of dementia is increasingly dominated by clinically accurate and considered narratives. This analysis incorporates a range of texts with varying perspectives in arguing for the potentially constructive role that *affirmative* examples can play in engaging and informing a general audience about dementia and as training and educational resources in a pedagogical setting.

The texts selected for inclusion in this analysis comprise the most recent releases up to and including 2018 (see Appendix One). The last decade, and in particular the last five years, have seen a small but significant increase in film and television storylines dealing with dementia from the perspective of the person with the condition. The third typology comprises depictions of the lived experience of dementia and represents the most influential form of audience address. Vivid, experiential depictions of the condition from a first person perspective represent the most potentially powerful means of providing insight into what it might feel like to live with dementia for both a broad viewing audience and health care professionals working in the residential aged care setting. In the latter context, the specific insights offered by first person accounts provide a potentially powerful and accessible way to convey pivotal ideas around understanding the lived experience of dementia and developing a person-centred approach to dementia care.

Data collection

Films that form the focus of this analysis are primarily English language texts. Box office figures for Australian cinema attendances for each year of the survey period reveal that the top 50 films each year are English language films, so on this basis, it is clear that most films seen by contemporary Australian audiences have English language dialogue (Box Office Mojo, n.d). In order to explore the potential influence of specific film texts on the predominantly English-speaking audience in Australia, English language films therefore form the focus of this discussion. A further rationale for focussing on predominantly English language texts is their suitability as a resource in a health care education and training context. While acknowledging the multicultural composition of contemporary Australian society and the Australian residential aged care workforce (34% of the current direct care workforce in residential care are born outside Australia), English language predominates in both contexts and therefore justifies the choice of English language films (Department of Health and Ageing, 2012).

In addition to English language texts, the data collection process for this thesis involved viewing a range of non-English language films that deal with the topic of dementia. These texts represented national cinemas from most of the major continents and were a vital part of the research process. While not referred to in the discussion, these films assisted in reinforcing or clarifying the significance of issues and themes identified in English language texts or offered an alternative perspective to the discourse around dementia not found in their English language counterparts. Of the films viewed, only the feature length Spanish animation film *Wrinkles* is included in this analysis.

Search engines, databases and other sources for the literature review included Pubmed/MEDLINE, Age-info; Social Care online; National Library for Medicine (US NLM); National Library of Australia (Health and Medicine); Australian Institute of Health and Welfare (AIHW), PsychINFO; CINAHL (Cumulative Index for Nursing and Allied Health Literature); OVID and Google Scholar.

The limited scholarship around dementia in film and television from earlier decades was useful in suggesting potential texts to consider in addressing the historical, pre-1990s context for this discussion. More recent analyses addressing the post-1990s period in journal articles, books and other sources in the gerontology and humanities fields contributed to identification of relevant contemporary examples. Online film journals, including the only non-English language journal dedicated to examining health in the context of representations in film and television, also helped refine the search process (*The Journal of Medicine and Movies*). Film reviews (capsule, long form and otherwise), analyses and general commentary around the selected texts drawn from film review, film scholarship and related sources assisted in determining the suitability of the film or television series for inclusion.

The International Movie Database (IMDb) warrants a special mention here. As one of the largest, longstanding and most comprehensive online film databases, as noted above, it is an important resource in terms of data collection. It is also significant for its extensive collection of user reviews. These provide a valuable source of feedback about films and television series from a broad audience perspective. IMDb encourages consumer reviewers to focus on the film or television series' content and context and to include a rationale for why a title was either liked or disliked (IMBb, 2019). Reviews can be submitted by any individual but are required to adhere to specific criteria and are monitored for inappropriate content. Given the emphasis in this analysis on the impact of mainstream film and TV series on a broad audience, user reviews can offer significant insights into those potential impacts. A number of user reviews have been quoted verbatim in support of my analysis of a range of texts in the following chapters. Given the authors are mostly anonymous or de-identified, they have been acknowledged throughout the thesis in in-text citations but are not included in the reference list.

Where possible during the data collection period, feature films were viewed in first release in the cinema as intended for a general audience. This assisted in giving an anecdotal sense of the general audience response to the film and notes to this effect were included in summary table entry. Given the limits of the data collection period (2012 – 2018), and the substantial number of films and television series included in this discussion that either pre-dated this period or were not accessible when originally released, many of the texts included were purchased and viewed as DVDs. A small number were also viewed online and relevant details in relation to sourcing and viewing these were also recorded.

For each selected feature film text, details including director, year of release, box office gross (if available), major awards and distribution information were recorded. Data around episode and series numbers, and audience figures for TV series were included where available. These commercial details were pertinent primarily to texts discussed in the first typology, Dementia at the Margins. Each viewing was accompanied by note taking, which recorded details under the broad headings of Plot/Character/Themes and the key criteria of Relevance/Positive Representation of Dementia/Limitations (see Appendix One). The accuracy of symptoms, diagnosis (cognitive and other tests), pharmacological and non-pharmacological interventions and care options (community and residential aged care) was recorded. The texts that were selected for inclusion were then viewed again and subjected to a more detailed critical and close analysis. When key scenes, passages of dialogue or other features of a text were identified for close analysis, online film review databases including IMDb, Rotten Tomatoes, Metacritic and Movie Review Query Engine (MRQE) were checked for comments and analysis by professional and user reviewers specifically addressing these aspects.

If 'extra' features were available on individual DVDs, these were also viewed. The additional commentary by key creative personnel involved in the film or TV production often provided valuable insights into the rationale for the creative choices that informed the representation of dementia on screen. The Australian TV movie *After the Deluge* is a useful example. The DVD extras include a revealing discussion between director Brendan Maher and writer Andrew Knight that provides an important context for understanding how the filmmaking team made choices about how to most effectively render the subjective experience of dementia. The film's innovative approach to scenes depicting the older character's felt experience of dementia were inspired by Knight's recall of his own father's struggles in living with the condition.

Why Pop Culture? Feature Films in Focus

It has been argued that the specific medium of feature length film offers a singular forum in which to canvass the themes and particularities of ageing including health-related issues.

> Feature-length films (and feature-length documentaries) offer much greater complexity of characterization, a broader scope of the depiction of themes relevant to aging, and a higher level of subtlety and complexity in the interaction among characters. Feature-length films are to educational videos what novels are to short stories.
> (Yahnke, 2003, p. 428).

Others have argued that the formal components of conventional film language itself – the narrative basis of mainstream film, changes in time and space facilitated through editing and the ability to render perspective through the use of the close-up – allows for a considered exploration of the ageing process.

> Film's ever-growing ability to delineate the workings of the remembering consciousness, the omnipresent use of cutting and editing by which to examine the various layers and meanings of dramatic conflict, and film's unique capacity for a direct, sense-based multi-layered notion of life's journey as a metaphor for the experience of living all suggest an immense potential for the "cradle-to-grave" theme. (Cohen-Shalev and Marcus, 2007, p. 88).

This central focus of this analysis is feature length films. The term 'feature length' or 'feature' has several specific meanings; it can refer to both to the length of the film and distinguish between films that are first shown theatrically compared with those made for television. In this context, I will be using it in the more commonly understood definition relating to the length of the film. This in itself is something of a contested classification. The category of 'feature' film has been variously defined by different national film bodies, organizations and other vested industry interests and variably in different periods of film history. The American and British Film Institutes and the Academy of Motion Picture Arts and Sciences currently stipulate a shorter length (i.e. greater than 40 minutes) as qualifying for feature film status. For the purposes of this analysis, I will adhere to the more general understanding that defines a contemporary feature film as having a running time of 90 minutes or more.

Feature length films that form the focus of this analysis could be categorized as primarily mainstream in contrast to 'art ', 'independent' or 'arthouse' films. These definitions are arguably increasingly fluid but are nevertheless useful here in helping to define target audiences and the potential demographic reach and impact for individual films. These sorts of distinctions have implications when evaluating the potential influence a film might have had on a first theatrical release, particularly in relation to the first of my typologies, Dementia at the Margins.

‘Mainstream’ films are generally understood as films that are created for commercial purposes and disseminated widely to a mass audience. Films produced in Hollywood have the widest global distribution and the term mainstream is often deployed interchangeably with Hollywood. Many of the examples discussed in this thesis are Hollywood or US-produced films, but mainstream films in this survey are also drawn from the United Kingdom, Canada, Australia and other English and non-English speaking countries. ‘Art’, ‘arthouse’ or independent films by contrast are typically independently produced outside the major film studio system and attract a more limited release. Arthouse films are often described as representing the filmmakers’ personal artistic vision, and may include more challenging or experimental formal and thematic elements. This in turn might limit the appeal of these films to a more narrowly defined audience compared with their mainstream counterparts.

These are broad descriptors for both categories of film, and there are always exceptions. Arthouse films can cross over to attract a mainstream audience and sometimes achieve significant commercial success. *Still Alice*, a significant text for this thesis, arguably blurs mainstream and arthouse distinctions. The film’s modest budget and treatment of the subject of early onset dementia conforms in many ways with an arthouse approach but the film ultimately adopts mainstream filmmaking conventions to appeal to a broad audience. The filmmakers have acknowledged that while *Still Alice* has the hallmarks of an arthouse film, it was driven by the dual imperatives to be both entertaining and instructive and was aimed squarely at a mainstream audience (Stearns, 2015).

The Third Coming of Television

If cinema represents a valuable resource for educating the general public and health professionals about the complexities of an illness over an extended time frame and from a variety of perspectives, television arguably represents an even more expansive forum in which to explore these issues. The serialized structure of television, and its capacity to develop lengthy storylines over multiple episodes or entire seasons, offers a sustained opportunity to present individual or multiple perspectives on a range of age related concerns, including a progressive illness such as dementia.

Age related themes and concerns, including physical and mental health issues have provided fertile ground for television writers in the past (*As Time Goes By* [Lotterby, 1992 – 2005] and *The Golden Girls* [Harris, 1985 – 1992]). As with cinema, dementia has featured intermittently on the small screen over its nine decade history, and increasingly in the last three decades (*Boston Legal* [Kelley 2004 – 2008], *Grey's Anatomy* [Rhimes, 2005 -], *Packed to the Rafters* (Lee, 2008 – 2013], *Neighbours* [Watson, 1985 -], *Outnumbered* [Hamilton and Jenkin, 2007 – 2016], *The Fear* [Bricknell, 2012] and *Exile*).

This discussion will include references to formative examples from 20th century television history including the seminal Australian comedy series *Mother and Son* (Atherden, 1984 – 1994). However, it is the rapidly changing nature of television production and consumption over the last two decades that justifies the inclusion of contemporary examples from the 1990s onwards. The rise of what has been referred to as 'high quality' television, and the emergence of the 'long-form' format, has given the medium renewed relevance and a substantially reinvigorated global audience. ' … the recent shift of interest towards television series of high quality that many consider to have replaced the cinema as a locus of serious adult entertainment' (Morrison, 2014, p. 3). This has clear implications in considering both the influence of representations of dementia on Australian television viewing audiences and in arguing for the importance of examples drawn from contemporary television as teaching resources in the residential age care sector.

The last two decades of primarily US-produced television product have been referred to as the 'Third Golden Age' of television history - the preceding golden periods being TV's incipient phase in the 1950s and the network drama-dominated 1980s (Reese, 2013, para. 1). Landmark *Home Box Office*

(HBO) series such as *The West Wing* (Sorkin, 1999 – 2006), *The Sopranos* (Chase, 1999 – 2007) and *Six Feet Under* (Ball, 2001 – 2005) signalled the rise of 'high quality' television production in the late 1990s. Rather than the traditional 22-episode series structure, this new HBO model inaugurated a shorter format, somewhat paradoxically referred to as 'long form' TV, consisting of 12 -15 episodes per season. These shows were seen as a watershed in concentrating increasingly sophisticated, visually distinctive, character-driven storylines into a shorter narrative trajectory. 'Unfolding over multiple episodes, hours, and even years, these TV shows are seen to provide a content, often dark and difficult, and an innovative style that strain against the conventions of cinema as well as network television' (Morrison, 2014, p. 3).

The appeal of the new 'long form' television series has been at least partly explained by the ever-contracting length of our collective attention spans in the current digital age. According to this argument, this has conversely resulted in a craving for content that represents the reverse – lengthy, nuanced and complex stories that challenge and engage a viewer across multiple episodes, seasons and even years. As David Mattin observes, 'perhaps only in long-form narrative can we find an art form complex and subtle enough to accommodate those new complexities.'(Mattin, 2013, para. 6). As with cinema, but arguably in some respects even more compellingly, this approach to television production clearly lends itself to an examination of challenging and complex topics, including ageing and health-related concerns. Whereas cinema is limited by constraints of a 90-minute format, long form television offers the possibility of examining in depth both the minutiae of an illness and the 'big picture' implications for the characters concerned. The clinical details of a disease including symptomatology, diagnostic assessments, treatment and care concerns can be examined literally in close-up. For television writers, the emotional and psychosocial ramifications for carers, family members, health professionals, and most significantly the person with the illness, provide fertile dramatic and even comic territory. In Chapter Seven, episodes from *The West Wing* and *Exile* will illustrate the way in which this reinvigorated approach to television content and style can address health related issues in a substantive way.

This ‘Golden Age’ of television has also been responsible for increasingly attracting prominent writers, directors and actors across to the television platform and the traditional demarcation between cinema and television is becoming increasingly blurred and arguably less meaningful. As a TV streaming company executive noted recently in relation to the resurgence of the long-form format, ‘These are films, as far as I'm concerned, but they're told in eight or 10 parts’ (cited in Dawes 2013, para.13). The widespread perception that contemporary television now provides a high quality and innovative product informed the choice to include television texts in this analysis. ‘Has a 90-minute film ever captured life in all its glorious, terrifying, mundane complexity as *The Sopranos* did?’ (David Mattin, 2013, para. 6).

The other significant rationale for including examples from television in this analysis is the penetration of the contemporary format. As with TV production, consumption has been radically transformed in recent decades; the increased accessibility and concomitant influence of contemporary television production has obvious implications in the context of this discussion. The standard 22-episode television series of the 1970s and 1980s was delivered as a drip feed of weekly episodes and adhered to the dominant broadcast TV networks’ strict definition of a ‘TV season’. From the 1990s onwards, the rise of cable TV stations and the advent of television streaming services have profoundly changed viewing habits, including those of Australian audiences. The choices for the Australian community have expanded exponentially with ‘catch up’ viewing options available on free-to-air channels, and the ubiquity of digital download and other streaming and viewing-on-demand services. First release television series can be screened and streamed simultaneously, and the endemic, so-called box set ‘binge watching’ behaviour has redefined television consumption in Australia and elsewhere. The global availability of these reinvigorated, contemporary television formats represents a powerful source of potential influence in shaping knowledge about and attitudes towards dementia in the viewing community (Doyle et al, 2012).

Towards a Typology of Dementia on Screen

The tripartite typology outlined in the introduction to this thesis has been developed as a framework for analysing how the selected texts depict dementia on screen. Each typology represents a different perspective and can be differentiated in relation to how each speaks to or informs audiences about the complexities of dementia. The inclusion of feature films or television series where dementia features *only briefly or peripherally* constitutes a critical distinction from previous scholarship in this area which has overwhelmingly focussed on texts with a central or substantive focus on the disease (*Iris, Away From Her, The Savages* and *Still Alice*). These kinds of texts might consist of a couple of scenes touching on the subject, or involve a minor character or subsidiary plotline. Prominent examples include *Friends with Benefits* (2011) and *Gone Girl* (2015). TV counterparts include the globally successful BBC sitcom *Absolutely Fabulous* (Plowman, 1992 – 2012) and the internationally syndicated, Australian/American ABC-HBO co-production *Angry Boys* (Lilley, 2011). The rationale for including these examples focussed on the following questions:

- How is dementia incorporated into the storyline and how does it function in terms of the narrative trajectory, character development and other considerations?
- What are the target audiences for these films or TV series and what kind of potential impact could references to dementia exert on viewers?
- Is this impact different from or complementary to the impact of films or TV series in the other typologies?
- Given the preponderance of comedies and other non-drama genres in this group of films, is genre a significant factor in considering the potential influence of these texts?

Alternatively, was dementia deployed more particularly as a *catalyst to foreground other issues or concerns* (*After the Deluge* [Maher, 2003], *Aurora Borealis* ([Burke, 2005], *The Savages*, *The Good Life* [Berra, 2007], *Diminished Capacity* [Kinney, 2008], *Happy Tears* [Lichenstein, 2009], *Nebraska* [Payne, 2013])? Was the perspective of the person living with dementia represented on screen or did the point of view of other characters dominate? If the latter, what kinds of attitudes and beliefs about dementia did these characters exemplify? How might this these kinds of films and TV series influence a viewing audience in relation to the experiences of carers, spouses or partners, family members and others?

Finally, if the subject of dementia was central to the storyline, was the treatment substantive, depicting symptoms, diagnosis, care options and other issues? Was the narrative presented from the perspective of the person living with dementia, their carer or a combination of both (*Iris*, *Away From Her*, *The Iron Lady*, *Robot and Frank*, *Still Mine* [McGowan, 2012] and *Still Alice*)? If a text offered multiple perspectives, did any one point of view dominate? If the lived experience of dementia was the central focus, how was that experience rendered - were particular techniques specific to the medium of film or television critical to engaging an audience? And if so, was this approach effective in conveying to an audience what it might feel like to live with dementia?

As a result of the thematic analysis described above, I developed three typologies under which all of the selected texts were classified. These were given following titles, indicative of the role and function of dementia in the storyline: *Dementia at the Margins, Dementia as Dramatic Device and Dementia Takes the Lead*. The typologies provide a framework for analysing how the selected texts depict dementia on screen, representing different perspectives and addressing a range of associated issues and concerns. This in turn suggests how the selected texts might address or inform different audiences about the complexities of dementia. The categories are not mutually exclusive and the occasional feature film or TV series can be classified in several typologies. Aspects of the storyline and characterization in the feature film *Away from Her* and TV series *Exile* could be categorized in the latter two categories. The proposed typologies and analysis of differences in genre, narrative structure, theme and perspective also informs the way in which examples from film and television might be utilized in a pedagogical setting to educate residential aged care staff about the lived experience of dementia and key concepts in relation to the provision of person-centred dementia care.

CHAPTER FOUR – LITERATURE REVIEW

Introduction

Bringing together the fields of screen studies and ageing studies, this thesis is cross disciplinary in nature and is situated within the broader discipline of cultural gerontology. The increase in screen depictions of dementia over the last three decades has been accompanied by a corresponding response in scholarship in cultural gerontology and related fields examining the impact of these depictions. This thesis aims to make a constructive contribution to this burgeoning field, particularly in relation to the value of popular culture texts in improving understanding of dementia and encouraging practice change in the delivery of dementia care in the Australian residential aged care sector. This chapter examines the body of literature that has explored the role of popular media in public perceptions and understanding of ageing and dementia and the specific use of film and television texts as resources in the training and education of health care professionals.

Scholarly studies that specifically address cultural representations of older age, ageing and dementia, with a focus on film and television, and fit within the broad descriptor of cultural gerontology comprise the central focus of this review. These include earlier analyses of dementia in contemporary cinema (Dastoor, 1991, Segers, 2007, Cohen-Shalev and Marcus, 2007 and Rubio 2007) and studies over the last decade that explore ageing in mainstream cinema and television and address representations of dementia in some form (Basting 2009; Chivers, 2011; Gerritsen, Kuin and Nijboer, 2013; Gravagne, 2013; Zeilig, 2014 and Swinnen and Schweda, 2015). Smaller scale analyses, evaluating an individual film, group of films or TV series exploring dementia-related characters, narratives and themes are acknowledged briefly. Some of these take the form of reviews and vary in approach from opinion pieces to more formal theoretical analyses.

Key debates in contemporary studies exploring the use of mainstream film and television texts to educate health professionals are also discussed here. The use of non-fiction film and television texts as teaching and training resources has a longstanding tradition (Dans, 2011). ‘Cinemeducation’ – a term first coined to describe the use of mainstream *fiction* films to educate medical students in relation to the ‘psychosocial aspects of medical care’ - is a more recent pedagogical development and one with clear relevance for this thesis (Alexander, Hall and Pettic, 1994, p. 430). As a formal pedagogical approach, cinemeducation has generated increasing interest and debate over the time frame encompassed by this thesis (Alexander, Lenahan and Pavlov, 2005; Alarcon and Aguirre, 2007, Moyer-Gusé, 2008; Morris, 2010 and 2014, Karasik, Hamon, Writz, Reddy 2014; Capstick, Chatwin and Ludwin, 2015; Hoffman, Shensa, Wessel, Hoffman and Primack, 2016). Scholarship in the field over this period comprises the final component of this literature review, with a focus on the limited number of studies that deal specifically with the application of film and television texts in the education of health professionals about dementia.

Screening Older Age

Popular cinema has always featured older characters, but while they were rarely seen on the screen in the first half of the twentieth century, older characters and age-related themes became increasingly prominent from the mid century onwards (Cole, 2006). In recent years, a number of studies have addressed the topic of ageing on screen (Yahnke 2003 and 2010; Cohen-Shalev and Marcus, 2007 and 2016; Chivers, 2011; Gravagne 2013 and Shary and McVittie, 2016). It has been argued that while older characters have appeared on screen, historically, they have been relegated to supporting or minor roles with their concerns rarely defining the central storyline or driving the action (Chivers, 2011). Stereotypes have often, unhelpfully, defined the representation of older age in mainstream cinema. Avuncular older figures, coded explicitly as aged by the presence of grey hair, wrinkles and the signifiers of senescence (rocking chairs, pipes, spectacles, knitting and companion animals) have historically stood in for fully-fledged characters (Chivers, 2011). For others, the 1930s saw the newly recognized socio-economic category of 'seniors' translated on the American mainstream screen into older characters that were stereotyped in different but equally limited ways as 'saintly mothers, out-of-touch millionaires and pillars of the community' (Shary and McVittie, 2016, p. 20).

Studies of contemporary cinema indicate some important shifts in the depiction of older characters and age-related themes. According to one analysis, older male and female characters appeared more frequently from the 1970s onwards, at least in part because actors themselves were ageing on screen (Cole, 2006). Yahnke's comprehensive survey of English and foreign language feature length films from 1951 – 2006 identified 130 examples dealing with age-related themes (Yahnke, 2010). The author's detailed content analysis identified consistently positive representations of ageing, with an emphasis on mutually beneficial intergenerational relationships and the wisdom and experience that accompanies older age (Yahnke, 2010). Yahnke's analysis and other accounts suggest that narrative patterns cohere around affirmative themes including the resolution of past difficulties and relationships, redemptive events and new beginnings (Yahnke, 2010 and Cohen-Shalev and Marcus, 2007). Negative aspects of ageing (ill health, social isolation and other issues) are addressed and a small number conclude with the death of the older character, but most focus on healthy, active and engaged older people living fulfilled lives (Yahnke, 2010).

More than two thirds of the films Yahnke surveyed were produced from the 1990s onwards. This increase accords with other studies identifying the increasing prominence given to age-related themes and older characters in popular culture, including in the traditionally youth dominated and oriented mainstream American cinema (Basting, 2009; Chivers, 2011; Gravagne, 2013; Shary and McVittie, 2016). Given that most screen depictions of dementia are associated with older age, this post 1990s period reflects a corresponding increase in mainstream feature films and TV series exploring dementia and sets the temporal parameters for this thesis.

Where Yahnke argued that depictions of older age and age-related themes were primarily positive in this period, other studies have suggested that while older characters and storylines are more prominent on the mainstream screen, this has not necessarily guaranteed representational complexity (Cohen-Shalev and Marcus, 2007, Chivers, 2011 and Gravagne 2013). Despite the ageing of the global population, and associated improvements in health and lifestyle in Western populations in the latter part of twentieth century and beyond, these changes have not been accurately reflected on screen. 'While cinema is replete with elderly characters, it is very sparse with realistically satisfying pictures of old age' (Cohen-Shalev and Marcus, 2007, p. 86). The simplistic stereotypes characteristic of the incipient periods of film history persist. 'Grannies in cardigans and men shuffling about their gardens remain dominant depictions …' in film and elsewhere (Whelehan and Gwynne, 2014; p 11.). This stereotypical representation is particularly marked in relation to female characters, where older women tend to fall into one of two representational categories: the comfortingly benign granny or troublingly sinister older woman (Chivers, 2011). Others have argued that the increase in older female characters on small and big screen *is* encouraging given that some of these characters and narratives offer more diverse, complex and challenging depictions of older women (Gravagne, 2013). According to this analysis, an increasing number of contemporary representations of the lived female experience of ageing offer a contrast to the kindly grandmother or cranky 'crone' stereotypes that have historically been on offer (Gravagne, 2013 and Fairclough-Issacs, 2014).

Analysis of formulaic, age-related plotlines and predictable narrative outcomes in films associated with ageing themes (including dementia) has attracted considerable interest in recent years (Yahnke, 2003; Cohen-Shalev and Marcus, 2007, Gravagne, 2013, Shary and McVittie, 2016). The 'elder odyssey' or 'elder journey' is a longstanding and dominant narrative tradition that can be traced throughout most of mainstream Western cinema history. This specific narrative trajectory often combines the 'road movie' or journey film with a quest for some kind of resolution or redemption for the older central character (Shary and McVittie, 2016). In these scenarios, one or more older characters 'go on the road' to seek knowledge and very often, reconciliation with estranged or long lost family members, friends or lovers.

According to one account, these films have typically featured men engaged on personal quests and offered an ' ... opportunity for long-delayed enjoyment and escape' (Shary and McVittie, 2016, p. 107). Contemporary examples include *The Straight Story* (Lynch, 1999), *The World's Fastest Indian* (Donaldson, 2005) and *Nebraska* (Payne, 2013). The 'elder odyssey' and related narratives are typically structured retrospectively and rather than affirming the benefits of wisdom or experience, they have been interpreted as examining unfulfilled youthful ambitions or past failures and marked by a powerful sense of loss or regret (Chivers, 2011). As Chivers and others have suggested, the increasing number of popular films dealing with later life characters and plots in recent decades have not necessarily offered audiences an improved understanding of or insight into the lived experience of older age and age-related issues. '… even with the increased visibility of old age and prevalence of age-centred plots, recent mainstream films try to reduce old age to a manageable and controllable set of representations' (Chivers, 2011; p. xviii).

The emergence of the 'elder romance' in the last three decades has for some scholars offered a more encouraging discourse on ageing on the mainstream screen (Shary and McVittie, 2016, p. 158). In arguing for the modest but increasing prominence of films ' …that narrate anti-ageist counter-stories …', Cohen-Shalev and Marcus assert a vision of 'old love' and companionship in older age that moves beyond the formulaic plots and character stereotypes outlined above (Cohen-Shalev and Marcus, 2016, p. 63). While Cohen-Shalev and Marcus focus on European arthouse films (most prominently Michael Haneke's *Amour* [2012]*)*, there are corresponding numbers of mainstream Western films exploring romantic love in older age (*Something's Gotta Give* [Meyers, 2003], *Mama Mia* [Lloyd, 2008], *It's Complicated* [Meyers, 2009], *The Best Exotic Marigold Hotel* [Madden, 2011], *The Big Wedding* [Zackham, 2013] and *Hampstead*, [Hopkins, 2017]). Many of these conform to what has been described as the 'gerontocom', a sub-genre of the romantic comedy featuring older protagonists (Smith, 2010).

Where the 'elder odyssey' typically centred on the travails of an older male protagonist, it is notable that many of these 'gerontocoms' focus on a central female protagonist (Smith, 2010). Noting that many of these are genre films, employing standard conventions of amongst other genres, the romantic comedy, it has been argued that this does not detract from their contribution to '…the emerging effort to present an increasingly authentic picture of old age…' (Gravagne, 2013, p. 126). Rather than the melancholic tone characteristic of the elder journey narratives, scholars have observed that the geronotocom and representations of 'old love' sound a conspicuously positive note by contrast (Cohen Shalev and Marcus, 2016; Gravagne, 2013).

Diagnosing Dementia on Screen

If older characters and aged-related issues are becoming increasingly prominent on the mainstream screen, there has been a more modest but conspicuous increase in representations of dementia on screen and scholarship associated with it. As the defining age-related health issue in the 21st century and a complex neurocognitive disorder, the clinical aspects of the condition are, not surprisingly, a central focus for many earlier analyses of representations of dementia on screen. The issue of clinical accuracy or otherwise is also an important consideration for this thesis as outlined earlier. A series of studies dating from the start of the thesis time frame form the initial focus for this review (1991 - 2007). Cohering around a clinically informed approach to specific film texts or groups of films, these studies focus on the clinical accuracy or otherwise of depictions of dementia. This offers a specific theoretical framework through which to understand the potential impact the selected films might have on an audience but these seminal studies are also important in foregrounding key issues and critical questions around narrative emphases, thematic concerns and audience engagement that have been central to subsequent research initiatives including this thesis and will be discussed in detail accordingly.

Dastoor's 1991 modestly scaled but influential survey of five films dealing exclusively with representations of Alzheimer's disease (AD) inaugurates this review. The survey comprises a short telemovie and feature length fiction and non-fiction films spanning the 1980s and including both English and foreign language texts (*There Were Times, Dear,* [Malone, 1985]; *Mercy or Murder?* [Gethers, 1987], *Mindshadows* [Honigmann, 1987], *Sonia* [Baillargeon, 1987] and *Someone I Once Knew*, [Apsell, 1982] respectively). As a health professional, the author's interest lies primarily with the clinical accuracy of the depiction of AD including the elucidation of diagnostic processes, symptoms and the overall disease trajectory. ' …film producers must first and foremost be responsible for accuracy of information ' (Dastoor, 1991, p.42).

Dastoor notes that on screen clinical accuracy varies considerably and while most films deal with the disease in its early stages and sympathetically, there is a tendency to oversimplify or misrepresent symptoms (Dastoor, 1991). In *Mercy or Murder?*, the symptoms of AD and another medical condition are conflated and the course of the illness depicted in unnecessarily fatalistic terms. Dastoor's concern for the effect of misrepresentation on a 'susceptible' audience is prescient and has been reflected in subsequent studies in succeeding decades (Dastoor, 1991, p. 42). Equally importantly in the context of this thesis, Dastoor notes that tonally, the surveyed films are collectively characterized by an 'acute sense of pessimism' (Dastoor, 1991, p. 42). This correlates precisely with the defeatist tenor of mainstream media commentary about dementia outlined in Chapter 3.

Dastoor's article, 'The subjective experience of Alzheimer's disease: portraits from films', signals the importance of subjectivity in the portrayal of the disorder. For the purposes of this thesis, his most significant observations relate to the way in which the filmmakers present the illness scenario from both the point of view of caregivers and the person with AD. 'The producers of these five films have tried to authentically depict the turmoil and tragedy caused by this disease, from both the victims' and the caregivers' points of view' (Dastoor, 1991, p. 42). Setting aside for the moment the description of dementia as an unequivocally tragic experience, Dastoor makes broad but crucial distinctions in relation to the impact these films might have from the perspective of the uninformed versus the informed viewer (those with direct experience of AD). Some films are described as 'teaching tools' for caregivers and health professionals. Others offer insights into 'special issues of caregiving, diagnosis or in examining what to do once a diagnosis is made' or might potentially ' … *sensitize* the general public to the ravages of this disease' (italics added) (Dastoor, 1991, p. 40).

While small in scale and dealing with films that pre-date the focus of my research, this incipient study is instructive in foreshadowing some of the key approaches to analysis applied to films dealing with dementia released in subsequent decades. Dastoor (1991) makes some rudimentary but important observations about the way in which the films attempt to accommodate the twin imperatives to entertain and educate intended audiences. These provisional observations set out the basic theoretical parameters for this thesis, namely, an exploration of the way in which screen depictions of dementia offer multiple perspectives on the condition, potentially engaging audience cohorts in different ways and collectively encouraging an improved understanding of dementia and its consequences.

Kurt Segers' expands on some of Dastoor's earlier claims and characterises his work as the 'first systematic review of the depiction of dementia patients and their medical care described in fiction films' (Segers, 2007, p. 55). Segers' larger, targeted survey (22 feature length fiction films, four shorts and two telemovies) focuses on films that feature a main character with a 'degenerative dementia' (Segers, 2007, p.55). These include English and foreign language films spanning four decades (1970 to 2004), with a significant increase in films produced after 1999 (53% of the total number surveyed were released in this five year period).

As with Dastoor, Segers' background as a health professional (in the latter's case attached to a major North American memory clinic) ensures his theoretical perspective is fundamentally underpinned by an interest in the clinical accuracy with which various forms of dementia are depicted. Segers' concerted clinical perspective even extends to analysis of the functional decline and behavioural symptoms of central characters, using 'real world' clinical assessment tools. This is an inventive approach adopted in other subsequent studies, however Segers' substitution of the actor's actual age when a screen character's age is 'not explicitly stated', is a methodologically dubious if revealing conflation of actual and on screen worlds (Segers, 2007, p 56).

Segers' discusses the selected films in terms of gender (80% of central characters with dementia are women), profession (professionals are disproportionately represented, arguably for dramatic contrast and particularly where male characters are concerned) and caregiver categories (realistically depicted as predominantly a spouse or family member with the attendant emotional complexities). The 'Clinical Picture' is extended in a detailed discussion of the types of dementia depicted (43% clearly identified as Alzheimer's dementia), diagnosis (less than 60% of the films directly or indirectly indicate that a medical consultation has resulted in a diagnosis) and medical follow up (often perfunctory or entirely absent). By contrast, analysis of symptoms is described as for the most part, realistically handled (Segers, 2007). What he describes as typical markers of dementia - including memory loss, deterioration of executive function and socially inappropriate behaviour – as prominent in most storylines. Segers' notes that these are often deployed as useful dramatic and narrative devices; memory loss allows temporal narrative shifts and wandering behaviour offers an opportunity to change spatial and geographical locations (Segers, 2007).

Where symptomatology is 'rather well documented', Segers' argues that treatment is either ignored or unrepresentative, with few characters appearing to receive appropriate pharmacological or other interventions (Segers, 2007, p. 58). Importantly, Segers' notes that as a result of the relative absence of detail about medical follow up or treatment, these films are collectively characterised by a tone of 'therapeutic and diagnostic nihilism' (Segers, 2007, p. 58). This is consistent, regardless of the decade of release, reinforcing the perception that despite the increase in awareness about dementia, the condition remains 'one of the last medical taboos' with health practitioners reluctant to diagnose or offer treatment and care options (Segers, 2007, p 58). The 'therapeutic and diagnostic nihilism' identified by Segers corresponds with the 'acute sense of pessimism' noted in Dastoor's earlier analysis and reflects real world studies in primary health and other care settings noted in the introduction.

Segers' concluding paragraphs acknowledge the 'dramatic' (i.e. pragmatic and entertainment-oriented) rather than educational imperative underpinning these mainstream films. While drawing on some aspects of Dastoor's earlier research, Segers' does not take up Dastoor's preliminary observations in relation to differentiated viewer experiences and responses to films. In foregrounding the characteristically bleak scenarios and omission of critical details about dementia on screen, both Dastoor and Segers sound a cautionary note about the potentially unhelpful impact these films might have on an audience's understanding of the condition. Equally, both authors draw careful attention to the constructive role mainstream films *can* play in educating audiences about the disease. 'Television and cinema have an important influence on how the public sees disease and patients' (Segers, 2007, p 55). The latter cites the example of the long running British soap opera *Coronation Street* (Warren, 1960 -) where the inclusion of a character with AD (Mike Baldwin) resulted in a significant, quantifiable increase in calls to dementia helplines and requests for information from related support outlets (Segers, 2005). This emphasis on the potentially affirmative impacts of mainstream film and television representations of dementia on a viewing audience supports the central focus of this thesis.

In her discussion of three contemporary Spanish language films, Rubio takes this clinically informed approach in a more idiosyncratically medicalized direction. Rubio suggests that historically, cinema depictions of dementia have not differentiated between different sub-types and their symptoms, 'hindering its diagnosis and its understanding from the spectators' point of view' (Rubio, 2007, p. 139). In an oddly structured but useful discussion, a comparative analysis of the three films is contexualized in relation to recent screen depictions and interspersed with tables detailing key clinical considerations including epidemiological information, differential dementia diagnoses and diagnostic criteria.

Rubio's approach replicates that of a clinician, essentially treating the central characters in each film as case studies. As with Segers, she applies clinical assessment tools and other criteria to a discussion of the character's symptomatology and illness trajectory. Commending the three films for exploring Alzheimer's disease from the perspectives of the person with the illness, the caregiver and family members, Rubio nevertheless decries the absence of accurate diagnostic detail in two of the three films. '…both productions help us to better understand Alzheimer's disease and the repercussions that it has on patients' immediate families and on society, although neither offers much as regards the diagnostic details of the clinical picture' (Rubio, 2007, p. 142).

Despite her speculative assumptions about the respective filmmakers' motivations and unfortunate reference to 'inmates' of residential aged care facilities (this could be a translation issue), Rubio's analysis is significant for this thesis in several respects. There is a genuine attempt to explore how the three films, and other English language films referred to in the course of the discussion, might have an impact in terms of 'sensitisation of the population to the disease' (Rubio, 2007, p. 149). Rubio notes that in *And Who Are You?* (Mercero, 2007), the psychosocial ramifications of dementia and the importance of early diagnosis, timely support and treatment are emphasized. Her argument for the positive influence that this might exert on an uninformed audience offers a constructive contrast given the pervasive tone of therapeutic and diagnostic nihilism noted above. Finally, notwithstanding her clinical focus, Rubio's overall emphasis on the potentially instructive impact of these films in improving knowledge about dementia offers a framework for considering the pedagogical application of screen depictions of dementia central to this thesis.

Gerritsen, Kuin and Nijboer (2013) describe themselves as geropsychologists interested in the depiction of the clinical features of dementia portrayed on screen. Their analysis examines feature films because of their potential influence on the beliefs and attitudes of general public and ' … because information about a specific issue or disease is often processed unintentionally and unconsciously by the viewer' (Gerritsen, Kuin and Nijboer, 2013, p.1). Surveying 23 feature films from the US, UK and the Netherlands released after 2000, their contemporary study offers a dissenting opinion on the theme of clinical accuracy.

Unlike the Dastoor (1991), Segers (2007) and Rubio (2007), Gerritsen et al argue that dementia is depicted misleadingly because the typical and more challenging symptoms associated with the condition, including agitation and combativeness, are not portrayed on screen. Combined with moments of miraculous lucidity and other clinical improbabilities, this conveys a 'mild and sympathetic' view of dementia that risks romanticizing the condition and in turn encouraging unrealistic expectations for caregivers and the person living with dementia alike (Gerritsen, Kuin and Nijboer, 2013, p. 4).

An interesting if tentative contribution to the field, the study's contingent findings nevertheless pose an important question: would more realistic depictions of dementia on screen be helpful in educating the broader public about the condition? (Gerritsen, Kuin and Nijboer, 2013). Rather than engaging with this question, the authors suggest that future research could address this by focusing on the 'impact of movies on attitudes of the general public toward dementia', effectively articulating the raison d'etre for this thesis (Gerritsen, Kuin and Nijboer, 2013, p. 4). An additional and significant concluding observation - that the films surveyed emphasize impairments and rarely focus on capacities – is also not explored but again, provides a substantive focus for this thesis in the following chapters.

Importantly, Gerritsen, Kuin and Nijboer propose ways of classifying films according to the role played by the person with dementia that are similar to my typologies - leading in all or part of the film, supporting and minor roles respectively (Gerritsen, Kuin and Nijboer, 2013, p. 2). To my knowledge, this is also the only extant study that identifies dementia-related minor or supporting character roles although the authors do not discuss the significance of these in any detail. While acknowledging the similarities, my typologies were developed independently, and there are also clear distinctions between the rationale for my typologies compared with the groupings proposed in Gerritsen, Kuin and Nijboer's study. Their four categories are purely structural in order to categorize their selected films for data analysis. Gerritsen, Kuin and Nijboer's interest lies with the depiction of clinical accuracy so their subsequent classification of films according to 'features of dementia' (including cognitive, emotional, physical and behavioural features) provide the principal foundation for their discussion and findings.

Each of my typologies discusses a series of films in detail, a discussion that includes the assessment of clinical accuracy. My analysis addresses the impact of major and minor roles in terms of audience engagement and impact and the pedagogical application of these films as a teaching resource in the residential aged care sector. Gerritsen, Kuin and Nijboer note the 'wide variety in the amount of time and number of scenes in which the focus was on dementia…' (2013, p. 4). I analyse the time devoted on screen in terms of the potential contribution that these films might make in improving understanding of dementia. Where Gerritsen, Kuin and Nijboer observe that it would be worth analyzing the effect of different genres in relation to the depiction of dementia, my discussion in the following chapters explores the implications of genre differences in some detail.

Swinnen's brief but useful account offers a different way of classifying dementia-related films (Swinnen, 2015). While noting the diversity of depictions of the condition in fiction and non-fiction films, she argues that many films cohere around a few standard tropes. The first of these is the perspective of carer; this often dominates screen depictions of dementia with an emphasis on the 'burden' of care (Swinnen, 2015). This equates to my second typology Dementia as Dramatic Device and the associated issues are addressed in detail in Chapter Seven. Swinnen identifies a second trope in depictions of prominent figures that lived with dementia, suggesting that their experience is somehow more poignant or singular given their profile. Exceptionalism in relation to the lived experience of dementia can be seen in films including *Iris* and *The Iron Lady* (Swinnen, 2015). Finally, Swinnen suggests that the commonly used device of the flashback and retrospective narrative account of dementia tends to privilege the point of view of the youthful character in comparison with the older version (*The Notebook* is a key example).

Beyond Clinical Considerations

Three substantive critiques of screen representations of older age and age-related themes published in the last decade have played a formative role in shaping this thesis, so all three will be discussed in detail. Moving beyond a primary focus on clinical accuracy or otherwise, each of these authors explores the ideological implications of representations of cognitive impairment and dementia in shaping the broader community's knowledge of and beliefs about dementia.

As indicated by the numerous references to her work in preceding chapters, Anne Basting's *Forget Memory* (2009) has been an influential publication in contemporary cultural gerontology and a theoretical touchstone for this thesis. Basting's wide-ranging analysis of the way in which memory loss, cognitive impairment and dementia have been depicted in mainstream media and popular culture offers an important context for the textual typologies discussed in the following chapters. Basting's detailed discussion of examples from contemporary television is particularly significant given this is an area less well researched than its mainstream cinematic counterpart.

Basting's analysis is underpinned by a deceptively simple question: 'Is the experience of dementia *only* a tragedy? (Basting, 2009, p. 44). Her persuasively argued response suggests that while dementia can entail significant losses, this is not the only way it has been (and can be) experienced and understood. Rather, we consider dementia in this way because historically, the mainstream media and popular culture (amongst other influences), have framed the condition definitively in terms of loss, incapacity and tragedy. Basting contends that the tragedy is posited as two-dimensional: the first the collective, global calamity of dementia that can only be resolved if medical science is given enough time and money to find a 'cure' (the hegemony of the biomedical model again). The second dimension is personal: the 'tragic' loss of history, skills, memory and capacity experienced by the individual living with dementia (Basting, 2009, p. 33).

Forget Memory includes detailed textual analyses of key feature films over the last three decades, some of which are also central to this thesis - though with different critical emphases. Unlike the studies outlined above, Basting's polemic is less interested in clinical accuracy but takes issue more broadly with unrealistic representations of dementia and narratives that rarely attest to the preservation of self or ' …that growth and learning are possible, that social memory remains when individual memory falters … ' (Basting, 2009, p. 156).

Contesting the 'tragic narrative' is an urgent imperative that Basting argues is achievable by moderating the emphasis on finding a cure and doing what she describes as the 'culture work' (Basting, 2009, p. 155). The latter involves producing more complex and considered cultural representations of dementia offering an alternative narrative that promotes a better understanding of the condition in the broader community (Basting, 2009). This includes positioning accounts from people living with dementia front and centre of public commentary and cultural representations. Basting notes that this 'culture work' is already underway, even in the five years prior to the publication of her book. She describes a noticeable shift in language in the broader mainstream media, public health campaigns and messaging by dementia advocacy organizations after 2003 that corresponds to similar changes in newspaper coverage over the same period discussed in the previous chapter (Basting, 2009).

This thesis responds directly to Bastings' call to cultural arms. In moving beyond the limited critical lens of clinical accuracy and identifying the importance of both minor and major depictions in contemporary film and television, I argue for the constructive role that affirmative representations of dementia can play in educating the broader community and the residential aged care workforce. Each of my three textual typologies makes a distinctive contribution to extending our understanding of the way in which cultural representations of dementia can and do move beyond the constraints of the dominant 'tragic narrative'. My specific focus on the importance of texts foregrounding the lived experience of dementia (Dementia Takes the Lead) is informed by amongst other sources, Basting's insistence that hearing and seeing first person accounts of dementia is a critical part of the 'culture work' required to reframe community attitudes to the condition.

Sally Chivers' *The Silvering Screen* (2011) and Pamela Gravagne's *The Becoming of Age* (2013) explore representations of ageing in mainstream cinema more broadly and both devote a chapter to depictions of cognitive impairment and dementia. Each draws inspiration from Basting's work, with latter making the debt explicit in her chapter title (*The Cultural Work of Alzheimer's*). Chivers acknowledges the increasing presence of older characters and themes on screen in recent decades but argues that these are for the most part underpinned by conventional ideologies that work to constrain rather than expand audience ideas about how older people should look and behave. Older age on screen is therefore 'controlled' through 'age-defying' narratives - and the equally age-defying (denying), cosmetically adjusted appearance of older actors appearing in them (Chivers, 2011, p. 7). Chivers cites actors including Harrison Ford, Melanie Griffiths and Jack Nicholson and films including *About Schmidt* (Payne, 2002), *Something's Gotta Give* (Meyers, 2003) and *The Bucket List* (Reiner, 2007) by way of example. According to Chivers, both work to deflect or minimize social anxieties about the ageing process. Taking inspiration from Basting's notion of the discursive hegemony of dementia's 'tragic narrative', Chivers' contends that despite attempts to control anxieties around older age on screen, ageing remains ineluctably linked with loss and disability, with all the potential assumptions, biases and stigma associated with this (Chivers, 2011).

Chivers' argument for the pathologization of older age on screen is compelling and while not convinced of all aspects of her bleak assessment, some of her specific claims in relation to depictions of dementia are useful. Not unlike the historical conflation of 'senility' with older age outlined in Chapter One of this thesis, Chivers argues that in the 21st century, Alzheimer's disease has become a potent signifier for the generalized decline and corresponding fears and anxieties associated with older age (Chivers, 2011, p. 59). This includes representations on the mainstream cinema screen. ' … a character that is becoming demented appears on the silvering screen to neatly signify a set of simple losses rather than to convey the complex transformations that cognitive decline invites and entails' (Chivers, 2011, p 60).

Her observations about films that purport to explore the perspective of the person with the illness are particularly pertinent in relation to my second typology (Dementia as Dramatic Device). Citing *The Savages* as a typical example (a significant text in Chapter Seven of this thesis), Chivers argues that many films tackling the subject of dementia appear to acknowledge the loss of selfhood for the person with dementia, but are actually more interested in issues of selfhood and identity for characters associated with that person. 'The horrifying loss of self much mourned in Alzheimer's discourse is such a given in these films that it serves mainly to magnify the self-explorations it enables in surrounding characters '(Chivers, 2011, p. 73).

Gravagne (2013) argues for a fundamentally more optimistic reading of older age on screen. As with Chivers, Gravagne's detailed analysis acknowledges the historical (and ongoing) constraints that representations of older age, particularly on the mainstream screen, impose on viewers. As with Basting's plea for alternatives to dementia's dominant 'tragic narrative', Gravagne argues that the overarching 'narrative of decline' that has traditionally defined the ageing process on screen has been increasingly contested over the last couple of decades (Gravagne, 2013, p. 13). This alternative narrative is one of ' becoming' and allows for ' … ambiguity, vulnerability and creativity – the ongoing becoming of the old – to take centre stage' (Gravagne, 2013, p. 158).

In her analysis of a small group of films depicting Alzheimer's disease including *Iris*, *The Notebook* (Cassavetes, 2004), *Aurora Borealis* and *The Savages*, Gravagne asks a series of questions central to this thesis. Does the film simply reinforce the stereotypes and stigma associated with dementia through a typical narrative of decline or is there a genuine attempt to ' … capture the ambiguity and the complexity of the Alzheimer's experience…'? (Gravagne, 2013, p. 132). As with my analysis, Gravagne is interested in which perspective(s) the film adopts and whether a biomedical model of disease still prevails. Importantly in the context of this thesis, Gravagne develops some of Basting's earlier observations by asking whether the experience of watching each film would encourage the viewer to ' … learn to expand rather than contract' notions of identity, memory, self and personhood in relation to dementia (Gravagne, 2013, p. 134). These are questions I am equally and vitally interested in and which are explored in detail in subsequent chapters.

Situating her discussion within critical gerontology – a discipline that as she defines it – challenges some of the cultural norms of ageing - Hannah Zeilig describes her approach as one that 'queries the stories told about dementia and the language that we use to tell these stories' (Zeilig, 2014, p. 258). As with Basting, Zeilig's analysis represents a prominent intervention in contemporary scholarship exploring cultural representations of dementia and a formative influence for this thesis. Arguing that the word dementia has taken on a metonymic function – symbolizing an unremittingly frightening decline in older age – Zeilig interrogates the way in which language and metaphor in the mainstream media and a range of cultural forms has shaped contemporary attitudes to the condition. Her observations about the way in which popular discursive practices, including film and television narratives, have conflated older age and dementia with disaster on an overwhelming scale have been influential in the field and for this thesis (Zeilig, 2014).

Zeilig's argument that the ' … exploration of dementia through a central character or situation has also been a means of questioning politics, social mores, morality, and the nature of our humanity' is instructive (Zeilig, 2014, p. 262). Claiming that 'more mainstream films' including *Iris*, *Away From Her*, *The Savages* and *The Iron Lady* (all significant texts for this thesis) ' …tend to encourage the viewer to look dispassionately at the person with AD' is valuable in terms of framing my analysis for films focusing on the caregiver role in Chapter Seven (Zeilig, 2014, p. 263).

Positing The ‘Productive’ Rather Than Pessimistic

Focussing on representations of ageing on screen including the depiction of dementia, co-authors Amir Cohen-Shalev and Esther Lee Marcus have contributed a series of influential analyses over the last decade (2007, 2011, 2012, and 2016). Their analyses primarily focus on independent rather than mainstream films but their conclusions around the potential audience impact of these films are germane. Their 2012 study is particularly significant in relation to my analysis of representations of the lived experience of dementia in Chapter 8. In that publication, the authors argue that three low budget foreign language films, (*Cortex* [2008], *Pandora's Box* [2008] and *Old Cats* [2010]) privilege the subjectivity and interiority of the central characters living with dementia. The biomedical model of dementia, with its emphasis on problematic symptoms and loss of capacity, is eschewed in favour of uncompromising and realistic depictions of older individuals negotiating new ways of living and relating to others in their respective worlds. The central characters are seen ‘ …as fully sentient, complex and complete human beings, despite, sometimes because of, their cognitive impairment’ (Cohen-Shalev and Marcus, 2016, p. 92).

Cohen-Shalev and Marcus describe the depictions of the lived experience of dementia in these films as a ‘… condition-in-progress, a problem to be negotiated, not a verdict to be contained as loss’ (Cohen-Shalev and Marcus, 2012, p. 76). These provocative observations, and their subsequent conclusions about the powerful impact of experiential, first person depictions of dementia contributed to my emphasis on the importance of films that focus on the lived and felt experience of dementia in Chapters Eight and Nine (Dementia Takes the Lead). ‘By facilitating identification with the protagonist affected by the disease, the movies create a change of attitude in the viewer’ (Cohen-Shalev and Marcus, 2012, p. 93).

Swinnen and Schweda's anthology *Popularizing Dementia* (2015) is the most recent and focussed collection of writings on dementia and popular culture and has clear purchase for this thesis. The anthology interrogates the representation of dementia across a range of sources including literature, newspapers, popular magazines and film. The two chapters dealing specifically with film expand on some of the theoretical propositions outlined above and are important contributions to the field. The respective authors offer an alternative reading of key film texts (Käll, 2015) and a critique of the efficacy of 'cinemeducation' in relation to films specifically addressing dementia (Capstick, Chatwin and Ludwin, 2015, p. 230). The former supports some of the central contentions in this thesis while the latter, discussed in the concluding section of this review, assists in clarifying the merits of this pedagogical approach.

In contrast to previous scholarship that has typically concentrated on negative screen portrayals and their consequences, Lisa Käll explores what she describes as more productive ways of reading depictions of dementia on film (Chivers, 2011; Cohen-Shalev and Marcus, 2012; Gravagne, 2013). To some extent, her approach answers Basting's call to provide alternatives to the discourse of tragedy that has defined screen depictions of dementia (Käll, 2015). This approach also reinforces Swinnen's observation that films about dementia that appear 'formulaic in structure and scope can be read against the grain' (Swinnen, 2015, p. 71). Käll's detailed analysis of two films, including *Away from Her*, suggests that the complex relationships between the central characters are continuously evolving and *relational* (italics added). Unlike many previous readings of this film, Käll asserts that the central female character experiences significant changes over the course of her illness trajectory, as does her spouse and others around her, but importantly, she retains a degree of agency and identity in the process. This draws on amongst other sources, Steven Sabat's concept of selfhood and identity as a fundamentally relational proposition, a relationality that becomes more acute in the context of the preservation of selfhood and identity for a person living with dementia.

Käll describes subjectivity in dementia in *Away From Her* as ' … radically altered rather than lost and as remaining in continuous becoming throughout the development of the condition' (Käll, 2015, p. 269). This more nuanced reading echoes Gravagne's notion of ageing on the contemporary mainstream screen as a process of continuous 'becoming of age' (Gravagne, 2013, p. 158). Equally, Käll's understanding of subjectivity in dementia aligns with Cohen-Shalev and Marcus's description of dementia on screen as a 'condition-in-progress' (Cohen-Shalev and Marcus, 2012, p. 76). Käll's approach differs in some respects from my own, due in part to her emphasis on phenomenological notions of embodiment, relationality and intercorporeality, but her constructive re-reading of key film texts accords with my focus on the influence of affirmative representations of dementia on screen. My argument for the particular potency of depictions of the lived experience of dementia is supported by Käll's emphasis on the preservation of agency and identity for the central character with dementia and the affective power of these first person representations. '… what happens on screen can intimately affect the spectator and her world in transformative ways' (Käll, 2015, p. 268).

The Case for 'Cinemeducation'

The use of mainstream film as a resource for educating health professionals has a lengthy history that can be traced back in various forms to the 1970s (Dans, 2011). Matthew Alexander first deployed the term 'Cinemeducation' to promote the use of what he described as an innovative approach using 'popular movies' to ' … educate family practice residents in the psychosocial aspects of medical care (Alexander, Hall and Pettic, 1994, p. 430). Alexander's original research suggested that the use of popular film to present psychosocial issues encouraged a different style of learning. Participants were exposed to a range of situations on screen and this provided an emotionally engaging experience with the characters that contrasted with other teaching approaches. The use of films ' … anchor residents' insights about patients from clinical practice and illustrate family life cycle issues' (Alexander et al, 1994, p. 430.) The value of using film and television texts to address psychosocial issues is particularly important for this thesis given my own emphasis on way selected texts can make a positive contribution to improving understanding of the psychosocial aspects of dementia and dementia care. 'Cinemeducation encourages the development of psychosocial competencies by providing an effective medium for focussing on exactly the situations we wish to explore' (Alexander, Lenahan and Pavlov, 2005, p. xiii).

The field has subsequently developed to encompass a wide ranging series of studies from those exploring the use of film in the teaching of health-related disciplines more broadly (Wilt, Evans, Muenchen and Guegold, 1995; Blasco, 2001; Downey, Jackson, Puig and Furman, 2003; Alexander, Lenahan and Pavlov, 2005; Moyer-Gusé, 2008; Colt, Quadrelli and Lester, 2011; Scheidt, 2012; Karasik, Hamon, Writz, Reddy 2014; Felippa, Delgado, Sabelli and Zamboni, 2015; Swinnen, 2015 and Lupton, 2018) to studies with a specific focus on education related to mental health issues including dementia (Dastoor, 1991; Bhugra, 2003; Pirkis, Blood, Francis and McCallum, 2005; Wedding, Boyd and Niemiec, 2005; Vivek, 2009; Thomason, 2013, Morris, 2010 and 2014, Orr and Teo, 2015; Vize, 2015; Capstick, Chatwin and Ludwin, 2015; Hoffman, Shensa, Wessel, Hoffman and Primack, 2016).

The Spanish language *Journal of Medicine and Movies* (*Revista De Medicina Y Cine*) is devoted exclusively to considering the way in which cinema (and television to a lesser extent) can inform the practice of medicine and other health-related disciplines. To my knowledge, it is the only journal in any language with this specific focus and warrants a special acknowledgement here. Despite limited English language translations, many of the published studies focus on mainstream, English language films. As indicated by the inclusion of Rubio's analysis above and citations of other studies elsewhere, the journal's critical engagement with 'cinemeducation' has made a valuable contribution to the field and this thesis. Individual articles exploring the application of film and television in the teaching of diverse areas from nursing and bioethics to palliative care and psychiatry foreground the way in which popular culture can play an effective role in illustrating clinical and psychosocial issues. 'It is a very important vehicle for health education because it can facilitate the debating and learning of attitudes in care for the sick…' (Alarcon and Aguirre, 2007, p. 32).

The arguments in support of the use of film and TV in teaching health professionals in this journal and elsewhere take various forms. Given the reinvigoration of contemporary television and the ubiquity of multimedia viewing platforms, the appeal of film and television in a pedagogical context is clear. Teaching strategies vary widely, from a case studies analysis approach and experiential activities built around particular scenes to the exploration of key concepts and theories in the context of an entire film or films (Karasik et al, 2014).

For some advocates, the formal language of film (and television) allows insights into health-related issues that other forms of popular culture do not afford. It has been argued that cinema's specific attributes including camera angles, framing, point-of-view shots and temporal and spatial shifts, are the most apposite cultural form for explorations of ageing and health related issues.

> Among artistic media, cinema is best suited for the task of faithfully capturing the plight of old age. The vehicles of representation at the disposal of the filmmaker simply cry out for a mindful, intelligent, and profound picture of aging: the free manipulation of time and space, the back and forth movement of flashback and flash-forward, mapping vast territories of the mind (Cohen-Shalev and Marcus, 2007, p. 88).

Others have argued that the expansive length of feature films, the complexity of characterisation and themes in relation to ageing, mean they offer a more instructive opportunities for exploring themes relevant to a gerontology curricula compared with their non-fiction and educational video counter parts (Yahnke, 2003).

Cinema and television's ability to generate empathy in audiences - where the formal language of cinema including camera angles and framing can encourage viewers to engage or empathize with particular characters or perspectives – offers significant opportunities to give audience insights into older characters and the ageing experience (Chivers, 2011, p. xxi). For some, this constitutes a significant part of its appeal and usefulness as a teaching resource for health professionals (Wilt et al, 1995; Blasco, 2001; Alarcon and Aguirre, 2007; Moyer-Guse, 2008; Dans, 2011; Morris, 2010; Morris, 2014; Lupton, 2018). Viewers exposed to health-related screen narratives can identify with a character and their situation and gain insights into how a particular illness might be experienced and understood. For health professionals, this can be extrapolated into real world clinical situations for teaching and learning purposes. The use of 'entertainment films' has been described as 'creative teaching strategy in nursing education' that assists with ' … not only the experience of empathy, but also the transference of the experience into helping interventions' (Wilt et al, 1995, p.8).

Morris's 2014 study involving mental health nurses is illustrative of this approach and the most directly relevant piece of research for this thesis. A small group of mental health student nurses were given a range of first person accounts of dementia including film, television (non-fiction), newspaper and Internet narratives. Subsequent interviews and focus groups with the participants showed that the students demonstrated improved understanding and empathy in relation to the lived experience of dementia. This included a reframing of what they had previously thought of as 'challenging behaviour' and new insights into the experiences of family members and carers.

It is notable that of all the first person narratives, the television documentary *My Life on a Post It Note* (Clough, 2006) and the feature film *Iris* were reported as having the most impact in terms of 'emotional intensity' and enhancing the student's level of understanding about the lived experience of dementia (Morris, 2014, p. 439). Acknowledging that his group was small and that findings required further exploration on a larger scale, Morris's conclusions are nevertheless significant for my analysis. Noting that ' … individual narratives cannot simply be generalised to fit a wider range of experience…', he nevertheless argues that exposing health professionals to first-person accounts can assist them to become ' … more questioning and mindful when working in practice …' and assist in broadening understanding and developing appreciation of the felt experience of dementia (Morris, 2014, p. 445). Morris is equally careful to emphasize that the use of mainstream media texts is not intended as an exclusive approach but rather as one of a range of complementary training and education resources in conjunction with clinical placements (Morris, 2014). One of the few studies to specifically address the use of mainstream film and television to educate health professionals about dementia, Morris's study is particularly apposite in relation to the discussion of first person depictions of dementia in Chapters 8 and 9 (Morris, 2014).

For others, cinema and illness share an inherently narrative-based structure; the former lends itself to depictions of the latter and can therefore resonate with health professionals in a singular way (Silenzio, Irvine, Sember and Bregman, 2005; Alarcon and Aguirre, 2007). The narrative basis of film and TV offers the potential for a complex and instructive depiction of illness. Symptomatology, diagnostic processes and treatment and care options can be examined in detail, over time and from multiple perspectives, including those of the person with the condition, their family members and health professionals.

Advocates for cinemeducation in the gerontology discipline argue that this is precisely why mainstream film and television texts are such potentially valuable teaching resources. Screening of entire films and TV episodes can open up discussions on a range of ageing and health-related issues, from the implications of a short term illness to the psychosocial considerations around family relationships over the life course. Shorter excerpts can be used for introducing and consolidating a key concept, in what has been described as a process of 'concept acquisition' (Karasik et al, 2014, p. 96). This can be achieved either through a preliminary discussion of the concept followed by screening an excerpt that illustrates it or screening the excerpt first, identifying the concept within the fictional scenario and consolidating it in post-screening discussions. My analysis demonstrates how crucial ideas around person-centred dementia care and associated issues can be explored, and practice change encouraged, through concept acquisition.

Film and television texts also provide valuable opportunities for reflective exercises in perspective taking, an approach that is central to the analysis in this thesis (Karasik, 2014, p. 99). Drawing on entire films, TV episodes or short excerpts of either, participants can be encouraged to adopt the perspective of different characters within the fictional scenarios to compare and contrast how each character might feel and respond to actions and events (Karasik et al, 2014, p. 99). This approach fundamentally underpins my discussion of texts depicting the point of view of the carer, family members or the person living with dementia, and the impact these texts might have in enhancing a viewer's understanding of the challenges involved in either providing support for someone or as a person living with dementia.

Capstick and others argue that perspective taking and a focus on generating empathy, underpinned by film and television's 'entertainment' imperative, is misguided. This approach undermines the need to critically engage with the subject matter and constitutes one of cinema's potential 'dangers' (Capstick, Chatwin and Ludwin, 2015 p. 229). According to Capstick et al, the same parameters of an illness might be presented in a misleading or truncated fashion in order to suit narrative and dramatic purposes and conform to the running time of a feature film or TV episode.

Recent depictions of dementia as a condition characterized by a precipitous decline have been criticized for encouraging the belief that this is an accurate portrayal of dementia's typical trajectory (Capstick et al, 2015). The same authors point to the unhelpful tropes and stereotypes in contemporary film and television - memory loss, aggression and complete dependence on carers - that in turn reinforce misleading assumptions and beliefs about the realities of living with dementia. Warning of the dangers of the general public absorbing these depictions 'uncritically', the authors go on to suggest that these texts are being used in an equally uncritical way - with the attendant risks of misrepresentation - to teach health professionals (Capstick et al, 2015, p. 229). Interestingly, the *Coronation St* storyline involving the Mike Baldwin character (2005 - 2006) is cited as an example of a misleading and unhelpful depiction of dementia compared with Segers' 2005 reference to it as a positive example of the impact of popular culture.

In response to these criticisms, advocates for cinemeducation argue that the way in which these texts are presented and analyzed is crucial and that even negative or inaccurate depictions of health-related issues can be used constructively in a teaching and learning context. The use of ' ... misleading or stereotypical content can promote effective learning if challenged and discussed within an educational milieu' (Morris, 2010, p.143). Many of the authors in this review acknowledge the potential impact of negative depictions of dementia on screen but suggest this does not mitigate against the usefulness of popular culture texts in educating the broader public and health professionals. Dastoor's early analysis was exemplary in this context, warning of the deleterious impact of 'fatalistic' depictions of dementia on 'susceptible' audiences while equally advocating for the same films as potentially effective teaching tools for caregivers and health professionals working in the dementia care field (Dastoor, 1991, p. 42).

It is inarguable that in a pedagogical context, all 'mainstream films need to be approached carefully' and that students (health professionals and otherwise) need to be given the necessary critical tools to understand and interpret these texts in order for them to be useful resources (Capstick et al, 2015, p. 235). The focus on mainstream film and television's capacity to engage audiences and a perceived lack of methodological rigour is cited as a conspicuous failing in the cinemeducation approach, with recent studies by Alexander, Lenahan and Pavlov (2005) and Morris (2010) singled out for particular criticism (Capstick et al, 2015). In advocating for the superior merits of their own participatory approach (a filmmaking project involving people living with dementia), Capstick et al arguably adopt an unnecessarily dismissive attitude towards the constructive potential of mainstream film and TV. They neglect the many extant studies that recognize the importance of a critical approach to the use of film and television texts and the need to incorporate appropriate methodologies in the teaching and evaluation of these approaches accordingly.

As noted in a recent analysis in the gerontology education field, mainstream film and television can be deployed in various ways to appeal to different learning styles but importantly, the strategies and techniques applied need to be consistently evaluated against learning outcomes (Karasik et al, 2014, p. 87). In arguing for the usefulness of cinema in teaching key principles of palliative care and bioethics, the co-authors of a 2007 study note that this approach must be underpinned by '…a rigorous definition of objectives and a logical, coherent and structured educational design' (Alarcon and Aguirre, 2007, p. 32). Other studies identified the need for methodological consistency in teaching approaches using film and television texts and the ' … importance of adequately preparing students for what they were accessing…' (Morris, 2014, p. 434). Swinnen notes that the use of fiction film in gerontological research requires knowledge of cinema history and the critical skills to analyse cinematic form and style including mis-en-scene, cinematography and montage (Swinnen, 2015). While the methodologies vary, this commitment to pedagogical rigour is a consistent theme over the last two decades (Blasco, 2001; Downey et al, 2003; Alexander, Lenahan and Pavlov, 2005; Morris, 2010 and 2014; Karasik et al, 2014; Felippa et al, 2015).

The discussion in the following chapters acknowledges the potentially problematic nature of cinemeducation as outlined above while equally insisting on the important role that representations of dementia in film and television can play in educating the broader viewing public and the Australian residential aged care workforce. The discursive analysis in the following chapters demonstrates how the individual characters, scenes, passages of dialogue and entire narrative trajectories in the selected feature films and TV episodes can make a contribution to that educational imperative.

CHAPTER 5 – SCREENING DEMENTIA

Introduction

This thesis analyses a selection of film and television texts from 1990 - 2018, all of which depict the subject of dementia in various ways. In order to contextualize the contemporary examples that form the basis of the proposed typologies, this chapter will present an overview of representations of dementia in mainstream Western film and television in the preceding period.

Depicting Dementia In The 20th Century: A Short History

Dementia has featured infrequently on the mainstream screen throughout the 20th century. The lexical and semantic transformations associated with the words senility and dementia outlined in Chapter Two suggested that both were in common usage in the medical and broader public domains in the 20th century. In the early decades of cinema however, older characters were frequently depicted as eccentric or oddly behaved but dementia was not specifically identified on screen. Euphemistic descriptions were employed to account for uncharacteristic behaviour; older characters were typically described as 'not themselves', 'not of sound mind' or 'dotty'.

One account describes these early depictions as ' … timid representations of elderly persons with dementias …' that tended to be associated with secondary or minor characters with little relevance to the main storyline (Rubio, 2007, p. 139). In the civil war epic *Gone with the Wind* (Fleming, 1939), the character of Gerard O'Hara (Thomas Mitchell) is clearly showing signs of cognitive impairment and is described by other characters including his daughter Scarlett (Vivien Leigh) as 'strange', 'not himself' and having 'lost his mind' (*Gone with the Wind*, 1939). His memory dysfunction is most clearly and poignantly indicated in the recurrent distress caused by his inability to recall that his wife has died.

The delusional, fading silent film star Norma Desmond (Gloria Swanson) in Billy Wilder's mid-century classic *Sunset Blvd.* (1950) displays symptoms of what could be understood as cognitive impairment. Norma's behaviour is described by her former husband and devoted carer Max (Eric Von Stroheim) as '… moments of melancholy' (*Sunset Blvd.,* 1950). An analysis of the film, subtitled 'Illusion and Dementia', attributes Norma's 'madness' to the exploitative demands of the Hollywood studio system (Dean, 1984, p. 97). Sally Chivers' suggests the 'portrayal of dementia' in *Sunset Blvd* is a combination of Desmond's mental instability and 'diva personality' culminating in a terminal inability to acknowledge her increasing age and on screen irrelevance (Chivers, 2011, p. 45). Swanson's character has also been described as a direct forerunner of a group of horror films featuring malevolent older women unkindly dubbed the 'pyscho biddy films', with all the gendered and ageist connotations that go with such a label (Shary and McVittie, 2016, p. 80).

Two American feature films released in 1970 represent a significant milestone in the history of mainstream cinema representations of dementia. *Where's Poppa?* (Reiner, 1970) and *I Never Sang for My Father* (Cates, 1970) are tonally distinct films but uncompromising depictions of an older person living with dementia and the challenges for family members in caring for them. Both films deploy dementia as the catalyst for examining longstanding familial tensions and if classified according to my contemporary typologies, would fall firmly into the category of Dementia as Dramatic Device.

An absurdist black comedy, *Where's Poppa?* focuses on the combative relationship between an older woman with clear signs of dementia (type unspecified) and the efforts of her adult son to care for her. The title refers to Mrs Hocheiser's (Ruth Gordon) repeated enquiries about the whereabouts of her long dead husband. Rather than identifying dementia, DVD publicity material associated with the film resorts to typical euphemisms, describing

Gordon's character as the ' … batty, eccentric mother…'(MGM, 2002). Despite – or perhaps because of - the tone of high farce throughout, the film tackles a series of substantive dementia-related issues. These include memory dysfunction, the impact of fluctuating cognition, the challenges of the carer's role including balancing issues of risk and safety, validation versus reality orientation and residential aged care placement.

The parent and son relationship is also central to *I Never Sang for My Father* but the film is pitched firmly in the dramatic register. A compelling exploration of a dysfunctional family, the film focuses on the demands of an autocratic but ailing father Tom Garrison (Melvyn Douglas) and his academic son Gene (Gene Hackman). Torn between moving away for his own personal and professional happiness and loyalty to his unforgiving father, Gene's decision is made more difficult by indications that his father is developing cognitive impairment. *I Never Sang for My Father* makes the filial relationship rather than dementia the central focus, but the latter – signified by telling memory lapses - is an understated but significant factor in the way in which the drama plays out.

Announcing Alzheimer's Disease On Screen

From the 1970s onwards, the multidisciplinary research focus on dementia and increased awareness about the condition in the public domain can be traced in the proliferation of depictions of dementia in film, television and other forms of popular culture. The first mainstream Western feature film to directly address Alzheimer's disease was released in 1985. The award-winning CBS telemovie *Do You Remember Love? (*Bleckner, 1985) took years to make because according to writer Vickie Patik, studio executives consistently told her ' … no-one would want to watch a film about something as depressing as Alzheimer's …' (Segers, 2007, p. 55).

Patik describes TV executives' responses to requests for funding as characterized by ignorance, fearfulness and hostility (Segers, 2007). Her difficulty in attracting support for a film about AD suggests that despite increased awareness, attitudes towards dementia remained entrenched in the mid 1980s. The film's screening and subsequent acclaim represented something of an attitudinal watershed for the film and television industry. The three Emmy Awards (1985), 1986 Humanitas Prize (an award for film and television writing promoting human dignity, meaning and freedom) and the numerous other accolades the film subsequently garnered suggested that there *was* an audience for film and television content that dealt with a challenging topic such as dementia in a considered way.

Do You Remember Love? focuses on Barbara Wyatt-Hollis (Joanne Woodward), a prominent poet, academic, mother and grandmother. The film quickly establishes that she is fit, happily married to husband George (Richard Kiley), is being considered for tenure and a prestigious award for poetry and is rapidly reaching the apogee of her career. Her increasing irritability, memory dysfunction and confusion are equally quickly established – interestingly, identified primarily by Barbara's mother when she comes to convalesce at their home. George enlists a psychiatrist friend for his opinion and then a formal series of tests establish Barbara's Alzheimer's disease diagnosis. Over the course of the film, Barbara loses her academic job, becomes increasingly disinhibited in social situations (she is arrested for making a scene in a public park) and frustrated with the challenges imposed by AD. Anne Basting describes the film as both a typically tragic account of dementia and 'enormously brave - it tackled an illness almost unheard of at the time… ' (Basting, 2009, p. 42).

The publicity material that accompanied the film included statistics about AD, including the early onset form of the disease, indicating the producers' commitment to raising awareness and improving knowledge about AD in the public domain. On a minor but poignant note, when the film was screened, Woodward disclosed in the press that her character was an homage to her mother who was living with AD. Woodward herself was subsequently diagnosed with Alzheimer's disease in 2008. TV audience numbers for the screening are not available but the positive critical reception, subsequent awards and DVD uptake indicate the film's considerable impact. Contemporary film reviews are revealing of the period in terms of the language used. Barbara is a 'victim of Alzheimer's disease' and her decline will leave behind ' … a shell that seems terrifyingly empty' (O'Connor, 1985, p. 17). However, reviewers also noted the sensitivity of Patik's script emphasizing the love story underpinning the film and importantly, the singularity of each person's experience of dementia.

User reviews cite the authenticity of the depiction in terms of the symptoms and challenges presented by AD, and the emotional impact for viewers, particularly those with direct experience of people living with dementia.

' I was amazed at the similarities between the behavior of the main character of this movie (played by Ms Woodward) and my father's own behavior at the time. It was like I was watching my own father on television' ("This is a Great Movie", 2011).

In its ambition to inform as well as entertain audiences, *Do You Remember Love*? established a model that was replicated some three decades later with the release of *Still Alice*. The two films share striking narrative similarities, most notably the focus on a relatively young, white, middle class academic as the central female character. Alice and Barbara's diagnoses of Alzheimer's disease are followed by a rapid decline including loss of academic status; both characters have the benefit of considerable economic resources and the loving support of their respective families. As with the producers of *Do You Remember Love?,* the media campaign that accompanied *Still Alice* had an educative component aimed at improving awareness and knowledge about dementia, particularly the early onset form depicted in the film. *Still Alice* and the media campaign associated with its release will be explored in detail in Chapter Nine.

The positive reception for *Do You Remember Love?* encouraged the release of a series of films dealing with dementia in some form over the remaining years of the 1980s. These included two telemovies: *There Were Times, Dear,* (Malone, 1985) and *Mercy or Murder* (Gethers, 1987), the latter one of the five films included in Dastoor's 1991 analysis, and two feature films *Age Old Friends* (Kroeker, 1989) and *Driving Miss Daisy* (Beresford, 1989). Of these, *Age Old Friends* engages most comprehensively with dementia and its consequences.

Based on Bob Larbey's Broadway play *A Month of Sundays,* the film retains a distinctly chamber piece feel with most of the action taking place within a residential aged care facility. The central character John Cooper (Hume Croyn) is physically frail but cognitively intact and is witness to the decline of his long time friend and co-resident Michael Aylott (Vincent Gardenia). The storyline centres on the changing dynamics of their friendship as Michael's memory deteriorates and he deals with the frustrations of advancing dementia.

Described as a comedy, the humour in *Age Old Friends* is determinedly dark. The two main characters are united in their efforts to resist 'joining the zombies' – as they describe their fellow residents living with dementia (*Age Old Friends*, 1989). The 'zombie' trope is deployed throughout as the film deals explicitly with John and Michael's fear of developing dementia and the potential repercussions; for the two men the most feared consequences are the perceived loss of independence and identity. Michael's gradual cognitive decline and John's efforts to support him are all the more compelling as a result. Life in residential aged care is also examined in detail. The film makes clear John's frustration with the many constraints imposed by living in an institutional setting but the positive aspects of relationships between residents and carers are also explored with some sensitivity. Family relationships are dealt with less sympathetically, represented by John's acrimonious dealings with his only daughter and what appears to be the wholesale abandonment of most residents by their respective family members.

Seriously Funny: A Brief Word About The Comedy Genre And Ageing On Screen

Despite the unfortunate – though as noted earlier – not uncommon use of the zombie metaphor, *Age Old Friends* is many ways a complex and thoughtful exploration of dementia and its consequences that ushers in the time frame for this thesis. As a black comedy, the film is also significant given that a number of the examples discussed in this thesis can also be classified in various sub-genres of comedy. Where drama is arguably an apposite generic choice for the exploration of a subject such as dementia, the choice of comedy is arguably less so. It is important to acknowledge why comedy offers an alternative approach to exploring the complexities of dementia and how humour might engage audiences in a potentially different but effective way.

The appeal of comedy broadly, and film and television comedy specifically, has been explained at least in part by the perception of the form as a relatively 'safe and unthreatening' genre operating in the realm of pure entertainment (King, 2008, p. 2). Conversely, comedy's perceived status as a 'lightweight' genre has also allowed it the freedom to address subjects deemed too confronting or subversive to tackle in other generic forms. In this way, it offers a potential platform for incisive social and cultural commentary, particularly in the modes of satire and black comedy (Urish, 2016).

The role of humour has been and continues to be central to many representations of ageing in mainstream film and television, often reinforcing stereotypes of older people and ageing through unhelpfully prescriptive characters and storylines. 'Older people and aging are used a lot for comic effect, often in less-than-flattering ways (Harwood, 2007, p. 159). Historical examples include everything from the gleeful killers in Frank Capra's classic *Arsenic and Old Lace* (Capra, 1944) and the gothic grotesquerie of *What Ever Happened to Baby Jane?* (Aldrich, 1962) to a legion of older TV characters who are the target of humour in shows including *Bewitched* [Saks, 1964 – 72] and *One Foot in the Grave* [Belbin, 1990 – 2001]). *The Golden Girls* (Harris, 1985 –

1992), an American comedy TV series regarded as a landmark for its positive representation of older characters and ageing experiences, is instructive in this context. Despite countering a number of unhelpful ageist assumptions and beliefs, a contemporary analysis concluded that ' … the humor in the show often centered around ageist stereotypes in unfortunate ways' (Harwood, 2007, p. 164). A recent overview of contemporary American TV comedy notes that a number of prominent older actors including Alison Janney, Margo Martindale, James Caan and Ellen Barkin (*Mom* [Baker, Goredesky, Lorre, 2013 -], *The Millers* [Garcia, 2013 – 2015], *Back in the Game* [Cullen and Cullen, 2013 – 2014] and *The New Normal* [Adler, Murphy and Shaffer, 2012 - 2013] respectively) are reduced to playing characters defined by stereotypical traits of older age including flatulence, technological incompetence, garrulousness and grumpiness (Genzlinger, 2013).

The comedy genre can also address potentially difficult or challenging topics in relation to ageing. It has been argued that older age is often explored humorously on the mainstream screen through a deconstructive approach, contesting stereotypes about ageing through exaggeration, role reversal, sight gags and word plays (Gatling, 2013, p. 74). This has the effect of destabilizing certainties and encourages audiences to question their own assumptions and beliefs about older people and the experience of ageing (Gatling, 2013).

In recent decades, the comedy platform has allowed mainstream TV series and feature film comedies to address substantive age-related issues from cognitive impairment and sexual dysfunction to bereavement and family estrangement. A modest but notable increase in mainstream English language romantic comedies featuring older characters - dubbed 'gerontocoms' - has led the way (Smith, 2009). A growing sub-genre, the gerontocom has been described as typically centering on ' … ageing heterosexual protagonists embarking on love affairs, despite their advancing years, in a culture which typically colonizes romance as the province of the young' (Jermyn, 2014, p. 137). Many of these gerontocoms and TV series feature older women in the lead roles (*Something's Gotta Give* [Meyers, 2003], *Mama Mia* [Lloyd, 2008], *It's Complicated* [Meyers, 2009], *Hampstead* [Hopkins, 2017], *Book Club* [Holderman, 2018] and TV series *Grace and Frankie* [Kauffman and Morris, 2015 -]). While the primary motivation is commercial entertainment, these comedies explore important issues around the lived experience of female ageing including friendship, intimacy and sexuality.

Contemporary romantic comedies and TV series also focus on the imperative for older male characters to be physically fit for romance, including humorous references to the assistance of virility or general fitness enhancers (the aforementioned *Grumpy Old Men* [Petrie, 1993], *Something's Gotta Give*, As *Good as It Gets* [Brooks, 1997], *Space Cowboys* [Eastwood, 2000], *Last Vegas,* [Turteltaub, 2013] and the TV series *The Kominsky Method* [Lorre, 2018 -]). As with their female counterparts, the benign platform of comedy offers the opportunity for more serious issues relating to fitness, health, intimate relationships and sexual dysfunction to be addressed.

It is unsurprising then that explorations of dementia in film and television are found in the comedy genre - and frequently in the darkest sub-genre, black comedy. As with the exploration of broader themes around ageing cited above, humour offers the opportunity for light hearted depictions of dementia-related scenarios but equally importantly allows for the exploration of more substantive and challenging concerns related to the condition. *Mother and Son* represents one of the earliest and most detailed comic explorations of dementia and will be discussed in detail below. Other examples in the comedy or hybrid dramedy genre include the feature films *Friends with Benefits, Happy Tears, St Vincent* (Melfi, 2014), *Robot and Frank* and *The Leisure Seeker* and TV series *Angry Boys*, *Outnumbered, Derek* (Gervais, 2012 – 2014), *Absolutely Fabulous, The Nanny* [Drescher et al, 1993 – 1999]) and *Golden Girls*.

Mother and Son: A Singular Australian Sitcom

If they think you are a bit 'eccentric' they might put you in a home.

— Arthur Beare (Garry McDonald) to Maggie Beare (Ruth Cracknell) (*Mother and Son*, 1984)

The Australian TV comedy series *Mother and Son* (1984 – 1994) marks as prominent a global milestone in representations of dementia on the small screen as the inaugural screening of *Do You Remember Love?* The first TV series to feature a central character with dementia, *Mother and Son* remains to my knowledge the only English language TV series which posits the challenges presented by ageing and dementia as its principal premise. The global reach of the series across numerous platforms is worth outlining in detail here in order to emphasize its potential contribution to audience awareness and understanding about dementia in Australia and internationally. Screened over six seasons for ten years from 1984 – 1994 at the Australian Broadcasting Corporation (ABC), *Mother and Son* was an immediate ratings winner for the ABC. Described as '…one of Australia's best-loved television shows', *Mother and Son* won numerous Australian TV awards (Bell, n.d). The complete series was released on DVD in Australia and subsequently sold throughout Europe.

The British Broadcasting Corporation (BBC) commissioned Atherden to adapt his original version for British audiences and two eight-episode seasons entitled *Keeping Mum* (Boden and Carrivick, 1997 – 1998) aired in Britain in 1997 and 1998. More recently, the series has found a new – or perhaps renewed - audience through its Australian digital streaming service releases: Netflix in 2016 and Stan in 2018 respectively. The critically well-received *Keeping Mum* was described as ' … a sitcom about senility and filial guilt …' (Sutcliffe, 1997, n.p). The most recent publicity material associated with *Mother and Son* on Stan describes Maggie as ' … ageing, widowed and slightly senile …' ('Mother and Son', 2019). Despite the disappointingly retrograde account suggesting that linguistically, not much has changed in the intervening decades, the release of the series on streaming platforms in recent years underscores the ongoing appeal and contribution this series continues to make. *Mother and Son* foregrounds issues central to many of the texts included in this thesis and its global significance warrants its inclusion here. The discussion in Chapter 8 further acknowledges the importance of *Mother and Son* for the prominence given to the perspective of the person living with dementia.

Geoffrey Atherden's dark comedy explores the troubled relationship between Maggie Beare and her journalist son and beleaguered primary carer Arthur Beare. There is no documented association between *Where's Poppa* and Atherden's series but the similarities in tone and content are striking: both are mordant comedies featuring the combative relationship between an adult son trying to juggle a professional career and a romantic relationship with caring duties for his inventively mischievous, cognitively impaired mother. The first episode of *Mother and Son* makes clear Maggie's symptoms including memory dysfunction, agnosia (inability to recognize familiar objects), confusion, repetitive questioning, word finding difficulties and confabulation. In subsequent episodes, wandering, disinhibited behaviour and loss of executive function are all woven into storylines[1]. As with earlier representations of dementia on screen, Maggie's dementia is never definitively identified. She describes it as 'losing my memory' and Arthur and other characters simply refer to her 'condition' (*Mother and Son*, 1984).

The first episode also establishes the central themes for the series. Arthur's inability to cope with the demands of caring for his mother is made clear from the outset: 'I can't do it on my own – I don't have the right attitude' (Mother and Son, 1984). Arthur's well meaning but frequently misguided efforts to care for his mother are primarily aimed at containment and control. He

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[1] This episode and a number of others are available on YouTube. The first episode, *The Nursing Home*, can viewed at: https://www.youtube.com/watch?v=NFSfMvRl28s&t=1512s

ridicules Maggie when she is forgetful, is blunt about the burden she imposes on him (and others in the community), and threatens to lock her up if she continues to wander off. Arthur's brother Robert (Henri Szeps) is a self-absorbed dentist who pays obsequious lip service to his mother but is reluctant to assist in any substantive way. Both sons demonstrate little insight into their mother's illness and subsidiary characters frequently adopt Robert's ill-informed and dismissive attitude.

Throughout the series, there is little evidence of meaningful medical intervention or treatment for Maggie. In one notable episode, the doddering GP who assesses Maggie appears to be more cognitively challenged than his patient. Arthur's occasional reminders to Maggie about 'taking tablets for your memory' typify the perfunctory references to treatment in the series (*Mother and Son*, 1984). The intermittent interventions of a well intentioned but ineffectual social worker and a risible episode involving Maggie's potential minder - a teenage babysitter - flesh out the extent of the ancillary 'care' on offer. Arthur's brutal self-assessment of his own inadequacy as a carer and his frustration with the lack of support is a recurring theme in the series and many of the texts discussed in this thesis.

Maggie is alone at home for long periods when Arthur is at work. Her adventures beyond the family home often unwittingly embroil members of the community, cause confusion and chaos and occasionally require the intervention of the local constabulary. The blunt threat of incarceration in the family home – or a nursing home – is a regular reprise. Atherden's grim view of residential aged care is made clear in the first episode of *Mother and Son*, appropriately entitled 'The Nursing Home'. Arthur dismisses the idea of a nursing home as an 'el cheapo fibro shed with fifty geriatrics and the chooks' but then warms to Robert's proposal to place Maggie in care (*Mother and Son*, 1984). The episode concludes with his brief and spectacularly unsuccessful attempt to move Maggie into Autumn Park, a more superior 'care situation.' This firms her resolve to avoid aged care at all costs: 'If I went into a home I would know no-one wants me anymore' (*Mother and Son*, 1984). The prospect of alternative care is however regularly raised. The jaundiced view of residential aged care is a constant trope in *Mother and Son* and a recurrent theme in the mainstream films and TV series that follow.

As with Mrs Hocheiser in *Where's Poppa,* the impact of Maggie's unspecified but recognisable dementia is amplified by her manipulative personality and the broader context of family dysfunction. Atherden creates endlessly entertaining scenarios of mutual confusion, family tension and mayhem but the series is revealing for the way in which it reflects contemporary knowledge and attitudes about dementia. As Basting noted in relation to the release of *Do You Remember Love?,* dementia was '…an illness almost unheard of at the time…'(Basting, 2009, p. 42). In the contemporaneous *Mother and Son,* this limited knowledge is clearly reflected in the collective lack of insight demonstrated by family members and other characters in their interactions with Maggie.

Equally importantly, *Mother and Son* foregrounds themes and concerns that would have resonated with audiences at the time and remain pertinent today. The comedic context allows the series to highlight potentially confronting issues: the frustrations and challenges for the person living with dementia, the demands of the informal caring role for family members, and conflicting attitudes and beliefs about dementia within the family group and beyond. *Mother and Son* also explores the lack of broader clinical, psychosocial and community support for the person living with dementia and their family members, and albeit rather broadly, the limitations of the residential aged care model.

The series' expansive exploration of dementia-related concerns makes it a valuable and accessible teaching resource in the residential aged care context. Individual episodes and key scenes can be used as the basis for discussions addressing a range of issues outlined above. In addition to presenting a useful illustration of the way in which knowledge and attitudes about dementia have shifted in the intervening decades, *Mother and Son* offers opportunities for aged care staff to consider the challenges Arthur and others encounter in providing appropriate care and support for Maggie.

Discussions could consider whether Maggie's needs and preferences are respected, the ways in which the care provided is person-centred or otherwise and whether the various risks involved in leaving Maggie alone are balanced with dignity, autonomy and quality of life. This in turn offers the opportunity to consider how these issues apply to supporting people living with dementia in a residential aged care setting.

Conclusion

As with the significant shifts in the conceptualization of dementia traced in the historical overview, and the changes in tone and content noted in relation to contemporary newspaper coverage in previous chapters, there have been analogous changes in depictions of dementia in mainstream film and TV over the last three decades. These changes can be traced from euphemistic references to characters 'not being themselves' in the early twentieth century and overt references to the 'zombies' in the 1970s, to the first, direct feature film exploration of Alzheimer's disease in the mid 1980s. These lexical and representational shifts reflect changing knowledge and attitudes about dementia in the broader community and in turn provide a framework for analysing the quantitative and qualitative increase in depictions of dementia on the big and small screen that follow in subsequent decades. The following chapter focuses on the first of my proposed typologies, Dementia at the Margins.

CHAPTER 6: DEMENTIA AT THE MARGINS

Introduction

In arguing for the educative potential of film and TV, the texts selected for analysis in this thesis have been grouped into three thematic categories: Dementia at the Margins, Dementia as Dramatic Device and Dementia Takes the Lead. The title and rationale for each indicates the way in which these films and TV series can be understood to deploy dementia in the narrative or depict dementia from a specific point of view. The discursive analysis suggests how each typology might engage differently with an audience and be utilized as an educational resource in the residential aged care sector. The screen time devoted to the depiction of dementia, the level of detail in relation to symptoms, diagnosis, treatment and care and the dominant perspective (carer, spouse or person with the illness), are all typological determinants. Close textual analyses of examples in each typology will illustrate how each presents knowledge or insights about dementia and its consequences.

As outlined in the thesis introduction, the discursive analysis and associated typologies are distinguished from preceding scholarship in several ways. The literature review makes clear that previous analyses have overwhelmingly emphasized the unhelpful effect of negative depictions of dementia in popular culture (Basting 2009; Chivers 2011; Capstick et al, 2015). Scholarship has also predominantly focussed on film and television texts that deal with dementia as a *central theme* (Dastoor 1991, Segers 2007; Basting 2009; Chivers 2011, Gravagne, 2013, Swinnen, 2015). My analysis suggests that negative or inaccurate depictions of dementia can be used in a pedagogical context to improve knowledge and awareness about dementia and discussion of a small selection of examples will demonstrate this. Equally importantly, and distinct from extant scholarship in the field, the texts selected for inclusion in this thesis deal both substantively *and briefly* with the topic of dementia. This chapter will focus on texts in the latter category comprising the first of my proposed typologies, Dementia at the Margins.

Dementia at the Margins – definitions and rationale

The treatment of dementia in these texts might only consist of a couple of scenes touching on the subject, or involve a minor character or subsidiary plotline. Despite the brevity of the depiction of dementia, these examples can potentially exert considerable influence in shaping opinion about dementia in the public domain. Given their emphasis on detailed depictions of dementia including symptomatology, care and emotional import, the other two taxonomic classifications are, unsurprisingly, dominated by the drama genre. In contrast, Dementia at the Margins is significant for its generic breadth and diversity, and this accounts at least in part for this category's broad reach and potential contribution.

In addition to *Friends with Benefits* and *Gone Girl*, Dementia at the Margins includes dramas (*The Daughter* [Stone, 2015]), comedies (*Grosse Pointe Blank* [Armitage, 1997], *Choke* [Gregg, 2008]), dramadies (*The Descendants* [Payne, 2011]) and coming of age films (*Billy Elliot* [Daldry] 2000)). TV series encompass an equally diverse generic range include political and crime dramas (*The West Wing* and *The Sopranos*), comedies (*Absolutely Fabulous, Outnumbered, Golden Girls* and *The Nanny*) and dramadies (*Derek* and *Angry Boys*).

For most texts included in Dementia as Dramatic Device and Dementia Takes the Lead typologies, the subject of dementia is made clear in promotional and publicity material (for example, *Away From Her, The Savages, Still Alice*). In other films in these typologies, prominent public figures and their experiences with dementia are the central focus and the dementia storyline is prominent *(Iris, The Iron Lady*). Viewers make an informed choice about watching these films and engaging with the subject of dementia accordingly. In contrast, the trailers, poster designs, taglines and other marketing strategies for films such as *Billy Elliot, Friends with Benefits* or *Gone Girl* do not make direct reference to, and are not suggestive of plotlines, characters or scenarios involving dementia. A potential viewer would be drawn to the central comedic, romantic or thriller premise and arguably unprepared for, and even surprised by, exposure to the subject of dementia. It is the *unanticipated* nature of the references to dementia, and the contrast these brief scenes provide compared with the overarching storyline or prevailing tone of the film that in part gives them their potential potency and influence.

In these and other examples, despite the brevity of the depiction or reference, the physical and psychological realities of dementia are often explored with considerable insight and sensitivity. Conversely, in the context of the global reach of a commercially successful mainstream film or TV series, seemingly unsympathetic or simplistic depictions of the subject, however cursory, might also be constructive in foregrounding specific issues or offering insights into the challenges of living with or caring for someone living with dementia (*The Descendants*, *Gone Girl* and *Absolutely Fabulous* are key examples). My contention here is that the broad audience reach and the understated way texts in this typology incorporate dementia into the storyline could make a contribution to knowledge and insight about the condition that is different to but commensurate with the influence of films or television series that deal with the subject as a central theme.

Gerritsen and others have argued for the 'unconscious' effect of cinema in relation to negative depictions of dementia. '… information about a specific problem or disease is often processed unintentionally or unconsciously by the viewer' (Gerritsen, Kuin & Nijboer, 2013, p. 1). Anne Basting has made similar claims arguing that popular culture imagery operates in the realm of implicit memory. Viewers may not 'recall it consciously, but it still influences you' (Basting, 2009, p. 25). She notes the particular potency of negative stereotypes of older people including those with dementia. Where Basting has argued that the depiction of stereotypical traits on screen, including dependency and impairment, can exert a powerful influence and encourage discrimination and stigma in relation to older people with dementia, this argument could equally be made in the opposing direction (Basting, 2009). Nuanced and complex depictions of people living with dementia, and the empathetic and compassionate responses of carers and family members, however brief or fleeting, could make a potentially *positive* impact. The analysis in this chapter argues that lingering or 'unconscious' effect of minor characters or scenes in storylines unrelated to dementia could exert a powerful affirmative effect.

Texts included in Dementia at the Margins typically appeal to a large, broadly defined audience - one that might not otherwise encounter the subject of dementia on the big screen. A blunt measure of the extent of this potential influence is provided in the box office figures for mainstream films, TV viewing numbers and DVD sales. Of the feature film examples cited above, many were commercially successful. *Gone Girl* is the most prominent recent example, grossing US $370,000,00 worldwide while *Friends with Benefits* earned in excess of US $150,000,000 (Box Office Mojo, 2014). The modestly budgeted UK global box office hit *Billy Elliot* made $109,000,00 worldwide and *The Descendants* grossed more than $170,000,000 globally (Box Office Mojo, 2011). *Absolutely Fabulous* had similarly impressive figures for the five seasons of the TV series, eight 'specials', global DVD sales and the 2016 feature film spin off (the feature film grossed $38,000,000) (Box Office Mojo, 2016). Australian TV examples are equally instructive with the Chris Lilley's *Angry Boys* achieving critical and commercial success in free-to-air viewing and DVD sales in Australia and internationally and achieving ' …1.4 million plays, the highest ever amount of program plays on *iview* recorded to date' on the ABC's time-shift platform ("New Chris Lilley Series", 2013).

Texts included in Dementia at the Margins potentially reach a broader demographic compared with the other two typologies and the nature of this broad audience reach suggests the usefulness of such popular texts in shaping public attitudes and opinions. As Byrne has noted in relation to films about mental health:

> Direct links between seeing one negative film and behaving in a particular way are impossible to prove. People who love films, love talking about them, and films that explore characters with mental health problems with integrity and imagination will help promote understanding and reduce stigma (Byrne, 2009, p. 6).

If providing qualitative information, emphasizing the personal experiences of people living with dementia, to a young adult cohort can 'dramatically' enhance their understanding of the condition, exposing a young adult audience to a screen depiction of dementia might also improve understanding and empathy (Sabat, 2012). The shared experience of viewing a film at the cinema, participating in post viewing discussions, repeat viewings of the film or specific scenes, and associated discussions on YouTube and other social media platforms constitutes a cumulative exposure to qualitative information not dissimilar to Sabat's undergraduate cohort model.

There are many texts that can be classified in this particular typology but this discussion will focus on four feature films and two TV series. Detailed textual analysis of scenes from *Friends with Benefits*, *Billy Elliot, The Descendants* and *Gone Girl* and TV series *Absolutely Fabulous* and *Angry Boys* will illustrate the way in which these texts can make a contribution to a general audience's understanding of dementia. The discussion will also point to the contribution these texts can make as teaching resources in the residential aged care sector.

Minor Character Major Impact

Friends with Benefits

A romantic comedy and what is colloquially referred to as a 'date night film', *Friends with Benefits* is described in marketing and publicity material as 'the coolest, freshest and sexiest movie about life, love and relationships in years' (*Friends with Benefits*, DVD title cover). The film's romantic comedy premise, high profile actors, suggestive title and MA 15 + rating indicate it is aimed firmly at younger adult viewers and the film's global box office success indicates it clearly reached this target audience.

In line with the film's unashamedly contemporary take on romance, the screenwriters tackle the topic of dementia in a straightforward and uncompromising fashion. When first introduced to lead character Dylan's father on screen, Mr Harper (Richard Jenkins) is showing clear symptoms of his Alzheimer's disease. Dylan's sister Annie (Jenna Elfman), refers to his diagnosis in this first scene and observes that his symptoms are worsening. This deterioration is illustrated by foregrounding Mr Harper's short term memory dysfunction (Annie corrects him crisply when he forgets his doctor stopped him from driving his speedboat) and disinhibited behaviour including walking around in his underpants - he 'doesn't like his trousers anymore' (*Friends with Benefits*, 2011). Mr Harper himself jokes 'I'm turning to mush' (*Friends with Benefits*, 2011). Annie's pleasure in her brother's visit includes an oblique reference to the increasing complexity of caring for her father, a role that Dylan, living on the other side of the country, does not have to share. This scene is significant in revealing how much Mr Harper's illness has advanced, and the way in which the two siblings have different relationships with their father and degrees of involvement in his care.

Mr Harper's dementia offers the opportunity to show how the lead character develops and changes. In a family setting, he is now a more fully fleshed out sensitive and caring son, sibling and uncle. This scene and others that follow equally offer a brief but sympathetic series of insights into Mr Harper's experience of living with dementia and contrast the way different family members and other individuals respond to his illness. In addition to his short-term memory dysfunction, Mr Harper has clear word finding difficulties and misrecognizes family members (he calls his grandson Dylan and mistakes both Jamie and a stranger for his former girlfriend Dee Dee). His frustration ('Stop telling me what to do!'), feelings of inadequacy and difficulty coping in social situations are also highlighted. As his primary carer, Annie makes reference to the challenges involved in that role, a challenge that her sibling was unwilling or unable to tackle. ‘Dylan doesn't know quite how to deal with the Alzheimer’s’ (*Friends with Benefits*, 2011). Despite the limited screen time devoted to exploring AD, the film illustrates how Dylan goes from being ‘unable to cope’ and describing his father’s behaviour as ‘embarrassing’, to developing insight and understanding of what his father is contending with (*Friends with Benefits*, 2011).

One scene illustrates his evolving understanding particularly well. Dylan is meeting his father for lunch at a busy airport café and as he approaches, Dylan can see that his father has removed his trousers and is sitting at the table in his underwear. Dylan’s initial embarrassment and awkwardness is transformed into a more considered and empathetic response. When his father asks if he is going to join him, he contemplates the situation, takes in the judgemental glances of fellow diners and despite the protestations of the waitress, replies ‘Absolutely’ and promptly removes his shoes and trousers. The waitress retreats, fellow diners get on with their meals and father and son chat amiably. As the scene progresses, Mr Harper calls out to a young woman who is passing by, misrecognizing her for a former girlfriend Dee Dee, who, as he goes on to explain to his son, was the ‘love of my life’ (*Friends with Benefits*, 2011).

This short, two-minute scene conveys a number of affirmative messages about dementia. It depicts what the experience of living with the illness might feel like, illustrates some of the more challenging symptoms in a forthright fashion, and importantly, depicts different, enabling (or otherwise) ways of responding to a person with dementia. Mr Harper’s disinhibited behaviour is an understandable response to the anxiety and discomfort he is experiencing sitting alone in a crowded and noisy cafe surrounded by strangers. Unlike the unsympathetic reactions of the waitress and his fellow diners, Dylan’s reaction to his father is ultimately a person-centred response. Adopting his father's perspective, he identifies his need for comfort in this potentially stressful environment – which equates to sitting in his underwear - and validates this by replicating his actions. This has the immediate effect of making his father feel relaxed, and defuses the tension and disapproval of the waitress and diners.

Earlier scenes have established Mr Harper's short-term memory dysfunction. When Mr Harper misrecognizes the young woman and goes on to describe to his son in detail the pivotal role Dee Dee played in his life, this emphasizes the clarity of Mr Harper's long-term memory. This is a valuable illustration of well preserved long term recall typical for people living with AD. The subsequent discussion between father and son about the importance of finding and maintaining a loving relationship is clearly a pointed reference to Dylan's equivocal situation with Jamie. The scene also underscores the importance of emotional connections, past and present, for a person living with dementia, particularly where cognitive and other capacities might be declining. Mr Harper's vivid recall of Dee Dee is clearly a powerful and ultimately positive emotional experience that gives him the opportunity to offer fatherly advice by extrapolating his own past experiences to his son's current situation.

It is significant that this particular scene has been uploaded to YouTube and had over 140,000 viewings. The lively associated discussion points to its powerful impact for many viewers as illustrated by the following comments:

'Touching scene. We want our parents to be different so we can accept them, but we have to accept them for being different. Hard to do.' (*'Friends with Benefits'*, 2013).

'Probably one of the most memorable things I have seen in a long time.' (*'Friends with Benefits'*, 2016)

In conjunction with other scenes, this exchange also emphasizes the vital role that relationships with family members, friends and carers play and the importance of the broader social environment in supporting the person living with dementia.

Interestingly in this context, Dylan's friend Jamie, who is not aware of Mr Harper's diagnosis when she meets him for the first time, offers the most perceptive observations about the importance of these ongoing relationships. Dylan is initially distressed by the changes in his father from the 'smartest man I know' to someone 'everyone stares at' because 'he walks around without his pants' (*Friends with Benefits*, 2011). Jamie counters with 'it doesn't matter – he's the same man and all that matters is the way *you* look at him' (*Friends with Benefits*, 2011). She offers equally considered insights in several other exchanges in subsequent scenes.

The scenes featuring Mr Harper account for fewer than five minutes in the film's overall running time of 109 minutes. For a young audience who may have limited if any knowledge or experience of dementia, the contribution these scenes could make is significant. The film offers viewers insights into the lived experience of dementia by ensuring that Mr Harper's perspective is acknowledged on screen. The film makes clear his frustration with his failing short-term memory and increasing dependence but equally emphasizes Mr Harper's well-preserved long-term memory and the important role that past and present relationships continue to play in his life.

Annie's role as the primary carer offers a realistic reflection of real world statistics given 60 – 70% of carers for people living with dementia are women ('Women and Dementia', 2015). In a few succinct scenes, the film spells out the significant impacts on her life caring for a parent with a progressive illness and raising a young child. *Friends with Benefits* is also instructive in depicting the way in which people respond differently to someone living with dementia. Annie's firm, 'hands on' approach to care, Dylan's evolving understanding of his father and Jamie's intuitive empathy offer positive and supportive exemplars of how to engage with someone living with dementia. This is effectively contrasted with the unsympathetic reaction of people Mr Harper encounters in the broader community. Common misperceptions about dementia in the younger population are encapsulated in a short scene towards the end of the film. Dylan's neighbour Dave agrees to look after Mr Harper in Dylan's absence. The extent of his understanding of dementia is revealed when he proceeds to simply shout sentences in slow motion at him from the other side of the room, as if Mr Harper is hearing rather than cognitively impaired. While the scene is played for laughs, the impact of Dave's ignorance is made clear.

As a teaching resource for aged care staff, *Friends with Benefits* offers specific insights in relation to a range of dementia-related issues. As Kitwood, Sabat and others have argued, the support provided by relationships and social interactions with others is critical for the preservation of personhood and wellbeing for the person living with dementia (Kitwood, 1993, 1995, 1997; Sabat and Harre, 1992, Sabat 2001, 2002 and Brooker, 2007; 2016). The film emphasizes the importance of family relationships and social engagement for Mr Harper's ongoing wellbeing and offers opportunities for staff to consider this in contrast to his interactions with others in the community who lack insight or are less supportive.

The scene involving Dylan and his father in the café provides a useful starting point for a concept acquisition approach and discussion around the broad principles of person-centredness. Mr Harper's removal of his trousers draws two distinctly different responses and analysis of these could form the basis for considering how to respond appropriately to a person living with dementia. Dylan's response models some of the central tenets of a person-centred approach including valuing the person with dementia and attempting to understand the physical and social environment from their perspective.

The film offers a number of opportunities for perspective taking. Contrasting the actions and attitudes of Annie, Dylan and Jamie could open up a discussion on the different ways in which these characters and other demonstrate different degrees of understanding and insight into the lived experience of dementia. In adopting Mr Harper's perspective, aged care workers could gain insights into the challenges of living with dementia and the in the residential aged care context, the importance of putting themselves in the position of the person they are caring for in order to better understand their needs and preferences (Kitwood, 1997; Brooker, 2007). Mr Harper's moving recall of his relationship with Dee Dee offers another useful focus for discussion. The scene foregrounds the value of reminiscing and the role of positive memories in enhancing wellbeing and underlines another central component of a person-centred approach. This and other scenes in the film can be used to engage staff in thinking about the significance of knowing the unique history of the person they are caring for in order to engage meaningfully with them and provide genuinely individualized care.

Billy Elliot

Variously described as a dance drama and coming of age film, *Billy Elliot* was a global box office phenomenon. Made for a modest US $5 million, the film grossed more than 20 times that amount worldwide in its theatrical release alone. DVD sales enhanced the film's reach and a multi-award-winning musical based on the film has been an even bigger success, touring globally in a variety of languages.

The film focuses on the eponymous 11 year-old central character and his efforts to pursue a career in dance. Billy (Jamie Bell) lives in a tough Northern England mining village with his combative older brother Tony (Jamie Draven), father known only as Dad (Gary Lewis) and grandmother Grandma (Jean Heywood). Family members are coping with the loss of Billy's mother in their own individual ways and home life is further complicated as Tony and Dad are caught up in a bitter and lengthy miner's strike.

The opening scenes establish the film's tone of gentle whimsy and Billy's sensitive and caring personality - and introduce the issue of dementia. Billy prepares breakfast for his grandmother, realizes that she is no longer in her bedroom and runs down the village streets searching for her. When he finds her in a nearby field, it is clear Grandma is disorientated and not for the first time, has walked away from the family home.

Billy approaches Grandma gently, introduces himself by name, and allows time for her to process this information and recognize him. He holds out his hand and offers to escort her home. This first scene is useful in establishing Billy's personality but equally in modelling a respectful and appropriate way to approach someone who clearly has some form of dementia and is confused and possibly distressed. It offers a salient contrast to the way in which in subsequent scenes, Tony and Dad ignore or silence Grandma and intimate she imposes a burden on the family – a burden Billy appears to be almost solely responsible for.

Grandma is only present in a few scenes, has a handful of lines and is depicted for the most part lying in bed looking confused or isolated in a corner of the room. She is however an important figure for Billy, and the inspiration for his dance career ambitions. She regales Billy with memories of watching Fred Astaire films and replicating his dance moves. In a key scene, Billy's father angrily refuses to pay for dance lessons, but Grandma intervenes recalling how much she loved dancing in her youth. 'I used to do ballet…they used to say I could have been a professional dancer if I'd had the training '(*Billy Elliot*, 2000). Her intervention is telling in validating Billy's aspirations. A brief flashback depicts her evident joy in dancing, a scene that provides a powerful visual match with Billy's exuberant dance audition in a later scene.

As with Mr Harper in *Friends with Benefits*, Grandma's excellent long term recall not only provides the opportunity to share positive memories but also allows the family elder with dementia to provide an important source of support and encouragement to a younger family member. When Billy leaves to take up a scholarship in London, Grandma's warm farewell embrace suggests her clear understanding of the importance of grasping an opportunity that she herself was never given.

Grandma is a minor character who shares only a few scenes with the central character but in those brief minutes on screen the scriptwriters convey a number of crucial messages about dementia. As with *Friends with Benefits*, *Billy Elliot* offers both a broad mainstream audience and the aged care workforce specific insights. Grandma's short-term memory dysfunction but clear long term recall offers a realistic depiction of what appears to be (though is never identified as) Alzheimer's disease. Grandma's vivid recall of her youthful dancing days indicates the importance of recalling positive memories that enhance her sense of well-being and reinforces the important emotional connection she has with her grandson. The significant role that positive memories can play for the person living with dementia is a concept that a broad audience would arguably appreciate.

As with *Friends with Benefits*, *Billy Elliot* also represents a valuable teaching resource in its illustration of the important role long-term memory can play for the person living with dementia. Reminiscing is one of a number of important strategies for meaningful engagement to enhance wellbeing. The emotionally powerful scenes involving Grandma's recall of her youthful dancing days – and her way of connecting with Billy - offer a useful starting point for aged care workers to explore the role of reminiscence in supporting the wellbeing of people they are caring for.

The film's emphasis on emotional wellbeing, including sustaining supportive relationships with family members, is also an important insight for both a broad audience and the aged care workforce. This is underlined by the fact that despite the variable responses of family members and her significant care needs, Grandma is depicted living in the family home and included in the village community. This further affirms the value of remaining in a familiar environment with all the visual and emotional cues that this can potentially provide.

Billy's approach to caring for Grandma – from knowing exactly how she likes her breakfast presented to his gentle and supportive manner when she becomes confused outside the family home – demonstrates a genuinely person-centred approach to care. This is in contrast to Tony and Dad who treat her for the most part as an irritant. As a teaching resource for the residential aged care workforce, the contrast between the way in which Billy and other family members engage with Grandma offers a constructive way of opening out a discussion about the best way to support someone living with dementia. As with *Friends with Benefits*, Billy's detailed understanding of and respect for Grandma's needs and preferences could be the basis for a concept acquisition approach to merits and principles of a person-centred approach to care (Brooker, 2007, Edvardsson et al, 2016).

The Descendants

The Descendants could be described as both a drama and comedy, or 'dramedy'. The film deals with the emotional fallout for the King family when wife and mother Elizabeth (Patricia Hastie) suffers a serious brain injury and her previously inattentive husband Matt (George Clooney) is forced to take on the care of his two young daughters. The older of the two King daughters, Alexandra (Shailene Woodley) is a troubled teenager who introduces her former schoolmate Sid (Nick Krause) into an already tense family situation.

Matt takes an instant dislike to the seemingly unsuitable Sid, but he has an improbably positive impact on the family.

The King family's visit to Elizabeth's parents reveals her mother Alice (Barbara L Southern) is living with dementia. Alice's husband Scott (Robert Forster) leads her gently into the living room where Matt and Alex introduce themselves by name, introductions reinforced by Scott. 'This is your son-in-law Matt and granddaughter Alex; this is your family' (*The Descendants*, 2011). Scott then explains they are taking her to visit Elizabeth in the Queen's Hospital. When Alice misunderstands this, thinks they are visiting Queen Elizabeth and remarks that she will 'have to put on a nice dress', Matt and Alex exchange meaningful looks but Sid laughs outright at her response. When Scott reacts furiously to Sid's apparent insensitivity, the latter defends himself by saying 'I was just laughing…it's funny…I mean I think she knows she is being funny' (*The Descendants*, 2011). Scott promptly punches Sid in the face.

This scene occupies 90 seconds but despite the brevity of the time on screen, writer/director Alexander Payne highlights several significant issues. The respectful way family members introduce themselves to Alice and reinforce their names and relationships demonstrate their insight and understanding of Alice's short-term memory dysfunction and confusion. Their collective approach demonstrates a supportive and person-centred way of engaging with a family member living with dementia, one that reinforces Alice's identity through the reaffirmation of familial relationships.

Scott's careful explanation of the reason for the visit, despite the fact that Alice misunderstands him, shows a good understanding of the importance of presenting information in a clear and accessible way, and not as Allen Power and others would say, setting up the person living with dementia to fail (Power, 2014).

Perhaps most interestingly, Sid's seemingly inappropriate response to Alice is potentially a nervous reaction to an uncomfortable situation but also one that arguably intuits and reflects back Alice's own confusion and could be read as a fundamentally empathetic response. While Sid is singularly unsuccessful in explaining this to Scott, his attempt to understand Alice's perspective is something that viewers could arguably identify with and learn from.

Alice's presence is even more limited in terms of screen time than Grandma in *Billy Elliot*. In the context of a mainstream family dramedy, the reference to dementia in *The Descendants* is so brief and incidental to the central storyline that it is almost subliminal. However, the 'unconscious' effect that Anne Basting argues popular culture can exert suggests that even this brief scene, and its succinct underscoring of the importance of supportive family members, effective communication and empathy, could have a potentially powerful impact on a broad audience.

Gone Girl

A contemporary thriller based on the best selling 2012 novel by Gillian Flynn, the film version of *Gone Girl* was a global box office hit. The plot centres on the disappearance of Amy Dunne (Rosamund Pike) from a fictional small town in Missouri and the efforts of her husband Nick Dunne (Ben Affleck) to clear himself as a person of interest in her suspected murder. Two brief scenes involving a minor character contrast with the two films discussed above and offer valuable audience insights into dementia.

In the course of the investigation into Amy's disappearance, Nick learns that his father Bill (Leonard Kelly-Young) left his aged care facility, became lost and has been brought into the police station. In the busy and noisy police station, the older man is combative and unco-operative with police officers and his son. Nick has a perfunctory conversation with him in the car and drops him off abruptly outside the facility, without waiting to see if he is accompanied safely inside. From Nick's attitude and an earlier phone call, it is made clear that Bill has absconded before and that the relationship between father and son is strained.

These two scenes are short but their overall import is significant. From a character development perspective, they underline Nick's unappealing qualities; he appears weary of his father's behaviour and treats him dismissively. From Nick's perspective, his father's behaviour is embarrassing and burdensome and an additional complication in his increasingly fraught personal situation. In the context of this discussion, the two scenes offer an ostensibly dispiriting view of older age as characterized by infirmity, indignity and dependence.

Despite the brevity of these scenes, the depiction of dementia in *Gone Girl* is useful in raising a series of important issues. Bill's cognitive impairment has presumably led to repeated episodes of absconding, a significant issue for people living with dementia at home and in residential aged care as illustrated in the opening scenes of *Billy Elliott*. At the police station, Nick's father displays frustration, verbal aggression and combativeness. While this behaviour is often routinely ascribed to people living with dementia, thereby potentially contributing to negative perceptions of the condition, this scene could also be read in alternative and constructive ways.

Bill's response to his situation is not unreasonable given the circumstances. Surrounded by officious looking strangers in uniform and disorientated in a busy, noisy and unfamiliar environment, Bill is unsurprisingly apprehensive and unsettled. Nick and the police officers demonstrate a lack of insight into Bill's distress, an unsympathetic response that arguably exacerbates his unease. However brief, the scene offers the opportunity for the audience to consider why a person with dementia might respond to their environment in this way.

As a teaching resource, these brief scenes also offer a platform for perspective taking and a discussion about effective approaches to supporting a person living with dementia in a potentially distressing situation. In *Friends with Benefits* and *Billy Elliot*, a person-centred approach to care was modelled in a similarly challenging situation, an approach which clearly reduced the distress and anxiety experienced by the family member involved. Nick's failure to understand the reasons for his father's combativeness – fatigue, confusion, fearfulness - and offer appropriate support offers a salient illustration of Kitwood's notion of Malignant Social Psychology (MSP) (Kitwood, 1997).

Bill's reaction to his physical and social environment in the police station, and Nick's unsupportive response represents a clear example of the impact of MSP. Aged care staff could be encouraged to analyse these two brief scenes, adopting Bill's perspective to identify factors contributing to his illbeing. The discussion could explore ways in which an alternative, 'positive person work' approach might have reduced Bill's distress. Scenes from *Friends with Benefits* and *Billy Elliot* could be used to highlight the way in which supporting rather than undermining wellbeing can produce better outcomes for the person living with dementia and to consider the application of these strategies and approaches in the residential aged care environment.

A Tale of Two TV Grans

Absolutely Fabulous

Broadcast over two decades, and followed by a feature film release, *Absolutely Fabulous* the TV series (1992 - 2012) focuses on two middle-aged women involved in the public relations industry. The increasingly desperate efforts of PR agent Edina Monsoon (Jennifer Saunders) and fashion magazine director Patsy Stone (Joanna Lumley) to remain relevant and conceal their visible signs of ageing offers an incisive and irreverent analysis of Western pop culture’s contemporary obsession with youth and celebrity culture. The character known simply as Gran/Mrs M (June Whitfield) appeared as a special guest star until the fourth episode of the third series after which she was billed as a regular cast member. Mother to Edina and Gran to Edina’s daughter Saffron (aka Saffy) (Julia Sawalha), in the context of this discussion, she is a minor character who exerts a major impact.

Gran lives elsewhere by choice but is a regular presence in the Monsoon home. Tapping into the pervasive stereotypes of older people in popular culture, she is often depicted in cardigans and sensible shoes. She is typically positioned in the background performing mundane domestic tasks or busying herself with knitting and other conventional activities associated with older people. In equally stereotypical fashion, she refers to everyone as ‘dear’ and regularly opines on ‘how much things have changed since my day’ (*Absolutely Fabulous*, 1992). Gran displays recognizable symptoms of Alzheimer’s disease including short term memory dysfunction (“It’s funny how you can lose things and not know where they’ve gone’), word finding difficulties (‘chapaccino’) and loss of executive function - she frequently starts a task, gets distracted and doesn't complete it (*Absolutely Fabulous*, 1992).

Variously referred to as ‘dotty’, and ‘senile’ by other characters, Gran is treated with hostility and contempt by Edina and detached courtesy by Patsy. In keeping with the series’ misanthropic tone, Edina complains about her endlessly, referring to her mother within hearing as ‘that thieving old person’ (Gran ‘donated’ various household items to the op shop) and a ‘burden ’ (*Absolutely Fabulous*, 1992). Edina suggests at one point that she is ‘junk’ and should trade herself in and in the feature film maliciously suggests having a lethal injection rather than the travel vaccinations Gran is contemplating (*Absolutely Fabulous*, 1992). Gran has a close relationship with Saffy and while she is kind and supportive of her grandmother, Saffy is at times visibly frustrated by Gran’s short-term memory dysfunction and the contribution this makes to the household atmosphere of domestic anarchy.

Despite her clear cognitive impairment, Gran holds her own in a completely dysfunctional and chaotic family setting, the dynamics of which would challenge the most robust and cognitively intact older person. Apparently oblivious to Edina's endless insults, Gran makes regular asides, often satirical in content, delivered sotto voce and identifying her daughter's numerous failings. Many of these rely on Gran's excellent long-term memory, correct Edina's distorted recall of her childhood and reveal entertaining and salacious details of family history. Gran's wit, intelligence and mischievous personality owes more than a little to Cracknell's Maggie Beare in *Mother and Son*, a matrilineal TV heritage that arguably also encompasses the charismatic, cognitively impaired Grandma Yetta in *The Nanny*.

Gran is a significant presence in the Monsoon household and communicates an affirmative message about dementia to a broad audience. A healthy and active older woman (she is depicted playing tennis in the feature film), Gran plays an important role in the family. Despite Edina's appalling treatment, and what appears to be wilful ignorance about dementia from most of the people around her, Gran functions as the family facilitator. She is the only source of genuine emotional support for Saffy as she experiences major life course events (the birth of her first child and the death of her grandfather, Gran's husband). Gran provides a buffer for the endless animosity between Patsy and Saffy and at times moderates the competing demands of the outrageously narcissistic personalities that make up Edina's extended family.

Gran's character and situation is instructive as a teaching resource in the residential aged care sector. Her symptoms are suggestive of AD and are often the target of humour. However, as with the family elders in the feature films discussed above, Gran's intact long term recall means she is the repository of family history and an important intergenerational link. Throughout the series and in the feature film, Gran retains agency and a well-preserved sense of identity. As Käll has argued, this kind of affirmative representation of the lived experience of dementia can exert a significant 'affective power' on the viewer (Käll, 2015, p. 268).

Gran's flexibility in adapting to the chaotic environment in the Monsoon family home also demonstrates what Allen Power has argued is the problem solving approach that people living with dementia constantly employ to negotiate the changes in their own cognitive function and the physical and social environment around them. ' … people with dementia continue to learn new information, incorporate data, and use problem solving skills to adapt to their changing perceptions' (Power, 2014, p. 20). Gran's example offers an opportunity for concept acquisition in relation to Power's key contentions. Drawing on his redefinition of dementia as ' a shift in the way the person experiences the world around her/him …', aged care staff could be encouraged to explore Power's experiential model of dementia in relation to Gran's responses to her situation and others around her (Power, 2014, p. 19). This in turn offers a valuable way of considering how the complex social and physical demands of the residential aged care environment offer similar challenges for people living with dementia requiring an approach from aged care staff that similarly supports identity, agency and autonomy.

Angry Boys

Angry Boys is an Australian comedy series presented in a faux documentary or 'mockumentary' style and features a 'Gran' of a rather different kind. Written by Chris Lilley, it purports to explore the attitudes, influences and aspirations of boys in contemporary Australia. An ABC/HBO co-production, the series showed initially on the ABC and was syndicated widely in international markets including the US, UK, New Zealand and Europe. *Angry Boys* features six very different central characters with distinct storylines, all of who are brought together in the last of series' 12 episodes. Chris Lilley plays all six characters, including Ruth Sims, referred to throughout as 'Gran'. The foul-mouthed, overtly racist 65 year-old youth detention officer and grandmother to twins Nathan and Daniel (also played by Lilley), is arguably the most politically incorrect of all Lilley's characters. In charge of a group of socio-economically and ethnically diverse young men in detention for various offences, Gran's particular brand of tough love manages to stereotype, stigmatize and potentially offend every one of the young men in her charge.

As with feature films such as *Friends with Benefits*, the show's global reach is an important consideration in terms of its potential impact and is worth outlining in detail here. On its ABC TV release, *Angry Boys* was the most popular 2011 program for the national broadcaster, went to the top of the worldwide Twitter trend list ('Gran' was one of the two top trending topics) and the show's Facebook fan page attracted over 70,000 fans (Ross, 2011). The series attracted a mixed critical reception but excellent ratings and it subsequently sold well internationally as noted above. In addition to free-to-air rights and DVD sales, the show has been released on several streaming platforms (it remains on Netflix). Numerous excerpts, individual scenes, series highlights and character compilations are also available on YouTube including many profiling Gran's character, one of which ('Tough Love') has attracted in excess of 400,000 views. Given the MA 15 + content, the series was aimed at a mature audience but as indicated by the viewing and social media statistics above, appealed to and attracted significant numbers of young male viewers, indicating that the overall audience reach was broad.

In the introductory episode, Gran takes obvious pride in her ability to control the most violent of the inmates through abuse and intimidation. 'The boys fear me, they're frightened of me and I can be a real fucking cow if I need to be '(*Angry Boys*, 2011). The boys describe her as a 'racist old bitch' and appear to be fond but wary of her; her colleagues observe she is 'a mother figure for these boys' but has a 'habit of crossing the line' (*Angry Boys*, 2011).

The first seven episodes establish Gran as a singular and uncompromising character whose only indication of vulnerability is her obsession with guinea pigs and soft spot for one of the frequently bullied boys (Talib). In episode eight, her boss's brief joke about her 'shocking memory' is followed up later in the episode by Gran's revelation to Talib that she has been diagnosed with AD. As Gran describes it, AD is a 'disease of the brain where you get very silly and forgetful…you get more and more forgetful until you forget everything ... it can be quite funny sometimes' (*Angry Boys*, 2011). When Talib responds by asking whether 'they can fix it' Gran replies with equanimity 'no, but that's ok' (*Angry Boys*, 2011). Subsequent episodes reveal Gran's diagnosis forces her to resign and move away from her 'special friend' Penny to live with her family including Nathan and Daniel.

Gran's short but compelling exchanges about her diagnosis with Talib, her boss, Penny and her grandson Daniel represent the most genuinely moving scenes in a series that as the title suggests, offers a concertedly abrasive and discomfiting exploration of disenfranchised masculinity and humanity. ' … when she revealed she was suffering from the early onset of Alzheimer's disease and would soon lose her job, which was clearly everything to her, it was heartbreaking' (O'Neill, 2011). Gran's Skype conversation with Daniel is particularly revealing. Her grandson's understanding of AD is basic: 'It's like when you forget shit … you seem normal … but do you remember my name?' (*Angry Boys*, 2011). Despite his limited grasp of AD, Daniel's close relationship with his grandmother means his support for her is steadfast and he is surprisingly forgiving when her forgetfulness causes a potential disaster with a long planned for and much anticipated party.

The few brief scenes that deal with Gran's AD make a potentially valuable contribution to an audience's understanding of her condition. Gran's description of and reaction to her diagnosis, and the response of others around her is a realistic reflection of the limited understanding about dementia that persists in the broader community. As with the notable change in Dylan's response to his father in *Friends with Benefits*, these scenes in *Angry Boys* offer an understated but powerful assertion of the way in which knowledge and experience of dementia can encourage a change in attitudes and perceptions. This is not unlike the effects observed on a young adult cohort in Steven Sabat's 2012 study. Daniel's blunt but supportive observations about his grandmother indicate that attitudinal changes and increased insight can be wrought through personal contact and improved understanding of the lived experience of dementia. 'I thought she'd be really sick and dribbling and shaking and stuff but she's alright so far' (*Angry Boys*, 2011). As Gran herself notes, 'I think the family thought I was going to be much more of an invalid that I am…I'm forgetful but I'm certainly no invalid' (*Angry Boys*, 2011).

Gran's politically incorrect and combative personality somehow makes the revelation of her diagnosis and change of circumstances even more poignant. For both a broad audience and the aged care workforce, Lilley's restrained script offers additional insights into the significant consequences of AD. Gran's forced retirement and relocation and the impact on her sense of identity is made clear. Lilley underlines the importance of maintaining that sense of identity and emotional wellbeing through social networks. In the penultimate episode, Gran is shown staying in the touch with 'the boys' and Penny via Skype. This point is made even more tellingly in the final episode by Gran's uncharacteristically emotive observation about moving home to live with her family: 'When you're lost, you turn to family…I feel like I am in a safe place' (*Angry Boys*, 2011).

As a teaching resource, *Angry Boys* raises a number of issues around the impact and consequences of a dementia diagnosis. Gran's experience with AD offers useful discussion points for residential aged care staff including how best to support a person (and their family) following a diagnosis of dementia. Exploring Gran's feelings of grief and loss in relation to changed circumstances and the impact on her self-identity and emotional wellbeing could be used to consider the analagous situation for individuals with a dementia diagnosis experiencing the transition to residential aged care.

Conclusion

The examples discussed in this chapter illustrate the way in which mainstream films and TV episodes that reference dementia in a brief or minor way can have a significant influence on a broad audience. All of the texts discussed in this chapter had considerable global commercial success, and in some cases significant social media impact, indicating the potential breadth of influence of their respective representations of dementia. Equally and despite the brevity of the references, in highlighting a series of dementia-related issues, these texts are useful as teaching resources for educating the residential aged care workforce.

In the short amount of screen time devoted to scenes dealing with dementia in *Friends with Benefits*, the film canvasses a series of significant issues with considerable insight. Amongst other concerns, *Friends with Benefits* foregrounds the complex demands of the caregiving role, contrasts the responses of different family members to dementia, illustrates the importance of a genuinely person-centred approach to care, depicts the impact of the social and physical environment on wellbeing, and most significantly, demonstrates how the central character develops empathy and insight into the frustrations and challenges his father experiences living with dementia. The depictions of dementia are even more cursory in *Billy Elliott* and *Gone Girl* but both films also offer opportunities to explore influences on wellbeing and illbeing and in particular, the importance of the social environment for the person living with dementia.

Two TV comedy series featuring grandmothers as minor characters provide contrasting but equally valuable learning opportunities on the small screen. Key ideas and concepts around a person-centred approach to care and Power's experiential model of dementia can be explored through the characters and situations depicted in *Absolutely Fabulous* and *Angry Boys*.

The analysis in the next chapter details the way in which films and TV series that deploy dementia as a dramatic device offer more detailed opportunities for educating a broad audience in relation to the role of the caregiver. These texts also have clear educative potential for the residential aged care workforce in relation to the way they engage with the central ideas and concepts underpinning the principles of a person-centred approach to dementia care.

CHAPTER 7: DEMENTIA AS DRAMATIC DEVICE

Introduction

In terms of absolute numbers of texts, Dementia as Dramatic Device is the largest of my three typologies and comprises film and TV texts that employ dementia in what I characterize as primarily a dramatic device. In these texts, dementia is deployed as a catalyst to foreground issues or concerns within the wider family. As noted in the literature review, and unsurprisingly given the relative numbers, these texts have attracted the most concerted scholarship (Chivers, 2011, Gerritsen, Kuin & Njiboer, 2013, Gravagne, 2013, Zeilig, 2014 and Swinnen, 2015). As the typology's designation suggests, drama dominates, with most feature film and TV examples falling into this generic category but there are also a small number of outlier examples in the comedy, action/adventure and thriller genres.

In this typology, dementia is frequently explored in considerable detail, including depictions of symptomatology, diagnostic tests, and treatment and care options. A wide range of issues and themes are addressed including the challenges and rewards of supporting a person living with dementia, determining decision-making capacity, community versus residential care options and end-of-life care. These concerns are typically explored from the point of view of a spouse, family member or informal caregiver. The question posed in the introduction to this thesis and addressed in this chapter is: how might this particular typology make a contribution to improving understanding about dementia in relation to the experiences of carers, spouses and family members for a broad viewing audience and the residential aged care workforce?

Typical Scenarios Of Carers And Caring

' … the perspectives of carers are a fully legitimate subject for cinematic treatment and exploration, with the potential for rich insights into how they may respond to the often intense dilemmas and pressures they face' (Orr and Teo, 2015, p. 83)

A recurring theme in this typology is the ailing parent and the resulting drama for adult children required to make decisions about treatment and care, including taking on the direct care for their parent. Prominent examples include the feature films *What They Had, The Savages*, *Happy Tears*, *Hanging Up*, *A Time to Remember* (2003) and two TV mini-series *After the Deluge* and *Exile*. Feature films that situate dementia as the catalyst for a drama involving other family members including spouses include *Speed of Life* (Schmidt, 1999), *Sundowning* (Cole, 2005), *Diminished Capacity,* Iris, *Away from Her*, *Lou* (Chayko, 2010), *Still Mine* (2012), *Angel's Perch* and *Head Full of Honey*. *Iris* and *Away from Her* are also significant for the amount of screen time they devote to the perspective of the person living with dementia and therefore also feature in the discussion in the following chapter. Familial tensions of various kinds, triggered by the presence of dementia, are also prominent in the historical drama *Convicts* (Masterson, 1991), black comedy *Choke* and dramedies *Barney's Version* (Lewis, 2010) and *Win, Win* (McCarthy, 2011).

Dementia is also commonly deployed as a dramatic device to either retrospectively recount a youthful romance (*The Notebook,* Cassavetes, [2004]), or position an older person with the illness as the backdrop for a contemporary romance (*Aurora Borealis*, *The Good Life*). Dementia is a catalyst for action in a variety of other scenarios including sci-fi action/adventure storylines (*The Rise of the Planet of the Apes*, Wyatt, [2011]), road movie/melodramas (*Nebraska*, 2013 and *The Leisure Seeker*, Virzì, [2017]), historical mystery/dramas (*Mr Holmes*, Condon, [2015]) and ensemble dramas set in residential aged care (*Quartet*, Hoffman, [2012]). Dementia drives characters and plotlines in varying degrees of significance in a wide range of TV genres include comedies (*Getting On*), dramadies (*Derek*, Gervais, [2012 – 2014]), soap operas (*Coronation Street*, Warren, [1960 -], *Neighbours*) and crime and political dramas (*The Sopranos*, *The Fear* and *The West Wing*).

Getting the Picture

DVD poster designs offer a simple but revealing insight into the way in which the concerns of characters other than the person with dementia are the focus of these narratives. Poster designs overwhelmingly foreground spouses, siblings or significant others, offering a transparent illustration of where the central narrative and emotional focus lies. The character with dementia is rarely included in the overall composition and when they are, their presence is minimized. *The Savages* is the clearest example; the DVD cover design composition positions the character with dementia seated and facing away so his expression cannot be seen. His two adult children stand either side of him facing towards the viewer.[2]

Unlike the preceding typology, with a few exceptions, the marketing material associated with texts deploying dementia as a dramatic device either intimates or makes apparent that ageing, dementia and associated issues will be explored. 'Sometimes what you lose is not as important as what you find' (Tagline, *Diminished Capacity*). 'Still Devoted. Still Determined' (Tagline, *Still Mine*). 'Sometimes the longest journey is the one that leads you home' (Tagline, *Angel's Perch*). In choosing to watch these films or TV series, viewers would reasonably be expecting to encounter the subject of dementia in some form on screen.

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[2] *The Savages* DVD cover can be viewed here: https://upload.wikimedia.org/wikipedia/en/6/69/SavagesFilmPoster.jpg

Critical Perspectives

Chapter Three outlined the way in which mainstream media stories about the personal experience of dementia were overwhelmingly presented from the perspective of carers or family members and rarely from the point of view of the person living with the condition (Kirkman, 2006). The preponderance of film and TV narratives that privilege the perspective of family members and carers - typically the demands, challenges and the 'burden' of care they experience - is an equally persistent focus of scholarship in the field. Swinnen argues that emphasis on the carer's perspective is the dominant trope in dementia-related narratives in mainstream films (Swinnen, 2015). Cohen-Shalev and Marcus observe that cultural discourses on AD have ' … consistently shifted attention away from the individual ''patient'' to the plight of the caregivers, paying little attention to the experience of living with this condition' (Cohen-Shalev and Marcus, 2012, p. 74). They go on to note that mainstream films including *Away from Her* and *The Savages* are more interested in the selfhood of the carers than that of the person living with dementia (Cohen-Shalev and Marcus, 2012). Chivers' detailed analysis of *The Savages* surmises that the film and others like it portrays a 'horrifying loss of self' for the person with dementia in order to ' …magnify the self explorations it enables in surrounding characters' (Chivers, 2011, p 73).

Where these analyses have been critical of the emphasis on characters other than the person with dementia, my focus in this chapter is on the potentially positive contribution to the improved understanding of dementia that the characters, storylines and approaches to care explored in these texts can make. As Käll has argued, films such as *The Savages* suggest a way of reframing our thinking about depictions of dementia on screen as not necessarily concerned with judgements about ' … what is good or bad conduct, of autonomy, respect and responsibility…' (Käll, 2015, p. 270). Rather, these films – and others that are the focus in this chapter – foreground and interrogate these issues as part of an ongoing discourse about how dementia and associated issues around care and caregiving is understood.

For both a general audience and the aged care workforce, presenting the perspective of a family member or carer could offer valuable insights into a range of issues around how best to support a person living with dementia. For viewers with experience of or knowledge about dementia, at least part of the appeal of the subject matter or storyline in these films and TV series might plausibly be precisely *because* they engage with the topic. These texts could arguably resonate with or reflect their own experiences – as spouses, partners, family members and informal caregivers. The narratives, characters and situations depicted might explore issues they have encountered, provide insights into analogous situations and offer a powerful means of engagement with their own lived experiences. Equally, if a viewer does not have prior knowledge of or experience with dementia, these texts could make a contribution to improving understanding of the condition, and the challenges and rewards of supporting someone living with dementia.

The texts that are the focus of this chapter address a series of dementia-related issues specifically from a carer's perspective and have a clear application in the context of educating the residential aged care workforce. They provide potentially valuable insights into dementia more broadly and address a range of approaches and care practices that provide fertile territory from which to explore issues around best practice dementia care in a residential aged care setting.

The Exemplar: *The Savages*

As indicated above, *The Savages* has been the focus of scholarship in the cultural gerontology area in relation to its depiction of dementia and exploration of the consequences for family members other than the person living with the condition (Chivers, 2011; Cohen-Shalev and Marcus, 2012, Swinnen, 2015 and Shary and McVittie, 2016). As a paradigmatic text for this typology, the way in which dementia functions as a dramatic device in *The Savages* will be briefly discussed in order to contextualize the texts that constitute the focus of this chapter.

A modestly scaled independent film, *The Savages* explores the fraught relationship between Jon Savage (Philip Seymour Hoffman) and his sister Wendy (Laura Linney) as they struggle to decide on care options for their recently widowed and increasingly cognitively impaired father Lenny (Philip Bosco). The film confronts the impact of dementia on a small, dysfunctional family in unflinching fashion. The film's central dramatic focus is on the longstanding tensions between the two siblings; Lenny's illness and urgent need for dementia care amplifies these tensions. Jon and Wendy's conflicting ideas about Lenny's dementia, what constitutes appropriate care for him and the contrasting ways in which they confront his impending death reveal their temperamental differences and deeper antipathies.

Where one analysis has taken issue with the film's refusal to represent Lenny's perspective and affirmation of ' … what Gen X will gain when freed from the burdensome demographic of the boomers …', I would argue that *The Savages* offers viewers bleak but compelling insights into the often complex and difficult realities of supporting a family member living with dementia (Chivers, 2011, p. 72). As another analysis noted, that the film even addresses residential aged care, including the very real financial implications, is noteworthy. ' The film covers contemporary eldercare routines that most Americans experience yet virtually never see portrayed in popular media'

(Shary and McVittie, 2016, p. 194). The feature films and TV series that are the focus of this chapter develop and expand on the insights offered by *The Savages* on a range of issues around the support and care for a family member living with dementia.

Heads Full Of Honey And Other Metaphors: The Key Texts

The discussion in this chapter will focus on two feature films (*Head Full of Honey* and *What They Had*) and two TV series (*Exile* and *The West Wing*). The two feature films have clear narrative and dramatic similarities with other films in this typology and engage in contrasting ways with a range of issues around how best to support a person living with dementia. The films address dementia from the point of view of adult children, a spouse and a granddaughter, with each text bringing different perspectives accordingly. Both films were released in 2018 and given their respective significance, support the contention that filmmakers are producing increasingly well-informed and constructive depictions of dementia. The two TV texts situate the depiction of dementia within the context of a broader political drama and make significant contributions in their respective examination of issues around familial roles and responsibilities in support of a family member with dementia.

What They Had is a classic example of the typology. As one reviewer notes: ‘Ruth isn't the central character, and her disease is not the focal point; this is a film about a family in crisis, a crisis precipitated by Ruth's illness, but fuelled by their own personal problems’ (Bertaut, 2019, para. 3). Ruth (Blythe Danner) is 60 years old and has been living with dementia for eight years but the recent progression of her symptoms brings family members together to decide on how best to support her. Ruth’s devoted husband Burt (Robert Forster) is adamant that Ruth is not going into residential care. Son Nick (Michael Shannon) is equally insistent that that is the best place for her while daughter Bridget (Hilary Swank) is equivocal, torn between the conflicting opinions of her domineering brother and father. Chomko's nuanced and acutely observed analysis of the impact of dementia on the extended family reveals long standing emotional fault lines amplified by the crisis of care. As the most recent release included in this typology, the film is significant for its restrained depiction of Ruth's progressive decline and her own response to it (an interesting counterpoint to the florid equivalent in *Head Full of Honey*) and sensitive exploration of the contrasting responses and coping strategies of individual family members.

A remake of the original 2014 German film Honig Im Kopf (Schweiger, 2014) which translates as 'honey in the head', the US feature film *Head Full of Honey* (Schweiger, 2018) is a valuable text in a number of respects. Unusual in the films selected for this thesis, it has a young protagonist whose voice-over and perspective on AD provides the central focus. Matilda's (Sophia Lane Nolte) close bond with her recently widowed grandfather Amadeus (Nick Nolte) becomes more intense when it is clear that what has previously been regarded as Amadeus's eccentricities are signs of significant cognitive impairment. Amadeus's confusion, word finding difficulties and loss of executive function escalate into verbal aggression, combativeness and behaviour that potentially endangers him and others. Matilda is the family member who best understands his increasing frustration and takes the initiative in improving his quality of life. A series of health professionals deliver well-informed advice about how best to support a person living with dementia, effectively setting out some of the fundamental principles of a person-centred approach to care. Matilda's endeavours to put these into practice to improve her grandfather's wellbeing make *Head Full of Honey* a singular contribution to this typology.

Both examples from the small screen situate dementia within a specific political context. A three-part BBC TV series, *Exile* (2011) deploys dementia explicitly as a dramatic device. A retired newspaper editor with advanced AD holds vital information about past political corruption if only his son, a jaded journalist with a fraught relationship with his father, could extract the information from his long-term memory. A gritty hybrid of investigative thriller elements, traditional political intrigue and family melodrama, *Exile* details the complexities and consequences of AD in a nuanced fashion. The series is valuable for the way it depicts the experience of dementia from multiple perspectives and the considered way it articulates the primary carer's learning curve in responding to the changing needs of the person living with dementia.

Entitled 'The Long Goodbye', episode 13 of the fourth season of *The West Wing* (Graves, 2003) also deals with AD. The self- contained episode features White House Press Secretary C.J. Cregg's (Alison Janney) return to her hometown of Dayton, Ohio for a school reunion and to visit her retired mathematician father. Her father's AD has clearly progressed significantly; the family house is in disarray, his wife has left him and as C.J observes, he is '… going to require care' (*The West Wing*, 2003). In the 42-minute running time, the episode is comprehensive in its coverage of clinical assessment, treatment and care options. Issues around balancing dignity, independence and risk for the person living with dementia are also explored in detail. The episode is notable for its dispassionate exploration of the rights of the person living with dementia and equally, the complex issues involved for those supporting them.

Feature Films

What They Had

As noted in the introduction to this thesis, a number of the texts selected for inclusion are inspired by the filmmakers' personal experiences of immediate family members living with dementia. Writer/director Elizabeth Chomko's first feature length film is based in part on her observations of her grandmother's experience with dementia. Ruth's declining cognition is the catalyst that exposes long family standing tensions allowing Chomko to explore a range of responses to her current and future care needs.

The film opens dramatically with Ruth leaving the house in the middle of the night and wandering the freezing Chicago streets alone. The family responds quickly; Bridget and her recalcitrant daughter Emma (Taissa Farmiga) fly in from California and meet Bert and Nick at the hospital. They are immediately confronted with the realities of Ruth's increased confusion; she has undergone a gynaecological examination to exclude the possibility of sexual assault. As with Grandma in *Billy Elliot* and Bill in *Gone Girl*, it is clear that this is not the first time that Ruth has left the house and become lost (though as Nick later points out, her direction was purposeful in that she was endeavouring to find her parents and was eventually found riding the train line to her childhood family home). The doctor treating her sums up the situation and quickly moves the discussion on to the advisability of care in a memory support unit. As she dispassionately observes, 'they are often better in a memory unit…they do better among their peers strange as it might sound' (*What They Had*, 2018). The linguistic import of the marginalizing use of 'they' and 'peers' to describe residents living with dementia (even if unintentional) is not lost on the family. The doctor's recommendation of residential care sets in train a protracted and at times bitter family dispute about Ruth's care needs that extends for the entire length of the film.

The basis of Bert's refusal to countenance residential care is two fold. He notes that Ruth herself '… spent 30 years working in one [nursing home] and they're horrible' (*What They Had*, 2018). He equates a memory care unit with 'lock down' and describes the residents as 'a bunch of loons' (*What They Had*, 2018). Bert argues he has cared for Ruth for the eight years since her diagnosis, and in a memorable line worth quoting here in full, asserts that his approach to care is better than anything that could be provided in an institutional setting. 'I'm the best memory care in Chicago. I bathe her, I feed her, I give her her memory pills, I wipe her arse. I am better than some aide who doesn't know who she has spent 60 years becoming' (*What They Had*, 2018).

Several scenes, some of the most moving in the film, attest to his devoted care from frantic searching of the freezing streets at night to his meticulous painting of her toenails. While a devoted husband and committed primary carer, Bert's domineering personality has clearly wielded a significant influence over the lives of his wife and children, an influence that becomes even more apparent when decisions must be made about Ruth's future care. Bert's well-intentioned but ultimately paternalistic method of direct care is informed by his devout Catholicism and military career, and associated notions of loyalty and service. He is dismissive of contemporary knowledge about dementia ('stages are horseshit…') and the benefits of residential aged care (*What They Had*, 2018). Bert's approach is guided by what he believes is in his wife's best interests and not necessarily informed by what Ruth's preferences and care needs might actually be. This replicates a traditional attitude to care that is proprietorial rather than person-centred and is neatly symbolized in his angry and impassioned declaration to his children: 'She's my girl; you can't take her away from me' (*What They Had*, 2018).

As the adult child helping care for his mother, Nick's role is one typically reserved for – on screen and in real world statistics – the adult female children of the family. ' … the largest proportion of family caregivers of persons with ADRD [Alzheimer's disease and related dementias] are adult daughters' (Gaugler, Jutkowitz, Peterson and Zmora, 2018, p. 690). Nick supports his father and is closely involved in Ruth's care. As he himself notes, he is the one who ' … gets the calls in the middle of the night and has the geriatrician on speed dial' (*What They Had*, 2018). Not unlike Jon in *The Savages*, Nick takes a pragmatic view of the care his parent needs and unlike his father, this includes an understanding of the benefits of residential aged care. Nick has done his research, pulled a few strings in the 'assisted living' sector and bluntly pushes his father and sister to agree to Ruth's admission to the tweely named Reminiscence Neighbourhood facility. His pragmatism is evidenced in one of many beautifully understated and humorous moments in the film. The family attend a church service and when Emma points out that Ruth has drunk the Holy Water, Nick dryly observes, 'at least she's hydrated' (*What They Had*, 2018).

Bridget is clearly conflicted about everything – her daughter, her marriage, her relationship with her father and Ruth's future care needs. Emotionally close to her mother but geographically removed from the family in recent years, she has been less directly involved in Ruth's care than her father and brother (a point Nick ensures she is made well aware of). Bridget is affectionate, supportive and intuitively attune to her mother's needs. In one of the most restrained but revealing scenes in the film, mother and daughter discuss Ruth's future. When Ruth asks Bridget directly 'Should I be in a home?', rather than answering prescriptively, Bridget responds simply and respectfully with 'What do you think?' (*What They Had*, 2018). Resentful of her brother's bullying approach to family decision-making, Bridget is nevertheless gradually persuaded of the merits of residential aged care. With the death of her father toward the end of the film, Bridget is shown accompanying Ruth back to her aged care facility. Ruth enters the facility willingly and is warmly embraced by a carer.

The contrast in sibling personalities and conflicting opinions about Ruth's needs continues a consistent theme in the typology that plays out in films including *Nebraska*, *The Savages*, *A Time to Remember* and *Happy Tears*. Unlike the dysfunctional parent and child dynamics in those films, Nick and Bridget both have a close relationship with their mother; decision-making about appropriate care is complex and contested but not underpinned historical antipathies. *What They Had* indicates an interesting development in discourses on caring in this typology in several respects. Chomko's more expansive depiction of the issues represents a progression from earlier films that focus predominantly on sibling conflicts (*The Savages*, *Happy Tears*, *A Time to*

Remember) or spousal perspectives (*Still Mine*, *Iris*, *Away from Her*, *The Leisure Seeker*). *What They Had* incorporates a considered exploration of sibling differences about Ruth's care needs and a depiction of Bert's caregiving.

Equally significantly, where Chivers and others are critical of films including *The Savages* for effectively silencing the person with dementia, Chomko ensures Ruth's perspective is consistently acknowledged (Chivers, 2011; Cohen-Shalev and Marcus, 2012). These differences are neatly symbolized in the marketing images for both films. Where *The Savages* marginalizes Lenny in both the DVD design and the film, the DVD poster design for *What They Had* gives each individual in the family group equal compositional weight. Interestingly, all are facing away from the viewer. [3] The first 30 minutes of Chomko's film are dominated by the voices and on screen presence of other family members, but from that point on and despite word finding difficulties, Ruth's voice is heard. She is present at everyday and important family gatherings, often leavening potentially tense discussions about her future with humour, even if at times inadvertently. Ruth's important exchange with Bridget about residential aged care represents the most explicit acknowledgement of her perspective.

For both a general audience, *What They Had* offers valuable insights into the challenges involved in supporting a person living with dementia. The physical and emotional demands of providing care have an impact on Bert's health, highlighting the very real issue of carer 'burnout'. In this respect, the film shares similarities with several films that predate it including *Iris* and *Still Mine,* where the role of the spousal caregiver constitutes the dominant focus.

Bert's situation attests to the reality of significant health impacts on spouses caring for partners with dementia as evidenced by recent research findings

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[3] The DVD cover design for *What They Had* can be viewed here: https://www.imdb.com/title/tt6662736/mediaviewer/rm250103040

(Etters, Goodall and Harrison, 2008; Brodaty and Donkin, 2009; Gaugler, Jutkowitz, Peterson and Zmora, 2018). The complexities of decision-making on future health care needs for a family member living with dementia, including the merits of home based versus residential aged care, are explored in equal detail. The film could engage an audience on these issues, regardless of their degree of personal experience or knowledge of dementia, as evidenced by viewer reviews.

> As a family member who is experiencing this scenario with a parent and a very close aunt I can say it is very representative of the feelings and maybe guilt family members experience about the decision to confine them in a facility (Houchin, 2019).

'Just as in my family situation in the past. Each child has a different viewpoint when it comes to an aging parent with health issues' (Potten, 2019).

'It was touching and heartfelt. I don't have personal experience with dementia and alzheimers but it was moving to see how it was portrayed on screen' (Kharrazi, 2019).

For the aged care workforce, the film offers equally valuable opportunities to reflect on the impacts of Ruth's cognitive decline on individual family members and how each has a different approach to dealing with the situation. Bert, Nick and Bridget are all 'carers' who conceptualize the idea of care somewhat differently. Bert's belief that he alone can provide optimal care reflects a situation often encountered following admission of a family member to a residential aged care facility. Lack of consensus and internal family conflict about decision-making on treatment and care options are also familiar scenarios for aged care staff. The film offers the opportunity for perspective taking and reflective discussions that could compare and contrast the respective responses and consider the associated issues, including the debate around the merits of residential care. *What They Had* is valuable text for prompting discussions about how to negotiate these issues and act as advocates in achieving the best possible care outcomes for the individual living with dementia.

Head Full of Honey

'I think I understand how grandpa feels…don't worry too much about the future…just about what's going on right now…' (*Head Full of Honey*, 2018)

As noted above, *Head Full of Honey* is unlike other films in this category in having a youthful protagonist – the grandchild of the character with dementia – in the central caring role. Matilda's voice-over in the opening scene directly addresses her grandfather's diagnosis of AD and asserts her point of view as the dominant perspective in the film. Subsequent scenes quickly establish that her recently widowed, retired veterinarian grandfather is unable to keep living alone given the squalor of his rural American home and his propensity to keep loaded guns lying around the house. When Amadeus moves with Matilda, his son Nick (Matt Dillon) and daughter-in-law Sarah (Emily Mortimer) to London he becomes increasingly confused and frustrated. Disastrous attempts to help with the gardening (he demolishes part of a prize hedge) and cooking (the kitchen is nearly incinerated) and the unwitting sabotage of a lavish garden party follow. This in addition to Amadeus's increasingly disinhibited behaviour (urinating in the fridge, leering at younger women) causes increasing friction between Nick and Sarah. Sarah is openly unsympathetic towards Amadeus but interestingly, more aware than Nick of his probable diagnosis and their need for support. 'He's got Alzheimer's or something…we can't manage on our own…we need help.' (*Head Full of Honey*, 2018). A consultation with the medical profession eventually results in a diagnosis of AD and discussions about progressive decline and the need for residential aged care.

While Nick does his best to support Amadeus, Matilda demonstrates more initiative and insight into her grandfather's situation than either of her parents. Where Nick dissembles - 'old people get confused … he'll settle down' - Matilda consults her own doctor about Amadeus's condition in an attempt to genuinely understand what he is experiencing (*Head Full of Honey*, 2018). It is in these scenes that some of the film's most considered observations about dementia are communicated. Dr Edwards (Jake Weber) draws on the metaphor of the bookshelf-as-brain to explain AD; books gradually fall over and then off the shelf signifying a gradual loss of information as with Amadeus's progressive decline in cognitive function.

This is a reasonable enough analogy for an 11-year old to grasp, but when Matilda asks what she can do to 'make him better', Dr Edwards really spells things out. He suggests when Amadeus says or does things that seem odd, Matilda should respond 'as if that makes perfect sense to you ... step inside his world…that will help him' (*Head Full of Honey,* 2018). It is a proposition Matilda enthusiastically embraces. She observes and listens to her grandfather attentively, entering into his reality, whether that involves following his lead in sabotaging the rules of a board game, smearing his face with Aioli in a restaurant or revisiting happy memories of his wife Margaret.

The GP's emphasis on 'stepping inside the world' of the person with dementia and responding respectfully to their words and actions conforms precisely with Kitwood's seminal observations. Adopting the perspective of the person with dementia and attempting to understand the world from their point of view fundamentally underpins Kitwood's person-centred approach to care. As Dawn Brooker notes:

> Look at the world from the perspective of the person with dementia, recognising that each person's experience has its own psychological validity, that people with dementia act from this perspective, and that

> empathy with this perspective has its own therapeutic potential (Brooker, 2007, p. 63).

To my knowledge, this is the first instance where the fundamental principles of person-centred dementia care are clearly outlined in a mainstream English language film or television text in the time frame encompassed by this thesis. The idea of stepping inside the world of the person living with dementia underpins best practice dementia care and is a vital concept for an audience to hear (and see) articulated on screen. Despite the film's limitations, this makes *Head Full of Honey* a critical text for this typology.

Dr Edwards's crucial advice is followed by an equally important observation about giving Amadeus 'things to do that make him feel needed and useful', echoing Amadeus's own, earlier insistence that he would only move to London if 'I have something to do' (*Head Full of Honey*, 2018). In addition to the importance of engaging in activities that are personally meaningful, Dr Edwards also emphasizes the preservation of long-term memory in AD and the positive role memories can play in enhancing emotional wellbeing. This forms the basis for Matilda's subsequent actions – a care plan of sorts – to encourage Amadeus to reminisce. She and her grandfather regularly look through his photo album and talk about people and places from his past. Matilda films him talking about his life 'so when he forgets…he'll really like to watch these videos' (*Head Full of Honey*, 2018).

The discovery of a notebook Margaret created – with image and word prompts about key people in Amadeus's past and present life – suggests Margaret was cognizant of his probable diagnosis and provides another reminiscence tool for Matilda to engage her grandfather with. Finally, Matilda's evolving understanding of the importance of memory prompts her to plan her most daring intervention - a trip back to Venice, the location where Amadeus has his most vivid and meaningful memories of married life. While the trip itself is inevitably problematic, this ambitious attempt to support her grandfather's emotional wellbeing by 'stepping inside his world' conforms unequivocally with the principles of a person-centred approach.

This emphasis on adopting the perspective of the person living with dementia is also underscored consistently through interactions with other characters. When Amadeus attempts to file a missing person's report about his wife, a young policewoman in the busy police station listens attentively to his account (an interesting contrast with analogous scenes in *Gone Girl*). A waiter's intuitively calm and sympathetic approach helps alleviate Amadeus's confusion and distress during birthday celebrations in a noisy and chaotic restaurant (again, offering an interesting contrast with a similar scene in *Friends with Benefits*). In one of the more improbable sequences during the trip to Venice, Amadeus's anguished nocturnal search for Margaret draws empathy and understanding from a community of nuns.

Viewers are provided with further insights into how to best support someone living with dementia through the insights and advice from a series of health professionals. In addition to the contributions from Dr Edwards, the film includes several consultations with geriatrician Dr Holst (Eric Roberts). His assessment of the uncooperative Amadeus and advice to Nick is frank and compassionate. 'Caring for someone with dementia is a full-time job and it's not easy…' (*Head Full of Honey*, 2018). Holst's emphasis on being realistic about the challenges of supporting Amadeus at home and the need for future residential aged care is framed in the context of his own father's experience with dementia (*Head Full of Honey*, 2018). The short exchange between the two men is made more compelling because of both the personal and professional insights Holst brings to the consultation.

When Nick subsequently visits a prospective aged care facility, he encounters several clinicians who offer equally well informed and thoughtful observations about how best to support their residents living with dementia. The facility itself is physically appealing (a relative rarity on the mainstream cinema screen) and the residents appear happy. Emphasizing the need to ensure that there is 'joy' and 'meaning' in older people's lives, a carer also notes that for people living with dementia, maintaining affectionate and supportive social relationships with family members provides an essential source of emotional wellbeing.

The explicit references to the importance of joy, meaning and social connection draw specifically on the most recent ideas around person-centred dementia care as articulated by amongst others, Allen Power (Power, 2014). Power argues that enhancing wellbeing is the key to improving the lives of people living with dementia and suggests that seven domains are critical for creating and maintaining that wellbeing (Power, 2014). Three of his proposed domains are identified in the film's dialogue: joy, meaning and connectedness. In a subsequent scene, the importance of music and its ability to ' … transform the lives of people with AD …' is underlined (*Head Full of Honey*, 2018). As with the principles of a person-centred approach, these are simple yet profoundly important observations about the lived experience of ageing more broadly, and dementia specifically that are rarely spelt out in mainstream cinema. Interestingly, three of the four texts discussed in this chapter reinforce the importance of music for emotional wellbeing. Two of the characters living with dementia are accomplished pianists (Tal and Sam in *The West Wing* and *Exile* respectively) and retain their skill, and importantly pleasure, in playing.

The clinician-based observations, combined with Matilda's person-centred approach and the empathetic responses of other characters, communicate important ideas to a general audience about how best to support someone living with dementia in both a community and residential aged care setting. The use of metaphor in the film makes a further contribution to the audience's understanding of dementia. In addition to Dr Edwards' brain-as bookshelf-analogy, honey is a consistent trope - as indicated in the film's title and Amadeus's obsessive hoarding and consumption of the food. When

Matilda asks her grandfather: ‘How does it feel to forget everything?’, he replies ‘I’m all gummed up…like a Head Full of honey’ (*Head Full of Honey*, 2018). With its connotations of viscosity and opacity, this simple but powerful metaphor conveys to Matilda and the audience the frustration Amadeus experiences when struggling to navigate his new world in London and undertake activities he previously found straightforward.

Presenting the central messages about dementia from an 11-year-old protagonist’s point of view accounts at least in part for the effectiveness of their impact. Matilda’s intuitive understanding of her grandfather’s difficulties and her interpretation of Dr. Edwards’ advice arguably cuts through to an audience, regardless of their knowledge or experience of dementia, in a way that an adult character’s actions might not. In this respect, the film has a useful contemporary counterpart in the 2010 Australian film *Lou*. *Lou* also features an 11-year old girl as the central female protagonist and her relationship with her grandfather Doyle (John Hurt) presents an even more challenging situation than the one depicted in *Head Full of Honey*.

A stranger before he comes to live with the family, Lou (Lily Bell-Tindley) is initially resentful of Doyle’s presence and wary of his confused behaviour but the two quickly develop a rapport. When Doyle begins to believe Lou is his long dead wife and his attachment becomes more intense, Lou’s mother decides to separate them. This triggers an escape from the remote Queensland family home comparable with the conspiratorial adventure that Matilda and Amadeus embark on. Unlike *Head Full of Honey*, *Lou* does not spell out its messages about dementia in overt fashion. There are no health professionals involved but Lou’s connection with her grandfather and willingness to enter into his world conveys some equally important insights. As with *Head Full of Honey*, the impact of these insights is arguably more compelling because they are delivered through the eyes and voice of a clear-sighted and empathic 11-year old girl.

Head Full of Honey has some significant limitations. The film's uneven tonal shifts from melodrama to high farce at times threaten to undermine the effectiveness of its observations about dementia. Amadeus has a marked tremor that is unaccounted for in the course of the film. This exaggerated symptom could appear to a general audience to be part of Amadeus's AD, contributing to a misapprehension that the condition necessarily involves cognitive and physical incapacities. It is the kind of unhelpful misrepresentation of dementia symptomatology that critics of cinemeducation have identified as potentially problematic (Capstick et al, 2015).

Despite these limitations, *Head Full of Honey* takes a general audience on a significant learning curve about AD and the best way to support someone living with the condition. The film opens with Matilda's forthright statement: 'My doctor told me everything I know about grandpa's illness AD …' but over the course of the film, Matilda and viewers in fact build considerably on that initial, advice (*Head Full of Honey*, 2018). Viewers learn about adopting the perspective of the person with dementia and attempting to see the world through their eyes. As Matilda quickly grasps, this involves responding respectfully to the words and actions of her grandfather, even if they are difficult to interpret or understand. The film consistently emphasizes the importance of supporting emotional wellbeing, from the vital role played by loving and supportive social relationships to revisiting positive memories and engaging in activities that are personally meaningful.

Finally, an understated but valuable point made in the film relates to the benefits of expert residential aged care. Dr Holst suggests that 'a good nursing home' will be needed in the future (*Head Full of Honey*, 2018). As noted above, Nick's visit to an aged care facility is a positive one and unlike many screen representations of residential aged care, depicts appealing surroundings with cheerful residents and supportive and well-informed staff. The film's final scenes confirm this impression showing Amadeus happily ensconced in the same facility and affirming the reality of Dr Holst's positive message about residential aged care.

For residential aged care staff, this film is a useful resource in highlighting a range of relevant issues. Matilda could be regarded as a 'carer', though not in the conventional sense of the definition. Her evolving understanding of how to support her grandfather's emotional well-being by 'stepping inside his world' offers a detailed and nuanced scenario through which to explore multiple concepts in relation to the principles of a person-centred approach to caring for someone living with dementia. Amadeus's difficult transition to life in London involves a significant change in culture as well as a physical relocation. His bereavement, and the complex challenges he faces in adapting to a new home living with family members, in many ways approximates issues faced by residents living with dementia and entering the unfamiliar environment of communal residential aged care. Amadeus's spatial disorientation, loss of independence and feelings of frustration, boredom and helplessness are challenges often experienced by residents entering and adapting to residential aged care. These scenes provide multiple discussion points for aged care staff in considering analogous situations and issues in relation to the residents in their care.

One of the film's central messages - and an importance focus for this thesis – is the emphasis on adopting the perspective of the person with dementia to understand the way they are experiencing their social and physical environment. This is a particularly critical concept for aged care staff to grasp in order to understand an individual's needs, preferences and behaviour in response to environmental and other factors and to plan and provide supportive, person-centred dementia care. Key scenes that explore these issues include the interactions between Amadeus and characters he encounters in the police station, at the restaurant, the convent and later with Matilda in Venice. Adopting a perspective-taking approach, discussions could be opened out by using contrasting scenes in the first half of the film involving Sarah's often angry, frustrated and unsympathetic interactions with Amadeus. Sarah's inability to understand the way Amadeus is experiencing the challenges of his new environment – to step inside his world - arguably compounds his confusion and distress.

The issue of 'dignity of risk' is a conspicuous theme in *Head Full of Honey* and a topical issue in the provision of dementia care in both community and residential aged care settings (Clarke, et al, 2009; Clarke et al, 2010; Clarke, Keady, Wilkinson & Gibb, 2011; Ibrahim & Davis, 2013; Clarke, & Mantle, 2016; Croft, 2017; Mapes, 2017; Stevenson, Savage & Taylor, 2019). A 'risk averse' approach has been embedded in residential aged care over many decades, an approach which has tended to focus on the potential for negative outcomes, particularly in relation to the actions and activities of people living with dementia (Neill, 2009). More recently, the emphasis has shifted to exploring how the rights of the person with dementia are respected, including opportunities to undertake potentially risky activities with appropriate assessment and planning. Allen Power's notions of 'surplus safety' and 'all-or- none thinking' have been influential in shaping ideas around how to mitigate historically risk averse attitudes in dementia care and implement decision-making around risk-taking that respects autonomy and enhances wellbeing (Power, 2014, p. 116).

Balancing potential risk with the rights of the person living with dementia in the context of a genuinely person-centred approach to care is a challenging proposition for many residential aged care staff. *Head Full of Honey* provides a series of complex scenarios that foreground issues around autonomy, wellbeing and risk taking. Amadeus's battles with garden hedges and ovens, his hair-raising drive through busy London streets and other exploits offer useful ways for staff to explore the complexity of issues arising around individual rights, decision-making and reasonable risk for someone living with dementia and the roles and responsibilities for those supporting them.

Where The Personal Is Indeed Political: Dementia As Small Screen Drama

The West Wing: 'The Long Goodbye'

'The Long Goodbye' is a self-contained story within the West Wing series, or what in TV parlance is referred to as a 'bottle episode' (a single set of characters in a single space for an entire episode). It is unusual in the overall context of the series in that playwright Jon Robin Baitz was commissioned by series creator and principal writer Aaron Sorkin to write a stand alone 'one-act play…'(Hirway and Malina, 2018). Sorkin's brief simply required a scenario around White house Chief of Staff C.J. Cregg and it was Baitz who developed the 'dramatic device' of the storyline involving Alzheimer's disease.

C.J.'s father Talmidge Cregg (Donald Moffat) is a mathematician, who as C.J. recounts to a colleague, has become increasingly forgetful and refuses to countenance the words Alzheimer's or doctor. 'He forgets things, he forgets what's going on … he snaps back in but …' (*The West Wing*, January 15, 2003). C.J.'s visit home to Dayton, Ohio reveals that his AD is progressing even more quickly than she has realized; Tal forgets the names of family friends and can't locate familiar objects in 'this hell hole of a kitchen…' (*The West Wing*, January 15, 2003). Most tellingly given he is a mathematician, Tal gets simple calculations wrong. Near misses when driving, bouts of confusion and episodes of verbal aggression add to the picture of cognitive decline. As a man used to being in control – of numbers and everything else in his life -Tal is clearly frustrated by these changes and worried about the prospect of what the future holds.

When C.J finally persuades her father to see a neurologist - a longstanding golfing friend who respects Tal as a 'straight shooter' - he delivers the prognosis bluntly. This includes statistics on AD in his age bracket, medications currently on offer and their likely effect (slowing it down at best), the typical progression of the disease and impact on family members. 'It is probably going to be harder on the people around you than on you' (*The West Wing*, January 15, 2003). As with the advice from clinicians in *Head Full of Honey*, the neurologist also stresses the importance of not living alone ('having someone there keeps it at bay') and that good residential aged care is available and should be planned for as soon as possible (*The West Wing*, January 15, 2003).

'The Long Goodbye' draws on some typical dementia tropes, from the episode title itself (a phrase many people living with dementia dislike), to its referencing of 'senior moments' and Tal's concern around the 'burden' his condition is likely to impose on family members. The episode canvasses many of the issues addressed in the films and TV series in this typology, including diagnostic processes, treatment and care options. While the scenario is written from the perspective of C.J's character, as with some examples in this typology, Baitz's script also pays careful attention to Tal's perspective at key moments.

The scenario is distinct however from many of its typological counterparts and makes an important contribution in several ways. As noted by Robert Egge, public policy officer of the American advocacy organization Alzheimer's Association, at the time it was released in 2003, it was ' …one of the first times someone spent as much time as this episode did going into Alzheimer's … we were at a point then that this was a conversation that was hidden in a sense' (as cited in Hirway and Malina, 2018). A comparison with the commercially successful, contemporaneous feature film *The Notebook* is instructive here. Jeremy Leven's screenplay for *The Notebook* deploys dementia overtly as a dramatic device but over simplifies, romanticizes and misrepresents key aspects of the condition. Given the film's worldwide box office takings of more than US $115,000,000, *The Notebook's* clinically inaccurate and at times alarmist depictions of AD symptomatology and disease trajectory made a singularly unhelpful global contribution to improving understanding of the condition.

It is not simply Baitz's accurate and sympathetic examination of clinical and other considerations around dementia but his dissenting take on the role of the carer that makes this *The West Wing* episode significant. The scenario is a thoroughly 21st century one with a blended family imposing an additional layer of complexity in relation to Tal's future care. His third wife Molly declares that she and Tal were '… two withered married ancient people' waiting for years to be together, and she has left him because 'diapers' were not part of the scenario she envisaged in their older age together (*The West Wing*, January 15, 2003). Her flight from Tal offers an interesting contrast with Bert's equally determined efforts to retain the right to care for 'his girl' Ruth in *What They Had*. Both offer viewers acutely observed, emotionally complex and compelling representations of the issues involved in coming to terms with a spouse with a dementia diagnosis.

As Tal's only child working in a high profile job hundreds of miles away, when C.J. broaches the issue of care, Tal observes he is ' … not built for it' and rejects outright her offer to 'quit and take care of him…' (*The West Wing*, January 15, 2003). When C.J. has to leave suddenly and farewells her father saying she will see him next week, they both tacitly acknowledge that this – and frequent visits from C.J. in the future – are not feasible.

Many examples referred to in this thesis explore the challenges involved in caring for a family member with dementia, from Arthur's declaration of inadequacy some two decades earlier in *Mother and Son* ('I can't do it on my own – I don't have the right attitude') to the on screen rewards and struggles of spouses to care for their partners in films including *Iris*, *Away from Her*, *Still*

Mine and *The Leisure Seeker* (*Mother and Son*, January 19, 1984). What distinguishes 'The Long Goodbye' from these examples is the candid examination of why the two women closest to Tal, who would be expected to take up the caring role, for different reasons decline to do so.

Molly's angry and impassioned defence of her actions in leaving Tal is equally an expression of grief and loss for the future she thought she had with him. 'I failed, I know… I didn't get to spend time with your father …' (*The West Wing*, January 15, 2003). When admonished by C.J, Molly admits she is ashamed but doesn't resile from her decision. It is a raw and devastating exchange, matched only in intensity by subsequent scenes between father and daughter. Torn between her commitment to her father and her job, C.J.'s conflicted feelings spill over into anger when Tal fiercely defends his independence and resists the idea of any kind of assistance. Molly appears briefly with Tal in one of the final scenes suggesting a possible reconciliation, but this does not detract from the unflinching depiction of the struggles both women have with their own feelings and the expectations of others in relation to Tal's future care.

Baitz's willingness to confronting the complexities of a dementia diagnosis from multiple perspectives resonated with viewers at the time and continues to do so as evidenced by comments accompanying a YouTube episode excerpt (viewed more than 33,000 times). 'Not even a minute into this and I was bawling. One of the most powerful ones yet, and I'm experiencing this with my grandmother right now' (Dawn, 2011). 'So wonderful, thankyou. So rare to see this in the TV in popular shows' (Bayes, 2014). 'Poignant beautifully done those of us who have been here' (Martin, 2018).

> Best of all I got out the WW episode and watched it probably for the fourth time…and was so impressed by the man acting the father. The look in his eyes was so like Mac's; hurt and bewildered. I am lifted up

> by the knowledge that if I respond gently with something we can both giggle at, I can soften the hurt' (Mackenzie, 2019).

A contemporary podcast discussing individual *The West Wing* episodes broadcast a discussion of 'The Long Goodbye' in January 2018, reinforcing how the episode remains relevant for viewers some 16 years on. Promoting the show in advance of the broadcast, *The West Wing Weekly* creators noted the strong interest in this particular episode and that listeners ' … have told us about their experience watching the episode either during or after a loved one had been diagnosed with Alzheimer's and how much it affected them just to even see it discussed… ' (Hirway and Malina, 2018).

'The Long Goodbye' made a significant impact on TV audiences at the time of its release and subsequently, and the episode is also instructive as a teaching resource in the residential aged care context. Baitz's thoughtful exploration of Alzheimer's disease raises a number of issues and expands on themes explored in other examples in the typology.

Most prominently, as with *Head Full of Honey*, the episode addresses the concept of 'dignity of risk'. Both Amadeus and Tal have dismissed their respective housekeepers and are living in domestic disarray. Tal smokes and leaves the gas on and his risk taking when driving makes clear his reduced insight into the consequences of his actions. His heartfelt plea to C.J. for 'a little more time…' so he can '… go down with my music, with some grace….' offers an opportunity for a detailed exercise in perspective-taking. Residential aged care staff could be encouraged to consider how C.J and Molly perceive the potential risks involved in Tal remaining at home living alone compared with Tal's point of view (*The West Wing*, January 15, 2003). How might an approach to decision-making balance Tal's desperation to remain living at home, playing music and retaining the things that make life meaningful for him with concerns about his personal safety? As with *Head Full of Honey*, these are complex issues that provide useful talking points for staff in thinking about analogous situations that might arise in a residential aged care setting.

Exile

A three-part mini-series and the final example in this chapter, *Exile*'s title suggests multiple meanings relating to all three of the central characters. Sam Ronstadt (Jim Broadbent) is effectively exiled from his previous life as a senior journalist and newspaper editor as his Alzheimer's disease progresses while his son Tom Ronstadt (John Simm), who has followed in his father's footsteps, has just been sacked from his journalist position with a tabloid magazine. Nancy Ronstadt (Olivia Colman) has sacrificed whatever plans she had to be her father's full-time carer and is in exile of sorts, isolated with Sam in the family home. When Tom visits his father and sister after an absence of several years, he confronts the reality of his father's condition and the dynamics between the three quickly shift.

Exile is a classic example of the typology; as a dramatic device, dementia underpins the family melodrama and drives the thriller narrative. While Sam's failing memory represents the main obstacle in uncovering a past political corruption scandal, scriptwriter Daniel Brocklehurst ensures that it is more than simply the catalyst for suspense. The storyline focuses on Tom but the three part series plunges viewers immediately into the realities of Sam's advanced AD. The thriller narrative is informed at every turn by the impact of Sam's condition on each family member.

As the adult female child, Nancy reflects real world statistics about the typical primary carer for people living with dementia and her exhaustion in the role is made clear from the outset (Gaugler, Jutkowitz, Peterson and Zmora, 2018). She does not hold back in a phone message to Tom spelling out the litany of daily challenges in caring for her father on a 'bad day': spitting out tablets, incontinence, refusing to get out of bed, mood swings, aggression, hallucinations and uncontrollable tears (*Exile*, 2011). Subsequent exchanges between Tom and Nancy establish the uncompromising way AD is described and depicted in *Exile*.

Tom is soon confronted with the reality of the carer's role when Nancy abruptly leaves him in charge of looking after his father. A couple of pages of his sister's hastily scrawled notes and padlocks on the kitchen cupboards are Tom's only 'care plan'. Subsequent scenes showing Tom trying to persuade his father to get out of bed and get dressed, use the toilet, take his medications and eat a meal are confronting - for him and viewers alike. As with *The Savages*, Sam's AD heightens longstanding tensions between father and son culminating in a scene that is difficult to watch. Tom's attempt to get a combative Sam into bed unleashes decades of suppressed anger and frustration and culminates in him hitting his father and railing against him. 'Trust you to get this – you couldn't get heart disease or cancer – you had to make us all suffer' (*Exile*, May 1, 2011).

There are only a handful of examples in this typology that deal in comparable detail with the realities of direct care for someone living with dementia. The most prominent of these are the feature films *Speed of Life*, *Iris*, *Happy Tears* and *Still Mine*. A little seen, low budget American drama focussing on the relationship between a retired academic and his primary carer son, *Speed of Life* is particularly notable for its frank and sensitively handled depiction of scenes including showering, changing of continence aids and other aspects of direct care.

In *Exile*, the scenes described above and others illustrate how Tom's understanding of his father's dementia develops through the exigencies of 'hands on' caring. Not unlike Matilda's learning curve in *Head Full of Honey*, Exile takes the viewer on a trajectory with Tom as he grapples with assisting his father to complete basic daily living tasks. Where the emphasis in *Head Full of Honey* is on learning to support emotional wellbeing, *Exile* initially immerses viewers in the minutiae of Sam's physical care needs. This gives Tom and viewers insights into the broader impacts of AD on Sam's quality of life.

Nancy's advice about communicating effectively with Sam and stimulating his long-term recall provides Tom and viewers with additional input.
' Prompts help - smells, music - and talk to him in the present if you want to talk about the past' (*Exile,* May 1, 2011). Tom's attempts to engage with Sam and retrieve long term memories – partly in the service of investigative journalism and partly personally motivated - are increasingly better informed and more successful, indicating his growing understanding of the cognitive challenges his father is living with.

As with the 'The Long Goodbye', the detailed and uncompromising picture of dementia in *Exile* provides a general audience with a range of insights into the physical and cognitive consequences of AD from the perspective of those supporting the person. The considered way the series explores the challenges for the primary caregiver makes a contribution to the discourse on caring that expands on other examples discussed in this chapter. Nancy's weary elucidation of her responsibilities and Tom's rapid induction as his father's primary carer provide a dual narrative that communicates effectively to a general audience some of the key physical and emotional challenges involved in responding to the changing needs of a person living with dementia. Regardless of the degree of a viewer's personal experience with dementia, this could make a valuable contribution to a general audience's understanding of the condition as indicated by a selection of user reviews below.

> All of the main characters were played fantastically well and it felt real. My mum has Alzheimers and I did wonder whether I would be "up" to watching something that was obviously so close to home, but the

> illness as a main strand of the story was treated with sensitivity and humour (farmertrouser, 2011).
>
> But special mention has to go to Jim Broadbent, based on personal experience Broadbent's portrayal of an Alzheimers-sufferer is just heart-wrenching (Cox, 2011).
>
> Essentially a three-hander between Simm … the wonderful Colman … and the mighty Broadbent, the latter's portrayal of this terrible condition must be among the most devastatingly accurate ever placed on screen. Shocking and extremely moving, with a final scene that's – ironically – quite unforgettable (Catterall, 2011).

Exile also offers the aged care workforce a number of useful ways of considering aspects of best practice dementia care. Where *Head Full of Honey* illustrates a person-centred approach to care, Tom's initial efforts to support his father in many ways represent the antithesis. His clumsy attempts to impose care result in Sam becoming more defensive, less co-operative and at times combative. These scenes have clear relevance for the provision of care for people living with dementia in a residential aged care setting. Using these scenes as a starting point, staff could be encouraged to identify what is ineffective and inappropriate about Tom's manner and what might have worked better and produced improved outcomes in terms of Sam's wellbeing. *Head Full of Honey* offers a useful contrast in foregrounding the importance of adopting the perspective of the person with dementia when planning and implementing care.

The discussion could also incorporate associated issues in relation to the importance of non-verbal cues and Tom's initial inability to communicate effectively with his father. Decades of research have demonstrated that many people living with dementia, including in the advanced stages, are acutely sensitive to non-verbal cues (Kitwood, 1997, Sabat, 2002, Brooker, 2007 and

Power, 2014). Key scenes in *Exile* offer the opportunity to explore the importance of tone of voice, gesture and facial expression as critical components of effective communication with someone living with dementia.

The issue of elder abuse in the community and in residential aged care settings is an urgent and topical one in Australia and elsewhere (Kurrle and Naughtin, 2008; Hempton et al, 2010; Kosberg and Garcia, 2014). The scene detailing Tom's attempt to force his father into bed culminating in assault is confronting but instructive in a pedagogical context. The scene could be used to initiate a discussion with staff about the contributing factors that resulted in the assault, consolidating ideas and concepts around the importance of a person-centred approach and the impact of non-verbal communication cues. The discussion could also be opened out to explore the issue of elder abuse more broadly, including reporting requirements and other considerations.

Conclusion

Dementia is employed as a dramatic device in a wide range of mainstream film and TV genres, from intense sibling dramas to sci-fi action adventures. These texts, particularly those that are the focus of discussion in this chapter, can offer viewers valuable insights into a range of complex issues relating to dementia and dementia care. The examples cited in this typology typically focus on characters other than the person living with dementia but explore important aspects of how best to support that person and the challenges, rewards and other impacts for those providing that support.

Each of the four texts central to the discussion was selected for the distinctive way in which it addresses notions of caregiving and associated concerns. Each also therefore potentially engages a general audience and the aged care workforce in different and instructive ways on a range of issues, from family conflicts over different approaches to caregiving to the conceptual and practical challenges involved in the notion of 'dignity of risk'.

Head Full of Honey introduces a new, person-centred lexicon to the big screen. For the first time in a mainstream English language film, viewers are exposed to contemporary best practice dementia care concepts. Key principles including the importance of seeing the world from the perspective of the person with the condition, to how to support emotional well-being through the positive power of long term memories and the provision of personally meaningful activities are explored in detail. These concepts are articulated by a series of health professionals but the film arguably communicates its central messages about a person-centred approach effectively because they are delivered through the forthright words and actions of an 11 year-old girl.

What They Had features a triumvirate of carers, offering multiple perspectives on the role. Fiercely protective spousal caregiver, committed but pragmatic son and emotionally close but conflicted daughter – each offers different ways of understanding what the respective responsibilities might be in relation to Ruth's current and future care needs. Unlike *Head Full of Honey*, Chomko's film does not present new ideas about dementia or dementia care but rather, in presenting a range of characters responding to a situation that viewers might recognize or identify with, offers different points of engagement and opportunities for insight.

Both feature films acknowledge the complex demands for family members involved in supporting someone living with dementia. *Exile* explores these demands in more, and at times confronting, detail. Minutes into the first episode, Nancy's exhausted and exhaustive litany of Sam's symptoms and her responsibilities sets the scene for what is in store for Tom when he is thrust into the role of primary carer. It is a compelling induction into the caregiving milieu. In the course of three episodes, the audience alongside Tom acquires increasing insight into the best way to support Sam's physical and emotional wellbeing as his dementia progresses and the political thriller plays out.

'The Long Goodbye' takes the carer's learning curve in a related but alternative direction, foregrounding a scenario where for different reasons, family members decline to take on the challenge of caregiving. An unflinching examination of the consequences of an AD diagnosis for all concerned, the episode offers a rare riposte to what Chivers' has identified as the tendency for caregiving in popular culture narratives dealing with dementia to be '… downloaded onto the "family" 'thereby relieving anyone else of caregiving responsibilities' (Chivers, 2011, p. xvii).

The introduction to this thesis acknowledged the ubiquity of this typology, with its collective focus on the experiences of individuals other than the person living with dementia. It is important to note that while family members constitute the central focus in each text, all four to varying degrees, also acknowledge the perspective of the person living with dementia.

In *What They Had*, Ruth's point of view and opinion is represented, most critically in the scene where she questions her daughter about the necessity of residential aged care. While the political thriller narrative clearly revolves around the character of Tom, *Exile* screenwriter Daniel Brocklehurst ensures that viewers have a powerful sense of the frustrations Sam experiences, the capacities he retains and ultimately the importance of the presence of both adult children in his life. In 'The Long Goodbye', viewers get a visceral and at time profoundly moving insight into Tal's perspective. He is dismissive of what he regards as the disempowering world of care ' … the expertise, the solicitude…' (*The West Wing*, January 15, 2003). As Tal pleads with C.J for ' … a little more time…if I let it in at its own pace, it will just get darker faster', Moffat makes his character's desperation to remain independent at home palpable (*The West Wing*, January 15, 2003).

In *Head Full of Honey*, a series of pivotal exchanges between Matilda and Amadeus mark the film's attention to the perspective of the person living with dementia. Amadeus cries when trying to describe to Matilda his struggle to put words on a page. 'It's so awfully awful…if you want to write, you can't…there's just something inside that's stopping it from happening…' (*Head Full of Honey*, 2018). When Matilda subsequently asks her grandfather what it feels like to 'forget everything', his use of honey to describe the feeling inside his head gives another simple but powerful insight into his lived experience of dementia.

As suggested in the introduction to this thesis, the increasing interest in and depiction of dementia on screen in the last three decades can be attributed to a general increase in community awareness about dementia informed by research efforts and an increasingly vocal advocacy movement represented by people living with dementia. The latter has in particular contributed to recognition of the importance of depicting the experience of dementia from the point of view of the person living with the condition. In the following chapter, the discussion will concentrate on the small but growing group of film and TV texts that make the lived experience of dementia the central narrative focus.

CHAPTER 8: DEMENTIA TAKES THE LEAD

Introduction

> 'Putting oneself in the shoes of someone with dementia is not an easy or trivial process' (Brooker, 2007, p. 65).
>
> 'What's it like…what's it actually feel like?' (Still Alice, 2014)
>
> ' … accessing first-person accounts (of the lived experience of dementia) can help those involved in health care to become more questioning and mindful when working in practice' (Morris, 2014, p.434).

Accounts of dementia in the mainstream media have historically been dominated by the perspectives of carers, family members and health professionals and have rarely emphasized the voices of people living with dementia (Clarke, 2006). This hegemony has been noticeable on cinema and television screens where it is apparent ' … how scarce the voices of people with dementia have been as a result' (Orr and Teo, 2015, p. 9).

Anne Basting's plea for more complex and considered cultural representations of dementia emphasized the need to prioritize accounts from people living with dementia in public commentary and cultural representations as a crucial component of improving understanding about dementia in the broader community. These personalized or first person accounts offer an alternative to what Basting described as the 'tragic narrative' that dominates stories around dementia in the public domain (Basting, 2009). Individuals living with dementia, advocacy organizations and research findings have supported the contention that first person accounts and depictions of the lived experience of dementia play an important role in improving awareness and understanding about dementia in the community and the health care sector (Jonas-Simpson, Mitchell, Carson, Whyte, Dupuis and Gillies, 2012; Sabat, 2012 and 2019; Swaffer, 2014 and 2015; Power, 2014; Morris, 2014; Brooker, 2007 and 2016; Käll, 2015; Bryden, 2016). 'Personal accounts of living with dementia are very powerful … ' (Brooker, 2007, p. 66).

The texts chosen for analysis in this chapter develop and expand on the insights and educative potential of the previously discussed typologies. Collectively they reflect advancing knowledge and awareness about dementia in the time frame encompassed by this thesis. Each individual text offers a range of insights into the subjective experience of dementia, the importance of relationships with partners, family members and friends and the preservation of capacities and abilities.

'What's It Actually Feel Like?'

Screen depictions of the subjective experience of dementia can play a critical educative role in this context, in both the broader community and the residential aged care sector. In *Still Alice*, Lydia Howland (Kristen Stewart) asks her mother: ' … What's it actually feel like?' (*Still Alice,* 2014). It is a fundamental question that many in the community are equally interested in knowing the answer to. It is a question that the texts discussed in this chapter directly address by offering insights into the experience of living with dementia *from the perspective of the person with the condition*.

First person depictions encourage the viewer to see through the eyes of the person with dementia facilitated by a process of cinematic engagement. ' … the camera angle, when it simulates the sight-lines of a particular character, literally puts viewers in the position of the character and therefore makes those viewers more likely to identify with the character…' (Chivers, 2011, p. xxi). In an early scene in *Still Alice,* Alice becomes disorientated while running through her university campus. The delirious, 360-degree pan renders previously familiar landmarks a confusing blur and communicates to viewers a potent sense of Alice's rising panic. In *Robot and Frank*, the local librarian Jennifer (Susan Sarandon), with whom Frank is on friendly terms, is revealed in the denouement to be his former wife. As viewers we are genuinely surprised because we enter into Frank's world from the outset and are firmly aligned with his perception of Jennifer as a new romantic interest.

Film and television texts that depict the subjective experience of dementia can engage an audience in a way that is arguably distinct from the previously discussed typologies. First person accounts can convey ' … the immediacy of what is experienced and a real feeling of involvement with those featured' (Morris, 2014, p. 440). The impact of these first person depictions is potentially powerful, immersing the viewer in the world of the character with dementia and communicating a range of complex experiences and emotions. The specific vocabulary of the cinema and the process of viewer engagement with a character on screen can encourage empathy with and insights into the character's experience of dementia. The potentially powerful impact of this enhanced understanding of the 'felt experience of dementia' is reflected in a user review of *Still Alice* (Morris, 2014, p. 437).

> ' … the viewer can't help but get irreversibly emotionally involved with her character. We feel for her, we cry with her, we wish she would get better, although it is clear that is sadly not going to happen' (drakula, 2005, 2014).

As Cohen-Shalev and Marcus have noted, representing the subjective experience of dementia does not always involve dialogue but can often be conveyed more effectively through camera angle and movement, framing and lighting and other effects. 'In shifting the expressive centre of aesthetic gravity from abstract linguistic cognition to the figurative, tangible expressive modality of the moving picture, these films stand to encourage a deeply felt understanding of the human aspects embedded in the phenomena of dementia' (Cohen-Shalev and Marcus, 2012, p. 93). These alternative modes of expression are deployed to varying degrees in the selected texts, from the seamless temporal segues indicating the fluidity of memory in *The Iron Lady* to the elegiac montage of a slowly emptying aged care facility lounge room in *Wrinkles*.

Seeing Through Their Eyes: Educating the Aged Care Workforce

In the course of his seminal work in the dementia care field, Tom Kitwood noted that it was impossible ' … to enter fully into the experiential frame of another person, simply because each person is unique' (Kitwood, 1997, p. 71). Kitwood went on to observe that stepping into and describing the world of someone living with dementia, particularly in the more advanced stages, involved additional complexities given that first person accounts typically describe the early stages of dementia. Any depiction of the later stages would invariably rely on inference, and the kind of language used may not reflect or communicate what the person with dementia is actually experiencing (Kitwood, 1997). Kitwood goes on to propose that there are nevertheless, some important strategies that can help with understanding the subjective experience of dementia. Key amongst these are exposure to the personal accounts of people living with dementia and attending ' … carefully and imaginatively …' to their words and actions, noting that the former may employ expressive modes other than 'everyday speech' (Kitwood, 1997, p. 74).

These ideas have informed the work of leading scholars in the field including Dawn Brooker, Allen Power and Steven Sabat and underpinned key concepts around person-centred support for people living with dementia in subsequent decades. The 'P' in Brooker's VIPS approach to person-centred dementia care stands for perspective (Brooker, 2007, p. 13). Brooker emphasizes the importance of understanding the subjective experience of a person as their individual reality, in turn facilitating ' … taking the perspective of the person with dementia as the starting point for care …' (Brooker, 2007, p. 64). Power's experiential definition and understanding of dementia is similarly informed and emphasizes the importance of learning how to better ' … enter the world of persons living with dementia and appreciate how they might view the world differently' (Power, 2014, p. 19). For Power, this more than any other endeavour, will contribute to educating health care professionals working to support people living with dementia.

Sabat's 2012 study, referred to in the introduction to this thesis, extends some of Kitwood's original contentions beyond the health care field. The findings from Sabat's study showed that learning about the *personal* experiences of people living with dementia 'dramatically enhanced students' appreciation of persons with AD' and generated increased levels of sympathy and empathy 'in ways that cannot be achieved by learning about the biomedical aspects of the disease' (Sabat, 2012, p. 107). These findings correlate with the kind of exposure to the lived experience of dementia that Kitwood suggested could contribute to improved understanding of the condition.

The analysis in this chapter focuses on depictions of dementia in film and television where the perspective of the person with dementia occupies either a significant amount of screen time or the story is told entirely from their point of view. These first person depictions can be understood as screen counterparts to the first person accounts of the lived experience of dementia emphasized by Kitwood, Sabat and others (Kitwood, 1997; Sabat, 2012). As Morris has noted, the appeal of screen-based 'biographical narratives' is their enhanced ability to convey and contextualize the felt experience of dementia (Morris, 2014, p. 437). These biographical narratives or first person screen depictions can provide a form of qualitative knowledge about and insight into the experience of living with dementia and make an important contribution to improving knowledge and attitudes about dementia in the broader community (Sabat, 2012).

As Kitwood, Brooker, Power and others have emphasized, a central tenet of a person-centred approach to care is seeing through the eyes of the person with dementia and adopting their perspective on the world. These first person screen depictions offer valuable insights and raise relevant issues in relation to key concepts around best practice dementia care and are a valuable educational resource in the residential aged care sector. Engaging with characters living with dementia can be used to explore a range of issues from the frustrations of short-term memory dysfunction and word finding difficulties to the impacts of the environment and the importance of maintaining supportive relationships for emotional wellbeing. The scenarios and issues explored on screen have a direct application to aged care roles and responsibilities around the understanding, planning and delivery of person-centred dementia care and associated issues.

The argument for using first person accounts of dementia as teaching resources in the specific context of the residential aged care sector is supported by several recent studies highlighting the impact of these accounts on clinicians' understanding of dementia and approach to practice in health care settings. A 2012 Canadian study analysed the influence of a research drama on the ways in which healthcare professionals ' … understand, think about and relate with persons living with dementia' (Jonas-Simpson et al, 2012, p. 1944).

Based on five studies of people living with dementia and one involving family members, the ethnodrama *I'm Still Here* drew substantively on experiences and observations from study participants. Staged for an audience of informal and formal caregivers, the play offered an immersive approach giving audiences an insight into the subjective experience of dementia and the deleterious impacts of stigma and isolation. The initial findings related specifically to health professionals and concluded that viewing the drama ' … transformed healthcare professionals' understandings, images and intended actions with persons and families who live with dementia' (Jonas-Simpson et al, 2012, p. 1952). The authors argued that this shift in understanding and intended actions, and the subsequent production and distribution of a DVD version of the play, has clear implications for the improved delivery of dementia care in a range of health care settings.

Described as an 'experiential' educational approach, the positive impact of viewing *I'm Still Here* suggests useful parallels with the similarly experientially based exposure to first person depictions of dementia in the feature films and television series that are the focus of this and the following chapter. Gary Morris's 2014 study involving student mental health nurses offers further support for this claim. Morris's participant group of student mental health nurses were given a series of cinema, TV, newspaper, autobiographical and Internet first person accounts of dementia (Morris, 2014). *Iris* was included in the media sources; amongst other observations, the study found that the film and TV sources generated the highest level of enhanced understanding of dementia (Morris, 2014). The findings included participates developed an improved awareness about the influence of the social and physical environment and reframed previous assumptions about 'challenging behaviour' in the context of a ' … person's internal experiences' (Morris, 2014, p. 436). Importantly in the context of this chapter, the broader conclusions noted that most students developed an increased appreciation of the subjective experience of dementia and the changing nature of relationships for the person living with the condition (Morris, 2014). Acknowledging the relatively small scale of the study and the need for further research, Morris nevertheless argues for ' …the value of accessing first-person narratives in terms of broadening understanding and heightening appreciation of the lived dementia experience' (Morris, 2014, p. 445).

The Feature Film Forerunners

As noted in the introduction to this thesis, it is important to acknowledge that the typologies developed in this thesis are not mutually exclusive and key film and TV texts – *Iris, Away From Her, Still Mine, Angel's Perch, Head Full of Honey, After the Deluge, Neighbours, Packed to the Rafters, Exile and The West Wing* – allocate significant amounts of screen time to both the person with dementia and their spouse, carer or family member. Of these, *Iris, Away From*

Her and *The Iron Lady* are key texts that could be classified in both typologies and all three have generated a considerable amount of scholarship in the cultural gerontology and wider fields (Basting, 2009; Anderson, 2010; Chivers, 2011; Wearing, 2013; Käll, 2015).

There are only a handful of feature films and TV series where the perspective of the person with dementia occupies either a significant amount of screen time or the story is told entirely from their point of view but it is an expanding category. The final chapter focuses on the most significant of these, the three feature films: *Still Alice, Robot and Frank* and *Wrinkles*. Significantly, three of feature films discussed in this and the following chapter were released within a year of each other – *Wrinkles* (2011), *The Iron Lady* (2011) and *Robot and Frank* (2012). The release of *Still Alice* (2014) several years later suggests an increasing interest in and creative momentum around first person depictions of dementia on screen. It is notable that a burgeoning group of literary counterparts has provided inspiration for some of these screen depictions. A number of recently published novels have explored the issue of dementia, and several of these are told from the perspective of the person with dementia including *Still Alice* (Genova, 2007), *The Night Guest* (McFarlane, 2013) and *Elizabeth is Missing* (Healy, 2014). The feature film adaptation of *Still Alice* is a focus of analysis in the next chapter while *Elizabeth is Missing* was recently adapted into an acclaimed BBC TV film. It screened on UK TV in November 2019 but at the time of writing, was not available for viewing in Australia. The momentum continues with the lived experience of dementia at the centre of two feature films scheduled for release in 2020. The Australian film *June Again* (Winlove, 2020) and British production *The Father* (Zeller, 2020) promise to be interesting contributions to the typology.

As part of the analysis of first person depictions of dementia, this chapter will examine the importance of relationships, and the way in which these are dynamic and evolving in the context of the lived experience of dementia. As one recent study has suggested, rather than focussing simply on which character's perspective is privileged in the narrative, considering the changing nature of those central relationships offers ' … more productive readings…' in rethinking our understanding of dementia and its consequences (Käll, 2015, p. 269). Each of the films discussed in this chapter acknowledges the progressive nature of dementia and the cognitive decline experienced by the central character but does so in the context of exploring the new possibilities within those core relationships.

In arguing for the potentially affirmative impact of these film and TV texts, my analysis also identifies the ways in which first person depictions emphasize the skills and capacities of the person living with dementia. As noted in a 2013 survey of the clinical depiction of dementia in film, of the 23 films surveyed, most emphasized impairments and '… while we looked for capacities, relatively few capacities were depicted in relatively few movies' (Gerritsen, Kuin and Nijboer, 2013, p. 279). This emphasis on deficits rather than abilities supports Basting's earlier contention that narratives about dementia in the mainstream media and popular culture are overwhelmingly shaped by the notions of incapacity and tragedy.

The coping abilities of the person with dementia emerged as a key theme in Morris's 2014 study involving health care workers' exposure to first person accounts of dementia. Student participants identified the positive impact of depictions emphasizing ability and capacity when living with dementia as a challenge to typical depictions of decline and dependence (Morris, 2014).

Setting the Scene with *Mother and Son*

Mother and Son represents a landmark in English language popular culture representations of dementia. The series, based around a character living with dementia, remains unique in terms of its central premise. As indicated by the title, the relationship between Maggie and Arthur is the central focus but importantly in the context of the analysis in this chapter, Maggie's perspective is privileged and she is depicted living with a degree of autonomy, capacity and ingenuity.

Mother and Son reflects the relatively limited level of knowledge about dementia at the time and while the humour is often dark, the series also gives viewers rich and engaging insights into how it might feel to live with dementia. The series frequently makes Maggie's cognitive challenges the source of comic inspiration, but equally, she is seen as an independent character navigating the complex social and physical environments in the home and wider community on her own terms. From inveigling free 'meals-on-wheels' to vetting and rejecting Arthur's potential girlfriends and manipulating both sons to her own advantage, Maggie's approach embodies Power's notion of the person living with dementia as a superior problem-solver (Power, 2014). Atherden's series established a contemporary template that acknowledged the challenges but equally asserted the potential for a person with dementia to live a socially and emotionally rich and engaged life.

As with *Mother and Son*, *Iris*, *Away From Her* and *The Iron Lady* focus on a charismatic central female character. In *Mother and Son*, Maggie's cognitive capacities appear unchanged over six seasons, whereas the three feature films explore the physical, emotional and psychological complexities that accompany the progression of the respective character's dementia symptoms. Each film portrays the subjective experience of dementia to varying degrees, offering a range of insights that provide an important context for the analysis of the three films that follow in the final chapter.

Iris and *Away From Her*

In Richard Eyre's biopic of the writer and philosopher Iris Murdoch, the dual narrative structure moves constantly between her life as an iconoclastic young woman and her later years, prior to and following her Alzheimer's disease diagnosis. The film deals with Iris's early symptoms of dementia, most significantly for her, word-finding difficulties. Diagnostic tests, the confirmation of a dementia diagnosis and the progression of her symptoms follow. Based on Iris's husband John Bayley's account of their life together, the film is presented primarily from his point of view. It conforms in some respects to Basting's notion of the typically tragic dementia narrative. Given Murdoch's verbal acuity and fierce commitment to 'the life of the mind', her cognitive decline is presented as a particularly cruel and tragic irony (*Iris*, 2001). Eyre is careful however to present Murdoch's point of view and provide viewers with a strong sense of her identity and agency, including in the advanced stages of the disease.

Canadian writer/director Sarah Polley's assured debut feature *Away From Her* explores how Fiona (Julie Christie) and Grant Anderson (Gordon Pinsent) come to terms with Fiona's dementia diagnosis. The producer describes the film as a love story that examines a long-standing but at times troubled marriage made the more complicated by the presence of dementia. 'The role of Alzheimer's in the film is a metaphor for how memory plays out in a long relationship: what we chose to remember, what we choose to forget' (Urdl, 2007, p. 3).

Despite Grant's misgivings, Fiona decides to admit herself to the Meadowlake aged care facility in the early stages of dementia. Rather than simply charting her cognitive deterioration, this allows Polley to explore the way Fiona adapts to the challenges created by her new environment. Fiona's growing emotional attachment to a fellow resident throws longstanding issues in the Anderson marriage into high relief forcing Grant to confront some emotional realities of his own.

Both films deal in considerable and occasionally confronting detail with some of the realities of advancing dementia, although the constraints of a feature length film result in the disease trajectory being unrealistically but predictably condensed. More importantly, both films also spend a considerable amount of screen time portraying the experience of dementia from the point of view of the respective female characters. Iris and Fiona make telling and not dissimilar observations about how they feel in the early stages of the condition. Iris observes to her husband, 'I feel like I'm sailing into darkness…' (*Iris*, 2001). When describing what it feels like to search for something important but not being able to recall what it is, Fiona remarks to Grant and close friends that '… I think I may be beginning to disappear…' (*Away From Her*, 2006).

Framing, camera angles and editing create point of view shots offering compelling insights into this subjective experience. Fiona and Iris both leave the family home and become lost for a considerable period of time (a common scenario in dementia-related narratives). Each film renders the visceral sense of bewilderment and panic that the two women experience. At critical moments in each film, both lie on the ground alone at night, contemplating an increasingly confusing and isolating world. It is a view and a world that the audience are compelled to contemplate with them.

Not unlike Kitwood's emphasis on recognizing expressive modes of communication in dementia other than every day speech, many of these scenes and moments eschew dialogue and rely on framing, lighting, sound design and other effects to communicate the character's interior world. Moments of heightened pleasure are shared equally forcefully with the audience. Some of the most memorable include the simple but intense enjoyment of the natural world, from Fiona's silent appreciation of the pristine snow bound landscape to Iris's solitary, wordless contemplation of the ocean. The intensity of these moments and scenes, and the 'real feeling of involvement' and 'immediacy' they generate between character and viewer offer tangible insights into the lived experience of dementia and potentially an improved understanding of the condition (Morris, 2014, p. 440). As an analysis of *Iris* noted, engaging with Iris's subjective experience ' … could inspire them (viewers) into striving to help dementia sufferers or at least have an improved awareness of their needs ' (Anderson, 2010, p. 1295).

Longstanding marriages are central to the two films and both explore the way in which those relationships change but remain a crucial source of support and wellbeing for Fiona and Iris. Described as an 'illness narrative' contextualized in relation to other equally important narratives about love, marriage and relationships, *Away From Her* interrogates longstanding tensions in the Anderson marriage in the context of Fiona's dementia (Käll, 2015, p. 262). On the drive to Meadowlake, Fiona's recall of Grant's past infidelities is well preserved but within a month of her admission, she appears to recognize her husband only as a vaguely familiar face. Fiona's rapid attachment to fellow resident Aubrey, with whom she had a youthful romance, adds another layer of emotional complexity.

Eyre's portrait of the Murdoch-Bayley marriage is equally interested in exploring the way in which the relationship evolves over time. Initially overawed by the young and enigmatic Iris, the older Bayley notes that his relationship with his wife has changed in the face of her advancing dementia. In one of most powerfully understated and moving lines of dialogue in the film, Bayley observes that rather than the distance he often felt between them in the earlier days of their marriage, they now live '… the next day and the next day, getting closer and closer together' (*Iris*, 2001). This is spelt out on screen in the way they are initially shot from a distance in separate rooms absorbed in their own writing projects, but as Iris's symptoms progress, she increasingly shadows John and they are rarely depicted apart in the family home. The film acknowledges Bayley's moments of frustration and distress at this increasing proximity but there are scenes that equally celebrate and affirm their new intimacy and understanding.

As part of the evolving nature of the central relationships in *Iris* and *Away From Her*, both films feature epiphanic moments between husband and wife.

In *Iris* this includes amongst other scenes, a shared moment of unbridled relief and exuberance on a dark and busy freeway verge. In *Away From Her*, Grant and Fiona reach a new level of understanding at a more conventional narrative point in the film's final moments. These scenes are distinguished from the kind of idealized romanticism of *The Notebook.* In the latter, having relived their own story in flashback - a life review of sorts - husband and wife miraculously (and utterly improbably) die together. *Iris* and *Away From Her* offer viewers a more realistic and considered acknowledgement of the changing nature of longstanding relationships in the context of a dementia diagnosis. Interestingly, the importance of social connections in the life of a person living with dementia is underscored equally powerfully in both films by scenes that do not involve John or Grant. Iris's poignant embrace and slow dance with her friend Janet and Fiona and Aubrey's distressing, wordless farewell are arguably two of the most profound moments of human communion in the respective films.

Away From Her is also significant for its emphasis on Fiona's response to her situation. As noted in several analyses, in distancing herself from her husband and developing a relationship with Aubrey, Fiona's actions can be read in a variety of ways and not simply through the prism of her cognitive decline (Chivers, 2011; Käll, 2015). Grant questions whether Fiona's attachment to Aubrey is a response to his past indiscretions. Fiona's concern for Aubrey and involvement in his care can be read as both an assertion of autonomy and evidence of her ability to develop skills and capacities in a new and challenging environment. The Meadowlake nursing staff acknowledge that Fiona's physical and emotional support for Aubrey, including encouraging him to walk again and adopting some of his hobbies and interests, has made a significant contribution to his rehabilitation. In taking on a new role and responsibilities in the context of her own cognitive decline, Fiona's actions offer the kind of positive example of abilities and strengths identified by Morris's study as a valuable counterpart to previous screen depictions of dementia emphasizing impairment and incapacity (Morris, 2014). As a recent analysis noted in relation to the constructive contribution that screen depictions of dementia can make: ' …it should be recognised that living with dementia does not exclude opportunities for change and potentially even growth' (Orr and Teo, 2015, p. 16).

'Putting oneself in the shoes of someone with dementia': *The Iron Lady*

The Iron Lady charts the political and personal events in the life of the first female Prime Minister of Britain, Maggie Thatcher. A multi-award winning biopic, the film attracted acclaim and opprobrium, the latter primarily in relation to the fact that it was 'premature' and 'distasteful' for documenting Thatcher's dementia while she was still alive (Postrel, 2012, para. 2). These criticisms are revealing in underlining the persistent stigma associated with the condition and reinforce the central argument in this thesis that there is an urgent need to improve awareness and understanding about dementia in the broader community. Interestingly, other analyses contest the idea that the film depicts dementia at all (Schweda, 2019). Arguing that because there is no explicit reference to the word, the subject is never openly addressed and Thatcher is not depicted as being diagnosed with the condition, Schweda suggests the film deals more particularly with Thatcher's attempt to let go of the past (Schweda, 2019). Schweda's argument is unconvincing on several levels. Thatcher is depicted in the film in older age after her husband has died when she was known to be living with dementia and there are in fact a number of direct references to her memory loss and declining cognitive function. There are numerous examples of texts over the last five decades where it is clear the central character has some form of dementia but this is never referred to or definitively identified (*Mother and Son*, *Convicts, Robot and Frank* and *Quartet*). Setting aside these concerns and others around the film's 'distastefulness' and alleged historical inaccuracies, *The Iron Lady* is important for this typology as one of the most persuasive contemporary depictions of the subjective experience of dementia on the mainstream screen.

The film commences with the older Thatcher (Meryl Streep) purchasing milk at the corner shop and returning home to have breakfast with her husband Denis (Jim Broadbent). A couple of quick edits make clear to viewers that while Denis is real to Thatcher, he is not actually sitting opposite her and the former PM has some degree of cognitive impairment. In subsequent scenes, Thatcher's housekeeper June (Susan Brown) whispers conspiratorially with other staff about 'managing' her behaviour and her daughter Carol (Olivia Colman) remarks on her mother's increasing forgetfulness. We are privy to Thatcher's anxiety as she strains to hear conversations about her behind closed doors and feel her acute awareness of the well-intentioned but patronizing way in which carers, health professionals and family members treat her faltering cognition.

As noted in an earlier chapter, unsurprisingly, memory plays a central role in many films dealing with dementia. Extended flashbacks to indicate earlier, generally happier periods in a character's life are commonplace, and memory loss is often deployed, sometimes hyperbolically, as a dramatic device. *The Notebook* is emblematic on both accounts, with the youthful central romance recounted in flashback. *The Iron Lady* devotes a significant proportion of the film's running time to the older Thatcher, whose failing short term memory but vivid long term recall triggers a series of flashbacks that flesh out the details of the younger Thatcher's rise through the political ranks.

As with *Iris* and *Away From Her*, rather than chronological shifts between past and present, Lloyd's film explores the mutability of memory. References to specific pieces of music and key political and historical events prompt flashbacks, but these are not ordered consistently or sequentially. Home movie footage of the young Thatcher children morphs seamlessly into 'real' life and back again in a series of persuasive temporal segues. The frequent shifts in time are suggestive of the selectivity of memory; the non-linear narrative structure effectively conveys Thatcher's experience of time as an imbrication rather than a discrete separation of past memories and present events.

The hallucinations involving Denis are the most transparent and consistent manifestation of Thatcher's dementia. A recurring and ambivalent presence, Denis appears at times supportive, challenging and occasionally punitive. Thatcher's exchanges with her husband explore the emotional terrain of their long and stable marriage but his appearances often startle and at times infuriate her. In these hallucinatory sequences, Lloyd's innovative use of abrupt edits, jump cuts, fades, overlapping dialogue and other effects draw the viewer unequivocally into Thatcher's interior world. We share her intense pleasure in recalling personal and professional achievements but equally experience her difficulties negotiating the competing realities of conversations with Denis and those around her.

These inventively constructed scenes demonstrate a progression from earlier screen representations of cognitive impairment in attempting to render the felt experience of dementia in a more complex and immersive fashion. Of the films surveyed for this thesis, only one earlier, contemporary English language example approaches a similar level of complexity. The Australian TV movie *After The Deluge* (Maher, 2003) explores the family patriarch's rapidly progressing dementia and the way his three sons respond differently to his illness. Writer Andrew Knight drew on his own father's experience with dementia as inspiration for the character of Cliff (Ray Barrett). Knight and director Brendan Maher had lengthy discussions about the most effective way of conveying Cliff's subjective experience of dementia. Eschewing the use of conventional flashbacks, the past and present were rendered as temporally fluid to indicate Cliff's fluctuating cognition and the intensity of his long-term memories (*After the Deluge*, DVD extras, 2003). In several extended sequences, violin music (Cliff played the instrument), wartime trauma and family memories combine with the present to render a compelling depiction of Cliff's subjectivity.

One analysis of *The Iron Lady* has argued that the film's uneven tone and ambivalent attachment to Thatcher's character undermines the viewer's ability to ' … enter fully into identification with its subject (Wearing, 2013, p. 322). I would argue that any tonal fluctuations are insignificant in the context of our consistent alignment with Thatcher's point of view and the vivid, experiential way her dementia is conveyed. While many reviews at the time were critical of the film's unconventional approach to Thatcher's life, many also responded positively to Lloyd's thoughtful depiction of Thatcher's vulnerability and her subjective experience of dementia.

> 'The fact that this movie focuses on the aging process and its tipping of the strength versus weakness balance is NOT a bad device. In fact it is probably one of the more unique ways to portray Alzeheimers. Not just as a sad deterioration, but the more complex medical phenomenon that it truly is. (jd7myers-1, 2012)

> 'Younger reviews have criticized it for the confused transitions and perhaps Streep's depiction of the doddering aging Thatcher - but I thought it was wonderful and her transformation remarkable. That sense of confusion perfectly matched the waxing and waning lucidity of Margaret Thatcher's recollections' (albertpaao, 2012).

> 'Much like an emotional roller coaster ride, this film bounces back and forth between the now and the past and in-between and the now again and... Had this been a lateral step by step progressional film it possibly would have had much less impact. Instead, as viewers we are intensely involved with the context because we feel we're inside the head of Mrs. Thatcher as she lives either in the present or the past ' (mmipyle, 2012).

As described in this last review, *The Iron Lady* offers the kind of intensely felt cinematic experience that as with the ethnodrama *I'm Still Here*, could have a powerful impact on a viewer's understanding of the lived experience of dementia (Jonas-Simpson et al, 2012). The film's perceptive treatment of Thatcher's subjectivity and its singular immersive quality makes it a useful resource for the residential aged care workforce. As an exercise in perspective taking, *The Iron Lady* offers aged care staff a compelling insight into what her character is feeling and experiencing, encouraging as Morris noted in relation to first person accounts, an enhanced understanding of the 'felt experience of dementia' (Morris, 2014, p. 437).

The film is set almost entirely within Thatcher's apartment, a defined space not unlike the residential aged care context. It is a space that comforts, challenges and at times frustrates her, as do the people that surround and support her. As with the scenarios in *Head Full of Honey* and *The West Wing,* Thatcher's brief foray to the shop in the opening scene of the film, and the panicked response of her staff, foregrounds issues around independence and dignity of risk. Thatcher's impatience with the efforts of staff and family members to 'manage' her and her assertion of her independence offers opportunities for discussions around issues of risk-autonomy and identity. As she remarks crisply to her daughter, 'I'm not for the knackers yet' (*The Iron Lady*, 2011).

Thatcher's response to her situation offers useful ways for aged care staff to explore key concepts in a person-centred approach to care, particularly in relation to the impacts of the physical and social environment. The film's depiction of past events – both traumatic and pleasurable – raise issues around the impact of fluctuating cognition and the significance of positive long term memories for people living with dementia. Discussions could explore the importance of stepping into the world of the person with dementia and seeing the environment from their perspective in order to tease out the complexities of these physical, social and emotional influences to encourage aged care staff to consider equivalent scenarios for individuals they are supporting in residential aged care environment.

Conclusion

The subjective experience of dementia features prominently in *Iris, Away from Her* and *The Iron Lady*. All three films offer a general audience important insights into what it might feel like to live with dementia and the impacts on relationships with spouses and family members. All three also represent valuable teaching resources in the residential aged care sector. Each film addresses a range of concerns from the perspective of the person with the condition and could be used to explore key concepts in relation to a person-centred approach to caring for someone living with dementia. These include identifying the importance of social connections and the changing nature of relationships over the course of the dementia trajectory, emphasizing abilities and capacities and identifying the potential impacts of the physical and social environment on a person living with the condition. The three feature films that are the focus of analysis in the following, final chapter represent the most comprehensive and considered first person depictions of dementia and associated themes and concerns in this typology.

CHAPTER NINE: DEMENTIA CENTRE STAGE

This final chapter deals with three feature films that in different ways expand on the themes and concerns explored in Chapter Eight. Each film has been chosen for its compelling first person account of dementia but each presents this in a distinctive and singular way. A relative rarity given its focus on a character living with dementia and considerable commercial success, *Still Alice* is also notable for the involvement of dementia advocacy organizations in the film's script development and the dementia awareness campaign associated with the film. *Robot and Frank* presents a comprehensive portrait of the lived experience of dementia in the unlikely form of a caper film. The film's offbeat subject matter and dark comedy contrasts with the sombre style of *Still Alice* but conveys key messages about dementia in an equally effective way. The only non-English language text included in this thesis, *Wrinkles* is distinguished by its animated form and setting in a residential aged care facility. Combining dark humour, pathos and an uncannily accurate depiction of residential aged care, the film offers viewers a singular insight into the lived experience of dementia.

Still Alice

Released in 2014, *Still Alice* represents a watershed in contemporary mainstream depictions of dementia on screen and is a crucial text for this typology. The film is significant for several reasons. *Still Alice* is the first mainstream, English language live action film to present a comprehensive portrait of dementia from the perspective of the person with the condition. Secondly, the film was made and promoted with the involvement of dementia advocacy organizations. In addition to being a commercial endeavour, the clear secondary objective was to use the film to inform the broader community about dementia. The production and promotion of *Still Alice* effectively supports the central contention in this thesis - that mainstream films and TV series can be powerful tools in influencing knowledge and attitudes about dementia in the public domain. The critical and popular response to *Still Alice* will be discussed in the context of the film's educative agenda.

Based on Lisa Genova's novel, *Still Alice* centres on academic Alice Howland and her response to a diagnosis of younger onset Alzheimer's disease and the progression of her symptoms. Where the role of the carer/husband was the principal focus in *Iris* and *Away From Her,* and screen time was shared between the younger and older Thatcher in *The Iron Lady*, *Still Alice* places the character with dementia unambiguously centre stage. The filmmakers described their directorial approach as fundamentally based around the ' … subjectivity of Alice's experience — that the audience should understand her point of view and be privy to her internal life in a way other characters in the story weren't. It would require a deeply personal camera and editing style — responding to her mental state, her moods, her perception — breathing with her' (Glatzer, *Still Alice* Press Kit, p. 5).

Word finding difficulties are the most prominent and troubling early sign of Alice's condition and as with Murdoch's experience in *Iris*, this is made clear at a public speaking event and presented as cruelly ironic given Alice's academic discipline is linguistics. Adding a further layer of irony, the word Alice is unable to recall during her address is lexicon. The film charts the process of assessment and diagnosis, and following the confirmation of the rare familial form of the disease, the difficult discussions of the consequences with her three adult children. Unsurprisingly, Alice focuses on maintaining her vocabulary as a means of staving off cognitive decline (word lists on the fridge, games of Words with Friends and other linguistic challenges) but the loss of her academic position and increasing dependence on family members follows.

We are positioned to see and experience Alice's confusion, frustration and fear with her, from the aforementioned spatial disorientation when out on a run to a later scene when, unable to locate the toilet in the family holiday house, she is experiences a distressing episode of incontinence. Alice's poignant video message to herself to future proof against an undignified end and her failure to recognize her actor daughter Lydia (Kristen Stewart) after she has come off stage are confronting scenes to watch. While these are memorable, it is the small, seemingly unremarkable moments that register Alice's felt experience equally tellingly: her bewildered expression when unable to automatically recall steps in a well known recipe and the revealing, point of view shots from her perspective, excluded from family discussions on her future care needs. The film foregrounds the pervasive fear and stigma that still attaches to dementia in the broader and health care communities when Alice bluntly describes her feeling of shame at her diagnosis. 'I wish I had cancer ... I wouldn't feel so ashamed—when people have cancer, they wear pink ribbons for you' (*Still Alice*, 2014).

As with *Head Full of Honey*, it is a daughter's direct question to her parent that articulates for viewers what the lived experience of dementia might feel like. In a quiet moment during preparations for a family meal, Lydia asks her mother: 'What is it like…what's it actually feel like?' (*Still Alice*, 2014). Alice replies that on a bad day, 'I can see the words hanging in front of me and I can't reach them and I don't know who I am or what I am going to lose next' (*Still Alice*, 2014). It is a short but powerful scene and echoes an earlier pre-diagnosis exchange with John where Alice's fear and anger erupts: 'It feels like my brain is fading daily…it's like something drops out from under me' (*Still Alice*, 2018). Both statements offer acute insights into Alice's felt experience and an acknowledgement that the most profound threat to her identity is not simply word finding difficulties but envisaging what might follow. Both scenes also emphasize that as Alice's cognitive skills decline, it is the close relationships with immediate family members that become increasingly important. The film's focus on the importance of relationships, social connection and the ability to live well with dementia is most clearly articulately in Alice's address to an AD advocacy group.

'I have people I love dearly; I have things I want to do with my life. I rail against myself for not being able to remember things, but I still have moments in the day of pure happiness and joy' (*Still Alice*, 2014).

Critical Reception

As with the polarized reviews for *The Iron Lady*, the response to *Still Alice* was mixed (though for different reasons). For many people living with early onset dementia, the film is an accurate reflection of their own experiences. As a man diagnosed with early onset AD at a similar age, Keith Oliver found Alice's rapid decline confronting but affirmed that her story closely resembled his own:

> "The film confronted each stage I've gone through, like a checklist," Keith says. "It captured how dementia crept up on me, how it knocked my self-esteem and brought doubts into my mind before I even knew what I was dealing with. It captured how insidious the disease is, how it can subtly eat away at you. It captured how I tried to fight it, how I found coping strategies, how I tried to hide it (Seymour, 2015)

Wendy Mitchell, who Moore drew inspiration from in her portrayal of Alice, described the film as '… a shockingly accurate reflection of my own experience. It felt like I was being shown my own future" (Seymour, 2015). Other consumer reviews, both with and without direct experience of the condition, responded to the convincing nature of the first person depiction and the insights offered into the felt experience of dementia.

> 'Few movies about Alzheimer's show things almost entirely from the perspective of the victim, and even fewer try to grapple with her internal thoughts and feelings as the disease progresses. Still Alice does just that. Taking an exceptionally verbal and smart person and giving her early onset Alzheimer's and watching how she deals with it and

> how she feels about it made this an exceptional film.' (Richard1967, 2014)
>
> 'It's not just about the struggle of Alice (Moore), it's also an in- depth and informative medical drama that not only breaks your heart, but provide valuable information and sensitivity to anyone who may know or will know someone in the future' (ClaytonDavis, 2014).
>
> 'Glatzner (who himself has been diagnosed with ALS) and Westmoreland do not manipulate us into feeling pity for Alice as a victim but allow us to feel what Alice is feeling and see the world through her eyes' (howard.schumann, 2015).

The film attracted equally concerted criticism from consumer reviews, film critics and dementia specialists. Some consumer reviewers took issue with the representation of dementia arguing that the film minimized the more confronting symptoms and consequences and failed to acknowledge dementia's impact on family members and carers.

> 'The movie ends about where Alzheimer's would become a real strain on the family, but as always with a Hollywood depiction, the tragedy that is to follow is hidden. Real Alzhimer's patients forget who their families are, scream mindlessly about nothing in particular, foul themselves, cannot feed themselves. The bodies are there but the minds are not. The person that once was is gone, but the outward shell is there reminding us what once was and playing havoc with our emotions. Only a sanitized hint of all that is present in this movie' (john_seater, 2015).
>
> 'I have worked with dementia sufferers for the last 35+ years and can honestly say that the depiction of that cruel thief of minds and bodies was totally totally lacking. None of the daily struggles that the brave

> carers have to deal with on a multiple basis each day was even alluded to, let alone covered (So disappointing, 2015).

As noted throughout this thesis, the majority of mainstream films that depict dementia focus on the perspective of family members and carers, rather than the person with the condition. This is what makes the films discussed in this chapter, and their collective focus on the perspective of the person living with dementia, so significant. As a faithful adaptation of Genova's novel, Alice's perspective dominates the story and the film's strength is its single-minded commitment to depicting her experiences. Given that focus, and the limits of a feature length film, in these and other films in the typology, family members are literally and necessarily relegated to supporting roles. Key family relationships and the impact on family members are nevertheless an important concern. In *Still Alice*, Alice's relationship with her husband John and daughter Lydia are explored in the most detail. Early scenes in the film establish Lydia's strained relationship with her mother but as Alice's condition deteriorates, Lydia is the family member who best understands what Alice is experiencing and ultimately volunteers to be her mother's carer.

Other analyses from dementia researchers and academics took issue with the narrow representation of the condition, arguing that as an affluent, tertiary educated 50-year old woman with a rare, younger onset form of AD, Alice does not reflect the reality of dementia statistics (primarily people in older age) and experiences (a disease that affects people from diverse ethnic and socio-economic backgrounds) (Andrews, 2015) . ' … yes, we see her raging against the diagnosis. But it's all comfortably cocooned in cashmere sweaters, summer houses, and a functional family dynamic… and it's not even half of what people with dementia and their families deal with on a daily basis' (O'Dwyer, 2015).

Consumer reviews had similar concerns:

> ' "Still Alice" should, by contrast, carry the label "Sanitized for your protection." Everyone involved is highly attractive, articulate, compassionate and virtually devoid of any flaws that would mark them as human' (Vlad_Imirivan, 2015).

These criticisms are again revealing and conversely, reinforce my central contention in this thesis: analysing a range of representations of dementia in mainstream film and television illustrates the diverse ways these texts can contribute to enhancing understanding about the condition. Dementia takes many forms, from the rare, familial type of early onset AD depicted in *Still Alice* to the most common, later life form of AD seen in *Iris* and *Wrinkles*. The film makes clear that Alice's diagnosis is a rare form of AD. While there are established symptoms and disease trajectories associated with different dementia types, each person with the condition will experience it in a singular way because of their unique personal history and circumstances. Rather than homogenizing the experience of dementia, it is important to recognize that how it will manifest and what it might feel like will vary for each individual living with the condition. As Tom Kitwood observed and what has since become a defining mantra in the dementia care field, 'When you've met one person with dementia, you've met one person with dementia' (Kitwood, 1997).

The texts discussed in this thesis explore a variety of characters and situations across a range of genres from Billy Elliot's grandmother in a Northern British working class village to an offensively racist prison officer in the Australian black comedy TV series *Angry Boys.* One particularly excoriating analysis of *Still Alice* argued that we should reject the film and instead ' … insist on great films about real people that are compelling, well scripted, well acted, and beautifully made' (O'Dwyer, 2015). It is difficult to argue against the desire for mainstream films about dementia to be well crafted, compelling and to embrace representational diversity. This however then begs the question of why Alice is any less 'real' than characters living with dementia from backgrounds cited by O'Dwyer (CALD, LGBTI and low socio-economic amongst others) simply because of the educated, middle class milieu in which she exists. While younger onset is undoubtedly a much less common form of AD than its later onset counterpart, a point that is made clear in the film, Alice's character and her lived experience of the disease is as valid, 'real' and instructive as any other.

It is important to further contextualize the critical response to the film by pointing to the involvement of dementia advocacy organizations in the making of *Still Alice*. The filmmakers worked closely with the American advocacy organization the National Alzheimer's Association. Individuals living with Alzheimer's disease, volunteers and experts were involved in script and character development at every stage. In developing Alice's character and portraying her experiences, Julianne Moore consulted directly with Alzheimer's Association National Early-Stage Advisor Sandy Oltz, herself diagnosed with younger-onset Alzheimer's at age 46.

The association was also involved in a dementia information campaign that extended well beyond the film's theatrical release under the banner of ' … a movie to inspire hope and ignite change' (Alzheimer's Association, 2019). The campaign featured interviews with key figures from the film including Moore and Stewart, supported screenings of the film by community organizations and provided information and promoted conversations about dementia-related issues more broadly, effectively harnessing popular culture in the service of dementia literacy in precisely the way that I have argued is possible throughout this thesis.

The widespread debate and discussion about the film's merits has arguably made a contribution to raising awareness and enhancing understanding of dementia in the wider community. In the years following the release of *Still Alice*, the film's ongoing impact can be measured by the fact that the film and the debates and publications associated with it have been incorporated as permanent resources in a number of global dementia advocacy organizations including the National Alzheimer's Association, Alzforum and Dementia Australia.

In the context of this thesis, the film has clear relevance as a resource for residential aged care staff. Morris concluded that exposing health care workers to first person accounts of dementia including the feature film *Iris* contributed to ' …broadening understanding and heightening appreciation of the lived dementia experience' (Morris, 2014, p. 445). The concerted focus on Alice's perspective provides aged care staff with the opportunity to literally step into her world to the extent as the filmmakers observed, we are literally ' … breathing with her' (Glatzer, Still Alice Press Kit, p. 5). As with other films in this typology, *Still Alice* highlights the fundamental importance of adopting the perspective of the person with dementia in order to best support them. For residential aged care staff, the film raises a number of valuable questions that can be applied to their own workplaces and clinical practice. How might Alice feel when she becomes disorientated in familiar surroundings, is undergoing challenging cognitive assessments or cannot recall the names of close family members? How can those insights be applied to observing the way in which residents respond to their environment or in identifying their needs and preferences? How might Alice's lived experience of dementia inform their own work practices in better supporting the people they care for in a residential aged care setting?

The film also offers opportunities for staff to consider the way in which family members respond differently to Alice's situation. As Alice's dementia progresses, relationships become increasingly important for her wellbeing but family members respond differently to her symptoms and care needs. Unlike the consumer reviewer who claimed that only the 'outward shell' of a person with advanced dementia remains, *Still Alice* shows how Alice's emotional connection with her family remains strong and in the case of her daughter Lydia, develops in a new and deeper direction. The film raises important issues for aged care staff to consider: how do different family members respond to Alice's symptoms, needs and preferences? How and why do John and Anna react differently to Alice's diagnosis and cognitive changes? Key scenes - when Lydia identifies her mother's early signs of memory loss, recognizes her need to feel in control of daily events and asks her mother directly what the experience of dementia feels like – could be used to open out a discussion of why Lydia's approach demonstrates more insight and a more genuinely person-centred and supportive approach. As a recent phenomenological analysis suggested, *Still Alice* makes a significant contribution by encouraging a ' deeper understanding of how a person's emotions and self-identity change with the progression of AD [which] will help healthcare workers and caregivers respond to and care for these individuals more effectively (Halpin and Caston, 2019, p. 9).

Robot and Frank

Robot and Frank opens with a subtitle signalling its context in the 'Near Future' and a scene depicting what appears to be a man committing a burglary, subsequently revealed to be Frank (Frank Langella) mistakenly breaking into his own home. What follows is a scenario familiar in the context of the examples discussed in this thesis: an older man living alone in obvious domestic disarray. His son Hunter (James Marsden) and daughter Madison (Liv Tyler) make contact and it is clear that Frank is vague about their names and current activities and has forgotten that he divorced their mother 30 years ago. Hunter's solution to his father's 'gross' living conditions and cognitive decline ('You've got a problem…you get worse every time I see you') is a robot health care aide (*Robot and Frank*, 2012). Frank is defensive ('you're not sending me to that brain centre…there's nothing wrong with my memory … I'm fine') and utterly resistant to being 'spoonfed' by a 'death machine' (*Robot and Frank*, 2012).

The film includes many of the typical features of a dementia-related narrative – a forgetful older character who denies cognitive decline, struggles to cope at home but resists assistance and has problematic relationships with family members (*Head Full of Honey*, *Mr Holmes*, *The Good Life*, *The Long Goodbye*, *The*

Savages, *Win, Win*). *Robot and Frank* however takes viewers in a less conventional direction. Frank has a criminal past (high end jewellery theft), a robot is cast as his primary carer and the broader theme of dementia is explored in a caper (crime comedy) scenario. To my knowledge, *Robot and Frank* is the only extant mainstream English language film about dementia that tackles this crime sub-genre.

Robot and Frank is significant in this typology for the idiosyncratic but compelling nature of its first person perspective and the way the film embeds important ideas about how best to support someone living with dementia in the improbable context of crime comedy. Where clinicians articulated key observations about dementia in *Head Ful of Honey*, in *Robot and Frank* a small, determined machine spells these out. The robot makes a series of pronouncements about the need for Frank to get up early, follow a healthy diet, exercise and have a focus or 'project' in life in order to 'stimulate cognitive function' (Robot and Frank, 2012). This is accompanied by amusing scenes of Frank's disgust at artfully arranged plates of vegetables, reluctant participation on daily walks and refusal to engage in the robot's vegetable garden project. Frank does however develop an alternative 'project' of his own, one that embraces – in a somewhat aberrant fashion - the robot's directive about meaningful engagement.

Frank's initial resistance to the robot dissipates when he realizes that his mechanized carer can be co-opted as a literal partner in crime. His poor diet, lethargy and disaffection are replaced by a renewed energy and focus as he teaches the robot how to pick locks, defeat security systems and plan and carry out a robbery. Frank observes that 'my project is teaching you', knowledge that he was never able to share with Hunter (Robot and Frank, 2012). Tellingly, at one point, he momentarily confuses his robotic co-conspirator with his son.

Memory and identity are central themes in the film and are treated in a distinctive way. Frank's memory dysfunction is made clear in the opening scenes but he interprets Hunter's suggestion of the 'memory centre as a place that can help you' as an unambiguous threat to his independence (' … you're trying to put me in the nuthouse') (Robot and Frank, 2012). The film establishes that while Frank's short term memory often fails him, his long term memory for criminal methodologies is exemplary. Unlike many dementia-related narratives that focus on memory loss, director Jake Schreier eschews the conventional device of the flashback. Family photos are the trigger for significant revelatory moments - in the opening scene a framed family photo prompts the realization that Frank is attempting a break and enter in his own home. Towards the end of the film, Frank finally recognizes Jennifer as his former wife when contemplating a family photo on her office wall.

Memory is also central to the robot's identity; its ability to record and store data is a function Frank harnesses with enthusiasm to assist with the planning and execution of two burglaries. The robot makes reference at several points to the possibility of destroying its memory, an action that would wipe all data relating to Frank (including his criminal activities) and erase the history of their partnership. This course of action eventually becomes essential in order for Frank to avoid arrest. In the most moving scene in the film, the robot instructs Frank on how to wipe its memory, effectively signifying the robot's 'death.'

The film however resists a simplistic analogy between robotic memory erasure and the obliteration of memory and identity in dementia by underlining Frank's enduring capacities and asserting his potential to sustain meaningful, ongoing relationships. This is spelt out in the final, somewhat idealized scenes. Surrounded by his family, Frank is depicted living happily in a serene, light-filled, vaguely futuristic aged care facility. His knowing smile indicates he recognizes and is reassured by the presence of mechanical carers who appear to be exact replicas of his own robot.

A recent analysis of crime dramas featuring male protagonists with dementia argued that unlike the 'tragic narratives' that are typical of most genres dealing with the subject, the tone in these crime genres is by contrast, surprisingly optimistic. Drawing on the TV series *The Fear* and *Wallander* and the feature film *Mr Holmes*, Wearing argues that these texts assert the potential for family relationships to be re-established and that ' … emotional growth can be found even in the midst of an otherwise bleak condition' (Wearing, 2017, p. 140). A crime comedy rather than a drama, the narrative in *Robot and Frank* nevertheless supports this contention. The film's denouement firmly reinstates the family as an important element of support for Frank's well-being. Having experienced a collaborative partnership with the robot and a renewed enthusiasm for life, the final scene suggests the possibility of Frank living a new and meaningful phase of his life supported by like-minded robot carers.

Robot and Frank offers a general audience and the aged care workforce valuable insights into the subjective experience of dementia delivered in the appealing form of a caper film. As with *The Iron Lady*, in *Robot and Frank* we are unequivocally aligned with the central character's perspective from the outset. We share in Frank's struggle with some of the typical challenges of living with dementia - forgetfulness, poor self-care, boredom and social isolation – and some less typical ones in being on the wrong side of the law. Rather than the potent, experiential impact of Lloyd's film, *Robot and Frank's* caper premise and droll tone conveys the felt experience of dementia in a different but equally effective way. We see through Frank's eyes from the opening scene and are drawn into his world through his inventive criminal endeavours, determination to remain independent and evolving friendship with the robot. It is a perspective and a world no less absorbing or instructive than Thatcher's cloistered apartment and vivid hallucinations.

In addition to its persuasive depiction of the lived experience of dementia, *Robot and Frank* is also useful in raising a series of issues relevant for the residential aged care workforce. The film emphasizes Frank's physical and cognitive capacities, resourcefulness and renewed vigour when focussed on a personally meaningful project (albeit a criminal one). As noted earlier, films depicting dementia rarely focus on the person's capacities and abilities (Gerritsen, Kuin and Nijboer, 2013). This reflects historical attitudes in the broader and health care communities. Informed by the biomedical model of dementia, the focus has traditionally been on impairment, loss and incapacity rather than strengths and abilities (Power, 2014). This extends to the way in which programmed activities and other therapeutic interventions have been designed and implemented in community-based and residential aged care. 'The approach is also often deficit based, rather than drawing on existing strengths ' (Power, 2014, p. 177). Acknowledging the humorous interpretation of 'projects' and 'meaningful activities' (they are in fact planned robberies), the film explores the positive impact of maintaining current skills and capacities, and encouraging participation in activities and experiences that are meaningful for the person living with dementia.

Robot and Frank also emphasizes the importance of sustaining existing relationships and developing new friendships. Frank gradually sheds his resistance to being assisted by a 'death machine' and learns to value the friendship and support of his health care aide. He is emotionally estranged from his son and unable to recognize his former wife but in the final scenes, the family is depicted as reconciled and supportive. As a teaching resource, this raises another pertinent issue for discussion - the importance of relationships with family members and care staff in supporting the well-being of the person living with dementia.

The film also depicts several models of care that suggest useful discussion points for aged care staff. Moving from a didactic position on Frank's daily care routine, the robot gradually learns to see things from his perspective. The robot's professional ethos shifts from a position of imposing care (strict early rising, eating and exercise regimes) to a more genuinely person-centred approach in acknowledging and incorporating Frank's preferences (including criminally motivated ones). For both characters, what begins as an unequal client and carer dynamic develops into a partnership based on reciprocity and mutuality.

This positive model of care is further supported in the film's resolution. In contrast to Frank's earlier, pithy descriptions of the memory centre as a 'nuthouse', in the film's final scenes, his residential care facility is depicted as an idyllic and supportive environment (Robot and Frank, 2012). As with the equally brief but positive portrayals of residential aged care in *Head Full of Honey* and *What They Had*, *Robot and Frank* offers a welcome counterpoint to the historically bleak representations of care facilities and dementia care and that have dominated the big and small screen in previous decades.

Spanish Exceptionalism - ***Wrinkles***

In the data collection process for this thesis, I viewed a number of non-English language feature films, some of which addressed dementia from a first person perspective. Of these, the most memorable for different reasons were the Japanese film *Memories of Tomorrow* (Tsutsumi, 2006), Spanish film *And Who are You?* (Mercero, 2007), the South Korean film *Poetry* (Lee, 2010), the Chilean feature *Old Cats* (Peirano and Silva, 2010), the Iranian film A *Separation* (Farhadi, 2011) and the Paraguayan film *The Delay* (Plà, 2012). The characters and situations portrayed in these films and others contributed to clarifying the key themes and concerns in the three typologies. *Wrinkles* is the only film selected for inclusion on the basis that the distinctive and original manner in which the film depicts the felt experience of dementia has no English language equivalent. The film's striking animated style, concentrated focus on the central character with dementia and residential aged care setting offers a general audience a unique perspective and represents a valuable teaching resource for the residential aged care sector.

A multi award-winning, 2D animation feature, *Wrinkles* is based on a graphic novel of the same title by Paco Roca. As with many of the films discussed in this thesis, Roca's inspiration was close to home: observing his own parents age and the changes in a close friend's father who was diagnosed with AD. As part of his research for the novel, Roca visited aged care facilities and interviewed residents and staff. The results are apparent in his nuanced depiction of the physical environment of the aged care facility environment and the interactions between residents and facility staff.

The film opens from retired banker Emilio's perspective. A bank manager rejects a young couple's loan application but a couple of quick edits contradicts this by presenting another 'reality' - the young couple are actually Emilio's son and daughter-in-law who are trying to persuade him to eat his dinner. As with the opening sequence in *The Iron Lady*, this indicates from the outset that Emilio is a potentially unreliable narrator but as with Thatcher's character, we are unequivocally aligned with his story and perspective throughout.

The narrative follows Emilio (voiced by Tacho González) as he enters an aged care facility with symptoms of dementia (later confirmed as AD). *Wrinkles* charts Emilio's cognitive decline and as with Fiona in *Away From Her*, his dreaded but inevitable transition 'upstairs' to the floor for residents with more complex needs - or as described by fellow resident Miguel (Álvaro Guevara) ' … the land of lost souls' (*Wrinkles*, 2011). As with Polley's film, Ferreras is not interested in simply detailing Emilio's deterioration but rather exploring the way he negotiates the social, emotional and physical challenges of his new environment in the context of his changing cognition.

Wrinkles is set entirely in the aged care facility and we get a telling first impression of the environment through Emilio's eyes when his roommate Miguel takes him on a 'tour'. Ferreras captures in uncanny detail the typical features of a standard aged care facility: long, beige coloured corridors with endless rows of identical doors, each bedroom indistinguishable from the next (Emilio and other residents frequently lose their way). Residents doze uncomprehendingly in recreational areas in front of huge noisy TVs adjacent to a big, busy dining room. Miguel cynically observes that the facility pool is not for residents but rather 'consumers' (family members and the government who pay for the rooms), a point Emilio's son later unwittingly confirms.

The film's reflective pace indicates Emilio's perception of the slow passing of time and his gradual adjustment to facility life. The minutiae of facility routines are beautifully observed, often in wordless, expressive sequences that convey Emilio's muted grief and social dislocation more powerfully than any verbal exchange. Elegiac montages detail the monotony of meals cleared by disembodied hands, medications mechanically administered and the nightly emptying of the gloomy lounge room. Emilio's mournful gaze through facility windows observes seasonal changes – falling leaves followed by snowdrifts and then springtime buds. The consistent use of extreme close-ups record his attentive observation of fellow residents – the silent Modesto, lovingly assisted by his wife Dolores, the disorientated Carmen perpetually yearning for sons who rarely visit and the perseverative, retired radio broadcaster Ramone – all of whom also live with dementia. Ferreras uses fades judiciously - and occasionally simply allows the screen to go blank - an unconventional but potent expression of Emilio's interiority.

The significant contribution *Wrinkles* makes to the typology lies principally in its vivid, immersive first person account of dementia. As viewers, we see from Emilio's point of view and are drawn completely into his world in a way that transcends other films in the typology. A significant factor in the film's impact is the striking, traditional 2D animated style. An analysis of the film noted that the format allows the director '… much more freedom to explore the impact of memory loss from the perspective of his characters and is able to illustrate not just their everyday lives but their innermost thoughts' (Wilkinson, 2012, para. 2).

A consumer review supports the appeal of the animated treatment of the subject matter.

> ‘Getting older, coping with age, and facing life-threatening/altering ailments isn't something we generally like to talk about, which is why Wrinkles presents it to us through beautifully simplistic, 2D animation created through use of an animation cell. The film's brightly colored visuals and clean-cut presentation make us look at age not through a softened lens, but one that allows us not to get blinded through our tears to actually focus on the bigger picture’ (StevePulaksi, 2015).

Framed photos of Emilio’s family come alive and merge into long term memories in a way that recalls similar sequences in *The Iron Lady* and *After the Deluge* but the animated effects make Emilio’s fluid experience of time and memory even more palpable and poignant. Several memorable sequences from the perspective of other characters reinforce the efficacy of the animated format in conveying the felt experience of dementia. Mrs Rosario sits by her bedroom window every day believing she is travelling the Orient Express to Istanbul. The sequence begins from her perspective as a glamorous young woman and then the nostalgic, sepia palette changes to the present where Miguel masquerades as the train’s conductor; as he and Emilio retreat, the soundtrack cues viewers to return to Mrs Rosario’s point of view.[4] Carmen’s fear of aliens is captured in brief, colourful shots of swooping spaceships conveying the graphic, febrile quality of her paranoia. These and many other sequences transport viewers into the character’s intensely felt world – a world of funny, moving and at times challenging emotions and experiences.

As with many of the films in this typology, *Wrinkles* emphasizes the importance of relationships and social connection in supporting emotional wellbeing for the person living with dementia. Emilio’s family are rarely glimpsed; his friendship with roommate Miguel is the defining relationship in

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[4] This sequence can be viewed here: Wrinkles: Orient Express https://www.youtube.com/watch?v=Pk_5FoYmSXQ

the film. A wily and cynical older man who is the mouthpiece for the film's dark humour, Miguel exploits the vulnerabilities of his co-residents for his own ends. However, he is redeemed by his support for Emilio in the face of his friend's increasing confusion and paranoia. Their relationship recalls John and Michael's friendship in *Age Old Friends* and their determination not to 'join the zombies', the only other film included in this thesis that takes place entirely in a residential aged care facility (*Age Old Friends*, 1989).

As director Ferreras observes 'It's not a film about a disease but a film about a friendship, and about how that friendship is possible and necessary for both characters, despite the disease" (Zahed, 2011). The film also underscores the camaraderie and collegiality of the resident community. While dealing with their individual physical and cognitive challenges, collectively residents share resources and knowledge, laugh together and look out for each other. This collegiality is symbolized by Miguel's thoughtful actions in the final scenes of the film where he makes reparation with those he has previously exploited and in the ultimate gesture of friendship and support, moves 'upstairs' to help care for Emilio.

This positive emphasis is noted in the following consumer review:

' Along with scenes depicting the aging process, there are also scenes that show how friendships can develop at any age, and that no matter how old someone gets they still have feelings and opinions too' (tbolo, 2017).

For both a general audience and the aged care workforce, the combination of animation, humour and pathos in *Wrinkles* delivers potentially powerful insights into the lived experience of dementia unlike any other first person account on screen. Ferreras has remarked on the overwhelmingly positive response from viewers of all ages, including those with family members living with dementia.

‘Other people have approached me with similar stories which have been, I don’t know, using the word ‘humbling’ sounds pretentious but I can’t think of another one,” he admits. “It’s also been very good to have had both old people and young people coming up to say that they really liked the movie …’ (Zahed, 2011). As Paco Roca observed in relation to the inspiration for his graphic novel, his choice of an aged care facility setting and focus on older characters was deliberate one given the abs in ensuring that the film takes the “In ‘Wrinkles,’ you don’t see any young people. You see everything through the eyes of older people, so we can understand how they feel and see what it is we can do for them.” (Betancourt, 2014).

For residential aged care staff, the film’s focus on the lived experience of dementia and the residential aged care context raises a range of important issues and opportunities for insights. Emilio’s transition to residential aged care is a difficult one and his grief, boredom and social isolation are common experiences, as noted in this consumer review:

‘For someone who works with older people, often in a care capacity, much of this rang true with me, particularly the boredom and loneliness that many experience when they move into a home. (Christof_McShine, 2014)

The film offers opportunities to explore the challenges involved in the transition to residential aged care. How might Emilio’s admission experience have been improved? What role do aged care staff have in helping make the transition a more positive experience? How might staff support the well-being and improve outcomes for new residents in their facilities during the admission process?

Wrinkles paints a graphic picture of the multiple, unhelpful impacts of the physical environment of the facility, from the anonymity of spaces and way finding difficulties to the deleterious effects of noise, light and inappropriate TV programming on amenity and quality of life. Emilio’s perspective on the social environment is at times equally confronting, particularly in relation to the facility staff. The gym instructor's inability to intuit the lack of enthusiasm for her exercise class is comic but also damning. Activities are limited and do not appear to engage Emilio or other residents. Nursing staff are often absent or indifferent and care needs are not always met. The long dining room queue post meal is because as Miguel observes, there are 'not enough nurses to help them get into bed', testifying to systemic failures in resourcing but also in the fundamentals of person-centred care (*Wrinkles*, 2011).

Balancing this is the supportive friendship between Emilio and Miguel, Dolores and Modesto's example of devoted partnership and the camaraderie and emotional resourcefulness of the resident community. As an educational resource, the film offers opportunities for discussion around the importance of a person-centred approach to care and the positive and negative impacts of the physical and social environment in residential aged care for someone living with dementia.

Conclusion

For a general audience, seeing through the eyes of a character living with dementia is not always an easy perspective to adopt. The texts discussed in this chapter focus on characters whose experiences encompass a range of emotions from joy and exhilaration to frustration, anger and despair. Each of the three films addresses the realities and complexities of living with dementia in different ways but collectively encourages viewers to have a better understanding of that lived experience.

As an educational resource for residential aged care staff, these first person depictions raise relevant issues and offer valuable insights into key concepts around best practice dementia care. Adopting the perspective of the person with dementia and attempting to see the world through their eyes is a central tenet of a person-centred approach to care. The texts discussed in this chapter offer residential aged care staff the opportunity to do precisely that.

Engaging with characters living with dementia can encourage insights into and enhance understanding of a range of issues, from the frustrations of short term memory dysfunction and word finding difficulties to the impact of the physical environment and the importance of supportive relationships in maintaining emotional well-being.

For both a general audience and the aged care workforce, each film acknowledges the challenges of living with dementia, but equally important affirms the possibility of sustaining and developing existing relationships, forming new friendships and maintaining abilities and capacities. As Moore says of her portrayal of Alice, 'I wanted to understand how, as she loses her intellectual capabilities, Alice moves toward a very profound emotional connection with her family' (Seymour, 2015). The final moments of the film attest to this when Alice identifies that beneath the florid language of the monologue Lydia reads aloud to her, 'love' is the playwright's fundamental message.

In *Robot and Frank*, not only does Frank outsmart the forces of law and order but more importantly and somewhat ironically, through his partnership with the robot he rediscovers the value and importance of human connection. In the concluding scenes in *Wrinkles,* Miguel carefully assists the now silent Emilio with his meal and in the face of another resident's disrespectful remarks, firmly asserts that his friend is 'still in there.' Emilio's fleeting smile in response is the film's most profoundly moving moment.

CONCLUSION

> A major ethical issue to be addressed is the framing of dementia by writers, artists, the media and even film makers. Does a popular movie about a health issue have moral worth or is it a just another source of cinematic thrill? (Andrews, 2015, para. 7).

> By facilitating identification with the protagonist affected by the disease, the movies create a change of attitude in the viewer' (Cohen-Shalev and Marcus, 2012, p. 93).

In her criticism of the depiction of dementia in *Still Alice*, June Andrews tackles what has been an enduring debate around the broader question of the value of popular culture. Rather than frame the question in Andrews' ethically overburdened terms, the analysis in this thesis argues for the importance of the selected film and television texts based on the conviction that popular culture has a clear and compelling *educative* 'worth' in relation to the urgent global public health issue of dementia.

Popular culture can function as both a mirror reflecting back prevailing attitudes but it can also suggest new ways of thinking, influence opinion, and change attitudes and behaviour in the broader community. Being a ' … source of cinematic thrill' does not preclude a mainstream film or television episode from simultaneously offering viewers insights into a health related issue. The raunchy romantic comedy in *Friends with Benefits* is central to its appeal to a youthful demographic. In *Robot and Frank*, we are drawn into and are complicit in Frank's criminal endeavours. In *Still Alice*, we engage with the central character's many frustrations and small triumphs as she comes to terms with her changing cognition. In the process of participating in these 'cinematic thrills', we gain insights into the emotions, relationships, challenges and the lived experience of these characters.

This thesis acknowledges that dementia has been variously depicted on the small and large screen over the last three decades and that some of these representations have been simplistic, unhelpful and occasionally alarmist. The texts selected for this analysis illustrate that mainstream film and television can equally be influential source of *affirmative* and *instructive* depictions of dementia.

The 2019 World Alzheimer's Report surveyed global attitudes to dementia across 155 countries and nearly 70,000 participants. Their findings highlighted the stigma and poor understanding around dementia that persists in the global community, significantly, including the health profession. The need for 'specialised education about dementia-related stigma and person-centred care practice for healthcare practitioners' was one of the report's key recommendations (summary, p 11). Increased public advocacy by people living with dementia and 'amplifying the voice of lived experience' was also identified as an important source of information and influence (summary p.11).

The report's emphasis on the urgent need to improve awareness and understanding about dementia in the broader community and the health care sector underscores the rationale for this thesis. For a broad audience, the examples of mainstream film and television discussed in this thesis provide a potentially valuable source of information about dementia and its consequences. Viewers bring varying degrees of knowledge and experience to the screen. The texts discussed offer different ways of engaging with the subject from simply absorbing information about symptomatology to strongly identifying with the issues and challenges involved as a spousal caregiver.

Mainstream film and television texts constitute one of a range of potential teaching resources in the residential aged care context. In the most pertinent study for this thesis, the author was careful to point out that the use of first person accounts of dementia, including but not limited to mainstream media, was only one of a number of educational initiatives that could be used to enhance health professionals' understanding of dementia (Morris, 2014). 'The use of media products complement what is learnt from other core sources including clinical practice, personal experience and related research' (Morris, 2014, p. 437). The texts discussed in this thesis, in combination with other education and training initiatives, can be utilized as important teaching tools for enhancing understanding about dementia, contributing to practice change and improving the quality of dementia care in the residential aged care sector.

This analysis has proposed that selected examples from mainstream films and television series that depict dementia can be grouped under three broad but not mutually exclusive typologies. Each typology can be influential in shaping attitudes and improving knowledge in different ways. The first of these typologies, Dementia at the Margins, includes mainstream films and television series that feature minor characters and references to dementia in narratives that do not focus specifically on the condition. This distinguishes my research from extant scholarship, which has focussed on films dealing substantively with dementia.

Anne Basting suggests that popular culture imagery operates in the realm of implicit memory where viewers may not 'recall it consciously, but it still influences you ' (Basting, 2009, p. 25). The brief, unanticipated but well observed nature of these representations could influence viewers in corresponding and potentially positive ways. Typically found in the comedy, action and thriller genres in globally successful films and TV series, these examples reach a substantial audience, different in size and demographic to the other two typologies. *Billy Elliot* and *Angry Boys* exemplify mainstream films and TV series that could influence attitudes and beliefs about dementia in an equally powerful way as an independent film with a more narrowly defined audience focussed specifically on the subject.

Dementia as Dramatic Device is the second and largest of the three typologies and is distinguished by its emphasis on the role and concerns of carers, supporters and family members of the person living with dementia. While acknowledging that this is the dominant perspective around dementia on the mainstream screen, unlike existing analysis of these texts, I argue for the instructive value of the typology for both a broad audience and as teaching resource for residential aged care. Films and TV series including *Head Full of Honey* and *Exile* can engage and inform viewers about the complexities and challenges of supporting someone living with the condition, regardless of their direct experience of dementia. The texts in this typology offer useful contrasts in the attitudes of family members and approaches to care, exploring key concepts around person-centred care and other issues relevant to the residential aged care setting.

The third and final typology is the most potentially influential of the three categories. The 2016 ADI World Alzheimer Report identified 'experiential methods of teaching' as one of the key components in improving the delivery of health care for people living with dementia. The proposed experiential approach should engage students 'at an emotional level with the experiences of patients' (ADI, 2016, p. 66). While the report framed these recommendations in relation to educating health care staff in acute care settings, the recommendations are equally if not more relevant for other health settings including residential aged care.

This endeavor to engage students experientially and emotionally corresponds with the way in which I have argued selected films and TV series discussed in this typology can have a significant impact. These texts position the viewer to see through their eyes of the person with dementia engaging directly 'at an emotional level' with the central character's felt experience. As Morris noted, these first person accounts of dementia convey ' … the immediacy of what is experienced and a real feeling of involvement with those featured' (Morris, 2014, p. 440). Engaging viewers directly with the central character's experience of dementia addresses the 2019 ADI Report's emphasis on improving knowledge and awareness about dementia by 'amplifying the voice of lived experience' (ADI, 2019b, p. 11).

Still Alice and *Wrinkles,* amongst others in this typology, encourage viewers to think and feel what the challenges and complexities of living with dementia might feel like. Adopting the perspective of the person with dementia and seeing through their eyes underpins one of the central principles of a person-centred approach to care. I have argued that the texts in this small but expanding typology offer residential aged care staff specific insights into the complex interplay of social, emotional and physical factors in the environment of a person living with dementia. These screen depictions provide valuable ways for aged care staff to consider what constitutes a person-centred approach and how best to support someone living with dementia in the residential aged care environment.

Experiencing Dementia: Immersive And Experiential Technologies

The films in this typology offer a broad audience and residential aged care staff potentially powerful insights into the lived experience of dementia but also suggest useful connections with other experiential approaches in the field of dementia training and education.

The development of virtual reality (VR) technologies and related 'immersive' approaches is one of the most promising and innovative areas of research in the dementia education field over the last decade. These initiatives aim to simulate various aspects of the environment and the daily challenges faced by a person living with dementia. Immersive virtual reality or 'virtual experience' programs include Alzheimer's Research UK's 'A Walk Through Dementia,' the US-developed 'The Virtual Dementia Tour' and the Australian virtual reality based initiatives, 'Experience Dementia' and 'The Virtual Dementia Experience' (Dementia Australia).

These programs conform with the kinds of 'experiential methods of learning' that the 2016 ADI report argued were critical in conveying the lived experience of dementia and engaging students or participants 'at an emotional level with the experiences of patients' (ADI, 2016, p. 66.). The two Australian programs are indicative of these immersive programs; the way in which they can harmonize with the use of popular culture texts warrants a brief overview here. Renee Brack's virtual reality game the 'Experience Dementia' aims to increase awareness and understanding about the lived experience of dementia by creating ' … a virtual world with a sequence of visual experiences based on stories and recorded symptoms of Dementia as well as appropriate sound design to enhance the experience' (Aubert, 2018, p. 1). Users are required to navigate through a series of different environments and a sequence of structured events. The game is aimed at caregivers but also students and 'career dementia researchers' to encourage users to ' … sympathise and understand more of what the experiences are like and … how Dementia can affect a person in many ways' (Aubert, 2018, p.1).

Dementia Australia's award-winning Virtual Dementia Experience offers a similarly immersive, educational experience. Designed in conjunction with carers and people with lived experience of dementia, participants are exposed to a simulation of a home environment involving light, sound, colour and visual effects. Participants are required to navigate this environment while also undertaking typical tasks of daily living. The program's objective is to deliver ' … experiential learning aimed at increasing empathy' (Dementia Australia). Dementia Australia have subsequently developed additional VR initiatives 'Enabling Edie' and 'a day in the life – mealtime experience', both of which provide participants with the VR perspective of a person living with dementia in a variety of environments.

As one of the key members of the program development team at Dementia Australia noted, there has been a long history of traditional approaches to teaching about best practice dementia care that has largely involved ' telling people what dementia is and what good dementia care looks like…' (Cheu, 2020, p. 46). As she went on to observe, the powerful impact of immersive, experiential programs has produced better results. ' … from our experience in VR to date, we're finding you're much more likely to get practice change with the use of VR.' As noted in a recent discussion of emerging experiential approaches in the dementia education field, 'It is one thing to be told how another person feels; quite another to come close to feeling the same way' (Joosten, 2015, para. 13).

As with the conceptually analogous immersive research drama that transformed 'healthcare professionals' understandings, images and intended actions …', these virtual technologies suggest useful synergies and a clear complementarity with the way in which I have argued that mainstream film and TV texts can be deployed, particularly in relation to first person accounts of dementia on screen (Jonas-Simpson et al, 2012, p. 1952). This potential to exert a real and powerful impact on a broad audience and tangible practice changes in the residential aged care sector makes this third typology particularly significant.

Teaching the Typologies – Recommendations

This thesis has argued for the use of mainstream film and television texts as teaching resources in the Australian residential aged care sector but there are clear implications for an equivalent impact and application in the global residential aged care context. The fundamental nature of popular culture - its mass production and consumption - means that the selected texts in this thesis, and many others, provide a globally accessible and legible means of exploring complex issues and ideas in relation to dementia and dementia care.

Examples in each of the three typologies can be used to guide general discussions, underpin concept acquisition and conduct perspective-taking and experiential exercises in relation to key concepts and issues in best practice dementia care. In the following recommendations, I have included a number of additional texts, viewed during the data collection process, that were not the subject of analysis in this thesis but provide useful insights on a range of issues.

The nominated texts (and many others) can be used in a pedagogical context to:

- Illustrate how direct experience with a person with dementia can encourage understanding and insight (*The Descendants*, *Angry Boys*, *Friends with Benefits*, *The Good Life*, *Head Full of Honey*, *Still Alice*, *Exile* and *Wrinkles)*
- Contrast approaches to care and support for the person living with dementia and the respective outcomes in terms of illbeing and wellbeing (*Mother and Son, What They Had, Head Full of Honey, Billy Elliot, Friends with Benefits, The Good Life, Angel's Perch, Exile*, *Packed to the Rafters, Derek, Neighbours* and *Wrinkles*)
- Explore the way in which a dementia diagnosis has differential impacts for different family members (*Friends with Benefits*, *Billy Elliot*, *The Savages, What They Had, Lou, After the Deluge, Hanging Up, Choke, Head Full of Honey, Happy Tears, A Time to Remember, Speed of Life, Diminished Capacity, Sundowning, Nebraska, Angel's Perch, Mr Holmes, Packed to the Rafters, Neighbours*)
- Address unique issues faced by spousal caregivers (*Away From Her, What They Had, The Leisure Seeker, Still Alice, Still Mine, Iris, The West Wing*)
- Explore the importance of caregivers adopting the perspective of the person living with dementia through first person accounts of the lived experience of the condition (*Iris, The Iron Lady, Still Alice, Head Full of Honey, Mr Holmes, The West Wing, Exile, After the Deluge*)

- Foreground one of the guiding principles of person-centred care -

knowing the individual you are providing care and support for (*Speed of Life, Friends with Benefits, Billy Elliot, What They Had, Head Full of Honey, Angel's Perch, Still Alice, Robot and Frank* and *Wrinkles*)

- Explore the positive and negative impacts of the physical and social environment on the person living with dementia (*Mother and Son, The Good Life, Angry Boys, Wrinkles, Billy Elliot, Friends with Benefits, Gone Girl, Head Full of Honey, The West Wing, Mr Holmes, Angel's Perch, Quartet* and *Nebraska*)
- Demonstrate the importance of supporting agency and identity and preserving skills and capacities in living with dementia (*Mother and Son, Absolutely Fabulous, Angry Boys, Wallander, Diminished Capacity, Robot and Frank, Away From Her, Iris, The Iron Lady, Head Full of Honey, Angel's Perch, Still Alice, Wrinkles, Mr Holmes*)

There are important considerations around the use of mainstream texts as educational resources in the residential aged care sector that need to be reiterated here. The careful selection of individual film and TV texts, specific scenes, characters and situations, and the careful contextualization of these are vital in ensuring their efficacy and impact as educational resources. As critics of 'cinemeducation' have noted, the participants - health professionals and otherwise - need to be given the necessary critical tools to understand and interpret these texts in order for them to be useful resources (Capstick et al, 2015). As with a general audience member bringing their own perspective and experience of dementia to the big and small screen, it is also important to be attentive to the varying personal experiences and responses participants might bring to these texts in a pedagogical context and to provide the appropriate support in the post viewing phase (Morris, 2014).

Implications, Future Directions and Final Thoughts

An earlier, related study looking at the representation of mental health issues in mainstream film and television suggested that collaboration with the film and television industries was vital in order to reduce stigma and negative stereotypes and encourage more positive portrayals of mental health issues on screen in the future (Pirkis et al, 2005). The study recommended cultivating productive relationships in the relevant industries to facilitate opportunities for input into script and character development.

This recommendation applies equally compellingly to the depiction of dementia and is exemplified by the collaborative creative process involved in the production of *Still Alice*. Despite the dissenting views on the representative nature of the depiction of the condition, the film was developed at every stage with the involvement of people with lived experience of dementia, health professionals and researchers and dementia advocacy organizations. The VR projects outlined above adopted similarly inclusive methods, developing program content derived from stories and anecdotes from people living with dementia, confirming that this genuinely consultative process is the way forward in the future.

While acknowledging that the mainstream film and television industries in Australia and elsewhere are fundamentally driven by commercial rather than educational imperatives, *Still Alice* offers an encouraging model for how the two might combine productively. Encouraging collaboration between these creative industries, people living with dementia, the health care sector and dementia advocacy organizations could work towards future productions of affirmative portrayals of people living with dementia that, as with the impact of the texts that have been the focus of this analysis, could contribute to improved knowledge and understanding of the condition.

The inspiration for this thesis was two fold, in part informed by a long-standing fascination with and admiration for the Australian TV series *Mother* *and Son*. Writer Geoffrey Atherden's provocative and prescient choice to place an older woman with dementia at the heart of a TV comedy was repaid by critical acclaim and the enduring affection of local and international audiences. This suggested that despite what could be regarded as a challenging central premise, there was an appetite for mainstream popular culture that dealt with the subject of dementia. The second source of motivation was a growing awareness of the growing number of mainstream film and TV series that tackled the topic of dementia in recent decades in an increasingly detailed, and in many cases, considered way.

Many of the reports, articles and other sources cited in this thesis have noted the urgent and ongoing need for targeted education to reduce stigma and improve understanding of dementia and promote best practice dementia care. Some have specifically called for further research into the positive impact of mainstream media, including film and TV, in this context and I hope that this thesis has answered that call in some small measure (Doyle et al, 2005; 2012, Gerritsen, Kuin and Nijboer, 2013; Morris, 2014).

As a clinician with more than three decades of experience working in the residential aged care sector and passionately committed to improving the way we support people living with dementia, I witness the urgent, ongoing need for an aged care workforce that is better educated and skilled. As a film scholar, it appeared self-evident to me that many of these texts provided a valuable and untapped source of information and influence. The objective of this thesis is to make a contribution to thinking about ways in which examples from mainstream film and television can enhance understanding about dementia in the broader community and contribute to tangible practice change in the residential aged care sector. In my role as a dementia care specialist and educator at a modestly scaled residential aged care facility in Australia, I intend to lead by example.

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