

## 'This is killing me inside'

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**“This is killing me inside”: the impact of having a parent with young-onset  
dementia** Helen J Aslett<sup>1</sup>, Jaci C Huws<sup>2</sup>, Robert T Woods<sup>1</sup>, & Joanne Kelly-Rhind<sup>4</sup>

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### **Abstract**

This study explored the experience of young adults having a parent with young-onset dementia. In-depth interviews were undertaken with five participants aged between 23-36 years of age and these were analysed using interpretative phenomenological analysis (IPA). Participants were found to experience a number of stresses in relation to their parent's illness, many of which were linked to loss and guilt. Five main themes were identified related to relationship changes, shifts in roles and responsibilities, support for the non-affected parent, support for self and the impact of living with their own potential risk of dementia. These findings are discussed in relation to the existing literature and suggest that individuals with a parent with young-onset dementia have needs which service providers should consider in the wider context of young-onset dementia care.

**Keywords: interpretative phenomenological analysis, parent, psychological impact, qualitative, young-onset dementia**

## **Introduction**

It is estimated that there are 42,235 individuals in the UK living with a young-onset dementia (YOD, Alzheimer's Society 2014). YOD is defined as dementia diagnosed before age 65. YOD has greater heterogeneity than dementia in individuals over 65, where the Alzheimer's type predominates (62% - Alzheimer's Society, 2014). The needs of people with YOD also differ both as a consequence of faster disease progression and socially as a result of being at a different life stage (Brown et al., 2012). Individuals may still be in employment, raising families and have financial commitments (e.g. mortgages). As dementia is perceived as a disease of old age, the impact on young-onset families may also be greater as it is "out of sync" with the normal life course (Harvey, Skelton-Robinson & Rosser, 2003).

Spouses and partners of those with YOD report higher burden, poorer emotional health and less social support than those providing informal care to older individuals with dementia (Arai, Matsumoto, Ikeda & Aria, 2007; Freyne, Kidd, Coen & Lawlor, 1999; Luscombe, Brodaty & Freeth, 1998; van Vliet, de Vugt, Bakker, Koopmans & Verhey, 2010). Spousal and partner distress in caregiving for someone with YOD may also impact on other members of the family, as individuals struggle to juggle the competing demands of caregiving for an ill spouse and raising a family (Gelman & Greer, 2011).

Adolescence and emerging adulthood is a stage in life where autonomy is sought, romantic relationships formed and aspirations followed. However, a parental diagnosis of YOD may complicate these aspects of development. Recently a number of predominantly qualitative cross-sectional studies have been published investigating

the impact of having a parent with a YOD diagnosis (Allen, Oyebode & Allen, 2009; Barca, Thorsen, Engedal, Haugen, & Johannessen, 2014; Gelman & Greer, 2011; Millenaar et al., 2013; Nichols et al., 2013; Svanberg, Spector & Stott, 2010a; Svanberg, Stott & Spector, 2010b; van Vliet et al., 2010). Three studies have specifically considered the experiences of individuals aged under 18 years of age (Gelman & Greer, 2011; Nichols et al., 2013; Svanberg et al., 2010b), and three other studies have considered the experiences of adolescents and young adults (Allen et al., 2009; Barca et al., 2014; Millenaar et al., 2013). Despite wide age ranges in participants, similar themes have been reported across the studies suggesting that a parental diagnosis of YOD places significant stress upon children.

Svanberg et al. (2010b) in a mixed-method study of 11-18 year olds caregiving for a parent with YOD found that over 30% of their sample experienced clinically significant levels of low mood, and 50% were experiencing significant burden. This is related to children and young adults experiencing “anticipatory grief” where struggles are observed with the decline of the parental relationship, and the sense of who their parent was, even though their parent is still alive (Allen et al., 2009; Barca et al., 2014, Gelman & Greer, 2011; Millenaar et al., 2013; Nichols et al., 2013; Svanberg et al 2010b).

Role conflicts wherein children and young people take on roles and responsibilities which conflict with their age and stage of development (Allen et al., 2009; Barca et al., 2014; Millenaar et al, 2013; Nichols, 2013, Svanberg et al., 2010b), concern for the well-being of the non-affected parent (Allen et al., 2009; Millenaar et al., 2013; Nichols et al., 2013), and levels of family conflict within the home due to behavioural

changes in the parent with YOD (Allen et al., 2009; Barca et al., 2014; Millenaar et al., 2013) and the ability of the non-affected parent to manage this (Barca et al., 2014) have also been reported as leading to stress and distress. Children and young people may experience isolation as they struggle to find an outlet for their concerns both in and outside of the family (Allen et al., 2009; Barca et al. 2014; Gelman & Greer, 2011; Millenaar et al., 2013; Nichols et al., 2013).

Until now research has focused upon identifying themes of shared experience in this population. To date no published study has explored the subjective lived experience of having a parent with YOD. This is important as although individuals may be experiencing the same situation, their perceptions, experiences and processing can potentially vary considerably. This study addresses this by using Interpretative Phenomenological Analysis (IPA, Smith & Osborn, 2003), a qualitative method which aims to capture lived experiences and the meaning of such experiences to the individual.

By using IPA methodology this study aims to explore the personal meaning attached to having a parent with YOD; to consider how this impacts on relationships with other family members; and to consider positive as well as negative impact of having a parent diagnosed with YOD. The findings may be considered in relation to establishing the needs of this population and what interventions and services may best meet these.

## **Method**

### ***Design***

This qualitative study collected data via semi-structured face-to-face interviews with individuals who had a parent diagnosed with dementia before 65 years of age. The study utilised IPA methodology (Smith & Osborn, 2003). IPA is an idiographic approach which focuses on in-depth analyses of how small and homogenous groups of individuals make sense of their experiences and attach meaning to them. This is achieved through a process known as the “double hermeneutic” in which the researcher tries to make sense of the participant’s experience of making sense of their own experience (Smith, Flowers & Larkin, 2009).

### ***Ethics***

Local Ethics Review Committee approval was obtained for this study.

### ***Participants***

Participants were recruited by healthcare professionals (HCPs) working within dementia services in a demographically rural area of the UK (population c.680000). Participants were aged 18 years of age or above with a parent with a diagnosis of dementia confirmed before the age of 65, who were between 6 months and 5 years of diagnosis and still alive. Participants needed to be aware of their parent’s diagnosis and be fluent in English.

Five participants aged between 23-36 years were recruited (2 males and 3 females). All participants had daily contact with their parent whether in person or by phone. One participant was the main caregiver for her parent with YOD and two of the participants had children of their own. Parents were aged between 51 and 63 years of age at the time of diagnosis and were between 1-5 years from diagnosis. Alzheimer’s

disease was the main type of YOD within this sample. Further patient characteristics are presented in Table 1. Pseudonyms are used to protect participants' identity.

\*insert Table 1 here\*

### ***Procedure***

At scheduled appointments prospective participants were either approached directly by HCPs if accompanying their parent, or an information pack was given to the attending partner or friend to pass on to them. Prospective participants then contacted the first author directly.

The first author conducted semi-structured interviews with participants in their home or work establishment. Written consent was obtained from participants prior to interviewing, this included consent for the audio-recording of the interview.

A bespoke interview schedule was developed by the first author in consultation with the research team. Interviews lasted between 32 and 90 minutes, and the mean length of interviews was 57 minutes. Each interview was transcribed verbatim. To protect participants' identity, participants' transcripts were assigned pseudonyms and potential identifiers were removed. Participants were offered a gift voucher for participating and were telephoned 48 hours after each interview in case the interview had raised any difficulties for them.

### ***Analysis***



In line with the IPA approach (Smith, Flowers and Larkin, 2009), each transcript was initially read alongside listening to the audio recording of the interview. Transcripts were then read and re-read several times on a case-by-case basis. Line-by-line analysis of each transcript was carried out, and three types of codes were identified: (i) descriptive codes – key words describing content (ii) linguistic codes – the words employed to describe the experience (iii) conceptual comments – where data was questioned for meaning to provide an interpretative context. Identification of these codes provided insight into the ways in which participants spoke of and thought about issues. These were used to develop emergent themes which captured the participant's individual experience. Emergent themes within each transcript were then collated and connections between themes were made. This process was repeated for each transcript. The themes that had arisen in each transcript were compared and the themes were integrated. Super-ordinate and sub-ordinate themes were identified. A summary table of themes with illustrative quotes from participants was then created (see Table 2). Yardley's (2000; 2008) four principles for validity in qualitative research were attended to throughout the study to ensure that the research was sensitive to context, rigorous, transparent and coherent.

### **Findings**

The analysis revealed five overarching themes. They describe participants' experiences of having a parent with YOD diagnosis. The five themes are:

- (1) "Like I know them but I don't know who they are"
- (2) "You just look up to them for all your life and then now they're looking to you for help"
- (3) "I feel like she can get things off her chest"

(4) “You are never going to understand until you are in my position”

(5) “Hang on a minute, this could happen to ... to me”

\* Insert Table 2 about here \*

### **Theme 1: “Like I know them but I don’t know who they are”**

This theme addresses relationship changes between participants and their parent with YOD. This comprises two sub-themes: (i) “And they’ve just gone, that’s ... that’s the worst part”, considers relationship strength, and (ii) “You are sort of treading on eggshells”, examines communication within the relationship.

*“And they’ve just gone, that’s ... that’s the worst part”*: All participants struggled with loss of a meaningful relationship with their parent. Kate felt her father had: ‘just gone, that’s ... that’s the worst part about it’. Kate still wanted her father to fulfil the parental role and struggled with this loss: ‘I’ve just wanted him to like ... hug me, or just tell me everything’s going to be okay’. Kate felt she was left with ‘nothing’, even though her father was still alive: ‘Last night I went to see him and he forgot who I was, he couldn’t even tell me my name, and I thought ... ah, it’s just ... that’s heart-breaking’.

Matthew spoke of a subtle loss and reflected on the conundrum of knowing, yet not knowing who his father was anymore: ‘So you look at someone and you know who they are but ... you’re not quite sure... [...] but the way they’re talking is like ... completely different to how they would be’.

Quality of pre-diagnosis parental relationship impacted on relationship quality post-diagnosis for participants in different ways. Ben’s relationship with his father had often felt uncertain and he felt that dementia had ‘robbed’ him of a chance to

reconcile this. Ben struggled with this, positioning his experience against those of his peers:

I just kind of ... I think ... I think ... frustrated; frustrated and kind of ... robbed of a ... of one ... a big relationship that, you know, I see some people ... get to share with their dads, why they have ... they have a dad, they know that their dad was proud of them or something, [...] whereas I don't think ... I don't think I've ever really had...

For Anne the irony of the situation was that it had enabled her to rekindle her relationship with her mother. This had been 'a battle', but disease progression had led Anne to become more accepting of her mother in the presence of loss:

...we didn't have an awful relationship, but we didn't have a ... brilliant one either [laughs]. [...] it was pretty horrific really, she ... you know, living in your Mum's home when she doesn't want you here is quite hard. [...] fortunately as ... as her disease has progressed I think she's just relaxed a lot more and ... actually its ... it's no problem, you know.

**“You are sort of treading on eggshells”:** Participants spoke of how they had become more aware of their communication style in interactions with the parent and how they manage this. Diana felt a strong need to be compassionate in communication to what her parent was experiencing, yet this was sometimes difficult:

You have to remember not to lose your temper with them because ... it's ... they can't help it, its ... part of what's happening inside them and ... their mind. [...] not get frustrated with them and ... get angry or anything, because it is ... it's not helping you and it's not helping them.

Matthew described the process as ‘treading on eggshells’ which required a conscious effort to show greater sensitivity and patience in communication: ‘You are sort of treading on eggshells, you’re just ... things you say and that, you don’t know if they know the ... quite get it’.

Participants struggled with their parent’s changing thought processes, cognitive inflexibility, and one-sided communication which left them feeling unfulfilled. Diana grappled with this unpredictability: ‘Some days you can get a really good conversation out of her, and then other days ... it’s a bit ... mixed really’.

Anne clung on to her mother’s residual language as the dementia progressed, but there was a cruel irony: ‘Years into her Alzheimer’s, she couldn’t pick up a fork, she’d ... she’d quote Shakespeare whilst eating dinner’.

In trying to understand his father, Ben questioned what his father could understand. However such questioning did not provide Ben with answers and added to feelings of helplessness:

...he’s an enigma, we’re just like ‘I don’t know ... I don’t know what he’s thinking’. You can make assumptions, like is he ... is he scared about it? Is he worried about it? Is he upset? Does he really just think that there’s nothing wrong with him, and he just gets up and he does his daily routine?

## **Theme 2: “You just look up to them for all your life and then now they’re looking to you for help”**

This theme captures participants’ adaptation to role changes since their parent’s diagnosis. There are three subthemes (i) “I never thought I’d be doing for her”

considers caregiving responsibilities (ii) “It’s kind of on hold at the minute” relates to participants sacrifices to their own life, and (iii) “It’s splitting me” examines responses to caring.

***“I never thought I’d be doing for her”***: Participants differed in the level and type of care they were providing, but they all seemed to experience similar feelings as they adjusted to their new role. For Kate the impact of her father’s illness felt relentless, ‘a nightmare’ and she struggled with the reversal of roles:

It's just seeing someone that you love so much, like ... they are the ones that ... oh I don't know, you just look up to them for all your life and then now they're looking to you for help. [...] that's all I can say really, it's just a living nightmare. I hate it.

Anne’s life had been significantly disrupted by her mother’s illness, she reflected on this and how her mother would be ‘mortified’ of her daughter being responsible for her personal care:

I never ever thought I'd be living back in my family home in my thirties [...] she needs full care, which I never thought I'd be doing for her, and I'm sure she never ever dreamt I'd be doing it for her; she'd be mortified if she knew, you know, what was happening now. She was a very dignified lady in that sense, and very private.

Role reversal was expressed by Diana as a sense of needing to protect her mother like a child yet experiencing helplessness:

I suppose really ... you just want to be there for them, or you want to ... you know, I suppose it's like with a child, you want to protect them don't you?

But then with this you don't know how you ... how you can do that.

For Diana and Anne there was an additional sense of role reversal as their mothers could not perform grandmotherly duties. Anne reflected on this in terms of social comparison and a silent mourn over such a loss of role for her mother and resignation to this were clear:

I often wonder what it would be like to have a family without my Mum [...] sometimes you see my friends and they've got their grandparents who look after their children, they go back to work and it's ... it is support rather than us supporting her. But it's just the way things are and I suppose you've just got to get on with it.

***“It's kind of on hold at the moment”***: Some participants spoke about how they felt their own life had been placed ‘on hold’. Anne reflected on the scale of changes to her own life:

You know, I changed what I thought was my career to having to come back to the UK, which was ... I never thought I'd be back in this country to be honest, I was quite happy where I was. [...] I ... we've still got our lives ahead of us [...] But it's kind of on hold at the moment. [...] I didn't realise I was giving up everything then

Anne was ‘quite happy’ with her previous life and how the changes had been ‘huge’. Anne juxtaposes her own future with her mother's. This aided acceptance of her life

being 'on hold'. Although Anne adopted a pragmatic approach to how her own life has been affected, the impact of the change is tinged with regret at not realizing how much she was 'giving up'.

Kate compared her situation to that of her peers, and felt that caring for her father had deprived her of 'enjoying stuff':

I don't feel like a normal twenty-seven should do. I just feel like too much things have changed and ... you know, I ... I should be out there living my life, enjoying stuff, and I just don't feel like I've had that opportunity to. So it's ... yeah its bad.

For Kate there was a sense not just of her life being on hold, but of being 'held back'.

This stemmed from a sense of duty:

I want to do more stuff but I can't; I feel like my Dad holds me back...He's not holding me back, it sounds awful to say that as well, but I feel like, as if there's no-one here for him so I need to be here.

***"It's splitting me"***: All participants expressed difficulty managing their parent's illness as well as other responsibilities, but the personal impact and reasons for the burden varied. Anne describes this process as 'juggling' and approached it with a degree of humour:

I suppose it's a part of my life. It's not something I would want to do, but it's not particularly a huge issue, its more ... its more juggling the time with him [baby] and Mum; you can guarantee accidents always happen at the same time [laughs] [...] I think err ... sometimes I do feel quite guilty, because you ...

sometimes you snap, or you say ‘Come on, let’s get going’, and its pushing my Mum, moving her because ... I have him as well. So it’s ... it’s not always easy on her in a sense, it’s splitting me.

Anne perceived herself to have adapted to the situation, yet still declares it is ‘not easy’, and is ‘split’ by her mother and young son physically and emotionally leading to guilt. Anne reflected on how her mother is metaphorically as demanding as a ‘baby’, drawing analogies to her son and how life now lacks spontaneity: ‘I can’t even just nip to the shops, for example, I can’t leave my Mum here. So in that sense it’s like having a baby [laughs]’.

Ben describes the shock of responsibility and the sense of isolation and abandonment he experienced being put in charge of a family business: ‘In the past few years I’ve been in tears in that workshop, practically having breakdowns standing there, just because ... I could ... I was not prepared for it at all’.

Kate struggled with feelings of failing her father as she was unable to support him at home: ‘I felt like I’d failed him for that, because maybe I should have took the time out to look after him and give him a bit more attention, but ... I didn’t. I couldn’t do it’.

Sole decision-making responsibility and needing to ensure ‘everything is right’ for her father highlights Kate’s sense of isolation and the enormity of the burden she feels over decisions she makes ‘carrying that to my grave’:

So everything else is just ... my decision. [...] I’ve got nobody to make the decision with, [...] I’ve got a lot of guilt, I’ve got a lot of hate ... and I ... I’ve got to live with that for the rest of my life. But ... I’ll obviously regret it when



he's gone. I think maybe I should have done more with him, or ... yeah, but ... hard.

### **Theme 3: "I feel like she can get things off her chest"**

This theme considers issues related to concern for the non-affected parent. For three of the participants this was predominant and was related to awareness of potential caregiver burden and the limits this placed on their non-affected parent's life. Diana worried about her dad having time for himself, and taking a break from caregiving responsibilities:

But my main concern is my Dad really more than anybody because, as I say, he's there day in, day out, and okay he goes out a little bit, but then ... you know, I worry about him, that I don't want him to feel that he can't ask somebody for help, you know. And that's why I've said to him ... and he's sort of said to me 'Oh no I'll be fine, I'll be fine'.

Diana offers her father support, but her father appears to downplay the impact of his wife's diagnosis on him, this feeds into Diana's concerns for him.

Ben placed his concerns for his mother within the context of long-standing family relationship dynamics. Ben's concerns for his mother resulted from a recognition that his mother will always be a constant in his father's life:

I just tend to find myself worrying more about ... about Mum. I just ... I think that's the thing, is that I think the lasting ... the lasting thing of my existing relationship with Dad is that ... I was always closer to Mum, and that now, in this ... at this point my main concern is that Mum's alright and supporting her

[...] So ... I know that Mum will look out for Dad, and I'm ... my priority seems to be more well I'll look out for Mum.

Ben spoke about the sorrow he felt for his mum and how she was now 'doomed' by his father's diagnosis denied of a relaxed retirement. Ben attempts to see his father's dementia diagnosis through his mother's eyes and empathise with her experience and the impact this may have on her:

I know she was looking forward to ... them being able to retire and do stuff together. [...] Dad's not the same ... person, he's changed; it's a subtle change, but it's enough of a change that if you've been married to someone for forty-odd years that's not the same person; looks the same, sounds the same, isn't ... isn't quite the man that she was in love with, you know.

The powerlessness in the support participants were able to provide the non-affected parent was acknowledged by Matthew:

I see her upset and it's like ... wishing you ... you wish you could do something, like if it was an organ and you can give it to someone, just so ... even if it just stopped the progression you'd ... you'd do that, I' feel like I'd want to do that straightaway, but ... I can't, got nothing to do about it is there?

Matthew saw his role as being someone for his mother to talk to:

I try and talk to her about it, but then it gets ... easier and easier. Well not, it doesn't get easier, but ... I just feel like she can get things off her chest and stuff like that.

As a result Matthew assumed the role of confidante, by adopting this role he was happy for other family members to share their concerns with him and in return felt that this helped him to cope:

I think I feel stronger because I know how bad everyone else is going to be, so I know ... I think to myself 'I have to be stronger for them', for when they need the help or whatever.

#### **Theme 4: "You're never going to understand until you are in my position"**

This theme examines both informal and formal support for participants. Most participants valued being able to talk to others about their situation, but limits in the utility of this were apparent. Ben preferred talking to family members rather than friends as he found that communication with them had become superficial: that he was 'trotting' things out, retelling his story but without the emotional involvement:

I find myself talking to them, and then you kind of ... I find myself saying the same thing. [...]is it ... am I really thinking about that or is that ... is that just an ... that's just how I've decided I feel about it and now that's just what I say.

Others such as Kate preferred not to talk. Kate's reluctance was perpetuated by her perception that others could not understand her situation as they lacked shared experience. Even though the experience was 'killing her inside', Kate rejected others' attempts at empathy choosing to isolate and distance herself, she also appeared to worry about what to say to others:

People always ask me at work 'Oh you must be going through a really bad time, I understand', well you're never going to understand until you're in my position, and that really gets my back up. But it ... it's difficult, I mean what

do you say to people? [...] I'll sort of like distance myself, but I will never say like 'This is killing me inside'. And it is, but I ... I don't talk about it to my friends because I just feel like that's something that people don't need to know.

Kate's reaction to the concern of others for her was not just limited to friends and colleagues, her sense of not being understood extended to the HCPs involved in her father's care: "Every one of them in that hospital turned round and said 'I understand your position, it must be really difficult', and I thought 'You don't. You're never going to understand it because you're not me'."

Matthew and Ben found it easiest to talk to friends who, although did not have parents with YOD, had relatives with either a neurodegenerative or terminal illness. Ben reported how this was one of the most 'helpful' experiences in identifying with the illusion of coping with a parent with a degenerative illness and the reality of it: 'It kind of just gives you a bit of ... perspective on it. And I think that's the hard, one of the hardest things to get'.

However, Ben reported that what would have helped most would have been to have spoken to others in the same situation:

...it would probably help ... help more because, like I say, you might not ... necessarily have to go into the real ins and outs of it ...you can ... you can get a bit of insight into ... into how the situation looks from the outside right? Because it's really difficult when you're stuck in the middle of it.

Participants suggested that formal services needed to be more proactive in addressing and attending to their needs. Anne felt that even though she was a health care professional navigating health care services was often difficult: ‘I think if I hadn’t been a nurse and I didn’t understand the systems and how...how awkward they can be I wouldn’t be able to access half of what I have been able to’. Ben also felt that services needed to be more visible: ‘We kind of felt like we needed ... the support givers to be a bit more proactive ... and come and tell us stuff’.

Ben acknowledged that the support would be available if he asked, but he felt strongly that the support available for those with a parent with YOD should be formally stated from the outset:

My brother, myself and my sister don’t ... have never really had anybody ... say ‘actually I’m coming to see ... to see you guys, to see how you’re getting on’ or to get ... to provide sort of ... support in that respect. I ... I think that ... they would ... they would happily do it if we said ‘Oh well actually can I have a ...’, you know, ‘... can we talk about it?’, and they’d be more than happy to do it, but I don’t ... it’s not actually happened.

### **Theme 5: “Hang on a minute, this could happen to ... to me”**

This theme looks at how participants’ own lives were affected by their parent’s diagnosis of YOD. It comprises 2 subthemes (i) “It just...knocks you about” addresses the threat of YOD to self (ii) “you only live once” considers how participants view their future.

**“It just...knocks you about”:** Participants spoke of ‘shock’ upon discovering their parent’s diagnosis. Kate described this in physical terms: ‘it just ... knocks you about. It’s knocked me about, I still am as well’. Even where family history was significant such as in Kate’s, the diagnosis still challenged preconceptions: ‘and I think dementia is for someone who is old, not for fifty-three’. Feelings of uncertainty led some participants such as Ben to question their own mortality. A dialectic is present between what is ‘inevitable’ and what is ‘possible’ in respect of his own dementia risk:

I could find myself in Dad’s situation, you know [...] well hang on, is this ... is this inevitably going to happen to me or is it possibly going to happen to me, have I got an increased likelihood?

For Kate the dual uncertainty in respect of her father’s health and her own potential genetic risk led to difficulties in planning ahead. Kate speaks of not being able to have ‘any plans’ which imbues a sense of lacking direction. Kate defines her own risk of dementia as ‘always a big worry’, but despite this there is resistance to genetic testing which would clarify her risk and reduce uncertainty; this appears to have come from her experience meeting a genetic counsellor:

I think the worst thing that they said to me was ‘If you’ve got it you would need to break the link’, as in I couldn’t progress in life to have children. And I just ... I can remember sitting there thinking ‘You bitch’. Because I thought if my Dad would have known would I be here today?

Kate’s sensitivity to such comments led her to reflect on the trajectory of YOD. Kate expressed hopefulness that it can ‘skip a generation’, yet shortly after this is contradicted by ‘and I know more than likely one day I’m going to get it’. Reflecting

the processing of uncertainty by Kate, there is an interesting dynamic between earlier comments regarding her risk being ‘a big worry’ and her comments regarding the utility of ruminating on potential risk and how she considers the potential of other illness. Kate appears to be attempting to be pragmatic yet contradicts herself.

**“You only live once”:** All participants appeared to value life more as a result of their parent’s dementia diagnosis and their own potential risk. For Ben ‘living in the moment’ offered him a way of managing the uncertainty as well as giving himself time off from the burden of responsibilities he had taken on. This sentiment was echoed by Anne. Anne’s approach to managing the uncertainty was informed by witnessing her mum ‘scraping and worrying about her retirement’, but then not being able to enjoy it:

She’s got to retirement and actually ... she can’t enjoy anything that she’s saved or, you know, scraped and really worked hard for. [...]I’ve thought about it more than I would have done had this have not happened.

Kate struggled more than any of the participants with her father’s dementia and at times during the interview was overwhelmed about her future. There was defiance towards the dementia preventing her from living the life she wanted:

I’m going to have children. I’m not going to let this stop me. And I feel like as if it is cruel ... if it is, but I’m not going to go ... my life, living a 50:50 chance that ... you know, I could get cancer tomorrow so what’s the point in me worrying about dementia? If it happens it happens.

## Discussion

This study investigated the subjective experiences of having a parent with YOD. Five main themes emerged from the analysis highlighting changes in relationships with the parent living with YOD, shifts in role and responsibilities, concern for the non-affected parent, the need for participants to be supported and the personal impact to self of the parental YOD diagnosis.

The experiences of participants in this present study showed some consistencies with previous published findings (Allen et al., 2009; Barca et al., 2014; Gelman & 2011 Millenaar et al., 2013; Nichols, 2013; Svanberg et al., 2010). However, this study also highlights important individual differences in the perception of, and response to, their circumstances. It provides unique insights into how young adults process the experience, navigate relationships and role changes, and how they manage the potential risks associated with a YOD diagnosis in terms of their own life stage when they are at an age of having their own family, relationship and career responsibilities.

The relationship between participants and their parent was defined by “anticipatory grief” and presence of an ongoing sense of loss. This had a significant impact on participants and how close they felt to their parent (Allen et al., 2009; Barca et al., 2014; Svanberg et al., 2010). The opportunity to review and renew parental relationships facilitated participants coping with the degenerative changes witnessed, but where denied, feelings of guilt, anger and frustration were exacerbated. The stress-process model of caregiving in dementia (Pearlin, Mullan, Semple & Skaff, 1990) suggests that relational deprivation and loss of closeness within a relationship



can have a negative impact on caregivers and family members, with poor relationship quality affecting both emotional and physical well-being.

Participants adapted their own lives in light of their parent's YOD. This took place in the context of role reversal. Increasing dependency of parents often magnified the ironies of dementia, particularly for those with families of their own. For some this evoked a sense of their own lives being interrupted and put on hold. This, combined with perceptions of their own life course being "out of sync" with that of their peers, illustrates how YOD impacted on participants' own life stage development and the social norms associated with being a young adult (Harvey et al., 2003) and how it is likely to differ from offspring of those diagnosed with dementia over the age of 65 (Brown et al., 2012).

Most participants were not responsible for primary caregiving duties. However, distress associated with caregiver burden was prominent and manifested itself in feelings of guilt. There was individual variation in how participants managed this. Where caregiving duties were tangible, participants appeared to employ problem focused coping strategies. However, when participants experienced a lack of mastery or control of the caregiving situation, feelings of hopelessness were experienced. It may therefore be that perception of the caregiving role and ability to manage it, rather than actual level of role, may be the most influential feature in the level of burden experienced by individuals (Pearlin et al., 1990).

In accordance with other studies, concern for the non-affected parent was often the predominant worry (Allen et al., 2009; Barca et al., 2014; Millenaar et al., 2013). By

providing space and support for the non-affected parent, participants assumed the role of protector as this was perceived to minimize burden for the non-affected parent. However, this concern could be constrained by existing relationship quality with the non-affected parent (Barca et al., 2014). The triadic relationship involving the child and both parents was strongly influenced by the previous relationship as well as relationship changes.

Participants' own care needs were many, but central to this was for others to understand, identify, and empathize with their situation. Lack of personal experience of YOD acted as a barrier to communication. Participants felt that they were better understood by friends who also had experience of illness within their families. However, the opportunity to meet with others in a similar situation to themselves was deemed invaluable. This adds to the findings of Barca et al (2014) that participants desired support groups which were personally meaningful to them.

Participants in this present study felt that their own needs were not specifically considered by HCPs. Although HCPs supported the non-affected parent, participants felt that they lacked visibility and a presence in their own lives. Participants wanted HCPs to respond proactively to their needs to help them manage feelings of stress, burden and guilt and to enhance their understanding of YOD. Although recent policy drivers such as the "Dementia Triangle" (Royal College of Nursing, RCN, 2013) recommend that the whole family is considered within dementia, in practice focus is on the primary caregiver or partner (Roach, Keady & Bee, 2012; Svanberg et al., 2010a; van Vliet et al., 2010).

Participants experienced uncertainty about their own future. Most were able to manage their worry, but at times it overshadowed their lives. Fears over risk were managed by adopting mindful coping strategies which focused upon living in the moment rather than looking ahead and trying to live their lives before the possible onset of any dementia. This potentially helped participants cope with the day to day realities of YOD (Allen et al., 2009). Only one participant had been offered the option of genetic testing. Her reaction to such testing and implications in terms of her own future fertility was similar to findings reported in studies addressing attitudes to pre-symptomatic testing in those at risk from Huntington's Disease (Duncan, 2008; Taylor, 2004; Wahlin, 2007)

### ***Study limitations***

There are several limitations to this study. Due to the rural location in which the research was carried out, the potential pool of participants to draw from was small; this created greater homogeneity, but meant that recruitment was limited. Potential participants were often not present at clinical appointments where information about the study was given out. Their awareness of the study was dependent upon parents sharing the information. The interviews were carried out at a single point in time, which meant participants were often recalling events that had happened some time ago. The experience of having a parent with YOD is likely to vary as time passes from initial diagnosis to palliation. To map the YOD journey experience more coherently, future research could focus on obtaining longitudinal qualitative data sets either at different time points or disease phases within the dementia pathway.

### ***Clinical Implications***

This study has shown how young adults who have a parent with YOD are a population who potentially go unnoticed by HCPs. Current service provision focuses on the primary caregiver and services are designed with that in mind (Roach, Keady & Bee, 2012; Svanberg et al., 2010a). Given the isolation experienced by participants in this present study, both from services as well as their peer group, it is vital that dementia services take account of the needs of the whole family. Although it may be easier to identify children that are still living in the family home, this should not take away from the impact a parental diagnosis of YOD may have on young adults living away. Young adults have differing needs, due to their specific life stage and personal responsibilities. It is important that HCPs take a full family history and that their availability to other family members is made clear. This should be undertaken in a proactive rather than responsive manner from an early stage.

Young adults with a parent with YOD may benefit from one-to-one support in understanding the diagnosis, disease trajectory and personal implications in terms of potential genetic risk. It is important that HCPS also acknowledge the role played by young adults in supporting their non-affected parent and how they are able to manage their own lives in light of the YOD. Attempts should be made by HCPs to develop support groups for those who have a parent with YOD. This is something participants in this study identified as being valuable (see also Barca et al., 2014). Face-to-face groups or the development of an online forum, may suit this age group.

### ***Conclusions***

This study reveals the personal impact of a parental diagnosis of YOD for young adults in terms of relationship changes, impact on own life and threat to self. Participants experienced isolation and stress as a consequence and felt that their needs were often unmet. A spouse or a partner may often be the primary caregiver for the individual living with YOD, but as this study shows this is not always the case. It is vital that HCPS working within dementia services recognise this, and also identify and reach out to all members of the family so that those who have a parent with YOD are not left isolated and uneducated about their parent's condition. Information provision, psycho-education, providing points of contact, and developing an online support network for young adults with a parent living with YOD, may be some ways to reduce this isolation. Online support networks have already been successfully implemented in relation to other illness and conditions such as cancer.

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**Table 1: Background participant information**

Pseudonym	Age at time of interview	Age at time of parent's diagnosis	Parent with YOD	Age of parent at time of diagnosis	Time since diagnosis*	Type of YOD	Family demographics
Kate	27	25	Father	53	1 year 5 months	Frontal lobe dementia	Only child parents divorced, lives alone Father in care home, has a partner
Anne	36	30	Mother	60	5 years	Alzheimer's Disease	One brother living abroad. Lives in mother's house with, mother, partner and young baby. Primary carer for her mother with assistance from carers.
Diana	35	33	Mother	63	1 year	Alzheimer's Disease	Lives with partner and young baby and daughter aged 4. Parents live 3 miles away. Brother nearby.
Ben	36	35	Father	63	2 years	Frontal lobe dementia	Lives next door to parents, brother nearby, sister has moved away.
Matthew	23	21	Stepfather	51	1 year 6 months	Alzheimer's Disease	Lives in family home with parents and 3 siblings aged 14, 17 and 24). Been brought up by mother and stepfather since 18 months old

\*confirmed by nursing team



**Table 2 - Interview Themes arising from the IPA analysis**

<b>Super-ordinate theme</b>	<b>Sub-ordinate theme</b>	<b>Sub-themes</b>
“Like I know them, but I don’t know who they are”	“ <i>And they’ve just gone, that’s...that’s the worst part</i> ”	<ul style="list-style-type: none"> <li>• Parent not able to fulfil parental role</li> <li>• Loss of knowing the parent as they used to know them</li> <li>• Parent becoming a shell</li> <li>• Relationship quality</li> <li>• Pre diagnosis relationship quality</li> <li>• Social comparison of peers relationships with their parents</li> </ul>
	“ <i>You are sort of treading on eggshells</i> ”	<ul style="list-style-type: none"> <li>• Patience</li> <li>• Frustration</li> <li>• Cognitive inflexibility/set-shifting</li> <li>• Unpredictable communication</li> <li>• Comprehension/understanding</li> <li>• Trying to understand what parent is thinking</li> </ul>
“You just look up to them for all your life and then now they’re looking to you for help”	“ <i>I never thought I’d be doing for her</i> ”	<ul style="list-style-type: none"> <li>• Impact of role change</li> <li>• Adaptation to role change</li> <li>• Views on role change</li> <li>• Assuming the parent role</li> <li>• Parent becoming infantilised</li> <li>• Loss of role for parent</li> <li>• Maintaining dignity in presence of role change</li> </ul>
	“ <i>It’s kind of on hold at the moment</i> ”	<ul style="list-style-type: none"> <li>• Restrictions on own life</li> <li>• Life on hold</li> <li>• Being held back</li> <li>• Giving up own career</li> </ul>
	“ <i>It’s splitting me</i> ”	<ul style="list-style-type: none"> <li>• Juggling responsibilities</li> <li>• Guilt associated with caring role</li> <li>• Caregiver burden</li> <li>• Coping versus not coping</li> </ul>
“I feel like she can get things off her chest”		<ul style="list-style-type: none"> <li>• Parental caregiver burden</li> <li>• Supporting parent</li> <li>• Awareness of impact of YoD on healthy parent</li> <li>• Powerlessness versus becoming the strong one</li> <li>• Pre-existing relationship dynamic</li> </ul>
“You’re never going to understand until you are in my position”		<ul style="list-style-type: none"> <li>• Communication with peers</li> <li>• Being understood versus nobody understanding</li> <li>• Rejection of empathy</li> <li>• Shared experiences</li> <li>• Formal support</li> </ul>

<b>Super-ordinate theme</b>	<b>Sub-ordinate theme</b>	<b>Sub-themes</b>
<b>“Hang on a minute, this could happen to...to me”</b>	<b><i>“It just knocks you about”</i></b>	<ul style="list-style-type: none"> <li>• Physical impact of the diagnosis</li> <li>• Preconceptions about dementia being challenged</li> <li>• Realisation of own potential risk of YOD</li> <li>• Future planning</li> <li>• Attitude to genetic testing</li> </ul>
	<b><i>“You only live once”</i></b>	<ul style="list-style-type: none"> <li>• Living in the moment</li> <li>• Escaping responsibilities</li> <li>• Leading a valued life in spite of own risk</li> <li>• Defiance against dementia</li> </ul>