

## Autonomy in old age

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## 1. Introduction

In many European countries health care reforms are taking place as a response to an aging population. Citizens, including older people and those who are physically or mentally frail, are encouraged to seek care arrangements within their own networks, through support from volunteers, or in the commercial segment of the care market. This means that caring responsibilities are reallocated from caring professionals to the individual and to his or her networks. This shift is legitimized by referring to the ethical principle of autonomy. It is assumed that older people want to stay in control of their lives and have the freedom to make their own decisions. In the Netherlands this transition is accompanied by a shift from residential to non-residential care. Older people are expected to live independently within the community for as long as possible. Also, the organisational and financial structure of care for the elderly have been adjusted. Various responsibilities that were previously organised at a national level were transferred to the municipalities and health insurance companies.<sup>1</sup> This transition was accompanied by a budget cut of 25% for individual support and home care.

Other articles in this online journal are concerned with legal issues that have become prominent for older people, for instance, with questions regarding whether something is or is not allowed according to the laws and jurisdiction. For example, in the Netherlands it is prohibited by law (WBGO) to surpass the will and autonomy of an older person if this person is competent, meaning able to make decisions regarding their treatment. In this article we take an empirical approach to the ethical and normative issues by focussing on how the autonomy of older people is realized in practice. For our

empirical approach we shall use the concepts of autonomy as self-determination and relational autonomy. By combining these concepts, we expect to match the complexity of the cases where the enactment of autonomy allows the older person to take decisions and at the same time to relate this decision-making process to others. We often need others to arrive at an understanding of situations and ourselves, and to handle our limitations.<sup>2, 3, 4, 5</sup> In this article we focus on responsibilities, assuming that older people can re-establish their responsibilities together with others and redirect their lives without losing their dignity<sup>6</sup> and integrity.<sup>7</sup> In order to gain a deeper understanding of the redistribution of responsibilities, we follow an empirical approach towards ethics by presenting and discussing two narratives.<sup>8</sup> Empirical ethics aim to articulate the moral understandings of people by eliciting and analysing their experiences and narratives.<sup>9</sup> Narratives help people to make sense of and understand moral problems and experiences in life.<sup>10</sup> In personal stories people identify who they are, how they relate to others and what they value in life. Narratives of identity, relations and value illuminate the normative expectations that people have of themselves and others, and thereby constitute the assignment of responsibilities.<sup>11</sup> From the ethical perspective that we choose here responsibilities are not understood in a legal way in terms of accountability, or in a functionalist way in terms of assigned tasks or duties, but in a moral way. Moral responsibilities refer to relationships of care. This moral view on responsibilities is contextual. The specific interpretation of the question who is responsible for whom and for what, is relational and context-bound and depends on the particular circumstances and the people involved in a situation. Narratives help us to gain an understanding of the situation, and how people understand themselves in relation to others and what they value.<sup>12</sup> We start with an overview of the principle of autonomy in the field of bioethics, and how it can be applied in our empirical study. Then we present two cases and narrative accounts: a) a context of insufficient care for a person to be autonomous, and b) a context with sufficient care, but the risk of overruling the autonomy. Both cases are evaluated with the concepts of autonomy as self-determination and relational autonomy. The key to our empirical approach is that an understanding of what autonomy means in old age requires an in-depth inquiry of the particularities of the case (the person, the situation, the biography) and its complexity. An understanding of the lived experiences can be enriched with relevant theoretical insights based on various concepts of autonomy developed in the field of bioethics.

## 2. Concepts of autonomy

In today's health care the principle of respect for the patients' autonomy is highly valued, and legally ensured by laws. Until the

1960s it was assumed that patients lacked the competence for an understanding of what was good for their health and well-being. This incompetence was related to their illness (physical or mental) which made them incapable of managing their situation. As a result, patients received treatments imposed on them by external parties, even if they clearly stated that they did not wish to go along with a decision made by others. This paternalistic approach has been discredited and has given way to the development of a new discipline, the field of bioethics. In this field the principle of respect for autonomy is very prominent, next to the principles of doing no harm, doing good and social justice.<sup>13</sup>

The rise of the liberal principle of autonomy in health care has had positive consequences. While the patient was formerly treated as an object of concern, he is now seen as a person who has rights. The volition and choice of the patient is now taken into consideration, and patients are better protected against decisions made by others against their will. A crucial element of the principle of respect for autonomy is the right to refuse treatment. Treatment can only be performed if the patient gives his consent, based on adequate information (informed consent), as regulated by law (in the Netherlands: the WGBO). But in spite of all this a lot of questions cannot be addressed properly if we rely on the principle of autonomy as self-determination alone. For example, what if someone refuses treatment, and subsequently gets himself into trouble? What if the patient cognitively understands what is going on, but is disconnected from his feelings and values? Or vice versa: what if a person is not considered competent due to serious health problems or hazards arising from a mental disorder, like dementia or Alzheimer's in the case of old people, but can grasp what is 'good' in terms of his own value commitments and identity?<sup>14</sup>

George J. Agich has done a lot of work in the field of old age to refine the principle of autonomy for older people. Agich,<sup>15</sup> a phenomenologist who studied autonomy in nursing homes in the US, criticized the idealization of autonomy as a trait of a competent rational free agent. Agich focused on what autonomy actually meant for old people in the everyday world, and questioned whether autonomy as self-determination was realistic in all situations and contexts. He noticed, for example, that relationships between staff and older people in long-term care were more enduring and complicated than in a medical context, and that many decisions were not as discrete as in a medical context where a treatment decision has to be made. Autonomy as the freedom to decide was not so much related to 'big' treatment decisions in a nursing home context but rather related to everyday ethical issues, like deciding when to get in and out of bed, taking a shower or not, or when to have what kind of meal.<sup>16, 17, 18</sup> Those 'smaller' but very important decisions tended to be determined in this context by the *regime* of the institution, as Erving Goffman<sup>19</sup> and Michel Foucault<sup>20</sup> had already revealed in the context of psychiatry. Overruling someone's will in such a situation was a matter

of the intentions of the care workers – who were often just as hospitalized as older people themselves – but rather the outcome of a subtle structural hierarchy built into the system and discourses. In our own work we have also demonstrated how system values like productivity, safety and efficiency can rule out or undermine moral values of attentiveness, solidarity and sense of belonging,<sup>21</sup> and that older people tend to embrace many ‘smaller’ everyday values more easily and tend to associate those values with the principle of autonomy.<sup>22</sup>

Given the empirical nature of this study we shall restrict our theoretical framework to the concepts of autonomy that provide us with new insights when applied to the case studies that involve older people. The concept of autonomy as self-determination provides us with a useful differentiation between decisional and executive autonomy that can easily be overlooked in the medical practice of long-term care.<sup>23</sup> Decisional autonomy refers to the capacity to make one’s own decisions, executive autonomy to the realization of those decisions. As Naik and others point out limited executive autonomy can easily be confused with limited decisional autonomy. This risk is particularly apparent in the case of old age where ageist stereotypes may lead people to think that the limited capacity of self-sufficiency implies that someone has limited decisional capacity as well.

The concept of relational autonomy may help us to focus on the contextual complexity of the decisions that older people make.<sup>24</sup>

According to Marian Verkerk<sup>25</sup> people are always interdependent. That is why people are not autonomous despite their relationships with others, but due to their relationships with other people.

In the following section we will illustrate this point with two narratives which are based on naturalistic case study research.<sup>26</sup> This is a research approach aiming to generate deep interpretive understanding of the lived experiences and multiple perspectives of those engaged in a particular socio-cultural practice.

### **3. Narrative of mrs. Caritas**

Mrs. Caritas was an 81 years-old married woman, whose husband had died five years earlier. One of her three children had died as well, the other two were married. Mrs. Caritas had five grandchildren. She had a Catholic background, but was not a regular churchgoer anymore. Her father had been engaged in the labor movement, and Mrs. Caritas shared his political consciousness. Like many of her generation and social status she attended primary school only, started working when she was a young girl and quit her job when she got married. When the children were grown-up and her husband lost his job due to a labor conflict, she reentered the labor market by working night shifts in nursing homes. Caring about and for others had always been the core value in her life. This was not only reflected in her work, but also in many other activities such as taking care of her grandchildren and

being a sort of ‘aunt’ and regular visitor of a group of intellectually disabled people. This caring orientation was also reflected in her motto: ‘ubi caritas et amor’. In her own words: where there is love, there is God. This motto also colored her identity, which was typical for many older women of her generation.

Mrs. Caritas became seriously ill in her mid-seventies, and received chemotherapy for non-Hodgkin cancer. She recovered and spent several good years with her husband, but then her husband’s health began to deteriorate. This started with symptoms of dementia, something Mrs Caritas had always feared. So she arranged for them to move to an apartment where he could receive proper care. Her husband did not like it very much and he never settled down. Finally, he died of lung cancer.

His death had an enormous impact on Mrs. Caritas. She had known her husband since she was 14, and they had developed a very close and intimate relationship. They had always been together, and life never became the same after his death. Mrs. Caritas felt lonely, and despite the presence of her children and various social contacts, she could no longer find a meaning or purpose in her life. The doctors diagnosed a depression, but anti-depressive medication only seemed to worsen her situation. She had no appetite or energy, felt listless and suffered continuously from pain in her neck and shoulders. Taking care of herself was something she had never learned, whereas she found it difficult to accept help and support from others. But the issue that bothered her most was how to carry on with her life that had become meaningless to her. She felt that ‘it had been good enough’ and that her life had been fulfilled. She spoke about death oftentimes now, and made it clear to her children and her general practitioner that she did not wish to be reanimated or kept alive if something should happen to her. Then the non-Hodgkin cancer came back, which almost felt as a relief to her, because the end was now close by.

Mrs. Caritas was informed about treatment options by her oncologist and she deliberately chose not to start chemotherapy that would extend her life. Instead she chose, in close consultation with her children, a treatment which was less intrusive and was aimed at improving the quality of her life. And so it did. The Prednisone treatment improved her general condition. She felt less pain, had more energy and psychologically she felt motivated to make something out of the months she still had left. She went out more often, and developed a clear idea of how to say goodbye to everyone she was close to. Despite this mental improvement her physical frailty gradually increased. She could hardly walk anymore, she ate very little, she still suffered pain, and it became increasingly difficult for her to get out of bed, take a shower, get dressed etc. She had a weekly house cleaner and her daughter helped her one day a week, but in fact she needed daily care, which unfortunately was not available. Then one night she fell, and broke her hip. Since she was not able to reach for the telephone or alarm, she lay on the floor the whole night, until

she was found the next morning and taken to the hospital. When admitted Mrs. Caritas made it immediately very clear that she did not want a hip operation. She could not be convinced that this was the only way to reduce the pain, and the doctors and nurses found her stubborn and foolish to refuse treatment. Mrs. Caritas asked for pain medication but her request was denied. She was told that this was not possible legally. In fact, the doctors thought that the pain reduction would hasten her death, which was exactly what Mrs. Caritas had in mind, but this was not discussed with her openly. It was not until the family came and the oncologist was consulted that proper medication against the pain was finally given. The family and the oncologist talked extensively to Mrs. Caritas about the consequences that the pain medication could have, and Mrs. Caritas made it very clear that this was what she wanted, and not a hip operation. Her oncologist thereupon concluded that Mrs. Caritas was terminally ill, suffered from continuous pain and wished to die. Her family confirmed her frame of mind: she had been lonely since her husband had died. Life no longer had any meaning or purpose to her since she could not take care for others. Mrs. Caritas died peacefully five days later.

#### **4. Mr. Powell's narrative**

Mr. Powell was 92 years old when we first met him. He had been widowed about five years earlier. He had three married children. He had been a civil servant all his life and had held various managerial positions. Now his kidneys were failing and he had been suffering from diabetes for the past three years. Complications (limited vision, paralysis, falls) relating to these renal problems and diabetes meant that, 18 months after the death of his wife, it had become unsafe for him to live at home. He was admitted to hospital, rehabilitated in a nursing home, and then he returned home. But the difficulties with taking care of himself persisted. Eventually he moved to a residential home. Contrary to his prior experience where safety and autonomy had gone hand in hand, they became trade-offs in later life. Mr. Powell's family doctor and his children urged him to search for round-the-clock care, because he was no longer able to take care of himself properly: he forgot to have hot meals in the evening, to take his medication on time etc. From his side, Mr. Powell did not believe all this was serious; he thought he could manage as he had always done before.

Throughout his life, Mr. Powell had highly valued his autonomy. After his wife's death he had taken good care of himself: he had done the housework, washed the dishes, vacuumed, and arranged his medication. He was not only self-sufficient, but also independent in making decisions and giving a direction to his life. He had, for example, already arranged his funeral. Mr. Powell thought that worrying about safety would limit his autonomy. He did not want to become dependent and he did not like the fact that he needed help,

during his stay in hospital. Upon his return home, he became prone to falls; his personal safety had become an issue. Although he gradually and grudgingly began to accept his frailty and the importance of personal security, which his family and doctor had pointed out to him, Mr. Powell still felt that accepting help might result in a conflict with his autonomy. He feared that others might make decisions for him behind his back. He wanted to remain in control. When he was admitted to the residential home, he accepted care reluctantly. He did not expect help from his fellow residents, who were all, in his eyes, frail, but he did expect it from the professional caregivers. In his view professionals were even obliged to help him, and it was Mr. Powell who instructed the nurses to come to his apartment at night. He had realized that he could find a compromise between autonomy and personal security, since he noticed that his autonomy in fact increased when he accepted the care that was offered to him.

Mr. Powell slowly learned to become receptive to the care offered by professionals. He found it harder to accept help from fellow residents who were just as vulnerable as he was. He was inclined to help others. As soon as he could walk again he would go out to push a fellow patient around in a wheelchair. He lived up to the promise of doing one good deed a day, a credo from his youth as a Boy Scout. And the residential home encouraged him to help others. He was particularly fond of a discussion group on existential matters. He liked to give the participants personal presents. To channel his energy into expressions of goodwill, Mr. Powell planned various events for the residents. He wrote short stories for the house magazine, arranged puzzle competitions and bought little presents for the winners. However, it seemed to him, that most of his ideas were not appreciated by the management and his fellow residents. Mr. Powell began to think they considered him to be troublesome and felt disappointed. Some of the staff members admitted that they were often rather strict when it came to dealing with residents' individual wishes. It was also said that Mr. Powell was somewhat naïve, even paternalistic, in his relations with others. Apparently Mr. Powell came up with various ideas without checking whether the others were actually interested in his plans.

## **5. Evaluation of autonomy in both cases**

Both Mrs. Caritas and Mr. Powell are self-determined people. They were always decisive, making plans and proactive, and continued to be so in later life. They still had clear ideas on how they want to lead their lives and what is of value to them. Their autonomy as self-determination is most stark and straight-forward in their refusal of proposals and decisions that others make for them without consulting them or taking into account what really matters to them. Mrs. Caritas refuses the hip operation even while several health care professionals try to persuade her, because she is convinced this is not the right thing

for her. This is not just an impulse of Mrs. Caritas. She has thought it through beforehand and sticks to her decision, so she asks for pain medication only. In a similar vein, Mr. Powell initially refuses the admission to a residential facility; he feels this is not the right place for him to be himself. Also, in both cases we can see how their executive capacity is limited; Mrs. Caritas asks for pain medication but does not get it. Mr. Powell is limited in the capacity of taking care of himself at home. Also, in both cases the limited executive capacity is confused with the decisional capacity. This is not just the outcome caused by unwilling professionals, but also it is influenced by the context wherein the institutional regime is such that decisions are made for people, the risks need to be assessed and controlled and ageist stereotypes shape the background of the institutional way of thinking.

The case of Mrs. Caritas also shows us that a different approach towards autonomy, when applied timely and correctly, could lead to a more harmonious solution from the very beginning. The oncologist as well as Mrs Caritas's family respect her decision, because they had the time and the opportunity to talk with her about it beforehand. They engage in the process of coming to the best decision for Mrs Caritas, because they can recognise her *interdependence* on their understanding and support. The staff at the hospital operates under time pressure, and if no room is explicitly made for explanations and, if necessary, for the negotiating of the older patient's wishes, no relations other than observing the formalities will be built between her and the staff, no goals other than recovery and helping by the book will be considered. Zooming in to the case, we can see how in spite of the good intentions of all parties, the framework of the legal system fails to guarantee the execution of the patient's right to self-determination. Only when the vulnerability and dependency of Mrs Caritas becomes a matter of discussion in which the staff of the hospital is involved will the autonomy of the patient be incorporated into the legal proceedings and, more importantly, into the practice of the health care professionals.

From Mrs. Caritas' narrative we can also learn that her autonomy extends to the freedom to choose. Bereavement after the death of her husband as well as not being able to find purpose and meaning in life are an important threads in her story. Her life had meaning as long as she could care about and for other people. The death of her husband has an enormous impact upon her. She cannot overcome this loss. Her bereavement and immense grief show the possibility or perhaps even inevitably that one's identity changes through the loss of an important other. In the case of Mrs. Caritas, her husband was tied to and constituted her identity and autonomy. Judith Butler<sup>27</sup> has indeed made it very clear that our autonomy is not in opposition to another important person in our life; one's identity is interwoven with the other person, and the loss of another person can mean a loss of the



self. The enormous loss and pain Mrs. Caritas feels, not only physically but also mentally, shows how her identity is connected with her husband. His death is also a confrontation with the impossibility to be completely in control. Mrs. Caritas has planned many things in life, such as the move to an apartment, but this goes beyond her scope and will. Her autonomy and idea that things can be controlled comes under serious pressure; the precariousness of life is an overwhelming experience. This implies that autonomy involves more than making decisions without the interference of others. Human beings can be vulnerable and interdependent on other people to realize their autonomy.

Relational autonomy stresses the relations of dependence and connection as being constitutive for one's autonomy. Care ethicists emphasize that autonomy can only be developed in relationships with others, in situations of dependence.<sup>28</sup> People require support in order for them to understand what is important in their lives, for example, in the case of Mr. Powell, staying healthy, and how to arrange their lives accordingly such as, in Mr. Powell's case, having hot meals, moving to a residential home, taking insulin etc. Sometimes one needs to be warned or supervised in anticipation of future situations. By helping people protect themselves against their impulses – a dislike of cooking in Mr. Powell – or from their limitations – forgetting to take his insulin – their autonomy is actually reinforced. Mr. Powell functions much better since the caregivers started to drop in on him on a daily basis. Others helped him to remind him of the person he once had been. They thereby fostered his identity, and thus his autonomy. Like those who noticed that Mr. Powell had many talents and found a way to channel these talents, in order to help him be the helping Boy Scout he once was. In the discussion group, Mr. Powell continued to be the well-educated, well-read and animated person he was in the past. This shows that autonomy can be fostered through intervention from others and that people need other people to develop and maintain their identity, integrity and dignity.

And yet all Mr. Powells' initiatives were turned down. He was confronted with the managerial staff and a residents' board that did not expect him to act autonomously. He was given the impression that he should not be too entrepreneurial and creative. His sense of duty was not well managed. His own sense of identity clashed with what others expected of him. He wanted to participate in the residential home community, and considered it his duty to help others –just like a Boy Scout doing one good deed a day. So he came up with all kinds of initiatives. Yet, these initiatives were not developed *with* others but *for* others, without consulting others. Even the residents' board – a natural forum for presenting his ideas – was not consulted. This non-reciprocal approach (I do a good deed for you) did not get him very far; all his ideas were turned down. One might argue that Mr Powell

should have received more support from the professional staff to help him carry out his plans, for example, by confronting him with his non-reciprocal approach. From a relational concept of autonomy, this can be legitimated as a crucial interference to foster the empowerment and self-development of Mr. Powell. This is in line with Agich's<sup>29</sup> notion that individuals are never fully formed, but are part of a dynamic process of development, in interaction with their environment. It is also in line with Jessica Benjamin's work<sup>30</sup> on mutual recognition in a relationship: that we can only get full recognition from those who we respect, and that we need others to contain our will to power and overrule others. Helping people to see their limitations is, in this respect, an essential part of good care; it gives people the opportunity to learn and mature. In addition to Mr. Powell's non-reciprocal approach to responsibilities, it can be observed that the managerial staff and residents' board members were not particularly constructive when it came to finding an appropriate role for Mr. Powell. The organizational constraints and policies were quite 'rigid'.

## 6. Good care in old age

According to Agich '*respecting autonomy requires attending to those things that are truly and significantly meaningful and important for elders*' (1993, p. 113).

The only way to know what an older person finds meaningful and important is to 'identify' that person, for instance to place her/him in the context of her life narrative, with its intricate web of relations and interdependencies. Posing the question *what do you want?* will most likely not generate a comprehensive answer. The question *who are you?* can result in a life narrative that can be fruitful to define what can be proper care for a certain older person.<sup>31, 32</sup> So the main approach towards creating a setting with proper care for older people is to define and create conditions under which their identities can be unfolded, their personal values are identified and fostered and the relational contexts of their lives are taken into account and respected. Will one's autonomy nevertheless be influenced by the creation of such conditions? Undoubtedly, yes, but their influence is of a productive nature. If we agree that realization of one's identity is possible in interaction with others, then the execution of autonomy cannot be absolutely autonomous at the same time. Next to taking decisions autonomously we need others to ask for advice and to provide advice, to warn us against a bad decision and to be warned against taking one, to care for somebody we love, but also to be the one who is taken care of. Interdependence is the core of relational autonomy, that gives a person not only a feeling of freedom, but in fact protects her/him against profound autonomous loneliness. The translation of this intersection between autonomy as self-determination and relational autonomy into actual practice may require various interventions. One of the starting points on the path

towards an informed decision taken by an older person and supported by people in his/her surroundings, is her/his own motivation.<sup>33</sup> Such motivation cannot be taken for granted. According to Moody this is a result of a complex process of deliberation and negotiation, in which such interventions as advocacy, persuasion and empowerment play an important role.<sup>34</sup> The role that the professional plays in this process reaches beyond being a merely listening party. A good professional provides information, acts as an expert and at the same time fulfills the role of a friendly advisor. The professional sees and accepts the older person as a unique and autonomous individual. At the same time, the professional's engagement is comparable with the role of a catalyst, who enables deliberation and re-evaluation of the older person's former convictions by bringing the personal, organizational and legal contexts of the older person's case together. So while the professional may try to persuade the older person, as in the case of Mrs. Caritas to accept the hip treatment, ultimately the principle of autonomy as self-determination implies the respect for and acceptance of the choice, even if it is not understood or unmotivated. In that specific case the hospital staff was not sufficiently motivated to take the unique perspective of the older patient into consideration and thereby to help her to reinforce her autonomy. Instead coercion was used as a leverage in the conflict. And it failed.

The place of coercion in the care for older people entails a complex discussion within bioethics. Moody already showed this by demonstrating a vast variety of subtle differences that exist between informed consent and negotiated consent. Strictly speaking negotiated consent can be regarded as a form of coercion, but following the developments within psychiatric care we would rather call it compassionate interference.<sup>35</sup> Compassionate interference boils down to a limited influence on the autonomy of the older person, in order to reinforce her or his responsibilities. When interference leads to reestablishing interactions and interdependencies within the older person's life, the feeling of her or his autonomy will be amplified as well. This kind of interference can be applied only when motivational encouragement and support have failed to ignite the dialogue. There are at least two conditions under which compassionate interference can be used. Firstly, the older person in question must experience it as a means of self-development. If Mr. Powell, for example, had been timely encouraged to fine-tune his ideas with the staff and the fellow clients, then he would probably have learned some diplomacy and could have recruited a few members for his Boy Scout activities. In actual fact, the absence of interference resulted in diminishing Mr Powell's autonomy all together. Secondly, whenever compassionate interference is applied it is imperative that the actions taken will be evaluated thoroughly afterwards.

## 7. Discussion

The two cases both contain similarities and differences in how they relate to the contemporary societal context and the debates about proper care and autonomy in old age. In October 2017 Statistics Netherlands (CBS) published a report that showed a 60% increase in people falling as the cause of death in the past five years. 75% of the Dutch people who died for that reason in 2016 were 80 years or older (CBS, 2017). The current health care system in the Netherlands promotes self-sufficiency and self-reliance concerning the health and well-being of the older generation. The cases of Mrs. Caritas and Mr. Powell could easily be regarded as true-to-life examples, like real faces breaking through the anonymity of the statistical outcomes.

Mr. Powell and Mrs. Caritas are both quite articulate in expressing their will, which goes against stereotypical images of older people. Of course, not all older people are as active and articulate. Several studies stress that older people, especially the older generation in residential or nursing homes tend to want to please. They point out that older people do not want to pester the staff, they do not make demands or complain.<sup>36</sup> Mr. Powell and Mrs. Caritas were self-determined, not afraid to ask questions and of acting non-conformably. Although they both want to direct their lives and stay in control, and autonomy is said to be valued, we find here that their attitude is not appreciated at all. Mr. Powell's plans are rejected, Mrs. Caritas wish to die is a non-issue. We see here the ambivalent relation our society has to the enactment of autonomy in old age. In both cases, the limited executive capacity led people to believe that the decisional capacity was also limited. Furthermore, we can see that autonomy as self-determination is embraced, leading to non-interference, regardless of personal costs and misery. In the case of Mrs. Caritas, she had to stay at home despite her frailty and need for support. Tragically, she first had to break her hip before help came along.

The findings of this study raise the question as to whether alternatives to institutionalized care, such as day care, home care or ambulatory care, are more appropriate when it comes to supporting the autonomy of older people. One might assume that staying in their own environment enables older people to maintain their identity and stay involved with their own activities. Yet, professionals who visit older people in their own homes do not automatically support their autonomy. Helping people at home to deal with dependency and vulnerability is far from simple, and requires the development of trust.<sup>37, 38, 39</sup> Furthermore, frail older people sometimes prefer the safety of an institution, since it provides them with the context to enact their autonomy.<sup>40</sup> Improving residential care may be an appropriate way to foster the autonomy of older people, in the sense of enabling them to continue a life in accordance with their own values. The trend toward deinstitutionalization does therefore not automatically – as sometimes assumed – imply more autonomy. On the contrary, many older people complain that they no longer have a choice because they have to stay home, whether they like it or not.

One might argue that Mr. Powell's and Mrs. Caritas's narratives are not about autonomy, but about identity, self-worth (dignity) and personal integrity. This argument, however, presupposes a conceptualization of autonomy as making decisions without others intervening. From a relational perspective, identity, integrity and dignity are integral to the notion of autonomy. Autonomy is not just about making decisions without external intervention; it entails self-worth and self-development. Autonomy is not just an individual exercise, but an interactive process, requiring the help and support of others. We recognize this in both stories. Mrs. Caritas's identity is closely tied to her husband, and his death has an enormous impact on her identity and autonomy. Mr. Powell is pleased that the caregivers stop by on a daily basis to see how he is doing. The idea that he is in good hands, that they recognize and keep an eye on him, fosters his feeling of being able to deal with the situation and live in accordance with his values. He is no longer afraid of having a heart attack, a black-out, or a fall etc., he is more relaxed and open about the future. This helps him maintain a sense of self and self-worth (dignity). Mr. Powell also feels more dignified since he is looked after by a freelancer who addresses his social talents and helps him continue to be the cultivated man he once was.

Our analysis of the two cases brings the issues of diversity among the older generation to the fore. While both respondents pursue a similar goal, namely to preserve their sense of identity by translating their values into decisions concerning independency, the meaning that they give to their lives at that stage differs a lot.<sup>41</sup>

Mrs. Caritas is the embodiment of a life narrative which is class- and gender-determined. Her care-centered life meets the current societal expectations of being a perfect house wife and a mother in the way it has been promoted for a long time within the Dutch society.<sup>42</sup> The development of emancipation and her personal family situation encourages Mrs. Caritas to reenter the labor market in order to support her family. But at the end of the day, the care-giving function that she turned into her vocation overrules all other options for self-development. Mrs. Caritas never incorporated self-care in her worldview. When she becomes ill she feels that life itself loses its meaning for her, because she does not want to be the one who is taken care for.

Mr. Powell's life is career- and duty-centered. He meets Walker's description of 'the fit, energetic, and productive individual who sets himself a course of progressive achievement within the boundaries of society's rules and institutions, and who's orderly life testifies to his self-discipline and individual effort'.<sup>43</sup> The principles that he aspires to are based on the ethics of duty. The increasing fragility of his health has taught Mr Powell to consider interdependency instead of absolute autonomy. But the habits and style of his former privileged social position get the better of him within the residential facility. As a result, his autonomously taken decisions are not appreciated.

The differences between these cases cannot be addressed with the help of one universal concept of autonomy. Yet the policies and the legal definitions for the older generation do not consider a unique human being, but address the 'average older person', which is a mere figure of speech disconnected from the context of everyday life. It is time to integrate this diversity into our social and legislative system, and also into the organizational approach adopted by our health care institutions.

## 8. Conclusions

In this article we have analysed two cases where a decision-making process by an older person, placed within a care institution, was involved. With help of the two concepts of autonomy, namely autonomy as self-determination and relational autonomy we tried to understand which of the concepts meets the complexity of each of the empirical cases best. The richness of the cases convinces us that both self-determination and relational interdependencies are of utmost importance when freedom of choice and the well-being of the older person are at stake. The crux of our conclusion is that these two types of autonomy have to be known and applied not only by older people and their informal environment themselves, but particularly by the care professionals who work with them. The value of the professional ability to identify the intersections between independence and interdependence in case of an older patient or a client, can serve as a guiding principle in the cases where autonomy of an older fragile person is involved. We see an important task for the educational institutions who prepare professionals for work in elderly care here. Autonomy, as understood here, is an empirically applied concept. Given the historical developments that have been described above, it is quite an important evolutionary aspect of human life. That is why it cannot be seen as a given set of principles, applicable to everyday actions. Autonomy is a challenging process, the quest to find a balance between the personal experience of freedom and interdependencies with which each life is saturated. This brings us to an enriched understanding of autonomy. But as we can see in the case studies, the empirical applications of autonomy within individual lives are highly complex. Being and acting autonomously means considering a broad scale of perspectives, including your own. It means that a person has to possess certain negotiating skills and has to be able to receive support from those who are willing to enforce your sense of responsibility. Therefore, autonomy is not a fixed right, given by birth. Autonomy is a competence that a person needs to develop in order to apply it in a variety of life situations. And as with any competence, it takes time and practice to master it. Older people grew up and grew old in a world that started from paternalism, accelerated through autonomy understood as self-determination and just recently reached a point where relational autonomy is being considered as well. We can leave

them to discover on their own what autonomy means nowadays, or, together with the health care professionals, we can engage them in a constructive dialogue that addresses today's ethical dilemmas and use that dialogue as a learning process that can empower the autonomy of the older generation and of the health care professionals at the same time.

*\* Mr Powell is a pseudonym. The original Baden Powell was the founder of the Scout Movement.*

## Noten

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