Exploring the whole family experience living with younger onset dementia from a social model perspective

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Contents

CHAPTER 1: ***Introduction, theoretical framework and methodology***

CHAPTER 2: ***Identity, impairment and disablement: exploring the social processes impacting identity change in adults with acquired neurological impairments***

CHAPTER 3 : ***Feeling invisible and ignored: families' experiences of marginalisation living with younger onset dementia***

CHAPTER 4: ***The emotional well-being of young people having a parent with younger onset dementia***

CHAPTER 5: ***Empowerment of young people who have a parent living with dementia: a social model perspective***

CHAPTER 6: ***Developing a theoretical framework to underpin the co-creation of family focused services living with younger onset dementia***

CHAPTER 7: Discussion and conclusion

APPENDICES:

Abstract

Background

Adults with acquired neurological impairments encounter unique challenges at a socially significant time in their lives - being under the age of 65 years. Discriminatory social attitudes towards adults with physical and/or cognitive impairments can be a product of social stereotyping based on their diagnosis. The social model of disability has been a valuable tool in improving our understanding of the cultural, economic and environmental barriers experienced by individuals living with physical impairments and, more recently, with intellectual and mental health impairments. This model has proven useful in facilitating a more socially orientated approach to services and support opportunities for these population groups. However, there has been very little application of the social model in the dementia sector. Therefore, we have engaged with this model for the purpose of explaining and understanding lived experiences of persons living with YOD and of their family members, as well as to help guide constructive development of relevant services.

Methods

In this qualitative research we explored individuals' lived experiences through collecting data from twenty-six semi-structured interviews with parents living with YOD, as well as spouse caregivers and children in the families. Interviews were also conducted with ten people living with a range of acquired neurological impairments under 65 years, and seven health and social care providers supporting families with YOD. Interview data was analysed thematically, using the social model of disability as a theoretical framework through which to outline the cultural, economic and environmental barriers experienced. More detailed methodology is outlined in the five publications included in this thesis.

Findings

Chapter 2; *Identity, impairment and disablement: The exploration of social processes affecting identity change in adults living with acquired neurological impairments* studied the social processes that impact on identity formation in adults living with acquired neurological impairments and progressive and non-progressive physical and/or cognitive impairments. Identity change was considered from the combined perspective of the social model of disability and the social identity theory.

Social inequalities were identified as being experienced by individuals living with all types of impairments. However, those living with cognitive impairments under 65 years, were identified as being less understood by society, and associated with experiences of significant discrimination. The following Chapter 3; *Feeling invisible and ignored: families experiences of marginalisation living with younger onset dementia* explored from a social model perspective, the social factors which impact on the experiences of families living with YOD, including children and young people.

In Chapter 3, our attention was drawn to the negative impact of society's response and attitudes, adding to the marginalisation of families - affecting their relationships and ability to function together. The consequences of these lived experiences for children and young people having a parent with YOD, was highlighted as a gap in the research literature. The subsequent Chapter 4: *The emotional well-being of young people having a parent with younger onset dementia* looked at the societal influences on the emotional well-being of these children and young people from the perspective of the social model of disability.

Chapter 4 confirms the ongoing emotional distress faced by children and young people at a particularly challenging time in their own lifecycle. The authors then delved further in an attempt to make sense of their lived experiences, having a parent with younger onset dementia. The outcome of this research resulted in Chapter 5: *Empowerment of young people who have a parent living with dementia: a social model perspective,* which considered what social factors, could facilitate better support and social inclusion for these children and young people.

At this juncture the research demonstrated YOD impacts the whole family unit, thus highlighting the need for greater social inclusion, societal acceptance and enablement. Tailored formal services and support to address the complex and challenging needs of all family members, an area that has had little focus in the research literature, needed further exploration. This challenge was undertaken in Chapter 6: *Co-creation of a family-focused service model living with younger onset dementia* using the combined perspectives of the social model of disability and the family systems illness model**.** Bringing together the viewpoints of healthcare and service providers with all family members was critical to making sense of the multifaceted societal challenges faced in providing and receiving age-appropriate services. A theoretical framework was proposed as the basis for a co-created, family-focused service model.

Conclusion:

Throughout this thesis the common theme that has linked these chapters together, from the perspective of the social model of disability, has been the lack of understanding and largely unmet needs of people living with YOD and their family members. Experiences of socially constructed disablement impacts family function, relationships and connectedness. Hence, looking through the social model lens in relation to dementia allows us to see things differently, to redirect attention away from a diagnosis, personal tragedy, and disablement; and instead to focus on choice, control and enablement of the whole family. The proposed co-created, family focused service model could provide the foundation for developing social model principles to service policies and practices through greater cooperation, communication and learning between service users, service providers and stakeholders. With the aim to change societal views, and improve understanding and social inclusion, thereby enabling the whole family to feel valued and live well with dementia.

Aims

This thesis seeks to address current gaps in the research literature particularly in relation to developing the social model of disability as a theoretical framework, to improve understanding of the societal influences impacting on individuals living with cognitive impairment and their family members. Through this process we hoped to explore the utility of the social model as framework to advance the social approach to service development for families living with YOD.

Objectives

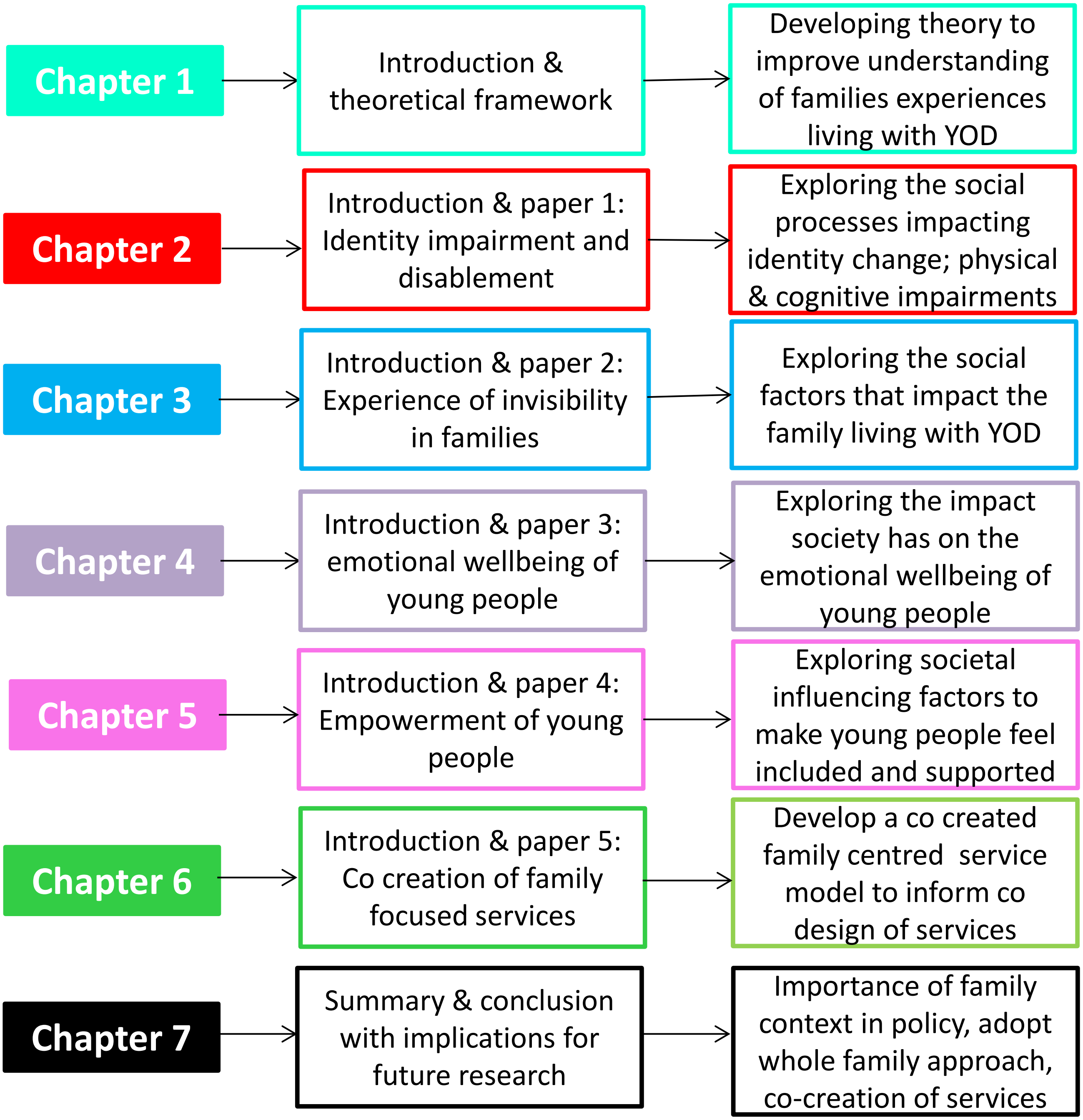
1. To compare the experiences of adults of working age living with a progressive or acute onset acquired neurological physical and/or cognitive impairment, and consider the social processes that influence their identity.

2. Exploring the unintentional, socially disabling experiences of individuals living with YOD, their family members, and the whole family, to broaden our knowledge and understanding of the impact of societal experiences on relationships, interactions, and the functioning of the family throughout changing lifecycle and developmental stages.

3. To develop a theoretical framework as the foundation to building family focused practices, featuring shared knowledge and understanding, to address the unique needs of these families and of individual members over life cycle and developmental stages.

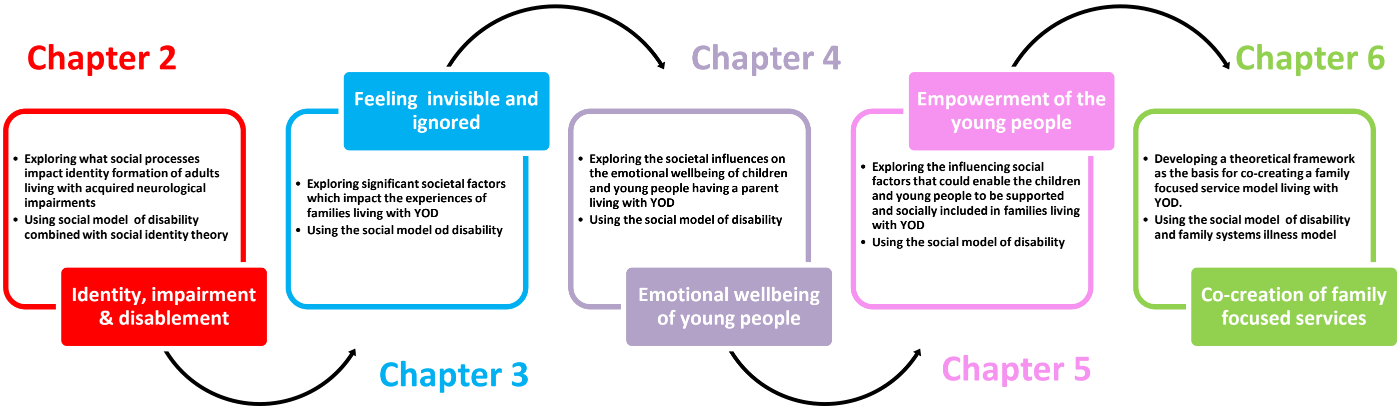
Concept map of PhD thesis

Figure 1.1 Concept map of thesis



Using the theoretical framework of the social model of disability to explore the impact of younger onset dementia on the person and their families

Figure 1.2: Publications related to thesis chapters



Chapter 2

- Exploring what social processes impact identity formation of adults living with acquired neurological impairments
- Using social model of disability combined with social identity theory

Identity, impairment & disablement

Chapter 3

Feeling invisible and ignored

- Exploring significant societal factors which impact the experiences of families living with YOD
- Using the social model od disability

Chapter 4

- Exploring the societal influences on the emotional wellbeing of children and young people having a parent living with YOD
- Using the social model of disability

Emotional wellbeing of young people

Chapter 5

Empowerment of the young people

- Exploring the influencing social factors that could enable the children and young people to be supported and socially included in families living with YOD
- Using the social model of disability

Chapter 6

- Developing a theoretical framework as the basis for co-creating a family focused service model living with YOD.
- Using the social model of disability and family systems illness model

Co-creation of family focused services

List of figures and tables

Figures:

Tables (numbers linked to chapters):

List of abbreviations

AD	Alzheimer’s disease
CVA	Cerebrovascular accident
DAI	Dementia Alliance International
EOAD	Early onset Alzheimer’s disease
FTD	Frontotemporal dementia
LBD	Lewy body dementia
LOD	Late onset dementia
MND	Motor Neurone disease
MS	Multiple sclerosis
PD	Parkinson’s disease
SCI	Spinal cord injury
VD	Vascular dementia
WHO	World Health Organisation
YODKW	Younger onset dementia key worker
YOD	Younger onset dementia

Dedication and Acknowledgments

Dedication

This thesis is dedicated to all the wonderful people who so willingly participated in this work. They welcomed me into their world and shared their stories with such openness and honesty, to improve the future of other families living with younger onset dementia.

Acknowledgements

To my supervisor, Associate Professor Chris Roberts, who started me on this transition from clinician to researcher. I sincerely thank you for your guidance, encouragement and support you've given to me over the years. This amazing achievement is basically down to you and your belief in me, which has gone so far beyond my own expectations. I would also like to thank my other supervisor Professor Susan Kurrle for providing me with amazing opportunities whilst conducting this research, helping me with funding and gaining a masters scholarship, becoming a member of the Cognitive Decline Partnership Centre and supporting me throughout the process of the research.

I would like to thank my lovely family, husband Paul and children Sam 21, Beth 18 and Rory 12 for supporting me as I have been on this roller coaster journey. I particularly liked the frequent encouraging comments 'When are you going to finish this PhD?' 'Haven't you finished it yet?' I know it has not been easy living with a wife or mother juggling a busy family life, work and PhD but I just want to tell you how lucky I am to have you all and I do appreciate and love you all. I must make a particular mention of Paul who really has been so supportive and encouraging (may have been different if he'd known what he was letting himself in for), taking on single parenting role while I went on writing retreats to speed the process up or spending long days in Hornsby. I am truly grateful and thank you from the bottom of my heart. My friends have been amazing, continually touching base with me to check all is well and encouraging me to keep going. My family overseas, although somewhat removed from the impact of this, have remained interested in the progress of this PhD.

I would like to sincerely thank Michele Daly, who has been an author in three of the papers, as she supported me greatly through the early days of my transition to researcher and has been an ongoing supporter of myself and this research throughout, which I really appreciate. The other

contributing authors, Pamela Roach and Caroline Bulsara, have been very encouraging and supportive of both me personally and the research.

I cannot believe how long I have been a part of the Northern Clinical School at Hornsby hospital. I thank you all for supporting and encouraging me to keep going. I am also grateful for the use of a desk space, my retreat, throughout this whole process. Thank you to Tracey Bayliss, Karyn, Mossman, Susan Barr, Narelle Shadbolt, Carol Gifford, Sylvia Guenther, Premala Sureshkumar, Greg Don, Joel Cohen and Jennifer Shone. Special mention to Tracey, for all the lunch break debriefing sessions!

A big thank you goes out to my proof readers Brooke Elder, Carmel Mezrani, Mary Coney and Peita Duggan. I would like to make a very special mention of a truly inspirational lady called Peita who sadly passed away at a young age, from motor neurone disease, before this PhD was submitted. Her willingness to help me whilst her condition rapidly declined, demonstrated real humility. I will be forever grateful to her.

My Profile

I have been a physiotherapist for many years working with people living with a range of neurological impairments, predominantly in community settings. In the past I have been involved in setting up community neurological rehabilitation teams in England and Australia. There seemed a general lack of insight among healthcare professionals into the impact of having a neurological impairment in the working aged population. In many situations disregarding the additional challenges they faced, around belonging to families with children, employment and financial repercussions and a changed life trajectory.

I had the opportunity to apply for and successfully gained a Primary Health Care Research Development Programme (PHCRED) scholarship. My supervisor Associate Professor Chris Roberts helped to start my research career and has continued to be my supervisor throughout this whole process. In starting this huge learning journey as a qualitative researcher, I hoped in some way to help raise awareness and understanding on the impact of living with a neurological condition in working age, an area that I was and still am passionate about.

Towards the end of the year scholarship I was fortunate to receive a grant to begin working on a project to explore the impact of younger onset dementia on the person and their family, including children and young people in the families. It was during this time I decided to apply to for a Masters in Philosophy (MPhil) through the University of Sydney, Sydney Medical School. I was successful with this application and began this as a part time Master's student in 2013. My other supervisor Professor Sue Kurrle had extensive experience in the area of Dementia. I was lucky enough to be offered a 15 month Masters scholarship with the NHMRC Cognitive Decline Partnership Centre, which terminated in April 2015. I then applied to transfer to a PhD in Philosophy, which I successfully started as a full time student in July 2015.

I made the decision to do a PhD thesis by publication as I wanted to be contributing to social change throughout my PhD. I believed having published papers would contribute more favourably to this process. This whole journey has definitely had its highs and lows, with the amount of work and effort involved in writing a paper being beyond my naive expectations. The amazing and inspiring people that I had the honour of interviewing, sharing their challenging life experiences so honestly and with a desire to be part of a change to make a difference and improve understanding, have given me the impetus to keep going. To contribute in some way to improve knowledge and raise awareness of the negative social influences on families living with complex needs and offer a way of advancing social change, is important to me both personally and professionally.

Throughout this entire long journey my family has supported me greatly, although I don’t think they anticipated it would take me so long. I know I have been rather distracted and overwhelmed at times but they have accepted this as something I have and needed to do. This research has really drawn my attention to the importance of encouraging open communication; understanding and positive relationships within the family unit as having this strong foundation could be the means to managing and surmounting difficult times. This greater insight and understanding has benefitted me clinically and personally.

Chapter 1

Introduction, theoretical framework and methodology

Overview

My thesis is presented as a series of five papers, bookended by opening chapter and discussion section. This qualitative study explores the impact of younger onset dementia on the person living with the illness and their family members, including the experiences of children and young people. This introductory chapter will provide a background to the research, a rationale for the need for this type of study; introduce the theoretical framework used across all five papers and reflections on methodology. All references for Chapters 1 and 7 can be found at the end of the thesis from page 181 to 186.

1.1 Introduction

1.1.1 Younger onset dementia

Dementia is a syndrome that causes a progressive decline in cognitive function, most commonly affecting the elderly population. However, some people develop dementia under the age of 65 years, which is referred to as either ‘younger’ or ‘early onset’ dementia, or ‘presenile’ dementia. Whilst I agree with the terminology surrounding this life cycle onset of dementia debated in the literature, for this thesis I have used the term ‘younger onset dementia’ (YOD) (Koopmans & Rosness, 2014). The significance of the age of 65 in defining YOD appears to be arbitrary, with little international consensus around diagnostic criteria - for example, whether the person has symptoms before 65 years, or is diagnosed at 65 years (Koopmans & Rosness, 2014). Age should be considered important, not just from a pathological perspective of the condition, but in regards to the person’s stage in the life cycle. People living with YOD face unique social challenges in employment, managing financial commitments and in the home – specifically with children and young people (Rossor, Fox, Schott, & Warren, 2010). Nevertheless, YOD is regarded as both a ‘psychosocial and medical health problem’ (Koopmans & Rosness, 2014, p. 1931), with far reaching consequences on the person living with YOD and all their family members (Allen, Oyebode, & Allen, 2009; Bapista et al., 2016; Johannessen & Moller, 2013; Roach, Keady, Bee, & Williams, 2014; Rossor et al., 2010; Spreadbury & Kipps, 2017;

Svanberg, Spector, & Stott, 2011). This research captures the diversity of family units, recognising differing family structures, as well as the disparate ages and developmental stages of affected family members.

1:1.2 Social versus biomedical model

Even though dementia is an acquired neurological condition in adulthood, it is thought that people living with dementia do not associate or consider themselves as belonging to the disabled community, despite experiencing physical, environmental, attitudinal and emotional barriers to full inclusion in society (Shakespeare, Zeilig, & Mittler, 2017; Thomas & Milligan, 2018). This is partly due to their socialisation into a biomedical model of health and social care (Gilliard, Means, Beattie, & Daker-White, 2005; Keyes, 2014), and the perception of taking on 'another stigmatising label' (Shakespeare et al., 2017, p. 3). This thesis takes a social model approach to dementia, which is at odds to the dominant biomedical model that ultimately medicalises dementia, reinforces personal tragedy and emphasises the need for medical intervention (Thomas & Milligan, 2015). The value of the social model is the way in which it reframes living with dementia. The social model consider the needs of the individual and whole family, recognising and respecting age of all family members, identities and interactions within and outside the family. This doctorate thesis begins by exploring both the commonalities and differences of individual experiences with acquired neurological, physical and or cognitive impairments under 65 years.

1:1.3 Epidemiology and prevalence of YOD

Dementia is a worldwide 'major public health concern' (Rossor et al., 2010, p. 793), currently affecting over 46.8 million people, and predicted to impact 131.5 million people by 2050 (World Alzheimer's report 2015). Within Australia, recent statistical estimations indicate more than 425 416 Australians living with dementia, estimated to increase to 536 164 by 2025. According to recent figures, 264 423 of people living with dementia in Australia, are under 65 years, which is approximately 15% of all people living with dementia. This is expected to rise 29 375 by 2025 (Dementia Australia key stats Feb 2018). However, YOD does not consist of a single disease process. Rather, there are many different types of dementia, including frontotemporal dementia (FTD), vascular (VD), dementia with Lewy bodies, and the more prevalent Alzheimer's disease (AD) (Rossor et al., 2010; Spreadbury & Kipps, 2017), each causing differing types of impairment (Rossor et al., 2010) particularly among younger people (Carter, Oyebode, & Koopmans, 2017). At the time of writing, there is a sense, compared with the large-scale problem of late onset dementia (LOD), (i.e. those in the over 65 age group), that people living with YOD and their supporters, often feel overshadowed.

This overshadowing could in part be due to the lack of precise epidemiology studies, both nationally and internationally, exploring the prevalence of YOD, which may contribute to YOD being identified as a 'rare condition' (Roach et al., 2014, p. 1398). Lambert et al. (2014) conducted a systematic review of the prevalence of YOD. This review highlighted 'many difficulties encountered when trying to estimate numerically the disease burden', with great differences in prevalence rates based on the lack of standard methodological approaches to study designs required to achieve a true estimation (Lambert et al., 2014, p. 569). Another recent systematic review and meta-analysis explored the rate of early-onset Alzheimer's disease (EOAD), the most common form of dementia, demonstrating that the rate of EOAD worldwide was 6.1%. This was felt to be a more accurate estimation than the 1-2% that is frequently mentioned (Zhu et al., 2015). However, the lack of international consensus on the definition and language describing YOD makes comparability of research in this area very difficult (Carter et al., 2017).

1:1.4 Younger onset dementia; a growing concern for the whole family

The definition of YOD needs to not only highlight the distinctions from LOD, but encompass the diversity and significance of age within the younger age group (Carter et al., 2017). A literature review by Sansoni et al. (2016) pointed out that underestimating prevalence of YOD 'may have major implications for service utilization and planning' (Sansoni et al., 2016, p. 3). A recent systematic review demanded the uptake of more research to help design and develop age-appropriate services. This review noted there had been little change in services for people living with YOD and their caregivers over the last 26 years, even with the diagnoses of YOD increasing worldwide (Mayrhofer, Mathie, McKeown, Bunn, & Goodman, 2017). The rise in the diagnosis rates of YOD has significance economically, as highlighted in a Singapore study, which reported that the economic cost of YOD on society was more than double that of the older population (Kandiah et al., 2015). This was attributed to the 'loss of socially and economically productive individuals to society' (Carter et al., 2017, p. 1).

As well as a financial and social impact on the individual, there is an effect on the whole family especially when children and young people are involved. There has been growing interest in research exploring the perspectives of all family members, which in the past largely excluded the persons living with YOD and their children. Much of the research relating to YOD focused on caregivers and healthcare and service providers' perspectives, highlighting discrepancies in their viewpoints on essential aspects of life with YOD (Beattie, Daker-White, Gilliard, & Means, 2004). More recently, there have been growing opportunities in research where people living with YOD have been able to share their lived experiences and participate in studies – a process which is crucial for enhanced understanding (Carter et al., 2017; Millenaar et al., 2016). Beattie et al. (2004) demonstrated that interviews could be conducted well with people living with YOD (Beattie et al., 2004), and involving these individuals in the research process could assist in understanding their experiences. Also, identifying the person living with YOD as an integral part of the family, and not as a separate entity, highlights the importance of understanding social experiences and relationships within the whole family, as a functioning social unit.

In this thesis whole family experiences were sought from immediate family which includes the parent living with YOD, other parent and the children. It is important however, to adopt holistic practices that regard 'the whole family as a collective' whilst at the same time recognising the shifting social change in the makeup of families (Clarke & Hughes, 2010, p. 528; Hall & Sikes, 2018). Extended family members do impact immediate family experiences living with YOD, as mentioned by several participants, but their perspectives were not collected for this research.

Identifying family members across ages, with their individual and shared needs, is significant to understanding dementia experiences within the family unit. This is particularly relevant with changing relationships between children, parents and significant others within the context of family 'intergenerational dynamics' (Roach, Drummond, & Keady, 2016, p. 27). Hence draws our attention to the uniqueness of families and the impact of altered family relationships on the children and adults as they move through different stages in the life cycle, over the trajectory of YOD (Hall & Sikes, 2018; La Fontaine & Oyebode, 2014; Gelman & Rhames, 2018). The impact of challenging family circumstances is known to generate 'ripple effects to all family members and their relationships' (Walsh, 2003, p. 3) impacted by YOD. The intergenerational family and relationships between family members is integral to service design and practice, which requires great consideration.

Consequentially I consider the experiences of the whole family to determine the critical factors that can contribute to the shift away from a biomedical approach which focuses on the diagnosis and impairments of dementia and the associated personal tragedy. Instead, I employ a social approach ascertaining the role society plays in defining and influencing the lived experiences of the individual with dementia and their whole family. There is an emerging literature on viewing the lives of people living with YOD, from a social science perspective (Thomas & Milligan, 2015, 2018). Experiencing barriers to participating in meaningful activities in the community, ‘low societal expectations', and being exposed to inadequate support and understanding, can all manifest in negative behaviour changes in people living with YOD, which can in turn impact family life (Boyle, 2014, p. 1140). These behavioural changes are often directly attributed to the dementia, which supports the biomedical model perspective. However, this may also be a reflection of the personal feelings of lack of control and self-worth, impacting them individually, and also their family circumstances, which can be associated with the social model of disability (Boyle, 2014; Oliver, 2009; Thomas & Milligan, 2015). In research literature, informal family caregivers have reported higher demands placed on them as a consequence of the unexpected diagnosis of YOD in their relevant stage of lifecycle - being employed, bringing up a family, and having financial commitments (Brodaty & Donkin, 2009; Millenaar et al., 2016; van Vliet, De Vugt, Bakker, Koopmans, & Verhey, 2010). They often experience more significant physical and emotional problems, family conflicts, relationship issues, financial and employment concerns.

1:1.5 Children and young people in families living with YOD

The experiences of children and young people belonging to a family having a parent with YOD, is a relatively new phenomenon in the research literature. As with people living with YOD, the experiences of children and young people were reported by parents without dementia through a survey. This survey indicated seventy-five percent of children experienced emotional or psychological problems. These children also had difficulties at school and more significant conflict with the parent with dementia - mainly if this was the father (Luscombe, Brodaty, & Freeth, 1998). When Svanberg et al. (2011) conducted a literature review on the impact of YOD on the family, it was concluded that although YOD does impact the whole family, the effects on children were only considered briefly in a few studies (Svanberg et al., 2011). Through listening to the lived experiences of children and young people in these families, it is clear that their lives have been impacted in various ways. Recognition of the many influences on their life needs addressing and support provided accordingly (Allen et al., 2009; Barca, Thorsen, Engedal, Haugan, & Johannessen, 2014; Hall & Sikes, 2016; Roach, Drummond, & Keady, 2016; Svanberg, Spector, & Stott, 2010). The literature review also highlighted the need for more research to consider life from the perspective of affected children and young people. It has also stressed the need to understand the parent without dementia's dual caring role, having both a partner with YOD, and dependent children, as well as the implications of the hereditary element of dementia on the children (Svanberg et al., 2011). However, Cabote et al. (2015) reported in a systematic review, studies conducted on the predicted caring burden on adults and spouses of people with YOD discounted child and young people as caregivers (Cabote, Bramble, & McCann, 2015), which is consistent with the prevailing dyadic view of the family. Most of the research to date has investigated the impact of YOD on the person and their significant carer, which is a model typically derived from the examination of older adults with dementia, often assuming the principal caregiver in families with YOD will be the spouse or another adult (Diehl, Mayer, Förstl, & Kurz, 2003; Nicolaou, Egan, Gasson, & Kane, 2010; Rosness, Mjorud, & Engedal, 2011).

1:1.6 Understanding of the needs of families living with YOD

Current literature explicitly highlights the experiences of social exclusion and discrimination that are associated with having a parent with YOD. The impact on the young people is profound and complex, often leaving them feeling alone and isolated, demonstrating the need for more focused services and support for families (Allen et al., 2009; Barca et al., 2014; Carter et al., 2017; Gelman & Greer, 2011; Johannessen, Engedal, & Thorsen, 2015; Luscombe et al., 1998; Svanberg et al., 2010). Greater knowledge about these families' social experiences, interactions, and relationships, could be the impetus to changing social practices (Boyle, 2014). It was recommended that change needs to happen through better training of social and healthcare providers, to equip them with a greater understanding of the family biography and storyline, in order to create family centered care, and interventions that are focused and responsive (Roach, Keady, & Bee, 2012; Roach et al., 2014).

Identifying the life cycle stage of the person living with YOD as well as other family members can help health and social care providers understand these impacts on family relationships. This is vital to the functioning of the family (Millenaar et al., 2016; Roach et al., 2014; Rolland, 1987). Exploring family beliefs and background can help ascertain resilience and adaptability to a changed life circumstance that may have repercussions on future situations of all family members (Rolland, 1999a,b). There needs to be recognition of differing financial situations, family and individual's perceived level of need, access to information, and suitability of services available. Lack of understanding and appropriate assistance contributes to the failure to uptake services and support, which can impact access to future interventions (Cations et al., 2017).

1.2 Theoretical framework

1.2.1 The social model of disability

At the onset, this thesis focused on the social underpinnings of living with acquired neurological impairments, which included physical and cognitive impairments. I wished to further explore living with cognitive impairments from a social context, as this group tends to be 'trapped within the dominant medical discourse' which reinforces marginalisation, discrimination and oppression (Shakespeare et al., 2017, p. 4). The utility of the social model of disability (Barnes & Mercer, 2011; Oliver, 2009) as a theoretical framework to help understand and explain experiences living with YOD from an individual and family perspective was appropriate to develop in this thesis. The application of the social model to assist understanding of experiences of dementia has been considered by only a few researchers (Boyle, 2014; Gilliard et al., 2005; Mental Health Foundation, 2015; Thomas & Milligan, 2015, 2018) but has proven its worth in other clinical areas of research (Beresford, Nettle, & Perring, 2010; Chappell, Goodley, & Lawthom, 2001; Tew et al., 2012). The social model offers a different viewpoint to explain the social, attitudinal, environmental and physical barriers that are imposed on individuals living with YOD and their families, influencing their capacity to fully participate in society (Boyle, 2014; Mental Health Foundation, 2015; Thomas & Milligan, 2015). The social model draws our attention away from the personal tragedy and hopelessness of the situation based on the biomedical model, instead focusing on experiences of marginalisation and discrimination within society, which impact the right of equal citizenship as experienced by people living with dementia (Gilliard et al., 2005; Thomas & Milligan, 2015).

1.2.2 Development of the social model

The social model of disability was created by Michael Oliver to bring attention to the social barriers experienced by people living with physical impairments (Oliver, 1983). The social model drew a sharp distinction between impairment and disability, such that 'impairment' is the functional limitation within the individual caused by physical, mental or sensory impairment. Disability meanwhile, 'is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' (Barnes, 1992, p. 20). There has been much debate about the inclusion of impairments into the social model which led to the development of an 'affirmation model of disability' that 'celebrates difference and values people irrespective of race, sexual preference, gender, age and impairment' (Swain & French, 2000, p580). The social model does not disregard impairments and implications of, or necessary treatments required, but believes too much focus on these could enforce a personal tragedy view (Barnes & Mercer, 2011), detracting from the societal influences. Failure to appreciate the relevance of social, political and cultural factors is a failure to recognise the diversity of impairments, lived experiences, and real-life challenges of disability (Barnes & Mercer, 2003). Barnes & Mercer (2003) focus on the quintessence of the social model - shifting understanding from a strictly medical perspective, to one that examines social inclusion.

1.2.3 Social model and dementia

Over the years the social model has helped facilitate social change in society, offering principles that can enhance the lives of people with disabilities and their significant others, to help remove barriers to create a more socially inclusive society. The social model has not been adopted often within dementia research. This is attributed to the dominant perception of dementia impacting the older population and not being viewed as a disability within the aged care and disability sectors (Mental Health Foundation, 2015; Thomas & Milligan, 2018). However, recent research has explored the social model of disability in relation to dementia, highlighting the current debate regarding dementia's fit under the umbrella of disability, despite similarities in the fundamental social barriers experienced (Mental Health Foundation, 2015; Thomas & Milligan, 2015). Nevertheless, it is important to consider those under 65 years with dementia who don't fit neatly within the aged care sector and are often excluded from the disability sector too. This is an area that needs greater exploration, through reviewing literature in other contexts such as mental health illness and learning difficulties (Beresford, 2004; Beresford et al., 2010; Chappell et al., 2001; Tew et al., 2012), in conjunction with more recent work in the field of dementia from a social model perspective (Mental Health Foundation, 2015; Thomas & Milligan, 2015, 2018). This research highlighted labeling and stigma, as significant issues within these contexts, indicating the impact of societal attitude and responses to different impairments. The way they are categorised or identified, do impact one's social experiences, and can also have repercussions on the individual's response or behaviour (Beresford et al., 2010; Chappell et al., 2001; Murray & Barnes, 2010). The social model of disability recognises the barriers created by terminology, negative labels, stereotypes and identities, which can perpetuate loss of self-worth and value, contributing to oppression and further distress. Kate Swaffer living with YOD, stresses in her book the need to 'continue to battle against stereotypes to break with the traditions that are steeped in bias, stigma and discrimination that maintain the lack of equity for the sick and disAbled, and that isolate us' (Swaffer, 2016, p. 190). The social model could help inform the way forward in the development of socially responsive policy and practice, and change public views to break down social barriers, support inclusion and acceptance through mutual understanding and collaboration (Beresford et al., 2010; Mental Health Foundation, 2015).

1:2.4 Social model informing practice

It is important to recognise that it is not only the individuals with impairments that are impacted, but also significant others in the family who face barriers and disablement by association with the person living with impairments. These family members are also exposed to discrimination, stigma and exclusion (Beresford, 2004; Beresford et al., 2010; Mulvany, 2000; Tew et al., 2012). The social model of disability is valuable to understanding discrimination and stigma, which is still hugely problematic within society, often contributing to mental health illness (Beresford et al., 2010; Tew et al., 2012). By drawing attention to these social factors that impact individuals and families, the social model could help find ways for change. This change could be initiated through supporting positive relationships with families, friends and with the community. Consequentially, this would assist them to feel connected and included socially, helping to overcome the negative social experiences (Tew et al., 2012). Exploring the social model of disability together with dementia could be useful in informing practices and understanding of the social forces and factors that impact relationships and interactions of individuals and families living with YOD. Their ability to influence or initiate change could be explored within this model. Many services are designed and delivered without consultation with service users; therefore don’t reflect specific needs of individuals and families, which could contribute to their persistent marginalisation and discrimination. However recognising potential and providing an appropriate level of support relevant to need, offers opportunities for people with cognitive impairments and younger family members, often ignored due to age, ‘to exercise their capacity’ to shape their social world (Boyle, 2014, p. 1141).

The concept of a whole family approach to support families with complex needs, not specific to dementia, has been explored within a social context. This approach suggests that services could be integrated and ‘tailored to their specific circumstances’ and needs (Clarke & Hughes, 2010, p. 528). Taking a whole family approach suggests inclusivity and understanding of relationships and functioning within this ‘social unit’ (Murray & Barnes, 2010, p. 535). In this context, the changing roles of different family members are recognised as the ‘family is fluid and ever changing in social space’ (Murray & Barnes, 2010, p. 535), which suggests a more socially responsive support network. Health and social care providers can overlook the age of children and young people adopting caring roles, and the changing developmental needs throughout the carer’s experience (McAndrew, Warne, Fallon, & Moran, 2012). This oversight is often due to the lack of understanding of the functioning of the family and a failure to consider individual and shared needs of family members together due to the focus being exclusively placed on the person with dementia (Aldridge, 2006). The lifecycle stage of families with children and young people is not routinely supported in service intervention, often adding to the whole family’s social exclusion (Beattie et al., 2004), which is contrary to the social model approach.

1:2.5 Generation of social change

The core foundation of the social model of disability, as a theoretical framework, is to make sense of and inform the societal influences that affect the experiences of individuals with impairments and their families. Adopting a social approach involves a societal paradigm shift from supporting a person with a disease, to advocating and working together with individuals and whole families, to provide support and care, according to need. This model could help generate ideas on the way forward for social change and to help eliminate barriers towards a more enabling and inclusive society. These changes can contribute to a more positive social attitude towards those living with impairments and their families.

This doctorate thesis explores and extends the potential for the social model of disability to better understand the lived experiences of individuals living with YOD, their family members and the whole family as a social unit. Considering all affected family members can assist in reframing the way services are designed and delivered, to be more socially inclusive and enabling. The knowledge gained in this thesis could further substantiate the need for a more collaborative approach to the development of policies and practices that respect and respond to specific need. This in turn would encourage more social and meaningful participation by all family members.

1.3 Reflections on Methodology

1.3.1 Methods

Although each individual paper included in this thesis has the specific methodology, data analysis, quality and ethics outlined, it is important to reflect over the methodology of the thesis as a whole. See Table 8: Overview of five publications in PhD thesis on page 192 in appendix Firstly the overarching aim of the research is to improve understanding of the societal influences impacting individuals living with a cognitive impairment under 65 years and their family members. To achieve this aim I needed to delve into the experiences of all members of families living with YOD, within the context they live. With this in mind a qualitative research approach pragmatically provided the means to explore these social experiences in a holistic manner. Qualitative research is valuable in listening to the voices of those who are subjected to societal marginalisation through using their own words to convey the phenomena (Liamputtong, 2014). Taking a holistic approach ensured the participants' whole experience, within the context of their lives, was considered in its entirety and not divided up into components (Ritchie, Spencer, & O'Connor, 2003). Essentially qualitative research is about capturing the 'lived experiences of the social world and the meanings people give to these experiences from their own perspectives' (Corti & Thompson, 2004, p. 327), which is crucial in developing deep, rich understandings of the complexities of life for these families. In my role as a qualitative researcher it is critical to make sense of this world that became more visible to me through the interviewing process and seek 'answers to questions that stress how social experience is created and given meaning' (Denzin & Lincoln, 2005, p. 10). This necessitated further exploring the differences and commonalities living with physical and cognitive neurological impairments and gaining perspectives of health and social care providers supporting families living with YOD. Interpretive practices can provide clarity to others providing greater depth of understanding and meaning, which is a crucial part of this research's aims. In qualitative research there are opportunities to develop theories to improve understanding of these phenomena. In this research it supported the development of the social model of disability as a theoretical framework to better understand living with YOD.

The framework method for analysis and management of the data was chosen in this research. A framework analysis was developed by Ritchie and Spencer in the 1980s as a systematic and flexible approach providing structure to reducing the data (Ritchie & Spencer, 1994). It offers clear steps and yields condensed data, which makes it much easier to organise large amounts of qualitative data. This method is frequently used in thematic analysis of semi structured interviews, which validates this being our chosen approach to manage and analyse the data (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Gale et al (2013) aptly described this method as identifying 'commonalities and differences in qualitative data, before focusing on relationships between different parts of the data, thereby seeking to draw descriptive and /or explanatory conclusions clustered around themes' (Gale et al., 2013, p. 2). In this research we took an inductive approach where the themes were generated from the data through the process of coding.

The framework analysis follows five structured steps to manage the data but there is fluidity back and forth between steps to continually refine the analysis. Just to reiterate this analysis is ‘not a linear process’ (Braune & Clarke, 2006, p. 86). The initial step is the researchers’ familiarisation with the data obtained from audio recordings, transcriptions and reflective notes in this research. Together, these all contributed to building the strong foundations to the analysis process (Gale et al., 2013). The aim of this stage is for the researchers to totally ‘immerse’ oneself in the data to look for patterns and meanings (Braune & Clarke, 2006, p. 87). The next step begins the analysis through researchers coding the data. Coding was conducted using pen and paper and through Nvivo qualitative data analysis software (NVivo, 2012). The purpose of coding is to systematically categorise and identify relationships and meanings in the data so the whole dataset can be compared (Ritchie et al., 2003). Importantly all researchers’ viewpoints were considered in this process to reduce risk of researcher bias (Morse, 2015; Noble & Smith, 2015). Having the contribution of clinical and research experts was valuable in the whole process. Extracts from the written or audio data are attached to the codes to help illustrate and understand code meanings. The third step is developing a thematic framework, which starts the interpretation of the data (Braune & Clarke, 2006). Themes emerge from clustering of codes and all the codes are then collated into appropriate themes. Themes were divided up into an overarching theme, main theme and three sub themes but a process of ongoing refinement was adopted until everyone agrees on the final themes. A thematic map or mind map (see figures5 & 8) to help in developing the thematic framework is useful as a visual representation of themes can help improve clarity (Attride-Stirling, 2001; Braune & Clarke, 2006). These themes are refined by researchers over a period of time to become the framework that is applied to the whole of the dataset. The themes in this research were informed by the social model of disability throughout, which is how the themes were finally framed. Additional theories were also used in a couple of papers, social identity theory (Tajfel & Turner, 1979) and family systems-illness model (Rolland, 1999a,b), which are explained further in the chapter 2 and 6 respectively. The final step is the application of this framework to the whole dataset, which was conducted by myself in all papers.

1.3.2 Data collection

As with most qualitative research, the number of people to be recruited is hard to determine in early stages of the research. Purposive sampling of participants to gain rich information was conducted through advertising with various diagnostic specific NGOs and Young Carers NSW. The numbers of participants recruited was determined by reaching data saturation; when it was agreed among researchers that there was no or little new data arising and there was enough quality data in the emerging themes (Liamputtong, 2014). The preferred data collection for this research, as already mentioned, was provided via semi structured interviews. Using this interview type allowed the researcher to phrase the questions to accommodate the diversity of participants, and supported the ability to be spontaneous and delve deeper into responses (Docherty & Sandelowski, 1999; Murphy, Jordan, Hunter, Cooney, & Casey, 2015; Serry & Liamputtong, 2014). Having some flexibility is important, which supports the use of prompts, props (pens and paper with children) and cues to assist in the interviewing process. There is an example of a drawing by a 10 year old during the interview in the appendix. Adopting a flexible approach is particularly apt when interviewing people with cognitive impairments and children (Docherty & Sandelowski, 1999; Murphy et al., 2015). Some demographic information was obtained prior to the interview, which prompted more informal discussions and offered opportunities to get to know each other. The questions adopted in the interview process began with an initial open question, which endeavoured to put the participants at ease and provided an opportunity to give a more detailed response about a subject that is easy to talk about. With the progression of the interview more probing questions were utilised to delve deeper into responses and explore more specific points (Serry & Liamputtong, 2014). Taking this questioning approach was considered more sensitive and meaningful to the range of participants involved and allowed the interview to flow more easily. Each interview was audio recorded and transcribed verbatim by a professional organisation.

One focus group was organised in this study after initial interviews with the children of parents with YOD. This was also audio-recorded and transcribed verbatim by a professional organisation. There was commonality within the group, all being over 18 years and having parents with YOD, which is important in stimulating group interactions (Davidson, Halcomb, & Gholiadeh, 2014). The group interaction can generate unique data and perspectives as well as highlight how certain people talk about dementia, in this instance. Shared experiences are extremely relevant considering the discrimination and stigma associated with dementia is very prevalent in society. The moderator of the group has an important role in facilitating discussions and viewpoints in a safe and inclusive environment (Davidson et al., 2014). As the group moderator, I had been fortunate to meet all participants previously through an individual interview. I felt this approach improved group dynamics and also provided confidence to share beliefs and views around challenging experiences, achieving richer data (Morse, 2015).

1.3.3 Research rigour and quality

Due to the descriptive nature of qualitative research it is important that the rigour of the research is maintained throughout, similar to quantative research. The four criteria adopted by qualitative researchers for maintaining rigour (Guba & Lincoln, 1985) is briefly explained here. Throughout this research these four criteria were considered by all researchers in this study to ensure standards of the research were upheld.

Table 1: Comparison of rigour criteria employed in qualitative and quantitative research

Qualitative research	Quantitative research
Credibility	Internal validity
Transferability	External validity
Dependability	Reliability
Confirmability	Objectivity

Source (Liamputtong, 2014, p. 17)

Credibility: To ensure the match between the participants' voice/ stories and the researcher's accurate portrayal of these perspectives.
Transferability: To make sure the ability of the research is applicable to inform and gather insights about other population groups and in other contexts.
Dependability: To confirm the rationality of the whole research process, visibility is maintained throughout and the process is clearly recorded.
Confirmability: To guarantee the analysis and interpretation of the findings accurately reflects the data collected (Liamputtong, 2014).

It is important to understand that the researcher is considered part of the study in qualitative research and brings with them their own 'knowledge, insights and experiences' (Stenbacka, 2001, p. 553). With this comes continual reflection by the researcher throughout the study to help 'in the process of generating understanding' to others (Stenbacka, 2001, p. 553). Prior to conducting this research I have worked in the area of adult neurological rehabilitation, in hospital and community settings, for most of my working career as a physiotherapist. Therefore, from a professional perspective I acknowledged some pre-understanding of experiences living with cognitive and physical neurological impairments, which I reflected on and highlighted throughout the research. Delving deeper into these experiences, by immersing in the stories of the participants, helps to get closer to the phenomena so that accurate perspectives can be communicated through the research to others (Morse, 2015). In other words it is crucial that the 'findings accurately reflect the data' using an analytical process that is consistent and transparent to everyone (Noble & Smith, 2015, p. 34). Engaging in continual reflection of self as a researcher and the chosen research process was vital to ensuring positive connectivity and commitment to all participants, disabled and non-disabled.

1.3.4 Ethics and confidentiality

This research was approved by the Human Research Ethics Committee, the University of Sydney for two studies (see appendix for approval letters);

1. Delving into living with a chronic and complex neurological disability: personal stories; reference 06-2011/13824
2. The impact of younger onset dementia on the person and their family; reference 14926 on 27th June 2012

Participation for both studies was voluntary. No monetary reimbursements were made to the participants. Respecting confidentiality, to protect participants from any unfavourable consequences was assured throughout the research process and emphasised at different occasions throughout the research (Denzin & Lincoln, 2005). All participants and parents/guardians were informed about the research and provided with a written information sheet prior to making a decision to be involved and then complete a consent form prior to participation (Liamputtong, 2014). Verbal communication of this information process was also conducted to ensure that the aims and procedures of the research were understood clearly by all participants, including those with cognitive issues and younger family members. All were given opportunities prior to commencing the interviews to highlight any issues and concerns, which were then duly discussed and addressed. The emotional impact on the participants due to recall of sensitive events or situations were considered and strategies implemented to safeguard them through the research. The participants were informed of the freedom to withdrawal at any time and point throughout the research. However in the focus group, withdrawal could only occur prior to the group as the data would be too hard to extract during the audio recording of the group. They were reassured that withdrawing would not affect their relationship with the researcher in any way. Everyone was advised that the information gathered would contribute to greater societal understanding to benefit families living with YOD and be disseminated at conferences, publications in journals and posters. The data was de-identified through giving each participant a number prior to any data analysis and pseudonym in the writing up. The data was locked in a cabinet and on secure databases.

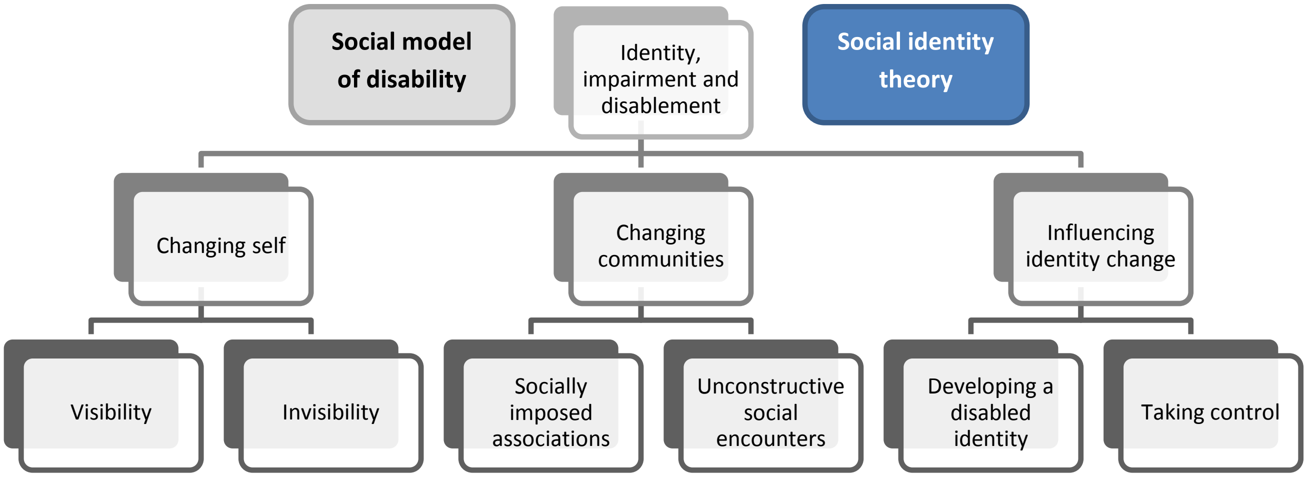
Chapter 2

Identity, impairment and disablement: Exploring the social processes impacting identity change in adults with acquired neurological impairments

Overview

This chapter aims to address a gap in the literature by improving understanding of the social processes that impact on the changing identity of an individual with an acquired neurological impairment at a socially significant time of life. It is important to consider perspectives from people living with physical, cognitive or both impairments, to better understand the societal attitudes and biases towards such impairments. The combined perspectives of the social model of disability and social identity theory were used to develop a theoretical framework to explain the way social groups are formed, the value attributed to them, and the role society plays in this process. Integrating these two models was an innovative way to help explain the issues surrounding socially constructed disablement of identity - in other words, disabling of identity - and inform the social change needed to value a disabled identity. This chapter helps provide greater awareness of the commonalities and differences of experiences of individuals living with cognitive and physical impairments in contemporary society, and examines the fit of cognitive impairments within the disabled identity.

Figure 2: Thematic analysis of identity, impairment and disablement



Identity, impairment and disablement: Exploring the social processes impacting identity change in adults living with acquired neurological impairments

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Abstract

The social model of disability acknowledges the impact of impairments but argues that disablement is socially constructed. Taking a theoretical perspective, underpinned by the social model of disability and elements of social identity theory, we investigated the relationship between impairment, disablement and identity change in adults living with an acquired neurological impairment. Through the thematic analysis three themes emerged*; changing self*-described the personal factors for identity change in people acquiring impairment; *changing communities* explored the contextual factors creating both socially constructed disablement and identity change, and *influencing identity change* considered strategies adopted by individuals to counter both socially constructed disablement and promote exploration of identity. A systemic change towards acknowledgement and valuing a disabled identity, may counter socially constructed disablement and support enablement and social inclusivity.

Keywords: social model of disability, social identity, identity change, adults, acquired neurological impairments, disablement

Introduction

It is increasingly recognised that acquiring a neurological impairment, whether physical, cognitive or combined in adulthood can result in experiences of disablement arising from the individual's interaction with their community. Exposure to a range of social, psychological and physical barriers results in experiences of marginalisation and discrimination, critical aspects of disablement. This is compounded in those who have dependents, with each stage in family life bringing associated challenges and responsibilities, altering future plans. From the perspective of the social model, disablement is considered to be socially constructed, with societal attitudes rendering impairments of the body, mind or both, into a disability (Oliver 2009, Barnes and Mercer 2011). Although traditionally thought of in terms of those living with physical impairment, the utility of the social model has been helpful in understanding how social influences affect those living with a range of non-physical impairments (Beresford, Nettle, and Perring 2010, Chappell, Goodley, and Lawthom 2001). Some studies have considered the social model's application in understanding the experiences of people living with acquired cognitive impairments, specifically related to younger people with dementia (Gilliard et al. 2005, Hutchinson, Roberts, Daly, et al. 2016, Hutchinson, Roberts, Kurrle, et al. 2016). Within the social model, the notion of a disabled identity can be imposed on individuals as their defining identity even though this is only a part of who they are. Some may be resistant to adopting the disabled identity when acquiring impairments in adulthood due to previous socialisation towards the personal tragedy perspective (Barnes and Mercer 2011). Whilst there is much debate about the notion of the 'disabled identity' (Rhodes et al. 2008) within disability studies, but there have been few empirical studies which have explored the relationship between acquired neurological impairments and identity, from the perspective of the social model of disability (Swain and French 2000). We were interested to explore these relationships within a program of research looking at the experiences of families living with young onset dementia.

Social Identity

In theorizing the intersection of the disabled identity and the social model, we used social identity theory in which collective identities are thought to have a powerful influence on human behaviour (Tajfel and Turner 1979). Social identity theory offers a lens to examine the social self, inter group relations and processes within groups which can create feelings of belonging and provides definition of who one is in relation to the social category that they fall into (Hogg, Terry, and White 1995, Harris, Gringart, and Drake 2014). Importantly, by identifying with certain groups, an individual can gain an overall sense of well-being (Ysseldyk, Matheson, and Anisman 2010) and have meaningful interactions and improved opportunities within the wider society (Harris, Gringart, and Drake 2014). However when an individual's group membership is based on a label or categorization such as having a spinal injury or cognitive decline, many aspects of an individual's social life are overshadowed. Such an individual adapts their behaviours influenced by societal beliefs that disabled people are different (Beart, Hardy, and Buchan 2005, Carnevale 2007, Goffman 1986, Swain and French 2000). Jenkins (2008, 5) relates identity to the 'mapping of the world and our places in it, as individuals and as members of collectivities' and the concept of self being both individual and social in nature. The mind helps to relate self to the environment as mind/self together forms an identity which is 'embedded in society and created through the communication and interaction with others'

(Burke and Stets 2009, 35). Individuals can be members of a range of social categories which vary in overall importance to self, and each membership is considered a social identity (Hogg, Terry, and White 1995). Within group categories there are stereotypical and discriminatory practices in play which influence membership, contributing to the 'them and us' scenario where individuals are dismissed from groups to create social distance (Byrne 2000, 66).

On acquiring neurological impairments an identity change ensues, altering the sense of self, affecting the meaning and position of one self in a group, and how one functions in different relationships, and as an individual. Individuals living with an acquired neurological impairment may have to revise their identity with family and friends, employers, co-workers and healthcare and social care practitioners (Mathieson 1995). On gaining a new identity, an adjustment of other identities is also required, allowing the fluidity of change to incorporate all identities (Burke 2006, Hogg, Terry, and White 1995). Some literature however emphasises the negative view of living with impairments in society, which can adversely impact an individuals' ability to embrace an identity that is formed around disability or specific social category, within other multiple identities (Cameron 2014, Galvin 2005, Rhodes et al. 2008). Thus being defined by impairments either imposed or by choice, could result in the disabled identity becoming the primary identity.

In the context of identity change, individuals are often no longer perceived by self or others to have valid characteristics to belong to a specific social category. Altering categorisation, can influence their sense of self, no longer regarded as part of the societal norm (Beart, Hardy, and Buchan 2005) which can be viewed as social oppression, affecting what individuals can do and aspire to be (Reeve 2004). Consequently, group membership could be changed willingly or unwillingly to another group with a perceived lower social status, such as identifying as disabled (Hogg, Terry, and White 1995). For many, these dominant societal attitudes, increases resistance to identifying as disabled in adulthood, often being considered a personal tragedy associated with experiences of stigma and negative labelling (Barnes and Mercer 2011, Swain and French 2000, Link and Phelan 2001).

The social model

From the theoretical lens of the social model, disability is characterised as socially created, through an association between impairments and discriminatory behaviours, and attitudes in society. At this present juncture, the social modellists have been dismissive of considering identity and impairments alongside this model believing this would encourage a personal tragedy view of disability and impairment and de-politicise the social model (Oliver 2013). The literature around disability stresses the unfavourable implications on identity based on discrimination, personal tragedy and stigma within society (Jenkins 2008, Cameron 2014, Goffman 1986, Swain and French 2000). However the 'affirmative model of disability', developed by Swain and French (2000; 579), builds on the social model of disability by acknowledging the positive experiences and identity of disabled people, being impaired and disabled, challenging presumptions of non-disabled people and essentially rejecting a tragic view of disability.

Whilst there has been much research about the social model of disability, there is little exploration of the intersection of the social model and social identity theory. The degree of disability is independent of impairments, as identified through the social model of disability, nevertheless individuals are often judged by their differences from others and their own sense of self, creating barriers to inclusion in society (Barnes and Mercer 2011, Oliver 2009). In the context of identity, there is an understanding that a sense of self is also socially constructed and 'identity is revised and responsive to events and situations' (Brown and Addington- Hall 2008, 201), fluctuating in nature (Rhodes et al. 2008). However for those people living with cognitive decline, holding onto a sense of self and positive yet 'fragile identities' is particularly problematic (Harris and Keady 2009, 442). The social model helps determine social barriers and inequalities with disabling implications on all aspects of life including identity (Thomas and Milligan 2015).

Many experience stigma which was defined as an 'attribute that is deeply discrediting' by Goffman (Goffman 1986, 3), with a loss of respect in society (Carnevale 2007). Link & Phelan (2001, 377) observed that 'stigma exists when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them.' Frequently people living with acquired neurological impairments in the social world experience these factors coming together impacting social interactions and self-identity, often adopting strategies to counteract these. Three strategies were described by Goffman; first was 'passing' whereby individuals control the information revealed about self that may discredit them: second was the 'covering' of differences that cause stigma, often by limiting social interactions and hiding impairments; and third was 'withdrawal' by no longer interacting socially with non-disabled people (Barnes and Mercer 2011, 48, Goffman 1986).

An opportunity to explore the links between impairment, socially constructed disablement and social identity arose in the context of our research, exploring the lived experiences of adults under 65 years, living with an acquired neurological condition, characterised by sudden onset or progressive impairments. In drawing these contexts together, our research question was formulated from the combined perspective of social identity and the social model of disability, to gain an understanding of the impact of social processes on identity, and the experiences of living with acquired neurological impairments in adulthood.

Methods:

The authors anticipated that bringing together the viewpoints and experiences of adults living with a range of acquired neurological conditions, physical, cognitive or combined, in this small Australian qualitative study will help enrich the worldwide conversation and provide insight on social factors influencing identity change. The people participating in this study had a range of neurological conditions including cerebrovascular accident (CVA), Parkinson's disease (PD), motor neurone disease (MND), multiple sclerosis (MS), spinal cord lesion (SCL) and younger onset dementia (YOD).

Participants were recruited through emailing disease specific Non-Governmental Organisations (NGO), Parkinson's NSW, Motor Neurone Disease Association NSW and Alzheimer's NSW. Approval was obtained from the Stroke Recovery Association NSW, Australia, to approach the Working Aged Group-Stroke on the Central Coast NSW. The organizations distributed emails to the appropriate aged individuals, who then in turn contacted the main researcher via email highlighting their interest in participation. Some individuals contacted the researcher directly after hearing from other participants about the research.

Data was collected through 14 semi - structured interviews with adults in the working-age stage of life (25-65), as adopted by Australian Institute of Health and Welfare (AIHW), living with acquired chronic and complex neurological impairments. Interviews were conducted in a venue of their choice, or alternatively via skype or telephone. Interviews were conducted by the first author (KH) for about 1-2 hours with breaks. Each interview was recorded and transcribed verbatim.

Sampling was purposive, incorporating a diversity of impairments, social settings and gender balance. The interviewer gave participants opportunities to describe particular events and activities in the home, at work, or in their social lives in order to give a rich picture of their lived experience. Probing questions were asked to promote reflection on what life is like, how it might have changed since acquiring the impairment, what were the barriers and enablers, and what strategies they adopted in doing the things they want and need to do.

Ethics approval by the University of Sydney ethics committee was obtained for the study. A cognitive ability to understand the research process was necessary for the purpose of this research project. Written consent was obtained for all participants but for people with dementia an additional guardian's signature was required.

Data analysis

After initial familiarization with the interview data and acknowledgement of the value of our own rich health and social care experiences, interviews were analysed using framework analysis (Ritchie and Spencer 1994). We used framework analysis as a basis for discussing and developing our understandings and interpretations of the transcriptions through a series of meetings and emails. This helped in refining or re-labelling the initial codes. In clustering these codes, we discussed and negotiated the value of integrating the key constructs of the social model of disability and social identity theory into developing a theoretical framework, which appeared to resonate with our preliminary themes and sub themes. This theoretical framework was applied to a portion of the dataset (three transcripts), by three authors (KH, CR and MD) to test its trustworthiness. There followed a process of refining, applying and refining the analytical framework by all authors, until no new codes were generated. The final framework was then applied to the whole dataset by author KH. Subsequently, we checked for any new and emerging issues of importance that would extend the analysis. Data was managed using Nvivo qualitative data software (NVivo 2012).

Participants:

Each participant was given a pseudonym to preserve their anonymity (see Table 2).

Table 2: Characteristics of participants at time of the interview

Name	Diagnosis	Age	Age of onset	Marital status	Children	Demographics
Neil	SCL	52	21	single	0	regional
Patricia	MS	65	43	divorcee	3	regional
Steven	PD	51	41	married	3	regional
Dawn	MND	42	40	married	2	regional
Fred	MND	54	39	married	0	city
Andy	MND	63	53	divorcee	1	city
Debra	PD & YOD	61	59	married	3	rural
Stan	CVA	58	51	married	2	regional
Anne	CVA	54	39	divorcee	3	regional
Claire	MS	38	25	single	0	regional
Craig	Alcohol related dementia	49	46	divorcee	2	city
Ellen	AD	57	52	married	4	regional
Belinda	PCA & Lewy body dementia	51	49	divorcee	3	regional
Grace	AD and Lewy body dementia	43	42	married	4	regional

Abbreviations explained:
Spinal cord lesion (SCL); multiple sclerosis (MS); Parkinson’s disease (PD); motor neurone disease (MND); cerebrovascular accident (CVA); younger onset dementia (YOD); Alzheimer’s disease (AD); posterior cortical atrophy (PCA)

Results

Three key themes emerged: *Changing self,* explored the personal factors for identity change and the ensuing challenges with the acquisition of physical and or cognitive impairments: *Changing communities* investigated the factors influencing both socially constructed disablement and identity change with acquiring impairments, and *Influencing identity change* considered the strategies adopted by participants to counter socially constructed disablement and promote exploration of identity.

Changing self

Individuals with unexpected physical and or cognitive changes face challenges causing significant alteration to their life course. Two sub themes looked at the connection of self-identity, impairment and disablement: *visibility* explored the challenges living with observable impairments, and *invisibility* investigated the implications of living with less obvious impairments.

Visibility

Rich descriptions by participants gave insights into their experiences, illustrating the complex interrelationship between impairments and identity in their social environment. Fred living with motor neurone disease (MND) used self-depreciating imagery to capture his ambivalence to advancing impairment

> *It's really- it's getting towards being a head on a stick now that my arms are starting to go. The finer things with your arms….I can move them around but picking up that glass, it's not easy. So you do need someone with you to do all that sort of stuff.*

Fred used language that depicted individual deficit as he referred to his physical body as the '*stick,*' which gave a sense of his body's helplessness and unresponsiveness. Fred also implied a lack of connectivity between his mind and physical self by referring to his '*head*' separately. He felt frustration and '*at times undignified'* response to his physical dependency, which suggested some internalised oppression and self-devaluing. He sensed being a '*burden on everyone,'* causing him to become increasingly socially isolated, restricting activities and refusing help. Fred reflected on his sense of social isolation, acknowledging he did '*kind of miss being in society really*.' Fred's identity of self seems trapped in the personal tragedy view, as a consequence of his loss of physical ability, causing additional disablement.

Steven described the effects of Parkinson's disease as he '*turned into a statue, I just became so stiff.'* Steven illustrated the unpredictable nature of the disease, causing his body to fluctuate between being reasonably physically able, to having '*weird jerky'* movements to then being '*turned to stone',* which was *'frustrating.'* He felt watched and judged by the way he moved.

> *I just went out to get some milk or something, and I was a bit wonky, so I was meandering, and some guy, when I walked past him, whispered to his mate, and I heard it, drunk - he's had* a *drink - no, he's had a couple of drinks already. I thought, and again my brain was slow, so I couldn't think quick enough to say anything to him. But yeah, that hurt a bit*

Wheelchair users also described a tension between being stared at or ignored as people make comments and talk over them, diminishing their sense of self being offered less social respect than non-disabled individuals in the community. Dawn, a mother of two teenage boys, living with MND, conveyed her bitterness and despair as she had '*to put up with it (wheelchair)'* to get out and about as the other option was to '*be housebound and not be able to get out at all*,' which would isolate and disable her even more. Stan living with a stroke, described being like a '*mannequin*,' where non-disabled people in the community failed to engage with him whilst in his wheelchair, illustrating societal attitudes that failed to view and respect him as a living human being, challenging his sense of value and self-worth.

Invisibility

Participants living with cognitive impairments described their experiences within their social world and the impact on their self-identity. Belinda diagnosed at 49 years with posterior cortical atrophy (PCA) and Lewy body dementia, described dementia as the *'invisible illness.'* She felt the invisibility of the disease came from the lack of awareness and understanding of dementia impacting people under 65 years. She went on to describe the difficulty others face in understanding her fluctuating symptoms.

> *The problem is with my type of dementia is that it's a quite - can be rapid fluctuation of cognitive strengths and weaknesses. So I can be perfectly bright, aware and switched on and then half an hour later just the lights are on but no one's home. Then half an hour after that, good as gold.*

Steve too described times living with Parkinson’s disease where the struggle to process information was misunderstood as having a lower level of intelligence.

> *Your thinking processes aren't as quick, and it's just like, you run into a brick wall - your thoughts don't run as smoothly, people ask you things, you've got to think harder. It's weird, it's like suddenly becoming dumb. Yeah, like suddenly your brain slowed down. It's not nice.*

Both Belinda and Steve explained their inner challenges using descriptions like ‘*lights are on but no one’s home’* and ‘*run into a brick wall*’ giving a glimpse into their world and the effort involved in maintaining a sense of normalcy, which often goes unnoticed.

Grace, at 43, a mother of 4 children, graphically described grappling with the impact of living with Lewy body dementia and Alzheimer’s disease.

> *How do I tell my children I have this abhorrent disease that slowly peels you apart like an onion with no mercy and no grace?*

Her feeling of hopelessness and frustration related to the looming cognitive decline was portrayed, and being denied a voice whilst the essence of her still exists, added to her despair. Unfavourable attitudes impacted Grace’s identity as illustrated.

> *I see a person who I was and I just want her back. I hate the fact that no one takes your word anymore…. It’s like I’m not here anymore, I may as well be the cushion or lounge…. my voice has gone*.

Referring herself to inanimate objects, like the ‘*cushion or lounge,*’ is similar to Stan’s ‘*mannequin*’ demonstrating their loss of social status and lack of self-worth. Being denied a voice based on physical and cognitive impairments demonstrated here, created further disablement and emphasised their loss.

Our findings illustrated some of the personal factors underpinning a change in identity with acquiring impairments. Irrespective of the type of impairment, societal stereotypical and discriminatory behaviours, shaped by the medical model, view impaired bodies as abnormal and worthless (Loja and Costa 2013) and cognitive impairments as one of hopelessness and loss (Harris and Keady 2009), triggering the self-depreciating imagery of identity. Impairments are commonly viewed as a personal problem or tragedy instead of a ‘socially mediated phenomenon' that can be changed to promote enablement (Swain and French 2000, 409, Galvin 2005). Challenging discriminatory behaviours can be daunting for many individuals as their self-worth is often diminished in their social encounters (Galvin 2005, Edwards and Imrie 2003). In addition for individuals experiencing cognitive issues, the ability to retain their identity becomes an even more 'daunting and complex challenge' particularly due to the often invisible nature of impairments (Harris and Keady 2009, 437).

Changing communities

This theme explores the social and environmental factors underpinning socially constructed disablement and identity change in acquiring neurological impairments. Certain attributes impact how individuals are defined by others, often being forced out of one community group into another.

This theme is illustrated by two sub-themes: *socially imposed associations* explored the way in which experiences of ruptured routines and lifestyle changes were amplified by social interactions and *unconstructive social encounters* investigated the implications of stereotypical and discriminatory behaviours that influence social status and relationships.

Socially imposed associations

How the community perceives and understands impairments in adults could have a profound impact on the process of identity change. Steven diagnosed at 42 with Parkinson's disease (PD), emphasized his conflict between normative expectations for health and capabilities and how he felt others observed him.

> *I've still got a body image of being…..I like being strong and fit, well not fit so much as active, and be able to dance when I want to, and being able to swim when I want to, and not being some old codger…You are forced to look at yourself, or you see yourself in a negative way…I like to think of myself, like I said, as someone who's active and out there, attractive to people, not someone who's, can't do anything, and who's stuffed.*

There appears to be juxtaposition between the sense of self identity and social identity constructed by others in the context of societal expectations related to age. Steven eluded that Parkinson's disease is generally perceived as impacting older people, believing others saw him as an '*old codger*' and '*stuffed,*' conflicting with his own sense of self as active and independent. '*Forced*' to take a negative view of self, illustrated being compelled, unwillingly, to look at himself as different. Steven attempted to influence labelling by choosing to be selective with social interactions, controlling engagement with others and in what situations, to manipulate how he was portrayed and treated.

Craig, diagnosed at 46 with YOD, was assigned day respite with elderly people based on his diagnosis. He described having no one his age '*was hard at first, it was really hard*…. *There's not much I can do about it, life goes on.'* Craig felt he had no choice available to him and found not fitting into the group, because of age, was '*really hard'* to cope with. In a similar scenario relating to confronting age issues Dawn, aged 42, living with MND, was wrongly identified as her mother's carer at the MND support group. Once clarified, she described uncomfortable conversations with older members of the group, who indicated how they had '"*lived our lives." Now that's not easy to hear'* being a mother with school aged children.

Craig and Dawn live with life limiting neurological impairments which challenges their ability to maintain the essence of self, in particular their parenting and paid working roles. Both were required to terminate employment with little options being offered, creating financial concerns. They agree that being with people of a similar age they could relate and connect with was important, '*so you're not the only one that age.'* Ultimately age of group members is significant in helping to achieve a sense of belonging and connection to communicate age related challenges, within a more understanding environment.

Unconstructive social encounters

The interaction between the individual, living with impairments, and the environment is particularly challenging when 'dealing with negative labels, stereotypes and stigma' (Lundberg et al. 2011, 221). Claire, 38 living with multiple sclerosis (MS), described how she was compelled to relinquish her mobility permit as '*she couldn't handle the stares'* from the non-disabled community.

> *I know they (public) need to understand, there's different types. Like I look totally, utterly normal and I remember I had a mobility parking permit and I'd get out and they'd be like you haven't got a disability, why are you parking there?"*

Interestingly, Claire felt the community had some justification in their responses, yet the outcome for her was to become a '*hermit*', limiting social interaction, as '*everything seems too much of an effort now.'* Being exposed to unwelcome labelling and stereotyping by the non-disabled community, caused her to question her own identity and limit socialisation, which in effect disabled her further.

Craig, on disclosing his diagnosis of YOD to his employer, had no choice but to terminate employment immediately, which Craig found devastating.

> *I felt like the world could end, the end of the world, you know what I mean. I couldn't work anymore. I couldn't work anymore and then I was fighting for the pension.*

In addition he faced attitudes of disbelief arranging a disability pension. He was questioned about the reason for his inability to work, '*it can't be dementia, he's too young to have dementia. They all said that… I just felt like giving up.'* These doubting attitudes augmented his already low self-esteem and lack of value, whilst striving to obtain financial support for his family.

With regards to gaining employment, Steven believed the failed attempts, applying for jobs that he felt '*perfectly qualified*' for, was attributed to disclosing his diagnosis of PD. On another occasion he did not reveal his diagnosis:

> *I didn't tell them and I did get the job. So work it out. I know people discriminate. If they can get away with it they will.*

Steven expected to be treated equally and fairly being a competent professional, obtaining employment on his own merits, having the capabilities to perform work similar to non-disabled individuals. His experiences reinforced beliefs that disclosing his diagnosis diminished employment opportunities and fostered disablement.

Debra encountered negative attitudes from healthcare professionals, which compounded her feelings of loss, living with cognitive impairment and Parkinson's disease. She reported increasing frustration due to limited understanding among healthcare providers about memory issues. This was demonstrated in the initial consultation with a rural GP who

> *.. got quite angry when I couldn't remember the medication I was on……..She said "well how do you expect me to prescribe it when I don't know what it's called?"*

Although Debra did tell the GP she '*didn't appreciate the way she spoke,'* it demonstrated the impact of healthcare professionals attitudes in disempowering and further disabling individuals, by failing to understand and provide appropriate support to manage their impairments.

In summary the theme of *changing communities* demonstrates the experiences of individuals who acquire neurological impairments, being assigned to social groups where they fail to connect and get a sense of belonging. Most would like to have choice over personal associations particularly related to age, which can influence one's identity and sense of belonging within the community in which they live. It is necessary to understand 'identities exist within the structural framework of society and are influenced by their position in that' (Burke 2006, 93) so when one belongs to a marginalised group the prejudices of the more dominant group can affect how the disabled person functions in society (Reeve 2004). Social interactions can strongly influence how one views oneself and if favourable they can positively shape one's world and identity within it (Galvin 2005). Nevertheless unconstructive societal beliefs are stereotypical and discriminatory in nature, exemplified by being denied equal opportunities to continue or obtain employment. Exposure to discriminatory attitudes can disable individuals further, limiting socialisation and feeling unsupported in managing impairments, which may cause an 'identity crisis' (Lundberg et al. 2011, 218) if improvements in societal understanding is not achieved. However some feel belonging to a group of people with similar characteristics, could create a safe social bubble where one can share experiences, gain support and feel included (Carnevale 2007).

Influencing Identity Change

Many participants reflected on the impact of their impairment and how they developed a sense of purpose and belonging in the communities in which they live. This indicated a more affirmative sense of self-identity, being valued equally in their community. This was demonstrated through two sub themes: *developing a disabled identity* by engaging in strategies to define one's own identity and *taking control* which explored the complex management of social encounters and associations.

Developing a disabled identity

Earlier we have shown how the acquisition of impairments forced a change in both self-identity, through adjustment to the impairment, and one's social identity, through social constructed disablement. In particular, the medical model shaped community perceptions and that of healthcare and social care services. The notion of recovering one's self identity and reconstructing one's social identity is about becoming enabled through the development of an affirmative disabled identity, one that rejects the medical model (Swain and French 2000). Grace stated

> …*just because I got diagnosed with this thing (YOD) I'm not a different person, I'm still me.*

Grace believed that having dementia caused her to be viewed by others as a '*different person'* which she challenged in the hope of being recognised for who she was and not just by a diagnosis. Grace felt trapped in a society that viewed her impairments as a personal tragedy and treated her as such.

Andy living, with MND, was impacted being unable to obtain regular paid employment. When he was offered volunteer work by a NGO he felt valued.

> *It gives me something to do; otherwise I'd be terribly bored. Also historically, how this came about, is when you have this kind of a condition, things deteriorate. So I was at rock bottom at the time.*

He described this change as '*fun……* *I found it relaxing*,' renewing his confidence in his abilities and once again feeling productive in society. He was able to choose the frequency of work which importantly added an element of control.

Stan took on an important voluntary role providing a stroke survivor's perspective to the Stroke Foundation. By engaging in activities, as part of a working aged stroke support group improving community '*exposure to stroke',* added favourably to his sense of self and social identity, giving him a purpose in life. Neil on the other hand, living with quadriplegia after a motor accident, remarked on the importance of being seen as the employer that pays the wages, and organises his own 24 hour formal care. Maintaining his '*boss*' status was important and validated a greater self-worth in society. Financial independence was retained through ongoing personal injury compensation after the accident, allowing him to manage his life, make independent choices so he could *'live closer to normal than a lot'* of disabled people. Actively engaging in life, overcoming socially constructed barriers, enabled him to form an affirmative disabled identity.

The capacity to regulate the development of one's identity is deemed important. These participants preferred not to be defined by their impairments or what people thought they should be, but focus on what they could do, ultimately enabling the positive development of a disabled identity.

Taking control

Some participants needed to overcome many hurdles and societal prejudices to gain a sense of personal autonomy. Neil recalled, after his accident, he wanted to be like any other 23 year old male and live outside the family home. This option was not supported by the family, causing family conflict.

> *I employed nurses to get me up in the morning and I got guys to stay over 24 hours a day, 7 days a week to look after me through the day and night. I carried on like that for about six months and proved to mum and dad that it could be done and they were happy that I did do it. I suppose it made life easier for me as well whereas I could do what I wanted to do as a 23 year old guy would want to do.*

Neil had to deflect his family's focus away from his dependant physical body to his ability to look after himself, by demonstrating his capacity to organise the necessary care he needed, to live independently and safely away from them. Neil summarised what was most important to him was

> *…the independence and your own satisfaction that you can organise your life and not other people organising it for you….living independently is a big deal.*

Neil wanted to be identified as a 23 year old man, not by his physical impairments. Although he accepted his physical limitations, he did not want to be defined by them. Neil took control of his identity, having a purpose and responsibilities, affirming '*we all deserve to be able to live a normal life'*

Belinda, diagnosed with PCA and Lewy body dementia, explained the way dementia was presented could impact the way one lives their life after diagnosis. She demonstrated the importance of gaining information and connecting with the right people when she

> *…researched information and then spoke to a senior psychologist and geriatrician…..it wasn't such an end of life diagnosis as it was presented, which it is so often presented 'to get affairs in order.' Whereas it is possible to live well (with dementia).*

Belinda recalled conversations with these healthcare professionals that helped change her outlook on life, for the better. She accepted '*life does change*' but felt empowered to live well with dementia. She suspected others thought she was in denial by taking this approach to life, but '*I became involved in advocacy'* to help remove prejudices, that people with dementia should not be '*written off.'*

Stan, experiencing challenges after his stroke, with balance, speech and vision, felt it was important to be viewed as a '*normal*' person and contested opposing perceptions, taking control of the situation and fighting for recognition and inclusion.

> *I think, not seeing myself as different to them…… I've developed a range of strategies to overcome many disabilities …..I've never accepted someone telling me that I couldn't do something.*

Stan drew attention to the fact that he was not different to anyone else, by not letting his impairments define him. He demonstrated, through social encounters, how to '*overcome many disabilities,*' helping to raise social awareness of enablement. Ann, living with a stroke, felt greater community exposure of disabilities would be beneficial, through '*really listening to what a person needs'* and improving understanding that '*everyone's different.'*

Influencing identity change illustrates how individuals can be empowered to resist being only defined by their impairments, whether they are cognitive, physical or both, progressive or non-progressive. The participants demonstrated various ways that they countered socially constructed disablement to feel valued, developing an affirmative disabled identity (Swain and French 2000). Our findings resonated with Vick (2013, 186) who surmised that impairments should be seen as a 'shifting set of experiences and circumstances' that is within the normal trajectory of life. Being treated equally, achieving full citizenship and being engaged in society were believed to be important factors in affirming a positive disabled identity.

Discussion

Our findings consider the complex interplay between identity, both self and social, as a moderator between impairment and disablement. The first theme of '*changing self'* resonates with the work of others who associated the onset of impairments with the disruption to the anticipated and normative life history. Bury (1982, 172) described this change as a 'biographical shift from a perceived trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging.' Some consider the onset of their neurological condition as a 'biographical disruption' which was described by Bury (1982, 169), implying a change in self, relationships and the social world they reside (Putnam 2005). However, others believed it to be more of a 'biographical flow' (Faircloth 2004, 242), framing changes and adaptations as an ongoing process, after acquiring the neurological condition. Our findings indicate that acquiring impairments, can significantly affect both self and social identity. For the person living with impairments, feelings of difference were emphasised over feelings of inclusion and acceptance into society. This could cause internal oppression, affecting a sense of self and influencing beliefs and activities (Reeve 2004, Cameron 2014). However the majority of society learns about disability through a process of socialisation, engaging with disabled people, and less commonly through personal experiences. Limited socialisation with disabled people could lead to unfavourable societal stereotyping around impairments, stemming from reactions and behaviours related to the general lack of understanding of different types of impairments. Common engagement with the medical model however treats impairments as a personal tragedy so for those living with the disability, negativity could create an internal conflict on whether to accept this perceived undesirable identity, or to attempt to retain or re-frame the identity of their former selves. Where possible, and often after prolonged reflection or serendipitous events, this process could be a powerful enabling strategy, deflecting discrimination and stigma by others. Those individuals that experience episodic impairments that fluctuate between highly visible to less visible, or those with mostly non-visible impairments, could face greater barriers, demanding profound cultural rethinking to respond to the diversity within the identity of disability (Vick 2013).

The second theme of '*changing communities'* adds to the understanding of how societal associations and encounters can have a direct impact on 'how people come to see themselves once they develop impairments' (Galvin 2005, 397). Faced with ruptured routines and lifestyles many individuals with impairments emphasised the significance of age when associating with others. They admit a conflict between normative expectations for their age, health considerations and how they were perceived by others. Although group membership, based on diagnosis, can define who one is, in group and out group, stereotypical influences particularly related to age and type of disability was evident. Our findings emphasised a significant factor to achieving a sense of belonging in social groups for disabled individuals, was associating with people at a similar stage in life trajectory, who they could relate to.

Also being selective over social interactions was considered important to help manage how they were defined and treated by others as negative stereotypes created social oppression which could lead to internal oppression, generating further disablement (Reeve 2004). The widespread societal failure in recognising the capabilities and other identities of adults living with neurological impairments contributed to socially constructed disablement, impacting their socialisation and social identity. The evidence highlighted that being in the working-age stage of life, seemed to be out of the 'comfort zone of understanding' (Vick 2013, 187) for many in the community, which challenged social values and norms in attempting to preserve their other non-disabled identities and actively participate in society.

The last theme of *influencing identity change* explored the strategies adopted to counter socially constructed identity and promote social inclusion. Our findings resonate with others supporting opportunities for renegotiating identity, resisting disablism and developing a greater sense of self and purpose is essential for all, irrespective of the diagnosis and type of impairments (Smith et al. 2015).Common societal beliefs consider the impact of physical and cognitive impairments are the core determinants in the sense of loss. However as Hahn (1997, 34) mentions 'viewing disability as an experience rather than a loss' is a perspective corroborated by participants as beneficial to getting on with life and validating full citizenship. Endorsing empowerment gives a sense of belonging, value and purpose, which are enablers for positively affirming the disabled identity, giving a sense of normalcy to the identity renegotiating process. Taking control of the process of identity change is empowering and important for long lasting positive change. So socialising with people that supports this identity change is a potential source of enablement, allowing the renegotiation process to occur with greater confidence and liberty to be one's self.

Implications

This research proposes that the intersection between social model of disability (Barnes and Mercer 2011, Oliver 2013) and social identity theory (Tajfel and Turner 1979) can provide a useful theoretical and activist framework to assist in understanding how the individual overcomes social influences and makes identity change an affirmative process. Our data has shown that socially constructed disablement, environmental and emotional barriers, can impact the process of identity change following an acquired neurological diagnosis in adulthood. This perspective suggests it is not the impairments that impact the process of changing identity, but the prevailing societal norms and values that characterise impairments in a way that fosters unwelcome discriminatory and stereotypical behaviours, ultimately becoming a 'threat to identity' (Mathieson 1995, 296).

Socially constructed disablement is a social issue not an individual concern and our theoretical viewpoint could assist in raising awareness of the social processes in place that influence identity change. From this different outlook it could add further understanding to the essence of one's existence in changed situations (Charmaz 1999). Our theoretical insights bring greater depth to the literature, such as the identification of multiple life experiences that underline the societal influences that impact changing identity. These experiences include loss, disablement, and threat to identity, renegotiations and enablement. Using the social model of disability can assist in our understanding and help guide the societal changes needed to overcome the barriers and problems faced in identity formation.

Individuals undergoing altered life styles and routines, at a life stage where social expectations are high, observe changing relationships and sense of belonging within their lived environment. Our research suggests there is the potential for critical moments and junctures to hugely influence the process of change in individual identities. A critical moment could be the time of diagnosis or a sudden event resulting in neurological impairments. For example, the attitudes of healthcare professionals to the diagnosis or disability can be significant for the individual adjusting to the impairments. Our findings suggest the community still remains socialised towards the medical model, including a sense of loss and negativity this new identity brings, which in particular is highlighted more overtly with a diagnosis of YOD. Damaging attitudes and actions of healthcare and social care providers at this critical juncture can generate more disablement, producing greater vulnerability and helplessness, ultimately impacting confidence and purpose in life. For those with living with life limiting neurological conditions, like motor neurone disease (MND) and younger onset dementia (YOD) then a ‘lack of biographical continuity’ (Roach, Drummond, and Keady 2016, 27) adds additional challenges in maintaining essence of self and self-worth which needs a collaborative approach to ensure this is addressed (Brown and Addington- Hall 2008, 206, Roach and Brown 2010, Harris and Keady 2009).

Developing education programmes collaboratively with disabled adults and their families could improve current clinical practise and perceptions of different impairments, as demonstrated in other research (Edwards, Voss, and Iliffe 2014, Galli et al. 2015) which could provide the explicit evidence to improve services and support. Our research concurred that understanding individual and family perspectives could help dispel the often pervading negative attitudes and help healthcare professionals better develop ‘a positive relationship with patients, supporting them to live their life with as much normality as possible’ (Brown and Addington- Hall 2008, 206, Edwards, Voss, and Iliffe 2014). Promoting enablement, inclusion and self-worth, has been shown to be important in improving healthcare professionals engagement and experiences. This potentially influential change in attitudes and encounters could facilitate discussions with more emphasis on a positive outlook on life, after diagnosis or sudden neurological event, for the individual, family and friends, dispelling ‘the view that nothing much can be done’ (Edwards, Voss, and Iliffe 2014, 117). This change in emphasis may help in social acceptance and help individuals embrace their impairments as an important part of their identity (Hahn 1997).

Age featured substantially in relation to identity, and considering the socially significant age of the participants, this is critical to understanding their experiences. Also age is an important consideration for out group membership (Stets and Burke 2000), particularly relevant for conditions like YOD and PD, perceived to predominantly impact adults in older age. Living with YOD for example, leads to greater social exclusion and stigma compared to the older population with dementia and this is supported by the research (Greenwood and Smith 2016). It was reported in this research that, being socially valued and respected for one’s capabilities was particularly important. So being supported to actively participate within society and family life provides opportunities for overcoming discrimination and stereotypes, based on a medical condition and age, helping to foster self-worth and social inclusion.

With regards to the age set of participants, choice and opportunities for supported employment was desired. Employment contributed positively to one’s social status and feelings of being a valued member of society. Encountering a range of unconstructive societal responses to impairments, denying any prospect of work, was validated repeatedly by participants. The negativity associated with the loss of or inability to retain some form of employment threatened an important facet of identity in their social world. This disabling situation explained by the social model of disability, illuminates society's focus on the medicalisation of impairments as disempowering (Barnes and Mercer 2011). In addition social influences can promote personal awkwardness with impairments, guide community opinions about impairments as well as structure formal organisational processes, expediting the disablement of identity. Adopting a personal tragedy perspective, indicated by low self-worth and value in society, was common when experiencing loss of or changed working identity, and was an additional threat to their identity (Galvin 2006). However this research did highlight social inconsistencies in work options made available for those with physical compared to cognitive impairments, around retaining or obtaining employment. Our data in fact emphasised society's attitudes and discriminatory behaviours placed greater value on the presence of cognition for employment, which resonates with Mithen et al (2015) who identified that employers were more accepting of physical impairments. This could imply social biases between impairments with cognitive impairments being categorised or stereotyped into a group of lesser value (Galli et al. 2015). The research confirms the need for choice and control, with opportunities to retain or obtain some employment, irrespective of type of impairments, communicating 'respect, value and celebrate what they can do' (Thomas and Milligan 2015, 5). These considerations should be recognised as the 'critical ingredients of a new sense of identity and empowerment' (Hahn 1997, 35) revising social values and norms as directed by the social model of disability.

Undergoing a 'dramatic shift' in life's trajectory prompts the 'renegotiation of identity' (Mathieson 1995, 296). For effective renegotiation, more understanding is essential in negating the requirements of individuals to conform to dominant social norms and values of society. Some participants demonstrated attempts to overcome stereotypical views by choosing the way they projected themselves rather than having it imposed, like being '*the boss'* and not perceived as a '*bludger,'* (an informal Australian term for someone who is idle or lazy). However, overcoming stereotypical influences is reported to be particularly problematic for people with dementia, retaining 'fragile identities' (Harris and Keady 2009, 442), within a society that disables their sense of being and denies them a voice.

Adopting enabling strategies to overcome societal disablement is fundamental to the social model of disability (Beresford 2004, Oliver 2009, Barnes and Mercer 2011). Integrating the social model with social identity theory, helps to rethink strategies that support the way forward for inclusion and enablement, advocating for greater independence, choice and control over individual lives and subsequent identity change. Taking on a disabled identity should not set a precedent for socially constructed disablement, as reported in this research, but should affirm 'their sense of self and worth' (Brown and Addington- Hall 2008, 206), ultimately being appreciated for who one is and who one can be in their social world (Reeve 2004). Essentially taking on a disabled identity should allow individual's the right to influence cultural and societal change whilst capturing their other identities, as demonstrated by participants being a parent, spouse and worker. Replacing the focus on tragedy and loss to one of 'engagement and opportunity' (Kirsh et al. 2009, 400) is crucial to the disabled identity as confirmed by participants who embraced their impairments and overcame socially imposed barriers to define their own identity. Ensuring the presence of positive opportunities to overcome disablism will largely contribute to constructive identity recovery or renegotiation improving one's overall sense of self, self-worth and value in society. Systemic change is needed to counter the socially constructed disablement of identity which could help alter the stereotypical factors influencing changing identity. This could improve overall social status, acknowledge and value a disabled identity, promoting equality and full citizenship regardless of the nature of impairments.

Conclusion

This research highlights the complexity of changing identity in working aged adults in the event of acquiring neurological impairments. Attention is drawn to the connection between society and identity formation through the theoretical perspective of the social model of disability and elements of social identity theory. The disabling of identity is deemed as socially constructed based on social norms and values, which affect relationships, routines and lifestyles and the rights to equal inclusion within society. By revealing the social injustices, related to the assumed competency of people living with impairments, and the disparity of resources associated with certain social groups that are discriminatory in nature, could ultimately help to counter the barriers to the process of identity change. A systemic change could impede the disabling of identity by respecting and valuing individual impairment disparities and identities, promoting enablement and inclusion for all within society, principles which are quintessential to the social model of disability. Illustrating the complexity of affirming a positive disabled identity may help raise awareness of the societal influences that create barriers to the process of identity change.

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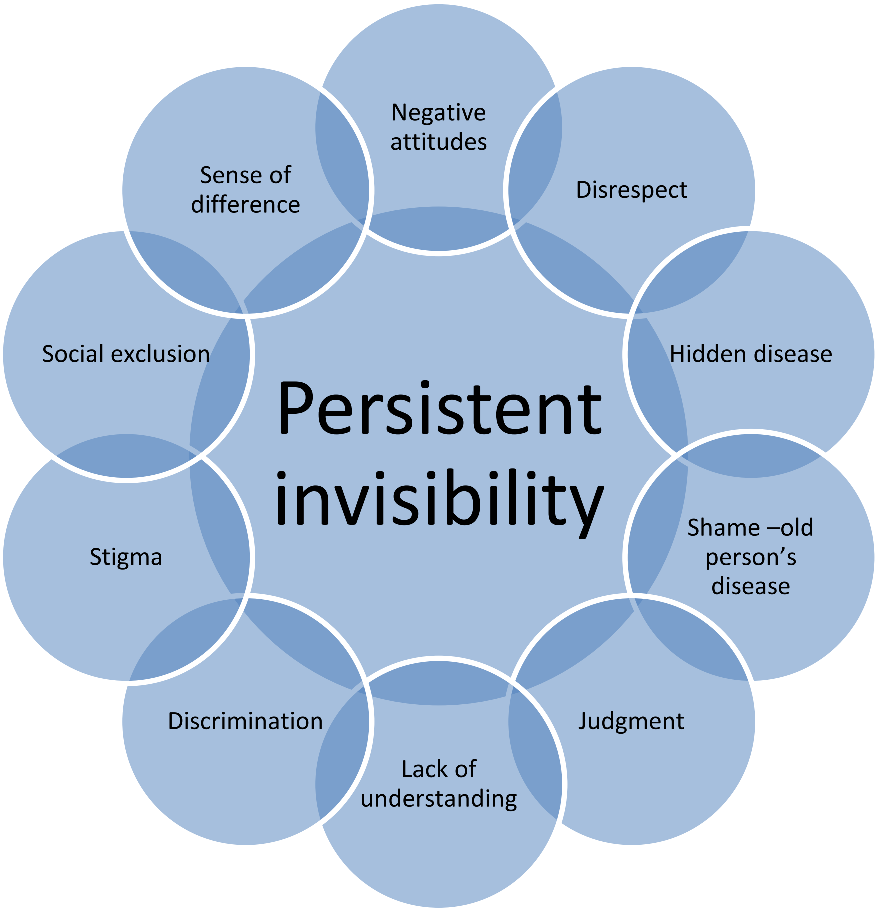
Chapter 3

Feeling invisible and ignored: Families' experiences of marginalisation living with younger onset dementia

Overview

Chapter 3 came about as a consequence of the findings in chapter 2 regarding the varying social inequalities and experiences that result from society's disparate responses towards people living with cognitive, compared with physical impairments at a socially significant stage of life**.** This chapter describes the marginalisation of people living with younger onset dementia (YOD), as well as that of other family members including children. Families living with YOD report feelings of invisibility through disengagement, social exclusion and negative societal attitudes, which simultaneously undermine a family's capacity to support each other. This chapter explains these feelings using the social model of disability as a theoretical framework to underpin the analysis. Socially constructed disablement of the family impacts family relationships, family functioning and family connectedness. Changing societal perceptions and reframing family centred services specific to dementia can ameliorate this social disablement and improve family functioning. See figure 3, which diagrammatically highlights social factors that contribute to persistent invisibility.

Figure 3: Social factors that contribute to persistent family invisibility



Feeling invisible and ignored: Families' experiences of marginalisation living with younger onset dementia

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Abstract

This chapter describes the marginalisation that people living with younger onset dementia (YOD) and family members including children, experience in society. Families living with YOD report feelings of invisibility through disengagement, social exclusion and negative societal attitudes, which undermine a family's capacity to support each other. This chapter explains these feelings using the social model of disability as a theoretical framework to underpin the analysis. Socially constructed disablement of the family impacts family relationships, family functioning and family connectedness. Changing societal perceptions and reframing family centred services specific to dementia can ameliorate this social disablement and improve family functioning.

Introduction

This chapter reports on a research study that explored the impact of living with younger onset dementia (YOD) on both self and family members, including children and young people, from the perspective of the social model of disability. Through excerpts from interviews with people living with YOD, their partners, their children and lone children caring for parents with dementia we illustrate their social isolation and discrimination. All the participants in our study spoke of feeling invisible and ignored, demonstrating poignantly, the powerful impact of societal marginalisation on those living with dementia, including their families, and ultimately, communities. By using the lens of the social model of disability, our study reframed living with dementia from a personal medical tragedy to a social issue which affects whole families. Such a shift in community perceptions could help bring about a social change that supports enablement and inclusion in society for all those impacted by dementia. Taking this social approach demands that support and services should be designed and developed collaboratively with impacted families to ensure their rights to receiving timely age-appropriate care and support is achieved and becomes the norm.

Living with YOD has been described as ‘contextually different’ to that of living with the more prevalent late-onset dementia (LOD) (Spreadbury and Kipps 2017: 2). It is known to bring extra challenges for those of working age. This includes greater financial obligations, addressing the fact that there are more likely to be dependent children and young adults living at home (Brodaty and Donkin 2009; Gelman and Greer 2011) who will require specially tailored support services. However, it seems that levels of support and services to individuals and families living with YOD have been impacted by the problem of determining the global prevalence of YOD (Lambert *et al.* 2014). Accordingly, there has been little change in services for people living with YOD and their caregivers over the last three decades, even with an increase in the diagnosis of YOD worldwide (Mayrhofer *et al.* 2017). This is socially significant, and the needs of families living with YOD have gone largely unnoticed over this period of time. The lack of development in age-appropriate support and services not only impacts the lives of people living with YOD but all their family members, including children and young people (Allen *et al.* 2009; Van Vliet *et al.* 2010b; Svanberg *et al.* 2011; Johannessen and Moller 2013; Barca *et al.* 2014; Hall and Sikes 2016; Hutchinson *et al.* 2016b; Johannessen *et al.* 2016). Despite these issues, there have been few studies that have focused on the range of support services required to address the needs of the family as a whole over the trajectory of living with YOD (Van Vliet *et al.* 2010b; Gelman and Greer 2011; Roach *et al.* 2014).

Much of the research related to individuals and families living with YOD emphasises family dysfunction, social isolation and unmet support and service needs for the whole family (Roach *et al*. 2014; Johannessen *et al.* 2017; Hutchinson *et al.* 2016b). Although families living with YOD are at risk of adverse impacts (Clarke and Hughes 2010) they are often neglected by health and social care service providers (Johannessen and Moller 2013; Barca *et al.* 2014). This failure to provide necessary formal support leads to a range of detrimental effects on immediate and extended family members (Roach *et al.* 2014) across a range of ages and developmental life stages. Effects include impacts on family members’ mental health, employment, financial stability and social isolation.

A recent review of service delivery drew attention to policies and practices that frequently fail to address unmet needs and issues of isolation for individuals living with YOD and their families

(Sansoni *et al.* 2016). This has placed higher demands on family members of all ages, at socially significant times in their lives, to provide informal support often at the expense of their own emotional and physical wellbeing (Van Vliet *et al*. 2010a; Roach *et al.* 2014; Hutchinson *et al.* 2016b). The recent Clinical Practice Guidelines for Dementia in Australia pointed out that 'people with younger onset dementia have unique needs and, accordingly, organisations should tailor their services so that they are age appropriate and address the needs of the person with younger onset dementia and their carer(s) and family' (Laver *et al.* 2016: 8).

A gap remains in the literature for the provision of a theoretically informed view on the ways in which societal influences impact the abilities of family members living with YOD to become more visible in society, to live inclusively and equally in their community. So far, broader society does not appear to have an appreciation of the significance of the social environment in the 'disabling experiences of people with dementia' (Keyes 2014: 9; Thomas and Milligan 2018). There is also a lack of appreciation of the fact that socially-constructed disablement is not only experienced by a younger person living with dementia but also by their families. As the needs of younger people with dementia and their families are largely unmet, their experiences of invisibility and disablement can be profound.

Reflections on the social model of disability as a theoretical lens

The social model of disability has been used extensively in disability research over the years to explain social barriers affecting the rights of those living with impairments and their ability to participate in society. This model draws attention to 'the economic, environmental, and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, sensory or intellectual' (Oliver 2009: 47). It contextualises disablement as a societal responsibility resulting from social exclusion and discrimination (Tregaskis 2002; Oliver 2009; Barnes and Mercer 2011).

Whilst the main focus of the social model has been to tackle disability, through adopting social change and a human rights perspective, there has been much debate amongst researchers as to whether dementia should be linked with disability, similarly to the way in which intellectual and mental health impairments have been (Thomas and Milligan 2018). Even though people with dementia, or others associated with them, do not necessarily identify dementia with disability, they still ‘qualify for disability rights and legal protection’ (Shakespeare *et al.* 2017; Thomas and Milligan 2018: 118), which would improve their social positioning. However, a ‘tendency to over-medicalize’ (Shakespeare *et al.* 2017: 4) those living with dementia, focusing on deficits and personal tragedy, has been attributed to the dominance of the biomedical model in service provision. In the biomedical model, living with dementia is defined and described in medical terms; reinforcing disempowerment through an emphasis on how little can be done for people with dementia until there are breakthroughs in medical research. This perspective is challenged by proponents of a social model who consider rights and equality issues for those living with dementia and advocate for inclusive service provision.

In earlier research, we used the social model of disability to explore the lived experiences of children and young people who have a parent with YOD (Hutchinson *et al.* 2016a, 2016b). We found that the children and young people in our study were marginalised, alongside their parent/s, and that they too experienced socially-constructed disablement, a significant factor in the feelings of exclusion and isolation they reported. This persistent disablement resulted in an emotional toll on these young people (Hutchinson *et al.* 2016b). From a social model perspective, to properly support families living with dementia, service providers will be required to shift from an individualistic and isolating view of their lived experiences to a more social context, in which lives are shared and linked with other family members, friends and their community. Taking this viewpoint would improve overall understanding and help tackle the social barriers and discrimination experienced by all those living with YOD, particularly as these relate to different age categories. Adopting this approach would ultimately acknowledge the importance of equal participation and inclusion of the whole family within society (Burchardt 2004; Thomas and Milligan 2015). Taking a social model of disability approach will assist in exploring and understanding experiences of individuals living with YOD, spouse/partners, children/young people and whole families, and better demonstrate the influences of societal barriers and unfavourable attitudes.

The social model is beginning to be used as a research framework for informing service user support in the dementia sector (Gilliard *et al*. 2005; Thomas and Milligan 2015; Hutchinson *et al.* 2016b). Gilliard and collaborators (2005: 280) described a ‘conspiracy of silence’, in which healthcare professionals become gate-keepers, unwilling to communicate the diagnosis of dementia and manage the repercussions – just one of the many socially-constructed disablements facing people living with dementia and their families. The Mental Health Foundation in the United Kingdom (2015: 30) recently noted that, although dementia is not viewed routinely as a disability, the social model could be considered useful to 'reframe and reconstruct the world of dementia'. Changing the current way of thinking would not only benefit the rights of the person living with YOD to be supported to live a meaningful life but also support other family members to participate fully in life.

To conceptualise how services can be reframed around the experiences of the service users and their families, we illuminate the complex relationships and experiences of those living with YOD and their families through the lens of the social model of disability in order to inform service development (Oliver 2009; Gilliard *et al.* 2005).

The research approach

In this qualitative study, data was obtained through semi-structured interviews with 26 people; five parents under 65 years living with YOD, six partners or spouses of a person living with YOD and 15 children and young people who had a parent living with YOD. Although all the participants in the study belonged to families living with YOD, not all family members participated, and in some families, only one person contributed. Individuals were recruited through Alzheimer's New South Wales, Young Carers New South Wales, the younger onset dementia key worker programme and by the snowball sampling method. The study received ethical approval from the University of Sydney, Australia.

We used the WHO definition of a young person as one between the ages of ten and 24 years. However, the ages of younger family participants ranged from nine to 33 years, and the older of these participants retrospectively described their earlier experiences (up to and including the age of 24). It was anticipated that stories from the past would be recalled and reflected upon from the perspective of their present age and life experiences with a parent living with dementia, and they could then provide insights into how they adjusted to the changes and complex relationships (Hutchinson *et al.* 2016b).

The first author (KH) carried out an introductory phone call or sent an email before conducting the interview and responded to any questions and concerns about the study. KH led face-to-face interviews in the participants' preferred location. Interviews were also conducted by Skype and telephone, so that all interested participants were able to share their stories, regardless of location in Australia. Interviews ranged from one to two hours, with breaks as required, using probing questions. Follow-up phone calls or emails, depending on participants' preference, were conducted post interview, and information was provided on organisations and resources that were considered useful.

The three authors familiarised themselves with the data by repeatedly listening to the interviews and reading the interview transcripts to identify recurrent themes and subthemes. The interview data were analysed using a Framework Analysis (Ritchie *et al.* 2013) which is suitable for creating themes from within and between participants (Gale *et al.* 2013). The data was managed using NVivo qualitative data software (NVivo 2012). The research team met regularly to discuss codes and to clarify relationships between codes and group codes. Also to develop new codes to account for alternative interpretations of the socio-cultural underpinnings of family and societal experiences, interactions and interventions that shaped family members' experiences of marginalisation and that had contributed to the overarching theme of invisibility. Transcripts were coded into four voice groups: the person with dementia's voice (5), the partner's voice (6), the child/young person voice (15) and child/young person (4) who was the primary carer for their parent. Themes were developed both within and between groups to look at similarities and differences in the family experience. Where possible, transcripts belonging to different members of the same family were also analysed separately and together (4).

This multi-levelled analysis allowed for the development of a better understanding of the whole family experience (Ritchie *et al.* 2007). At this point the theoretical framework of the social model of disability was applied to the dataset and samples were coded by all three members of the research team. Variances with regards to the coding of the data were discussed as a team until an agreement was reached about the thematic coding. The first author then applied this coding to the rest of the dataset. The individuals providing their stories here have been given pseudonyms to retain their anonymity.

Family experiences of invisibility: interpersonal invisibility

Through the analysis of interview data across different groups of people in families living with YOD, an overarching theme of *invisibility* emerged. This captured their personal experiences of social oppression, isolation and exclusion, all of which shaped interactions within families, with friends and in engaging with broader society. Invisibility appeared grounded in families experiencing socially imposed barriers, including a lack of understanding around living with YOD. Two subthemes also emerged: *interpersonal invisibility*, giving insights into how individual, attitudinal and behavioural barriers impact interactions and relationships between family members, friends and significant others. The second subtheme, *contextual invisibility*, described the way in which specific policies, practices and attitudes adopted by the very organisations and service providers they sought support from, could add to whole family's experiences of isolation, discrimination and marginalisation when living with YOD.

The theme of interpersonal invisibility illustrated social factors that can impact on the relationships of individual family members, parents living with YOD, spouses as caregivers or offspring, as well as in the role of caregivers. Many participants reported that their needs were not understood, going unrecognised within the whole social context of living with YOD. Their stories highlighted many ways in which they experienced invisibility.

Sarah, living with YOD

Sarah (42 years old) is married and a mother of four children, aged between nine and 18 years. Sarah described how her diagnosis of YOD, a year ago, had adversely impacted relationships within her family:

> *In this house with my husband, flowing down to children, I can say something, and no one listens. It's like I'm not here anymore. I may as well be a cushion or lounge (sofa). Something that needs to be fed, something that talks, my voice has gone.*

Sarah shows insights into her enforced dependency in the family, with no opportunity to exhibit choice and control over situations she is part of. This disempowerment has added to her loss of self-esteem and self-worth. She uses the metaphor of herself as a cushion or sofa to describe her feeling that her needs are sat upon, with no one listening to her anymore. These experiences highlight a loss in her personhood as a result of the disabling behaviours and attitudes of significant others in the family. In Sarah's view, her children are modelling her husband's interactions and relationship with her that seems to stem from the medical model, focusing on her deficits and her need to be cared for, rather than the social model targeting her abilities and what she can do.

Joanne, caregiver

Joanne cares for her husband Fred, diagnosed with YOD at 64 years old. Their two children, one son and one daughter, now in their early 20s, were living at home prior to and at the time of Fred's diagnosis, but at the time of the study had moved out. Joanne reflected personally on how hard the few years were prior to and after Fred's diagnosis. Their son left home due to work and she encouraged her daughter to leave home to '*live the life of a young woman'*. Joanne herself was dealing with the changes to her own future, which is often unrecognised.

She ended her career to care for and support Fred, because '*I just want to be with him through this to help him through it because it's just – it's awful*'. She describes how difficult this was:

> *I was really, really, really struggling because I just felt so alone. So alone and yet so still young and still able to – if we were in a different situation be working full-time and have a really active life … Like how tragic is that?*

Joanne lamented the lack of active participation usually associated with her age. Her social isolation and invisibility led to a change in her sense of social connectedness, '*from being a wife to just a carer, and I find that loss of identity really hard to – a real struggle*'. Being '*just a carer*' gave the sense that this role and change in identity was considered unvalued and insignificant, which contributed to the caregiving role going unrecognised.

From Joanne's perspective, her family was '*amidst the train wreck of our lives'*. However, this was not commonly recognised by others in her social circle. For example, a former work colleague asked Joanne, '*how Fred was*' but did not ask about her or her family. This confirmed her belief that there was a general lack of understanding that the changed family circumstances with dementia had affected them all. She revealed her difficulty in communicating with others, after experiencing their discomfort and inappropriate responses to her family circumstances; '*how do you tell them what the loss is?*' Over time these negative responses caused her to disconnect from family, friends and former work colleagues.

As described by Sarah and Joanne, they felt disconnected and undervalued with the change in their family circumstances. They both highlight problems communicating with their family and friends around their loss, which could contribute to their persistent feeling of being alone. From a medical model perspective, it is the dementia that should be held responsible for their sense of loss and isolation. However, a social model perspective highlights the disabling impact of attitudes and responses to dementia which contributes to their social exclusion and feeling alone.

Mary and Russell, caregivers

The passage of time can bring new insights, as Russell acknowledged when reflecting on his family experiences with his father, Steven, living with YOD. We spoke to Russell when he was 23 years old, the youngest of four children, and his mother, Mary. Over the previous nine years, since Steven's diagnosis, Russell admitted hiding his feelings, never dealing with his distress associated with his father's deterioration. This contributed to Russell's sense of being alone even though he still lived in the family home. On the other hand, Mary recalls juggling her parenting and caring roles, prioritising everyone else's needs over her own. Mary felt alone and her emotional and physical health deteriorated. Russell, recognising his mother's need for help, remembered how difficult it was to offer support to her while at the same time being overwhelmed himself emotionally: '*I'm dealing with it myself and I can't – I just have to kind of put my arms up and walk away*'. Family members, of all ages, living together can find it challenging supporting each other, trying to cope with their own concerns.

This often goes unnoticed by those outside the family, which can ultimately leave people without support options, affecting family connectivity as well as physical and emotional health, as was the case for Russell and Mary. Russell felt he understood Mary's decision to arrange permanent residential care for his father, which Mary acknowledged as a difficult decision. Russell acknowledged the huge demands of caregiving on his mother in addition to other family life pressures, but unknown to his mother; he perceived permanent care as a failure to look after his father, which was hard for him to accept. This had further negative repercussions on Russell's mental health. He described himself as becoming

> *…really very emotionally unstable. I just got to a point where I was kind of just entirely shutting down kind of emotionally. I was just starting to just seize up and try to just not feel anything anymore.*

An act of self-harm made Russell finally notice his own emotional state, prompting him to acknowledge his need for counselling and support to manage the situation. He admitted he had been hiding his grief from himself, his family and others around him. Russell and Mary's stories demonstrate the importance of maintaining and supporting functional family relationships and connectivity, to keep open avenues of informal support and communication.

Beth, sole young carer

Beth was the primary carer for many years, growing up as the only child to her single mother, Tracey, living with YOD. Beth recalls being eight years of age when there were noticeable changes in her mother's behaviour. They had managed for several years living with her mother's dementia but, when aged 13 years, Beth began '*hanging around with the wrong people' and mentions her 'Mum was too sick to put those boundaries in place'*. Extended family members told Beth '*your Mum would be better off if you weren't here. You're just causing more trouble*'. Family interventions were unsupportive and harmful at a particularly challenging and vulnerable time of life, triggering Beth to run away from home. This left her isolated from her mother for about a month, which caused, according to Beth, further deterioration in Tracey's mental status: '*I didn't come home because I thought the best thing I can do is to stay away because that's what she (Auntie) told me'*.

On Beth's return to live with her mother, the extended family intervened again, taking both Beth and Tracey to live separately with different family members. When she eventually returned to her young carer's role at 14 years, still without either formal or informal support, her mother's condition had progressed. Beth then hid the desperate state of home circumstances for fear of being separated from her mother again, either by the authorities or extended family members. In effect, Beth's fear of asking for help in attempt to safeguard herself and her mother from unwelcome judgements and decisions, contributed to her own and her immediate families' greater social isolation and invisibility.

Rachel, sole young carer

Rachel – the now 27-year-old daughter of a younger person with dementia – reflected on the 16 years looking after her mother with YOD. She felt her situation was invisible to others: '*maybe everyone thought that somebody else was taking care of it or maybe if I was a bit older I would say we need this and I could delegate*'.

Rachel felt that her age affected her confidence communicating with adults about what support she and her mother needed. She highlighted a commonly reported situation, in which the views of children and young people were not always taken into account, valued or put into action, resulting in experiences of isolation, hopelessness and vulnerability (Hutchinson *et al.* 2016b). This lack of adequate support and persistent invisibility did eventually take its toll on Rachel. She describes: '*the end of Year 12 when I just started to get worse and worse, really bad depression and self-harming.'*

From a social model perspective, the deterioration of Rachel's mental health was not a direct consequence of her mother's cognitive impairment or her young carer role. Rather it appeared to be the general isolation within the family and community, with inadequate formal and informal support, placing barriers to managing the situation well. While participants in this research described a variety of significant relationships with families and their communities, the common thread is one of *invisibility.* These participants illustrate the social barriers that can disable the abilities of families to function well together under complex family circumstances, the social exclusion they face and the general lack of understanding and recognition of their needs to participate fully in life. Rachel and Beth's stories resonated with other young carers' in other circumstances who described themselves as '*the forgotten'*: young carers say that 'being forgotten undermined them as people' (McAndrew *et al.* 2012: 16). Consequentially this demonstrates a disregard for the meeting of their needs and their rights as valued citizens based on their age.

Experiences of social isolation and feeling alone and unvalued negatively impacts all family members in the way they connect, interact and relate to each other and their social world. Our data indicates that consistent support that addresses the needs of individuals and families is necessary to maintain relationships and connectivity within families. Opportunities for meaningful communication for all are crucial in the process of understanding and engaging, ensuring all family members' voices are heard.

Family experiences of invisibility: contextual invisibility

The theme of *contextual invisibility* highlights factors that impact on interactions and relationships with organisations and healthcare and service providers from whom people seek support and services. This includes the many ways in which people living with YOD and family members feel excluded or unfairly treated based on perceived inequality of services, care and support. In particular, they reported on the tunnel vision of service providers.

Sarah, YOD

Sarah describes living with YOD as being in a world with a ‘tunnel vision’ attitude to dementia in younger age. She points out the frequent omission of younger people from dementia-specific research and services, commenting, ‘*my brain is the same (as older people with dementia), but my age isn’t. Really upsets me. Their children have grown up… I feel like a tiny ant waving at people walking around*’. By drawing attention to her ‘*tiny ant’* status, Sarah demonstrates her sense of unimportance, as well as her insignificance and the discrimination against her within the world of dementia research and dementia sector. Barriers based on age and diagnosis should not be an inevitable part of living with YOD and need readdressing. The social model perspective supports the non-discriminatory right to be treated equally and be given the same rights and opportunities as others.

Phoebe, YOD

Phoebe, diagnosed with Lewy body dementia at 49, has been living alone with formal supports since her diagnosis. She described how her diagnosis was negatively portrayed by a health professional:

> *Everyone has a choice when you’re given a diagnosis. When I was given my diagnosis, it was basically an end of life diagnosis like, okay, you need power of attorney. Get – do an advanced medical directive and go home and wait to die.*

Based on the medical response to her diagnosis, Phoebe felt worthless and disempowered, deprived of the freedom of choice on her right to life. She defined her diagnosis of YOD as the ‘*invisible disease’*, feeling this explained behaviours of fear and avoidance attributed to the lack of understanding, which led to experiences of stigma and marginalisation. Fortunately, a positive experience with a both geriatrician and a psychologist ‘*undid the end of life diagnosis and said you can do anything you want to do*’. This brought about a positive change in her overall attitude, promoting freedom and autonomy to live life as she chose, and she then went on to become an advocate for others living with YOD. Phoebe’s healthcare providers initially focused on her deficits: her life was over and she should prepare for end-of-life care. From a social model perspective, the attitudes of clinicians should help portray her situation more optimistically, supporting her right to be actively involved in decision-making, to engage in life and focus on the things she was capable of and not on her deficits. Examples like these serve to illustrate the disabling nature of the medical model which often fails to recognise people living with YOD as having the human right to choose, take part in supported decision-making and actively participate in society.

Joanne, caregiver

Joanne had personal experience of caring for a family member with cancer, as well as her husband, Fred, living with YOD. She discussed the disparity between carer education and services offered by the dementia sector, compared with the cancer sector. Joanne's observations reflected those of other participants, in emphasising the invisibility of their situation where service provision appeared to be siloed around diagnostic labels rather than need. Joanne summarised these feelings:

> *..because of the education around cancer, everyone gets it, they understand it, there's no stigma around it, there's incredible support. Cancer has such a high profile, and people get it, but with Alzheimer's it's – yeah, they think it's something that's lurking there that's waiting to pounce on you.*

Freya, caregiver

Freya is one of two children providing care for her single mother, Grace, living with YOD. She used the words '*hidden disease'* when talking about her mother's life with YOD in comparison with the experiences with her father, James, who had terminal cancer. Freya noted disparities in the way people communicated, often ignoring her mother, but engaging with her father, asking after his health. These opposing responses could stem from the more significant public awareness or public profile attached to cancer over dementia, and the ambiguity surrounding YOD which fails to see people living with YOD as active citizens with rights.

Joanne and Freya, from different families but both caregivers, have experienced first-hand the negative impact of a label of dementia, influenced by a lack of community education and awareness and understanding around the experience of YOD. It is important that dementia sectors globally disseminate information more widely to make YOD more visible. Inclusive education is required to help change attitudes and improve responses and service opportunities, particularly for those of a younger age. The successful approaches implemented by the cancer sector to increase profile and visibility could potentially be adopted and modified by the dementia sector.

Navigating support and service as sole carer for a parent

Navigating a complex system with little support and direction adds to the overall distress of families living through the progression of cognitive impairment. Participants of all ages revealed their traumatic experiences when deciding to place the person with YOD into permanent residential care, as is consistent with other studies (Bakker *et al.* 2010; Barca *et al.* 2014; Cabote *et al.* 2015). Once the decision is made, the process to identify a suitable facility for someone under 65 years is challenging and often leads to further anguish on the part of family members.

Rachel, young carer

When Rachel was in her early 20s, she was faced with the daunting task of obtaining permanent residential care for her mother in a location near where she lived. She recalled her frustration:

> *I just don't know where people want me to go. I go to dementia specific, they don't want me there. Well, that's what Mum's got so then I go another place, and they won't have me there. I can't travel to Wollongong to go to the younger persons place, and I don't think I'll be able to get her in. So I want her close to me, and I don't know what to do.*

Rachel cried with overwhelming relief when her mother was finally accepted into a good quality permanent residential care home. For many years Rachel's life had revolved around caring for her mother with little external support, but the opportunity of living autonomously was now a possibility for Rachel who phrased this as '*this is my world and Mum's world is separate*'. Rachel was finally able to be a daughter again, rather than a full-time carer, and adopt a healthier lifestyle, to '*do sport, I exercise every day, and I can plan my meals out. It's just so much better*'. The lack of understanding of family circumstances and needs on the part of agencies charged with assisting people such as Rachel, had left her unsupported and battling a complex system to obtain the necessary formal care for her mother. In this way, Rachel had been experiencing socially-constructed disablement that limited her ability to participate in daily activities that many people take for granted, such as exercise and social interaction with peers.

Young carers' support can be a 'lifesaver'

Suitable services and supports can be challenging to find or access, and service availability varies with location. With the added complexity that most services do not adopt a family approach, young carers are often not visible to service providers. This contributes to most children and young people believing they are alone in their experiences of having a parent with YOD, which adds to their sense of difference and isolation. For some, having opportunities for sharing personal experiences and meeting with other young people facing similar life situations is helpful. Rachel joined a group where she could meet other young people with parents living with dementia and referred to this group as a '*lifesaver*': '*I think the best thing that's happened was meeting those young people that are in the same boat because I think the problem with Alzheimer's is that nobody understands'*.

Young people described the benefits of being noticed and afforded proper attention, specific to individual need and age. With this recognition, they felt empowered and more able to cope with changing family circumstances. Also, being considered as belonging to the family by people providing formal services improved their overall self-worth and value, which others have also reported (McAndrew *et al.* 2012). Social isolation and exclusion is a shared experience with family members living with YOD. It is a consequence of the failure to recognise the rights of everyone in the family to have equal access to services and supports, relevant to their age and situation. Reframing of dementia as a social concern would influence the way in which services were designed and how families engage and respond to services and support being modelled around need, not a diagnosis. Also, adopting this social approach could be the impetus for change in policy and practice within health and social care, to help remove social barriers, enabling choice and control, offering alternative approaches and responses (MHF 2015).

Implications of 'invisibility' in families living with younger onset dementia

Our findings illustrate how the complexity of interactions and relationships within families living with YOD, their social circle and with their service providers can impact in such a way that they experience disablement, irrespective of the extent of their impairment. The ability to engage in experiences similar to other families or even in a way that is socially consistent with the stage in their lives can be considerably impeded by their social oppression, isolation and exclusion. The theme of *interpersonal invisibility* highlights the complexity of maintaining meaningful relationships and connections with family members and significant others when lives deviate from their expected trajectory. Often, individual needs remain unrecognised and unmet based on negative attitudes and a lack of understanding of YOD, thus adding to their disablement. *Contextual invisibility* exposes the impacts of organisations, particularly health and social care providers, in the experiences of exclusion, disablement and isolation of family members. Current policies and practices can contribute to denying the rights for full participation and inclusion in society, based on the persistence of the medical model approach to dementia.

The experiences presented in this study demonstrate that feelings of isolation, marginalisation and exclusion by all family members are socially constructed. The cognitive impairment from YOD in these cases did not explicitly, nor directly, lead to invisibility, but rather the reactions of individuals across the range of social contexts within which these families lived. Consequently, each family member's capacity to function and adapt to ongoing complicated circumstances in their lives was dependent on their ability to maintain healthy and supportive relationships, within the family and with significant others. The capacity of a family to support each other's needs and function well together can be dependent on receiving family-centred formal support, services and information that recognises needs across ages.

Reflections on ways forward

One approach through which to overcome the invisibility of family members and their capacity to support each other, be supported and to function together, relates to understanding previous family functioning (La Fontaine and Oyebode 2014; Roach *et al.* 2014). There can be internal negotiation within families around caregiving and support, but the success of this can be contingent. Its outcomes are not predictable: it may create greater intimacy within the family or exacerbate distance (Carpentier *et al.* 2010: 1502). Our findings indicate that the experience of isolation for family members living with YOD stems from marginalisation, discrimination and a general lack of understanding: their experiences often go unacknowledged by both formal caregivers and other family members. This can deter young people from sourcing information that might be helpful (McAndrew *et al.* 2012; McDonald *et al.* 2016). Meeting the needs of families to both access and be able to share information could sustain positive informal family support and reduce the risk of emotional distress (Svanberg *et al.* 2010; Roach *et al.* 2014; McDonald *et al.* 2016).

Interviews with family members demonstrated the relationship between lack of social support or negative social support and psychological wellbeing, leading to the mental distress reported by

Brodaty and Donkin (2009). Specialised practical and emotional support for the whole family, that acknowledges the influence of family history and connected lives, is necessary throughout the progression of the dementia. This will undoubtedly help to reduce overall strain, improve capabilities of all family members to cope with a changing life course and improve future outlook (Carpentier *et al.* 2010; Johannessen *et al.* 2017).

To be effective, services and resources available need to be designed and delivered in ways that are responsive to, and mindful of, changing needs, circumstances and challenges faced by each specific family. A sense of inclusion and being valued within one's family remains essential; arguably more so when one member is living with dementia. This can promote each family member's emotional wellbeing and sense of self (Harris and Keady 2009; Hutchinson *et al*. 2016b). This is particularly relevant for the person with YOD, who becomes more vulnerable over time, and thus feels increasingly disempowered and without a voice. A sense of inclusion is also especially important for children and young people in these families, who can feel insignificant and excluded because of their age (Smyth *et al.* 2011; McAndrew *et al.* 2012; Barca *et al.* 2014).

Despite this tendency to overlook children and young people, they are at times still expected to navigate complex systems and advocate for services on behalf of their parent with YOD, without any acknowledgment by healthcare and social care providers of their existence within the family (Hutchinson *et al.* 2016a). Their experiences and viewpoints can also be disregarded and dismissed by older family members, even when they are the primary caregiver for their parent. Family members, friends, healthcare and social care providers need to be more aware and mindful of the vital role children and young people play in keeping the family together and functioning, and in providing mutual support. Greater understanding of their roles will help in the inclusion of their needs in family focused service design and development (McAndrew *et al.* 2012; Hutchinson *et al.* 2016a, 2016b).

Family breakdown and conflict are real concerns; fragmented families lose informal support options, leaving individual family members more isolated. The combination of limited in-family support and inadequate formal support options can, in some cases, hasten the admission of the person with YOD to residential care. This is one of the most stressful and emotionally distressing transitions for families living with dementia (Allen *et al.* 2009; Lockeridge and Simpson 2012). Poor management of invisibility and complex family circumstances can, for some family members, instigate the development or worsen already present mental health issues. A family-focused approach is essential to recognising and responding to the age-based needs of all family members so that they receive adequate, timely and ongoing formal support and guidance (Millenaar *et al.* 2016; Sansoni *et al.* 2016; Cations *et al.* 2017). Only in this way can needs be recognised and family crises averted.

Avoidance and discriminatory behaviours by other family members, significant others and service providers, causes people to feel invisible, adding to their distress. Family members can lose their sense of self and togetherness: life spins out of control without proper attention from family, friends and formal support networks (Roach *et al.* 2014; Hutchinson *et al.* 2016b). Changing roles and responsibilities, such as becoming a caregiver within the family, affects self-identity and emotional wellbeing, especially if these changes have been imposed without choice and control, and are not acknowledged by others. Family members then experience 'fear, loss and abandonment' (Harris and Keady 2009: 442), affecting their ability to cope and adjust to difficult and unexpected challenges: a diagnosis of YOD comes at a point in life when this circumstance is rarely anticipated. The resulting social disablement, as in Russell's case above, may trigger a decline in one's mental health, creating further difficulties (Tew *et al.* 2012). This deterioration in mental health can also be considered as socially-constructed disablement, directly related to the stresses experienced as a result of the inadequate social support and lack of supportive connections within the family and with significant others (Lockeridge and Simpson 2012).

Changing service provision and enabling families

Improving the visibility of people living with YOD and their family members is a social concern. We have drawn attention to the socially-constructed disablement that results from their invisibility that acts as a barrier to participating as equals in society. Awareness of these disabling factors will direct the change needed to design and develop family-focused services that affirm the non-discriminatory rights of all members of these families.

The under-representation of people and families living with YOD continues to be evident in research. This is a major contributing factor in the experiences of invisibility for those living with YOD. As a consequence, the development of dedicated services are rare for these families (Brown *et al.* 2012: 8; Millenaar *et al.* 2016), because of the lack of awareness of their specific needs. Lack of appropriate support enhances isolation, marginalisation and inequality.

We argue that this lack of support can be addressed in a large part by adopting the social model of disability. Dementia has not been considered a good fit with this model but recent studies are highlighting its relevance across the whole trajectory of dementia (MHF 2015; Thomas and Milligan 2018). The social model promotes choice, decision-making and control over the way one participates in life. Many people living with dementia are now recognising this as their right and are advocating for more equality (MHF 2015). The social model of disability clearly identifies the failure to identify and provide for families living with YOD, addressing age-appropriate services and support, as a barrier to social equity and inclusion.

Considering there is currently a dearth of services, a paradigm shift is necessary. This requires moving away from the present focus on deficits and what people living with dementia cannot do – the focus of the medical model – to embracing a can-do approach and the right of choice in everyday life, under a social model. Reframing services and support to be socially-orientated would mean people living with YOD and their families would be recognised and supported based on their needs, and actively involved in the process of change. No longer would their circumstances be considered a personal tragedy, where nothing can be done and they become passive recipients of services. Negative attitudes towards impairments are barriers to social equality and inclusion, as the social model of disability identifies (Thomas and Milligan 2015). Bringing about attitudinal change is crucial and will be facilitated through creating opportunities for all people affected by a diagnosis ‘to communicate and interact’ (Wenger 2000: 232). These opportunities will deepen the societal understanding of experiences living with YOD. Supporting positive interactions can be the foundation for making the invisible features of living with YOD visible, thereby bringing attention to how society currently disables these families from participating fully in life.

To make the invisible visible, there needs to be leadership to drive the change, committed to renegotiating opportunities, connecting people to share experiences, including communicating needs and offering tangible and tailored support (Wenger 2000). This could be accomplished through the backing of the dementia sector, but needs cross-sector cooperation to take in awareness of the range of ages of family members involved. Implementing a fully-inclusive approach would enable families living with YOD to participate in public and health awareness strategies without judgement and discrimination.

It is well known that discriminatory attitudes to impairments are disabling, as highlighted in disability research. This needs to be addressed in policy, even if challenging (Fisher and Purcal

2017). Social attitudes towards those with dementia can result in oppressive and exclusionary practices (Thomas and Milligan 2018), often based on misunderstandings, general lack of knowledge and the undervaluing of difference. However, the dementia sector and dementia-related policies have been slow in adopting a social approach to dementia because of the dominance of the biomedical model (MHF 2015). We must learn from and adopt practices to raise awareness of dementia as has been done in the disability and mental health sectors, so as to improve the right to inclusion and equality for the whole family (Beresford *et al.* 2010; Barnes and Mercer 2011; Oliver 2013). We know that the practice of diminishing social barriers requires a multifaceted approach (Fisher and Purcal 2017).

The inclusion of the families living with YOD will be essential to effective public raising awareness campaigns advocating for more social contact with families living with YOD in the community, to improve familiarity with dementia and for education programmes across schools and various organisations including health and in the community. Children, the future citizens, can be informed about dementia through specifically-designed education programmes at schools, which will assist in changing perceptions of dementia and promote a dementia-inclusive society (Baker *et al.* 2017).

It is crucial that attention is drawn to the whole family’s needs, regardless of age, so that people are no longer disabled by their invisibility. The parent with YOD is an integral family member, so the entire family should be enabled to function together and be fully supported to participate in life. Roach and collaborators (2014: 1414) have argued that ‘the way the family functions can ultimately impact the life of the person with dementia and how the person living with dementia experiences their diagnosis can impact how the family functions’. This supports the view that all family members should be identified at the outset of any service provision and their input into informing specific family-focused services and support must become routine (La Fontaine and Oyebode 2014). Adopting a cross-sectorial collaborative approach with family members would ensure that no one is left alone, isolated and uninformed; ultimately assisting them to remain connected to the family and be routinely informed of support options to improve experiences of living with YOD.

Changes in approaches to service provision could be facilitated through development and implementation of ongoing education and training programmes with a social model focus. Healthcare professionals participating in education programmes which provide valuable real-life insights into the many social factors that create barriers to families living with YOD, would hopefully embrace a social approach to dementia in their practice. This would help in the process of removing these barriers. Shifting the focus from deficits of YOD, as described by Phoebe, can bring hope that life is worth living and can enable the family to actively engage in life with dementia, with the necessary support. For some healthcare and social care providers, this will involve becoming more aware of their own need to explore and overcome their negative perceptions of dementia (Edwards *et al.* 2014). This greater self-awareness may help them adopt a more enabling approach in their practice, improve interactions with families and provide greater job satisfaction.

In conclusion

Dementia research, policies and practices need to unify dementia within the broader context of societal relations and responsibilities rather than simply treating it as a diagnosis. This should include more innovative strategies for raising awareness of the experiences of dementia in younger people and their family members. Age is a significant factor in living with YOD, a major contributor to explaining the invisibility of all family members. Taking a social model approach to YOD will shift societal perceptions; better inform policy and practice changes; optimise service development and interactions; and promote enablement and inclusion of all family members living with YOD.

Dementia sectors are becoming more responsive and inclusive of all types of dementia. They now need to address the perceived insignificance of those with YOD and their family members, so that no one feels like ‘a tiny ant’. Collaborative development and implementation of health and community education and activities to raise awareness will assist challenge the negating and unfavourable views of dementia and thus eliminate social barriers. Collectively these advancements will be an impetus to countering family experiences of socially-constructed disablement when living with YOD, promoting greater visibility in the community. Reframing YOD will ultimately improve the health and wellbeing of all family members, acknowledge their rights to services and supports based on need and irrespective of age, in turn enabling their feelings of social inclusion.

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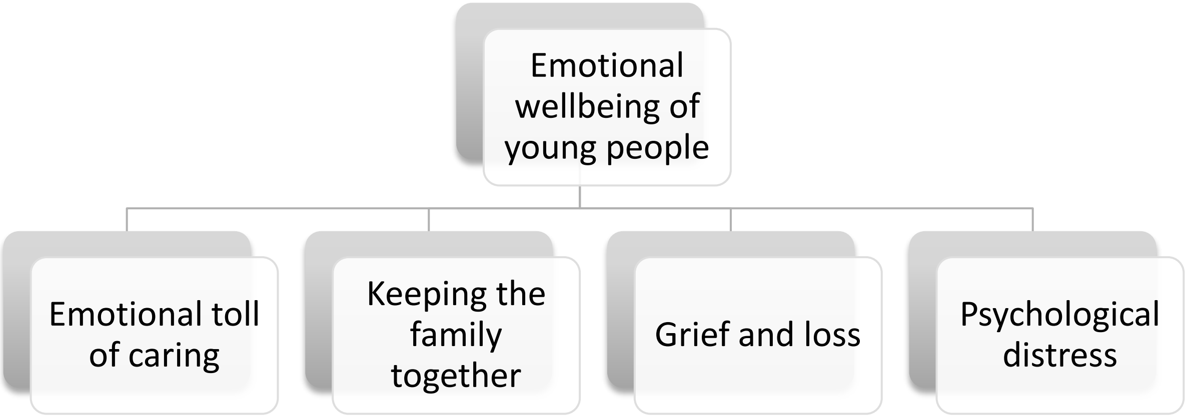
Chapter 4

The emotional well-being of young people having a parent with younger onset dementia

Overview

As demonstrated by Chapter 3, younger onset dementia not only impacts the individual with the diagnosis, but the whole family. This chapter explores the experiences of children and young people in affected families – an area that has had little consideration in the research literature until recently. The social model of disability assisted in explaining the experiences of children and young people, particularly in relation to the societal influences on their emotional wellbeing. See figure 4 for the overarching and main themes from the data analysis. Applying the social model provided a useful framework to have meaningful conversations with the children and young people in affected families, and helped understand the societal triggers that resulted in deterioration of their emotional wellbeing. For some, experiences of emotional distress led to a diagnosis of mental health illness. This chapter then explored how this framework could provide opportunities for improving the way services are designed, such that they better reflect the needs of these young people and families, and support their emotional wellbeing.

Figure 4: Emerging themes for emotional well-being of children and young people



The emotional wellbeing of young people having a parent with younger onset dementia

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Abstract

Younger onset dementia (YOD) not only affects the person with the diagnosis but the whole family, which often includes young people. A limited body of research on this group of young people indicates that they experience varying degrees of emotional trauma. We explored the lived experiences of young people having a parent with YOD from the perspective of the social model of disability. Data was available from semi-structured interviews with 12 young people who had a parent with YOD looking at their lived experiences between 10 – 24 years. Thematic analysis identified four main themes: *the emotional toll of caring, keeping the family together, grief and loss and psychological distress*. The social model of disability theory provides a helpful framework for these families who experience significant emotional distress, demonstrating that the disability is often socially constructed by a society, which marginalizes and excludes them. A 'whole family' approach is proposed, where the needs of young people and their parents are respected and responded to age appropriately.

Keywords: Emotional trauma, lived experiences, social model of disability, young people, younger onset dementia

Introduction

Research that privileges the experiences of the young people whose parents are living with younger onset dementia (YOD) is a relatively new phenomenon. It is increasingly acknowledged that persons living with YOD will often have dependent children. In 2013 it was estimated that 24 400 Australians were living with younger onset dementia, but there was no data as to how many young people in the families might be impacted (Australian Institute of Health and Welfare, 2012).

There are a few population-based studies on the epidemiology of younger onset dementia, from which rough estimates of the number of families might be inferred.

Harvey and colleagues (Harvey, Skelton-Robinson, & Rossor, 2003 p.1208) estimated that, in two London boroughs in the UK, the prevalence of dementia with onset between the ages of 30 and 65 years was 54 per 100 000 and 98 per 100 000 between the ages of 45 and 65 years.

In a Dutch sample of 92 people living with YOD (van Vliet et al., 2011 p. 1396), it was noted that one had an unborn child at the onset of diagnosis, seven had children between 0–10 years, thirty between 11–20 years, seventy-seven between 21–30 years, and forty-eight had children over 30 years of age. Seventeen patients within this sample had a total of 23 children living at home.

There are insufficient facts about the scale of the problem and very little is known about what impact having a parent with YOD has on the young people (Svanberg, Spector, & Stott, 2011). Most of the research to date has investigated the impact of YOD on the person living with the condition and their primary carers. Persons living with YOD are often diagnosed in the later stages of the disease, and behavioural and psychological symptoms of dementia in this group are more frequent than in the elderly population with dementia (Harvey et al., 2003; Johannessen & Moller, 2013; Luscombe, Brodarty, & Freeth, 1998; Koedam et al., 2010).

Service provision has tended to focus on the person living with dementia and their primary carers. However, many of the young people living with a parent with YOD can have emotional problems themselves, problems at school and conflict with the parent with YOD, said to be more common if the father is affected. (Luscombe et al., 1998, p. 329) Moreover these young people can feel isolated and are often ill equipped for the caring role they find themselves in (Brodaty & Donkin, 2009, p. 224). A recent report looking at caring responsibilities of young carers (Cass et al., 2011) across a broad range of situations, not specific to YOD, has emphasised the association with young carers' mental and physical health and its deterioration over time, particularly as young carers move into adulthood. Much of the existing research assumes that it is the spouse that will be the principal caregiver in YOD (Diehl, Mayer, Förstl, & Kurz, 2003; Nicolaou, Egan, Gasson, & Kane, 2010; Rosness, Mjørud, & Engedal, 2011), a model typically derived from older adults with dementia (Lin, Macmillan, & Brown, 2012). Whilst research has outlined the impact on young people living with a parent with YOD it has not been considered in depth, (Svanberg et al., 2011, p. 370) and from theoretically informed perspectives. Furthermore, the inter-related caring role between parents caring for their children and young carers caring for their parents is a further gap in the available research literature (Allen, Oyebode, & Allen, 2009; Gelman & Greer, 2011; Svanberg et al., 2011; Thompson, 2012).

The known impacts on young people include effects on emotional well-being, social stigma and exclusion, and financial hardship. Three quarters of parents who were not affected by YOD consider their children to be impacted emotionally by having a parent with YOD (Allen et al., 2009, p. 456; Luscombe et al., 1998, p. 326). There were many stresses for young people living with a parent with YOD, particularly with 'feelings of hopelessness, embarrassment and irritation' (Thompson, 2012, p. 24; van Vliet et al., 2011 p.1397). Typically shame of their parents' behaviour caused social isolation, for example, where friends were not invited to their house which further impacted their relationship with their parent (Thompson, 2012, p. 24). The distress associated with living with a parent with YOD needs to be seen in the context of the health and wellbeing with the broader population of young people. In 2007, 9% of all young Australians aged 16–24 years had high or very high levels of psychological distress. One in four young people had experienced at least one diagnosable mental disorder in the previous 12 months, and of these only 22% accessed professional help (Australian Institute of Heath and Welfare, 2011). This occurred despite the evidence that a young person's well-being can be enhanced with early identification of need and early intervention. It can be as simple as health practitioners initiating conversations that can help to mitigate risk of harm, increase awareness of family situation and initiate support services (Australian Research Alliance for Children and Youth, 2012, p. 8).

In addition to the lack of research on the impacts on young people of living with a parent with YOD, there is little guidance in the literature around service needs of these young people. Psychosocial interventions for carers have been considered a promising approach as a means of reducing the burden on the carers of dementia sufferers in general (Johannessen & Moller, 2013). However a recognised theme in developing recommendations for the provision of integrated health care services is that much service development is not based on meeting the needs of those who would use the service but based on diagnostic categories of the population (Beattie, Daker-White, Gilliard, & Means, 2004).

Young people are affected in many ways when a parent develops a disability whether it is physical or psychological (Roberts & Hutchinson, 2011), and there is often a significant financial hardship (Thompson, 2011; 2012, p. 24). In many families the other parent has to take on more paid work as well as the dual role of caring for their partner and family, which can often lead to the impacted young people going unnoticed and “lost in the chaos” (Allen et al., 2009, p. 468). The Australian Productivity Commission report (Productivity Commission, 2011) noted the amount of financial support is dependent on how the disability was attained, resulting in an inequality in funding for the person living with disability and their family. This is true for people who develop dementia in working age and have a family to support. They have to revise many aspects of their life including work, finances and financial obligations often adding to the burden of care on the young people. Young carers in general are more commonly living with single parents than young people not in the caring role, be living with disability themselves and live in reasonably low-income households (Smyth, Cass, & Hill, 2011). Thus in several important ways the needs of a parent with younger onset dementia and their family are very different to the older person with dementia. It has been suggested that there is a need for an integrated approach to services and support during the whole course of the illness in order to reduce both the suffering of the person living with YOD, but also to relieve the family carers’ burden (Johannessen & Moller, 2013).

In drawing these contexts together, in which young people are living with a parent with YOD, the research has suggested that the families are potentially stigmatized and discriminated by association with the disability that their parent is living with, which can be as disabling as the difficulties experienced (Tew et al., 2012). In order to understand to what extent the young people living with a parent with YOD are impacted and what this means in terms of service provision, it is important to understand their lived experiences and to develop a theoretical view of the young people’s perspectives.

Theoretical Framework

The social model of disability argues that ‘disability’ is socially constructed, and asserts that it is, not impairment, which disables a person, but social and economic exclusions, which people with impairments face in society (Finkelstein, 1980; Oliver, 1983,1998, 2009). The social model draws a sharp distinction between impairment and disability such that “impairment is the functional limitation within the individual caused by physical, mental or sensory impairment. Disability meanwhile, is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (Barnes, 1992, p. 2). Disability is not a matter of personal tragedy. The so-called "personal tragedy theory of disability" represents disabled people as victims of some tragic happening or terrible chance event and, therefore, is closely connected to the individualized and medicalised concepts of disability, ones which require a solution to a problem (Oliver, 2009). The social model has been extended to explain the way in which the situation of a family living with a person who themselves is living with a disability is a social problem rather than an individual or family situation (Barnes & Mercer, 2011; Oliver, 2009). Social barriers are present causing exclusion and discrimination to the whole family. There is a growing body of literature broadening the context in which the social model has been applied outside of living with physical disability. It has been used to consider people living with dyslexia (MacDonald, 2009), and young people living with intellectual disability (Stevenson, 2010). People with an intellectual disability are often disabled and socially excluded by assumptions of global incompetency. Whilst some of them may have enhanced support needs in some areas, they have acquired skills and have inherent talents, which, as the social model would envisage, are often underestimated and unsung because of deficit focused models and perceptions of intellectual disability.

As a theoretical framework the social model helps to make sense of how society disables people by not treating everyone as equals in their own right. With this in mind the contextual societal issues can inform experiences which can be both positive and negative depending on the community acceptance and support they experience (MacDonald, 2009). The social model of disability has been applied to dementia care (Gilliard, Means, Beattie, & Daker-White, 2005) as a means to helping non-demented people understand their impact on others and can 'reconsider the value of hearing and responding to personal experiences; and can reframe the focus to consider abilities instead of losses; and can better understand the impact of public policy' (Gilliard et al., 2005, p. 571).

In the context of living with younger onset dementia, it is not only the person with younger onset dementia who is impacted by society but also the other family members particularly the young people. Existing research has challenged health and social care professionals and community (Gilliard et al., 2005) to reconsider the value of hearing the young people's experiences in the light of the social model, and to focus on the abilities of them and their families.

Young people often become carers as part of their family life as the parent develops a disability, but when this has negative impacts on the young person, it can reflect the failure of society to adequately support them and the family (Aldridge & Becker, 1999).

The social model has also been used to explore the social impact of mental distress, which is conceptualised as both a response to, and an implicit revolt against, experiences of injustice, enforced loss or abuse (Tew, 2002). Using the language of the social model, separating impairment from disability is particularly problematic in mental health, and the subject of much critical debate (Beresford, 2004). However underpinning the argument is the strength of the social model of disability. The philosophy of independent living for service users, and meaningful user involvement in services is a core foundation of the disability studies movement, which needs to be prioritised and built into the values and operation of the organisational partners (Boxall & Beresford, 2013).

In this context we explored the lived experience of young people living with a parent with young onset dementia from the perspective of the social model of disability. We focused on exploring what impact society has on the emotional well-being of the young people.

Methods

Data collection

Data was collected through semi-structured interviews with purposively sampled participants, undertaken by the first author, an experienced physiotherapist working in the field of community neurological rehabilitation. The WHO definition of young people was obtained on the website (http://www.who.int) being between the ages of 10-24 years. Young people who were not aware of their parents' diagnosis of dementia were not involved in this study. Data was available from 12 participants including 11 females and 1 male reflecting on events from the age of 8 to 24 years, when their parent was noticeably impacted by YOD. Most of the participants were aged between 19-33 years at the time of the interview, although one was just 10 years of age (see Table 4).

Table 4: Participant information

Gender of young person	Age of young person at interview	Approximate age when signs of YOD noticed by young person	YOD Parent affected	Young person's family
Female	10	8	Father	Mother, 2 siblings
Female	19	16	Mother	Single parent, 2 siblings
Female	22	18	Mother	Single parent, 2 siblings
Male	22	14	Father	Mother, 3 siblings
Female	24	22	Father	Mother, 2 siblings
Female	24	19	Mother	Stepfather, 1 sibling
Female	25	18	Father	Mother, 2 siblings
Female	26	11	Mother	Single parent, no siblings
Female	27	8	Mother	Single parent, no siblings
Female	28	16	Father	Mother, no siblings
Female	30	22	Mother	Single parent, 2 siblings
Female	33	24	Mother	Single parent, 2 siblings

The participants' immediate family group is shown in table 1. Although pseudonyms were used in the writing of this article it was felt, with such a small group of participants, that names should not be attached to individual information in table 1, to maintain confidentiality. In depth, semi structured interviews (Mishler, 1991) were conducted with the participants in their homes, place of work or local library. Nine prompt questions encouraged participants' memories, particularly related to activities of daily living, their interaction in the community, and service they had or thought they should have received. Incidents from any stage in their experiences were particularly sought. It was anticipated that the older participants' stories from their own past would be told from their current state of relative wisdom and give insights into how they assimilated the complex relationships.

Ethical Considerations

Following institutional ethical approval, participants were invited into the study via advertising through Alzheimer's Australia NSW and Young Carers NSW. Permission was obtained from both organisations to advertise the research. Participants were given an opportunity to ask questions prior to interview and gave written consent. Data was anonymised prior to analysis and reporting. Further consideration was required when a parent or person responsible for the young person between the ages of 10-16 years, excluding the parent with YOD, completed the consent form. The emotional impact on the young people throughout the interview and after was considered. After the interview the interviewer discussed with the participant and consenting parent options for help if experiencing psychological distress. A handout with relevant contact numbers was given.

Data Analysis

Each interview was recorded and transcribed verbatim. A detailed thematic analysis was undertaken using Framework Analysis. The initial analysis was inductive and grounded in the data and conducted by all four authors on a sample of the interviews. We familiarised ourselves with the data, initialising the generation of codes (Braune & Clarke, 2006). The aim was to identify recurrent themes and subthemes in the dataset, and inform the development of a coding framework (Ritchie, Spencer, & O'Connor, 2003). Coding focused on identifying the socio-cultural underpinnings of the experiences, interactions, and interventions that influenced the young people's emotional well-being. We applied the theoretical lens of the social model of disability foregrounding the perspective of the young people. In subsequent analysis of data, we noted that the emergent themes from the initial inductive analysis resonated with key constructs within this framework. Thus we extended our analysis, by comparing, contrasting, and mapping emergent themes.
This involved an iterative process of moving between the raw data, emergent themes, and the theoretical literature, in order to clarify and negotiate understandings among all authors. NVivo 9 (NVivo, 2010) was used as the qualitative data analysis software.

Results

Our analysis supported four main themes in the context of the emotional well-being of young people living with a parent with younger onset dementia. These were the *emotional toll of caring*, *keeping the family together*, *grief and loss,* and *psychological distress*. Illustrative quotes are identified by pseudonyms for the young people.

The emotional toll of caring

Love, respect and maintaining the dignity of their parent with YOD underpinned all the conversations but often at the expense of the young person's own emotional well-being. Amongst our participants a number of them perceived that they had substantive caring roles, and in two cases were the main carer. The literature suggests (Cass et al., 2011) that many marriages break up in this context, so more young carers are taking on caring roles in living with the affected parent. The impact of caring and dealing with the cognitive as well as the physical changes of a parent with YOD over a long period of time takes its toll on the young people. Trudy at 19 describes how she felt as the only carer for her mum. She had noticed cognitive changes in her mum from the age of 8 years, so had been caring for her for over a decade.

> *It was 24/7, it was around the clock. She'd scream in the middle of the night. She'd have nightmares, you'd have to be awake at seven, when she woke up to say hi, good morning…. you'd have to prompt her to get up and change her and dress her, put her socks on…it was a pleasure to be able to do that for her. But at the same time it took a lot of energy…. I knew I was going to burn out so that's why I looked at getting her moved into residential care permanently.*

The Economic Value of Informal Care report (Economics Access, 2010) suggests that a large proportion of young carers do not access support services and remain 'hidden' to potential providers. With regards to respite care Trudy felt she had to '*jump through hoops to get it.' She* openly states she '*just felt really alone. Didn't feel like I could talk to anyone about that stuff.'* Society played an important part in the *'burnout'* described by Trudy, not only because of the lack of support for either Trudy or for her mother. There was a more subtle process at work in asking for that support. The adverse effects of care giving as a young person leads to social isolation, and for some, the "code of silence" around the caring and the stigma present within society about dementia may prevent young carers, such as Trudy, from seeking out help (*Svanberg, Spector, & Stott, 2010, p. 745).*

Finding ways to cope with the multitude of caring needs of a parent with YOD sometimes required the young person to depersonalize the caring, burying their emotions deep within. In Debra's case caring for her mother who was almost, 'child like', took its toll.

> *I treat her as a job…it seems to work better for her and for me. But then I get sad afterwards because there's the emotional detachment I have to do now because otherwise it's too upsetting to think your mum isn't there for you and doesn't want to, just doesn't care. It's all just her, her, her all the time and it's pretty exhausting*.

In Debra's situation obtaining additional support at home was not an option, because as for many young carers (Cass et al., 2011, p. 20) the services were not specific to her mother's needs, partly due to her mothers' younger age. The sense of stigma present within the community, around her mother's diagnosis made this a real concern to Debra and her siblings, as they wanted to protect their mother from discrimination. The social model of disability (Gilliard et al., 2005) helps us understand the impact that societal attitude has on dementia by causing further marginalisation and discrimination to the people living with dementia and their families, ironically by '*the way services are designed and delivered'* (Gilliard et al., 2005, p. 582).

In Emma's case when her father was taking things from the local shop without paying, she separated her father from the dementia, helping her deal with difficult behaviours.

> *I don't care what people think if he's being difficult or even if we get busted by security….he has dementia, he can't help it.*

This is a strategy of many young people, where detaching oneself emotionally from the situation or separating the parent from the dementia helped with their coping mechanism (Svanberg et al., 2010, p. 745). Whilst emotional detachment helped them adapt to the changes in their family life, there was a cost to this process to the detriment of their emotional well-being (Svanberg et al., 2010, p. 745). The fear of socio-legal issues and a lack of information and awareness of potential services added to the anxiety generated by the situation.

Many young carers talked about the loss of opportunities they would have expected when growing up, due to the commitment of caring for their parent. For some there was the very specific worry of dealing with the fear of developing dementia themselves, and who would care for them. Many young people described how their life plans had changed as a direct consequence of their parents' diagnosis. Sandra, for example, had to decline prestigious scholarships to be near her mother as there was no one else to care for her.

> *..that made me really angry and just negative towards Mum. But I think she would have died if she knew that I had passed up those scholarships but there was no one else there.*

Sandra described feeling "*trapped*," a feeling echoed by most of the young people interviewed. Gail described a "*life that revolves around their parents*" which was very different to her friends both interrupting and altering her life path. These increased responsibilities at a time in early adulthood where they seek independence from the parents can affect their 'sense of self' (Roach, Keady, & Bee, 2012, p. 170).
Sam also felt trapped and lost her opportunity for career progression internationally to be near home to help her mother care for her father and felt the pressure of social stigma.

> *I don't really want people that I'm going to work for to think that I could potentially have Alzheimer's myself. So I usually say that he was very unwell.*

The added stress of the unknown with regards to developing YOD herself impacted on her life plans. The social stigma and potential genetic component behind the diagnosis affected Sam so much that she did not reveal her father's diagnosis to her work colleagues in case it impacted on her employment opportunities. This uncertainty about the future could lead to anxiety within family members (Roach & Brown, 2010, p. 169; Werner, Stein-Shvachman, & Korczyn, 2009, p. 634).

Our data supports the observation that the young people perceive themselves as having extensive caring roles, whilst to date that role has principally been reported as that of the partner or spouse (Diehl et al., 2003; Nicolaou et al., 2010; Rosness et al., 2011).

Keeping the family together

The literature indicates the ways in which a teenager's ability to develop their own sense of identity and independence from parents can be impacted by the caring role (Gelman & Greer, 2011). Although our participants described the love and respect for their parent with YOD they found it hard witnessing the disintegration of their parent with no hope for a cure. To be able to cope with this, some had to physically remove themselves from the home causing the breakdown of the family.

Sandra describes both horns of the dilemma in continuing to care for her mother, and deciding between her mother's health and her own. Whilst '*it would tear my heart out to be there*' with her mum, her love of her mum made her feel she '*couldn't think of anything worse than the future because she was so important to me.*' Even with these strong bonds, Sandra knew that she '*couldn't go there because I was struggling to stay alive.'*

This need for the physical escape to get some normality into the young person's life was a common theme in our data. In Sandra's case, limiting the responsibility by getting away necessitated community services to become more involved.

> *I was glad to get out….and away from Mum….because I wasn't there all the time, other people from community services they took over responsibility.*

In this situation, it was not until the family breakdown, where the young person physically escaped by removing them self from the family situation, was some intervention by the community service providers initiated. Their life course had been affected by their parents' diagnosis, having taken on adult responsibilities at a young age, adding to their distress and strain (Cass et al., 2011; Roberts & Hutchinson, 2011).

Other young people in similar situations to Sandra talked about the guilt of feeling an urge to get away as they felt totally overwhelmed with all the adult responsibilities. Allen et al (2009 p.475) also found that the young people distanced themselves physically to be more able to 'protect themselves emotionally.' However, from a social model perspective, society had failed to support this young person affecting her emotional well-being which necessitated the need to remove herself from the situation to be able to survive.

For some young people, homelessness seemed the only option of a physical escape as in 13-year-old Trudy's situation, an only child living with her mother with dementia.

> *I have memories of spending two nights in the elevator…because it was the warmest place in the winter.*

An unpredictable home life drove this young person to being in a very vulnerable situation. No community support was given to this family. Being labeled as a difficult child and being told she was the reason for her mother's problems by extended family members made the whole situation worse resulting in her 'taking off' for long periods of time living with other families.

For some cases in this study the young person lived with other family members, which gave them opportunities to live similarly to other young people. Some described how they welcomed the freedom of not having to be the main carer for their parent with YOD. Many appreciated the role of their parents carer whoever that was, in the very challenging role they had taken on. Clara describes her time with her mother as '*just being with her'* whereas her stepfather *was*

> …*just there and he's very good at it and he's sort of accepted that as his role so I haven't had to be her main carer all that much.*

This had given Clara the opportunities to continue with her studies and spend time with her mother doing more fun activities. However even in this case and others, the need to organise their future around their family responsibilities was very clear. Some studied part time to take on some of the caring role and to relieve the main carer. In some situations the young person was the only carer of their parent restricting their daily activities. So although the decision with regards to nursing home placement was not taken lightly by the young person there was more of a desperate feeling of need for this to be organised. The breaking up of the family unit when a parent is admitted into a nursing home causes a conflict of mixed emotions to surface from overwhelming freedom, to a deep sadness and feelings of failure. Some did acknowledge that this allowed them to spend quality time with their parent without the burden of caring and get on with their life, which resonates with Allen et al (2009, p. 471). However the stigma of having a parent in a nursing home when so much younger than other residents was hard to overcome as well as finding an appropriate facility that catered for the needs of the younger person with YOD. There was also the welcomed release of the other parents' time in the caring role giving the young person the opportunity to reconnect with this parent. However, as has been observed, carer relief of caring duties 'does not necessarily reduce caregiver distress' (Brodaty & Donkin, 2009, p. 222). Our data supports the pivotal role of the young people in the family keeping the family together, a role which is often unacknowledged and not particularly well supported.

Grief and loss

Grief and loss is acknowledged by the spouses of people living with younger onset dementia, characterized by concerns of dependency, fear, and increased depression (Kaiser & Panegyres, 2006 p.401). In the case of YOD from the perspective of the young person, there is a gradual loss of their parent; a stranger takes their place, with no hope of this person coming back (Allen et al., 2009). John illustrates the complexity of the situation here.

> *The person is physically there but there's also grief of losing someone…That person is not here anymore. But they are. But I can't reach them. But they're right there… is hard emotional circumstance for anyone to deal with…. especially a young person who really doesn't have that emotional framework and faculties to kind of try to process it.*

Clara also recognized how hard it was dealing with grief and loss when her mother was physically there '*but not in a mother capacity, like that's a strange concept to process mentally.*' Annie sums up the reaction from her friends at school to the changes in her mum, 'your mum's weird.' This resonates with the work of others (Allen et al., 2009, p. 466), who found that when young people described their fathers' behaviour being 'less representative' of the person they knew but more as a consequence of the disease, this was highlighting the loss of their 'real' parent.

Many compared their situation to a diagnosis of cancer. Emma talked about the 'glimmer of hope' treatments that can be offered with many cancers but not for YOD. The older participants reflected on the inequality of funding and services for dementia compared to cancer, as well as the differences in community acceptance.

Gail experienced a father dying with cancer and a mother diagnosed with younger onset dementia. She describes the impact that society's acceptance of the situation had at this time, adding further grief to her already emotionally charged situation.

> *It’s so different having a parent sick with something physical like cancer to a parent sick with something like Alzheimer’s…there’s this real shame around Alzheimer’s. No one wants to talk about it. No one wants to acknowledge it.*
>
> *Everyone wants to say she’s fine, there’s such denial. Where with dad it’s much more, how’s your dad and how’s chemo and oh you poor things.*

Gail was not alone with this conflict about the unfairness of the diagnosis of Alzheimer’s compared to other diagnoses, particularly cancer. Jasmine at 10 years old feared her father might die from a smoking related cancer and would not be around to see her into adulthood but was not aware that dementia was terminal too. She demonstrates how graphic television advertising around prevention meant that cancer is conveyed dramatically to the general public including children. By contrast dementia remains poorly publicized particularly in relation to younger onset. Raising public awareness about younger onset dementia may help to reduce the stigma and ignorance about the condition helping to support families in the community without discrimination (Harris & Keady, 2009, p. 442).

Gail described her grief and disappointment for her loving, independent mother lost to Alzheimer’s who is now forsaken by society.

> *I get really mad when people treat her not like a citizen and not like a person…it annoys the crap out of me.*

This abandonment not only affected her mother but Gail herself. The discrimination, that she witnessed in society led to her own exclusion and shame, and added another dimension to the grief and loss process. This social isolation, often due to family and friends keeping their distance compounded the loss of a future the young people had imagined for themselves, as well as feelings of resentment (Allen et al., 2009, p. 470; Roach et al., 2012, p. 170). These young people were grieving over a long period of time, facing a non-accepting society while losing the essence of their parent, all adding to affect their emotional wellbeing. In her memoir, Marie Williams, a dementia advocate, echoes the marginalisation felt in their family even within the Alzheimer’s community (Williams, 2013). Similar experiences are also reported by people living with and caring for people with mental health issues (Martin, 2009).

Our data supports the notion that there is a grief and loss that is personal to the young people but that society compounds the issues in terms of creating social isolation for themselves and their family, adding to their sense of stigma.

Psychological distress

Many young people reported negative feelings like ‘*anger’, ‘sadness’, ‘frustration’, ‘shame’, ‘guilt’, ‘fear’, ‘trapped’, ‘hopelessness’,* and being *‘judged’*. All participants reported some psychological distress due to the family stresses experienced. Emma describes trying to make sense of her feelings of living on the edge, where the smallest of triggers could set off a strong negative emotional response beyond what she expected as normal for her.

> *I feel like this big pot of boiling water that’s constantly about to overflow so the smallest thing can set me off.*

She felt anger towards everyone because of his or her lack of acceptance of her father with dementia and as a result was ready to fight for him to ensure he was not affected negatively by the discrimination she witnessed. She was desperately trying to maintain his respect and feeling of being a valued member of society at the expense of her emotional needs.

For four participants, a healthcare professional had proffered a mental health diagnosis for them, and mental health care plans outlining ongoing treatment, involving the General Practitioner, Psychiatrist and Clinical Psychologist. A range of diagnosed mental health conditions were reported by our participants, including depression, anxiety, psychosis, obsessive-compulsive disorder (OCD), self-harm, and alcohol and substance addiction. Participants frequently described symptoms related to their mental health for example in suicide ideation as part of their depression.

Those four young people with a diagnosed mental health illness, who were themselves living with a disability by virtue of their own mental health, were almost apologetic and embarrassed about their psychological distress. The stigma behind mental health issues, compounded with a person with YOD in the family, often caused the young people to hide their diagnosis and physically remove themselves from the stressful situation. This provided a crisis of identity for such young people demonstrating the importance of society recognizing young carers' role as a component of their identity (Smyth, Blaxland, & Cass, 2011, p. 158). Both society and young people accepting this component of their identity would help with accessing the support required to perform this caring role. On the other hand society's failure to provide adequate support appears to cause further discrimination and isolation, often leading to the young person taking on a more demanding caring role (Aldridge & Becker, 1999, p. 311) and thus developing the kinds of issues affecting our participants.

> *Now I can put names to things because I work in the industry. I look back and go oh gosh, god I had depression. But then at the time I didn't really understand or recognise what it was….I think my way of dealing with that, was to remove myself from the situation because I didn't know how to cope with it.*

For this young person seeing things in a new light helped to make sense of those difficult years. It also demonstrates that young people find it difficult to recognise what is happening and need support to help deal with all the issues they face. Decisions made at times of great stress can impact them into adulthood as Trudy highlights.

> *It is really hard looking back on decisions you make at the time. Whether they're right or wrong ones now, it's done. It's still a difficult thing to talk about because she's very close to me.*

The complex interplay between the development of a young person's mental health condition in the context of living with a parent with YOD is illustrated by John's situation. He wondered if his mental health disorder of Obsessive Compulsive Disorder diagnosed at 14 after his father's diagnosis of YOD was

> *A brilliant distraction that I made for myself, just to kind of give me a bit of a mental distance, or something, from having to think about it.*

In John's situation, not knowing where or who to turn to, he was 'lost in the chaos' (Allen et al., 2009, p. 468) while his parents and other family members dealt with their own issues. He continued to demonstrate an aura of normality at school and in the community disguising the real emotional impact on him. It has been suggested that many young carers show resilience beyond their years often disadvantaging themselves in the future, as their own needs are often overlooked (Svanberg et al., 2010, p. 745). In talking as a 21 year old, John demonstrates the long-term impact of these negative emotions. His distress was exacerbated at the time his father was admitted to residential care.

> *I stabbed myself in the thigh with the fork, just because I didn't understand what was happening and I just was I guess just really gritting my teeth against freak out and depression and anxiety and dealing with the whole situation. I couldn't quite comprehend what was happening. But I knew something was bad. Something was very bad.*

He acknowledged he had to become more '*genuine*' with his emotions as '*it was all cooking in there*'. This resonates with Allen et al (2009, p. 468) findings that many young people became overwhelmed and often failed to admit their feelings using 'a shell to protect them from the possibility of emotional hurt.' Once this protective shell was removed, as in John's case, self-harming through stabbing became a 'maladaptive emotion regulation strategy' for the relief of his many negative emotions (Nixon & Heath, 2009, p. 49).

Sandra describes how, in year 12, after caring for her Mum on her own since she was 11 years old with the pressure of caring, studying and applying for prestigious scholarships she felt '*outcast and a failure*' and '*melted down*.' She then went on to develop

> *..psychosis and depression….I thought everyone was out to get me… I was on schizophrenic drugs and things but the psychiatrist said he thought it was too much pressure.*

Emma, Trudy, John's and Sandra's stories resonates with the literature about young adult carers concerns about their health issues both physical and mental, particularly at the time of transition from young carer to young adult carer (Cass et al., 2011). As with many young carers, Sandra had been taking on adult responsibilities for a long period of time at the expense of her own needs (Svanberg et al., 2010, p. 746). These mental health issues were a real concern among young carers due to the ongoing emotional and physical stress and strain of the burden of caring, in a society that offered little support and in which they were isolated from their friends (Allen et al., 2009; Cass et al., 2011; Gelman & Greer, 2011; Roach et al., 2012). For many hiding their feelings behind a protective ‘shell’ (Allen et al., 2009 p.468) gave a sense that they were coping to their well parent (Chow, 2012).

Many of our participants found that the support at home or by the family was not always available, because of the complex situation. For example they might be living with a single parent with YOD, or the non-affected parent was juggling work, a dual caring role, and dealing with their own emotional issues. For John’s mum, ‘*she was kind of too deep in her pain to be aware of it*’ to offer much support to him. Thus the partner of the person living with YOD experiences greater burden as they are often working, have financial commitment for the care of their partner, as well as having dependent children (Brodaty & Donkin, 2009, p. 224). Young peoples’ concerns for their non-affected parents well-being has been acknowledged (Allen et al., 2009, p. 475), as well as their fear of ‘overburdening’ their parent with their issues. Other family and friends often were not present to support them due to the stigma of dementia or the family’s ‘sense of shame’ (Allen et al., 2009, p. 475). This reinforces the need for a whole family approach to caring, which has been supported in the literature to help maintain cohesiveness in the family (Aldridge & Becker, 1999; Cass et al., 2011; Gelman & Greer, 2011; Svanberg et al., 2010).

Our data shows that the young people experience a greater burden of mental health issues, compounded by their sense of isolation and restricted availability of age appropriate services (Brodaty & Donkin, 2009). This complex situation resonates with the social model of disability theory with regards to dementia (Gilliard et al., 2005) in that families of people living with younger onset dementia suffer from significant mental illness, chronic stress and stressors which are socially constructed by a society, which stigmatizes them and does not provide appropriate services for their individual needs.

Discussion

Four main themes have emerged from our data that illustrate the lived experience and in particular the emotional well-being of young people living with a parent with younger onset dementia. These were the emotional toll of caring, keeping the family together, grief and loss, and psychological distress. Young people perceived themselves as having extensive caring roles, either with a single parent or in a complex interplay with their other parent. Young people have an important role in keeping the family together, a role which is often unacknowledged and not particularly well supported. For some, grief and loss is characterized as losing a parent to a disease which can be fatal, like cancer, but to one that society stigmatises creating an aura of uncaring. In addition to high levels of psychological distress, there is a concerning level of need for mental health services amongst the young people, compounded by their sense of isolation and difficulty in obtaining age appropriate services. The social model of disability theory provides a helpful framework of a social approach to disability, where families of people living with YOD can be supported through significant mental illness, chronic stress and despair (Gilliard et al., 2005). Our data supports the notion that for some young people at least, their burden of mental distress is such that society appears to have marginalised and excluded them, in effect disabling them. Furthermore there appear to be no clear strategies to provide the kinds of services that acknowledge the complexity of the situation to help keep families together, and at the same time care for complex mental health problems and psychological distress.

Implications

The theoretical framework of the social model of disability (Barnes & Mercer, 2011) provides a powerful model with which to understand the experiences and truth of disability. It draws attention to the real problems of disability, the attitudes, which disadvantage people, and the social barriers that affect full participation in society. We acknowledge that mental health service users have never been central to the social model of disability, but the dynamic is changing through healthy debate. As such, there is a growing emphasis on developing goals and strategies through the development of a social partnership approach to disability for mental health service users (Beresford, 2004).

The social model of disability theory provides a means to developing an improved understanding as a society of our accountability for some of the issues faced by the young people and their families living with YOD. The social model of disability theory in relation to dementia (Gilliard et al., 2005) makes us reflect on the way families living with dementia experience discrimination and marginalisation possibly exacerbated by the ‘way services are designed and delivered’. This theory helps us recognise the importance of dementia care services being tailored to the individual needs of the person with YOD and their family members, as is their social right, to help prevent isolation and crisis within the community. Our findings resonate with the observation that ‘care professionals do not consult with young people living with a parent with young onset dementia as service users, although the principles of good practice suggests that they should ’(Gilliard et al., 2005, p. 582). Recommendations for the provision of integrated health care services must include the service being based on the needs of individuals and be family orientated (Beattie, Daker-White, Gilliard, & Means, 2004).

From a social model of disability perspective, we argue that the stigma behind having cognitive decline is considerable and the concealment of diagnosis of YOD, and also mental health issues within affected families is common. Accordingly, young people can experience a life disadvantaged by a society that fails to support their emotional well-being and their engagement in social, educational, and economic opportunities for their age, preventing their inclusion in full participation in society. Our data suggests that all the young people in this study, by virtue of their family, have experienced living with disability themselves due to the loss of opportunities available to live equally in society by the social barriers in place (Tregaskis, 2002, p. 3). Emotional trauma varies from ongoing stress to a medically diagnosed mental health condition, which then compounds their disability. This double jeopardy highlights the vulnerability of this group and alerts us to the potential crisis they face.

Many report difficulties in the process of their parents’ getting a diagnosis of YOD, then dealing with the social stigma, discrimination and lack of understanding that is present in the community about the diagnosis, which intensify their families’ difficulties in being included equally in society (Gilliard et al., 2005). Being treated differently can enhance the distress of the diagnosis to the individual and their family due to the lack of community understanding (Pipon-Young, Lee, Jones, & Guss, 2012, p. 610). Young people living with a parent with YOD are discriminated against by society, in the same way as their parent. This highlights how more needs to be done in accepting these young people, and in doing so help develop a more inclusive society enabling them to look to a more positive future (Smyth, Blaxland, & Cass, 2010, p. 156). However our data also suggests that at least a third of the young people will have themselves experienced mental health problems requiring the use of mental health services, and therefore are experiencing disability in their own right. It is likely that there is a complex interplay between the mental health impact of changing family dynamics coping with YOD, and the recognised mental health problems associated with transitioning from child to adult (McGorry, Bates & Birchwood 2013).

The social model of disability (Finkelstein, 1980; Oliver, 1983, 1998, 2009) can provide the wider community with a framework to have meaningful conversations so as to contribute to a shared understanding as to what impacts they, as non –disabled people, might have on the lives of those families living with young onset dementia. The community needs to move from a model based on personal tragedy, social discrimination and exclusion, to one of proactively providing enhanced care, celebrating the acquired skills and inherent talents of affected families, and as the social model would envisage, changing societal perceptions of living with a cognitive disability.

It will be important to understand more about how families are affected in planning service provisions, and the ways in which families can be identified and supported. Our findings indicate how difficult it can be to find and support young carers with parents with YOD where there are perceptions of discrimination and exclusion of people with cognitive impairments and their families. The numbers of young carers nationally, not specific to YOD, is underestimated as many are reluctant to reveal what is happening at home or may not want to identify themselves as carers. Young carers want to live ‘normal’ lives similar to their peers and don’t want to appear different. Hiding their role is often through the fear of drawing attention of their home situation to social services and also the consequential stigma that may ensue on disclosure. This is particularly relevant to young carers of parents with mental illness often isolating them from accessing support services (Smyth, Blaxland, et al., 2011, p. 147). It is perhaps unsurprising the way fragmented service provision consistently appeared to let our participants down. A family approach to supporting these families is so important to prevent family breakdown (Gelman & Greer, 2011). Unfortunately for some young people severe mental health issues arose, requiring very person centred mental health plans. Society needs to acknowledge the loss of their carefree adolescence and the sequelae of taking on the adult role prematurely (Allen et al., 2009).

More research is needed to understand what adequate and age appropriate support is required to prevent social isolation and to promote emotional and physical wellbeing, and particularly to avoid the ‘derailment’ of the entire family at times of crisis. The literature demonstrates that social support helps to alleviate some psychological distress and reduce overall stress in many carers (Brodaty & Donkin, 2009). As a community, many working within the area of dementia, have experience that is more likely to be from an aged care perspective. Dealing with young people in the context of a family affected by dementia requires specialist knowledge and expertise to provide effective intervention and support that meets their needs. The young people need to feel empathy, support and a sense of belonging, and have a voice in challenging these services to develop ways to incorporate support services for all family members. In our data a common issue with the young people was that service providers were so overwhelmed by their situation that they inadvertently contributed to the younger peoples’ despair and were unable to help them move forwards.

In the Australian context, there is a new initiative to provide federally funded key worker roles for YOD families (Alzheimer’s Australia, 2013). This gives an opportunity for workers to develop theory and practice in the prevention of some of the consequences of long-term emotional trauma in these young people. Service providers and health practitioners can become engaged in a more positive action towards monitoring the situation to prevent crisis development. Particularly vulnerable times where emotional distress is more common, where a young carer moves from youth to adulthood, needs to be targeted (Cass et al., 2011). Programs and support need to be put in place to alleviate some of the caring responsibilities of these young people, as well as control the amount and intensity of their caring roles. Failure of society in providing adequate support and care for the parent with YOD places more burden on the young carer. It is a matter for further research to understand how the establishment of this nationally supported YOD key worker role will provide a common point of contact encouraging a family approach to dementia care, develop preventative strategies and integrate support services for all age groups within the family.

The affordances of social media can provide innovative ways for a widely distributed group of young people living with a parent with YOD to keep in touch, and share information. This may cover socio-legal issues and raise awareness of potential services whilst providing a rich social network of support. For example the Alzheimer’s Australia NSW has a young people support group, which provides an opportunity for them to meet other people in similar situations, share experiences and understandings. The Alzheimer's Australia blog provides a forum for discussion on line but again, so far these services are for the over 18s and more research is required to develop services like these for those under 18. Internationally much can be learned from similar organisations, e.g. Alzheimer's Foundation of America website for teens: http://www.afateens.org/learn_dementia.html.

Strengths and Limitations

Our study represents an analysis of the lived experience of young people living with a parent with young onset dementia, which is an area under represented within the literature. Our findings represent the views of one particular group of young people and are not intended to be generalised to other groups of young people. This research is one of the first theoretically informed papers to apply the social model to young people with a parent living with dementia.

We acknowledge that females are over represented in our sample. This concords with work in other research domains where the stories of young men disclosing challenging emotions have been difficult to harvest (Haskett, Marziano, & Dover, 1996). As Australian data on young carers suggests, three quarters of young carers above 18 years tend to be female which could represent the gender differences or males may be reluctant to acknowledge their caring roles (Smyth, Blaxland, et al., 2011 p.146) in looking after a parent with YOD.

The youngest participant was 10 years and only one teenager was represented in this sample although there was more data obtained retrospectively about teenage years. This is a limitation to the study and having more representation within 10-18 years age group would have been beneficial.

Conclusion

This research describes the factors underlying the varying degrees of emotional trauma of young people living with a parent who has young onset dementia. Using the social model of disability to interpret the data, it is suggested that society adds to the emotional trauma due to the exclusion and discrimination experienced as well as the inadequacy of appropriate age support and services available. It is imperative that further research is undertaken to both add to theory and the practice of health and social care professionals and service providers in order that they can better support these young people emotionally within the family helping them to live a life without discrimination. A ‘whole family’ approach is proposed, where the needs of young people and their parents are respected and responded to. Whilst some of these families may have enhanced support needs in some areas, they have acquired skills and have inherent talents, which, as the social model would envisage, are often underestimated and unsung because of deficit focused models and perceptions of cognitive disability.

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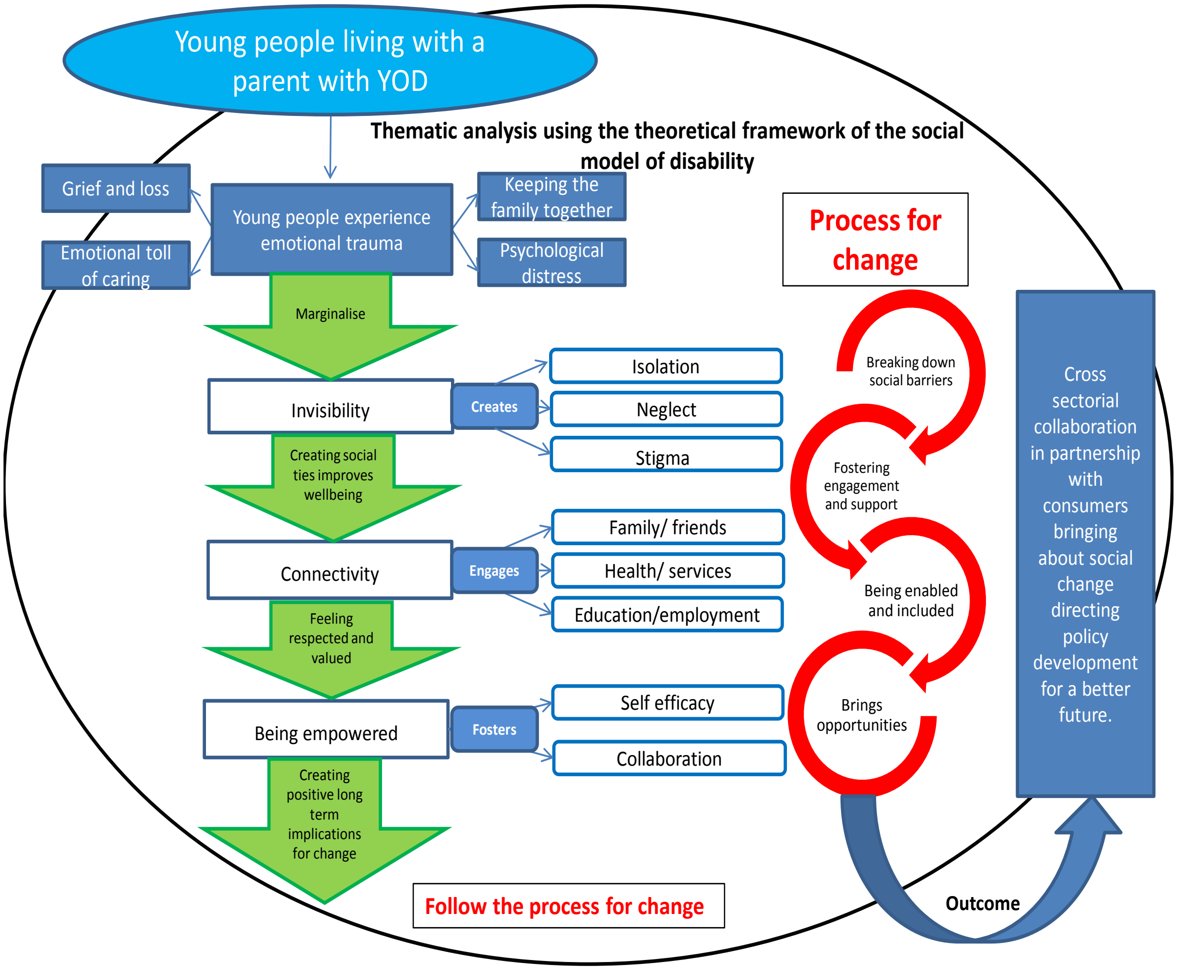
Chapter 5

Empowerment of young people who have a parent living with dementia: a social model perspective

Overview

The common problem, as highlighted in previous chapters, is the mismatch of the services and support provided to families living with younger onset dementia relative to need, which ultimately socially disables individuals and families. Considering the emotional impact on young people highlighted in chapter 4, this chapter uses the social model of disability to further explore the social impact on the lived experiences of young people. Chapter 5 demonstrates their experiences of ongoing isolation, neglect and stigma by association. Attention is drawn to the need for change in current service delivery models to ensure these young people are included and supported - applicable to adopting a social model of care. To address a gap in the research literature, social factors that can give rise to social change were drawn from the data and explored. Being connected to a significant individual was found to be crucial through the process of engagement to overcome invisibility, which can lead to empowerment thereby promoting progress towards an inclusive and enabling future (see figure 5).

Figure 5: Thematic analysis related to empowerment of children and young people



Empowerment of young people who have a parent living with dementia: a social model perspective

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Abstract:

Objectives

Socially constructed disablement has marginalised young people in families where a parent has younger onset dementia (YOD). This has contributed to inadequate societal support for their complex situation. Impacts on such young people include significant involvement with mental health services for themselves. In this paper we explored the young people's lived experiences in these families and the influencing factors to enable these young people to be included and supported within their community.

Methods

In this qualitative research study the social model of disability was used as the theoretical framework in conducting a thematic analysis of interviews with 12 participants.

Results

Three themes emerged; *invisibility* highlighting the issues of marginalisation; *connectivity* foregrounding the engagement of young people with family, friends and their social networks, and *being empowered* through claiming their basic human right to receive the age appropriate support they needed.

Conclusion

The current plight of young people living with a parent with YOD demands a fundamental shift by society in developing inclusive cross-sectorial cooperation linking service providers across youth and dementia sectors. This requires working in partnership with the service users responding to the identified needs of individual family members.

Keywords: young people, younger onset dementia, lived experiences, social model of disability, marginalisation, and collaboration.

Introduction

Families living with dementia have generally been placed in a siloed care environment that is specific to the diagnosis rather than one sensitive to the requirements of the whole family (Brodaty & Donkin, 2009; Gelman & Greer, 2011). Internationally, there is increasing recognition of mental health services' need to change their focus from clinical diagnosis and management to one that is centred on the needs of service users, their families, and carers (Beresford, Nettle, & Perring, 2010; McDaid & Delaney, 2011; Tew et al., 2012). The mismatch between clinical models of care for dementia and the wider needs of the family are amplified in those living with young onset dementia (YOD). In Australia it has been estimated people living with younger onset dementia (YOD), under the age of 65 years, make up 6 to 9 % of all those living with dementia (Australian Institute of Health and Welfare, 2012). Norwegian data suggests that one third of people diagnosed with YOD have a family member under 18 years when the disease process begins, taking in to account the often lengthy delays in diagnosis (Barca, Thorsen, Engedal, Haugan, & Johannessen, 2014).

Parents living with YOD who have young people or children, experience unique stresses due to a reliance on services and resources that do not holistically meet their family needs (Denny et al., 2012; Roach, Keady, & Bee, 2012). Within a more socially orientated model of care, there have been calls for the emotional impact on all the family members to be addressed (Barca et al., 2014; Hutchinson, Roberts, Kurrle, & Daly, 2014). In a model of care focused around a diagnostic label, it is perhaps not surprising that clinicians reported that finding out information about the family members was not valued clinically nor was it regarded as influential in planning (Roach et al., 2012). Subsequently, service providers are overlooking young people who are at increased risk of experiencing emotional distress and may require mental health services when caring for a parent who is living with YOD (Hutchinson et al., 2014). The young family members frequently report being unnoticed by service providers and despite being significantly impacted over an often lengthy period of time, there are few offers of emotional and social support (Gelman & Greer, 2011; Johannessen & Moller, 2013; Svanberg, Spector, & Stott, 2011). These young carers belong to a much larger group of young carers who are at greater risk of developing mental health issues than their peers (Australian Institute of Heath and Welfare, 2011). Studies that reviewed the impact of different parental illnesses on children have similar findings to those of families living with YOD. They highlighted age, gender, length of time living at home, coping ability of the young people and family members as being influential in managing their parents' illness (Barca et al., 2014). For example, young people who have a parent living with multiple sclerosis were three times more likely to experience psychological distress than the general population (Pakenham & Bursnall, 2006).

Isolation, financial hardship and parental disharmony are common themes for young carers in general (Mayberry, Ling, Szakas, & Reupert, 2005). Many young carers live in single parent families, often adding to their burden of caring particularly if they are the principal carers (McAndrew, Warne, Fallon, & Moran, 2012; Smyth, Cass, & Hill, 2011). All aspects of young carers' lives need to be considered in planning inclusive services (Pakenham & Bursnall, 2006). Enhanced social support, information about the parents' diagnosis, adequate finances and good family relationships help to shield the young people from developing psychosocial issues (Barca et al., 2014; Bogosian, Moss-Morris, & Hadwin, 2010; Pakenham & Bursnall, 2006).

Generally, young carers do not seek help and support because of a fear of 'unwanted scrutiny and intervention from social support services' and 'fear of stigma' (Smyth, Blaxland, & Cass, 2011, p. 2). This suggests that society is failing to acknowledge and meet the needs of these young people leading to social exclusion and discrimination (Hutchinson et al., 2014). In addition, concerns with confidentiality and trust are further barriers for young people in seeking help and connecting with appropriate services (Gulliver, Griffiths, & Christensen, 2010).

Stigma is commonly associated with people living with dementia and has been defined as a sign of disgrace or discredit, which sets a person apart from others (Byrne, 2000). Transferring stigma to significant others associated with particular illnesses is of real concern. This can contribute to the 'hidden nature' of young carers failing to be recognised in their role by others and themselves (Smyth, Blaxland, et al., 2011, p. 10). This challenging notion where the rights for citizenship and respect within society are significantly impacted, adds to the distress of the families (Alzheimer's Australia NSW, 2010; Tew et al., 2012). Stigma by association has contributed to societal disablement of the whole family and further marginalisation (Tew et al., 2012). Additionally, prevailing societal views of dementia being a progressive, terminal disease of old age have also contributed to young peoples' experiences of disablement and marginalisation in these families (Alzheimer's Australia NSW, 2010; Hutchinson et al., 2014).

Given this socially constructed disablement of young people living with a parent with dementia, the question arises as to what extent these young people can engage with enabling strategies, to help them become empowered to overcome this disablement.

There are two promising strands of inquiry in providing a theoretical perspective from which to envision potential enabling strategies. The first involves a concept drawn from social psychology. Connectedness within a young person's social world through the building of positive relationships may help them to form linkages and networks that promote resilience, through a sense of belonging (Kawachi & Berkman, 2001; Mayberry et al., 2005; Tew et al., 2012). Connectedness is at the heart of the theory of communities of practice (Wenger, 2000). This theory is increasingly being used to envisage how communities of practice can work on improving specific aspects of health and social services. Robinson et al., (2005) described 'strategies that health professionals and their colleagues in multi-agency, multi-professional teams use to overcome barriers and to strengthen team cohesion' working cooperatively for the benefit of young people and families (Robinson & Cottrell, 2005, p. 1). The second strategy recognises individual empowerment as described by Masterton and Owen (2006). Being empowered requires positive person centred associations to be developed and encourages individuals to be part of the decision making process (Masterton & Owen, 2006). These young people are thought to need recognition in their own right while responding to the changes in the family circumstances and dealing with marginalisation in society (Thomas et al., 2003).

Theoretical framework

The social model of disability maintains that 'disability' is socially constructed, and it is this rather than the impairment which results in societal disablement (Barnes & Mercer, 2011). The social model promotes the difference between impairment and disability such that 'impairment is the functional limitation within the individual caused by physical, mental or sensory impairment. Disability meanwhile, is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' (Barnes, 1992, p. 20).

The social model of disability concept is continually being developed and theorized in many contexts. More recently, the social model has been explored from a mental health perspective as an alternative to the medical model. The medical model can amplify the stigma connected with mental health service users (Beresford, 2004; Beresford et al., 2010; Mulvany, 2000). The social model demonstrates the link between mental distress and experiences of oppression and inequality (Tew, 2002). Tew et al., (2002) suggest that social factors particularly 'major social trauma,' may increase the risk of breakdown or distress through stigmatisation and discrimination (Tew, 2002, p. 148). The opposite association is equally plausible, that stigmatisation and discrimination may be the reason for the original mental distress in the first place. A social model perspective calls for a shift from individualisation of distress to considering the role of society with regards to the economic, cultural and environmental barriers in relation to families with mental illness and dementia (Gilliard, Means, Beattie, & Daker-White, 2005; Tew et al., 2012).

In this context we first set out to explore what are the lived experiences of young people having a parent with younger onset dementia from the perspective of the social model of disability. Secondly we explored influencing factors that could enable these young people to be included and supported within their community

Methods

The first author collected data through semi-structured interviews with purposively sampled participants who had been informed of their parent's diagnosis of YOD. In the course of identifying potential participants to be interviewed, some fell outside the age sample criteria aligned with the WHO definition of young people between 10 to 24 years. They described their retrospective experience of living with a parent with YOD. Table 5 illustrates some demographic detail about the participants' ages at the time of the interview and the time of the events they were recalling. The authors agreed to include these older participants in the study because of their rich experience and level of wisdom gained with maturity. Data was collected also through a focus group of 4 participants, previously interviewed, to validate the emerging themes.

Table 5: Participant information (n=12)

Gender of participants	**Age of participant at interview**	**Age of participant at onset of parents symptoms**	**YOD parent affected**	**Young person's family**
Female	10	8	Father	Mother, 2 siblings
Female	19	16	Mother	Single parent, 2 siblings
Female	22	18	Mother	Single parent, 2 siblings
Male	22	14	Father	Mother, 3 siblings
Female	24	22	Father	Mother, 2 siblings
Female	24	19	Mother	Stepfather, 1 sibling
Female	25	18	Father	Mother, 2 siblings
Female	26	11	Mother	Single parent, no siblings
Female	27	8	Mother	Single parent, no siblings
Female	28	16	Father	Mother, no siblings
Female	30	22	Mother	Single parent, 2 siblings
Female	33	24	Mother	Single parent, 2 siblings

Flexible, in depth, semi structured interviews were conducted with the participants' in a range of settings (Ritchie, Lewis, Nicholls, & Ormston, 2013). Data was generated through sharing their stories and facilitated by nine prompt questions related to their experiences of daily living, their interaction in the community, and services they had or thought they should have received. Probing questions helped contribute to richer understanding of the participants' stories (Ritchie et al., 2013).

Following institutional ethical approval from the University of Sydney, Alzheimer's NSW and Young Carers NSW agreed to advertise the research and participants were invited into the study. Participants were encouraged to ask questions before the written consent and interview. Data was de-identified prior to analysis and reporting. An additional consent form was completed by a guardian or parent without YOD for the young person aged between 10-16 years. During and after the interview the interviewer carefully considered the emotional impact on the young people. Each participant received an extensive contact list of useful support organisations.

Data Analysis

Individual interviews were recorded and transcribed verbatim. A detailed thematic analysis was conducted using framework analysis (Ritchie, Spencer, & O'Connor, 2003). The framework analysis involved all authors coding three transcriptions each, then negotiating and discussing coding framework. At the foreground of the coding was identifying the socio-cultural underpinnings of the experiences, interactions, and interventions that influenced the young peoples' ability to rise above social marginalisation. We reported from the perspectives of the young people in the families using the theoretical lens of the social model of disability as a framework (Hutchinson et al., 2014). Further analysis of the dataset highlighted emergent themes which resonated with key concepts within this particular framework. Additional comparisons, linking, and mapping of emergent themes were conducted by moving between the raw data, emergent themes, and the theoretical literature, in order to clarify and negotiate understandings among all authors. This negotiated framework was applied by a single author to the whole dataset (Hutchinson et al., 2014). QSR NVivo version 10 was used as the qualitative data management software for the analysis (NVivo, 2010).

Findings

From our analysis three main themes emerged; *invisibility,* which described the marginalisation of these young people within society; *connectivity* depicting how they interacted with their social world and the impact of this interaction on them; and *being empowered,* which illustrated enabling strategies to increase control over their lives and achieving a balance between acceptance and adaptability to changing circumstances. In order to maintain the participants' anonymity we used pseudonyms to protect their identity.

Invisibility

Our theme of invisibility supported three sub themes of *isolation*, *neglect* and subsequent *perceptions of marginalisation*. Most participants felt a lack of recognition, understanding, and support of their roles within their family, by other family members, friends and community.

Isolation

Isolation described how participants felt separated from their usual social environment due to the changed family circumstances with the parent's diagnosis of YOD and the consequential social exclusion. Combined with experiencing the prevailing societal view of dementia affecting the older generation, young people often felt unrecognised and unsupported. This feeling of isolation also occurred within the family because of other family members, often unintentionally, dealing with their own issues, in the context of the response of the wider community. Carol described her perception thus;

> *Everyone is going through their own private crisis and mine's just one of them, like it's just extra stuff for them to deal with and I don't want to put that on them.*

Young people avoided burdening other family members, hiding their own concerns, fears and needs. Other research has noted this lack of opportunity for young people to safely share their own experiences as a contributing factor to their loneliness and lack of support (Allen, Oyebode, & Allen, 2009; Gelman & Greer, 2011; Hutchinson et al., 2014). Sam '*pulled a pretty good disguise'* when he was at school to avoid drawing attention to himself;

> *With everyone kind of busy …. I could present well in most circumstances and kind of be whatever you want me to be or at least look like you wanted me to be.*

Maintaining a level of secrecy offered protection from the scrutiny and stigma experienced outside the home and was a consistent theme in the data. Some participants felt the threat of separation from their family by authorities was a real concern especially in their younger years.

Neglect

This theme describes the ways in which participants faced physical, emotional and societal neglect in differing social contexts. Their ability to cope and respond to changing family circumstances depended on the support available within the family, from health and service providers, and their own community. Chris faced challenges juggling school, paid work and caring for her mother with limited finances for bills and food due to her mother's inability to manage finances. In desperation, she temporarily secured extra finances by asking;

> *..mum to get me a packet of cigarettes. …With that packet I'd sell them to other kids at school and I'd make money…I'd maybe buy a couple of cigarettes and then buy bread and milk and spaghetti and stuff- groceries…I guess these are the financial impacts of having a parent with dementia, is that you don't have the things your friends have.*

Chris normalised their poverty by suggesting this was a direct outcome of having a parent living with dementia. From a social model perspective, Chris's case demonstrates society's failure to provide adequate support for her family. This leads ultimately to the neglect of a fundamental human right regarding the meeting of basic needs.

Being an only child of her mother living with YOD, Bec reported some nutritional concerns. Her mother would cook something '*the dog wouldn't even eat'* which was compounded by hygiene issues as her mother fed the animals with the same plates and cutlery as they used. This ultimately resulted in Bec, unsupervised, preparing family meals at 11 years of age. In addition her mother's alcohol dependency habits, contributed further to the neglect and stress she experienced at home. Neglected by her extended family and support services, Bec had a breakdown in year 12 at school, developing '*bad depression and self-harming*.' At the time her GP suggested she moved into a '*safe environment'* but having no financial assistance or alternative care for her mother, this was not an option.

The situations described by both Chris and Bec resonated with the reported experiences of young people living with a parent with mental health issues where their own mental health declined on account of being largely unsupported (Patel, Flisher, Hetrick, & McGorry, 2007).

Perceptions of marginalisation

Stigma and marginalisation are commonly recognised as impacting people living with dementia, but little consideration has been documented about the effect on other family members, particularly a younger member. Chris described the '*big turning point*' at 11 years old when her friend's mother:

> *Told a couple of the other mothers that my mum was a bit different and she thought she might have been smoking marijuana. She said my mum was sick……then suddenly no one was allowed at my house anymore….then asking questions about why she was different was difficult.*

Having a mother labeled in this way excluded her from friendships and as a consequence, she faced discrimination and marginalisation in the community. Henderson et al., (2009) had also concluded that such socially constructed discrimination and exclusion related to mental health disorders can be worse than the illness (Henderson & Thornicroft, 2009). It was the social constructed disability that forced people such as Chris, to the outer margins of society.

Young people observed discriminatory behaviour around dementia, which they did not perceive in families living with other diagnostic labels such as cancer. The differing reactions of others to dementia and cancer were described by Chloe;

> *There's this real shame around Alzheimer's. No one wants to talk about it; no one wants to acknowledge it. Everyone wants to say 'she's fine': there's such denial. Where with dad it's much more, 'how's your dad, how's chemo' and 'oh you poor things'.*

In summary, our research theme of invisibility could be considered a manifestation of the lived experiences of the young people through their experiences of isolation, neglect and marginalisation. Our data showed many examples where the young people '*struggle quietly on their own*' or describe '*feeling alone'.* Other researchers have also reported invisibility among young carers in general, which is secondary to negative societal attitudes to their caring role within the family (Moore & McArthur, 2007; Rose & Cohen, 2010).

Connectivity

The theme of connectivity was explored through the sub themes related to the ways in which the young carers interacted with *family and friends, health and service providers* and *education.* Through a process of connectivity young carers' accessed support as relationships were formed between people who need to talk or between people who need help and people who can offer help (Wenger, 2000). Negotiation of social barriers through engagement and relationship building by concerned others can aid in the formation and maintenance of the young people's social bonds.

Family and friends

Positive connections with family and friends can alleviate some young peoples' concerns caring for a parent through this mutual support by significant others. Sonia alluded to the conflict of a mother-daughter role reversal where she as a young person felt she was parenting her mother. At the same time Sonia was thankful for her sister's support;

> *I feel like I have a teenage daughter*…..*thank god I have my sister because we can talk about it together.*

However, as is often seen within families living with YOD, connectedness can be difficult to maintain especially through familial conflict. Sam described '*a big conflict in the family'* which affected relationships between two of his siblings and his mother, who was the primary carer for his father. This conflict resulted in both brothers not communicating well with their mother over many years along with developing ongoing anxiety issues. The observation that stressful situations can disrupt families and friendships leading to further loss of potential support networks for young carers in general (Mayberry et al., 2005; Pakenham, 2012), also applies to YOD families too.

Carol used a metaphor of connection in social media discussion groups to emphasise her sense of disconnection in the social world.

> *…..no one [is] keeping the thread of where you are and how you are going.*

Paradoxically, connections with her peers were helpful for Carol since they provided a degree of normalcy.

> *Friends provide me with relief precisely because they are not going through the same thing as me and they can provide distraction or they cannot remind me of it.*

Whilst family and peer connectedness is important for promoting the kind of resilience that Carol showed, there is often reluctance for young people to seek support from peers. This is often due to their general lack of understanding of having a parent living with YOD. However the maintaining of a meaningful relationship with at least one person is widely acknowledged as being important. It is known to help with the overall adjustment and the emotional well-being of young people (Mayberry et al., 2005; Pakenham & Bursnall, 2006).

Health and Service Providers

Health and service providers are not known for engaging particularly well with the whole family, across a range of ages, where a member is living with dementia (Barca et al., 2014; Gelman & Greer, 2011; Hutchinson et al., 2014). Loren experienced a sense of failed connection with service providers where no realistic options for support were considered for the family or her mother, yet alone provided.

> *..the biggest stress that I have with this is that we don't know where to go. What we had, well we had three and a half years of trying to get it done and then after it was diagnosed it was a bit anti-climactic because it was diagnosed and then we were just kind of left standing there with the diagnosis and you don't know what to do with it.*

Receiving a clinical diagnosis of YOD left many families feeling disempowered and disconnected from health professionals often working within silo-based services, and perceived them as failing to acknowledge the impact on the whole family. One particular GP failed to engage and understand Carol's situation;

> *I was just so shocked. She said like well this is the sort of thing you're going to be dealing from now on and you're your mum's only sort of resource……I just remember thinking like God it's…. you're not giving me much options here.*

On the other hand Loren reported the benefit of having a YOD key worker assigned to her family, which is an Australian federally funded government initiative. This key worker accessed and negotiated with a range of potential service providers.

> *She was pretty much pivotal – I wouldn't be sitting here talking to you guys (young person focus group) if she wasn't involved at all because we'd still be sitting around…..They're trained in early onset dementia and she knows exactly what you need to do and she knows everything about it.*

Loren confirms the importance of being connected to relevant support and information as found by Allen et al., (2009). The contrary to this was health and service providers' lack of knowledge of YOD friendly services left many of our participants largely disconnected and unsupported in a highly vulnerable situation, also reported by Allen et al., (2009).

Education

For young carers in general, school is widely recognized as a place where they can behave as children and experience respite away from their concerns about their parent's illness (Maynard et al., 2013; Rose & Cohen, 2010). Schools or education facilities can potentially provide stability when family life is unpredictable. For Chris being recognised as a carer by one teacher led her to the belief that:

> *It was the most stable thing in those years when I was a teenager, was to have that high school.*

Nevertheless, the routine recognition of young carers within the school environment remains problematic. This is particularly noted in our research due to the prevailing societal view of dementia as a condition of older age therefore young people in schools are rarely considered to be in anyway involved. Despite support from her teacher, Chris experienced exclusion by her peers similar to other young carers who have reported difficulty forming friendships at school (Rose & Cohen, 2010). Chris felt alienated from school being labeled a '*trouble maker'* due to her unexplained absences. She found it hard to express her concerns, acting out in response to the challenges faced, typical of other young carers (McAndrew et al., 2012).

Participants living with a parent with YOD felt a sense of stability and purpose in a learning environment alongside school support, both practical and emotional, was particularly important and protective of their mental health. This is similar to the experience of young carers who have parents living with other forms of disability (Gilligan, 2000; McAndrew et al., 2012; Rose & Cohen, 2010).

In summary our research theme of connectivity demonstrated the importance of young people maintaining or developing relationships with significant people within their social world. It is well established that there is a relationship between social isolation and a reduced sense of emotional wellbeing (Kawachi & Berkman, 2001). This was supported by our participants who reported the overall lack of engagement particularly related to their age and parent's diagnosis of YOD, added to their vulnerability and social exclusion. As a result failed connectivity contributed to issues of adjustment and emotional distress for many.

Being Empowered

Being empowered consisted of two sub themes of *self- efficacy* and *collaboration*. *E*mpowerment is described as the observable change in oneself and the interaction with the environment (Tew et al., 2012) around the young person.

Self – efficacy

Self-efficacy refers to the confidence in one's ability to behave in a certain way or to create a preferable outcome (Bandura, 1977) and is strongly associated with the individual's sense of empowerment (Wallerstein, 1992). Having a sense of direction and purpose can instill confidence and hope for the future. Once Chris acknowledged herself as a *'carer'* she applied for financial recognition of her role, realising that '*I need a plan.'* A new approach was considered;

> *It wasn't so much my thinking of them (services) doing me a favour. It was my thinking of; this is something she's (her mum) entitled to.*

Her self-belief and self-efficacy was enhanced when she no longer viewed support as something that had to be earned but rather as a human right. During this process of reflection, she achieved greater confidence through these new insights. The greater confidence that self-efficacy creates alters the way people 'feel, think and act' (Singh & Udainiya, 2009, p. 2). Stephanie meanwhile described the importance of meeting other young people in a group situation who had managed similar challenges;

> *..that other kids my age have been through some really horrible, horrible things. But they got through it and they came out the other side fine. It's always motivational when we're having a crisis.*

This group was perceived by Stephanie and others as '*the biggest lifesaver in the world'.* This justifies Bandura (1993) views on the importance of shared experiences and witnessing other similar young people overcome their challenges as provides the impetus to succeed in challenging situations. For Bec, eventual success in organising residential care for her mother gave her a sense of purpose and direction to her life. She had time to look after herself as she no longer lived:

> *…out of a bag, eating MacDonald's. I've lost 16kgs since I don't have to go down there. I can do sport, I exercise every day and I can plan my meals out. It's just so much better.*

Bec demonstrated how the advantages of obtaining permanent care for her mother helped her reshape her life; improve her own health and emotional wellbeing. Sam noted that self-recognition of his '*dad's illness being a contributing factor*' to his own deteriorating emotional status helped him to change his attitude to be '*more genuine'* to others. In turn they encouraged him to source some crucial emotional support.

Collaboration

Involving young people to work in partnership with organisations is important in drawing on the 'perspectives, insight and expertise' of the young people (Hagen et al., 2012, p. 1; McAndrew et al., 2012). Ann comments on her willingness to share her stories.

> *I'm happy to talk to everyone or anyone who will listen. I've given lectures at … University for the med students.'*

Opportunities for sharing real life experiences can raise awareness and understanding of the impact of YOD within the community. Carol emphasised whilst dealing with her parent's '*death sentence'* policy makers need to develop some '*structure of support*' to help people like her.

> G*iving doctors more of a sense of the avenues out there to refer people when they get that diagnosis. Seems just generally a bit of a blind spot, on peoples' radar, especially early onset.*

A collaborative advocacy approach, raising public awareness of YOD and its impact on young carers, was sought by some participants. Service providers can potentially collaborate and translate the service models that have been successful within cancer and youth mental health services in supporting young people and their families (CanTeen, 2014; Montague, Varcin, & Parker, 2014).

Our data highlight that whilst having a parent with YOD is a constant in the young person's life, gaining self- confidence and a sense of direction through creating personal goals or having a purpose can be empowering. Being informed, knowing their rights and having access to necessary resources about YOD can empower young people's self-advocacy, support their own well-being, and promote inclusion (Hutchinson et al., 2014; Rose & Cohen, 2010).

Discussion

Three themes emerged from our data illustrating the influence society has on the lived experiences of young people and the complex interplay with their social world. The socially constructed disablement experienced by young people in families having a parent with YOD have left many feeling marginalised and disempowered, which society has an obligation to address.

The first theme of *invisibility* identified young peoples' experiences of isolation, neglect and marginalisation similar to young carers of parents living with a range of mental illnesses. Current services did not respond to the whole families' needs and therefore did not take a social model approach to service design. Further limitations in knowledge and access to age appropriate services within the dementia sector contributed to young carer social exclusion and isolation. In some cases, failure of access to the necessary support led to economic hardship, where issues of neglect arose. According to the social model, this is a societal issue not an individual concern specific to a diagnosis, and therefore should be managed appropriately (Barnes, 1992; Barnes & Mercer, 2011; Oliver, 2009).

Our findings of the relationship between invisibility and mental health issues in young people in families with YOD have not been considered before. There are similarities with the findings of Patel et al., (2007) in that living with parents with a mental health disorder as well as social disadvantage is strongly associated with developing mental health disorders in young people. So raising the awareness about young peoples' experiences of marginalisation in families with YOD is imperative in terms of negating *isolation*, *neglect* and subsequent *perceptions of marginalisation*.

The second theme of *connectivity* explored the repercussions of failed engagement within their social world and highlighted the significance of fostering social connectedness safeguarding them against life's challenges. Although being connected to the family was preferred by most participants, maintaining a significant relationship with at least one person was recognised as important in terms of adjustment and emotional well-being. Appropriate early health professional engagement with young people, as observed similarly within the mental health sector, is fundamental in the recognition of their rights in these families, connecting them to necessary social support and beneficial for their psychological well-being (Kawachi & Berkman, 2001; Patel et al., 2007). This is also true for the education sector where engagement can provide some form of stability within an unpredictable world. Participants in this research pointed out the disparity in being acknowledged in a school environment as a young carer, due to the lack of public awareness about YOD impacting young people.

The third theme of *being empowered* explored the development of self- confidence and the role of self-efficacy. Being empowered supported young people's ability to be more in control of their future and assisted them in determining and accepting what they could or could not be in control of. However, the process of empowerment encouraged the breaking down of social barriers and permitted individual's development of positive and meaningful relationships, focused on their needs. Importantly young people often want to speak up and should be encouraged to do so. Being involved in the process of policy development will ultimately affect the future of families impacted by YOD.

Implications

This new research considers the social model of disability (Barnes & Mercer, 2011) as a theoretical framework to help in the understanding of how society contributes to the experiences faced by young people in families living with YOD. From this perspective the parent's diagnosis is not the only reason for the young people feeling overwhelmed within the family. The failure of society in recognising individual needs, and supporting accordingly, contributes significantly to disempowering and marginalising individuals (Aldridge & Becker, 1999; Gelman & Greer, 2011; Hutchinson et al., 2014).

The social model of disability focuses attention on the real barriers and problems faced within these families from the perspective of living with a parent with YOD. Their socially constructed disablement is a social issue rather than an individual or family concern. This theory helps in recognising that the present isolation and crises experienced within families can be exacerbated by the 'way services are designed and delivered' (Gilliard et al., 2005, p. 582). However the social model of disability not only demonstrates societal issues but guides researchers and health service providers down a pathway for social change for families and people living with YOD. This is a social change that is seen more commonly within the physical disability sector and more recently the mental health sector (Barnes & Mercer, 2011; Beresford, 2004; Oliver, 2009). Integrated health care and support services need to be tailored to individual needs, enabling young peoples' connection to appropriate support and organisations through the practice of routine engagement with the whole family.

Gilliard et al., (2005) described a 'conspiracy of silence' surrounding a family member with dementia as being common due to societal stigma (Gilliard et al., 2005, p. 580). Unsurprisingly Alzheimer's Australia reported that young people try to cope with their parents' diagnosis without the involvement of others in an effort to maintain their parent's respect and dignity (Alzheimer's Australia NSW, 2010). The corollary to this is that recognition and support of young carers irrespective of parent's diagnosis can reduce experiences of marginalisation as observed in other discriminated groups (Robson 2004). This emphasises the importance of dealing with issues of labelling and stigma promoting inclusion of all family members to begin creating more equity within society. Rose et al., (2010) exposed inequality depending on diagnostic labels. They noted that young carers of family members with cancer did not experience the same amount of 'invisibility, shame and stigma reported by young carers of adults with mental health difficulties' (Rose & Cohen, 2010, p. 480). This suggests that support networks need to address individual needs rather than being diagnosis specific which can lead to a greater sense of individual empowerment for young carers. This is particularly important within dementia services as there is a prevailing focus on the aged care model of care.

Maintaining social connectedness is valuable for overcoming social barriers creating resilience and empowerment. The authors agree with other studies that being connected with support specific to need could potentially prevent or reduce family breakdown, alleviate anxieties and stress, and maintain connections with their social world (Allen et al., 2009; Gelman & Greer, 2011; Hutchinson et al., 2014; Roach, 2010). Without a positive relationship the accumulation of negativity in these young people's lives can have a ripple effect into adulthood if this process is not addressed and social change is not fostered (Gilligan, 2000). So meaningful connectivity needs to be fostered to help individuals become empowered but this will be limited without the accompanying social change (Masterton & Owen, 2006).

Taking a social model perspective, the dementia sector should be more actively engaged with young people in order to counteract marginalisation and advocate for social change and equity in access to services. Maynard et al., (2013) have emphasized the importance of communication and connection to resources and support opportunities that can enable families to plan effectively for the future and deal with the ongoing grief and eventual loss of a parent. The idea of health and social care practitioners and policy makers engaging and collaborating with young people in families within the dementia sector is relatively new. As reported elsewhere knowledge from youth organisations demonstrated young people's contribution to social change is valuable and empowering (Hagen et al., 2012; Robinson & Cottrell, 2005). In accord with Patel et al., (2007) there is a need for health professionals to develop a 'particular style' and skill to engage young people which unfortunately is often lacking (Patel et al., 2007, p. 7). Many young people do not have a regular GP and a common barrier to seeking help is stigma, embarrassment and an expectation of managing on their own. Training for health professionals can help in this regard.

From a social model perspective, there appears to be many shortcomings in policies where these young people have been in effect disabled by a society that is not inclusive. The social model of disability demands campaigning and advocating for inclusion and equality and for the young people to be acknowledged as experts in their own right, both as carers and service users. Promoting self-efficacy of young people to achieve a level of mastery by adapting and adjusting to the specific situations they find themselves in is important. Through the practice of connectivity mediated by the process of engagement leads to empowerment (Masterton & Owen, 2006) that could promote change to enhance their futures.

Furthermore the social model of disability stresses the responsibilities of society to respect individual needs, and shifting the focus for services design and delivery away from a medical model to a social model (Barnes & Mercer, 2011; Beresford et al., 2010). Professional support is pivotal to families living with YOD but is not routinely adopted. There is a need for more cooperation across sectors, between services and health workers, to effectively manage and support these families having had appropriate interdisciplinary training (Barca et al., 2014; Gray, Robinson, & Seddon, 2008). In the Australian context, further development of the YOD key worker could provide a vital negotiator between the young people and relevant services which otherwise can be challenging to navigate.

There is an opportunity for young people living with a parent with YOD to have greater connectivity by embracing technology. For example, social media usage within youth mental health sector opens up possibilities for reducing stigma, promoting help seeking behaviour, and developing more innovative ways to responding and connecting to individuals (Christensen, 2014; Kauer, Mangan, & Sanci, 2014). The dementia sector could potentially maximise their reach by harnessing new technologies creating flexibility in practice and thinking.

It is important to contemplate all the opportunities that currently exist for collaboration, translation of service and support frameworks from other health, service and education sectors where the complexity and powerful influences of society have been considered to some extent. Using the social model of disability as a framework calls for service providers to move away from silo based, diagnostic specific services and adopt a more integrated approach which encourages partnership with service users in planning and designing services.

Limitations

Our findings represent the views of a small group of young people who volunteered for the study. We acknowledge that females were over represented in our sample however this reflects Australian data which suggests females over 18 years tend to be more likely to report being a young carer confirming the gender difference (Smyth, Cass, et al., 2011). Only 6 people were from the 10 - 24 age group, at the time of interview, although data was obtained retrospectively from older participants reflecting on their younger years.

Conclusion

The current plight of young people living with a parent of YOD encourages a fundamental shift to a social approach to service design and delivery addressing individual needs within these families. Using the social model of disability as a framework can help in the development of enabling strategies that encourage and maintain social connections. Cross sectorial collaboration and cooperation with service users, incorporating technology opportunities, is essential to promote social inclusion, societal acceptance and empowerment of individual family members. Family's impacted by YOD, feel that dementia can no longer remain within silo-based services and must now embrace specific individual requirements building new ways of working together.

Conflict of interest

None

Description of authors' roles

K Hutchinson designed the study, collected the data, analysed the data and wrote the paper. C Roberts designed the study, supervised the data collection, analysed the data and assisted in writing of the paper. M Daly analysed the data and assisted in writing the paper. C Bulsara analysed the data and assisted in the writing of the paper. S Kurrle designed the study, supervised the data collection and assisted in writing the paper.

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Chapter 6

Co-creation of a family-focused service model living with younger onset dementia

Overview

Ample evidence has been provided in this thesis to demonstrate the significance of society in contributing to the socially constructed disablement of individuals and families living with younger onset dementia. In this chapter we further explore the societal influences on family relationships and interactions living with YOD, as well as service issues as identified by family members, healthcare and service providers, from the combined theoretical perspective of the family system illness model, and the social model of disability (see figures 6.1 and 6.2). There have been small areas of service development for families living with YOD shown in the research literature, but nothing that has been adopted globally. The potential to address the changing issues and needs of families living with YOD through the development of a theoretical framework came about in this research. The current gap in the provision of socially minded, family-centred services is a global concern. The utility of combining the theoretical framework of the social model of disability and family system illness model to inform the design and development of a co-created family focused service model to support complex need was explored. Developing and integrating this model into current practices and service interventions requires further research, but presents a useful foundation to underpin the co-creation of collaborative inter-agency family services.

Figure 6.1: Social interactions and relationships

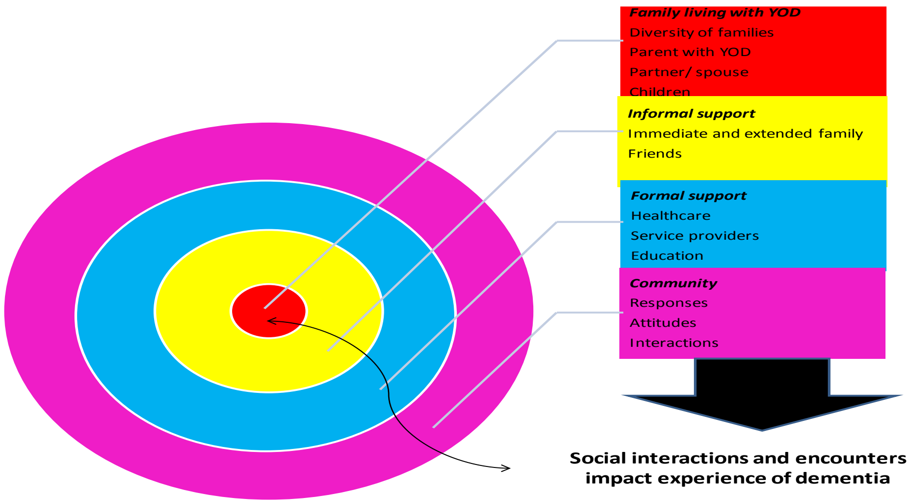
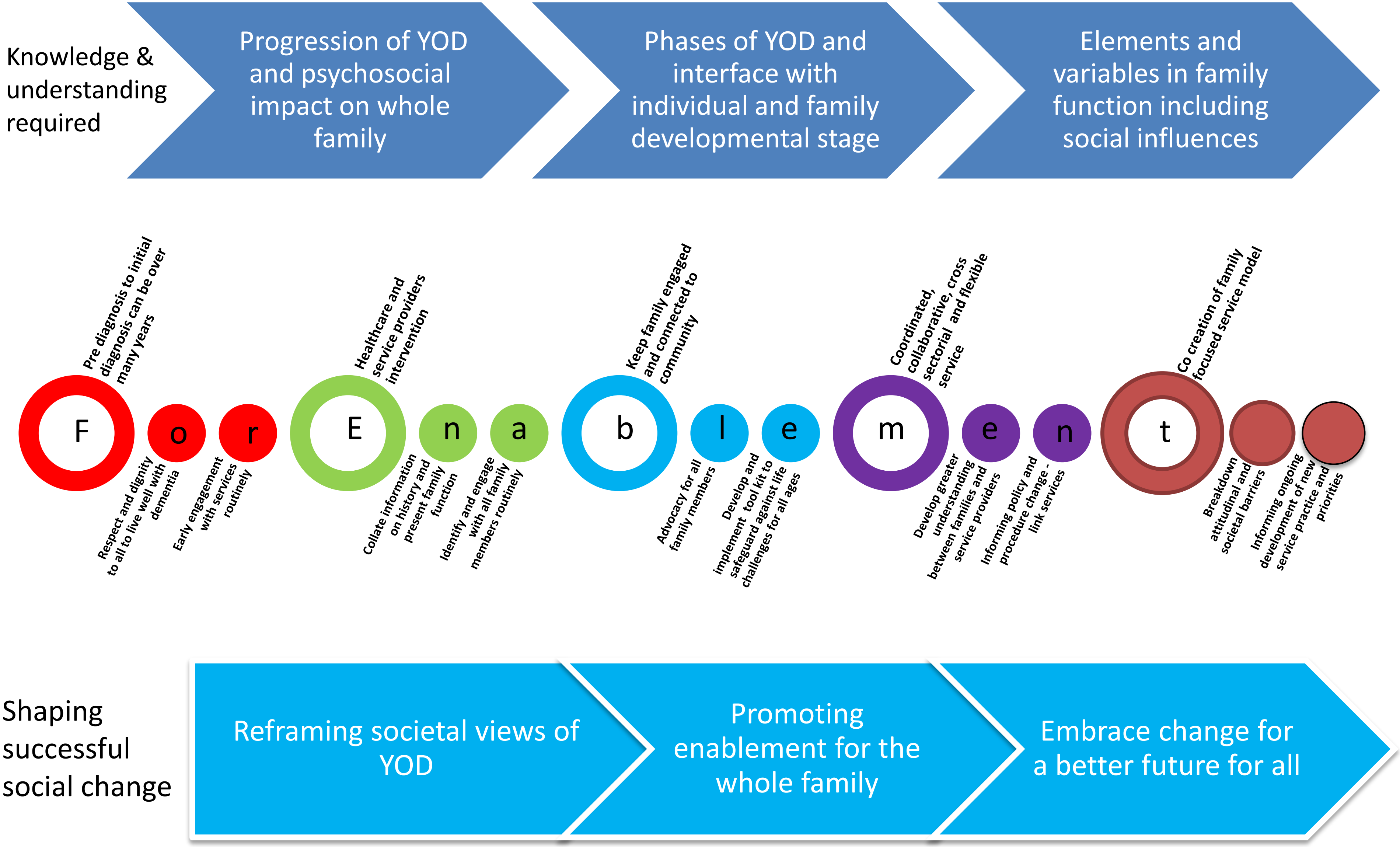


Figure 6.2: Social approach to families

Developing a framework combining family systems illness model and social model of disability to assist with the co-creation of a family focused service model living with YOD



Knowledge & understanding required

Progression of YOD and psychosocial impact on whole family

Phases of YOD and interface with individual and family developmental stage

Elements and variables in family function including social influences

F o r E n a b l e m e n t

Pre diagnosis to initial diagnosis can be over many years

Respect and dignity to all to live well with dementia

Early engagement with services routinely

Healthcare and service providers intervention

Collate information on history and present family function

Identify and engage with all family members routinely

Keep family engaged and connected to community

Advocacy for all family members

Develop and implement tool kit to safeguard against life challenges for all ages

Coordinated, collaborative, cross sectorial and flexible service

Develop greater understanding between families and service providers

Informing policy and procedure change - link services

Co creation of family focused service model

Breakdown attitudinal and societal barriers

Informing ongoing development of new service practice and priorities

Shaping successful social change

Reframing societal views of YOD

Promoting enablement for the whole family

Embrace change for a better future for all

Co-creation of a family-focused service model living with younger onset dementia

Hutchinson, K., Roberts, C., Roach, P., & Kurrle, S. (2018). Co-creation of a family-focused service model living with younger onset dementia, *Dementia, the international journal of social research and practice, 1-22, doi.org/10.1177/1471301218793477*

Abstract

Families living with younger onset dementia (YOD) face unique social challenges, which services do not currently address. There is a gap in understanding the experiences of families affected by YOD, including the interactions and relationships within the family units, and with existing services and supports. In this qualitative research study, semi-structured interviews were conducted across Australia with seven health and social care providers, five persons living with YOD, six spouse/carers, and seventeen children. A thematic analysis was conducted using a theoretical lens drawn from the combined perspectives of the social model of disability and family systems-illness model. Two central themes emerged in the data: 1) *Understanding the social demands on the family* - lifecycle challenges living with YOD from a social and family context; and 2) *Interactions of health and social care providers with families living with YOD* - opportunities and challenges in providing support and services geared to a whole family approach. In order to provide families for those living with YOD with optimal assistance and support, co-creation of a family-focused services model is proposed. Its purpose is to support effective therapeutic interactions and service development among service users, service providers, and stakeholders.

Keywords: Family systems-illness model, younger onset dementia, service design and delivery, co-creation, social model of disability

Introduction

There is an international consensus that current health and social care services for people living with dementia and their families are predominantly designed for the older population, and do not meet the specific needs of younger people living with dementia (Cations et al., 2017; Greenwood & Smith, 2016; Millenaar et al., 2016). A recent systematic review reported little ‘service development’ for people living with younger onset dementia (YOD) and their families during the last 26 years, even with YOD diagnoses increasing worldwide (Mayrhofer, Mathie, McKeown, Bunn, & Goodman, 2017, p. 7). Although there are many types of dementia with differing presentations, particularly in younger people, Alzheimer’s disease (AD) is considered the most prevalent (Carter, Oyebode, & Koopmans, 2017; Rossor, Fox, Schott, & Warren, 2010). Dementia is considered an unexpected illness before the age of 65 years with social, emotional, psychological, and financial consequences for the individual and family members associated with unique social challenges compared to late onset dementia (LOD) (Roach, Keady, Bee, & Williams, 2014; Withall, Draper, Seeher, & Brodaty, 2014). To date, few research studies have considered the experiences of the whole family living with YOD and their interactions with existing services and support (Beattie, Daker-White, Gilliard, & Means, 2002; Gelman & Greer, 2011; Luscombe, Brodaty, & Freeth, 1998; Roach, 2010; Roach, Drummond, & Keady, 2016; Svanberg, Spector, & Stott, 2011). These studies corroborate that services should become more socially aware to ensure they target the complex needs of the individuals and family members living with YOD.

Understanding the way services are designed and delivered is a fundamental prerequisite in meeting the specific needs of families living with YOD. Shaping services and support based on the experiences of families living with YOD is crucial in informing the development of such services (Barca, Thorsen, Engedal, Haugan, & Johannessen, 2014; Bate & Robert, 2006; Evans-Roberts, Weatherhead, & Vaughan, 2013). Research on ‘families’ tends to focus on the perspectives of and impacts on spouses with dementia and spouse caregivers, with little consideration of other family members (La Fontaine & Oyebode, 2014: Roach et al., 2014). This research approach does not depict whole families’ experiences, internal dynamics, and relationships. The few studies exploring the impact on whole families living with YOD indicate that every member and their relationships with one another are impacted by complex challenges (Millenaar et al., 2016; Roach, Keady, Bee, & Williams, 2014; Svanberg et al., 2011; Roach, Drummond, & Keady, 2016). Families’ experiences living with YOD are unique in many ways, particularly related to the developmental stage of the family, change in family members’ roles and responsibilities, and financial commitments (Rolland, 1999). Typically, these needs are not reflected in the design of services or policy development, suggesting a lack of focus on ‘family-centred paradigms’ in dementia research (Roach et al., 2014, p. 1416).

Currently, the way services are designed and delivered do not reflect whole family needs, nor consider the person with YOD as an ‘integral member’ of the family (Barca et al., 2014; La Fontaine & Oyebode, 2014; Roach et al., 2014, p. 1399). Even with an increase in the diagnosis of YOD, there remain few age-appropriate formal services available, particularly when the variety in forms of dementia and presentation of symptoms in YOD is considered (Millenaar et al., 2016). This results in an increasing reliance on informal family support (Sansoni et al., 2016); often over a longer time frame than with LOD (Carter, Oyebode, & Koopmans, 2017). Moreover, families often find it difficult to relinquish care of the younger person with dementia due to this lack of fit between need and service provision, isolating families further from other support opportunities (Cations et al., 2017; Millenaar et al., 2016). Subsequently, informal caregivers across a range of ages can experience adverse effects on their emotional and physical well-being, because they are inadequately supported in their role (Hutchinson, Roberts, Kurrle, & Daly, 2016; Millenaar et al., 2016; van Vliet & al, 2010). Receiving necessary support can assist caregivers' capacity to manage their daily roles and commitments, particularly those linked to their phase of life such as employment, financial responsibilities, education, family relationships, and dependents (Brodaty & Donkin, 2009; Hutchinson, Roberts, Kurrle, et al.,2016; Millenaar et al., 2017; van Vliet & al, 2010).

Many health and social care providers in dementia care agree that identifying and engaging with family members of all ages and developmental stages is essential in YOD. However, this does not routinely occur even though family members are known to be influential on experiences and management of dementia (Gelman & Greer, 2011; La Fontaine & Oyebode, 2014; Roach et al., 2014). There is a dynamic interplay between complex family relationships, specific roles, and approaches to managing challenges which have implications for practice (La Fontaine & Oyebode, 2014; Roach et al., 2014). Frequently the concept of families has been based on the traditional view of family structure, a basic 'social unit' including parents and children (Murray & Barnes, 2010, p. 535). This view often ignores the functional relationships and social diversity of families including 'ethnicity, sexual orientation, and divorce' (La Fontaine & Oyebode, 2014, p. 1268; Murray & Barnes, 2010).

Formal care providers face many challenges engaging with and supporting both the younger person with dementia and their families. Providers report they are working with a lack of resources and that there are few age appropriate services that cater for the complex and diverse needs of families living with YOD (Carter et al., 2017; Mayrhofer et al., 2017; Pratt, Clare, & Kirchner, 2006). It is also reported that working within service models that are focused on LOD is frustrating and contributes to families feeling 'marginalized within existing service provisions' (Beattie, Daker-White, Gilliard, & Means, 2002, p. 205), stigmatised and discriminated against (Millenaar et al., 2016). Also, the failure to receive a timely diagnosis can frequently be a barrier to accessing appropriate information, interventions and services (Pratt et al., 2006).

An opportunity to address these gaps in the literature arose on a larger doctoral research project exploring the impact of YOD on the individual and families. This current research aims to develop a theoretically informed appreciation of the relationships and interactions of those living with YOD within current dementia care provision in Australia, with the view of informing the co-creation of appropriate services.

Theoretical framework

Two theoretical approaches were considered in this study; the social model of disability (Oliver, 1983, 2009) and the family systems-illness model (Rolland, 1990). The development of a socially focused theoretical framework requires a collaborative research approach with all family members and service providers that share the necessary experience to co-create family-centred services (Clare & Cox, 2003; Mayrhofer et al., 2017). Such an approach allows family members to regain an element of control in the way they are managed, providing a number of benefits for those living with impairments, and those family members living alongside them (Mayrhofer et al., 2017; Clare & Cox, 2003).

For families of those living with YOD, the social model of disability (Barnes & Mercer, 2011; Oliver, 2009, 2013) can add valuable research insights into the significant impacts of societal perceptions, whilst also focusing on interactions and relationships of both family members and health and social care providers, including the consequences (Chappell, Goodley, & Lawthom, 2001; Hutchinson, Roberts, Daly, Bulsara, & Kurrle, 2016, Hutchinson, Roberts, Kurrle, et al., 2016). With a focus on the experience of the service user, a social model perspective illustrated the way in which interventions are currently designed around health professional roles and patient diagnosis, and have unintended impact on families living with YOD (Gilliard, Means, Beattie, & Daker-White, 2005; Hutchinson, Roberts, Daly, et al., 2016). The social model has value in informing and guiding service design and delivery because it is not diagnosis-specific but socially inclusive, and supports shared involvement of people living with complex needs and their families (Clare & Cox, 2003). Utilizing the social model can help reframe dementia to offer ‘alternatives to current responses and approaches’ (Mental Health Foundation, 2015, p. 29).

From a family context, Rolland's family systems-illness model (Rolland, 1987, 1990, 1999) proposes a structure which advances understanding and knowledge of families’ ‘changed life-cycle demands’ (Rolland, 1990, p. 229), in order to help anticipate interventions and facilitate problem-solving. This model has been applied to families living with YOD (Roach et al., 2014) and other complex conditions (Rolland, 2005). This model provides a guide to managing challenges across the trajectory of family experiences. Understanding the impact, demands, and uncertainties of parental illness or disability on the intergenerational family unit are essential in appreciating need. Relating understanding to individual and family life cycles; openness of communication between family members; and family beliefs is beneficial. Also, knowing family backgrounds, family history, and family functioning is vital to appreciate the whole of the family circumstances (Roach et al., 2014).

The family system-illness model considers three phases: (a) the illness progression and psychosocial impact, (b) phase of illness and interface with individual and family developmental stage, and (c) elements and variables of family functioning (Roach et al., 2014; Rolland, 1990, 1999, 2005).

The *onset* of YOD is usually gradual, with cognitive changes occurring over a lengthy timeframe prior to a formal diagnosis. The time of the formal diagnosis, can be described as the *initial crisis, a* ‘highly emotional and vulnerable period’ (Rolland, 1999, p. 231), with families sensing their loss of control, ultimately threatening usual family life. Overall a distressing time for the individual and family, especially around age of onset of YOD, work and family related disruptions (van Vliet et al., 2011). The views and attitudes of healthcare providers at this time can impact the future outlook on life, their access to necessary information, and vital services (Barca et al.,2014; Pratt et al., 2006). The progressive *course* of dementia creates a great deal of uncertainty and challenges at a socially significant time and developmental stage, generating tensions and disruptions within the whole of the family, and their lived community (Roach et al., 2014). The unpredictable and often lengthy *chronic* phase can place psychological and physical strain on families as they continually adapt to changing lifestyle, roles and responsibilities, and they are frequently inadequately supported (Cations et al., 2017). The *outcome* of death causes family members to experience a range of emotions over the trajectory, dealing with ‘anticipatory loss’ of the person living with YOD (Rolland, 1999, p. 229). Families may become ‘more present focused rather than future focused’ (Rolland, 1999, p. 233) particularly during this *terminal* phase. Understanding of the ‘interface of the illness, the individuals and the family life cycle’ (Roach et al., 2014, p. 1401) alongside the historical and biographical functioning of a family unit, as well as societal influences around the perception of disability, would be valuable for health and social care providers. In considering the interplay between the two models, the social model of disability (Oliver, 1983, 2009) has recently been used to explore the ‘social position’ and rights, living with dementia (Shakespeare, Zeilig, & Mittler, 2017; Thomas & Milligan, 2018, p. 117). The social model, therefore, can help explain families’ experiences over the three phases living with YOD, by relating their experiences to the social landscape they live in (Barnes & Mercer, 2011; Gilliard et al., 2005; Hutchinson, Roberts, Kurrle, et al., 2016; Oliver, 2009). Therefore, considering data from the perspective of the social model of disability and family systems-illness model may lead to more nuanced theory building, and also inform current practice and service provision collaboratively at the level of both service user and their families (La Fontaine & Oyebode, 2014; Mayrhofer et al., 2017; Nolan, Ryan, Enderby, & Reid, 2002).

In this context, we aimed to develop a theoretically informed appreciation of the relationships and interactions of those living with YOD within current dementia care provision in Australia to determine the critical factors that need to be addressed in co-creating appropriate family-focused service.

Methods

This qualitative study was undertaken in New South Wales (NSW), Australia, based on active interactions between researcher and participants in families living with YOD, and with health and social care professionals (Fontana & Frey, 2005). Ethics approval was obtained from the University of Sydney.

Participants

Participants were recruited through advertising with non-governmental organisations, Alzheimer's NSW and Young Carers NSW, and via snowball sampling. A total of twenty-six family members participated, including people living with YOD (5), spouse caregivers (6), and children and young people in families (17), who were aware of their parents' diagnoses. The age of the children and young people ranged from 9 to 33 years, with the older participants in this group describing retrospective experiences, adding the benefit of maturity (see Table 6.1). Seven health and social care providers who had experience supporting families living with YOD, including children, were recruited. These included one geriatrician, nurse, occupational therapist, psychologist, and counsellor, and two YOD key workers (see Table 6.2).

Data Collection

Interested participants had initially contacted the first author (KH), and those eligible for inclusion received initial study information via email, with a follow-up phone call once consent to proceed was received. Basic demographic information was also collected before the interview, which prompted discussion of family background and helped judge how best to conduct the interview (Irwin & Johnson, 2005; Murphy, Jordan, Hunter, Cooney, & Casey, 2015). KH discussed the interview process prior to obtaining written consent to alleviate any fears and concerns, ensuring that confidentiality and the rights of the participants were considered at all times (Murphy et al., 2015). To manage any risk to the participants' emotional wellbeing, KH explained her duty of care as a health professional and a researcher. The participant had to agree that if they became extremely distressed or concerned during the interview a referral would be made to an appropriate clinician for further support. No referrals were required after the interviews. Additional written consent to safeguard the interests of children under 16 years and adults living with YOD was obtained from an adult (parent or guardian). Important ethical considerations ensured probing, open ended questions were conducted in a 'sensitive and considerate manner' (Roach et al., 2016, p. 28).

With the younger participants, coloured pens and paper were provided and they were given a choice to draw a picture of their family, which helped to generate discussions and improved comfort levels to participate (Irwin & Johnson, 2005). Also, KH carefully considered questioning techniques with younger participants and those living with dementia to build trust and rapport. They were given the option to have someone remain with them throughout the interview, which some accepted. After the interview a resource list of support and services was provided to participants.

Data was predominantly collected via individual semi structured interviews with family members, but on four occasions they were conducted in pairs. Observations and field notes at interviews were also considered as part of the data collected. Interviews were audio-recorded by KH in participants' preferred venue, by Skype or by telephone due to distance. Data was gathered through the sharing of stories, aided by the use of probing questions associated with the lived experiences of family members impacted by YOD over the trajectory of YOD, and health and social care provider's experiences supporting families over this time. After every interview each participant was thanked and advised of the importance of their contribution. The sensitivity of the subject was acknowledged, and the interviewer debriefed with each participant afterwards to establish their emotional well-being.

Data Analysis

Interviews were transcribed verbatim by a professional agency, anonymised by first author (KH), and participants were provided with a pseudonym. A framework analysis (Ritchie, Lewis, Nicholls, & Ormston, 2013) was used, being a flexible analytical tool that can assist in generating inductive themes that emerge from qualitative data (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Initially there was a period of familiarisation with the data, and each author independently analysed three transcriptions. Significant key issues and themes were identified, highlighting a relationship between family members' interactions and their social world. This focused coding of transcriptions on the socio-cultural underpinnings of families, health and social care provider's experiences, interactions, and relationships that shaped family functioning, service and support provision. The authors then collaboratively discussed and negotiated to cluster codes and develop a theoretical framework that resonated with our preliminary themes and sub-themes. Refinements were made to the theoretical framework that captured this relationship until all the authors reached an agreement, and then KH applied the framework to the whole dataset. Inductively the combined paradigm presented by the social model of disability and the family systems-illness model created a theoretical framework that resonated with our central and sub-themes.

Results

Two major themes emerged from the data. The first theme: *Understanding the social demands on the family* - described lifecycle challenges and pressures on families living with YOD, within a social context. The second theme: *Interactions of health and social care providers with families living with younger onset dementia -* depicted opportunities and barriers experienced in service provision including advocating for change in the health and social care system. The three subthemes underpinning each central theme will be explored.

Understanding the social demands on the family

When a family member receives a diagnosis of YOD, there are a number of impacts, or social demands, on relationships and interactions between immediate family members, extended family and friends, and health and social care providers. These social demands are illustrated by the following three sub-themes: *Social challenges for people living in the family with young onset dementia*; *Coping with the unexpected as a child of a parent with younger onset dementia*, and *Balancing the demands between dual roles as a parent and caregiver.* Each of these three sub-themes will be described in detail below.

Social challenges for people living with young onset dementia

People living with YOD provided rich descriptions of the complex social challenges they experienced within a family context. Brian diagnosed with alcohol-related dementia at the age of 46, describes himself as a '*loner*' and a consumer of large quantities of alcohol, which contributed to his impairment. Although separated from his wife Jane, they continued to live together. Jane became his main carer post-diagnosis and described their life together as stressful, particularly with three children aged between 10 and 21 years. Challenges of family life were compounded with Brian's forced termination of employment and being unable to contribute financially to support his family. He '*felt like the world could end,'* and was not coping well with the loss of his sense of purpose associated with his unemployment. Throughout this early phase post-diagnosis, while he was '*fighting for the pension,*' he began increasing his alcohol intake. This had been his consistent response to difficult situations in the past, but in this instance he went onto to attempt suicide. It was only after this crisis did Brian and Jane receive any services, but no formal support or information was offered to their children.

Another participant, Sylvia, married with four children aged between 9 and 18 years, was diagnosed with YOD at 42 years. She recalls feeling *'the floor was giving way beneath'* when the GP mentioned the possibility of dementia. Sylvia was about to start a new career and described dementia as the '*biggest hit in the guts.'* She then felt in '*limbo*' anticipating the formal diagnosis, which took some time to confirm. Some family members refused to accept her diagnosis and her other social networks diminished, stating *'fantastic friends…they've all just disappeared.'* Sylvia believed these '*painful*' reactions were based on dementia and she was concerned about the impact of reduced socialising may have on her children, '*as we don't see each other my kids miss out.*' Exposure to negative attitudes and responses added to her sense of loss and exclusion, leaving Sylvia apprehensive and vulnerable informing her children about dementia. Believing they had already lost so much, Sylvia wanted to protect her children and so delayed telling them about her diagnosis, not wanting to add to her children's '*emotional baggage.'* She was unsure how to approach the conversation, as was evident during the interview, '*What do you say? How do you tell them (children)?'*

Sylvia also felt disconnected from her family and that communication within the family was limited. This altered the family dynamics, with each family member taking on new roles and responsibilities without her input. Sylvia lamented the loss of meaningful activities and a feeling of connection related to her historical place in the family.

> *I tend to stay at home, my license has been suspended. My family is busy and I don't have friends that come around.*

Sylvia had insight into the ways in which her cognitive impairment impacted her, but also the way attitudes of others was disabling. For example, she tried attending school meetings to organise more support for her children. She experienced disbelief when she disclosed her diagnosis, causing her to lose confidence and want to disengage from any social situations. Fortunately, the involvement of a health care professional that she trusted supported her to re-engage with the schools resulting in a more favourable outcome. A significant person, either within or outside the family, to openly communicate and connect with, can help counter vulnerability or manage uncertainties. An unfavourable alternative for those living with YOD, is to keep things hidden based on their experiences of misunderstanding, and discriminatory behaviours. Support services need to anticipate and better manage families living with YOD as ‘blocked communication can fuel anxieties' (Rolland, 1999, p. 257).

Coping with the unexpected as a child of a parent with younger onset dementia

The experiences of children and young people in families living with YOD demonstrate complex challenges frequently related to their age, which are often not understood or recognised. Evie was 11 years old when she noticed some behavioural changes in her mother, Freda. Evie’s story demonstrates some socially significant experiences over the progression of her mother’s dementia, throughout her own challenging developmental period. As an only child with divorced parents, she divided her time living with both parents. However, she did not have a good relationship with her father, therefore, was reluctant to burden him, leaving her frequently unsupported in caring for her mother.

> *I don't know what it was, but I just had people around me that just didn't care or didn't want to get involved. I think I'd just been a bit unlucky*.

Six years later, Freda was formally diagnosed with YOD when Evie was seventeen. Evie’s initial experience of formal services at this time was in a group format on ‘*how to take care of someone with Alzheimer's’.* She learned useful strategies but recalled standing out wearing her *‘school uniform*.’ A sense of belonging and inclusion is important for young people in accessing support and services. As Evie recalls, ‘*I'm glad I didn't (attend YOD support groups) because that would have made me feel more of an outcast.’* However, a few years later, Evie attended a specific group for young people with a parent with dementia. She believed being connected to people of a similar age was extremely beneficial.

Evie received dementia-specific counselling, but this ‘*sometimes could give me more of a feeling of hopelessness than before I came in,’* which she felt was focused around a medical model that was fixated on the tragedy of her age and situation. At eighteen, Evie's situation deteriorated; a recognised significant developmental stage in a young adult's lifecycle. Increasing demands on her caring role and school work resulted in a 'nervous breakdown.' She sought help from her GP, who advised her to leave home, but she had nowhere to go and no other support options were offered by her father or formal services. Throughout this difficult time, it was arranged by a family friend for her to obtain the enduring power of attorney on her 18th birthday, something not often contemplated as applicable to this age group. Consideration of the social diversity and background of families is crucial. She describes the enormity of taking on this role for her mother at her stage in life; '*it was like everything I was doing, it was setting up for something horrible*.'

After many years caring for her mother, Evie moved to another city to live her own life. Not long after her departure, Freda was admitted to a nursing home. Evie recalls feeling '*worried about, the fact that I had the responsibility of choosing when I had to put her in a home, and when do you know how horrible is horrible?'* This level of responsibility in navigating complex processes is daunting for most adults but additionally so for young people, being unexpected at their stage of life.

John was the youngest sibling out of four and 14 years old when his father, Trevor, was diagnosed with YOD. He described feeling lost and alone in the family while his mother Flora was *'kind of too deep in her pain to kind of be aware of it (his distress),'* so he hid his emotions for years, demonstrating a lack of openness, not wanting to add to his family's distress. He reached a crisis in his early twenty's when he self-harmed. This crisis was related to his feelings of guilt with the permanent placement of his father in residential care. Certain events or transitions can spark an emotional or family crisis, like the situation John described. Young people portray different coping mechanisms at times of crisis, which include *'escaping'* the family home like Evie, engaging in risk-taking behaviours such as drug and alcohol abuse to '*make myself happy', or* self-harm, revealed by John. This could all be anticipated and managed by service providers with open communication; improved connectivity with families (Hutchinson, Roberts, Daly et al.,2016); knowledge and understanding of potential responses to life cycle challenges; knowing potential impact on the family through transition phases of dementia; and more access to age-appropriate family-focused services.

Balancing the demands between dual roles as a parent and caregiver

There are many challenges experienced being both a caregiver and a parent. This results in a deviation in their life trajectory as a consequence of changed family circumstances, associated with partner's diagnosis of YOD. Ann and her husband, David, were living with their two young sons (one in the first year of school and the other in year 3), when he was diagnosed with YOD at 50 years. Although challenged with her dual role, Ann believed throughout the upheaval of their family's day to day life:

> *…the thing that's really kept me going has been the boys. I think that's been my motivation to keep on going. Because it would have been really easy just to really go into victim mode here… knowing though that if I fell over then it was going to fall over for everybody.*

Acknowledging the family was now dependent on her, Ann took control of her own emotional wellbeing in the early stages by self-sourcing and connecting with a psychologist. Taking care of everyone’s needs and juggling the many appointments required regular travel, living in a rural community. She gave up work for a couple of years, something her employer sympathetically supported. Although facing many challenges, Ann lived in a supportive, small community and believed ‘*the medical support has just been amazing. I couldn't have asked for anything better.*’ Access to a psychologist and psychiatrist directly to obtain support at times of need, improved her confidence and ability to deal with complex situations. Being bulked-billed - not being charged for medical services - also alleviated some family financial concerns being unable to work. Positive interactions and attitudes towards her situation helped to reduce her vulnerability and offered her some control over the situation.

However, Flora, John’s mother, described her life as a parent and caregiver as ‘*hell on a stick.*’ This metaphor could convey feeling trapped in an adverse situation, ‘*hell*,' all directed onto Flora the ‘*stick*.' After Trevor's diagnosis of YOD, John at 14 years developed a mental illness, which required ongoing treatment. Flora also shared her own mother's care with her sister, prioritising everyone's care needs over her own. She described how her

> *[Son] was my priority because he was the child - if I needed to make a choice between anyone my duty as a parent I felt he had to be the number one. But I was coping with the other two as well.*

> *So the next few years became fairly difficult. I certainly was very, very, very depressed that first year. Did consider suicide, but I did finally get some treatment. I've realised that it was just so much pressure that I couldn't handle it.*

Flora experienced a health crisis some years later, being admitted to a hospital, which triggered input from formal services. This crisis enforced her to reconsider her situation. She arranged permanent residential care for Trevor so she could better manage her health and parental responsibilities.

Interactions of health and social care providers with families living with younger onset dementia

This theme explores the perspectives of health and service providers to understand better the social factors impacting their role in supporting families living with YOD. Three sub-themes were used to further explain: *Barriers to providing services and support to families; Working collaboratively can make a positive difference to family life, and health care and service provider's contribution to changing practice.*

Barriers to the provision of services and support to families

Health and social care providers report their primary role and responsibilities are with the person with dementia and primary caregiver. They confirm a lack of engagement with the children or young people in families, reporting '*we mostly go through the families and they filter out the information.'* A significant challenge is ensuring that this information is communicated to younger family members whilst recognising they are often isolated and not connected to any support. However, *'trying to figure out how to give parents information to connect them (young people) to services so that they can provide them with information'* is an ongoing challenge. Parents were sometimes described as '*gatekeepers*' limiting or denying service providers engagement with younger family members. This was believed by some as a combination of parents' protection of their offspring, not being aware of their children's need for support and information, or their perception of support being a parental or family responsibility. However, a lack of open communication could in effect be more destructive, contributing to isolation, misinformation, and exclusion of younger members from the family (Hutchinson, Roberts, Daly et al 2016).

Health and social care providers face many challenges that oppose their values and beliefs in providing age-appropriate support to families living with YOD. They describe '*frustration*' with restrictive guidelines in their roles; difficulty navigating and sourcing age-appropriate services; limited opportunities to be flexible and responsive to need; challenged by the aftermath of changing government and funding structures; limited time and opportunities to develop interagency collaboration; and dealing with the general lack of understanding and negative attitudes towards YOD. Teresa, a healthcare professional, discovered '*that with a lot of services I had to educate them before they knew enough about dementia to help support*' the family as a whole and understand their needs.

Limited opportunities for upskilling to work with younger families and lack of family-minded policy and procedures can result in ethical challenges and dilemmas, being constrained in the provision of responsive services. One service provider described guidelines as '*prescriptive*' and another as '*very focused on the person with dementia, not their children.'* Without a social change, the way services are designed and delivered will continue to challenge professional values and responsibilities supporting whole families. This could be a possible factor in moral distress and high turnover of staff, an ongoing problem, which affects the development of strong connections and relationships with families.

Kate, a service provider working over an entire state in Australia, is expected to be responsive to and engage with families diagnosed with YOD. She reported '*burnout*' in many colleagues, another factor causing high staff turnover. Kate is not alone, feeling:

> *Helpless. I feel like it's hopeless and its difficult for me to turn up to an assessment with underlying hopelessness….because I intend to provide that person with a sense of, you have dementia but you can live well with dementia and this is how, but I – there's a big gap. There's help but we can't access too much and that's what I struggle with.*

Jan, another service provider, highlighted in many cases there is '*no opportunity to get funding*' to access necessary services. They felt disempowered in meeting their professional responsibilities to the family, which disables the family from moving on with their life.

Working collaboratively can make a positive difference in family life

Providing support to the whole family is deemed a necessary action by most, but can be challenging with limited resources and unsupported by policy and procedures. Ideally, developing strong links with many sectors and agencies is crucial but currently not routine practice. This justifies the importance of understanding the family's social position as well as their historical and biographical functioning as demonstrated by Fran.

Fran, a service provider, supported a single mother, Sophie, living with YOD. Sophie struggled to get her teenage child, Annie, to school on time, which caused her to be bullied. Fran attended a school meeting as Sophie's advocate, obtaining prior consent from Sophie to talk about the home situation. Fran describes the school as being initially '*process based,'* until the whole family situation was explained and some understanding of the complexity of the situation was acknowledged. The school instigated *'band-aid solutions'* for Annie, but Sophie remained unsupported in her parenting role, which was the main issue. Annie developed depression and anxiety, feeling alone, having '*no one to talk to.*'

Fran obtained relevant family background information. Sophie, diagnosed with YOD, lived alone with Annie, 13-years-old. Annie's father lived far away from the area, and her other siblings had left home and reportedly '*abused alcohol and drugs …being physically aggressive with each other and very well known to the police.'* This information was helpful in Fran's role as she was aware that the social interactions with other family members would not be a useful resource. Sophie's parental judgements were impacted by the dementia, and Annie urgently needed access to age-appropriate supports. After many frustrations a favourable outcome for the family was eventually achieved. Fran did highlight some ethical considerations, '*recognising I'm not trained in that field, and I'm not trained to counsel and nor am I employed to do that*.'

Teresa worked with complex family situations living with dementia, and routinely gained knowledge about the family. In her role she identified specific family needs before implementing '*multi-system case reviews,'* bringing relevant agencies and family members together to develop services and support that addressed the specific family situation. It was time-consuming, with many obstacles and processes in the way particularly related to the way services were funded. But '*at the end we'd always walk away with a really good package that would meet the needs of the people'* in the family*.* This service model discontinued due to a lack of funding.

Healthcare and social care provider's contributing to changing practice

Raising awareness and understanding of the challenges families living with YOD experience is necessary for advocating for social change. Teresa, a health care professional, has adopted this as

> *…part of my role now is to build the capacity within our staff to actually understand and see the importance of younger people within the families.*
>
> *I think we need to be doing assessment around what all the family members need, not clinical assessments but what are the needs of each family member.*

Stan, a healthcare professional specialising in aged care, stated medical training focuses on '*diagnosis, managing and treating patients*' but identifies inadequacies in this approach concerning families with YOD. Even with his limited experience with children and young people he appreciated '*if I don't know what these young people are going through, I'm not even going to connect with them.'* He demonstrates a moral obligation through self-learning to invest in the whole family over the long term, and his responsibility '*to prepare this person and their family members.'*

He acknowledged the way dementia is framed can have long-term repercussions on the whole family, advocating for the inclusion of all family members in sharing information and connecting them with appropriate support. But he admitted this is not the case with other work colleagues, as many take the attitude '*dementia means there is nothing can be done*.' The adoption of these negative views often results in a failure to provide vital information and support opportunities, which can have detrimental effects on family members as already highlighted. A significant shift in thinking and approaches taken by health and social care providers is essential.

Stella, a healthcare professional, suggests a '*buddy system'* across sectors, which could improve confidence with children and young people through

> ..*learning from another youth-focused clinician on how he or she is doing that, and they would be learning from me with dementia-specific stuff.*

Attitudes and communication styles adopted by health and social care providers can have a lasting effect on whole families' approach to living with YOD and future interactions. Those with a willingness to learn, explore own strengths, weaknesses, beliefs, and values to engage and understand values, hopes, and fears of those in the midst of challenging situations exhibited sensitivity, positive, and non -judgmental attitudes, which improved job satisfaction and relationships with families (Rushton, 2016).

Discussion

Our findings have illuminated a number of the relationships and interactions of those living with YOD within current dementia care provision in Australia. The ability of the family to surmount the daily challenges of living with dementia can be dependent on the quality of relationships, openness of communication, emotional connectedness, and the level of understanding of dementia (La Fontaine & Oyebode, 2014; Patterson, Clarke, Wolverston, & Moniz-Cook, 2017). The research concurs that poorer family relationships and stress were linked to less positive adaptation to dementia, ineffective communication, and lack of connectedness for all family members, which has been demonstrated here in this paper (Keady & Nolan, 2003; La Fontaine & Oyebode, 2014). Unfavourable interactions and lack of informal and formal support can compound these experiences. Moving the focus of service provision from the individual with YOD to the whole family is supported in this research. Advocating for the entire family's involvement in early communications about dementia could significantly impact the family's future functioning and interactions. It is vital to obtain early knowledge about families' background, history, and beliefs to help gauge service interventions, and reduce the risk of a family crisis is consistent with other research (McDonald et al., 2016; Rolland, 2005). Knowing the developmental stage of families is essential, with individuals across different ages juggling roles and responding to family demands. This can affect their ability to look after their own and other's needs. However, the more vulnerable and less confident members of the family, the parent living with YOD, and younger family members often have a less powerful voice in society and within the family. Opportunities to communicate and connect with significant individuals safely are crucial (Hutchinson, Roberts, Daly, et al., 2016; Patterson et al., 2017).

This research highlights that health and social care providers' roles are currently organised around the biomedical model, with a focus on the person living with YOD and primary caregiver. The life cycle stage of the family and individual members with their specific needs are often overlooked in the way services are designed and delivered (Cations et al., 2017; Millenaar et al., 2016). The lack of shared responsibility, cross sectorially, to support these families can disable them in managing life challenges, and affects healthcare and social care providers' ability to maintain core values and commitments to the families. This can affect relationships with the families, being unable to fulfill professional obligations with associated narratives of frustration, hopelessness, and challenge. Accessing resources and services to address family-specific issues and concerns is currently time-consuming due to the limited cross-sectorial collaboration opportunities available, but can produce favourable outcomes for everyone as demonstrated in this research. The research verifies that health and social care providers' ability to adapt and respond to challenges, explore and manage own perceptions of dementia are favourable. Developing the capacity to establish a positive relationship with the family can bring about the change needed for greater 'understanding, acceptance and adjustment,' benefitting all (Fallowfield & Jenkins, 2004, p. 317).

Implications

How then can these critical factors in the lived experience of families living with YOD be synthesized into a framework for the co-creation of appropriate family-focused services. In considering first the theoretical framing, we propose the combination of the family systems-illness model (Rolland, 1987, 1990) and the social model of disability (Barnes & Mercer, 2011; Oliver, 2009) as an innovation in providing explanations as to why the family needs should be at the centre of service design and planning process (Cations et al., 2017; Mayrhofer, Mathie, McKeown, Bunn, & Goodman, 2017). The co-creation of a family-focused service model underpinned by the theory of these two models can inform policy change and guide clinical practice, appreciating the dynamic interplay between all family members living with YOD, health and social care providers, and the broader community (Mayrhofer et al., 2017).

This co-creation of family services model shifts the focus of interventions from the biomedical model to the social model, fostering social engagement and a change in clinical practice, and the promise of better service user outcomes. In the initial phase of YOD, a particular time of family turmoil, early engagement with the whole family by a community liaison person or similar role, can help identify a family' s social position, functional background and beliefs. The way in which these early encounters are framed can set the precedence for future interactions. Fostering the whole family's engagement in joint discussions conveys the importance of inclusion in the process of change and adapting expectations, which can ultimately help direct focus away from experiences of loss (Millenaar et al., 2016; Rolland, 1999). Facilitating crucial family discussions helps to reduce the risk of crisis, alleviate fears and isolation, and improves resilience to manage life's challenges. Ideally, those in this community liaison role would 'work, communicate and learn together' (Robinson & Cottrell, 2005, p. 558) with GPs, medical specialists, nursing and allied health professionals across sectors to identify these families as early as possible and engage promptly with the whole family. In this liaison role it would be possible to develop strong links cross sectorially with health and social care providers, and connect with the whole family, which could reduce family vulnerabilities and improve confidence to manage challenging situations. Collaborative options for improved communication, routine information transfer, and stronger links and learning across agencies and sectors could be facilitated through ‘electronic databases and single points of entry to dementia services' (Robinson et al., 2009, p. 141). The family's access to age-appropriate services and support would then be simplified and more responsive, with more established cross-sectorial links.

Considering the whole family approach to service provision as the norm, is crucial over the progression of dementia. Family vulnerability and emotional manifestations can vary with stages of dementia; socially significant and developmental ages of family members and the community in which they reside. Routine engagement and connectivity with services and support that understand these family’s needs would help foster positive relationships and interactions. The adoption of this model could assist in the identification of potential transition periods or life events that result in negative implications on family members as demonstrated in this research, and prompt scheduling of family reviews over the chronic and into the terminal phases (Rolland, 2005). In clinical practice, being able to conceptualise and action prompt responses to challenging circumstances could prevent a crisis, alleviating further anxieties and worries. However, the enablement of responsive actions is a cross-sectorial responsibility, fostering seamless links and partnership with other sectors and agencies, irrespective of funding source. Improving the capacity to respond to need could improve current job satisfaction and promote mutual learning opportunities. As reported by Cations et al (2017, p. 12) having access to ongoing sustainable, ‘unique’, coordinated, and flexible ‘good’ services are clearly recommended by the family members. Their inclusion in service design gives them some control over their life and is empowering (Mayrhofer et al., 2017)

The co-creation of a family-focused services model can help inform service design, taking into consideration the dynamic relationships and interactions between the person living with YOD, family members and service providers. This model encourages more attention to interpersonal relations through adopting a socially inclusive approach. In principle, ‘citizens are looked at as co-creators of their own well-being' (Freire & Sangiorgi, 2010, p. 2). Family members are best placed to contribute to the design and development of services that are applicable and responsive to individual and family orientated solutions, around need (Edvardsson, Tronvoll, & Gruber, 2011; Freire & Sangiorgi, 2010; Mayrhofer et al., 2017; Sansoni et al., 2016). Considering the co-creation of services, where the users are ‘central not only to the design of services but also to their production and continuous development' (Freire & Sangiorgi, 2010, p. 3) is empowering, and improves social value and overall well-being (Mayrhofer et al., 2017; Mental Health Foundation, 2015). The theory underpinning the co-creation model draws attention to the societal influences on complex family's ‘cohesion, adaptability, and communication' (Rolland, 1990, p. 2). Raising awareness of societal influences living with YOD (Thomas & Milligan, 2018) could promote constructive attitude change towards a sense of hope (Surr, Smith, Crossland, & Robins, 2016); improve sensitivity and understanding of complex issues; break down barriers between healthcare, service providers, and family members, to assist in the adoption of more socially orientated practices. Challenging one's issues and beliefs in this process, including societal expectations and norms, can make valuable contributions to the successful shaping of enabling practices (Edwards, Voss, & Iliffe, 2014).

Adopting the framework for the co-creation of family-focused services model would ensure services are tailored to the unique needs of families (Cations et al., 2017; Mayrhofer et al., 2017), taking into account lifecycle and psychosocial demands (Rolland, 1990,1999; Mental Health Foundation, 2015; Thomas & Milligan, 2018), over the progression of dementia. Individual and family history, and biography and developmental stages would be routinely contemplated along with the fundamentals and variables of how families’ function within the community they reside (Oliver, 2009; Roach et al., 2014; Rolland, 1990). Families’ contribution to the design of future services would support equity for all, irrespective of geographical location, availability of appropriately skilled staff and specific services. Embracing technological platforms (Robinson et al., 2009) where health and social care providers, and family members come together to receive or deliver appropriate services, support, information and education opportunities is vital in this changing social world.

Strengths and limitations:

Our study is one of the first to explore a theoretical framework to inform a family-focused service design model for individuals and family members living with YOD. Although the sample size is not predetermined in qualitative research, the limited numbers of people living with YOD, spouse carers, health and social care providers could be seen as a limitation. Further research is necessary to broaden understanding of family experiences through conducting interviews with all family members, ideally from diagnosis and at different times along the trajectory of dementia. Service providers supporting these families could also be interviewed at the same time to deepen understanding.

Conclusion

The co-creation of a family-focused services model for families living with YOD could provide a valuable foundation that underpins effective interactions, and informs service and policy development opportunities between service users, service providers, and stakeholders. The proposed model offers a socially focused theoretical paradigm for rethinking and fostering health and social care providers' approach to design and development of services and support, incorporating cross-sectorial cooperation and education opportunities in collaboration with family members. This innovative model would focus on actions that foster enablement of the whole family unit to function well together as the dementia progresses. Enabling participation and engagement in the community, and appropriately investing in maintaining the emotional and physical well-being of the whole family to live and function well with dementia, is crucial. Further advancement and integration of this theoretically underpinned co-created, family-focused service model requires additional research but presents excellent opportunities for social change.

Table 6.1: Demographic characteristics of participants (YOD = 5, Spouse/carer = 6, Children/young people = 17)

Family	Diagnosis	Relationship to person with dementia	Age at interview	Age of participant at family member diagnosis	Other immediate family Members not interviewed	Person with YOD marital status & resides with
1	Alcohol related dementia	Self Ex-wife Daughter	49 46 10	46 44 7	3 children	Separated blended family, lives with ex-wife and 3 children
2	Alzheimer’s disease	Daughter Daughter	19 22	19 22	Mother (AD), I child	Divorced, lives with daughter (19)
3	Alzheimer’s disease	Son Wife	22 68	14 58	Father (AD), 3 children	Married, lives in nursing home
4	Alzheimer’s diseases	Daughter Daughter	30 33	24 28	Mother (AD), 1 child	Divorced, lives with daughter (30)
5	Alzheimer’s disease & Lewy body dementia	Self Daughter Son Daughter	43 9 10 15	42 8 9 14	Husband, I child	Married, lives with husband and 4 children
6	Frontotemporal dementia	Wife Son	48 13	44 9	Father (FTD), 1 child	Married, lives in nursing home
7	Alzheimer’s disease	Wife Daughter	57 28	49 21	Father (AD)	Deceased
8	Frontotemporal dementia	Daughter	24	23	Mother, Father (FTD), 2 children	Married, lives with wife
9	Semantic dementia	Daughter	25	18	Mother, Father (SD), 2 children	Married, lives with wife and 2 children
10	Alzheimer’s disease	Daughter	26	16	Mother(AD)	Divorced, lives in nursing home
11	Huntingdon’s disease	Daughter	27	teenager	Mother (HD) in NH	Single, lives in nursing home
12	Posterior cortical atrophy & Lewy body dementia	Self	51	49	3 children	Alone
13	Alzheimer’s disease	Wife	53	51	Father (AD), 2 children	Married, lives with wife
14	Frontotemporal dementia	Self Husband	58 57	52 51	3 children	Married, lives with husband
15	Alzheimer’s disease	Daughter	24	20	Mother (AD), stepfather, 1 child	Remarried, Lives with husband
16	Alzheimer’s disease	Self Daughter	52 21	57 16	Husband, 2 children	Married, lives with husband

Abbreviations explained:

Alzheimer’s disease (AD), Frontotemporal dementia (FTD), Semantic dementia (SD), Huntingdon’s disease (HD), nursing home (NH).

Table 6.2: Health and social care provider interview information (n=7)

Roles	**Sex**	**Sector**	**Years working with dementia**	**Years working with families living with YOD**	**Youngest child supported (years)**	**Most challenging age to support (years)**	**Interview (mins)**
Counsellor/ coordinator of early intervention	F	NGO	9	8	15	20-24	72
Geriatrician	M	Health	8	5	8/9	5-9	78
Case manager/YOD key worker	F	NGO	19	9	4	10-19	67
YOD key worker	F	NGO	12	3	7	15-19	72
Registered nurse	F	Private	> 25	11	9	10-14	65
Occupational therapist	F	NGO	1	1	12	10-14	74
Psychologist	F	Health	7	7	7	15-19	72

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Chapter 7

Discussion and conclusions

Introduction to the chapter:

This chapter synthesizes the findings of my doctoral research across the five empirical studies within the broader context of current literature relevant to the lived experience of families living with YOD. In six sections I will:

7.1 Summarise the main findings across the papers making up this doctoral thesis.

7.2 Discuss how the development of a social model approach to improve family orientated services has been built upon a rich understanding of the experiences of those living with YOD. I include the perspectives of individual family members, health and social care providers.

7.3 Outline how the utility of the social model of disability in dementia research is an innovative contribution to theory. I expand on the social model of disability as a framework to aid understanding of the societal influences and consequential social constructed disablement, impacting lives of people of all ages living with YOD in complex family situations.

7.4 Outline two ways where families' involvement could inform social change and policy and practice development. I consider opportunities where family members are valuable as co-creators of education programmes and service models with health and social care providers and stakeholders.

7.5 Reflect on the ethical considerations and the maintenance of qualitative rigor throughout the research.

7.6 Concluding chapter reflects on the strengths and weaknesses of this study and make recommendations for further research.

7.1 Main findings

The common theme that has linked these chapters together is the lack of understanding and significant unmet needs of people living with YOD and their family members. As such, the thesis contributes to the generation of conversations about a new paradigm of understanding living with dementia in younger age. There is validation of the social model of disability's significant contribution to reframing the way people consider dementia; with particular consideration of individuals and families together in a social context. Adopting this social approach is fundamentally crucial in driving social change to improve real-life experiences of families living with dementia. Importantly, this thesis improves understanding of the social and psychological influences on the lived experiences, which I feel can play a significant role in generating an inclusive and enabling society for all, irrespective of diagnosis. We do not need dementia friendly societies as such, but societies that are inclusive, non-discriminatory and stigma-free, so everyone feels a sense of belonging and value, and be rightfully supported to live as equals. This approach will be explored further through summarising the findings in each paper included, in relation to the questions asked.

Chapter 2, paper 1: Identity, impairment and disablement: Exploring the social process impacting identity change in adults living with acquired neurological impairments
Question*: What social processes impact identity formation of adults living with acquired neurological impairments, progressive and non-progressive, physical and or cognitive impairments, from the combined perspective of the social model of disability and the social identity theory?*

Using both the social model of disability and the social identity theory as a theoretical framework confirmed that identity change is a complex process with many social influences. Being exposed to the disabling of identity is viewed as socially constructed, based on societal norms and values, and stereotypical influences, which impact all aspects of life and the right to be socially included. There are discriminatory practices between different impairments, noting cognitive impairment is stereotyped or categorised into a social group of less value. However to counter disabling of identity requires a cultural change, to promote enablement and inclusion, respecting and valuing all living with acquired neurological impairments, which is quintessential to the social model of disability.

Chapter 3, paper 2: Feeling invisible and ignored: Families' experiences of marginalisation living with younger onset dementia
Question*: What are the significant societal factors which impact the experiences of families living with YOD, including children and young people?*

Many societal factors and barriers impact these families, and younger age in particular is a significant barrier in creating invisibility in society. Experiences of social oppression, discrimination, and exclusion are leading barriers in these families' lives that contribute to socially constructed disablement. It is a societal responsibility that these families living with YOD become visible and are enabled to live equally in society. The social model of disability can help explain the processes in place and guide the way forward to a social and cultural change where no one feels ignored or isolated.

Chapter 4, paper 3*:* The emotional well-being of young people having a parent with younger onset dementia
Question: *What are the societal influences on the emotional well-being of these children and young people from the perspective of the social model of disability?*

Society contributes to the emotional distress of children and young people due to their exclusion and discrimination. The inadequacy of available age-appropriate support and services is a contributing factor. Many children and young people are unrecognised in their caring role, being left alone and isolated while going through significant developmental challenges. These children and young people are disabled by association with their parent living with YOD, with lost opportunities to live equal to their peers, further explained by the social model. Adopting a social approach to understanding and responding to the needs of all family members is required. Changing focus would ensure that services and supports would be tailored to individuals and families, helping to keep families connected and better manage emotional well-being. Essentially, being socially focused takes into account everyone's needs in the family, so no one is disadvantaged and isolated.

Chapter 5, paper 4*:* Empowerment of young people who have a parent living with younger onset dementia: a social model perspective
Question: *What are the influencing social factors that could enable these children and young people to be supported and socially included?*

It is crucial to recognise and support all young carers in families, irrespective of parent’s diagnosis, which can reduce their experiences of marginalisation, discrimination, and emotional distress. Societal silence suggests an indifference to their needs or a perception they are invisible within society. However, fostering connectedness is vital to safeguarding them against life’s challenges and provides the opportunity for meaningful communications. Being empowered to have control and choice in life, can help them gain self-confidence and improve self-worth to assist the breakdown of social barriers created around difference. Overcoming issues of labeling and stigma are necessary so no one is disadvantaged or experiences negativity associated with a diagnosis. Everyone has a right to be included and to engage in his or her community living with a diagnosis or by being associated with someone with a diagnosis.

Creating equity within society ensures that everyone receives support and services as required, which gives them the confidence to speak up.

Chapter 6, paper 5*:* Co-creation of a family-focused service model living with younger onset dementia
Question*: In developing a theoretically informed appreciation of relationships and interactions of those living with YOD, we hoped to determine what are the critical factors that need to be addressed in co-creating family-focused services?*

Presently there is not a framework that helps to guide service development, which is critical to the process of changing practice. A theoretical framework to underpin a co-created family-focused service model was developed as a result of the common thread in all the papers about a lack of specific family-focused age-appropriate services and support. The socially constructed disablement experienced by all family members living with YOD is unacceptable but could be countered with the social model offering a way of rethinking and reframing the way services can be designed and implemented. The unique needs of families, their stage in the life cycle and psychosocial demands need to be fully understood by everyone involved in providing services and support. Appreciating the diversity of families and the interplay between family members supports the linking of the social model with the family systems- illness model. This theoretically informed understanding provides a valuable framework to guide collaborative activities and constructive communication between service users and providers in the co-creation and co-production of new policies and practices. In addition, service providers will be better informed to challenge disabling policies and practices that fail in meeting the needs of the whole family and restrict them in their role. Also, developing humility is crucial in recognising the value of everyone in the process of change. Figures 6.1, 6.2 and 9 give some diagrammatical representation of linking these two models but I acknowledge the need for further development before proposing integration of the co-created family-focused service model into existing practices. This model could present excellent opportunities to begin the process of social and practice change.

7.2 Building the social model approach on the rich understandings of the whole family and service providers

This thesis sheds light on the perspectives of family members across developmental ages and at different stages in the lifecycle, through a social lens. Obtaining a broad range of perspectives from family members living with YOD is fundamental to gaining an appreciation of family diversity and the dynamic interdependence of family members. To date, these perspectives have been largely overlooked in the research literature, but this thesis brings them to the forefront. The silence within the research and social community could underpin these families sense of insignificance in society, which this thesis hopes to readdress. Each family member faces their own specific challenges and concerns, which can affect relationships within the whole family and their community. With this understanding, it is essential we recognise and consider the individual and family circumstances together.

Families have unique configurations which reflect the description of the whole family as a ‘social unit’ (Murray & Barnes, 2010, p. 535), with each having their own history, background, and beliefs. The social model of disability can explain the complexities of social factors that affect families living in their community. The knowledge and understanding gained from the social model can be used to ascertain tailored support needs, paying particular attention to important transition stages that could potentially trigger a social crisis for individuals and the whole family/social unit. Considering the perspectives of health and social care providers included in Chapter 6, is crucial, as they too are challenged in their role supporting families. Many feel disadvantaged due to their limited experience working with families living in these difficult circumstances and working with service models largely focused on late-onset dementia. However, within the radically changing climate of service provision, particularly relevant to Australia with the implementation of the National Disability Insurance Scheme (NDIS), YOD has been located within the disability sector rather than aged care. This has been a significant change and has certainly created many challenges in the dementia sector. However, service provision still remains largely focused on an individual diagnosis and needs, which stems from a biomedical model focus and less on the social aspects of life.

7.2.1 Challenging society to recognise children and young people in families

Understanding the impact on children and young people in families is an area that until recently has had little attention in the research literature. To readdress this, Chapters 4 and 5 have focused explicitly on this group, using the social model of disability to assist understanding and explain the influences of social factors on their lives. From my observations, there exists a general lack of appreciation and acknowledgment that parents, with children living at home, can be diagnosed with dementia. This is considered a deviation from ‘normal’ family life, which is stressful and confronting to accept (Gelman & Greer, 2011), but it demands more focused attention from health and social care providers and the broader society. The needs and issues faced by children and young people in these families are relevant to many sectors other than dementia, including children and youth, education, health, and work, and there is potential for greater cross-sectorial communication and collaboration.

On reflection, a challenging area throughout this study has been the repeated failure by many, including health and social care providers, to recognise the impact of individual and society's negative response to YOD on all the family members. These negative responses affect family relationships and interactions, which can contribute sadly to children and young people's isolation and neglect, in the families and their community (Gelman & Rhames, 2018; Hutchinson, Roberts, Daly, Bulsara, & Kurrle, 2016). More surprisingly, even with the increase in YOD diagnosis worldwide, it is still perceived as the ‘hidden disease' by most people living with YOD and family members. Maybe this substantiates why children, in the context of dementia, are frequently presumed to be grandchildren, even by those that work in the area of dementia. I was exposed to these particular assumptions during my research whenever children were mentioned. These assumptions, I believe, substantiated their sense of difference and did not support their inclusion in the dementia sector.

In general, people appeared confronted listening to personal stories and presentations as well as reading about the challenges faced by families with children and young people living in our communities. This was particularly noted when stories related to everyday experiences of marginalisation and discrimination. It is unacceptable that the exclusion and invisibility of these young family members’, similar to some other young carers (Rose & Cohen, 2010), continues in today’s society. Even more controversial is the occurrence of marginalisation and discrimination within dementia sectors that state publically they represent and support everyone living with all forms of dementia, their families, and carers. I believe even with the more recently implemented service models, like the YOD key worker programme in Australia, full family inclusion in the dementia sector still has a long way to go. This sector needs to acknowledge that children and young people still don’t feel they belong and unequivocally stand out due to their age and situation. Essentially, there needs to be more opportunities for children and young people to safely and accurately voice their concerns and issues, without judgement. This could be better managed through peer support programmes, akin to those undertaken in youth mental health organisations. Developing children and young peoples’ leadership programmes to build skills in mentoring and supporting other children in families with YOD, should be given more serious attention. Several young people wanted this to happen as they understood how, with recent technological advances in our society; this type of opportunity is not restricted to geographical location. We ought not, as a society, underestimate the wisdom of our future generation as their insights and perspectives can make valuable contributions to directing the crucial changes needed in service practice and supporting social inclusion for all (Gelman & Rhames, 2018; Hall & Sikes, 2016, 2018).

On reflection, I felt these young people have to cope with so much change and unpredictability in their life, with little real understanding from others. There seems little appreciation of the reasons behind any negative behaviours or attitudes within the family and wider community, other than their developmental age, being a teenager for example. There seems an unwillingness to talk about dementia within and outside of the family, creating a greater reliance on ‘google’ for sourcing information and support (Sikes & Hall, 2017). As reported in this research, the lack of informal and formal support; limited open and honest communications and engagement modeled by parents and other family members as well as by health and social care providers, reinforced children and young peoples’ sense of exclusion and perpetuated their ongoing silence of their experiences (Gelman & Rhames, 2018). It is vital to acknowledge, these children and young people have developmental age challenges, alongside the progression of their parent’s dementia. In addition, they have caregiving roles and responsibilities beyond their years, and many of their own difficult age-related transitionary stages to navigate (Johannessen, Engedal, & Thorsen, 2015, 2016; Rolland, 1999). They are frequently left unsupported and their needs unrecognised, reporting other family members are too busy or distracted dealing with their own challenges; "lost in the chaos" (Allen, Oyebode, & Allen, 2009). Typically, within this younger age group they do not wish to be seen as different or draw attention to themselves or their family. So consequentially, they do not make their needs or concerns known to others. This state of affairs could ultimately lead to a loss of control of their situation, which could result in the need for ‘greater personal distance’ (Johannessen et al., 2016, p. 6), as in moving away from home- the ‘physical escape’- and or engaging in risk-taking behaviours (Hutchinson, Roberts, Kurrle, & Daly, 2016, p. 617). These responses and reactions ought to be better understood and managed by all those involved, through providing regular opportunities for them to ‘express their thoughts, feelings, and perceptions of their present needs and situation’ in a safe and non-judging environment (Barca, Thorsen, Engedal, Haugan, & Johannessen, 2014; Johannessen et al., 2016, p. 2; Svanberg, Spector, & Stott, 2011). Any significant person, within or outside their family, could provide the means for safe disclosure of issues or concerns. By not communicating their needs, within or outside the family, they could be wrongly perceived by others that they do not require or want support.

It is important to understand that children and young people lack the range of responses, decision making or problem-solving attributes that comes with maturity, so they cannot be expected to respond or behave in the same way as adults to complex situations (Johannessen et al., 2016). Children's 'social clock' (Roach, Drummond, & Keady, 2016, p. 27) is disturbed by taking on parental roles and responsibilities whilst dealing with the anticipated loss of their parent and 'grief prolonged over a long time' (Johannessen et al., 2016, p. 8; Rolland, 1999a,b; Sikes & Hall, 2017). Their future holds many uncertainties, and justifiably a real fear of the unknown. Without the security of parental support into the future, similar to others with a parent with a terminal illness such as cancer, they are considered more vulnerable to many of life's challenges (Allen et al., 2009; Maynard, Patterson, McDonald, & Stevens, 2013; Sikes & Hall, 2017).

Most young people that participated in this research adopted a caring role in some capacity, either by choice or as a family duty. Irrespectively, those who reflected back on challenging times with the benefit of maturity, were apologetic or embarrassed by their behaviours and attitudes at periods in their life, growing up with a parent living with YOD. Most did not like their behaviours and judged this as a personal failure rather than a societal one. They often felt unvalued as young carers, a common viewpoint in a society that frequently refutes a 'caring identity' (Rose & Cohen, 2010, p. 479). A few wondered, with the benefit of hindsight, if they had been depressed through particularly difficult times, which helped them validate some of their unconstructive responses to situations. Interestingly however, many did highlight their feeling of disconnection from immediate and or extended family and their peers; an absence of being included in information sharing and decision-making and struggling to manage their many roles and responsibilities. Overall they reported a general sense of exclusion and isolation similar to other young carers (Barca et al., 2014; Gelman & Rhames, 2018; Hutchinson, Roberts, Daly, et al., 2016; Pakenham & Cox, 2015; Smyth, Cass, & Hill, 2011). Many pointed out that the lack of understanding, age appropriate or family orientated support and services in their life, were an ongoing issue and contributed to greater stress. Some did feel disadvantaged by their young age, with often no understanding of their rights, which was particularly significant to those in single-parent families, lacking the customary parental guidance. They described frustration at the general lack of understanding of their situation and annoyance at being compared to those with grandparents with dementia. This all attributed to their sense of difference and a lack of confidence or know-how on approaching people (adults), including service providers, for help. Frequently, blaming themselves for their inadequacies and inability to manage the situation well as a child or young person, led to associated feelings of guilt and failure, which impacted them at the time and, for a few, many years afterwards. The social model can explain these issues as a direct consequence of being let-down by a society that has neglected to provide support and services to help them live a life equal to others of a similar age.

Particularly noteworthy, in this research, was the frequently unrecognised impact on the emotional well-being of the young people. It is important to recognise other research that explores the experiences of young people in these families (Allen et al., 2009; Barca et al., 2014; Hall & Sikes, 2018; Johannessen et al., 2015; Svanberg et al., 2011). International recognition within the dementia community is needed to acknowledge that greater 'caregiving responsibilities have direct and indirect adverse effects on youth mental health in the context of parental illness' (Pakenham & Cox, 2015, p. 875). An association with the deterioration in psychological health, the developmental age of the young person with caregiving responsibilities, demographics, and unmet needs, was demonstrated in this research and resonates with recent cancer-specific research (McDonald et al., 2016). More research is required to understand these relationships further to support the development of tailored family-focused support options that address and react to needs, not just respond to a diagnosis (Kallander et al., 2017; Pakenham & Cox, 2015). However, an increase in mental health illness and risk-taking behaviours were identified in this research around the socially significant time in their lifecycle, transitioning to adulthood (Hutchinson, Roberts, Kurrle, et al., 2016). Having and caring for a parent with YOD creates greater challenges during the significant time of transition. This situation becomes a social responsibility to provide 'targeted support services' for these young people (Hutchinson, Roberts, Daly, et al., 2016; Johannessen et al., 2016; Pakenham & Cox, 2015, p. 875). This particular stage in the life cycle is referred to as 'centrifugal' (Rolland, 1999a, p. 6), when young people typically anticipate distancing themselves from the family but may feel frustration anchored to the family for the unforeseeable future. Also, this research draws attention to a relationship between the length of time living at home with a parent with YOD and the lack of formal and informal support opportunities. And so, the longer one is living at home without adequate support can significantly contribute to the deterioration of one's emotional well-being and justifies particular attention in research (Barca et al., 2014). It is important to appreciate that feeling alone and isolated can occur within families, along the trajectory of dementia and beyond, irrespective of the number of other family members. Thus, it is crucial to develop an understanding of the nature of family interactions and functioning in the early stages.

Many who work within the dementia sector, although aware of some of the issues in families, report they are neither skilled nor funded to include all family members in their role, or feel they lack an appropriate level of experience to support the younger family members. This research informs us that supporting whole families living with YOD should be regarded as standard practice in their provider roles and not seen as the exception. The changes that result from this, as endorsed by the social model, would advocate for the provision of services and support based on family needs, as lives are intimately connected and ought to be recognised as such. The lack of integration and cross-sectorial collaboration of organisations and agencies in service design and delivery could be recognised as not only disabling families, but also hampering healthcare and service providers in their roles. In addition, the availability of opportunities to be upskilled in managing and supporting whole families are currently lacking, which highlights an ongoing unmet need for sustainable learning and education opportunities. This failure to take a whole family approach could be a socially constructed barrier to changing the way services are designed and delivered.

7.2.2 Essential considerations for understanding a parent living with younger onset dementia

This study noted that there are discrepancies associated with societal response to the type of impairments, with cognitive impairment associated with less social worth and social value, compared to physical impairments (Hutchinson, Roberts, & Daly, 2018). As cognitive impairments can be hidden or disguised for a period, disclosure to others can be delayed. However, although these frequent practices can be based on protection of self and family from discrimination and stigma (Rose & Cohen, 2010), this can also affirm the negativity and lack of understanding towards cognitive impairments. More focus needs to be on making the invisible more visible by adopting opportunities for people living with YOD and their families to participate positively and meaningfully in the family and society, supporting their valued inclusion (Johannessen & Moller, 2013; Roach, Drummond, & Keady, 2016). Discrimination between impairments needs to be addressed as a societal concern so that everyone is treated equally, and people living with cognitive impairments continue to feel valued and worthy, as is his or her human right (Convention on the Rights of Persons with Disability (CRPD)).

Parents living with YOD can be perceived by others as no longer being an integral family member (Roach, Keady, Bee, & Williams, 2014). This exclusion is often a consequence of the way society responds to dementia and is emphasised in the way services are designed and delivered. These parents frequently feel constrained in their attempts to retain their identities due to lack of support, formal and informal, and 'conflict in their needs and interests' (Boyle, 2014, p. 1140; Harris & Keady, 2009).There is a general lack of understanding on the importance of interdependence and mutual understanding in families. If these factors are not fostered, there can be subsequent impact on families' ability to function as a social unit (Roach et al., 2014). If, for example, the person living with YOD presents with behavioural issues, this can be perceived by others to be a direct consequence of dementia, but on the contrary may be a reflection of poor family dynamics, unmet needs, family conflict and crisis (Bakker et al., 2014).

In this research, parents living with YOD demonstrated insight about dynamics in the family, but felt this was not considered or unacknowledged by others. Another, often forgotten factor in the lives of parents with dementia is their wish to maintain their parental role and identity under these challenging circumstances. To continue functioning as a parent is often not considered in relation to support and services offered. To highlight this, over the research period, parents living with YOD have approached me after my presentations at conferences or talks to ask what they could do to help their family members, particularly their children. They demonstrated great insights, being concerned about the uncertainties that confront their offspring, particularly related to their own future ability to support their children and keep them safe, as expected in a parental role. They described feeling powerless in obtaining support for their family, not knowing where to get help, often undermined by stereotypical attitudes and responses to their impairments that ultimately affect their confidence and question their parenting abilities. It is important these parents are offered vital support in their family roles to continue as integral family members, as is their right in a socially orientated culture. Widening the focus on the person with YOD, seeing them holistically in the context they live, can help in reframing how they can be supported as an integral family member.

7.2.3 Acknowledging the dual parent and caregiver role

This under identified dual role, taken on by the parent without dementia, has had little focus in the research until recently (Gelman & Rhames, 2018). Again, this is probably impacted by the predominance of the biomedical model and dementia in the older age group. Therefore, consideration of this challenging time with life spinning out of control, juggling parental and caregiver responsibilities and duties, is an area that needs more attention. Considering the whole situation, the dementia sector and research community need to bring to light the complexity of families' social situation (Gelman & Rhames, 2018; Johannessen, Helvik, Engedal, & Thorsen, 2017; Svanberg et al., 2011). This thesis has highlighted the importance of health and social care providers having a good understanding of the dynamics of the family, interactions, and relationships (Johannessen et al., 2017; Roach et al., 2014). The ability to maintain a parenting and caregiving role as well as adapt to different phases in family life, is impacted by the availability and appropriateness of informal and formal support. Service providers' positive early engagement with these family members could assist with their understanding of the family's social situation, background, and functioning with a diagnosis of dementia, and should be considered routine practice. Establishing who the other family members are at this time could be achieved by simply constructing a family tree, as suggested by a/one healthcare provider. Fostering better ways of communication between service users and service providers, in a non-judgmental manner, would provide opportunities for greater knowledge sharing and understanding. Ideally, this would be upheld through adopting a more social orientated practice, reducing any negative impacts on the family and providing the necessary support to assist those to function well in a dual family role.

Ensuring socially focused support for the parent with the dual role and responsibilities, could minimise associated negative feelings of guilt and inadequacy that are familiar narratives with this group of individuals. It is hard to prioritise one family member's needs over another, but it does become a necessity in certain situations when no other options seem available to the person, as highlighted in the research. This situation would not occur, if services and support options are available and relevant to address need, as well as easy to find and navigate. Without adequate support this can often lead to the consequential neglect of the parent's own needs. Many go onto report feeling unable to cope and failing in maintaining both roles, which communicates a sense of letting their family down. Some conveyed being judged by other family members and their community. They perceived a general lack of understanding by others, related to their efforts to uphold their responsibilities to limit unfavourable impact on other family members. The overall lack of understanding to their situation was reported as undeniably challenging and emotionally distressing (Gelman & Rhames, 2018; Johannessen et al., 2017; Rosness, Mjorud, & Engedal, 2011; van Vliet, De Vugt, Bakker, Koopmans, & Verhey, 2010). However, by receiving a specifically targeted and socially responsive level of formal support could change their current challenging reality, for the better. As a consequence, having physical, emotional and financial needs addressed would help transform their experiences, from being alone and disadvantaged in keeping the family functioning together.

However, the early recognition of this dual role in families is crucial. To receive support to manage the family situation is a social responsibility, not just a family concern (Cations et al., 2017). To safeguard themselves and their family against experiences of socially constructed disablement, they ought to be connected to and engaged with appropriate timely support to respond to their own and family needs (Gelman & Rhames, 2018). The societal failure to provide adequate information and well-timed support of this parent/carer role has been shown to potentially increase risk of early placement of the younger person with dementia in residential care (Rosness et al., 2011)

7.3 The utility of the social model of disability in dementia research

In the introduction, I emphasized the aims of this thesis were to build on current gaps in the research literature, particularly related to proposing the social model of disability as a theoretical framework (Barnes & Mercer, 2011; Oliver, 2009). Adopting this socially focused approach helped develop insights into the societal influences experienced by individuals living with YOD, their family members, and the whole family unit. The findings from this study have contributed to gaps in current understanding of the impact of YOD on relationships, interactions and functioning of the family in their social world. Individual family members and the whole family unit face limited opportunities to exercise or influence their capacity to live equally in society, which could be readdressed by developing a social model approach to dementia. This social focus has recently been attracting attention in the dementia and research communities (Mental Health Foundation, 2015; Thomas & Milligan, 2018). Due to the lack of understanding of individual and family needs, and unfavourable practices and attitudes imposed on them, they often experience oppression, social exclusion, and discrimination (Thomas & Milligan, 2018). These experiences are deemed more pronounced in younger people with dementia and their families, being a socially significant time in their life, with financial and employment commitments and younger family dependents (Harris & Keady, 2009). This research further develops the utility of the social model as a theoretical framework to advance understanding of social challenges for the whole family living with YOD. The social model has been shown to be worthy in other sectors, facilitating and directing conversations and actions towards socially orientated service developments and practices (Beresford, 2004; Chappell, Goodley, & Lawthom, 2001; Tew et al., 2012). These important conversations have been fundamentally absent in the area of dementia due to the overriding dominance of the biomedical model in this forum, which thankfully appears to be starting to change.

7.3.1 Socially constructed disablement

This study revealed challenging experiences, faced by all family members, are commonly misunderstood to be a consequence of the tragedy of living with dementia. The dominant socialisation within the biomedical model, focusing on a specific diagnosis, I feel could be replaced with the social model, as demonstrated throughout this research. The predominant message from this study, is people living with YOD and their family members all experience socially constructed disablement in varying degrees, based on social oppression, barriers and exclusion to participate equally and wholly in society (Hutchinson, Roberts, Daly, et al., 2016; Hutchinson, Roberts, Kurrle, et al., 2016). Societal categorising and labelling according to diagnosis reinforces stereotypical and discriminatory practices, which tends to position individuals living with YOD and associated family members, in a lower social status (Hutchinson et al., 2018). Socially constructed disablement is a direct consequence of these practices and is confirmed through discernable inequality in support and services options for different diagnosis groups. They often have limited opportunities to engage in meaningful, age-appropriate activities, which promote value and worthiness in society. Unfortunately children and young people in this research were exposed to these discriminatory practices, noticing others at school being offered more support if their parent had cancer for example. This research challenges dominant views and narratives of dementia, reframing dementia as a social disability rather than a medical disability. The social model is considered a valuable theoretical lens to argue the negative societal responses and attitudes to people living with YOD and their families, essentially disabling their rights to full citizenship (Mental Health Foundation, 2015; Thomas & Milligan, 2018). Adopting a social viewpoint reinforces the need for a cultural change in the approach to those impacted by dementia, to cultivate enablement and engagement of these families' rights to full inclusion in the community.

However, the utility of the social model of disability within dementia research and practices, is an area that requires much more development to challenge the medically dominant discourse (Boyle, 2014; Gilliard, Means, Beattie, & Daker-White, 2005; Thomas & Milligan, 2015). The fit of dementia with the social model of disability, to influence policy and practice, is an ongoing debate, which has been attracting more attention recently in the research literature (Mental Health Foundation, 2015; Thomas & Milligan, 2018). Although dementia and disability are still often referred to separately the Dementia Alliance International (DAI), a group of people living with dementia, have been advocating for similar rights to people living with other disabilities (Shakespeare, Zeilig, & Mittler, 2017). These conversations have promoted greater discussions on a social model approach to dementia, but the challenge remains with people living with dementia and those associated with them, in accepting the disabled identity (Shakespeare et al., 2017; Thomas & Milligan, 2018).

This brings attention to the issues of disabling of identity and the disabled identity, which can be explained using the social model and social identity theory, as highlighted in Chapter 2 of this doctoral thesis (Hutchinson et al., 2018). The disabling of identity is also socially constructed and can be imposed on the person with a diagnosis and, probably more surprising, on family members too. This disablement can adversely influence relationships, interactions, and lifestyles of all family members, to equitable participation in society as other people of similar ages. However, adopting the disabled identity could potentially improve social position, and also be a positive step towards advocating for human rights to equal treatment and care, which has been noticeably absent concerning dementia (Hutchinson et al., 2018; Thomas & Milligan, 2018).

Age is another socially-imposed disabling barrier highlighted in the social model and dementia debate, compounded by the dominant stereotypical view of dementia impacting the older population. We do need to bring families living with YOD more into the public domain to ensure they are no longer disadvantaged by disabling discrimination and prejudices that do not account for their developmental age and phase in the lifecycle. Persistent, inaccurate assumptions about the age of those affected by dementia could further substantiate the absence and preclude the development of family-focused services. This could ultimately intensify these families overall disablement in meaningful participation in their social world. The social model of disability advocates for the equal rights and just inclusion of everyone. It offers a way forward through helping to understand lived experiences of all family members to instigate the development of socially orientated policies and practices, that truly reflects needs (Gilliard et al., 2005; Oliver, 2009).

7.3.2 *Limited employment opportunities*

Many, in this study, discussed concerns over employment and obtaining crucial financial support. Particularly challenging is the lack of opportunities available to continue paid employment for people with cognitive impairments, which directly impacts the individual and family's social status as they are no longer contributing to society, through employment. Consequentially, navigating the complex processes in attaining financial support, at a time when financial commitments are high, is compounded by cognitive impairment. Being confronted by a society that queries and challenges difference in unconstructive ways can undermine confidence and questions worthiness. These unhelpful attitudes by non-disabled people can create barriers to obtaining the crucial financial support entitled to, impacting the lives of the person with YOD and their family.

This study demonstrated discrimination between different kinds of impairments in relation to retaining employment, with employers and society placing a higher value on cognitive over physical function (Hutchinson et al., 2018). Employers were described as more accommodating in ensuring the working environment met the needs of the person with physical impairments, but gave much less consideration to the person with cognitive impairments (Mithen, Aitken, Zeirsch, & Kavanagh, 2015). The latter group, in this research, report difficulties prior to diagnosis and are more likely to have their employment terminated at the time of diagnosis, offering no choice or control over the situation. So the repercussions of these observable prejudices can result in the additional sense of loss of value and self-worth. The ramifications on the family can be profound with associated financial hardship and injustices that adds to uncertainties and complexity of family life. Reframing the way people with and without dementia approach and understand employment issues is something that needs to be explored in more depth as it requires a 'multifactorial approach' (Ohman, 2001, p. 42). The social model of disability could provide a useful framework to educate and train potential employers to ensure no one is discriminated by a diagnosis or impairments. This would advocate for equal opportunities to participate in paid employment for as long as possible. Collaboration between employers, people living with YOD, service providers and the dementia sector is crucial in this process, in realising the rights of people with dementia to be supported in continued employment.

7.3.3 Lack of policy and practice development

There has been little exploration in the research of the family members living with YOD informing policy and practice, to mitigate the impact of the changed family circumstances. Most service developments to date continue to be fragmented, rely on project-specific funding, are time-limited, and lack sustainability and continuity for supporting all family members over the progress of dementia (Mayrhofer, Mathie, McKeown, Bunn, & Goodman, 2017). The absence of foresight and understanding in policies globally, disadvantages whole families including children and young people living with YOD, in receiving age-appropriate support over the trajectory of YOD. This is another drawback of policies and practices, which are based on the biomedical model, focusing on a diagnosis that predominantly impacts older people. The alternative of adopting a more inclusive social model approach would be more favourable. The ongoing lack of acknowledgement of the connected and interdependent lives of individuals with YOD, their families including children and young people and the wider society is alarming, but can be informed by the social model, as demonstrated in this research. The current policies and practices are predominantly developed around the label of dementia with associated personal tragedy, stereotyping and oppression, and little consideration of the social factors influencing lives, such as being exposed to ongoing social barriers and discrimination. The significant lack of uptake in current services by families is not surprising, faced with so little understanding, choice and control (Carter, Oyebode, & Koopmans, 2017; Cations et al., 2017). Dissatisfaction with service options, highlighted in this research, could also contribute to overall isolation and exclusion from other services, affecting physical and emotional well-being of all family members.

It is important to understand the potential ‘snowball effect of service use in which engagement with each service improved social support and access to the next service’ (Cations et al., 2017, p. 10). So for future changes in policy and practice, there needs to be a move away from the biomedical model, with current emphasis on the person living with YOD’s potential loss of capacity to make informed decisions; which in turn reinforces being passive recipients of services, and lack of recognition of other family members (Mental Health Foundation, 2015; Roach et al., 2014). To adopt a social model approach to policy and practice development, encourages supported decision making and opportunities to actively engage in the co-production of individualised and family orientated services with health and social care providers (Batalden et al., 2016). This research substantiates other research findings that service providers need mutual understanding of whole family situation, effective communication and the ability to work collaboratively with service users and stakeholders, to develop socially focused policies and practices (Batalden et al., 2016; Sansoni et al., 2016; Smyth, Blaxland, & Cass, 2011).

7.3.4 Socially imposed associations

This study took an innovative approach to not only explore the utility of the social model to explain the challenges faced by people living with YOD, but also their family members existing alongside them, over the trajectory of dementia. The person living with YOD is not the only one to experience socially imposed associations impacting their identity living with dementia. Other family members report being treated differently (similar to families living with mental health illness), noting social biases towards them and their family (Hutchinson, Roberts, Daly, et al., 2016; Tew et al., 2012). This often resulted in lack of disclosure of dementia within the family, not informing others outside the family and no longer inviting people over to the family home. Spouse/carers often found the change of identity from being the wife or husband to predominantly being the carer was socially imposed, which for some was particularly hard to adjust to. Families witnessed their sense of difference within society, through others responses and attitudes to the person with YOD and their family. As previously mentioned, in the case of the younger family members, they do not want to feel different or stand out in the crowd but can feel disconnected to their social environment. Although young carers do not always recognise themselves as such (Smyth, Blaxland, et al., 2011), there seems, within the realm of dementia, even less association between young carers and dementia. Young people reported feeling an ‘outcast’ with no sense of belonging, even within dementia specific services. This lack of belonging was reinforced in dementia specific conferences that I attended in Australia, with a consistent dearth of families with children and young people attending, and their powerful voices sadly absent in many discussions. Maybe facing the confronting and frustratingly inaccurate imposed association that they have a grandparent with dementia, not a parent, deters them from attending these types of events. They believed that communicating their parent had dementia, confirmed to them, the sense of discomfort others had towards their situation. A sense of hopelessness was frequently conveyed to them, associated with negative attitudes towards dementia, which impacted their future conversations and outlook on life.

Consequentially, it is crucial to bring about change that gives hope and confidence for the future ahead. The ability to function in a good way and live well with the diagnosis of dementia in the family should be a social responsibility. No family member should be impacted by others imposing associations and prejudices on them. Taking a social approach provides the impetus for change to create an inclusive and accepting society where difference is acknowledged as a normal part of society. Support should be based on who is in need and the nature of need, not the funding source, diagnosis or geography.

7.4 Two ways to inform social change and policy and practice

In this research I have highlighted many of the issues and concerns experienced by family members, reinforcing reasons for bringing about a social change. As most people know, social change is not something that can happen quickly or easily. So it is vital that we explore opportunities that could instigate the social change long awaited by these families. The insights gained from this research drew my attention to two specific opportunities that could provide the important impetus for change. These opportunities will be presented in this section.

7.4.1 Healthcare and social care education and learning opportunities

Health and social care providers can be influential in advocating for change in the way services are designed and delivered. Facilitating the change to be more socially informed, hence challenging negative attitudes and prejudices, is necessary to living well with dementia. This approach would require service providers to alter their outlook, develop new skills and attain greater knowledge and understanding (Batalden et al., 2016). In this study, negative responses to YOD were believed by the family members to foster the tragedy and resounding hopelessness of the situation, which undoubtedly needs to be readdressed. We must develop ways to readjust relationships and communication between service providers and service users to develop mutual understanding and respect. Predominantly, clinical practice and service provision is still based on a diagnosis, due to the dominance of the biomedical model. This approach assumes the diagnosis is the primary cause for altered family circumstances. However, significant societal influences can impact relationships and interactions and act as barriers to social change. This is commonly taken for granted with the persistent emphasis on the diagnosis. In the process of reframing approaches and attitudes towards dementia, more opportunities for engaging with all family members should be undertaken routinely, to improve understanding of the barriers and enablers that influence their lived experiences.

One young person in this research valued the opportunity to talk to medical students at an Australian university about her experiences living with a parent with YOD. Although challenging and confronting to both herself and those listening, she felt this helped to raise vital awareness among the medical practitioners of the future. Routinely, adopting this learning approach could be considered a welcome step towards social change and a positive addition to the student learning curriculum across all healthcare professions. Overall, it could help in the process of changing current dominant responses and approaches to dementia at an early stage in professional development and support of integrated healthcare professional practices. Integrated learning practices are being adopted more frequently in higher degree courses, to improve management of health conditions, which is something that could be employed in relation to dementia practice.

Being informed by the social model, could result in health and social care providers becoming more socially orientated; more empathetic to the real-life circumstances and challenges faced by all family members. Young carers, in particular, want more ‘recognition respect and understanding' and to be better informed about their rights (Smyth, Cass, et al., 2011, p. 513). Adopting this social approach would help develop greater awareness of the consequences of health and social care providers' actions towards the family, and encourage them to take ownership of the resulting outcomes.

Redirecting the overall emphasis away from individual experiences living with dementia to the whole family experience, has social significance in changing the approach to services and clinical practice. Leadership is necessary for this process, which I feel ought to come from the dementia peak body in each country. Regardless, whoever adopts this leadership role would provide opportunities for mutual learning between service users and service providers and incorporate these collaborative activities in the co-creation of interprofessional learning and education programmes (Batalden et al., 2016). It is crucial that learning and education opportunities accurately represent the diversity of families’ lived experiences. Using the technological advances available in the current society, brings with it many opportunities for improving collaborative training and developing learning platforms, that overcome geographical barriers. One option that would be worth exploring is blended online and face to face education programmes using case-based learning, clinical simulations, practice and feedback sessions, which are identified as effective educational techniques (Gyorki et al., 2013). A well designed, continuing education programme that is based on sound educational principles can result in quality learning experiences and positive outcomes. Case studies or vignettes would be created to be reflective of the whole family and family members’ age-related issues and concerns living with YOD, to aid knowledge translation. Developing a flexible online course for service providers, based on social model principles, would be beneficial to encourage more choice and control over active participation and engagement in learning. Adopting a socially orientated education approach would help to inform health and social care providers on best practices to manage complex family situations. For some, it would entail changing their current practice to be more inclusive and supportive of all family members irrespective of age, taking a more person and family-focused approach to service design and delivery.

An education program that accounts for service providers’ time restraints could reduce barriers to commencing and completing learning opportunities. Online healthcare, professional educational platforms have been used successfully in the cancer sector and chronic disease management for some time. This format facilitates equal access to education opportunities irrespective of location within Australia. One of these platforms used successfully in clinical practice is Q stream, developed at Harvard Medical School (http://**qstream**.org). This platform is based on the online method of learning called spaced education, resulting from a ‘ psychological finding that educational encounters which are spaced and repeated over time result in more efficient learning and improve learning retention’ (Robinson et al., 2017, p. 477). Developing and implementing a socially orientated interprofessional education programme to better inform and support collaboration, could be fundamental to improving job satisfaction of health and social care providers in their clinical practice (Edwards, Voss, & Iliffe, 2014). To be able to offer more significant opportunities for interprofessional and organisational learning and collaboration, should enhance health and social care providers relationships with families and create more targeted support options for families living with YOD.

7.4.2 Co-creation of a family-focused service model that supports families living with YOD

As highlighted in this study, the full partnership and inclusion of individuals and families living with YOD in all facets of service and support design and delivery are beneficial, but currently is not routine practice in the area of YOD (Gittell, Godfrey, & Thistlethwaite, 2013). The importance of individuals and families living with YOD, learning and working together with service providers, stakeholders, and policy developers, is critical for the necessary change in policy and practice (Batalden et al., 2016). These practices are credible, transferable across sectors and adopted currently, in some capacity, within sectors where the impact of parental illness on families is known to be profound, for example cancer and disability. For families facing challenging situations, being encouraged to have some ownership in guiding a more socially orientated policy and practice, is empowering and instills feelings of value and self-worth. The alternative, being a passive recipient of services, is based on the biomedical model, resulting in a lack of choice and control (Mental Health Foundation, 2015).

Throughout this study, the lack of a theoretical framework as a foundation for the development of family-focused services is considered a contextual barrier to change. There is a predominance of poorly formulated, uncoordinated services, which are known to be ineffective in appropriately managing complex family needs that require addressing (Johannessen et al., 2017; Sansoni et al., 2016). The absence of cross-sectoral, collaborative and tailored approaches to support and services, contributes to the underuse of services, which is currently a massive area of concern (Cations et al., 2017). This under usage can be wrongly perceived as there not being a need for services for people living with YOD, and increasing dependency on informal care. These families face countless social factors that add to the complexity of their situation, many of which have been highlighted throughout this research. The complex issues they experience cannot be managed through silos and necessitate a collaborative, coordinated, cross-sectoral approach. Hence to tackle this problem and aid formulation of innovative solutions, a co-created family-focused service model underpinned by a theoretical framework was developed. Bringing the social model of disability and the family systems-illness model together formulated a conceptual framework that considered the life cycle stage and diversity of families within their social situation (Oliver, 2009; Rolland, 1999a,b). Using this innovative theoretical framework helped guide interpretation of experiences and the process of individual and family change that follows a parental diagnosis of YOD (Bate & Robert, 2006). Drawing on shared knowledge (Freire & Sangiorgi, 2010; Greenhalgh, Jackson, Shaw, & Janamian, 2016) creating strong partnerships with service users, service providers, stakeholders, community and policy developers is crucial and can be influential in societal and service change. The service users unique experiences, highlighted in this study, should not only be central to designing services but also their development and ongoing evaluation and improvement (Freire & Sangiorgi, 2010). Service users should be routinely encouraged to take an active role in designing service models, to ensure they address and are tailored towards their unique needs. The overall principles of co-creation demonstrated in this study, are about enriching human experience, finding innovative ways together to respond to unpredictability and challenges of life, and developing strong relationships for greater understanding, which agrees with the principles of the social model.

The co-created family-focused service model acts as a platform for reframing the way services are designed and delivered to be more socially orientated, which ought to be adopted in policy and practice. Figure 6.2 Social approaches to families, outlines a way forward to promote enablement of the whole family living with YOD. This model can be transferable across other sectors and fosters health and social care providers' early engagement with all family members. To further build on relationships, interactions need to be dynamic, fluid and non-prescriptive, with the understanding that family life is non-linear. A health care or social care provider should initiate the process of coordinated, early engagement with the family in a key worker or family liaison officer role. This significant contact person for the family should be funded and supported to work collaboratively across sectors, coordinate services and support, and act as a resource while fostering positive relationships with the entire family. In this role, the person should remain connected to the whole family over the progression of YOD, which may span several developmental stages and changes though the life cycle. Adopting this socially focused model will help anticipate real-life circumstances and experiences through the progression of YOD. There would be greater understanding of the interface of YOD with the individual family members, family developmental and life cycle stages, and identification of opportunities for interactions and engagement with health and social care providers.

The family liaison role would facilitate the adoption of an interagency approach which contributes to breaking down social barriers and promotes more opportunities for communication and learning between agencies. Creating more occasions for cooperation and collaboration would help develop a greater mutual understanding of the age-related challenges faced by these families. Using this innovative model can also help uncover assumptions and attitudes among service users and service providers that need readdressing, to allow change to occur and transformation of current practice. The person in this role would be required to have knowledge and understanding of families with children functioning under complex circumstances. Also, having routine access to databases or information about people diagnosed with YOD and centrally located clinical notes could help facilitate early connection of families living with YOD to service providers. Adopting this approach enables collaborative clinical practice, streamlines administrative processes and allows for seamless transfer across sectors and agencies for support and services (Robinson et al., 2009). Through establishing positive interactions and developing relationships with the person in the role of the key worker or family liaison officer, health and social care providers could open more positive communication channels with family members, supporting informed decision-making and promote help-seeking behaviours. See Figure 9, page 203 in the appendices, for a diagrammatical outline of the model.

7.5 Ethical considerations and qualitative rigor

Although most considerations and concerns have been outlined in each paper included in the thesis, I felt it was important to reflect on this, particularly related to the inclusion of people with cognitive impairments and children under 16 years old in the research.

7.5.1 Ethical responsibilities

This qualitative study was novel and ethically complex from a research perspective considering the social context, which included the participation of both younger family members and those living with dementia. The ethical considerations traditionally observed in qualitative research, is informed consent, the right to privacy and protection from harm (Denzin & Lincoln, 2005). Researching with these two diverse groups did add ethical complexities, both groups being considered vulnerable populations, requiring particular strategies to protect them from harm and provide reassurance to parents or guardians that participants would not be disadvantaged.

The study was given ethics approval from the University of Sydney; however, the inclusion of children under 16 years and their parents with cognitive impairment required additional responsibilities of the researchers to ensure participants overall wellbeing, rights, safety, and dignity were retained throughout. Additional signatures were obtained from parents or guardians for informed consent purposes. Written information about the research was provided to each participant and guardian/parent, for more vulnerable groups. Also probing questions were also sent prior to the interview to each participant and guardian/parent to be more explicit about the areas of discussion in the interview, so that they were better prepared and more informed in their decisions to participate. Before each interview, I verbally explained the process, in age and cognitively appropriate manner, to clarify understanding and give an opportunity for questions and reinforce the voluntary nature of the research. My responsibility as researcher to protect confidentiality was emphasised verbally, throughout the study. Also, it was vital for me to clarify before the interview, that although I am a health professional, it is not in this capacity that I am engaging with participants; therefore no therapeutic interventions would be part of the process. This was crucial as many families were very vulnerable and often keen for any support they could obtain. I also reinforced that the interviews were non-judgmental, as many exhibited feelings of guilt and were apologetic over particular aspects of their stories. I reiterated at all times the focus on developing a mutual understanding, gained from their rich descriptions of what life is like for them.

There were further ethical responsibilities put in place due to the sensitive nature of the subject being discussed, which could potentially trigger emotional distress. This was addressed openly before the interview in my capacity as a health professional and researcher, pointing out my duty of care and responsibility to refer the participant to an appropriate clinician or services if judged necessary. This decision was based on clinical judgment working with people with acquired neurological impairments for many years. A follow-up email or phone call was conducted after each interview to safeguard participants against any ongoing emotional adverse effects post interview. The action to refer participants for support was not required with any of the participants in the research. A resource list of potentially relevant support organisations and websites were provided post interview. This information was received favourably as many people were unaware of where to source information, support, and advice. Having access to this information allowed them some freedom of choice on approaching or making contact with services. This information has been updated throughout the study and included in the appendices on page 204. Routine consultation and debriefing with PhD supervisors ensured ethical responsibilities were upheld to participants. In addition, these sessions offered me, as the interviewer, the opportunity to discuss some emotionally challenging interviews.

7.5.2 Qualitative Rigor

Several strategies were used to ensure rigor while conducting qualitative research as introduced by Guba and Lincoln (1985). The quality of research was upheld through the transparency of the research process and its underpinning theory using the social model of disability (Bunniss & Kelly, 2010). To accurately portray the perspectives of the participants was extremely important to ensure the credibility of the research. However, there was no opportunity in the research to get validation from all participants of the data analysis apart from via one focus group with some of the young people previously interviewed. A one day collaborative workshop '*Supporting young people having a parent with Younger Onset Dementia (YOD)'* **(**supported by the NHMRC Cognitive Decline Partnership Centre) was organised during the study. Stakeholders, a government official, researchers, health professionals, people living with YOD, their children and other family members attended, coming together to share experiences. This event did help to confirm credibility of the themes with young people and children in families, but did not contribute to the research as it was not part of the ethics approval (see appendices for summary workshop report on page 194).

All ethical considerations were attended to as specified in ethics approval provided by the University of Sydney. Explicitly stating the relationship between participants and researchers during the research process ensured the quality of the research was maintained. The qualitative methodological rigor was safeguarded by disclosing the method of interpretation throughout the design, conducting semi-structured interviews, analysis, and interpretation (Attride-Strling, 2001). Dependability was achieved through the development of a coding structure with all investigators and achieving consensus between coders (Morse, 2015). Discussions between investigators assisted in developing theory behind the research.

7.5.3 Addressing bias:

In this PhD thesis, I conducted the interviews and one focus group. I had interviews transcribed by a professional service and analysed all the data, with my supervisors and authors in separate papers. In the research literature, the consensus around qualitative research is the researcher is critical to the whole process and can influence the data quality collected and the analysis (Denzin & Lincoln, 2008). I was aware that my interactions with the participants could influence responses so tried to make sure they felt comfortable, relaxed and valued, at all times.

To minimise any additional bias, I was reflective of my situation as both researcher and health professional and tried to focus on my researcher role. I valued my pre-understanding of neurological disability to help connect with participants. Total immersion in the data to develop a greater understanding of all the participants' world from their perspectives, whilst remaining empathic and non-judgmental throughout, was enlightening. The emotionally charged subject and listening to some hard hitting stories, in these interviews, was challenging at times. The stories collected from the children and young people were, on the whole, thought provoking and confronting. However, I believe these evoked feelings contributed to my greater empathy and improved sensitivity of interactions with participants, producing greater openness and honesty in the stories related. The participants' sincerity and humility provided me with the impetus and passion to accurately relate participants' experiences with significant meaning, throughout the thesis.

7.6 **Concluding section**

This final section of Chapter 7 concludes this thesis and reviews some strengths and limitations, recommendations for future research and a final summarising conclusion.

7.6.1 Strengths and limitations of the study

The strengths of the study begin with the innovative addition to theory improving understanding experiences living with YOD from an individual and family perspective. Dementia is commonly considered under a biomedical model, so this research provided an opportunity to transform thinking of dementia from a social perspective. The thesis provided a theoretically informed interpretation of experiences and offered insights into the challenges all these family members faced. The whole thesis looked into the utility of the social model of disability not only to explain experiences of people living with cognitive impairments, which is novel in its own right, but also recognised the application of the social model with family members experiences associated with the person living with dementia. Although, there is much work to be done to develop a social model of dementia, this research is making a valuable contribution to the process for a more social approach to dementia within society. The utility of the social model to inform potential service models is valuable in the process of change to ensure policies and practices become more socially constructed.

Being able to include people living with YOD and children under 16 years ensured their important insights and experiences were included in the research. Although there were only four in the under 16 years age group, the value of having their voices heard and echoed in writing up the research, is a real strength. In this age group there was equal representation of male and female. However, in the over 16 age group, only one male participated, which I feel is a limitation due to gender under representation. It is well recognised in other research that young men do not tend to volunteer to tell their stories about emotional circumstances (Haskett, Marziano, & Dover, 1996). The original intention was to include young people up to the age of 24 years, but several were interviewed above this age, but reflected back to younger years. This I believe was a strength as, from their current state of wisdom, they were able to recall stories from their near past and give measured insights into how they adjusted to complex family life at the time.

As whole families did not fully participate in the research, this may be seen as a limitation as YOD does impact the biography of the whole family (Roach et al., 2014). Exploring the transitions within the same family from individual and whole family perspectives as they happen, would have been useful to include. However, there were some participants from the same family, so some comparisons were made at times of transition. Also, people from different cultural or ethnic backgrounds did not come forward for this research, which I feel is a limitation. Although it was not the intention of this thesis to focus on the early and mid-stage of dementia, it is important to acknowledge limitations in the lack of inclusion of family experiences at end stage of dementia and beyond.

Only seven health and social care providers participated, which could be regarded as a limitation. However, those that did participate provided extremely valuable insights. They worked in several states in Australia, which highlighted differences in interpretations of policies and practices in the same role, across states. The uncovering of this information was seen as a strength in providing greater understanding in some translational differences related to guidelines and practices, which could further impact their role.

7.6.2 Recommendations for future research

The co-design, development, and evaluation of an online cross-sectorial education platform for service providers

Service users and service providers coming together, to create a socially conscious education programme. Using social model principles to upskill service providers in their role supporting whole families' needs is recommended for future research. A collaborative cross-sectoral approach would be needed in the process of identifying the problems; developing learning outcomes; designing ways to achieve results; construction of learning material and delivery; implementation of the online educational programme and finally evaluation of outcomes. To develop evidence-based educational opportunities for improving the understanding and knowledge of those working with families affected by YOD is considered valuable in the process of bringing social change to service design and practice. Ultimately, this could help challenge assumptions and attitudes to families living with YOD, to transform practice and improve service outcomes. Healthcare and social care providers becoming more socially informed through having more established opportunities for collaboration, could improve management of complex situations and change their current practice to be more enabling and socially inclusive. Raising social awareness that their role does include supporting families to be more engaged and live well in their social world, could also potentially improve satisfaction and well-being in their professional role.

Further development and integration of co-created family-focused service model into service design and delivery

As this is an innovative theoretically informed service model, implementation into current service models needs to be explored, to evaluate its effectiveness in changing current practice and supporting the needs of families living with YOD. This model could stimulate more exceptional creativity in designing services, problem-solving and developing solutions that could improve outcomes for the whole family and provide an opportunity for the model's transferability across sectors to be explored. Evaluating the effects of implementing this model on the psychological well-being and functioning of family members would be essential as there is a strong relationship between this and support provision. Establishing this family-focused model as the routine, not the exception, reinforces the family’s social rights to be included and supported by society. Feeling a sense of belonging in the family's social world could promote help-seeking, be empowering and offer some hope for the future, therefore, minimising crisis management and promoting crisis prevention. Included in the evaluation of this model, would be the impact on health care and service provider roles and whether this translates to an improvement in job satisfaction

Explorations of the social influences on dual parenting and caregiving roles and responsibilities

The dual parenting and caring role is an underexplored area in the research literature as most of the research focuses on their caregiving role in the dementia literature. Some aspects of this dual role were acknowledged in this study, in the context of family experiences. To gain greater insight and understanding requires further exploration of their lived experiences in this challenging dual role. Having these parents' needs unmet and the subsequent impact on family functioning would be essential to explore. New research would be beneficial to help direct socially focused future interventions and support that addresses unmet needs so that they can sustain this challenging role without anyone and the family being disadvantaged.

Exploration of the link between psychological well-being, developmental age and unmet needs of children and young people in families living with YOD

The need to further explore this area of concern was brought to my attention in the research. It is consistent in other areas of research that there is a strong relationship with the failure to meet needs with higher levels of emotional distress in young people with a parent living with other diagnoses (Kuhne et al., 2012; McDonald et al., 2016). Exploring this issue further could be the impetus to develop a successful working alliance with health care and service providers to improve the current practice, to be inclusive of the whole family. This research could potentially assist in the development of strategies or tools to socially acknowledge and better support children and young people at higher risk of developing more severe psychological issues. Also, exploring other sectors models of services and support for families with children and young people affected by parental illness should be considered, as this may be relevant and provide potential for knowledge translation to develop support opportunities for families living with YOD.

7.6.3 Conclusion

This PhD thesis has expanded the contribution of the social model, to not only improve understanding and explain the social influences on the lives of the person living with YOD, but also their family members. The social model has been demonstrated as a valuable theoretical framework to underpin the reframing of policies and practices, which is critical to changing approaches and attitudes to YOD and family life. Looking through the social model lens in relation to dementia, allows us to see things differently to redirect attention away from a diagnosis, personal tragedy, and disablement; and instead to focus on choice, control and enablement of the whole family. Applying the social model principles to dementia invites service users and service providers to consider new ways of interacting, building relationships, and developing services and support collaboratively. However, implementing new paradigms brings many challenges and issues to surmount, but these should not restrict the utility of the social model of disability to help reconstruct the world of people living with dementia and their families. Fundamentally, working towards the success of positive multifaceted interactions, co-creating and co-producing services, and fostering favourable attitudes to dementia, can bring about the positive cultural change required to allow these families to feel like valuable citizens and live equally in society. Particularly noteworthy is the innovative ways in which the social model can combine with other models and theories, social identity theory and family systems-illness model, to construct theoretical frameworks to further explore, explain and develop socially constructed practices in dementia. Hence, I believe the social model of disability can make an essential contribution to the theory required for socially informed change to enrich the lives of everyone impacted by dementia.

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THE UNIVERSITY OF SYDNEY

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27 June 2012

A/Professor Christopher Roberts
Academic General Practice Unit
Hornsby Ku-ring Gai Hospital
The University of Sydney
Email: Christopher.roberts@sydney.edu.au

Dear A/Professor Roberts

Thank you for your correspondence dated 22 June 2012 addressing comments made to you by the Human Research Ethics Committee (HREC).

On 27 June 2012 the Chair of the HREC considered this information and approved your protocol entitled **"The impact of younger onset dementia on the person and their family".**

Details of the approval are as follows:

Protocol No.: **14926**

Approval Date: **27 June 2012**

First Annual Report Due: **30 June 2013**

Documents Approved:

Document	Version Number	Date
Advertising Flyer	2	13/6/2012
Advertising Flyer	2	5/6/2012
Parental (or Guardian) Consent Form (Form PCF 1)	2	5/6/2012
Participant Consent Form (Form PCF 2)	2	5/6/2012
Guardian Consent Form (form PCF 3)	2	13/6/2012
Participant Information Statement (Form PIS 1)	2	6/6/2012
Guardian Information Statement (Form PIS 3)	2	6/5/2012
Carer Participant Information Statement (form PIS 5)	2	6/6/2012
Letter of Invitation	1	24/4/12
Demographic Information Questionnaire	1	Submitted 28/5/2012
Interview Questions for Young People	1	Submitted 28/5/2012

HREC approval is valid for four (4) years from the approval date stated in this letter and is granted pending the following conditions being met:

Special Conditions of Approval

1. Please provide letters of support/permission from all participating organisations prior to the research commencing.
2. Please notify the HREC of the location of the focus groups when known.

Condition/s of Approval

- Continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans.

- Provision of an annual report on this research to the Human Research Ethics Committee from the approval date and at the completion of the study. Failure to submit reports will result in withdrawal of ethics approval for the project.

- All serious and unexpected adverse events should be reported to the HREC within 72 hours.

- All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.

- Any changes to the protocol including changes to research personnel must be approved by the HREC by submitting a Modification Form before the research project can proceed.

Chief Investigator / Supervisor's responsibilities:

1. You must retain copies of all signed Consent Forms (if applicable) and provide these to the HREC on request.

2. It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely

Associate Professor Ian Maxwell
Chair
Human Research Ethics Committee

cc. Karen Hutchinson karen.hutchinson@sydney.edu.au

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.

THE UNIVERSITY OF
SYDNEY

Research Integrity
Human Research Ethics Committee

Thursday, 3 December 2015

Assoc Prof Christopher Roberts
Northern Clinical School: General Practice; Sydney Medical School
Email: christopher.roberts@sydney.edu.au

Dear Christopher

Your request to modify the above project submitted on 5 November 2015 was considered by the Executive of the Human Research Ethics Committee at its meeting on 24 November 2015.

The Committee had no ethical objections to the modification/s and has approved the project to proceed.

Details of the approval are as follows:

Project No.: **2012/1895**

Project Title: **The impact of younger onset dementia on the person and their family**

Approved Documents:

Date	Type	Document
05/11/2015	Interview Questions	health care professional interviews
05/11/2015	Recruitment Letter/Email	email/ letter
05/11/2015	Participant Consent Form	Health care participant consent form
05/11/2015	Participant Info Statement	health care professional information statement
05/11/2015	Advertisements/Flyer	Advertising for health care professionals

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely

Helen Mitchell

Dr Helen Mitchell
Chair
Human Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.

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6 June 2011

Associate Professor Chris Roberts
Associate Dean (Educational Development)
Sydney Medical School – Northern
Hornsby Ku-ring-gai Hospital
The University of Sydney
Email: Christopher.roberts@sydney.edu.au

Dear A/Prof Roberts

Thank you for your correspondence dated 23 and 30 May 2011 addressing comments made to you by the Human Research Ethics Committee (HREC). On 6 June 2011 the Executive of the HREC considered this information and approved the protocol entitled **"Delving into living with a chronic and complex neurological disability: personal stories".**

Details of the approval are as follows:

Protocol No.:	**06-2011 / 13824**
Approval Period:	**June 2011 to June 2012**
Authorised Personnel:	**Associate Professor Christopher Roberts** **Mrs Karen Hutchinson**
Documents Approved:	**Letter of Invitation (version 1, 02/05/2011)** **Participant Information Statement (version 3, 30/05/2011)** **Participant Consent Form (version 2, 23/05/2011)** **Semi-structured Interview Questions**

The HREC is a fully constituted Ethics Committee in accordance with the National Statement on Ethical Conduct in Research Involving Humans-March 2007 under Section 5.1.29.

The approval of this project is conditional upon your continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans. A report on this research must be submitted every 12 months from the date of the approval or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of consent for the project to proceed. Your report is due by **30 June 2012**.

Chief Investigator / Supervisor's responsibilities to ensure that:

1. All serious and unexpected adverse events should be reported to the HREC within 72 hours for clinical trials/interventional research.

2. All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.

3. Any changes to the protocol must be approved by the HREC before the research project can proceed.

4. All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The following statement must appear on the bottom of the Participant Information Statement: *Any person with concerns or complaints about the conduct of a research study can contact the Manager, Human Ethics, University of Sydney on +61 2 8627 8176 (Telephone); + 61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).*

5. You must retain copies of all signed Consent Forms and provide these to the HREC on request.

6. It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

7. The HREC approval is valid for four (4) years from the Approval Period stated in this letter. Investigators are requested to submit a progress report annually.

8. A report and a copy of any published material should be provided at the completion of the Project.

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely

Dr Stephen Assinder
Chair
Human Research Ethics Committee

cc: Karen Hutchinson
karen.hutchison@sydney.edu.au

Table 8: Overview of five published papers in the PhD thesis

Publication	Aims	Theoretical framework	Data collection	Demographic of participants	Data analysis
Chapter 2 *Identity, impairment and disablement: Exploring the social process impacting identity change in adults with neurological impairments*	To identify what social processes impact identity formation of adults living with acquired neurological impairments	Social model of disability and social identity theory	14 Semi structured interviews aged between 25-65 years	9 people with physical neurological impairments only (ONLY included in chapter 2) 4 people living with cognitive impairments 1 physical and cognitive impairments (all 5 included in chapters 2,3 and 6)	Framework analysis to generate themes from qualitative data. Coding of transcriptions on socio-cultural underpinnings of experiences that impact identity change.
Chapter 3 *Feeling invisible and ignored: Families' experiences of marginalisation living with younger onset dementia*	To explore the societal factors which impact the experiences of families living with YOD, including children and young people.	Social model of disability	26 semi structured interviews aged between 9 - 65 years	5 people living with YOD (chapters 2,3 & 6) 6 spouse/carers of person living with YOD (chapters 3 & 6) 15 children and young people having parent with YOD (12 included chapters 3-6, 3 included chapters 3 & 6)	Framework analysis to generate themes from qualitative data. Coding of transcriptions on socio-cultural underpinnings of experiences, interactions and interventions that shaped family experiences of marginalisation and contributed to invisibility.
Chapter 4 *The emotional well- being of young people having a parent with younger onset dementia*	To explore the social influences on the emotional well-being of those.	Social model of disability	12 semi structured interviews aged between 10- 33 years	12 children and young people having a parent with YOD (included in chapters 3-6)	Framework analysis to generate themes from qualitative data. Coding of transcriptions on socio-cultural underpinnings of experiences, interactions and interventions that influenced young peoples' emotional well-being.
Chapter 5 *Empowerment of young people who have a parent living with dementia: social model perspective*	To highlight the social factors that enable children and young people to feel supported and socially included.	Social model of disability	12 semi structured interviews aged between 10 – 33 years. Focus group of 4	12 children and young people having a parent with YOD (included in chapters 3-6)	Framework analysis to generate themes from qualitative data. Coding of transcriptions on socio-cultural underpinnings of experiences, interactions and interventions that influenced young peoples' ability to rise above social marginalisation.
Chapter 6 *Co–creation of a family focused model living with younger onset dementia*	To determine the critical factors that need to be addressed in co-creating family-focused services living with YOD.	Social model of disability and family systems –illness model	28 semi structured interviews aged between 9 - 65 years	5 people living with YOD (chapters 2,3 & 6) 6 spouse/carers (chapters 3 & 6) 17 children and young people (12 included chapters 3-6, 3 included chapters 3 & 6) 7 health and social care providers (ONLY paper included)	Framework analysis to generate themes from qualitative data. Coding of transcriptions on socio-cultural underpinnings of families, health and social care providers experiences, interactions and relationships that shaped family function, service and support provision

Hutchinson, K., Roberts, C., Kurrle, S. (2014) Invisible Carers. Australian Journal of Dementia Care, 3(1), 19-21

Invisible carers

Karen Hutchinson, **Chris Roberts** and **Susan Kurrle** discuss a research project recording the difficult journeys of young people caring for a parent with younger onset dementia

Some readers might be surprised to see an article about young people in this journal, but dementia can impact on people of every age. Most often, young people under 25 are affected when a grandparent develops dementia, but some must live through the challenge of their parent developing younger onset dementia. This diagnosis is devastating for the person with dementia, but how might it impact their child?

There are noticeable gaps in the literature about the outcomes for young people living with a parent who has dementia (Svanberg *et al* 2011). Most of the research to date has investigated the impact of younger onset dementia on the person living with the condition and their primary carers, often their partners. Worryingly, a recent report looking at caring responsibilities of young carers across a broad range of situations not specific to dementia has found that young carers' mental and physical health deteriorated over time. Importantly, the authors noted that this deteriorating health seemed to get worse as young carers moved to adulthood (Cass *et al* 2011). As dementia can impact families with children and young people it is important that we as a community understand the experience of these young people.

Based on data from our qualitative research project, *The impact of younger onset dementia on the person and their family*, we would like to take you on a journey with three young people who have lived with a parent with younger onset dementia. This is an ongoing project collecting the stories of young carers. The experiences of these three people are representative of the larger group involved in our research project. To date, we have interviewed 12 young carers, and hope to interview two more aged between 10-18 years, particularly male young carers. We have also interviewed two people with younger onset dementia and three carers and parents to get the family perspective on these situations.

The young people's stories

Bryan*, Timothy* and Morag* come from three separate families, each with a parent who was diagnosed with dementia when the children were in their teens. They are now all young adults. Looking back, all of them acknowledged that some changes in their parent's behaviour were apparent for quite a few years before diagnosis.

Bryan was nine when his mother first showed signs of what he much later knew to be cognitive decline. Timothy was 11 when he had to start cooking, claiming that even the cat wouldn't eat the food his father was serving up. Morag was 13 when she was first told about her mother's diagnosis.

The social discrimination and exclusion often experienced by young people caring for a parent with dementia can have devastating effects on their mental and physical health

Both Bryan and Timothy were only-children and lived mostly with their parent with dementia. Morag lived with her two siblings and both parents. The diagnosis of dementia in parents with young children and teenagers sends shockwaves through the family as well as the local and wider community. However, the focus of service providers, health professionals, as well as family and friends has not necessarily been on providing support for the young people involved.

Bryan and Timothy became their parent's main carer from a very young age, with little support until they turned 18 and became their legal guardians. Until then, life was very challenging. These young men simultaneously dealt with a very unpredictable situation at home, while also coping (or not coping) with their own issues of growing up. They knew their home life was different from others in the communities in which they lived, and found themselves isolated. For many young carers the general lack of knowledge about dementia leads to discrimination. These young people discovered that many friends and family just disappeared from their lives.

With the deterioration in their parent's condition increasing the stress, a full-blown crisis was almost inevitable at some point. What triggered this crisis was different for each individual and family.

Bryan

For Bryan, the crisis hit when he was studying for the Higher School Certificate (HSC), working part-time, caring for his mum and trying to obtain a university music scholarship. His stress level was high and life was challenging. He was completing his education with minimal support. Many of his friends were planning to leave the area to start a new life, gaining some freedom and independence from their parents, but he knew in his heart he could not leave home.

Bryan was in Year 12 when his GP recognised his crisis and counselled him to move out of home for the sake of his health. However, there was no financial support to make this a realistic plan. Bryan developed severe depression and his negative emotions drove him to self-harm.

He was successful in receiving several offers of music scholarships but declined these to remain near his mother. He admits that his mother would have been very upset if she had been aware of his decision, as she had recognised his talent and supported him from a young age.

Having made the decision to remain nearby to care for his mother, Bryan still needed to escape from the situation so he moved out of his mother's home and lived locally. However, life was a blur trying to save his own life while caring for his mother when he was physically and emotionally able to manage this. The guilt of not being able to care for her upset him greatly, but he was not emotionally stable enough to do so, even when on medication. His future seemed bleak with the knowledge he was losing his only present parent.

Bryan describes attending counselling sessions where the counsellor was almost brought to tears by his situation. Bryan pointed out how sympathy was not what he wanted, but rather guidance. He experienced feelings of increasing hopelessness after each session failed to provide the necessary support. The counsellor's inability to provide tangible support just added to Bryan's despair and sense of exclusion from society, causing him to feel more of an outcast. Bryan's perceived unfairness of the situation was intensified by the lack of understanding from a professional who was supposed to help him.

Bryan eventually returned to caring for his mother after leaving home, but reached a point where he had to organise nursing home care for her. He described this as a challenging, difficult process due to his mother's age and his lack of knowledge and understanding of the procedures.

Morag

Morag's family situation was quite different. Her father worked full time and was also her mother's main carer. Morag felt that, as she was the youngest, she was shielded from a lot that was going on. However, not long after her mother's diagnosis, Morag developed a mental health condition.

She concealed her emotions, hiding behind a façade of what was expected of her in the family and community. She was a bright girl and well liked. She did well enough in the HSC to go to university. As her father was her mother's main carer, she was able to live at home and attend university while providing back-up support for her father.

Morag was 20 when her crisis hit. Her mother had to go into a nursing home for respite, with plans for her to become a permanent resident. Morag was not prepared for how emotionally difficult this would be. She was distressed at the thought of her mother living in a place with people at least 30 years her senior. Her emotions built up to the point where she self-harmed. Things were getting worse. She told us that she felt life was not worth living, but luckily, a supportive friend stepped in to help her regain perspective.

Morag's life had been totally derailed by her mother's deterioration. The enormous sense of guilt she felt was focused on the belief that they, as a family, had failed her mother. She felt they should somehow have managed to keep her at home even though rationally she knew this was not possible – not without a huge amount of support and commitment from the whole family, which was not available. Community support services could not provide enough care at home, and because of an incident in the dementia day care centre, Morag's mother was not allowed to retun. Her father's health was deteriorating and he needed to take care of himself.

Children and teenagers affected by the need to care for a parent with dementia need support from service providers, health practitioners and the community

Morag described the grief of losing a mother who was still physically present but out of reach emotionally. Most of her friends did not understand at all and not being able to talk about it made her feel very alone. She missed her mother immensely and cherished her memories of her, which she desperately held onto.

Timothy

Timothy grew up in a regional beach-side community where his father, who had undiagnosed younger onset dementia, was labelled a drug addict because the community could see no other reason for the change in his behaviour. At the age of 12, and an only child of parents who were living apart, Timothy was unable to give his friends and their parents a name for his father's condition. Consequently, they were both socially ostracised and discriminated against, causing his father to withdraw further from social activities. His father no longer met up with friends and started drinking more at home. This affected their relationship as well as leaving them with little or no money for food and to pay bills.

This socially isolated life drove Timothy to hang with 'the wrong crowd' where skipping school was common. He stayed away from home at nights and slept on the streets. For Timothy, the crisis came when his father became increasingly stressed and his extended family intervened. They labelled Timothy as the troublemaker and separated the two of them. Timothy was sent to live with his grandparents. Denied contact with his father, Timothy eventually ran away from his grandparents' home and returned to his father to care for him. He was only 14 at the time.

Timothy cared for his father for many years. His father continued to deny his diagnosis and Timothy worried that they would end up being separated if he let anyone know his real home-life situation. Although academically bright, Timothy struggled to get good grades. He was his father's full-time carer, worked to pay for food and bills, as well as studying at school. He described the stigma of being poor and having a parent with dementia: he certainly did not feel like he belonged in the same world as his peers.

After leaving school, Timothy reached an emotional crisis point when he was juggling work and caring, under increasingly difficult circumstances, while trying to maintain some normalcy in his life. He too had to leave home, forcing other family members to care for his father. Timothy was very angry and depressed, which negatively affected his relationship with his father. He knew he probably had many years of caring ahead of him, but he needed some time out to recover emotionally in order to keep going. After Timothy left home, care services for his father were put in place, but the service providers struggled to manage his father at home and he was admitted to a nursing home shortly after Timothy's departure.

The first aged care facility was not equipped to care for people with dementia and struggled with caring for someone as young as Timothy's father. Timothy also wanted to have his father closer. Whenever issues arose, he had to keep travelling back and forth to deal with them. Timothy tried to find a more appropriate facility, but because he was living and working in a different area, he had to spend many nights sleeping in his car as he travelled back and forth. Though he was successful in finding alternative residential care for his father, it proved to be an arduous process requiring substantial time and energy with considerable financial stress for Timothy.

The decision to move a parent into an aged care facility can be traumatic, as was the case for Morag. However, both Bryan and Timothy acknowledged that it also lessened some of their responsibilities, which in turn, actually improved their relationship with their parent. With the strain of being a carer removed, they were able to reconnect with their parent and spend valuable quality time with them. Morag agreed with this too, but for her, it meant she was also able to improve her relationship with her father now that he was no longer caring for her mother full-time.

Looking to the future

At this point in the research project we have analysed the data from the perspective of emotional trauma. The more we listened, the more we realised that these young people had experienced significant difficulty due to the consistent lack of support and understanding by their communities. While we were not surprised by their deteriorating health (Cass *et al* 2011), the severity of that deterioration and the degree to which they were stigmatised by their own families and local communities was surprising. Equally challenging was the way that fragmented service provision consistently let them down. These young people were living with their own grief and trauma as well as struggling to support their parent's mental health, but society seemed to be making things worse for them.

In order to further understand the experiences of the young people we interviewed and to be able to formulate a framework within which to develop further research and recommendations for support and service delivery, we looked at our research participants from the perspective of the Social Model of Disability. This model helps us understand the experiences and truth of disability as a social problem rather than an individual or family issue. It draws our attention to the real problems of disability, the attitudes which disadvantage people and the social barriers that affect full participation in society (Barnes & Mercer 2011).

From this perspective, these young people were at a greater disadvantage because society failed to support their emotional well-being and engagement in the social, educational and economic opportunities relevant to their age. This caused them unnecessary isolation and exclusion from fully participating in society. The diagnosis of dementia created social stigma, discrimination and lack of understanding. Because that stigma is common in the community, this only added to their family's difficulties. We began to ask whether young people living with a parent with younger onset dementia – in experiencing similar discrimination by society as their parent – are therefore, in effect, disabled themselves.

As a wider community we need to ask questions like this and have these conversations so we can understand what social factors impact on the lives of these families and young people. We can see this personal tragedy of social discrimination and exclusion happening not only to the person with dementia, but also to their families and dependants. We need to understand that changes must be made to prevent social isolation and to promote emotional and physical well-being by providing adequate and age-appropriate support, thus avoiding the 'derailment' of the entire family at times of crisis.

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A common issue revealed in our research was that young people found that service providers were so overwhelmed by the young person's situation that they inadvertently contributed to their despair and were unable to help them move forward. This indicates that professionals need more training to be able to support younger carers and children of people with dementia. Almost all services are focused on aged care and the common situations of counselling partners and adult children or relatives. Dealing with young people in the context of a family affected by dementia requires specialist knowledge and expertise to provide effective intervention and support that meets their needs: empathy, services and practical advice.

Supporting young people

With the new Australian Government funded key worker roles for people with younger onset dementia and their families (Alzheimer's Australia 2013) there are opportunities to help prevent some of the consequences of long-term emotional trauma in these young people. Paying particular attention around the vulnerable time when young people move from youth to adulthood is important.

Service providers and health practitioners can develop positive action towards monitoring the situation to prevent a crisis. As soon as a formal diagnosis of dementia is made, programs and support need to be put in place to reduce the caring responsibilities of these young people, as well as to control the amount and intensity of their caring roles. The provision of immediate support is important as issues have often existed for a long time prior to diagnosis.

For some young people over 18 years of age, the Alzheimer's Australia (NSW) young people support group has provided an opportunity for them to meet others in similar situations and share experiences. A feeling of belonging is important for these young people to give hope for the future. Alzheimer's Australia (NSW) runs the young people's support group every second month at the Sydney Dementia and Memory Community Centre in North Ryde.

We must support the development of more services like this and help to make the children and teenagers affected by the need to care for a parent with dementia more visible to service providers, health practitioners and the community. With this aim, we are planning a workshop this year with relevant organisations to look at the issues and highlight opportunities for working together.

By doing this we may identify better ways of meeting the needs of these young people. In the meantime, we are still planning to recruit a few more participants in the 10-18 year age group for our research and run a focus group with some of the young carers who participated, to learn more about their experiences. We are continuing with the data analysis and further analysis of the emergent themes from the data is ongoing. ■

For more information on the young people's support group, call (02) 9805 0100 or go to: http://www.fightdementia.org.au/services/support-groups.aspx

*** Names have been changed to protect privacy**

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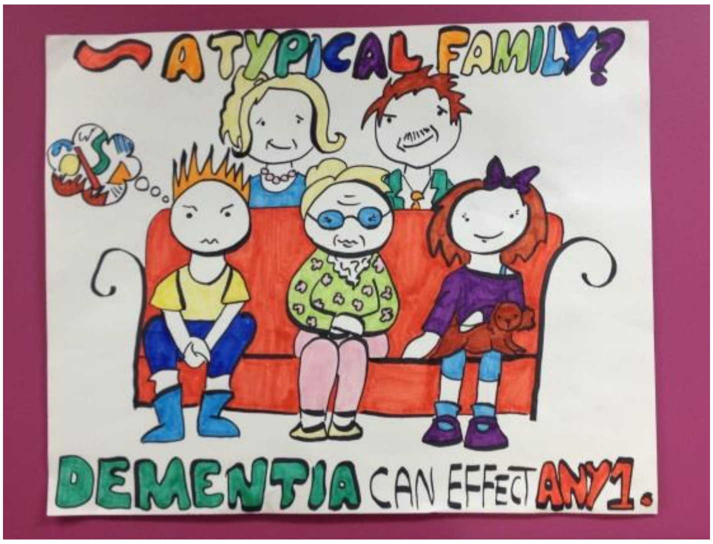
Report summary on a collaborative workshop '*Supporting young people having a parent with Younger Onset Dementia (YOD)*'

on 26th August 2014 at Royal North Shore Hospital (RNSH), St Leonards

Supported by NHMRC Partnership Centre for Cognitive and related Functional Decline in Older People (or Cognitive Decline Partnership Centre – NHMRC CDPC)

Produced by Karen Hutchinson, Research Masters Student, NHMRC CDPC, University of Sydney



Picture by Caitlin Priestley aged 11, Junior Archibald Winner 9-12 years

Aims

1. To improve attendees overall understanding of the impact on young people having a parent with YOD.
2. To provide a platform for cross sectorial collaboration and networking from representatives of government, general practice, aged care, researchers, youth mental health and support service providers in partnership with consumers, namely young people and their parents living with a diagnosis of YOD
3. To harness the creativity and ideas of service providers and consumers, the young people, in considering the development of a model or pathway of support to better support young people who have a parent living with a diagnosis of YOD.

Brief workshop overview:

Thirty people attended this interstate multi sectorial workshop where we collaborated to develop some recommendations to be considered for future policy developments.

Throughout the day we heard from a range of service providers on the opportunities and services presently available. We listened to young peoples' powerful personal stories about their experiences of having a parent with YOD and experiences of using youth mental health services.

The key messages from the workshop were:

1. Personal stories from the young people are a powerful tool in developing greater insight and understanding around the real impact of living with a parent with YOD on individuals and their families.
2. Collaboration opportunities with youth, dementia sectors and consumers need to be addressed utilizing their expertise to design interventions that support the needs of the young people and their families
3. Consider developing young people in a leadership role as part of an advocacy programme similar to other youth organisations.
4. Increase awareness of the impact of YOD on the young people and their family through networking and education opportunities within and across various sectors, including the public arena
5. Develop web based and social media options to support, mentor, inform and connect with members of these families living with a diagnosis of YOD.
6. Offer strong mentorship arrangements for the young people combined with developing own responsibility for self-care rather than in overly formal structured programmes.
7. Make available collaborative funding opportunities to further explore recommendations to develop and design, tools and interventions that offer more age appropriate support to the families with YOD.

Recommendations:

The workshop highlighted a number of recommendations to inform government policy makers and support change. This could be a achieved through networking and collaborating across sectors and sourcing funding for development of life changing innovative models and pathways of support that could be translated across areas where young people are impacted by a parent's diagnosis.

Opportunity for empowering the young people - young person's advocacy group

1. Developing a young person's advocacy group to improve overall awareness among service providers, collaboration for developing resources and support networks, advocating for other young people, attending conferences etc.
2. Collaborating with other youth organisations like Headspace and Young Carers organisations to assist in the development of a model of youth leadership.
3. Supervision and mentorship of young people due to the emotional element involved in telling their personal stories

Connecting with young people by developing a youth friendly website, website directory, social media opportunities and age appropriate resources

1. Developing a website and website directory to assist with information sourcing, support options, service options, legal issues, genetic information etc. to negate the navigational issues many face. Comments around '*I don't know what I need to know'* are common.
2. Include a section within a recognised website, such as Alzheimer's Australia, for young people with parents or grandparents with dementia. This site could contain links to organisations across sectors and funding organisations, which can be readily accessed for support, resources and services for all members of their family.
3. Collaborate with youth organisations to have links to Alzheimer's Australia and specific designated websites supporting young people with a parent with YOD included on their websites.
4. Proposed development of social media communication platform connecting with young people in a way that suits their needs and age.
5. Design more developmental age appropriate resources.
6. Connecting with experts supporting the use of modern technology for improving health and wellbeing.
7. Continuing to promote and develop the young person's face to face support group already established in Sydney. Consider including young people in developing alternative ways to bring them together to reduce feelings of isolation.

Connecting with the wider community - education opportunities to improve community awareness and reduce marginalisation

1. A roadshow option was discussed as a mechanism to raise awareness of issues facing young people in dementia and encouraging a whole family approach to providing assistance.
2. Education awareness programmes involving schools, universities, employer groups, community youth groups, health professional forums, service provider groups and general community.

3. Opportunities to work with other well established youth groups to incorporate a component of dementia awareness into their programmes.
4. Proposed use of interactive performing arts to spread the word.

Integration and collaboration opportunities for health and service providers

1. More opportunities made available for collaboration and networking with government and various organisations within youth mental health and dementia sectors to promote more integrated services for a whole family approach to support management.
2. Organising specific collaborative workshops to develop pathways and models of support that assist health and service providers provide consistent and appropriate care and support to all family members throughout the progression of dementia. Some specific suggestions made:
    a. Develop a more consistent protocol offering support and mentorship for the young people when the parent is diagnosed with YOD, helping them with direction and connections to appropriate services and support. This service should be integrated and offer easy access to support when required throughout the journey with YOD. The YOD key worker programme is an excellent resource to develop collaborations with the youth sector.
    b. Developing a “toolkit” to support health and service providers. This resource could be in written form or accessed on online to promote consistency of information and support offered.
3. Using the medicare locals as a ‘one stop shop’ where there is access to a wide variety of services and support within the community, providing a wellness and holistic approach to care options.

Promoting quality of life and wellbeing within residential facilities for the parent with YOD

1. More appropriate residential accommodation for people under 65 years’ of age – group home option discussed, which would accommodate and value family interaction and help alleviate some distress of finding the appropriate care.
2. Having more age appropriate accommodation opportunities as well as a more streamlined referral and assessment process would alleviate some of the stress from the young people and other family members.

Summary of the workshop:

Reflections - The next steps: where to from here

The workshop highlighted the complexity of living with a person with a diagnosis of dementia, YOD in particular, from several peoples’ perspectives. The workshop reinforced the need for working in collaboration across sectors, including the consumers, to develop ways to adequately support all family members impacted by a diagnosis of YOD. Partnership with key organisations and engaging with experts in the fields was identified as being of particular relevance. Throughout the workshop the dominant theme was identified as the need to find ways to increase information awareness and access of support for young people and the other family members living with a parent with a diagnosis of YOD.

The workshop provided an invaluable opportunity for information sharing across sectors, and explores collaborative opportunities. A surprising statistic for attendees was the comparable figures of people living with MS to YOD within Australia. Although it is often mentioned that the numbers of people with YOD are small in comparison to other diagnostic groups, these figures reiterated the need to increase public awareness of the issue.

Attendees acknowledged there are services available that offered support and information to young people within dementia and the youth mental health sectors but the main concern was the navigation of appropriate services and their accessibility. A matter for consideration is within which support space the services need to be placed as many of the issues are not attributable to the dementia itself but rather the failure of society to adequately support the family, contributing to the marginalisation experienced.

In the past there seems to have been a failure in recognising the young people within the families and the important roles they have in keeping the families together. The new YOD key worker programmes provide opportunities of support and information to the families as well as engage with the young people at the time of diagnosis and throughout their journey with YOD. Also, the YOD key workers programme may raise the prospect of connecting young people with each other, which is important when isolation is a common experience, an overwhelming feeling highlighted by the young people in the workshop.

The figure of one in four young people developing a mental illness before the age of 25 highlights the need for prevention strategies rather than focusing on the cure, especially when faced with a life-changing event. The depths of despair these young people report caused great concerns within the service provision sector and recognition that early engagement with the young people is crucial. Adding to this were the issues around decision-making skills, which are recognised as not being fully developed until around the age of 25, necessitating access to adequate support and mentoring opportunities.

However it has been noted that the majority of young people have access to the internet and the use of this platform for support and information sharing is an opportunity to be developed within the area of dementia. Social media is another way to connect with other people in similar situations and needs further investigation and development. Dementia services could certainly learn from the youth sector on developing partnership with young people and explore some of the developmental age issues.

An additional point raised within the workshop was that resources are dispersed depending on the funding sources of these services. When searching for services for example some will come up under one organisation while other services are available within another organisation. This complexity adds another challenge to young people navigating service options.

Many people reported hearing the personal stories were very valuable in gaining greater understanding and insight in relation to the impact on the young people. Some of the young people have expressed that they would certainly consider becoming advocates for young people by having dementia in the family. These young people could work in partnership with service providers in developing support models and resources that support their age-specific needs. The marginalisation these families experience is considerable. The attendees heard how others judge the parent without dementia and this puts considerable pressure on the family. A parent may be dealing with their own mental health issue while trying to cope in a society that fails to understand the overwhelming stress and pressure of providing for a family in these circumstances. It is clear that health and service providers need to be fully aware of who are the actual carers in the family, with the caring role being adopted by the young people for both parents in some cases.

Also described at the workshop was the inequality of support and understanding for the young people living with a parent diagnosed with YOD within the school environment. Support opportunities for individuals and family experiencing more recognised illnesses were deemed important but failed to be validated in the case of YOD. This example demonstrated the lack of public awareness around the needs of families with YOD and the feeling of inequality experienced by these families.

Parents with and without YOD describe how heartbreaking it is to see their children struggling to manage the many complex emotions that develop over the progression of dementia. In addition, trying to cope with the partner's diagnosis often leaves the other parent with little time and energy to support their children. Health and service providers need to understand that the opportunities of varied support could alleviate some of these pressures.

Acknowledgements:

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Alzheimer's Australia - for supporting the attendance of representatives from the CDRN and their family members.

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1.Hutchinson K, Roberts C, Kurrle S, Daly M (2014) The emotional well-being of young people having a parent with younger onset dementia*, Dementia* published online 29th April 2014 DOI: 10.1177/1471301214532111

2.Hutchinson K, Roberts C, Kurrle S (2014) Invisible carers *The Australian Journal of Dementia Care* Feb/ Mar 3 (1) 19-21

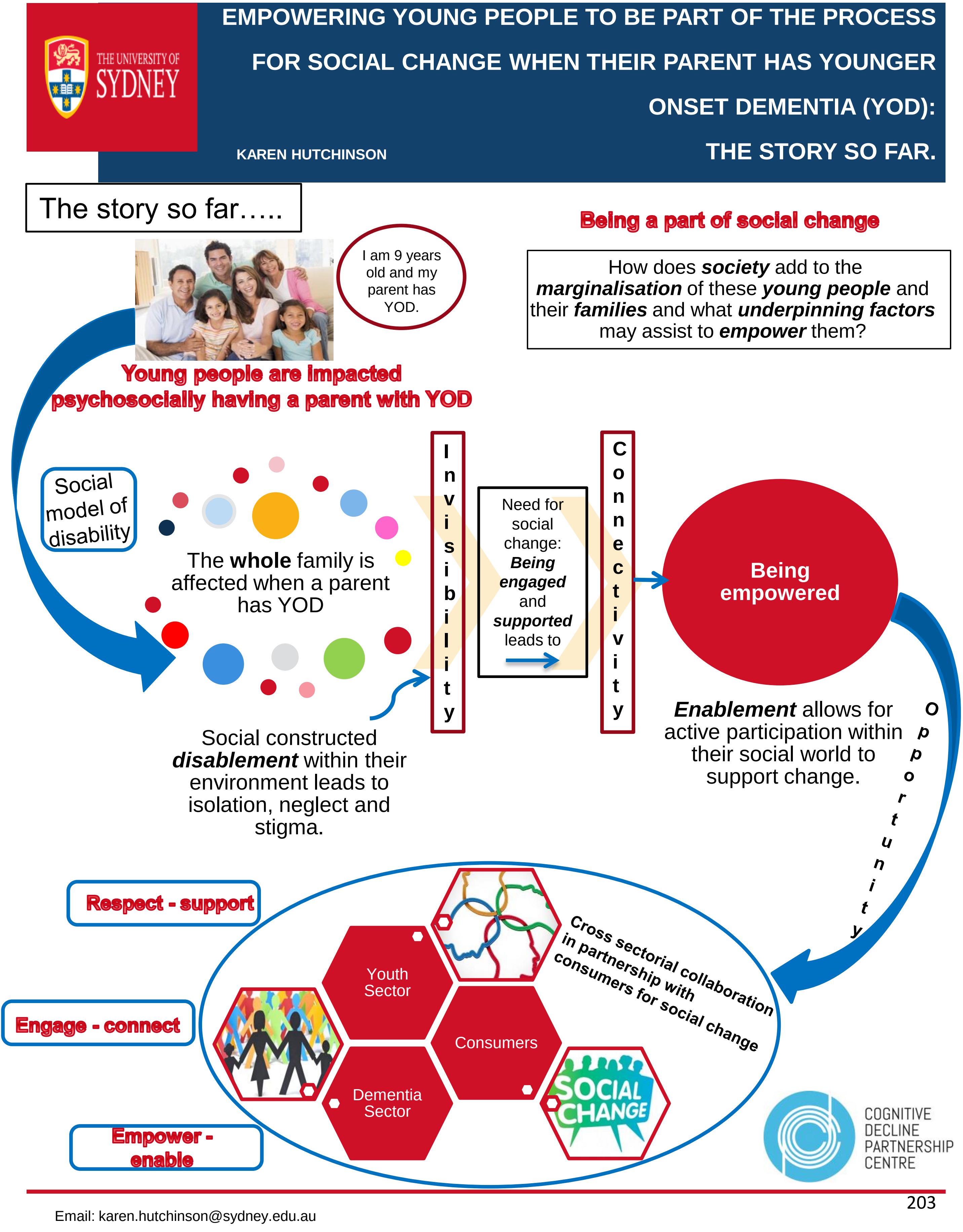
3. Australian Institute of Health and Welfare. (2012). Dementia in Australia (pp. 1–239). Canberra: AIHW.

4. MS Australia website: http://www.msaustralia.org.au/understanding-ms

Contact Karen Hutchinson by email for more information: karen.hutchinson@sydney.edu.au

This report is a summary of the workshop only.

Figure 7: Empowering young people in families living with YOD poster



THE UNIVERSITY OF SYDNEY

EMPOWERING YOUNG PEOPLE TO BE PART OF THE PROCESS FOR SOCIAL CHANGE WHEN THEIR PARENT HAS YOUNGER ONSET DEMENTIA (YOD): THE STORY SO FAR.

KAREN HUTCHINSON

The story so far…..

I am 9 years old and my parent has YOD.

Young people are impacted psychosocially having a parent with YOD

Social model of disability

The **whole** family is affected when a parent has YOD

Social constructed ***disablement*** within their environment leads to isolation, neglect and stigma.

Invisibility

Need for social change: ***Being engaged*** and ***supported*** leads to

Connectivity

Being a part of social change

How does ***society*** add to the ***marginalisation*** of these ***young people*** and their ***families*** and what ***underpinning factors*** may assist to ***empower*** them?

Being empowered

Enablement allows for active participation within their social world to support change.

Opportunity

Respect - support

Engage - connect

Empower - enable

Youth Sector

Consumers

Dementia Sector

Cross sectorial collaboration in partnership with consumers for social change

COGNITIVE DECLINE PARTNERSHIP CENTRE

Email: karen.hutchinson@sydney.edu.au

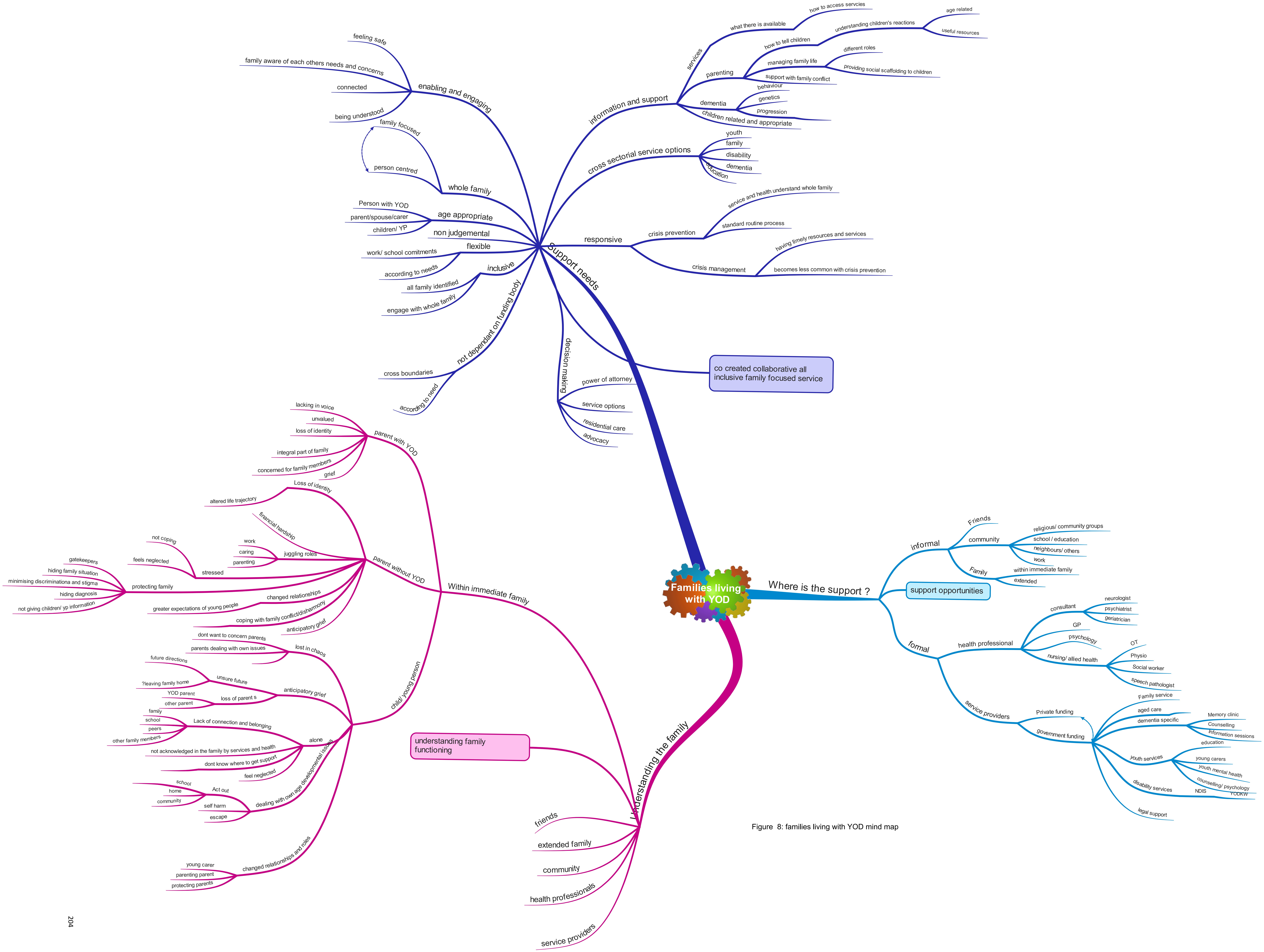
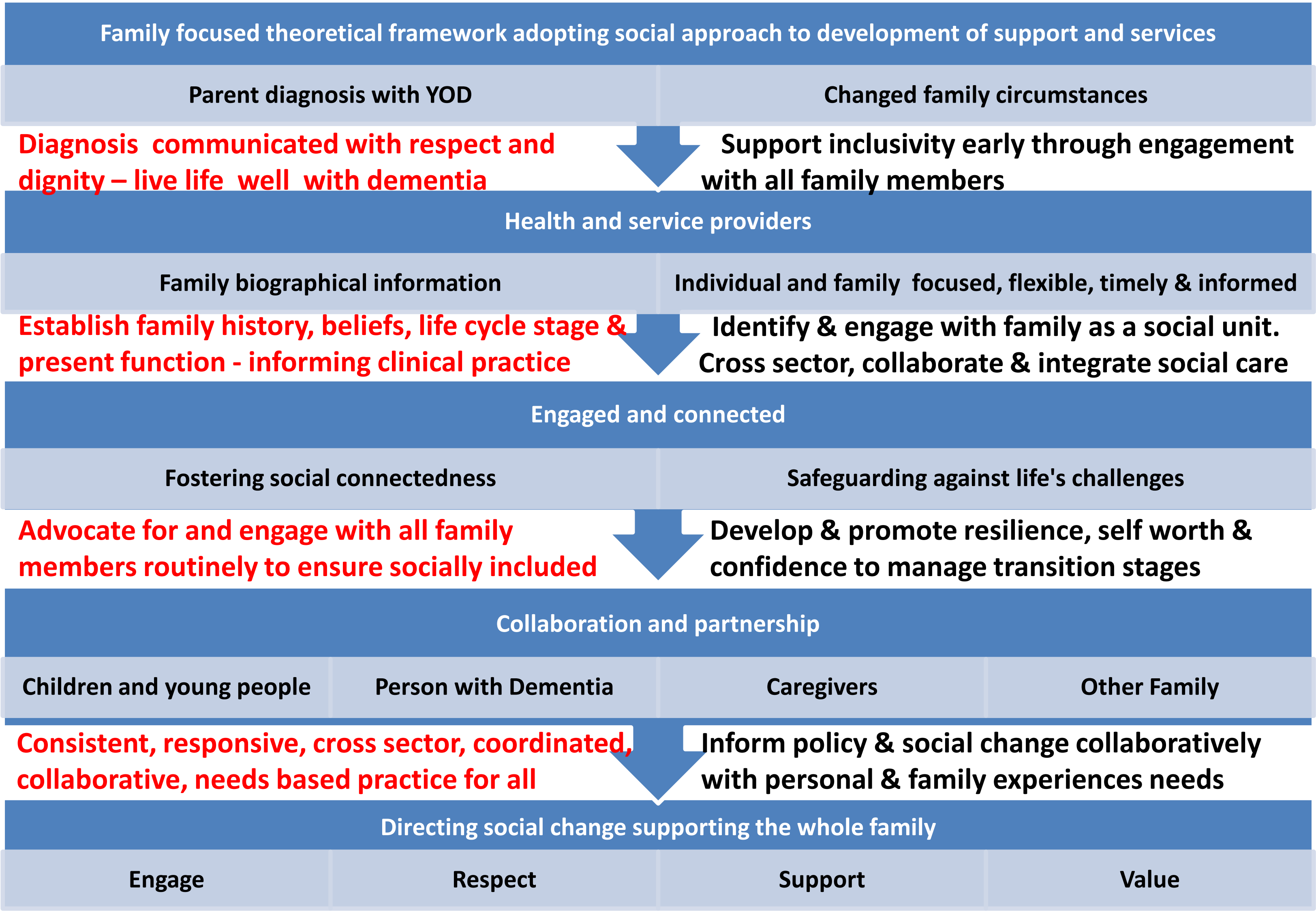


Figure 8: families living with YOD mind map

Figure 9: Proposed co-created family focused service model



Family focused theoretical framework adopting social approach to development of support and services

Parent diagnosis with YOD

Changed family circumstances

Diagnosis communicated with respect and dignity – live life well with dementia

Support inclusivity early through engagement with all family members

Health and service providers

Family biographical information

Individual and family focused, flexible, timely & informed

Establish family history, beliefs, life cycle stage & present function - informing clinical practice

Identify & engage with family as a social unit. Cross sector, collaborate & integrate social care

Engaged and connected

Fostering social connectedness

Safeguarding against life's challenges

Advocate for and engage with all family members routinely to ensure socially included

Develop & promote resilience, self worth & confidence to manage transition stages

Collaboration and partnership

Children and young people

Person with Dementia

Caregivers

Other Family

Consistent, responsive, cross sector, coordinated, collaborative, needs based practice for all

Inform policy & social change collaboratively with personal & family experiences needs

Directing social change supporting the whole family

Engage

Respect

Support

Value

A co created family focused service model to inform the design and development of cross sectorial collaborative service model addressing the specific life challenges of the family living with younger onset dementia.

Where do I get information and help?

Useful resources and information for families, children and young people living with dementia in the family.

Dementia Australia *1800 100 500*

- *National dementia helpline Mon-Fri 9am -5pm*
- *Counselling telephone or in person*
- *Young person support group, younger onset dementia key worker*
- *Website: www.fightdementia.org.au*
- *Alzheimers NSW blog for young people over 18 yrs*

http://youngeronsetdementiaandme.blogspot.com.au

Kids helpline *1800 551 800*

- *5-25 years*
- *7 days a week*
- *Telephone, email or web counselling*
- *Website: www.kidshelp.com.au*

Lifeline *13 11 14*

- *7 days 24 hours per week*
- *Telephone and online counselling*
- *Website: www.lifeline.org.au*

Headspace *1800 650 890*

- *12-25 years*
- *On line and telephone counsellng*
- *9 am to 1 am*
- *Website: www.headspace.org.au*

Dementia Behaviour Management Advisory Service (DBMAS)
1800 699 799

- *24 hour national helpline 7 days a week*
- *Behaviour having impact on care.*
- *Email: nswdbmas@hammond.com.au*
- *Website: www.dbmas.org.au*

Carers and Young Carers *1800 242636*

- *Contact between 9am - 5pm*
- *Specialist carer counselling*
- *Website: www.carersnsw.asn.au*
- *Website: www.youngcarers.net.au*
    - *Up to 25 years*

Young carer state websites

- *Website NSW : www.youngcarersnsw.org.au*
- *Website QLD: www.carersqld.asn.au/services/young-carers*
- *Website SA: www. carers-sa.asn.au/how-can-we-help/young-carers*
- *Website VIC: www.carersvictoria.org.au/how-we-help/young-carers*
- *Website: TAS: www.carerstas.org/how-we-help/young-carers*
- *Website WA: www.youngcarerswa.asn.au*
- *Website NT: www.carersnt.asn.au/young-carers*

Black Dog Institute NSW *(02) 9382 4523*

- *Contact between 9am- 5pm*
- *Website: www.blackdoginstitute.org.au*
- *Website: www.biteback.org.au*
    - *Ages 12-18 years*

NSW Mental Health Line - 24-hour contact: 1800 011 511

Salvo Youth Line – (02) 9360 3000

Salvo Care Line - (02) 9331 6000

Other useful websites:

- ***Children of parents with mental illness*** *(COPMI)*
  www.copmi.net.au
- ***ReachOut*** *-helping young people manage mental health difficulties*
  www.reachout.com.au
- ***Itsallright.org*** *(SANE) mental health information*
  www.itsallright.org SANE 1800187263/online counselling
- ***Black Dog Institute*** *-self -help programme for mild to moderate depression and anxiety*
  www.mycompass.org.au
- ***Alzheimers Foundation of America website for teens:***
  http://www.afateens.org/learn_dementia.html.
- ***Commonwealth Respite and Carelink centre*** 1800 052 222
  http://www.carersnsw.asn.au

- ***ARAFMI – Association of Relatives and Friends of the mentally Ill***
  http://www.arafmi.org 1800 655 198
- ***Young Carers Project***
  http://www.youngcarersproject.ca
- ***Alzheimer's Association***
  http://www.alz.org/living_with_alzheimers_just_for_kids_and_teens.asp
- **When Dementia is in the House**
  http://lifeandminds.ca/whendementiaisinthehouse/ts_home.html
- **Young adult children with parents with YOD Facebook page**
  https://www.facebook.com/YACPYOAD/timeline
- **Carers and young carers information resources website**
  https://www.carersgateway.gov.au
- **Alzheimer's Research UK**
  https://kids.alzheimersresearchuk.org/
- **Alzheimer's Society (school information)**
  http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2890
- **Tune into Dementia (Understanding dementia)**
  https://www.youtube.com/watch?v=LSAzAeBvh-E#t=108
- **Brain changes**
  https://www.alzheimers.org.uk/braintour
- **Younger onset dementia**
  http://www.youngdementiauk.org
- **Dementia in the family – Australian**
  http://www.dementiainmyfamily.org.au

Books

Before you forget (for teenagers)
https://julialawrinson.com.au/julias-books/for-teenagers/before-you-forget

Publications

Abstracts and Posters:

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Hutchinson K., (2014). *Hidden Carers: the young people caring for their parent with younger onset dementia,* Risky Business 2 conference, Sydney 26-27 June 2014

Hutchinson, K., Roberts, C., & Kurrle S.(2014). *Empowering young people to be a part of the process for social change when their parent has younger onset dementia: the story so far,* New Horizons conference, North Sydney 17-19 November 2014

Abstracts and Oral Presentations

Hutchinson, K., & Roberts, C. (2011). *Who is the stranger in the Mirror? Struggling with the disabled identity*, RDP NSW forum, Sydney November 2011

Hutchinson, K., Roberts, C., & Kurrle, S. (2013). *Coping with a parent living with younger onset dementia – the experiences of the young people*, Alzheimer's National Conference, Hobart 15-17 May 2013

Hutchinson, K. Roberts, C., & Kurrle, S. (2013). *The emotional journey of the young people having a parent with younger onset dementia*, New Horizons conference, North Sydney November 2013

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Hutchinson, K., & Roberts, C. (2015). *When young people have a parent living with dementia: a social model perspective*, New Horizons conference, University of Technology Sydney, November 2015

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<u>Publications:</u>

Hutchinson, K., Roberts C, & Kurrle, S. (2014). Invisible Carers. *Australian Journal of Dementia Care, 3*(1), 19-21.

Hutchinson, K. (2014). Supporting young people who have a parent with younger onset dementia workshop summary, report only from inter agency workshop 26th August 2014

Hutchinson, K., Roberts, C., Kurrle, S., & Daly, M. (2016). The emotional wellbeing of young people having a parent with younger onset dementia. *Dementia: the international journal of social research and practice*, 15(4), 609-628, doi:10.1177/1471301214532111

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