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## Review Article

# How Can Autonomy Be Maintained and Informal Care Improved for People With Dementia Living in Residential Care Facilities: A Systematic Literature Review

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## Abstract

**Background and Objectives:** For people with dementia living in residential care facilities, maintaining autonomy and receiving informal care are important. The objective of this review is to understand *how* caregiving approaches and physical environment, including technologies contribute to the maintenance of autonomy and informal care provision for this population.

**Research Design and Methods:** A literature review of peer-reviewed articles published between January 1995 and July 2017 was performed. Realist logic of analysis was used, involving context, mechanism and outcome configurations.

**Results:** Forty-nine articles were included. The improvement of the relationship between residents and formal/informal caregivers is important. This increases the knowledge (sharing) about the resident and contributes to their autonomy. A social, flexible, and welcoming attitude of the formal caregiver improves the provision of informal care. Specially designed spaces, for instance, therapeutic gardens, create activities for residents that remind them of themselves and contribute to their autonomy. Use of technologies reduces caregiver's time for primary tasks and therefore enables secondary tasks such as interaction with the residents.

**Discussion and Implications:** The results revealed *how* residential care facilities could maintain autonomy of their residents and improve informal care delivery using caregiving approaches and the physical environment including technologies. The results are supporting toward each other in maintaining autonomy and also helped in enhancing informal care provision. For residential care facilities that want to maintain the autonomy of their residents and improve informal care delivery, it is important to pay attention to all aspects of living in a residential care facility.

**Keywords:** Person-centered care, Realist evaluation, Long-term care, Physical environment, Technology

More than 47 million people live with dementia worldwide; this number is steadily increasing (World Health Organization, 2015). As dementia progresses, a proportion of people with this disease are admitted to residential care facilities to receive the intensive and complex care that can no longer be provided in the home. Originally, residential

care facilities had a strong focus on physical care and resident safety (White-Chu, Graves, Godfrey, Bonner, & Sloane, 2009). Over the last decade, person-centered care has been receiving greater interest. In consequence, more attention has been given to preferences of residents in the provided care setting (Kitwood 1997; Mitchell & Agnelli, 2015).

To facilitate a more person-centered care approach, residential care facilities try to stimulate autonomy of their residents (Brownie & Nancarrow, 2013). The complexity of the concept autonomy for people living in residential care is recognized by others (Bennett et al., 2017; Welford, Murphy, Rodgers, & Frauenlob, 2012). For the purpose of this research we chose a definition of autonomy used in relation to person-centered care. According to McCormack (2001) autonomy has two sides: (a) decisional autonomy refers to the ability and the freedom to make choices; (b) executional autonomy refers to the ability and the freedom to carry out and implement choices. Residential care facilities must be aware of the fact that just because persons with dementia may not have the capacity to carry out a decision they do not lose the right to be involved in the decision making itself (Kitwood 1997; McCormack, 2001). To stimulate autonomy of residents with dementia formal caregivers should maintain and facilitate decisional autonomy when capacity for executional autonomy is reduced (McCormack, 2001).

In addition to autonomy, stimulating informal care in residential care facilities is essential to providing person-centered care (Natan, 2009). Informal care is unpaid care and support provided by family, friends, or neighbors (Reinhard, Given, Nirvana Petlick, & Bemis, 2008) and therefore providers of informal care are familiar with the likes and dislikes of the resident (Eurocarers, 2009; Reid & Chappell, 2017). Due to lack of clear communication between formal and informal caregivers regarding possibilities for informal care provision, informal caregivers often experience difficulties in staying involved in care after admission (Bauer, 2007; Reid & Chappell, 2017). For this review, we were interested in these two essential elements of person-centered care: autonomy and informal care provision (Edvardsson, Fetherstonhaugh, & Nay, 2010; McCormack, 2001).

As explained earlier, involvement of the residents themselves and informal care provision is essential to developing and carrying out appropriate care plans. Therefore, the relationship between residents and formal and informal caregivers is one of the main elements for maintaining autonomy and increasing informal care (Beach, Inui, & the Relationship-Centered Care Research, 2006; McCormack, 2004; Rahman & Schnelle, 2008). For this reason, the way residents and their informal caregivers are approached by formal caregivers during care and welfare activities are of importance. For the purpose of this review, we refer to contact and approachability between formal caregivers, residents, and informal caregivers as the caregiving approach. In addition, the physical environment in residential care facilities is important for autonomy and informal care (Chaudhury, Cooke, Cowie, & Razaghi, 2017; Day, Carreon, & Stump, 2000). Of late, some changes in the environments of residential care facilities can be observed. Examples are small-scale living facilities, with separate bedrooms for all residents built around a communal kitchen

and living room area (Verbeek, van Rossum, Zwakhalen, Kempen, & Hamers, 2009); therapeutic areas with special bathrooms to comfort people with dementia (van Weert et al., 2004); and gardens (Gonzalez & Kirkevold, 2014). Also, new technologies such as chip cards and watches with a GPS tracker allow residents to move freely within and outside the residence; this can contribute to the autonomy of the resident (Gordijn & Have, 2016; Robinson, Brittain, Lindsay, Jackson, & Olivier, 2009).

Many recent studies consider the influence of caregiving approaches or the physical environment or technologies, on the wellbeing of persons with dementia. This may be due to increased attention on the need for autonomy and informal care for this population. However, these studies do not provide a clear explanation of *how* caregiving approaches and the physical environment, including technologies, influence these aspects of residents' experience (Anderberg & Berglund, 2010; Baalen, Vingerhoets, Sixma, & Lange, 2011; Natan, 2009; Roberts & Ishler, 2017). The aim of this literature review was to understand *how* caregiving approaches and the physical environment influence autonomy and informal care for people with dementia living in residential care facilities.

To achieve this aim, we made use of the realist approach (Pawson & Tilley, 1997). This is a theory-driven evaluation approach increasingly used for studying the implementation of complex interventions within health systems (Marchal, van Belle, van Olmen, Hoérée, & Kegels, 2012). The purpose of the realist method was to determine what works, for whom, in what contexts, in what respects and how, instead of determining whether an intervention works or not (Pawson & Tilley, 1997). Realist evaluation seeks to unpack the relationships between context, mechanism and outcomes, that is, how particular contexts trigger (or interfere with) mechanisms to generate the observed outcomes. The context includes such elements as organizational context, features of participants, staffing, geographical and historical context. A mechanism is a human understanding and response that cannot be directly observed, such as preferences, reasoning, norms, or collective beliefs. Outcomes could include change for people and their lives, but also might involve other kinds of alterations (i.e., in organizations, workers, or governments) (Westhorp et al., 2011).

The relationship between the context and mechanisms leading to certain outcomes is called the context-mechanism-outcome (CMO) configuration. In our review, the context was the residential care facility (organizational context) in which people with dementia live (features of participants). The outcomes (changes for people) were autonomy and informal care. Our hypothesis was that elements of caregiving approaches and physical environment, including technologies, were triggering mechanisms (responses of people) and, as such, influencing autonomy and informal care. Our research aims were the following (Figure 1):

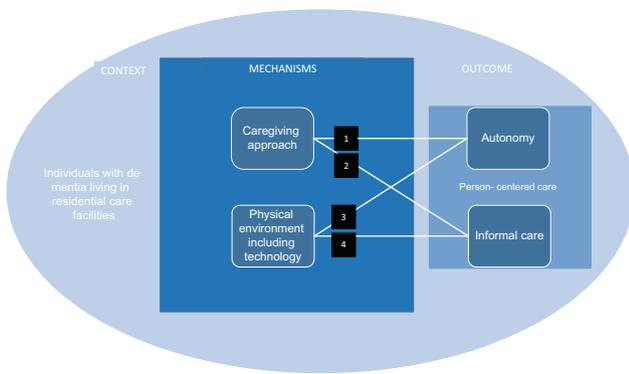


Figure 1. Research aims of the literature review.

1. To understand how caregiving approaches contribute to the maintenance of autonomy for people with dementia living in residential care facilities.
2. To understand how caregiving approaches contribute to the improvement of informal care for people with dementia living in residential care facilities.
3. To understand how the physical environment, including technologies, contributes to the maintenance of autonomy for people with dementia living in residential care facilities.
4. To understand how the physical environment, including technologies, contributes to the improvement of informal care for people with dementia living in residential care facilities.

## Research Design and Methods

### Search Strategy

To investigate the current knowledge about maintaining autonomy and informal care for people with dementia living in residential care facilities, we included databases from multiple research disciplines. Six databases were systematically searched in February 2016 and updated in July 2017 for relevant publications (Supplementary Table 1). As from mid-2000s transformations in the health care systems of the developed countries are noticeable (Paparella, 2016; Rahman & Schnelle, 2008). For the residential care facilities, this implies also a change toward more person-centered care (O'Connor et al., 2007). Therefore, studies from the year 2005 and onwards are included. Studies on maintaining and stimulating autonomy and informal care for people with intellectual disabilities in residential care facilities were also included; because we expected the same challenges in maintaining autonomy and receiving informal care among persons with intellectual disabilities.

A combination of six groups of key words was used to search the databases. These groups of keywords consisted of search terms from all six databases: mesh terms (PubMed), thesaurus (psychINFO), sociological thesaurus (Social Services Abstract and Sociological Abstracts), and

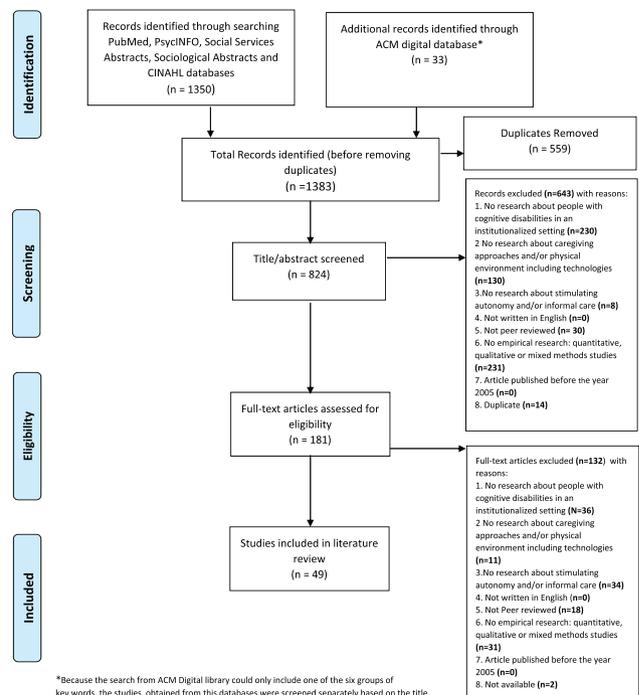


Figure 2. Flowchart of the literature review.

headings terms (CINAHL). Also, synonyms and free text words were used. Four search strings were formed based on the objectives of this review (Figure 1). Supplementary Table 2 gives an overview of the groups and keywords used. Supplementary Table 3 provides an overview of the search strings.

### Assessment of Rigor and Quality of Primary Studies

Two researchers independently assessed the studies' rigor with the following selection criteria during the title/abstract and full text selection. (a) Research about people with cognitive disabilities in an institutionalized setting; (b) Research about caregiving approaches and/or physical environment including technologies; (c) Research about stimulating autonomy and/or informal care; (d) Written in English; (e) Peer reviewed; (f) Empirical research: quantitative, qualitative, or mixed methods studies; (g) Article published after the year 2005. Results were discussed in pairs (J. Boumans and L. van Boekel; J. Boumans and K. G. Luijkx) until consensus was reached, Figure 2.

The quality of the included studies was assessed using the Mixed Methods Appraisal Tool (MMAT Tool). MMAT is a unified quality assessment tool used to assess qualitative, quantitative, and mixed methods studies (Pace et al., 2012). The tool includes 2 screening questions and 19 items for appraising the methodological quality of 5 categories of studies: qualitative studies (4 items), RCTs (4 items), non-randomized studies (4 items), quantitative descriptive studies (4 items), and mixed methods studies (3 items). When

appraising a qualitative or quantitative study one set of items is used. For mixed methods studies, three sets of items are assessed: the qualitative set, a quantitative set (either the RCT, nonrandomized studies, or quantitative descriptive studies), and the mixed methods set. Each item is rated on a categorical scale (yes, no, and cannot tell). The number of items rated “yes” is counted to provide an overall score. The tool does not rank quantitative studies higher than mixed methods studies or qualitative studies. The appraisal was performed independently by two researchers, and the results were discussed in pairs (J. Boumans and L. van Boekel; J. Boumans and K. G. Luijkx) until consensus was reached. Relative outcome scores and the percentage of these scores are reported in [Table 1](#).

### Data Extraction and Analysis

Data were extracted by three authors independently and discussed in pairs (J. Boumans and L. van Boekel or J. Boumans and K. G. Luijkx) until consensus was reached; when necessary, a third author was consulted. All authors used a data extraction form specifying the following information: author(s), title, publication year, study methodology, setting, participants, and object of the study (caregiving approach or physical or technological development). During the extraction phase the realist evaluation approach was used to identify CMO configurations in each study. These configurations described how contextual factors (people with dementia living in residential care facilities) and mechanisms (human responses to elements of caregiving approach and/or physical design and technologies) led to the desired outcomes (autonomy and/or informal care). For each study, one or more CMO configurations were drafted. Analyses were performed by exploring patterns within these CMO configurations. During analyses the quality of the studies was taken into account. CMO configurations from studies with a low MMAT score (50% or less) were only used to support CMO configurations found in studies with a MMAT score above 50%.

### Results

We included 49 studies in the review (which were performed worldwide). Most of the studies used qualitative methods. Thirty-two studies described caregiving approaches (Construct A). Ten studies considered physical environment (Construct B), and seven studies discussed technologies (Construct C). [Table 1](#) provides an overview of the characteristics and designs of the studies.

We were interested in *how* elements of caregiving approaches and the physical environment, including technologies, led to maintaining autonomy and increasing informal care for people with dementia. Therefore, the mechanisms found in the results are described in detail. [Table 2](#) provides a summary of the results.

## Construct A: Caregiving Approaches

### Element A.1: Attitude of the formal caregiver regarding the resident → Autonomy

The attitude of formal caregivers is of importance for residents to experience decisional but also executional autonomy. Two mechanisms were found that explain which attitudes of formal caregivers could increase autonomy of the residents: flexibility and social inclusion. In addition, a facilitating element was found that indirectly could lead to more autonomy among residents: facilitate an attitude change of formal caregivers in order that they could be more aware of the autonomy of the residents.

*Flexible attitude of formal caregivers.* The first mechanism that improves the decisional autonomy of residents is a flexible attitude of the formal caregivers, with respect to residents’ particular needs. Six studies ([Bigby et al., 2014](#); [Carr et al., 2011](#); [Fetherstonhaugh et al., 2016](#); [Milte et al., 2016](#); [Raber et al., 2010](#); [Scerri et al., 2015](#)) showed that with a flexible attitude a formal caregiver could meet the needs of residents, even if the facility routines dictated something else. This might entail, for example, satisfying the request of a resident who wants to have dinner at a unique time or to eat something different:

Resident Kelly was given a pureed dinner with brown meat, white potatoes, and green vegetables. Kelly: I can’t eat all that, I am sick. [Becoming angry] Caregiver Ursula: Yes, you are right. This is too much. Let me change it. Then staff Ursula went to the kitchen and brought back a small dish of mashed potatoes. Ursula: Kelly this is a small dish of mashed potatoes with gravy on the top. Kelly: Oh thank you. I will eat it. (caregiver; [Hung & Chaudhury, 2011](#), p. 10)

*Social inclusion.* Two studies ([Bigby et al., 2014](#); [Scerri et al., 2015](#)) revealed that feelings of autonomy in people with dementia are enhanced when they feel they are full members of the social group. Therefore, formal caregivers should be aware that an activity does not feel like a planned activity ([Bigby et al., 2014](#); [Milte et al., 2016](#); [Raber et al., 2010](#); [Scerri et al., 2015](#); [Teitelman et al., 2010](#)).

Nell enjoyed activity therapy the most when she felt that she was assisting the activity therapist. (caregiver; [Teitelman et al., 2010](#), p. 329)

[Raber and colleagues \(2010\)](#) provided another example of social inclusion that leads to executional autonomy: modification of occupational forms. The acceptance of formal caregivers of the changes people with dementia make while performing certain activities. For example, playing games entailed following the residents’ lead rather than existing rules.

**Table 1.** Characteristics of the Studies

Author; country	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy (M = mechanism)	Main results regarding informal care (M = mechanism)	Study quality
<i>Construct A: Caregiving approach</i>							
Bigby, Knox, Beadle-Brown, and Bould (2014); Australia	Seven group homes residents with a severe level or profound of intellectual disability were staffed 24 hr a day	Total = 37 PID = 37	Mixed methods, questionnaires, checklists, observations, semi structured interviews	The reaction of people with intellectual disabilities on actions and behavior of staff assessed using the quality of life domains	Interpersonal relations between staff and residents (M) create a more joyous or upbeat interaction between staff and residents Flexible solutions of caregivers can lead to engaging in or performing (parts of) the activities themselves Via social inclusion (M) people with intellectual disabilities are given the feeling that they are full members of the community	When caregivers stimulate contact between the care recipients and their family (M) the family is more involved in the life of the care recipients	82% (9/11)
Bramble, Moyle, and Shum (2011); Australia	Two long term care facilities with a dementia-specific special care	Total = 116 Staff members = 59 Family members = 57	Quantitative questionnaires	FIC partnership mode (family involvement in care)		The FIC intervention (M) improved family knowledge about dementia and ways of increasing family involvement in care	50% (2/4)
Buron (2010); USA	Secure dementia units within nursing home facilities	Total = 41 PwD = 5 Staff members = 36	Quantitative questionnaires	A life story collage of the resident was created based on information given by family members	Life story collage (M) significantly improved nursing staff knowledge about the resident		75% (3/4)
Carr, Hicks-Moore, and Montgomery (2011); Canada	Urban tertiary care center, on a specialized and secure unit designed for the care of elderly persons admitted with moderate to severe dementia	Total = 29 PwD = 8 Staff members = 11 Family members = 5 Other (hospital chaplains) = 5	Qualitative interviews, observations	The meaning of spiritual care (connecting with person; attention for person's preferences; helping person to connect with sacred in life, for persons with moderate to severe dementia Change, and predictors of change, in social skills among residents with dementia in nursing homes Facility provides and encourages resident participation in 10 activities common in long-term care (e.g., exercise, personal care, social, housekeeping, meal preparation, crafts)	Spiritual care (M) helps health care providers to address and respond to the physical, emotional and social and spiritual needs of persons with dementia		100% (4/4)
Chappell, Kadlec, and Reid (2014); Canada	18 large-scale nursing homes	Total = 344 PwD = 149 Staff members = 195	Quantitative questionnaires		The proportion of residents whose social skills had not declined was related to staff-to resident communication (M)		100% (4/4)
Dobbs et al. (2005); USA	35 residential care/ assisted living facilities and 10 nursing homes	Total = 400 PwD = 400	Quantitative questionnaires		Family involvement in assessing activities, family social involvement (M), and staff encouragement of activity involvement were all related to more activity involvement		75% (3/4)

Table 1. Continued

Author; country	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy (M = mechanism)	Main results regarding informal care (M = mechanism)	Study quality
<b>Doyle and Rubinstein (2014); USA</b>	Religiously affiliated home that provided both assisted living and nursing home care to people with dementia	Total = 45 PwD = 20 Staff members = 25	Qualitative interviews, observations	An established organizational model of PCC including weekly care meetings	The impact that a dementia label (M) had on staff members' perceptions of residents' abilities was shown in the way that residents were ignored as potential contributors during social exchange	Main results regarding informal care (M = mechanism)	100% (4/4)
<b>Egan et al. (2007); Canada</b>	Two long-term care facilities in a small, rural community and large, urban tertiary care teaching hospital	Total = 14 PwD = 4 Staff members = 10	Mixed methods, observation and interviews	One-page narrative of the life history of the resident placed in the chart and central location where staff were likely to see it (e.g., above the resident's bed)	Approximately half of the staff reported positive changes in the care they provided after they read the life history (M) Information about hardship in the lives of the residents did not appear to be linked with negative judgment by the staff, but rather to appreciation		75% (3/4)
<b>Eritz et al. (2015); Canada</b>	Six long-term care facilities	Total = 172 PwD = 73 Staff members = 99	Mixed methods	Life history narrative of the residents life of approximately two pages, including one page of photographs	Approximately 60% nurses reported changing their care based on the intervention changes in verbal interactions with residents, specifically being able to converse with residents more about past interests and experiences (M)		82% (9/11)
<b>Fetherstonhaugh, Tarzia, Bauer, Nay, and Beattie (2016); Australia</b>	14 residential care facilities	Total = 80 Staff members = 80	Qualitative interviews, focus groups	To explore the ways in which direct care staff in Australian residential care facilities perceive that they support and facilitate decision making for people with dementia	Taking the time to get to know the person with dementia (M) was perceived by the staff as being an important precursor to being able to assist with decision making, particularly when the person was unable to communicate verbally or had other difficulties with communication People who did not wish to eat at scheduled mealtimes could be offered snacks or sandwiches when they were hungry (M)		75% (3/4)
<b>Gendron, King Seymour, and Welleford (2016); USA</b>	One continuing care retirement community	Total = 30 PwD = not mentioned Staff members = not mentioned Family members = not mentioned	Qualitative focus groups	Catch a Glimpse of Me videos intervention: a person-centered approach to care by capturing the essence of an individual with dementia	Assist staff members to gain insight into their residents (M) as they progress with dementia		25% (1/4)
<b>Hanssen and Kuven (2016); Norway</b>	Three nursing homes	Total = 57 Staff members = 31 Family members = 26	Qualitative interviews	Institutionalized patients with dementia are served dishes they recognize from childhood and youth	Being served traditional dishes (M) boosted the patients' sense of identity		75% (3/4)

**Table 1. Continued**

Author; country	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy (M = mechanism)	Main results regarding informal care (M = mechanism)	Study quality
Hemingway, MacCourt, Pierce, and Strudsholm (2016); Canada	One long-term care facility	Total = 28 Family members = 28	Qualitative interviews, focus groups	Contextual understanding of the lived experience of spousal caregivers	Main results regarding autonomy (M = mechanism)	Main results regarding informal care (M = mechanism)	50% (2/4)
Hung and Chaudhury (2011); Canada	Two urban long-term care facilities; one presented institutional features of traditional nursing home, the other had homelike characteristics	Total = 28 PwD = 20 Staff members = 8	Qualitative interviews, focus groups and document analysis	Personhood aspects of dining	Staff knowing the details of the residents' personal habits (M), helped the residents feel important, valued, and respected	Formal roles for spousal caregivers make these caregivers feel as though they still have a role (M) and continue to be a part of their spouse's care	75% (3/4)
Hunter, Hadjistavropoulos, Thorpe, Lix, and Malloy (2016); Canada	One large rural long-term residential care facility	Total = 108 Staff members = 108	Quantitative questionnaires	The contribution of employee personal factors and organizational factors to self-reported person-centered residential dementia care	One organizational variable, person-directed environment for residents (M), showed significant positive association with autonomy		75% (3/4)
Kelletr, Moyle, McAllister, King, and Gallagher (2010); Australia	Everyday care for persons with dementia in one long-term care setting	Total = 21 PwD = 7 Staff members = 7 Family members = 7	Qualitative focus groups	Family Biography Workshop. The workshop was designed to provide a defined role for family caregivers of people with dementia in care to assist staff in personalizing nursing care	Knowledge about the person with dementia (M) enhanced the staff's appreciation and respect of the person with dementia as a person embedded in a family and intergenerational context		75% (3/4)
Koskenniemi, Leino-Kilpi, and Suhonen (2015); Finland	Eight different long-term care facilities	Total = 40 PwD = 10 (living in nursing home) Family members = 20 Other (pwd living at home) = 10 not included in results of this review	Qualitative interviews	Manifestation of respect in the care of older patients in long-term care settings from the perspective of older patients	Respect was shown when nurses did not underestimate, neglect, or label patients because of their memory disorders (M)	Respect was shown when nurses did not underestimate, neglect, or label patients because of their memory disorders (M) Nurses who came to know the patients (M) spent time with their patients and were interested in patients' habits and the way they behaved and expressed themselves	50% (2/4)

Table 1. Continued

Author; country	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy (M = mechanism)	Main results regarding informal care (M = mechanism)	Study quality
McKeown, Clarke, Ingleton, Ryan, and Repper (2010); UK	Intermediate and assessment care wards with 24 beds in a city and a general nursing care home	Total = 3 (one person that did not meet our institutionalized criteria and was excluded from the review) PwD = 3	Qualitative multiple case study, interviews, observations	Life story book	Life story book helped staff and family to see the person with dementia beyond being a patient (M) Staff was able to make links between the person's past and the present because of the life story book (M)		100% (4/4)
Milte et al. (2016); Australia	Two residential care facilities	Total = 38 PID = 12 Family members = 26	Qualitative interviews, focus groups	To describe the meaning of quality residential care from the perspective of people with cognitive impairment and their family members. They live the way they want.	Participants being identified and respected as a person with individual likes, dislikes, preferences and needs (M) providing good quality care with some participants expressed frustration when they were not able to continue living due to perceived pressure to fit in with the routines of the facility (M) For the activities to be meaningful to the participant activities should be tailored to the individual's interests and preferences (M), rather than people being offered more traditional diversion activities that may provide no context to participants		50% (2/4)
Moyle et al. (2013); Australia	One long-term care facility owned and operated by a large not-for-profit provider	Total = 18 PwD = 5 Staff members = 7 Family members = 6	Qualitative semi-structured interviews, video call records, video observational data	The capabilities model of dementia care	The education was helpful in expanding the understanding of residents' needs and the possibilities for care and placed significant importance on resident independence (M) and described encouraging residents to assist in their own care where possible	Staff and family members who attended the training workshops reported significant increase in the quality of staff-family relationship (M) Staff believed that these improved relationships were valuable in improving residents' care, family involvement in care and nurses' experience of the relationship with the family	100% (4/4)
Orulv and Nikku (2007); Sweden	People with intellectual disabilities living in an institutionalized setting	Total = 13 PID in = 7 Staff members = 6	Qualitative observations and video-recording	Conflict-solving dignity work done by staff in dementia care	Respecting dignity in terms of autonomy and agency occurs when the residents as a collective are given an opportunity to find a constructive solution on their own (M)		25% (1/4)

**Table 1. Continued**

Author; country	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy (M = mechanism)	Main results regarding informal care (M = mechanism)	Study quality
Palmer (2013); USA	14 different long-term care facilities	Total = 15 Family members = 15	Qualitative interviews	Efforts to preserve the personhood of individuals with advanced dementia when they moved to a long-term care facility How volition expressions are recognized by staff and how these expressions are used to engage people in meaningful activities	Staff relating to individuals with dementia by acknowledging their history, likes, and dislikes (M)	Caregivers maintained their family members' personhood through their involvement with care (M)	75% (3/4)
Raber, Teitelman, Watts, and Kielhofner (2010); USA	One memory support assisted living unit	Total = 24 PwD = 8 Staff members = 8 Family members = 8	Qualitative questionnaires, interviews and observations		Family members' identification of participants' past interests (M) was used by caregivers to provide cues for participants to recall interests The ability to participate and find meaning in occupations was restored for participants through modification of occupational forms (M) (e.g., playing games following the participant's lead rather than existing rules to fit participants' abilities better) The women were observed to assist with menu planning, preparing the meals, and baking. These activities required staff support at times (M), but it was clear that the women were active participants while baking and cooking and the women experienced leisure independently and spontaneously	Building a relationship between staff and family members was also perceived as important. Care workers acknowledged the role of family members as a source of information (M) and assistance in regaining the patient's previous loss of function.	100% (4/4)
Rosow-Kimball and Goodwin (2009); Canada	Two small-scale group homes for people with intellectual disabilities	Total = 10 PID = 5 Staff members = 5	Qualitative interviews and observations	Self-determination and leisure experiences of women living in group homes	Care workers stressed the need to get to know the patient better (M) to understand the patient's behavior Staff mentioned approaches with which they managed to maintain "normality" and the patient's identity (M) Hospital staff felt that positive experiences with dementia patients can be achieved if they went the "extra mile"; when they adopted initiatives or carried out actions that were not part of the normal care routine or that fall within their job description (M)		100% (4/4)
Scerri, Innes, and Scerri (2015); Malta	Two geriatric rehabilitation wards	Total = 43 Staff members = 33 Family members = 10	Qualitative interviews	Explore quality dementia care from the point of view of formal care workers and family members of inpatients with dementia			75% (3/4)

Table 1. Continued

Author; country	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy (M = mechanism)	Main results regarding informal care (M = mechanism)	Study quality
Snoeren, Janssen, Niessen, and Abma (2016); The Netherlands	Nursing home with 22 residents	Total = 6 Staff members = 6	Qualitative action-research	Action-research project, aimed at the improvement of daily activity for older people with dementia	Caregivers could better understand and respond to resident's actions and personal expressions when they knew more of a resident's background (M) Meaningful activity was no longer solely regarded as activities for groups of residents, but also as involving the individual resident in everyday (care) activities. Exploring and adapting to the resident's interests and needs became more important (M)		100% (4/4)
Söderlund, Cronqvist, Norberg, Ternstedt, and Hansebo (2016); Sweden	Three nursing home wards	Total = 8 PwD = 4 Staff members = 4	Qualitative videotaped one-to-one conversations	Specific validation method techniques for communication, with the aim of increasing feelings of self-worth and well-being among persons with dementia	When the nurse stopped treating the person as a "nonadult" and instead asked how the person felt at the moment (M), they got a clear answer		100% (4/4)
Söderman, and Rosendahl (2016); Sweden	Two linguistically different care group homes for people with dementia	Total = 27 Staff members = 27	Qualitative semi-structured interviews	Serving traditional food, celebrating holidays and playing familiar music and other cultural elements in the group home	Most of the residents expressed that they appreciated being served traditional food (M) All nursing staff described how the residents appreciated the opportunity to listen to music in their native language, (M) the music was familiar and touched the residents emotionally		100% (4/4)
Teeri, Välimäki, Katajisto, and Leino-Kilpi (2008); Finland	Wards for long-term patients in four Finnish cities	Total = 337 Staff members = 222 Family members = 115	Quantitative questionnaires	The influence of factors related to patients, relatives, nurses, the care organization and society associated with the occurrence of ethically problematic situations on the maintenance of patient integrity	According to informal caregivers persons with dementia had difficulties expressing themselves due to ethically problematic care situations (M)		100% (4/4)
Teitelman, Raber, and Watts (2010); USA	One memory support unit using an Eden Alternative environment	Total = 8 PwD = 8	Qualitative interviews, observations	Showing that the social environment is a factor in facilitating occupational engagement in persons with dementia	If activities are performed in a natural context and it doesn't feel like a planned activity (M) persons with dementia are feeling more engaged Knowledge about the history of a person with dementia (M) enables caregivers to come up with modified activities the person enjoys		100% (4/4)

Table 1. Continued

Author; country	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy (M = mechanism)	Main results regarding informal care (M = mechanism)	Study quality
van der Ploeg et al. (2013); Australia	Two dementia units and seven specialist psychogeriatric nursing homes	Total = 44 PwD = 44	Quantitative randomized clinical trial	Application of the Montessori intervention (intervention to help provide personalized stimulation, meaningful activity, and engagement for people with dementia)	For those who lacked fluency in English, analyses show that once all the interactions and fluency were accounted for, (M), there was a significantly larger fall in agitated behaviors during the Montessori than the control sessions	Main results regarding informal care (M = mechanism)	75% (3/4)
van Weert, van Dulmen, Spreunenberg, Ribbe, and Bensing (2005); The Netherlands	12 psychogeriatric wards at six nursing homes	Total = 129 PwD = 129	Qualitative observations	Snoezelen (an approach that actively stimulates the senses using light, sound, smell, and taste of people with dementia)	Significant treatment effects were seen in the following outcome measures after the intervention (M)		75% (3/4)
<i>Construct B: Physical environment</i>							
Chenoweth et al. (2015); Australia	Different types of housings for people with dementia	Total = 172 Staff members = 99 Family members = 73	Qualitative interviews, case reports, observations	Understanding the inconsistencies in Person-Centered Dementia Care and Environment (PerCEN) in a randomized controlled study	The personalization of the environment was one positive outcome		75% (3/4)
De Vreese et al. (2012); Australia	Special dementia care home for adults with intellectual disabilities	Total = 60 PID = 60	Quantitative questionnaires	The influence of a specialty dementia care home (special care unit (SCU) on adults with intellectual disabilities	Nurses and care staff described a more peaceful and homely environment (M) in which people with dementia felt comfortable and safe		50% (2/4)
Herandez (2007); USA	Two specifically designed dementia-care facilities including garden space	Total = 45 Staff members = 28 Family members = 12 Other = 5 (architects)	Qualitative case studies, interviews, observations, behavioral mapping	Investigating therapeutic gardens for people with dementia	Family members identified differences in care quality and well-being for people with dementia between weekdays and weekends arising from differences in staff to resident ratios and skills (M)		75% (3/4)

Table 1. Continued

Author; country	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy (M = mechanism)	Main results regarding informal care (M = mechanism)	Study quality
Hutchings et al. (2011); Canada	Residents with dementia relocated from an institutional environment to an assisted-living environment	Total = 10 Family members = 10	Qualitative interviews	The Protective Community Residences (PCR) were constructed to provide a homelike environment, with common areas and private space to meet the needs of persons with dementia	The family members indicated that staff is drinking tea with the residents and engage them in everyday, routine activities including personal grooming and baking (M)	Several family members commented that the PCR facilitated more frequent visiting (M) because their family members were similarly more content Staff contributed to the homelike, welcoming environment through their everyday interactions with the residents and family members (M). Family members indicated that they were encouraged to drop in at any time and had been invited to stay for a meal	75% (3/4)
Lee, Chaudhury, and Hung (2016); Canada	Two dementia care facilities	Total = 15 Staff members = 14 Family members = 1	Qualitative focus groups	Examining staff perceptions on the effect of physical environmental features on residents' behaviors and their care practices in two care facilities	Residents were in better mood and more receptive to care when personal items were present in the environment or when the environment was arranged in a personalized way (M) Staff highly valued the small size of units (M) that helped them feel safe	Residents were in better mood and more receptive to care when personal items were present in the environment or when the environment was arranged in a personalized way (M) Staff highly valued the small size of units (M) that helped them feel safe	100% (4/4)
Lichtenberg, Kemp-Havican, Macneil, and Schafer Johnson (2005); USA	Two new homelike special care units for individuals with dementia	Total = 20 PwD = 20	Quantitative assessment	The Pleasant Events Schedule for Alzheimer's disease combined with brainstorming sessions by the nursing assistants on other areas of pleasurable events for each resident, comprised the way activities were matched with residents	Mood ratings right after the pleasant event went up (M) but no differences were seen in the long-term depression measurement	Mood ratings right after the pleasant event went up (M) but no differences were seen in the long-term depression measurement	100% (4/4)
Smith, Mathews, and Gresham (2010); Australia	Home living cottages designed to create a homelike environment for high care residents with dementia	Total = 90 PwD = 90	Mixed methods, environmental assessments, observations, behavior mapping	Specially designed group home living facility for high care residents with dementia and a workshop for caregivers to engage residents in life-skill activities	Staff members were observed to being more engaged in resident interactive task after the move to the new group home living facility (M)	Staff members were observed to being more engaged in resident interactive task after the move to the new group home living facility (M)	75% (3/4)

Table 1. Continued

Author; country	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy (M = mechanism)	Main results regarding informal care (M = mechanism)	Study quality
van Zadelhoff, Verbeek, Widdershoven, van Rossum, and Abma (2011); (NLD)	Two group living units located on the grounds of a traditional large-scale nonprofit nursing home	Total = 29 PwD = 20 Staff members = 5 Family members = 4	Qualitative observations, interviews	Experiences of daily life in two group living homes		Family members are treated as group members (instead of visitors) and have the unit's key (M) Family members actually help their relative with daily care and carry out everyday activities in the unit	100% (4/4)
Verbeek et al. (2010); The Netherlands	28 houses in small-scale living and 21 regular wards from seven nursing homes	Total = 793 PwD = 259 Staff members = 305 Family members = 229	Quantitative questionnaires	Effects of small-scale living compared with regular care in nursing homes in the Netherlands		Family caregivers in small-scale living facilities (M) experienced less burden than family caregivers in regular wards. No effects were found for involvement in care	100% (4/4)
Verbeek, Zwakhalen, van Rossum, Kempen, and Hamers (2012); The Netherlands	28 houses from five small-scale living facilities and 21 regular wards from seven nursing homes	Total = 439 Staff members = 309 Family members = 130	Mixed methods, questionnaires, interviews	The experiences of family caregivers and nursing staff with daily care processes in small-scale living facilities in the Netherlands	The limited number of residents per house (M) provided opportunity to build a personal relationship between staff members and residents and also for residents among each other	Family caregivers indicated that nursing staff's attitude was open, friendly and involved. Sense of involvement with daily life and care provided was enabled by the active role family could fulfill (M) in activities in the household	90% (10/11)
Construct C: Technology Aloulou et al. (2013); Singapore	Residents in a nursing home	Total = 8 PwD = 8	Qualitative log sheets	A technical ambient assistive living solution, consisting of a set of sensors and devices controlled by a software platform. Via sensors and interaction devices, care recipients are monitored and helped in their daily activities.	Technical solution that remind the care recipient or guide the care recipient with their actions regarding showering or washing their hands (M), can lead to retain some level of independence for the care recipient		75% (3/4)
Lazar, Demiris, and Thompson (2016); USA	26 apartment memory care units for people with mild-to-severe dementia	Total = 16 PwD = 5 Staff members = 4 Family members = 7	Mixed methods questionnaires, individual interviews	Commercially available computer system	Reminiscence was a benefit residents experienced from using the system (M) The resident gaining self-esteem through the use of the system. This was due to using a computer as well as winning games (M).		90% (10/11)

Table 1. Continued

Author; country	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy (M = mechanism)	Main results regarding informal care (M = mechanism)	Study quality
Margot-Cattin and Nygård (2006); Switzerland	One unit specialized short-term treatment for dementia care	Total = 28 PwD = 15 Staff members = 13	Qualitative interviews and observations	Access technology system	The system promoted privacy for the residents by controlling the access to the rooms (M), and by offering a secure, private place (M) Physical security was closely associated with the access control system; the staff relied on the system to guarantee security by not unlocking doors for unauthorized persons (M) This seemed to create in their minds a feeling of security (M); in turn, the staff projected this feeling of security to the PwD		100% (4/4)
Moyle et al. (2014); Australia	Three long-term care facilities; they all had both high (nursing home) and low (assisted living) beds, and similar staffing and environments	Total = 25 PwD = 6 Staff members = 12 Family members = 7	Qualitative semi-structured interviews, focus groups	A telepresence robot to enhance engagement between family and a person with dementia living in long-term care	Though the use of the telepresence robot (M) the contact between family members and the PwD improved		100% (4/4)
Peters, Hermann, Wachsmuth, and Hoey (2014); Germany	Residential home for people with mild to moderate cognitive disabilities	Total = 7 PID = 7	Qualitative interviews, observations	TEeth BRushing Assistance system assists people with cognitive disabilities in the execution of brushing teeth	The system is helpful (M) in task execution from a user's subjective point of view		75% (3/4)
Wang, Kontos, Holliday, and Fernie (2011); Canada	Veterans care home, cognitive support unit	Total = 17 PwD = 3 Staff members = 11 Family members = 3	Qualitative interviews and observations	Nimble Rocket™ power wheelchair modified with a contact sensor skirt that caused movement of the power wheelchair to stop on contact with an obstacle The larger unit restrained wandering through key coded entryways and patio doors, as well as regular use of geriatric chairs with locked trays The smaller unit did not lock the doors and residents could walk freely	People preferred the social aspect of a push wheelchair (contact with the pusher) over the impendence aspect of the power wheelchair		100% (4/4)
Wigg (2010); USA	A larger unit and a smaller facility, specializing in dementia care	Not mentioned	Qualitative observations		Sometimes when residents yanked on the doors (M), staff would be alerted by the noise and try to redirect the individual away from the door Being able to walk out the front door to the outside, (M) avoided the potential for conflict and anxiety inherent in trying to open a locked door		50% (2/4)

Note. FIC partnership mode = family involvement in care; M = mechanism; PCC = person-centered care; PCE = person-centered environments; PCR = protective community residences; PID = person with intellectual disability; PwD = person with dementia; SCU = special care unit.

**Table 2.** Summary of the Results in Context-Mechanism-Outcome Patterns

Context	Mechanisms		Outcome
People with dementia living in institutional care facilities	<i>A. Caregiving approach</i>		
	Facilitating element A.2: Improving the relationship between formal caregivers and residents	Element A.1: Attitude of formal caregiver regarding residents	Autonomy
	Mechanisms:	Mechanisms:	
	• Knowledge of the resident	• Flexible attitude of formal caregiver	
	• Frequency of the contact	• Social inclusion	
	Facilitating element A.4: Acknowledging role of informal caregiver	Element A.3: Attitude of formal caregivers regarding informal caregivers	Informal care
	Mechanisms:	Mechanisms:	
	• Welcoming attitude of formal caregiver toward informal caregivers	• Contact between formal and informal caregivers	
		• Stimulating contact between residents and informal caregivers	
	<i>B. The physical environment</i>		
	Element B.1: Specially designed spaces	Autonomy	
	Mechanism:		
	• Provide residents with activities that remind them of themselves		
Facilitating element B.2: Small-scale living facilities		Facilitating element A.1: Improving the relationship between formal caregivers and residents	
Mechanism:			
• Smaller number of residents contributes toward more knowledge of the residents			
Facilitating element B.3: Homelike setting		Facilitating element A.4: Acknowledging role of informal caregiver	
Mechanism:			
• Enables welcoming attitude of formal caregivers regarding informal caregivers			
<i>C. Technology</i>			
	Element C.1: Assisting residents in performing ADL tasks	Autonomy	
	Mechanism:		
	• Residents having control about their own life		
Facilitating element C.2: Assisting formal caregivers in performing core		Facilitating element A.1: Improving the relationship between formal caregivers and residents	
Mechanism:			
• Formal caregivers having time to perform secondary tasks			

**Facilitating element A.2: Improving the relationship between caregivers and residents → Attitude of the formal caregiver toward residents**

The attitude of formal caregivers toward residents is closely related to the quality of the relationship. Two mechanisms were found that improved this relationship: knowledge about the resident and frequency of the contact. Within those two mechanisms, a similarity could be detected (increasing the frequency of contacts; this also led toward improving the knowledge of the resident). As these mechanisms individually could contribute to improving the relationship between formal caregivers and residents, we mention them separately.

*Knowledge of the resident.* If formal caregivers make an effort to get to know a resident, this has a positive influence

on the relationship between the caregiver and the resident. One means of doing so is to become familiar with the residents and their history (Egan et al., 2007; Fetherstonhaugh et al., 2016; Koskenniemi et al., 2015; Palmer, 2013; Raber et al., 2010; Scerri et al., 2015):

It's a privilege to know more about [the resident]. She became more like a real person. (caregiver; Egan et al., 2007, p. 28)

Four studies (Carr et al., 2011; Eritz et al., 2015; Snoeren et al., 2016; Teitelman et al., 2010) reported that when formal caregivers have more knowledge about residents, they are more likely to come up with tailor-made solutions to stimulate them to engage in activities and respond to individual needs.

Also, seven studies (Burton, 2010; Egan et al., 2007; Eritz et al., 2015; Kellett et al., 2010; McKeown et al., 2010; Moyle et al., 2013; Snoeren et al., 2016) showed that when formal caregivers have more knowledge about the resident they are able to see the person behind the patient. Formal caregivers would no longer attributed all behavior expressed by the residents to the dementia. This can lead to a change in the attitude of the formal caregiver: seeking to understand the factors underlying residents' behavior, focusing on residents' capabilities rather than weaknesses and encouraging residents to assist in their own care when possible (Doyle & Rubinstein, 2014; Moyle et al., 2013; Söderlund et al., 2016).

If a challenging behaviour comes up that we don't understand now we can think about it in the light of the person's history. So it becomes an expression of need rather than a difficult behaviour and the history helps you to connect and manage the situation more effectively. (caregiver; Kellett et al., 2010, p. 1711)

Interventions are used to gather information about the person with dementia (Burton, 2010; Gendron et al., 2016; Kellett et al., 2010; McKeown et al., 2010). A common element is the representation of the resident's life story in a photo book, video, or a poster, with the purpose of making this information readily accessible to formal caregivers. Also, interventions are used to develop meaningful tailor-made activities for the resident (van der Ploeg et al., 2013; van Weert et al., 2005). Two studies (Hanssen & Kuven, 2016; Söderman & Rosendahl, 2016) provided examples of interventions for persons not living in their country of birth or who were raised with specific traditions. Ethnic food and music are used to engage these residents and stimulate their own identity.

*Frequency of the contact.* Three studies (Bigby et al., 2014; Chappell et al., 2014; Fetherstonhaugh et al., 2016) showed that residential care facilities who invested in moments between caregivers and residents, had a more upbeat and closer contact between formal caregivers and residents. Fewer residents in a care facility could also contribute to improving contact moments between formal caregivers and residents (Hung & Chaudhury, 2011). When formal caregivers and residents have more contact, the quality of the contact increases, and it is easier for residents to show their likes and dislikes. For formal caregivers, it becomes easier to pick up on these preferences, and to come up with individualized solutions in which the autonomy of residents is maintained. More frequent contact could lead toward more familiarity with the resident:

I think the small environment helped our staff to work in a not-so-fixed manner. With fewer residents on the unit, our staff get to know the residents so well; I see they are able to do a lot more for the residents. (manager, Hung & Chaudhury, 2011, p. 6)

### Element A.3: Attitude of formal caregiver regarding informal caregivers → Informal care

The second element that emerged was the attitude of the formal caregiver regarding informal caregivers which influences the improvement of informal care. Two mechanisms were found that explain which attitudes of formal caregivers could increase informal care provision: contact between formal and informal caregivers and stimulating contact between residents and their informal caregivers.

*Contact between formal and informal caregivers.* Two studies (Hemingway et al., 2016; Moyle et al., 2013) found that the informal care provided by family members to people with dementia in residential care facilities increased when the contact between formal and informal caregivers increased.

*Stimulate the relationship between residents and their informal caregivers.* To improve the frequency of informal care, two studies (Bigby et al., 2014; Palmer, 2013) found that it is important that formal caregivers stimulate the relationship between residents and their informal caregivers. Palmer (2013) found that after this relationship was encouraged, informal caregivers brought favorite foods and personal items from home. They also planned or participated in activities the person with dementia enjoyed. In this manner, informal caregivers became more involved in the life of the resident.

### Facilitating element A.4: Acknowledging role of informal caregiver → Welcoming attitude of formal caregiver toward informal caregivers

Acknowledging the role of the informal caregiver functions as a facilitating element because it contributes to an attitude change of the formal caregiver and therefore indirectly could contribute to increase informal care provision. Formal caregivers need to acknowledge the role of informal caregivers as a source of information about residents. Families and significant others often know about the person's likes and dislikes; these can be useful in improving the relationship with residents and personalizing their care (Fetherstonhaugh et al., 2016; Raber et al., 2010; Scerri et al., 2015). The more formal caregivers know about the resident, the more they are able to assist with decision making, (Fetherstonhaugh et al., 2016).

Sometimes you can talk to the family and just find out, you know, what their habits used to be because, in the old days there wasn't always enough water to have a shower and they wouldn't have been used to showers. They would have bathed rather. (caregiver; Fetherstonhaugh et al., 2016, p. 218)

### Construct B: The Influence of the Physical Environment

Some mechanisms of the influence of the physical environment are supporting to the (facilitating) elements mentioned

for the caregiving approach. The physical environment creates conditions that could contribute to the autonomy of residents but more often it could influence the development and improvement of the relationships among residents, formal and informal caregivers.

#### **Element B.1: Specially designed spaces → Autonomy**

Specially designed spaces could contribute to the maintenance of the identity of people with dementia. These spaces could be outdoors, for example, a garden in which the residents might grow vegetables or water plants, or inside the facility where a corner of the living room is decorated as a nursery (Chenoweth et al., 2015; De Vreese et al., 2012; Hernandez, 2007; Lee et al., 2016). Such spaces provide residents with an activity that reminds them of who they were or what they loved in the past; this in turn can make them feel more comfortable and confident:

Some days when he remembers, he says, “Oh, it’s time now, I want to go take care of my flowers. He’ll say something like that. And once outside, he’ll say, “It’s time, you know, to water,” or something like that. He’s aware that gardening is part of his life and enjoys it. (caregiver; Hernandez, 2007, p. 140)

#### **Facilitating element B.2: Small-scale living facilities → Improvement of relationship between residents and formal caregiver**

Small-scale living facilities are usually configured with six to eight bedrooms located near a kitchen/living area. The limited number of residents in such spaces is of importance for the relationship between residents and formal caregivers. When the number of residents is limited, the span of control is much smaller. Five studies (Chenoweth et al., 2015; Hutchings et al., 2011; Smith et al., 2010; Verbeek et al., 2012; van Zadelhoff et al., 2011) found that, due to small-scale living arrangements, caregivers had closer contact with fewer residents; this improved their knowledge of each person.

#### **Facilitating element B.3: Homelike setting → Enables a welcoming attitude of formal caregivers regarding informal caregivers**

A more homelike setting stimulates caregivers to develop a more welcoming attitude toward family members. Informal caregivers feel more involved in homelike settings such as small-scale living facilities than they do in traditional nursing homes. They are treated as group members instead of visitors: they may have the unit’s key, and nursing staff is open to issues that they bring up. Three studies (Hutchings et al., 2011; Verbeek et al., 2012; van Zadelhoff et al., 2011) showed that this welcoming attitude stimulated the provision of informal care:

Sometimes we bring food and make coffee for all of us. It is like being at home. For the visitors this is far more pleasant. (family member; van Zadelhoff et al., 2011, p. 2494)

### **Construct C: Technology**

Compared with the studies of the other constructs, the technology studies were about improving one distinct and tangible aspect of the lives of people with dementia. The result is therefore more concrete than the results mentioned at caregiving approach and physical environment. Also, for technology a facilitating element was found.

#### **Element C.1: Assisting residents in performing ADL tasks → autonomy**

Our main finding was that, when technological interventions assist residents with activities of daily living, like brushing their teeth or moving around the facility, those persons maintain autonomy (Aloulou et al., 2013; Lazar et al., 2016; Margot-Cattin & Nygard, 2006; Moyle et al., 2014; Peters et al., 2014). Being in control of opening and closing the door to their own room also could improve feelings of privacy for people with dementia. Knowing no uninvited visitors could enter the room also increased the sense of autonomy (Margot-Cattin & Nygard, 2006; Wigg, 2010):

[The facility in which Rose is living is using access technology. A chip card makes sure only authorized persons can enter certain rooms.] “One of the staff said: ‘She [Rose] found it [privacy] in her room, because she knows no other patient may come in and disturb her.’ (caregiver; Margot-Cattin & Nygard, 2006, p. 119)

#### **Facilitating element C.2: Assisting formal caregivers in performing core tasks → Improvement of contact between residents and formal caregiver**

Two studies (Margot-Cattin & Nygard, 2006; Wigg, 2010) showed that technological interventions also could have an influence on the behavior of formal caregivers. When technological systems such as chip cards assist formal caregivers in keeping the residents secure and safe, they have more time for quality interactions with those in their care. This results in a more relaxed interaction between residents and formal caregivers:

Nurses did not have to worry about ‘losing’ the people in their care, which put their minds at rest and allowed them to relax when interacting with residents. (caregiver; Margot-Cattin & Nygard, 2006, p. 118)

### **Discussion and Implications**

This literature review provides answers to questions regarding *how* caregiving approaches and the physical environment, including technologies, contribute to the maintenance of autonomy and the improvement of informal care for people with dementia living in residential care facilities. To obtain these answers we used the realist approach, which seeks to unpack the relationships between context, mechanism, and outcomes (Pawson & Tilely, 1997). Context was identified as people with dementia living in residential care facilities. Outcomes were identified as autonomy and

informal care. Our hypothesis was that elements of caregiving approaches and the physical environment, including technologies, were triggering mechanisms (responses of people); as such, they had an influence on autonomy and informal care.

We found that the triangle between resident, formal, and informal caregiver is essential; this has been acknowledged by others (McNeil, 2013; de Rooij et al., 2012; Stanbridge, Burbach, Rapsey, Leftwich, & McIver, 2013). Our review explains and gives a summary of how this triangle can be improved. First, if formal caregivers gain familiarity with the resident; by these means they are able to understand and fulfill the needs of the residents. This is also acknowledged in another study (Edvardsson et al., 2010). Second, to better understand the behavior of residents, formal caregivers should have frequent contact with the residents. Third, caregivers should include residents in activities that take place in a natural context (e.g., cooking or folding laundry). This form of social inclusion is also acknowledged by others (De Bruin et al., 2015). Fourth, formal caregivers should have a flexible attitude regarding the needs, wishes and behavioral expressions of residents (e.g., offering different breakfast options). These last two mechanisms of attitude, as exhibited by the formal caregiver, help maintain autonomy for the resident. Improving relationships between formal and informal caregivers may be achieved as follows: if the attitude of the formal caregiver is more welcome regarding informal caregivers, this could indirectly lead to the provision of informal care.

Also, the elements from physical environment could contribute to the maintenance of autonomy of residents. Specially designed spaces, such as a garden in which residents can grow vegetables, enables residents to perform activities that remind them of themselves. A new finding of this review is that some elements of one construct are supporting toward elements of another construct. For example, small-scale living facilities (element physical environment) could contribute to the relationship between residents and formal caregivers (facilitating element caregiving approach). Often, small-scale living environments create a situation where a steady relatively small group of formal caregivers' services a smaller group of residents. Because the formal caregivers have fewer residents to care for, they have more contact moments with these residents and thus gain deeper knowledge of them. Elements of the physical environment also can enhance the relationship between formal and informal caregivers and therefore indirectly influence the informal care provision. A more homelike setting (element physical environment), for example, may stimulate formal caregivers to develop a more welcoming attitude toward informal caregivers (facilitating element caregiving approach). This could lead toward the situation that the informal caregiver feels more at home and feels free perform informal care.

In a more concrete way, technologies can contribute to the autonomy of the residents. Technology assists the resident in performing tasks themselves and increases the resident's sense of autonomy. This is in line with a recent study

(Jodrell & Astell, 2016). Also, the results of technology revealed a supporting element. Technology can assist formal caregivers in performing core tasks; this could free up their time for more interaction with the residents and therefore could contribute to the improvement of the relationship between residents and formal caregivers (facilitating element caregiving approach).

Overall, the results reveal how several elements of the caregiving approach, physical environment, and technology could contribute to maintaining autonomy and improving informal care but also that elements of the physical environment and technology can be supporting regarding elements of the caregiving approach.

We searched for studies in a broad context, namely people with intellectual disabilities living in a residential care facility. The mechanisms we found in the studies were present in very diverse care settings. For example, the mechanism of knowledge about the resident was found in 14 studies with contexts varying from a small nursing home in the Netherlands (Snoeren et al., 2016); to a larger study setting of 14 different long-term care facilities in the United States (Palmer, 2013). Therefore, the identified mechanisms may be applicable in different context situations.

## Limitations

Our literature review has some limitations. We only included empirical studies written in English. In addition, the primary studies have some limitations. First, the majority of the yielded studies used qualitative methods. Second, except for one study conducted in Singapore, all studies were performed in Europe, Australia, or Northern America. Therefore, generalization of the results may be limited to Western countries. Third, we limited our search to studies from the year 2005 because from mid-2000s transformations in residential care toward more person-centered care are noticeable. However, this cut-off point creates a possible bias and may limit the generalization of the study. Last, although diverse databases, including one database on technological studies, were used to find relevant literature, more than half of the yielded studies had a care or welfare perspective. We used a broad definition and a broad range of search terms to cover the comprehensive construct autonomy. Therefore, our results elaborate on different aspects of the construct autonomy (i.e., the freedom to explore the physical environment but also the attitude of caregivers). Future empirical research should reveal whether these different aspects of autonomy are complimentary toward each other. Furthermore, the focus of our review on informal care was from the point of view of residential care facilities. From this perspective, informal care is mainly seen as a way to enlarge/expand the possibilities of instrumental care and a way of making care more personal. The social part of informal care, meaningful interaction with family members, friends, and volunteers, is therefore not explicitly taken into account in this review.

## Practical and Research Implications

To our knowledge no study has examined all five constructs (caregiving approach, physical environment, technology, autonomy, and informal care) in relation toward each other to answer the question *how* they contribute toward maintaining autonomy and improving informal care. The results of the review show that for residential care facilities that want to maintain the autonomy of their residents and improve informal care delivery, it is important to pay attention to the caregiving approach, the physical environment and technologies, because all of these elements could individually contribute toward autonomy or informal care and some elements from these constructs do not stand alone but can be supporting to each other (considering their impact, directly or indirectly on the autonomy of the resident and informal care delivery).

The literature review provides an overview *how* the caregiving approach and the physical environment, including technologies, directly or indirectly, influence the maintenance of autonomy and improve informal care for residents with dementia living in residential care facilities. However, the realist evaluation question of *why* these mechanisms lead to the desired outcomes is not yet explained. To gain a deeper understanding of the processes involved in these mechanisms, empirical research should be performed in which these questions could be asked in interviews with the stakeholders.

## Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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## Conflict of Interest

None reported.

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