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Title Page

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

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.

Key words: 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 Health 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 1 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 1: 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*. Empowerment 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.

Giving 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 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, & Sancu, 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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