

## ARTICLES

### WHAT IS IT TO BE A DAUGHTER? IDENTITIES UNDER PRESSURE IN DEMENTIA CARE

MINKE GOLDSTEEN, TINEKE ABMA, BARTH OESEBURG, MARIAN VERKERK,  
FRANS VERHEY AND GUY WIDDERSHOVEN

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#### ABSTRACT

*This article concentrates on the care for people who suffer from progressive dementia. Dementia has a great impact on a person's well-being as well as on his or her social environment. Dealing with dementia raises moral issues and challenges for participants, especially for family members. One of the moral issues in the care for people with dementia is centred on responsibilities; how do people conceive and determine their responsibilities towards one another? To investigate this issue we use the theoretical perspective of Margaret Walker. She states that ideas about identity play a crucial role in patterns of normative expectations with regard to the distribution of responsibilities in daily practices of care.*

*The results of this study show how the identity of a family-member is put under pressure and changes during her loved one's illness that leads to difficulties and misunderstandings concerning the issue of responsibility. These results offer an insight into the complexities of actual practices of responsibility and highlight the importance for those caring for people with dementia of attending carefully to how they see themselves and how they see other people involved (Who am I? Who do I want to be for the other?). Answers to such questions show what people expect from themselves and from one another, and how they, at any rate, are distributing responsibilities in a given situation. Professional caregivers should take into account that family members might have different ideas about who they are and consequently about what their responsibilities are.*

Address for correspondence: Minke Goldsteen, RIAGG Midden Limburg, Minister Beverstraat 3, 6042 BL Roermond, The Netherlands, E-mail: mgoldsteen@riaggmiddenlimburg.nl, Telephone: ++31-43-3882458 / Fax: ++31-43-3670932

## INTRODUCTION

Progressive dementia is a growing problem in our society. In the Netherlands for example, over 175,000 people are currently afflicted with a dementing disorder and it is estimated that in forty-five years there will be more than 400,000 people with dementia.<sup>1</sup> Dementia is characterized by cognitive disorders that often involve disturbances in memory, mood, behaviour and character.<sup>2</sup> The most common cause of dementia is Alzheimer disease. Becoming demented has radical consequences for people's lives; for the lives of demented people themselves but also for their relatives. In this sense, dementia is sometimes described as 'a disease of the relatives'. Families (as well as friends and neighbours) are confronted with the situation in which the mental faculties of a person they know well gradually decline, causing all kinds of changes in existing relationships. Bit by bit, people with dementia seem to withdraw into their own world. And they become increasingly dependent on others for daily activities like washing or getting dressed. As a result family members cease to be just husband, wife, son or daughter, as they take on the identity of 'family carer'. What is said here in one small sentence refers to complex processes of change in which the lives and identities of family members of people with dementia come under pressure.

A great deal of research has been done on the impact of dementia on family members. Most studies focus on the burden of care borne by family members, for example what kind of tasks they perform, how much time they spend on caring for their demented partner or parent, how heavy their burden is, and what kind of influence this has on their personal lives.<sup>3</sup> Further attention is paid in the literature to the needs and wants of family care givers.<sup>4</sup> In this article we would like to concentrate more

explicitly on the processes family members go through when their loved one becomes demented. How do family members see themselves, what do they expect from themselves and others (for example, the professionals involved in the demented person's care) and how do they handle their specific situation? We presuppose that the process of dealing with dementia raises moral issues and challenges for participants, especially for family members.<sup>5</sup> One such issue is centred on responsibilities; people must determine their responsibilities towards one another and redesign their lives. The way people do this is the issue at stake in this article. One can learn much about how family members conceive of their responsibilities by studying the narratives they tell about their situations. The American philosopher Margaret Walker formulates this use of narratives in our moral lives in the following ways:

*A story is the basic form of representation for moral problems. We need to know who the parties are, how they understand themselves and each other, what terms of relationship obtain, and perhaps what social or institutional frames shape their options.*<sup>6</sup>

People make sense of, or give significance to, events in their and others lives, including their own and others' actions, by embedding them in some story or other.<sup>7</sup>

In accordance with Walker's observation, we believe that the study of a single case can be interesting in itself, provided that it is one that can be studied in depth. The case we have selected meets this criterion, as well as R.E. Stake's preference for a case with maximum learning potential:

*My choice would be to take that case from which we feel we can learn the most. That may mean taking the one that we can spend the most time with. Potential for learning is a different and sometimes superior criterion to representativeness.*

<sup>1</sup> Gezondheidsraad. 2002. *Dementie*. Den Haag: Gezondheidsraad.

<sup>2</sup> American Psychiatric Association. 1994. *Diagnostic and statistical manual of mental disorders* (4<sup>th</sup> ed.). Washington, DC: K. Ritchie & S. Lovestone. The dementias. *The Lancet* 2002; 360: 1759–1766.

<sup>3</sup> M.E. Szinovacz. Caring for a demented relative at home: Effects on parent-adolescent relationships and family dynamics. *J Aging Stud* 2003; 17: 445–472; P.P. Vitaliano et al. Predictors of burden in spouse caregivers of individuals with Alzheimer's disease. *Psychol Aging* 1991; 6: 392–402.

<sup>4</sup> J.M. Timmermans ed. 2003. *Mantelzorg. Over de hulp van en aan mantelzorgers*. Den Haag: Sociaal en Cultureel Planbureau.

<sup>5</sup> R.H. Binstock, S.G. Post & P.J. Whitehouse. 1992. *Dementia and Aging. Ethics, Values, and Policy Choices*. Baltimore and London: The Johns Hopkins University Press; H.R. Moody. 1992. *Ethics in an Aging Society*. Baltimore and London: The John Hopkins University Press; J. Lindemann Nelson & H.L. Lindemann Nelson. 1996. *Alzheimer's: answers to hard questions for families*. New York: Doubleday.

<sup>6</sup> M.U. Walker. 1998. *Moral Understandings. A feminist study in ethics*. New York / London: Routledge: 110.

<sup>7</sup> Ibid: 120.

*Often it is better to learn a lot from an atypical case than a little from a magnificently typical case.*<sup>8</sup>

In the first part of this article we will present the story of a forty-year-old woman, Carolien Franssen, and her seventy-three-year-old mother. In the second part we will reflect in more detail on her story. We will focus on the way the identity of this family member is put under pressure and changes during her mother's illness-process. We take as our starting point the view that personal identities (who am I and who is the other?) colour the normative expectations that people have towards themselves and other people in specific situations.<sup>9</sup> We will investigate what these normative expectations mean with regard to the daughter's ideas about her own responsibility and the responsibility of others in the process of care.

With the analysis of this case we hope to contribute to current discussions in health care policy about the division of responsibilities between professional caregivers and family-members. In these discussions the concept of responsibility is often used in a rationalistic, instrumental manner. This understanding of responsibility has to do with determinations of who is doing what in the care process; the tasks that are properly assigned to a specific caregiver and the tasks that others ought or ought not to undertake.<sup>10</sup> But formal arrangements of responsibilities in terms of rules, guidelines, and programs of care with different packages of tasks for different caregivers, can be at odds with the way in which people define and deal with responsibilities in daily practice. The lack of fit between the formal and the actual can result in problems for the people concerned. With this article we hope to provide more insight into these issues and to give recommendations about how to deal properly with moral aspects of the division of responsibilities in the care for people with dementia.

<sup>8</sup> R.E. Stake. 1994. Case Studies. In *The Handbook for Qualitative Research*. N.K. Denzin & Y.S. Lincoln, eds. Thousand Oaks, C.A.: Sage: 236–247.

<sup>9</sup> M.U. Walker. 1998. *Moral Understandings. A feminist study in ethics*. New York / London: Routledge.

<sup>10</sup> C.A. Baan, J.B.F. Hutten & P.M. Rijken eds. 2003. *Coordination of care. A study into the care for people with a chronic condition*. Bilthoven: RIVM.

## I. THE STORY OF CAROLIEN FRANSSSEN

*My mother has always cared a lot for other people and where is the care for her right now?*

Where is the care? This question is asked by Mrs. Carolien Franssen, daughter of a woman with dementia.<sup>11</sup> In her story she describes her experiences with her mother, Mrs. Franssen. Carolien Franssen portrays her mother as a loving, caring woman who has been taking care of her invalid husband for more than two decades. Mr. Franssen had a stroke twenty years ago, after which he never fully recovered. For some years he has suffered from diabetes and he now goes for haemodialysis on a weekly basis. Mr. and Mrs. Franssen have been married for almost fifty years. They have three children; two daughters and one son.

At a certain moment it becomes apparent that Mrs. Franssen cannot organize the care for her husband anymore. Her family initially thinks that she might be a little depressed and that she is becoming too old to care for her husband, but gradually they realize that more is going on: their mother is becoming demented. A period starts in which the family – the two daughters in particular as the son lives in France – seek appropriate care for both their parents. During this process more and more people become involved: staff members of the Regional Individual Needs Assessment Agency (RIO)<sup>12</sup>, the general practitioner, volunteers, a private domestic help, the staff of a domestic care institution, the staff of the day care centre, the staff of the Regional Institution for Ambulatory Mental Care (RIAGG) and finally also the staff of a nursing home. The daughters, and in particular Carolien Franssen, coordinate this care and tend to do all the things the formal healthcare institutions do not provide like shopping, paying visits to the hospital, arranging the transport, buying medication, and filling in forms. Eventually, after being cared for at home for one year, Mrs. Franssen moves to a nursing home.

<sup>11</sup> Carolien Franssen is not her real name but a pseudonym.

<sup>12</sup> Since 1998 there is a regulation in Dutch healthcare that anyone who wants to be eligible for financed care needs to submit an application to the 'RIO'. The RIO is an institution that makes recommendations regarding the care that is needed in a given situation.

### Forced to make choices

The case of Mrs. Franssen shows how a more or less stable family life – in which Mrs. Franssen arranges everything and takes care of Mr. Franssen – is transformed by dementia into an uncertain situation; an unknown world in which the family is not sure how to handle things and what kinds of choices to make. Especially at the beginning it is very difficult for the family to grasp the situation. As Carolien Franssen puts it:

*You really are in a jungle and you don't know if you should go forward or backward, to the left or to the right.*

The word 'jungle' calls up associations of complexity, uncertainty, and loneliness, not knowing where to go and how to get what you want. The family members find themselves in a strange territory where they cannot fall back on 'taken-for-granted' skills, knowledge or former experience and where the context itself offers little guidance to handle the situation.

Within this situation Carolien Franssen experiences no real help from the Regional Individual Needs Assessment Agency (RIO) whose job it is to determine the kind and amount of care her parents need. In her story she depicts the attitude of the RIO as at odds with her own expectations. She describes how she constantly felt compelled by the RIO to make choices in the care for her parents, whereas she did not consider herself capable of making these choices. She is filled with indignation about this:

*You always have to indicate what you want (. . .) but I do not know what I want, because I do not know what kind of things are possible (. . .) Yes . . . what do you want? That was the standard question they asked.*

A discrepancy becomes visible between the expectation of the daughter and the RIO's apparent expectation that a family member would know what the demented patient needs and therefore is capable of indicating what kind of care she would like to have.<sup>13</sup> But Carolien Franssen depicts herself differently. In her story she says that she did not know what kind

<sup>13</sup> In policy and legislation concerning the indication and allocation of care the demands of the client are seen as the starting point in the process of individual needs assessment. A client is considered as an

of care to request for her mother because she was not familiar with the different healthcare services available to her. This made it difficult for her to formulate concrete care needs. She also argues that she does not know how the illness of her mother would develop, relating this ignorance to her identity as a daughter:

*No, I am not a nurse, I am not a caregiver, it is my mother and I want her to get the best care possible. But should this be arranged? I don't know. From the beginning, I had to sort this out all by myself. I thought, aren't there people who have done this already? Couldn't they tell me what to do? But no, somehow this never happened, not at the RIO and not at the RIAGG . . .*

By emphasizing her identity as the daughter of a woman with dementia and not a nurse or another caregiver, Carolien makes it clear that she does not consider herself competent to take on the responsibility of arranging the care for her mother and making decisions for her. This point is underscored in her story when she describes how her mother at a certain moment became very agitated at the day care centre and something needed to be done about this. The day care centre asked for a re-adjustment of the medication, and this was done in consultation with the general practitioner and the RIAGG. According to Carolien Franssen she was actually dragged into this consultation:

*Umm, yes we got involved in these consultations again and again, we had to . . . I: And did you like this or . . . ? R: Actually no, because I also didn't know what I had to do with this. I mean, I only have one mother and I've never been through anything like this, a mother who is becoming demented, so . . . And they're the ones who have experience with*

independent civilian who takes the responsibility for his situation himself as long as possible. When he is not able anymore to take care of his own situation, he can submit an application for professional care. A representative is expected to look after a client's interests in case he is not able to determine his position himself. In the official policy documents a model of autonomy is used that is based on the notion of informed consent; clients receive information and are supposed to formulate their needs independently and well-considered. If the clients are unable to make decisions for themselves, a representative should act on their behalf. On the basis of the client's wishes, the RIO will provide an objective expert judgement about the level of care needed. The statements of Carolien Franssen can be interpreted as a criticism against the consumer-directed care model.

*this; I mean, it wouldn't be the first time that someone became agitated at the day care centre, I think.*

Being a daughter who never had the experience of having a mother becoming demented, Carolien Franssen does not expect to have to contribute significantly to the decision-making process. In this situation, she sees herself primarily as Mrs. Franssen's daughter and under that self-conception she does not recognize any responsibility to give her opinion and to make decisions about her mother's care. That she assigns this responsibility to the professional caregivers is apparent in her expressing the expectation that they could make the right decisions on the basis of their expertise, education and experience. Professionals, she suggests, have decision-making responsibilities here; daughters don't.

*They make a diagnosis. I can't do things like that, so I thought: if you think this is what my mother needs, then you should do it.*

As a daughter Carolien Franssen only wants her mother to get 'the best care possible'. This is for her the most important value with regard to her mother's illness and she wants to hold on to this position. However, the progressive nature of her mother's dementia and the expectation on the part of the health caregivers that she will contribute to the decision making process are at odds with her own understanding of her responsibilities and her sense of what she can reasonably expect from others, and this puts pressure on her identity.

### Becoming a 'care-hunter'

Six weeks after the first recommendation by the RIO, the Franssen family is still without care; the homecare institution that was initially called in happens to be short of staff. At this point Carolien Franssen decides to take on the role of coordinator of care herself:

*And then I said we will take control ourselves and we will buy care ourselves with a personal budget.<sup>14</sup>*

With this decision Carolien assumes the burden of 'taking-care-of-the-care':

<sup>14</sup> Recently in Dutch healthcare people can ask for a personal budget with which they are able to buy the care that is indicated.

*And then everything was arranged very quickly, but in fact, we were left, I was left, with the care for this personal budget.*

Taking care of the care entails a great deal of responsibility. At the most practical level it involves massive amounts of paperwork:

*Yeah, in a way I like to do this, but it's a lot of bureaucracy and paperwork. Really a lot! If patients have to do this by themselves, I can't imagine how they could get everything in place.*

Secondly taking care of the care requires both initiative and attentiveness to get the care you need. Carolien Franssen compares her role in the care for her mother with that of a hunter:

*But I really had to go after it myself. I felt like a hunter . . . yes I had to go after everything . . .*

A hunter is someone who cannot wait passively till his prey comes to him. He has to go after it actively, otherwise he will come home empty-handed. The 'hunter-metaphor' strikingly summarizes the daughter's experience of the role she takes in the care of her parents. She must constantly take the initiative in making arrangements. But in addition to taking initiative 'taking-care-of-the-care' also requires her to be attentive. Only with this kind of attitude results – that is: more and better care – can be achieved.

*Then more and more care was indicated, so again and again I returned to the RIO. But again and again I had to take action myself. Again and again I had to raise the alarm. I had to be really alert about everything.*

Carolien Franssen does not feel happy with her role as a vigilant hunter. Frustration can be heard in the threefold expression 'again and again'. Having learned the hard way that others involved will not make the first move, she has the feeling that everything depends on her own efforts, her own initiative:

*If I wanted to have more attention from the general practitioner, I had to go after it myself, because otherwise he wouldn't come.*

But it is not only the many practical tasks and the lack of initiative on the part of healthcare

professionals that burden Carolien Franssen. At a certain moment in her story she states:

*Yes, you aren't used to taking care of your parents. You had a father and a mother who took care of you.*

This brings in a whole new dimension to the struggle around taking the responsibility to organize the care for her mother, namely, that through the illness and fragility of her parents the roles in the family are reversed. The former parent-child relationship – is shifting and responsibilities attaching to each role are switched around. For Carolien Franssen this is hard to deal with. In her view caring for your parents is not a 'normal' part of being a daughter.

### Caring together?

What is striking in the story of Carolien Franssen is that her set of expectations does not include any conception of 'caring together'. Her utterances show that she does not experience the care of her parents as a joint undertaking between professional caregivers and family members. At first she expected the professional caregivers to take responsibility for organizing her mother's care. When this expectation was not met she took on the co-ordination and arrangement of care herself.

She sees her effort as an individualistic struggle and feels that she has been thrown own upon her own resources:

*I had to arrange it all by myself.*

And:

*You had to go after everything yourself.*

She describes herself as the one who actually arranged her mother's care in its entirety:

*Yes, finally I am the one who, yes I quite could say finally I am the one who had to organise everything.*

The way she formulates this, reveals that she in fact felt forced to arrange the care; she 'had' to go after everything, she 'had' to arrange it and she 'had' to organise it. Her expectations – that healthcare institutions would take the initiative in providing care for her mother, that they would guide the family's decision making, and that they would intervene

when appropriate – were violated during the whole process.

As long as her mother remains at home, Carolien Franssen takes the coordination of care upon herself, though this responsibility is pretty much forced on her. But when – after a serious crisis in which her mother behaved very aggressively towards her father – her mother is finally admitted to a nursing home, Carolien relinquishes the responsibility she never wanted, handing over the care of her mother to this institution. Here again, however, she finds that her expectations are at odds with those of the nursing home staff. She sees no opportunity to share the care for her mother with the professional caregivers, although this is the intention of the nursing home:

*The nursing home is very open and they say: 'We are taking care of your mother together with you' . . . But that is not possible. My care would be completely different from the care of the nursing home.*

In Carolien Franssen's view, 'caring together' is impossible not only because her care would be different from that of the nursing home, but also because of the distance and the changing relationship with her mother:

*The nursing home is giving the care now. And it is better to leave it like that. [. . .] Yes, I could be worrying about that a lot, wishing things were different, but that isn't possible. The distance is too great and mother isn't mother anymore.*

She experiences the admission of her mother in the nursing home as something that causes a fundamental change in their relationship; actually she implies that the relationship between her and her mother no longer exists:

*You don't have a mother anymore – it's a woman there in the nursing home just like all the other residents.*

'A woman there in the nursing home' expresses quite clearly the distance this daughter feels between her and her mother. The story about the relation she had with her mother is not 'working' anymore because, as she sees it, there is no 'mother' anymore to relate to. The 'death' of the relationship is

brought about not only by the progression of her mother's illness. It is also established through the change in context – the admission of her mother to the nursing home – that prevents the family members from doing things they used to do to maintain their relationship with Mrs. Franssen. At home they tried to preserve the relationship with and the individuality of Mrs. Franssen by taking care of her and by giving attention to particular things that were once characteristic of her. In the nursing home, where these things are getting lost Carolien Franssen sees no further opportunity to maintain the individuality of her mother through the care she gives her:

*... Mother isn't mother anymore. She has lost all the skills that we in fact preserved, little things from buttering bread to caring for herself, painting her nails, her lipstick, all these things, she has lost them all, they're gone.*

While on the one hand the 'broken' relationship is created through the change in context, on the other hand it also seems that in a way Carolien Franssen intentionally chooses to distance herself from her mother. In a sense 'letting go of the care for her mother' functions as a kind of norm, one she believes her family ought to share:

*Yes you need to let that go, only this is very hard to do. You always think along with the caregivers like 'yes, wouldn't it be better to do it like this or ...' [...] My sister is still taking care of the laundry, but I have told her that gradually she has to give this up too.*

Doing the laundry which might be viewed as an activity to uphold the relationship between the demented person and her family, is described here as useless; there is no way, in Carolien Franssen's mind, that this practical work could contribute to the maintenance of the mother-daughter relationship.

With the admission of her mother to the nursing home, Carolien Franssen seems to accept no further responsibilities for the care for her mother. She emphasizes that she has no specific expectations concerning the professional caregivers of the nursing home. The less concrete her expectations are, she reasons, the less she will be disappointed. This atti-

tude flows from her earlier experiences with professional caregivers when her mother was still at home:

*No, I just let it happen, I don't have expectations anymore. So yes, of course you could have expectations, but then you make things very difficult for yourself. Because I, yes I have had expectations when my mother was still at home and then you notice that it is just very difficult to make these things come true.*

Nevertheless, it is not completely true that she does not expect anything anymore of the caregivers at the nursing home. Although she has no specific expectations with regard to the content of care, she does have the general expectation that the caregivers in the nursing home will do their job. As she sees it, this includes preserving her mother's unique personality and practical skills as well as informing the family of any problems with regard to her health. Carolien ascribes the responsibility for this to the professional caregivers because 'they are busy with my mother twenty-four hours a day'. With these words she addresses not the individual caregiver, but the institution as a whole. She sees the nursing home as a moral agent responsible for taking care of people twenty-four hours a day. This view of the nursing home's identity, however, gives rise to attributions of responsibility that are not met in the daily care for her mother:

*But on the other hand you think: they're busy with my mother twenty-four hours a day ... so then it's not our business to say things like: 'Should you do an urinalysis since she seems to have a bladder infection?' ... No, that isn't up to me. ... Although we did say it ... I mean my sister takes care of the laundry and she thought, 'This is not possible, something's wrong'. I mean, the nursing home, they're busy with her twenty-four hours a day and it's up to them to notice this, it isn't up to us I think. [...] But I think it's a very strange thought, then I think: 'Oh my mother is coughing a lot, do I have to say something like maybe my mother has a cold or maybe she has a sore throat? That isn't up to me, is it? [...] I mean, I do mention it because I want to take care of her, this is how I take care of her, you see ...*

This fragment shows how Carolien Franssen is struggling with what to expect from others and what to expect from herself in the care for her mother. The reason that she takes action in this case is that she wants to take care for her mother, even though she believes that the nursing home caregivers bear the full responsibility for this care; she expects them to provide it and is frustrated when they do not.

## II. SHIFTING IDENTITIES AND RESPONSIBILITIES

Dementia has a great impact on a person's well-being as well as on his or her social environment; families, friends and others. It also has moral consequences. In order to make these consequences clear, we will concentrate more explicitly on the way the identities of family members – and in this case the identity of Carolien Franssen – can shift in the course of their loved one's illness, paying particular attention to what this means in terms of normative expectations and ideas about responsibility.

### Shifting identities

Personal identities convey understandings about who we are ourselves – ‘who am I?’ – and who we take other people to be – ‘who is she?’ With these senses of identity certain expectations are established for how we ought to behave and how other people are supposed to behave.<sup>15</sup> These expectations can be described as normative because they embody person-specific standards of conduct, including what should be done by whom to whom.<sup>16</sup> In the case at hand, for example, the daughter has some expectations about how she should behave and how her mother should behave; she knows what is expected of her. But when her mother becomes ill, the daughter finds herself in a very unusual, uncertain situation in which things are changing and the

identities – of both mother and daughter – slightly begin to shift.

At first the woman tries to hold on to her idea about being a daughter: because she is ‘*only her daughter*’, she believes she should not be expected to arrange the proper care for her mother and to make the right decisions as her illness progresses. This is in contrast with her view of the professional caregivers: she identifies them as ‘experts’ in the care for people with dementia; they are the ones with the experience, knowledge and skills. Her understanding of who the professional caregivers are sets up certain normative expectations on her part: she expects them to know how to care for her mother and she further expects them to provide the appropriate care. According to the daughter, the professionals are the ones who should take action in this particular situation, yet her expectations are at odds with what the professional caregivers expect of her: they identify her as a kind of spokeswoman for her mother. Often healthcare professionals assign family members this role of proxy decision-maker, precisely because they are seen as closely related to the patient, knowing and respecting the patient's values and opinions. But this daughter clearly has a different idea about what it means to be a daughter.

However, when the situation of her mother gets worse and professional caregivers offer no immediate appropriate care, the woman starts organizing the care for her mother herself. With this reaction to the deteriorating situation of her mother and to the lack of response of the professional caregivers, her identity as a daughter changes and is redefined; she becomes a family caregiver. But this new role involves a great deal of struggle and ambivalence. In addition to her belief that professional caregivers have the experience and knowledge necessary to care for dementia patients and her own sense that she is not equipped to give this care, the daughter also expresses her difficulty with the reversion of the roles. In her story caring is described as something parents do for their children. It is part of the identity of a parent that he or she cares for the child; this responsibility is embedded in the relationship that exists between them. For this woman it is hard to see this change; to accept that as a daughter she must now take the role of a parent. She does not see

<sup>15</sup> H.L. Nelson. 2001. *Damaged Identities, Narrative repair*. Ithacata: Cornell University Press. H.L. Nelson. What child is this? *Hastings Cent Rep* 2002; 32, no. 6: 29–38; H.L. Nelson. 2003. On the mend: Narratives of repair, manuscript, unpublished.

<sup>16</sup> M.U. Walker. 1998. *Moral Understandings. A feminist study in ethics*. New York / London: Routledge.



it as a 'normal' part of the identity of a child to care for her parents.

When her mother goes into a nursing home, the identity of the daughter changes again. At home she had to organise the care of her mother herself due to the lack of response by the healthcare-system, but with her mother in a nursing home, she sees herself as absolved of all further responsibility. Does the altered context mean that the daughter can get back her old identity and behave and relate to her mother according to her own understanding of the daughter she is? In the story we don't see this happen. Instead, the admission to the nursing home is experienced as a final breaking point: *'Mother is not mother anymore'*. In the new, unfamiliar context of the nursing-home the daughter sees no possibilities to reverse this process and it seems like she cannot relate to her mother as a daughter: *'She is a woman there in the nursing home just like all the other residents'* – a woman one could visit now and then, but who one cannot see as a mother. It may seem as if her 'daughter' identity now means nothing to her. This conclusion would be drawn too quickly. Although in her view the identity of her mother has disappeared, the daughter does not act as if she is just a visitor and her mother just one of the residents in the nursing home. One of the moments when this becomes visible is when things are going wrong with her mother's care. Then the daughter does take action. For example she notices that her mother is coughing a lot, which implies that she is keeping an eye on her, and she does mention this to the caregivers of the nursing home. In these matters it appears that the daughter still sees herself as connected with her mother: *'I do mention it because I like to take care of her'*.

In this final phase of the mother's illness we see a daughter who is struggling with 'what it means to be a daughter when your mother is in a nursing-home'; a daughter who is trying to redefine her identity in this context. On the one hand, she cannot regain her former identity as a daughter because of the relationship that no longer exists ('Mother is not mother anymore'); on the other hand, it appears from her actions that there is still a sense of relationship left.

In general we tend to think about dementia in terms of a change of, and in a sense also a loss of

the identity of the patient, resulting in problems for him or herself and for him or her relatives.<sup>17</sup> The story of Carolien Franssen illustrates that it is not only the identity of the demented person but also that of family members that change over the course of illness. There is a constant struggle on the daughter's part to hang on to her identity and later on to redefine her identity. This struggle takes place within a complex, dynamic interaction between the daughter, the health caregivers, the healthcare system and the ongoing illness of the mother.

### Normative expectations and the distribution of responsibility

Identities embody normative expectations. What I expect of others and myself is directly entailed by my sense of who I and they are. Normative expectations are a function not only of identities but also of relationships with others and with what we value.<sup>18</sup> The way people define who they and others are, what they care about, and to whom they are related, produce the normative expectations they have for all their interactions with others.

According to Walker the stories by which we make sense of identities, relationships, and values, on the one hand, and the normative expectations that are embedded in these stories on the other, play an important role in our understandings of how responsibilities are assigned and distributed:

*It is in practices of responsibility that we make each other accountable to certain people for certain states of affairs, we define the scope and the limits of our agency, affirm who in particular we are, what we care about and reveal who has standing to judge and blame us. In the way we assign, accept or deflect responsibilities we express our understanding of our own and others identities, relationships and values. At the same time, as we do so, we reproduce or modify the very practices that allow and require us to do this.*<sup>19</sup>

<sup>17</sup> W. Moyle, H. Edwards & M. Clinton. Living with loss: Dementia and the family caregiver. *Aust J Adv Nurs* 2002; 19, no. 3: 25–31; A. Phinney & C.A. Chesla. The lived body in dementia. *J Aging Stud* 2003; 17: 283–299.

<sup>18</sup> M.U. Walker. 1998. *Moral Understandings. A feminist study in ethics*. New York / London: Routledge.

<sup>19</sup> Ibid: 16.

The story of Carolien Franssen and her mother focuses in particular on the issue of changing identities and to a lesser degree on changing relationships and values. How does her story depict the connection between identity and normative expectations and what does this mean for the way responsibilities are divided?

The story showed that the daughter and the health care professionals have different perspectives on the situation, having to do with differences in how they understand themselves and others. At several moments there is a clash in normative expectations between the daughter and the professionals with regard to who is supposed to do what in the care for Mrs. Franssen. Defining herself as a daughter and not as a caregiver is for Carolien Franssen a reason to assign to the professional caregivers the responsibility for organizing appropriate care and for making treatment decisions. However, the professionals see the daughter as her mother's spokeswoman and consider her also a 'partner in care'. For example: the RIO asks her to formulate her mother's care needs, caregivers of the day care centre ask her to give an opinion about how to deal with her mother's agitation, and the nursing home staff says that they will share the care for mother with the family. In all these situations the daughter, for her part, attributes the responsibility for these matters to the professionals.

The clash in normative expectations (which has to do with different ideas about 'who am I?' and 'who is the other?') together with the progressive nature of her mother's dementia, put the identity of the daughter under pressure and create shifts in this identity involving an alternate set of normative expectations. We saw that despite her own ideas about who she is and what she could do, when the care system fails to respond promptly and her mother's condition deteriorates, Carolien Franssen takes on the responsibility of coordinating her mother's care herself. She starts to manage the personal budget and takes the initiative in arranging both short- and long-term appropriate care. Doing these things that were no part of her self-conception changes her sense of who she now is.

The case of Carolien Franssen shows, we believe, that normative expectations about who should

take action (who is responsible, and who should respond), are integral to our personal identities. Identities thus play a crucial role in the assignment of responsibilities. There can, of course, be 'violations' of normative expectations, and as we have seen, these violations can produce changes in people's identities. In Carolien Franssen's case, responding to her mother's illness forced her again and again to redefine not only her own identity, but also the identity of others, and to redefine too what to expect of herself and others in the process of caring for her mother. It causes her a lot of struggle and ambivalence to find a way of dealing with these issues.

## CONCLUSION

Currently in Dutch health care there are debates around the issue of 'continuity and integration of care' that centre on the question of who is doing what – what is my responsibility as professional caregiver, and who coordinates the process of care? Healthcare organisations are developing programs and protocols that set forth standards of care as well as the tasks and responsibilities of the health care institutions. But such 'formal' arrangements are not always well suited to the complexities of people's actual practices of responsibility.

We have concentrated here on the care of people who suffer from progressive dementia. We chose to approach this kind of care from the perspective of the family by asking family members what it means for them to care for a relative (partner, mother, or father) who is becoming demented. How do they understand themselves? What do they expect from themselves and from other people in this specific situation? And what does this tell us about the way they are dealing with responsibilities? The close description and critical analysis of the case shows how different attributions of identity between family members and professional caregivers might lead to difficulties and misunderstandings in the distribution of responsibility.

What normative conclusions can be drawn from our analysis? Following Walker's theory, we would like to emphasize the limitations of general

normative principles. Since morality is situated in social practices there are no universal ethical theories from which can be prescribed how practices ought to be and how people ought to behave. The focus should be on the experiences and ideas of people involved in a certain practice. The story of Carolien Franssen teaches us that using a general notion of autonomy, which is characteristic of the approach of the RIO, does not do justice to the daughter's experiences. Her way of making sense of her situation is much more intricate. If we want to understand what the daughter feels and respond to it, we will have to be careful not to judge her expressions from a general normative theory. If Carolien's story makes one thing clear, it is that one cannot determine beforehand what it means to be a good daughter in relation to a parent who becomes demented.

Does this mean that how people act and what they say is by definition morally right? We think this conclusion is too easy. In the first place, people themselves are not always sure about whether their behaviour is morally right. Carolien's story shows that she is actually wrestling with her obligations. She is not claiming to be right, but looking for adequate ways of handling the situation. She is certainly open to other views on what is morally appropriate. Her story is interesting because it does not state what is right or wrong, but expresses the experience of a moral quest. As a reader or as a person involved in the situation one might wonder in the case of Carolien Franssen whether it is morally appropriate how she feels and acts in relation to her demented mother. From one's own normative background one might judge that Carolien is not a good daughter because she says: mother is no more mother anymore. We do not want to deny the possibility of such a normative judgement. Yet, it may be doubted whether it is not too crude. If we read Carolien's story as a whole, she at no moment denies a moral relationship with her mother. Even in the nursing home, she keeps concerned. Carolien Franssen is struggling with her identity and the responsibilities she has in relation to her mother, but she is not flying away from the difficult situation she is in nor is she neglecting the relationship between her mother and herself. In fact, during her mother's illness-process

she is constantly seeking how to respond to her mother's needs.

For those caring for people with dementia it is important to attend carefully how they see themselves and how they see other people involved (who am I? Who do I want to be for the other? What is my relation with that person?). Answers to such questions show what people expect from themselves and from one another, and how they, at any rate, are distributing responsibilities in a given situation.

Professional caregivers should take into account that family members might have different ideas about who they are ('what it means to be a daughter') and consequently about what their responsibilities are. They should also be aware that family members might have different views from their own concerning professional caregivers' responsibilities. And as if all this weren't complicated enough, professionals should be aware as well that identities and attributions of responsibility might change as an illness runs its course, not because caregivers are fickle but as a result of changes in the situation and as a response to what other caregivers are doing (or leaving undone) and to how the care-system is organized.

The best way to heighten professional's awareness of these matters is by listening attentively to the stories of family members – particularly to the way families express issues of identity and responsibility in their stories – and to openly discuss these issues with them by making these issues regularly recurrent themes within consultations. The fact that family members themselves are often not certain about their responsibilities opens up the possibility for investigations and debate. Professional caregivers can start these kinds of conversations for example by asking family members what they think they owe their demented parent or their husband in this specific situation and who they think should be responsible for what in the care for their demented family member. It is important that they do not confine themselves to general statements, but focus on the concreteness of the situation. Taking (changing) identities and (changing) attribution of responsibilities into account can help to build up a practice of care that can rightly be called a moral practice.

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