**Identity work of children with a parent with early-onset dementia in the Netherlands: Giving meaning through narrative construction**

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Abstract: In this article I analyse the narratives of adult children with a parent who has early-onset dementia in the Netherlands. I argue that because early-onset dementia is not a very well-known disease, adult children engage in identity work by relating their experiences to those of others. I illustrate that the comparative process of relating to others’ experiences helps the children to reflect on the impact that their parent’s illness has on their own lives, which in turn aids them in contextualising and making meaning out of their changing lives and relationships. This contextualization and recovery of meaning is shaped by three processes. The first concerns the ways in which these adult children draw comparisons between their own lives and experiences and those of their peers of the same age group. The second process entails comparative understandings of having a parent with early-onset dementia versus having a parent with late-onset dementia. The third process explores how having a parent with early-onset dementia compares to having a parent with other diseases. I demonstrate how the processes of contextualisation which the adult children engage in are shaped by what the children perceive to be normal and thus also by their socio-cultural contexts. This article thus also reveals how the primary experiences of having an ill parent are not a direct result of the symptoms of the illness itself but rather are deeply embedded in the socio-cultural context. Finally, it illustrates how the particular narratives offered by this socio-cultural context shape how the children are able to give meaning to their experiences.

Keywords: early-onset dementia, children, parent, identity work, narratives, the Netherlands

For many years, the perspectives of children with parents who had early-onset dementia were neglected in academic literature (Hall & Sikes, Invalid data; Hutchinson, Roberts, Kurrle, & Daly, 2016; Rosenthal Gelman & Greer, Invalid date; Sikes & Hall, Invalid date). This gap has recently begun to be filled and research on these children has emerged as a vibrant field. The majority of the up-and-coming research has been written from a psychological perspective. Major themes in psychological research have included the experiences of these adult children, the impact that their parent’s illness has on their lives, and their resulting needs (Gelman et al. 2011; Gelman & Rhames 2016; Millenaar et al. 2014; Svanberg et al. 2010; Barca et al. 2014; Aslett et al. 2017; Allen et al. 2009; Hall & Sikes 2018; Sikes & Hall 2018; Johannessen et al. 2015; Hall & Sikes 2020). Other authors have studied emotional wellbeing (Hutchinson et al. 2016), coping strategies and resilience (Johannessen, Aud, Engedal, & Thorsen, 2016; Svanberg et al. 2010; Allen et al. 2009), and service gaps (Gelman et al. 2011; Barca et al. 2014). Few authors, however, have focused on the socio-cultural context in which the adult children’s narratives and experiences take place. One exception to this has been Hall and Sikes (2017) who discussed how broader cultural narratives of dementia may shape the extent to which children can express their experiences—especially when it comes to taboo topics such as admitting that one does not like the ill parent, that one would prefer if the parent were dead, or other experiences which may run counter to the ‘still the same person’ narrative conventionally surrounding people with dementia.

 This article builds on previous research to provide insight into the far-reaching consequences of parental early-onset dementia for adult children in the Netherlands.[[1]](#footnote-1) In addition, it shows how such children contextualize their experiences by comparing their situations to those of others. Looking for a story can help to make sense of an experience with illness (Frank 2010, Kleinman 1989; in Grue 2016). In times of adversity, re-examining one’s narrative can also be of help to maintaining a sense of identity (Bury 2001: 264). Given that early-onset dementia is not a very well-known disease, adult children engage in identity work by relating their experiences to those of others. I illustrate that the comparative process of relating to others’ experiences helps the children to reflect on the impact their parent’s illness has on their own lives, which in turn aids them in contextualising and making meaning out of their changing lives and relationships. A story is always an edited version of reality and the storyteller chooses what to tell and what not to tell (Riessman 1990: 1197, in Bury 2001). Likewise, tone The examples adult children use thus reveal which aspects of their experience they want to emphasise and convey to outsiders. The aim of this article is not to compare the experiences of having a parent with early-onset dementia with other experiences. Instead, by following the children’s perspective and by attempting to look at the situation through their eyes, we learn about what matters to them. The examples the children use often do not describe ‘real’ situations but rather contain idealised perceptions or simplifications which help them to think about their own situations.

I suggest that the contextualization and recovery of meaning that adult children with a parent who has early-onset dementia go through is shaped by three processes. The first concerns the ways these children draw comparisons between their own lives and experiences and those of their peers of the same age group. The second process entails comparative understandings of having a parent with early-onset dementia versus having a parent with late-onset dementia. The third process explores how having a parent with early-onset dementia compares to having a parent with other diseases. While illness and suffering are universal human experiences, they are coloured by cultural meaning. Cultural understandings can be “seen as tools (which both enable and constrain interpretive possibilities) available to navigate the ambiguity surrounding illness and other troubling experiences” (Garro 2000: 306). Narratives are likewise told within a cultural setting which offers specific forms of language, clichés, and symbolic repertoire that serve to enable or restrict what can be expressed (Bury 2001: 278).

I demonstrate how the processes of contextualisation which the adult children engage in are shaped by what the children perceive to be normal and thus also by the socio-cultural contexts in which they live. This article thus also reveals how the primary experiences of having an ill parent are not a direct result of the symptoms of the illness itself but rather are deeply embedded into the socio-cultural context. Furthermore, it illustrates how this context provides for particular narratives which in turn shape how the children are able to give meaning to their experiences.

***Early-onset dementia***

The Dutch Alzheimer’s Society estimates that of the 260,000 people with dementia in the Netherlands approximately 12,000 are under the age of 65. A Norwegian study estimated that about twenty-five percent of people with early-onset dementia have children (Haugen 2012, in Hall & Sikes 2020), though no specific statistics could be found regarding the respective Dutch situation. Early-onset dementia comes in a variety of forms which include symptoms that differ from those which may manifest in dementia at a later age. The symptoms associated with early-onset dementia include social withdrawal, loss of empathy, disinhibition, exhibitionism, hyper-sexuality, aggression, impulsivity, short temper, obsessive compulsion, difficulty with planning and judgement making, visual disturbances, loss of physical functions, aphasia, and communication disorders (Hall & Sikes 2017; Sikes & Hall 2018; Gelman & Rhames 2016). Forgetfulness, which is often associated with late-onset dementia, is not a predominant symptom. As one can imagine, the symptoms of early-onset dementia thus have a different effect on the family than the symptoms of late-onset dementia. For instance, an aggressive parent can be more threatening to children than a forgetful parent.

Because the initial symptoms of early-onset dementia can resemble symptoms of depression or burn-out, it often takes up to twice as long to properly diagnosis (Sikes & Hall 2018). Van Vliet et al. (2013) found that the average time between the first symptoms and diagnosis for early-onset dementia is 4.4 years compared to 2.8 years for late-onset dementia. This period often involves a lot of confusion, uncertainty, and a disruption of ‘normal’ family practices (Sikes & Hall 2018: 594; Hoppe, 2018). It is a stressful period for even a grown person and for a developing child it can be even more stressful. In order to mature emotionally and cognitively and to be able to lead an independent life, children need support from parents who can function reasonably well in their parental roles. Having a parent with early-onset dementia means both being deprived of this support and facing a transformed parent-child relationship (Johannessen et al. 2016).

In addition to the differences in prevalence and symptoms, the disease is “out of sync” with a ‘normal’ life course (Aslett et al. 2017) and is perceived as untimely (Hall & Sikes 2020). Parents are often working and raising a family and may have financial commitments such as mortgages to attend to (Aslett et al. 2017:2). A person with dementia often loses the ability to provide an income for their family, which can lead to financial difficulties (Allen et al. 2009: 456; Gelman & Rhames 2016: 2). Moreover, people with dementia struggle to increasing degrees to fulfil the roles of parent or spouse (Gelman & Rhames 2016: 2). This can manifest in no longer being able to help children with their homework, pick them up from soccer training, prepare meals or provide emotional support and care. Meanwhile, in a partnership the healthy parent might have to work less in order to care for the sick parent (Hutchinson et al., 2016: 611) and also take over the tasks normally performed by the parent with dementia (Gelman & Rhames 2018: 3). Moreover, the healthy partner must balance these care needs with the needs of the children (Aslett et al., 2017). In summary, while some aspects (such as witnessing a family member change and deteriorate) are present in both early- and late-onset dementia, other aspects are tied to the specific moment in time in which the disease occurs and to the specific symptoms.

**Methods**

The material for this article is based on 16 semi-structured interviews with adult children of a parent with early-onset dementia in the Netherlands. The d Participants were recruited via a call on the National Alzheimer’s Society’s website and three care institutions specialized in early-onset dementia. In some cases, the children actively reached out in response to my call. In other cases I spoke to children either together with their healthy parent or after I had spoken to the parent. The youngest child I interviewed was 19 and the oldest was 43. Most children lived in urban areas.

 Three of the sixteen interviews were done with a pair of siblings, seven were conducted with a parent, and six interviews with a single child alone. Additionally, three of the children were interviewed twice. The majority of the interviews took place in the children’s homes, and the remainder took place in cafés. Interviews lasted between 1–3 hours, 1,5 hours on average.

All interviews were recorded and then transcribed. In the interviews I did not explicitly ask the children to compare having a parent with early-onset dementia to having a parent with late-onset dementia or another disease. However, all children referred to situations of people they knew or to idealized situations in order to clarify their own situations.

During open coding I focussed on passages which described the impact that their parent’s early-onset dementia had on them. The themes of my topic list helped me to categorize the descriptions of the impact, distinguishing how it changed the children’s relationship to their parents and relationships with others, as well as how it impacted their emotional well-being and their career choices. Many of these themes have been discussed in other literature, largely from a psychological perspective. Based on both primary and emerging themes, I then asked myself “why was the story told that way?” (Bury 2001: 281) and used the narratives to analyse the ways in which the children’s’ identity work is embedded into their socio-cultural context.

Ethical approval for this research was granted by the Amsterdam Institute for Social Science Research Ethics Committee before the start of fieldwork. Prior to the interviews, participants were informed about the aims and objectives of the research and verbal consent was obtained. Pseudonyms are used for all research participants in order to ensure anonymity.

**Findings**

As introduced above, the findings of my interviews illustrated that adult children of a parent with early-onset dementia struggle with questions of identity and engage in comparative processes to give meaning to their situations. The type of identity work which children engage in emerged organically within the interview data.

In the following section, I present empirical examples which illustrate the three-part comparative processes I described above. One important question I considered was whether these comparative processes were limited to the interview or also occurred outside of it. I take the position that identity work through comparison is an iterative process, meaning that the children share their experiences with others and, based on the reactions they receive, adapt both their narratives and their own interpretations of the situation. This process became visible in the empirical data. Children mentioned how they told their stories to others and how this made them realise how bad their situations really were (i.e. how young their parents were or how little others knew about early-onset dementia). Reactions from others likewise made them re-evaluate and reinterpret their situations and sometimes attribute new meaning to their experiences. I take the interview to be a snapshot of this process. The interview was a space in which children could attribute meaning to the situation because they were given the space to reflect on their experiences, but that this process began before the interview took place and continued afterward.

***Having a parent with early-onset dementia versus imagining growing up normally***

All the children I interviewed expressed that their relationship to the parent with early-onset dementia had changed.

Charlotte (36): Well, your father should care for you and that no longer is the case. So, we care for our Dad and he has never been the father who helps with jobs around the house. You care for your father instead of your father caring for you and that’s not how it should be. In your head it is very weird, because that’s not how it should be.

Most reported that roles became reversed.

Lejla: When he still lived at home, I took over quite a lot of care tasks, I felt like I was being a kind of parent for him. I thought, that’s not what a twenty-year-old should have to deal with. I have my job on the side, I have school. I want to occupy myself with other things, maybe that sounds shitty…

Maja: No, I get it. Because that was also with our mother, we had to be there for her. We basically had no one.

Lejla: Yes, you are coaching or caring for your parents. Reversed roles. That was difficult.

Maja: Yes, that is very heavy.

When discussing what is ‘normal’, adult children often referred to a culturally specific ideal, which is constituted in a complex web of norms and values. The children I interviewed compared themselves to peers of a similar age who received support from both parents and thus were able to more fully enjoy their lives. They thereby increased the contrast between themselves and their age-peers.

 Juliette, who was 19 at the time of the interview, had twice decided to temporarily live with a friend’s family for several months because she could no longer cope with the situation at home.

Juliette (19): Actually, I don’t have a mother, never had, because before she cared a lot for my [disabled] brother, so I received very little attention. So actually, I never had a mother. Physically yes, but not someone who had cookies ready when I returned from school, who asked about school, how are you, how was school, she never did that, no. This really is because of the Alzheimer’s, because you cannot put yourself in the shoes of another.

Juliette’s statement that she never really had a mother is based on her assumptions of what a mother should do and should not do. She thus has a cultural model in her mind which she uses as a reference. One could say that Juliette refers in her speech to an idealized view of a mother in the Netherlands. This ideal is comprised of loving parents who care for their children, are available to their children, and always have the best interests of their children in mind.

Another aspect that the children mentioned was how their plans for the future had been shaped by their parents’ illness. In the case of Juliette, the stress at home meant that it took her two years longer to finish school than her peers and that she choose to study close to her hometown because she did not want her father to live all by himself. Robin and Koen also adapted their plans to the situation at home.

Robin (25): I notice that within our family, that you live around that. Dad’s illness determined a lot of activities and everyone’s life. Because Koen is studying in Utrecht and he probably would have liked to live there as well. And I wanted to go to Amsterdam after finishing my studies and go on a journey. For about ten years you adapt your choices, and that is your own choice, but I notice that it has determined all our lives.

Koen: For sure, also with moving out. I found it very difficult to leave the house. It felt like leaving a sinking ship. But it just was not healthy anymore to stay longer…

We can see that Koen is torn between his wish to lead his own life, on the one hand, and his loyalty towards his family on the other (for a more detailed analysis see Hoppe, 2020). During the interview he stated that he and his mother were going against mainstream ideas because they wanted to care for their family member with dementia for as long as possible.

Freedom, individuality, and independence are important values in the Netherlands and, furthermore, there is an increasing emphasis on individual choice (Giddens 1991, in Hall & Sikes 2020). These factors shape the perception of how the children’s parent’s illness influences their own lives. The children are clearly influenced by their parents’ illness, but whether they perceive it as a restriction, abnormal, or unhealthy depends to a large degree on the socio-cultural context in which they grow up.

***Having a parent with early-onset dementia versus imagining having a parent with late-onset dementia***

Most children commented on the life stage in which their parent’s illness took place and compared it to dementia occurring in later life. Upon closer analysis, many different dimensions are revealed in their comparisons. The underlying motivation for the comparison seems to be to assess the severity of the situation.

Lejla: We were really young when it happened, also if you tell it to people, then I think ‘wow, but you lost your father at a really young age’.

Maja: Sometimes it happens to me, that only then I realise how intense it all is.

Lejla (26): Yes, sometimes I think I will never get to know my father as a grown-up person. I just knew my father as a child, a teenager and adolescent.

Although their father was still alive, to the sisters it felt as if he was already dead. In this statement the severity of the situation is predominately linked to the phase in which the illness developed and not so much to the symptoms themselves. Lejla’s last statement also reveals the idea that one knows a person differently based on the life stage one resides in. One could say that because of the dementia, she mainly encountered her father in his role as father and she did not have to chance to meet him independently from that role.

In all interviews, research participants stated that the illness did not fit the life stage in which it occurred.

Bodil (43): I struggle with the fact that my mother is young and has it. I can imagine that if she were 80 and she would become forgetful, that would fit better with her age. I don’t know whether I would accept that better, because you still have to say goodbye to a person you love…

The severity of the illness is linked to the age of the person concerned. But how dementia is experienced is not only related to the life stage, but also to the relationship one has with the person and the role that person fulfils in one’s life.

 Some children also pointed out that there can be large differences with regard to age within early-onset dementia.

Juliette (19): Lately I read something about Alzheimer’s in younger people and then they refer to someone who is 65. And then I think ‘65. I wish my mother got it with 65, then I would have moved out a long time ago. Maybe already had my own family’. So it is a very different story, hearing that you have Alzheimer’s when you are 50. This is real early-onset dementia. I can get pretty angry about that. That some people do not take into consideration that there are people who are younger than 65.

The severity of the illness in this case is not only related to the life stage of the sick person, but also to one’s own life phase. Juliette basically says that if she had her own family, her mother’s illness would have impacted her differently as she would have been less dependent on her mother and on her mother’s care and support. Moreover, her statement reveals that she does not feel understood by her environment and how this lack of recognition makes her angry (see Hoppe, 2018).

 Next to the life phase in which the illness occurs, the symptoms were also mentioned as a distinguishing feature.

Maja (21): For a long time, he was the youngest. With the others I notice, they are just elderly people who have Alzheimer’s or something else. And you can just talk to them. We talk about the weather, but that’s still possible.

Lejla (26): With him, it was no longer possible relatively early in the trajectory

Maja: (21) Yes, you couldn’t have a conversation with him.

Lejla (26): That is true, he really is different from the other residents. The elder people who also have Alzheimer’s also still look decent/clean.

It is thus not only the life phase in which the illness occurs that shapes the experience, but also the type and severity of symptoms. In younger people, it is not so much forgetfulness but rather neuropsychiatric symptoms which stand at the foreground (van Vliet, Deliane, de Vugt, Bakker, Koopmans, Raymond T C M, & Verhey, 2010). Again, what counts is likely not so much what the symptoms are but how the symptoms shape the child’s relationship to their sick parent. Likewise, how the parent’s symptoms are experienced by the child depends on the kind of relationship they had and what is valued. For the sisters, looking neat seems to be important and having a father who is no longer ‘clean’ affects them differently than the idea of a father who, for example, can no longer walk.

 The empirical material in this section demonstrates that the perception of the illness is shaped by many different aspects which are not necessarily connected to the illness itself but much more to the life phase in which the illness occurs.

***Having a parent with early-onset dementia versus imagining having a parent with another disease***

In interviews, early-onset dementia was often compared to other diseases. Strikingly, the majority of the children interviewed referred to cancer in these comparisons. They used their imagined experience of having a parent with cancer to demarcate what it is like to have a parent with early-onset dementia, evoking certain characteristics of cancer and leaving out others.

Juliette (19): This is something I have been struggling with in the past months, and also discussed with a psychologist. Because I cannot really say goodbye. I can’t say ‘Hey Mom, I feel very bad that you are so sick, I find it horrible, I really miss you’. Other people who have sick parents, for example who have cancer, their mind is still there, they are only physically sick. And this is the other way around. This is terrible, because that’s not what you want. You don’t want to say goodbye, but if you have to say goodbye, you want to do it solemnly, properly and lovingly. But well, she cannot hear me, she doesn’t understand me, so how do you want to do it?

The reference to cancer was used to emphasize that it is important whether one can still say goodbye to one’s parent or not. The quote further illustrates how a delineation between body and mind is drawn. For Juliette, saying goodbye is a dialogue and requires a shared reality or consciousness—in other words, the presence of both body and mind.

Another aspect which was compared to cancer in interviews was the presence or absence of pain.

Charlotte (36): Until he got really sick, he never really was in pain, pain in his head, but at a certain point you are no longer aware of it. You also have people with cancer, who lie in bed for a year and contort with pain. Look, in the end, he had no pain, well, a different kind of pain, he became less motoric and walked a bit crooked. I hope that he was happy in his own way. Well, you can wonder about that, but you won’t get an answer anymore.

This fragment highlights that children can experience their parent’s illness very differently. Whereas Juliette points out an aspect that, according to her, is more difficult when it comes to having a parent with dementia, Charlotte relativizes her experience and instead points to cases that are worse than that of her father. Of course, suffering or perception of the severity of an illness cannot be compared. Likewise, people with dementia might be suffering from pain without being able to communicate that pain. Clinical studies indicate that undertreatment of pain is common in dementia patients (Scherder et al., 2009) and dreaded by family members (Lemos Dekker 2018), but none of the children brought this up in interviews. Charlotte, however, mentioned another kind of pain: not knowing whether her father was happy. From her perspective, in cases of cancer this can be asked and one can receive an answer. In the case of dementia, receiving an answer might be impossible.

The narratives of these children should not be read as direct representations of reality. Instead, they provide insight into how the children give meaning to their situations and the process of doing so by comparing and differentiating their own situation to the situations they imagined of others.

 In the interviews, more references to cancer were made.

Robin (25): It is difficult, because for example cancer, everyone has something in his environment. It’s a very different process. But also a much more familiar process to people from our age, I think.

Koen (21): And also it is much more discussed in the media. If you see how people at school or whatever, jump onto it, if one of the parents has cancer, that is very different from dementia. Probably also because it is such a long-running process…

Robin (25): But also a less familiar one I think…

~~The first thing that comes to mind when one thinks of cancer is probably that it is a very serious illness that everyone in the Western world has heard of.~~

Thamara (33): 100000 jokes are made, in the media, in comics, it’s everywhere, Alzheimer’s, dementia. Often, it is treated with a joke. It’s funny, isn’t it? But I mean, do that with cancer and then half of the world will protest if you make jokes about that. But with Alzheimer’s it is just accepted. That’s what I find frustrating.

The lack of media attention combined with negative representations of people with dementia results in the social environments of these children (consisting of relatives, friends, teachers, etc.) not necessarily having a realistic picture of the situation. It can therefore be harder for the children to access understanding and support.

In other cases, children drew on cancer to point out not contrasts but similarities. Thamara stated that if her mother had breast cancer she would probably check her own breast every day, just as she tries to stay healthy in order to avoid getting dementia in the future. Juliette pointed out that because her boyfriend had lost his father to cancer, he better understands her situation.

**Discussion**

In this article I have analysed the narratives of children of a parent with early-onset dementia in the Netherlands. I argued that because early-onset dementia is a relatively unknown condition, children struggle to relate to broader cultural narratives in order to tell their stories. As a result, they instead construct their stories by relating to culturally salient experiences of others. Their constructions are shaped by three comparative processes: relating to children with healthy parents, relating to having a parent with late-onset dementia, and relating to having a parent with another disease.

Various scholars have pointed out how illness experiences are only shaped by not only individual circumstances but also by broader socio-cultural, structural and historical context. To put it differently, “different illness experiences become available at different times” (Klawiter 2004: 845). Klawiter (2004) describes how a woman who was diagnosed with breast cancer in two different decades experienced her illness. When the woman was first diagnosed in 1979, the broader context was characterised by the sovereign power of physicians, the isolation and disempowerment of patients, and the invisibility of women with breast cancer in the public domain (resulting in the absence of a group identity). In the 1990s, when she was diagnosed for a second time, breast cancer had become a visible presence in the public domain, breast cancer survivors were seen as heroes rather than as victims, and patients had access to education workshops and support groups and were treated by a healthcare team consisting of a range of professionals. “Instead of feeling isolated and powerless, as she had in 1979, Clara felt like the captain of a well-functioning team dedicated to aiding and assisting her treatment and recovery” (Klawiter 2004: 861). The broader socio-cultural context thus shaped both her experiences and the language and terminology that was available to her.

Similarly, support groups can shape illness experiences by constructing a collective illness identity and giving patients a vocabulary with which to talk about their illness. This subsequently serves as the basis for individual identity work. Powers Koski (2014) has demonstrated in the case of eating disorder support groups that collective construction has significant power; when eating disorders were constructed as a chronic condition rooted in the self and uncontrollable, the framing was show to have unanticipated and potentially adverse consequences for participants who internalized it. Political discourse can also shape how groups of people are viewed. ~~“Dementia, and further citizens living with dementia, is never simply a once and for all stabilised meaning” (Nedlung & North 2015: 131).~~ Policy discourses are shaped by collective narratives and in turn play a role in shaping these narratives.

I map the context in which these children live and distinguish aspects that can shape their experiences and narratives. As mentioned above, it is considered normal in the Netherlands for children to be cared for by their parents and raised to live independent lives. When children express that they have lost their parent while the parent is still alive, they are describing not the biological but the social death of their parent. (Glaser and Strauss 1966: 108, in Sweeting and Gilhooly 1997: 94). In other words, the parent is no longer able to fulfil their culturally prescribed role. The extent to which this role is fulfilled and the strength of the parenting is defined within this cultural context, but can vary considerably across individual understanding. This point is important to the present discussion because it underlines that the impact of early-onset dementia in a parent is experienced differently depending on the parent-child relationship. For example, if a child’s relationship to their parent is characterized predominately by physical contact and proximity, the impact of the disease will be different than if the relationship is based mainly on verbal exchange.

In recent years, the Netherlands has a shift from a welfare state model—in which it was normal for older people to be moved into a home for the elderly—to a participation society, in which family members and neighbours are expected to care for the sick and elderly (Da Roit and de Klerk 2014; Vollenberg, Schalk, and Merks-Van Brunschot 2013). In spite of this shift, the ideal is still that children should have a carefree childhood and youth (Hall & Sikes 2020) in which they should not carry too much responsibility and should not be confronted with too much burden. Thus, overall, the children I interviewed felt that it was not normal that they were burdened and restricted by their parent’s illness.

Next to these larger structures such as how the health care system is set up, narratives on dementia also shape how children experience the illness of their parent. Moreover, these larger dementia narratives can provide a reference for anyone talking about dementia. Across cultures, dementia can be seen either as a natural part of the ageing process or as the result of a brain disease (Hillman & Latimer 2017: 1). Within the Western world, dementia is approached in two contrasting ways. On the one hand, cultural narratives on dementia often describe dementia as a terrifying disease. “Alzheimer disease (AD) and other Alzheimer-like dementias personify all that is most feared about growing old” (Lock in Hillman & Latimer 2017: 1). Peel (2014) analysed media representations of dementia and found that dementia was represented in either catastrophic terms or in terms of individualistic recommendations to keep the illness at bay, thereby implying personal responsibility for the condition. People with Alzheimer’s Disease are often depicted as zombies in scholarly and popular literature (Behuniak 2011), such that one poll found that people fear dementia even more than death (Brooks 2011: 42, in Peel 2014: 890). Researchers have coined the term ‘dementia worry’, finding that “there is emerging evidence that DW is a relatively widespread and probably increasing phenomenon in Western societies and that DW is at the top of all disease worries” (Kessler, Bowen, Baer, Froelich, & Wahl, 2012: 277). On the other hand, there are movements that focus on living well with dementia and enabling approaches, in which the master narrative centres around the idea that people with dementia are still the same person they were before the onset of the disease (Hall & Sikes 2017). In reality, the cultural meanings attached to dementia are very diverse. ~~“Meanings of dementia are interpreted, embodied, or resisted by people in their social context, and these processes are shaped according to their social location (gender, social class, and ethnicity) and their individual biography” (Hillman & Latimer 2017: 1).~~

The children I interviewed did seem to relate to either of these broader narratives on dementia. Instead of referring to catastrophic depictions of dementia, they referred to a view in which a decline in health and cognitive abilities is seen as a normal part of ageing (Higgs & Gilleard 2015: 2) and where the death of older people is considered natural or appropriate (Sweeting & Gilhooly 1997: 96). They hence increased the contrast they were drawing between dementia in elderly people versus dementia younger people. “When things happen out of order at unexpected times, they seem to have a greater impact than when events happen ‘on time’” (Hagestad, 1990, in Barca et al. 2014: 1941). A central element of the narratives of these children is that the illness of their parent did not happen ‘on time’. In a sense, the illness of their parent does not happen ‘on time’ in their lives either. Hall and Sikes (2020) have argued that these children are in a liminal phase until their parent’s death, because their parents are both present and absent. They show how the lives of these children are somehow put on hold and such that the children fall between socially recognized categories.

At first sight, the distinction between early-onset and late-onset dementia seems clear-cut. However, in reality the diagnosis is arbitrary and not related to physical symptoms, but instead is based on the age when people receive a pension (Garre-Olmo et al. 2010). Although this distinction does not have any biological significance, it makes cultural sense because it demarcates a drastic change in people’s lives. The children take over this clear distinction, regardless of whether their parent is diagnosed in their forties or sixties. Thus, the experience of the illness is not so much shaped by the age of the parent, but by the perception of age and by the relationship. Indeed, if a parent was to have children later in life and be diagnosed at the age of 64, their children might still perceive the illness as happening ‘too soon’.

 Meanwhile, while the discourse that dementia patients are ‘still the same person’ is relevant for person-centred care, the children did not reference it. Sikes and Hall (2016) have demonstrated how going against this narrative can work as a safety mechanism for the children because they can believe that their parent would never act the ways that they are if they were not sick. In the interviews, children protected the identities of their parents by emphasising that certain behaviour was caused by the illness or by stating that their parent could not do anything about it. They delineated a difference between the parent before the onset of the illness and after. Tolhurst et al. (2016) argue that framing dementia in positive terms generates a zero-sum situation, in which the dignity of the person with dementia is protected but the vantage point of the family member gets diminished. As suggested above, I argue that how the children narrate their experiences depends on their needs and on their audience. In the interviews, the majority of children wanted to get across how much their parent’s illness had changed their lives and how difficult the situation was for them. Therefore, they comparatively referenced situations which they considered to be ‘less bad’ so that the contrast would become clear. No child I interviewed made a comparison to age-peers growing up with a single parent. This is likely because while such as situation might have similarities to their own, there would be a risk that the listener might not understand the pain of losing the person they knew.

 The children have united forces with groups that believe that dementia should receive more attention and funding. A British newspaper article writes that cancer research received almost twelve times more money than dementia research, although the economic effects of dementia were larger than those of cancer and heart disease combined (Brooks 2011: 42; in Peel 2014: 890). Moreover, cancer received much more media attention than dementia (Peel, 2014: 886). In the Netherlands, most people see cancer as a serious disease and do not make jokes about it. It is used as a swear word (Rassin & Muris 2005: 1673) which only underlines how bad cancer is considered to be. In interviews, the children used this contrast to underline that dementia, ~~let al.~~one early-onset dementia, receives too little attention. I believe that this was not mentioned as a matter of principle but because the children’s lives and relationships have been directly affected by this lack of attention and recognition. In their daily lives they are confronted with people’s stereotypical views on dementia and resulting lack of understanding, which, as I have argued elsewhere (Hoppe, 2018), can add to their struggles and make their situations more difficult for them.

 None of the children I interviewed participated in a support group, although some stated that they would have appreciated contact with age-peers. The only groups that were available to them were targeted at older people and the children felt that the issues being discussed were too greatly removed from the problems they encountered. They were not ‘exposed’ to a collective narrative on early-onset dementia. As a consequence, they individually constructed their own narratives drawing from examples in their familiar environment. Despite these individual constructions, in this article I have shown how the narratives still all centred around patterns of comparisons with children with healthy parents, children whose parent have late-onset dementia, and children whose parents have another disease. Their experiences and narrations of their parent’s illness also depended on other factors such as gender (of the child, but also of the parent), age, ethnicity, education, etc. The ways in which these factors shaped the narratives and whether differences of importance could be ascribed to these factors is outside the scope of the present study, but I believe that they can be understood to have coloured the narratives nonetheless. More research is necessary to analyse the narratives from this point of view.

In this article, I have discussed three comparative processes that children used to communicate what it means to have a parent with early-onset dementia and to give meaning to their experiences. Analysing these processes of identity work and what children considered important to communicate pointed to the specificities of having a parent with early-onset dementia and how these specificities impacted the children. Furthermore, I have shown how the children’s narratives were imbedded in and shaped by the socio-cultural context and how children made use of this context to give meaning to their situations. On a micro scale, one can say that their narratives also contributed to the context (c.f. Hillman et al. 2018). Research on the experiences and narratives of children who have a parent with early-onset dementia in other parts of the world is needed to deepen our understandings of the extent and forms which this socio-cultural shaping of experiences and narratives can take.

1. I refer to children not as an age category, but rather to indicate a family relation. The children mentioned in this article are all adults. [↑](#footnote-ref-1)