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“It Would Be Easier If She’d Died”: Young People With Parents With Dementia Articulating Inadmissible Stories

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Abstract

In the U.K. context where the emphasis is (quite rightly) on living well with dementia, on positivity and enabling approaches, it can be difficult for researchers to investigate and report negative experiences. Failing to re-present perceptions and experiences as they are lived, however, does a serious disservice to the research endeavor and can prevent policy and service development and positive change. In this article, we present some stories told by participants in an Alzheimer’s Society (United Kingdom) Funded project uniquely investigating the perceptions and experiences of children and young people who have a parent with dementia. Sometimes the stories were not easy to hear, especially when they challenged dominant master narratives around dementia. We discuss our view that when the young people we spoke with told us how things were for them, we were ethically bound to respect and disseminate their accounts.

Keywords

Adolescents; youth; young adults; children; dementia; families; illness and disease; qualitative; Biographical approaches; UK

Background

Dementia, the umbrella term given to a multitude of diseases affecting the brain, can emerge at any age. As well as Alzheimer’s—the commonest and best known form—dementias include frontotemporal and vascular variants, dementia with Lewy bodies, posterior cortical atrophy, Creutzfeldt–Jakob disease, and dementias associated with Parkinson’s disease, HIV/AIDS, and alcoholism. Symptoms often involve extreme behavioral changes (Stewart, 2006) such as aggression, social withdrawal, loss of empathy, exhibitionism, short temper, obsessive compulsions, difficulties with planning and judgment making, visual disturbances, hallucinations, loss of physical functions, aphasia, and other communication disorders. Approximately 850,000 people in the United Kingdom have a dementia diagnosis, of whom approximately 42,500 have “young onset dementia” (YOD), that is, dementia before the age of 65, with numbers rising due to enhanced life expectancy and medical advances (Alzheimer’s Society, 2014). Concomitantly, the numbers of children and young people who have a parent with dementia are also increasing. While some research documents certain social and psychological consequences of having a parent with dementia (Allen, Oyeboode, & Allen, 2009; Barca, Thorsen, Engedal, Haugen, & Johannessen,

2014; Gelman & Greer, 2011; Harris & Keady, 2009; Hutchinson, Roberts, Kurrle, & Daly, 2016; Johannessen, Engedal, & Thorsen, 2015; Luscombe, Brodaty, & Freeth, 1998; Millenaar et al., 2014; Roach, Keady, Bee, & Williams, 2013; Robertson, 1996; Svanberg, Stott, & Spector, 2010, 2011; van Vliet et al., 2011), children and young people’s own stories have usually been neglected, with existing knowledge tending to be informed by spouses, adult children, and grandchildren of those diagnosed after age 65 (Celdron, Triadó, & Villar, 2011; Celdron, Villar, & Triadó, 2012; Harper & La Fontaine, 2009). A need for qualitative, direct engagement with children and young adults has been identified (Green & Kleissen, 2013; Roach, Keady, Bee, & Hope, 2008). This study sought to address this need.

Exploring children’s and young people’s perspectives of dementia is uncharted territory. This article explores our experiences of eliciting hitherto untold stories. Part of

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the reason that they have gone untold is that they may be construed as being inadmissible in nature.

Inadmissible Stories

Some stories are regarded as more “tellable” than others (Smith & Sparkes, 2008), either from the narrator’s perspective because some subjects constitute socially acceptable conversation or from the audiences’ point of view, for whom certain topics might make for uncomfortable listening. Previous research has facilitated the sharing of traditionally untellable stories with relation to, *inter alia*, illness, sexuality, and trauma (Frank, 2013; Plummer, 1995). Reflecting on the consequences of narrativizing lives, Plummer draws attention to the personal, cultural, ethical, moral, and political outcomes of storytelling. There may be therapeutic outcomes derived from the process of sharing one’s story: for example, providing space to reflect on one’s life and making sense of an experience or an event, or offering a sense of connection with others through hearing someone’s story and having it resonate with one’s own situation, thus providing a sense of legitimacy and reducing isolation, that is, “this situation was/is hard and I am not alone in facing it.” Culturally and politically, narratives can raise awareness and have the potential to change attitudes and behaviors toward marginalized groups (Sikes & Piper, 2011; Solinger, Fox, & Irani, 2008). It can, therefore, be vital to illuminate inadmissible stories.

Stories are not solely inadmissible not only because of their content but also because of who is telling them. When it comes to children and young people, this is something of a gray area and is largely subject contingent. However, children and young people have occupied a marginalized position when society renders them “seen and not heard.” The “new paradigm” in childhood studies (James & Prout, 1997), however, considers children as social actors in their own right and encourages a move away from research by proxy—that is, with adults about children—toward research directly involving them. This approach can shed light on aspects of their lives, such as school and health. However, there are complications. H. Davies (2015) urges children’s voices be sought within the context of the family and other key social relationships to understand the individual and the family. There are also some subjects where children’s voices are more readily accepted as legitimate. Sikes and Piper’s (2010) research on allegations of sexual abuse demonstrates the problems of the master narrative “that children never lie about sexual abuse.” Other topics are also regarded as no-go areas: bringing us onto the problem of doing research with children about dementia. The field is correctly concerned that research focusing on dementia should involve those with the condition as fully as

possible—“nothing about us, without us” (Bryden, 2015; Swaffer, 2016). Research with children and young people about their parent with dementia, without parental input, may be considered to be in breach of this.

Research Design

Study Design

As the aims were to give “voice to silenced lives” (Goodson & Sikes, 2001; McLaughlin & Tierney, 1993; Plummer, 2001) and to explore social and cultural experiences of having a parent with dementia, the research used narrative auto/biographical methodologies. Auto/biographical approaches have tended not to be used with children and young people. However, as James (2005) argues, “despite the brevity of their lives, children have much to say not only about their pasts but also about the plans and the ideas they have for the future” (p. 22). Indeed, narrative approaches with children and young people have revealed insights into issues around mental health and well-being (McNamara, 2013) and community projects (Goodley & Clough, 2004). Furthermore, we wished to give participants an opportunity to have their feelings listened to and validated. In our study, M.H. did not go into the interviews with specific questions, rather, she “simply” invited participants to “tell me your story.” All the participants responded enthusiastically to this and provided accounts of their parents’ illnesses, from their own perspectives, usually beginning with a “landmark” event or unusual behavior that, with hindsight, became attributed to dementia. Participatory activities such as “my day,” timelines, and family trees were used with under 10s (Appendices A to C).

A thematic approach was taken to analysis. Narratives were considered in their complete form, for example, detailing context and developments in the story over time, while teasing out key themes (Riessman, 2008). Transcripts were repeatedly read by both authors in an iterative and cross-checking process of thematic organization. Themes explored to date include the period leading up to diagnosis, experiencing significant changes in their parent (Hall & Sikes, 2016a; Sikes & Hall, 2016), grief (Sikes & Hall, 2017), and the impact of dementia on family relationships (Hall & Sikes, 2016b).

Data Collection

Twenty-two children and young people aged 6 to 31, the majority between 16 and 24, participated in the research. The age range reflects United Nations and World Health Organization (WHO) definitions of youth (15–24). We had originally anticipated interviewing 7- to 25-year-olds, although four older participants who volunteered were

included. We considered (a) exclusion would have breached our ethical standards and (b) retrospective accounts were relevant. The sample includes only children, those with divorced parents and sibling pairings. Two participants had lost their parents prior to, and two during, the research. A range of dementia types are represented (frontotemporal dementia, early onset, dementia with Lewy bodies, vascular dementia, posterior cortical atrophy). The younger participants were in school; at the upper end of the age bracket, participants were in employment or at University.

The research was advertised on platforms including the Alzheimer's Society, Young Dementia UK, Facebook, and Twitter. There was also a project website, and this yielded volunteers who, while conducting Internet searches for information and support, inadvertently came across the study. The University of Sheffield provided ethical approval. Potential participants, and in the case of under 18s, their families, were provided with details and given time—at least 2 weeks—to decide upon their involvement. Consent was taken at each interview and participants were reminded that involvement was voluntary and that they could withdraw at any point (two chose not to participate in follow-up interviews due to their parents' declining conditions). Consent specifically included use of anonymized data in academic articles. In the case of under 18s, parental consent was sought. Where it seemed appropriate, we recommended counseling or suggested contacting support agencies such as the Samaritans. M.H. checked with participants that they were okay following the interview and also a week or so after.

Volunteers took part in two to three interviews, which were from 45 minutes to 2 hours in length, carried out over an 18-month period. This ensured coverage of changes in the situation throughout the duration of the research. Interviews were conducted in participants' own homes or in a public place, such as a coffee shop, depending on their preference. In the case of the sibling pairings, two sets were interviewed separately, and one together.

Findings: Articulating Inadmissible Stories

Researchers have to make difficult decisions about how to re-present their findings. Here, we have chosen to discuss the inadmissible under the following headings:

- The process of narrating dementia;
- "Taboo" subjects;
- Portrayals of dementia by people without dementia

The Process of Narrating Dementia

The process of narrating dementia can be difficult, not least because of the stigmas (Goffman, 1963) related to age and

mental illness associated with the disease. Accounts revealed how challenging it was to open up about a parent's condition. For some, there was an element of wanting to preserve their own or their parents' privacy:

He's a private person, doesn't like anyone knowing his business, it was a struggle letting a carer in because I know that he wouldn't want strangers in the house looking after him, he's quite a proud man . . . "It was really hard [to tell my boyfriend] because I really don't like talking about it."

He's too weird for having people round to the house . . . I aren't really one to talk about it, not go "oh my Dad's ill."

Some found, when they did refer to parental dementia, their experiences were dismissed:

I got married in France in August and people said, "at least your mum could come to the wedding" . . . it sounds ungrateful to say, but it was actually massively stressful having her there because I wanted it in France and when we started planning it, she wasn't as bad. It's really hard to admit that because people expect you to sort of be like "yeah at least she's here, . . ." but she's not! She's not.

I've always been incredibly close to my mum, she's always been my best friend, especially as my parents were divorced, it was like me and my mum, then she started getting really withdrawn and then we started arguing and we'd never really argued before and whenever I complained to them, they were like "what's the matter" and I was like well "we're arguing" and they were like, but everyone argues and I was like "no, no they don't."

It is widely acknowledged that losing a relative to dementia means that grieving starts while they are alive (Sikes & Hall, 2017; Sweeting & Gilhooly, 1997). However, some participants found this difficult:

It makes me sad that I can't grieve for her. Not because she's not, you know I will lose her, it makes me sad that you know, the whole grandchildren, won't be around for that, lots of memories of my time at school that she's forgotten about it.

It's almost like an in a tandem place to be, you're not bereaved, but you're not *not* bereaved. You have a Dad but you haven't got a Dad.

Participation in the research therefore presented a rare opportunity to talk about their experience and it was found helpful, as some stated at the end of the interview, "That was therapeutic." Some divulged that the distress of their parent's condition had led to self-harm or suicidal thoughts, and that this was not widely known:

I tried to end things for myself if you know what I mean by that . . . I will point out that I have not told my family that I

tried to end things. There's a few friends that know but not many. I've kept that very much to myself. Partly because I don't think there's many people that you can talk to about that sort of thing and certainly in the circumstances . . . it's a touchy, sensitive topic.

I got down quite a lot of the time. There were times I just wished I wasn't here at all. Which is hard to say. I was being bullied at school and then not having a Mum to be there to go to, not wanting to stress my Dad out because he had that on his plate as well.

We had anticipated that the research encounter would be emotive. On occasion, participants were visibly upset:

I wanna make him feel amazing because I'm just like he must be aware, I just wanna make him feel valued [starts to cry]. Because he said that to Mum, he said "I'm useless" . . . sorry . . .

In these instances, M.H. offered to pause or end the interview, yet all continued, keen to tell their story.

I don't really feel like there's anyone I can talk to, who I can relate to, I don't know anyone who has a parent with dementia.

“Taboo” Subjects

Social researchers are constantly seeking to prompt debate about often unspoken, social phenomena, thus taboo subjects are par for the course. They may remain taboo for people to tell, and they are the themes we anticipated would be difficult for others to hear. Discussions about dementia raised a number of such “taboo” subjects or perspectives.

I Don't Like My Ill Parent

Constructions of the family place emphasis upon it as an harmonious idyll (Morgan, 1996). There is limited space for querying this, especially when the parent is ill and their behaviors are not their fault. The narratives elicited in this research raised the possibility that dementia can undermine familial relations in a way that makes people dislike their parent. Participants told their stories using frank language, that does not distinguish between the person and the illness, which a person-centered approach to dementia advocates (Kitwood, 1997). Consequently, these accounts challenge notions around dementia as well as family.

Before we got the diagnosis, I used to just think he were being horrible if I'm honest, because you don't think “awww, it's dementia, he can't help it,” so I kind of felt guilty but some of the things he said to me, I'd be “Dad that's awful.”

It makes someone who was a lovely character really easy to dislike and you have to really fight to not hate your own parent. Sometimes I have to say, I do severely dislike my own mother, but it's not her fault and I suppose it's not my fault, it's just the natural reaction you're going to have as well.

I don't like Mum at all. I said to my friends, a while ago, my Mum, by all social concepts, my Mum is an utter bitch. If she was a normal person and you met her, by any normal human standards, she is . . . selfish; it's not her fault but she doesn't know my name 99% of the time; she doesn't remember what I do, she's rude, always talking about herself, really negative bringing the conversation down, talks over, over and over, talks over you and doesn't let you talk to anyone else—how is that a nice person? If anyone is feeling like they don't like their Mum SOME of the time, I think that's generous! Mum would hate to be like this.

These excerpts do not convey the love and grief they were experiencing, as expressed throughout the interview. One talked about how they were unable to sleep at night because they worried whether their Dad was sleeping in his carehome; another talked about how they missed their old relationship with their parent; another spoke of the upset about their parent's illness. Family relationships in the face of dementia are not distinct from relationships before: difficult relationships prior to dementia will not necessarily be resolved at this time (Keady & Nolan, 2003). Certain family dynamics may make dementia more challenging and dementia may challenge family dynamics. For example, one, aged 17, for whom one parent had dementia and the other lived overseas, stated,

I can't talk to my Dad about that because the only thing he will remember is the emotional part so I don't wanna bring him down because that's not fair, he's not well . . . I feel like why would anyone want me if my own Mum don't? My Dad does but he can't show me that he does . . . I went in to give him his tablets when he got home and he just threw them on the floor and he was like “get out, leave me alone, you're trying to drug me.” I was just “we're done,” I couldn't be bothered anymore.

Family constitution adds further dimensions as, for example, when there are older siblings, from previous relationships:

Some members of my family were not truly appreciative of my age . . . I never felt I was getting extra something for being much younger. Very big difference to where you are in life. I kind of feel because it was so bad for them, they kind of assumed it was the same, maybe it was, I don't know. But I feel like it probably wasn't because you're at a different stage of life. [They're] never gonna know my kids if I have any and that's sad. I get angry that my [sibling] has had the

luxury of having [my parent] there at their wedding and knows their kid and things like that and I think “you’ve had the experiences that I am never gonna have.”

Every time I hear stories of [parent] having an accident, I think “we’re getting closer to a home.” Who makes that decision? Will it be my [well parent]? My [sibling] won’t cope with that very well. I can just see the family dynamic problems that are gonna occur when that talk starts to happen. We don’t have the same parent. They are going to respond very badly if they think he is doing it too soon. What do you do at that point? I would support my [parent’s] decision either way. I believe that if the carer thinks it’s best for her . . . they shouldn’t be being cared for someone who doesn’t think they can care for her, that’s an awful situation to be in. But whether everyone sees it the same way . . .

Death or Other Illnesses as Preferable

Within the interviews, some participants reflected on whether it would be better if their parent had died of another cause, perhaps a quicker one, or one that ravages the body rather than the brain.

People who have a parent who dies when they are in their teens or 20s, it’s like quick, and it’s awful but then you’re allowed to grieve, you can have a few months of just like this is whereas people don’t see that with this, they just think actually you should be grateful that your Mum is still here and she’s not dead and it’s like well, it’s really not that simple but I think admitting that to anyone is really hard because people don’t expect you to think that.

This is not to say they wished their parent dead, but the intimation here is that death is a conclusion. Particularly challenging was distress at watching their parent deteriorate while continuing their own lives, with some feeling like their lives were on hold. There was a sense of “waiting” for their parent’s inevitable death, over an unknown period of time:

I said to my counselor, I felt really bad, I kind of am saying I want my Mum to die and he was saying “no you’re not. What you’re saying is that you want the situation to end and if you could choose her not to have Alzheimer’s, you would.”

Every day, I’d have my phone out all the time . . . I felt that I was just waiting for him to die really, as horrible as it sounds that’s what it felt like because you know that’s the only outcome that there is.

Such sentiments echo experiences of caregiving stress and relief of death in dementia carers (Schulz et al., 2003). However, the lack of support means that young people are not aware of this phenomenon. In addition, a lack of time frame was seen as problematic:

You also don’t know when the end is either, so there’s no like, with my friend’s mum who had motor neurone disease, she was given 6 months, a year and that’s what it was in the end. Whereas every year, I think it could be the last year and every year I review what I’m doing. I’m just surprised to be honest. When I look back a couple of years, I thought to myself, he won’t be there when I’m 25 but, I look to the future and I think even if I got married 28, 29 he probably won’t be there. But then, looking back when I was 25, I’d think he wouldn’t be there but he is, not to say he’ll be there forever but I have no idea where it will take a sudden turn or if it will be a gradual turn or just be a sudden, I have no idea at all.

Following on from the above participants’ point about motor neurone disease was the perception that sudden death or an illness such as cancer could even be preferable to dementia.¹ Many cancers are now treatable and the disease is not necessarily the death sentence it once was (Tritter, 2009). Dementia, on the contrary, has no cure. Yet, its terminal nature is often not understood by the general public. Participants reflected on the terminal nature of their parent’s condition, and through this, the cancer comparison emerged. Clearly, no one articulated the view that cancer was a positive thing or that they wished cancer upon their parent. They did, however, identify some of the “advantages” afforded by cancer as compared with dementia.

Whereas historically cancer was a stigmatizing condition (Sontag, 1978), nowadays it invokes considerable public sympathy (Gibson, Broom, Kirby, Wyld, & Lwin, 2016). What this means is that when someone shares that their parent has cancer, a certain reaction is prompted: People know what cancer is, they understand that it does not discriminate according to age, there are social conventions to hearing this news. This is because cancer has a script, whereas YOD currently does not (Sikes & Hall, 2016):

At work, people would say “oh how’s your Dad doing?” you know knowing I had two ill parents and everyone wanted to know about my Dad’s cancer because there was progression there, there was stuff they could do and they understood it, and people understand pain in the body and people have a story. Loads of support in place and it just isn’t for Alzheimer’s, especially early onset. It’s just completely under the radar and the fact that everyone was kind of wanting to know about my Dad and I’d be saying like “yeah, my Dad’s just, you know, just getting on with it really, it’s fine in a way, but erm it’s my Mum that’s the problem, she’s got a lifelong degenerate disease which is making her turn into someone that she would hate to be’ you know?”

Cancer is absolutely horrible and there’s a lot of people that have lost their lives but because it’s quite common, people can sympathize . . . everyone understands what cancer is . . .

but dementia is a bit of an unknown . . . I think there is that stigma towards dementia, it being an old people thing.

You tell people, and they're like, "how old's your dad then, I don't get it." I almost feel like if I had said another illness, and dementia is a terminal illness and I don't think as many people see it like that, I think most people see it as "that's just what an old person does" . . . not that cancer is better than dementia but people would be like "gosh I'm so sorry, what can I do to help you?"

Crucially, there are also substantial differences in the manifestations of these diseases and potentially in their trajectory. Cancer, of course, is a life changing experience (Timmermann & Toon, 2012) with the potential for psychological impacts for the patient and their family, but unlike dementia, this is not directly attributed to the illness: it is the illness *experience*. Diagnoses of dementia, however, are in part informed by changes in behaviors and to former personality traits.

It's not like with cancer, they get treatment and can recover from it but this is only going to get worse, just like with Parkinson's. It's never gonna get better.

It's just hard to explain really. And I don't feel I know, "oh it's gonna be this many years" or "this is gonna happen" or I feel like with some other diseases, it's like "you're gonna go for this scan, then you're gonna have this treatment."

Whereas sometimes with other things, you've always got that little bit of hope but with Alzheimer's that's it.

There was also the perception that cancer garnered significantly more attention:

All this money into research for cancer and support for cancer, which is amazing, my Grandma had breast cancer, my Grandad had throat cancer, but for dementia there's nothing and I think as with any illness, unless it affects you, you turn a blind eye to it.

Similarly, comparisons were made with other diseases such as multiple sclerosis and motor neurone disease, which, in these young people's experience, had not attacked personality²:

My friend's mum recently died of MS, and her mum's had MS for I don't know, like 15 years or something or maybe longer actually, maybe 20 years and that's been gradual and deteriorating but she was still her Mum right to the end.

I've got a friend with mum that has MS and it's not the same but I appreciate now how much that that must affect her, but that's been all her life though so it's a very different experience to having the sudden bomb dropped I think. That

is comparable at least. The irony is that I always used to pity her and feel sorry for her, now I go over to her house and her Mum is much more alive than my mum is.

Dementia affects key skills, so the loss of communication skills such as speaking and listening challenges existing relationships as well as existing family practices, as this participant indicated (see Hall & Sikes, 2016b, for further exploration of this theme):

My friend had a parent with motor neurone disease and it was devastating for her but she could still talk to her parents.

In telling these stories, young people have been able to articulate their frustrations regarding the lack of understanding of what it is to have a parent with dementia, the ways dementia can change personalities, and, of course, the current lack of a cure.

Difficult Dementia Behaviors

While public perception equates dementia with memory problems, certain dementia behaviors are embarrassing or damaging and talking about them meant portraying a loved parent in a negative light.

So it was like "Mum, Dad's got cancer" and she's like "yeah yeah yeah anyway." She just wasn't . . . It's so sad, they've been married 42 years and they've had the happiest marriage I've ever seen up until this point, it's just so sad . . . Dad was going into hospital and we were all crying around the dinner table, Mum was completely oblivious: that was just really sad. If Mum could see herself . . . she would have absolutely hated it.

He grabbed my arm . . . he twisted it and I knew it wasn't really him . . . it didn't hurt me, but the way he did it. He wasn't letting go . . . something had changed . . . I blamed myself completely . . . if I'd not said anything about him hurting me . . . but he had to go in [care]. I still hate it.

Other behaviors may be difficult to talk about, for example, issues around privacy, nudity, and sex:

He comes into the room inappropriately, if you're getting changed.

He was sexually frustrated and that was really difficult. Childsafe on everything in case he does something that gets him into trouble and making sure he's not speaking to anyone . . . my friends haven't been able to go home. My brother's girlfriend goes home but I don't know if she realizes or not, we're all making sure she's never alone with him . . . Mum told me in the pub, it gets you in the tummy in exactly the same way as when a guy dumps you. Really weird. You just feel like "ugh," you don't really wanna

know that. Parents don't have sex! You'd never get this out of my brother, he'd be far too polite.

Particularly distressing for some was incontinence.

She's incontinent now. It starts to be traumatic because you're seeing your mother basically become a baby. My poor Dad, he's going to start having to change the bedsheets or buying nappies, things like that . . . like she stood in the kitchen and turned to me and said "I'm weeing" and I just said "why didn't you go to the toilet" and she just said "I don't know." And she needs the toilet every half an hour when she goes out, things like that. And it's now getting to the point where I'm not qualified to . . . my Dad, they've raised children, they know how to deal with this, I have no idea what to do. What do I do with a woman who is incontinent?

It feels important to recognize these difficult and embarrassing aspects of dementia and to acknowledge the ways in which they can challenge young people's experiences of, and relationships with, their parent with dementia. At present, there is considerable ignorance of the realities of dementia in general and young onset variants in particular and support for families dealing with these conditions is, on the whole, seriously lacking. There is a need both for education and for the young onset focused support all of our participants said was not available for their parent or for them. A few had sought counseling—but they had had to actively do so, rather than it being offered as default. Those support services, which did exist, were deemed inappropriate by participants. For example, all eschewed support for carers, as they did not identify with the carer label, while dementia services were targeted at "older" adults, such as spouses or the middle-aged children of those with older onset variants, with sessions held at inconvenient times, that is, during school or working hours (Hall & Sikes, 2016a, 2016b). For our younger participants, the "well" parent had pushed for psychological support and awareness sessions within schools, for example, Dementia Friends training, but, for various reasons, not all parents are in a position to be able to do this.

Portrayals of Dementia by People Without Dementia

Some stories become untellable because of the master narratives surrounding dementia—namely, that the person is "still the same" (Sikes & Hall, 2016) and the more recent notion of "living well with dementia," which echoes the title of the United Kingdom's national dementia strategy (Department of Health, 2009). These are of course important features of the dementia landscape, seeking to ensure that persons with dementia are treated

with respect and dignity and given the opportunity to live as full a life as possible. However, the young people's accounts force a confrontation with negative perceptions of dementia that both precede the parent's illness and reflect the parent's fears about living well with the illness. We find the notion of "living well with dementia" to be complex, and our young people's accounts confirm this. Inequalities in terms of, for instance, financial and social capital and the absence of adequate support services often render living well with dementia difficult. In addition, some people receiving a diagnosis of dementia do not want to live well with their condition—although it is too simplistic to say they are "in denial." Consequently, when reflecting on their parents' own attitudes to dementia, it appeared that these contravened this particular narrative:

She always used to say "if I ever get like that just shove me in a home, just give me a bottle of gin and a straw and just leave me to it or shoot me."

He also says things like he doesn't want to like end up in a really awful state, like he would go to Switzerland if he could.

Participants talked at length about the fundamental changes that had occurred: a parent who has become aggressive or disinterested, for example. In their experience, their parent was categorically not the same person and, perhaps as a form of self-protection, nor did they wish to believe that they were, because that parent would not hurt them and would express love and care (see Sikes & Hall, 2016, for detailed discussion of this theme).

At a wider level, the tendency for young carers to be portrayed as angels (Aldridge, 2008) also means admission of feeling frustrated becomes difficult:

Sometimes I will snap at her, or I will express my frustration . . . if she gets shouted at, she's absolutely fine, she can often give as good as she gets, if not better, she's getting increasingly aggressive as well . . . she will throw things at me, whereas she never used to do that, especially if you try to take her Sudoku off her. Even when you're trying to help her . . . she was unscrewing a lightbulb, from a lamp, and the lamp was still on and I was getting really quite worried about that and I told her to let go of it and she said no, I said let go again she said no, I shouted let go, she said no, so I had to physically come in and pull her hands away from it, and she just pushed me off her.

In offering participants a "safe" space to narrate their experience, it is not surprising that coarse and even politically incorrect language, certainly in relation to mental health and dementia, is employed:

This person looks like Mum, but they're not Mum at all . . . completely different! Completely *barmy* and completely not

a person. She's gone completely *mad*, she's trying to escape from the house, she's like screaming, in the garden, in her dressing gown, she just looks like a complete *crazy* woman.

Dad has an infection a few weeks ago, and he went super *crazy*, he thought I was trying to drug him, he didn't know who I was at all, didn't know who anyone was.

If he were to have cancer and he was to be laid in bed all day every day, and he looked ill, I'd probably be upset but he doesn't seem ill. He just seems weird, like a *retard*, because he is.

Some narratives could be interpreted as being disparaging about old people, but rather, perhaps, reflect the division of older and younger people, exacerbated by the omniscient construction of dementia as an older person's issue. Our participants were weary of the one-dimensional understanding of dementia and that support services did not cater to their needs:

I mean they were *really* old. Like it felt they were all white hair, perm. Funny on their feet, they just looked *old*.

Politically incorrect it may be, but this is how the young people chose to describe their experience. We not only support the use of positive language but also acknowledge the need to give credence to young people's experiences, and reporting these accurately is a tension. Indeed, participants reported that an already difficult experience was exacerbated by the stigma and isolation of not being able to share their parent's behaviors with others. It may also be that some of this language mirrors broader views within society, such as ageism and stigma around mental health.

It is not our intention to undermine notions of "living well," or "nothing about us without us." What we are arguing is that it is vital that there is a place for children and young people who are in the process of losing their parent to have a voice if they are to receive the support they require. We are also mindful of the policy rhetoric at play, that places emphasis on domestic care settings and the considerable fears that surround dementia as a condition (Academy of Social Sciences, 2016; Alzheimer's Disease International, 2016).

Reflections on Telling and Potential of Narrative

These young people's stories were incredibly difficult for them to tell. Young people may not be accustomed to having a space to talk at length, and in dementia research, this certainly seems to be the case. The process of narrating parental dementia was upsetting, yet cathartic, raising taboo subjects, using frank language that

challenged dominant discourses on dementia and family. We were able to offer our participants a safe space to talk about their experience with their parents' dementia. M.H. was also able to reflect back to the young people and provide them with a sense of legitimacy for their feelings, for example, stating that other people had aired similar views.

In reflecting on the narratives our participants shared, there was a resonance with Plummer's (1995) work on sexual stories. He suggests that there has been a call for people to "tell about your sex," sharing trauma, sexuality, desire, dysfunction, and so on, all within the context of confessional society. Plummer's analysis indicates that the end result is not just that people have the space to share their accounts but doing so can invoke change. Similarly, young people telling their dementia story are telling their stories in their own right. But this research has much wider ramifications. Stories may serve as a catalyst for social change. They are not stories for their own sake but stories which, to paraphrase C. Wright Mills (1959/1970), make personal troubles public concerns in a way that can be transformational. Part of this endeavor relates to ensuring that these rich narratives are given the platform that they deserve. We now go on to explore the process of *sharing inadmissible stories*.

Sharing Inadmissible Stories

To date, our findings have been reported in a number of articles. We are discovering that as Gair and Moloney (2013) suggest, some stories are not welcome. Although there was positive feedback from some journal reviewers, "I applaud the authors for challenging the accepted narratives as not being representative of a family," this has not been the case across the board. A reviewer for an article submitted to a leading childhood studies journal commented,

The focus in the article only on negative outcomes for children and young people of living with parents with dementia is inappropriate and potentially damaging . . . The dangers in describing the onset of parental dementia as "identity spoiling" for children and young people unfairly puts the blame on the affected parent . . . Academics and researchers also have a responsibility not to add to negative perspectives and stereotypes about people with serious health conditions such as dementia by suggesting that such conditions contribute to "spoiling" children's identities and social credibility.

We have spoken with 22 children and young people, and, with the exception of the 8- and 6-year-old siblings whose parent had only just been diagnosed and who was currently mildly affected, their stories of the impact of dementia on their lives have been negative. We

consider not acknowledging these experiences would be unethical.

In addition, there is presently substantial media interest in dementia (NHS, 2011), so it was no surprise that our research attracted attention; it is novel research that brings a “young” angle to the subject. Our commitment to using stories to help other people meant that we were keen to reach a wide audience. Therefore, when journalists and television companies approached us, we accepted their invitations.

We were very anxious about exposing participants, largely due to the lack of anonymity incurred, and exacerbated by the potentially controversial nature of the stories. These young people’s accounts challenge dementia narratives that place emphasis on notions of “living well” with the condition and that the person is “still the same.” Many of our participants were emphatically *not* living well with the disease that had robbed them of the parent they once knew. This meant taking great care which participants were included. Proponents of childhood studies have called for children’s voices to be heard and for adults to avoid constructing them as vulnerable. But clearly, there are tensions in pursuing this endeavor. We felt asking a child to participate in a television interview that is likely to remain in the public domain (e.g., on YouTube) for the foreseeable future, regarding an event that is still unfolding, was inappropriate. Similarly, we did not feel able to put young people with significant experiences of self-harm and depression forward to participate. We were certain that each of our participants had a worthy story to tell, but were concerned that public exposure was not desirable for everyone. To date, our principle mainstream media coverage has featured two participants. We will now reflect on our experiences with this.

We were initially approached by a weekly national broadsheet paper. However, it became apparent that they were keen to produce a story with potential to sensationalize: They wanted us to put forward the youngest parent and youngest participant in the study, rather than focusing on the story in hand. We decided, therefore, not to pursue this avenue. *The Huffington Post*, however, offered one of the research participants the opportunity to write a blog post. This ensured mainstream coverage of the project online, written by the participant without a journalist’s interpretation (Williams, 2016).

In May 2016, as part of Dementia Awareness Week, one was interviewed for a feature on BBC Radio 1’s Newsbeat (Butterly, 2016a). This participant’s account refers to his love for his mother and how he wishes things were different. He does state, “What I’m effectively saying is in some scenario, I would prefer that she wasn’t here.” There were positive responses to the features, including on Twitter:

A moving story of the impact of #dementia from a son’s perspective. (Duxbury, 2016)

@Alz_Soc_Media@HallyGolightly@BBCNewsbeat@BBCNews can also relate 2this!The stories of young carers is so vital as they need support (Little, 2016). (Gemma Little, May 16)

@BBCNewsbeat A very open and honest interview. So sad for Chris. (Light, 2016)

Two were featured on Channel 4 news (Originally aired: May 16, 2016, 7:00 p.m., Channel 4, 2016). Again, this sparked positive comments, with the piece being described as “moving” and “powerful.”

Moved by the story on @Channel4News & the incredibly brave young people sharing their grief as they lose their parents to #dementia. (Abbey, 2016)

Moving piece on @Channel4News about #research into the effect of #earlyonset#dementia on families. For anyone who has suffered #bereavement. (Whittle, 2016)

However, there was also controversy. The headline on the BBC website was “Dementia has made my mum less human but I still love her.” Some interpreted the emphasis as on “less human” rather than on the participant acknowledging the qualities that made his mum the *human that he knew*:

So Radio 1 Newsbeat are running a supergross disablist story today, about the impact that dementia has on families. (Jamie, 2016)

My heart aches for this family, but I don’t think the angle of dementia making someone “less human” is very helpful. (West, 2016)

A student doctor working in a dementia unit (Butterly, 2016b) commented on the feature. She wrote, “There were lots of happy moments [in the dementia unit] and it’s just embracing the person they’ve become and accepting they have changed.” Caring for a person in a paid capacity is quite different to having a parent with dementia. Putting narratives such as these in the public domain is imperative if people like Sophie are to be enabled to “begin to imagine” what people in his position are going through. Similarly, the *Channel 4 News* piece was headlined “Children of sufferers,” which contravenes The Dementia Engagement and Empowerment Project (DEEP; 2015) guidelines and would not have been our chosen terminology. Nevertheless, we are grateful that our participants’ stories have received due recognition and consider this the start of coverage. The promotion of our research has proven to be a learning curve, reaffirming the need for close working with producers who

are empathetic to the situation and the need to take care in who is selected to participate.

In addition, given the many negative aspects of our young people's narratives, we have also been concerned about locating the research in the wider dementia research landscape. It has been a challenge to share honest accounts, while avoiding further stigmatization of people living with dementia. Key sources of support and validation have been, first, one of the Alzheimer's Society Research Monitors assigned to our project. This person has YOD and believes that it is essential to acknowledge young people's negative experiences. Second, in reporting our research via Young Onset Dementia UK, and to various national and local fora for people living with such dementias, we have received nothing but positive comments.

Conclusion

To return to the "nothing about us, without us" mission, it is important to acknowledge that there are two primary "groups" living with dementia. Those with dementia undoubtedly have a primary role to play in understanding what it is to live with dementia, but so too do their families. This is not to diminish the impact of, or the need to research, what it is to have a dementia diagnosis. What it does suggest is that further research is required. Narrative research provided an opportunity to offer young people safe spaces to tell their stories. It is vital and ethical to report experiences, even—maybe especially—if they are negative, if we are to achieve change and the provision of essential support.

What is clear is that "ethical practice in this sense is not so much tied up with regulation and representation (though it is partly that), but with the practice of listening for that which cannot yet be said" (B. Davies, 2014, p. 11). And it would appear that there is much to be achieved in this endeavor. Participants' narratives have resonated with other young people, reducing isolation and acknowledging their pain. Indeed, one young man, who was not a research participant, was one of six people similarly motivated by the TV feature to write to P.S.:

Watching the report it really struck me as this has been an experience for my family and myself that is often very lonely, confusing and frustrating. Though dementia has become more visible in the media lately, I never feel the full extent of the disease's effects on both the person and their loved ones is put across, usually covering either the elderly or people in the very early stages where things like forgetfulness are creeping in. The report covering your study was the first thing I have seen that I can truly relate to, with people around my age talking about their experiences and the mourning of losing a parent over time. I also found it very interesting and comforting to know that these people have many of the same feelings I have been through, for

example of anger and envy towards others. (Correspondence, May 22, 2016)

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Notes

1. It is acknowledged that dementia can be a symptom of some brain cancers. In addition, two participants' parents had died of cancer while having a dementia diagnosis, so had experienced both.
2. Again, it is acknowledged that motor neurone disease can occur with dementia, as is the case for one of our participants.

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