Maintaining and enhancing the autonomy of nursing home residents with physical impairments

A qualitative multi perspective study

Jolande van Loon

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General introduction

Mrs Bel is a 74-year-old socially active person and a former schoolteacher. After a stroke, she remained semi-paralysed. She needed a lot of care with dressing and undressing and going to bed. Staying in her own house was difficult. She moved in with her daughter for a while and eventually decided herself to move to a nursing home, but it had to be near her daughter. She wants to be able to visit her daughter independently, using her mobility scooter. Mrs Bel found a nursing home that is of her liking. The rooms on the floor where she lives have morning sun and the opposite neighbours cannot see into her room, so she never has to close the curtains. She loves being able to look outside.

In the nursing home, the support she gets is not like what she was used to with her daughter. Mrs Bel is stimulated to do as much as possible herself – even buttoning up those little buttons on her blouse. She regularly argues with the nurses. Some nurses insist that Mrs Bel must do what she can do herself.

Although Mrs Bel prefers to eat alone in her room, she is not allowed to do this. Due to her swallowing problems, the protocol of the nursing home requires that a staff member has to be near her at mealtimes. She dislikes this: she is not very handy with cutlery with one hand, and it does not help that other residents and staff are watching her. Mrs Bel hears the same concerns from other residents during mealtimes and checks when the next living room meeting is scheduled.

1.1 The importance of autonomy for older adults with physical impairments living in nursing homes

As the story of Mrs Bel illustrates, older adults with chronic conditions and physical impairments prefer to continue to live at home for as long as possible (1). However, if living at home is no longer possible – for example, due to severe physical impairments – and 24/7 care is needed, moving to a nursing home is unavoidable (2).

Mrs Bel initially tried to age in place and eventually decided to relocate to a nursing home when this was no longer possible.

In nursing homes, the autonomy of older adults might be challenged. Dependence on care staff or other persons, and the care environment in which care is given might influence the way autonomy can be maintained. Staff members often act with good intentions without asking older adults about their preferences and life goals (3). Furthermore, staff must balance between protocols, safety issues, the situations that occur on the unit, and sustaining the autonomy of the residents. Moreover, in nursing homes, several residents with physical impairments live together and can simultaneously have incompatible needs and wishes, a phenomenon that might also hinder autonomy.

Because more older adults with swallowing problems live on this unit, it was obvious for the staff to organise mealtimes for these older adults in the living room of the unit. In this way they could help more residents at the same time. This is an example of the conflict of individual wishes, safety, and the co-occurring needs for care of other residents.

To improve the quality of care and autonomy of residents, there has been a shift in nursing homes from a biomedical model towards a more person-centred approach (4). The principles of autonomy and shared decision making have become increasingly important. Residents should be able to make choices based on their personal values (5). These choices can concern the way they want to spend time or with whom they spend time. Where to live and treatment decisions are other overarching issues that older adults might want to decide (6, 7).

Mrs Bel's story reveals that she herself decided to move to a specific nursing home. She likes the room and the view. Moreover, it is near her daughter's house, so she can visit her daughter independently.

There has been an explicit shift towards more person-centred care and autonomy in recent decades in the agendas and embedded in the policies of care organisations, governments, and professional nursing organisations (8, 9). However, it is challenging to establish how autonomy can be maintained and enhanced in practice. Furthermore, the concept of autonomy is ambiguous: people can have different notions of it.

The nurses who urge Mrs Bel to do as much as she can herself have a different view of what autonomy is than Mrs Bel. Being able to care for oneself is one notion of autonomy. For Mrs Bel, autonomy means making decisions herself.

1.2 Theoretical background of autonomy and person-centred practice

The aim of person-centred care is to place residents at the centre: in other words, each resident is seen as a unique person with a personal history, future, and life goals. When care is given in a person-centred way, autonomy of older adults can be respected and enhanced in the later stage of their lives (10, 11).

McCormack and McCance (12) formulated a leading theory of person-centred practice (PCP), which offers a theoretical and evidence-based framework (Figure 1). PCP is seen as a multidimensional concept. The model is still developing and the key domains and the aspects of healthcare delivery that compose the framework are being refined (12, 13).

The framework considers five key domains. The first and central domain is 'person-centred outcomes', the result of which is effective person-centred care. It contains the following aspects: 'good care experiences', 'involvement in care', 'feeling of well-being',

and ‘a healthful culture’. The second key domain is ‘person-centred processes’ and can be described as delivering care to the resident by means of varying activities, that is, ‘working with patients’ beliefs and values’, ‘engaging authentically’, ‘being sympathetically present’, ‘sharing decision-making’, and ‘providing holistic care’. The third key domain, the ‘practice environment’, is the context in which care is given. This domain includes ‘appropriate skill mix’, ‘shared decision-making systems’, ‘effective staff relationships’, ‘power sharing’, ‘the physical environment’, ‘supportive organisational systems’, and ‘the potential for innovation and risk taking’. ‘Prerequisites of staff,’ is the fourth key domain; it comprises the attributes of the caregiver, including ‘being professionally competent’, ‘having developed interpersonal skills’, ‘knowing self’, ‘clarity of beliefs and values’, and ‘commitment to the job’. The last key domain, the ‘macro-context’, affects the extent to which person-centred care can be given and comprises ‘health and social care policy’, ‘strategic frameworks’, ‘workforce developments’, and ‘strategic leadership’ (12). Even though the model was developed for a clinical setting, these key domains with underlying aspects are also relevant in nursing homes, where older adults live and receive care in the same environment.

The framework has been further refined to incorporate the fact that older adults are also living in long-term care. Recently, the aspect ‘fundamental principles of care’ for residents living in long-term care has been added to the key domain ‘person centred processes’. These principles include ‘having meaningful relationships,’ ‘living in a familiar, person-in-care, friendly, and home-like environment,’ ‘maintaining identity and self-esteem’, ‘experiencing meaning in everyday life’, ‘being free in decisions’, and ‘participating in social life and current events’. These fundamental principles of care, together with the abovementioned key domains, constitute the Person-centred Practice Framework in Long-Term Care (PeoPLe) (13).

With this addition, using PCP as a framework is even more appropriate for the current study of the autonomy of older adults in nursing homes. The fundamental principle that is most related to the current study of autonomy is ‘being free in decisions’. This principle involves one of the dimensions of autonomy, decisional autonomy, which is described later in this chapter. ‘Being free in decisions’ is defined as ‘an autonomous, self-determined lifestyle, self-determination, and co-determination as well as accompaniment in the individual daytime organisation are created for the persons in care. Independence and self-organisation are promoted’ (13 p 10).

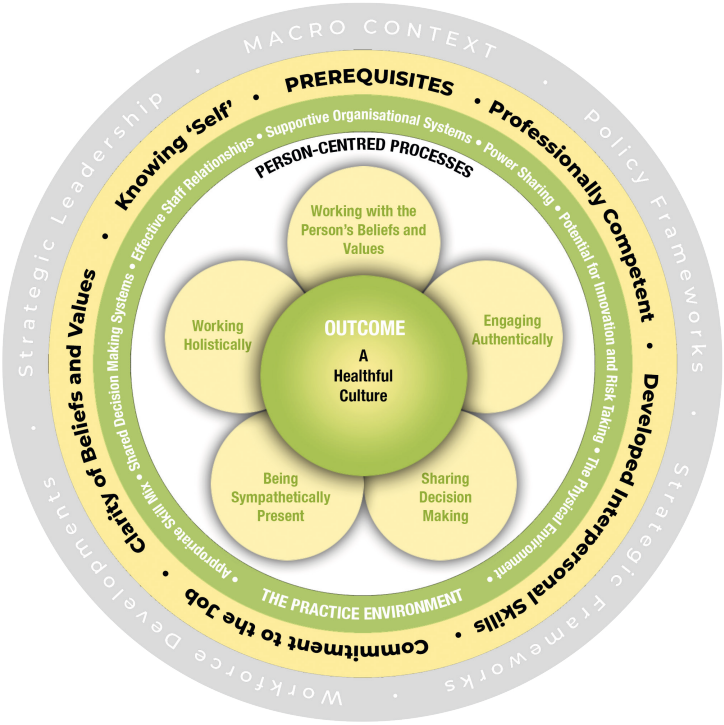

Figure 1. The person-centred practice framework
Note. Retrieved from the Centre for Person-centred Research Practice (CPCPR) of Queen Margaret University Edinburgh. Reused with permission from McCormack and McCance (12).

The key domains that are represented as circles around the outcomes for the residents demonstrate that studying autonomy in nursing homes should not and, indeed, cannot be limited to the older adults themselves. The key domain 'person-centred processes' and the domain 'prerequisites of staff' can help to design the studies of how older adults maintain and how the staff enhances autonomy. The key domain 'practice environment' is important to study how the environment of the care processes between the older adults and the staff influences autonomy. The 'macro-context' influences the autonomy of older adults with quality frameworks related to care and staffing, finances, and access to care. When bringing together the findings of the research in the general discussion, the connections between the key domains related to enhancing and maintaining autonomy are sought and described.

Autonomy can be seen as an overarching term that needs to be specified. It has been studied and described from different scientific views, and it also has several dimensions and characteristics. Collopy (14) describes multiple dimensions of autonomy in long-term care, including decisional, executional, and delegated autonomy. Decisional autonomy is the freedom and ability to make choices without pressure or restrictions from others. Idealistically, the decision is followed by an execution of the choice made – executional

autonomy. However, execution is often not possible for older adults living in nursing homes. In general, the frailty of older adults with physical impairments partially or completely decreases their ability to execute decisions. However, the ability to decide is often left intact (14). If executional autonomy is decreased, then the older adult may choose to have others perform activities for them. The concept of delegated autonomy is important for this situation (14). Thereby, Collopy (14) points to the reciprocal nature in the care relationship. Older adults living in nursing homes interact and cooperate with others, such as the staff or family, to maintain their autonomy. Autonomy can develop in this relationship. Therefore, the relational dimension of autonomy can be perceived as a shared responsibility for older adults and the staff in the unit (5, 15, 16).

Collopy (14) organises the dimensions of autonomy into possible polarities, which must be considered in the context of nursing homes. One of the polarities is 'decisional versus executional autonomy'. This polarity can arise if the realisation of the resident's decisions is challenged, while for others decision-making can be at risk. Another example of a polarity is 'direct versus delegated autonomy'. The staff might not be aware that relatives are particularly important to delegate matters to and that they are being left out. To ensure that autonomy of older adults living in nursing homes is understood more comprehensively and acted upon more appropriately, Collopy (14) asks for more consideration of the nuances of autonomy and more research into the dimensions in daily practice. The relationship between autonomy and person-centred care helps to study autonomy in greater detail.

A description of how autonomy is regarded for the persons of this study – older adults with physical impairments due to age-related decline and chronic health conditions (hereafter residents with physical impairments) who are living in a nursing home – has been developed to better understand their autonomy. The description is based on the literature about this specific group (15, 17-20). "Autonomy is a capacity to influence the environment and make decisions irrespective of having executional autonomy to live the kind of life someone wants and desires to live in the face of diminishing social, physical and/or cognitive resources and dependency and it develops in relationships" (21 pp. 1038-1039).

1.3 Research objective, study design, and thesis outline

Even though autonomy is a well-studied subject, little is known about the way autonomy is maintained by older adults or influenced by the staff and the care environment in day-to-day life in a nursing home unit. Empirical insight into the process whereby older adults living in nursing homes maintain autonomy from an insider's perspective is not yet available. Investigation into how autonomy is maintained in day-to-day life can lead to a more accurate perception of autonomy in daily (care) practice. Because older adults and nursing home staff are concerned with the implementation of autonomy-enhancing policies in actual care practice, it is important to gain insight into their experiences and perspectives. The general aim of this thesis is to gain knowledge on how older adults with physical impairments, living in nursing homes, together with the staff in the care environment, maintain and enhance autonomy. This aim led to the following main research question: '*How do residents with*

physical impairments, together with staff in a nursing home environment, maintain and enhance autonomy?

This thesis comprises seven chapters in which five research questions are addressed. There are three sections; the first section includes a theoretical exploration of the literature of factors that influence the autonomy of older adults living in nursing homes. The second section provides insight into the practices and policies from the perspectives of those involved. Finally, the third section describes a participative approach to initiate change in practice. The sections are elaborated on in more detail below.

Section one: a theoretical exploration of the literature

Section one, chapter two of the thesis describes the theoretical exploration of the literature relevant to the thesis by answering the first research question: which facilitators and barriers to autonomy of older adults with physical impairments due to ageing and chronic health conditions living in residential care facilities are known? The aim was to gain an overview of what is already known in the literature about autonomy of older adults with physical impairments living in nursing homes. This literature review provided a theoretical basis for the subsequent empirical studies.

Section two: the perspectives of older adults, staff, and stakeholders in the care environment

Section two includes three empirical studies and provides insight into the daily practice and policies from the perspectives of older adults, staff, and stakeholders in the care environment of the two selected nursing homes.

Chapter three addresses the following research question: how do older adults with physical impairments who live in a nursing home maintain autonomy in daily life? The aim was to explore the perspectives of older adults on autonomy in practice. To understand what older adults do to shape and express their autonomy and how their autonomy could be perceived in daily practice, shadowing, a non-participative observational method, was chosen for this study. The participating older adults were shadowed for one day. The observation ended with a brief interview.

Chapter four addresses the research question: how do staff members act and what do they experience in relation to the autonomy of older adults with physical impairments living in nursing homes? This study aimed to explore what staff members do and their experiences in relation to the autonomy of older adults. Shadowing combined with a brief interview was used to understand how staff members respond or do not respond to the autonomy of the residents.

Chapter five addresses the research question: which policy, aimed to enhance the autonomy of older adults with physical impairments in nursing homes, is developed and implemented? The aim was to gain a deeper insight into the development and implementation of organisational policies targeted to enhance the autonomy of older adults with physical impairments who live in nursing homes. A qualitative descriptive design

combining two methods was used: a document study on plans and proceedings of policies, and interviews with managers and stakeholders involved in part of this policy.

Section three: participatory action research to enhance autonomy

Section three, chapter six, offers a description of a participative action research (PAR) process on one unit of a nursing home to enhance autonomy in daily life in a collaborative manner – that is, between older adults and staff members. The research question was: what processes occur between residents and staff in PAR to enhance the autonomy of residents at the unit level? The aim was to gain insight into the PAR processes in which residents and staff propose actions and then explore and evaluate them, aiming to enhance autonomy in day-to-day practice. The PAR, a cyclical, participatory process of gaining evidence used to bring change to the practice environment, was chosen for this study (22).

The thesis concludes with chapter seven, a general discussion that includes a reflection on the main results of the five studies.

1.4 The selected population and nursing homes

Nursing homes in the Netherlands provide 24/7 care by registered and practice nurses (2). Paramedic professionals such as dieticians and physiotherapists provide treatment and can be involved after multidisciplinary consultation. An elderly care physician is responsible for the entire care process (23). In general, Dutch nursing homes have separate units for older adults with physical impairments and for older adults with dementia (24).

This study concerned older adults with psychical impairments who live in nursing homes. Generally speaking, these individuals are able to make deliberate decisions on how they want to live their lives. However, they are often hindered in executing these decisions due to the underlying physical conditions that led them to move into the nursing home.

Selection of the nursing homes

The board managers of two care organisations (A and B) gave permission to collect data in their organisations. Both organisations are partners in the Academic Collaborative Centre for Older Adults (25) and have committed to learn and share knowledge about autonomy. Both board managers developed policies to enhance autonomy at the time the research was initiated. The board managers agreed to participate in the study because the design was not limited to just collecting data for scientific research. The design also included a study in which change was envisioned in the studied unit itself, by conducting PAR (22).

The aim was to explore autonomy in daily practice; therefore, two nursing homes were selected for the empirical studies. Two units were chosen in the two nursing homes to study the perspective of the residents and staff of the same unit. By selecting two organisations, it was possible to study multiple perspectives in different care environments (26). Studying two organisations should provide insight into different practices and policies towards autonomy in the nursing homes and thus to collect richer data. In this way the autonomy of older adults living in nursing homes could be studied in depth.

The organisations differed with respect to the selected locations. The locations were housed in two very different buildings and differed regarding the deployment of staff, which are aspects of the key domain 'care environment' of the PCP framework (12). Furthermore, location A is situated in a large town and location B in a small town. The common characteristics are the location in the south of the Netherlands, the national healthcare system for admission, and the 24/7 care given by the organisations.

Organisation A had in total 2700 clients, 2600 employees, and 1150 volunteers. It provided care in 14 locations in a large town. Organisation B had 960 clients, 870 employees, and 600 volunteers and provided care in five locations in a small- and medium-sized town and its surroundings. Organisation A participated in the study from January 2017 to September 2018 in studies 2-4. Organisation B participated from January 2017 to December 2019 in studies 2-5.

The board manager of each organisation selected one care unit (referred to as unit A and unit B) in which older adults live that met the inclusion criteria: age 65 years and older, physical impairments, and live in a long-term care unit in a nursing home. Unit A accommodated 40 older adults with physical impairments and employed 25 full-time equivalent (FTE) staff. Unit B accommodated 28 older adults with physical impairments and employed 23 FTE staff.

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Section I

2

Facilitators and barriers to autonomy: A systematic literature review for older adults with physical impairments, living in residential care facilities

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Abstract

Introduction

Autonomy is important in every stage of life. However, little is known about how autonomy is enhanced for older adults living in Residential Care Facilities (RCFs). This leads to the research question: which facilitators and barriers to autonomy of older adults with physical impairments due to ageing and chronic health conditions living in RCFs are known? The results will be organised according to the framework of person-centred practice because this is related to autonomy enhancement.

Method

To answer the research question, a systematic literature search and review was performed in the electronic databases CINAHL, PsycINFO, PubMed, Social Services Abstracts and Sociological Abstracts. Inclusion and exclusion criteria were derived from the research question. Selected articles were analysed and assessed on quality using the Mixed Methods Appraisal Tool.

Results

Facilitators and barriers for autonomy were found and arranged in four themes: characteristics of residents, prerequisites of professional care-givers, care processes between resident and caregiver, and environment of care. The established facilitators and barriers are relational and dynamic.

For a better understanding of the facilitators and barriers to autonomy for older adults with physical impairments living in RCFs, a description is based on the 35 included articles. Autonomy is a capacity to influence the environment and make decisions 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 it develops in relations'.

Implications

The results provide an actual overview and lead to a better understanding of barriers and facilitators for the autonomy of older adults with physical impairments in RCFs. For both residents and care-givers, results offer possibilities to sustain and reinforce autonomy. Scientifically, the study creates new knowledge on factors that influence autonomy, which can be used to enhance autonomy.

Introduction

In many Western countries, governments see active citizenship as an important theme. A neoliberal philosophy has influenced and changed healthcare systems during the last decade. Now, citizens should take personal responsibility and participate in society as independent individuals. This responsibility also concerns health and welfare (1). The worldwide trend in healthcare is that older adults with chronic conditions and physical impairments continue to live at home (2-4). Policies are directed towards self-management and informal care from family and friends.

If living at home is no longer possible—for example, due to severe physical impairments—admission to a residential Care Facility (RCF) is permitted. How is participation achieved in a facility that is a place to live as an individual, as well as a place where the resident is dependent on others to receive appropriate care? The authors focus on older adults with psychical impairments due to age-related decline and chronic health conditions (further to be called: residents with physical impairments). Generally speaking, these persons are able to make decisions on how they want to live their lives, but are often not able to execute the decisions they make themselves. The focus of this review article is to gain insight in which facilitators and barriers influence autonomy of older adults with physical impairments.

Living in residential care influences autonomy. The authors are investigating this influence, because they have the presumption that intervening on these facilitators and barriers for this specific group, will create better opportunities for their autonomy.

The concept of participation is discussed in the light of diverse psychological and sociological research and is described with words as ‘control’, ‘agency’, ‘mastery’, ‘autonomy’, ‘self-management’ and ‘self-determination’ (5). The authors of the current review chose to use the word autonomy, because of the decisional versus executional polarity. This polarity was described by Collopy (6) as follows: a resident can have a desire and make decisions on how she/he wants to live her/his life, even if she/he cannot actualise them.

Moreover, in RCFs, several residents with physical impairments live together and can simultaneously have incompatible needs and wishes (7). Autonomy is given shape in a relational context between staff and other residents (8-11). McCormack (12) challenges the ‘individualistic concept of autonomy’ as used in neoliberal tradition and gives a different view based on interconnectedness and person-centred care.

The aforementioned relationship between autonomy and person-centred care can help to study autonomy in more detail. The aim of person-centred care is to place residents at the centre: in other words, each resident is seen as a unique person with a personal history, future, and life goals. With person-centred care, care-givers can respect and enhance autonomy of residents in the last phase of their lives (13, 14). McCormack and McCance (15) formulated a leading theory of person-centred practice (PCP) which can help to reflect upon facilitators and barriers to autonomy. It offers a theoretical, evidence-based framework. PCP is seen as a multidimensional concept and it is still developing. It takes into account person-centred outcomes (e.g. involvement in care), person-centred processes (e.g. sharing decision-making), the care environment (e.g. appropriate skills mix in the nursing team), prerequisites

of staff (e.g. providing holistic care), and the macro context (e.g. health and social care policy) (15).

A better understanding of the factors that strengthen autonomy (facilitators) or undermine autonomy (barriers) can help to enhance practices in RCFs that lead to interventions to preserve and facilitate autonomy of older adults with physical impairments living in RCFs. For a better understanding, the authors will underpin the concept of autonomy for older adults living in RCFs with a description that will be derived from the literature.

A systematic literature review will be executed with the research question: which facilitators and barriers to autonomy of older adults with physical impairments due to ageing and chronic health conditions living in RCFs are known?

Method

To answer the research question, a systematic literature search was conducted in the following databases: PubMed, CINAHL, Social Services Abstracts, Sociological Abstracts and PsycINFO. These databases include articles about care, cure, and psychosocial functioning. For the central aspects, living in an institution for long-term care and autonomy, the thesaurus (Social Services Abstracts, Sociological Abstracts and PsycINFO), MESH terms (PubMed) and headings (CINAHL) were used to select search terms that best matched the research question (Table 1). The search was conducted in March 2016 and updated in July 2017. A limit of ten years (beginning from 2006) was chosen, because the neoliberal approach of participation and the role of autonomy has only been put into laws and regulations over the last decade. The question of how autonomy can be enhanced for the more vulnerable members of society also emerged in this period.

Selection

Figure 1 shows the results of the database search. Using the inclusion and exclusion criteria (Table 2), the titles of the 3,030 unique articles were screened by the first author (JvL). When in doubt, the article went to the next stage. Selection by abstract was performed independently by JvL and three co-authors: (KL), (IdR) and (BJ). These co-authors each reviewed one-third of the articles; JvL reviewed all articles. Afterwards, the selections were discussed in pairs of reviewers in order to reach a consensus. When no consensus was reached on an article, it was included in the next stage. The same procedure was followed for the full text selection. When no consensus about inclusion or exclusion was reached in this stage, a third author was consulted and a consensus was reached.

Inclusion and exclusion criteria were established to be sure to review articles that concern the residents under study, namely older adults with physical impairments due to ageing and chronic conditions who live in RCFs (Table 2).

Table 1. Search terms and strategy.

Autonomy:
Actualisation OR
Self-actualisation OR
Self-determination OR
Self-management OR
Self-efficacy OR
Client participation OR
Patient participation OR
Autonomy OR
Personal autonomy OR
Coping OR
Resilience OR
Self-care OR
Patient autonomy OR
Adaptation OR
Hardiness
AND
Care setting:
Residential facilities OR
Long-term care OR
Residential care OR
Nursing home patients OR
Homes for the aged

Table 2. Inclusion and exclusion criteria for autonomy and its facilitators and barriers

Inclusion:
Older adults living in RCFs with physical impairments.
Autonomy.
Time period March 2006–July 2017.
Written in the English language.
Empirical research.
Peer reviewed journal article.
Health technology as far as it concerns the autonomy of residents.
Care-givers/family care as far as it concerns the autonomy of residents.
Professional caregiver issues as far as it concerns the autonomy of residents.
The decision to move, or process of moving, to long-term care.
Exclusion:
Persons suffering from dementia, psychiatric disorders and mentally challenged persons.
Place of living: in community, hospital and rest home.
Average age younger than 65 years.
Specific diseases and impairments.
Specific treatments of diseases.
Self-management of diseases like diabetes and blood pressure control.

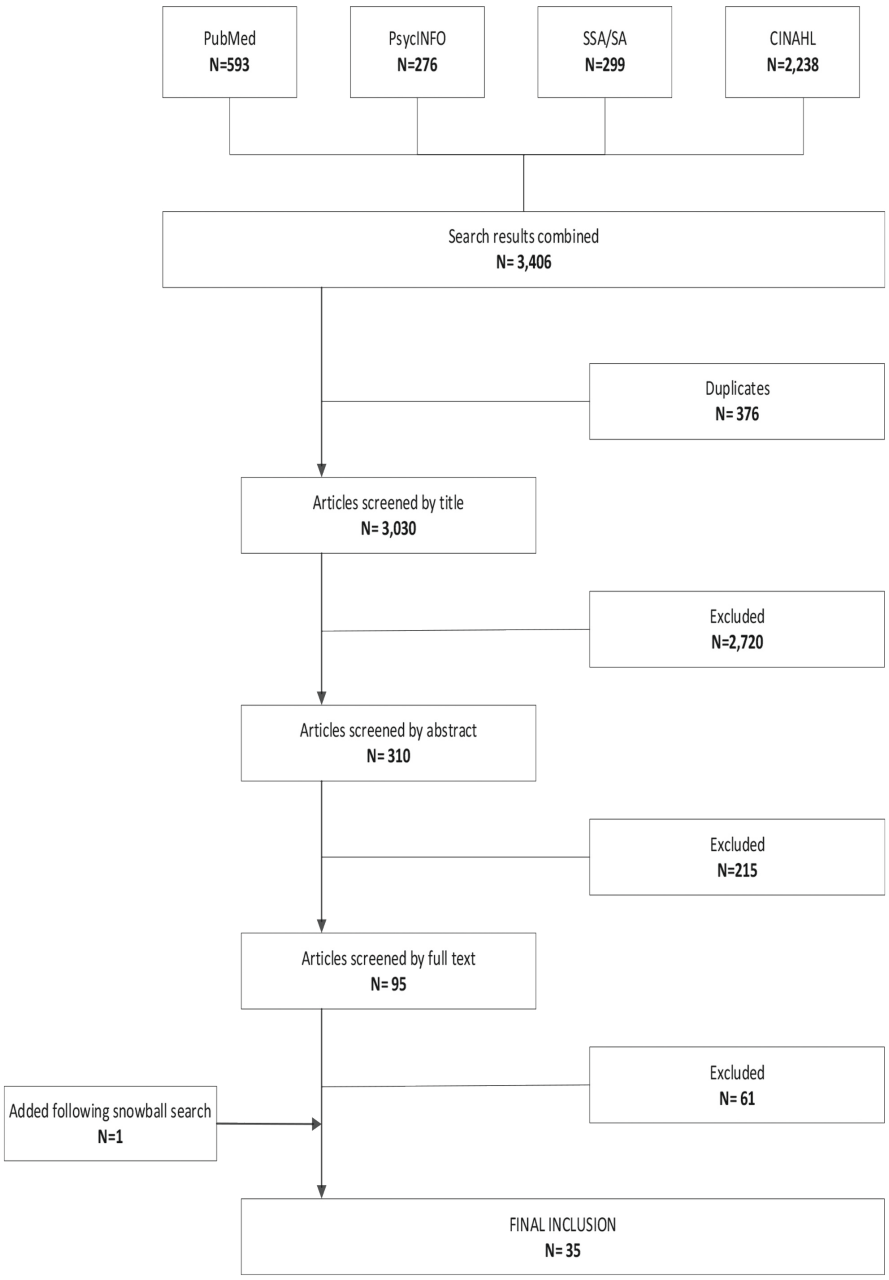

Figure 1. Flowchart of database search of facilitators and barriers to autonomy.
Note: SSA/SA: Social Services Abstracts and Sociological Abstracts

Data extraction and quality assessment of the articles

The data extraction of the full texts was performed using a format wherein the authors independently noted the description and the position of autonomy (i.e., cause, mediator, or result). Apart from one article (16), the descriptions were given in the introduction section in which the authors clarify how they were going to use the concept in their study.

Subsequently the authors noted facilitators and barriers as given in the results sections of the articles. Afterwards JvL and KL, JvL and IdR and JvL and BJ compared and discussed the extracted data in order to compare and interpret the data.

Each article was also assessed on quality, again independently by JvL and KL, IdR and BJ. The results of the assessed quality were also discussed in bilateral sessions. Because the systematic review includes articles with qualitative, quantitative, and mixed methods designs, the Mixed Methods Appraisal Tool (MMAT) was used to assess the quality of the selected articles. The MMAT is developed to facilitate the concurrent appraisal of articles with different designs, and provides elements to assess the quality of the articles to be included (17). In order to do so, four elements for studies with a qualitative or quantitative design are defined; for mixed method designs, 11 elements are defined. The scores are reported in column 3 of Table 3.

Data synthesis

The facilitators and barriers (see Table 3, column 7 and 8) were organised by JvL, KL, IdR and BJ in three themes derived from the PCP framework (15). Because a large group of facilitators and barriers found in the included articles concerned the residents themselves, the authors decided to add the theme 'characteristics of residents'. The current article thus uses four themes that affect autonomy, namely characteristics of residents, prerequisites of professional care-givers in RCFs, processes in the relationship between residents and professional care-givers and the care environment. When the context of the facilitators and barriers in an included article was not clear enough to assign it to one theme, the authors chose to assign it to more than one.

The included studies did differ in method and quality. However, the authors decided not to exclude the six articles scoring below 75 per cent because they provided relevant information on the research question. Moreover, in the analyses and presentation of the results, articles with a low MMAT score will not dominate.

Elements from the descriptions (Table 3 in column 6) were used to make a general description of autonomy for older adults with physical impairments in RCFs.

Reliability

The authors started with an individual review of ten abstracts using the inclusion and exclusion criteria. In a meeting, they discussed the similarities and differences in the selection. The same was done in the stage of the full text selection, this time with two articles. In this way, a uniform selection procedure of abstracts and full texts was achieved. At each selection stage, the first author JvL reviewed all the articles and the co-authors (KL, IdR and BJ) each reviewed one-third of the articles. The articles were discussed bilaterally between JvL with KL,

IdR and BJ. When no consensus was reached, the article was reviewed again in the next stage. At each stage, the articles switched to another reviewer. The stage of data extraction and quality assessment was also preceded by a meeting with all reviewers to discuss the analysis and assessment process.

Results

The search identified 3,030 unique articles, of which 35 were included. Table 3 (column two) shows that most of the articles originate from North-West Europe, Australia and North America. The MMAT scores (column three) vary from 25 per cent to 100 per cent. Generally speaking, the methodological quality of the articles is appropriate: the mean quality score is 82.9 per cent and 19 articles score 100 per cent. Column five shows us the designs ('D'). Qualitative designs (23 articles, 65.7 per cent) were used most frequently, followed by quantitative (nine articles, 25.7 per cent) and mixed methods designs (three articles, 8.6 per cent). Interviewing (22) is the method most used. In three articles, these interviews are combined with questionnaires and one of the interview studies is combined with a document review. There are ten questionnaire studies, of which two combined the questionnaire with observations. The other methods used in the articles are: observation (two) and action research (one). Seven articles evaluated the effect of interventions on autonomy. In 32 of the 35 articles (see column five 'P'), the perspective of the resident was explored.

Table 3. Description of the included articles and results

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Abma *et al*. 2012	The Netherlands (NL)	100 per cent	Responsibilities in elderly care: Mr. Powell's narrative of duty and relations.	D: Qualitative: observations N: 1 P: Resident A: 92 M: Not applicable (N/A)	Autonomy is relational and 'entails self-worth and self-development' and is 'an interactive process requiring the help and support of others' (p. 28).	Helping to see limitations. Reciprocity and mutuality. Listening to life stories.	Not listening. Not helping to adapt expectations.
Anderberg and Berglund 2010	Sweden	100 per cent	Elderly person's experiences of striving to receive care on their own terms in Nursing Homes (NH).	D: Qualitative: interviews N: 15 P: Residents A: 73–98 M: 82.4	Maintaining the 'abilities in order to have a sense of control in their life' (p. 67).	Learning dimension: the ability to find your way in the NH.	
Andresen *et al*. 2009	Denmark	50 per cent	Perceived activity choices among physically disabled older people in nursing home settings: a randomised trial.	D: Quantitative: questionnaires N: 50 P: Residents A: 65–97 M:-	Perceived autonomy in choice and control over activities in daily life.	Individually tailored programmes for activities.	Schedules for activities such as rest.

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Baur and Abma 2012	NL	100 per cent	The taste buddies: participation and empowerment in nursing homes.	D: Qualitative: action research N: 7 P: Residents A: 82–92 M: –	Empowerment through collective participation.	Relational process as a catalyst for change. Supporting environment; role models facilitate empowerment.	
Bolmsjö, Sandman and Andersson 2006	Sweden	100 per cent	Everyday ethics in the care of elderly people.	D: Qualitative: observations N1: 12 observed P1: Residents A: – M: – N2: – P2: Staff of P1 A: 20–60 years M: –	Autonomy is '… having the possibility to decide, influence and have choice in … daily life (self-determination) and also by not being dependent …' (p. 253).	Ethical competence of staff leads to autonomy.	Ethical incompetence leads to less autonomy and wellbeing.

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Brandburg *et al*. 2013	United States of America USA	100 per cent	Resident strategies for making a life in a nursing home: a qualitative study.	D: Qualitative: interviews N: 21 P: Residents A: 65–93 M:-	Resilience: ' … ability to adapt successfully to challenges in life …' (p. 866). * given in the results section.	Personal resilience and strategies for coping and adapting (after a move).	Unplanned move to NH interferes with successful adaptation.
Chao *et al*. 2008	Taiwan	50 per cent	Predictors of psychosocial adaptation among elderly residents in long-term care (LTC) settings.	D: Quantitative: questionnaires P: Residents N: 126 A: 65–102 M:81	Psychosocial adaptation: '… the ability of elders to maintain a sense of self-identity and continue valued roles and interactions with others while adapting to life in a long-term care facility' (p. 150).	Voluntary admission. Having roommates. Higher functional status. Financial resources. Having family support.	Absence of family support.

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Cooney, Murphy and O'Shea 2009	Ireland	100 per cent	Resident perspectives of the determinants of quality of life (QoL).	D: Qualitative: interviews N: 101 P: Residents A: 65–90+ M: -	Quality of life: '… sense of wellbeing, perceived happiness and life satisfaction … independence, social activity and perceived control over life' (p. 1030).	Maximising potential: ethos of care, sense of self and identity, connectedness, activities and therapies. Physical environment: homely atmosphere. Social environment: good relationships with continuity and reciprocity.	Physical environment: absence of homely social spaces; poor toilet and bathroom provisions. Social environment: staff are seen as too busy; negative social relations; no potential to stay connected.
Curtiss, Hayslip and Dolan 2007	USA	25 per cent	Motivation style, lengths of residence, voluntariness and gender influences on adjustment to long-term care.	D: Quantitative: questionnaires N: 75 P: Residents A: 69.5–88.8 M: –	Self-determination style that is related to adaptation.	Self-determined coping style helps to cope with institutional life.	

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Custers *et al*. 2011	NL	100 per cent	Need support and wellbeing during morning care activities.	D: Quantitative: observation and questionnaires N: 20 P: Residents A: 54–93 M: 79.1	Autonomy: '… one can choose activities, make decisions and regulate behaviour in accordance with own goals' (p. 1428).	Care-givers that fulfill the need for autonomy, relatedness and competence.	
Custers *et al*. 2012	NL	25 per cent	Relatedness, autonomy and competence in the caring relationship: the perspective of nursing home residents.	D: Mixed Methods: questionnaires and interviews N: 35 P: Residents A: 55–93 M: 79.9	Autonomy: '… one can choose activities, make decisions and regulate behaviour in accordance with one's goals' (p. 320).	Higher ADL dependency. Match between individual preferences and support. Asking for preferences. Facilitating care-givers to act upon the preferences. Higher education of staff.	

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Custers *et al*. 2010	NL	75 per cent	Need fulfilment in caring relationships.	D: Quantitative: questionnaires N: 88 P: Residents A: 50–97 M: 78.5	Autonomy: '… one can choose activities, make decisions and regulate behaviour in accordance with own goals' (p. 732).	High-quality care relationships contribute to need fulfilment, less depressive feelings and more life satisfaction.	
Danhauer, Sorocco and Andrykowski 2006	USA	75 per cent	Accenting the positive recent 'uplifts' reported by nursing home residents.	D: Mixed Methods: questionnaires N: 93 P: Residents A: 65–104 M: 83.46	'… domains of quality of life to accentuate the positive … [including] autonomy …' (p. 40).	Experiencing moments of good life: uplifts.	
Donnelly and MacEntee 2016	Canada	100 per cent	Care perceptions among residents of long-term care (LTC) facilities purporting to offer person-centred care.	D: Qualitative: interviews N: 23 P: Residents A: 58–97 M: 83.43	'Person-centred care … enhance … autonomy …' (p. 150).	Outspoken residents maintain some sense of autonomy.	Staff impose activities or care.

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Dunworth and Kirwan 2012	USA	100 per cent	Do nurses and social workers have different values? An explorative study of the care of older people.	D: Mixed Methods: questionnaires N: 65 P: Staff of RCF A: 40 ≥ 40 years M: –	No description.	Care qualified staff have fewer ageist assumptions.	Non-care qualified staff give priority to safety as opposed to autonomy.
Gleibs, Sonnenberg and Haslam 2014	UK	75 per cent	We get to decide: The role of collective engagement in counteracting feelings of confinement and lack of autonomy in residential care.	D: Qualitative: interviews N: 10 P: Residents A: 76–99 M: –	'Confinement … as it related to … control or autonomy' (p. 268).	Empowerment: enable voice, choice, control and belonging through group activities. Helping others. Social relations.	Ageism and stereotypes. Physical environment: needing help going outdoors and to other spaces. Lack of control. Physical mobility.

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Hall, Dodd and Higginson 2014	UK	75 per cent	Maintaining dignity for residents of care homes: A qualitative study of the views of care home staff, community, nurse, residents and their families.	D: Qualitative: interviews N: 121 *P1: Staff *P2: Family *P3: Residents (15) A P3: 56–93 Median:80.5	'Independence, autonomy, choice and control are related concepts concerning self-determination (not being restrained, influenced or coerced by others) and not relying on others for aid or support' (p. 57).	Maintain dignity through: independence autonomy choice privacy control Values of staff. Communication skills of staff.	Lack of privacy. Persuasion. Prioritising physical care and safety above autonomy. Workload of staff.
Hellström and Sarvimäki 2007	Sweden	50 per cent	Experiences of self-determination by older people living in sheltered housing.	D: Qualitative: interviews N: 11 P: Residents A: 73–93 M: –	'… autonomy was conceived as self-determination' (p. 413). 'Self-determination … is connected … to activity, mental agility, survival, social wellbeing, self-image and health …' (p. 414).		Disempowerment by the environment—for example, lack of information and shortage of staff—does not strengthen individual self-determination, participation and control. Feeling worthless. Being immobile.

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Hillcoat-Nallétamby 2014	UK	75 per cent	The meaning of independence for older people in different residential settings.	D: Qualitative: interviews N: 91 P: Residents *subset NH: N: 29 A: 74.5–89.5 M: 82	Autonomy has the dimensions: delegated, decisional, authentic, executional, consumer and direct autonomy.	Accepting help at hand. Doing things alone. Having friends, family and financial resources. Preserving physical and mental capacities.	
Hwang *et al*. 2006	Taiwan	100 per cent	Correlates of perceived autonomy among elders in a senior citizen home: A cross-sectional survey.	D: Quantitative: questionnaires and interviews N: 121 P: Residents A: 65–92 M: 78	'… Autonomy … is being able to recognize one's own individuality, having the freedom of self-determination, and … the freedom to act …' (p. 431).	Satisfaction of social support. Functional ability. Life attitudes. Literacy.	

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Johnson and Bibbo 2014	USA	75 per cent	Relocation decision and constructing the meaning of home: A phenomenological study of the transition into a nursing home.	D: Qualitative: questionnaires and interviews N: 18 P: Residents A: 68–97 M: –	'… autonomy … the experience of having freedom and/or choice in daily living' (p. 61).	Self-adjustment: coping with the situation. Looking for some autonomy within the institutional limitations. Making the decision to move. A safer place than the previous housing. Room for possessions.	Not participating in the choice to move. Giving up control. Lack of choice. Restrictions on going outside.

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Knight, Haslam and Haslam 2010	UK	100 per cent	In home or at home? How collective decision-making in a new care facility enhances social interactions and wellbeing among older adults.	D: Quantitative: questionnaires and observations N: 27 P: Residents A: 67–92 M: –	Collective decision-making, engagement and ownership.	Enhanced by participating in group decision-making in the context of the living environment.	
Knight *et al*. 2011	Australia	100 per cent	Environmental mastery and depression in older adults in residential care.	D: Quantitative: questionnaires N:96 P: Residents A: 64–98 M: 83.5	Environmental mastery '… managing one's environment, an ability to control external activities and to select or develop contexts suitable to one's needs' (p.875).	Mastery leads to better mental health in cases of illness and functional impairment.	

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Lagacé *et al*. 2012	Canada	50 per cent	The silent impact of ageist communication in LTC facilities: Elders' perspectives on quality of life and coping strategies.	D: Qualitative: interviews N: 33 P: Residents A: 60–100 M: -	'Communication is an essential component of the caring relationship, … maintain strong and empowering social bonds' (p. 335).		Ageist communication leads to feelings of being patronised and controlled: it discourages autonomy. Elders react with avoidance strategies (thus reinforcing ageist communication).
Lee, Simpson and Froggatt 2013	UK	75 per cent	A narrative exploration of older people's transitions into residential care.	D: Quantitative: interviews N: 8 P: Residents A: 65–97 M: –	Mastery over environment.	More control and involvement in the environment.	Withdrawal, giving up.
Morgan and Brazda 2013	USA	75 per cent	Transferring control to others: process and meaning of older adults in assisted living.	D: Qualitative: interviews N: 77 P: Residents A: 59–99 M: 85	Sense of personal control in the face of diminishing physical, cognitive or social resources.	Transfer of control to others is seen as proactive and positive to attain goals.	Over-helping, incongruent support and taking over control.

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Nåden *et al*. 2013	Norway/ Sweden/ Denmark	100 per cent	Aspects of indignity in nursing home residents as experienced by family care-givers.	D: Qualitative: interviews N: 28 P: Family care givers of residents (also dementia) A: 47–89 M: –	'… dignity … respect for personal autonomy' '… central elements in dignity are respect, privacy and control' (p. 749).		Being abandoned and deprived of dignity due to: 1) Feelings of not belonging 2) Acts of omission/ offences 3) Deprivation of confirmations 4) Physical humiliations 5) Psychological humiliations 6) Aspects of institutional life; Staff are not able to provide good care; Ageist communication.

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Oosterveld-Vlug *et al*. 2014	NL	100 per cent	Dignity and the factors that influence it according to nursing home residents: A qualitative interview study.	D: Qualitative: interviews N: 22 P: Residents A: 49–97 M: 77	'Dignity … personal, subjective valuing of oneself, … valuing oneself by others' (p. 98).	Preserving personal dignity through good professional care and a supportive social network.	Lack of privacy. Staff not knowing the resident. Leaving behind loved ones.
Oosterveld-Vlug *et al*. 2013	NL	100 per cent	Changes in the personal dignity of nursing home residents: A longitudinal qualitative interview study.	D: Qualitative: interviews N: 30 P: Residents A: 49–102 M: –	'… personal dignity, a type of dignity that is subjectively experienced by an individual' (p. 1).	Coping mechanism and professional care helps to maintain or regain personal dignity by feeling in control of life. Being regarded as a worthwhile person by themselves and others.	

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Palacios-Ceña *et al.* 2013	Spain	100 per cent	Is the mealtime experience in nursing homes understood? A qualitative study.	D: Qualitative: interviews N: 26 P: Residents A: ≥ 60 M: 83	No description.	Work with preferences on mealtimes: maximise autonomy, promote positive social experience, optimise dietary intake and improve quality of life.	Dining table allocation by staff and/or as reward or punishment.
Råholm *et al.* 2014	Norway/ Sweden/ Denmark	100 per cent	Perspectives of dignity of residents living in nursing homes: Experiences of family care-givers.	D: Qualitative: interviews N: 28 P: Family care-givers of residents (also dementia) A: 47–89 M: –	'… in the concept of dignity: the concrete level, the relational level, and the existential level' (p. 37).	Providing a confirming culture and a caring and confirming relationship.	The existence of a non-confirming and non-caring relationship.

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Sæteren *et al.* 2016	Denmark/ Sweden/ Norway	100 per cent	The dialectical movement between deprivation and preservation of a person's life space.	D: Qualitative: interviews N: 28 P: Residents A: 62–103 M: –	Dignity is experienced in 'maintaining personal life space in relation to the physical environment, confirming interpersonal relations, and a feeling of inner freedom and worth … despite the onset of aging, disease and disability' (p. 139).	Using the inner resources residents have. Giving as much space as possible to protect the residents' responsibilities and inner freedom. Express needs and desires in a negative way: claim the right.	Being dependent in terms of mobility. Not complaining; accepting withdrawal.
Sikorska-Simmons 2006	USA	75 per cent	The effects of organizational policies on resident perceptions of autonomy in assisted living.	D: Quantitative: questionnaires N: 412 P: Residents A: 59–101 M: 83	Decisional autonomy: '… perceptions of influence and independence' (p. 62).	Higher levels of choice-enhancing policies.	

Table 3. Description of the included articles and results (continued)

Authors and year	Country	MMAT Quality score (%)	Title of the article	D: Design N: Number of participants P: Population A: Age M: Mean age	Description of autonomy (as described in the introduction section)	Facilitators (as described in the results section)	Barriers (as described in the results section)
Walent and Kayser-Jones 2008	USA	75 per cent	Having a voice and being heard.	D: Qualitative: interviews and document review N: 17 P: Residents A: 66–94 M: –	'Self-advocacy … ability to voice one's own needs and concerns and to persist until they were heard and met' (p. 39).	Formal advocacy: the organisation promotes the residents' voice by pairing employees with residents. Residents who are advocates for other residents.	Personal, organisational, social and cultural barriers.
Walker and Paliadelis 2016	Australia	100 per cent	Older peoples' experiences of living in a residential aged care facility in Australia.	D: Qualitative: interviews N: 18 P: Residents A: 77–96 M: –	'… losing control over making life choices' (p. e7).	Meaningful relations with staff, family and friends. Acceptance. Making the best.	Trading independency for safety and assistance in NH. Exclusion from formal decision-making.

Notes: 1. Given in the Results section. MMAT: Mixed Methods Appraisal Tool. NL: The Netherlands. USA: United States of America. NH: nursing home. ADL: activities of daily living. LTC: long-term care.

Description of autonomy in the included articles

For a better understanding of the facilitators and barriers to autonomy, the authors first aim to underpin the concept of autonomy for residents with physical impairments. The word autonomy is used in 16 articles (see column six, description of autonomy, in Table 3). The polarity of decisional and executional autonomy (6) was mentioned in four articles (18-21). Most of the other included articles only used one element of the polarity, the decisional aspect.

Autonomy, self-determination and dignity seem to be linked. Various relationships between these concepts were described in the included articles, as causes, intermediate factors or outcomes of one another. For example, dignity as a cause for autonomy (22). Also, an opposite perspective is mentioned: autonomy, amongst other aspects, leads to dignity (23). Dignity as a result of choice and autonomy is also described (11). Three articles use the motivational theory of Ryan and Deci (24): in this theory, autonomy leads to self-determination (25-27). Self-determination is also seen as a subcategory of autonomy (18).

Based on the elements from column six of Table 3 (description of autonomy), a description of autonomy was formulated in such a way that it best matches the population in this review: older residents with physical impairments in RCFs. In the current article, autonomy is described as a capacity to influence the environment (28-30) and make decisions (5, 7, 10, 18-20, 22, 23, 25-27, 31-38), irrespective of having executional autonomy (35), to live the kind of life someone desires to live (7, 25, 26, 29, 32, 36-39, 40) in the face of diminishing social, physical and/or cognitive resources and dependency (5, 29), and it develops in relationships (7, 8, 11, 29, 31, 37, 40-43).

Facilitators and barriers to autonomy of older adults with physical impairments in RCFs

The results of the literature review are organised in four themes of which characteristics of residents is the first theme. This theme is based on the included literature that provided rich information on the older adults themselves. The other themes are derived from the PCC framework: prerequisites of professional care-givers in RCFs, processes in the relationship between residents and professional care-givers and the care environment (15). Often the results reveal an ambiguity: aspects can either be facilitators or barriers. These will be elaborated on below, starting with the resident characteristics.

Characteristics of residents: facilitators

First, psychosocial characteristics of residents were identified (Table 4). Visits from family and friends help older adults to experience a sense of continuity of the life they lived before moving into the RCF (35). As a consequence of these visits, the valued roles they used to have for family and friends can be maintained. This offers a sense of belonging and autonomy (11, 19, 33, 38, 44). If older adults have financial resources, possibilities are created to make decisions on spending money and having choice and control in their lives in RCF (10, 35, 44). The presence of meaningful activities can give control and social engagement. Through these

activities, older adults can help each other and, as a result, have useful recognised roles (10, 13, 26, 35, 38).

Also, diverse intrapersonal characteristics are distinguished. Coping skills, which older adults developed earlier in their life history, lead to more control over the situation and autonomy (11, 14, 16, 27, 31, 33, 39, 40, 42). Relations with staff are important for exercising autonomy. In these relationships, older adults' need to be regarded as worthwhile persons can be fulfilled. Especially when residents lack family and friends who can act as advocates, relations with staff become more important (10, 11, 35, 38, 42, 44). The possibility of deciding themselves about moving into the facility seems to have a positive impact on the feeling of autonomy and control (5, 28, 36, 44).

The last characteristic of the residents is the level of physical functioning. A higher level results in more control and choice in activities. Also, there is a higher use of living and other spaces in the RCF. In addition, there are more possibilities for going out (19, 35, 42, 44).

Characteristics of residents: barriers

As said before, the aspects reveal an ambiguity, they can either be facilitator or barrier. The barriers are now given for the same aspects as above.

Psychosocial characteristics were identified, such as the absence of family and friends. In addition, being over-helped by others or receiving incongruent support are barriers to autonomy (5, 11, 38). If older adults do not have family and friends, they have to rely on staff or other residents for attention and help. Often older adults hesitate to state their wishes and needs. They suppose that staff are too busy. Sometimes older adults assume that complaining or asking help will have a negative effect on the care they receive (5, 7, 14, 18, 33, 38, 41).

Barriers in the intrapersonal characteristics, such as being unable to participate in the decision-making process of moving into the RCF, affect autonomy negatively (28, 33, 36, 44). Furthermore, shared decision-making is not taken for granted, because rules and time schedules are often accepted by older adults (5, 14, 18, 28, 36, 38, 40, 44).

In physical functioning, as the last characteristic of residents, barriers are also found. Immobility and a diminished ability to communicate might act as barriers. A lack of energy can interfere with residents being able to live the lives they want to live (10, 11, 18, 38, 42).

Table 4. Characteristics of residents

Facilitators	Barriers
Psychosocial characteristics:	
Having financial resources	Absence of family and friends
Helping family and friends	Over-helping by others
Relations with staff	Incongruent support
Group activities	Leaving behind a husband or wife
Social engagement	Not complaining
Helping each other	Interpreting that staff are too busy

Intrapersonal characteristics:	
Having a sense of meaning	Being unable to make decisions on moving
Continuity of identity	Sense of ineffectiveness
Awareness	Acceptance of rules instead of questioning them
Coping abilities	
Learning abilities	
Uplifts	
Taking responsibility	
Educational level	
Decision-making on moving	
Information seeking	
Optimism and hope	
Mastering life in the institution and the wisdom to accept	
Positive attitude	
Feeling of being in control	
Cognitive functions	
Physical functioning:	
RCF offers protection	Diminished ability to communicate
	Being dependent

Prerequisites of professional care-givers in RCFs: facilitators

The second theme used to organise the results is the prerequisites of professional care-givers in RCFs (Table 5). The awareness of beliefs and values is established as prerequisite. Staff that are able to provide good professional care and are able to build high-quality relationships with residents help to preserve autonomy. So does staff who are able to treat residents with respect. The ability to take care of the physical appearance of residents also enhances autonomy (25, 45, 46)

More highly educated nurses, and nurses in higher positions, seem to be more capable of supporting autonomy. They are more reflective in their attitude and have fewer ageist assumptions (34).

Also, ethical competence and creativity of the staff are seen as facilitating autonomy (7, 23).

Prerequisites of professional care-givers in RCFs: Barriers

Barriers are also seen in the prerequisites. Dissatisfaction with the job and lack of ethical competence are barriers to autonomy. Negative beliefs and values as ageist assumptions in staff, expressed in ageist communication and adverse relationships, are also barriers to autonomy (7, 10, 23, 34). An example of unethical behaviour in staff is seen when tables in the dining rooms are allocated as a punishment or reward for certain behaviours of older adults, thus leaving residents no choice of dinner companions (43). Another threat to autonomy is undignified care, like forced-feeding situations (22).

Often encounters between staff and residents are scarce and show a lack of reciprocity. The last aspect in this theme is that staff seem unable to identify the underlying messages in the communication. This can lead to an unfulfilled desire for autonomy (7).

Table 5. Prerequisites of professional care-givers in residential care facilities

Facilitators	Barriers
Beliefs and values:	
The ward covers a set of positive values which is reflected in the actions of staff	Ageist assumptions Stereotyping and stigmatising Absence of underlying values
Relationship:	
High-quality, caring relationships:	Coercing relationships: punishing, rewarding
Commitment to the job	
Higher educational level or job function	No satisfaction with the job
Ethical competence:	
Reflection Creativity	Talking about choice but not acting upon it Not reacting to individuals' needs
Communication skills:	
Confirming communication	Ageist communication

Processes in the relationship between residents and professional care-givers: facilitators

Communication is the first aspect that is distinguished in the processes between residents and care-givers (Table 6). Staff that have a good relationship with the older adults contribute to their need fulfilment. So does respectful communication and care for their physical appearance (27).

Relations between residents and staff can reveal how diverse adaptive strategies are applied by older adults to have a life of their own in the RCF. Knowing and working with these individual strategies facilitates autonomy and assists older adults in dealing with problems (16, 32).

Staff can find out what autonomy means for older adults by listening to life stories. These stories reflect the values of older adults in life, their personal identity and relations (8). With an empowering strategy, involvement in care and shared goals can be realised and ownership is enhanced (9, 29).

Processes in the relationship between residents and professional care-givers: barriers

The lack of constructive communication can act as a barrier to autonomy. For example, when staff use routines, or impose activities of care or let older adults wait for help (11, 14, 22, 43). The possibility of participating in decision-making can be hindered by a lack of information

and choice (18, 38). Furthermore, conflicts with staff might discourage older adults from expressing their wants and needs (23, 38, 41).

Table 6. Processes in the relation between residents and professional care-givers

Facilitators	Barriers
Communication:	
Shared decision-making	Talking about persons Persuasion
Relations:	
Friendly, trustful relationships Respecting and knowing the person and her/his past Reinforcing, empowering Reciprocity	No information and choice Conflicts
Caregiving:	
Giving space Individual tailored programmes	Prioritising physical care Having to wait, ignoring Physical humiliations

Care environment: facilitators

The last theme to organise the results is the care environment (Table 7). RCFs that have high levels of choice-enhancing policies and have an adequate staff seem to increase the residents' autonomy. Also, financial resources and a conforming physical outline seem to act as facilitators (20, 37, 38). For example, the management can support the participation of older adults in organisational choices, such as selection of menu, gardening and social activities. This enhances the sense of mastery (9, 28, 30). Another example is the employment of skilled and permanent staff who share the same language, which facilitates autonomy (25, 33, 34, 38, 40). A combination of appropriate shared and private spaces for older adults enhances choice, feelings of safety and participation (23, 35, 36, 44).

Care environment: barriers

A lack of choice and control in daily life, such as the use of schedules is found as a barrier. These schedules force older adults to fit their lives into routines, which might undermine autonomy. Also, routines for activities such as morning procedures, meals, washing, going to the toilet and bedtimes can act as barriers to autonomy (23, 32, 36, 39).

Understaffing and employment of temporary employees can be barriers to autonomy. There is no time to get acquainted, to build relationships and to get to know the preferences of residents (11, 23, 38).

Shortages in resources due to directives and political decisions is one of the causes of understaffing. This affects autonomy because there are fewer staff to respond to older adults' needs (10, 18). The physical outline of the building and decoration of the rooms influence the experience of feeling at home. RCFs that appear like a hospital have a non-confirming atmosphere (10, 11, 22, 33, 41).

Table 7. Care environment

Facilitators	Barriers
Choice and control:	
Formal involvement in decision-making Supportive systems	Schedules and regulations Lack of choice Organisational decisions instead of professional
Staffing:	
Skilled personnel Continuity of staff Ethnical and cultural congruity Background of management	Inadequate staffing Deployment of temporary personnel
Physical and financial environment:	
Shared and private spaces	Lack of resources Little or shared physical space House is not a home

Discussion

The current literature review was executed to gain more insight into facilitators and barriers to autonomy of residents with physical impairments living in RCFs. Based on the literature search and the subsequent synthesis of the data of the included articles, the facilitators and barriers to autonomy were identified and organised. Three themes were based on the framework of PCP (15). Particular aspects in the care environment act as barriers to autonomy. Relationships between staff and residents can either facilitate or inhibit autonomy, depending on the prerequisites of the care-givers and characteristics, e.g. coping skills, of the residents.

Although the framework includes elements of PCP, the care recipient her/himself is not present in the model. In the current review, characteristics of residents that influence autonomy were determined. The theme 'characteristics of residents' is added to arrange the results of the older adults. The majority of the articles investigated this perspective, so a large set of attributes of residents that influence autonomy were distinguished.

Facilitators and barriers to autonomy can be allocated to elements of the PCP framework. The macro context, which contains aspects such as health policies and strategic frameworks, is not investigated in the included articles. The PCP framework seems to encompass all the distinguished influencing aspects for autonomy in the included articles. The culture change to more person-centred care can enhance autonomy. Realising a culture change in RCFs, however, is difficult with so many challenges to deal with (14).

Based on the descriptions of the included articles, a description of autonomy was formulated. The authors established this description because it compiles the core elements of autonomy for older adults with physical impairments living in RCFs, as used in the included articles. Autonomy is described as a capacity to influence the environment (28, 29, 30) and make decisions (5, 7, 10, 18-20, 22, 23, 25-27, 31-38), irrespective of having executional

autonomy (35), to live the kind of life someone desires to live (7, 25, 26, 29, 32, 36-40) in the face of diminishing social, physical and/or cognitive resources and dependency (5, 29), and it develops in relationships (7, 8, 11, 29, 31, 37, 40-43).

Based on the included articles, the description focuses on decisional and relational autonomy. This might be explained because the literature search was performed for physically impaired older adults living in RCFs. These residents are generally able to make choices, but physical impairments can obstruct the execution of the decisions taken. They often need practical help from others to carry out their decisions. Also, the relational aspect was prominent in the included articles, which can be related to the fact that living in an RCF means living with other residents and staff, and thus in relation to others.

The aspect of forced autonomy, using force to make decisions and act upon them independently, was not present in the included articles. However, paternalism was present: making choices for persons who are able to make decisions on their own.

Nonetheless, we found barriers to autonomy related to force, for example the forced use of services, such as eating, following regulations, transfer to the residential care and transfer of tasks and responsibilities. Autonomy, in the included articles, is often hindered by care-givers and institutions, and is not forced upon residents. (19, 30, 34, 41, 45, 47).

Strengths

In this review, results from articles that focus on dignity, self-determination and autonomy are aggregated. The different positions in the relationships between the three concepts and their intertwined use in the included articles made it rewarding to merge all facilitators and barriers. As a result of the merging, the review offers a comprehensive overview of factors that influence autonomy of residents with physical impairments living in RCFs.

The execution of the systematic review by four of the five authors was established first independently and later through meetings to achieve a uniform procedure at the start of each stage of the selection, quality assessment and data extraction. The first author assessed all articles. Three of the co-authors reviewed a selection of the articles. At each stage of the selection process, consensus was reached about inclusion or exclusion of articles by means of bilateral discussions.

Limitations

A limitation in organising the results according to the PCP framework is that some of the included articles lack specific information, so the allocation of a facilitator or barrier can be difficult. For example, the framework makes a distinction between being prepared for the job (prerequisites) and delivering care (person-centred processes). However, there is not enough information in the included articles about preparation for the job or educational background. The consequence is that it is difficult to allocate results such as communication to either prerequisites (communication skills) or care processes (communication). The same can be said for building relationships (prerequisite) and relations (care processes). In that case, barriers and facilitators were allocated to both themes, so a repetition is seen.

In this study, the authors aimed to include residents with physical impairments. However, it cannot be certain that persons with dementia were totally excluded because of the lack of precise information about the assessment of mental status. The content of the articles, however, gives confidence that the research is not done on persons with moderate or severe dementia.

The same can be said for the inclusion of persons with an average age of 65 years. The authors screened the articles thoroughly to exclude studies on residents under 65 years. However, if some individuals under this age participated in the studies, the authors calculated the mean age. The mean in all these articles was 77 years or more. This mean of 77 was used as a rationale to include the article as describing residents above 65 years. For three included articles, the authors were not able to calculate a mean age because the individual ages of the participants were not given. However, an age range of 49–102 (42) 62–103, (29) and 60–100 (41) was provided for the participants of their studies. The subject of the articles gives us the assurance that the group had age-related impairments.

Implications for practice and science

The current review leads to a better understanding of autonomy-enhancing elements for residents with physical impairments in RCFs. Autonomy is a broad, complex, multifaceted and relational concept that can be influenced by many factors in various ways. The results have implications for practice for both residents and care-givers, because they offer possibilities to preserve and enhance autonomy. The knowledge of facilitators and barriers established in this review can be used in the education of current and future nurses or other care personnel to make them aware of how to enhance autonomy. Based on the results in all four themes, RCFs can systematically develop autonomy-enhancing practices.

Scientifically, this study creates new knowledge and provides an actual overview on autonomy for older adults with physical impairments in RCFs and how to support autonomy. The results accentuate the influence of multiple aspects to achieve autonomy in RCFs.

More empirical research should be done on autonomy in practice. What significance does autonomy have for residents and staff and when is autonomy (not) enhanced or perhaps forced? Do we recognise (parts of) the description of autonomy in daily care practice? Because autonomy is a complex, relational and dynamic concept, it can best be investigated through observational methods that examine the perspectives of residents and care-givers. Shadowing is a method that can be used in an environment where autonomy is manifested, e.g. in RCFs (48). Research can give insight into how factors established in this review interrelate and how they are expressed in the care process. It is advisable to investigate dimensions of the concept of autonomy other than executional and decisional autonomy which dominate in the results of this systematic review. It is possible that important aspects of autonomy – e.g. the relational aspect of autonomy- are getting less attention or can be overlooked if further research restricts itself to this polarity. More attention should also be paid to the facilitators and barriers in the macro context. RCFs are strongly dependent on government health policies and funding to achieve autonomy-enhancing practices.

Furthermore, the knowledge can be used in participatory transformational action research. Action groups with different stakeholders in RCFs can experiment with actions to strengthen autonomy. In this way, the perspectives of residents, care-givers and organisations can be studied in relation to each other. Supportive practices for autonomy can be identified and examined by means of this bottom-up development.

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Section II

3

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.

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 adults stay at home for as long as possible, with help from informal caregivers or community health care (1). Older adults who need 24-hour care, and who cannot organise this care at home, can move to a nursing home (2). 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 (3, 4). 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 (5, 6). 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 (7).

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 (2) 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 (8). Nursing homes have separate units for older adults with physical impairments and for older adults with dementia (9). 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 (10). Collopy (11) 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 (12). More recently, a relational dimension has additionally been studied, described as the dependence of frail persons on those who care for them (13). Relational autonomy develops between older adults seeking care and persons providing care (14).

Three interrelated factors have been identified that are important for maintaining autonomy of older adults with physical impairments living in nursing homes. The first factor is characteristics of older adults, these include psychosocial characteristics such as having sufficient financial resources (12, 15, 16) and the help of family and friends (17-19); relations with staff (19, 20); and social engagement (21, 22). The second factor that affects the autonomy of nursing home residents involves the intrapersonal characteristics of the older adult, for example learning (23) and coping abilities (17, 24), optimism and hope (21), and the

feeling of being in control (25). The third and last factor consists of physical characteristics, such as being dependent on (26), or benefiting from the protection of the care facility (20).

The characteristics of professional caregivers also have an effect on autonomy of older adults. Factors such as their beliefs and values (27), ethical competences, creativity and reflection, and commitment to the job and communication skills (28), have been identified by prior research as important to maintain autonomy.

Autonomy is also affected by the care processes between older adults and caregivers, such as the way that decisions are made (9), the relationships between older adults and staff (29), and the way care is given (18).

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 (16) and supportive systems (30), are supported in their autonomy. Adequate staffing is important, including continuity of staff, skilled personnel and ethnical and social congruity (19). Also the physical environment affects autonomy, such as having shared and private spaces (4), and the financial resources of the nursing home (26). 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 (31).

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 (32).

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 (33). Based on a literature review, the authors selected three periods for engaging in shadowing:

morning care, mealtimes and activities. Custers and Kuin (9) state that morning care involves the most interaction between a resident and staff. Palacios-Ceña and Losa-Iglesias (34) discuss mealtimes as periods in which to decide what, where, how and when to eat. Gleibs and Sonnenberg (16) 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 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 data set 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 (33). 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 nonverbally, 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. (35) 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 finalize 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 (35). 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 appendix A. All five authors were involved in discussing each step in the analysis until consensus was reached.

Results

Description of the context

Table 1. Characteristics of the care organisations

	Organisation A	Organisation B
Number of clients	2700	960
Number of employees	2600	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

Structure of the building

The units were built in 2007 (A) and 2004 (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 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 age range was 64 to 96 (mean = 81). In Unit A, eight women and one man participated; in Unit B four women and four men. The older adults had lived in Unit A for 1 to 7 years (mean = 4.2) and in Unit B for 1 to 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.

Table 2. Description of participants and data collection.

Participant	Gender	Age	Living in Nursing Home (NH) years	Self-reported reason to move to Nursing home	Observed disability	Shadowing[1] during	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[2]	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

Table 2. Description of participants and data collection. (continued)

Participant	Gender	Age	Living in Nursing Home (NH) years	Self-reported reason to move to Nursing home	Observed disability	Shadowing[1] during	Duration of shadowing (hours)	Duration of interview recording (minutes)	Number of coded fragments per respondent
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 TV 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

Table 2. Description of participants and data collection. (continued)

Participant	Gender	Age	Living in Nursing Home (NH) years	Self-reported reason to move to Nursing home	Observed disability	Shadowing[1] during	Duration of shadowing (hours)	Duration of interview recording (minutes)	Number of coded fragments per respondent
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
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

Table 2. Description of participants and data collection. (continued)

Participant	Gender	Age	Living in Nursing Home (NH) years	Self-reported reason to move to Nursing home	Observed disability	Shadowing[1] during	Duration of shadowing (hours)	Duration of interview recording (minutes)	Number of coded fragments per respondent
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]Shadowing during: C, morning care; A, activity; M, mealtime; remarks if information is missing. [2]ADL: activities of daily living.

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 had 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 nonverbal 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 practice 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 e-mail 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 they did not get along with. 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 e.g. 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 was not 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 cooperate 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 (14) refer to this as 'relational autonomy".

The elements found in this study were only effective to maintain autonomy when staff and/or informal caregivers 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 (36). 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 (19).

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, that are communicated in a nonverbal 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 (ADL), 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 (12, 37). 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 nonverbally 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 was 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 and Dodd (36) 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 (18, 26, 28, 38). 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 (12, 19). The literature has described the negative effects of unchosen task transfers, such as financial exploitation (25). 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 to, 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 (17, 39, 40). 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 (16, 17, 21, 41, 42). 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 (3). 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 and Sandman (28). 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 theme 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 time span.

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 (43). 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 (44). 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 in which situations 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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Appendix A. Themes and assigned codes

	Theme	codes
1	*Deciding and executing decisions*	Being able to care for appearance: hair/nails Being able to care for appearance: shaving Being able to dress independently Being able to eat independently Being able to wash independently Having autonomy about planning a holiday
2	*Maintaining autonomy by active involvement*	Thank/offer something Greeting Using gestures Use of humour Take the lead in a conversation Giving permission Give instructions Appreciation of staff Help of fellow residents Creating a sense of community Deciding about the choice of food Deciding when to eat Deciding about ADL support Deciding about how often to wash or shower Deciding about pace Deciding about going to the toilet Deciding which clothes to wear Deciding on resting/ staying in bed Deciding on time/waiting Deciding about grooming products Distrusting the environment Negative expressions
3	*Maintaining autonomy by transferring it to others*	Role family: general Role family: daily visit Role family practical matters: shopping Family role practical matters: mail Family role practical care: washing clothes Family role: social contact Role of family: grooming Role of friends Volunteer knows needs of client structurally
4	*Using preferred spaces*	Enjoying the living environment Deciding about how to furnish the apartment Deciding how to use spaces Deciding how to use the apartment Deciding where to eat and drink Deciding to move to another room Deciding to go out or to another part of the nursing home

5	*Choosing how to spend time in daily life*	Deciding about smoking Deciding about social activities Deciding about sportive activities Deciding about trips Deciding about hobbies/activities Deciding about who to live with Residents care for others Residents want to be informed about fellow residents Adjusting goals Enjoying small things
6	*Deciding about important subjects*	Having goals Exerting formal influence Being recognised as a person Expressing a will to live Deciding about moving to the nursing home Deciding about finances Want to be informed about the environment Want to be informed about policy Deciding and having control over medication/ oxygen Deciding over medical condition Wants to be consulted/shared decision-making Exerting autonomy in the past Deciding about food preparation Use of expertise and know-how

Section II

4

How staff act and what they experience in relation to the autonomy of older adults with physical impairments living in nursing homes

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Abstract

Autonomy is important for people, even when they have physical impairments and are living in nursing homes. The way staff responds to residents is important for the realisation of autonomy.

In order to gain knowledge about what nursing home staff, registered and assistant nurses, occupational therapists and nutritional assistants do and experience in relation to the autonomy of residents, a qualitative study design was chosen.

Shadowing, a non-participatory observation method, was used. A total of 15 staff members of a care unit from two different nursing homes participated. Short interviews followed these observations to reflect on intentions of observed activities. The COREQ guidelines were used to report on the study.

Four activities to enhance autonomy were identified: getting to know each older adult as a person and responding to his/her needs; encouraging an older adult to perform self-care; stimulating an older adult to make choices; and being aware of interactions.

The exploration showed that staff considered it important to strengthen autonomy of older adults living in nursing homes and that they used different activities related to autonomy. However, activities could both enhance as well as hinder autonomy.

Introduction

Autonomy is seen as important for persons, even when they are older and need help. Most older adults with physical impairments and chronic conditions continue to live at home for as long as possible, with the help of informal caregivers or community health care (1). Older adults who need 24-hour care, and who cannot organise this care at home, can move to a nursing home (2). However, living in a nursing home might influence autonomy.

Based on a systematic search of the literature, autonomy was approached in this study as the capacity to influence the environment and make decisions irrespective of having executional autonomy, to live the kind of life someone wants and desires to live in the face of diminishing social, physical and/or cognitive resources and dependency, and it develops in relations (3).

In 1988, Collopy (4) identified several dimensions regarding autonomy in the context of long-term care, i.e. decisional, delegated, executional, authentic and direct autonomy. All dimensions can be seen in nursing homes; however, most studies concerning older adults with physical impairments focus on decisional and executional autonomy (5). Decisional autonomy refers to deciding how to live in a nursing home, while executional autonomy refers to the ability to carry out these decisions independently (4).

In the Netherlands, nursing homes provide 24-hour care for older adults with physical impairments and for older adults with dementia (2). The residents live in separate units according to their condition (6). Care is provided by registered and assistant nurses (hereafter called nurses) (7). Usually, nutritional assistants (NA) also work on the unit to provide meals, as well as occupational therapists (OT) who facilitate activities. An elderly care physician is responsible for the entire medical care of an older adult (8).

Older adults, i.e., 65 years or older, with physical impairments due to age-related decline or chronic health conditions (hereafter referred to as older adults with physical impairments) generally do have the capacity to decide how they want to live their lives in a nursing home. However, they are often hindered in terms of executing these decisions due to the underlying physical conditions that made them move to the nursing home. To compensate for this lack of executional autonomy, older adults with physical impairments try to maintain autonomy by active involvement in how, when and where daily activities take place (9, 10).

Whether their active involvement is successful depends on how nurses and other staff react to the verbal or non-verbal expression of wishes and needs of older adults (11-13).The literature reveals that the way care is given can act as either a barrier to or as a facilitator of the autonomy of older adults with physical impairments in nursing homes. Nurses who are familiar with and work with individual strategies to maintain the autonomy of older adults themselves and listen to their life stories can enhance autonomy (11, 14). The absence of effective communication skills in nurses can act as a barrier to autonomy (e.g., when routines dominate or activities are imposed on residents) (15-18). The attributes of nurses, such as ethical competence and creativity, can act as a facilitator of autonomy (12, 19). Conversely, ageist assumptions and ageist communication are barriers to autonomy (10, 20).

To deepen our insight into how staff react to the expression of wishes and needs, the authors wanted to explore and describe how staff act and what they experience in relation to the autonomy of older adults with physical impairments living in nursing homes, in daily life in care units.

Methods

To explore and describe how staff act and what they experience, a qualitative descriptive design was chosen (21). Shadowing was used, which is a phenomenological method to explore and describe the reactions of staff towards autonomy with non-participatory observation (22). The researcher followed a participant who was performing diverse activities over a period of time, in this study parts of one dayshift of eight hours. Shadowing provided detailed data because actions were observed and participants did not only give their verbal opinion about why they acted in a certain way. Another advantage was that it provided holistic information, because it also revealed unconscious activities. To understand the intentions of activities and interpret what occurred during the day, a brief recorded interview with the participant was conducted (23). Questions that were asked included 'How important is autonomy to you?', 'How important is autonomy to the older adults you care for?' 'Can you enhance autonomy in your work in this unit?' and 'Which situation today is the best example?'

To report on the quality of the study, the COnsolidated criteria for REporting Qualitative research (COREQ) guidelines were used (24).

Context and setting

Two nursing homes in the southern region of the Netherlands agreed to participate in the study. Both nursing homes stated in their mission that they aimed to support the autonomy of their residents. In each organisation, one unit, A and B, was selected to participate in the study. Unit A was part of an organisation that provided care in a large town (200,000 citizens) and offered places to 40 older adults with physical impairments and employed 25 full-time equivalent (FTE) staff. Unit B was part of an organisation serving a small (23,000) and medium-sized (36,000) town and the surrounding area. This unit employed 23 FTE staff and cared for 28 older adults with physical impairments living in the unit.

This study investigated staff, i.e., nurses, NA and OT who were working on one of these two units.

Recruitment/sample

Purposive sampling was used, in which the authors selected participants who had knowledge and experience with the phenomenon (25). Beforehand, the authors aimed to shadow 10 individuals per organisation to ensure reasonable coverage of variation. To shadow diverse activities in which autonomy can be observed, such as morning care (6) provided by nurses, organised activities (10) facilitated by OT and meals (16) served by NA, individuals in these various positions were contacted. The researcher made contact with an informant working on unit A or B to talk about recruitment and the study procedure. After this, she informed the

staff about the aim and design of the study in a regular team meeting for units A and B. The staff was invited to participate in the study; information and an informed consent form were given to them. There was a two-week period for the staff to read the information, consider participation, ask questions and return a signed copy of the informed consent form. The informant was available to answer the questions of colleagues and share this information with the researcher.

Of the 16 persons who decided to participate in the study and signed the informed consent form, 15 actually participated. On arrival to the unit, one person who had agreed to participate was scheduled to work in another unit.

As shown in Table 1, the age of the participants in unit A ranged from 21 to 64 years (mean 43 years). In unit B, the age range was 21 to 57 years (mean 37 years). In both units, only female staff participated, which reflected the gender distribution on the units. In unit A, staff worked for half a year to 28 years (mean 9 years), and in unit B, from 1 year to 20 years (mean 8 years). Each staff member participated in the shadowing for approximately 4 hours, and on average spent 8 minutes (range 4.48-16.49 minutes) in the concluding interview. One interview is missing due to a misunderstanding.

Table 1. Description of participants and data collection.

	Unit A	Unit B
No. of shadowed staff and gender	8 women	7 women
Mean age (years)	43 (21-64) years	37 (21-57) years
Function	Occupational therapist: 1 Nutritional assistant: 1 Registered nurse: 1 Assistant nurse: 4 Nursing student: 1	Occupational therapist: 1 Nutritional assistant: 1 Registered nurse: 2 Assistant nurse: 3
Mean time working in the unit (years)	9 (0.5-28) One missing value	8 (1-20)
Observed organised social activities	3	2
Observed morning care	14	13
Observed mealtimes	16	17
Observed breaks/reporting time and handover in the nurses' office	4	7
Mean interview time (min)	9 (4.58-16.49) minutes One missing value	7 (4.48-11.13) minutes

Values in parentheses are range.

Data collection

Possible shadowing dates on various days of the week, Sundays and public holidays over three months from April 2017 to June 2017, were suggested to participants of both care units. They could choose a date that fit their work schedule. For shadowing, the dayshift was chosen

because morning care, meals and activities were planned during the day. Furthermore, NA and OT only worked dayshifts. The first author (JvL), who is a female registered nurse, collected the data.

On unit A, eight registered or assistant nurses had dayshifts starting at 7:00 am or 8:00 am, and on unit B, there were six nurses working the dayshift. The researcher informed the staff after arrival on the unit who she was and who she was going to shadow that day. The researcher as shadower closely followed the participant during the day. In total, 76 situations were shadowed, such as morning care, mealtimes, organised social activities, walks from one room to another, breaks, reporting and handovers in the nursing office. During these breaks, meals, reporting and handovers, the researcher could observe in what tone or words was spoken about the residents' preferences and wishes and the granting of them.

During the shadowing, the researcher tried to be like a fly on the wall. She tried to stay outside the field of view. However, she moved along with what happened, she entered the apartments of the older adults with the participant, ate lunch in the same space and engaged in small talk when this was considered to be more comfortable in the situation.

In the course of shadowing, the researcher made field notes of everything that happened, such as conversations and non-verbal expressions, complemented with contextual information, such as knocking on the door, waiting to enter the apartment, smells and the position of the participant. Although the literature provides general information about facilitating and hindering activities of staff towards autonomy, an inductive way of collecting data was chosen. Ahead of time, it could not be known what would be seen during shadowing and which activities, after analysis, would be identified as directed towards autonomy.

The brief interviews after the shadowed shift were recorded. The field notes were typed out in observation records, and the recorded interviews were transcribed on the same day. The observation records and interview transcripts of each participant were combined in one report to study the observed activities, together with the stated intentions.

Data analysis

The researchers started with an individual reading of the observation report of one participant, and they used open coding to code the text fragments. Afterwards, these four authors (JvL, BJ, IdR and KL) discussed the interpretation of the text fragments, exchanged their views in a meeting and decided on the appropriate codes. After coding and analysing one report with four authors, co-coding was carried out in pairs of researchers. JvL coded all 15 reports, while BJ, IdR and KL each coded four to five reports. After 10 co-coding sessions, similarities and differences in coding were discussed in a meeting with four of the five authors (JvL, BJ, IdR and KL). This led to the revision and/or refinement of codes. The same was done after the last report was coded.

After consensus was reached concerning the names of the codes, the fragments with codes were processed using ATLAS.ti version 8. This tool offered the opportunity to summarize the codes in groups and to check, discuss and adjust them a final time. In the writing process, ATLAS.ti was used to describe the results and search for suitable quotes.

After coding was finished, two authors (JvL and MJ) analysed the data thematically. Together, they followed a procedure of finding, explaining and describing patterns and their meanings within the data. (26) The codes that were about a similar way of enhancing autonomy were grouped in the main codes in ATLAS.ti. A name was given to the overarching theme of one or more main code(s). In this way, an answer to the research question could be provided. All researchers discussed the analysis until consensus was reached regarding the themes.

Box 1. Coding tree for theme I.
Getting to know each older adult as a person and responding to his/her needs
Working together as a team in the unit

1. Focussing on the preferences and wishes of the older adult
   - Searching for opportunities to answer to needs and wishes
2. Involving family and friends
   - acknowledging the role near ones (want to) have
3. Knowing needs
   - inquiring needs anyway
   - knowing structural needs about morning care, meals, activities, aids, cloths, personal items
   - responding to incidental needs
4. Having talks
   - chatting about mutual background
   - chatting about the background of the resident

Box 2. Coding tree for theme II.
Encouraging aspects of self-care

1. During morning care
   - inviting to wash, dry parts of the body
   - inviting to comb the hair, put on make up
   - inviting to dress themselves (partly)
2. During eating and drinking
   - Inviting to eat independently and butter bread
   - Inviting to poor coffee and tea
   - Not giving the chance to prepare food (this is done in the kitchen)
3. During activities
   - inviting older adults to participate according to their possibilities
   - inviting older adults to help each other
   - not giving choices to older adults and taking over when something is not carried out properly

Box 3. Coding tree for theme III.
Stimulating older adults to make choices

1. Around morning care asking to make choices about
   - where, when, how morning care will be provided
   - care products
   - which cloth to wear and how hair is done
   - whether or not to wear the cloth again
   - when and where going to the toilet
   - pace, stopping, continuing with care, order of care
   - the use of mobility aids
   - subjects even if there is no preference
2. Around mealtimes asking to make choices about food and drinks, the amount of food and drinks, where and when to eat
3. During individual/group activities asking to make choices about how to carry out the activity

Box 4. Coding tree for theme IV.
Being aware of interactions

1. Way of behaving towards the older adult
   - Asking permission to do something
   - Giving compliments and feedback
   - Thinking out loud, checking the preference of the older adult
   - Announcing care activities
   - Responding to nonverbal communication of older adult
   - Responding to signs in communication of older adult
   - Using inclusive language
   - Using humour
   - Convincing and patronising
   - Using task oriented communication
2. Using empowering interactions
   - Encouraging the residents to stand up for themselves
   - Standing up for known preferences of older adults
   - Facilitating mutual contacts between residents and family
3. Working from a set of values about autonomy
   - Combining care activities with personal attention
   - Being aware that enhancing autonomy has positive effects for the nurse as well
   - Being a role model (senior nurse, having quality as field of attention)
   - Seeing autonomy as a right
   - Respecting choices made
   - Not responding to preferences of older adults in order not to have to make an exception

Ethical considerations

The Ethical Review Board of the Tilburg School of Social and Behavioural Sciences of Tilburg University (registration number: EC-2016.62) approved this study. Moreover, this study was performed in compliance with the Declaration of Helsinki (27) and regulations on data protection, i.e. all methods were carried in accordance with the relevant guidelines and regulations.

The Ethical Committee of unit A (dated 16-12-2016) also gave permission for this study. Unit B did not have such a committee, but the management board approved the study (dated 23-11-2016).

Older adults, their first contact person, and volunteers on the unit received a letter with information about the study. They were not included in this study, although they were present in the context during data collection. The researcher informed persons she met during the shadowing verbally. No personal data was collected about them.

To consider specific and implicit assumptions and values concerning autonomy and how these could influence the study, the first author, as a researcher and a nurse, reflected regularly (before and during the study) on her role with a mentor who was not involved in the research. She repeatedly wrote down and shared these insights with the other authors.

Findings

The thematic analysis resulted in four themes, which are described below and illustrated with fragments of the observation records and/or interview transcripts.

Getting to know each older adult as a person and responding to his/her needs

Staff tried to get to know each resident as a person. This was seen in various ways. They behaved as if they knew the older adult. They talked about topics, such as where the older adult used to live, his/her former profession and the reason for admittance to the nursing home. They used dialect when suitable and used a first name when this was decided upon and approved by the older adult. They showed they were aware of and acknowledged the role of family and friends for the resident.

Knowing the needs of an older adult was observed during morning care. Nurses knew the preferences of the resident with regard to when they get out of bed in the morning and the place for morning care (bed or bathroom), care products, the order of care activities and the way activities should be carried out. They provided care with remarks such as, ‘I know you like to get up early, that’s why I start my shift helping you’. Staff showed that they knew whether the older adult used hearing aids or wore glasses. They offered those before starting a conversation. It was observed that staff knew which activities were preferred, such as taking a walk in the garden, spending the weekend with family, listening to music or joining an organized activity. As a part of small talk during the day, they referred to these activities, ‘Are you going to visit your wife today?’ or ‘The weather is beautiful. Are you going out today’? Furthermore, staff showed they knew where, with whom and what older adults liked to eat.

Notably, the observation that, although the participants knew these needs, they still asked the residents for their preferences to check. In the interviews afterwards, they explained that they used this verbal check to involve older adults in the interaction or to check whether preferences had changed. Participants also aimed to reassure residents that they knew what the resident preferred. They intended to prevent stress. For example, a nurse used verbal checks on every step of morning care with a resident who had aphasia; this made the resident feel better because she knew that morning care would be provided following her wishes.

> Participant A2, told in the interview, 'I know [name], do you see the blouse hanging there? It is meant for today, everything is laid out there, combined with this necklace, and everything is prepared. Her husband tends to this every evening. I know this is what she wants to wear. Nevertheless, I always check, 'Is this what you want to wear?' I let [name] be involved. I think this is important'.

> In an observed conversation a resident said, 'The nurse of the nightshift didn't turn me tonight. You always do'. Participant B7, 'You asked me to wake you up and turn you, even if you are fast asleep. I reported that the others do this as well'. 'It is not necessary', the resident answered. Participant B7, 'You wanted it, so I act upon it. It is better to prevent pressure as well'. The resident said, 'Then please do so, I always easily fall asleep again…I sleep so well'.

Knowing the preferences of the older adult and responding to it was not always possible. In the interviews, nurses reflected that they have to work within the conditions of the care environment that might act as barriers to enhance autonomy. Nurses felt understaffed to respond to the call system in a timely fashion or help with going to the toilet on time; they did not have enough time to respond to needs in a proper way. One nurse mentioned that, if she took the time needed to offer choice and act upon these choices, she had to cope with the comments of her colleagues who had to work harder or with the comments of her family at home when she arrived late from her shift.

Participants stated in the interviews that not every colleague was sensitive to the needs of an older adult. For example, instead of taking a resident out for a walk on a day that the work was done early, some nurses spent their time drinking coffee in the sun together with colleagues.

Encouraging aspects of self-care

Nurses invited older adults to take an active role during morning care, washing and drying their face, hands, arms and/or upper body, combing their hair and putting on clothes. They gave compliments when an older adult did this spontaneously. In several observations, it was seen that nurses gave older adults control over their appearance by placing them in front of a mirror and asking to comb their hair.

> The resident said, 'I do everything that I can do myself. Participant B7 replied, 'You can start washing yourself; I will leave you for a moment because somebody else needs help'.
> On her return, she asked, 'Is everything OK? I see your hair is already done, shall I proceed with washing your back and the other arm'?
>
> In the interview, participant A6 gave an example of autonomy-enhancement. 'The morning care of [name]. I asked her to wash her face and to put on some clothes herself. She decided herself how long she wanted to stay on the toilet. I see the decisions about what she can or cannot do herself as autonomy. I take over the 'pieces' she can't do. The rest is up to her. Did you see she could raise herself up? I did not even have to help. My colleague offered assistance with the transfer, but I wanted to see what happened. [Name] did it herself, another thing that she did independently today'.

Sometimes, nurses did not seem to be focused on the wishes of an individual resident regarding self-care and the actual context. Comments from nurses to older adults, such as 'It is good to keep doing all you can do' and 'We share the work', were commonly heard during the observations. However, nurses did not check if older adults wanted to do these activities themselves or how the older adults wanted to spend their energy during the day. In the interview after shadowing, in which the participants were asked how they related to the autonomy of older adults in their unit, some staff referred to autonomy as being independent and doing things themselves.

In unit B, older adults had an active role during breakfast and lunchtime when they ate in the living room. The table was set by the NA, and they could take bread, butter, spreads, cheese and coffee or tea themselves. NA encouraged the older adults to prepare their breakfast themselves and help each other to pass the butter and spreads or pour tea. After the meal, older adults helped to clear or clean the table. In unit A, self-care during mealtimes was not encouraged. Residents were asked what they would like to eat and then it was prepared in the kitchen by the NA.

Stimulating older adults to make choices

During the observations of morning care, nurses provided many choices about where to wash: on the bed, in the bathroom or whether or not to shower. In addition, choices were given about the time of care and the order and place in which activities were done. Furthermore, the choice of care products, such as shower gel and deodorants, was seen. Residents were invited to choose which clothes to wear and how they wanted their hair styled. Nurses often offered a choice about when the resident wanted to go to the toilet, i.e. before, during or after the care was provided.

After morning care, nurses gave the option to have breakfast in bed, in the apartment or to eat in the unit's living room. The NA offered a choice of breads, spreads, porridge, dairy products and drinks. The products were shown to point out the choice or verbally listed until

a non-verbal reaction was observed. During the observation, the shadowed NAs mentioned that, although they knew the answers, they kept on asking about the preferences of the residents about their meals. When older adults of unit B ate breakfast in the living room, the food was presented in such a way that residents could take the items of their choice themselves.

> Participant B3 stated during the interview that every resident had a book with a hundred warm meals. It changed every season. On Sunday, residents could hand in their choice for the next week. They could fill in the preferences themselves or ask their family or friends for help. There were photographs, so even residents with aphasia could point out their choice. If needed, a member of the staff helped.

However, this system of choosing individual meals had a disadvantage; residents could not choose fresh ingredients, such as salads, because the supplier did not provide them. Not every choice was granted, e.g. the NA could not offer a soft-boiled egg, because this might negatively impact the health of the residents. An NA chose the two soups of the day and was aware that not everyone would like the options. She justified this by referring to a normal family in which only one soup is prepared.

Residents were members of different preferred 'clubs' e.g., music, painting, walking and cooking clubs. These organised activities were often scheduled weekly and were facilitated by the OT. Other activities were proposed on an individual basis.

> Participant A7 asked the resident, 'Would you like to take a walk with me this week? Perhaps Wednesday'? (..) 'Do you wish to go for a walk? We can also choose something else'. The resident mumbles. 'Perhaps you can think about it? We can also go to the garden together and have a drink'.

The OT invited residents to make choices while engaging in activities, e.g., to peel potatoes or clean strawberries. At the end of the cooking club, the menu to be cooked next week was chosen by the older adults. The OT invited all participating residents to mention what they liked to eat most.

Being aware of interactions

Some nurses announced every care activity verbally, such as 'can you lift your leg'. Others used the time they spent with older adults during morning care to talk about subjects, such as living in the nursing home or the loss of a child. Often, small talk was used, concerning the life of the older adult or a mutual background. Staff also invited residents to share their knowledge and experience. For example, the OT invited a resident with a high spinal cord injury to lead the preparation of a cheesecake in the cooking club. Although the resident could not use her hands, she led the group activity. Empowering communication was seen when staff advised residents that they really should express their needs, such as asking for help to go to the toilet or sharing opinions about how care was provided in the unit.

When interacting with persons with aphasia, hearing impairments or a non-native speaker, non-verbal communication was used to determine the wishes of the older adult. Nurses asked residents deliberately for permission to do things, such as opening or closing curtains and windows, turning on the light or putting dirty clothes in the laundry. Nurses respected choices if no permission was given on these matters. The OT aligned with what happened without a plan of her own, adapting her pace and slowing down. She showed confidence that the resident would succeed.

> Participant B6 helped a resident with an e-mail. The computer was working slowly. The resident was upset. Participant B6 stayed calm; she asked permission in every step she assisted with, 'May I look here'?

Often, staff used humour to break the ice, to ease tensions and to wave aside feelings of shame, for example when someone was too late to ask for help with toileting. Sometimes, this way of interaction did not seem to be effective.

It was also observed that two nurses provided care to an older adult and while talking to each other about subjects as coordinating care activities, leaving the resident as an object of care.

Moreover, patronizing communication was seen, for example when the cheeks of an older woman were pinched or words such as 'love' or 'dear' were used.

Some of the nurses referred to organisational issues regarding whether or not to take an active role in autonomy enhancement, as it was not in their job description or not expected based on their level of expertise. Additionally, they defended themselves by saying they could not make exceptions to the rules to give someone a choice.

> It was lunchtime and most of the residents were in the living room. One resident called loudly for a nurse that she needed to go to the toilet. Participant A5 approached her and said she was responsible for the lunch and therefore she could not help [name] to the toilet.

Other participants were very explicit about their values and standards, and they tried to preserve and enhance autonomy. Given the circumstances, they did their best (e.g., they often stayed longer than scheduled). They left with a good feeling about their shift if they were able to give all residents the care and attention that was needed that day. They tried to improve aspects of the care environment to enhance autonomy (e.g., addressing understaffing, expressing their views on autonomy to the team or taking an exemplary role as a head nurse or as a person).

> In the interview, participant A3 reflected on what she knew about autonomy. 'In the first year of the nursing education, there is a lot of emphasis on autonomy. School teaches the importance of, when it is safe, giving patients choice and independence. Only if it is safe, otherwise you have to act as a nurse …) personally, I give residents

> a choice, if they can; they have a right to do so ...) if I cannot understand what they want, I use non-verbal communication: looking at facial expressions, nodding, just seeing how they react ...) Staff that are working on routines take over very quickly. It is easy, the work is done faster. However, it is not my way of working; I try to stand up for my opinion on this'.

Some nurses said they did not see others enhancing autonomy. They mentioned some of their colleagues following their own preferences on who to help first in their shift or trying to have everyone 'out of bed' before the coffee break.

Discussion

In the study on the actions and experiences of staff, four activities were found in relation to the autonomy of older adults. Staff were concerned with getting to know the older persons and meeting their needs, encouraging self-care, stimulating choices and were aware in interactions.

The study showed that staff do consider it important to strengthen autonomy and used various activities to get to know the older adults and strengthen their autonomy. It was seen that some staff were unconsciously using autonomy-enhancing activities, although they were not aware of this and also that they acted in a different, more autonomy-enhancing way than their colleagues. Having limited time sometimes led to a situation in which staff did not even try anymore to respond to residents' needs. Routines and time schedules to provide care sometimes seemed to prevail above the needs and preferences of residents. This has also been described in other studies (20) in which safety and physical care were seen as more important than autonomy. However, the theme of being seen as a person is also recognized as being important to the dignity of older persons (19). Advice for staff is to be sensitive to situations in which a lack of time is experienced, to respond to needs and to address this problem with colleagues.

Two underpinning approaches to the autonomy of older adults, i.e., executional and decisional autonomy, were also found in the activities of staff. Encouraging aspects of self-care reflected the executional dimension of autonomy: being able to make decisions and to carry them out (4).Self-care was emphasized, without verifying whether this was also the preference of the resident. Orem's model for nursing, with self-care theory at its core, has been taught in nursing education for a long time. Therefore, staff had learned to help residents to do as many things as possible themselves. Only when this was no longer possible did nursing interventions seem appropriate (28). This was exemplified by participant A3 who stated: 'When it is safe, you give residents choice and independence, but only when it is safe; otherwise, you have to act as a nurse'. However, self-care has been found to be a one-sided view of autonomy as independence, which can hinder autonomy (11). Facilitating self-care seemed to be a helpful activity for autonomy if it was done in accordance with the residents' preferences.

Stimulating residents to make choices themselves refers to decisional autonomy, i.e., the ability and freedom to make decisions without external persuasion or restrictions (4). In the current study, it was seen that staff who gave choices to residents in care or social situations achieved a positive effect on choice. For residents who were able to make decisions about participating in social activities or clubs, the feeling of being in control was increased. This was also seen in a study on social activities in a nursing home (10). Maintaining a resident's autonomy through respecting choices such as clothing and food was also found by other authors (19). Offering choices in day-to-day life was frequently used and seemed to be an effective activity to maintain autonomy.

Awareness of interactions was seen, which can enhance autonomy, but this was not always the case. In the current study, patronizing communication was also found, which is a way of communicating that can hinder the mutual characteristics of interactions. This was also found in a previous study to be a barrier to the autonomy of older adults (29). Communication should therefore be used consciously in order to enhance residents' autonomy. For this reason, a reciprocal relationship between residents and staff is important and of added value.

Strengths and limitations

The aspects of credibility, reflexivity, confirmability and transferability were taken into account to heighten the trustworthiness of the study. Lincoln and Guba, as cited in Korstjens and Moser, suggest these as quality criteria for qualitative research (30).

Using the method of shadowing proved to be insightful. The researcher intended to see unconscious behaviour, and this was found to be the case (i.e., unconscious activities that enhance or hinder autonomy were observed). In the interviews, the researcher noticed that participants were not always aware of the activities they used and actually did enhance autonomy. The triangulation of methods, the combination of non-participative observations and short interviews to clarify the meaning of the observed behaviour strengthen the credibility of the study (30).

This study explored and revealed the experiences and activities of the staff on two units in two nursing homes in relation to autonomy. The description of the context and participants in the study may help others to understand the applicability of the findings in their own context. In this study, the effect of these activities on the autonomy of older adults was not established (this was not the aim of the study); nevertheless, it provided insight into which activities might have a positive influence on enhancing the autonomy of older adults in nursing homes.

One measure to increase credibility was the prolonged engagement during the observations. To prevent bias, the other authors, not being nurses, were alert to implicit assumptions and noted them while discussing the fragments in group meetings (30).

To ensure that the interpretation was grounded in the data, the confirmability, the process of co-coding with three other researchers and consensus meetings were used to analyse the data. The four researchers reached consensus about the codes. A fifth researcher (MJ) and the first author (JvL) thematically analysed the data. This resulted in the four themes

of activities found in this study. The researcher was able to shadow 76 day-to-day situations, including care situations, mealtimes and activities. This provided no new information after 15 days of data collection. The researchers did not recruit more (of the intended 20) participants because data saturation was reached.

Implications and recommendations

Awareness of the four activities found in this research can help to enhance the autonomy of older adults with physical impairments living in nursing homes. This knowledge can be used in learning activities with the aim of improving care. Conversations between staff and older adults about how they perceive autonomy can be organised. To become more aware of activities that stimulate or hinder autonomy, staff can shadow each other to become more conscious of activities colleagues use in relation to autonomy and reflect on these together.

This study focused on the experiences and activities of staff members in relation to the autonomy of residents. This cannot be separated from the way in which the older persons maintain autonomy themselves and the way in which family and friends support or hinder autonomy. It is advised to look at the needs of older persons and whether the activities of staff lead to more autonomy. Further research into mutual actions and interactions to enhance autonomy is recommended.

The care environment, in which older adults and staff interact, influences the activities and intentions of staff. Further research into barriers and facilitators in the care environment regarding autonomy (e.g., the potential for innovation and risk taking, the appropriate skill mix and the physical environment) is recommended.

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Section II

5

Developing a person-centred care environment aiming to enhance the autonomy of nursing home residents with physical impairments, a descriptive study

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Abstract

Background

Enhancing autonomy is important within the context of the care environment in nursing homes. A nursing home is a place for older adults with physical impairments, who need assistance, to live and where staff work who help them to exercise autonomy. Previous research shows that older adults and staff are influenced by the care environment to apply autonomy-enhancing activities. Therefore, organisational policies regarding the care environment seem promising for enhancing autonomy. The aim is to gain a deeper insight into the development and implementation of organisational policies aimed to enhance the autonomy of older adults with physical impairments.

Methods

A qualitative descriptive design was chosen, using two methods. A document study was conducted on the policies, plans and proceedings in two care organisations. Moreover, interviews were conducted with 17 stakeholders involved in the policies, such as managers and members of the client council. The fragments of the 137 documents and 17 verbatim transcripts were coded and deductively categorised into the seven aspects (i.e., power sharing, supportive organisational systems, appropriate skill mix, potential for innovation and risk-taking, the physical environment, effective staff relationships and shared decision-making systems) of the key domain care environment, as defined in the person-centred practice (PCP) framework developed by McCormack and McCance.

Results

The aspect of power sharing was used the most in the policies of the two participating organisations. The organisations expected much from the implementation of indirect interventions, such as access to the electronic care plan for residents and the development of staff towards self-managing teams. Less attention was paid to interventions in the physical environment, such as the interior of the building and privacy, and the collaboration processes between staff.

Conclusions

The PCP framework poses that all aspects of the key domain care environment are important to develop a person-centred practice. This is not yet the case in practice and the authors therefore recommend using all seven aspects of the care environment in a balanced combination with the other key domains of the PCP framework to achieve person-centred practice and as a result the enhancement of the autonomy of nursing home residents with physical impairments.

Introduction

Background

Older adults with physical impairments due to chronical health conditions or old age (hereafter referred to as older adults with physical impairments), who need 24-h care and intensive help with activities of daily living (ADL) often move to a nursing home. This move to a nursing home contributes to feelings of dependency and challenges the older adult to find a way to be able to live their life as before and as preferred. Being able to maintain autonomy is important for older adults who live in a nursing home. Generally speaking, older adults with physical impairments are able to make decisions on how they want to live their lives. However, they are often hindered in terms of executing these decisions due to the underlying physical conditions that made them move to the nursing home. Tensions between freedom and best intentions of staff, autonomy and dependence, individual preferences and the pressures of collective care, can be present (1).

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 (2). However, autonomy should also be considered from a broader perspective. Both older adults (3) and staff (4) indicate that they are influenced by the care environment of the nursing home to apply effective mechanisms and activities to enhance autonomy. Schedules, checklists, and protocols can for example, be helpful to organise care, but if they prevail above the persons, i.e., the resident and staff, they can hinder autonomy.

Person-centred care is seen as a way to enhance autonomy i.e. when caregivers consciously engage in the care for older adults who are striving to live the life they desire to live, autonomy can be maintained (5). The board managers of nursing homes recognise the importance of autonomy and aim to enhance the autonomy of older adults and therefore they seek to develop and implement autonomy enhancing policies (6).

There is little research done about how the care environment is shaped by organisational policies with the aim to enhance autonomy for older adults with physical impairments. In one study, two mechanisms i.e., choice enhancing and control enhancing policies were found to strengthen the autonomy of residents (7). Results of that study show that organisations mostly used choice enhancing policies aimed to give residents choice in daily routines such as the time to go to bed and what and when to eat. This policy seemed to be related to higher feelings of autonomy in residents. One intervention to strengthen autonomy, related to enhancing control at the organisational level, was found (8). However, this study did focus on autonomy related to resident participation in formal decision making, rather than on improving autonomy in day-to-day care. The current study will concentrate on enhancing autonomy in the care environment from a wider perspective.

Aim

The objective of this study is to gain a deeper insight into the development and implementation of organisational policies aimed to enhance the autonomy of older adults with physical impairments in nursing homes. This will be done by answering three research questions (RQs), i.e., RQ1; which policy is developed by board managers of nursing homes with the aim to enhance autonomy, RQ2; what is reported in the proceedings and evaluation of this policy and RQ3; what are the perspectives and experiences of stakeholders involved in the implementation of the policy in daily practice?

Theoretic framework

As previously stated, person-centred care is considered to enhance and respect autonomy of older adults living in a nursing home (5). Because different interpretations of person-centred care are used in the literature, the authors choose for an evidence-based framework. McCormack and McCance (9) present a Person-centred practice (PCP) framework which offers evidence based aspects that are important to enhance autonomy. Three key domains are described in this framework: i.e., person-centred processes, the care environment, and the prerequisites of staff. The PCP framework is presented in Figure 1.

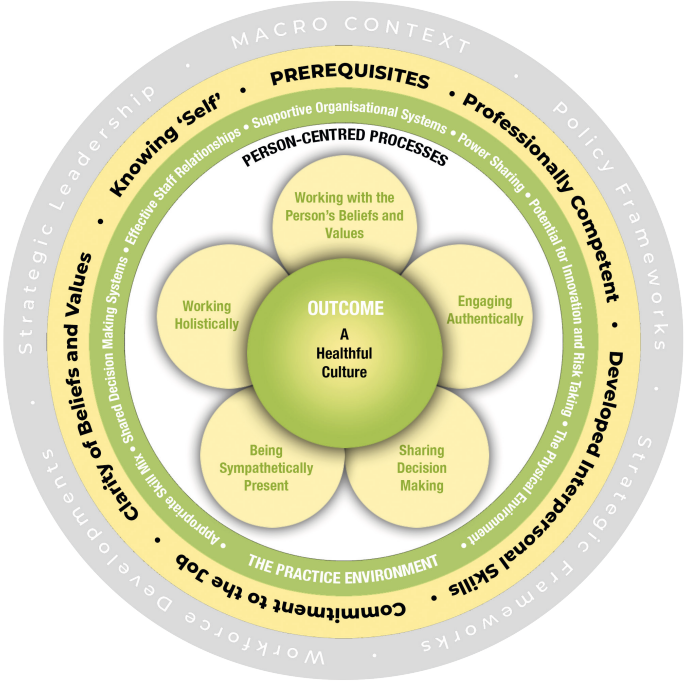

Figure 1. Person-centred practice framework

Note. Retrieved from The Centre for Person-centred Research practice (CPCPR) of Queen Margaret University Edinburgh. Reused with permission from McCormack and McCance (9).

The care environment, in Figure 1 named practice environment, is situated between the person-centred processes and the prerequisites of staff. It can either function as a facilitator or as a barrier to PCP. Aspects of the care environment are expected to have the potential to implement (10) and enhance PCP (5). Therefore, the aspects of the key domain care environment from the PCP framework of McCormack and McCance (9) were chosen to present the results of the current study. The aspects of the key domain care environment are defined in Table 1.

Table 1. Aspects of key domain care environment as defined by McCormack (see also Figure 1) (9).

Power sharing	Power sharing concerns the non-dominant, non-hierarchical relationships that do not exploit individuals, but instead are concerned with achieving the best mutually agreed outcomes through agreed values, goals, wishes and desires
Supportive organisational systems	Supportive organisational systems are systems that promote initiative, creativity, freedom, and safety of persons, underpinned by a governance framework that emphasises culture, relationships, values, communication, professional autonomy, and accountability
Appropriate skill mix	An appropriate skill mix is most often considered from a nursing context and means the ratio of registered nurses (RNs) and non-registered nurses in a ward/ unit nursing team. In a multidisciplinary context, it means the range of staff with the requisite knowledge and skills needed to provide a quality service
Potential for innovation and risk-taking	The potential for innovation and risk-taking concerns the exercising of professional accountability in decision-making that reflects a balance between the best available evidence, professional judgement, local information, and patient/family preferences
The physical environment	The physical environment in the healthcare context concerns the balance of aesthetics with function by paying attention to design, dignity, privacy, sanctuary, choice/control, safety, and universal access with the intention of improving patient, family and staff operational performance and outcomes
Effective staff relationships	Effective staff relationships are described as interpersonal connections that are productive in the achievement of holistic person-centred care
Shared decision-making systems[1]	Shared decision-making systems involve the organisational commitment to collaborative, inclusive and participative ways of engaging within and between teams

[1] *Sharing decision making on the level of the resident and staff is part of another key domain: person-centred processes.*

Methods

Setting

To examine the policy that board managers of nursing homes developed and implemented to enhance autonomy, two care organisations that aim to enhance autonomy were invited to participate in this study. Both organisations are partners in the Academic Collaborative Centre for Older Adults (11) and were willing to be part in generating knowledge about autonomy.

Through studying two organisations the authors aimed to get insight into different policies and thus to collect richer data.

Both organisations provide 24/7 care to older adults. As the current study focusses on the policy to enhance the autonomy of older adults with physical impairments, specific policies for geriatric revalidation units and the psychogeriatric units were not included. One unit from each of the two organisations has previously participated in two earlier studies to gain more knowledge of the perspective of older adults with physical impairments and staff concerning maintaining and enhancing autonomy (12, 13).

Care organisation A approaches autonomy as follows: 'autonomy and being active creates happiness.' This organisation has in total 2700 clients, 2600 employees and 1.150 volunteers. It provides care in 14 locations in a large town in the South of the Netherlands. Organisation B changed the word autonomy into ownership. This was done with the idea that autonomy can be limited or overridden, while persons can and always will be the owner of their life. This organisation has 960 clients, 870 employees and 600 volunteers and provides care in five locations in a small and medium-sized town and surroundings in the same region as Organisation A.

The data about the policies concerning the care environment, aimed at enhancing autonomy, were gathered on the organisational level as well as on the level of the two units that participated in the earlier studies.

Design

A qualitative descriptive design was chosen to answer the aim of this study using two different methods to collect data: a document study (RQ1-2) and an interview study (RQ 3).

Document study

To answer RQ 1, which policy is developed by board managers of nursing homes with the aim to enhance autonomy and RQ 2 what is reported in the proceedings and evaluation of this policy, a document study was conducted. In this way it was studied in detail how the policy was planned, discussed, implemented, and evaluated during a period of three years.

Inclusion criteria

Documents were selected on two levels: 1) organisational management plans and minutes and other documents regarding the policy towards autonomy enhancement of older adults with physical impairments living in this nursing home and 2) local documents of the two selected units, such as an information booklet about the unit for older adults and leaflets.

Data collection

The researcher and first author (JvL), was given access to the active archive by the board secretaries of organisations A and B. Documents were screened for plans to enhance autonomy and the evaluation of the goals mentioned in the plans. For reasons of confidentiality, the researcher was not able to make copies and was not left alone with the documents. However, JvL could make notes and write excerpts. These excerpts were typed

out and sent to both corporate secretaries for a member check. They gave written permission to use the summarized content. Some non-confidential documents such as the mission statement about autonomy and detailed plans of specific aspects to enhance autonomy were handed over in print to the researcher by the corporate secretary of both organisations. A contact person from the selected units was asked to provide local documents.

Data analysis

Two authors (JvL and IdR) analysed 137 documents (see Table 2) for the policies which were aimed at enhancing autonomy. Both authors had an individual reading of the printed excerpts and the printed documents. They developed and used a data extraction form which consisted of three questions: 1) which policy is described regarding enhancing autonomy 2) is this policy focused on one or more aspect(s) of the care environment (as defined in the PCP framework (9)) and 3) is the information part of a plan to enhance autonomy or is it an evaluation or proceeding of a plan. JvL and IdR wrote down the findings. They separately answered the questions, and subsequently presented and discussed the insights and text fragments to each other in four consensus seeking sessions.

Semi structured interviews

To answer RQ 3, i.e., what are the perspectives and experiences of stakeholders involved in the development and implementation of the policy in daily practice, semi structured interviews were conducted.

Respondents

After receiving permission of the Ethical Review Board of the department of Social and Behavioral Sciences of Tilburg University, no. EC-2017.EX144 and of the Ethical Review Board of organisation A and permission of the board manager of organisation B, stakeholders have been contacted. Purposive sampling was used, by recruiting those respondents who could provide in-depth and detailed information about the development and implementation of the autonomy enhancing policy in the practice of nursing homes (14). For each organisation, the intention was to recruit ten participants: managers at the strategic, location and the unit level. Furthermore, for each of the seven aspects of the care environment one stakeholder was asked to participate. For example, an educational officer from the HR department concerning if and how employees are trained to support the autonomy of residents (supportive organizational systems) and, in the case of power sharing, representatives of the client council and work council. They were identified by the corporate secretaries. Potential respondents were informed by the interviewers about the aim and design of the study with an information letter which was combined with an informed consent letter. The information letter included a paragraph about asking questions. The name of the contact person and contact information were mentioned. The interview format started with the mandatory topic of asking whether the respondents had any questions and answering them, before signing and handing in the informed consent letter.

Data collection

Two nursing students conducted the semi-structured interviews under supervision of the first author. One interviewer conducted all the interviews at organisation A and the second interviewer conducted the interviews in organisation B. They were both not involved in the organisation before and after this study.

To get acquainted with the context of the organisation, the interviewers spent one day on a unit of organization A or B. The first researcher and the interviewers prepared the topic list for the interviews by reading the documents that were collected for RQ 1 and 2. Each topic list was tailored to the interviewed stakeholder based on the aspect(s) of the autonomy enhancing policy the respondent was involved in. For example, the manager was asked how an effective skill mix in the unit was ensured. The member of the client council was asked about the participation in decisions on autonomy enhancing policies in the client council.

Eight respondents from organisation A and nine from organisation B gave written consent for an interview and actually participated. The respondents were interviewed in person in the organisations, one interview took place by telephone because this respondent had no scheduled visits to organisation B on the day of the interview. Each interview was audio recorded and the recordings were transcribed verbatim. The interviews lasted between 7 and 45 minutes, with a mean of 25 minutes. The respondent of the 7-minute interview was a representative of the residents in the management team, who found it difficult to express reflections on the topics of the interview.

Data analysis

Three authors (JvL, BJ and MJ) coded the transcripts (15). They started with one transcript which they coded independently from each other, followed by a consensus seeking session about the coding of the fragments. They used open coding to code fragments on what they reveal about the policy to enhance autonomy of older adults with physical impairments. After the consensus seeking session, it was decided that two authors coded all transcripts for organisation A as well as for organisation B to follow the process from the development of a policy to how it is implemented and evaluated in each organisation. JvL coded all transcripts of both organisations, MJ coded the transcripts of organisation A and BJ coded the transcripts of organisation B. JvL and MJ had two sessions to discuss the coding of organisation A and JvL and BJ did the same for organisation B. Afterwards BJ, MJ and JvL had a final session to discuss the coding of the fragments (16).

After consensus was reached about the codes, they were processed with ATLAS.ti. After coding was finished, JvL thematised the codes in a deductive way, using ATLAS.ti. JvL established which codes were related to a certain aspect of the care environment of the PCP Framework (9). MJ checked this step in the process. JvL and MJ discussed codes that could be related to two aspects of the care environment until consensus was reached about which aspect would be the best fit. When in doubt to which aspect of the care environment a code should be attributed, it was discussed until consensus was reached. Codes that referred to other key domains of the PCP Framework, i.e., to person-centred processes and prerequisites

of staff, have been assigned to these domains. These codes were not seen as results for the current study and therefore are not discussed in the results below.

Results

The 137 studied documents, presented in Table 2, consisted of ten non-confidential documents such as multiyear strategy plans and the mission statements on autonomy, and 123 confidential documents such as minutes, i.e., official records of the proceedings of the meetings of the board managers and/or the supervisory board and/or councils. The four local documents concerned for example an introduction of the unit for new residents and newsletters.

Table 2. Documents studied for RQ 1 and 2

D=Document code	Regarding	Type of document	Number of documents
Organisation A			
DA1	Multiyear strategy plan 2016-2019	Policy document	N=1
DA2	Executive framework 2018 (d.d.12-10-2017)	Policy document	N=1
DA3	Information about living in unit A Version 2017	Information booklet	N=1
DA4	Collected fragments on aspects of the care environment that are related to enhancing autonomy from documents of the executive board (minutes and annexes), of meetings of the executive board with the supervisory board, the work- and client council. April 2015- November 2017	Minutes with annexes	N=72
Total A			**N=75**
Organisation B			
DB1	Quick scan and reflection in 2017 The journey to autonomy by client and employee 30-3-2017	Evaluation rapport	N=1
DB2	Minutes of project team 7-4-2016	Record	N=1
DB3	Minutes of the guides 31-5-2016	Record	N=1

DB4	Collected fragments on aspects of the care environment that are related to enhancing autonomy from documents of the executive board (minutes and annexes), of meetings of the executive board with the supervisory board, the work- and client council and the nursing advisory council. December 2015- November 2017	Minutes with annexes	N=51
DB5	Plan for a pilot on unit B concerning autonomy	Local plan	N=1
DB6	Newsletter unit B concerning the pilot about enhancing autonomy	Local information	N=1
DB7	Description of a pilot concerning enhancing autonomy on unit B	Local plan	N=1
DB8	Multiyear strategy plan 2015-2018	Policy document	N=1
DB9	Proposal for participation in a national care innovation programme with the autonomy enhancing programme.	Organisational plan	N=1
DB10	Factsheet innovation programme concerning autonomy	Public information	N=1
DB11	Progress of the autonomy programme, 2016	Public information	N=1
DB12	Progress of the autonomy programme 2017	Public information	N=1
Total B			**N= 62**
Total			**N=137**

Table 3 shows the results of the analysis of the above-mentioned documents.

Table 3. Results of the document analysis

Aspect of PCP	Document type			
	Plan Organisation A to enhance autonomy	**Check in minutes, evaluations Local information**	**Plan Organisation B to enhance autonomy**	**Check in minutes, evaluations Local information**
Power sharing	D[1]A2,DA4: Encourage self-managing teams: employee autonomy and creativity This should lead to resident autonomy	DA4: Evaluations of the progress towards self-managing teams, show various interpretations of the concept and goals and a slow progress DA3: Living room meetings with residents on the unit	DB4: Encouraging self-managing teams with the expectation that this should lead to desired focus on autonomy of the resident DB4, DB12: Twenty so-called 'guides' are installed, and they advise the managers on enhancing autonomy, asked and unasked for DB4,DB9: The work-, resident council and nurses' advisory council are involved in the plans to enhance autonomy	DB3, DB4: Proceedings of the self-managing teams, coaches are appointed for impact self-managing teams DB2,DB3: Reports of sessions with guides are seen DB3: 'Guides' want less to-do lists and more regulation space to enhance autonomy. Such as: to let go of a list on which day a resident can have a shower DB3: Behaviour of the 'guide' and role of 'guides': to rely on, to inspire, stimulate, suggest ideas, challenge, delegate responsibility, disseminate the vision on autonomy DB4: Work council is asked to participate in the new management team DB4: evaluation of actions towards autonomy in the councils

Table 3. Results of the document analysis (continued)

Aspect of PCP	Document type			
	Plan Organisation A to enhance autonomy	**Check in minutes, evaluations Local information**	**Plan Organisation B to enhance autonomy**	**Check in minutes, evaluations Local information**
Supportive organisational systems	DA1,DA2: A vision for autonomy has been formulated DA4: Visiting all teams to share the vision on enhancing autonomy	DA3: Vision on autonomy is translated for the unit DA4: The quality indicator is audited: how is the resident maintaining autonomy DA4: Discussion on a culture change for autonomy: how will employees and volunteers do this? Working on autonomy, good communication, not patronising, dignified toilet visits, taking breaks with residents	DB4: Board managers develop a policy directed towards autonomy for the resident DB4: Share the vision on enhancing autonomy via workshops, theatre Theme meetings, workshops, dialogue sessions, autonomy game with the aim that staff is equipped to enhance autonomy Volunteers, therapists, and support services are involved to work together towards autonomy Awareness-raising project to respond to self-managing teams and autonomy DB4: The management team has been expanded with 2 caregivers and 2 care recipients	DB11,DB4: the mangers are 'drinking coffee' with the staff of the units in all locations, residents and their families, volunteers, client- work and nursing council and supportive services with the aim to talk about autonomy. The evaluation mentions a movement towards autonomy, although not everywhere in the same pace DB7: The organisation vision is translated to the studied care unit DB9: Coaching and support for the desired dialogue with the resident, training, the resident council is also involved in the training DB5,DB7: Dialogues with residents were conducted about their wishes in relation to autonomy DB9,DB10,DB11, DB12: The journey towards autonomy is highlighted with several annual reports on interventions and effects DB3: Training of 'guides' is described. DB4: the use of an instrument to evaluate the process on the units towards autonomy

Table 3. Results of the document analysis (continued)

Aspect of PCP	Document type			
	Plan Organisation A to enhance autonomy	Check in minutes, evaluations Local information	Plan Organisation B to enhance autonomy	Check in minutes, evaluations Local information
Appropriate skill mix			DB4: Sufficiently qualified staff which is related to autonomy Attention to training and retention of staff	DB10: Increased number and training level of staff DB4: concerns about employee mobility and absence from work

Table 3. Results of the document analysis (continued)

Aspect of PCP	Document type			
	Plan Organisation A to enhance autonomy	**Check in minutes, evaluations Local information**	**Plan Organisation B to enhance autonomy**	**Check in minutes, evaluations Local information**
Potential for innovation and risk taking	DA2 : New dinner concept with more choice in time of the day and menu selection A2, A4: The staff is given more room to experiment with autonomy enhancing activities	DA3: Choice of time and place to eat is mentioned in the local information	DB7: On the selected care unit there is a pilot with an intervention to enhance autonomy DB4, DB8: involving the family in realising autonomy of the resident	DB11: Evaluation report by external consultant on the management plans to enhance autonomy. Issues were: - Space versus rules: What must be done for profession, laws What is done by organisation B, how does this reflect norms, values and procedures What can the staff do to translate policy into action - Initially, working with self-managing teams was seen as a mean to enhance autonomy but became a goal in itself - No measurement of progress towards autonomy - Mistakes are repeated - No increase in the satisfaction of residents could be measured yet DB6: Family is expected to contribute to the care of the resident and activities of the resident/unit DB4: New technology is seen as promising for autonomy

Table 3. Results of the document analysis (continued)

Aspect of PCP	Document type			
	Plan Organisation A to enhance autonomy	**Check in minutes, evaluations Local information**	**Plan Organisation B to enhance autonomy**	**Check in minutes, evaluations Local information**
The physical environment	DA2, DA4: Plans for new housing concepts: private sanitary facilities, more spacious rooms that provide choice for the older adults with physical impairments that live in a nursing home which should lead to (more) autonomy	DA3: Having an own key to enter the location, unit, and the room	DB4, DB8: Residents can decorate their own apartment. Appropriate living environment to live the life residents want to live	DB11: The evaluation mention that standard offering of curtains and furniture is no longer present
Effective staff relations	DA4: Multidisciplinary collaboration on goals determined by the client		DB8, DB9: Strengthening the collaboration of all staff members with the aim to enhance the autonomy of the resident	DB3, DB4: In the evaluations reciprocity is mentioned as a value in the cooperation DB4: After agreements are made, everyone is responsible to call each other to account. Staff must search for new roles to do so DB9: being inclusive in the actions towards autonomy enhancement: e.g., also giving paramedic and medic professionals a role
Shared decision-making systems				

[1] *D= document A/B= organisation A or B, 1-12= document number*

The respondents who participated in the interviews represented departments or councils that were responsible for or involved in one or more aspect(s) of the implementation of the policy to enhance autonomy. Table 4 presents the demographics of the interviewed stakeholders.

Table 4. Demographics of the interviewed stakeholders in organisations A and B

	Job title	Years of working in the in current function
A1	Team manager	13
A2	Board manager	6
A3	Human resource management: educational officer	1,5
A4	Member of the work council	*
A5	Client advisor	15
A6	Quality and innovation manager	*
A7	Senior staff nurse	6
A8	Member of the client Council	1
B1	Occupational therapist	5
B2	Guide	9
B3	Human resource management: educational officer	0,5
B4	Location manager	2,5
B5	Team coach concerning autonomy enhancing	1
B6	Board manager	8
B7	Facility manager	*
B8	Paramedic professional	1,5
B9	Representative of the residents in the management team	2

** Missing values*

In Table 5, the codes, and their allocation to the aspects of the care environment are shown.

Table 5. Codes from interviews A and B

Aspects derived from PCC	Codes of organisation A	Respondents N=8 Followed by fragments	Codes of organisation B	Respondents N=9 Followed by fragments
Power sharing	Organisation of participation: client council (6 fragments)	A8:6	Organisation of participation: client council, management team extended with clients and advised by guides, bottom-up signals (13 fragments)	B2:1, B4:5, B6:3, B9:4
	Participation in decisions of daily life/ living together: living room meetings in the unit (1 fragment)	A1:1	Participation in decisions of daily life/ living together: living room meetings in the unit (3 fragments)	B2:2, B9:1
	Self-managing teams (3 fragments)	A1:1, A2:1, A3:1	Self-managing teams (1 fragment)	B6:1
Supportive organisational systems	Offering training, tools, coaching (9 fragments)	A1: 2, A2:2, A3:1, A4:1, A6:1, A7:2	Offering training, tools, coaching (16 fragments)	B1:2, B3:1, B4:1, B5:7, B6:5
	Establishing structures for: regulatory requirements, quality measurements, coaches, work schedules (5 fragments)	A1:1, A6:3, A7:1	Establishing structures for: regulatory requirements, quality measurements, coaches, guides, role models, organisational consultation structure (27 fragments)	B1:4, B2:6, B4:2, B5:6; B6:5, B8:3, B9:1
	Role managers: coach, policy making, intervene in case of discrepancies (7 fragments)	A1:1, A2:2, A3:1, A6:1, A7:1, A8:1	Role managers: support, coach, basis in order, intervene in case of discrepancies (21 fragments)	B2:2, B4:4, B5:8, B6:7
	Define vision and core values, communicate these to staff and clients, evaluate these and live by these (19 fragments)	A1:2, A2:5, A3:4, A4:1, A5:3, A6:3, A8:1	Define vision and core values, communicate these to staff and clients, evaluate these and live by these (31 fragments)	B1:2, B2:4, B3:1, B4:9, B5:5, B6:8, B7:1, B8:1

Table 5. Codes from interviews A and B (continued)

Aspects derived from PCC	Codes of organisation A	Respondents N=8 Followed by fragments	Codes of organisation B	Respondents N=9 Followed by fragments
Appropriate skill mix	Team composition: Mix of expertise/ well-trained (4 fragments)	A1:2, A2:1, A3:1	Team composition: Mix of expertise/ well-trained (11 fragments)	B4:2, B5:2, B6:2, B7:1, B8:4
	Sufficient permanent staff: not always possible, turnovers, effort to become a team again and again (12 fragments)	A1:2, A2:1, A4: 1, A7:7	Sufficient permanent staff: not always possible, turnovers, effort to become a team again and again (7 fragments)	B1:1, B2:1, B4:3, B5:2
Potential for innovation and risk taking	Organisational culture: the courage to develop a policy to enhance autonomy in the face of cut government budget (1 fragment)	A2:1	Organisational culture: the courage to develop a policy to enhance autonomy in the face of cut government budget (2 fragments)	B6:2
	Space to regulate: being allowed to make mistakes, to develop, to take initiatives, to plan duty rosters themselves, to budget. (16 fragments)	A1:1, A2:6, A3:1, A6:2, A7:7	Space to regulate: being allowed to make mistakes, to develop, to take initiatives, to plan duty rosters themselves, to budget. (21 fragments)	B1:3, B2:5, B3:2,B4:2, B5:2, B6:5, B8:2
	Expectations of care technology: maintaining autonomy (1 fragment)	A6:1	Expectations of care technology: ADL, electronic care record, medication administration, mobility (5 fragments)	B4: 4, B6:1
	Increasing choice: when to get up, when to eat, when to drink, choice for activities (12 fragments)	A1:4, A2:1, A5:2, A6:2, A7:1, A8: 2	Increasing choice: when to get up, when to eat, when to drink, choice for activities (15 fragments)	B2:6, B3:1, B6:2, B7:5, B9:1

Table 5. Codes from interviews A and B (continued)

Aspects derived from PCC	Codes of organisation A	Respondents N=8 Followed by fragments	Codes of organisation B	Respondents N=9 Followed by fragments
The physical environment	Adjusting to needs (6 fragments)	A1:2, A2:2, A5:1, A7:1	Adjusting to needs (5 fragments)	B1:3, B3:1, B4: 1
	increase freedom of choice: decorate own room (2 fragments)	A5:1, A7:1	Increase freedom to go outside: do residents have an own or lend key to enter the building (1 fragment)	B2:1
	limited choice to move to a preferred nursing home due to waiting lists (1 fragment)	A5:1		
Effective staff relationships			Dilemma as a staff member: working together as a team, working with a manager who does not want to go along with the policy? (3 fragments)	B1:1 B2:2
			Role of managers: do they actually want to share power? (2 fragments)	B2:2
Shared decision-making systems	Setting boundaries: professional code (1 fragment)	A5:1	Setting boundaries: professional code (2 fragments)	B6:1, B8:1

The overarching research question was which policy, aimed to enhance the autonomy of older adults with physical impairments in nursing homes, is developed and implemented. The results will be presented following the aspects of the key domain care environment of the PCP framework (see Table 1) (9). Per aspect, the results are structured as follows: the intended policy as described in the documents, proceedings and evaluation as described in the documents and the perspectives and experiences as shared by the interviewed respondents involved in the implementation of the policy.

Aspect 1 power sharing

Four policies were found in this aspect: i.e., the development towards self-managing teams, installing role models, participation from the councils and living room meetings and access to, and involvement in, the care plan.

The development towards self-managing teams

It was read in the documents, that the board managers of both organisations planned to approach the autonomy of residents indirectly with a policy to implement self-managing teams. These teams should provide care on a unit in a more autonomous way. In the plans of both organisations, it was claimed that self-managing teams would lead to more focus on autonomy of older adults living in the nursing home. In the minutes, a development of the teams in both organisations towards self-managing with a manager as coach, was found. The progress of the policy was regularly discussed by the board managers of both organisations with the supervisory boards and the councils. However, it should be noted that the discussion was merely limited to team development, and it was not related to enhancing autonomy of older adults. In the interview, respondent A2 put autonomy at the heart of the development of self-managing teams.

> Respondent A2 said: 'I think that if you want to give autonomy a place, value it. You will have to create a context for it in the staff on the units. That is where the focus is now. We work with self-managing teams and independent thinking professionals who are attuned to the client.'

Installing role models

In the plans and proceedings of organisation B, it was found that the management team was supported by 20 so-called 'guides' working in the teams. Guides were meant to have the responsibility to pioneer in activities towards enhancing autonomy of residents (role models). In the documents of organisation B, it could be read that the guides were in position. However, in the proceedings of the meetings of the guides, issues concerning responsibilities of the guides were found. It was read that they asked themselves 'how far can we go when acting outside the box'? One interview was with respondent B2 who was one of these guides. The guide mentioned that 'thinking out of the box' and challenging the team was not appreciated by the team manager. On the contrary, respondent B6 mentioned that the

board manager wanted to welcome bottom-up signals to the top and wanted to have direct feedback on plans from residents and staff in the management team.

Participation of work and client councils and living room meetings

In the minutes of both organisations, it was found that they had the legally required participation bodies such as a client council and a work council. Moreover, organisation B also had the recommended nursing advisory council. In the minutes of the board managers, it was read that the councils in their regular meetings with the board were consulted and asked for consent on the topic of enhancing autonomy of residents. Furthermore, it was read in the documents of organisation B, that members of the client council and work council participated in a training to enhance autonomy. This was a dialogue training to start the conversation with the client about autonomy, managers were trained to place the client at the centre.

In the local document of organisation A, it was found that power sharing on the unit level was implemented by living room meetings between residents and staff on the unit. In the interviews, the living room meetings were mentioned several times as a way to participate in decision making about daily life on the unit in both organisations.

> Respondent B9 said: 'once in a while, we have a meeting with everyone in the unit. For example, we talk about mealtimes, whether everyone still agrees with the times of the meals or whether the time should be changed. [Also, about] the location of the meals.'

Access to and involvement in the care plan

In the documents of both organisations, plans and proceedings were found about the older adult's access to their electronic care plan. Furthermore, references were found to protocols to ensure residents could be present in scheduled meetings to evaluate their care plans. In the minutes of both organisations, a follow-up of the proceedings of the access to the electronic care plan and the implementation was found. In the interview respondent B4 expressed that a further expansion of the access to the care plan towards a resident's full ownership could enhance autonomy in the future.

> Respondent B4 said: 'my ultimate goal is that every resident has his own tablet. And that he is the owner of his own device and of his information and that we log in to his device. And not as it is now that he logs in with us but that it really is his [care plan].'

Aspect 2 supportive organisational systems

It was found in the documents that a corporate vision on autonomy was formulated and communicated on the website and other public media by both organisations. The board managers of organisation A visited all locations and shared their vision with the staff on autonomy enhancement for the residents. The board manager of organisation B shared

the vision with the staff via workshops and theatre and visited locations as a follow-up. Furthermore, organisation B offered coaching, an autonomy game, and annual updates. Moreover, the management team of organisation B was expanded with two representatives of the residents and two of the caregivers. In the proceedings, it was found that the quality department of organisation A did an internal audit on autonomy enhancement and organisation B measured and evaluated the planned policy itself. However, there was no evaluation found in the minutes whether the autonomy of residents was enhanced. The interviewed respondents recognised the activities the organisation used to enhance autonomy in daily practice. They mentioned that one could learn and share experiences about enhancing autonomy inside and outside the organisation. Role models were appointed to enhance autonomy. Respondents stated that organisation A offered no special training; the vision on autonomy was merely communicated by the organisation and new employees were informed. The respondents in organisation B mentioned that training, tools, and coaches were available for staff to enhance autonomy of older adults. Furthermore, respondents mentioned that residents and nurses were included in the management team with the aim to strengthen the policy towards autonomy. The vision on autonomy was known by the respondents of both organisations and they tried to comply to the vision.

> Respondent B6 said: 'we have also set up a whole training programme. We have a number of workshops about autonomy, how to have a dialogue [with residents], what are the key moments in care, and when I say care, I mean (.) in the contact with a resident. That is constantly repeating, repeating, repeating, repeating. The good examples and also the things that aren't going well, with the purpose to learn from each other'.

Aspect 3 appropriate skill mix

No specific documentation regarding policies concerning skill mix to enhance autonomy were found in Organisation A. The policy of organisation B focussed on recruiting more staff and BN's. This was expected to enhance autonomy. In the minutes of organisation B concern was read about the discontinuity of care because of interim staff. In a factsheet of organisation B concerning the progress of the policy towards autonomy enhancement, an increase in the number of staff members in the nursing home and their educational level was described. In the interviews, respondents mentioned planning problems, because there was not sufficient and permanent staff. In terms of staff composition, the team needs to be competent in enhancing autonomy. New employees should be educated and able to fit in. But this appeared not to be the case. Respondents expressed they had 'to start all over again' to talk about the vision on autonomy when new staff was recruited. According to the respondents, nursing schools should change the curriculum regarding enhancing autonomy. The organisational aim to have a balanced team composition with a mix of expertise was known by the respondents of organisation B. However, the objective of the policy to have more BN's was not clear for the respondents. Respondent B5 expressed concerns that the team was more involved with the

new roles of the team members after BN's were recruited, than with the autonomy of older adults.

> Respondent B5 said: 'We used to have the auxiliary nurses as care coordinators. Then later on we got nurses with a bachelor's degree, and they became the care coordinators for residents, so that was already a bit awkward, but you could still explain that residents (…) needed more serious care (…). The BN sat almost on the chair of the team manager. And then you have two captains on one ship. And that in a team that has to enhance autonomy'.

Aspect 4 potential for innovation and risk taking

In the aspect potential for innovation and risk taking three policies were found: innovations towards autonomy enhancement in a financial difficult time, choice enhancing policies and expectations from autonomy increasing technology.

Innovations towards autonomy enhancement in a financial difficult time

The board manager of organisation B wrote explicitly in the plans that it is understandable that in such a learning process towards autonomy, mistakes can be made and should be allowed. Some respondents said that, given the conditions of a cut back of budgets on nursing homes by the government, it took courage and motivation of the management to start a programme to enhance autonomy. Prerequisites, such as time and space, to develop competences to enhance autonomy were arranged. Staff could take initiatives such as letting go of fixed times of care moments. However, the respondents expressed their concerns about the consequences of this freedom on the level of the units: financial problems, problems with scheduling, cooperation and employees who create their own work activities.

Choice enhancing policies

It was read in the documents that both organisations created opportunities for choice and preferences of the resident e.g., they both aimed to enhance choice through a new meal system. Choice was supposed to be an act of autonomy. The respondents of organisation A mentioned an increasing freedom of choice for the residents in the daily schedule, choice regarding eating and drinking, getting up at a preferred time and choosing activities.

> Respondent A6 said: 'autonomy can express itself in daily activities such as washing, dressing, and eating. Let's talk about food. If someone wants vegetarian food, I think we should think about how to organise that for that person. That is important to him for now.'

Expectations from autonomy increasing technology

In the minutes of organisation B new technologies within the nursing home, were considered as promising for autonomy, such as technology that supports activities of daily living (ADL) and mobility. One respondent of organisation A said that technology could be valuable for

older adults to enhance autonomy. Respondents of organisation B also expected much from technology to enhance autonomy for the assistance in ADL, mobility, the day structure and independently taking medication with a medicine dispenser. Although a lot was expected, no information about the implementation was found.

Aspect 5 the physical environment

In the documents, the physical environment as a means to enhance autonomy was reflected in the planned policy towards the interior, furnishing of the rooms and accessibility of the building. The board managers of organisation A had plans for a more suitable living environment for residents in the future: the current building still had shared bathrooms and the rooms were small, which was not considered as an autonomy enhancing environment. However, an actualisation of these plans was not found in the documents. Organisation B planned to vacate the rooms empty. New residents could furnish it themselves, which was seen as autonomy enhancing because they could, for example, choose which furniture was taken from home to decorate the room. In the minutes, it was found that this policy was realised. In the local document of organisation A, it was read that the older adults possessed a key to independently enter the location, the unit, and their private room. The physical environment was mentioned in the interviews in relation to increasing the freedom of choice. The respondents of the interviews confirmed the policy about furnishing the room (organisation B), the advantages of owning a key (organisation A and B) and a better adaptation of the rooms to the needs of older adults (organisation A). A respondent of organisation A mentioned that the existing building had a negative impact on achieving autonomy.

> Respondent A7 said: 'the rooms are very small as you can see, there is no possibility to make coffee or tea. They always depend on when we serve in the living room.'

Aspect 6 effective staff relations

In the plans of organisation A, it was described that a better collaboration within multidisciplinary teams towards the goals, set by the residents, was needed. The policy of organisation B was aimed at all the professionals working in the nursing home. The monitoring of the commitments, made in the process towards strengthening autonomy, should enhance relations between staff. They should work based on equality, towards autonomy of the residents. In the documents it was found that autonomy enhancement should not only be the responsibility of the staff on the unit but also of the other professionals, such as the facility department. In the interviews effective staff relations were hardly mentioned. One respondent mentioned the difficult collaboration with the manager when trying to be a role model for enhancing autonomy. Respondent B1 mentioned the slow development in the collaboration within the multidisciplinary team towards the autonomy enhancement of the residents.

> Respondent B1 said: 'we try to keep building as a [multidisciplinary] team so that in the end it all benefits the resident. But I think that if you are a team and you are there for each other, you can also be there for the resident. But we are not that far yet.'

Aspect 7 shared decision-making systems

Shared decision making systems as 'ways of engaging within and between teams' (9) are only mentioned in a few interviews, no specific policy was found in the document research.

Shared decision making was brought up in the context of possible conflicting views of professional staff and managers about the residents' autonomy. One respondent stated that the 'professional code' of the health care professionals could easily take precedence over the autonomy of the older adults. B6 declared to choose for the residents in this circumstance.

> Respondent B6 said: 'we collaborate with professionals here: assistants, carers, nurses, therapists, doctors. They all have professional ethics. Yes, and we do say that, if a resident says I do not want medication, I do not want treatment or I do not want that, they can have an opinion from the perspective of their professional ethics. But ultimately, we choose for that resident'.

Discussion

This study aimed to answer the overarching question: which policy, aimed to enhance the autonomy of older adults with physical impairments in nursing homes, is developed and implemented. The results were organised in the PCP framework. The care environment is one of the key domains of this framework and consists of seven aspects (9). The results showed that all seven aspects were, to a greater or lesser extent, found in the documents and/or interviews with the respondents. There seems to be a gap between the policies towards enhancing autonomy and the day-to-day practice in the organisations. In general, it can be argued that the intentions and policies at the top of the organisation are ambitious, but the policies are not holistic, often not supported by knowledge and often indirect. Furthermore, the policies don't seem to be implemented or fully known in the basis of the organisation.

Aspects of the care environment that seem easy to adjust with policies are dominantly addressed by organisations. More permanent aspects, such as the physical environment, receive less consideration. Most policies were directed at the aspects power sharing and supportive organisational systems.

Regarding the aspect of power sharing, there are two notable insights. First, in both organisations it was assumed that an intervention that is indirectly aiming to enhance autonomy, such as self-managing teams would lead to more autonomy of residents. Although it is known that teams with little freedom to regulate opt for rules and safety rather than preferences of older adults (17), there is no evidence for the opposite, i.e. whether self-managing teams will lead to enhanced autonomy of residents. The development of self-managing teams often originates from the ambition to create more organisational flexibility

through increasing employees' responsibility and autonomy (18). Autonomy for staff, however, is not only associated with the practice in the care unit, but also with decision making in the organisations and the way work is organized itself (19). The last two aspects i.e., decision making in the organisation and organising work itself, seem to be more prevalent in the organisations, where staff was more concerned with coordinating tasks and work, rather than with enhancing residents' autonomy.

Second, considering power sharing, the access to the electronic care plan by older adults is used as an autonomy enhancing policy in both organisations. In practice, few older adults in nursing homes have their own devices and access is often delegated to family members (20, 21). Equal access to information is important to enhance autonomy, but the policy was a means to itself of which it was not clear whether it contributed to the goal of power sharing.

Concerning the aspect innovation and risk taking it was seen that organisations made finances and time available for innovations to enhance autonomy and thus took financial risks to address the subject of autonomy. This showed a strong commitment that the board managers were willing to make a real change in the organisation. One of the innovations was that staff could let go fixed times for care and stop completing checklists. This led to tensions between staff members on the units and uncertainties in the teams about the finances, responsibilities, and scheduling in the unit. The structures within the care environment are often criticized as influencing autonomy in a negative way (4). However, when staff is given space to flexibly deal with changing schedules and using checklists, it also requires a certain determination of them to use this freedom (22).

Earlier research already showed that organisational policies mostly concerned choice enhancing or control enhancing policies (7, 8). This narrow interpretation of autonomy is also seen in the documents and interviews of the current study. Choice enhancing mechanisms in the policies directed at innovation and risk taking and the physical environment, such as innovations in the meal system and the furnishing of the rooms by residents, were found. These identified choice enhancing policies were consistent with the policies found in the study of Sikorska-Simmons (7).

Control enhancing policies were found to be directed at the physical environment, such as having an own key of the building and the residents' apartment. Control enhancing was found as well in power sharing, i.e., the participation of residents in client councils, living room meetings and the management team (MT) was realised. This participation of several older adults in formal decision-making went beyond mandatory representative bodies such as client councils. However, whether participation of residents in the MT is a suitable policy is discussed by Abma and Baur (8), who identify the risk for tokenism and frictions between the lifeworld of the older adult and the system-world of the MT/organisation. Residents' participation in collaborative actions in the nursing home is seen as a more effective way to realise power sharing by these authors (8).

The PCP framework indicates that all aspects of the care environment are important to develop a person-centred practice. In this study, the authors found that that there was an overrepresentation of two aspects i.e., power sharing and supportive organisational systems. The authors recommend a more balanced use of all aspects in the care environment in order

to create a more autonomy enhancing care environment for older adults in nursing homes (10). In the PCP framework, the care environment is situated as a key domain between two other key domains i.e., prerequisites of staff and person-centred processes. In the interviews, the respondents referred to these domains by spontaneously sharing some experiences how, in caring for the older adults -the person-centred processes- they explored a way to put autonomy into practice. These expressions also gave an insight into the involvement -prerequisites of staff- of the respondents in autonomy enhancement and the importance of the other key domains as well in enhancing autonomy.

Although the PCP framework poses that all aspects of the key element care environment are important to develop a person-centred practice (9), this is not yet the case in practice. The authors therefore recommend using all seven aspects of the care environment in a balanced combination with the other key domains of the PCP framework to achieve person-centred practice and as a result an enhancement of residents' autonomy.

Strengths and limitations

Lincoln and Guba, as cited in Korstjens and Moser, suggest credibility as a quality criterium for qualitative research (23).The following aspects of credibility were taken into account to heighten the trustworthiness of the study.

A strength of the study is that data triangulation, the use of multiple data sources, has been applied (23). An extensive document study was conducted and besides an analysis on the plans to enhance autonomy, evaluation reports, quarterly reports and annual reports were additionally studied. Also, an analysis was done on local documents in two nursing units. To get more insight into how the policy is known and implemented in the organisation, interviews were conducted in addition to the document analysis. With this triangulation the trustworthiness of the study was strengthened (23).

Another strength is that the respondents for the interviews were purposively selected. One or two stakeholders were interviewed about one or more aspects of the care environment they were involved in (14). However, this could have resulted in a response bias. In some cases, the respondents started guessing, improvising or expressing resentments because they did not know an answer to the question (24). These fragments in the transcripts were not used. The authors also aimed to include the voice of a representative of the residents in the management team about the experienced power sharing in this study. However, the authors realise that a semi-structured interview was not the best method to include resident's voices. Nevertheless, the resident did give an insight into the implementation of the power sharing policy that focused on participation of representatives among the residents. Furthermore, the resident considered the contribution to the management team as valuable, even if it was difficult to articulate what was important in that regard.

Another strength is that the board managers of both organisations allowed the authors to use confidential sources to increase the insights about how both organisations aim to enhance the autonomy. A limitation can be that these confidential documents were studied by one researcher, who could only take notes. This could have led to bias. To prevent this,

the notes were typed out and presented to the corporate secretary of each organisation. Through this member check, permission was asked and given to use the checked confidential information in the study. Moreover, non-confidential documents were available and could be copied and entirely analysed by two authors independently from each other.

A limitation can be that the interviews were conducted by fourth year BN students who were inexperienced in interviewing. However, the first researcher who has experience in interviewing and qualitative research methods, guided the interviewers during the data collection. Moreover, an expert in the field of the PCP framework and autonomy enhancement of the university of applied science, supervised these students.

A last strength is the use of investigator triangulation. The data extraction of the documents and interviews was done in pairs. After individual coding, a discussion in pairs followed, whereafter consensus meetings were held (23). The authors also found consensus on the allocation of the codes and fragments to in the different aspects of the key domain care environment or to other key domains of the PCP framework.

Recommendation for further research

As the current study was directed at the organisational perspective, the researchers did not ask older adults what changes in the care environment they would propose to exert more autonomy, nor was the impact of the policy on the autonomy of the older adults themselves studied. It is recommended to study aspects in the care environment that are considered as urgent or important, by older adults living in nursing homes. This can be done with a participative action research design: actions toward the enhancement of autonomy chosen by the older adults can be explored and followed by reflection, to bring about a change in the care environment (25). Furthermore, if researchers want to include the voice of older adults into research on autonomy enhancement, research methods tailored to the condition of older adults, will be needed. Such as creative materials that help articulate the residents voice better (26).

Implications for practice

The insights about policies to enhance the autonomy of older adults with physical impairments as found in the current study can provide guidance for the planning of new or current policies. The actual policies that are being implemented in organisations can be compared with the policies as described in this study.

Several lessons were learned in this study. First, it is advised to develop a holistic policy, that in a balanced way is related to all the aspects of the care environment. Second, it is of utmost value to consider both the perspectives of older adults and staff. Third, attention should be paid to supporting and training staff in implementing the policy. Staff certainly needs new skills e.g., how to navigate between rules, routines, procedures, and the life world of residents. An example is thinking about how coffee and tea facilities could be made available to residents. In this way, residents are able to drink coffee or tea whenever they like (they have a choice) and also, they can offer their visitors something to drink. Fourth and last, it is important to be clear what the expectations are, about enhancing autonomy

to those involved. For example, when organisations opt for implicit or indirect improvement of autonomy through a team intervention such as self-managing teams, it is advised to set goals, use interventions such as coaching for the older adults as well and evaluate the impact on autonomy enhancement of older adults. Another example is a policy aimed at recruiting specific staff, such as bachelor nurses. It should be clear to them, residents and other staff members what is expected of this specific role, responsibilities, and expectations with regard to autonomy enhancement.

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Section III

6

Working together to enhance autonomy: a participatory action research among residents and staff in a nursing home

Van Loon J, Janssen M, Janssen B, de Rooij I, Luijkx K.
Working together to enhance autonomy:
a participatory action research among
residents and staff in a nursing home.

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Abstract

Care in nursing homes is evolving from a medical to a person-centered orientation. Principles such as participation and autonomy are seen as the basis for person-centered care to live life as a resident prefers. However, often decisions are made for and about the resident by others, which might hinder autonomy. How can a more person-centered way of caring be achieved at the level of the unit with a focus on autonomy and participation? Participative action research (PAR) has promising elements to bring about a change.

The aim of the study is to gain insight into the processes by which residents and staff propose actions, exploring and evaluating these with the aim of enhancing autonomy in day-to-day practice. This led to the research question: what processes occur between residents and staff in the PAR to enhance the autonomy of residents on the unit level?

An action group consisting of residents and staff in one unit of a nursing home identified, undertook, and evaluated actions to enhance residents' autonomy. The generated data were analyzed with the critical creative hermeneutic analysis. In total, eight themes to describe the process were found.

Although there was no evidence that the actions undertaken during the PAR directly led to enhanced autonomy, the learning process and the collaboration of residents and staff is promising.

It is recommended to include residents and staff as partners in actions to enhance autonomy in the nursing home. The PAR process worked well for this objective. However, participants' physical conditions should be considered when choosing working methods. Creative work forms are not always appropriate for the population targeted.

Introduction

In the last decades, long-term care in nursing homes has made a cultural shift from a medical environment toward a model in which care is provided in a more person-centered way (1). Principles of autonomy and shared decision-making are important. Residents should be involved in deciding how and when care and activities are organized and provided and where and when to spend time with whom (1-3). However, Agich (4) emphasizes that providing choices in activities, meals, and outings without knowing what the person himself perceives as valuable does not automatically lead to autonomy. Agich (4) strongly advocates knowing and working with the resident's values.

The framework for person-centred practice (PCP) mentions the principles of working with residents' beliefs and values and sharing decision-making. These aspects are mentioned as processes underpinning PCP (5). Mayer and McCormack (6) further developed the PCP framework for nursing home care, adding fundamental principles of care to it; for example, 'the resident should be free in decisions and should have an autonomous [...] lifestyle within the nursing home' (p 10). These principles also apply to older adults with physical impairments who live in a nursing home, the intended population for this study. Generally speaking, these persons are able to make decisions on how they want to live their lives. However, they are often hindered in terms of executing these decisions due to the underlying physical conditions that made them move to the nursing home.

Staff are often aware of the importance of residents having autonomy. Moreover, they are motivated to enhance the autonomy of residents. Nevertheless, staff experience challenges in enhancing residents' autonomy such as organizational constraints in choices, time, and available staff (7). Furthermore, processes that hinder the autonomy of residents are often not recognized by staff. Unspoken rules could contribute to the risk of reduced autonomy and participation—for example, regarding what time to get up in the morning and when to enjoy breakfast (7). Moreover, policies to enhance autonomy are often shaped top-down in the organization without the involvement of residents (8).

There is considerable knowledge about the autonomy of residents. Moreover, staff are aware of the importance of enhancing residents' autonomy and taking their values into account. However, it remains challenging actually to enhance the autonomy of residents and to bring about change on the unit level.

Participative action research (PAR) has promising elements to make a difference. This type of research involves an action group, guided by a facilitator, which, in cocreation, proposes, explores, and evaluates bottom-up actions. By doing so, PAR is expected to lead to a process of change in the life world of residents and staff, and thus on a unit level, which might lead to enhanced autonomy (9).

The aim of this study is to gain insight into PAR processes in which residents and staff propose actions and explore and evaluate them, aiming to enhance the autonomy in day-to-day practice. This led to the research question: what processes occur between residents and staff in the participative action research to enhance the autonomy of residents on the unit level?

Methods

Study design

The researchers chose a qualitative PAR design. This is a cyclical, participatory process of gaining evidence used to bring change to the practice environment (10). In PAR, research is not conducted on persons but with persons (11); the residents and staff are therefore both objects and subjects in the study.

The key features of action research are that it is a social process, participatory, practical, collaborative, emancipatory, critical, and reflexive, and it aims to transform both theory and practice (9). These key features correspond with the aim collaboratively to enhance autonomy in the life world of the participants—i.e., residents and staff.

Kemmis and McTaggart (9) distinguish four phases in the PAR. 1) The reconnaissance phase is seen as the start of the study. In this first phase, the design of the study is aligned with the various perspectives of those involved in the context, relationships are built, the researcher's own perspective is explored, and the action group is formed. After this phase, the other three phases follow in so-called action spirals, with 2) a planning phase, 3) an action and observation phase, and 4) a reflection phase.

In the second phase—i.e., the planning phase—the action group reflects on themes that are identified in the reconnaissance phase and possible actions are prioritized. In the third phase—i.e., the action and observation phase—the chosen actions are explored in daily practice to observe how they contribute to the desirable situation. Observation is also used to generate new knowledge about how these actions are contributing to the desired situation. Finally, in the fourth phase—i.e., the reflection phase—the participants reflect on the evolution of their practice, understanding of the practice, and the situation in which they practice. This research design is open and flexible because of its iterative character in which the output of each step is the input for the following one (9). The first phase will be described in this methods section, phases two, three and four in the results section.

Ethical considerations

In PAR, participation is the underpinning principle. Therefore, the location manager, team manager and contact person of the unit participated in drafting the research design of the PAR in November 2017. This was submitted to the Ethics Review Board of Tilburg University and approved on 26 April 2018 (no. EC-2018.10).

The researcher and first author JvL facilitated the PAR. To prepare herself, she attended two courses on, respectively, the theory and application of PAR from the Centre for Person-centered Research Practice and a practice development course (12). JvL explored (implicit) assumptions about autonomy in advance with a mentor with a background in andragogy who was not involved in the study.

Description of the context

The researchers sought for a nursing home where older adults with physical impairments live, who require long-term care. Furthermore, recognition of autonomy as an important

part of residents' lives and the ambition of the organization to support autonomy in daily practice were important. The nursing home where the PAR eventually took place is part of an organization in the South of the Netherlands serving a small (23,000 inhabitants) and a medium-sized (36,000 inhabitants) town and the surrounding area. In the unit, 23 full-time equivalent staff were employed. During the PAR, 28 older adults with physical impairments due to chronic illness or older age lived in the unit. The nursing home was built in 2004 and offered a two-room apartment with a private bathroom for each resident. Two living rooms on the unit gave residents the opportunity to meet and enjoy their meals. Food could also be served in one's own apartment or in the restaurant, if preferred. The nursing home had spaces for activities and therapy, a restaurant, and surrounding gardens.

The board managers of the organization developed a policy directed toward autonomy for the resident. The managers shared the vision of enhancing autonomy via workshops, theatre, theme meetings, dialogue sessions, and an autonomy game with the aim to equip staff to enhance autonomy. The selected unit on which the research took place had initiated earlier pilots to enhance the autonomy of residents.

Sampling and recruitment

Autonomy in a nursing home always takes shape in the relationship between the resident who needs care and the staff who provide care (4, 13). Furthermore, Hedman, Häggström (7) advise considering both the residents' and staff perspectives to enhance autonomy and participation in the nursing home.

The researchers therefore aimed to include in the action group about five residents with physical impairments and five staff members. The researchers preferred to include staff members of different disciplines in the action group. In the nursing home, autonomy is manifested in diverse activities in the unit such as morning care, eating and drinking, and social activities (14). Purposive sampling was used to ensure that persons giving these distinct types of care would be represented: nutritional assistants, nurses, and occupational therapists of the unit were invited to participate. In recruiting the residents, the motivation to participate and the ability to attend (in terms of health condition and mobility) were decisive.

Recruitment was done by the unit's contact person, who was also involved in the two earlier studies conducted by this research group in this unit (14, 15). The contact person used the information and informed consent letters provided by the first author JvL.

Results

Descriptions of the participants and meetings of the action group

Five residents, a spouse of one of the residents, the contact person (an occupational therapist), and four other staff members consented to join the action group. The contact person and one of the residents withdrew their involvement after eight months due to their health situation. JvL planned an individual dialogue with both persons to reflect on and close their participation in the process. The contact person was replaced by another occupational therapist. In Table 1, characteristics of the participants in the action group are shown.

Table 1. Characteristics of the action group

Participant	Gender	Participant: resident (R)/staff (S)/spouse (Sp)
P1	Male	R
P2	Female	Sp
P3	Male	R
P4	Female	R
P5	Female	R
P6*	Female	R
P7* **	Female	S, occupational therapist and contact person
P8	Female	S, nutritional assistant
P9	Female	S, registered nurse
P10	Female	S, auxiliary nurse
P11	Female	S, manager

** Withdrew after eight months; ** another occupational therapist filled the vacant role*

Meetings of the action group

JvL was aware, based on literature, that power issues between older adults and staff could occur in action research (8, 16). Therefore, JvL aimed to create a safe environment (9) by scheduling the subgroup of residents every two weeks. The joint action group of residents and staff met every four weeks.

The meetings were organized on the ward itself, considering activities planned by the resident themselves or from within the nursing home and staff shifts, so that the possibility of participating was maximized. Given the health condition of the participating residents, each meeting was planned to last a maximum of one hour.

During all gatherings, JvL opened and sustained communicative spaces. Communicative spaces are described by Kemmis and McTaggart (9) as a situation in which persons together attempt to achieve a mutual understanding of a situation and find ways of acting in a collaborative way. Space could be seen as physical—the place on the unit—or as conceptual, creating circumstances for the action group meeting (17). In her facilitation, JvL followed the group's process and refrained from intervening with what, who and why questions.

Traditionally, dialogues take shape with the use of words. But words can have different meanings for participants. Giving words to feelings and experiences is a cognitive process. Creative work forms can help convey matters that are difficult to put into words. To share this implicit knowledge in a dialogue, the insights subsequently need to be transformed back into language (18). When choosing work forms, JvL considered the preferences and capabilities of the residents involved. She used an elicitation method with photo cards and cartoons to generate a dialogue to create ideas and knowledge about autonomy and participation (19). Also, more lingual methods were applied, such as word clouds, to clarify and identify shared meanings about ways to enhance autonomy for residents. Moreover, joint organizing

and prioritizing of text cards with actions and descriptions of autonomy was used as a combination of language and creativity.

JvL, as facilitator, always prepared the meetings, made notes, and combined them with photographs of the process. These records were not a literal representation of the individual contributions of the participants, but instead provided the main points about the proposed actions and their consideration. Depending on the preference of the participants, these records were sent by e-mail to the action group or printed and handed over by the contact person. Every subsequent meeting, the records and the proceedings of the intended actions were reflected upon. This joint reflection was also a member check to increase the credibility of the study.

The planning phase

Kemmis and McTaggart (9) distinguished the planning phase as the second phase in the PAR. In this phase, an initial exploration of possible actions takes place. A selection can be made, and the action group can choose which actions have the highest priority. In September 2018, the first action group of residents gathered. To have a shared understanding, the group started with an exploration of the concept of autonomy. When asked which actions were needed to experience more autonomy in the unit, nine possible actions were immediately mentioned. Discussion followed in the meeting of the joint action group, including staff. They talked about the proposed actions, prioritized them, and decided to work collaboratively on the actions.

The action and observation phase

In the action and observation phase, chosen actions are explored in daily practice to observe how they contribute to the desirable situation—i.e., a situation in which older people experience more autonomy over their lives in the unit. Moreover, data about the process are gathered. The unit explored prioritized actions and the action group members observed whether and how the actions contributed to the shared objective—in this case, enhancing autonomy.

Six action spirals were taken up by the action group. Prioritized actions were: 1) the availability of staff during breaks, a call system that functions well, and staff who respond to calls; 2) staff members being (better) able to receive feedback from residents; 3) an adjusted elevator button that can be used independently by residents; 4) knowing who is responsible for what in the team; 5) a direct contact for oral care; and 6) a dialogue between the residents and the facility manager about how and where residents prefer to sit when they visit the restaurant. A more detailed description of the action spirals can be found in Appendix 1.

Reflection phase

The reflection phase connects the findings of the action and observation spirals and attempts to answer the research question. The action group reflected twice, halfway through the research period and at the end. The research group reflected once, at the end. The method of data analysis and data synthesis is explained below.

Data analysis

The data collected during the PAR process were analyzed using the critical creative hermeneutic analysis (CCHA) method (20) to answer the research question: what processes occur between residents and staff in the participative action research to enhance residents' autonomy on the unit level?

This method for the analysis was initially developed by Boomer and McCormack (21) and refined by Van Lieshout and Cardiff (20) into the CCHA. The latter authors added to Boomer and McCormack (21) method a participative, inclusive, and collaborative way of data analysis with research participants. The CCHA is based on three principles: the principles of hermeneutics, being critical, and creativity. The principle of hermeneutics refers to finding a meaning for a phenomenon. Being critical refers to the principle that a critical discussion should be used to check the interpretation. This interpretation and discussion is executed with the use of creative methods, which gives space for cognitive and pre-cognitive knowledge (20).

The CCHA consisted of seven steps: (1) preparation: the collected data originating from the action-observation stage were shared with the group; (2) familiarization: the group members read/viewed the data and the members were aware of personal reactions; (3) contemplation: a silent individual consideration of what was read/seen in the data; (4) expression: each group member was asked to express the essence of the data in an individual creative expression; (5) contestation and critique: the group members discussed the creative expressions and sought a shared understanding; (6) blending: the group members aimed to find the more manifest themes as well as the more covert ones; and (7) confirmation: a synthesis of the data. In this step, the original data are explored, confirmation of the themes is sought, and the themes are reported (20).

The action group used the steps of the CCHA twice, on 8 January and 18 June 2019. The CCHA was conducted on the records and the individual experiences of the action group during the process. The data set is shown in the highlighted column in Figure 1.

Figure 1. Data set for the data analysis

Action group: residents and staff	**Log with first researcher's reflections**	**Possible actions**	**Artefacts**
Records of the action group: describing main points CCHA of the process twice: detailed records	Reflections explored with the research group and external mentor	Overview of the proposed actions and actions taken from the action and observation spirals	Photos, posters, and association materials

The research group analyzed the overall data set (Figure 1) on 3 July 2019 using the six steps of the CCHA analysis. This data set consisted of the action group's records—i.e., plans, evaluations and reflections; the researcher's reflection log; artefacts such as collages, photos; and the explored actions. This meeting was recorded and subsequently transcribed.

Figure 2. Creative expression. Step 6: contestation and critique in the research group's analysis of the PAR process

Data synthesis

Step 7, the data synthesis, was conducted by JvL for both the action group and the research group. To confirm the themes formulated by the action group, she explored the records of the action group meetings. By rereading the data, the themes found in step 6 of the CCHA were supported. The data set was limited in size and could therefore be analyzed on paper without the use of ATLAS.ti.

For synthesis of the research group's data, the researcher and first author (JvL) used ATLAS.ti to explore the original data to confirm the themes. This tool was used because of the comprehensiveness of the overall data set. MJ, as member of the research group, checked and analyzed the output of the exploration; JvL reported the rephrased and clustered themes in depth and in detail (20). The themes and subthemes are presented in Appendix 2.

Themes found in the analysis

The aim of the study was to gain insight into the processes that occurred between residents and staff in the PAR to enhance autonomy of residents. The action group found in total three themes in the two CCHA analysis. When the themes of the action group in Table 2 are compared with those of the research group, which relied on the overall data set, there is evidently a considerable amount of overlap. In the analysis, the action group had an insider perspective and was in the middle of the PAR process. The research group, as outsiders,

had another perspective to give meaning to the processes that occurred (22). The themes of the action group and research group will be presented next to each other as 1a, 1b, etc., concluding with the themes found solely by the research group.

Table 2. Themes from analysis of action and research groups' data

	Themes from the action group		Themes from the research group
1a	Frictions in the collaboration	1b	Collaboration between residents and staff
2a	Listening to each other	2b	Learning to learn together
3a	Taking small steps	3b	Working together on actions to enhance autonomy
		4	Acting from an existing role
		5	Needing a shared view of autonomy

Theme 1a: frictions in the collaboration

The collaboration between residents and staff and between action group staff members and other staff members in the unit regarding enhancing autonomy was predominant in the analysis. According to the staff members in the action group, their colleagues outside the action group mentioned that it seemed as if the residents came up with the actions and the staff had to carry them out. These colleagues showed anger and resistance, and asked whether they did not have a say in this as a team? The proposed actions were perceived as an undesirable interference in their way of working, and the proposed action—not to take breaks at the same time in order to be more available—was not accepted.

Sharing the feeling of the staff members in the action group of being stuck between the action group and their colleagues relieved the tensions between residents and staff within the action group. The residents now understood why the proposed action was not explored. The staff could share their feelings of disappointment that the planned actions did not work out. This process resulted in a new mutual understanding between residents and staff that they both felt vulnerable in the PAR process. One of the participating residents (P2) said: "autonomy is like a diamond. It is brilliant material, but so sharp." With this statement, she gave voice to the situation that autonomy is worth striving for, but that you can also hurt yourself and others in the process to achieve it. In this case, because both residents and staff tried to change things, they encountered resistance and frictions.

Also, it was observed that at the beginning of the PAR process, actions from the residents' group were automatically taken over by the staff in the action group. Ownership of the actions was not discussed. Consequently, the actions seemed to be the responsibility of the staff. For future actions, it was agreed to explore the actions jointly. This happened in May 2019, during action cycle six when residents and the facility manager discussed the place where residents prefer to sit in the restaurant. Action group members consulted other residents before meeting the manager of the restaurant to discuss their experiences and express their preferences.

Theme 1b: collaboration between residents and staff

The action group members came from a situation in which the residents and staff had their own habits and ways of working in the unit. In the beginning, they described themselves as being a community. After some time, when frictions arose between the participating residents and staff, it became clear how difficult collaboration was. One of the participants (P6) said:

> "We are in need of a tipping point. If I propose something, it is not taken seriously, brushed aside. In the end, it is not going to happen."

In a conversation between residents and staff of the action group, the perspectives of both living and working on the unit came to the fore and more understanding was reached as to how this influenced the collaboration in the action group. Power issues were found between the residents and staff in the action group. The staff members felt that they were ordered to take up actions. Residents felt that the proposed actions were not seriously taken up in the unit. Also, power issues were present between the staff participants and their colleagues outside the action group. The colleagues felt the proposed actions were unwelcome interventions in their working routines.

> "Everyone was impressed that we all want to work towards the same thing and that that can lead to so many emotions. There was a lot of talk afterwards. Several people talked to the manager [P11] and there is now confidence again"(Excerpt from an action group record).

After this stage, the participants were more united as a group and were better able to cooperate and to feel a joint responsibility to work on actions toward autonomy. This determination was seen in the collaborative actions taken toward the way the residents were placed and served in the restaurant.

The action group has ideas on how to improve the situation. The residents liked the idea of a concrete topic and prioritized this activity. The residents considered this action feasible to bring about a successful conclusion together (Excerpt from an action group record).

Theme 2a: listening to each other

In the second CCHA analysis of the action group, the residents were increasingly involved in the action group, they increasingly felt part of the group, they felt seen and heard in the action group, and residents and staff had much more dialogue.

During the CCHA analysis, P2, the spouse of a resident, explained her experience with the "build your story blocks". "The figures are facing each other. They are talking to each other, they are connected. It is the only way. Not filling in for someone else."

However, the most important insight was that listening to each other and knowing each other is important and of value and is helpful in being able to bring about change together.

Figure 3. Step 4 of the CCHA: an individual creative expression of listening to each other

Theme 2b: learning to learn together

Although JvL informed the participants in a letter before seeking consent, there was no advance knowledge in the action group as to what the change process in the PAR would and should be like. A process of learning to participate together in the action group was revealed. In the beginning, residents in the action group wished to keep actions to themselves and did not want to share them with other residents and staff in the unit. They only intended to do so when there was some kind of success regarding autonomy enhancement. There was no awareness that other residents in the unit could contribute to actions as well: their possible participation remained overlooked. At the same time, ownership of the proposed actions was not discussed and seemed to be passed to the staff members in the action group. Later, during the sixth action spiral, this changed, and residents and staff started to collaborate.

There appeared to be a knowledge gap between staff and residents on the unit in general. Staff shared information within the team in records of team meetings and through an intranet platform; staff used protocols, schedules, working arrangements, and had implicit customs on the unit which were not known or available to residents. One of the staff members from the action group described her specific role related to hygiene on the unit:

> "If there are any new insights [about hygiene], I can then post them on a 'teams' website just for the team" (P9).

In the PAR meetings, the residents realized that this knowledge gap existed. As a reaction, the residents did not want to share the records of their separate meetings with the joint action group or others in the unit. Staff members on the unit mentioned to the manager (P11) that:

> "The group is somewhat secretive. What is being said and discussed there. On whose behalf the participants are speaking."

Eventually, the residents decided to share the actions and experiences of the action group after all. They discussed how to actualize this: "Sharing the experience with [the unit] has not yet started. We did talk about a whiteboard before, but how do we make that interactive?" (Excerpt from an action group record).

Theme 3a: taking small steps

The action group experienced that some of the actions they prioritized were addressed and small steps were taken. For example, staff reacted faster to the call system, which was one of the proposed actions. An important understanding was the awareness that only small steps could be taken at any time. Change takes time, according to the participants.

The action group members reflected that the residents in the unit expressed resistance when decisions such as where to eat in the restaurant were decided without consultation of the residents. The possible actions proposed in the planning phase by the residents of the action group were reviewed and some were found to originate from the resistance as described above and were no longer relevant.

Theme 3b: working together on actions to enhance autonomy

As mentioned before, the participants in the action group, residents and staff, increasingly worked together as the action group meetings progressed. Exploration of taking actions together led to increasingly inclusive actions. For example, the occupational therapist (P7), a resident (P6), and the manager (P11) visited another nursing home to see how an elevator button was placed in such a way that residents with a physical impairment could use it independently.

Now residents outside the action group were also consulted for preparation of the meeting with the facility manager: "The residents planned to ask other residents about suggested actions. Are these things that are also of interest to others? Do they possibly have additional ideas?" (Excerpt from an action group record).

Theme 4: acting in an existing role

At the beginning of the PAR process, the staff tended to assume actions suggested in the action group independently without seeking collaboration with residents inside or outside the action group. This appeared to originate from both the 'doing for' culture in their role as staff on the unit, and from a lack of awareness of this behavior in the action group. In the first

meeting of the action group, the occupational therapist (P7) said: “I will pick up the action toward the elevator button.”

Later, the staff members of the action group realized that their role in the action group differed from their role as a professional in the unit. They expressed the need for inter-collegial conversations about what participating in an action group means for them as staff members. They did not feel free to do so within the joint action group.

The hierarchical role of the manager (P11) turned out to be important for the actions that were proposed in the action group. This was the case, for example, in the action for an adjusted elevator button to enable residents in wheelchairs to move independently to other floors of the building. All the managers of the location should have budgeted this adjustment. Neither the residents nor the staff in the action group were able to realize this action. Even P11 could not actualize this on her own; however, she could put the elevator button on the agenda with her colleagues.

Theme 5: needing a shared view of autonomy

To have a shared understanding, the action group explored the meaning of autonomy at the start of the change process. At the start of the PAR, the participants indicated that they obviously knew what autonomy was. The organization formulated and shared a clear vision on autonomy, and action group members joined to enhance the concept. When asked to explain what it meant, the residents said:

> “Autonomy is not ‘figure it out yourself’, nor is it ‘it is your responsibility’” (P1).

The staff described it as follows:

> “Autonomy is about what the residents really want. You must talk about it on admission and continue to do so during their stay. Having a continuous conversation about autonomy because it can differ every day. Autonomy is about expressing wishes. Staff needs to know how they can help the residents to live their own life” (Excerpt from an action group record).

Discussion

The aim of the current study was to gain insight into how the PAR process contributes to enhancing autonomy in day-to-day practice on the unit. The following research question was answered: what processes occur between residents and staff in the participative action research to enhance the autonomy of residents on the unit level?

Eight themes to characterize the processes were distinguished. The action group identified three themes: 1) frictions in the collaboration; 2) listening to each other; and 3) taking small steps. The research group found five themes: 1) collaboration between residents and staff; 2) learning to learn together; 3) working together on actions to enhance autonomy; 4) acting from an existing role; and 5) needing a shared view of autonomy.

The action group found in total three themes in the two CCHA analyses. This might have been because they were themselves in the middle of the process when they reflected on it. Possibly the issues that were most prominent at that moment came to the forefront. When the action group's themes, which relied on the overall data set, are compared with those of the research group, there is evidently an overlap. The themes of frictions in the collaboration and collaboration between residents and staff are similar. The overlap also applies to the themes of listening to each other and learning to learn together, and taking small steps and working together on actions to enhance autonomy.

The process in the PAR showed an unfolding of participation in the collaboration between residents and staff during the year the research took. The participants moved from learning to collaborate as an action group toward learning to learn together, to eventually being able to decide jointly on inclusive actions and act together. Below, some of the barriers that occurred in the collaborative process are discussed. Subsequently, the authors will discuss the actions undertaken and the participation of residents and staff in research.

How the processes in the PAR affected the residents

In the planning phase, the residents in the action group mentioned many ideas to enhance autonomy in the unit. However, they did not take up the actions themselves and implicitly left this to the staff in the action group. It was felt that residents acted in the way of ordering the staff to start actions, a power issue which was not anticipated by the researcher. It is possible that the participating residents were acting in their role as residents. For residents, it is not common to engage in the organization of the unit such as schedules, break times, and available devices.

JvL foresaw power issues between staff and residents and planned a separate meeting of the residents without staff every two weeks, assuming the staff would be dominant in the dialogues. It seemed to be the other way around. In other studies, this process of protection of participants is described as having a negative impact on the process of collaboration (16). In hindsight, protection of the residents in the PAR process was an inconvenient choice.

Furthermore, the residents in the action group wanted to keep information to themselves until an action was successfully completed. This hampered the other residents in the unit becoming part of the process of enhancing autonomy.

How the processes in the PAR affected the staff

The staff reacted with independently assumed actions without the participation of the residents in the action group. It seems that staff tended to respond in their role outside the action group—for example, as a nurse or occupational therapist. In that role, they are used to taking care of planned interventions. The staff were probably not used to the fact that the role of the residents can be altered when participating in an action group. The problems in the collaboration revealed that the good intentions of staff did not always lead to the desired outcomes. Becoming aware of one's own behaviors during the process could be perceived as stress-inducing. Hedman and Häggström (7 p 287) mentioned 'unspoken rules' in the nursing home in this context. Kemmis (23 p 461), referred to this process as 'unwelcome truths'

that can emerge during action research. However, he argues that to achieve real change in practice, researchers should actually have to look for those unwelcome truths.

How the learning process was affected

The learning process in the PAR could have been expected because none of the residents and staff had participated in research such as a PAR before. The participants had no idea what would happen along the way or how and what to expect from their participation. For example, ownership of actions as a joint responsibility was not discussed but left open. According to Bendien and Groot (24), an open conversation about how the process of collaboration is going in the PAR could possibly have prevented this.

Although initially there were problems with learning to work collaboratively, the participatory approach to support autonomy at the level of daily life in the unit seems promising. This can be combined with research into effects. A method such as practice development can also be used with the sole intention of collaboratively enhancing autonomy in the unit (12).

Actions aimed at enhancing autonomy

During the PAR, six actions were taken up by the action group. The participants were invited to propose them. The residents mostly used that opportunity. The actions seemed to go in all directions and seemed not to have much coherence. However, the proposed actions that originated from the life world of residents were surprising and quite different from the policies developed form the organizational perspective to enhance autonomy. Precisely because the participants suggested the actions, they can help to enhance acceptance of the proposed actions. This makes it valuable to listen to the ideas of clients and staff at the unit level.

The effect of the actions undertaken to enhance autonomy was not studied. Although participants mentioned in the observations during the action spirals that small steps were taken, the outcomes are not conclusive.

Participation of residents and staff in research

Older adults as participants

The residents in the action group were involved and had an active role. In most studies, older adults are left out or are not seen as co-researchers. There are ageist beliefs about the abilities of residents to act as participants in PAR (25). In the current research, it was the residents who put issues on the agenda and suggested actions. This shows that the residents were able to be both subjects and objects in the PAR. Notwithstanding their physical impairments, they were able to identify, prioritize, and monitor actions. The group remained intact for the most part during the entire research period: only one person had to step down due to health reasons.

Staff as participants

Staff realized that engaging in action research to enhance autonomy affected them as well. They expressed the need to talk this through in peer supervision. The involvement of staff on the level of the unit in research in long-term care is not usual. That probably made the researchers misjudge the vulnerability of this group. At the same time, including them was valuable because it was they who eventually explored the actions, first by themselves and later together with the residents.

Strengths and limitations

To ensure the trustworthiness of the study, the quality criteria of credibility, transferability, dependability, confirmability, and reflexivity were taken into account (26).

Credibility is about how true the results of the study are. This was increased through the prolonged engagement of JvL with the nursing home unit. JvL was present every two weeks during the year; she built trust and invested time to get to know the residents and staff. The unit developed the design and planning of the research together with JvL, amongst others. As discussed above, the action group largely stayed together during the research period, which showed a strong commitment. Despite residents' health problems that had prompted the move to the nursing home, they were able to engage in collaborative action toward autonomy.

Because of the participative nature of the research, information was given, laid down in records, shared with all participants, and analyzed by the participants of the action group itself through the process of action and reflection. This member check also increased the study's credibility.

A limitation is that the findings of the current action research are generated in the practice of the unit under study, a nursing home where older adults with physical impairments live and where staff work. However, the processes that have been identified are relevant to other settings. To enable transferability of the processes found to other contexts, the researchers have provided a description of the context, the participants, and the methods used. Furthermore, two additional tables describe the data collection with the six action spirals of the action group and the themes and subthemes of the data analysis of the process.

Dependability entails that participants assess the findings, interpretation, and implications of the study (26). Given the participants' presence and analysis in the PAR, the dependability of the study is enhanced. Furthermore, a strength is the presence of a rich data set which encompasses the records of the action group, evaluations of the process of the action group, a log with reflections explored with the research group and external mentor, the proposed actions and actions taken, and artifacts such as photos, posters, and association materials.

A strength is that the joint analysis and interpretation in the CCHA was applied to the overall data set. After following the six phases of data analysis, conformation of the themes—phase seven in the CCHA analysis—was sought in the data set. This was done by JvL, who coded the fragments of the data set deductively with ATLAS.ti using the themes that were found. MJ analyzed the output of this exploration and discussed the themes and the assigned

codes with JvL. Finally, JvL reported the rephrased and clustered themes. This going back and forth in the data heightened the confirmability.

Another strength is that reflexivity—i.e., systematic consideration of possible bias—was addressed by JvL throughout the entire study period. JvL reflected on her values concerning autonomy before (2016–2018) and during the research process (2018–2019) with an external mentor. JvL also reflected using a log and explored this log with the research group.

JvL was aware of the tensions in the action group that hindered the collaboration but waited until the process did its work. JvL withheld from fixing the process (27). Those tensions are an inherent part of the dynamic process involved in participating in the PAR because it changed ways of interacting with each other. JvL used inclusive language and slowed down the pace when necessary, not laughing or talking issues away. Time and space were needed by the group itself to start working in a collaborative way.

There is a delicate balance between the theory of conducting action research methodically and how this works in practice (28). A strength of the study is that it enabled observation of how action groups worked in practice, which was not always so systematic. The action group did not consistently act and reflect upon all actions. Some actions were taken up between action group meetings by individuals and not in collaborative action between (some) residents and staff.

The use of creative methods for dialogue needed further exploration for the residents in question, being older adults with physical impairments living in a nursing home. The residents' wheelchair trays hindered the use of creative materials such as markers, glue, paper, and fabric. The residents also preferred a language-based dialogue. In the PAR, creative methods are ideally used to facilitate and enlighten conversations. After some experimentation, a combination of creative and verbal methods worked well. The use of "build your story blocks" (29), cartoons about autonomy, and photo elicitation (19) did the intended use of creative methods in the dialogues and the data analysis (CCHA) justice.

Implications for Practice and Future Research

Organizations or units that aim to enhance the autonomy of older adults should consider using a participative method, including residents and staff as partners. In this way, both participation and autonomy can be enhanced in the life world of the residents.

Physical capacities should be considered when choosing methods: creative work forms are not always appropriate for the population targeted.

Enhancing autonomy needs a culture change and it is not achieved quickly. A long-term commitment to enhance autonomy with collaborative action on the level of the unit should be realized. All persons involved should be included. This also concerns residents and staff who did not participate in the action group itself.

It is also advised to make arrangements to involve staff that are not participating. This might support staff members in the action group. This can create opportunities to share the proposed actions and to increase the support to explore them on the unit.

It is advised to share the experiences of the participative process and actions outside the action group, in the unit and in other units in the nursing home. Other units and locations can learn from the process and the results of the actions on autonomy.

There are four lessons to be learned from the facilitation of the process.

Firstly, the staff and residents themselves should participate in the design of the study. They might have been able to indicate how they envisioned the participative meetings and react to the design JvL proposed. The separate meetings for the residents patronized the residents and disregarded the vulnerability of the staff.

The second lesson learned is that the process of cocreation is not understood by all the participants. Muller-Schoof and Verbiest (30) experienced the same in the PAR they conducted. In the preparation for the PAR process, it could be useful to share expectations of how this process of co-researching might go in practice (24). A significant focus in this regard is that it is not just about proposing actions but also about jointly considering actions, exploring and evaluating them.

The third lesson concerns the reluctance of the researcher to intervene in the communicative space. The researcher may have applied this too strictly. JvL could have addressed the processes in the group to a greater and more frequent extent. For example, by asking deeper questions, more clarification, focus, and speed could possibly have been brought to the process.

The fourth lesson is that action spirals should be continued for longer until actions are completed. In this study, many actions were proposed and started but were not fully explored. Having a facilitator involved in the preparation and support is essential to ensure progress in the group process.

Conclusion

This study answered the research question: what processes occur between residents and staff in participative action research to enhance the autonomy of residents on the unit level?

The participation of residents and staff and the collaboration between them made the learning process, to collaborate and participate, visible. It was a dynamic and challenging process to be able to learn together, to listen to each other, and to meet on a reciprocal basis, relying on each other, not taking over, and having influence, but having the courage and the shared will to enhance autonomy.

The process of working with an action group supported by a facilitator helped to identify and explore actions jointly to enhance autonomy. When a change in daily practice is taken up in collaboration with those concerned, the process aligns with the life world of residents and the work of the staff in the unit. This is a promising method to enhance autonomy in daily practice.

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Appendix 1. Overview of the PAR meetings

Time period	D = data M = method P = participants	Aim/focus
Planning phase		
September 2018	D: Description of autonomy, identification of nine possible actions M: Photo elicitation and cartoons P: Action group*	Start action group: Shared understanding of autonomy, identification and prioritizing of possible actions
Phase of action-observation spirals		
October 2018	D: Records of the actions and observation of the actions taken M: Dialogue about the records and observed outcomes P: Action group*	Spiral 1: The availability of staff during breaks, a call system that functions well and staff who responds to calls as an action to enhance the autonomy
November 2018	D: Records of the actions and observation of the actions taken M: Dialogue about the records and observed outcomes P: Action group*	Spiral 2: Being (better) able to receive feedback by staff as an action to enhance autonomy
December 2018	D: Records of the actions and observation of the actions taken M: Dialogue about the records and observed outcomes, a visit to another nursing home to see possible elevator buttons P: Action group*	Spiral 3: An elevator button that can be used independently by residents as an action to enhance autonomy
February 2019	D: Records of the actions and observation of the actions taken M: Ordering text cards with actions as: taken up, no longer an issue, or completed P: Action group* and guest: staff member with a specific field of interest	Spiral 4: Knowing who is responsible for what in the team as an action to enhance autonomy
March/April 2019	D: Records of the actions and observation of the actions taken M: Dialogue about the records and observed outcomes P: Action group*	Spiral 5: A direct contact for oral care as an action to enhance autonomy regarding the residents' agenda

May/June 2019	D: Records of the actions and observation of the actions taken. M: Preparation of the dialogue with photo elicitation, a dialogue with the manager and after this a dialogue about the records and observed outcomes P: Action group*	Spiral 6: A dialogue between the residents and the facility manager about how and where residents prefer to sit when they visit the restaurant

** Note: The resident action group met every two weeks. Every four weeks, the participating staff members and the residents united in the joint action group.*

Appendix 2. Themes and sub-themes from analysis of the overall research group data set

	Themes (+ number of fragments)	Sub-themes (+ number of fragments)
1	Collaboration between residents and staff (28)	Being a community (2) Different perspectives and notions (2) Reciprocity (7) Joint ownership (9) Power relations (8)
2	Learning to learn together (26)	Learning together (2) Equal access to information (10) Communicating inside and outside the action group (14)
3	Working together on actions to enhance autonomy (19)	Inclusive actions (17) Many steps taken (2)
4	Acting from an existing role (32)	Culture of doing (6) Professionals' perception of their tasks and responsibilities (8) Spheres of influence (2) Roles (16)
5	Needing a shared view of autonomy (4)	Shared vision on autonomy (3) Gap between vision and practice (1)

7

General discussion

7.1 Introduction

The general aim of this thesis is to gain knowledge on how older adults with physical impairments living in nursing homes, together with staff in the care environment, maintain and enhance autonomy. The following research question is addressed: *'How do residents with physical impairments, together with staff in a nursing home environment, maintain and enhance autonomy?'*

This involves not only the perspectives of those within the direct care relationship, older adults, and the staff. It also concerns the organisational perspective; with which policies do board managers together with other stakeholders in the care environment support autonomy? Therefore, it is important to obtain more insight into these multiple perspectives.

The thesis comprises three sections.

Section one (chapter 2) gives a theoretical explanation regarding what is already known about factors that act as facilitators for and barriers to maintaining autonomy in the nursing home.

Section two describes the perspectives of older adults, the staff, and the care organisation. Using shadowing as a research method, chapter 3 explores the perspective of older adults in maintaining autonomy and chapter 4 explores the perspective of staff when enhancing autonomy at the unit level. Chapter 5 elaborates on the policies that were developed by the board managers together with other stakeholders, such as members of the client council, policy staff and learning consultants, to enhance autonomy in the nursing home.

Section three (chapter 6) describes the process by which, through participation, autonomy can be enhanced at the unit level.

In this final chapter, the general discussion, we give an overall reflection on the results and the theories we used in the study. Then the strengths and limitations will be discussed, followed by considerations for future research and recommendations for practice and education. To complete the circle, the case of Mrs Bel, who was introduced in the general introduction, will be continued at the end of this general discussion.

7.2 Discussion of the main findings

Section one offers a theoretical exploration of the literature about the autonomy of older adults with physical impairments, living in nursing homes. Autonomy was found to be a broad, multifaceted and relational concept that can be influenced by many factors in various ways. A description of the concept of autonomy for older adults with physical impairments living in nursing homes was derived from the reviewed literature. 'Autonomy is a capacity to influence the environment and make decisions 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 it develops in relationships' (1 pp 1038-1039). Moreover, our literature review distinguished four themes to describe the facilitators for, and barriers to, autonomy that older adults living in nursing homes encounter. 1) 'Characteristics of residents',

such as having meaningful activities or having family and friends, 2) 'prerequisites of professional caregivers', such as awareness of beliefs and values and ageist communication, 3) 'care processes between resident and caregiver', such as empowering communication and persuasion, and 4) 'environment of care', such as private spaces for residents and employment of skilled and permanent staff.

These themes, used to organise the facilitators for, and barriers to, autonomy correspond with three of the key domains of the framework for person-centred practice (PCP) (2). 'Characteristics of residents' was not a key domain of the PCP framework. Other researchers who have become aware of the same issue that residents were missing from the framework, have recently further developed the PCP framework into the Person-centred Practice Framework for Long-Term Care (PeoPLe) (3).

In the next section we will discuss the findings of the empirical studies. First, we will discuss the results concerning the two actors in the care relationship: the residents and the staff who try to maintain and enhance autonomy. In the next two sections the influence of the care environment on autonomy will be discussed: first at the unit level and then the organisational level.

Maintaining and enhancing autonomy in the care relationship

In nursing homes, autonomy is almost always relational due to residents' limitations. It is shaped in the relation between nursing home residents and the staff. Below, the findings regarding their perspectives are discussed. These findings originate from both shadowing studies and the PAR study in which older adults and staff collaborated to enhance autonomy.

Shadowing revealed that older adults maintain their autonomy in the nursing home to a certain extent, but often require the help of others in executing their decisions. It identified six ways that nursing home residents maintain their autonomy. 1) 'Being able to decide and/or execute decisions'; 2) 'active involvement'; 3) 'transferring autonomy to others'; 4) 'using preferred spaces'; 5) 'choosing how to spend time in daily life' and 6) 'deciding about important subjects'.

The staff were found to be committed to enhancing the autonomy of residents and employed various ways, i.e., 1) 'getting to know each older adult as a person and responding to his/her needs'; 2) 'encouraging an older adult to perform self-care'; 3) 'stimulating an older adult to make choices' and 4) 'being aware of interactions'.

The ways in which older adults maintain their autonomy seem to fit with the ways employed by staff to enhance autonomy. We elaborate on three examples of how the ways to maintain and enhance autonomy match. The first example is when an older adult makes a decision and if possible, carries it out. Here, it is important that the staff do not take over and if necessary, stimulate the older adult to do as much as possible themselves. Moreover, staff can help the older adults to make choices. The second example is that the active involvement of residents is possible when the staff know the resident and respond to the specific needs of individual residents. The third example is making important decisions which requires the presence of the staff who know the person and interact in an appropriate way to enable an authentic conversation and to address the expressed wishes and needs.

To enhance autonomy from this relational point of view, it is essential for residents and staff to be in dialogue with each other to find out what is important for the older adult and whether the possibilities in the nursing home can match or be adapted to these preferences. The older adults' ways of maintaining autonomy will be less successful without a response from the staff and others near them. It is in this relationship that autonomy is expressed and flourished. These interactions between residents and staff to maintain and enhance autonomy have been studied by others and were described as the relational dimension of autonomy (4-6).

However, it must be said that we also observed that staff were missing the diverse and sometimes subtle signals of older adults aiming to maintain autonomy. The older adults' ways to maintain autonomy and the staff's ways to enhance autonomy were not always deployed and seemed to not necessarily correspond in the care processes. For example, we observed an older person who said she wanted to stay in her bed, but she was persuaded by the staff to get up and have a shower. For each of the four identified ways employed by staff to enhance autonomy, we observed interactions in which the ways were not deployed, or were deployed inappropriately, leading to frustration rather than facilitating the autonomy of specific residents. In another study on the autonomy support of nursing home residents with dementia, Hoek and Verbeek (7) found that in 60 percent of the interactions between the older adults and staff studied, the older adult was well involved, in 40 percent there were 'missed opportunities'.

Our research showed that the ways older adults strive to maintain autonomy were sometimes missed because the staff did not seem to be aware of these ways. Furthermore, aspects in the care environment appear to have a major impact on the possibilities for the staff to recognise and respond to the ways older adults try to maintain autonomy. For example, some staff were encountering time constraints and as a result, felt themselves less able to perceive the signals older adults used to attempt to exert autonomy. Hedman and Häggström (8) also found that although staff were committed to supporting the autonomy of residents, the circumstances in the care environment, such as the number of staff on duty, were found to hinder autonomy.

We not only explored how autonomy was maintained and enhanced in the relationship between older adults and staff in care processes. In the PAR study, older adults and staff also collaborated in an action group to increase autonomy at the unit level. The members of the action group analysed the process they went through during the PAR itself. They identified the following three themes: 'frictions in the collaboration', 'listening to each other' and 'taking small steps'. The group found it difficult to communicate about routines on the unit. These routines, such as staff taking breaks together, seemed to be blind spots. Unspoken rules about the practices that hindered the autonomy of older adults became visible. At first this caused frictions, as it was experienced as an unwelcome truth. Later older adults and staff were able to establish a dialogue.

There seem to be possibilities to improve the connection in the ways older adults seek to maintain autonomy and the ways staff try to enhance their autonomy. Older adults and staff

can evaluate and reflect on actions in the individual care processes. Furthermore, they can reflect on the influences of routines at the unit level.

Maintaining and enhancing autonomy in the unit

The results discussed in this section are from the PAR study, which aimed to collaboratively enhance and maintain autonomy at the unit level.

On the unit that participated in the PAR study, the participation of older adults beyond their individual care plan was not evident. However, we did find opportunities for older adults to exercise autonomy at the unit level. Meetings were regularly arranged in the living room so that residents and staff could discuss the daily affairs on the unit. Residents and staff considered the meetings to be a valuable way to share their experiences of and suggestions about living and working on the unit.

During our research, we created another opportunity to enhance autonomy at the unit level; meetings of an action group of residents and staff were facilitated by the first researcher in the PAR study. The aim was to enhance autonomy in the unit in a collaborative way. Processes such as 'learning to collaborate' and 'learning together to work on actions to enhance autonomy in the unit' were identified. Learning processes of both older adults and the staff thus became apparent in the PAR study, confirming that older adults and staff can learn and adopt new attitudes and behaviour. Work-based learning (WBL) is found to be an important but often overlooked way to learn in nursing homes (9). The review by Muller-Schoof and Verbiest (9) on WBL of caregivers in nursing homes identified conditions that support learning, such as organisational support, learning structures and scheduled time for learning. In our PAR study, such conditions were created prior to the process. The care organisation supported the meetings on enhancing autonomy, provided scheduled time and enabled the meetings to be held in the unit.

In conclusion, participation in organised meetings such as living room meetings or action (working) groups of older adults and staff were found to be both achievable and positive in addressing autonomy at the unit level. However, the preconditions we were able to create during the study, such as active facilitation and organisational support, are necessary for ongoing participation. The work-based learning process can help older adults and staff to adopt new attitudes and behaviour to maintain and enhance autonomy together on the unit.

Maintaining and enhancing autonomy in the wider care environment

When we focus on autonomy enhancement at the level of the care environment, organisational choices such as the architecture of the building, often designed and built decades ago, influenced autonomy as well. Mayer and McCormack (3) state that the PCP framework works from the key domain in the outside circle to the domain in the inside circles. To achieve person-centred care processes and outcomes, the care environment must first be modified. For this reason, altering aspects of the care environment are seen as having the most potential according to Mayer and McCormack (3) and enhance person-centred care processes and, as a result, autonomy (10).

Our study of policies of two care organisations to enhance the autonomy of older adults through strategies relating to the care environment revealed that the intention to enhance the autonomy and corresponding policies were ambitious. In both organisations, a vision of autonomy was developed and actively shared with all stakeholders, and a programme was initiated to increase autonomy. However, not all aspects of the key domain 'care environment', as distinguished in the PCP framework (2), were considered to the same extent. The aspects 'physical environment', 'effective staff relations' and 'shared decision-making systems' were hardly addressed in nursing home policies to enhance the autonomy of older adults.

We found most policies were on the aspects 'appropriate skill mix', 'power sharing', 'supportive organisational systems' and 'the potential for innovation and risk taking'. However, these policies were often indirect, for example the development of self-managing teams was expected to enhance the autonomy of residents, although we found no underlying evidence for this assumption. The process towards the aim of self-management was monitored among staff and managers. However, the assumed effect on the autonomy of older adults was not evaluated with the residents.

Although modifying the care environment was considered to have the greatest potential for enhancing person-centred care processes (3, 10), our PAR study found that the routines on the unit that hinder the enhancement of individual autonomy do not seem to be fully addressed by organisational policies. Noteworthy is that in the PAR study, residents and the staff on the unit proposed different actions to enhance autonomy than those found in the organisational policies of the board managers and other stakeholders. The suggested actions in the PAR focused on practical solutions to maintain and enhance autonomy and were thus closer to the lived experience of the older adults on the unit. Abma and Baur (11) suggest involving older adults to engage in collaborative actions to have more control over their lives in nursing homes. In their view, the more traditional ways of representation, such as client councils, are management driven instead of driven by the lives of older adults in the nursing home (11). This indicates that both types of participation; the legally required involvement of client councils at the organisational level and involvement of residents at the unit level can be complementary to enhance autonomy.

To conclude the discussion on the care environment at the unit level, and at the organisational level, we identified some possible ways for including residents in the development and evaluations of policies that are close to their lived experience. Organisational policies towards enhancing autonomy could be focused on this deeper layer: the older adults themselves. Board managers together with other stakeholders could consider a broader focus in the development and implementation of policies towards autonomy through a critical consideration of structures that exist in the organisation. Which rules, routines, protocols can be adapted to enhance the autonomy of older people?

7.3 Reflection on the theoretical basis

Our results revealed multiple dimensions of the concept of autonomy. When staff and care organisations strive to provide person-centred care for residents, it is always important to involve the nursing home residents themselves. Therefore, two theories, the person-centred practice framework (2) and the insights that Collopy shared about autonomy in long-term care (12), were applied in the studies. In this section, we reflect on their applicability for our research.

The PCP framework consists of five key domains: 'macro context', 'prerequisites of caregivers', the 'practice environment', 'person-centred processes' and 'person-centred outcomes' (2). In our research, we focused on three key domains and specified the terms used for the domains to fit the stakeholders in the nursing homes context, 'prerequisites of professional caregivers', 'care environment' and 'care processes'. The framework appeared useful for organising most of the results we found in the literature review. Furthermore, it helped to design the studies on the perspectives of older adults and staff. In addition, in the study about (implementing) policies concerning autonomy we used the aspects of the key domain 'care environment' to analyse and synthesise the data.

Because the PCP framework was not developed for long-term care as given in nursing homes, it has a limitation. The care recipients, in the current study nursing home residents, were not included in the framework. We added the domain 'characteristics of residents' to include the results of the older adults in the literature review. This addition was motivated by the finding that most of the reviewed articles investigated this perspective, and a large set of attributes of residents that influence autonomy could be distinguished.

The addition of the care recipient illustrates the need to give older adults an appropriate position in the framework for Person-centred Practice. In 2020, when data for our research were already collected, the PCP framework was further developed for nursing home care. Mayer and McCormack (3) experienced a similar shortcoming and conducted a study on how the client in long-term care could be appropriately positioned in the framework. The Person-centred Practice Framework for Long-Term Care (PeoPLe) was the result of this work. 'Fundamental principles of care' were added to the key domain 'person-centred processes'.

The second theoretical basis for the studies in this thesis was Collopy's work on autonomy in long-term care (12). Collopy (12) described various dimensions of autonomy, including executional, decisional, delegated, authentic and direct autonomy, and discussed autonomy in the context of nursing homes. Furthermore, Collopy explicitly asked for more consideration of the nuances of autonomy and more research into the dimensions in practice (12). Shadowing residents and staff revealed both decisional and executional dimensions of autonomy. Residents with physical impairments are generally able to make conscious decisions about how they want to live their lives, but they often experience limitations in executing them. The predominance of executional and decisional dimensions of autonomy has also been found in other studies on older adults in long-term care (13, 14).

In our shadowing study of older adults and the PAR study, we also found delegated and relational dimensions of autonomy. The older adults' ways to maintain autonomy could not

have been successful without a response from the staff and others near them. Delegating actions to trusted persons was an example of this.

With these results, the studies confirmed Collopy's thinking about autonomy in the nursing home and its results are based on a nuanced approach to the dimensions.

7.4 Strengths and limitations, recommendations for further research

In this thesis, several research methods have been used. The strengths and limitations of these methods have been addressed in the individual chapters. This section shows the overarching considerations about the strengths and limitations of our research.

To enhance the credibility of our research, we used different sources, investigators and methods (triangulation) (15) in the following three ways:

1) Data triangulation, which refers to the use of multiple data sources in time, settings and persons, was used. We involved older adults, staff, the board managers and other stakeholders in the care environment of the two participating nursing homes. Furthermore, we shadowed the day-to-day practice for a period of half a year. The research into the multiple perspectives to maintain and enhance autonomy is a strength.

2) The use of method triangulation, the use of multiple methods, i.e., the systematic literature review, shadowing, the document study, interviewing and PAR, led to in-depth insight into the many perspectives from which autonomy can be understood.

3) To prevent researcher bias – the first researcher collected most of the data on her own –investigator triangulation in the data analysis was applied. The data were co-coded by the research team and consensus seeking meetings were included in each data analysis.

Moreover, the researcher reflected on her own beliefs and values regarding autonomy with a mentor who was not involved in the research. Furthermore, the researcher explored how to apply the outcomes of these reflections in the studies. She kept a log when doing the empirical research from 2017-2019. With the deployment of reflexivity and the keeping of a log, trustworthiness is enhanced (15, 16).

The PAR study was conducted in one organisation. A point of attention of this single case study is the extent to which the findings about the process can be applied to other situations. In order to achieve this, the suggestions of Lincoln and Guba (1985) were used to strive for transferability which they define as "the responsibility of the researchers to ensure that sufficient context information about the fieldwork sites is provided to enable the reader to decide whether the prevailing environment is similar to another situation with which he or she is familiar and whether the findings can justifiable be applied to the other setting" (17 pp 69-70). In the PAR study, diverse measures to ensure transferability of the data were taken. With a detailed description of the context in which the research took place, the methods used, and the processes that were followed, it was made possible for readers to transfer the findings to other contexts.

Two units in two distinct nursing homes (one per organisation) participated in the shadowing studies aimed to gain insight into the perspectives of the nursing home residents

and staff. On the one hand, this was a strength because it was possible to observe the perspective of both residents and staff interacting with each other. On the other hand, including no more than two nursing homes could be a limitation of the study. The selected units were housed in two very different buildings. Furthermore, they differed in terms of the deployment of staff and the location. Unit A is situated in a large town and unit B in a small town. However, all the participating residents shared a working-class background.

Another limitation may be the descriptive nature of our studies. For example, they did not measure the effects on autonomy of the actions of the older adults, the staff and the policies in the care environment. However, such a descriptive study is a first necessary step to elucidating the autonomy of older adults in day-to-day practice, before explanatory or effect research can be conducted.

Recommendations for further research

Our research focused on older adults with physical impairments living in nursing homes due to ageing and chronic conditions. There exists the same need for knowledge on the autonomy of other groups, e.g., community dwelling older adults, clients needing geriatric revalidation, and older adults with cognitive problems. Within these care environments, questions also arise about how these older adults can maintain autonomy and how care staff and board managers together with other stakeholders in the care environment can best respond to this. The dimensions of autonomy are likely to be manifested differently. For instance, in care for community dwelling older adults, there will probably be more emphasis on the dimension of executional autonomy and maybe less emphasis on the care environment.

In our research, we focused on the main stakeholders concerned, the nursing home residents and the staff. However, they are not the only actors involved in maintaining and enhancing autonomy. Further research on the role of other stakeholders, such as family, (para)medic professionals and volunteers regarding the autonomy of nursing home residents is recommended.

Our research did not attempt to conduct effect research but was exploratory and descriptive in scope. To move to the next step of establishing the effect of the interventions and policies found, effect research is recommended. Further research is needed on the effects of chosen policies in the care environment on residents' autonomy. For example, the access to one's own care plan could provide valuable insights as to whether autonomy is a topic of conversation, what needs and wishes have been recorded and what has been agreed upon, in this regard.

A last recommendation concerns research in nursing home care for older adults. It is recommended that older people should be given a full role as partners in research. This also applies to staff at the unit level. Both older adults and staff are rarely co-researchers in improving care practices (18, 19). This addresses the two sources of knowledge that stand alongside that of scientific knowledge. These three sources together form the basis of evidence-based practice (20).

7.5 Recommendations for practice and education

Older adults and staff

Older adults can have more involvement in their direct care, both at the unit level and the organisational level. When they can articulate their preferences and wishes and give feedback, they can better maintain their autonomy. The staff can learn to understand the needs of nursing home residents with the use of a narrative method. An example of such a tool is the 'Story as a Quality Instrument', an open interview approach in which the resident is leading and talks about what is central in their lifeworld (21).

We recommend that the staff explore their beliefs and values about autonomy and reflect on how their practices affect older adults' autonomy. Possibly, 'Action Learning', which can be described as an approach to in-depth learning that builds on, synthesises and integrates multiple learning methods, could help teams to develop these skills (22). Checking and evaluating with the older adults themselves (see recommendation one) should be part of this process.

Also, by means of daily reminders such as reflection questions, prompts and dilemmas, staff can daily consider how they influence and enhance the autonomy of residents. An example of such a daily reminder is the autonomy calendar, which is based on the findings of our two shadowing studies. The calendar has been developed in co-creation with care staff, older adults, designers and researchers to stimulate reflection at the unit level. Staff and residents can talk about the 'page of the day' in an accessible and informal way (23).

To learn and reflect on how the staff enhance autonomy in their daily work, observational learning, such as the method of shadowing, can reveal how colleagues enhance autonomy in their daily work (24, 25). The findings of the shadowing studies offered ten ways in which autonomy was found to be maintained or enhanced (26). These 'ten viewpoints' can be used to shadow colleagues and residents during morning care, mealtimes and activities.

The recommended learning activities in the unit should be a continuous effort. When the composition of the team changes, new colleagues bring different insights and experiences. Also, the residents who live in the unit change; frequently new residents come to live in the unit and their physical condition can temporarily or permanently decline. In our research, we observed residents who had lost their ability to have executional autonomy, therefore their autonomy made a shift to the decisional and delegated dimensions of autonomy. Staff actions had to be adapted to this change.

Board managers and other stakeholders in the care environment

Board managers together with other stakeholders in the care environment mostly deployed indirect policies through the staff to enhance the autonomy of residents. It is recommended to direct interventions for autonomy on the older adults themselves. An action group of residents and staff seemed promising to enhance autonomy at the unit level. The investment in participation is aimed at improving the alignment of solutions with residents, it can generate innovative ideas, and it will create understanding and support broadly and for the chosen interventions. Furthermore, we advise initiating and sustaining such a process of

participation. To make the process more permanent, a key person acting as facilitator in the unit should support the dialogues between residents and staff. This can be a staff member working on the unit. We recommend, however, that this should be a designated person who is equipped to facilitate the dialogues. This can lead to a culture change towards enhancing autonomy, and a different way of thinking, acting and collaboration in the unit.

Organisations are advised to consider all aspects of PCP and all key domains to develop a broad approach to enhance autonomy. An integral approach is expected to place the older adult at the centre of care (3). Furthermore, organisations should use evidence-based policies to enhance autonomy. In the case where no evidence about interventions is available, organisations could develop and exchange best practices between nursing homes. Besides monitoring the progress of planned interventions, it is advised as well to evaluate the effects of the policies on autonomy with older adults.

Education of health care professionals

To increase the knowledge and use of autonomy-enhancing interventions, more attention could be directed to enhancing autonomy in internships during nursing education. Nursing students should be taught to reflect on their way of acting regarding autonomy and their beliefs and values about the autonomy of residents. They can also learn how 'conversation time' can be scheduled into the care processes. This could allow students to practise communication skills that support autonomy, such as really getting to know someone.

Furthermore, it is advised to examine how knowledge about and development of competences to enhance autonomy are embedded in the current curricula, as some adjustments may be needed.

7.6 The story of Mrs Bel continues

Mrs Bel was introduced in the general introduction.

> *Mrs Bel is a socially active person and former schoolteacher of 74 years old. After a recent stroke, she remained semi-paralysed. She needs a lot of care with dressing and undressing and going to bed. She lived a while with her daughter. Eventually Mrs Bel made the decision to move to a nursing home. Although she likes the location, she experiences some difficulties. She must dress herself, which costs her a lot of energy. Energy she prefers to use to visit her daughter using her mobility scooter. Mrs Bel also dislikes being obliged to eat in the living room, due to her swallowing problems.*
>
> *Recently in the nursing home, residents were invited to evaluate their care plan twice-yearly and Mrs Bel was invited to evaluate her care plan. She had formulated this six months ago with the elderly care physician and the coordinating nurse. For the initial care plan and all modifications to it, the older adults are asked to give consent. In this way, the plan is intended to be better aligned with wishes and needs*

and Mrs Bel could have more control over the care she receives. Mrs Bel asked her daughter to join her. In preparation, they read the report on the care plan together. They read the arguments between Mrs Bel and the nurses relating to 'doing as much as you can do yourself'. They found out that no agreements about this objective were set out in the care plan.

During the joint evaluation of the care plan, they had a dialogue with the elderly care physician and the coordinating nurse about the disagreement around 'doing as much as you can do'. Mrs Bel explained that she wanted to spend her energy on other daily activities, such as visiting her daughter. This was understood by those present, and they wanted to help to make sure Mrs Bel had enough energy for other activities, so this was formalised in the care plan.

However, this agreement in the care plan gave rise to a lively discussion at the nurses' station. One nurse said: 'If you take over tasks from residents, you take away their autonomy.' Others asked, 'Can it be an expression of autonomy if a resident says what she wants to spend her limited energy on?' It turned out that the team did not share the same opinion on what autonomy meant for the residents on the unit and consequently in what ways the team could enhance autonomy. They decided to have a dialogue about this topic in the team meeting. The exchange of experiences and views helped the team to become more aligned and to consider the autonomy of residents in the unit more broadly than just encouraging self-care.

To discuss the daily affairs in the unit, a monthly living room meeting for residents with staff was planned. Mrs Bel mentioned in this meeting that she did not like the mealtime situation. The protocol required that she always needed supervision, because of her swallowing problems. Mrs Bel realised that this is for her own good. However, she indicated that she felt watched by the staff and other residents as she fumbled with the cutlery. She asked the staff whether this could be organised in another way.

She appeared to have supporters among both residents and staff. It was agreed that a group of committed residents, together with the nutritional assistant and a speech therapist would form a working group. The group was going to explore whether there were appropriate alternatives. One of the actions that was explored by the group was to ask a family member or volunteer to be present in the apartment of the resident when eating dinner twice a week. To avoid overburdening relatives and volunteers, they decided nothing else should be altered for the other mealtimes.

The management is currently considering this proposal. They are examining what instruction or training the relatives or volunteers need to ensure the safety of the residents and how to arrange commitments for attendance.

Mrs Bel's story illustrates that nursing home residents have several ways that help them to maintain their autonomy. The staff are committed to enhance autonomy and different ways are deployed. However, the way residents want to exert their autonomy and the reactions of the staff are sometimes not aligned. Moreover, the care environment can hinder both the older adults and the staff.

Therefore, approaches should be used that ensure that a dialogue is initiated on maintaining and enhancing autonomy to learn with and from each other. At the individual level, this can be done during moments of care and in planned meetings such as the care plan evaluations. At the unit level, regular living room meetings can help residents and staff to share experiences of living and working in the same environment, which can lead to collaborative actions to maintain and enhance autonomy in the lived experience of the residents. These meetings should be complementary to the statutory required participation through client councils in which policies to enhance autonomy at the organisational level are discussed.

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Summary

Summary

The topic of this doctoral thesis is autonomy of older adults with physical impairments living in a nursing home.

In **chapter one,** the subject is introduced. Older persons prefer to live independently for as long as possible. If this is no longer an option, for example, due to severe physical impairments, and 24/7 care is needed, a move to the nursing home is often necessary. In nursing homes, however, exercising autonomy might be challenged. For example, there is dependence on others to fulfil needs. The environment in which care is provided also plays a role; there are always others with whom the older adult lives, who also - and sometimes simultaneously - need help. Furthermore, the staff needs to act in accordance with protocols. This can hinder autonomy as well.

Managers of care organisations emphasise the maintenance of autonomy as an important objective in their policies. Care should be person-centred and based on shared decision-making. A recurring question is 'How can we maintain and enhance autonomy in practice?' An additional factor is the fact that the persons involved have a different interpretation of the concept autonomy.

As the theoretical framework for the study, we chose McCormack and McCance's framework for person-centred practice. This evidence-based framework provides the following key domains to deliver person-centred practice: 1) Person-centred outcomes, such as feelings of well-being and good care experiences. 2) Person-centred processes that take place between the care recipient and staff, such as working with the person's beliefs and values. 3) The care environment within which person-centred processes take place, such as the availability of an adequate mix of staff. 4) The requirements that may be asked of staff, such as connectedness to work. 5) The macro context, such as health and social care policies. Consideration of all these domains should lead to (more) opportunities for autonomy.

Collopy's work was the second theoretical basis to explore the concept of autonomy. It distinguishes several dimensions of autonomy of older adults living in a nursing home. These dimensions of autonomy include, among others, decisional, executional, and delegated autonomy. For example, an older adult may decide how she/he would like to live but cannot execute these decisions himself because of his health condition. By delegating the purchase of clothes or the financial administration to family members, an older person can still give shape to how he would prefer to live. In the described dimensions, the relational aspect is present; without the response of others, an older adult living in a nursing home is hindered in exercising autonomy. With these insights, we could clarify the meaning of autonomy of older adults in the nursing home.

This doctoral research aims to gain more insight into how older adults with physical impairments, living in nursing homes, together with the staff in the care environment, maintain and enhance autonomy. The main research question for this thesis is therefore: *'How do residents with physical impairments, together with staff in a nursing home environment, maintain and enhance autonomy*?

The study was conducted in two organisations that provide nursing home care. For the empirical studies (described in chapters three, four, and six), the managers selected one participating unit. The basis for this selection was the population: adults 65 years or older who had physical impairments. The action research (described in Chapter 6) involved one unit within one organisation.

The main research question was further divided into five research questions. This thesis comprises three sections in which these research questions are addressed.

Section one, chapter two, is the theoretical exploration of the scientific literature relevant to the thesis. The research question was: *'Which facilitators and barriers to autonomy of older adults with physical impairments due to ageing and chronic health conditions living in residential care facilities are known?* We conducted a systematic review of the literature.

Reviewing the literature allowed us to describe the concept of autonomy for older adults with physical impairments living in nursing homes. Autonomy can be described as 'a capacity to influence the environment and make decisions irrespective of having executional autonomy, to live the kind of life someone wants and desires to live in the face of diminishing social, physical and/or cognitive resources and dependency, and it develops in relations'.

The facilitators and barriers were arranged in four themes that mainly overlap the key domains of the framework of person-centred practice. 1) Characteristics of residents that can help them to maintain autonomy. For example, being able to stay connected with relatives. Another example is maintaining a good relationship with staff, where the resident experiences being seen as a valuable human being. 2) Prerequisites of professional staff that help to maintain autonomy. For example, being able to build a good relationship with a resident helps to maintain autonomy. 3) Care processes between residents and staff. Staff members who start from residents' wishes and needs and are flexible about this in the (rules of the) organisation, support autonomy. 4) The environment of care that contributes to autonomy. For example, the use of adequately trained and permanent staff who know residents (and their wishes/needs) well. Also, a suitable mix of shared and private spaces in the building enables choice and autonomy.

The **second section** of the thesis addresses the perspectives of older adults, staff, and stakeholders in the care environment in three separate studies.

Chapter three describes the following research question: *'How do older adults with physical impairments who live in a nursing home maintain autonomy in daily life?'*. We executed this study by 'shadowing' older adults, which is a form of long-term and non-participatory observation. Seventeen older adults from two units (one unit per participating care organisation) gave permission to be shadowed for one day during care moments, mealtimes, and activities. While doing so, the researcher took notes and, at the end of the day, checked her interpretations with a short interview. The observation reports combined with the typed-out interviews were studied collaboratively with the research team. They were coded thematically and then analysed to answer the research question.

We identified six elements for maintaining autonomy. 1) Being able to decide and/or execute decisions. Older adults were able to perform some actions on their own and therefore had autonomy. For example, if they applied make-up, chose jewellery, and put

on perfume themselves after being assisted in having a shower. 2) Active involvement. If an older adult could not conduct a decision oneself, it works best if she/he made it directly clear how she/he would like it to be done. For example, when the staff member enters the room, someone can state that the curtains should stay closed, that she would like to have morning care in bed that day, or that the nurse should get that nice shampoo she got yesterday on her birthday. It was difficult for persons with speech disorders to make these wishes (verbally) clear. Permanent staff often understood non-verbal expressions and voiced them aloud. However, the study also revealed that not every staff member knew residents' wishes well. 3) Transferring autonomy to others. The conscious choice to transfer matters to others is a form of autonomy. For example, if someone is visually impaired, buying clothes can be left to one's child. Having the confidence that the other person knows the wishes and needs, ensures that something happens the way the person wants it. 4) Using preferred spaces. Being able to choose how to use the rooms in the nursing home is a way of exercising autonomy. For example, some residents prefer to stay in their own room with the doors closed and others want to keep the door open. 5) Choosing how to spend time in daily life. Sometimes the day seems like a sequence of care and meal moments. But in the space between set moments, life can go on (sometimes as before). Examples of spending time are meeting old friends, sending e-mails, knitting, painting, cooking food, seeing children and grandchildren, listening to music, or watching TV. In this multiplicity of preferences and choices, autonomy is manifest. 6) Deciding about important subjects. While shadowing residents, they spontaneously wanted to share how they thought about autonomy. For example, how they themselves decided to move to the nursing home to reduce the burden on the family. Another example is that a resident said that he really wants to be admitted to the hospital for heart failure, even though it does not make a difference according to the elderly care specialist.

All these six ways of exercising autonomy only become effective through the responses of others, such as staff, family, and friends who notice and follow up on signals and expressions. This fact demonstrates the relational nature of autonomy.

In **chapter four** we further explored the staff responses to and experiences of residents' expressions of autonomy. In this study, we sought to answer the question: *'How do staff members act and what do they experience in relation to the autonomy of older adults with physical impairments living in nursing homes?'* Again, we used 'shadowing' as a method. Fifteen staff members, including nurses, occupational therapists, and nutritional assistants from two units (one unit per participating care organisation) participated in this study. Each staff member was shadowed for several hours while working. We observed what action a staff member performed to support a resident's autonomy. We also observed how the resident responded to this. After the shadowing was completed, a short interview followed to ask clarification questions or check observations. The observation reports, combined with the typed-out interviews, were thematically coded and analysed by the research group.

Four activities to enhance autonomy were identified. 1) Getting to know each older adult as a person and responding to his/her needs. The staff tries to consider the wishes or needs of each individual resident. They do this, for example, by talking to a resident about their past or hobbies. They also often know each resident's preferences for morning care. It was interesting

to see that most staff still asked about someone's preferences, even if they already knew them. However, the staff did mention challenges in supporting residents' autonomy, such as staff shortages. 2) Encouraging an older adult to perform self-care. For instance, washing and drying the face or combing the hair. They also encourage residents to prepare and butter their own sandwiches and to clear the table collaboratively. It is important to do this in alignment with the resident. This allows a resident to indicate if she/he does not wish to do something to save energy for another activity that day. 3) Stimulating an older adult to make choices. During morning care, the staff gives a resident many choices, for example about the order of morning care, clothing, or where a resident wants to have breakfast. Nutritional assistants also give many choices about bread, spreads, and drinks. Nutritional assistants ask what a resident wants to eat or drink, even if this is already known to them. Both organisations work with prepared meals from elsewhere. This has the disadvantage that a resident cannot order, for example, fresh vegetables. Welfare staff offer residents a variety of activities within the location that a resident can choose from. 4) Being aware of interactions. These interactions with a resident take place in verbal and non-verbal ways. Most staff members find it important to support residents' autonomy. They do their best to achieve this, for example by sometimes staying longer at work and by discussing with colleagues how they can support a resident's autonomy. The staff finds it important to give each resident the attention they need. They often use humour in embarrassing situations. For example, because someone was late for the toilet. Yet there were also examples where a resident's autonomy was restricted. For example, when two staff members talked to each other without involving the resident in the conversation or when a staff member maintains their own order for residents' morning care without considering their preferences.

To gain more insight into the context in which the resident and the staff are using their actions to maintain or enhance autonomy, **chapter five** describes the policies related to the care environment that are developed and used to enhance autonomy. In this study, we answer the question: *'Which policy, aimed to enhance the autonomy of older adults with physical impairments in nursing homes, is developed and implemented?'*

We conducted this by studying various documents such as multi-year policy plans and minutes from two nursing homes. For example, we followed what is described about the organisation's vision of autonomy, what is written in the annual plans, quarterly reports, and evaluations of the plans. We also interviewed 17 persons to study whether they were familiar with the vision and the policy and whether they were able to put it into practice. These persons were, for instance, members of the client council, coaches, training staff, senior nurses, or managers.

We organised the results according to McCormack & McCance's framework of person-centred practice. One of the key domains of this model is the care environment. The care environment focuses on the context in which care is provided and involves seven aspects. 1) Power sharing as an equal collaboration based on shared values and goals. 2) Supportive organisational systems, when initiative and creativity are encouraged by the organisation. 3) Appropriate skill mix, where staff with the required knowledge and skills provide care. 4) Potential for innovation and risk-taking based on Evidence Based Practice. 5) How the physical

environment such as the building and furnishings affect privacy and security. 6) Effective relationships between staff to achieve person-centred care. 7) Systems for shared decision-making between professionals such as how teams in the organisation work together. We could conclude that the 'power sharing' aspect was used the most in the policies of the two participating organisations. The organisations expected much from introducing often indirect interventions. For example, they expected to enhance autonomy of residents with access to their electronic care plan and the development of self-managing teams. Less attention was paid to interventions in the physical environment and the process of collaboration between staff. A recommendation from this study was to use all seven aspects of the care environment to develop and implement policies aimed to enhance residents' autonomy.

In **section three** of this thesis, a participatory action research is described through which older adults and staff try to enhance autonomy at the unit level.

In **chapter six** we describe a participative action research (PAR) process in one unit of a nursing home to enhance autonomy in daily life collaboratively – that is, between older adults and staff members. The method of PAR was chosen because it uses a cyclical, participatory process of gaining evidence to bring change to the practice environment. The research question was: *'What processes occur between residents and staff in PAR to enhance the autonomy of residents on the unit level?'* The aim was to gain insight into the PAR processes in which residents and staff propose actions and then explore and evaluate them, aiming to enhance autonomy in day-to-day practice.

To do so, five older adults and a spouse of a resident met every two weeks. They shared ideas about how they felt autonomy could be enhanced in the unit. Once a month, five staff members from the unit joined the group. Older adults and staff collaboratively decided which ideas they wanted to try out on the unit: the actions. They did so for more than one year. The action group used all kinds of creative work forms to collaboratively discuss the actions they tried out and whether they contributed to autonomy. The researcher was always present to facilitate the dialogue.

We learned that it is important to create the conditions for older adults and staff to have this dialogue. For instance, a fixed time should be planned. A facilitator is also important in such a conversation. It also helps to use creative work forms to explain to one another what each person thinks. When the dialogue is organised in this way, older adults provide -sometimes surprising- suggestions. Two examples of actions suggested by older adults are 1) An extra button at the elevator to access it with a large electric wheelchair. This allows older adults to get to another floor or exit without help. 2) Being able, as a resident, to make one's own appointments with the dental service. In this way, they do not depend on a staff member for such an appointment.

We found that the start of the collaborative change process is also a learning process for older adults and staff. The roles of the care recipient and caregiver changed during the meetings: they became collaborating partners. The older adults and staff were increasingly engaging collaboratively to find more opportunities for autonomy.

Finally, we found that it remains difficult to specify what each person understands the term autonomy to mean. At the start, the participants thought they knew what they

understood by autonomy. However, over time they wondered whether they were talking about the same topic and started exploring together how they understood autonomy.

When older adults are involved, they can have a voice in what they think can contribute to enhancing autonomy. A dialogue between older adults and staff should be held, for example, in regularly scheduled living room meetings. Based on themes and guided by a facilitator, the conversation about enhancing autonomy can take place in the unit.

In the concluding **chapter seven**, we reflect in a general discussion on the answers that the five studies provide to the main research question: '*How do residents with physical impairments, together with staff in a nursing home environment, maintain and enhance autonomy?'* The most significant findings are discussed, and the scientific contributions of the studies are described. The main findings are:

- Older adults living in the nursing home have various ways of exercising and maintaining autonomy in the care relationship with staff members. Furthermore, older adults can contribute ideas and participate in decisions on what would help them to maintain autonomy at the unit level.
- Autonomy has a strong relational dimension; older adults living in a nursing home are dependent on how others -staff, family, and friends- respond to their signals to exert autonomy.
- Staff considers older adults' autonomy important and deploys several ways to support this autonomy in the care relationship. However, the connection between older adults' needs and staff intervention is not always present.
- A continuous alignment between older adults and staff is needed to maintain autonomy in the nursing home.
- Collaboratively exploring how the unit can support autonomy can cause tensions in the care relationship. Both older adults and staff go through a learning process to find their way as collaborative partners.
- Care organisations can use policies to design the care environment in such a way that autonomy is enhanced at the unit level and within the care relationship. However, they are not yet making optimal use of this.

We formulated recommendations for practice, management, and education. Older adults themselves should be able to express their wishes and needs and give feedback on the actions of staff and working methods in the unit. Where necessary, they should be facilitated in this by the staff, for example, by using a narrative method and dialogues in living room meetings. The staff should regularly reflect on their views, experiences, and actions regarding older adults' autonomy in planned peer supervision and with the use of daily reminders. Furthermore, they can learn by shadowing colleagues' actions. Managers should involve older adults in formulating and evaluating policies aimed at enhancing autonomy. Furthermore, they are recommended to deploy comprehensive and long-term policies to enhance autonomy. The education for care staff should include knowledge about autonomy and foster competencies to enhance autonomy.

Samenvatting (summary in Dutch)

Dit promotieonderzoek gaat over eigen regie van ouderen met een somatische aandoening wonend in een verpleeghuis. In **hoofdstuk een** wordt het onderwerp geïntroduceerd. Ook al willen ouderen bij voorkeur zo lang mogelijk zelfstandig wonen, kan er een moment komen dat dit niet langer kan. Als er 24/7 zorg en ondersteuning nodig is door bijvoorbeeld de ernst van de aandoening, is een verhuizing naar het verpleeghuis vaak nodig. In verpleeghuizen is het voeren van eigen regie echter niet altijd eenvoudig. Dit omdat er sprake is van afhankelijkheid van anderen om de behoeftes te vervullen. Ook de omgeving waarin de zorg wordt verleend speelt een rol; er zijn altijd anderen waarmee de oudere samenleeft, die ook - en soms tegelijkertijd- hulp nodig hebben. Verder kan de noodzaak tot veilig handelen, vaak vastgelegd in protocollen, de eigen regie negatief beïnvloeden.

Bestuurders van zorgorganisaties geven het behoud van eigen regie een belangrijke plaats in hun beleid. Zij vinden het belangrijk dat de zorg mensgericht is en gebaseerd op gezamenlijke besluitvorming. Een steeds terugkerende vraag is 'Hoe kunnen we in de praktijk eigen regie ondersteunen en bevorderen?' Een complicerende factor is dat het begrip eigen regie voor de verschillende betrokkenen een andere betekenis heeft.

Als theoretisch kader voor dit promotieonderzoek kozen we voor het raamwerk van mensgerichte[4] praktijkvoering van McCormack en McCance. Dat raamwerk benoemt, gebaseerd op wetenschappelijk bewijs, de volgende sleutel domeinen om de zorg meer mensgericht te maken. 1) Mensgerichte uitkomsten, zoals het gevoel van welzijn en goede zorgervaringen. 2) Mensgerichte processen die zich afspelen tussen de zorgvrager en zorgverlener, zoals werken met de opvattingen en waarden van de persoon. 3) De zorgomgeving waarbinnen de mensgerichte processen zich afspelen, zoals de inzet van een adequate mix van zorgverleners. 4) De vereisten die aan zorgverleners gesteld kunnen worden, zoals verbondenheid met het werk. 5) De macro context, zoals de politieke besluitvorming en financiering van zorg. Aandacht voor al deze domeinen, zou moeten leiden tot (meer) ruimte voor eigen regie.

Het gedachtengoed van Collopy was een tweede theoretische basis om het begrip eigen regie te exploreren. Het onderscheidt verscheidene dimensies van eigen regie van ouderen in het verpleeghuis. Deze dimensies zijn bijvoorbeeld besluiten nemen over-, uitvoeren van- en delegeren van eigen regie. Zo kan een oudere bijvoorbeeld besluiten hoe die graag zou willen leven, maar kan die deze besluiten door de aandoening niet zelf uitvoeren. Ook kan een oudere door bijvoorbeeld aankoop van kleding of de financiële administratie te delegeren aan bekenden, toch invulling geven aan hoe hij die zaken het liefst zou willen vormgeven. Steeds is de relationele dimensie aanwezig, zonder de respons van anderen wordt een oudere in het verpleeghuis belemmerd om eigen regie te voeren. Met deze inzichten kunnen we meer helderheid creëren over de betekenis van eigen regie voor ouderen in het verpleeghuis.

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1 Mensgerichte verpleeghuiszorg sluit aan bij de definitie van person-centredness van McCormack en McCance. Sommigen vertalen person-centredness als 'persoonsgericht'. Er wordt in dit proefschrift hetzelfde mee bedoeld.

Het doel van dit promotieonderzoek was om meer zicht te krijgen op hoe ouderen met een somatische aandoening die wonen in een verpleeghuis, samen met de zorgmedewerkers en in die zorgomgeving, hun eigen regie kunnen behouden of bevorderen. De onderzoeksvraag voor dit proefschrift luidde dan ook: '*Hoe kunnen ouderen met somatische aandoeningen in een verpleeghuisomgeving, samen met de zorgmedewerkers hun eigen regie behouden of bevorderen?'*

Het onderzoek is uitgevoerd in twee organisaties die verpleeghuiszorg aanbieden. Voor de empirische (beschreven in hoofdstuk 3, 4 en 6) selecteerden de managers een afdeling waar de beoogde doelgroep van het onderzoek woonde: ouderen van 65 jaar of ouder die een somatische aandoening hebben. Aan het actieonderzoek (beschreven in hoofdstuk 6) deed een afdeling van een organisatie mee.

De onderzoeksvraag is ongesplitst in vijf deelvragen. Dit proefschrift is ingedeeld in drie delen, waarin nader wordt ingegaan op de diverse onderzoeksvragen.

Deel een, hoofdstuk 2, is een theoretische verkenning van eigen regie vanuit de wetenschappelijke literatuur. De onderzoeksvraag luidde: *'Welke belemmerende en bevorderende factoren voor het voeren van eigen regie door ouderen met een somatische aandoening in een verpleeghuis zijn bekend?'* We onderzochten dat met systematisch onderzoek van de literatuur.

Door het bestuderen van de artikelen die we includeerden in de literatuurstudie konden we het begrip eigen regie voor ouderen met een somatische aandoening in het verpleeghuis beschrijven. 'Eigen regie is het vermogen om de omgeving te beïnvloeden en besluiten te nemen, ongeacht of men het vermogen heeft die besluiten uit te voeren, om zo het leven te leiden wat men wenst, in het licht van verminderende sociale, fysieke en/of psychische bronnen en afhankelijkheid. Het ontwikkelt zich in relaties'.

De resultaten, namelijk de belemmerende en bevorderende factoren voor eigen regie, ordenden we in vier categorieën die grotendeels corresponderen met de domeinen uit het model van mensgerichte praktijkvoering. 1) Kenmerken van ouderen die hen kunnen helpen in het behouden van eigen regie. Bijvoorbeeld contact onderhouden met familie en vrienden. Een ander voorbeeld is het onderhouden van een goede relatie met zorgmedewerkers, waarbij de bewoner ervaart dat hij als een waardevol mens wordt gezien. 2) Vereisten die zorgmedewerkers helpen om eigen regie kunnen ondersteunen. Bijvoorbeeld een goede relatie (kunnen) opbouwen met een bewoner helpt bij het ondersteunen van eigen regie. 3) Zorgprocessen tussen ouderen en zorgmedewerkers. Zorgverleners die uitgaan van wensen en behoeften van bewoners en hier flexibel in de (regels van de) organisatie mee omgaan, ondersteunen de eigen regie. 4) De zorgomgeving kan de eigen regie ook ondersteunen. Bijvoorbeeld door de inzet van voldoende opgeleide en vaste zorgmedewerkers die bewoners (en hun wensen/behoeften) goed kennen. Verder zorgt een goede mix van gedeelde en privéruimtes in het gebouw voor keuzevrijheid en eigen regie.

In het **tweede deel** van dit proefschrift komen de perspectieven van ouderen, zorgmedewerkers en de omgeving van de zorg in drie verschillende studies aan de orde. In **hoofdstuk drie** wordt ingegaan op de onderzoeksvraag: *'Hoe voeren ouderen met een somatische aandoening eigen regie in het verpleeghuis?'* We deden dit onderzoek door

het ‘schaduwen’ van ouderen, een vorm van langdurige en niet-participatieve observatie. Zeventien ouderen van twee afdelingen (een afdeling per deelnemende zorgorganisatie) gaven toestemming om hen een dag te schaduwen tijdens zorgmomenten, maaltijdmomenten en activiteiten. Daarbij maakte de onderzoeker aantekeningen en met een kort gesprek aan het einde van de dag controleerde zij haar interpretaties. De aantekeningen zijn samen met het onderzoeksteam bestudeerd en thematisch gecodeerd en vervolgens geanalyseerd om antwoord te krijgen op de onderzoeksvraag.

We vonden zes manieren waarop ouderen eigen regie voeren. 1) Ouderen voeren eigen regie door zelf te beslissen en deze beslissingen (deels) zelf uit te voeren. Ouderen konden sommige handelingen zelfstandig uitvoeren en daardoor eigen regie voeren. Bijvoorbeeld als ze na hulp bij het douchen zelf make-up aanbrengen, sieraden uitkiezen en parfum opdoen. 2) Ouderen voeren eigen regie door proactieve beïnvloeding. Als een oudere een beslissing niet zelf kon uitvoeren, werkte het het beste als hij/zij direct duidelijk maakte hoe hij/zij het zou willen. Bijvoorbeeld bij binnenkomst van de zorgmedewerker kan een oudere zeggen dat de gordijnen dicht moeten blijven, dat ze die dag op bed gewassen wil worden of dat de verzorgende die lekkere shampoo moet pakken die ze gisteren op haar verjaardag had gekregen. Voor mensen met spraakproblemen was het lastig om deze wensen (verbaal) duidelijk te maken. Vaste zorgmedewerkers begrepen non-verbale uitingen vaak en benoemden deze hardop. Maar in het onderzoek werd ook zichtbaar dat niet iedereen de wensen van bewoners goed kende. 3) Ouderen dragen eigen regie over aan anderen. De bewuste keuze om zaken over te dragen aan anderen is een vorm van eigen regie. Als iemand bijvoorbeeld slechtziend is, kan de kledingaankoop aan de zoon of dochter overgelaten worden. Het vertrouwen dat die ander de wensen en behoeften kent, zorgt ervoor dat iets gebeurt zoals iemand het wil. 4) Ouderen voeren eigen regie over het gebruik van de ruimtes om hen heen. Zelf de keuze kunnen maken op welke wijze gebruik gemaakt wordt van de ruimtes in het verpleeghuis is een wijze van regie voeren. De een blijft graag op de eigen kamer met de deur dicht, terwijl andere bewoners de deur graag openhouden. 5) Ouderen besluiten hoe zij hun tijd willen besteden. Soms lijkt het dat de dag een aaneenschakeling is van zorg- en maaltijdmomenten. Maar juist in de ruimte tussen vaste momenten, kan het leven (soms zoals vroeger) voortgang vinden. Voorbeelden hiervan zijn oude vrienden ontmoeten, mailtjes sturen, breien, schilderen, eten koken, kinderen en kleinkinderen zien, muziek luisteren of tv kijken. In die veelheid van voorkeuren en keuzes is eigen regie zichtbaar. Als laatste vonden we dat 6) ouderen blijven beslissen over belangrijke zaken in het leven. Tijdens het schaduwen van bewoners, wilden zij spontaan vertellen hoe zij over eigen regie dachten. Bijvoorbeeld hoe ze zelf besloten naar het verpleeghuis te verhuizen om de familie te ontlasten. Een ander voorbeeld is dat ze toch echt wel in het ziekenhuis opgenomen willen worden bij hartfalen, ook al haalt dat niet veel meer uit volgens de specialist ouderengeneeskunde.

Deze zes wijzen van eigen regie voering worden pas effectief door de reacties van anderen, zoals zorgmedewerkers, familie en vrienden die signalen en uitingen waarnemen en opvolgen. Dat gegeven maakt het relationele karakter van eigen regie zichtbaar.

In **hoofdstuk vier** beschrijven we het **perspectief** van zorgmedewerkers als antwoord op de vraag: *'Hoe handelen zorgmedewerkers en wat ervaren zij, bij het ondersteunen van de eigen regie van bewoners met een somatische aandoening?'* Ook hier gebruikten we 'schaduwen 'als methode. Vijftien zorgmedewerkers, zoals verzorgenden, verpleegkundigen, welzijnszorgmedewerkers en voedingsassistenten van twee afdelingen (een afdeling per deelnemende zorgorganisatie) deden mee in dit onderzoek. Elke zorgmedewerker werd een aantal uur gedurende de werkzaamheden geschaduwd. We observeerden welke actie een zorgmedewerker uitvoerde om de eigen regie van een bewoner te ondersteunen. We keken ook hoe de bewoner hierop reageerde. Na het afronden van het schaduwen volgde een gesprek om verhelderingsvragen te stellen of interpretaties te controleren. De observatieverslagen gecombineerd met de uitgetypte interviews, zijn thematisch gecodeerd en vervolgens geanalyseerd door de onderzoeksgroep.

We vonden vier wijzen waarop zorgmedewerkers eigen regie van bewoners ondersteunen. 1) Zorgmedewerkers proberen elke bewoner goed te leren kennen. Zij proberen rekening te houden met de wensen of behoeften van elke afzonderlijke bewoner. Dit doen zij bijvoorbeeld door met een bewoner over het verleden of over hobby's te praten. Zij kennen vaak de voorkeuren van elke bewoner voor de wijze van ochtendzorg. Het was bijzonder om te zien dat de meeste zorgmedewerkers toch vroegen naar iemands voorkeur, ook al kende de zorgmedewerker deze al. Zorgmedewerkers benoemden wel de uitdagingen in het ondersteunen van de eigen regie van bewoners zoals een tekort aan personeel. 2) Zorgmedewerkers stimuleren een bewoner om zoveel mogelijk zelf te doen tijdens zorgmomenten of tijdens het eten. Bijvoorbeeld het gezicht wassen en drogen of het haar kammen. Ook stimuleren zij om zelf een boterham te smeren en te beleggen en samen de tafel af te ruimen. Belangrijk is om dit in afstemming met de bewoner te doen. Dan kan een bewoner aangeven of zij/hij iets niet wil doen om energie te sparen voor een andere activiteit die dag. 3) Zorgmedewerkers stimuleren een bewoner om keuzes te maken. Tijdens de ochtendzorg geven zorgmedewerkers een bewoner veel keuze, bijvoorbeeld over de volgorde van de ochtendzorg, de kleding of waar een bewoner wil ontbijten. Ook geven voedingsassistentes veel keuze over brood, beleg en drinken. Voedingsassistentes vragen wat een bewoner wil eten of drinken, ook al is dat bij hen al bekend. Soms werkt een organisatie met extern bereide maaltijden. Het nadeel daarvan is dat een bewoner bijvoorbeeld geen verse groente kan bestellen. Welzijnsmedewerkers bieden bewoners binnen de locatie een variëteit aan activiteiten waar een bewoner uit kan kiezen. 4) Zorgmedewerkers geven aan dat zij het belangrijk vinden om zich bewust te zijn van interactie met een bewoner. Deze interacties met een bewoner verlopen op een verbale en non-verbale manier. Veel zorgmedewerkers vinden het belangrijk om de eigen regie van bewoners te ondersteunen. Daar doen zij hun best voor. Bijvoorbeeld door soms langer op het werk te blijven en met collega's te bespreken hoe zij de eigen regie van een bewoner kunnen ondersteunen. Zij vinden het belangrijk om elke bewoner aandacht te geven. Zorgmedewerkers gebruiken vaak humor in situaties met spanning of schaamte. Bijvoorbeeld omdat iemand te laat was voor het toilet. Toch waren er ook voorbeelden waarin de eigen regie van een bewoner werd beperkt. Bijvoorbeeld als twee zorgmedewerkers met elkaar praten zonder de bewoner bij het gesprek

te betrekken of als een zorgmedewerker een eigen volgorde aanhoudt voor de ochtendzorg van bewoners zonder rekening te houden met hun voorkeur.

We wilden meer zicht krijgen op de context waarbinnen de bewoner en de medewerker hun acties inzetten om eigen regie te behouden of te bevorderen. Daarom is in **hoofdstuk vijf** bestudeerd welk beleid met betrekking tot de zorgomgeving wordt ontwikkeld en ingezet om eigen regie te bevorderen. In dit onderzoek beantwoorden we de vraag: *'Welk beleid om eigen regie van verpleeghuisbewoners met een somatische aandoening, mensgericht te ondersteunen is ontwikkeld en geïmplementeerd?'*

We deden dit door diverse documenten, zoals meerjarenbeleidsplannen, kaderbrieven en notulen van de twee deelnemende verpleeghuizen te bestuderen. Zo volgden we wat er beschreven is over de visie van de organisatie op eigen regie, wat er in de jaarplannen, de kwartaalrapportages en de evaluaties staat. Ook interviewden we 17 personen met de vraag of ze de visie en het beleid kenden en of ze er in de praktijk handen en voeten aan kunnen geven. Deze personen waren bijvoorbeeld lid van de cliëntenraad, coach, scholingsfunctionaris, senior verpleegkundige of manager.

De resultaten ordenden we volgens het raamwerk van mensgerichte praktijkvoering van McCormack & McCance. Een van de sleuteldomeinen van dit model is de zorgomgeving. De zorgomgeving richt zich op de context waarin zorg wordt verleend en omvat zeven aspecten. 1) Delen van macht als een gelijkwaardige samenwerking op basis van gedeelde waarden en doelen.2) Ondersteunende organisatiesystemen, wanneer initiatief en creativiteit worden gestimuleerd door de organisatie. 3) Personeelssamenstelling, waarbij zorgmedewerkers met de vereiste kennis en vaardigheden de zorg verlenen. 4) Potentieel voor innovatie en risico's te nemen op basis van Evidence Based Practice. 5) Hoe de fysieke omgeving zoals het gebouw en de inrichting privacy, en geborgenheid beïnvloeden. 6) Effectieve relaties tussen zorgmedewerkers om mensgerichte zorg te realiseren. 7) Systemen voor gedeelde besluitvorming tussen professionals zoals hoe teams in de organisatie samenwerken. We concludeerden dat het aspect 'delen van macht' het meest gebruikt werd in het beleid van de twee deelnemende organisaties. De organisaties verwachtten veel van het invoeren van veelal indirecte interventies. Zo wilden ze eigen regie ondersteunen door een bewoner de mogelijkheid te geven om in te loggen in het eigen zorgplan en de ontwikkeling van zelfsturende teams. Minder aandacht was er voor interventies in de fysieke omgeving en de samenwerkingsprocessen tussen zorgmedewerkers. Een aanbeveling uit dit onderzoek is om alle zeven aspecten van de zorgomgeving te gebruiken om beleid te maken en te implementeren met als doel de eigen regie van bewoners ondersteunen.

Het **derde deel** van dit proefschrift gaat over het participatieve proces waarmee ouderen en zorgmedewerkers proberen eigen regie te bevorderen op afdelingsniveau. In **hoofdstuk zes** wordt ingegaan op de onderzoeksvraag: *'Welke processen treden op bij een participatieve aanpak van ouderen en zorgmedewerkers om eigen regie te bevorderen op de afdeling?'* Dat onderzochten we met participatief actie onderzoek (PAR). Daarbij hanteerden we met de volgende cyclus: bewoners en zorgmedewerkers stelden acties voor, probeerden deze uit en samen observeerden we de effecten van de acties, gevolgd door een reflectie of de actie

blijvend kan worden ingezet. Met deze cyclus onderzochten we gezamenlijk of en welke acties eigen regie bevorderden.

Voor dit PAR kwamen vijf ouderen en een partner van een oudere, iedere twee weken bij elkaar. Zij deelden ideeën over hoe eigen regie op de afdeling volgens hen bevorderd kon worden. Een keer per maand sloten er vijf zorgmedewerkers van de afdeling aan. Ouderen en zorgmedewerkers besloten samen welke ideeën zij wilden uitproberen op de afdeling: de acties. Dat deden ze meer dan een jaar. Ze gebruikten allerlei creatieve werkvormen om samen in gesprek te gaan over de uitgeprobeerde acties en of en in hoeverre dit bijdraagt aan eigen regie. De onderzoeker was steeds aanwezig om het gesprek te leiden.

We leerden dat het belangrijk is om randvoorwaarden te creëren om ouderen en zorgmedewerkers in gesprek te laten zijn. Zo moet er een vast moment gepland worden. Een begeleider is bij zo'n gesprek ook belangrijk. Het helpt ook om creatieve werkvormen te gebruiken om aan elkaar uit te leggen wat eenieder vindt. Als het gesprek op deze manier wordt gevoerd, komen ouderen met -soms verrassende- voorstellen. Twee voorbeelden van acties die ouderen voorstelden zijn: 1) Een extra knop bij de lift om er met een grote elektrische rolstoel bij te kunnen. Zo kunnen ouderen zonder hulp naar een andere verdieping of naar de uitgang. 2) Zelf, als bewoner, afspraken kunnen maken met de tandarts. Zodat ze niet afhankelijk zijn van een medewerker voor zo'n afspraak.

We leerden ook dat het voor ouderen en zorgmedewerkers een leerproces is om samen het gesprek aan te gaan. De rol van zorgvrager en zorgverlener verandert tijdens de bijeenkomsten. Ze worden samenwerkingspartner. Zij gingen steeds beter samen op zoek naar meer mogelijkheden voor eigen regie.

Tot slot weten we nu dat het moeilijk blijft om te benoemen wat eenieder onder eigen regie verstaat. De deelnemers dachten bij de start te weten wat ze verstonden onder eigen regie. Maar na een jaar vroegen ze zich af of ze het wel over hetzelfde hadden en gingen ze met elkaar verdiepen wat eigen regie nu eigenlijk betekent voor hen.

Als ouderen betrokken worden, kunnen ze meedenken en meebeslissen over, en meewerken aan wat zij belangrijk vinden om eigen regie te bevorderen. Een gesprek tussen ouderen en zorgmedewerkers zou bijvoorbeeld met regelmaat in geplande huiskamerbijeenkomsten gevoerd moeten worden. Aan de hand van thema's en onder begeleiding van een gespreksleider kan het gesprek gaan over het bevorderen van eigen regie.

In **hoofdstuk zeven** wordt in een algemene discussie gereflecteerd op de resultaten uit de vijf deelonderzoeken waarmee we antwoord kunnen geven op de hoofdvraag van het onderzoek: *'Hoe kunnen ouderen met somatische aandoeningen in een verpleeghuisomgeving, samen met de zorgmedewerkers hun eigen regie behouden of bevorderen?'*

De belangrijkste bevindingen zijn bediscussieerd en de wetenschappelijke bijdragen van de onderzoeken zijn beschreven. De belangrijkste bevindingen zijn:

- Ouderen die in het verpleeghuis wonen beschikken over verschillende manieren om eigen regie te voeren en te behouden in de zorgrelatie met de zorgmedewerkers. Verder kunnen ouderen meedenken en meebeslissen over wat hen op afdelingsniveau zou helpen om eigen regie te behouden.

- Eigen regie kent een sterke relationele dimensie: ouderen die in een verpleeghuis wonen zijn afhankelijk van de wijze waarop anderen -zorgmedewerkers, familie en vrienden- reageren op hun signalen om eigen regie te voeren.
- Zorgmedewerkers vinden eigen regie van ouderen belangrijk en zetten diverse manieren in om die in de zorgrelatie te ondersteunen. Maar de samenhang tussen de behoefte van de oudere en de inzet van de zorgmedewerkers is niet altijd aanwezig.
- Een continue afstemming tussen ouderen en zorgmedewerkers is nodig om eigen regie te kunnen behouden in het verpleeghuis.
- Het samen onderzoeken van de wijze waarop ouderen en zorgmedewerkers van een afdeling eigen regie kunnen ondersteunen, kan spanningen in de zorgrelatie veroorzaken. Zowel ouderen als zorgmedewerkers gaan door een leerproces om hun weg te vinden als samenwerkingspartner.
- Zorgorganisaties kunnen beleid inzetten om de omgeving van de zorg zodanig in te richten dat eigen regie ruimte krijgt op afdelingsniveau en binnen de zorgrelatie. Ze maken daar nu nog niet optimaal gebruik van. Met name ouderen zelf worden bij het ontwikkelen van beleid, niet rechtstreeks betrokken en bevraagd.

We formuleerden aanbevelingen voor de praktijk, management en de opleiding voor zorgberoepen. Ouderen zelf zouden hun wensen en behoeftes dienen te uiten en feedback te geven op het handelen van de zorgmedewerkers en de werkwijze op de afdeling. Waar nodig zouden ze hierbij gefaciliteerd kunnen worden door bijvoorbeeld de inzet van een narratieve methode en huiskamerbijeenkomsten. Zorgmedewerkers dienen regelmatig op hun opvattingen, ervaringen en handelen ten aanzien van eigen regie van ouderen te reflecteren in geplande intervisies en met behulp van dagelijkse reminders. Verder kunnen ze leren door het schaduwen van het handelen van collega's. De managers zouden de ouderen dienen te betrekken bij het formuleren en evalueren van beleid gericht op eigen regie. Verder wordt er aan het management aanbevolen om breed beleid in te zetten en langdurend te werken aan het bevorderen van eigen regie. Binnen het onderwijs voor zorgmedewerkers zouden de kennis over eigen regie en het ontwikkelen van competenties om eigen regie te bevorderen een plaats dienen te krijgen.

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Ik combineerde mijn werk als Science Practitioner, met die als Lecturer Practitioner bij De Wever en Fontys. Ik wil mijn collega's bij HRM van De Wever bedanken voor de interesse in mijn onderzoek. Een speciaal woord van dank heb ik voor de collega's van Fontys. Ze voedden me als Lecturer Practitioner met nieuwe kennis over (creatieve) onderzoeksmethoden en zetten me op het spoor van persoonsgerichte praktijkvoering. Beiden heb ik mee kunnen nemen in mijn onderzoek. Hoewel mijn aanstelling klein was, heb ik me steeds gezien en gesteund gevoeld.

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De WhatsApp groep van ons gezin had als naam Doctor(s) to be. Nu ik als laatste deze titel mag gaan dragen kan het woord ‘to be’ van de naam van de groep en het bordje ‘Casa di Dottori’ mag boven de voordeur gespijkerd.

Curriculum vitea and List of publications, presentations, media output and other knowledge transfer products

About the author

Jolande van Loon was born on 11 July 1961 in Veldhoven. After graduating from the pre-university education at Anton van Duinkerken College in Veldhoven, she was trained as a bachelor in nursing at Fontys University of Applied Sciences (1980-1984). She worked as a disctrict nurse in Breda for seven years. Meanwhile, she was pursuing a master's degree in health sciences, department of nursing science, at Maastricht University from 1988-1991. This was followed by a long career at various long term care organisations (district nursing and nursing homes) with various positions in research and innovation, project management, quality advise and as a policy officer. Jolande also developed education for nurses working in a general practice at Avans+. In 2013, in the position of Lecturer Practitioner at De Wever, she found a combination of both foci; innovation and education. Within a detachment to Fontys University of Applied Sciences, she supervised students of the Bachelor of Nursing with their graduation thesis. In 2015, De Wever, who is a partner organisation of the Academic Collaborative Centre Older Adults of Tranzo, gave her the opportunity to do doctoral research as a Science Practitioner. This completed the triangle 'education, practice and research'.

Over de auteur

Jolande van Loon is geboren op 11 juli 1961 in Veldhoven. Na het behalen van het vwo-diploma op het Anton van Duinkerkencollege te Veldhoven, volgde zij de opleiding tot hbo-verpleegkundige bij het huidige Fontys Mens en Gezondheid (1980-1984). Ze was zeven jaar werkzaam als wijkverpleegkundige in Breda. Ondertussen volgde ze de master opleiding gezondheidswetenschappen, afstudeerrichting verplegingswetenschap, aan Maastricht University van 1988-1991. Hierna volgde een lange carrière bij diverse VVT instellingen met verschillende functies in onderzoek en innovatie, projectmanagement, kwaliteitsadvisering en beleidsadvisering. Daarnaast ontwikkelde Jolande opleidingen voor praktijkverpleegkundigen, als docent verpleegkunde bij Avans+. In 2013 vond ze in de functie van Lecturer Practitioner bij De Wever een combinatie van beide foci; innovatie en onderwijs. Binnen een detachering naar Fontys Mens en Gezondheid, begeleide zij Verpleegkunde studenten bij hun afstudeerthesis. In 2015 gaf De Wever, als partnerorganisatie van de Academische Werkplaats Ouderen van Tranzo, haar de mogelijkheid om als Science Practitioner promotieonderzoek te doen. Daarmee was de driehoek 'onderwijs, praktijk en onderzoek' compleet.

International publications

- Van Loon, J. M. C., Luijkx, K. G., Janssen, M. M., de Rooij, I., & Janssen, B. (2019). Facilitators and barriers to autonomy: a systematic literature review for older adults with physical impairments, living in residential care facilities. Ageing & Society, 1-30. https://doi.org/10.1017/S0144686X19001557
- Van Loon J, Janssen M, Janssen B, de Rooij I, Luijkx K. How staff act and what they experience in relation to the autonomy of older adults with physical impairments living in nursing homes. Nordic Journal of Nursing Research. 2022;0(0). doi:10.1177/20571585221126890
- Van Loon, J., Janssen, M., Janssen, B., De Rooij, I., & Luijkx, K. (2023). How older adults with physical impairments maintain their autonomy in nursing homes. Ageing & Society, 1-23. doi:10.1017/S0144686X22001428
- Van Loon J, Janssen M, Janssen B, de Rooij I, Luijkx K. (2023). Developing a person-centred care environment aiming to enhance the autonomy of nursing home residents with physical impairments, a descriptive study. BMC Geriatrics, doi. org/10.1186/s12877-023-04434-8

Abstracts and conference proceedings

- Van Loon, J. M. C., Luijkx, K. G., de Rooij, A. H. P. M., & Janssen, B. M. (2017). Persoonsgerichte praktijkvoering rondom eigen regie van ouderen in de somatische langdurende intramurale zorg. Abstract 14e nationaal gerontologiecongres, Vernieuwing in veroudering. 5 ed. Bohn Stafleu van Loghum, Vol. 48. p. 223-260
- Van Loon, J.M.C, Luijkx, K.G., de Rooij, A.H.P.M., Janssen, B.M. (2018). Autonomy of older adults with physical impairments in residential long term care settings: a systematic literature review. In: Everink, I. et.al. (Red.), The 17th European Doctoral Conference in nursing science (pp. 117-118). EDCNS.
- Van Loon, J.M.C., Janssen, M.M., Janssen, B., de Rooij, A.H.P.M., & Luijkx, K.G. (2022). Autonomy in nursing homes: Viewpoints of residents with physical impairments and staff. Heilberufe Science, 13 (Suppl 1), s14-s14. https://doi. org/10.1007/s16024-022-00377-z

National publications

- Van Loon, J.M.C. (2016). Ruimte voor eigen identiteit en wensen. Interview in De Weef, een uitgave voor alle medewerkers, vrijwilligers en cliënten van De Wever, 8 (26), 6-7.
- Van Loon, J. M. C., Luijkx, K. G., Janssen, M. M., de Rooij, A. H. P. M., & Janssen, B. M. (2020). Bevorderende en belemmerende factoren voor eigen regie bij ouderen met een somatische aandoening in het verpleeghuis. Tijdschrift voor Ouderengeneeskunde, 1, 65-73.
- Van Loon, J.M.C. (2021). Hoe ouderen met somatische aandoeningen in een verpleeghuis eigen regie voeren. Artikel in De Weef, een uitgave voor alle medewerkers, vrijwilligers en cliënten van De Wever, 5, 22-26.

International presentations

- Van Loon, J. M. C. Luijkx, K. G., Rooij de A. H. P. M., & Janssen B. M. (2018). Autonomy of older adults with physical impairments in residential long term care settings: A systematic literature review. 17th European Doctoral Conference in Nursing Science, Maastricht, 22-23 June.
- Van Loon, J.M.C. (2022) Autonomy in nursing homes: viewpoints of residents with physical impairments and staff members. 19th European Doctoral Conference in Nursing Science, Bern, Switzerland, 9-10 September.

National presentations

- Van Loon, J. M.C. (2016). 'Eigen regie bij ouderen. Hoe kijk jij daar tegen aan?' UKON congres 'Trots op je vak!' Nijmegen, Nederland, 7 april.
- Van Loon, J.M.C. (2016). Eigen regie door ouderen in de langdurende intramurale zorg, De Wever, 'Samenscholing onderzoek', Tilburg, Nederland, 10 november.
- Van Loon, J. M. C., Luijkx, K. G., de Rooij, A. H. P. M., & Janssen, B. M. (2017). Belemmerende en bevorderende factoren voor eigen regie, UKON symposium 'Samen Doen, Samen Sterk', Eindhoven, Nederland, 13 april.
- Van Loon, J. M. C., Luijkx, K. G., de Rooij, A. H. P. M., & Janssen, B. M. (2017). Methode 'shadowing', illustratie van lopend onderzoek eigen regie ouderen, Universiteit voor Humanistiek, Utrecht, Nederland, 23 maart.
- Van Loon, J. M. C., Luijkx, K. G., de Rooij, A. H. P. M., & Janssen, B. M. (2017). Eigen regie door ouderen in de langdurende intramurale zorg, Keynote lezing. De Wever, 'Samenscholing onderzoek'. Tilburg, Nederland, 16 oktober.
- Van Loon, J. M. C., Luijkx, K. G., de Rooij, A. H. P. M., & Janssen, B. M. (2017). Persoonsgerichte benadering in de ondersteuning van eigen regie. Presentatie in het symposium mensgerichte ouderenzorg in het 14e nationaal gerontologiecongres. Ede, Nederland, 3 november.
- Van Loon, J. M. C., Luijkx, K. G., de Rooij, A. H. P. M., & Janssen, B. M. (2017). Eigen regie door ouderen in de langdurende somatische zorg. Research preview Academische Werkplaats Ouderen in De Wever, Tilburg, Nederland, 27 november.
- Van Loon, J. M. C. Luijkx, K. G., Rooij de A. H. P. M., & Janssen B. M. (2018). Eigen regie door ouderen in de langdurende somatische zorg. Netwerkavond VenVN platform Wetenschap in Praktijk, Breda, 5 februari.
- Van Loon, J. M. C. Luijkx, K. G., Rooij de A. H. P. M., Van Leent, J. A. M., & Janssen B. M. (2018). Met shadowing het perspectief van ouderen ontdekken. Symposium: Iedereen doet mee, Den Bosch, 10 april.
- Van Loon, J. M. C., Janssen, M. M., Janssen, B.M., de Rooij, A.H.P.M., & Luijkx, K. G. (2018). Praktijkvoorbeeld van kennisontwikkeling in de langdurige zorg. Congres: Thuis in het Verpleeghuis, Waardigheid en trots op elke locatie, Den Haag, 2 juli.
- Van Loon, J. M. C. , Janssen, M. M., Janssen, B. M., de Rooij, A. H. P. M., & Luijkx, K. G. (2018) Actieonderzoek naar eigen regie. Samenscholing onderzoek. De Wever, Tilburg, 15 november.

- Van Loon, J. M. C., Janssen, M. M., de Rooij, A. H. P. M., Janssen B. M., & Luijkx, K. G. (2018) In actie voor eigen regie. Symposium Zorg in goede Handen Rho-Chi, Utrecht, Nederland, 30 november.
- Van Loon, J. M. C., Janssen M. M., de Rooij, A. H. P. M., Janssen, B. M., & Luijkx, K. G. (2018) In actie voor eigen regie in het verpleeghuis. Symposium De regie bij de cliënt, hoe doe je dat? UNO-Vumc, Amsterdam, 13 december.
- Van Loon, J. M. C., Janssen, B. M., Janssen, M. M., de Rooij, A. H. P. M., & Luijkx, K. G. (2019). Met shadowing het perspectief van de ouderen met betrekking tot eigen regie in beeld brengen. Onderzoeksseminar FHMG, Eindhoven, 4 april.
- Van Loon, J. M. C., & van Vugt, M. M. A. (2019) Wat hoor je als je vraagt? Wat zie je als je kijkt? Congres 'Zoek het uit!' Vilans en AWO, Tilburg, 2 december.
- Van Loon, J., Janssen, M., Janssen, B., De Rooij, I., Volbeda, P., Van Vugt, M., & Luijkx, K., (2020). De rol van de verpleegkundige in de eigen regie van de zorgvrager. Symposium: Leadership in daily practice van RhoChi, VenVN Wetenschap in Praktijk en de alumnivereniging verplegingswetenschap Nederland, Online, 3 december.
- Van Loon, J.M.C. (2021) Onderzoek naar eigen regie van ouderen met somatische aandoeningen die langdurend in een verpleeghuis wonen. SANO wetenschapsdag, Online, 11 maart.
- Van Loon, J.M.C, (2021). Eigen regie voor ouderen met somatische aandoeningen in het verpleeghuis. Expo bij De Werkplaats: 'Dat bepaal ik zelf wel!', Tilburg, 5 oktober.
- Van Loon, J.M.C, (2021). Inleiding eigen regie. De Werkplaats: 'Dat bepaal ik zelf wel!', Tilburg, 5 oktober.
- Van Loon, J.M.C. (2021). Spreker bij Kenniscafé: eigen regie in het verpleeghuis. Onderzoeks- en Wetenschapscommissie SVRZ, online, 29 november.
- Van Loon, J.M.C (2022). Tien kijkpunten voor een gezamenlijke blik op eigen regie, presentatie bij 'Samenscholing onderzoek' De Wever, online, 13 januari.
- Van Loon, J. M. C., Janssen M. M., de Rooij, A. H. P. M., Janssen, B. M., & Luijkx, K. G. (2022) Eigen regie in verpleeghuizen, perspectieven vanuit ouderen met een somatische aandoening en medewerkers. SANO Wetenschapsdag: De voedingsbodem van de Wetenschap, Oegstgeest, Nederland, 22 september.
- Van Loon, J.M.C., de Rooij, A.H.P.M. (2023). Workshop en presentatie over eigen regie in verpleeghuizen. Thema bijeenkomst samenwerkende cliëntenraden De Wever, Tilburg, 6 april.
- Van Loon, J.M.C. (2023). Eigen regie van meerdere kanten bekeken, Keynote 'Samenscholing onderzoek' De Wever, Tilburg, 22 juni.
- Van Loon, J.M.C., de Rooij, A.H.P.M. (2023). Eigen regie van meerdere kanten bekeken. Lezing Probus afdeling Breda West, Breda, 24 oktober.

Media output and other knowledge transfer products

- Van Loon, J.M.C. (2018). Eigen regie in het verpleeghuis - Tranzo - Tilburg University - AW Ouderen 8 jan.

- https://www.youtube.com/watch?v=pyYC4ttgvUY
- Van Loon, J. M. C. (2020). Tool: bevorderende/belemmerende factoren eigen regie bewoners met somatische aandoening. Waardigheid en Trots, 21 augustus. https://www.waardigheidentrots.nl/tools/onderzoek-eigen-regie-bewoners/
- Van Erven, C.A.M., De Jong, E.C., Verspeek, L.A.M, Van Loon, J.M.C. & Luijkx, K. G. (2021). 10 tips voor een gezamenlijke blik - Eigen regie. Youtube, 28 oktober.
- Eigen regie van ouderen in de langdurende intramurale zorg. https://www.youtube.com/watch?v=pEKu-vvZeDc
- Casus 'Dopje' - Eigen regie van ouderen met een somatische aandoening in de intramurale zorg. https://www.youtube.com/watch?v=ks1BsOmLaiE
- Casus 'taart' - Eigen regie van ouderen met een somatische aandoening in de intramurale zorg. https://www.youtube.com/watch?v=oGydcdOpMwQ
- Casus 'Pinkeln' - Eigen regie van ouderen met een somatische aandoening in de intramurale zorg. https://www.youtube.com/watch?v=jHQ9cud6tTs
- Van Loon, J.M.C. (2023). Tool: 6 tips voor eigen regie in het verpleeghuis. Zorg voor Beter. 21 maart.
- https://www.zorgvoorbeter.nl/thema-s/persoonsgerichte-zorg/6-tips-voor-eigen-regie-in-het-verpleeghuis
- Hosseinion-Schilder, N., Looijenstein, J., Van der Ploeg, N., Smolders-van de Sande, L. in collaboration with the Academic Collaborative Centre Older Adults of Tranzo, Tilburg University. 'Eigen Regie' Calender, 2022.

Courses

- Action Research course, Buskerud and Vestfold University College, Drammen, Norway
  Three day course: 19-21 October, 2015
- Academic Writing in English for PhD researchers, Language Center, Tilburg University
  Fall of 2016, six 2-hour sessions.
- Participatory Research Course, Queen Margaret University, Edinburgh, UK
  Three day course: 16-18 October 2017
- Action research course, Tranzo, Tilburg University
  Three half days, Spring of 2018
- Qualitative Research Techniques for PhD students, Tilburg University, SBS.
  Two day course; 12 and 19 November 2019