Young people collaborating for social change so they no longer feel alone in the journey with their parent’s dementia

Karen Hutchinson
Associate Professor Chris Roberts
Dementia turns the whole family’s world upside down

BUT

Society contributes to their EXCLUSION, DISCRIMINATION, and EMOTIONAL DISTRESS.
Qualitative Research Study Focus

- To explore how the social model of disability informs an understanding of the societal influences on young people who have a parent living with young onset dementia.

- Secondly we wished to understand the nature of age appropriate societal support for their complex situation.
Research Process

• Conducted semi structured interviews with 12 participants looking at their experiences between the ages of 10 to 24 years in NSW, 1 male and 11 females.
• Retrospective data collected from people who were as young as 8 when their parent demonstrated symptoms of younger onset dementia.
• A focus group with 4 participants from the research and 2 Alzheimer’s NSW employees.
• Held a day workshop with representatives from youth and dementia sectors, health, government, young people, parents with dementia and academics.
Emerging themes from the research

• Invisibility

• Connectivity

• Being empowered
Taking a unique perspective on the impact on young people in families with YOD

Using the social model of disability as the theoretical framework
The social model of disability

- The social model of disability shifts our perception of disability from the individual to the interaction in their environment they live, work and play.

- Young people are in effect disadvantaged and disabled by their environment as they often experience exclusion and discrimination as well as emotional distress.
Young people feel invisible

Young people report feeling **outcasts** within dementia services

- Limited services
- Limited expertise in supporting young families
- Young people are not recognised or engaged

“ I just felt like they'd look at me and go oh my God, this is above me. When you're going to someone for help, you think I want help; I don't want someone saying oh dear and just having these long awkward pauses, trying to think what could they say or looking like they're going to cry.”

Listen to the experts – What do they need?
The big picture

Young people face *socially constructed disablement*

Young people presently feel

- Disempowered
- Excluded
- Unsupported
- Stigmatised
- Lonely
- Neglected
- Emotional distress
- Disengaged
- Isolated
- Invisible
- Lost in the chaos
- Unrecognised
- Different to their peers
- Disconnected
- Hopeless
- Uninformed

Young people want to be

- Connected
- Valued as citizens
- Recognised in the family
- Respected
- Hopeful for the future
- Informed
- Included
- The same as their peers
- Safe
- **EMPOWERED**

*They have rights too*
Their stories explain it all

“I think that's why we didn't get a lot of support as well because she didn't look or act like she wasn't well.”

“I didn't meet people that understood or could say anything that was comforting or could offer any good solutions or wanted to get involved properly.”

“I think having a mum with dementia left me really isolated as a teenager. I didn't have that one person that I could go to.”
The emotional derailment

Young people need to feel connected and engaged throughout as they deal with their own age developmental challenges

Triggers for an emotional crisis:

- Greater length of time living at home
- Transition from adolescent to adulthood
- Parent being admitted to residential care
- Deterioration of their parent with YOD
- Length of time being the main carer
- Other parent not coping
- Financial hardship
- Family conflict

The crisis experiences they describe:

- Nervous breakdown
- Depression/anxiety
- Suicidal ideation
- Psychosis
- Substance abuse
- Homelessness
- Self harm

Being engaged and connected with the right person that they trust can save these young people from being another statistic in youth mental health.
How to overcome isolation

• These young people need recognition in their own right while responding to the changes in the family circumstances and dealing with marginalisation in society.

• Being connected to your social world through building positive relationships helps to form linkages and networks that promote resilience through an overall sense of belonging.
Being Empowered

Taking control of your life and make the right connections.
Making connections are so important

• “But I used to talk to him a lot because I was worried about not being able to go to university and I wanted to study communications then. So I think he made me feel easy, even if I don't go to university that I'll find my way to contribute to the world somehow. It was just that kind of reassuring-ness that it would be okay no matter what happened. That the world would just keep on going. So he was really good to talk to.”

   (young person talking about a school teacher)
Empowering the young person they are the voices of the future

- To develop strong connections within many social contexts underpins successful resilience and break down barriers.

- By maintaining and supporting connections with these various social contexts, family, friends, communities and parents, influences a better sense of self and develops self efficacy.

- Changing how the environment impacts these individuals will greatly affect their future abilities to support change and resilience to cope with further challenges.
Why Should this matter?

YOD should not define the lives or futures of these families.

We should respond to individual needs

Taking a more social approach to support and service design addressing life’s personal challenges.
REACHING
for a better future with social inclusion and equality

• **R**edefine these families futures
• **E**ngage with the community using the best technology
• **A**ssist listening to the powerful voices of the family using the connected world of social media
• **C**ollaborate with a range of professionals to provide problem focused solutions
• **H**ave a sustainable, integrated and evidence base application
• **I**ncrease confidence and competency in professionals
• **N**ow connect and empower service users
• **G**et the age appropriate support and services they deserve.
Thee process of empowering

• Collaborate cross sectorially in mutual learning to create belonging and trust

• Be innovative together in developing professional competency and understanding with families living with YOD.

• Establish young people as advocates and leaders to be consulted and included in their part of the dementia experience.
Lets empower these young advocates

No more of this
Dementia organisations “didn't really understand what we were going through. They were very sympathetic, like oh you poor things, but that only makes us feel worse especially at the time when they were like, gosh I don't how you're going to do it or, gosh I don't know how you're doing it.” (young carers looking after their mum)

Encourage and support this
“I'm happy to talk to everyone or anyone who will listen. I've given lectures at ...University for the med students. I usually cry through my talks so it's not really useful but you know I'm just telling everybody about it. I'm just trying to educate people.” (young carer)
Thank you

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Contact: Karen Hutchinson
Email: karen.hutchinson@sydney.edu.au