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The impact of parental young onset dementia on children and young people's educational careers

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It is well established that having a parent with any illness or disability can have an adverse effect on individuals' experiences of education and on their educational progress. Advances in medical knowledge are leading to more people under 65 being diagnosed with young onset dementias and, concomitantly, to more children and young people who are in education having a parent with this diagnosis. Hardly any research has asked these young people directly about their experiences, but the limited evidence suggests that there will likely be significant emotional, mental and psychological damage with enduring impact on their lives. This article, drawing on findings from a unique narrative, auto/biographical study involving 24 British 6 to 31-year-olds, focuses on the consequences of parental young onset dementia for educational careers. These dementias are untimely progressive terminal illnesses with unpredictable trajectories and timelines, throughout the course of which physical, cognitive and emotional functions and abilities are inexorably lost. Participants' experiences show that living with a parent with young onset dementia, whilst negotiating the education system, can be extremely hard. Difficulties are exacerbated by the condition's distinctive characteristics, the current lack of any cure and anticipatory, pre-death grief. Lack of public awareness and understanding, both of young onset dementias and of dedicated resources and support services, also result in many feeling isolated and ignored. We make suggestions for positive provision and actions that educational institutions can make to begin to meet the particular needs of these young people.

Keywords: parental illness; educational careers; young onset dementias; narrative life history

Introduction

Dementia is recognised as one of the major global health and social care challenges of present times (Alzheimer's Disease International, 2016), having significant far-reaching consequences for the health, wellbeing and life courses of those with the diagnosis and also for their relatives. As the leading cause of death in England and Wales, it affects many families (ONS, 2017).

Within the media and in public perception, there is a tendency to equate dementia with Alzheimer's disease, characterised by memory loss and confusion affecting older people (Hillman & Latimer, 2017). However, there are many types of dementia, and advances in medical knowledge are leading to more people under 65 being diagnosed

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with young onset dementia (YOD). Current estimates suggest that YOD affects around 42,500 people in the UK (www.youngdementiauk.org/young-onset-dementia-facts-figures; Young Dementia UK, 2015), although, given the general under-diagnosis of dementia and of YOD in particular, the incidence is probably higher.¹ Whatever the ‘true’ figures, increasing numbers of children and young people, most of whom are in education, have a parent with YOD.

Despite a lack of research which has asked these young people directly about their experiences, let alone with a particular focus on their education, existing evidence suggests that parental dementia can lead to significant emotional, mental and psychological issues and have an enduring impact on lives (Allen *et al.*, 2009; Svanberg *et al.*, 2011; Barca *et al.*, 2014; Millenaar *et al.*, 2014; Gelman & Rhames, 2016).

YOD generally manifests when people are in their 40s and 50s, when most are working and meeting familial, financial and social commitments. Variants include: vascular dementia, dementia with Lewy bodies, fronto-temporal dementia, young onset Alzheimer’s, posterior cortical atrophy and dementias associated with Huntington’s and Parkinson’s diseases, and alcoholism. Some types are inheritable. Whilst memory loss may be, and always becomes, a feature of YOD, initial symptoms include: uncharacteristic behavioural changes, aggression, social withdrawal, disinhibition, lack of empathy, hyper-sexuality, difficulties with planning and judgement making, visual disturbances, hallucinations and communication disorders. Dementias are progressive terminal illnesses, throughout the course of which people lose functions and abilities and finally, although time scales vary, they die prematurely.

Diagnosis is usually a protracted process, often stretching over years, with symptoms regularly being ascribed to stress, depression or menopause (Chrisp *et al.*, 2011). By the time the disease is confirmed, families are likely to have gone through an extremely difficult period, involving confusion and uncertainty (Teel & Carson, 2003), likely job loss (Roach & Drummond, 2014) and significant disruption to what had been ‘normal’ family practices (Hall & Sikes, 2016a). After diagnosis, people with YOD and their families generally find there is very little dedicated support or resources available to help them understand, cope and deal with the disease and its various impacts on their lives (Mitchell, 2018).

At this point it is important to note that there is a substantial body of research and literature, including autobiographical accounts (e.g. Swaffer, 2016; Mitchell, 2018), that represents the subjective experiences and perspectives of people living with dementia. Here, however, our purpose is to privilege the children and young people whose voices around parental dementia have historically been marginalised or neglected.

Parental illness, disability and education

Research in the fields of social policy, health and childhood studies documents that those who have a parent with a disability or a serious or chronic illness report adverse consequences for their education. Given the importance of schooling for the future life course of most children and young people (Sanders *et al.*, 2016), it is clear that worries, pressures and disruptions at any stage of an educational career can have potentially far-reaching and profound consequences (and in a future article we will focus on our data from a life course/transitional perspective). Findings from research

with young carers² reports that key educational challenges include: poor attendance, tiredness, bullying, inability to participate in extracurricular activities, problems with concentration and application, difficulties completing homework, anxiety, behavioural problems, poverty and non-existent or limited parental involvement and communication with the school (Dearden & Becker, 2003; Aldridge, 2008; Hounsell, 2013). Those who do get to college or university may face problems due to caring responsibilities, financial hardship and emotional stress (Sempik & Becker, 2014). The Department for Education clearly recognises that this is an area warranting attention and, in the absence of existing education-based studies, has commissioned research that corroborates these findings (Aldridge *et al.*, 2016; Cheesbrough *et al.*, 2017). Looking specifically at dementia, a 2016 National Children's Bureau survey focused on children involved in caring for a person with dementia (usually a grandparent) also found all these issues (NCB, 2016).

The study

This article draws on an Alzheimer's Society-funded investigation, *The perceptions and experiences of children and young people who have a parent with dementia*, which sought to explore what it is like to be in this position with a view to informing practice and policy. Elsewhere we have written about the period leading up to diagnosis, experiencing parental change, grief and how dementia can affect family relationships (Hall & Sikes, 2016a,b,c, 2017; Sikes & Hall, 2016, 2017). Here our focus is on educational careers.

The study had auto/biographical origins in the first author's observations of the impact her husband's young onset dementia had on their children, who were 13 and 15 when their father first began to exhibit behaviours that were later attributed to the condition. Most aspects of their lives, including their educational careers, were and continue to be affected, since at the time of writing they are 26 and 28 and their father is still alive. A life historical, narrative approach (Goodson *et al.*, 2017) was employed. Acknowledging that narratives are constructions subject to a myriad of influences, we believe that, when biographically and contextually located, they can suggest something of the complexity of lives, indicating how individuals make sense of the things that happen to them, negotiate identities and create futures (Goodson, 2017). Participants were not asked specific questions but 'simply' invited to tell their stories of parental YOD, which were then considered in light of a relational model of disability which situates personal experiences of dementia—whoever is telling them—within the broader social context (Shakespeare *et al.*, 2017). Such an unstructured approach has not previously been used to explore experiences of parental YOD, but has the potential to inform the development of more appropriate and inclusionary interdisciplinary services than can follow from using 'traditional' methodologies (Hutchinson *et al.*, 2015).

The project was advertised on a project website, on Alzheimer's Society (UK) and Young Dementia UK platforms, and on Twitter and Facebook. With two exceptions recruited through snowballing, the 24 participants 'found' us when they were seeking YOD information and support for themselves or, in two cases, for their children, thus indicating the paucity of such resources.

Although we had specified an age range of 8 to 25 (following WHO and UN definitions of youth), participants were aged from 6 to 31 with the majority between 16 and 24. Feeling it would have been unethical to exclude them, we included four over-25s who approached us and whose retrospective accounts were clearly relevant. The youngest children (aged 6, 7 and 8) were also included on ethical grounds: their mothers contacted us saying they were eager for their children to talk about their fathers' dementias, both for potentially therapeutic reasons and to contribute to understanding. Having spoken with them, the children were deemed to have the capacity to consent.

Fourteen participants were currently in education—at school, college or university studying for bachelors, masters or doctoral degrees. The nine who were in work were all educated to degree level. One woman had dropped out of university due to her mother's declining condition, but was intending to return. This is, therefore, a self-selecting sample of predominantly white, British, middle-class participants who were willing and able to speak reflectively and fluently. However, extant research and anecdotal accounts from health and social care professionals (in the UK and North America) suggest that other young people who have a parent with YOD are likely to recount similar experiences.³

To capture the progressive nature of dementia, most participants were interviewed more than once over 18 months: 9 twice and 10 three times. During the project four parents died; two participants were already bereaved when they joined the study. Interviews, which were recorded and transcribed in full, lasted between 45 minutes and over 2 hours, with the average being an hour and a half. Sessions with under-10s involved play, drawing, family tree and 'my day' story-telling activities (James, 2005). Ethical approval was granted by our university. Participant consent, plus parental consent for under 18s, was ongoing before and throughout interviews.

We have employed pseudonyms and, when particularly sensitive topics are discussed, we alter the details to further avoid identification. We have signposted to medical practitioners or suggested contacting support agencies such as the Samaritans when deemed necessary. The second author checked up on participants following the interview and also a week or so after.

We took a grounded approach whereby accounts were interrogated for themes in a manner that retained the story as a whole (Riessman, 2008). Transcripts were repeatedly read by both authors in an iterative fashion, to cross-check themes. In this article, as we have a specific focus, we present the data in a thematic fashion. This does mean that some participants are quoted more than others, simply because of where they were in terms of their educational career and what was especially concerning them at the time of the interviews.

Stories of educational careers and parental dementia

All participants talked about educational experiences, often at length. We have taken extracts from their stories to illustrate some of the ways in which parental YOD impacts educational careers using the following headings: Locating parental dementia with reference to educational milestones; Dementia-specific challenges; Education as an escape/coping mechanism; Dementia and educational choices; Educational

institutions' responses. These themes are not exclusive, nor do they cover everything that was said relating to education. We can only share a fraction of what we were told which, although the norm when reporting qualitative studies, seems particularly ethically problematic given how generous participants were in offering what were often extremely painful accounts. In recognition of, and to honour, this, we have presented relatively substantial illustrative quotes with minimal commentary.

Locating parental dementia with reference to educational milestones

Given that education is a, if not the, major organising principle and system in and of most young people's lives (James, 2005; James & James, 2012), it is not surprising that events in educational careers were used to locate and date steps in parental dementia journeys:

It progressed really quickly from the summer when I finished my A levels. . . for a while she was alright but then. . . in my second [university] year. . . I made Christmas dinner for me and my parents and she had a live-in carer at that point and she was like, very different to how she was but she didn't need to wear a nappy at that point. . . she wasn't great but she was alright and then I went back to uni, and she started running away and getting lost and. . . having psychotic episodes so she was taken to hospital and it seemed to happen like within a week of Christmas and then BOOM. I don't. . . know what switched in her brain after I went back to uni that year. And then she was in hospital on the 18th January, I remember that date because. . . my dad called me just before I had a Spanish grammar exam, which I did abominably in, I passed it but not well, and then I came home straight after. (Lauren, 22)

I'd just finished my first draft of my dissertation and literally I just saved it and sent it to my tutor and a couple of minutes later Dad called to say the doctor's called to say its dementia. (Alexandra, 22)

Within the UK, widening participation in higher education means that for increasing numbers of young people educational careers culminate with graduations. Graduation has come to be a culturally important celebratory occasion and ritualised rite of passage which family and friends are expected to witness. Our participants reported feeling sad, stigmatised and aggrieved if their parent was unable to fully participate in this ceremony, or was deemed unable to attend. This is exacerbated when the parent in question has been a major supporter of their child's educational achievements.

I got a first in my degree and I was really happy about that but by then Mum had got no comprehension of what that was. She knew that I'd passed but there was no awareness of what it meant so it was kinda hard to take. . . she was there at my graduation. . . But it was marred when you know that someone is there but they're not. (Alexandra, 22)

It wasn't great. I got through it but it was upsetting. . . I didn't consider that I'd need a pin to put the green thing [hood] on and so one of my friend's Mums had to help me and I was like 'I want my Mum to help me'. That was a bit shit. (Lauren, 22)

Sam chose to stay away from his graduation altogether to avoid the pain of his mother's absence, whether cognitive or physical:

It was easier for me to just not go, I couldn't bear to have had her blank face there not knowing. A lot of people... went to their graduations for their parents... It bothered me a bit seeing them with their parents, I kind of wished it was the same for me which is pathetic because every other day it doesn't bother me. (Sam, 21)

Dementia-specific challenges

Young people described dementia-related behaviours that could be disruptive when they were trying to study:

My sister was going through her GCSEs at the time when we didn't have a diagnosis and I think she was flying off her nut a lot because Mum would walk into her room without knocking and stand there and watch her. (Alexandra, 22)

As the condition progresses, hindsight can lead to guilt and regret about interruptions whose possibility would now be welcomed:

I know I feel an awful lot of guilt because... when the symptoms were starting to show... there was one day she called me four times in an hour and every single time she'd say 'I've just put the washing machine on' and I was in the middle of doing an essay. I had three days to do it and I was like 'Mum you need to stop calling me, you've already told me this three times today' and I got really angry at her. I called Dad and told him to... get her to stop calling me and I suppose if we'd known, I would have been more patient but we didn't know and I feel guilty about the way I'd spoken to her and the way I dismissed her and because of that, she stopped calling altogether... and I... feel I missed an opportunity to hear her voice and if I could do it all again, I'd... stand there and appreciate that that was her voice and it was part of her and I'm not gonna hear that again and through my actions, I stopped her calling me. (Alexandra, 22)

The dementia trajectory is unpredictable and variable, although it always involves decline that, in YODs, can happen particularly quickly. The person is there in body whilst being progressively and profoundly altered in terms of the characteristics that made them uniquely them. Observing and experiencing this can take a particularly heavy toll on relatives, who have constantly to grieve losses whilst having to accommodate further changes:

Every time I see him he's the worst he's ever been and the best he'll ever be. (Alex, 24)

Thus, dementia involves anticipatory grieving (Lindauer & Harvath, 2014; Blandin & Pepin, 2015) prior to actual death:

I felt like I was in this long queue waiting for my number to be told that he's died because you know it's coming... you just don't know how long you've got to wait. That's the worst part, not knowing... They have one good day and three bad days and then the bad days outweigh the good days... It's been three years of constant grieving. (Remy, 21)

Not surprisingly, research indicates that anticipatory grief is a significant source of stress, depression and physical, mental and emotional health issues, and a major factor affecting quality of life generally, with negative consequences for relationships, career development and educational progress (Large & Slinger, 2015; Sikes & Hall, 2016, 2017). Experiencing such profound grief exacerbates the challenge of completing educational assessments:

She's at the end stage which I didn't know until a few weeks before my exams so that sucked. She's generally deteriorating. The worst timing. . . I just wanted to be home, didn't want to do my exams. It wasn't that I didn't care, I just couldn't focus. . . my brain was in such a mess that I had to focus on how I was going to get myself to the library to revise let alone do my exams when I was so upset and miserable. (Lauren, 22)

A few days before my dissertation deadline in May. . . I get this call from my Dad's care home saying 'your Dad's been rushed to hospital, they think he's got septicaemia'. . . I have anxiety anyway, very much preparing for the worst. . . Every day, I'd have my phone out all the time. . . I felt that I was just waiting for Dad to die really. (Remy, 21)

The rate at which people with dementia lose capabilities, memory and function varies. There can be periods of rapid decline followed by plateaus:

I get used to it and then she gets that bit worse and then. . . I get really upset again. . . you get used to a new normal every few weeks it seems, or even a shorter time, there's a new normal and it's so unpredictable. (Lauren, 22)

Living with someone day-to-day it can be possible to adjust to incremental changes without particularly noticing them. Going away to university, however, means that returning home and seeing the difference can be shocking:

I then went back to Uni and I didn't come home that semester so in the four months that I'd been away, she changed an awful lot. (Alexandra, 22)

Having to juggle university and home-based responsibilities can raise dilemmas over where to be and when:

I was in London over the summer from like August so I saw her twice a week, maybe three times, now I see her once a month. I wanna see her more but I don't know how to work it around uni. . . When I was in first year, I used to go home every two weeks, every three weeks but then because she doesn't really know who I am. . . it doesn't matter to her as much. It matters to me but I don't think she notices or knows. (Lauren, 22)

When she passed away I was about to graduate, so all of that has happened while I was doing my final exams, and that was all really important but I also wanted to be as far away from the situation as possible so I did bury myself a little bit in work but maybe I didn't spend the time I should have, even if she didn't appreciate it, I think now after she's gone. . . I feel bad for not doing that. (Blair, 21)

Education as an escape/coping mechanism

Going to school, being at university or college can provide a sense of 'normality' and valuable distraction (Carers Trust, 2016):

I can just come in, even on my days off. . . I can paint, I can draw, I can make a mess, I can make things, I can tear things apart, break things. And you can get away with everything being an art student because it's art. . . I've thrown myself into my work. I love art, it's my therapy. . . College is my stability. Because I do art, it's a good release. If I can't sleep, I do course work, so it helps me out. (Tamsin, 17)

This Masters is the last piece of the jigsaw, and one of the reasons I did it was so I wasn't at home. . . it's given me normality in all of this. . . it's given me something to focus on. . . I've got

friends here... that you can just do normal things with, go to the pub, go to lectures, normality, structure and routine in all of this and it's probably the one thing that's keeping me going. (Liam, 22)

As Liam notes, social relationships with peers can help in maintaining a sense of normality. However, participants talked of reluctance to mention their parent's illness, largely because of ignorance of dementia exacerbated by media focus on dementia as Alzheimer's and a disease of older people:

I find it really difficult with some of my friends who really don't get it and it's not their fault that they don't get it and that's what I need to keep telling myself because... they might be coming out with stuff like 'oh my grandma had it, you know, she wasn't great, she was a bit forgetful' and I'm like 'yeah, hmm hmm'. (Jennifer, 17)

It was the dementia side of things as well because when you are 14, 15, people who have dementia are normally really old people and it's like actually my Dad was 65 when he passed away which I think is still quite young and no my Dad wasn't an old man... And there's that phrase being 'demented' and when I was younger, that was a word that was thrown around a lot and that would really hurt me because it was used in such a derogatory manner, that's not who my Dad is. (Frankie, 23)

Frankie's account here alludes to the stigma and associated spoiling of identity (Goffman, 1963; Werner *et al.*, 2010; Gove *et al.*, 2015) attached to dementia, both for those diagnosed and for their families. Perceived 'difference', whether one's own or one's parent's, can lead to difficulties fitting in at school, to stigmatisation and bullying (Thornberg, 2015):

Just embarrassing. One day, he took the dog out and the dog ended up on our school field. My year were doing PE, the dog were running about, my Dad were just stood there looking at him. He came into school once, I don't know what for... brought the dog, tied the dog, you're not allowed to bring dogs into school, dog in school on the extendable lead but didn't lock it so the dog run out in the road, the lead got knotted, all my friends were like 'Jessie, your dog is tied up outside the school', they were stroking the dog... And people bring it up now, 'remember that time the dog were on the field'. (Jessica, 16)

Like at school it was hard because kids didn't understand and I used to get bullied for it because they used to say 'your mam's mad' because she'd go take the dog for a walk but she would shout stuff and it didn't make sense and kids being kids would just give me grief about it and then somebody from the school, their parent had had it, they did a talk to try and help understand. Kids just don't understand. (Claire, 31)

Dementia and educational choices

Several participants made educational choices at least partly because of parental dementia. For some, decisions were based on being close to, and spending time with, their parent:

One of the reasons I'd applied to do a Masters in London was to move closer to them and I was looking forward to going home every weekend and seeing them and actually that kind of turned out not to be the case [both parents died] but I'm really enjoying it anyway. (Erin, 24)

I wasn't entirely sure last summer what I wanted to do... I felt my life had been put on hold and I wasn't getting anywhere... I wasn't comfortable leaving home because I wasn't sure when I visited what stage Mum would be at and how much I would have missed... I looked around and my uni did a part-time January start course and I figured it out from there that I could travel down a couple of times a week and be at home... it is quite stressful... but it's manageable... I didn't want to waste any of the time we had left. (Alexandra, 22)

Looking after her was killing me. I was doing so much, was trying to do my uni work as well... I was working part time and trying to look after her, my Dad was working full time as well... So I've given it up now, left uni officially... I hope to go back one day. It's something that I've really enjoyed and I'd hate to waste it. (Hannah, 20)

After her GCSEs, Jennifer's school was not prepared to modify her sixth-form timetable to allow her to visit her dad during the afternoons when he was awake. She chose, therefore, to do her A levels by distance learning, despite the financial costs incurred:

Distance learning suits... I mean there's a lot of problems still... [but] I like it, I like that I've got my freedom, if I've gone to see Dad and it's been an awful visit, I can just sit and relax and get on with my work the next day, that's what I enjoy but there's nothing out there to help me with that, you have to pay for it all, your benefits get cut, everything that you had before is cut. (Jennifer, 17)

Jennifer's story also points to the difficulties posed by planning educational careers when the future is uncertain:

I don't know how the years will pan out, it's so unpredictable, that's the worse thing. Because when he got diagnosed, no one really knew anything was going on at school because I had it in my head, maybe when I start teaching, when I've finished university, Dad'll have to go into a nursing home... Maybe this'll be in about ten years, I never thought [it'd happen within] a year... I'll stay close to home probably with Dad because I feel like if I moved far away I'd feel like, 'what if Dad wanted, needed me', I would be quite on edge. I don't want to be like literally really close. I'm still thinking of going to X so I could go for the week and then come back on a weekend, that kind of thing. But I don't know, it still all kind of depends. (Jennifer, 17)

On a more positive note, there were those who found academic and/or potential career interests through their contact with dementia:

Mum's diagnosis probably was the fact that I started to get interested in neuroscience... When you relate to stuff like that you pick up a bit more in lectures rather than fall asleep at the back... I don't think I'd be doing the PhD I'm doing if it wasn't for that. (Blair, 21)

Educational choices and careers can be hard at the best of times. This participant's account points to how dementia can make negotiating one's way seem overwhelming:

During the summer, the same time we got the diagnosis, that was the same time I sent off my application to go to University. I was arranging accommodation. I'd got on my course, not the accommodation, I'd slightly messed up the paperwork they wanted... I thought I'd missed the boat regarding accommodation, and with everything over the past months with my [parent], it came to a head... I tried to end things for myself if you know what I mean by that. [name removed]

Educational institutions' responses

At a general level, some educational establishments are engaging with dementia awareness, for example, involvement with the Alzheimer's Society Dementia Friends programme (www.dementiafriends.org.uk) or other local initiatives focused on older people with Alzheimer's (e.g. DiBona *et al.*, 2017; Farina, 2017). On the whole, this involvement tends to be in terms of community service and/or fundraising, with very few schools having dementia education embedded in the curriculum (Farina, 2017, p. 1). However, such initiatives do not usually raise awareness of YOD and can reinforce the perception that dementia affects older people with memory problems which, many of our participants found, made it difficult for others to understand their experience.

The mothers of the primary-age participants, concerned about the uniqueness of their children's situations and wanting to do something to address potential teasing or worse, had approached the schools and had spoken about dementia, including YOD, in assemblies and staff meetings. At the prompting of their mother, Yasmin's (6) and Amber's (8) school had provided emotional literacy and art therapy sessions and were flexible in allowing time off for the holidays the family were taking with a view to building up positive memories. Sidney's mum was also proactive in getting him psychological support:

At school this lady comes to visit me about Dad and asks if I have any worries. I saw her last Friday. I see her on a Tuesday usually, I tell her how my week has been. (Sidney, 9)

Experiences at secondary schools were mixed. Sometimes the schools did not sensitively match their response to students' needs. Jess and Frankie, like many adolescents, found it difficult being marked out as 'different':

People are like 'are you alright Jess?' Just out of the blue... They've obviously had a meeting about it or summat. They can't make it anymore obvious if they'd tried. Like teachers that haven't taught me, 'ah Jess how are you feeling? How are things at home?'... I said specifically don't give me special treatment but I got it anyway. And it makes everyone think 'oh she's getting special treatment, what's she done?' (Jessica, 16)

My school didn't really understand what I was going through, no one was there to help me through it... the teachers weren't there, there wasn't a counsellor... My dad passed away on the Wednesday and I had a GCSE exam... on the Friday and so I went in to do the exam because I didn't like to give up on stuff... I don't like people taking pity on me, don't like that attention, didn't really want that at that age and I overheard a teacher say 'oh yeah she's in for this one exam but then delay it' and that was talking about me in front of a load of other people, not very respectful really. (Frankie, 23)

Ignorance about YOD, especially on the part of teachers, angered a number of participants, including Jennifer:

I spoke to the school counsellor a bit and she was quite helpful, but I mean the teachers and the heads did start to know... I think they still found it very difficult to understand you know? Like I think they just took it as, 'oh she's got someone in the family with dementia', I don't think they really got how much it can kind of affect you, you know. I mean, my head teacher, she was just like 'oh well, my Mum had it' and it's like NO! And she went 'I was relatively young, I was in my thirties with my Mum'. And I'm like 'hmmm hmmm' and I'm just trying not to say 'well, you

know, you really don't understand', you know trying to keep on top of everything, but it just kind of angers you, like as to how much people don't know. (Jennifer, 17)

At college and university the onus is on the student to inform staff about their circumstances. Those who had done so usually felt supported:

It's been hard especially in the last year it felt like I was struggling, trying to keep to deadlines. The uni was amazing, I probably handed in every assignment a week or so late. That was okay because they all knew. My tutors were amazing, they've always been aware of what's happening because several times I've had to walk out of lectures. . . because I'm upset. (Remy, 21)

I did actually ask for an extension on one assignment and I was given it, which was good. I didn't want to ask for one, but my fiancé was like 'you need to' and actually a few days after my Dad's operation was when my auntie died as well, it was a pretty tough time and he said 'you need to ask for an extension, you have to have one'. So I did. People ask for extensions but I felt almost as if I was sort of failing a little bit I don't know, like I didn't really deserve it. (Louise, 24)

Lauren and Frankie had found counselling easy to access whilst at university, but struggled upon leaving:

At Uni, I had counselling but because I'm not a student anymore, I don't get that and it's kind of annoying because I manage how I feel better when I have it. . . I don't really know how to go about getting it now. (Lauren, 22)

University was a breath of fresh air for me. . . I'd lost my Dad by the time I went but I spoke to the counsellor a couple of times, so there were services there. It wasn't in depth but I wanted to talk to someone. It was three years after, and that's not long when you are 16/17, caught up in A levels and then all of a sudden you're living by yourself. (Frankie, 23)

Conclusion/discussion

Having a parent with any terminal illness is painful and difficult for any child or young person. In focusing on YOD, it is not our intention to imply a hierarchy of terminal illnesses. However, this condition demonstrates unique characteristics that raise specific challenges and these certainly warrant attention. The unpredictable trajectory and duration of the illness, the untimeliness of the progressive and inexorable loss of functions and abilities which usually lead to a period of time when the parent is there bodily but not verbally, cognitively or emotionally, and the current lack of any cure are especially hard to bear. Indeed, our participants talked of having cancer envy (Hall & Sikes, 2017), because parents living with cancer may be able to continue to communicate, to advise, support with educational decisions and financing, and work to resolve the relationship problems that are not uncommon in adolescence. Living with a parent with YOD, who is very different from how they were, and who may be behaving in unpleasant, difficult and embarrassing ways, coping with ongoing uncertainty, grief and fear, whilst taking exams and negotiating the education system, places a considerable burden on young people who are living in a society where educational choices and performance are important influences on future life chances.

The key motivation for this project was to elicit evidence to address the lack of information, support and resources available to children and young people who have a parent with YOD. With regard to educational experiences, we were told stories which, when considered within a relational model of disability frame (Shakespeare *et al.*, 2017), offer some suggestions as to what might help make things at least a little better. Of paramount importance is addressing the ignorance surrounding YOD. Our data shows that many people working in educational establishments are not aware that dementia affects ‘younger’ people, that there are other variants than Alzheimer’s disease, or that the condition is terminal. Given that the majority of children and young people who have a parent with dementia attend schools and colleges, there would seem to be a case for a national steer to provide dementia education for staff, and also to include some coverage in initial teacher education. The Alzheimer’s Society’s Dementia Friends and Young Dementia UK, who are aware of our findings, could make a contribution here.

As we described, the mothers of the younger participants took the initiative in providing information to their schools. There does tend to be a closer relationship between parents and teachers during the primary years, with more opportunities for interaction simply because parents often go into school at the beginning and end of the day, thus facilitating conversations about what is going on at home. Such relationships may help with families that are facing challenges. But relying on families and children/young people to educate is unacceptable. When schools become aware that a student has a parent with YOD (or any uncommon condition), staff need to undertake the necessary research to be in a position to offer, or know how to access, support and information. And of course, they should be equipped with the resources for providing this. As Frankie noted:

School was such a massive part. School would have been the main thing, someone in the region that visits schools, not just for dementia, but like wellbeing, counselling, that would have been good. I think when you’re young, when I was 14, 15, having someone explaining to me about it probably would have made me realise the seriousness of it and that he’s not going to get better but also the kind of biological things that are happening because I didn’t realise that he was going to lose his speech or be hallucinating, he used to scream out which was shocking, not nice to see, it’s just that lack of explanation, more than anything. (Frankie, 23)

Ideally too, and on the basis of informed knowledge, schools should consider accommodations to make things easier for students to cope. For example, had Jennifer’s school understood that dementia made her father become sleepy as the day progressed, they might have been more understanding about her request for a timetable modification.

When young people get to college and university the onus does tend to be on them to inform tutors about problems, or to seek help from counselling services—although here too there may be a lack of awareness that needs to be addressed. Some students, like Sam, are reluctant to reveal their situation, even though they may recognise the sense in so doing:

If there could have been something through the University that would be good, something that could acknowledge that these things happen at the worst time. . . I mean how can the uni know, that’s the problem? But if you mention it there should be something that they can point you in the

direction of, it can lead to so many things... anxiety, depression, isolation, feeling in a different situation to everyone else, academically. I don't think it really affected my grades or anything but it certainly could have. It did make me very lethargic, unable to get out of the house... More input from the University, that is the key because I just kind of felt like I wished that my tutors knew but I didn't want to... but they've got so many people to worry about. (Sam, 21)

It is recognised that there is a crisis in children and young people's mental health care (Care Quality Commission, 2017; DOH/DOE, 2017). Those who have a parent with YOD are but one group in need of improved provision. They are a group, however, who, to date, have been largely invisible, although the limited evidence available points to the severity of their difficulties and to the ongoing impact their experiences can have on their education and future life. To date, children and young people have not been considered or given a place in dementia care, and there is no clear policy directed at how best to support them. Such developments are important and should incorporate directives for educational institutions, thus facilitating multi-agency support for children and young people. Children and young people require support if they are to fulfil their educational potential, enjoy the social opportunities education can bring and ameliorate the exclusion experienced by those who have a parent with dementia. Schools, colleges and universities are uniquely placed to provide such support, and of course should be enabled to do so.

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NOTES

- ¹ The Health Economics Research Trust in 2010 reported a figure of 64,000 but this may have been based on inaccurate estimates (www.futurelearn.com/courses/faces-of-dementia/1/steps/76481).
- ² It is important to note that not all young carers wish to identify as such, even when they take on carers' responsibilities (Hall & Sikes, 2016b). Nor do their parents choose to identify them as such (Aldridge, 2018).
- ³ Following reporting of the study on social media and UK TV and radio, a number of people have contacted us from North America to share their experiences of parental YOD. Barring contextual details (e.g. different healthcare and educational systems), the stories are the same.

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