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## Enhancing person-centered care to enable older adults to be involved in long-term care

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# CHAPTER 7

## ENHANCING PERSON-CENTRED CARE TO ENABLE OLDER PERSONS TO BE INVOLVED IN LONG-TERM CARE

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The prevalence of chronic conditions and limitations across all domains of health increases with age. Not all older persons are confronted with complex health and social care needs but, compared to other age groups, a large proportion of older persons do. Although this may lead to reduced self-reliance and increased dependence, older persons prefer to live their lives as they desire by making their own choices regarding different aspects of daily life. Over the last few decades, long-term care for older persons has been shifting from a biomedical model (aiming for safety and risk reduction) towards a broader concept of health that recognises the individual personhood of each older person. In this chapter, we make a plea to put the perspective of older persons at the centre in both research and care practice in order to contribute to person-centered care for older persons. After an introduction on person-centred care, our Academic Collaborative Center Older Adults (ACC) is described, in which we aim to create both scientific and societal impact to facilitate and stimulate professionals to involve older persons in their own care and support and to empower older persons to do so. As a new development in the ACC, the active participation – which is currently designed together with older persons – of older persons is described. Then, three examples of our research are discussed in which the perspectives of older persons are placed central to realise person-centred care: sexuality and intimacy, autonomy, and the story as a quality instrument. The chapter ends with some implications for care practice, policy and research, leading to a number of directions for the future.

## 1. Person-centred care

As people age, they often suffer from multiple chronic conditions and disabilities. These can challenge older persons' social participation and independent living and can require mobilisation of health and social care services (Fried et al., 2004; Verver et al., 2019; Vos et al., 2020). For some older persons, it is not possible to continue living independently in their homes and communities because care and support at home are unable to address increasing deteriorations in their health (Fried, Ferrucci et al., 2004; Fried, Tangen et al., 2001; Markle-Reid & Browne, 2003). To receive care and support that meet their complex care needs, older people move into residential care facilities when their health or cognitive status deteriorates. In 2019, 115,000 older persons lived in a residential care facility in the Netherlands (CBS, 2020).

The perspective on and, subsequently, the organisation of care and support for older persons has changed over the past few decades. For years, the traditional biomedical model of medicine was predominant, but the biopsychosocial model has become increasingly prevalent in the provision of care and support for older persons. The biomedical model focuses on biological (somatic) processes in human bodies, in which diseases were conceptualised as deviations from normal biological functioning (Engel, 1977). The doctor-patient relationship was paternalistic and predominantly doctor-centred. The patient's role was limited to reporting illnesses, signs and symptoms after which a doctor started a standardised investigation, diagnosis and treatment in order to restore the disease processes to 'normal' (Mead & Bower, 2000). In the movement towards a more biopsychosocial model of care, increasing attention is paid to approach the person as a whole to understand and promote older persons' health, including a combined biological (somatic), psychological and social perspective (Mead & Bower, 2000). As such, the biopsychosocial model can be considered an attempt to challenge and broaden the traditional biomedical model.

In line with this broader approach, several new definitions and conceptualisations of health have been developed over the years. The concepts of resilience and empowerment of older persons have received increasing attention. Common elements of empowerment include, among others, feelings of control over life or health, self-efficacy, development of personal abilities and partnership as a means or as a goal contributing to people's quality of life (Tengland, 2008; Shearer et al., 2012; Tsubouchi et al., 2021). According to Van Corven et al. (2021b), empowerment may be different for older persons with dementia because of cognitive impairments and behavioural changes. Important themes for people living with dementia include sense of personal

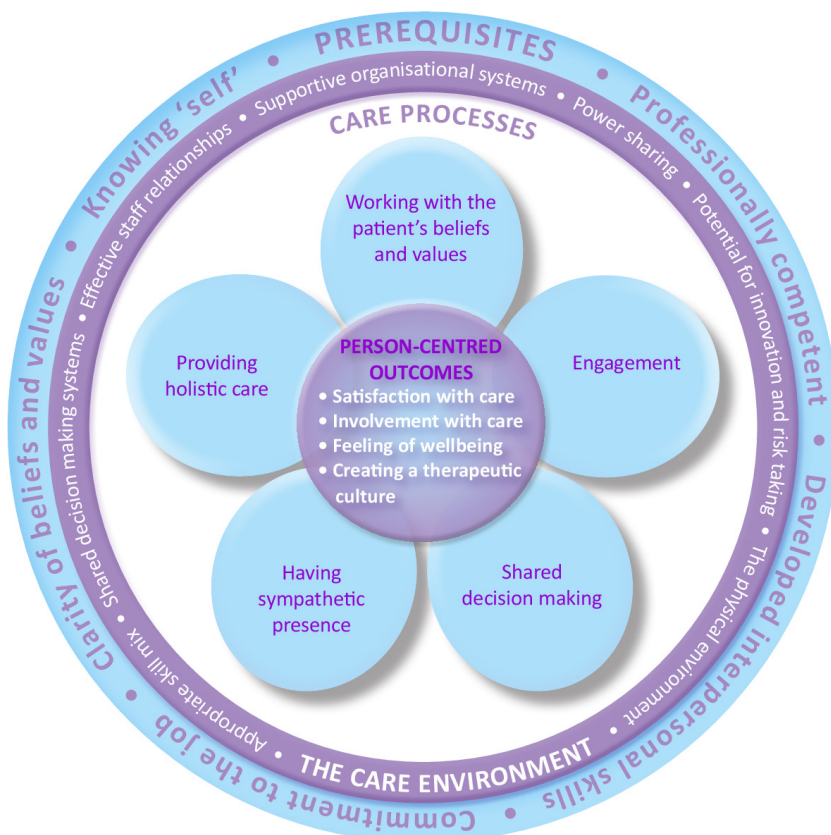
identity, usefulness, choice and control, and self-worth (van Corven et al., 2021a, 2021b). The development towards empowerment is widely supported and shifts focus from people's disabilities to their abilities, also when they face problems and limitations (Books, 2009; Huber et al., 2011). In addition to medical conditions such as physical ailments and disabilities, aspects such as meaningfulness, social participation and well-being are covered (Huber et al., 2016). Such new health concepts change thinking about care and support for older persons. Based on what is important to the person, empowerment shifts the focus: it is no longer exclusively on medical treatment but also using people's abilities to cope, adapt and self-manage to improve their situation and thus on empowerment of the individual (Huber et al., 2016).

Furthermore, this broader approach includes recognition of the individual personhood of each older person. This means that older persons are regarded as unique persons. As is essential for all people, an older person wants to be seen, heard and respected as a unique human being. Although chronic conditions and disabilities can cause considerable changes in the way older persons used to live, they prefer to be in control of their lives by making their own choices regarding different aspects of their life, such as the care and support they receive (Lette et al., 2017).

Person-centred care, as the term suggests, places older persons at the centre of their own care and support. Older persons, and if preferred their informal caregivers, are actively involved in decision-making and planning their care process in order to tailor the delivery of care and support to their individual needs and preferences across all domains of health, including meaningfulness, social participation and well-being, in order to empower them and give them control over their lives (Coulter et al., 2013; Langberg et al., 2019). The term *person-centred care* is widely used, and many different definitions and frameworks of person-centredness have been proposed over the years (Bechtel & Ness, 2010; Lepage et al., 2007; Mead & Bower, 2000). Empowerment and person-centredness show several similarities in which individual needs and preferences and partnership between care recipients and care providers play an important role (Holmström & Röing, 2010; Kitwood & Kitwood, 1997).

Although more insights of how to design and implement a person-centred care approach and an understanding of how to measure its outcomes and experiences are still needed (Rathert et al., 2013; Santana et al., 2018), person-centred care is expected to have a positive impact on older persons, informal caregivers and staff members. A recent systematic review of the literature found positive relationships between person-centred care processes and patient satisfaction and well-being (Rathert et al., 2013). Also on the staff level, several studies showed that person-centred care has beneficial impacts,

**Figure 7.1: Person-centred nursing framework.** Retrieved from T. McCance, B. McCormack, & J. Dewing (2011), 'An exploration of person-centredness in practice', *Online Journal of Issues in Nursing* 16(2), 1. Reuse with permission from the authors.



including higher levels of staff satisfaction and lower levels of job strain (Sjögren et al., 2015; van Diepen et al., 2020).

One of the theoretical frameworks that has been developed is the person-centred nursing framework by McCormack and McCance (McCormack & McCance, 2016, 2006). Person-centred practice focuses on 'the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives' (McCormack & McCance, 2016), and 'is underpinned by values of respect for persons, individual right to self-determination, mutual respect, and understanding' (Brendan et al., 2010).

The framework comprises four key constructs that are closely related to each other. First, prerequisites for person-centred practice: the attributes of the

nurses, such as being professionally competent. Second, the care environment: the context in which care is delivered, such as an appropriate skill mix in the nursing team. Third, person-centred processes: delivering care to the person through a range of activities, such as working with persons' beliefs and values. Finally, person-centred outcomes: the results of effective person-centred nursing, such as satisfaction with care (McCormack & McCance, 2016).

Although the framework has been developed as part of a large-scale project evaluating the effectiveness of person-centred nursing in a hospital setting (McCormack & McCance, 2016), it has been used widely across several countries in multiple contexts, including long-term care for older persons. Several studies describe how the framework has been used in many different ways in long-term care. The framework provides a basis for evaluating existing practices, determining changes needed and guiding the implementation and evaluation of developments in practice (McCance et al., 2011). For instance, a qualitative study explored nursing assessments and care plans of residents in long-term care for evidence of person-centred care using the person-centred nursing framework (Broderick & Coffey, 2013). In addition, a recent systematic literature review applied the framework to identify facilitators and barriers to autonomy of older persons with physical impairments living in residential care facilities (van Loon et al., 2019).

Although the framework has received much attention on an international stage and has been validated as an intervention to implement person-centred nursing (McCormack & McCance, 2016, 2006), the framework has also been critically evaluated. One potential limitation of the framework is the restricted role older persons play. Older persons (or 'patients', as the framework suggests) appear as subjects or passive recipients of care in the different constructs in the model rather than as active participants. In addition, two specific issues will be mentioned here.

First, the model has been developed, tested and refined in collaboration with co-researchers and practitioners from a range of clinical settings (McCormack & McCance, 2016). However, engagement of those whom person-centred care concerns mostly – in other words, older persons themselves – is vital to make sure that it reflects and respects what is important to them. Since older persons or their representatives (e.g. informal caregivers or representative organisations) were not explicitly engaged in the development of the framework, older persons' perspectives remain under-represented while their active participation is essential to refine and improve the concept of person-centred nursing.

Second, the framework appears to be used as a tool for practice which particularly covers the attributes of staff, the context in which they provide

care and a wide range of nursing activities (McCormack & McCance, 2016). Person-centred care as well as empowerment emphasise establishing an accommodating, ongoing partnership and collaboration between the older person receiving care (and the informal caregiver) and professionals as equal partners (Mead & Bower, 2000). Unfortunately, the framework provides no central role for the key players – the older persons as active, empowered participants in person-centred care.

These two issues illustrate the challenges to appreciate older persons as key actors in person-centred care. Many steps still have to be taken. Also, academia has an important role to place older persons at the heart of person-centred care and make sure they have an equal and active role in adopting and promoting a truly person-centred approach.

## **2. The Academic Collaborative Center Older Adults**

Tranzo, a department within the Tilburg School of Social and Behavioral Sciences of Tilburg University (the Netherlands), strives to connect science and practice in the field of care and well-being. In co-creation between scientists, professionals and citizens/clients, knowledge is developed and exchanged, with the aim to promote evidence-based practice. Collaboration takes place in so-called Academic Collaborative Centers (ACCs), which are long-term and structural collaborations between science and practice and in which scientists and professionals from practice define a research programme in an equivalent way (Tranzo, n.d.).

An ACC within Tranzo that aims to contribute to person-centred care for older persons and to empower older persons is the ACC Older Adults. As person-centred care for older persons requires a different position of older persons than has been common up to this point; it is essential to understand their perspectives in several respects, including their needs and preferences for care and support. Scientific research can help understand the different experiences, preferences and capabilities of older persons as unique individuals as well as a heterogeneous group. These insights are essential to facilitate and stimulate professional caregivers to involve older persons in their own care and support. Traditionally, scientific research is *about* older persons (not including them) and focuses on care professionals or their relatives as a proxy. However, scientific research can give voice to older persons who are receiving care and support by gathering data about their lifeworld. Older persons themselves should be the most important and primary source in research because the perspectives of older persons differ from the estimation



of proxies, such as loved ones and care professionals, as is shown by research (Dröes et al., 2006; Gerritsen et al., 2007; Kane et al., 1997; Larsson et al., 2019). These differences in perspective, although sometimes nuanced, may affect the older persons' experience of the genuine experience of person-centred care. Moreover, although physical or cognitive limitations – including dementia – may complicate older persons' position as the primary source in scientific research, it is possible and worthwhile (Roelofs et al., 2017).

Within person-centred care for older persons as the main theme of research in the ACC Older Adults, the following research lines have been developed: autonomy, informal care, quality of care, participatory research, technological innovation, palliative care and dementia care. The ACC Older Adults is a cooperation between Tilburg University (Tranzo department), ten organisations that provide long-term care for older persons and the CZ zorgkantoor (Luijkx et al., 2020). Of the ten care organisations, eight are located in the province Noord-Brabant in the south of the Netherlands, one is located in the province Zeeland in the south-west of the Netherlands, and one is located in the province Gelderland in the east of the Netherlands. All ten organisations provide long-term extramural and intramural care, of which eight also provide short-term rehabilitation care. The organisations differ in size. Six organisations provide intramural care in ten to twenty locations, three in twenty to thirty-five locations and one in more than sixty-five locations. The CZ zorgkantoor also participates within the ACC Older Adults. A *zorgkantoor* works on behalf of the Dutch government and makes agreements with care providers on cost and quality of long-term (residential) care. Moreover, a *zorgkantoor* advises persons who need long-term care about possible options regarding their unique personal care needs and preferences (Luijkx et al., 2020).

The slogan of the ACC Older Adults is 'science in practice to contribute to person-centred care for older adults' (Luijkx et al., 2020). We strive to create scientific knowledge and societal impact by conducting scientific research and creating products for practice in order to facilitate care professionals to involve older persons in their own care and support. We create scientific and societal impact in co-creation with older persons, care professionals providing long-term care to older persons, and researchers, in an equivalent way (Luijkx et al., 2020). The process of creating scientific knowledge and societal impact to contribute to person-centred care for older persons starts with a PhD study. In four to six years, a main research topic is studied through multiple sub-questions resulting in theoretical scientific knowledge. This knowledge is of value for scientists, managers and highly educated professionals (e.g. policy workers, elderly care physicians, psychologists) working in research

or long-term care practice. However, this theoretical knowledge is often too abstract to be used in daily care practice. Therefore, after a PhD study, a 'science-to-practice project' is started. A science-to-practice project is a scientific study in which the theoretical results of a PhD study are translated into a practical tool or working method. Intensive co-creation between the researcher, older persons and care professionals is key to ensure that the tool or working method suits daily care practice well and is feasible to implement and leads to involving older persons in their own care and support. During and after a PhD study and a science-to-practice project, a communication expert, an education expert and an implementation expert employed by the ACC are continuously involved to think along with the researcher to share the research findings in a comprehensible and attractive way and make scientific knowledge directly applicable for practice. In this way, they enable the use in daily care practice and thus contribute to the societal impact (Luijkx et al., 2020).

To be able to contribute to person-centred care for older persons and create scientific knowledge and societal impact, it is necessary to ensure that research questions arise from daily care practice, and thus from care professionals and older persons. In the ACC Older Adults, so-called science practitioners and research brokers play an important role. A science practitioner combines working in daily care practice – for instance, as a psychologist, policymaker, nurse specialist, or an elderly care physician – with a PhD study. A science practitioner formulates a research question starting from a question or problem in her or his daily care practice, which also fits within the main research theme of the ACC Older Adults (i.e. person-centred care) and one of the subthemes of study (i.e. autonomy, informal care, quality of care, participatory research, technological innovation, palliative care and dementia care). PhD studies are, for example, about intimacy and sexuality of older persons with dementia living in a nursing home (Roelofs et al., 2019a, 2019b), autonomy (Van Loon, Janssen et al., n.d.; Van Loon, Luijkx et al., 2019), access to care (Schipper et al., 2015a, 2015b), and the use of tobacco and alcohol by residents who live in a nursing home (de Graaf et al., 2021). Care organisations contribute to conducting the PhD studies of the science practitioners by enabling them to work on the research during contract hours. In the ACC Older Adults, science practitioners conduct about two thirds of the current PhD studies.

Moreover, five research brokers, who also work as senior researchers, work within the ACC Older Adults. In their role as senior researchers, they conduct scientific activities at the university like submitting grant proposals and supervising PhD students and science practitioners. In their role as research brokers, each research broker connects closely with two or three partnership

organisations to foster and strengthen the collaboration and knowledge exchange between science and care practice. They get to know care practice from within by participating in relevant committees, for instance a science committee, by meeting and talking with older persons and care professionals in daily care and by meeting regularly with professionals who are enthusiastic about scientific knowledge exchange and implementing research findings into practice work. Moreover, they are able to discover topics that are relevant to formulate new research questions on and to detect possibilities to implement or share our knowledge. As such, research brokers contribute to improving care practice by using scientific knowledge (Luijckx et al., 2020).

As explained above, in the ACC Older Adults, we aim to create new scientific knowledge about person-centred care for older persons to stimulate and facilitate professional caregivers to involve older persons in their own care and support to empower older persons. We strive to do so with, for and by older persons. Until now, older persons have mostly been included in our research in less active roles as research participants. Although their perspectives are the main focus of our research, older persons are usually not yet actively involved as co-designers of new studies or as co-researchers during execution of the study.

There are several motivations for actively involving older persons in research as research partners, including substantive, normative and instrumental reasons. The involvement of older persons is likely to improve the quality of research, as it better fits their knowledge, ideas, needs and priorities. Involvement of older persons in the dissemination and implementation of research products is likely to increase the fit and usefulness of products especially designed for these target group. Furthermore, older persons have the democratic right to be involved in the issues that matter to them ('nothing about us without us') (Baldwin et al., 2018; Scheffelaar, 2020). Inviting and encouraging them to participate as active and equal partners may contribute to feelings of empowerment, as they have more choice and control over the research which is performed with them, which also is likely to make them feel useful and significant.

Moreover, there are many different ways in which participation of older persons can be realised. Older persons can be involved in a more structural way by providing their ideas and feedback, on a regular basis and transcending individual. Several examples exist in the Netherlands using terms such as expert panel, older persons' council and pool of client representatives. Additionally, there are examples in which older persons are involved in a specific research. In the role of co-researcher, older persons can be involved in the definition of the research question or topic, the development of a study

design, and in data collection; for example, they can conduct interviews, analyse data, present the study findings, or help translate study findings into practical tools (Baldwin et al., 2018; Bindels et al., 2014; De Graaff et al., 2019; Scheffelaar et al., 2020).

Doing research with and by older persons in participatory research designs has high priority in the ACC Older Adults. To realise meaningful involvement of older persons, we decided to directly ask older persons themselves which contributions and roles they find important to make the ACC inclusive in the long term. In this way, we ensure that the cooperation and involvement of older persons does not remain instrumental or incidental, in other words, that older persons are only involved if researchers decide so. Instead, the participatory structure is co-designed together with older persons so that older persons can consider themselves when and how their contribution can be useful. By thinking along and making decisions together, a joint vision is created on the roles and tasks of older persons in our research and on the more abstract level of the ACC in general.

To start engaging older persons in the ACC Older Adults, a preparatory group was set up in 2021. The preparatory group consisted of three older persons, one postdoctoral researcher and one implementation expert. The older persons differed in age (from sixty-seven to seventy-seven years old), sex (two male, one female), relations with care provision, and personal and professional background. The group met once or twice a month for one and a half hours to gradually draft a proposal on the participatory structure.

The preparatory group developed a proposal for a Platform of Older Adults, in which eight to ten older persons would meet four times a year to give their requested advice and opinions on research issues of the ACC Older Adults as well as spontaneous advice. The proposal describes that the Platform of Older Adults should consist of older persons (sixty-five years and older) who receive care themselves or have experience with care in their close environment as relatives or volunteers. The preparatory group presented their proposal to the different stakeholders involved in the ACC Older Adults (including representatives of care organisations and researchers) and, after some minor adaptations, the proposal was formalised into a plan of action.

The preparatory group thereafter helped set up the Platform of Older Adults by developing 'job' profiles for the future older persons who would become involved. Moreover, they proactively developed a handbook with regulations to define the assignment of the platform, to name the formal status and position within the ACC, and to establish a number of practical agreements with regard to the composition, communication and meetings of the platform. The preparatory group thereafter developed recruitment

material and participated in the recruitment and selection of new candidates. A financial budget was made available for paying older persons an allowance for their participation and for their travel expenses. The Platform of Older Adults was launched in January 2022. In 2022, they are further concretising their role in the ACC, while they also start being involved in research taking place within the ACC.

### **3. Placing the perspective of older persons central**

In the ACC Older Adults, the perspective of older persons is placed central in the research. This way of working might empower the older persons themselves. Moreover, these insights help facilitate and stimulate professional caregivers to involve older persons in their own care and support. By giving voice to older persons who are receiving care and support, care professionals are supported to place older persons at the centre of their care and support. Therefore, in most of the research projects in the ACC, the first empirical research question studies the perspective of older persons to maximise the impact of understanding the perspective of older persons. Qualitative methods of data gathering prove to be the most helpful to understand perspectives, meanings and experiences of older persons as a heterogeneous group regarding their capacities, limitations, goals, preferences and habits (Luijkx et al., 2020).

To illustrate the value of studying the perspective of older persons, three examples of studies in the ACC Older Adults are provided below: two about living in a nursing home and one about the usefulness of narratives of older persons for quality improvement in care for older persons. These examples show how the perspectives of older persons are placed at the centre in both research and care practice to contribute to person-centred care for older persons.

#### **3.1 Sexuality and intimacy**

The shift from the biomedical model towards the person-centred care model in nursing home care (Koren, 2010; White-Chu et al., 2009) implies that nursing home residents, also those with dementia, are valued as unique individuals and are able to live their lives as they desire. Intimacy and sexuality, in a broad sense, are essential for all human beings during the whole life course, including nursing home residents with dementia (WHO, 2006). It is therefore important to enable experiences with intimacy and sexuality in nursing homes, despite the fact that it is often still a taboo.

Older persons with a more advanced stage of dementia live in nursing homes because they need daily care and support. Enabling residents to experience intimacy and sexuality in the way they prefer should be a natural part of person-centred caregiving. According to a psychologist working within one of the partnership organisations of the ACC Older Adults, staff in nursing homes often experience and label sexual behaviour as problematic behaviour and do not feel equipped to enable residents in this life domain. This insight from daily care practice motivated a psychologist to conduct a PhD study about intimacy and sexuality of older persons with dementia living in a nursing home (Roelofs, 2018).

The conducted study aimed to give voice to nursing home residents and their spouses (if relevant) and to make professional caregivers aware of these needs and to challenge them to act accordingly. Therefore, the study addressed the following overarching research question: ‘in what way can nursing home residents with dementia, and possibly their partners, be best supported in their wishes and needs with regard to intimacy and sexuality?’ (Roelofs, 2018). To discover the perspective of nursing home residents and their spouses, couple interviews have been held, but also individual interviews with residents and individual interviews with spouses (Roelofs et al., 2019a, 2019b). Although it was not easy to interview residents with dementia, it was possible and worthwhile (Roelofs et al., 2017, 2019a). The eight interviews with either individual residents or couples revealed that sexuality and intimacy is an individual matter that is interwoven with the whole life course. Different types of stories were shared by interviewees. Some stories started with the way spouses fell in love a long time ago, while other stories started with the onset of dementia. All interviews revealed that intimacy and sexuality are still important in their lives, despite the fact that dementia and the move to a nursing home had a great impact on these important aspects of life. However, residents and their spouses did not feel that the nursing home is a place where intimacy and sexuality can be experienced satisfactorily. This is prevented by practical, emotional and communicational issues, like the absence of a double bed, the lack of a secure feeling of privacy and the difficulty to talk about this topic with caregivers (Roelofs et al., 2019a). For example, although all participants found it important to be intimate within their relationship, only one couple experienced physical sexuality in the nursing home. Interviews with nine spouses of nursing home residents revealed similar experiences (Roelofs et al., 2019b). This knowledge challenges care professionals to think about how they can involve older persons and their partners in care and support to ensure that they can have such important experiences, also in nursing homes.

### 3.2 Autonomy

The second example about strengthening person-centred care and giving voice to older persons by placing their perspective central is about autonomy of older persons who live in a nursing home due to physical impairments. Based on a systematic literature review, autonomy can be described as the ‘capacity to influence the environment and make decisions irrespective of having executorial autonomy, to live the kind of life someone desires to live in the face of diminishing social, physical and/or cognitive resources and dependency’ (Van Loon et al., 2019). Two polarities of autonomy – decisional and executorial autonomy (Collopy, 1988) – are taken into account in this description. Older persons who live in a nursing home might be able to decide how they prefer something without being able to execute this decision themselves due to their physical impairments. Autonomy in a nursing home is an example of relational autonomy because it is not about being independent in daily life but about being in relation with others.

To be able to provide person-centred care, caregivers must establish and maintain a care relationship with older persons and get to know the core values of each resident. Autonomy needs to be seen as an interactive process, requiring the help and support of others (Abma et al., 2012). To find out how older persons with physical impairments living in a nursing home prefer to live their lives and maintain autonomy, one of the science practitioners conducted a PhD study about autonomy and has shadowed older persons. Shadowing is a non-participatory observational method in which the researcher, the shadower, observes the respondent, the shadowee, like a fly on the wall which comes close to experience, see, feel, hear and smell whatever the shadowee experiences (Van der Meide et al., 2013).

The method of shadowing gives the opportunity to include all older persons, also those who are not able to verbally express themselves well due to frailty, dementia or aphasia. Seventeen older persons with physical impairments who live in two nursing homes have been shadowed during several hours on one day during morning care, meal times and activities. During the shadowing, six elements were seen that older persons use to maintain their autonomy: ‘being able to decide and/or execute decisions’, ‘active involvement’, ‘transferring autonomy to others like family members or other informal care givers’, ‘using preferred spaces’, ‘continuing the life you like to live’ and ‘deciding about important topics’, e.g. about medical decisions, treatment in a hospital, or access to the elderly care physician (Van Loon et al., n.d.).

To enable older persons to be not only subject of research but also actively involved in care, the perspective of staff members has also been studied. Staff

members have been shadowed to find out which actions they take to enhance the autonomy of older persons with physical impairments. Moreover, an action research has been conducted in which older persons and staff members formulated concrete actions with the aim to strengthen the autonomy of older persons (Van Loon et al., 2022). By studying both perspectives of older persons and of staff members, and by facilitating a dialogue between older persons and staff members about the study insights, older persons become more empowered and actively involved in care; in this way, care and autonomy can be provided in a more person-centred way.

Another way to involve older persons in their own care and support is listening to the story of an older person for quality improvement, as is discussed in the third example.

### **3.3 The story as a quality instrument**

A transition related to realising person-centred care concerns the approach chosen in quality research. Quality of care is assessed traditionally by means of quantitative survey instruments, such as the Consumer Quality Index (CQ index) (Triemstra et al., 2010). With the use of a quantitative instrument, a reliable and valid measurement can be achieved on relevant quality indicators including safety, physical body care, provision of meals and hygiene. As a standard for quality, the CQ index was used for a number of years as an obligatory measure for external accountability in the care provision for older persons (Triemstra et al., 2010). However, it is not always sure whether the indicators measured are relevant from the perspective of older persons or only from the perspective of care organisations and health insurers (Van Campen et al., 1998). Although such quantitative findings provide a general view on the experiences of older persons, they do not provide insight into individual levels of expectations, needs and wishes of care provision. Furthermore, the mean scores do not adequately represent the lifeworld of each unique older persons.

In response to these observations, the ACC Older Adults has developed 'The Story as a Quality Instrument'. This is a quality instrument that primarily focuses on the experiences of each individual older person (Scheffelaar et al., 2021). The quality instrument is based on narrative research principles, in which narratives or stories are obtained by avoiding a question-answer structure and simply encouraging older persons to tell their story (Rosenthal, 2018). A rich description in a narrative helps to understand experiences of quality of care from each older person's point of view, combined with other experiences such as social ties and life history (Rosenthal, 2018; Wang & Geale, 2015). Rather than structuring the relevant topics for them by posing



standardised questions, older persons prioritise themselves by talking about the topics that matter to them.

To allow the older person to talk about their experiences freely, the interview is based on one simple open invitation: 'you have been receiving care at organization X for a while. Please tell me about this'. After this open invitation, the flow of a natural conversation is followed. The interviewer does not introduce any further themes, but keeps the conversation going by using non-verbal body language, such as nodding and verbal cues, like repeating the last sentence or using affirmative statements. When the older person seems to have finished a story, the interview moves on to the second stage. In the second part of the interview, probing questions can be posed using the wording of the older person to supplement information that is shared by the older person. Interviews are audio recorded and transcribed verbatim afterwards, and they are used to create a holistic portrait of each interviewed older person. A reliable representation of the respondent's story is achieved by staying close to the respondent's words. The holistic portraits can be used for a variety of purposes, including team reflection to achieve improvement in quality towards person-centred care (Scheffelaar et al., 2021).

Care professionals play a special role in the execution of the quality instrument. After a training, they perform the role of interviewer and analyst as 'insider researcher' (Leslie & McAllister, 2002; Unluer, 2012). In contrast to academics, care professionals benefit from their contextual knowledge of the care environment when relating to each older person and interpreting the interview content. Furthermore, listening to client experiences first-hand stimulates care professionals towards learning, increases their understanding of the client perspective, and supports their plans for improvement emerging from quality research. Care professionals interview older persons with whom they do not have a care relationship to ensure that older persons feel free to talk about anything that is important to them (Scheffelaar et al., 2021).

A follow-up study has started to develop a structured approach for care professionals to jointly translate the narrative portraits into actions targeting quality improvement in the long-term care of older persons (Scheffelaar et al., 2021). In this way, the rich stories of older persons including their experiences, needs and views become the key towards quality improvement of care.

#### **4. Future directions**

In the ACC Older Adults, we strive to empower older persons and involve them in their own care and support by creating scientific knowledge and

societal impact about person-centred long-term care for older persons, in co-creation with older persons, care professionals and researchers, in an equivalent way. We aim to place the perspectives of older persons central in each first empirical study of a PhD study. When older persons have a voice and can share insights into how they prefer to live their lives, they are empowered to share their needs and wishes.

However, getting insight into the perspectives of older persons is not enough for empowering older persons and will not evidently lead to involvement of older persons in their own care and support. Therefore, care professionals working in long-term care for older persons are as important as older persons themselves. For this reason, the perspectives of care professionals in addition to the perspectives of older persons are studied in the research of the ACC Older Adults (Roelofs et al., 2018; Waterschoot et al., 2022). These different yet complementary perspectives contribute to get insight into what is needed and can be done to empower older persons and involve them in their own care and support. Moreover, scientific knowledge is often not immediately applicable into care practice. Therefore, we started and will continue to translate our knowledge in co-creation with older persons, care professionals and researchers into practical tools and working methods that can be implemented in care practice (Haufe et al., 2019; Janssen et al., 2019).

An additional benefit of discussing and implementing the study results about the perspective of older persons and about person-centred care on different levels in a care organisation is that evidence-based practice is stimulated throughout the whole organisation. Hopefully, this fruitful approach will inspire others to do the same.

To benefit from the involvement of older persons in our ACC, we want to move beyond studying the perspectives of older persons and strive to involve older persons structurally, for example, by having them provide input about research topics that are important to them. The Platform of Older Adults was installed with a preparatory group of four older persons, a postdoctoral researcher and an implementation expert to set up structural participation of older persons in the ACC Older Adults.

The study results of the ACC Older Adults contribute to science as well as to policy and daily care practice. We recommend that the new insights from our studies are spread and implemented within care organisations at different levels. Most of the organisations providing care to older persons strive to provide care in a person-centred way. However, in daily practice, regulations and rules of care for older persons (e.g. time schedules for morning care or meal times, pragmatic habits and routines constraining, for example, sexuality and intimacy with a spouse) dominate daily care practice at the expense of

person-centred care. Therefore, a recommendation for policymakers and managers is to enable and stimulate professional caregivers to balance the perspective – in other words, the living world of each older person should be constricted only by rules and regulations that are essential. This would make it easier for care professionals to realise person-centred care in practice and might contribute to the empowerment of older persons. Limiting rules and regulations to the essential ones should provide care professionals liberty in being creative to involve older persons in their own care and support and to provide person-centred care. Moreover, is it recommended to share best practices of how to place the perspective of the older person central and how to care in a person-centred way within and between care organisations and preferably worldwide to encourage learning and improvement.

Research that is characterised by scientific and practical relevance and practical tools and working methods that are actually used by care organisations legitimise the existence and continuations of the ACC Older Adults. This motivates us to continue to develop new scientific knowledge and practical products based on this knowledge that fit care practice. Despite the realised results of the ACC, a thorough understanding of the impact and the implementation of practical tools and working methods is lacking. Whether and to what extent the ACC Older Adults is successful in contributing to person-centred care for older persons is still unknown. Therefore, to gain more insight into our impact on person-centred care in daily practice, three lines of development are valuable. First, at the scientific level, the way the ACC works needs to be scientifically substantiated; every step, including the development and implementation of different practical tools or working methods, based on our scientific insights, should be thoroughly evaluated. Second, an approach to evaluate and, if necessary, adapt the process of making scientific knowledge applicable for practice could bring the ACC a step further. Third, when the tools and working methods are implemented on a large enough scale, the impact and implementation should be evaluated in co-creation with older persons and care professionals to learn how, when and why our approach works and how it can be improved.

## Notes

1. Each author contributed equally to this chapter

## References

- Abma, T., Bruijn, A., Kardol, T., Schols, J. M. G. A., & Widdershoven, G. (2012). Responsibilities in elderly care: Mr Powell's narrative of duty and relations. *Bioethics*, 26(1), 22–31. <https://doi.org/10.1111/j.1467-8519.2011.01898.x>
- Baldwin, J. N., Napier, S., Neville, S., & Wright-St Clair, V. A. (2018). Impacts of older people's patient and public involvement in health and social care research: a systematic review. *Age and ageing*, 47(6), 801–809. <https://doi.org/10.1093/ageing/afy092>
- Bechtel, C., & Ness, D. L. (2010). If you build it, will they come? Designing truly patient-centred health care. *Health Affairs*, 29(5), 914–920. <https://doi.org/10.1377/hlthaff.2010.0305>
- Bindels J, B. V., Cox K, Heijing S, Abma T. (2014). Older people as co-researchers: a collaborative journey. *Ageing Society*, 34(6): 951–973. <https://doi.org/10.1017/S0144686X12001298>
- Books, Z. (2009). What is health? The ability to adapt. *The Lancet*, 373(9666), 781. [https://doi.org/10.1016/S0140-6736\(09\)60456-6](https://doi.org/10.1016/S0140-6736(09)60456-6)
- Brendan, M., Breslin, E., Dewing, J., Tobin, C., Manning, M., Coyne-Nevin, A., Kennedy, K., & Peelo-Kilroe, L. (2010). The implementation of a model of person-centred practice in older person settings final report.
- Broderick, M. C., & Coffey, A. (2013). Person-centred care in nursing documentation. *International journal of older people nursing*, 8(4), 309–318. <https://doi.org/10.1111/opn.12012>
- CBS. (2020). 115 duizend mensen in verzorgings- of verpleeghuis. [115 thousand people in care or nursing homes] <https://www.cbs.nl/nl-nl/achtergrond/2020/13/115-duizend-mensen-in-verzorgings-of-verpleeghuis>
- Collopy, B. J. (1988). Autonomy in Long Term Care: Some Crucial Distinctions. *The Gerontologist*, 28, 10–17. <https://doi.org/https://doi.org/10.1093/geront/28.Suppl.10>
- Coulter, A., Roberts, S., & Dixon, A. (2013). Delivering better services for people with long-term conditions. *Building the house of care. London: The King's Fund*, 1–28.
- De Graaf, L., Janssen, M., Roelofs, T., & Luijkx, K. (2021). Substance use and misuse of older adults living in residential care facilities: a scoping review from a person-centred care approach. *Ageing & Society*, 1–27. <https://doi.org/10.1017/S0144686X21001215>
- De Graaff M, S. A., & Leistikow I. (2019). Transforming clients into experts-by-experience: a pilot in client participation in Dutch long-term elderly care homes inspectorate supervision. *Health Policy*, 123(3), 275–280. <https://doi.org/10.1016/j.healthpol.2018.11.006>
- Dröes, R., Boelens-Van Der Knoop, E. C. C., Bos, J., Meihuizen, L., Ettema, T. P., Gerritsen, D. L., Hoogeveen, F., De Lange, J., & Schölzel-Dorenbos, C. J. M. (2006). Quality of life in dementia in perspective: An explorative study of variations in opinions among people with dementia and their professional caregivers, and in literature. *Dementia*, 5(4), 533–558. <https://doi.org/10.1177/1471301206069929>
- Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, 196(4286), 129–136. <https://doi.org/10.1126/science.847460>
- Fried, L. P., Ferrucci, L., Darer, J., Williamson, J. D., & Anderson, G. (2004). Untangling the concepts of disability, frailty, and comorbidity: implications for improved targeting and care. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 59(3), M255–M263. <https://doi.org/10.1093/gerona/59.3.M255>
- Fried, L. P., Tangen, C. M., Walston, J., Newman, A. B., Hirsch, C., Gottdiener, J., Seeman, T., Tracy, R., Kop, W. J., & Burke, G. (2001). Frailty in older adults: evidence for a phenotype. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 56(3), M146–M157. <https://doi.org/10.1093/gerona/56.3.M146>

- Gerritsen, D. L., Ettema, T. P., Boelens, E., Bos, J., Hoogeveen, F., Lange, J. d., Meihuizen, L., Schölzel-Dorenbos, C. J., & Dröes, R. M. (2007). Quality of life in dementia: do professional caregivers focus on the significant domains? *American Journal of Alzheimer's Disease and Other Dementias*, 22(3), 176–183. <https://doi.org/10.1177/1533317507299771>
- Haufe, M., Peek, S. T. M., & Luijkx, K. G. (2019). Matching gerontechnologies to independent-living seniors' individual needs: Development of the GTM tool. *BMC health services research*, 19(1), 1–13. <https://doi.org/10.1186/s12913-018-3848-5>
- Holmström, I., & Röing, M. (2010). The relation between patient-centeredness and patient empowerment: a discussion on concepts. *Patient education and counseling*, 79(2), 167–172. <https://doi.org/10.1016/j.pec.2009.08.008>
- Huber, M., Knottnerus, J. A., Green, L., van der Horst, H., Jadad, A. R., Kromhout, D., Leonard, B., Lorig, K., Loureiro, M. I., & van der Meer, J. W. (2011). How should we define health? *BMJ*, 343. <https://doi.org/10.1136/bmj.d4163>
- Huber, M., Vliet, V., Giezenberg M., Winkens, B., Heerkens, Y., Dagnelie, P. C., & Knottnerus, J. A. (2016). Towards a 'patient-centred' operationalisation of the new dynamic concept of health: a mixed methods study. *BMJ Open* 6:e010091. doi:10.1136/bmjopen-2015-010091
- Janssen, M. M., Vos, W., & Luijkx, K. G. (2019). Development of an evaluation tool for geriatric rehabilitation care. *BMC geriatrics*, 19(1), 1–10. <https://doi.org/10.1186/s12877-019-1213-0>
- Kane, R. A., Caplan, A. L., Urv-Wong, E. K., Freeman, I. C., Aroskar, M. A., & Finch, M. (1997). Everyday matters in the lives of nursing home residents: wish for and perception of choice and control. *Journal of the American Geriatrics Society*, 45(9), 1086–1093. <https://doi.org/10.1111/j.1532-5415.1997.tb05971.x>
- Kitwood, T. M., & Kitwood, T. M. (1997). *Dementia reconsidered: The person comes first*. Open University Press.
- Koren, M. J. (2010). Person-centred care for nursing home residents: The culture-change movement. *Health Affairs*, 29(2), 1–6. <https://doi.org/10.1377/hlthaff.2009.0966>
- Langberg, E. M., Dyhr, L., & Davidsen, A. S. (2019). Development of the concept of patient-centeredness—A systematic review. *Patient education and counseling*, 102(7), 1228–1236. <https://doi.org/10.1016/j.pec.2019.02.023>
- Larsson, H., Edberg, A.-K., Bolmsjö, I., & Rämgård, M. (2019). Contrasts in older persons' experiences and significant others' perceptions of existential loneliness. *Nursing ethics*, 26(6), 1623–1637. <https://doi.org/10.1177%2F0969733018774828>
- Leplege, A., Gzil, F., Cammelli, M., Lefevre, C., Pachoud, B., & Ville, I. (2007). Person-centredness: conceptual and historical perspectives. *Disability and rehabilitation*, 29(20–21), 1555–1565. <https://doi.org/10.1080/09638280701618661>
- Leslie, H., & McAllister, M. (2002). The benefits of being a nurse in critical social research practice. *Qualitative Health Research*, 12(5), 700–712. <https://doi.org/10.1177%2F104973202129120098>
- Lette, M., Stoop, A., Lemmens, L. C., Buist, Y., Baan, C. A., & De Bruin, S. R. (2017). Improving early detection initiatives: a qualitative study exploring perspectives of older people and professionals. *BMC geriatrics*, 17(1), 1–13. <https://doi.org/10.1186/s12877-017-0521-5>
- Luijkx, K., van Boekel, L., Janssen, M., Verbiest, M., & Stoop, A. (2020). The academic collaborative center older adults: A description of co-creation between science, care practice and education with the aim to contribute to person-centred care for older adults. *International Journal of Environmental Research and Public Health*, 17(23), 9014. <https://doi.org/10.3390/ijerph17239014>
- Markle-Reid, M., & Browne, G. (2003). Conceptualizations of frailty in relation to older adults. *Journal of advanced nursing*, 44(1), 58–68. <https://doi.org/10.1046/j.1365-2648.2003.02767.x>

- McCance, T., McCormack, B., & Dewing, J. (2011). An exploration of person-centredness in practice. <http://dx.doi.org/10.3912/OJIN.Vol16No02Man01>
- McCormack, B., & McCance, T. (2016). *Person-centred practice in nursing and health care: theory and practice*. John Wiley & Sons.
- McCormack, B., & McCance, T. V. (2006). Development of a framework for person-centred nursing. *Journal of advanced nursing*, 56(5), 472–479. <https://doi.org/10.1111/j.1365-2648.2006.04042.x>
- Mead, N., & Bower, P. (2000). Patient-centredness: a conceptual framework and review of the empirical literature. *Social science & medicine*, 51(7), 1087–1110. [https://doi.org/10.1016/S0277-9536\(00\)00098-8](https://doi.org/10.1016/S0277-9536(00)00098-8)
- Rathert, C., Wyrwich, M. D., & Boren, S. A. (2013). Patient-centred care and outcomes: a systematic review of the literature. *Medical Care Research and Review*, 70(4), 351–379. <https://doi.org/10.1177%2F1077558712465774>
- Roelofs, T. (2018). *Love, intimacy and sexuality in nursing home residents with dementia: An exploration from multiple perspectives*. [Doctoral dissertation, Tilburg University].
- Roelofs, T., Embregts, P., & Luijkx, K. (2017). A person-centred approach to study intimacy and sexuality in residential care facility (RCF) clients with dementia: Methodological considerations and a guide to study design. *Neuropsychological Rehabilitation*, 41(2), 359–373. <https://doi.org/https://doi.org/10.3233/NRE-172205>
- Roelofs, T., Luijkx, K., & Embregts, P. (2018). The attitudes of residential care staff toward the sexuality of residents with dementia: Organizational factors. *Innovation in Aging*, 2(Suppl. 1), 340. <https://dx.doi.org/10.1093%2Fgeroni%2Fgy023.1249>
- Roelofs, T. S., Luijkx, K. G., & Embregts, P. J. (2019a). Love, intimacy and sexuality in residential dementia care: A client perspective. *Clinical gerontologist*, 1–11. <https://doi.org/10.1080/07317115.2019.1667468>
- Roelofs, T. S., Luijkx, K. G., & Embregts, P. J. (2019b). Love, intimacy and sexuality in residential dementia care: a spousal perspective. *Dementia*, 18(3), 936–950. <https://doi.org/10.1177%2F1471301217697467>
- Rosenthal, G. (2018). *Interpretive social research: An introduction*. Universitätsverlag Göttingen.
- Santana, M. J., Manalili, K., Jolley, R. J., Zelinsky, S., Quan, H., & Lu, M. (2018). How to practice person-centred care: A conceptual framework. *Health Expectations*, 21(2), 429–440. <https://doi.org/10.1111/hex.12640>
- Scheffelaar, A. (2020). *About the client perspective. A participatory study evaluating the quality of long-term care relationships* [Doctoral dissertation, Utrecht University].
- Scheffelaar, A., Bos, N., de Jong, M., Triemstra, M., van Dulmen, S., & Luijkx, K. (2020). Lessons learned from participatory research to enhance client participation in long-term care research: a multiple case study. *Research Involvement and Engagement*, 6, 1–17. <https://doi.org/10.1186/s40900-020-00187-5>
- Scheffelaar, A., Janssen, M., & Luijkx, K. (2021). The story as a quality instrument: Developing an instrument for quality improvement based on narratives of older adults receiving long-term care. *International Journal of Environmental Research and Public Health*, 18(5), 2773. <https://doi.org/10.3390/ijerph18052773>
- Schipper, L., Luijkx, K., Meijboom, B., Schalk, R., & Schols, J. (2015a). Access to long-term care: Perceptions and experiences of older Dutch people. *Qual. Ageing Older Adults*, 16, 83–93. <https://doi.org/10.1108/QAOA-12-2014-0046>
- Schipper, L., Luijkx, K. G., Meijboom, B. R., & Schols, J. M. G. A. (2015b). 'It is a completely new world you step into.' How older clients and their representatives experience the operational access to Dutch long-term institutional care. *Journal of Aging Studies*, 35, 211–220. <https://doi.org/10.1016/j.jaging.2015.09.002>

- Shearer, N. B., Fleury, J., Ward, K. A., & O'Brien, A. M. (2012). Empowerment interventions for older adults. *Western journal of nursing research, 34*(1), 24–51. <https://doi.org/10.1177/0193945910377887>
- Sjögren, K., Lindkvist, M., Sandman, P. O., Zingmark, K., & Edvardsson, D. (2015). To what extent is the work environment of staff related to person-centred care? A cross-sectional study of residential aged care. *Journal of Clinical Nursing, 24*(9–10), 1310–1319. <https://doi.org/10.1111/jocn.12734>
- Tengland, P. A. (2008) Empowerment: A Conceptual Discussion. *Health Care Analysis, 16*(2), 77–96. <https://doi-org.tilburguniversity.idm.oclc.org/10.1007/s10728-007-0067-3>
- Tranzo. n.d. Tilburg University. <https://www.tilburguniversity.edu/research/institutes-and-research-groups/tranzo>
- Triemstra, M., Winters, S., Kool, R. B., & Wiegers, T. A. (2010). Measuring client experiences in long-term care in the Netherlands: a pilot study with the Consumer Quality Index Long-term Care. *BMC health services research, 10*(1), 1–11. <http://www.biomedcentral.com/1472-6963/10/95>
- Tsubouchi, Y., Yorozuya, K., Tainosyo, A., & Naito, Y. (2021). A conceptual analysis of older adults' empowerment in contemporary japanese culture. *BMC geriatrics, 21*(1), 672. <https://doi.org/10.1186/s12877-021-02631-x>
- Unluer, S. (2012). Being an insider researcher while conducting case study research. *Qualitative Report, 17*, 58. <http://www.nova.edu/ssss/QR/QR17/unluer.pdf>
- Van Campen, C., Sixma, H., Kerssens, J., Peters, L., & Rasker, J. J. (1998). Assessing patients' priorities and perceptions of the quality of health care: the development of the QUOTE-Rheumatic-Patients instrument. *British journal of rheumatology, 37*(4), 362–368. <https://doi.org/10.1093/rheumatology/37.4.362>
- van Corven, C., Bielderma, A., Wijnen, M., Leontjevas, R., Lucassen, P., Graff, M., & Gerritsen, D. L. (2021a). Defining empowerment for older people living with dementia from multiple perspectives: A qualitative study. *International journal of nursing studies, 114*, 103823. <https://doi.org/10.1016/j.ijnurstu.2020.103823>
- van Corven, C., Bielderma, A., Wijnen, M., Leontjevas, R., Lucassen, P., Graff, M., & Gerritsen, D. L. (2021b). Empowerment for people living with dementia: An integrative literature review. *International journal of nursing studies, 124*, 104098. <https://doi.org/10.1016/j.ijnurstu.2021.104098>
- Van der Meide, H., Leget, C., & Olthuis, G. (2013). Giving voice to vulnerable people: the value of shadowing for phenomenological healthcare research. *Medicine, Health Care and Philosophy, 16*(4), 731–737. <https://doi.org/10.1007/s11019-012-9456-y>
- van Diepen, C., Fors, A., Ekman, I., & Hensing, G. (2020). Association between person-centred care and healthcare providers' job satisfaction and work-related health: a scoping review. *BMJ open, 10*(12), e042658. <http://dx.doi.org/10.1136/bmjopen-2020-042658>
- Van Loon, J., Janssen, M., Janssen, B., De Rooij, I. & Luijkx, K. (2022). 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*. <https://doi.org/10.1177/20571585221126890>
- Van Loon, J., Janssen, M., Janssen, B., De Rooij, I., & Luijkx, K. (accepted for publication). How older adults with physical impairments maintain their autonomy in nursing homes. *Ageing & Society*.
- Van Loon, J., Luijkx, K., Janssen, 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, 41*(5), 1–30. <https://doi.org/10.1017/S0144686X19001557>

- Verver, D., Merten, H., de Blok, C., & Wagner, C. (2019). A cross sectional study on the different domains of frailty for independent living older adults. *BMC geriatrics*, *19*(1), 1–12. <https://doi.org/10.1186/s12877-019-1077-3>
- Vos, W. H., van Boekel, L. C., Janssen, M. M., Leenders, R. T., & Luijkx, K. G. (2020). Exploring the impact of social network change: Experiences of older adults ageing in place. *Health & social care in the community*, *28*(1), 116–126. <https://doi.org/10.1111/hsc.12846>
- Wang, C. C., & Geale, S. K. (2015). The power of story: Narrative inquiry as a methodology in nursing research. *International journal of nursing sciences*, *2*(2), 195–198. <https://doi.org/10.1016/j.ijnss.2015.04.014>
- Waterschoot, K., Roelofs, T. S., van Boekel, L. C., & Luijkx, K. G. (2022). Care Staff's Sense-making of Intimate and Sexual Expressions of People with Dementia in Dutch Nursing Homes. *Clinical Gerontologist*, *45*(4), 1–11. <https://doi.org/10.1080/07317115.2021.1928357>
- White-Chu, E. F., Graves, W. J., Godfrey, S. M., Bonner, A., & Sloane, P. (2009). Beyond the medical model: The culture change revolution in long-term care. *Journal of the American Medical Directors Association*, *10*(6), 370–378. <https://doi.org/http://dx.doi.org/10.1016/j.jamda.2009.04.004>
- WHO (2006). *Sexual and Reproductive Health and Research (SRH)*. <https://www.who.int/teams/sexual-and-reproductive-health-and-research/key-areas-of-work/sexual-health/defining-sexual-health>