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# How older adults with physical impairments maintain their autonomy in nursing homes

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## Abstract

Autonomy is important to persons, including when they are living in nursing homes. Especially the relational dimension of autonomy is crucial for older adults with physical impairments. They generally have the decisional capacity to make choices about how they want to live their lives, but are often unable, or only partially able, to exercise these decisions themselves. To execute decisions, older adults are dependent on those who support them or care for them. However, little is known about how nursing home residents maintain autonomy in daily life and how others are involved in the decisions and execution of the decisions. To examine how older adults with physical impairments living in nursing homes maintain autonomy in daily life, shadowing, a non-participative observational method, was used. Seventeen older adults were shadowed during the course of one day. The observation ended with a brief interview. After the shadowing, the detailed observation notes were typed out, combined with the verbatim transcript resulting in one extensive report per shadowee. All 17 reports were coded and analysed thematically. Six elements for how older adults maintain autonomy in relation with others were identified, *i.e.* 'being able to decide and/or execute decisions', 'active involvement', 'transferring autonomy to others', 'using preferred spaces', 'choosing how to spend time in daily life' and 'deciding about important subjects'. For all six elements established in this study, it was found that older adults with physical impairments living in nursing homes could only maintain autonomy in daily life when others, such as staff, family and friends, were responsive to signals of the needs of older adults.

**Keywords:** autonomy; nursing home; resident; older adult; shadowing; person-centred practice; long-term care

## Introduction

Most older adults with physical impairments and chronic conditions continue to live at home. Health-care policies in the Netherlands are aimed at helping older

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adults stay at home for as long as possible, with help from informal care-givers or community health care (Jacobs, 2019). Older adults who need 24-hour care, and who cannot organise this care at home, can move to a nursing home (Verbeek-Oudijk and van Campen, 2019). This move is a far-reaching experience for older adults and their loved ones. On the one hand, an older adult faces the challenge of adjusting to this new context and finding a way to maintain autonomy. This adaptation requires active coping processes in older adults (Brandburg *et al.*, 2013; Johnson and Bibbo, 2014). On the other hand, nursing homes have changed from following a biomedical model to more person-centred environments that combine housing and medical care with valuable personal attention, which should improve autonomy (Koren, 2010; Donnelly and MacEntee, 2016). Staff in nursing homes therefore face the challenge of providing person-centred care and supporting autonomy in order to enable older adults to continue to live the life they prefer, as far as possible (Custers *et al.* 2011).

People with physical impairments due to age-related decline and chronic health conditions (hereafter referred to as older adults with physical impairments) generally have the decisional capacity to make choices about how they want to live their lives, but are often not or only partially able to exercise these decisions themselves.

In the Netherlands, nursing homes provide 24-hour care (Verbeek-Oudijk and van Campen, 2019) by registered nurses and practice nurses. Paramedic professionals such as occupational therapists or physiotherapist provide treatment and can be consulted by nurses. An elderly care physician is responsible for the entire care process (Waterschoot *et al.*, 2021). Nursing homes have separate units for older adults with physical impairments and for older adults with dementia (Custers *et al.*, 2011). The deciding factor for admission to a nursing home is not the condition of the individual, but the level of care needed.

According to the literature, autonomy can be described as the capacity to affect the environment, irrespective of having executional autonomy, to live the kind of life someone desires to live in the face of diminishing social, physical and/or cognitive resources and dependency, and autonomy develops in relationships (Van Loon *et al.*, 2021). Collopy (1988) distinguished five dimensions in the concept of autonomy in long-term care: delegated, decisional, executional, direct and authentic autonomy. The main dimensions that have been studied in the context of nursing homes are decisional and executional autonomy. Residents can decide how they want to live their lives, but due to physical impairments they need help from others to execute these decisions (Hillcoat-Nallétamby, 2014). More recently, a relational dimension has additionally been studied, described as the dependence of frail persons on those who care for them (Abma *et al.*, 2012). Relational autonomy develops between older adults seeking care and persons providing care (Fine and Glendinning, 2005).

Three interrelated factors have been identified that are important for maintaining the autonomy of older adults with physical impairments living in nursing homes. The first factor is the characteristics of older adults, these include psychosocial characteristics such as having sufficient financial resources (Chao *et al.*, 2008; Gleibs *et al.*, 2014; Hillcoat-Nallétamby, 2014) and the help of family and friends (Walent and Kayser-Jones, 2008; Cooney *et al.*, 2009; Oosterveld-Vlug *et al.*, 2014); relations with staff (Walent and Kayser-Jones, 2008; Oosterveld-Vlug

*et al.*, 2013); and social engagement (Danhauer *et al.*, 2006; Råholm *et al.*, 2014). The second factor that affects the autonomy of nursing home residents involves the intrapersonal characteristics of the older adult, *e.g.* learning (Anderberg and Berglund, 2010) and coping abilities (Curtiss *et al.*, 2007; Cooney *et al.*, 2009), optimism and hope (Danhauer *et al.*, 2006), and the feeling of being in control (Morgan and Brazda, 2013). The third and last factor consists of physical characteristics, such as being dependent on (Hellström and Sarvimäki, 2007) or benefiting from the protection of the care facility (Oosterveld-Vlug *et al.*, 2013).

The characteristics of professional care-givers also have an effect on autonomy of older adults. Factors such as their beliefs and values (Dunworth and Kirwan, 2012), ethical competences, creativity and reflection, and commitment to the job and communication skills (Bolmsjö *et al.*, 2006), have been identified by prior research as important to maintain autonomy.

Autonomy is also affected by the care processes between older adults and care-givers, such as the way that decisions are made (Custers *et al.*, 2011), the relationships between older adults and staff (Andresen *et al.*, 2009) and the way care is given (Oosterveld-Vlug *et al.*, 2014).

Lastly, the environment in which care is given affects autonomy. Older adults who have choice and control, *e.g.* through involvement in formal decision-making (Gleibs *et al.*, 2014) and supportive systems (Baur and Abma, 2012), are supported in their autonomy. Adequate staffing is important, including continuity of staff, skilled personnel, and ethnical and social congruity (Walent and Kayser-Jones, 2008). Also the physical environment affects autonomy, such as having shared and private spaces (Johnson and Bibbo, 2014), and the financial resources of the nursing home (Hellström and Sarvimäki, 2007). These factors – the characteristics of staff, care processes and the care environment – are in line with the person-centred practice framework of McCormack and McCance (2017).

Given the overview of facilitators of, and barriers to maintaining autonomy in nursing homes, the authors sought to explore the perspectives of older adults with physical impairments in practice. The following research question was formulated:

- How do older adults with physical impairments who live in a nursing home maintain autonomy in daily life?

This has rarely been studied. The authors aimed to address empirically driven questions such as, how do older adults maintain autonomy in everyday life, and what actions do they take if they can decide on – but not execute – decisions, and help is needed? Insight into such questions can lead to the more accurate recognition of autonomy in daily (care) practice and, as a result, improvements in the ability of older adults to exercise autonomy.

## Method

### Design

The authors sought to include all older adults with physical impairments, including those who were not able to reflect on their actions in a conversation, such as persons with aphasia or in poor health. The authors also wanted to explore the actual

behaviour of individuals. For these two reasons, a qualitative descriptive design was chosen. The authors chose a phenomenological method, *i.e.* shadowing, to explore and describe autonomy (Van der Meide *et al.*, 2013). During shadowing, a non-participatory observational method, JvL was positioned near older adults as a shadow in their context – their apartment or unit – for a period of, on average, three hours. The aim of shadowing was that the researcher could experience what happened with regard to maintaining autonomy in daily life.

Autonomy and decisions were expected to arise in more intensive contact with different staff members, and therefore periods of interaction had to be chosen for shadowing (McNaughton Nicholls *et al.*, 2014). Based on a literature review, the authors selected three periods for engaging in shadowing: morning care, mealtimes and activities. Custers *et al.* (2011) state that morning care involves the most interaction between a resident and staff. Palacios-Ceña *et al.* (2013) discuss mealtimes as periods in which to decide what, where, how and when to eat. Gleibs *et al.* (2014) point out the importance of activities to foster autonomy.

The authors aimed to study a variety of ways in which older adults maintain their autonomy. JvL, who did the field work, communicated possible shadowing dates to two care units. The older adults could choose their preferred date. The dates were planned alternately for Unit A and Unit B, so the researcher was able to observe differences and similarities between the units. To enable the observation of various social activities, different weekdays were chosen during a total of two months, including weekend days and religious holidays.

### **Setting and participants**

The management of two care organisations in the south of the Netherlands gave permission to collect data in their organisation. Both organisations aim to support autonomy, which is reflected in their mission. The management of both organisations each selected one care unit (referred to as Unit A and Unit B) in which older adults live and that met the inclusion criteria: including older adults (65 years and older) who had physical impairments and lived in a long-term care unit in a nursing home.

After receiving permission from the Ethical Review Board of Tilburg University, and from the ethical commission of the organisation of Unit A (the organisation of Unit B did not have such a commission), the older adults were contacted. The researcher informed the older adults and a trusted contact person (a staff member working in the unit) about the aim and design of the study in a regular ‘living room meeting’. The older adults were invited to participate in the study. The information and an informed consent letter were given to the attendees of the meeting. There was a two-week period for them to read the information, consider participation, ask questions and return a signed copy of the informed consent letter. The trusted contact person was available to answer questions posed by the older adults, their families or friends, and share this information with the researcher.

About 15 people in each unit met the inclusion criteria, and purposive sampling with a quota of ten persons per organisation was therefore executed. The trusted contact person for Unit A asked the older adults to consider participation, resulting in ten people who agreed to participate. The contact person for Unit B asked the

older adults in the same way, and nine people agreed. In total, 19 persons handed in a signed copy of the informed consent letter.

Family, volunteers and staff were not included in the study, although they could be present in the context during the observation, and therefore received written information. When they visited the unit during the shadowing, they were also verbally informed about the study by the researcher. No personal data were collected on family, volunteers, staff or incidental visitors.

One person withdrew his permission prior to data collection during the study, and one person was excluded from the dataset when it became clear she did not meet the age criterion.

### **Data collection**

The data collection process typically proceeded as follows: after arrival in the unit, the researcher presented herself to the staff in the unit, explained who she was and who she was going to shadow that day. She waited until the nurse(s) went to the older adult for morning care and then she introduced herself and the study again to the older adult.

During the shadowing, she accompanied the shadowee: walking to other rooms with the shadowee, accepting a cup of coffee and engaging in small talk. During periods of personal care she tried to be like a 'fly on the wall', and sat outside the field of vision to avoid uncomfortable situations. The researcher took detailed notes of the conversations and activities that happened during the observation. Contextual information such as noises, smells, expressions and positioning in the room were included. All notes were written in a hardcover notebook. There was no selection regarding what was documented in advance, and all that the researcher observed and heard was written down. The meaning of what was observed would be revealed after coding and analysing. The length of observation (several hours) allowed ample time to write down all that happened. At the end of the day, the shadowee was briefly interviewed (on record), to explore how to interpret and understand what had occurred (McNaughton Nicholls *et al.*, 2014). Questions were used such as 'Did you experience autonomy in this situation' and 'Is this the way you want it to happen?' The interviews took place in the person's apartment. The researcher did not interview the two persons with aphasia, and instead only thanked them for their participation. The observations already provided insight into how these two persons maintained autonomy while not being able to express themselves verbally: respondent A5 was very clear non-verbally, and could also execute decisions herself. Respondent A2 was accompanied by her husband who spent most of the day with her, and transferred autonomy to him.

Seven out of 17 intended observations of social activities of the shadowees were missing. This was partly due to a miscommunication about where or when to meet the shadowee. Some other older adults did not engage in organised activities, so it was difficult to identify activities to observe in the privacy of the sitting room. Two observations were missing for morning care. One older adult did not want the researcher to shadow this activity, and the other wanted his morning care before the researcher arrived in the unit. One mealtime observation was missing because this person ate the meal in her sitting room and preferred to be by herself.

All collected data were processed shortly after collection: the observation notes were typed out in records and the recorded interviews were transcribed on the same day. The detailed notes of the observation and the verbatim transcript of the interview were combined into one report for each respondent.

### **Data analysis**

The authors used the analytical method of Spencer *et al.* (2014) to analyse the data. In order to increase the rigour of the analysis, four of the five authors (JvL, BJ, IdR, KL) approached the coding systematically with co-coding and consensus sessions. They started with an individual reading of one of the reports, which they explored and to which they applied open coding. Afterwards, the research team discussed the interpretation of the text and exchanged their views. They also decided which terms would be appropriate for labelling the data. JvL coded 17 reports, and three other authors coded five or six each. Afterwards, the same procedure of interpreting and exchanging views was used in pairs of authors. After ten co-coding sessions, similarities and differences in coding were discussed with the team. After consensus was reached concerning the codes, they were processed using ATLAS.ti. This tool allowed the researchers to summarise the codes and check, discuss and finalise them.

The coding check was done by the author (MJ) who was not involved in the original coding. She checked whether the fragments really referred to ways of maintaining autonomy used by older adults. This led to a discussion about the fragments concerning the role of relatives and the authors decided to approach the role of relatives in maintaining autonomy as part of the client system. The following adjustments were made: codes that on a closer look did not involve the perspective of the respondents were removed, and codes that occurred only a few times were added to another code.

After checking, discussing and adjusting the codes, two authors (JvL, MJ) analysed the data thematically. They used a procedure of discovering, interpreting and reporting patterns and meaning within the data, followed by the integration of themes (Spencer *et al.*, 2014). In order to answer the research question, how do older adults with physical impairments who live in a nursing home maintain autonomy in daily life?, the two authors grouped codes that described a similar way of maintaining autonomy. They then formulated descriptions for the main codes that summarised the codes in this group. A code tree emerged with six main codes: the six elements used to maintain autonomy with underlying codes. The code tree can be found in the online supplementary material. All five authors were involved in discussing each step in the analysis until consensus was reached.

## **Results**

### **Description of the context**

#### *Structure of the building*

The units were built in 2007 (Unit A) and 2004 (Unit B), and were structured differently. Older adults living in Unit A had a one-room apartment with a shared bathroom. Unit B offered a two-room apartment with a private bathroom. Both

**Table 1.** Characteristics of the care organisations

	Organisation A	Organisation B
Number of clients	2,700	960
Number of employees	2,600	870
Number of locations	14	5
Provides care	Concentrated in a large town	In a small and a medium-sized town and surroundings
Number of older adults living in the selected unit	40	28

units had two living rooms where older adults could meet and enjoy their meals. Both nursing homes also had spaces for activities and therapy, a restaurant and surrounding gardens (Table 1).

### *Social activities*

The nursing homes organised recreational activities where older adults could meet each other. They could choose activities that reflected their previous and current hobbies and preferences. Sportive activities took place, such as walking (or being pushed in a wheelchair), cycling and playing ballgames. Unit B also organised a cooking club and a classical music club. These activities were often facilitated by volunteers and co-ordinated by an occupational therapist.

### *Morning care*

Morning care was a private activity: the older adult and one or sometimes two nurses were present in their room or bathroom, to help them wash or shower, and to get dressed. Older adults were offered a choice regarding when, where and how morning care was given. However, showers were only offered a few times a week.

### *Mealtimes*

A meal was provided three times per day, for which nutritional assistants were responsible. The time for a bread-based meal or a hot meal was fixed for both units. This could be altered, if requested in time. No fresh meals were cooked in either unit; a system was used to reheat food. There were many choices regarding where to eat. *Ad hoc* choices could be made for eating in bed or in the sitting room of the apartment. A preference needed to be stated in advance for eating meals in either the living room of the unit or the restaurant of the nursing home. There was plenty of choice when ordering warm meals in advance, accommodating religion, taste and diets. *Ad hoc* choices could be made for breakfast and for the evening meal. Assistance was given to older adults who could not eat independently due to physical conditions. Persons with swallowing disorders were limited in their choices of what and where to eat, due to protocols.

### *Description of the participants*

Table 2 describes the participants; 17 persons in total participated in the study. The age of the older adults in Unit A ranged from 75 to 93 (mean = 82.8). In Unit B, the

**Table 2.** Description of participants and data collection

Participant	Gender	Age	Time living in nursing home (years)	Self-reported reason to move to nursing home	Observed disability	Shadowing <sup>2</sup>	Duration of shadowing (hours)	Duration of interview recording (minutes)	Number of coded fragments per respondent
A1	Female	81	7	Lung disease, leg amputation	Uses a wheelchair, needs assistance with ADL <sup>1</sup>	C, A, M	5.5	15	69
A2	Female	71	5	Stroke	Could not make phrases, uses a wheelchair, needs assistance with ADL	C, A, M	2.5	4, the aphasia worsened when asking questions. Researcher stopped the interview	44
A3	Female	83	4	Muscle disease, spinal cord injury	Uses a wheelchair, needs assistance with ADL	C A, M – stays in bed, no organised activities. Sent researcher away after the food was brought to her	1.5	6	39
A4	Female	93	4	Muscle disease, impaired shoulder	Uses a wheelchair, needs assistance with ADL, has bad eyesight	C, A, M	4	12	48
A5	Female	83	6	Stroke, lived with hemiplegia	Could not say words, uses a wheelchair, needs assistance with ADL	C, A, M	4.5	0, respondent has aphasia	46



A6	Female	75	2	General decline	Stays in bed, needs extra oxygen and assistance with ADL	C, M A – respondent does not participate in organised activities, stays in bed, watches television	2	0, interview was not possible; respondent did not want to turn the television sound low	21
A7	Female	90	5	Parkinson's disease, general decline	Uses a wheelchair, needs assistance with ADL	C, M A – respondent normally participates in activities, however not during the shadowing day because respondent felt too ill to participate	2	11	39
A8	Female	93	4	Does not know the reason for admission	Walks with walker, needs assistance with ADL	C, M A – respondent does not participate in organised activities	3.5	16	35
A9	Male	76	1	Stroke, lived with hemiplegia	Uses a wheelchair, needs assistance with ADL	C, M A – the researcher missed the respondent, who chose to do another activity of which the researcher was not informed	3	25	45
B1	Male	66	3	Stroke, lived with hemiplegia	Uses a wheelchair, needs assistance with ADL	C, A, M	4	12	54
B2	Female	86	1	Broken back, worn out vertebrae	Uses a wheelchair, needs assistance with ADL	A, M C – the respondent refused observation during morning care	2	45	75

(Continued)

Table 2. (Continued.)

Participant	Gender	Age	Time living in nursing home (years)	Self-reported reason to move to nursing home	Observed disability	Shadowing <sup>2</sup>	Duration of shadowing (hours)	Duration of interview recording (minutes)	Number of coded fragments per respondent
B3	Female	77	2	Parkinson's disease	Uses a wheelchair, needs assistance with ADL	C, A, M	2.5	6	42
B4	Female	96	1 (not sure)	Does not know the reason for admission	Uses a wheelchair, needs assistance with ADL	C, M A – the respondent does not participate in organised activities, knits in her room	4	9	70
B5	Male	90	1.5	Heart failure, kidney failure, hernia	Uses a wheelchair, needs assistance with ADL	C, M A – the respondent does not participate in organised activities	1.5, the shadowing was stopped because the respondent continued to talk to the researcher. He was exhausted and out of breath	12	41
B6	Male	88	3	Fracture, revalidation unsuccessful	Uses a wheelchair, needs assistance with ADL	C, A, M	5	8	84
B7	Female	81	1	Rheumatism	Uses a wheelchair, needs assistance with ADL	A, M C – the respondent did not want to wait for the researcher	3	0, sent the researcher away	42
B8	Male	64	1	Stroke, lived with hemiplegia	Uses a wheelchair, needs assistance with ADL	C, A, M	5	30	64

Notes: 1. ADL: activities of daily living. 2. Shadowing during: C, morning care; A, activity; M, mealtime; remarks if information is missing.

age range was 64–96 (mean = 81). In Unit A, eight women and one man participated; in Unit B four women and four men participated. The older adults had lived in Unit A for 1–7 years (mean = 4.2) and in Unit B for 1–3 years (mean = 1.7). The self-reported reason for admission to the nursing home was a combination of chronic illness and decline due to old age. The older adults had diverse former professions. Six of the older adults in this study did not have paid work, five worked in unskilled jobs, three in semi-skilled jobs and three in jobs that required higher education. Each older adult participated in the shadowing for approximately three hours, and in the concluding interview on average for 15 minutes (range = 4–45). Two persons were not able to answer questions due to aphasia.

### ***What do older adults do to maintain autonomy?***

The thematic analysis of the data found six elements used by older adults to maintain their autonomy on a day-to-day basis in a nursing home. The authors describe the elements on the basis of the underlying codes, and illustrated with one or two fragments from the observations or the interviews.

#### *Deciding and executing decisions*

The observations showed that autonomy was effectively maintained in cases where the older adults could independently do what they wished to do. However, the older adults could not always execute all decisions due to their impairments. For instance, this was seen in the ability to groom oneself, after receiving morning care. It was observed that participants used make-up, and chose and put on jewellery themselves:

Respondent A5 smiled at the researcher and moved with her wheelchair to the bedside table on which her mirror and make-up were arranged. She put on jewellery, lipstick and blusher. She used one hand, was very precise ... and chose one of her three perfumes.

Another example of maintaining autonomy was being able to eat independently:

Respondent B2 informed the researcher that her hand function is limited, but she showed how she could still grip with both hands, which enabled her to eat independently. The food was brought into her apartment where she ate alone, and was always to her liking. She could eat bread with her hands and did not have to mind her table manners because no one was around. When the food was well done, she needed no assistance to cut the food.

The researcher also observed independent shaving and caring for hair and nails. Older adults reported in the interviews that they were able to leave the nursing home independently and whenever they wanted. Mobility scooters enabled them to freely make long rides through the surroundings, to stay informed about the environment, to shop, visit friends or stay with family for a weekend. One person told the nurse during morning care that he was planning a holiday on a cruise for persons with a disability.

These experiences reflected an overlap in what older adults liked to do and what they could actualise: deciding and executing these decisions represented an element of maintaining autonomy.

*Maintaining autonomy by active involvement*

When older adults had preferences about how, when and in what way they liked actions to happen, but were not able to execute these decisions, active involvement usually turned out to be effective. This was, for example, manifested in morning care. Preferences about the time of care were discussed, as was the room in which it would take place: the bathroom, on the bed, in a chair or combinations of these. The respondents indicated whether or not they wanted to have a shower or have their hair washed. Preferred care products were chosen for washing and shaving. Older adults indicated the pace in which care should be given and were able to say when they needed to use the toilet:

Respondent B4 said to the nurse after morning care: ‘Is my hair properly combed at my neck? Would you take the handbag from the bedside table and hand it over to me, there must be a handkerchief in it.’

Older adults were often observed to take the lead in the conversation. They started a chat, showed interest in children, health, studies and the nurses’ shifts during the interactions. They also offered sweets or something to drink, including instructions for preparation. They gave permission to open closets and enter rooms. When morning care was complete, the respondents expressed their appreciation. This was observed to be successful when older adults were clear in their words and/or gestures. The successful maintenance of autonomy was observed when older adults would take turns in a reciprocal conversation with staff. They appeared to have known each other for a long time and were able to build on an existing relationship:

Respondent A9 said: ‘I am easy-going; if you want to be in the centre you make it difficult for yourself. I am dependent on the nurses, you have to behave properly ... but when something is bothering me, I will let them know.’

Barriers to autonomy were observed when older adults were not able to express themselves verbally, which led to stress and frustration in the older adults. This was especially the case when older adults had aphasia. When the staff did not ask – or listen to – the older adults, the researcher observed (non-)verbal expressions of anger, displeasure, wailing, and even kicking and hitting as an expression that respondents were hindered in maintaining their autonomy:

Respondent A8 was woken up by a nurse and asked: ‘Do I have to get up already, nurse? I am not feeling well.’ The nurse answered: ‘It is Friday, we are going to take a shower today.’ A8 said: ‘I do not want to take a shower.’ The nurse replied: ‘Otherwise it will be too late, you do not like that either.’ A8 asked: ‘Please let me lie in my bed.’ The nurse replied: ‘You can go back to bed afterwards if you want to.’ A8 again said: ‘I am not doing well.’ The nurse picked up the bedroom slippers, took away the blankets and tried to put on one of the slippers. A8 kicked the slipper away. ... The nurse put on the slipper anyway. A8 said: ‘Aw’ and kicked the slipper away.

The nurses seemed to follow their own agenda. In the example above, one of the nurses tried to persuade the older adult to go along with this agenda, through convincing her that this was what she wanted as well. When the older adult made her wishes clear, and when her pleading did not have effect, she turned to non-verbal reactions.

The active involvement of the older adult, whether positive or negative, is one way in which they can express needs and preferences, and is thus an element used to maintain autonomy.

### *Maintaining autonomy by transferring it to others*

When active involvement was not always (or no longer) possible, it was observed that older adults delegated autonomy to trusted others, often family or friends. The older adults reported in the interviews that their significant others knew their preferences, and acted upon them:

Respondent B3 said she had two children living in the same village. The youngest was divorced and then found a new wife. She could not have found a better daughter-in-law. She did everything for Respondent B3. She did the washing, she did the ironing, she prepared everything for the next day or, if she could not, she prepared it for two days ahead. She gave the room an extra cleaning. When B3 wanted to have contact with the outside world, the daughter-in-law dialled the number and then B3 could make a phone call. B3 was therefore regularly able to call her old friends.

Important others such as a wife, husband, (grand)children or friends visited regularly, and even daily. They bought clothes and washed and/or chose the clothes that would be worn the next day. They arranged them on a chair so the nurse knew what to do when morning care would be given. The same was seen in personal care products that were not provided by the nursing home, such as make-up, perfume and body lotion. Older adults asked family to take responsibility for correspondence, administration and finances. Family also participated in meetings about the older adult's official care plan and/or shared in decisions about care. When asked in the interviews, older adults stated their trust: 'they know my preferences'.

Respondent A4 said: 'My daughter chooses what I wear, I only have one child, she comes every day ... I never have to ask, I still have new blouses for Christmas – haven't worn them yet.'

Transferring tasks was not possible if an older adult did not have family and friends, or when significant others did not visit. If it is not possible to fulfil wishes and needs independently, delegating them to important others is a compensation mechanism for maintaining autonomy.

### *Using preferred spaces*

Older adults were observed to use the spaces in the environment in the way they chose. They used their bedroom and sitting room or the living room on the unit. Some older adults preferred their doors to be open, to see what was happening, and greeted everyone who passed. Others kept their doors closed and visitors

and nurses had to ring the doorbell before they were allowed to enter. Older adults sat with companions in the living room. They met and greeted others in the passageway. The older adults regularly visited the various areas of the nursing home, especially the restaurant and locations where activities took place. Respondents also went outside the building, to the gardens, the shops nearby or the places they had lived before moving to the nursing home:

The physical therapist talked with Respondent B8 about how he proceeded with his physical therapy goals. B8 said that he wanted to practise a certain transfer from his wheelchair to a duo bicycle. With his wife's help he could do the transfer and cycle to visit friends every weekend. He never thought he would be able to do that again.

The use of space was affected by the level of mobility, mobility aids such as walkers, mobility scooters, duo bikes or a customised car. This seemed to be the case especially in Unit B. In Unit A, only one of the observed older adults went to a hairdresser outside the nursing home. Both units organised a walking club, with older adults mostly participating in a wheelchair, which offered opportunities to go outside when mobility aids could not be used independently.

Older adults also experienced barriers to using preferred spaces. For example, Unit A had shared facilities, such as shared bathrooms. In Unit B, older adults were not able to operate the elevator buttons independently, and had to ask for help. Institutional rules hindered autonomy, such as fixed seats during mealtimes, and locations of activities.

Respondent B8 was, again, too late to the restaurant because of his full schedule. There was no place at the table where his acquaintances were sitting. He was placed at a separate table, and other residents had already ordered his meal without asking him: macaroni.

Another example is that persons with a risk of choking were obliged to eat in the living room because protocols required supervision. When the researcher asked respondent B4 where she sat, she said that there were no fixed seats. But a little later it turned out that she always sat in the same place. Everyone with swallowing problems or conditions that hinder independent eating had to eat in the dining room. Others were able to choose to eat in their own room or to go downstairs to eat in the restaurant.

The freedom to use spaces according to one's own preferences represents an element of maintaining autonomy. However, in some situations this is not always possible.

### *Choosing how to spend time in daily life*

In between care periods and meals, there was time for the older adults to do whatever they liked to do. Sometimes this meant resting, if a frail condition meant they were tired after morning care and breakfast. However, most of the observed older adults chose to engage in hobbies and went to clubs that fitted their preferences, or spent time with people they liked to meet. There was a wide choice of activities,

such as painting, sports, cooking, listening to classical music, and playing board games or puzzle games. Some older adults chose to stay in their apartment, alone or with family and friends. Some were digitally connected to others by means of email or Wordfeud.

Respondent A3 said: 'I spend the days in my apartment. I don't like to listen to the twaddle [in the living room]; I prefer to watch television. They offer good programmes. You can learn a lot.' She laughed: 'You can still learn when you are 80. I like the documentaries best. When they are not being broadcast I like programmes about wildlife.'

Engaging in activities was difficult for older adults who lived in a unit with persons or staff with whom they did not get along. One person detested the personal hygiene of others at her table, and refused to eat anything that others might have touched at breakfast. Sometimes a unit did not offer activities preferred by the older adults, or activities were forced upon the older adult.

Respondent A4 was pushed in her wheelchair by a volunteer to the restaurant where several game activities were organised. He put her at a table with bingo cards and said: 'You always liked bingo.' She accepted the tea and biscuits that were offered. A few minutes later she was pushed to another table by the occupational therapist, who said: 'She likes quizzes...'. This appeared to be true, B4 got all the questions related to songs right and sang in a loud voice, and was very involved in the conversation at her table.

As this example shows, it was sometimes observed that nursing home staff made assumptions regarding preferences, without properly checking.

Being able to choose activities that match one's individual interests and the use of personal and communal spaces is a way of maintaining autonomy. However, the physical environment as well as routines can hinder this way of executing autonomy.

### *Deciding about important subjects*

Besides the five above-mentioned elements in daily life, the respondents mentioned being involved in important decisions in their life as significant for maintaining autonomy. Autonomy was found to be important in, for example, medical and financial decisions and the decision to move into a nursing home. Older adults spontaneously shared information in the interviews about these important issues in their lives. One person had just left the hospital; he was glad he had been admitted and treated for heart failure. He was told he was not going to be treated any more, but he still had the will to live and wanted to decide himself whether he would continue being treated.

Other respondents said they preferred to have access to the elderly care physician in the nursing home, and to manage medication and oxygen administration themselves:

Respondent A9 asked the nurse: 'Can you make an appointment with the elderly care physician?' The nurse asked: 'Why?' A9 answered: 'I want to ask her certain

questions.’ The nurse replied: ‘She normally comes on Thursdays, we will ask her to visit you.’

When there was no dialogue about medical decisions, or access to the physician, the older adults felt their decision-making was obstructed. They expressed feelings of powerlessness about this situation:

Respondent B5 said: ‘I sometimes feel we are left behind to die ... I want to go ahead, I want to be of importance; others don’t have the will, but I do.’

Two people said during the interview that they actively chose this nursing home, or life in a nursing home:

Respondent B8 talked about his move to Unit B: ‘In Unit A, I had to receive my visiting colleagues in the bedroom.’ The respondent told the researcher he asked himself: ‘Do I have to age in this cage? Then pull the plug ... We came to look at this nursing home and I chose to move.’

Being in charge of financial administration was also expressed as important. One of the respondents engaged in formal decision-making in the client council of the nursing home. Finally, one respondent mentioned a discussion about rules and regulations on food and fire safety. He had a freezer on his table, did his own shopping and cooked for himself on an electric cooker. This was permitted after several discussions with the management.

A key point of this sixth element is that older adults mention that it is important for them to be heard in decisions about important topics for them such as financial and medical issues.

## Discussion and implications

This study builds on a growing body of literature that suggests that maintaining autonomy is important in all the different stages of life, including old age. This study adds new knowledge because maintaining autonomy of residents living in nursing homes has not been studied before by the method of shadowing. With shadowing, we could provide an in-depth insight into how older people living in nursing homes actually maintain autonomy in daily life. The researchers were able to make very precise and prolonged observations of respondents’ daily life, and were able to observe events potentially overlooked in retrospective studies. Moreover, it allowed the intensive study of the perspective of the older adults themselves rather than having to rely on asking proxies like relatives or staff.

Through this study, six elements of maintaining autonomy were identified, five of which related to day-to-day autonomy (‘being able to decide and/or execute decisions’, ‘active involvement’, ‘transferring autonomy to others’, ‘using preferred spaces’, ‘choosing how to spend time in daily life’), and one related to the ability to decide about important subjects in a resident’s life.

This research noted that older adults living in nursing homes interact and co-operate with others in order to maintain their autonomy. Therefore, autonomy



can be perceived as a shared responsibility for these older adults and their social environment. Fine and Glendinning (2005) refer to this as 'relational autonomy'.

The elements found in this study were only effective to maintain autonomy when staff and/or informal care-givers responded to the needs of the older adults. Relational autonomy between an older adult and staff can be challenging for several reasons. First, the nursing home is an environment with many routines, schedules and protocols (Hall *et al.*, 2014). Second, several older adults might have needs and wishes simultaneously, and an older adult might have to wait some time before the staff can respond to their needs. Third, a lack of continuity might prevent staff from becoming acquainted with individual desires (Walent and Kayser-Jones, 2008).

Considering the data through this relational lens suggests that staff, family and friends should be receptive to the signals of an older adult related to maintaining autonomy which are communicated in a non-verbal or verbal way. From the data in this study, several specific autonomy-expressing signals by older adults were observed that ask for specific qualities and skills from staff.

In this study, six elements were found to be important to maintain autonomy. The first of these includes deciding on and executing decisions. Even though older adults in nursing homes are dependent on 24-hour supervision and need assistance with several activities of daily living, they are most of the time able to decide but might be unable to execute their decision. These findings are supported by previous studies which have identified the importance of being independent in certain aspects of life (Hillcoat-Nallétamby 2014; Caspari *et al.*, 2018). In order to be open to these types of signals, it is of the utmost importance that staff and older adults identify through a dialogue which activities an older adult prefers to do independently. Moreover, staff should be aware of taking over actions when unwanted.

The second element in this analysis is active involvement in maintaining autonomy, which was verbally and non-verbally expressed by respondents. Moreover, it was found that older adults used proactive participation to maintain autonomy when they were not able to execute every decision. When staff were not responding to verbally expressed wishes, older adults were found to use negative behaviour, such as kicking away a slipper to bring the wishes to attention. Hall *et al.* (2014) found that staff used persuasion when the choices of older adults did not fit into the schedules, which might hinder autonomy. Earlier investigations have observed that personal aspects such as the level of physical functioning as well as psychosocial and intrapersonal characteristics can affect active involvement (Bolmsjö *et al.*, 2006; Hellström and Sarvimäki, 2007; Sandman *et al.*, 2009; Oosterveld-Vlug *et al.*, 2014). This suggests that professionals need to be alert to sometimes subtle expressions of wishes and needs in order to support the active involvement in maintaining autonomy.

The third element, maintaining autonomy by transferring it to others, has also been reported in previous research, which showed that transferring tasks in a proactive and positive way was closely linked to positive feelings of control (Walent and Kayser-Jones, 2008; Hillcoat-Nallétamby, 2014). The literature has described the negative effects of unchosen task transfers, such as financial exploitation (Morgan and Brazda, 2013). These were not observed in this study. This analysis observed that the maintenance of relationships and finances, as well as facilitating

social activities, buying care products and clothes, and care for clothing were transferred to relatives. Moreover, for older adults who do not have others to whom tasks can be transferred, maintaining their autonomy can be hindered.

Using preferred spaces is the fourth element which has also been described in other studies. It has been shown to have an effect on privacy, social activities, choice and interactions (Cooney *et al.*, 2009; Knight *et al.*, 2010; Nordin *et al.*, 2017). In this analysis, it was observed that there were ample opportunities to use different spaces in the apartment, unit, nursing home and surroundings. However, for this element, the accessibility of the nursing home is important. Barriers were noted, *e.g.* for wheelchair users who had to ask for assistance.

A fifth element is choosing how to spend time in daily life. This aspect has also been described by studies which show that ongoing social relations and activities are important for a sense of autonomy (Danhauer *et al.*, 2006; Cooney *et al.*, 2009; Gleibs *et al.*, 2014; Slettebø *et al.*, 2017; Clarke *et al.*, 2019). This investigation observed that there was a great range of organised social activities. Moreover, if older adults were of the opinion that there was no suitable activity for them, they were also able to choose not to participate and/or to do something for themselves. It was also found that respondents could not select their table companions. For staff, it is therefore important to know and respect the choices of older adults to follow their own daily schedule and activities, regardless of what the nursing home organises and plans.

The sixth and last element identified is being able to decide about important subjects. Such decisions were also noted as important in earlier studies, with examples such as the decision to move into a nursing home. It was found that it can be a positive experience if older adults make such a choice themselves (Brandburg *et al.*, 2013). This analysis confirmed the importance of making the decision about the move into the nursing home. Furthermore, it also showed the desire for shared decision-making about medical care. Not being able to decide about important subjects such as medical decisions caused feelings of powerlessness. These findings were also established by Bolmsjö *et al.* (2006). The above-mentioned findings demonstrate the importance of older adults and staff taking part in shared decision-making about essential matters such as moving to a nursing home and advanced care planning.

It is important to take the relational dimension of autonomy into account when looking at decisional, executional and delegated autonomy. This is meaningful because, in all six elements established in this study, older adults could only maintain autonomy when others, such as staff, family and friends, were responsive to the signals relating to wishes and needs from older adults to successfully maintain autonomy in daily life in the nursing home.

### **Strengths and limitations**

Shadowing was chosen as the research method for this study. The strength of shadowing is that the researchers were able to examine the perspective of older adults thoroughly. The older adults did not have to express their experiences in words, and so they could also participate if they were not verbally strong or were frail. Because shadowing focuses on what happens within the context, it helps to go beyond what

is consciously known and expressed. Shadowing, with a long presence in the nursing home, provided the opportunity to experience what the shadowee did. These experiences provided in-depth insights into the ways in which residents maintain autonomy, in a context in which they are dependent on others.

Another strength was the triangulation of two methods. The combination of shadowing with short interviews enabled the researcher to check the meaning of the observations. The interviews, however, did not add much additional information to the shadowing data. It seemed that autonomy was too abstract a concept for the participants to elaborate on. However, some older adults took the chance to talk about what they consider essential in autonomy. The sixth element, making decisions about important subjects, could not have been identified without the short interviews following the shadowing.

The rich description that was given of the context of both studied units can help future researchers to understand the implications of the findings for their own context, which is a strength.

Another strength is that the researchers discussed how to interpret the data until consensus was reached. This was specifically the case in understanding the role of family, friends and other residents. The decision was made to assign the codes concerning family and friends to element three: maintaining autonomy by transferring it to others. The other residents are part of the context in the nursing home and the findings concerning them are assigned to element five: choosing how to spend time in daily life.

After 15 observations, JvL observed that no new information was being gathered during the shadowing, and thus data saturation had been reached. She completed the data collection as planned and shadowed in total 17 older adults, to ensure no new information was missed.

One limitation of the data collection method is that the researcher observed the 17 older adults alone, which could induce bias. Moreover, maintaining autonomy can change over a longer period of time. Although the researcher followed the participants intensively on a single day, the respondents were not followed for several days, or for a longer timespan.

Other limitations of this study include that only a small number of older adults were shadowed. Moreover, the shadowed respondents were not representative of the Dutch population with regard to the length of stay, the percentage of participating males and the cultural backgrounds (Nederlandse Zorgautoriteit, 2018). Representability was not the aim of the study, however: the authors aimed to examine in depth how older adults with physical impairments living in nursing homes maintained autonomy in daily life.

### **Ethical reflection**

JvL, as a nurse and researcher, reflected regularly (before and during the study) on her role with a mentor who was not involved in the research. This was important to consider her explicit and implicit assumptions and values regarding autonomy, and how they could affect the research. These reflections were documented and shared with the other authors. This procedure was repeated during the research and evaluated afterwards. The other authors, not having been trained as nurses, also noted implicit assumptions when discussing the interpretation of the codes, fragments

and themes in the group meetings (Korstjens and Moser, 2018). These authors are experienced researchers in the care for older adults, and have a background in the social sciences.

Being near respondents for an extended period of time involved ethical reflection about staying or leaving. For example, in one case the researcher observed an older adult who had recently returned from hospitalisation for the treatment of heart failure. He continued to talk to her, and ran out of breath. She left the room, in order to give the respondent some privacy and rest, and returned later. Another respondent said that his son was coming to visit him after years of being estranged. The researcher did not want to disturb this family reunion. She avoided seeing shadowees naked, or looking down on them in bed.

Some respondents made it clear in advance that the researcher was not welcome during certain periods of the day, such as morning care or during dinner. Other respondents pointed this out during the observation. Naturally, these choices were respected.

When respondents started talking to the researcher during the observation, she made small talk to avoid uncomfortable situations. She made herself known to family and near ones, and people who were not aware of and/or involved in the research (e.g. volunteers in the restaurant or other people present during an activity). This helped to prevent unpleasant circumstances.

The researcher did not want to know about a participant's medical diagnosis to be able to observe without bias. She was once unwillingly informed of someone's compulsive disorder. She would rather not have known this and avoided conversations with staff before shadowing thereafter.

### **Implications for further research**

The current study focused on the perspectives of older adults. It is recommended that both the role of the staff (such as nurses and occupational therapists) as well as the role of the environment should be studied, to be able to recognise how they contribute to preserving autonomy in daily practice. This could help to recognise facilitating strategies, which could lead to (even more) increased autonomy in nursing homes.

Longitudinal action research could study the effect of interventions to maintain autonomy. Such action research could involve older adults and staff, and identify elements of interventions.

### **Implications for practice**

The executional autonomy of older adults with physical impairments is limited, due to their frailty. Older adults use compensation mechanisms, such as the elements that were found in the current study, to help them to maintain autonomy, despite a decline in resources.

It is important that care professionals recognise such mechanisms and can act on them. Older adults should be aware of the mechanisms and consciously apply them. If this is not feasible, they can be supported. Autonomy-enhancing interventions should be directed towards strengthening the decisional and relational

dimensions of autonomy, and to compensating for the lack of executional autonomy in a person-centred way.

A dialogue between staff and the individual residents is recommended, regarding the way older adults prefer to participate in decision-making. This could take the form of discussions about the situations in which an older adult prefers shared decision-making, and those situations in which they prefer to delegate to staff or family and friends. These are important topics when an older adult is moving into the nursing home, and during regular evaluations of the care plan.

Shadowing older adults is a valuable method, especially when dialogue about autonomy is not possible. Integrating this method in the interactions between staff and older adults might help staff to reflect on the way older adults maintain autonomy, and on their own assumptions. It might help staff to reflect on which activities could be helpful in enhancing the autonomy of older adults.

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**Author contributions.** JvL collected the data. JvL, KL, IdR and BJ coded the observation reports and transcripts. They started with an individual reading of one of the reports, they explored it and used open coding. Afterwards, four of the five authors (JvL, BJ, IdR, KL) discussed the interpretation of the text and exchanged their views. They also decided which terms would be appropriate to label the data. JvL coded 17 reports, BJ, IdR and KL five or six. Afterwards the same procedure was used in pairs of researchers. After ten co-coding sessions, similarities and differences in coding were discussed with four of the five authors (JvL, BJ, IdR, KL). The same was done after the last report was coded. JvL and MJ themed the codes. All the authors interpreted the findings and were involved in the drafting and revisions of the manuscript. All authors approved the publication of the article.

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**Ethical standards.** The study was approved by the Ethical Review Board of the Department of Social and Behavioural Sciences, Tilburg University (EC-2016.62). Also, the Ethical Review Board of De Wever Tilburg gave written permission on 16 December 2016. Informed consent was obtained prior to data collection, including permission for publication.

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