

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

Karen Hutchinson

Cognitive Decline Partnership Centre, University of Sydney, Australia

Chris Roberts

Northern Clinical School – Hornsby, University of Sydney, Australia

Susan Kurrle

Cognitive Decline Partnership Centre, University of Sydney, Australia; Hornsby Ku-ring-gai Hospital, Australia

Michele Daly

Northern Clinical School – Hornsby, University of Sydney, Australia

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

Corresponding author:

Karen Hutchinson, Northern Clinical School – Hornsby, University of Sydney, Hornsby Ku-ring-gai Hospital, Bldg 3, Palmerston Road, Hornsby, Australia.

Email: karen.hutchinson@sydney.edu.au

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 (Brodarty & 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, Oyeboode, & 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 well being 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 Health 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 1).

Table 1: 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 peoples 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 it's 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 mothers 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 societies 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 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. Further more 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 puts 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 concurs 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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