The Other Within Oneself: Understanding Care for a Family Member with Early-Onset Dementia Through the Lens of Dividuality

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Abstract In this article, I use the concept of the dividual to analyze the dynamics at stake in a family caring for a member with early-onset dementia. Drawing on anthropological fieldwork in the Netherlands, I argue that using a dividual framework reveals family dynamics that are overlooked when using an individual framework, and it allows one to better understand the emotional pain that family members experience during the care process. Approaching family members as fractal persons shows how their identity is composed of other family members and how this can lead to dilemmas and conflicts in the care situation. The majority of articles on dementia focus on dyadic relationships. This article advocates a systemic approach encompassing the whole family. Moreover, it underlines the importance of taking the historicity of family relations into account and not limiting the analysis to situational dynamics.

Nederlandse samenvatting In dit artikel gebruik ik het concept van het dividu om een gezin te analyseren dat met dementie op jonge leeftijd te maken kreeg. Baserend op antropologisch veldwerk in Nederland, argumenteer ik dat het concept van het dividu gezinsdynamieken blootlegt die over het hoofd worden gezien wanneer een individualistisch perspectief wordt toegepast. Dit concept helpt ons om de emotionele pijn die gezinsleden in het proces ervaren beter te begrijpen. Daarnaast laat het zien hoe de identiteit van een familiedlid niet afgebakend is, maar uit identiteitsdelen van andere familieleden bestaat. Deze verstrekkelingen kan tot dilemma’s en conflicten leiden. Dit artikel pleit voor een systemische benadering van dementiezorg en benadrukt het belang van de relatiegeschiedenis. [early-onset dementia, family, dividual, care, identity, personhood, the Netherlands]

The Dutch Alzheimer’s Society estimates that about 260,000 people in the Netherlands have a dementia diagnosis, of which about 12,000 are cases of early-onset dementia, which is diagnosed when the affected person is below the age of 65. Early-onset dementia affects the nuclear family even more than dementia in old age. In the first years after illness onset, people with early-onset dementia usually live at home with their families. Family members have to come to terms with gradually losing the person they have known. They have to readjust their outlook on life and accept that their future will probably be different than they had envisioned (Becker 1997; Bury 1982). Furthermore, they increasingly have to assist the sick person in daily activities. Usually, at some point, the family has to make the difficult decision to admit the person with dementia to a nursing home, where most people with dementia in the Netherlands die (Houttekier et al. 2010).
Recent developments in the Netherlands have led to a shift from the caring welfare state to a “civil society,” in which three trends can be observed: a transition from supply-driven to demand-driven care; a focus on community; and a transition from care in institutions to community care (Vollenberg, Schalk, and Merks-Van Brunschot 2013). The last two trends represent an attempt to reduce the rising costs of the healthcare system by relying on citizens to take up care responsibilities (Da Roit and de Klerk 2014; Vollenberg, Schalk, and Merks-Van Brunschot 2013). In the case of dementia, this decentralization has shifted the responsibility of day care for people with dementia from the central government to municipalities and communities (Macneil et al. 2012; Nowak et al. 2015). The threshold for accepting people with dementia into a nursing home has been raised. To support people with dementia and their families, several services are available such as day care and respite care, psychoeducation, discussion groups, telephone support systems, Alzheimer cafés, and meeting centers (Macneil et al. 2012). As day care is arranged by local municipalities, there are many regional differences, also with regard to facilities designed especially for younger people.

Within these health policy developments, families have to take up more care responsibilities, but little is known about how these responsibilities shape family dynamics and relationships. The majority of the literature on the experiences of caring for a person with (early-onset) dementia is written from a psychological perspective. The topics addressed, such as caregivers’ burdens, needs, and emotions, the impact on their life, and the resources they can tap into (Carbonneau, Caron, and Desrosiers 2010; Connell, Janevic, and Gallant 2001; Høgsnes et al. 2013; Nicolaou et al. 2010; Robinson, Clare, and Evans 2005; Wadham et al. 2016) are mainly described from an individualistic perspective. In anthropological literature, however, caring has been described as a relational practice. Buch (2013), for example, describes how low-wage care workers sustain their client’s personhood through embodied empathy. Seaman (2016) illustrates how families work to maintain relationality in the face of dementia, a condition which is said to threaten exactly that.

Different concepts describe the relational nature of care. With regard to dementia, much has been written about personhood. Kitwood defines personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being” (1997, 8). He observed that the personhood of people with dementia was often undermined as a consequence of what he calls “malignant social psychology.” In its origins, the concept of personhood mainly concerned individuals (Higgs and Gilleard 2016). Kitwood, however, argues that seeing personhood in relational terms is essential to understanding dementia. Care practices are seen to play a crucial role in shaping personhood (Kaufman and Morgan 2005). It has been described how other people can help preserve the personhood of the person with dementia (Hellström, Nolan, and Lundh 2005, 8). It is also implied that dementia reinforces the relationality between people: “It is not really possible to ‘tell the story of dementia alone’” (Phinney 2002 quoted in Hellström 2005, 8). Yet, although relationality is described, it is mainly depicted as unidirectional, focused on how “healthy” persons maintain the personhood of someone with dementia.
Intersubjectivity is another concept used to describe relationality between people. Jackson describes intersubjectivity as “a site of constructive, destructive, and reconstructive interaction” (1998, 8). In other words, intersubjectivity is an interactive “space between persons” (Parish 2014). In this article, my primary aim is not to analyze what happens between family members in a care situation but to demonstrate how they contain each other’s values, wishes, and identities within themselves. The concept of the dividual enables such a focus.

The concept of the dividual was developed to call attention to different conceptualizations of the self and is used in contrast to the individual. The individual is seen as indivisible; it has an essential core which defines it. The individual is atomistic, an autonomous social actor, a free agent, and the author of his or her own actions. The dividual is seen as divisible, containing interrelated dimensions. The dividual is fractal, socially embedded, performs a culturally written script, and is defined by cultural structures (Smith 2012, 53). “[T]he flow of social interaction and relation makes persons, rather than do unitary persons make the relationships between them” (Schram 2015, 320). In other words, “persons are frequently constructed as the plural and composite site of the relationships that produced them” (Strathern 1988, 13). Hence, a person contains and incorporates various collective identities of the people around him or her. A concrete example is when a parent sees him- or herself in the child or when a person refers to his or her partner as “my other half” (Jenkins 2014, 129). A dividual does not merely identify with a certain group or person, but contains something of the other in him- or herself (Smith 2016, 679). The dividual can be imagined as a “social microcosm” containing multiple relationships (Strathern 1988). In other words, the dividual is “extending into other persons and things, continuously divided and recomposed through social practices” (Pool and Geissler 2005, 118). The thoughts, feelings, and actions of the dividual are shaped by the feelings, thoughts, and actions of others (Markus and Kitayama 1991, 224). As a consequence, persons never simply are, but are always becoming (Taylor 1989, 47; quoted in Smith 2012, 56).

The concept of the dividual was developed in relation to South Asian cultures. Many anthropologists have pointed out, however, that the division between individual and dividual cultures is not straightforward (Lamb 1997, 2000; Gearin 2016; Hess 2006; Moore 2007; Mosko 2010; Smith 2012), and nowadays it is acknowledged that the self is characterized by both elements (Brison 2001; Englund and Leach 2000; LiPuma 1998). Instead of making statements about whether persons in the Netherlands contain mainly individual or dividual elements, in this article I use the dividual as a conceptual tool (Gearin 2016, 203) and thought experiment (Schram 2015, 319) to highlight elements that I argue are overlooked when focusing merely on individuals.

Several articles describe how family or professional carers sustain the personhood of a person with dementia. Articles showing that this is not a one-way street are scarce; those taking the family system as a starting point are even scarcer. With this article, I address this gap in the literature and contribute to a richer understanding of how a whole family is affected by early-onset dementia. I show how the person with dementia also sustains the personhood and identity of his or her family members. I use the concept of the dividual to illustrate
and highlight how family members are connected and contained in each other and how this containment shapes their choices, identities, and relations in a care situation. I argue that the concept of the dividual enables us to understand how the care receiver is contained in the caregiver and vice versa, how multiple family members are contained in each other, and how the history and type of relationship shape how the care situation is perceived.

**Methods**

For my anthropological research, I conducted semistructured interviews with seven people with early-onset dementia, and 20 partners and 16 children of a person with early-onset dementia, in the Netherlands. For this article I discuss the case of one family to show the micro processes and negotiations that occurred before and around the admission of the person with early-onset dementia into institutional care. Using a case study enables me to “catch the complexity” (Stake 1995, xi; quoted in Hellström et al. 2005, 12) of the caring situation. The family consisted of Eric (61), who was diagnosed with early-onset dementia at the age of 55, his wife Eva (60), and their four children aged 28, 26, 25, and 21. Eva contacted me after reading my call for participants in a newsletter of the Dutch Alzheimer’s Society. This family is not representative of all of the families I interviewed. Eva’s ability to circumnavigate regular medical care for a long time and to mobilize her own social network, plus the strong involvement of the children, both stand out. However, the dynamics and processes at play in this family also took place in, and are applicable to, other families I studied.

Over a period of more than two years, I held five semistructured interviews with various members of the family, covering the period when Eric still lived at home, after he had moved to a nursing home, and after he had passed away. In June 2014, a month before Eric was admitted to the nursing home, I interviewed Eva together with the youngest son in their house. In February 2015, I interviewed Eva alone at her home. In March 2015, I first interviewed the oldest son together with his wife at their home, and then spoke to the youngest son and the youngest daughter in Eva’s house. At that point, Eric had been in a nursing home for more than half a year. Half a year later, in July 2015, Eric passed away. In October 2016, I interviewed Eva again in a café close to the university. This was a little over a year after the death of her husband. I did not interview the oldest daughter because she was unavailable during my fieldwork period. According to the family, interviewing Eric was no longer possible as I would not get anything out of it. In an earlier stage it would have been valuable, but at the point of the first interview, Eric was no longer able to answer questions and talk about his experiences.

In the interviews, I asked the family members to describe their experiences with having a father/husband with early-onset dementia. The interviews were recorded and subsequently transcribed. I coded the interviews on paper and selected material that concerned family dynamics and their decision to care for Eric themselves for as long as possible. I then reread the material and chose fragments that revealed how interwoven they were as a family.

Ethical approval was granted by the Amsterdam Institute of Social Science (AISSR). The family was informed about the aims and objectives of the research. Verbal informed consent
was obtained from all family members. To assure anonymity, pseudonyms are used. As the family members are not anonymous to each other, I contacted each one individually when I started writing this article to ask whether they consented to an article written about their case. All except the oldest son agreed to appear in the publication; no material from his interview is used. Before submitting the article to the journal, I gave the family members the opportunity to provide feedback and check whether they felt well represented. Eva wrote that she was impressed by the article and that she felt well represented. Her son replied that he had all the faith in the article and would read it at a later stage. I talked to the daughter on the phone and understood that some things that I had written felt painful to her. These were passages in which I described her mother's and brother's position, but did not explicitly mention her perspective. In the specific passage that the daughter pointed out, I had only described the mother's and son's perspective because it was based on the interview with them. I did not want to make assumptions about the daughter's perspective, but this gave her a sense of feeling excluded. Sharing the article before submitting it was an ethical decision. I found it important that the family members were content with the result and recognized themselves in the story. This process taught me that as a researcher it is not possible to anticipate how research participants react to a text.

“This is Choosing for Ourselves”

Eva (60) and Eric (61) met in their early twenties. They married when Eva was 30 and together raised four children. From Eva's way of talking about Eric, I gathered that they had had a good marriage. Eva was a trained nurse who had worked with people with dementia and had cared for many years for her own mother with dementia. Her husband Eric had worked as an occupational therapist. At the age of 52, he started noticing difficulties in finding the right words. It took three more years until he received the diagnosis of frontotemporal dementia (see Hoppe 2019).

When Eric was diagnosed, all children except for the eldest still lived at home. Eva, who had seen many nursing homes in the context of her work, was determined to care for Eric at home as long as possible. Eva described herself as a headstrong person who liked to think about what she wanted and what she could do for Eric. During the whole illness trajectory, preserving her husband's dignity was very important to her. Instead of sending Eric to a regular day-care center, she arranged for him to go to a place where he could carve wood and sculpt stone. She felt that there he was appreciated more as a person and would feel more meaningful because he was able to produce art.

Eva also told me that two or three years earlier, together with Eric, she had prolonged his driver's license. Eric was no longer driving, but Eva knew that driving had always been important to him and that he valued having his driver's license in his pocket. In order not to raise suspicion, she had instructed Eric to leave the talking to her and simply sign the form when asked. Eva stated that prolonging his driver's license had afforded her a lot of pleasure.

At first sight, one could say that Eva got pleasure out of doing things for her husband. Yet, I would argue that there was more at stake. If we approach Eva as a dividual who contains
her relationships with others, we can say that she experienced pleasure because she did not identify as an “I” but as a “we.” Her husband’s identity and his passion for driving were contained within her. And since he was no longer able to fully fulfil his own wishes, Eva acted upon them. She did not merely derive pleasure from doing something for her husband, but also from knowing what pleased him and from being able to give this without needing anything in return.

Eva also mobilized her friends who, for example, would take Eric for a walk so that she could have some time for herself. After the diagnosis, a friend of hers suggested setting up a “support group” that met regularly to check on how Eva, Eric, and the children were doing, and whether they could do something to help. The support of her friends enabled Eva to give space to her dividuality. If she had been overburdened with tasks and had felt unwell herself, possibly there would have been less space for Eric in herself.

A year before our interview, Eva took Eric to an Ayurvedic clinic in India where he received daily treatments. Eva stated that many people thought she was out of her mind, but she described their stay as a “golden time.” Eva could see how Eric had enjoyed the daily treatments and the friendliness he experienced. “It was good for my soul, because he deserved it all those years.” Their long history together and deep connection enabled her to make this statement; not only was Eric contained in Eva, but their long and overall happy relationship too.

Eva and Eric’s children played an important role in maintaining the situation at home, and were, to different degrees, involved in their father’s care. These roles varied from intense involvement in daily physical care to supporting Eva with administrative or financial issues. The youngest two children, Robin (25) and Koen (21), had adapted their lives by deciding not to move far away for their studies. Robin was working as a social worker and had already begun to care for her father during her studies. After graduating, she decided to extend the care and work for her father three days a week instead of finding a new job. The physical care she offered Eric included helping him shower, eat, and go to the toilet. Furthermore, at the time of the first interview, Koen was sleeping at his parents’ place once or twice a week so that his mother could get a good night’s rest; when Eva was alone with Eric, she had to get out of bed five or six times a night to care for him. A week before the interview she had started taking sleep medication, because she had noticed that she was becoming more tired by the day and was afraid that her lack of sleep would impair her ability to care for Eric. She recognized that she needed to take care of her own needs in order to be able to care for him; but instead of saying that she needed to care of herself in order to care for him, I would say that caring for herself was an act of caring for her husband.

The living room in which my first interview with Eva (60) and her youngest son Koen (21) took place in June 2014 smelled of essential oils and was decorated with several stone sculptures made by Eric and family photographs. As we sat at the table, Karl the cat walked by and sat on my lap. Impressed by how they had arranged Eric’s care, I asked Eva and Koen whether all of the family members were on the same page. Koen explained that he and his
mother might be the most unrealistic ones of the family, as they always said that they wanted
to care for Eric at home till the end. Each family member needed to find his or her position
in the process of caring for Eric. The situation brought some family members closer and
created distance between others.

Eva claimed that caring for her husband was something she did for herself and that not caring
for him would increase her suffering.

Eva: I often hear that people from outside say to me, ‘Oh yes, but you also have to
look after yourself’. And then I reply, ‘Well, I very much look after myself’. Because my
sadness only begins once I have to bring Eric to a nursing home. Only then it begins.

Koen: But also the ‘look after yourself’… well, that’s easy to think, because ‘looking after
yourself’, this is looking after ourselves. This is important to me. I find it great to be able
to do this for as long as possible. I think that Dad, well, I know it for sure, would want
that I choose for myself, and this is where my consideration is coming from. Because if
I had my way, it is until death do us part, completely go for it. But I know that he finds
it important that I also choose for myself. Thus, actually the dilemma is the other way
around than you would expect.

(Interview June 2014, Eva and Koen)

Their statements point to the complexity of the issue. As Eva argued, it was not a question
of either caring for herself or caring for her husband. She described caring for Eric as an act
of caring for herself; Eric’s well-being was directly linked to her own well-being. In using a
dividual framework, instead of saying that Eric’s happiness made Eva happy, one would say
that his happiness was her happiness. Stating that her sadness would begin when Eric went
into a nursing home and she could no longer care for him underlined this. However, she
probably would not only have been sad knowing that he was sad, but also because she was no
longer able to show her love through caring for him. In other words, the dividual elements
of herself would no longer be expressed.

Koen’s words also show how interwoven he was with his father. He did not experience having
to choose between his father’s and his own well-being. I would argue that Koen not only
contained the relationship to his father but also his father’s values and beliefs. Thus, he was
not only concerned with caring well for his father but also considering what his father would
have wanted for him. This was possible because of the intimate relationship they had had
before Eric became sick.

A Crack in the System
At that point, the family members’ needs and goals were in line, but as Eric’s illness pro-
gressed the balance changed. After talking to a woman who had cared for her husband with
dementia and had consequently suffered from a five-year burnout, Eva became determined
that this would not happen to her. She decided to go to India for three weeks and planned to
send Eric to a nursing home for that time, because she did not want to burden her children.
The children, however, did not want to send their father to a nursing home and agreed to take over the care.

Koen: Especially the tendency to stretch your boundaries, you grow in such a situation, and that means that you go too far… and that happened to us a few times. Some time ago you went to India and all of a sudden it can be like, “Now it is too much,” and that has been a slap for us, because suddenly you had to go, you had to go to India. And that meant, at least for me, because just like Mom I wanted to care for Eric till the end, that we had to jump in and…Well, I found that difficult, and back then I had the feeling that the care situation had not been tackled ideally. And because of that it became too much and all of a sudden you had to pull the emergency break.

(Interview June 2014, Eva and Koen)

Up to that point, the fragments within their selves had been in harmony, though with the increasing intensity of the care situation things changed. In Eva’s case, she realized that she could only take care of Eric if she also took care of herself. In the end, taking care of herself meant taking care of Eric. This put pressure on the children. From a dividual perspective, Koen contained his mother, who needed a break in order to be able to care for her husband, and he contained his father, for whom a transition to a nursing home would have been difficult. One could say that Koen’s decision to take over his mother’s tasks while she was in India kept these parts within him in harmony. But at the same time, his own well-being came under pressure, and it affected his relationship with his mother. On the one hand, he was angry at his mother for leaving, and on the other hand, this enabled him to actively decide to continue caring for Eric at home.

The tendency to push one’s boundaries can be explained using a dividual framework. From an outside perspective, it can be hard to understand why family members want to continue caring in spite of the burden of care. If the suffering of the other does not only affect oneself, but also is one’s own suffering, it is understandable that family members want to prevent the person with dementia from suffering.

At the end of the first interview, Eric, who had made a friendly and calm impression on me, entered together with a friend who had taken him for a walk. Although Eric had been diagnosed with frontotemporal dementia, which is often characterized by changes in character, his family members emphasized how much he had kept his humour, tranquillity, and friendliness. This probably enabled his family to persevere and to see their care as meaningful.

Eric’s illness strongly shaped how the family related to each other. Robin and Koen, whom I interviewed together nine months after the interview with Koen and Eva, at their mother’s house in March 2015, both said that the situation had changed their relationship to their mother. Robin explained that it was hard to get her mother do something alone with her. Apart from the fact that it was hard to organize, because someone needed to be found to care for Eric, Robin also observed that her mother was not really able to relax. When together in the sauna, for example, Eva would be constantly thinking about Eric and was unable to enjoy
the time with her daughter fully. Eva could not disconnect from Eric, as he was contained in her, and this strained her relationship with her daughter.

Mother and daughter felt differently in the same situation. Like her mother, Robin probably found it difficult to leave her father, but she also needed quality time with her mother. Possibly, like her brother, she contained a part of her father that wanted her to enjoy life. Being his wife, Eva had a different relationship to Eric. Whereas for children separation from their parents is a normal development (though in this case disturbed by dementia), for Eva growing old together had been her vision of the future. Yet, how Eva felt about taking care of herself was also not fixed. She had decided to go to India to take care of herself, but she could not take care of herself in the sauna. She probably experienced parts in herself to be in conflict: she felt her daughter’s desire to spend time with her, her husband’s wish for her company, her own wish to rest, and feelings of guilt about not being with her husband. One could say that Eva was in a role conflict. Her role as a caring wife for her vulnerable husband was to some degree incompatible with being a caring mother for her children.

Even though Eva and Koen were on the same page regarding Eric’s care, their relationship was strained.

Koen: And of course, it puts pressure on the other relationships... the bond between me and my mother really has changed because of this. As a consequence of the tension, conflicts arise. Sometimes in fights things are said that taint the bond permanently. And I think, of course you don’t know how it would have been, but I can imagine that I would have had a better bond with my mother if we had not been that closely huddled together during the care period, the last period here.

Robin: And indeed, what Koen said before, it all bypasses Dad, even though it all has to do with him or is about him. So yes, the ones who see each other often, they absorb the shock. If it’s not your day then you take it out on the person who is closest and not on the sick person, thus I have been that person. Mom and I did that to each other, that is tough.

Koen: Yes, and when I still lived at home I was always that person for Mom.

(Interview March 2015, Koen and Robin)

The care situation put pressure on each family member, yet it seemed that Eric’s dementia protected the parts of him that resided in the other family members. Although his condition led to stress for the others, the fact that he could not be held accountable for his behavior meant that although his relationships changed, the family’s affections towards him did not. Between the other family members, however, the situation was different. Although Koen’s affection towards his mother had probably not changed, and although he knew that the care situation had put pressure on their relationship, his relationship to his mother nevertheless changed. Eric’s illness not only changed his family members’ relationships to him, but their relationships to one another. From a individual perspective, it seemed that Eric’s identity within
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the others was frozen by his condition. Things that he did or said were excused by his illness, but things that other family members said or did were not.

Nonetheless, the children voiced their respect for their mother. Koen emphasized his mother’s endless perseverance, and Robin was impressed by her mother’s abundance of love. The feelings of the family seemed to be intensified because they were so closely connected through the care situation. The dementia also magnified small moments of connection between Eric and his family. Eva, for example, recounted how Eric and Koen had been sitting on the couch together listening to the Beatles, and Koen had started crying. Although Eric’s dementia was advanced at the time, he had reached out to his son to ask him what was wrong. After Koen had replied, Eric stated that the situation was absolutely dreadful. Eva described this as a moment of great beauty. If Eric had not been sick, his behavior would have been considered normal and might have passed unnoticed. But in the face of dementia, the incident served as a reminder of the connection the family felt with Eric. Moreover, it was moving for Eva because it demonstrated Eric’s basic human capacities that had been threatened by his dementia.

“This is Suffering”

A month before the interview with Robin and Koen, I talked to Eva alone in February 2015, and I learned that Eric, since the summer of 2014, had been living in a nursing home. Eva explained that she and Eric had left the house for a few days in order to accommodate visitors. During this time, she had bruised her ribs and had been in so much pain that she was hardly able to help him go to the toilet. When she returned to the house on Friday, she had needed her daughter’s help for a small errand and had asked whether Robin could come by in the evening. When Robin had come with her boyfriend, they found that Eric was no longer able to climb the stairs. They prepared a bed for him in the living room, and the next day Robin called for a family meeting.

Eva: Robin had said, I want us to talk, because if it stays like this I cannot go on holidays on Sunday. She was also the one who helped at home. And then it happened that all the children [starts to cry], they one by one said that they had lost faith in the situation and that they did not think that I could still care for Eric at home. They all did it in their own manner and in their own words and the big message behind that was “Yes, we lose Dad, or partially we have already lost him, but we do not want to lose you. And if you go on like this, you will fall apart and then we have nothing.” And yes, if all four children say it like that, each of them in his or her own way, then you think “Yes, okay, the moment has arrived.”

(Interview February 2015, Eva)

As the above fragment reveals, at this point the carefully balanced web in which they had all resided had shifted. Not only would Eric have to go to a nursing home, but the family had also reached a moment in which their wishes and needs clashed. This moment of crisis led to a rearrangement of the individual elements of their selves. Although it was probably the case for all of the family members that Eric’s well-being was also their well-being, for the
children caring for Eric was no longer an act of caring for themselves. For Eva the situation was different. When discussing the draft of this article with her, she became emotional once again when reading the above quote and told me that it also had to do with the fact that she felt appreciated by her children and realized how important she was to them. Furthermore, once she could no longer count on the support of her children, she had been unable to maintain the fact that caring for Eric was an act of caring for herself. Finally, she did not want to go against her children’s wishes. For better or worse, her children enabled Eva to diverge from her path to care for Eric till the end.

That would have caused a lot of tension within the family. I thought, “Yes, that is true.” And yes, it almost feels like I have to make a sacrifice for the sake of the greater whole.

(Interview October 2016, Eva)

Her decision to arrange a place for Eric in a nursing home was not only informed by her children's wishes but also by her desire not to let the family fall apart. Her statement that she had to make a sacrifice for the greater whole could be seen as an attempt to express her experience of dividuality in her own words. Eva felt torn by the wishes and needs of her children, and this was why her statement was so emotionally charged. Not only did she want to take Eric's and her children's wishes and needs into consideration, but their wishes and needs were contained and embodied in her.

I argue that using a dividual framework can better illuminate the pain that family members experience when having to transfer a person with dementia to a nursing home. As stated above, if one member suffers, the whole family suffers. Moreover, the family was no longer able to show their love in the form of care. For Eva and some of her children, caring for Eric had become part of their identity. It had become something that defined them and brought them satisfaction. When these aspects disappeared, a painful hole in their self developed.

In earlier interviews, Eva had said that her suffering would begin when Eric was institutionalized. Once he started living in a nursing home, Eva confirmed this to be true. Eric had entered the nursing home walking, but within no time he was sitting in a wheelchair and had become incontinent. Especially at the beginning, he was very restless and constantly screamed Eva’s name. Just as Eric was contained in Eva, Eva was contained in Eric. She was a source of comfort and reassurance for him. Because of his dementia, Eric was probably unable to access this part within himself. He needed Eva’s or his children’s presence to feel soothed. Moreover, Eva had the feeling that the nursing home did not create opportunities to make people with dementia feel meaningful. The professional carers could not fill the hole that the distance from his family members created in him.

For Robin, the difference between how her father had been at home and how he was in the nursing home was very painful to witness.

Robin: At home he was always very calm and friendly, a dear, but most of all a very calm and tranquil man. There they are with twenty people in one department, with few care
workers, and Dad gets a lot of stimuli and he cannot filter them. As a consequence he was shouting all the time and screaming and very restless and one could not watch that… it really was super painful to go there… to see how much he was not himself, and he would only be put into his room, which was quite logical, but yes, to be sitting at home on your couch and thinking that your father sits in his room all day long… that was very difficult for me.

(Interview March 2015, Koen and Robin)

Being separated from a loved one is painful. Because of his dementia, Eric was no longer able to feel or imagine the presence and love of his family when they were not around. For Eric to feel dividuality, he needed his family’s physical presence. Robin stated that in the nursing home her father was not himself. He needed his familiar environment to be himself. For Robin, there was more to it than experiencing pain because her father suffered; she probably felt that her father needed her and the other family members to be himself, and it hurt her that she was no longer able to help her father be himself. Furthermore, she could no longer give expression to her dividual elements. She still felt connected to her father, but she was unable to express it in a way that was accessible to him.

New Ways of Relating

In the summer of 2015, exactly one year after being admitted to the nursing home, Eric passed away. The family then had to find new ways to relate to each other and make their own choices.

Eva: I feel like the situation brought us closer together. We did it with each other and had to do it with each other and we needed each other. And it was difficult with each other in that situation. And now there has come a period that is characterised by more distance, going your own way, again finding out how to relate to each other. But I think that we may say that the basis is strong enough to leave it like that and to have the faith that if we need each other we will find each other… it is not like we do not have contact with each other, but it is all different from when Eric was here.

(Interview October 2016, Eva)

In caring for Eric, the dividual elements among the family were shuffled each time a new situation arose. Upon his death, the elements needed to be rearranged again. Even though Eric was no longer present, the parts of Eric that were contained in the family did not dissolve. Caring for Eric had moved the dividual elements within the family to the foreground; they were connected through the care and had internalized each other’s wishes, needs, and values. Caring for Eric was not only a large part of their lives, it was also part of their identity. When they were no longer connected through the care, they had to find new ways of relating.

When I interviewed Eva in October 2016, she said that caring for her husband for 10 years had taken its toll. To those on the outside, it is often hard to understand why carers need so much time to “return to normal.” After Eric’s death, his family no longer needed to physically care for him or worry about him or the situation, but I would argue that because of the dividual
elements in themselves, they needed time to adjust. They not only had to process the loss of a loved one but also the loss of part of their identity.

**Discussion**

In the following, I will relate the empirical data to the literature. I do not contrast the concept of duality with the concept of personhood. Both concepts offer a framework to analyze the relationality of people in a care situation. The majority of the literature on dementia uses the concept of personhood. Therefore, I shall engage with the concept of personhood and indicate when it overlaps with aspects that are highlighted using the concept of duality. I have chosen the concept of the duality as my main angle as it throws light on how the care receiver is contained in the caregiver and vice versa; it provides space for a focus on systems and not only on dyads; and it encompasses the history of a relationship.

The concept of personhood is often used in relation to dementia. The majority of the literature, however, focuses on how the caregiver sustains the personhood of the care receiver (Buch 2013; Smbye and Kirkevold 2013; Surr 2006). Buch (2013), for example, discusses how professional care workers sacrifice their own bodily comfort and safety to sustain their clients’ personhood. We do not learn, however, whether or to what extent clients also sustain the personhood of their caregivers. Perry and O’Connor challenge the assumption that caregiving is a one-way process. They demonstrate that preserving personhood shows the interdependence of the carer and the person with dementia. They argue that when “spouse caregivers preserve the personhood of their partners, they also preserve their own identities as husbands and wives” (2002, 60). If, for example, the person with dementia has clean clothes and is shaven, this also affects and benefits the spouse.

Other authors go further and give more agency to the person with dementia. Hellström et al. (2005) show how a husband caring for his wife with dementia did not experience the caring situation as one-sided but rather as reciprocal. The husband experienced no burden in supporting his wife, since it provided him with a sense of purpose and was part of who he was. Kleinman describes how through caregiving he experienced a radical transformation of himself. When caring for his wife, he became fully alive and realized what it meant to be human: “What starts out as caregiving for others becomes caregiving for ourselves” (2010, 18). Taylor (2008) invites us to approach care “as something that makes life worthwhile.” This is similar to Eva’s and some of her children’s experience. One could thus say that in these cases, family members sustain each other’s personhood.

These authors describe a tension between individuality and duality in care. In line with these authors, this article shows how caring can become part of one’s identity. It explains the pain family members experience when they are no longer able to care for the person with dementia. As caring is tied to their identity, not being able to care not only means *not doing* something but *not being* something. Furthermore, the concept of the duality makes clear that caring for another or caring for oneself are not mutually exclusive. As I have shown in this article, in the early stages of the illness, for Eric’s family caring for him meant caring for
themselves. As the illness progressed, the balance shifted, and the family needed to reposition themselves.

Taylor (2008) beautifully illustrates how her mother with dementia still cared about her family and describes many ways in which her mother alleviated her family’s distress and filled them with joy. The situations she describes are comparable to moments that Eva and her children recounted about Eric. Taylor argues for a relational and systemic approach to personhood: “We may need to stop looking only to individuals as bearers of ‘selfhood’, and start looking more at how ‘selfhood’ is distributed among networks, sustained by supportive environments, emergent within practices of care” (2008, 326). Jenkins (2014) states that “recognising dividuality in dementia involves developing an appreciation of the transactive qualities of persons; specifically their ability to give out, from themselves, particles of their own coded substances that may then reproduce in others, something of the nature of the person in whom they have originated” (Marriott 1976, 111; quoted in Jenkins 2014, 129). He argues against the artificial distinction between carer and cared-for. People with dementia are not only care receivers but are also able to provide care. He maintains that we should not approach the care relationship as a one-way street but instead as a life-sustaining web (133). This article supports his argument. In line with Taylor (2008) and Jenkins (2014), I argue for a systemic approach that goes further than simply analyzing dyadic relationships, for instance between the person with dementia and his or her partner or child (cf. Globerman 1994; Roach et al. 2014). This article calls attention to the different positions of family members and illustrates what happens internally when family members get pulled into different directions as a result of role conflict.

Furthermore, the concept of the dividual highlights the role of the history and type of relationship in the care situation. The couple I describe in this article had a good marriage, and this shaped how they related to each other in times of sickness. Their dividual elements became strengthened over time. When Eric was no longer able to express his wishes, Eva and the children embodied his wishes and were able to act upon them. Various authors argue that it is important to take into consideration the different relationships and roles within families (e.g., Perry and O’Connor 2002). Spouses, of course, have a different relationship to their partner than children to a parent. The concept of dividuality encompasses such variances. But the variances go further than simply the roles people have. As seen in the case of Eva and Eric, there can be significant differences between how siblings relate to their parent; whether a child is willing to help a parent with intimate tasks, for instance, depends to a large degree on the relationship they had before. Through the care situation, the family’s dividual elements become amplified. In the case of the family in this article, as they were connected through their care for Eric, they also found themselves confronted with each other’s values, wishes and identities. After Eric’s death, the dividual elements in themselves containing the other family members became less relevant.

According to Higgs and Gillear (2016), the concept of personhood is tied to ideas of agency, autonomy, memory, and personal identity. The concept of the dividual is not rooted in these ideas, and language and cognition play a less important role. It shows how people remain
connected even if they can no longer communicate verbally (see Taylor 2008). Further, it counteracts the “loss of self,” “the funeral without end,” and “the death before death” (Cohen and Eisdorfer 1986; quoted in Herskovits 1995) discourse surrounding dementia. It is nevertheless important to note that the progression of dementia also leads to changes in how the person with dementia can experience his or her dividual elements. Once Eric moved to a nursing home and was separated from his family, it may have been more difficult for him to feel contained in his family. The progression of his dementia might have affected his awareness of his dividuality.

According to Hellström et al. (2005), the relational nature of personhood comes into sharper focus through dementia. Through dementia, the part of Eric that was contained in his family members became encapsulated. The intense care situation changed the relationships between the family members permanently. Eric was no longer able to fulfil the role of husband or father, but this did not change how his family felt towards him. If Eric’s condition caused stress, his family did not argue with him, but instead they took it out on each other. On the other hand, through the dementia, moments that before the illness would have gone unnoticed or been considered normal gained greater significance and were a source of comfort; they were moments in which Eric’s human capacities and dividual elements became apparent and were cherished.

In this article, I describe a family dealing with early-onset dementia. To a certain degree, the processes I depict can also be seen in families dealing with dementia in old age. The process of institutionalization is probably equally complex. In contrast to older family members, the decisions of younger people have more impact on their future life course. Possibly younger family members experience more tensions between their dividual elements. Potentially, the role conflict families experience when one member has dementia is larger in early-onset dementia than in late-onset dementia. Next to the age, the duration and quality of the relationships, the involvement of family members in other communities and groups, and the responsibilities that need to be fulfilled apart from the care for the person with dementia shape the care situation and how dividuality is experienced.

Although the concept of dividuality is well suited to study family relationships characterized by love and respect, it is less suited to analyze families characterized by an absence of love and proximity. Smebye and Kirkevold (2013) focus on professional and family relationships that do not sustain personhood. According to the authors, in such relationships care was motivated by a sense of duty and obligation, not love and affection. On a similar note, Cohen (2008), in his commentary on Taylor’s (2008) article, wonders whether all people with dementia are so fortunate to have the right abilities and relationships in order to have their personhood sustained. There is therefore a danger of romanticizing the care situation.

This article does not pose a moral judgment about how the situation should be. Its goal is to expose the dynamics at stake in a care situation characterized by love. Leibing (2018) asks how we can transcend frameworks that either depict family carers as heroes or focus on the “horror” of dementia. One solution she presents is Jenkins’ (2014) concept of the
interembodied self and a dividual understanding of personhood. Another is acknowledging the cultural context in which dementia care takes place and analyzing which deeds are considered heroic.

I began this article by describing changes in Dutch care policies. Because of these changes, more burden is placed on families. However, little is known about how this affects families. This article demonstrates that even in families characterized by a high degree of love, commitment, and inventiveness, conflicts and frictions arise that can have lasting effects. Moreover, this article cautions against underestimating what caring for a family member asks of people. The family I describe did not make use of the services that are there to support people with dementia and their family carers before institutionalization. Eva did not want to send Eric to a day-care center because she did not like how people with dementia are treated there, and she did not make use of a case manager. In this sense, she was unaffected by these policy changes.

On another level, however, one could say that she was affected. Innes points out how the view of dementia as being “worse than death” impacts the development of dementia services. “The low status that society awards to care workers and people with dementia contributes to the low priority that dementia care has occupied on the political agenda” (2002, 495). Eva did not want to send Eric to a day-care center because she did not like how people with dementia are treated there. She preferred to privately arrange activities for Eric that would make him feel valued and that were not merely set up to entertain or look after him.

**Conclusion**

In this article, I have shown how using a dividual framework does more justice to the experiences of family members caring for someone with early-onset dementia than an individual framework. Various authors have pointed out how person-centered dementia care does not capture the interdependencies of people (Smeybe and Kirkevold 2013) and reifies individuality (Jenkins 2014). These authors advocate for relationship-centered care (see Nolan et al. 2004, 45), and this article offers empirical support for such a claim. A dividual framework can capture how care receiver and caregiver are contained in each other, facilitates a focus on family systems, and takes the history of the relationship into consideration. In line with Jenkins (2014), this article suggests that respecting dividuality should be a core principle in dementia care. At the same time, more research is needed that considers families in which relations are fractured.

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**Notes**

**Acknowledgments.** My thanks go to the family for sharing their story and their vulnerable moments with me. I am very grateful for their time, openness, and trust in me. I thank Ria Reis, Robert Pool, Anne-Mei The, and
Leny van Dalen for their critical comments, Aaron Seaman for thinking along with me, and Annelieke Driessen for helping me out when I got stuck. Furthermore, I thank the anonymous reviewers for their valuable comments. This study was funded by Ministerie van Volksgezondheid, Welzijn en Sport, Universiteit van Amsterdam, Cordaan and a private foundation. The author states that there is no conflict of interest. Ethical approval for this study has been granted by the Amsterdam Institute for Social Science Research Ethics Committee.

1. https://www.alzheimer-nederland.nl/dementie/jongdementie (accessed 06.09.2018).
2. All ages mentioned are taken at the point of the first interview.
3. Robin had decided that she wanted to care for her father for as long as it felt good to her. From that moment on, it no longer felt good, regardless of the fact that she was going on holiday.

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