Autonomy in healthcare for older aldults

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Publication date:
2022

Document Version
Publisher's PDF, also known as Version of record

Link to publication in Tilburg University Research Portal

Citation for published version (APA):
Boumans, J. (2022). *Autonomy in healthcare for older aldults: A realist perspective*. Proefschriftenprinten.nl.

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A realist perspective

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The research described in this thesis was performed at department Tranzo, Tilburg school of social and Behavioral Sciences, Tilburg University, Tilburg, the Netherlands.

Printing of this thesis was financially supported by Tilburg University.

Cover: Peter Rooijakkers
Cover design: Proefschriftenprinten.nl – The Netherlands
Layout and printed by: Proefschriftenprinten.nl – The Netherlands

ISBN 978-90-832301-3-9

Autonomy in healthcare for older adults

A realist perspective

Proefschrift

ter verkrijging van de graad van doctor
aan Tilburg University
op gezag van de rector magnificus, prof. dr. W.B.H.J. van de Donk,

in het openbaar te verdedigen ten overstaan van
een door het college voor promoties aangewezen commissie
in de Aula van de Universiteit
op vrijdag 3 juni 2022 om 10.00 uur

door
Jogé Boumans
geboren te Zevenaar

Promotores
prof. dr. K.G. Luijkx (Tilburg University)
prof. dr. C.A. Baan (Tilburg University)

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prof. dr. H. Verbeek (Maastricht University)

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Chapters 2 to 6 are based on articles that are published in peer-reviewed journals.

Chapter 2

Published as:

Boumans J, van Boekel LC, Baan CA, Luijkx KG. How Can Autonomy Be Maintained and Informal Care Improved for People With Dementia Living in Residential Care Facilities: A Systematic Literature Review. Gerontologist. 2019 Nov 16;59(6):e709-e730. doi: 10.1093/geront/gny096. PMID: 30239712; PMCID: PMC6858830. dio: 10.1093/geront/gny096

Chapter 3

Published as:

Boumans J, van Boekel LC, Verbiest ME, Baan CA, Luijkx KG. Exploring how residential care facilities can enhance the autonomy of people with dementia and improve informal care. *Dementia*. July 2021. doi:10.1177/14713012211030501

Chapter 4

Published as:

Boumans, J., van Boekel, L., Kools, N., Scheffelaar, A., Baan, C.A., Luijkx, K.G. How staff characteristics influence residential care facility staff's attitude toward person-centered care and informal care. *BMC Nurs***20,** 217 (2021). dio: https://doi.org/10.1186/s12912-021-00743-8

Chapter 5

Published as:

Boumans J, Scheffelaar A, van Druten VP, Hendriksen THG, Nahar-van Venrooij LMW, Rozema AD. Coping Strategies Used by Older Adults to Deal with Contact Isolation in the Hospital during the COVID-19 Pandemic. Int J Environ Res Public Health. 2021 Jul 8;18(14):7317. doi: 10.3390/ijerph18147317. PMID: 34299774; PMCID: PMC8304333.

Chapter 6

Published as:

Boumans J, van de Mheen D, Crutzen R, Dupont H, Bovens R, Rozema A. Understanding How and Why Alcohol Interventions Prevent and Reduce Problematic Alcohol Consumption among Older Adults: A Systematic Review. *International Journal of Environmental Research and Public Health*. 2022; 19(6):3188. https://doi.org/10.3390/ijerph19063188

CHAPTER 1

General Introduction

In recent decades care and support for older adults has changed from a traditional medical model to a more humanistic approach by acknowledging the importance of ensuring that the care provision aligns with the preferences of the person (1-3). This model is referred to as person-centered care. The World Health Organization (4) defines person-centered or people-centered care as “care in which individuals, families and communities are served by and are able to participate in trusted health systems that respond to their needs in humane and holistic ways” (p.7). Under the influence of this change to person-centered care more focus is given to the autonomy of older adults.

Autonomy is formally identified as a basic human need that must be fulfilled to facilitate optimal functioning and subjective well-being (5, 6). It has been difficult for researchers to address the concept of autonomy due to the complexity of the construct and different use of terms in several disciplines. For instance, in sociological and psychological research different concepts are defined and used which are related to autonomy such as control (7), agency (8), mastery (9), self-efficacy (10). Though, the underlying emphasis is all these concurrent social movements are the rights and abilities of all individuals to have control over their bodies and decision-making For example, Ryan and Deci’s Self-Determination Theory defines autonomy as experiencing self-governance; a person is considered autonomous when their decisions are freely chosen and are instigated and fully endorsed by their conscious self (11). Another researcher specialized in the care of older adults has questioned whether autonomy as self-determination was realistic in all situations and contexts (12). According to Agich our time shows a strong tendency to include all that hinders humans from exercising their potential as autonomous individuals under the rubric of disease or defect; he suggests that actual (real life) autonomy must be “sensitive to the social nature of personhood and to complex conditions that actually support the unique identity of those individuals needing long term care” (12) (p134).

Therefore, autonomy is particularly at risk in care settings, especially due to the greater dependence and vulnerability that often accompanies with illness or disabilities. When a person is ill, having a disability or other vulnerability, they often experience greater dependency and thus a greater likelihood that their interests and values will be overruled by others.

The effort to maintain autonomy of older adults can be observed in different areas of care delivery. Residential care facilities adopt and implement person-centered care (interventions) intended to enhance residents' autonomy (13-15), whilst hospitals adapt their working methods towards person-centered care in order to enhance patients' autonomy (16-18). Similarly, interventions to prevent or reduce alcohol consumption implement methods to enhance patients' autonomy (19-21). Despite this, the importance and manifestation of autonomy in older adults largely depends on the care setting (22, 23).

While putting effort in the protection of persons autonomy it is sometimes unavoidable that persons are losing control over important decisions in their lives. Often there is a big gap between the ideal of independent, voluntary decision-making and the actual circumstances in which persons have to make choices, even when they are living independently

To gain a more comprehensive understanding of autonomy in older adults across different care settings, this dissertation focuses on three different care settings: 1) older adults with dementia receiving long-term care in residential care facilities; 2) older adults receiving care during contact isolation in hospital; and 3) community-dwelling older adults receiving interventions to prevent or reduce (problematic) alcohol consumption. For every setting a different perspective on autonomy was used. Also, for every setting a different aspect was or different aspects were researched that could facilitate autonomy of older adults.

Research aims

The general research aim addressed in this dissertation is:

> *Understanding the autonomy of older adults receiving care in different care settings*

Each setting has its own research aim tailored to that particular setting.

Table 1 Overview of the settings

Setting	Perspectives on autonomy	Facilitating element(s)
1. Autonomy of people with dementia living in residential care facilities	Decisional and executive autonomy in a residential care setting	Caregiving approaches of staff Physical environment of the residential care facility Informal care
2. Older adults receiving care during contact isolation in a hospital setting	Autonomy in contact isolation	Coping strategies
3. Community-dwelling older adults receiving interventions to prevent or reduce (problematic) alcohol consumption	Autonomy regarding decisions on alcohol consumption	Elements of interventions

Setting 1: Autonomy of people with dementia living in residential care facilities

Dementia is a disease with substantial effects on cognitive, functional, behavioral, and psychological capacities (24, 25). As dementia progresses a proportion of people with this disease is admitted to residential care facilities to receive intensive and complex care that can no longer be provided in the home. In the Netherlands approximately 70,000 people with dementia live in residential care facilities (26). Traditional residential care facilities are typically characterized by large wards with up to 30 residents per ward and daily life is mostly determined by organizational rules and routines (27). They evoked a hospital-like atmosphere; specifically, large buildings with long corridors and shared rooms. A global cultural change has taken place in recent decades regarding living and care facilities for people with dementia (28, 29). Nowadays residential care facilities are mostly small-scale wards which provide a more homelike environment where residents live within a joint household of six to eight people per ward but have their own private bedroom and in which activities are integrated into daily life (30). Within this culture change nursing homes focus on deinstitutionalization and the creation of a more home-like environment in which families fulfill a more significant role (31, 32).

Facilitating the autonomy of people with dementia living in residential care facilities is rather complex (33, 34). These residents often face challenges voicing their needs and wishes, and they may need support from others to express and execute their autonomy. Collopy (35) and later McCormack (36) both describe the concept of autonomy seen in the light of self-determination and describe the difference between decisional and executive autonomy. Decisional autonomy refers to the ability and the freedom to make one's own decisions and executive autonomy to the ability and the freedom to realize those decisions. Limited executive autonomy can easily be confused with limited decisional autonomy (36). Residential care facility staff must therefore be aware of the fact that, although people with dementia may not have the capacity to carry out a decision, they maintain the right to be involved in the decision-making itself (1, 36).

Encouraging family and friends to provide informal care for their loved ones living in residential care facilities is also vital for the autonomy of people with dementia (37, 38). Informal care provision could be defined as unpaid care and support provided by members of patients' social circle (39). Friends and family are familiar with the likes and dislikes of the person with dementia (40, 41) and having them involved in care could lead to more personalized care for the person with dementia. Tasks could include personal care (e.g., clipping fingernails or preparing dinner), instrumental care (e.g., laundry, shopping, transport to doctors or social visits), and socioemotional care (e.g., writing letters or emotional guidance) (42-44). In the Netherlands providing informal care for people living in long term care institutions is quite common. Residential care facilities often have policies to enhance this, but providing informal care is generally not obligatory.

For the successful manifestation of autonomy and informal care the way staff members approach residents, relatives, and informal caregivers is of the utmost importance (38, 45-49). Additionally, the physical environment of the residential care facilities (e.g., unit size, spatial layout, and homelike character) (50, 51) and the use of technologies (e.g., chip and pin cards and watches with a GPS tracker which allow residents to move freely within and outside the facility) (52, 53) influence the manifestation of autonomy and informal care.

However, these studies do not provide a clear explanation of how and why caregiving approaches and the physical environment influence the autonomy and informal care provision for people with dementia living in residential care facilities. If it becomes clear how and why certain elements lead to a certain outcome then it is easier to achieve the same kind of outcomes in a similar situation. Consequently, a better understanding of how and why caregiving approaches and the physical environment influence autonomy and informal care for people with dementia living in residential care facilities is needed.

In this setting autonomy for people with dementia is studied from the perspective of residential care facilities. People with dementia who are living in residential care facilities depend on different elements to maintain their autonomy. How do residential care facilities and staff help maintain the autonomy of their residents with dementia through those different elements?

The research aim is:

> *To understand how caregiving approaches and the physical environment influence autonomy and informal care for people with dementia living in residential care facilities.*

Setting 2: Older adults receiving care during contact isolation in a hospital setting

During the COVID-19 pandemic an increased number of older adults experienced contact isolation in a hospital setting. Contact isolation leads to separation from relatives, loss of freedom, and uncertainty regarding disease status (54-57). This unique situation provides a pathway to explore how autonomy manifests itself or can be maintained among older adults. We explore how older adults (55+) cope with contact isolation in a hospital setting in order to improve their physical and psychological wellbeing.

Older adults in contact isolation in hospital face a situation in which they have lost a considerable amount of autonomy, and usually very suddenly. The decision to place them in contact isolation is often made *for* them. The results of the contact isolation are that patients admitted to the nursing ward are no longer allowed to leave the hospital room or ward and are not allowed to see family and friends, although they are still physically able to move around and communicate. Older adults in contact isolation in a hospital therefore often experience stress. Patients in contact isolation have reported a poor understanding of the reasons and procedures for contact isolation and a greater level of dissatisfaction with their care as a result (58, 59).

Coping strategies, referring to behavioral and cognitive efforts, are used by individuals to deal with stressful situations and lower their stress level (60-62). Several studies have investigated coping strategies in contact isolation situations (63-66), in addition to the coping strategies of older adults (67-70). However, no study has been performed that considers how and why the care situation for older adults during a pandemic in a contact isolation hospital setting triggers coping strategies. Coping can help to better maintain (some form of) autonomy in this restrictive isolation environment. To gain insight into how and why coping behavior is triggered we investigated the experience of older adults during contact isolation situations.

In this setting autonomy is explored on the level of older adults who are placed in contact isolation in hospital during the COVID-19 pandemic. Coping behavior could help them maintain their autonomy.

The research aim is:

> *To understand how older adults cope with a contact isolation situation in a hospital setting.*

Setting 3: Community-dwelling older adults receiving interventions to prevent or reduce (problematic) alcohol consumption

In today's society consuming alcoholic beverages is a routine part of the social landscape for much of the population, including for community-dwelling older adults (71). Several studies have recently indicated that older adults are drinking more than previous generations at the same age (72-75). The prevention and reduction of alcohol use for older adults is critical because even in small amounts alcohol consumption can cause greater harm to older adults than to their younger counterparts. Older adults metabolize and excrete alcohol more slowly (76, 77). Moreover, alcohol can accelerate and aggravate the onset of conditions associated with aging (e.g., falls (78), cognitive impairment (79), and/or sleep disturbance (80-82)).

Autonomy is a common ethical principle in addressing problematic alcohol consumption**.** For many older adults, the consumption of alcohol has a central role in their social lives and therefore positively contributes towards their quality of life (83, 84)**.** Additionally, for some people the deterioration of human health with age leads to the use of alcohol as a coping strategy to overcome negative changes in both physical and mental health (85-87), including loneliness and social isolation (88),

unemployment, and economic downturns (89). Moreover, older people typically view alcohol risks as belonging to heavier and more problematic drinkers (84).
Healthcare settings could be used to screen for hazardous alcohol use, identify risks related to medication use, and to support older adults to make healthier decisions about their alcohol consumption. However, nurses and healthcare professionals are sometimes hesitant to discuss the use of alcohol with older people because they may be sensitive to perceived threats to their personal autonomy when a healthcare professional expresses concern about their alcohol consumption (90, 91).

Specifically, interventions to prevent or reduce the negative effects of alcohol consumption in older adults are needed but are limited in number as two recent reviews reveal (92, 93). Moreover, no overview is available showing how and why interventions to prevent or reduce alcohol use among older adults are effective and which are successful for older adults specifically. Therefore, more research is needed to understand how, why, and in which conditions alcohol interventions are effective for older adults in order to develop alcohol interventions to prevent or reduce their alcohol consumption.

In this setting autonomy is studied on the level of the successful elements of interventions (e.g., contact with care professionals, mode of delivery) to prevent or reduce (problematic) alcohol consumption.

The research aim is:

> *To explore how (i.e., which elements of interventions), in which contexts, and why interventions are successful in preventing or reducing (problematic) alcohol consumption among older adults*

Theoretical framework: Realist evaluation

To answer the research aims the realist evaluation approach was used. Realist evaluation is a theory-driven method; while traditional evaluation questions focus on *what* works, realist evaluation focuses on *how* it works, for *whom,* and what the influence of the *context* is. (94). Realist evaluation is an appropriate search approach for the current dissertation. It allows us to research autonomy for older adults in three different care settings or contexts. Revaluation is recognized in health policy and health system research as a useful methodology for the evaluation of complex interventions (95, 96). Realist evaluation is a collection of standard research methods (e.g., literature review, interviews, case studies, etc.) and research tasks (e.g., creating an interview guide, data collection, data analysis, etc.) (94).

Furthermore, realist evaluation presumes that it is not the intervention or program that works as such, but the people co-operating and choosing to make it work (94). Consequently, realist evaluation describes not only the intervention or program and its outcome (O), but also the context (C) and the underlying mechanism (M) in a so-called CMO configuration. This is achieved by discerning the psychosocial mechanisms (not directly observable preferences, reasoning, norms, or collective beliefs of people) that trigger intervention outcomes (changes to people and to their lives, but also including other kinds of alterations) in specific contexts (includes elements such as the organizational context, participant features, staffing, and geographical and historical context of implementation) (96). Realist evaluation does not strive for generalizable claims and universal regularities but for exploratory questions about how programs or interventions are shaped by particular contexts and how mechanisms are triggered when contexts are conducive.

Outline of the dissertation

To address the first aim within the setting of residential care facilities, three studies are described. **Chapter 2** describes a literature review about how caregiving approaches and physical environment, including technologies, contribute to the maintenance of autonomy and informal care provision for people with dementia living in residential care facilities. **Chapter 3** uses the findings of Chapter 2 and reports on two case studies; these are used to explore how residential care facility staff can enhance autonomy and improve informal care by looking at the influence of interactions (contact and approachability between residents, staff members, and informal caregivers) and the physical environment, including the use of technologies. **Chapter 4** reports on a study that explores the association between residential care facility staff characteristics and staff attitudes regarding perceived person-centered care provision and the inclusion of informal caregivers in the caregiving process.

To address the second aim within the setting of hospitalized patients, one study is included; specifically, this study examines older adults receiving care during contact isolation in a hospital setting. Subsequently, **Chapter 5** reports on a study that explores how older adults cope with contact isolation in hospital settings to improve their physical and psychological wellbeing. We studied which elements of this care setting trigger coping strategies that impact patients' physical and psychological wellbeing.

To address the third aim within the setting of older adults receiving interventions to prevent or reduce (problematic) alcohol consumption, one study is described. **Chapter 6** reports on a literature review about how (i.e., which elements of interventions), in which context, and why interventions are successful in preventing or reducing (problematic) alcohol consumption among (older) adults.

Table 1 Settings and aims in relation to dissertation chapters

Setting	Research aims	No. Chapter
Setting 1: Older adults with dementia receiving care in residential care facilities	To understand how caregiving approaches and the physical environment influence autonomy and informal care for people with dementia living in residential care facilities.	Chapter 2 Chapter 3 Chapter 4
Setting 2: Older adults receiving care in a contact isolation hospital setting	To understand how older adults cope with a contact isolation situation hospital setting.	Chapter 5
Setting 3: Older adults receiving interventions to prevent and/or reduce (problematic) alcohol consumption	To explore how (i.e., which elements of interventions), in which context, and why interventions are successful in preventing or reducing (problematic) alcohol consumption among older adults.	Chapter 6

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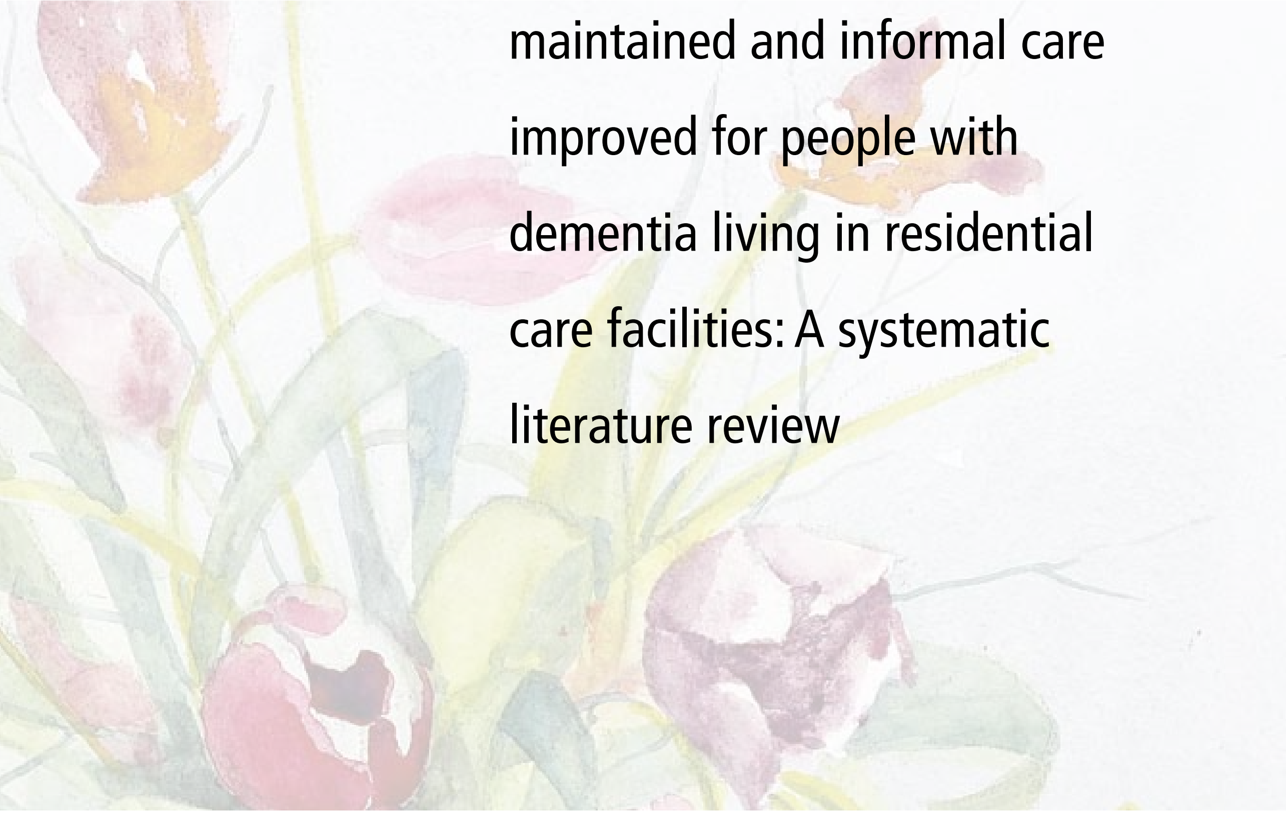
1

SETTING

CHAPTER 2

How can autonomy be maintained and informal care improved for people with dementia living in residential care facilities: A systematic literature review



Published as:
Jogé Boumans, LLM, Leonieke C van Boekel, PhD, Caroline A Baan, PhD, Katrien G Luijkx, PhD, How Can Autonomy Be Maintained and Informal Care Improved for People With Dementia Living in Residential Care Facilities: A Systematic Literature Review, *The Gerontologist*, Volume 59, Issue 6, December 2019, Pages e709–e730, https://doi.org/10.1093/geront/gny096

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 towards 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.

Background and Objectives

More than 47 million people live with dementia worldwide; this number is steadily increasing (1). 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 (2). 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 (3, 4).

To facilitate a more person-centered care approach, residential care facilities try to stimulate autonomy of their residents (5). The complexity of the concept autonomy for people living in residential care is recognized by others (6, 7) For the purpose of this research we chose a definition of autonomy used in relation to person centered care. According to McCormack (2001)(8) autonomy has two sides: 1) decisional autonomy refers to the ability and the freedom to make choices; 2) 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 (8, 9). To stimulate autonomy of residents with dementia formal caregivers should maintain and facilitate decisional autonomy when capacity for executional autonomy is reduced (8).

In addition to autonomy, stimulating informal care in residential care facilities is essential to providing person-centered care (10). Informal care is unpaid care and support provided by family, friends or neighbors (11) and therefore providers of informal care are familiar with the likes and dislikes of the resident (12, 13). 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 (13, 14). For this review we were interested in these two essential elements of person-centered care: autonomy and informal care provision (15).

As explained above, 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 (16-18). For this reason, the way residents and their informal caregivers are approached by formal caregivers during care and welfare activities is 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 (19, 20). 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 (21); therapeutic areas with special bathrooms to comfort people with dementia (22) and gardens (23). 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 (24, 25).

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 (26-30). 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 (31). This is a theory-driven evaluation approach increasingly used for studying the implementation of complex interventions within health systems (32). 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 (31). 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) (33).

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 (see Figure 1):

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.

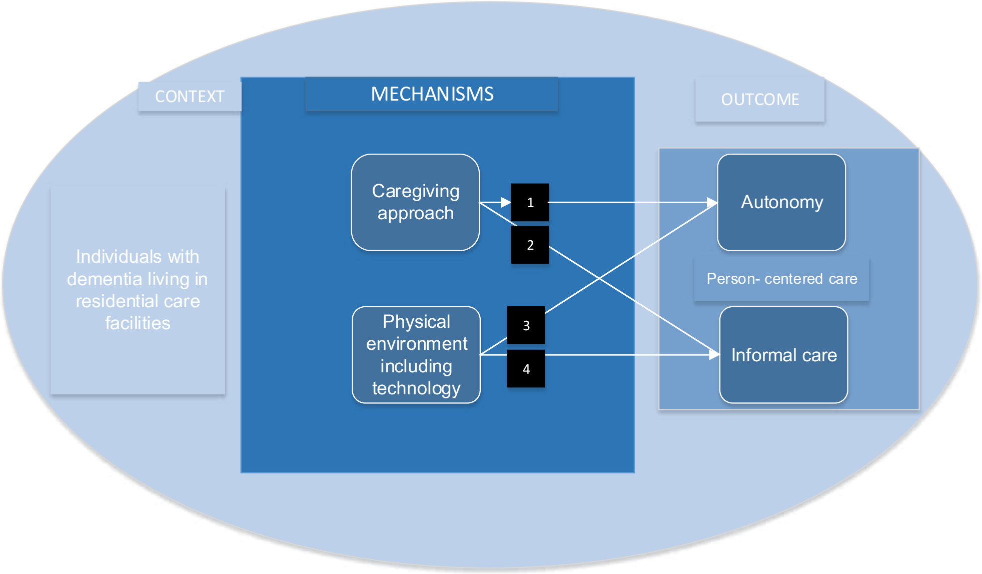


Figure 1 Research aims of the literature review

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 (see supplementary table 1). As from mid-2000's transformations in the health care systems of the developed countries are noticeable (34, 35). For the residential care facilities this implies also a change towards more person-centered care (36). 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 headings terms (CINAHL). Also, synonyms and free text words were used. Four search strings were formed based on the objectives of this review (see 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, see 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 asses qualitative, quantitative and mixed methods studies (37). 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), nonrandomized 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, 3 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 or J. Boumans and K. G. Luijkx) until consensus was reached. Relative outcome scores and the percentage of these scores are reported in table 1.

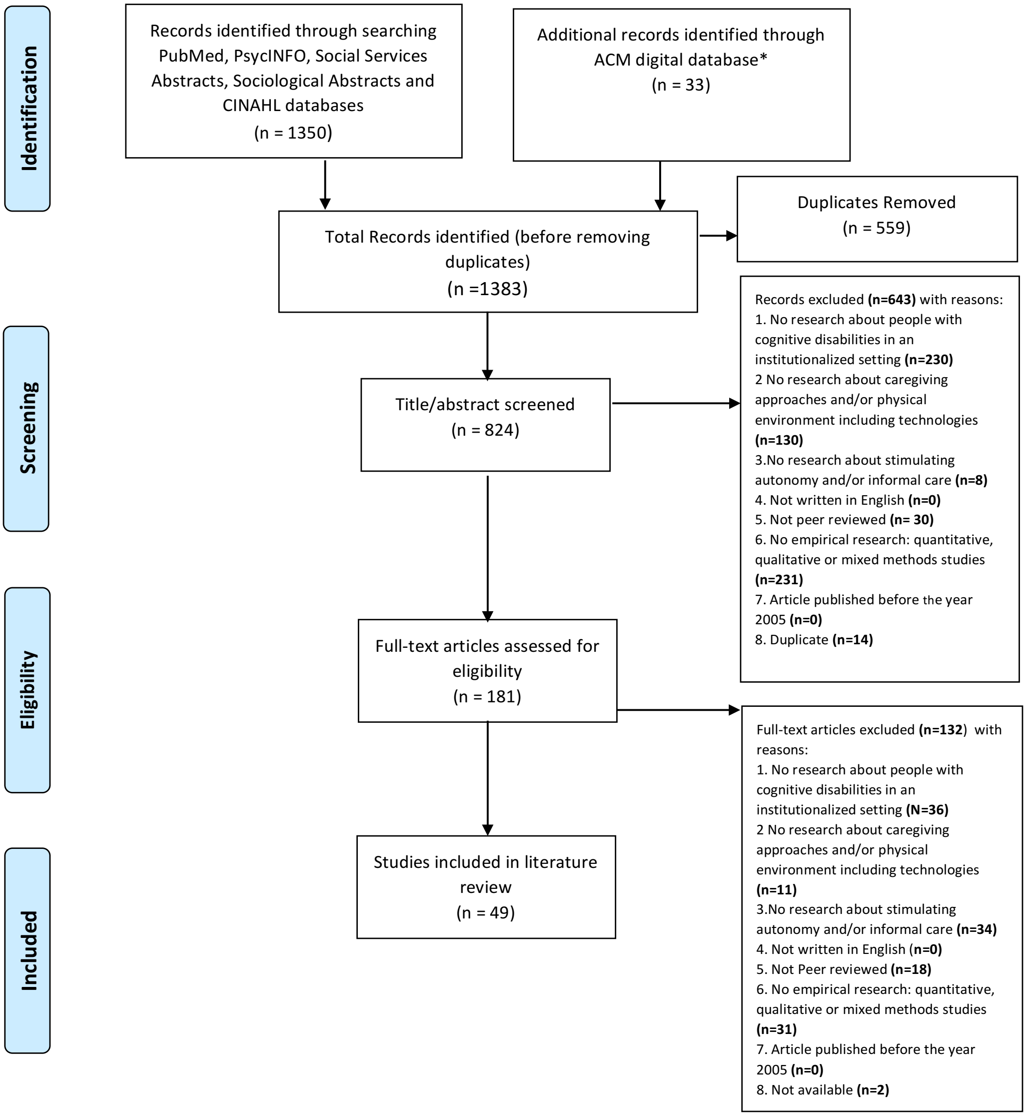


Figure 2 Flowchart of the literature review

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.

Table 1 Characteristics of the studies

Construct A caregiving approach

Author	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy (M=Mechanism)	Main results regarding informal care (M=Mechanism)	Study Quality
Bigby et al. (2014) (AUS)	Seven group homes residents with a severe level or profound of intellectual disability were staffed 24 hours 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 preforming (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 et al. (2011) (AUS)	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[1] = 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 et al. (2011) (CAN)	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	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 et al. (2014) (CAN)	18 large-scale nursing homes	Total = 344 Pwd = 149 Staff members = 195	Quantitative Questionnaires	Change, and predictors of change, in social skills among residents with moderate to severe dementia in nursing homes	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	Facility provides and encourages resident participation in 10 activities common in long-term care (e.g. exercise, personal care, social, housekeeping, meal preparation, crafts)	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)
Doyle & Rubinstein (2014) (USA)	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 the residents' abilities was shown in the way that residents were ignored as potential contributors during social exchange	100% (4/4)

Construct A caregiving approach

Author	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy (M=Mechanism)	Main results regarding informal care (M=Mechanism)	Study Quality
Egan et al. (2007) (CAN)	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)
Eritz et al. (2015) (CAN)	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 per cent of 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)

Fetherston-haugh et al. (2016) (AUS)	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)
Gendron,et al. (2016) (USA)	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)
Hanssen & Kuven (2016) (NOR)	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)

Construct A caregiving approach

Author	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 et al. (2016) (CAN)	One long-term care facility	Total = 28 Family members = 28	Qualitative interviews, focus groups	Contextual understanding of the lived experience of spousal caregivers		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	50% (2/4)
Hung & Chaudhury (2011) (CAN)	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, observations, 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		75% (3/4)
Hunter et al. (2016) (CAN)	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)
Kellett et al. (2010) (AUS)	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	Knowledge about the person with dementia (M) enhanced the staffs' appreciation and respect of the person with dementia as a person		75% (3/4)

				staff in personalizing nursing care	embedded in a family and intergenerational context The more insight staff gained in identifying aspects of family life and 'seeing' the person with dementia in the family context (M), the more empowered they felt to provide relationship-centered care rather than task-oriented care		
Koskenniemi,. et al. (2015) (FIN)	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) 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)
McKeown et al. (2010) (UK)	Intermediate and assessment care wards with 24 beds in a city and a general nursing	Total = 3 (one person that did not meet our	Qualitative Multiple case study,	Life story book	Life story book helped staff and family to see the person with dementia beyond being a patient		100% (4/4)

Construct A caregiving approach

Author	**Context**	**Participants**	**Methods**	**Intervention or objectives of the study**	**Main results regarding autonomy (M=Mechanism)**	**Main results regarding informal care (M=Mechanism)**	**Study Quality**
	care home	institutionalized criteria and was excluded from the review) Pwd = 3	interviews, observations		(M) Staff was able to make links between the person's past and the present because of the life story book (M)		
Milte et al. (2016) (AUS)	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		50% (2/4)

					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		
Moyle et al. (2013) (AUS)	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, 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 & Nikku (2007) (SWE)	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)

Construct A caregiving approach

Author	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	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 et al. (2010) (USA)	One memory support assisted living unit	Total= 24 Pwd=8 Staff members = 8 Family members = 8	Qualitative Questionnaires, interviews and observations	How volition expressions are recognized by staff and how these expressions are used to engage people in meaningful activities.	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)		100% (4/4)

Rossow-Kimball & Goodwin (2009) (CAN)	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	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		100% (4/4)
Scerri et al. (2015) (MLT)	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	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	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.	75% (3/4)

Construct A caregiving approach

Author	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy (M=Mechanism)	Main results regarding informal care (M=Mechanism)	Study Quality
					that were not part of the normal care routine or that fall within their job description (M)		
Snoeren et al. (2016) (NED)	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 et al. (2016) (SWE)	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,& Rosendahl (2016) (SWE)	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 et al. (2008) (FIN)	Wards for long-term patients in four Finnish cities	Total = 435 Staff members = 222 Family members = 213 (115 relatives had dementia themselves)	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	100% (4/4)
Teitelman et al. (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	If activities are performed in a natural context and it doesn't feel like a planned activity (M) persons with	100% (4/4)

Construct A caregiving approach

Author	**Context**	**Participants**	**Methods**	**Intervention or objectives of the study**	**Main results regarding autonomy (M=Mechanism)**	**Main results regarding informal care (M=Mechanism)**	**Study Quality**
				with dementia	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		
van der Ploeg et al. (2013). (AUS)	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		75% (3/4)
van Weert et al. (2005). (NLD)	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)

Construct B
physical
environment

Author	**Context**	**Participants**	**Methods**	**Intervention or objectives of the study**	**Main results regarding autonomy or informal care (M=Mechanism)**	**Main results regarding informal care (M=Mechanism)**	**Study Quality**
Chenoweth et al. (2015) (AUS)	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. Nurses and care staff described a more peaceful and homely environment (M) in which people with dementia felt comfortable and safe 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)
De Vreese et al. (2012) (AUS)	Special dementia care home for adults with intellectual disabilities Two specifically designed dementia-care facilities including garden space	Total = 60 PID= 60 Total= 45 Staff members = 28	Quantitative Questionnaires Qualitative	The influence of a specialty dementia care home (special care unit	After 3 years of life in the SCU, (M) the experimental group remained stationary in their daily functioning (basic activities of daily living, leisure activities,		50% (2/4) 75% (3/4)

<u>Construct B</u> physical environment

Author	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy or informal care (M=Mechanism)	Main results regarding informal care (M=Mechanism)	Study Quality
					and interests), mood, and behavior, whereas the control group subjects' scores overall worsened		
Hernandez (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	For people with dementia, therapeutic gardens (M) provide an activity that they still can enjoy and that reminds them of themselves		75% (3/4)
Hutchings, D. et al. (2011) (CAN)	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	75% (3/4)

						members indicated that they were encouraged to drop in at any time and had been invited to stay for a meal	
Lee, S. Y. et al. (2014) (CAN)	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		100% (4/4)
Lichtenberg et al. (2005) (USA)	Two new homelike special care units for individuals with dementia	Total = 20 Pwd = 20	Quantitative Asassessment	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		100% (4/4)
Smith et al. (2010) (AUS)	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)		75% (3/4)

Construct B
physical
environment

Author	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding autonomy or informal care (M=Mechanism)	Main results regarding informal care (M=Mechanism)	Study Quality
van Zadelhoff et al. (2011) (NLD)	Two group living units located on the grounds of a traditional large-scale non-profit 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) (NLD)	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, H. et al. (2012) (NLD)	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 methodes 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) 75% (3/4)

Construct C
Technology

Author	Context	Participants	Methods	Intervention or objectives of the study	Main results regarding informal care (M=Mechanism)	Main results regarding informal care (M=Mechanism)	Study Quality
Aloulou et al. (2013) (SGP)	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 et al. (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)
Margot-Cattin & Nygård (2006) (CH)	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)		100% (4/4)

Construct C
Technology

Author	**Context**	**Participants**	**Methods**	**Intervention or objectives of the study**	**Main results regarding informal care (M=Mechanism)**	**Study Quality**
					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	
Moyle et al. (2014) (AUS)	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 et al. (2014) (DEU)	Residential home for people with mild to moderate cognitive disabilities Veterans care home,	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 et al. (2011) (CAN)	Veterans care home, cognitive support unit	Total = 17 Pwd = 3 Staff members = 11 Family members = 3	Qualitative Interviews and observations	Nimble RocketTM power wheelchair modified with a contact sensor skirt that caused movement of the power wheelchair to stop on contact with an obstacle	People preferred the social aspect of a push wheelchair (contact with the pusher) over the impendence aspect of the power wheel chair.		100% (4/4)
Wigg (2010) (USA)	A larger unit and a smaller facility, specializing in dementia care	not mentioned	Qualitative Observations	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	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)

Abbreviations: M= mechanism; Pwd = person with dementia; PID= person with intellectual disability; FIC partnership mode = family involvement in care; PCC = person centered care; PCE = person-centered environments; SCU = special care unit; PCR = Protective Community Residences

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. Five studies (38-40) 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."* ((41) , p. 10) (caregiver)

Social inclusion. Two studies (39, 42, 43) 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. (38, 39, 44)

> *"Nell enjoyed activity therapy the most when she felt that she was assisting the activity therapist"* ((43), p.329) (caregiver)

Raber (45) 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.

Facilitating element A.2: Improving the relationship between caregivers and residents → Attitude of the formal caregiver towards residents. The attitude of formal caregivers towards 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 about 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 (42, 44, 46-48):

> *"It's a privilege to know more about [the resident]. She became more like a real person."* ((48), p. 28) (caregiver)

Four studies (43, 49-51) 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 (48, 52-59) 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 ((55, 59).

> *"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."* (60), p. 1711) (caregiver)

Interventions are used to gather information about the person with dementia (52, 53, 61). 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 (62, 63). Two studies (64, 65) 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 (66-68) 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 (41). 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."* ((41), p.6) (manager)

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 (55, 59, 69) 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 (38, 44, 47) found that it is important that formal caregivers stimulate the relationship between residents and their informal caregivers. Palmer (47) 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 towards 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 (44, 45, 68). The more formal caregivers know about the resident, the more they are able to assist with decision-making (68).

> *"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."* ((68), p. 218) (caregiver)

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 (70-73). 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* ((74), p. 140) (caregiver).

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 (70, 73, 75-79) 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 (75-77, 79) 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."* (((80), p. 2494) (family member)

Construct C: Technology

Compared to 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 (81-84). 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 (82, 85):

> *[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."* ((82), p. 119) (caregiver)

Facilitating element C.2: Assisting formal caregivers in performing core tasks → Improvement of contact between residents and formal caregiver. Two studies (82, 85) 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."* ((82), p. 118) (caregiver)

Table 2 Summary of the results in CMO patterns

Context	Mechanisms		Outcome
	A Caregiving Approach		
People with dementia living in institutional care facilities	**Facilitating Element A.2 Improving the relationship between formal caregivers and residents** Mechanisms: • *Knowledge of the resident* • *Frequency of the contact*	**Element A.1: Attitude of formal caregiver regarding residents** Mechanisms • *Flexible attitude of formal caregiver* • *Social inclusion*	Autonomy
	Facilitating Element A.4: Acknowledging role of informal caregiver Mechanisms: • *Welcoming attitude of formal caregiver towards informal caregivers*	**Element A.3: Attitude of formal caregivers regarding informal caregivers** Mechanisms: • *Contact between formal and informal caregivers* • *Stimulating contact between residents and informal caregivers*	Informal care
	B The physical environment		
		Element B.1: Specially designed spaces Mechanism: • *Provide residents with activities that remind them of themselves*	Autonomy
	Facilitating Element B.2: Small-scale living facilities Mechanism: • *Smaller number of residents contributes towards more knowledge of the residents*		Facilitating Element A 1: Improving the relationship between formal caregivers and residents

Facilitating Element B.3: Homelike setting Mechanism: → *Enables welcoming attitude of formal caregivers regarding informal caregivers*		Facilitating Element A 4 Acknowledging role of informal caregiver
C Technology		
	Element C.1: Assisting residents in performing ADL tasks Mechanism: → *Residents having control about their own life*	Autonomy

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 (31). 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 (86-88). 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 (89). Second, in order 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 (90). 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 towards 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 towards 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 increase the resident's sense of autonomy. This is in line with a recent study (91). Also, the results of technology reveled 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 fourteen studies with contexts varying from a small nursing home in the Netherlands (51); to a larger study setting of 14 different long-term care facilities in the United States (47). Therefore, the identified mechanisms may be applicable in different context situations.

Limitations

Our literature review has some limitations. We only included empirical studies from 2005 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-2000's transformations in residential care towards 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 towards 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 towards each other to answer the question *how* they contribute towards 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.

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Supplementary materials

Supplementary table 1 databases

Database	Reason	Limits
1. Pu**bMed**	biomedical literature	English, year 2005-present, human
2. PsycINFO	psychological literature	English, year 2005 – 2017, human, peer reviewed
3. ACM Digital Library	technological literature	Year 2005
4. Social Services Abstracts	sociological literature	English, year after 2004, peer reviewed
5. Sociological Abstracts	sociological literature	English, year after 2004, English, peer reviewed
6. CINAHL	nursing literature	English, year 2005 – 2017, peer reviewed

Supplementary table 2 groups of key words

Group 1 Persons with intellectual disabilities*

"dementia" or "intellectual disabilities" or "intellectual disability" or "alzheimer's disease" or "vascular dementia"

* For ACM Digital Library only group 1 was used because in this database it was impossible to enter all groups of search terms simultaneously due to constraints in the user interface.

Group 2 Living in a residential care facility

"residential facilities" or "assisted living facilities" or "nursing homes" or "homes for the aged" or "long term care" or "residential care" or "geriatric residents" or "nursing home residents" or "nursing home care" or "care unit" or "care home" or "institutionalized" or "institutional care" or "inpatients" or "inpatient care" or "long-term care facilities" or "institutionalization"

Group 3 Physical environment including technology

"smart homes" or "assistive technology" or "health care technology" or "e-health" or "assisted living" or "gerontechnology" or gerotechnology or "telemedicine" or "e-care" or "ecare" or "home automation" or "supportive technology" or "self-help devices" or "assistive technology devices" or "robotics" or "ambient assisted living"

Group 4 Caregiving approach**

"professional role" or "physician role" or "nurse role" or "professional-patient relation" or "professional patient relation " or "physician-patient relation" or "physician patient relation" or "nurse-patient relation" or "nurse patient relation" or "patient–nurse interaction" or “patient nurse interaction" or "attributes of caring" or "process of caring" or "person-centred care" or "person-centered care" or "person centred care" or "person centered care" or "patient centred care" or "patient centered care" or "patient-centred care" or "patient-centered care" or "holistic nursing" or "nursing care" or "nursing methods" or "geriatric nursing" or "nursing practice" or "nurse patient relationship" or "nurse-patient relationship" or "family centered care" or "family-centered care" or "nurse attitudes" or "resident oriented care" or "resident-oriented care" or "resident centered care" or "resident centred care" or "resident-centered care" or "resident-centred care" or "eden alternative" or "green housing" or "group-living" or "group living" or "group homes" or "small scale living" or "small-scale living" or "ambient assisted living" or "dementia care" or "sheltered living" or "green care farm" or "health services for the aged”

** For Social Services Abstract and Sociological Abstracts not used: nurse-patient relation or "nurse patient relation" or "patient–nurse interaction" or “patient nurse interaction"

Group 5 Autonomy

“autonomy” or "self-management" or "self-care" or "self care" or "self-medication" or "self medication" or "self-efficacy" or "self-help" or "self care skills" or "self-care skills" or "patient participation" or resilience or coping or "coping behavior" or “salutogenesis” or "health promotion" or "sense of coherence" or “empowerment” or “hardness” or "health promotion" or "self-control" or "self control"

Group 6 Informal care

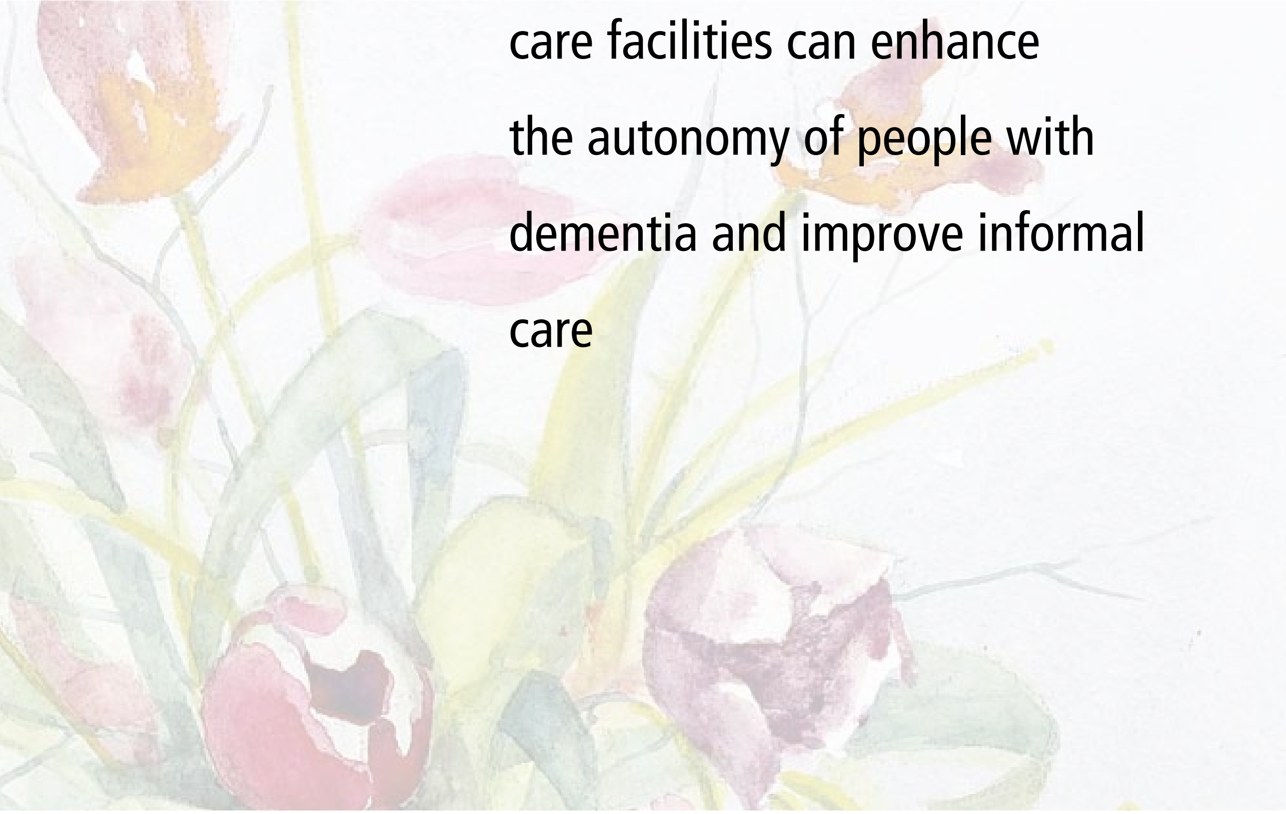
"informal care" or "family nursing" or "family caregiver" or "spouse" or "family"

Supplementary table 3 search strings

Search string	Groups of keywords
Search string 1 How caregiving approaches contribute to the maintenance of autonomy for people with dementia living in residential care facilities.	1 and 2 and 4 and 5
Search string 2 How caregiving approaches contribute to the improvement of informal care for people with dementia living in residential care facilities.	1 and 2 and 4 and 6
Search string 3 How physical environment including technologies contribute to the maintenance of autonomy for people with dementia living in residential care facilities.	1 and 2 and 3 and 5
Search string 4 How physical environment including technologies contribute to the improvement of informal care for people with dementia living in residential care facilities.	1 and 2 and 3 and 6

CHAPTER 3

Exploring how residential care facilities can enhance the autonomy of people with dementia and improve informal care



Publiced as:
Boumans J, van Boekel LC, Verbiest ME, Baan CA, Luijkx KG. Exploring how residential care facilities can enhance the autonomy of people with dementia and improve informal care. *Dementia*. July 2021. doi:10.1177/14713012211030501

Abstract

Background and Objectives: Residential care facilities (RCF) strive to enhance autonomy for people with dementia and to enhance informal care provision, although this is difficult. This study explored how RCF staff can enhance autonomy and improve informal care by looking at the influence of interactions (contact and approachability between residents, staff members and informal caregivers) and the physical environment, including the use of technologies.

Research Design and Methods: A realist evaluation multiple case study was conducted using document analyses, eight semi-structured interviews with staff members and relatives and 56 hours of observations of residents across two RCFs aiming to provide person-centred care. Realist logic of analysis was performed, involving Context-Mechanism-Outcome configurations (CMOC).

Findings: The behaviour, attitudes and interactions of staff members with residents and informal caregivers appeared to contribute to the autonomy of people with dementia and enhance informal care provision. The physical environment of the RCFs and the use of technologies were less relevant to enhancing autonomy and informal care provision, although they can support staff members in providing person-centred care in daily practice.

Discussion and Implications: The findings add to those of other studies regarding the importance of interaction between residents, staff members and informal caregivers. The findings provide insight for other RCFs on how successfully to enhance autonomy for their residents and to improve informal care provision, as well as, more broadly, how to implement person-centred care.

Background and Objectives

Many traditional long-term residential care facilities (RCFs) for people with dementia have changed their focus in recent decades from physical care, risk reduction and safety (1) to acknowledging the importance of ensuring that their care provision aligns with the preferences of residents (2-4). More RCFs are developing and innovating to shift to a more person-centred care approach. That many RCFs have their own strategies and ways of implementing person-centred care makes it interesting to explore which elements contribute to the diverse aspects of enhancing person-centred care.

Providing person-centred care involves ensuring that the people who are receiving care can make their own choices. However, facilitating the autonomy of people with dementia living in RCFs is rather complex (5, 6). Such people could face difficulties voicing their needs and wishes, and they may need support from others to express and execute their autonomy. RCF staff must therefore be aware of the fact that, although people with dementia may not have the capacity to carry out a decision, they maintain the right to be involved in the decision-making itself (4, 7). To gain insight into how RCF staff behaviours enhance the autonomy of residents with dementia, we chose a definition of autonomy used in relation to person-centred care. This definition has two elements: (a) *decisional autonomy,* which refers to the ability and freedom to make choices; and (b) *executional autonomy*, which refers to the ability and freedom to carry out and implement those choices (7, 8). Next to autonomy, encouraging relatives to provide informal care (unpaid care and support; see (9) for their relatives living in an RCF is essential to providing person-centred care (10, 11) Relatives are familiar with the likes and dislikes of the people with dementia (12, 13), and having them involved in care could lead to more person-centred care for the RCF resident with dementia. The current study focuses on these two essential elements of person-centred care: autonomy and informal care provision (7, 10).

The involvement of people with dementia themselves and informal care providers in healthcare provision is important for developing and carrying out appropriate (care) plans. The formation of good relationships between staff members, residents and relatives is thus an essential aspect of maintaining autonomy and increasing informal care in RCFs (11, 14, 15). For the purpose of this study, we refer to contact and approachability in the triangle between staff members, residents with dementia and informal caregivers as ‘interactions’.

The physical environment of the RCFs is also important for stimulating residents’ autonomy and informal care provision. Unit size, spatial layout and homelike character improve resident autonomy and also influence the provision of informal care (16, 17). An important element of the physical environment is the use of technology. For example, GPS trackers allow residents to move freely within and outside the facility and therefore contribute to their autonomy (18, 19). Digital technology also makes it possible to involve informal caregivers in a different and greater way in the care-giving process for residents of RCFs (14).

In sum, for people with dementia living in RCFs, different policies and/or staff behaviours are important in stimulating resident autonomy and improving informal care. The objective of our study was to provide insight into *how* interactions, the physical environment and the use of technology in RCFs contribute to maintaining the autonomy of residents with dementia and improving informal care provision.

Research Design and Methods

A realist multiple-case study was carried out to describe two RCFs and clarify how their care affects autonomy and informal care. Case study research is recognized as being particularly useful when the focus is on seeking answers to 'why' and 'how' questions (20). This approach is compatible with realist evaluation, which is a theory-driven method for understanding how and why complex interventions (such as those which depend on active staff decisions) work or fail to when applied in complex settings (21). Case studies appear to be useful to study healthcare according to the principles of realist evaluation (22, 23), which seeks to unpack the relationships between context, mechanisms and outcomes – that is, how particular contexts trigger (or interfere with) mechanisms to generate the observed outcomes. The *context* includes elements such as the organizational context, participant features, staffing, and geographical and historical context. *Mechanisms* are a combination of recourses offered by the (social) programme or intervention and human understanding and/or responses to that recourse. Mechanisms are not directly observable and include preferences, reasoning, norms or collective beliefs. *Outcomes* include changes to people and to their lives, but also include other kinds of alterations (e.g. in organizations, workers or governments; (24). The relationship between the context and mechanisms leading to certain outcomes is the so-called Context-Mechanism-Outcome configuration (CMOC). In this study, the organizational context was the RCF in which people with dementia live (features of participants). The outcomes (changes for people) were maintaining autonomy and/or improving informal care provision. We explored how and why interactions, the physical environment and the use of technology (organizational context) were triggering mechanisms (responses of people) and, as such, influenced autonomy or informal care provision (outcome). RAMESES II reporting standards for realist evaluations were followed (25).

Data Collection

Two RCFs in the southern part of the Netherlands took part in this study. Both provide long-term care for people with dementia and take a person-centred approach to care, but are not run by religious organisations. These RCFs were included in the study because they have different origins. RCF A is a newly developed RCF, whereas RCF B has been established in 1970. It is interesting to compare a new organisation that could implement a person-centred care approach from the start/beginning with an organisation that had to redirect their traditional care approach to a more person-centred care approach RCF A (2015) is a new, innovative RCF based on hospitality-style principles. RCF A seeks to provide service such that older adults (55 years and older) can age in a pleasant way together with their partner. At RCF A, joy of living, comfort and hospitality (e.g. offering quality food and luxurious rooms and restaurants) are central aspects. Providing care according to the wishes and needs of residents and relatives is valued above following rules and procedures where possible. RCF B has a longer history (since 1970), a more traditional design and has gradually shifted over time towards a person-centred care approach. RCF B states that everyone is able to participate: residents, family members and people from the community can join and participate in the care and support of residents in a way they prefer and are able to. Both RCF A and B qualify as small-scale living facilities within a larger nursing home (26). They both provide care for people with dementia in a homelike situation. A maximum of eight residents form a joined household. A common living room is provided, which includes a kitchen in which all meals are prepared. Facilities such as a restaurant and activity areas are attached to the ward.

Several data collection methods were used consecutively to understand *how* the interactions, physical environment and use of technology in both RCFs contribute to residents' autonomy and informal care provision. Using different data collection methods consecutively made it possible to incorporate the knowledge gained in earlier phases into subsequent phases. In the first phase of data collection (April–May 2017), relevant documents such as vision papers, annual reports, policies, reports, meeting minutes, newsletters and other documentation were collected from both RCFs (A, *n*=13; B, *n*=24) to provide data about the organizational context.

In the second phase (May–July 2017), non-participatory observations of residents with moderate to severe dementia, two from each site (*n*=4), and staff, two from each site (*n*=4), were held. The contact person of each RCF selected several staff members and legal representatives of people with dementia and informed them about the study with a letter, written by the researcher (JB). All participants who were willing to participate returned a signed informed consent form directly to the researcher and were contacted by phone and asked when the observation could take place. Residents were informed and asked for permission by the observer and a staff member about the observations prior to the observation moments. All residents were able to respond verbally and agreed to participate. We developed an observation guide based on our earlier review and the dimensions of observation (space, actor, activity, object, act, event, time, goal and feeling) suggested by Spradley (27). The observations focused on how elements of the interactions, use of the physical environment and technology by people with dementia and informal caregivers contributed to the autonomy of people with dementia. Observations of the residents and staff took place both during the day (7AM–3PM) and evening periods (3PM–9PM), Monday to Saturday, and took on average 3.5 hours. Notes were taken while conducting observations, and these were typed up after each observation day using the observation guide.

In the third phase (November–December 2017), semi-structured interviews were held with various people: board members of the RCFs, two from each site (*n*=4); staff, two from each site (*n*=4); and informal caregivers/relatives of residents with dementia, two from each site (*n*=4). The board members who were most knowledgeable about issues related to the subjects of the study (i.e. the design for caregiving at the RCF and which elements could enhance autonomy and information care provision for residents with dementia) where invited to participate. The contact person of each RCF selected several staff members and legal representatives of people with dementia and informed them about the study with a letter, written by the researcher (JB). Participants who were willing to participate returned the informed consent form directly to the researchers and were called and asked when an interview could take place. Staff had knowledge about the context and for whom the way of caregiving

works. Informal caregivers/relatives know how and why the care provided is working for the resident with dementia (28). The aim of the interviews was to unravel how the RCF as an organization – and in daily practice – maintained the autonomy of residents and improved informal care provision. Additionally, noticeable and unclear findings from the document analyses and observations were discussed during the interviews.
In the fourth phase (December 2017), a second round of non-participatory observations took place with staff, two from each site (*n*=4). The same observation method as in the second phase was used, although more focus was given to the specific details of the performance of regular care tasks, such as helping residents shower and dress. This strategy was chosen to unravel subtle differences between the caregiving approaches of both RCFs in these specific situations. Observations took place during the early morning (7AM–11AM) or late evening (9 PM–11.30PM).

Data Analyses

The interviews were transcribed verbatim, anonymized and coded using Atlas Ti (version number 7.5.18). Documents, observation reports and transcripts were coded by two authors (JB and LvB) independently concerning how interactions, the physical environment and use of technology contributed to the autonomy of people with dementia and to the improvement of informal care provision. The results were discussed until a consensus was reached. For both RCFs, the interactions, physical environment and use of technology to support autonomy for people with dementia or informal care provision mentioned in the documents, observations reports (both phase 2 and 4) or interviews were summarized in an EXCEL file. Based on this summary, CMOCs were drafted.

Ethical Considerations

Research ethics committee approval was granted by the Tilburg University Ethics Review Board (ERB, ref EC-2016.68). We also obtained ethical clearance from both research sites.

Findings

Table 1 provides an overview of the general characteristics of both RCFs. Although RCF A and B provide 24-hour care for people with dementia, RCF B provides care primarily for people with moderate to severe dementia, whereas RCF A also provides care for people with light to moderate dementia or somatic problems. People are eligible to reside and receive care in RCF B if they have a diagnosis of dementia and are in need of long-term care. To live in RCF A, an indication for long-term care is needed, but a diagnosis of dementia is not necessary. The findings below are presented as CMOCs, which we have themed by elements of the RCF – namely, interactions, physical environment and use of technology, and the influence of these elements on outcomes, autonomy and informal care provision. The COMCs are explained and illustrated by concrete findings from the data collection in the RCFs.

Table 1 Characteristics of the two study sites

General characteristics	RCF A	RCF B
Founded in	2015	1970
Location	City in urban area in the southern part of the Netherlands	City in urban area in the southern part of the Netherlands
Type of residential care facility	No closed care ward (no registration under the Dutch Exceptional Medical Expenses Act)	Closed care wards
Type of care	Long-term care / rehabilitation	Long-term care
Physical environment	RCF A	RCF B
Building	Two floors within a six-story building built in 2015	Three-story building built in 2013
Number of apartments	- 85 care apartments - 200 regular apartments	54 care apartments
Reception	Hotel-like bar	No reception
Outside area	Garden with goats and chickens	Courtyard

General characteristics	**RCF A**	**RCF B**
Facilities	Three restaurants and a café, hairdresser, grocery store, swimming pool and children day care.	A grand café, hairdresser, 'snoezelen' bathroom.
Design of care unit	Small-scale[a], homelike care facilities, two or three living rooms next to each other connected via an internal door, residents' apartments located in long hotel-like hallways.	Small-scalea, homelike care facilities, two living rooms on each floor, residents' apartments located around the living rooms.
Design of living room	Seats for eight to ten residents, open floor plan kitchen, dining table, seating area with television and a balcony.	Seats for six residents, open floor plan kitchen, dining table, seating area with television and an indoor balcony.
Design of residents apartments	On average 44 m2, kitchenette without cooking area, a living/sleeping room and a private bathroom with toilet. Some apartments have a balcony.	$23m^2$ to $55m^2$ apartments, a living and sleeping room; en suite bathroom with toilet is shared with the neighbouring apartment.
Staff characteristics	RCF A	RCF B
Number of staff in full time equivalent in 2017	74	59
Care staff	- 24 hours a day: nursing assistants - Daytime: licensed practical nurse, nursing assistants and interns	- 24 hours a day: nursing assistants - Daytime: registered nurse, licensed practical nurse, nursing assistants and interns
Welfare staff	Welfare guardians: do not perform care tasks and do not necessarily have education in healthcare. They assist during the daily lives of the residents in and around the living rooms (eating, drinking and activities). From 8AM until 10.30PM, there is one welfare guardian in every living room. Between 2 to 4PM, two welfare guardians are present to perform extra tasks, such as walking outside with the residents.	Hostess: works in two group homes between 8:30AM–12:30PM and 3:45PM–7PM. They do not necessarily have education in healthcare and do not perform care tasks, but assist the residents with breakfast, lunch and dinner and perform domestic chores.

General characteristics	RCF A	RCF B
	Buddies: resident gets assigned two staff members who function as 'buddies'. Buddies are the first contact person for residents and relatives. Their task is to get to know the residents' preferences and to inform the other staff about them.	
Resident characteristics	RCF A	RCF B
Number of residents	56	54
Number of residents with moderate to severe dementia	*n*=25 (45%)	*n*=48 (89%)
Profiles of residents with moderate to severe dementia	Extensive need for 24-hour care	Extensive need for 24-hour care
Technology use	RCF A	RCF B
Technologies	- Eclectic trapeze bar (against payment) in the room - Care watches (against payment) equipped with an alarm button - Tablet device in apartment with alarm	—
Records	Tablet to review and update residents' records	Tablet to review and update residents' records
Freedom of movement	Transmitter in watch (against payment and should be approved by relatives)	Tag on clothes (should be approved by the relatives).

[a] small-scale living is provision of care organized around small groups (approximately 8 residents); residents and staff form a household together, so daily activities (cooking, cleaning, etc.) are integrated within daily care (2).

A) INTERACTIONS AND AUTONOMY

We identified five mechanisms for interactions that enhance the autonomy of people with dementia. Two of them contribute *directly* to autonomy: enabling residents to make their own choices and enabling residents to carry out own choices. We also found three mechanisms that might indirectly lead to more autonomy for residents: social inclusion, staff's respectful approach and knowledge of residents.

CMOC (A1) Enabling residents to make their own choices. Both RCFs have policies aimed at enabling residents to make their own choices, such as asking residents their opinion *(context).* This form of decisional autonomy was observed in both RCFs, where staff consulted people with dementia before they acted, and staff considered the opinions of the residents seriously in most situations *(outcome),* which is illustrated by the following observation:

It is 5.30 PM and most of the residents are sitting at the dining table. The staff member is preparing a meal. According to the menu, boiled potatoes should be served, but Mrs X has indicated that she prefers French fries. Therefore, the staff member orders French fries from the restaurant in the building. (Observation RCF B)
In the interviews, staff as well as relatives at both RCFs indicated that staff enable residents to perform activities and the freedom to make their own choices *(outcome).*

Explanation of the mechanism: RCF policies to enable residents to make their own choices (*context)* could result in staff consulting residents before they act and also in taking the opinions of residents seriously *(mechanism)*, which confirms that the decisional autonomy of residents is being respected *(outcome).*

CMOC (A2) Enabling residents to carry out their own choices. In the documents from both RCFs, policies were found regarding residents making decisions and acting upon their own choices *(context).* We observed that residents in both RCFs were better able to perform activities themselves *(outcome).* However, because of the hospitality-style approach *(context)*, the staff in RCF A apply a restaurant-style approach to serving food and drinks. Coffee and tea were served, including milk and sugar. Lunch and dinner were prepared by staff and served on plates, comparable to a restaurant. Residents thus had less opportunity to execute such tasks themselves *(outcome).* The hostess and staff in RCF B also make coffee or tea for residents, but place milk and sugar near the residents so that the residents have to add it themselves. In cases where residents were able to serve coffee themselves, they were encouraged to do so. Lunch and dinner were presented plated or in bowls, and residents served themselves *(outcome).*

Explanation of the mechanism: If RCFs encourage residents' executorial autonomy though policies *(context)*, staff members may be more likely to encourage residents to perform activities themselves or to help residents implement their choices *(mechanism).* This leads to residents experiencing more executorial autonomy *(outcome).*

Explanation of the counter-mechanism: RCF A demonstrates a different outlook on executorial autonomy regarding eating and drinking. The view of staff working in an RCF based on the hospitality-style approach *(context)* could lead to staff members carrying out eating and drinking support activities for residents because staff members find it important to be hospitable *(mechanism)*, which yields less executorial autonomy for residents regarding food and drink activities *(outcome)*.

CMOC (A3) Social inclusion of residents. Document analyses of both RCFs revealed policies for social inclusion of residents (residents are given the feeling they are full members of the social group): (a) staff do not wear uniforms; (b) staff join residents at table for meals; and (c) staff have to include residents in activities (not only activities especially designed for them but also in household chores like peeling potatoes) (*context).* During our observations in both RCFs, we established that no staff members wore uniforms and the term 'nurse' was seldom used. Staff included residents in tasks, such as setting the table, making dinner and folding laundry. During meal times, staff sat with residents and included them in conversations about everyday things such as the weather or events in the city. Residents enjoyed having a meal together under these circumstances. We also observed that staff included socially residents by speaking directly with them and treating them as people instead of patients *(outcome)*. During conversations with the residents, the staff members' tone of the voice was not patronizing but respectful, and the topics were relevant for the residents, such as (previous) holidays and having children.

Explanation of the mechanism: RCF policies regarding the social inclusion of residents, staff not wearing uniforms and staff and residents performing activities together and dining together *(context)*, as well as the tone of voice used by staff and the topics discussed between residents and staff, could lead to staff members looking and acting as though in an ordinary social situation. This could lead residents to feel like a member of a social group *(mechanism).* This staff approach may contribute to greater person-centred care *(outcome),* which in turn could contribute to encouraging resident autonomy.

CMOC (A4) Respectful approach of staff. The analyses of documents from RCF A and B revealed that both RCFs consider the way staff approach residents to be of great importance. RCF A focuses on a hospitality-style, respectful approach that should facilitate residents in living the life they desire. RCF B emphasizes a 'welcome, homelike and a respectful' approach regarding resident preferences *(context).* The observations confirmed this approach; staff asked for approval from residents before acting, knocked on doors before entering and considered resident preferences. In addition, residents' questions were answered in a respectful manner, even when a resident asked the same question multiple times *(outcome).* During the interviews, the relatives of residents at both RCFs expressed that they were pleased with the approach of the staff because the tone of interactions between the resident and staff is social and respectful *(outcome)*.

Explanation of the mechanism: RCFs have policies regarding the staff's respectful approach to residents to facilitate residents in living the life they desire *(context).* Resident preferences about their lives are considered as much as possible by the staff *(mechanism).* This approach may contribute to greater person-centred care *(outcome)*, which could in turn enhance resident autonomy.

CMOC (A5) Knowledge of the resident. Analyses of documents from both RCFs revealed several policies focusing on the importance of staff members getting to know the preferences of residents by being involved in the residents' lives *(context)*. Observations in both RCFs showed that the staff members who work with residents on a regular basis are familiar with residents' needs and preferences *(outcome)*. Furthermore, during interviews, relatives acknowledged that staff at both RCFs possessed a lot of knowledge about the residents *(outcome).*

Explanation of the mechanism: RCF policies to encourage knowledge of the residents *(context)* could lead to staff members showing motivation to get to know the residents' preferences and to act upon this knowledge *(mechanism).* For residents, this could mean that care delivery is personalized to their needs and preferences *(outcome)*, and this person-centred care delivery may facilitate residents' autonomous choices.

B) INTERACTIONS AND INFORMAL CARE

The importance of informal care is acknowledged in the policies of both RCFs. Staff members at both RCFs enhance informal care provision, which contributes both *directly* and *indirectly* to more informal care provision.

CMOC (B1) Encouraging informal care provision. Both RCFs have policies actively to involve informal caregivers. In our document analyses, we found that RCF B explicitly states the types of care tasks in which staff can involve relatives for informal caregiving, such as taking a walk with residents. RCF A emphasises the importance of a fixed contact person for relatives. This contact person is a member of the staff and actively involves relatives in informal care tasks by explaining what is expected of them *(context).* During our observations, we saw some instances in which relatives provided informal care. In RCF B, relatives helped with residents' laundry or prepared a sandwich for them. In both RCFs, relatives took residents on a day out or went on a holiday with them *(outcome).*

Explanation of the mechanism: RCF policies to enhance informal care provision could lead to staff members explaining why the help of the relative is needed *(context).* If relatives understand why their help is needed *(mechanism)*, they may be more willing to perform such informal care tasks *(outcome).*

CMOC (B2) Positive attitude of staff regarding informal caregivers. Both RCFs use different methods to encourage staff to have a positive attitude regarding informal caregivers. Both RCFs have policies regarding a welcoming (RCF B) of hospitality-style attitude (RCF A) towards informal caregivers. RCF B offers staff a course on the importance of informal caregivers *(context)*. We observed that, although relatives were welcomed by staff members in both RCFs, relatives in RCF A were offered coffee by staff, whereas in RCF B staff encouraged relatives to make coffee for themselves and their resident relative to create a homelike environment *(outcome)*.

During the interviews, relatives of residents at both RCFs gave positive feedback about the attitude of the staff towards them: '*I have many acquaintances who visit my mother when I am not there (…). I tell them to ask the welfare guardian for a cup of coffee (…). And the welfare guardian brings two cups of coffee with biscuits to my mother's room (…). The atmosphere is really very warm and welcome (…)'.* (Interview relative RCF A)

Explanation of the mechanism: If RCFs encourage staff to have a positive attitude regarding informal caregivers *(context)*, this could lead to staff showing a positive attitude towards relatives. When relatives feel welcomed in the RCFs *(mechanism)*, they feel free to perform activities for the relatives *(outcome)*, which may result in (an increase in) informal care activities.

C) PHYSICAL ENVIRONMENT AND AUTONOMY

Although RCF A offered a wider range of technology use, most was only available at a charge. and most residents of RCF A thus did not use this technology. We therefore could not observe the use of this technology and the difference between RCF A and B with respect to used technology was very small. We identified two mechanisms related to the physical environment that directly contributed to enhancing resident autonomy: design of the physical environment and private rooms**.**

CMOC (C1) Physical environment design enables freedom of movement. Both RCFs have policies involving freedom to walk around on the premises. In both RCFs, most doors are open. Nevertheless, the front door of RCF B is locked for residents because RCF B is a closed ward. In RCF A, the front door was not locked due because it is not a closed care ward, although staff members were alerted when residents walked out the front door and guided the residents back to the ward *(context).* During our observations, we did not see any signs of agitation regarding freedom of movement among residents at either RCF. Residents of RCF A have the option of wearing a GPS watch that detects their movements. We observed that the physical environment enhanced resident autonomy inside the ward because it allowed residents to move around freely there. For example, a resident in RCF A was able to visit a fellow resident who sat in another living room, and they had a cup of coffee together. A resident in RCF B was able to take the elevator downstairs and use a scale because she wanted to know her weight. In the interviews, none of the family members reported problems regarding restrictions to freedom of movement. During interviews with staff working in RCF B, they reported that greater freedom of movement requires good communication amongst staff regarding the location of residents. A staff member of RCF A explained that they are trained to approach residents in a respectful and friendly way when they walk outside the care unit to guide the resident back to the unit. There are the differences between RCF A (open ward) and B (front door locked) on paper in terms of freedom of movement, but due to the actions of RCF A staff members, no differences in autonomy were found, and there were no great differences in where and when residents chose to move inside the wards (outcome).

Explanation of the mechanism: In RCFs that provide residents freedom of movement through a combination of open doors, monitoring options and good communication between residents and staff *(context)*, residents are able to go where they want within the RCF *(mechanism)*, which facilitates residents' autonomy to choose where and when they want to move *(outcome).*

CMOC (C2) Private rooms**.** Both RCFs have policies about respecting resident privacy. In both RCFs, residents have a special key or key card to enter their private room. Staff members at both RCFs are asked to respect the privacy of residents by knocking on the door or ringing the doorbell and waiting for confirmation before entering *(context)*. During observations, we saw that residents in both RCFs spent some time in their own room *(outcome)*. In RCF B, a resident only joined other residents for meals in the shared living room upon invitation of the staff. She preferred to stay in her own room and do crossword puzzles. In RCF A, we observed a resident who spent the afternoons in the shared living room and the evenings in her own room embroidering pillows.

Explanation of the mechanism: RCF policies about respecting resident privacy lead to residents have their own key for their private rooms, and staff have to knock or ring the doorbell before they enter the room: no other person can enter the private room *(context).* This could lead towards residents experiencing privacy (*mechanism)* and facilitating residents' autonomous choices *(outcome).*

D) PHYSICAL ENVIRONMENT AND INFORMAL CARE

We identified one mechanism related to the physical environment that directly contributes to informal care provision.

CMOC (D1) Providing access for relatives. Both RCFs created easy entry for relatives of the residents by providing them a key to enter the care unit (RCF A was closed from the outside to prevent unwanted visitors) and the apartment of their relatives *(context)*. Our observations showed that relatives regularly visited residents and sometimes also brought clean laundry or food. This indicated that granting access to relatives encourages relatives (as informal caregivers) to perform care tasks*(outcome)*, although this could be seen as undermining the privacy that residents were afforded. The RCF tries, however, to replicate the resident's home situation, in which the family member often also has the key to the resident's home.

Explanation of the mechanism: RCFs providing access for relatives to the care unit and apartment of the residents *(context)* leads to relatives being able to visit the residents easily *(mechanism)*, which could lead towards engaging relatives as informal caregivers in care tasks, such as doing laundry or bringing food *(outcome).*

E) USE OF TECHNOLOGY AND AUTONOMY

Within both RCFs we identified one mechanism where the use of technology could *indirectly* lead to more autonomy for residents by improving knowledge of the resident.

CMOC (E1) Improving knowledge of the resident. In the RCF documents, the use of digital devices and digital dossiers was mentioned (*context).* While this study took place, we observed the use of tablets by staff to review and update residents' records and care plans in both RCFs. In interviews, formal caregivers at RCF A stated that the use of tablets makes personal information of the resident easily accessible, also for (new) staff *(outcome).*

Explanation of the mechanism: The use of tablets in RCFs *(context)* enables staff to access the (personal) information of the residents *(mechanism)* easily, which enables staff to provide care that is personalized to the residents' needs and preferences *(outcome)*. This may facilitate residents' autonomous choices.

F) USE OF TECHNOLOGY AND INFORMAL CARE

Within both RCFs, we identified one mechanism which explained how the use of technology could *directly* lead to more informal care provision.

CMOC (F1) Enhancing contact between caregiver and relatives. Staff in both RCFs used a computer program to report on the status of the residents. Relatives of residents at RCF A could also respond or ask questions using this system *(context).* Some staff members used the system to ask relatives whether they could help out with an activity *(outcome).* One relative stated during an interview: *[showing the computer program to the interviewer] 'Look, here is a message from the caregiving team of my father: We are making plans for Christmas. You are invited to join us for coffee on Christmas Day at 11 AM. You can sign up (...)'.* (Interview relative RCF A)

Explanation of the mechanism: The use of a two-way communication computer system for staff and relatives *(context)* facilitates communication between them, which may enhance the ability of staff to involve relatives with care tasks *(mechanism)*, possibly resulting in more informal care provision *(outcome).*

Discussion and Implications

We performed a multiple case study to explore *how* interactions between residents, staff members and informal caregivers; the physical environment; and the use of technology within RCFs contribute to resident autonomy and improve informal care provision. Interactions between residents, staff members and informal caregivers appeared to be most important in both enhancing the decisional and executorial autonomy of residents with dementia and improving informal care provision. An example of the effect of interaction between staff and residents on the executorial autonomy of residents was found in the way food and drinks were served. RCF A deliberately choose 'service' above autonomy for their residents, which means coffee and tea were served to them and dinner was served in restaurant style. In RCF B, however, residents participate as much as possible; residents were, when possible, supported in preparing their own coffee or tea, and food was served with plates and bowls as normal at home. Residents in RCF B were encouraged to serve themselves, or at least to try to eat and drink by themselves. This may promote resident independence, which in turn may promote their decisional and executorial autonomy, despite cognitive or physical impairments.

The importance of the triangle between residents, staff members and informal caregivers in the care of older adults has been widely acknowledged (29-31). When staff members approach residents in a respectful manner, have knowledge of the residents and encourage autonomous behaviour, this leads to more autonomy for residents. This holistic approach of seeing the person instead of a patient is also recognized in other areas of care. Issel (32) has noted that health care organizations that support staff members in seeing the patient as a whole person will likely have better patient outcomes. We also found that using this holistic approach of seeing the whole person, including context and history, also applies to enhancing informal care provision. Staff members who acknowledge the importance of informal caregiving for residents and who actively encourage relatives to perform informal care could enhance informal care provision. This finding is in line with another study (33) which found that staff acknowledging the role and expertise of informal caregivers is essential to facilitate good collaboration.

Our findings indicate that, although less apparent, the physical environment and technology may facilitate interactions between residents and formal and informal caregivers and consequently contribute to the decisional autonomy of residents and to informal care provision. Using an electronic device to register medical data, as well as personal information about residents, makes it is easier for formal caregivers to provide care that is in line with the preferences and wishes of residents, which may contribute to the decisional autonomy of people with dementia. Easy entry to the building for relatives appeared to enhance visits, which in turn may lead to more informal care provision. Other studies also found that technology may strengthen the knowledge of people with dementia (34, 35). Improving the use of communication technology between staff members and relatives appeared to increase relatives' involvement and collaboration. Other studies have also found that technology can be used to educate and communicate with the relatives of residents living in an RCF to improve both quality of care and quality of life (36, 37).

Our findings are in line with the research of Santana (38), who has developed a framework for practical guidance on the implementation of person-centred care. This roadmap consists of three steps. The first step takes place at the structure/organizational level and relates to the context in which care is delivered. On this level, a culture of person-centred care should be created by developing and co-designing policies and education programmes and supporting staff to commit to person-centred care. The second step takes place on the process level and includes domains associated with the interaction between patients and health-care providers. The third step takes place on the outcomes level and is reached when the value of implementing the person-centred care model in daily practice can be shown. When we apply the roadmap to our findings, we determined that when RCFs strive to create a person-centred culture by including certain expectations about the actions of staff members in (policy) documents (step 1), this may result in certain interactions between residents, staff members and informal caregivers in daily practice (step 2), which in turn may enhance person-centred outcomes (step 3), such as greater autonomy among residents with dementia and more informal care provision.

Limitations and Strengths

This study has some limitations. The severity of dementia experienced by the residents varied between the RCFs. In RCF B, almost all residents suffered from moderate to severe dementia, whereas in RCF A several residents had mild to moderate dementia or no cognitive problems. For the purpose of this research, we only considered the residents with moderate to severe dementia. However, the difference in dementia severity was noticeable during our observations. The atmosphere at RCF A was livelier, and staff and residents with only somatic problems had conversations that were more ordinary and such residents helped with domestic tasks or even helped other residents with more severe problems.

The data collection took place in only two Dutch RCFs, and we observed a rather small number of residents and RCFs. Generalization of the findings may thus be limited. RCF A was founded in 2015 and was therefore relatively new when we conducted our study in 2017. The period between the start-up and data collection in RCF A was therefore short, and as a result, few policy documents (for example) were available. We would have preferred to include the opinions of residents with dementia themselves. Because of the focus of the study: how people with dementia living in an RCF are stimulated by the policies of RCFs and behaviours of staff to make autonomous choices or to perform autonomous actions, it was important to observe the interactions between residents and staff members and study if staff members were providing care according to the policies of the RCFs and, as such, stimulated residents to make autonomous choices or to perform autonomous actions. Observations were also a good research method because it allowed us to see the reactions of residents, including visible emotions. Involving staff members in the recruitment of participants may have introduced selection bias. Although the residents and staff were asked to maintain their usual routine, potential participant bias might have affected the outcome, because participants may have behaved differently knowing that they were being observed. This could have led to more autonomy-supporting observations in which residents were better engaged in making or executing choices. Unfortunately, due to the methods used, it was not possible to assess whether or not residents themselves experienced more or less support for their autonomy during the observations.

Despite these limitations, this realist evaluation explored theories developed from the existing evidence and based them in case study sites with different cultures for dementia care. More or less the same mechanisms were found to operate at both study sites, which provided insight in the different aspects of person-centred care in daily practice. This could increase the transferability and usefulness of the findings beyond the local context, which could be used for other RCFs to implement a person-centred care approach successfully, with an emphasis on maintaining autonomy for their residents and improving informal care provision.

Conclusion

By investigating the culture and policies as well as observing the daily practice of two different RCFs, we provided insight into how RCFs can successfully implement person-centred care to enhance the autonomy of people with dementia living in RCFs and improve informal care provision. The behaviour, attitude and interaction of staff members with residents and informal caregivers appeared to encourage the autonomy of people with dementia living in RCFS and enhance informal care provision. The physical environment of the RCFs and the use of technologies were less relevant in stimulating resident autonomy and informal care provision, although they could support formal caregivers to provide person-centred care in daily practice.

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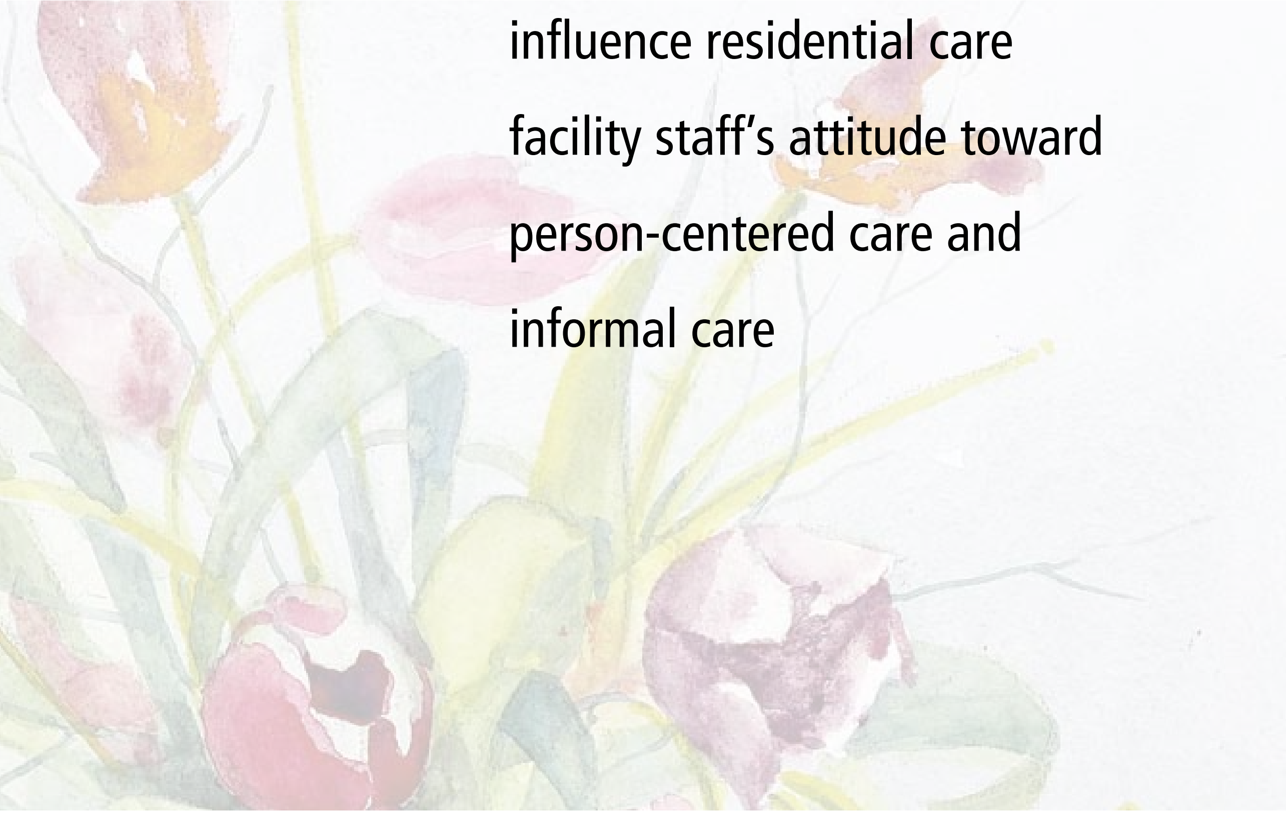
CHAPTER 4

How staff characteristics influence residential care facility staff's attitude toward person-centered care and informal care



Publiced as:
Boumans, J., van Boekel, L., Kools, N., Scheffelaar A., Baan C.A., Luijkx, K.G. How staff characteristics influence residential care facility staff's attitude toward person-centered care and informal care. *BMC Nurs* **20**, 217 (2021). https://doi.org/10.1186/s12912-021-00743-8

Abstract

Background: Staff members, and their attitudes, are crucial for providing person-centered care in residential care facilities for people with dementia. However, the literature on the attitudes of nursing staff regarding person-centered care is limited. The objective of this study is to explore the association between staff characteristics (age, education level, years of work experience and function, i.e., care or welfare) and staff attitudes toward perceived person-centered care provision and including informal caregivers in the caregiving process in residential care facilities.

Methods: A convenience sample of 68 care staff (nurses and nurse assistants) and welfare staff members (activity counselors, hostesses, and living room caretakers) of two residential care facilities filled out a questionnaire. Staff attitudes regarding perceived person-centered care were measured with the Person-centered Care Assessment Tool (P-CAT). Staff attitudes regarding informal care provision were measured with the Attitudes Toward Families Checklist (AFC). Multiple linear regression analysis explored the association between variables age, work experience, education, and function (care or welfare).

Results: A higher age of staff was associated with a more negative attitude toward perceived person-centered care and informal care provision. Welfare staff had a more negative attitude toward the inclusion of informal caregivers than care staff. The perceived person-centered care provision of the care and welfare staff was both positive. Work experience and education were not associated with perceived person-centered care provision or informal care provision.

Conclusion: This study is one of the first to provide insight into the association between staff characteristics and their attitude toward their perceived person-centered care provision and informal care provision. A higher age of both the care and welfare staff was associated with a more negative attitude toward their perceived person-centered care and informal care provision. Welfare staff had a less positive attitude toward informal care provision. Additionally, future studies, also observational studies and interview studies, are necessary to collect evidence on the reasons for negative attitudes of older staff members towards PCC and informal care giving, to be able to adequately target these reasons by implementing interventions that eliminate or reduce these negative attitudes.

Background

Over the last decades, the focus in dementia care has been increasingly directed toward person-centered care (PCC). PCC refers to a focus on the care and treatment of the person with dementia and their psychological needs (1) rather than the person's disease (2). PCC is advocated as critical for good and effective dementia and nursing home care (3-5), showing significant benefits with respect to decreasing behavioral symptoms (6), psychotropic medication use (7), and improved quality of life for people with dementia (8, 9).

Staff members and their attitudes are crucial when providing PCC in residential care facilities for people with dementia because in the care relation, they have to place the person with dementia at the center of the care dynamic rather than placing the emphasis on the condition (2). However, the literature on the attitudes of nursing staff regarding PCC is limited. Most studies have focused on how to increase PCC delivery (10, 11) and how PCC influences job satisfaction of the staff. Studies have shown that care staff with more positive attitudes regarding PCC are more satisfied with their jobs (12-17).

Several studies show that characteristics of staff members, such as age, education level, and working experience in long-term care for older adults could influence their PCC attitude though the results are mixed. A study reported that staff over the age of 50 had less person-centered attitudes than staff under the age of 40 (18). Oppositely, to other studies found that age was not associated with attitudes toward residents with dementia (19, 20). Also, the role of education is researched in several studies. Moreover, previous research focusing on the role of education found that higher education levels were related to more positive attitudes toward residents with dementia (12, 19). As for research focusing on the effect of work experience on attitudes, results are rather mixed. One study showed that staff members who worked between one and two years had a higher PPC attitude in comparison with staff members having more work experience (12). This is in contrast with another study which reported that staff with less than 10 years of experience had less person-centered attitudes (18). Two other studies found that attitudes did not differ by work experience in long-term care (19, 20). No studies regarding the function of the staff member (i.e., care or welfare) have been located. Though, the function of the staff member might also influence their PCC attitude. For example, for welfare staff it might be easier to focus on the person with dementia and their psychological needs rather than the person's disease because they are not or less involved in the physical care of the person with dementia.

PCC provision in residential care facilities does not depend on paid staff only. Forming and maintaining good relationships between staff members, clients, and their families is essential to PCC (21). Families, but also other informal caregivers like friends and neighbors, are familiar with the preferences of the resident (22), and their involvement in care could lead to more PCC for the person with dementia. A few studies have been conducted on staff attitudes toward family members of residents with dementia (23-25), with all indicating that a positive attitude on the part of staff regarding family members is important for the resident's well-being. Whether the individual staff characteristics influence the attitude of staff regarding the inclusion of informal caregivers is yet unknown because no study has been located that has investigated the correlations between staff characteristics and staff attitude regarding the inclusion of informal caregivers.

There is a need for empirical measures to determine the association between attitudes of staff regarding PCC and the attitudes of staff regarding informal care. A better understanding of unique individual factors that underlie and contribute to attitudes may enable more targeted staff training in the area of PCC and the inclusion of informal caregivers.

Therefore, the objective of this study is to explore the association between staff characteristics (age, education level, years of work experience and function, i.e., care or welfare) and staff attitudes toward perceived person-centered care provision and including informal caregivers in the caregiving process in residential care facilities. Our research questions were as follows:

1. What is the association between staff characteristics (age, education level, years of work experience in long-term care for older adults and function, i.e., care or welfare) and staff attitudes toward PCC provision?
2. What is the association between staff characteristics (age, education level, years of work experience in long-term care for older adults and function, i.e. care or welfare) and staff attitudes toward the inclusion of informal caregivers?

Methods

Participants and Settings

A cross-sectional convenience sample of a total of 68 staff members (care staff [*n* = 36] and welfare staff [*n* = 29] missing functions [*n* = 3]) of residential aged care staff was recruited within two psychogeriatric care units of residential care facilities (RCFs) located in the south of the Netherlands (RCF A *n* = 45; RCF B *n* = 23). All levels of (care) staff at these facilities were considered eligible for participation. We also intentionally aimed to include staff who provided non-care tasks but assisted residents with daily activities since they are essential in PCC. Non-care staff is hereafter referred to as welfare staff. Staff were invited by their team manager to participate voluntarily and were informed about the process and aim of the study. We did not track non-responses or reasons why staff members did not participate in the study. Participants completed the questionnaire on paper or online.

Both RCFs provide 24-hour care for people with dementia and take a person-centered approach to care. RCF A provides care for people with light to moderate dementia or somatic problems. To live in RCF A, an indication for long-term care is needed. A diagnosis of dementia is not necessary. RCF B provides care mostly for people with moderate to severe dementia. People are eligible to reside and receive care in RCF B if they have a diagnosis of dementia and need long-term care. RCF A and B qualify as small-scale living facilities in the area of a larger nursing home (27). They both provide care for people with dementia in a homelike situation. A maximum of eight residents form a joint household. A common living room is provided, including a kitchen in which all meals are prepared. Facilities such as a restaurant and activity areas are attached to the ward. The physical environment of the two care organizations regarding the use of PCC elements has been mapped to see if the work conditions of staff members with respect to the environment were compatible with providing PCC.

Measuring Instruments

Physical Environment

The physical environment of both care locations has been systematically mapped by means of the OAZIS-Dementia (26). The tool was developed to measure the physical environment of long-term care environments in a Dutch setting (27). With this tool, it is possible to map the extent to which the physical environment meets the conditions for

PCC and thus provides an indication of the extent to which the physical environment contributes to the well-being of the residents. The OAZIS-Dementia consists of 72 items, which assess aspects of the environment on a five-point Likert scale, ranging from 1 (not at all) to 5 (completely). The checklist is divided into seven themes: 1) privacy and autonomy, 2) sensory stimulation, 3) view and nature, 4) facilities, 5) orientation and routing, 6) domesticity, and 7) safety. Higher scores indicate a higher probability of the environment meeting the conditions for PCC. Two independent researchers (n = 2) observed both care locations and filled out the OAZIS-Dementia for each care location.

Staff Questionnaires

The Person-Centered Assessment Tool (P-CAT) is a widely used questionnaire with good psychometric properties (i.e., Cronbach's α = .84), and content and construct validity have been proven to be good (28). The P-CAT is a questionnaire constructed to evaluate the extent to which staff in residential aged care perceive the care provided as being person-centered. The questionnaire consists of 13 items, rated on a five-point Likert scale ranging from 1 (disagree completely) to 5 (agree completely). In total, 13 items were summed up to generate a total score between 13 and 65, where higher scores indicate a higher perceived PCC attitude. The questionnaire consists of three subscales, namely: 1) the extent to which care is tailored to the individual (Cronbach's α = 0.81); 2) the extent to which employees experience support from the organization (Cronbach's α = 0.77); 3. the extent to which the environment is accessible and suitable for people with dementia (Cronbach's α = 0.31) (28). The Dutch version of the tool was translated by a research institute and showed appropriate psychometric properties (29). In our study, the internal consistency of the scale was Cronbach's α = 0.80. Subscale 1 and subscale 2 had an acceptable internal consistency (both Cronbach's α = 0.77). Subscale 3 could not be taken together in a separate scale because of an unacceptable internal consistency (Cronbach's α = 0.48).

The Attitudes Toward Families Checklist (AFC) was used. Reported Cronbach's α was .74 for the scale (30, 31). The AFC is designed to assess staff attitudes about family members of residents with dementia (30). Staff rated the items on a 7-point Likert-type scale (1 = strongly disagree to 7 = strongly agree). An overall sum score of all 16 AFC items was calculated. High scores indicated that the staff had a positive attitude toward family visitation, requests, and caregiving roles for their relatives. The items of the AFC had satisfactory estimates of reliability which were comparable with the internal consistency of previous findings (30). The AFC consisted of three subscales:

1) calming, reflecting whether family members are seen as having a calming effect or a disruptive effect on residents; 2) partner, reflecting whether family members are seen as equal partners in care or not; and 3) relevant, reflecting whether family members are seen as relevant to residents and staff. For this study, we translated the questionnaire from English to Dutch using a forward and backward translation process using native speakers. Internal consistency of the subscales was not sufficient, and therefore only an overall score was used in the analysis since internal consistency of the overall scale was sufficient (Cronbach's $\alpha = 0.73$).

Staff characteristics: Gender, age, education level, years of work experience in long-term care for older adults, and function (care or welfare) were assessed. The functions 'certified nurse', 'registered nurse', 'nurse assistant', and other clearly care-related functions mentioned under 'other' were classified as care staff ($n = 36$). The functions 'activity counselor', 'hostess', 'living room caretaker', and other welfare-related functions mentioned under 'other' were classified as welfare staff ($n = 28$), missing functions ($n = 3$).

Analyses

SPSS version 24 was used to perform the analyses. Descriptive statistics were used for all staff characteristics to map averages, minimum and maximum values, and standard deviations. Descriptive statistics were used to map scores on the P-CAT and the AFC for the entire sample and separately for care and welfare staff.

The Shapiro-Wilk test was used to check normality. Results indicated that scores on the P-CAT sum score ($W = 0.95$; $p < 0.05$), as well as scores on P-CAT subscale 1 ($W = 0.96$; $p < 0.05$) and the P-CAT subscale 2 ($W = 0,95$; $p < 0.05$) were not normally distributed. Therefore, Mann-Whitney U tests were used to compare sum scores of P-CAT, P-CAT subscale 1 ('extent to which care is tailored to the individual') and P-CAT subscale 2 ('the extent to which staff experience support from the organization') between care and welfare staff. Other assumptions for Mann-Whitney U test were not violated since there were no outliers and observations were independent. Overall scores on the AFC were normally distributed, and therefore an independent t-test was used to compare scores on AFC between care and welfare staff.

Two multiple linear regressions by means of the enter method were used to investigate first whether overall score on P-CAT could be explained by 'age of staff member', 'education level' 'number of years that staff member has been working in long-term care for older adults' and 'function of staff member (care or welfare)'. Second, multiple linear regression was used to assess whether the overall score on AFC could be explained by ‘age of staff member’, ‘education level’, ‘number of years that staff member has been working in long-term care for older adults’, and ‘function of staff member (care or welfare)’. Assumptions for multiple linear regression were tested for both multiple regression analyses to explain P-CAT and AFC. Multicollinearity was not a problem since VIF values were between 1 and 2 and tolerance was not below 0.1. Durbin-Watson test was 2.122 (P-CAT as the dependent variable) and 1.991 (AFC as the dependent variable), indicating that errors were uncorrelated. The assumption of homoscedasticity of variances, linearity, and non-zero variances were also met. One respondent had an outlier (rather low) score on overall P-CAT score. We decided, however, to maintain this respondent in the analyses since answers seemed realistic.

Ethics

The study has been approved by the Ethics Review Board of the School of Social and Behavioral Sciences of Tilburg University (EC-2019.06) and by the ethics committee of residential care facility B. Written informed consent was obtained from all subjects involved in the study.

Results

The results section consists of six parts: 1) the physical environment regarding PCC, 2) demographics and job-related characteristics of the staff members, 3) results of the P-CAT questionnaire, 4) associations between staff characteristics and perceived provision of PCC, 5) results of the AFC questionnaire, 6) associations between staff characteristics and attitude toward informal care provision

Comparison of the Physical Environment Regarding PCC

To gain insight into whether the physical environment of the two care organizations differ from each other or have considerable similarities regarding the use of PCC elements, the physical environment of both care locations has been systematically mapped by means of the OAZIS-Dementia. Results of the systematic mapping of the physical environment regarding PCC are shown in Table 1. RCF B scored (slightly) higher on almost all themes than RCF A, with the exception of the view and nature theme. Both RCFs scored relatively high on the themes privacy and autonomy, facilities, domesticity and relatively low on the themes view and nature and orientation and routing, though the physical environment of both RCFs met most of the conditions to realize PCC.

Table 1 Results of the observation of the physical environment by means of the OAZIS-Dementia

	Residential care facilities			
	RCF A (*n* = 2)		**RCF B (*n* = 2)**	
Themas	***M***	***SD***	***M***	***SD***
1. Privacy and Autonomy	4.14	.00	4.86	.00
2. Sensory Stimulation	4.36	.04	4.37	.06
3. View and Nature	3.72	.12	3.23	.32
4. Facilities	4.11	.00	4.72	.08
5. Orientation and Routing	3.64	.10	4.18	.45
6. Domesticity	4.50	.12	4.59	.00
7. Safety	4.00	.00	5.00	.00
Total	4.07	.01	4.42	.11

Notes: *M* = Mean SD = Standard deviation.

Demographics and Job-Related Characteristics of the Staff Members

A total of 68 staff members (care staff [*n* = 36] and welfare staff [*n* = 29], missing functions [*n* = 3]). completed the questionnaire; 45 staff members from RCF A and 23 staff members from RCF B. Three staff members mentioned functions that could not be classified as a care or welfare function and were therefore coded as missing in the dichotomous score for care or welfare function.

The demographics and job-related characteristics of the staff members are shown in Table 2. All respondents had Dutch nationality. Of these respondents, 90.9% were women. The mean age of the respondents was 42.9 (*SD* = 11.9). When comparing care and welfare staff, it was found that care staff had more years of experience in care for older adults (*M* = 14.8; *SD* = 10.7) compared to welfare staff (*M* = 8.83; *SD* = 10). Due to the low response of male respondents, the correlation between gender and staff attitudes could not be studied.

Table 2 Demographics and job-related characteristics of the staff members

Variables	**Care staff (*N* = 36)**	**Welfare staff (*N* = 29)**	**Total (*N* = 68)**[a]
	n (%)	n (%)	n (%)
Age (in years) (*SD*)[b]	40.4 (12.0)	46.6 (11.0)	42.9 (11.9)
Gender			
Female	33 (90.9%)	25 (88%)	58 (89.6%)
Years of experience in long-term care for older adults M (*SD*)	14.8 (10.7)	8.83 (10.0)	12.6 (SD=11,1)
Number of hours worked per week M (*SD*)	27.8 (5.3)	25.7 (5.2)	26.6 (5.3)
Education level			
Low (no education, elementary and vocational education)	6	7	13
Middle (secondary and average vocational education)	26	20	46
High (high vocational education, high professional education university)	4	2	6

Notes: M = Mean. SD = Standard deviation. [a] Total (*N* = 68) = *Care staff* (*N* = 36) + Welfare staff (*N* = 29) + missing functions (*N* = 3) [b] TAge significantly different between care and welfare staff t(61) = -2.115 p < 0.05.

Results of P-CAT Questionnaire

Attitudes toward PCC of both care and welfare staff members are presented in Table 3. The answers of four respondents are missing. Both care and welfare staff were convinced that they provided PCC to a relatively high degree (P-CAT *M* = 3.82; *SD*= 0.46). The difference between the two types of staff members in the extent to which they were convinced that they provided PCC was investigated using Mann-Whitney U tests. Care staff members (*M* = 3.69) did not differ in their perceived provision of PCC compared to welfare staff members (*M* = 3.77), *U* = 467.00, *p* >.05, *r* = -.06.

The difference between two types of staff members (care or welfare) in the extent to which they offered personalized care (P-CAT subscale 1) was investigated. Care staff (*M* = 4.00) did not differ in the extent to which they personalized care compared to welfare staff (*M* = 3.86), *U* = 390.00, *p* >.05, *r* = -.19. The difference between care and welfare staff in the extent to which staff experience support from their organization (P-CAT subscale 2) was investigated. It appeared that care staff (*M* = 3.75) did not differ in the extent to which they experience support from their organization compared to welfare staff (*M* = 4.00), *U* = 427.50, *p* >.05, *r* = -.13.

Table 3 Descriptive statistics P-CAT

P-CAT	N =	Range (minimum – maximum)	Mean (*SD*)	Median	Care staff mean (*N*)[d]	Welfare staff mean (*N*)
OVERALL SCORE	67	3 (2–5)	3.82 (0.46)	3.69	3.89 (36)	3.75 (28)
Items						
SUBSCALE 1 EXTENT OF PERSONALIZING CARE [a]	67	3 (2–5)	3.98 (0.480)	3.86	4.07 (36)	3.86 (28)
1. We often discuss how to give person-centered care.	66	3 (2–5)	4.00 (0.823)	4.00	4.11 (36)	3.79 (28)
2. We have formal team meetings to discuss residents' care.	67	4 (1–5)	3.95 (0.697)	4.00	4.04 (36)	3.79 (28)
3. The life history of the residents is formally used in the care plans we use.	67	4 (1–5)	3.54 (0.943)	4.00	3.64 (36)	3.39 (28)
4. The quality of the interaction between staff and residents is more important than getting the tasks done.	67	3 (2–5)	4.07 (0.724)	4.00	4.11 (36)	4.04 (28)
5. We are free to alter work routines based on residents' preferences.	67	2 (3–5)	4.28 (0.545)	4.00	4.42 (36)	4.14 (28)
6. Residents are offered the opportunity to be involved in individualized everyday activities.	67	2 (3–5)	4.10 (0.606)	4.00	4.17 (36)	4.07 (28)
7. Assessment of residents' needs is undertaken on a daily basis.	67	3 (2–5)	3.90 (0.800)	4.00	4.03 (36)	3.79 (28)

P-CAT	N =	Range (minimum – maximum)	Mean (*SD*)	Median	Care staff mean (*N*)[d]	Welfare staff mean (*N*)
OVERALL SCORE	67	3 (2–5)	3.82 (0.46)	3.69	3.89 (36)	3.75 (28)
Items						
SUBSCALE 2 AMOUNT OF ORGANIZATIONAL SUPPORT	67	3 (2–5)	3.79 (0. 723)	4.00	3.791 (36)	3.86 (28)
8. I simply do not have the time to provide person-centered care.	67	3 (2–5)	3.85 (0.839)	4.00	3.92 (36)	3.82 (28)
9. The environment feels chaotic.	67	4 (1–4)	3.48 (0.877)	4.00	3.50 (36)	3.54 (28)
10. We have to get the work done before we can worry about a homelike environment.	67	4 (1–5)	3.82 (1.072)	4.00	3.78 (36)	3.93 (28)
11. This organization prevents me from providing person-centered care.	67	4 (1–5)	4.03 (0.953)	4.00	3.97 (36)	4.14 (28)
SUBSCALE 3 DEGREE ENVIRONMENTAL ACCESSIBILITY [c]						
12. It is hard for residents in this facility to find their way around.	67	3 (2–5)	3.19 (0.892)	3.00	3.25 (36)	3.07 (28)
13. Residents are able to access outside space as they wish.	67	4 (1–5)	3.45 (1.118)	4.00	3.61 (36)	3.29 (28)

[a] Cronbach's a for subscale 1 was .77

[b] Cronbach's a for subscale 2 was .77

[c] Cronbach's a for subscale 3 was .48. Because of low internal consistency, this subscale was not further used in the analyses.

[d] Three staff members mentioned functions that could not be classified as a care or a welfare function.

Associations Between Staff Characteristics and Perceived Provision of PCC

Table 4 displays the results of the two multiple linear regression analyses in which we investigated whether the attitude of staff members toward PCC provision (P-CAT) could be explained by the staff member's age, years of work experience in long-term care for older adults, function (care or welfare), and education level. We found that the age of staff members, number of years working in long-term care for older adults, function (care or welfare), and education level explained 16% of the variance in the attitude of staff toward their conviction about their own PCC provision: $F(4, 56) = 2.628$, $p < .05$, $R^2 = .158$ R^2Adjusted = .098. Years of work experience in long-term care for older adults, function (care or welfare), and education level were not significant explanation of staff attitudes about their perceived PCC provision. The staff's age was an explanation of the attitude of staff members about their perceived PCC provision (*б*= -.37, $t(56) = -2.16$, $\mathrm{p} < .05$). This represented a negative effect, which means that a higher age of staff members is associated with a more negative attitude toward their perceived PCC provision.

Table 4 Results of multiple linear regression analyses to explain attitude of staff toward PCC (P-CAT) and toward informal caregiving (AFC).

Dependent variable attitudes of staff toward PCC (P-CAT)					
	B	***SE B***	***б***	**t**	***p***
Variable					
Constant P-CAT	4.927	0.623		11.391	.000
Function: care or welfare	-0.086	0.135	-0.90	-.632	.530
Age staff member	-0.15	0.007	-0.365	-2.156	.035*
Years working in long-term care for older adults	-0.001	0.007	-0.034	-.206	.838
Education level	-0.081	0.059	-.176	-1.372	.175
Dependent variable attitudes of staff toward informal caregiving (AFC)					
Constant AFC	5.025	0.623		8.074	.000
Function: care or welfare	-.107	0.196	-.079	-.546	.587
Age staff member	-.022	.010	-.385	-2.245	.029*
Years working in long-term care for older adults	.014	.010	.216	1.312	.195
Education level	.045	.085	.069	.531	.598

Notes. B = unstandardized coefficients, *SE* = standard error, β = standardized coefficients
P-CAT:R^2 = 0.158, Adjusted R^2 = 0.098 $F(4, 56) = 2.628$
AFC: R^2 = 0.154, Adjusted R^2 = 0.093 $F(4. 55) = 2.505$

Results of AFC Questionnaire

Attitudes toward informal care provision of both care and welfare staff members are presented in Table 5. For each item of this questionnaire, 4-5 responses were missing. The difference between two types of staff (care or welfare staff) regarding their attitudes toward informal care provision was investigated using an independent t-test. Care staff had a significantly more positive attitude toward informal care provision (M = 4.57; SE =.11) compared to welfare staff (M = 4.21; SE = .12), $t(62) = 2.14$, $p < .05$. This represented a small to medium effect, r =.26.

Table 5 Descriptive statistics AFC.

AFC[a]	***N* =**	**Range (minimum – maximum)**	**Mean (*SD*)**	**Care staff mean (*N*)**[b]	**Welfare staff mean (*N*)**
Items					
1. Family members make too much noise and disturb other residents with Alzheimer’s.[a]	67	5 (1–6)	3.40 (1.338)	3.47 (36)	3.29 (28)
2. It seems that when families come to the Alzheimer’s unit, the residents get more agitated.[a]	67	5 (2–7)	3.54 (1.295)	3.58 (36)	3.54 (28)
3. Family members should remember that they are visitors at the institution and should strictly follow our rules.	65	6 (1–7) 5 (2–7)	3.57 (1.912)	3.97 (35)	3.07 (27)
4. The institution’s rules about family member visits should be more strict.[a]	66	5 (2–7)	5.18 (1.435)	5.39 (36)	3.96 (27)
5. When families are with their relatives, they often stay too long.a	66	5 (2–7)	5.32 (1.361)	5.49 (35)	5.18 (28)
6. Family members often bring ideas that are helpful about how to care for their relatives.	67	5 (2–7)	4.7 (1.206)	4.75 (36)	4.54 (28)
7. Working with the family is an important part of my work.	67	5 (2–7)	5.85 (0.942)	5.97 (36)	5.61 (28)
8. Family members are good about helping with the care of the residents with Alzheimer’s.	67	6 (1–7)	4.85 (1.258)	5.08 (36)	4.50 (28)
9. Family members should have as much say as possible concerning the care of their relatives.	67	5 (2–7)	4.55 (1.699)	4.97 (36)	3.93 (28)
10. Most family members rarely come to see their relatives with Alzheimer’s.[a]	67	6 (1–7)	4.30 (1.337)	4.42 (36)	4.07 (28)
11. Most family members won’t accept that their relatives with Alzheimer’s are mentally incompetent.[a]	67	6 (1–7)	3.84 (1.298)	3.92 (36)	3.75 (28)

AFC[a]	***N* =**	**Range (minimum – maximum)**	**Mean (*SD*)**	**Care staff mean (*N*)**[b]	**Welfare staff mean (*N*)**
Items					
12. Family members have too many requests that make my work more difficult.a	67	6 (1–7)	3.91 (1.535)	4.11 (36)	3.54 (28)
13. Most family members know a lot about how to relate to their relatives with Alzheimer's.	66	6 (1–7)	4.08 (1.328)	4.20 (35)	3.93 (28)
14. When family members are on the Alzheimer's unit, they seem to not know what to do.a	66	5 (2–7)	4.35 (1.330)	4.47 (36)	4.22 (27)
15. Family members understand that we care for a number of residents with Alzheimer's and cannot always do the things they request.	67	5 (2–7)	4.03 (1.359)	4.03 (36)	4.04 (28)
16. Most residents with Alzheimer's ignore their families that are with them and don't seem to care if they are there or not.a	67	5 (2–7)	5.22 (1.391)	5.14 (36)	5.29 (28)

[a] Cronbach's a for the overall scale was 0.73.

[b] Three staff members mentioned functions that could not be classified as a care or a welfare function.

Associations Between Staff Characteristics and Attitude Toward Informal Care Provision

Table 4 shows the results of the multiple linear regression in which we investigated whether the attitude of staff members toward informal care provision (AFC) could be explained by the staff member's age, years of work experience in long-term care for older adults, function (care or welfare), and education level. We found that the age of the staff member, the number of years working in long-term care for older adults, function (care or welfare) and the education level explained 15% of the variance in the attitude of staff member toward informal care: $F(4. 55) = 2.505$, $p > .05$, $R^2 = .154$, R^2Adjusted =.093. Function (care or welfare), years of work experience in care for older adults, and education level were not significant explanation of staff attitudes to informal care provision. The staff member's age was an explanation of the attitude that staff had about informal caregiving ($б = -.39$, $t(55) = -2.25$, $p < .05$). This represented a negative effect, which means that a higher age of staff members is related to a more negative attitude toward informal caregiving.

Discussion

This article provides insight into the association between staff characteristics and the attitudes of staff regarding providing PCC and the inclusion of informal caregivers. Staff members with a positive attitude toward PCC and the inclusion of family members in care could lead to more PCC for persons with dementia, which contributes to residents' well-being.

Findings showed that in a physical environment that met most of the conditions to realize PCC, both care and welfare staff were convinced that they provide PCC to a relatively high degree. Also, staff members held a rather positive attitude regarding informal care provision. When comparing care and welfare staff, we found that care staff held a more positive attitude toward informal care provision than welfare staff. Furthermore, a higher age of staff was related to more negative attitudes about their perceived PCC provision and informal care provision. Years of work experience in long-term care for older adults and education level were not significant explanations of staff attitudes toward their perceived PCC provision or informal care provision. Due to the low response of male respondents, the correlation between gender and staff attitudes was not possible to study.

When comparing the study findings to previous studies, the finding that older staff members take on a less person-centered attitude has been confirmed elsewhere (18). Still, this finding seems surprising at first sight. It could be reasoned that older staff members have more experience in caring for people with dementia and therefore might have more opportunities to gain knowledge and skills through experience and on-the-job training and therefore have a more positive attitude regarding PCC. An explanation for the opposite finding may be that due to the focus of dementia care being on PCC over the last decades, younger care and welfare staff are increasingly being trained in PCC. In another study, older staff members, relative to younger staff members, showed significantly higher rates of emotional exhaustion and showed a tendency toward higher feelings of depersonalization and lower rates of personal

accomplishment (32). Moreover, younger staff may adopt a more optimistic attitude and suffer less from exhaustion.
Our results about the role of education could not confirm the existing research that care staff with higher levels of education have more positive attitudes towards residents with dementia (12, 19). Our results regarding the years of work experience in long-term care for older adults do confirm the findings of two other studies which stated that attitudes regarding PCC did not differ by years of work experience in long-term care (19, 20). This seems odd because it could be reasoned that staff who have worked longer with dementia patients may have gained knowledge education via on-the-job training and through experience, thereby improving their attitudes. A reason could be that recently graduated care staff have received more education about PCC than care staff who graduated longer ago. Though, age and number of years of work experiences do not always have to go hand in hand. For example, research facility A had a lot of lateral entrants who had worked in other sectors before and later in their life changed their career to work in the care sector.

The results of our study did not indicate that the function of the staff member (i.e., care or welfare) had much influence on their perceived PCC attitude. Both types of staff members indicated that they thought that they provided PCC to a high degree. Other elements could be of influence on their attitude regarding people with dementia, like on-the-job training or the physical environment. Both research facilities qualify as small-scale living facilities and a person-centered attitude to care is more often reported by staff working in small-scale living facilities (12, 26, 33). This could mean that because all staff was working in a small-scale living facility their function, level of education and years of working experience had less influence on their attitude than their working environment, and might be an explanation of the findings.

With regards to informal care our study indicated that care staff had more positive attitudes toward informal care provision than welfare staff. There is not much research available about these different stances of care staff and welfare staff. In a study (34), among staff of rural nursing homes, a comparison was made between nurses, aides, and activity workers concerning their experience of job strain. The results showed that activity workers felt a particular responsibility to meet residents' needs for social interaction and meaningful activity and felt extra pressure to meet the multiple and conflicting demands of different groups of residents. Due to this ambivalence, the function of an activity or welfare staff member regarding informal care provision could be more difficult than that of a care staff member. Care staff usually take care after one resident at a time, whereas, activities organized by welfare staff often concern group-focused activities for residents. This means that the demands of several residents should be considered at the same time, including individual wishes from family members, or including informal caregivers could make a complex situation even more complex. This might explain the less positive attitude of welfare staff toward informal care provision.

Strengths and Limitations

This study has some limitations. We are aware that the sample size is rather small. A convenience sample of 68 staff members of only two RCFs from the southern part of the Netherlands was included. Both RCFs qualify as a small-scale living facility in the area of a larger RCF. This limits the generalizability of the study results because small-scale living is only one of the several different contexts in which care for people with dementia can be provided. Due, however, to the same setting of the RCFs, we were able to gain insight into the specific physical environment of the care organizations regarding the use of PCC elements. The demographic characteristics of the current sample were consistent with those of the Dutch nursing sector (35, 36) regarding the characteristics of sex, mean age, and average number of years of work experience, which supports the likeliness of the representativeness of the sample. Also, this study is a perceived result by questionnaire rather than observation of person-centered care for dementia patients by staff. Observational studies retrieve more standardized information collected by an observing researcher instead of subjective staff responds in the self-completed questionnaire.

A strength of this study is that we made use of existing and validated questionnaires. In addition, our study included both care and welfare staff members. Often, studies regarding PCC and informal care include only care staff members, whereas welfare staff members also are involved and important in PCC provision and including informal caregivers.

Relevance to clinical practice

This study is one of the first to provide insight into the association between staff characteristics and their attitude toward their perceived PCC provision and informal care provision. The results of the study show that the characteristics of staff members (i.e., age and being care or welfare staff) provide an indication of whether staff members are more inclined to provide PCC or include informal caregivers.

Future studies are necessary to collect evidence on the reasons for the negative attitudes of older staff members toward their perceived PCC provision and informal care provision. Future studies are also necessary to collect evidence on if and/or why years of work experience in care for older adults and education level are not explaining staff attitudes to PCC provision and informal care provision. Observational studies and interview studies need also be considered. Observational studies retrieve more standardized information collected by an observing researcher instead of subjective staff responses on the self-completed questionnaire. And interview studies with staff members could gain insight in their perceptions how and why age, years of work experience in care for older adults , function and education level are or are not of influence on the attitude of staff members regarding PCC and informal care. The facility culture of a dementia care facility can evolve over time (37) and administrators of dementia care facilities may be able to adequately target the reasons for the negative attitudes of staff members regarding PCC and informal care by implementing interventions that eliminate or reduce these negative attitudes.

Conclusion

New insight into the association between staff characteristics and their attitude regarding perceived PCC provision and informal care provision are given. A higher age of both care and welfare staff was associated with a more negative attitude toward their perceived PCC and informal care provision. Welfare staff had a less positive attitude regarding informal care provision. Additionally, future studies are necessary to collect evidence on the reasons for negative attitudes of older staff members towards PCC and informal care giving, to be able to adequately target these reasons by implementing interventions that eliminate or reduce these negative attitudes.

List of abbreviations

PCC: person-centered care

RCFs: residential care facilities

P-CAT: Person-Centered Assessment Tool

AFC: Attitudes Toward Families Checklist

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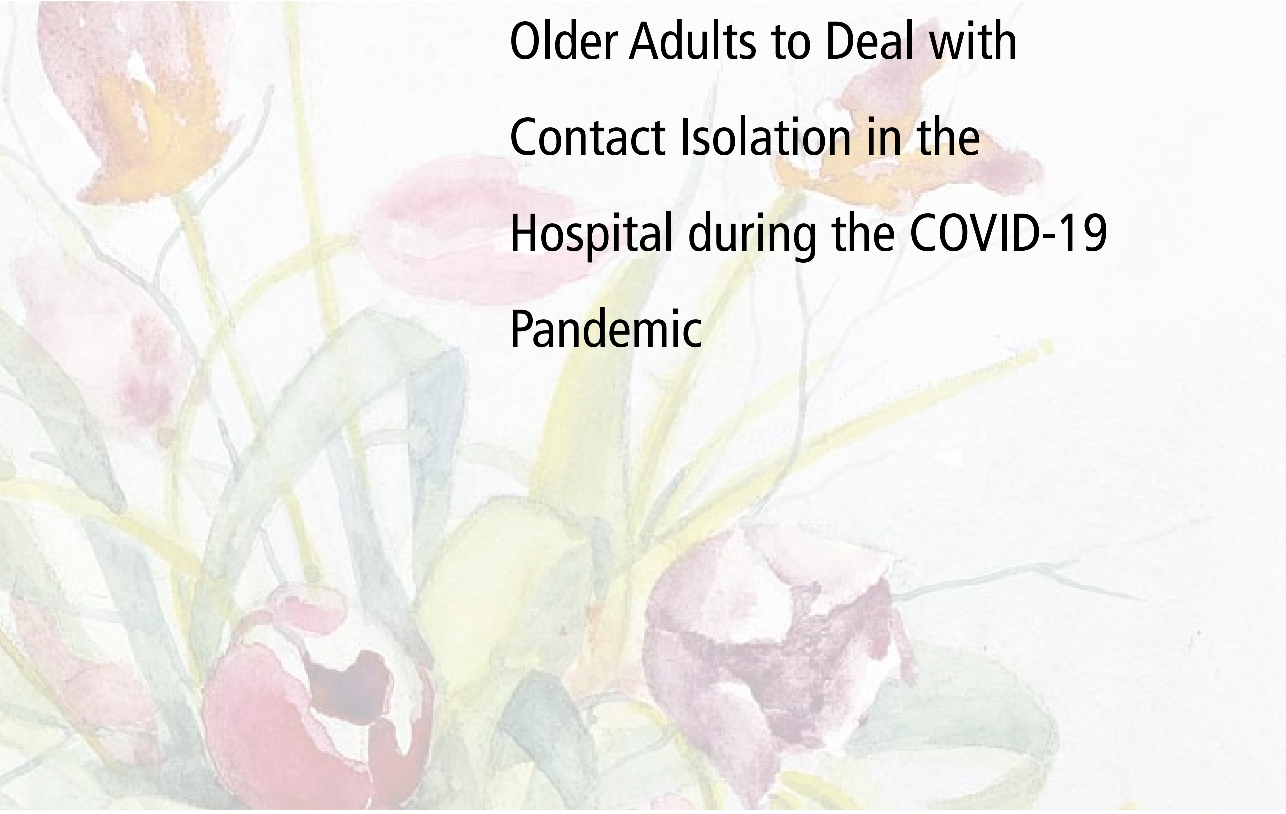
SETTING 2

CHAPTER 5

Coping Strategies Used by Older Adults to Deal with Contact Isolation in the Hospital during the COVID-19 Pandemic



Publiced as:
Boumans J, Scheffelaar A, van Druten VP, Hendriksen THG, Nahar-van Venrooij LMW, Rozema AD. Coping Strategies Used by Older Adults to Deal with Contact Isolation in the Hospital during the COVID-19 Pandemic. Int J Environ Res Public Health. 2021 Jul 8;18(14):7317. doi: 10.3390/ijerph18147317. PMID: 34299774; PMCID: PMC8304333.

Abstract

Due to the COVID-19 pandemic, many older adults have experienced contact isolation in a hospital setting which leads to separation from relatives, loss of freedom, and uncertainty regarding disease status. The objective of this study was to explore how older adults (55+) cope with contact isolation in a hospital setting during the COVID-19 pandemic in order to improve their physical and psychological wellbeing. The realist evaluation approach was used to formulate initial program theories on coping strategies used by (older) adults in an isolation setting. Twenty-one semi-structured interviews with older patients (n = 21) were analysed. This study revealed that both emotion-focused coping strategies as well as problem-focused coping strategies were used by older adults during contact isolation. The study also uncovered some new specific coping strategies. The results have useful implications for hospital staff seeking to improve the wellbeing of older adults in contact isolation in hospitals. Problem-focused coping strategies could be stimulated through staff performing care in a person-centred way. Trust in staff, as part of emotion-focused coping strategies, could be stimulated by improving the relationship between patients and staff.

1. Introduction

Contact isolation is often an unpleasant experience. Isolation is characterised by the separation from loved ones, the loss of freedom, uncertainty over disease status, and boredom (1-4). Patients in contact isolation are more likely to develop symptoms of depression and have longer lengths of stay than non-isolated patients [(5, 6)]. Additionally, when compared with non-isolated patients, physicians and nurses have been shown to have fewer direct interactions and perform fewer examinations on isolated patients [(7-9)]. Patients in contact isolation have reported a poor understanding of the reasons and procedures for contact isolation and a greater level of dissatisfaction with their care as a result (10),(11).

Coping strategies, in the form of behavioural and cognitive efforts, are used by individuals to deal with a variety of stressful situations in order to lower the levels of stress (12),(13),(14) . For this study, the theory of Richard Lazarus and Susan Folkman regarding different coping strategies was followed because much of the literature about coping behaviour of older adults (15),(16, 17),(18) is based on their theory that two different coping strategies can be distinguished, namely problem-focused and emotion-focused coping[(19, 20),(21)]. Other works such as Carver and Scheier's multidimensional coping strategies have been used mainly for other target groups and were therefore not selected for the current study.

Problem-focused coping includes those strategies that involve different mechanisms like acting on the environment (e.g., seeking support from others to solve the problem) or the self (e.g., cognitive restructuring) to modify the problem at hand (21). Problem-focused coping strategies typically include elements such as generating options to solve the problem, evaluating the pros and cons of different options, and implementing steps to solve the problem (21) . There are several studies on the use of problem-focused coping strategies in relation to contact isolation in hospital settings (22),(23),(24). Various studies showed that contact isolation affected patients' feelings regarding the sense of control over their health (25), (26),(27), isolation situation (4),(23),(27), and their day- to-day living in isolation [(24),(23),(25),(26),(28),(29). Providing patients with more control over their health (for example by providing sufficient information (30), isolation situation (for example by including patients in decisions (27), and/ or day-to-day living situation (for example by providing a radio or a clock (25) could trigger problem-focused coping strategies.

Emotion-focused coping does not address the problem at hand; however, it deals with the feelings and perceptions associated with the stressful situation and includes those strategies used to regulate one's stressful emotions (21). The range of emotion-focused strategies is quite broad, including denial, the focusing on and the venting of emotions, the positive reinterpretation of events, and seeking out social support (31). To our knowledge, there are no studies on the use of emotion-focused coping strategies with contact isolation in a hospital setting.

Studies show that the use of coping strategies changes over the course of life (32),(33),(34),(35, 36). Folkman and Lazarus's (21) transactional model of stress and coping propose that age differences in coping strategies could be the result of changes in what people must cope with as they age. According to other studies on the relationship between age and coping, younger adults use more problem-focused coping strategies and older adults use more emotion-focused coping strategies (16), (34), such as distancing oneself from a negative event (18). This could be related to the fact that increasing age is usually associated with increased chances of chronic diseases such as cancer, cardiovascular disease, Alzheimer's disease, Parkinson's disease, arthritis, diabetes, and obesity (37). In addition, older adults may have the advantage of years of experience and wisdom (38).

Due to the COVID-19 pandemic, many older adults have had to experience a contact isolation situation in a hospital setting. To our knowledge, no study to date has been performed that considers how and why the care situation for older adults during a pandemic in a contact isolation hospital setting triggers coping strategies. We performed a study on this specific care situation for older adults using the realist evaluation approach in order to improve care processes and the care environment. Realist evaluation was chosen as a research approach as it is designed to answer the why and how questions regarding the coping behavior of older adults while also taking into account the specific care context of the contact isolation situation in a hospital setting.

2. Materials and Methods

A qualitative study was performed to explore the experiences of older adults in a contact isolation setting and to identify the coping mechanisms applied. First, the theoretical framework based on realist evaluation is described, followed by the program theories. Thereafter, the selection of the participants, the interview, and the analysis are described.

2.1 Theoretical Framework

This study was informed by the realist evaluation approach (39). Realist evaluation is a theory-driven method and examines what works for whom, in what context, to what extent, how, and why (39). A realist evaluation describes not only the intervention and its outcome (O), but also the context (C) and the underlying mechanism (M). This is performed by discerning the psychosocial mechanisms (not directly observable and which include preferences, reasoning, norms, or the collective belief of people) that trigger intervention outcomes (changes to people and to their lives, which also includes other kinds of alterations) in specific contexts (including elements such as the organisational context, participant features, staffing, and the geographical and historical context of implementation)[(40)]. In the current study, the intervention was the contact isolation setting, the context was the hospital setting during a pandemic, the mechanisms were the coping strategies used by older adults, and the outcome was the influence of the use of coping strategies on the physical and psychological wellbeing of older adults.

A realist evaluation begins with the formulation of the theory behind the development of an intervention, known as the initial program theory. The function of the initial program theory is to describe and explain, as much as possible, how and why the program (i.e., the intervention) may be working for some people and not others, depending on which mechanisms are or are not triggered in specific contexts. The program theory is formulated on the basis of previous research and/or knowledge and the experience of stakeholders involved in the intervention. At the start of this study, scientific literature about contact isolation (in a hospital setting), coping strategies, and coping strategies used by (older) adults were searched, synthesised, and discussed between the first author (J.B.) and the last author (A.D.R.). Based on this process, the initial program theories were established (see Table 1). Realist evaluation involves theory testing and refinement; therefore, the results found during this study were used to refine the initial program theory (41). RAMESES II reporting standards for realist evaluations were followed (42).

Table 1 Initial program theories

Context	Mechanism	Evidence	Outcome
Problem-focused coping strategies			
If older adults experience contact isolation in a hospital setting during a pandemic problem-focused coping strategies could be triggered by:	1. approach of staff: via the mechanisms: • personalised approach • Provision of information to the patient	(23),(26, 30)	This will impact their physical and psychological wellbeing
	2. a sense of control over their: - health situation - isolation situation - day-to-day living in isolation via the mechanisms: A. shared decision making B. providing (1) personal items or (2) a single room	A (27) B (4),(23),(24),(25),(27),(28),(29)	
Emotion-focused coping strategies			
If older adults who experience contact isolation in a hospital setting during a pandemic and use emotion-focused coping strategies like:	1. trust in staff	(30),(43)	This will impact their physical and psychological wellbeing
	2. positively evaluating conflict situations	(31)	
	3. seeking support from family/friends	(31)	
	4. increasing impulse control	(44)	

2.2 Participants

Respondents were approached by a doctor in the outpatients' clinic for post COVID-19 patients approximately 6 to 8 weeks after being discharged from the hospital. In total, 221 patients were eligible for participation; 156 patients agreed to be contacted by the researchers were invited for an interview and received written information. Of these, 138 patients provided their informed consent, and 32 patients agreed to give an interview. Of those 32 participants, 21 participants met all the inclusion criteria for the current study. The following inclusion criteria were used to select participants for this part of the study: (1) 55 years or older; (2) capable of verbally communicating in Dutch; and (3) a minimum stay of two days on the COVID-19 ward. Patients were excluded from the study if they were admitted to the intensive care ward (receiving more than 25 L of oxygen per day) or if they were diagnosed with dementia. Patients who experienced a delirium during hospitalisation were included unless the researchers concluded that their memories were too limited, making them unable to answer the questions.

All the interviews were conducted by one researcher (V.P.v.D.) who was coached and supervised by the two last authors (L.M.W.N.-v.V., and A.D.R.). Interviews were conducted by telephone and took place between June 2020 and September 2020. Informed consent was initially given verbally (by phone) and confirmed at the time of the interview. Sociodemographic data were obtained from the participants' electronic patient files.

2.3. Data Collection Setting

Semi-structured interviews with older adults focusing on the patients' experiences of COVID-19 care were conducted in a multidisciplinary teaching hospital in the southern part of the Netherlands. At the start of the COVID-19 pandemic, the outbreak was the most severe in this part of the Netherlands (45). This hospital is one of the largest in the region with 630 beds (46). The current study concerned a secondary data analysis of data collected for a larger study, 'Consequences of COVID-19 care'.

2.4. Interview

Semi-structured interviews were performed using an interview guide including optional probing questions for clarification to explore the experiences of the respondents receiving COVID-19 care in contact isolation in the hospital. The interviews lasted between 35 and 90 min. The interview guide was based on the four constructs of the framework for person-centred nursing, which describes prerequisites for person-centred practice (47) and on the taxonomy of patient preferences for patient-centred healthcare (48). The topics of the framework for person-centred nursing are: (1) the attributes of the nurse (professional competence, interpersonal skills, commitment to the job, and personal characteristics); (2) the care environment (the context in which care is delivered); (3) person-centred processes (caring as perceived by patients and including providing for patients' physical and psychological wellbeing needs); (4) the results of effective person-centred nursing (feeling of wellbeing (affective and physical), patient satisfaction, and the effect on the environment) [(47)]. The topics of the taxonomy of patient preferences are: (1) Patient Uniqueness (individual human beings with their own life stories, history, culture, and backgrounds); (2) Patient

Autonomy (personal decision to participate in decision-making or not); (3) Professional Compassion (personal touch/disclosure); (4) Professional Professionalism (open to reflection and professional collaboration); (5) Professional Responsiveness (committed and responsible execution of care); (6) Interaction Partnership (involvement in planning and (shared) decision making); and (7) Interaction Empowerment (ability to contribute to self-management and trust) (48). The questions were designed to uncover the open feelings and thoughts of respondents regarding their experience with COVID-19 care in the contact isolation situation, without a direct relationship with the initial formulated program theories. All interviews were recorded and transcribed verbatim. Table A1 provides the translated semi structured interview guide.

2.5. Analysis

Only the parts of the interview that referred to the contact isolation situation were analysed. Interviews were audiotaped, transcribed, and analysed applying the Context–Mechanism-Outcome configurations (CMO configurations) as the analytical tool (49),(50). Identifying essential similarities and differences between experiences of older patients enabled the grouping and aligning of CMO configurations to identify patterns guided by the following questions: what had an impact on patients' physical and psychological wellbeing (outcome)? What (if possible, which coping strategies) caused these effects (mechanisms)? What where the isolation circumstances when these effects occurred (context)? The goal of the analysis process was to identify CMO configurations that underpin the initial program theories about coping strategies used by (older) adults in an isolation setting and to identify CMO configurations that may lead to new insights about coping strategies and changes in the initial program theory. The transcripts were imported in the qualitative data analysis software program Atlas-Ti for data analysis (51),(52),(53). Based on the initial program theories, a code tree was drafted by JB on possible coping strategies. Coding was based on the link between context-mechanism-outcome and the performed or intended coping strategies. Researchers (J.B. and A.S.) independently coded two interviews and discussed differences in interpretations to establish and refine the code tree. Thereafter, the first author coded the remaining interviews independently and discussed the sections which she was not certain how to code with the second author. To increase the inter-researcher reliability, a check was performed by the second author. She independently coded two and randomly selected other transcripts during the coding process of the first author and the coded sections were compared. After discussion, extra codes that had emerged from the data were added. The main findings were discussed by the first two authors and a structure was determined to report on the main findings.

2.6. Ethics

The study was approved by the Medical Research Ethics Committee Brabant (MREC Brabant) (NW2020-42). Participants were given both written and verbal information about the study, including the purpose, confidentiality of interviews, the voluntary nature of participation, and the opportunity to withdraw at any time. Interested participants took part after providing verbal consent at the beginning of the interview.

3. Results

The results section starts with the description of information on the setting and respondents, presented in Table 2. This table provides an overview of the two settings which were studied, the Suspected COVID-19 Ward and the Cohort COVID-19 Ward. In the results, the specific setting was identified but no comparison between the two settings was made. Twenty-one older adults participated in the present study; their background characteristics are provided in Table 3. Thereafter, the findings are described in detail following the structure of the initial program theories.

Table 2 Description of the setting

Suspected COVID-19 Ward	Cohort COVID-19 Ward
Admission: Patients were awaiting the results of the COVID-19 test. After the diagnosis had been determined, the patient was transferred either to the cohort ward or regular wards.	**Admission:** Patients who tested positively for COVID-19
Average stay: 24 h	**Average stay:** 6 days
Room situations: (1) A single room with a dedicated bathroom. The room door had to remain closed, and the patient was not allowed to leave the room. Some single rooms had a staff entrance and changing room before the room. If the room was not equipped with a staff entrance the staff had to put on safety clothing in front of the room prior to entering. (2) A single room with a bathroom located in the hallway. The patient could leave the room to go to the bathroom but had to wear a face mask.	**Room situations:** Depending on availability, patients were placed in a single or a shared room. A staff entrance and changing room was at the entrance to the ward. The doors of the patient rooms could be left open. Patients could move more freely in the locked ward.
Staff dress code: Both on the suspected and cohort ward, all medical and cleaning staff wore protected disposable clothing on top of their normal work clothes including: a hair net, latex gloves, mouth-nose-masks (FFP2), goggles, and protective clothing.	

Table 3 Baseline characteristics of the study participants (*n* = 21).

Characteristics	Categories	n (%)
Sex	Male	14 (66.7)
Female	7 (33.3)	
Age (Years)	55–59	7 (33.3)
60–69	6 (28.6)	
70 and older	8 (38.1)	
Education	Low	4 (20)
Middle	8 (40)	
High	8 (40)	
Length of stay (days)	2–4	7 (33.3)
5–7	9 (42.9)	
8–10	3 (14.3)	
>11	2 (9.5)	

3.1. Problem-Focused Coping Strategies

3.1.1 Approach of Staff

One of our program theories focuses on the approach of staff. We studied two existing mechanisms on the approach of staff which were already distinguished in the literature: (A) staff personalised approach and (B) provision of information to the patient. Additionally, two new mechanisms came to the fore: (C) professional competence of staff and (D) the provision of information by staff to family members.

(A) Staff personalised approach

We hypothesised that a personalised approach of staff could be an important mechanism for coping among older patients. We found four explanations for this theory. First, patients on the suspected and on the cohort ward explained that they noticed that staff spent time with—and paid attention—to them on a personal level. For example, staff did not only ask about the health of the patients but also how the patients were dealing with the whole situation of being in the hospital. This made the patients feel that they were being treated as people rather than numbers. Second, on some occasions, both on the suspected and on the cohort wards, staff would sit at the patients' bedsides to talk with them about their feelings or reassure them when they were feeling emotional. For example, on one occasion on the suspected ward, a staff member just sat next to the patient who expressed feelings of panic. Just by being present, the staff member reassured the patient and the patient's breathing returned to normal.

'I was so short of breath and of course I was lying alone and then she sat with me for an hour, really for an hour. Then she sat with me, just sat, I was lying down [on the bed] of course........I was short of breath, she said nothing else, just sat, just being there, that was already quite something. I liked that.' (Respondent 5 suspected ward).

Third, staff took their own initiatives for (care) tasks and sometimes performed extra tasks besides the usual work, which patients did not expect. Several patients on the cohort ward explained that staff provided them with food and drink without them asking for it. Additionally, one patient provided the example of a care professional who printed out photos of the patient's relatives and put them up in the patient's room. This made the patient feel seen as a person. The fourth example of personalised approach was staff starting reciprocal conversations with patients about topics not related to caregiving, such as conversations about their children or hometown.

Explanation of the coping: staff spent time with—and paid attention to—patients on a personal level, they took time to sit at the bedside to talk with the patients, they took their own initiatives with regard to (care) tasks, and had reciprocal conversations with patients about topics not directly related to caregiving (mechanism). This personalised approach made individual patients feel treated as a person (coping).

(B) Provision of information to the patient

One of the hypotheses based on the coping literature concerned the provision of information by staff. This could be an important mechanism for coping strategies of older patients because it provides patients with certainty and/or an understanding of the situation. The findings confirmed the relevance of information provision for the coping mechanisms of patients in the cohort ward. Open and honest communication by the staff about the medication and about the health circumstances (e.g., level of oxygen, relapse in health condition) of the patients gave patients a feeling of trust. Although this open style of communication was not always felt to be pleasant or easy to hear by the patients, it helped them to understand the situation.

‘Interviewer: And the doctor had also said to you: we can’t do anything for you. Respondent: Yes. Interviewer: How did you feel about the doctor saying that? Respondent: Well, (…) that came across in a harsh way. (...) Interviewer: And how did you experience that? Respondent: Yes, he said it, and he explained it. So that was a shock (…) but it was also immediately explained, and I understood it. So, it was a shock for a moment and then it was over.’ (Respondent 1 cohort ward).

Explanation of the coping: open and honest communication by the staff about the (health) circumstances of the patients (mechanism) gave the patients a feeling of trust and helped them to understand the situation (coping).

(C) Professional competences of staff

A new mechanism regarding the approach of staff was found during the data analysis which was not yet identified in the literature. Patients in the suspected ward and in the cohort ward explained that they relied on the professional competences of the staff, related to two specific approaches. First, several patients reported that the staff were conducting their work in a very professional way (e.g., in a very routinised and competent, self-aware way of operating, showing significant commitment) and second that staff members were keeping a close eye on the patient by taking regular measurements (e.g., asking patients how they felt and measuring blood pressure and oxygen level). This made the patients feel closely monitored by professionals and, therefore, safe.

‘And they performed all the various measurements, so sometimes about five times a day they came by to measure this, measure that, and that gave a certain, yeah a safe feeling, you thought you were well monitored.’ (Respondent 21 cohort ward).

Explanation of the coping: professional competences of staff and regularly monitoring checks upon the patients (mechanism) made the patients feel looked after and safe (coping).

(D) Provision of information from staff to relatives

Another new mechanism regarding the approach of staff was found during the data analysis: the regular contact with—and information provision to—relatives. Patients on the cohort ward mentioned that the staff had daily contact with their relatives about their health situation and to arrange the delivery of personal items. It was comforting for the patients to know that their relatives were informed regularly, especially because some patients were not able to contact their relatives themselves due to the condition of their illnesses.

Explanation of the coping: awareness that of the fact that relatives were kept up to date about the health situation of the patient by the care professional who also made practical arrangements (mechanism) made the patients feel reassured and comfortable (coping).

3.1.2. Sense of Control

One of our theories focuses on the control that patients have over their health, isolation situation, and day-to-day living situation. We looked to two existing and two new mechanisms of this approach for the use of problem-focused coping strategies of older patients: (A) patient involvement in decision-making by staff; (B) patients taking the initiative on shared decision making (a new mechanism); (C) the provision of personal items or a private room; and (D) the increased recognisability of staff (a new mechanism).

(A) Patient involvement in shared decision making

Both patients from the suspect ward and from the cohort ward described situations in which they were included in decisions regarding day-to-day living situations. In one instance, a patient on the suspect ward wanted his bed to be placed in a different direction. In another instance, a patient on the suspect ward wanted to sit on a chair. In both instances, the staff responded to their needs; the bed was replaced, and a chair was brought to the room. Patients of the cohort ward also gave examples of staff actively asking them about the light settings or about placing photos of their relatives in the room. This would make the patients feel more at ease.

On the cohort ward, staff included patients in decision making for both medical or disease-related decisions (e.g., health status changes, increase or decrease in oxygen supply) and preferences regarding quality of life (e.g., diet choices, timetable, and activities related to physical care). An example showed the importance of communicating clinical guidelines to patients. In one instance, the patient wished for an extra opiate to relieve the pain which was not given by the staff with the explanation that a certain schedule was retained. The explanation helped the patient understand why his wish was not granted. On the suspected ward, very few examples of including patients in decision making regarding their health and isolation situation were found. Explanation of the coping: when staff included patients in decision making regarding their health or regarding day-to-day living situations through explanation or by actively asking patients about their preferences (mechanism), this could make the patients feel in control of health or day-to-day living situation (coping). Conversely, some patients trusted staff and relied on them to make decisions about their health without expressing the need to be in control of their own health situations.

(B) Patients taking the initiative on shared decision making

A new mechanism regarding sense of control was found during the data analysis: patients on the cohort ward occasionally took their own initiative to be included in decisions regarding their own health. Patients asked staff for information regarding their own health (e.g., to provide them with information regarding health procedures or if they could be discharged earlier) and asked staff to perform tasks like measuring their oxygen saturation or providing extra nutria drinks. This made the patients feel as they were taken seriously by the staff and made them feel listened to.

'I say: please take the ears. Then they [the staff members] took the fingers and the ears (...) [For measuring the oxygen level in the blood] So of course I had a say in that. Interviewer: And how was this responded to by the care professionals Respondent: Right away. They also did it right away and they also looked at it and yes, it was just well responded to. Interviewer: And what kind of feeling or idea did that give you? R: Well, also a safe feeling. They listen to me.' (Respondent 10 cohort ward).

Explanation of the coping: when patients indicated a desire to be included in decision making regarding medical decisions by requesting staff for information or requesting specific care tasks and when staff respond to these requests (mechanism), this made the patients feel in control of their health situations.

(C1) Provision of personal items

During their stay at the suspect ward and the cohort ward, the patients described situations in which they felt more at ease because they had access to personal items, like a tablet, laptop, or a television. This made their stay less monotonous, because they were in control over what they wanted to see and hear. For the patients in a single room, personal items like the television and the tablet gave them the opportunity to turn on music when they felt the need to do so. Patients sometimes used the video conference option on their devices; this is described in more detail in the emotion-focused coping strategy ‘seeking support from family and friends’.

Explanation of the coping: when patients have access to personal items (mechanism) they could have more opportunities to control their day-to-day living situation in an isolation situation because they are in charge of what they wanted to see or hear (television, tablet, laptop).

(C2) Provision of a single room

The preconceived situation in the hospital where this study took place was that patients on the suspect ward would be placed in a single room and that patients on the cohort ward would be placed in a room with more persons. Several patients on the suspect ward were content with the single room because they were very ill and appreciated the calm environment. Some patients thought it was a normal procedure in case of an infectious disease and had no trouble with this situation. One patient expressed feelings of loneliness.

The patients of the cohort ward described positive and negative responses towards a shared room. A positive effect was the support and company of other patients. A negative effect was not having a calm environment and also sometimes experiencing frightening situations with other patients (e.g., patients who were suffering from breathing troubles or patients who were passing away). The theory that a single room could help older patients cope with a contact isolation situation could not be confirmed by our findings nor could it be refuted.

Explanation of the coping: the benefits of having a single room could be related to the preferences of the patient. If a patient preferred a single room (mechanism), this created a calm environment for the patient in which they could focus on their own health (coping). However, when a patient did not prefer a single room, this led to loneliness.

(D) Increased recognisability of staff

A new mechanism regarding sense of control came to the fore. Patients from the suspect ward and from the cohort ward explained that the protective clothing (apron, gloves, mouthguards, hairnet, goggles) of the staff made patients feel uncomfortable. The staff were difficult to recognise which made it difficult to connect with the staff and caused the care to be perceived as anonymous. The patients on the cohort ward observed that some staff wore name tags or a photo of themselves on their clothing to increase recognisability. This made it easier for patients to see the person behind the clothing and connect with staff.

Explanation of the coping: if staff dressed in protective clothing could be less anonymous by wearing name tags or photos of themselves (mechanism), this could help patients to recognise and connect with the staff members who were helping them (coping).

3.2. Emotion-Focused Coping Strategies

3.2.1. Trust in Staff

One of our program theories was that if older adults felt confidence in the staff, this would help them cope better with the isolation situation. We found four explanations for this theory. First, patients did indeed state that they felt very confident because the hospital was the best place for them to be cared for. Second, this feeling was enhanced because patients felt closely monitored and regularly checked on each day. Third, feelings of trust were increased when staff paid attention to the circumstances of patients and when staff discussed and agreed on the treatment with the patient. Fourth, trust seemed related to the availability of staff, and patients indicated that staff members were easily reached when they called or asked for help.

'I just felt confident in the fact that they were keeping everything under control [the staff members] and were monitoring me very closely in all kinds of ways. That gives you confidence, that you are being treated well and that you are in good hands.' (Respondent 8 cohort ward).

Some of the patients, a number of whom felt very ill, took a more indifferent attitude: they let staff decide for them because they were confident that the best choices would then be made.

'I was like yes it has to happen anyway so yes they will know. So, that's just because I didn't know myself so, and yes I don't know, yes I just let it happen, they know what they are doing' (Respondent 9 cohort ward).

Explanation of the coping: professional care provision, regular monitoring, attention of staff, and the availability of staff (mechanism) contributed to feelings of trust in the patients (coping).

3.2.2. The Positive Evaluation of (Conflict) Situations

One of our program theories was that if older adults could positively evaluate conflict situations, this would help them cope better with their isolation situation. We did not find support or explanations for this theory in our findings.

3.2.3. Seeking Support from Family and Friends

One of our program theories focuses on the support for patients by their family and friends. One existing and one new mechanism came to the fore: (A) seeking support from family/friends and (B) seeking support from fellow patients (a new mechanism).

(A) Seeking support from family/friends

Patients from the cohort wards described that contact with family and friends for support via their own mobile telephone and the opportunity to consult with family and friends gave them strength and reassured them. Patients sometimes used the video conference option. This made them feel less isolated and lonely. However, some patients also explained that they were feeling ill and that having contact with friends or family was too exhausting.

Explanation of the coping: being able to contact family and friends via a mobile device for support and to consult with family and friends (mechanism) gave patients strength, reassured them, and helped the patients to feel less isolated and lonely (coping).

(B) Seeking support from fellow patients

Some patients from the cohort ward were placed in a room with more people, leading to the emergence of a new mechanism. Patients reported that contact with fellow patients gave them the opportunity to talk about the situation and to realise that they were not the only one in the contact isolation situation.

'*Interviewer: And what kind of feeling did that give you? R: Yes, some peace, that you are not the only one, that you are not alone.' (Respondent 5 cohort ward).*

Explanation of the coping: contact with fellow patients, which provides an opportunity to talk about the situation (mechanism), helped patients realise that they were not the only one in the contact isolation situation (coping).

3.2.4. Increased Impulse Control

One of our program theories focuses on older adults having increased impulse control. We did not find support or explanations for this theory in our findings.

3.2.5. Acceptance and Rationalisation

A new program theory came to the fore. Acceptance and rationalisation were used as coping strategies by older adults in a contact isolation setting. Patients were able to put their situations into perspective. Some patients showed signs of resignation.

Many patients from both the suspected ward and the cohort ward explained ways in which they used acceptance and rationalisation as a way of coping with the situation. For example, some patients indicated that they understood that the staff had to wear protective clothing and therefore they accepted the consequences of these dress codes, namely the care professional being less recognisable. A second example was that patients indicated that they were affected, but they went beyond that negative feeling. For example, people indicated that they were aware of the fact that they were not allowed to leave the ward, but that they had to accept that situation.

'You're located in a ward with large doors at the front of it, and red barrier tape and I didn't feel confined though, but I mean you're of cours, isolated, from the rest of the world. Interviewer: And what kind of feeling did that give you? Respondent: Yes, I am a man of freedom, so that is not pleasant, but on the other hand, there's just no other way, it has to be this way, so that is resignation of some sort.' (Respondent 3 cohort ward).

A reaction which was also frequently identified was people reacting indifferently to the contact isolation situation. They indicated that they were too ill to be concerned about the consequences of contact isolation.
Explanation of the coping: by using acceptance and rationalisation (mechanism), patients understood the situation or accepted the negative feeling (coping).

3.2.6. Downwards Comparison

Another new program theory that was found during the analysis concerned downwards comparison. A few cohort patients explained they were stimulated to think more positively about their own situations because they were confronted with other patients who were in worse conditions compared with their own situations:

'I thought, when I see them [other patients] lying there and they are getting even sicker. I thought to myself: boy, you shouldn't be grieving at all because there are patients who are in a much worse condition then you are, so move on!' (Respondent 11 cohort ward)

Explanation of the coping: downwards comparison (comparing themselves with patients who were in worse condition) (mechanism) stimulated patients to think more positively about their own situations (coping).

Table 4 provides an overview of the program theories about coping strategies in this specific context and setting.

Table 4 Overview of the program theories about coping strategies in this specific context and setting

Context	**Mechanism**	**Explanation**	**Confirmed ***	**Outcome**
	Problem-focused coping strategies			
If older adults experience contact isolation in a hospital setting during a pandemic problem-focused coping strategies are triggered by:	1. *approach of staff*: via the mechanisms: A. personalised approach B. Provision of information to the patient C. NEW: Professional competences of staff D. NEW: Provision of information from staff to relatives	A. Attention to patients on a personal level; taking time to sit on or next to the bed of the patients to talk with them about their feelings of reassure them - Providing own initiative for (care) tasks, reciprocal conversations with patients about topics not related to caregiving	✓	This will impact their physical and psychological wellbeing
		B. - Open and honest communication by the staff about the (health) circumstances of the patients	✓	
		C.- Professional approach of staff and regularly checking upon the patients	✓	
		D. - The awareness that relatives were kept up to date about the health situation of the patient by the staff	✓	
	2. are given a *sense of control* over their: -health situation -isolation situation -day-to-day living in isolation via the mechanisms: A. shared decision making B. NEW: Patients taking initiative for shared decision making C. Providing (1) personal items or (2) a single room D. NEW: increased recognisability of staff	A. - The patients feel in control of their health or day-to-day living situation - The patients understand the isolation situation	✓	
		- Conversely, some patients trusted and relied on the staff with decisions about their health, and did not express the need to be in control of their own health situation	~	
		B. The patients feel in control of their health or day-to-day living situation - Staff listen to the needs of patient - Staff try to actively involve patients	✓	
		C. 1. Personal items: patients have more opportunities to control their day-to-day living situation because	✓	

		they are in charge of what they wanted to see or hear. 2. Single room: this theory could not be confirmed or refuted by our findings - Positive: create a calm environment for patients in which patients could focus on their own health - Negative: loneliness D. Staff could be less anonymous by wearing name tags or photos of themselves on their clothes	~ ✓	
	Emotion-focused coping strategies			
If older adults experience contact isolation in a hospital setting during a pandemic and use emotion-focused coping strategies:	1. trust in staff	- professional care provision; - regular monitoring; - attention of staff; - availability of staff	✓	This will impact their physical and psychological wellbeing
	2. positively evaluate conflict situations	No explanation	–	
	3. seeking support via the mechanisms: (A) seeking support from family/friends (B) NEW: seeking support from fellow patients	A. Give patients strength and reassure them - Patients feel less isolated and lonely B. Realisation that the patient is not alone	✓ ✓	
	4. increased impulse control	No explanation	–	
	5. NEW: Acceptance and rationalisation	- Patients understand the situation - Patients can get past the negative feeling	✓	
	6. NEW: Downward comparison	- Stimulated patients to think more positively about their own situation	✓	

* ✓ = Theory confirmed; ~ = Theory could not be confirmed nor be refuted; – = Theory not confirmed

4. Discussion

This study revealed that both emotion-focused coping strategies as well as problem-focused coping strategies were used by older adults during contact isolation. Moreover, this study also provided insight into the specific ways in which older adults used problem-focused and emotion-focused coping strategies in contact isolation situations in a hospital setting.

This study showed that the coping strategies of the respondents were related to the behaviour of different groups of people. Some of the emotion- and problem-focused strategies were related to the behaviour of the patients themselves (problem-focused: patients taking the initiative for involvement in shared decision-making and emotion-focused: acceptance and rationalisation and downwards comparison). Other strategies were specifically related to staff behaviour (problem-focused: approach of staff and shared decision making and the emotion-focused: trust in staff). Emotion-focused coping strategies were also related to the behaviour of other groups, specifically relatives and fellow patients (support of family and relatives and support from fellow patients).

Coping strategies related to staff behaviour are important in order to improve the physical and psychological wellbeing of older adults in contact isolation in a hospital setting. The basis of these types of coping strategies is the reciprocal relationship between patients and staff members. Staff members are able to influence the use of these coping strategies. This influence is made visible when the program theories related to staff behaviour are compared with the framework of person centred-nursing (47) and of the taxonomy of patient preferences (48). The program theory: the approach of staff is reflected in the construct of nurse attributes from the framework and in the constructs of the taxonomy, specifically Professional Responsiveness, Professional Professionalism, and Professional Compassion. All these constructs emphasise the importance of interpersonal skills and professional skills of the staff members providing person-centred care. Shared decision making is reflected in the construct of person-centred processes from the framework and in the constructs Patient Autonomy and Interaction Partnership from the framework. These constructs include communicating with the patient and sharing decision-making as an important element for providing person-centred care. The program theory trust in staff is reflected in the construct of person-centred processes from the framework and in the constructs Interaction Partnership and Interaction Empowerment from the framework. These constructs include elements that could improve the relationship between patients and staff members because staff members are providing for patients' physical and psychological wellbeing needs. In other words, activities of staff members that qualify as person-centred care could also stimulate the problem-focused coping strategies of older adults when they are in a contact isolation situation in the hospital. Person-centred care for (older) patients is increasing in popularity and importance [(54)]. The current study contributed to this development by demonstrating that the coping strategies of older adults in a contact isolation situation in a hospital are also stimulated by person-centred care.

The findings showed that trust in staff is an important emotion-focused coping strategy. However, staff should be aware of the imbalances of power and invite patients openly for shared decision-making regarding healthcare decisions. Several studies address the imbalances of power in nurse-patient relationships that could increase the vulnerability and dependency of the patient (55),(56),(57). Other studies showed that trust is an essential component of the relationship between staff and patients (30),(43),(58). Moreover, the literature about the patient-staff relationship usually explains the fact that if patients trust staff, they are also better able to express themselves (59),(60). However, the current study results showed the opposite: because patients trusted staff members, they did not feel the need to be included in decisions. This extra dimension might be a relevant finding to consider in possible imbalances of power.

The strategy of acceptance and rationalisation was often mentioned in the findings. In a different study regarding acceptance as a coping strategy (61). Two forms of acceptance as general coping reactions were studied. First, active acceptance (acknowledging a negative, difficult situation and dealing with it in a constructive way) had a positive effect. Second, resigning acceptance (not only to stop controlling the actual situation, but becoming passive in other areas of life as well) had a negative effect. The findings of the current study also suggested that older adults who showed active acceptance (acknowledging the contact isolation situation as a difficult situation but dealing with it in a constructive way) could cope with the isolation situation. This might support the findings of previous studies showing that older adults are better capable in their ability to control emotions (18),(62).

In addition to the emotion-focused coping strategy of seeking support from family/friends, the strategy to seek support from fellow patients is a new one derived from our study's findings. Traditionally, in contact isolation settings, patients are usually placed in a single room (3). This could cause feelings of loneliness (3),(63). The current study revealed that an isolation situation in which patients are placed together might stimulate the use of an emotion-focused coping strategy, as the contact among patients might provide some distraction and opportunities for conversation. However, a shared room could lead to other problems like patients not having a calm environment and frightening situations like critically ill patients passing away. Therefore, it could be important to select those patients who are not too ill to be placed in a shared room (e.g., if the state of their illness is not too stressful for other patients).

4.1. Strengths and Limitations

This study had some limitations. In realist evaluation literature, an intermediate step is ideally included in which the initial program theories are discussed with stakeholders to verify them. Due to practical reasons, this check was not performed in the current study. Alternatively, the initial program theories are based on a thorough and extensive literature search on the use of coping strategies in (isolation) situations which supports the initial program theories in this way. Another limitation is that the study was conducted in one hospital. The inclusion of multiple hospitals could provide a more generic view on the care provided during the COVID-19 pandemic and the coping strategies used by older adults to cope with the contact isolation situation. A last limitation is that the study was based on patient experiences collected in retrospect on situations which took place three to five months prior to the interviews. The results could have been different if the older adults were interviewed during admission. This study provided unique insights and evidence as it reported on one of the toughest periods of the COVID-19 pandemic: just after the initial outbreak, when hospital care was under enormous pressure. Another strength is the thorough realist evaluation method used, as it is one of the first qualitative studies that provides explanations for why certain coping strategies work in contact isolation in a hospital setting.

4.2. Practical Implications

To improve the physical and psychological wellbeing of older adults in contact isolation in a hospital setting, it is important that emotion-focused coping strategies and problem-focused coping strategies are stimulated. Problem-focused coping strategies can be stimulated through staff performing care in a person-centred way, including taking the time to listen to patients, providing sufficient information, exercising shared decision making, and by increasing the recognisability of staff by adjusting clothing or by using a photo or a name tag. Emotion-focused coping strategies are more difficult to stimulate because they relate to intrinsic strategies to regulate one's emotions of stress. Trust in staff can be stimulated by improving the relationship between patients and staff. However, future studies and implementation of the strategies may reveal whether these strategies are applicable and workable in other hospitals and target populations under isolation circumstances.

5 Conclusions

This study reported on coping strategies studied in a unique contact isolation situation in a hospital setting caused by the COVID-19 pandemic, which was explored just after the direct outbreak. Explanations of concrete applications of coping strategies were found through the use of realist evaluation. This study adds to previous literature which found that emotion-focused coping strategies are also used by older adults in this specific situation and provides new insights in the use of problem-focused coping strategies in this specific setting. In particular, problem-focused coping strategies can be stimulated through staff performing care in a person-centred way. Emotion-focused coping strategies are more difficult to stimulate because they are intrinsic strategies used by patients to regulate stressful emotions. Nevertheless, trust in staff is an emotion-focused coping strategy that could be stimulated by improving the relationship between patients and staff. These findings can be implemented by hospital staff to improve the wellbeing of older adults in contact isolation in hospitals in the future.

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Appendix A

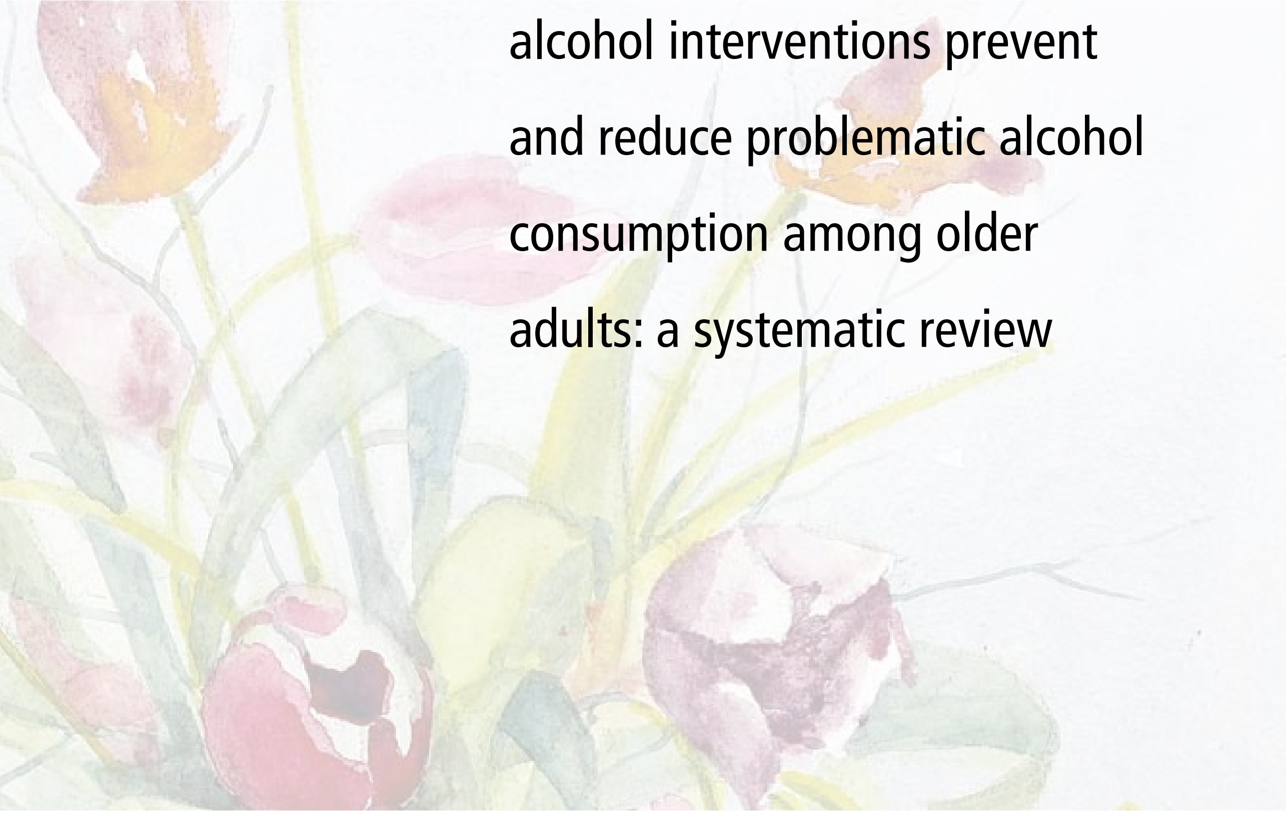
Table A1. Semi-structured interview guide.

	Semi-structured interview guide
Admission:	- You were admitted to the hospital with symptoms. Could you tell me how your admission went and how you experienced it?
Closer look at health care providers (e.g., medical specialists nurses and paramedics)	- How did you experience the contact between you and the care professionals *(Creating a therapeutic culture)*? - How would you describe the skills of care professionals (including professional, information provision, commitment/motivation, conversation skills)? (Appropriate skill mix) *(Professional Competent)* and *(professional professionalism)* and (professional responsiveness) *(Interpersonal Skills) and (professional professionalism) (Commitment to the job)* - To what extent were you involved (included/informed/ encouraged) to have a say in (e.g., treatment/medication) the care that was provided? (How did you perceive decisions made about your care within the care setting?) (Shared Decision making systems) *(Sharing decision-making) and (patient autonomy) (Having sympathetic presence) (professional compassion) (Clarity of Beliefs and values) and (Interaction Partnership) (Involvement with care)* (Interaction empowerment) (Effective staff relationships) (interaction partnership)
Care environment	- If applicable, how did you experience the COVID suspect ward and/or cohort ward? - To what extent was the environment (you were in) supportive? (Supportive organisational systems) - How did you experience the isolation measures that applied to your situation? (Potential for innnovation and risk taking) - How did you experience the hospital environment in which you were admitted?
Feelings during care moments	- What was your well-being (mental and physical) during the care moments (How did you feel)? *(Feeling of well-being)* - How did you experience the involvement of the care professionals? *(Engagement) (professional compassion)* - To what extent were your personal needs and your opinion considered? *(Working with patients beliefs and values) and (patient uniqueness)* - How was contact with your loved ones/how did you experience this? - How did you experience the rules regarding the visitation arrangements? - How did you experience the physical care provided by the care professionals (e.g., nutrition/care/nighttime/medication/oxygen)? *(Providing for physicial needs)*
Concluding questions on received care, consequences, discharge and tips	- Overall, how did you experience the care (and the care provided by the care professionals)? What did you like, and what did you dislike? *(Satisfaction with care) (Knowing 'Self')* - What effects/results did you experience from the care obtained? (outcomes) - How was your discharge procedure? (e.g., the provision of information)? How did you experience this? - What suggestions would you like to give the hospital?

SETTING 3

CHAPTER 6

Understanding how and why alcohol interventions prevent and reduce problematic alcohol consumption among older adults: a systematic review



Published as:
Boumans J, van de Mheen D, Crutzen R, Dupont H, Bovens R, Rozema A. Understanding How and Why Alcohol Interventions Prevent and Reduce Problematic Alcohol Consumption among Older Adults: A Systematic Review. *International Journal of Environmental Research and Public Health*. 2022; 19(6):3188. https://doi.org/10.3390/ijerph19063188

Abstract

Problematic alcohol use has been increasing in older adults (55+) in recent decades. Many of the effective interventions that are available to prevent or reduce the negative effects of alcohol consumption are aimed at adults in general. It is unclear whether these interventions also work for older adults. The objective of this review was to understand how (i.e., which elements), in which context, and why (which mechanisms) interventions are successful in preventing or reducing (problematic) alcohol consumption among older adults. A systematic review of articles published between 2000 and 2022 was performed using PubMed, PsycINFO, Web of Science and CHINAHL. Realist evaluation was used to analyze the data. We found 61 studies on interventions aimed at preventing or reducing problematic alcohol use. Most of the interventions were not specifically designed for older adults but also included older adults. The findings of the current study highlight three major effective elements of interventions: (1) providing information on the consequences of alcohol consumption; (2) being in contact with others and communicating with them about (alcohol) problems; and (3) personalized feedback about drinking behavior. Two of these elements were also used in the interventions especially designed for older adults. Being in contact with others and communicating with them about (alcohol) problems is an important element to pay attention to for developers of alcohol interventions for older adults because loneliness is a problem for this age group and there is a relationship between the use of alcohol and loneliness.

1. Introduction

The World Health Organization has identified alcohol-related harm among older adults as an increasing concern [1]. Researchers in biology often define old age as starting at the chronological age of 55+ because at that age changes in body systems become more evident [2,3]. Over recent decades, alcohol use among older people has increased in several countries, including Spain, the United States, and the Netherlands [4–6]. One reason for this is that older adults experience more freedom; that is, they have more time for leisure activities, such as attending social gatherings and participating in clubs, many of which routinely involve alcohol consumption [7,8]. Another reason is that some people use alcohol as a coping strategy to overcome negative changes in physical health and mental health that come with ageing [9–11], including increased loneliness and social isolation [12], unemployment and economic downturns [13]. In developing countries, alcohol use has been increasing in line with economic development and global marketing. The increased availability and affordability of alcohol among lower socio-economic groups has also played a role [1,14]. For developing countries, this is in line with increasing economic development, global marketing and the greater availability and affordability of alcohol among lower socio-economic groups [1,14].

The consumption of alcohol, even in small amounts, can cause greater harm among older than younger adults. Alcohol can accelerate and aggravate the onset of conditions associated with aging (e.g., falling hazards [15], cognitive impairment [16] and/or sleep disturbance [17–19]). Older adults often receive medication for these conditions. The use of alcohol alongside prescription medications, such as benzodiazepines for insomnia [20], leads to negative interactions, particularly because older adults metabolize and excrete alcohol more slowly [21,22]. The combination of alcohol and prescription medicines could lead to increasing alcohol levels in the blood, reducing the efficacy of medication and exacerbating its side effects [9,23].

The development of effective interventions to prevent or reduce alcohol use in older adults is crucial, not only because of the problems that alcohol consumption causes for older individuals, but also because of the increase in the number of older people. It is expected that, in 2050, one in six people worldwide will be aged 65 years or over [24]. As the population of older adults increases, so will the number of older people who have alcohol-related problems. First, prevention is needed because of the problems that alcohol causes in this group; second, the group of older adults is expanding, resulting in more alcohol-related problems.

Numerous effective interventions have been developed to prevent or reduce alcohol consumption, for example interventions carried out by general practitioners, brief interventions [25,26], psychosocial interventions (e.g., motivational interviewing [27]) and e-health interventions (e.g., web-based interventions [28] and smart phone interventions [29]). However, many of these interventions are aimed at adults in general and not specifically at older adults. It is unclear whether these interventions also work for older adults. Older adults were raised in a different period and may have different norms and values regarding drinking alcohol than young adults [30,31].

Two recent reviews on alcohol consumption among older adults have indicated that interventions to prevent or reduce the negative effects of alcohol consumption in older adults specifically are limited in number. Armstrong-Moore et al. [32] found seven interventions, of which five resulted in alcohol reduction. Kelly et al. [33] identified thirteen studies, of which six reduced alcohol consumption. Most effective interventions include elements of (brief) motivational interventions, (brief) advice or personalized reports on risks and problems. Moreover, it is known only whether the interventions are effective and not which elements of the intervention lead to this outcome or in which context and by which mechanisms. With this information more targeted interventions for alcohol use among older adults could be developed.

Objectives

To date, no overview is available showing *how* interventions to prevent or reduce alcohol use in older adults work and which are successful for older adults specifically. Therefore, we performed a literature review, following a realist approach, on interventions for (older) adults and extracted the elements of the interventions that were effective. When possible, we also explained why these elements were effective. To understand why an (element of an) intervention leads to the desired outcome, it is also important to understand the context in which the intervention is offered to the target group. Therefore, we also took the context into account. The objective of this review is to understand how (which elements of interventions), in which context and why (by which mechanisms) interventions are successful in preventing or reducing (problematic) alcohol consumption among older adults.

2. Materials and Methods

2.1. Realist Evaluation Approach

This literature review was informed by the realist evaluation approach. A realist evaluation describes not only the intervention and its outcome (O) but also the context (C) and the underlying mechanism (M) [34]. The context includes elements such as the organizational context, participant features, staffing, and geographical and historical context. Mechanisms are a combination of recourses offered by the (social) program or intervention and human understanding and/or responses to that recourse. Mechanisms are not directly observable and include preferences, reasoning, norms or collective beliefs. Outcomes include changes to people and to their lives, but also include other kinds of alterations (e.g., in organizations, workers or governments) [35]. In the current study, the *interventions* are the programs that help older adults to prevent or reduce their alcohol consumption successfully, the *context* is operationalized as the way in which the intervention is offered to the target group (e.g., digitally, by phone, in-person, individually or in a group setting), the *mechanisms* are the reasons why elements of the interventions work and the *outcome* is the prevention or reduction of alcohol consumption.

2.2. Search Strategy

A literature review of peer-reviewed articles published between 2000 and 2020 was performed in April 2020 and updated in February 2022 using PsycINFO, Web of Science (WOS), PubMed and CINAHL (see Table 1). This time span was chosen because the focus on older adults in relation to alcohol issues dates back to the beginning of this century [36]. A combination of five groups of keywords was used to search the databases. These groups of keywords consisted of search terms from all four databases: PsycINFO (thesaurus), Web of Science (no special terms), PubMed (MeSH terms) and CINAHL (heading terms). In addition, synonyms and free text words were used. Four search strings were formed based on the objectives of this review. Due to the scarcity of studies specifically about older adults, we chose to include two groups: a very wide range, which includes older adults (18+), and a specific age range, which only consists of older adults (55+). Table 2 provides an overview of the groups and keywords used. Table 3 provides a summary of the search questions. The review is reported according to PRISMA [37].

Table 1. Databases

Database	Limits
PsycINFO	Peer-reviewed journals, age group: adulthood 18+, English, Dutch, years 2000–2022
Web of Science (WOS)	Articles, publication years 2000–2022, English, Dutch [1]
PubMed	Adult: 19+ years, [2] publication years 2000–2022, English, Dutch
CINAHL	Peer-reviewed, publication years 2000–2022, English, Dutch [1]

[1] No limits for age were provided. Therefore, the word group "Not child" was used. [2] The only age limit that was provided was 19+.

Table 2. Groups of key words.

Group 1 Alcohol	alcohol or "alcohol consumption"
Group 2 Older adults	elder or elderly or senior or old or pension or retire or retirement or "later life" or geriatric or geriatrics or "older adults" or ageing or aging or gerontology or aged
Group 3 Reduction	intervention or treatment or reduction
Group 4 Prevention	prevent or prevention or preventing
Group 5 Not child	NOT child or "young adult" or teenage or adolescent

Table 3. Search strings

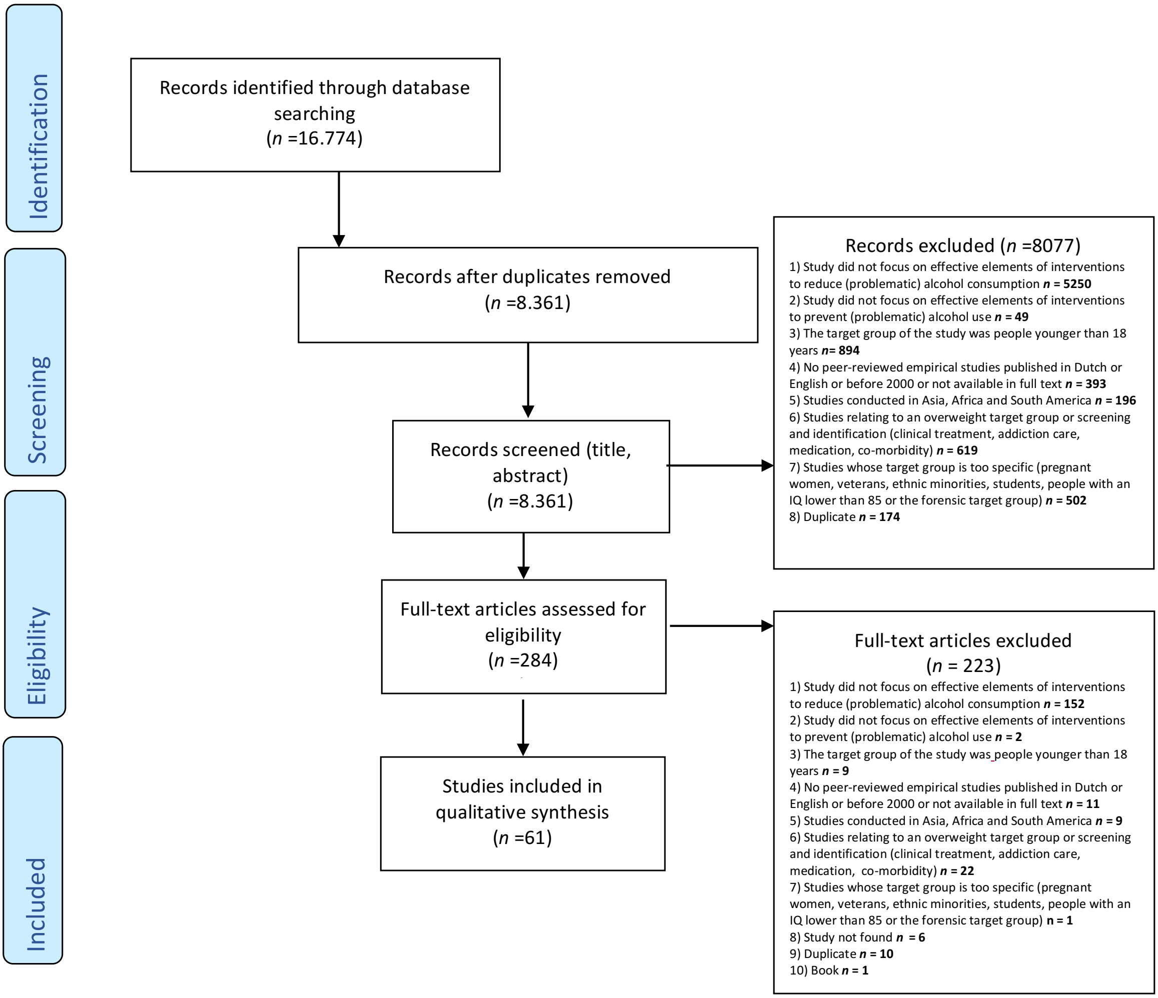
Search Questions	Groups of Keywords
What are the effective elements of interventions for the **general population** with regard to **reducing** (problematic) alcohol consumption?	1 (*title*) and 3 (*title*) not 5 (only for WOS (*topic*) and CINAHL (*title*)) * only for WOS (*topic*) and CINAHL (*title*)
What are the effective elements of interventions for **older adults (55+)** with regard to **reducing** (problematic) alcohol consumption?	1 (*title*) and 2 (*title*) and 3 (PsycINFO (*abstract*), WOS (*topic*), PubMed (*title/abstract*), CINAHL (*abstract*))
What are the effective elements of interventions for the **general population** with regard to the **prevention** of (problematic) alcohol consumption?	1 (*title*) and 4 (*title*) not 5 (only for WOS (*topic*) and CINAHL (*title*))
What are the effective elements of interventions for **older adults (55+)** with regard to the **prevention** of (problematic) alcohol consumption?	1 (*title*) and 2 (*title*) and 4 (PsycINFO (*abstract*), WOS (*topic*), PubMed (*title/abstract*), CINAHL (*abstract*))

2.3. Inclusion Criteria

The studies were selected with the following inclusion criteria: (1) studies that focused on interventions for outpatients to prevent or reduce (problematic) alcohol consumption and that mentioned effective elements; (2) the target group of the studies consisted of people aged 18 years or older; (3) peer-reviewed empirical studies published in English after 2000 and available in full text; and (4) studies conducted in Western high-income countries (e.g., Europe, North America, Australia and New Zealand). The exclusion criteria were the following: (1) studies aimed at inpatients; and (2) studies with a very specific target group (i.e., pregnant women, veterans (due to the specific approach of this group, often carried out by the military), ethnic minorities, students, people with an IQ lower than 85 or the forensic target group).

2.4. Study Selection

Based on the inclusion and exclusion criteria, titles, abstracts and full-text articles were screened by the first author (JB). The last author (AR) also screened 20% of all the records (titles, abstracts and full texts). The deviation was less than 10% in all three phases. In the case that JB had doubts about other articles than these 20%, AR was consulted. See Figure 1 for the flowchart of the selection process.



Records excluded (*n* =8077)

1) Study did not focus on effective elements of interventions to reduce (problematic) alcohol consumption ***n* = 5250**
2) Study did not focus on effective elements of interventions to prevent (problematic) alcohol use ***n* = 49**
3) The target group of the study was people younger than 18 years ***n*= 894**
4) No peer-reviewed empirical studies published in Dutch or English or before 2000 or not available in full text ***n* = 393**
5) Studies conducted in Asia, Africa and South America ***n* = 196**
6) Studies relating to an overweight target group or screening and identification (clinical treatment, addiction care, medication, co-morbidity) ***n* = 619**
7) Studies whose target group is too specific (pregnant women, veterans, ethnic minorities, students, people with an IQ lower than 85 or the forensic target group) ***n* = 502**
8) Duplicate ***n* = 174**

Full-text articles excluded (*n* = 223)

1) Study did not focus on effective elements of interventions to reduce (problematic) alcohol consumption ***n* = 152**
2) Study did not focus on effective elements of interventions to prevent (problematic) alcohol use ***n* = 2**
3) The target group of the study was people younger than 18 years ***n* = 9**
4) No peer-reviewed empirical studies published in Dutch or English or before 2000 or not available in full text ***n* = 11**
5) Studies conducted in Asia, Africa and South America ***n* = 9**
6) Studies relating to an overweight target group or screening and identification (clinical treatment, addiction care, medication, co-morbidity) ***n* = 22**
7) Studies whose target group is too specific (pregnant women, veterans, ethnic minorities, students, people with an IQ lower than 85 or the forensic target group) **n = 1**
8) Study not found ***n* = 6**
9) Duplicate ***n* = 10**
10) Book ***n* = 1**

Figure 1. Flowchart

2.5. Data Extraction and Analysis

A data extraction form was used, specifying the following information: author(s), title, publication year, study methodology, setting, participants and objective of the study (prevention or reduction), effective elements of the intervention, context, mechanisms and outcome (CMO). Data were extracted by JB and AR independently and discussed thereafter until consensus was reached. A realist evaluation approach was adopted to identify CMO configurations in each study where possible. These configurations described how contextual factors and mechanisms (human responses to elements of interventions or prevention strategies) led to the desired outcomes (prevention or reduction of alcohol consumption). For each study, one or more elements of interventions and/or one or more CMO configurations were drafted. The analyses were performed by JB and AR, focusing on the patterns across elements of interventions and the CMO configurations. The quality of the included studies was assessed using the Mixed Methods Appraisal Tool (MMAT Tool) [38]. The tool includes two screening questions and 19 items for appraising the methodological quality of five categories of studies: qualitative studies, RCTs, non-randomized studies, quantitative descriptive studies and mixed-methods studies. Each study category consists of five items. 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 (0 is low; 5 is high). The appraisal of all the included articles was performed independently by two researchers (JB and AR), and the results were compared; when inconsistencies were apparent, they were discussed until consensus was reached. Studies with a low MMAT score (2 or lower) were only used to support the results found in studies with an MMAT score of 3 or higher.

3. Results

3.1. Study Selection and Characteristics

We included 61 articles in our review. The characteristics of each included paper are presented in Table 4. A total of 33 studies were quantitative and randomized, 19 studies were quantitative and non-randomized, five studies were qualitative interviews, three studies were quantitative descriptive studies, one study was mixed methods. Of these 61 studies, three described interventions specifically for older adults and were quantitative and randomized studies [39–41]. The studies were performed in the following countries: the United States of America (25), the United Kingdom (7), Germany (4), Australia (5), Denmark (4), Canada (4), the Netherlands (4), Spain (2), France (2), Ireland (1), Italy (1), Estonia (1) and New Zealand (1).

The aforementioned three studies [39–41] that specifically targeted older adults focused on interventions with personalized feedback and information provision. Interventions for the general populations included therapy sessions, frequently including motivational interviews or motivational enhancement with other educational material. Some interventions offered a stepped care process with personalized feedback on alcohol. The way in which the interventions were delivered differed widely. Personal treatment and the Internet were the most mentioned ways.

The quality assessment results (MMAT score) are shown in Table 4. Overall, the quality of the studies was generally high (4 or 5) or moderate (3). Only three studies were rated low (2) [42,43] or poor (1) [44].

3.2. Themes

We were interested in *how* (which elements of interventions), *in which context* and *why* (which mechanisms) interventions prevent or reduce (problematic) alcohol consumption among older adults. The results were first categorized according to their mode of delivery (i.e., the context): (1) practitioner or no practitioner involvement; (2) in-person or not; and (3) individual treatment, group treatment or treatment with relatives' involvement. Consequently, six different modes of delivery were found: (A) practitioner—in-person—individual; (B) practitioner—not in-person—individual; (C) practitioner—in-person—relatives; (D) practitioner—in-person—group component; (E) no practitioner—not in-person—individual; and (F) no practitioner—not in-person—group component. Then, for every mode of delivery, one or more findings were provided about how (which elements of interventions) and, when found, why (by which mechanism) these elements contributed to the prevention and reduction of (problematic) alcohol consumption for (older) adults. Table 4 provides a summary of the studies' characteristics. Table 5 provides a summary of the results.

Table 4. Characteristics of the studies.

A. Context (C) [1]: Therapist—In-Person—Individual				How	Why	
Author; Country	**Participants; Age Mean (SD)**	**Method**	**Intervention or Aim**	**Intervention Elements (E) [2] and Outcome (O) [4]**	**Mechanisms (M) [3] and Outcome (O) [4]**	**Study Quality (MMAT)**
Andréasson et al. (2002); SE [45]	N = 93; >18+ years Mean age 50.2 years (Not given)	Quantitative randomized controlled trial	*Intervention*: Treatment of alcohol-related problems with cognitive behavioral therapy and motivation enhancement *Control*: One assessment session; one session of feedback/advice, guided by the same motivation enhancement principles; and a 24-page self-help manual	*Intervention*: Four treatment sessions on cognitive behavioral therapy and motivation enhancement (E) → alcohol reduction (O) → reduction in the number of drinking days (O) *Control*: (1) One session of feedback/advice, guided by the same motivation enhancement principles (E) → reduction of alcohol (O)	Not studied	3
Baumann et al. (2015); DK [46]	N = 9415; 30–60 years Intervention: mean age 46.1 (7.9) Control: mean age 45.7 (9.8)	Quantitative randomized controlled trial	*Intervention 1A*: Screening, risk assessment and individual lifestyle counselling; participants at high risk of ischemic heart disease were also offered group-based counselling *Intervention 1B:* High-risk people in the intervention group were offered group-based counselling on smoking cessation or on diet and physical activity *Control*: No intervention	*Intervention 1A*: Sessions were conducted by a nurse, dietitian or doctor (E) trained in motivational interviewing (E) → greater reductions in binge drinking during the 5 years of intervention (O) *Intervention 1B*: Additionally, high-risk people in the intervention group were offered group-based counselling on smoking cessation or on diet and physical activity (E) → reported greater reductions in binge drinking during the 5 years of intervention (O)	Not studied	4
Connors et al. (2016); USA	N = 63; 18 and 65 years	Quantitative non-randomized	*Aim*: Examined therapeutic alliance. Participants seeking treatment	Not studied	(1) Higher therapeutic alliance scores (M) (2) achieved though	5 3

A. Context (C) [1]: Therapist—In-Person—Individual

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) [2] and Outcome (O) [4]	Mechanisms (M) [3] and Outcome (O) [4]	Study Quality (MMAT)
[47]	Mean age 48.27 (10.64)		for an alcohol use disorder received 12 weeks of cognitive behavioral therapy (CBT) for alcohol dependence and completed weekly assessments of the alliance		therapist and patient collaboration in the identification of additional sessions as judged best to meet the patient's clinical needs (M) → fewer drinking days (O) in the period until the next treatment session → fewer heavy drinking days in the period until the next treatment session (O)	
Csillik et al., (2022); FR [48]	N = 45 >18+ years Mean age: 44.6, (11.6)	Randomized controlled trial	*Intervention*: The efficacy of three MI intervention plans using a randomized matched pre-test/post-test design spanning a 10-week period	*Intervention*: Five individual face-to-face motivational interview (E) sessions conducted over a ten-week period → reduction of alcohol consumption (O)	Not studied	3
Ilgen et al. (2006); USA[49]	N = 785; Age not specified Mean age not specified	Quantitative randomized	*Aim*: Investigated whether a positive therapeutic relation is particularly beneficial for patients entering alcohol use disorder treatment with low motivation *Intervention*: Project MATCH. Patients were randomly assigned to twelve-step facilitation, cognitive behavioral coping skills or motivational enhancement therapy	Not studied	(1) High-quality therapeutic relationship (M) was more strongly associated with → reductions in alcohol use (O) among patients with (2) low motivation (M) than among those with high motivation	5
Karno et al. (2002); USA [50]	N = 47: Age not specified Mean age 38.8	Quantitative non-randomized	*Aim*: Examined the effects of interactions between patient attributes and therapist interventions on alcoholism	*Intervention*: cognitive behavioral therapy (E) → had significantly better drinking outcomes (O) than family systems therapy (E)	(1) Use of interventions early in treatment that emphasized emotional experiences (M) → less alcohol consumption (O)	4

			treatment outcome. The partners of these patients participated in treatment but were not a focus of this study Intervention: Psychotherapy session from either cognitive behavioral or family systems therapy		(2) The relationships between emotional distress and therapist focus on affect (M) and patient reaction and therapist directness (M) → were important predictors of alcohol use (O) during the maintenance phase of treatment	
Kavanagh and Connolly (2009); AUS [51]	N = 204; Age 19–80 years Mean age 47.8 (10.8)	Quantitative randomized controlled trial	*Intervention*: General practitioners (GPs) received a letter providing a summary of baseline assessments plus standard guidelines on management of alcohol disorders in general practice. They were informed of their patients' progress. Participants received information about alcohol's effect, a self-help booklet and self-monitoring forms *Control group*: Received information about alcohol's effects, a self-help booklet and self-monitoring forms. Posted self-monitoring forms each fortnight and received letters that summarized progress, encouraging continued self-monitoring and self-monitoring forms	*Intervention*: GPs receiving information about the alcohol behavior of patients (E) and at monthly intervals over the following 6 months, an update about their patients' progress (E) → drank on fewer days (O)	Not studied	5
Khan et al. (2013); UK [52]	N = 141; >18+ years Mean age not specified	Quantitative non-randomized	*Aim*: Possible benefits of offering a brief alcohol intervention within community pharmacies *Intervention*: Hazardous drinkers received a full brief intervention from the pharmacist based on the	*Intervention*: (1) Full brief intervention given by the pharmacist (E) based on the Feedback, Listen, Advice, Goals and Strategies technique (E) and (2) an alcohol unit wheel calculator (E), (3) a "Units and	Not studied	4

A. Context (C) [1]: Therapist—In-Person—Individual

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) [2] and Outcome (O) [4]	Mechanisms (M) [3] and Outcome (O) [4]	Study Quality (MMAT)
			Feedback, Listen, Advice, Goals and Strategies (FLAGS) technique	You” booklet (E) and a leaflet with contact details of local and national specialist alcohol services (E) → reduction in the number of drinking days reported by hazardous drinkers (O) → a highly significant reduction in the number of alcohol units consumed by hazardous drinkers (O)		
***Kiluk et al. (2016); USA [53]**	N = 68; >18+ Mean age 42.7 (1.9)	Quantitative randomized controlled trial	*Intervention 1*: Treatment as usual plus on-site access to computerized cognitive behavioral therapy targeting alcohol use *Intervention 2*: Computerized cognitive behavioral therapy plus brief weekly clinical monitoring *Intervention 3*: On-site access to computerized cognitive behavioral therapy targeting alcohol use *Control*: Treatment as usual	*Intervention 1*: Weekly group or individual motivational psychotherapy delivered by masters-level counsellors at the outpatient facility (E) → lower alcohol consumption (O) *Intervention 2*: Computerized cognitive behavioral therapy plus brief weekly clinical monitoring (E) → reduction of alcohol consumption (O) *Control*: (1) Weekly group or individual motivational psychotherapy (E) → reduction alcohol use (O)	Not studied	4
Kingree and Thompson (2011); USA [54]	N = 268; >18+ years Mean age not specified	Quantitative non-randomized	*Intervention 1*: Assessed participation in meetings *Intervention 2*: Having a sponsor	*Intervention 1*: Not effective *Intervention 2*: Having a sponsor (E) → subsequent abstinence from	Not studied	4

				alcohol (O)		
Mowbray (2013); USA [55]	N = 271; >18+ years Mean age 44.6	Quantitative non-randomized	*Aim*: Could setting drinking goals be a mechanism of change *Intervention 1*: Classic abstinence-based treatment models *Intervention 2*: A drinking programme that helped individuals to reduce, but not to stop, their drinking	*Interventions* (1) Individuals with abstinence as a drinking goal (E) → significantly increased abstinent days (O) → significantly fewer heavy drinking days (O)	Not studied	4
Nielsen and Nielsen (2018); DK [56]	N = 276; Intervention: mean age 42.6 Control: mean age 40.3	Quantitative non-randomized	*Intervention*: (1) All patients in the intervention received a single motivational session after assessment and before treatment assignment; (2) patients were allocated to one of the four treatments by the actuarial matching system described above, without discretion for clinical judgement *Control*: Treatment based on clinician judgement	*Intervention*: A single motivational session after assessment and before treatment assignment (E) → significantly more likely to complete treatment and show a greater reduction in drinking (O)	Not studied	3
Orford et al. (2006); UK [57]	N = 211; Age not specified Mean age 42 years	Qualitative interviews	*Aim*: To develop a model of change during and following professional treatment (social behavior and network therapy and motivational enhancement therapy) for drinking problems, grounded in clients' accounts *Intervention 1*: Three sessions of motivational enhancement therapy over 12 weeks	*Intervention 1*: Not studied *Intervention 2*: Not studied	(1) Thinking differently (M) (2) Family and friends support (M) (3) Acting differently (M) (4) Treatment delivers new insights (5) Down to me: clients often expressed the view that change was self-directed (M) (6) Seeing the benefits (M) (7) Catalyst (M) is a simple summary of a set of processes that were talked about at greater length by clients during pre-	5

A. Context (C) [1]: Therapist—In-Person—Individual

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) [2] and Outcome (O) [4]	Mechanisms (M) [3] and Outcome (O) [4]	Study Quality (MMAT)
			Intervention 2: Eight sessions of social behavior and network therapy over 12 weeks		treatment interviews → less alcohol consumption (O)	
Orford et al. (2009); UK [58]	N = 397; Age not specified	Qualitative interviews	*Aim*: Social treatment (social behavior and network therapy and motivational enhancement therapy) to explore the factors to which clients attributed positive changes that might have occurred in their drinking *Intervention 1*: Three sessions of motivational enhancement therapy over 12 weeks *Intervention 2*: Eight sessions of social behavior and network therapy over 12 weeks	*Intervention 1*: Not studied *Intervention 2*: Not studied	(1) Involvement of other people (excluding therapists or other professionals) in supporting own behavior change by attending treatment sessions or in any other way (M) (2) Communicating better and more openly (M) (3) Awareness of, and thinking about, the consequences of drinking (M) (4) Feedback of results from assessment (M) (5) Thinking about what is important in life (M) → change in drinking (O)	5
Richardson et al. (2011) NZ [59]	N = 125; 17–59 years Mean age 37.6 (10.4)	Quantitative randomized controlled trial	*Intervention 1*: Motivational enhancement therapy: four sessions *Intervention 2*: Non-directive reflective listening: four sessions *Control*: No sessions	*Intervention 1*: No significant effect Intervention 2: No significant effect *Control*: No significant effect	Therapeutic alliance (M) was significantly higher for clients who attended all four sessions (E) More therapeutic alliance because of more attendance (M) → more abstinent days (O)	3
Team UR (2005); UK [60]	N = 742; >16+ Mean age 41.6 (10.1)	Quantitative randomized controlled trial	*Intervention 1*: Social behavior and network therapy: three 50-min sessions over eight to 12 weeks to	*Intervention 1*: Network therapy to build social networks (E) → reduction of alcohol (O)	Not studied	3

			help clients build social networks *Intervention 2*: Motivational enhancement therapy comprised three 50-min sessions over eight to 12 weeks, combining counselling in the motivational style with objective feedback	*Intervention 2*: (1) Counselling in the motivational (E) style and (2) including "significant others" in only the first session to provide only confirmatory information (E) → reduction of alcohol (O)		
*** Walitzer and Dermen (2004); USA [61]**	N = 64; Male clients mean age of 42.0 years (11.3); Spouses mean age of 39.3 years (9.6).	Quantitative randomized controlled trial	*Intervention 1*: Treatment for problem drinkers only *Intervention 2*: Couples' alcohol-focused treatment *Intervention 3*: Couples' alcohol-focused treatment + behavioral couple therapy	*Intervention 1*: Specific strategies for changing drinking patterns and informational lectures on current alcohol and other health-related topics (E) → less alcohol consumption (O) *Intervention 2*: Not applicable see **C. Context: therapist—in-person—relatives** *Intervention 3*: Not applicable see **C. Context: therapist—in-person—relatives**	Not studied	4
Wiprovnick et al. (2015); USA [42]	N = 59; Age not specified Mean age 40.25 (11.79)	Quantitative randomized controlled trial	*Intervention 1*: Goal of moderation and a detailed structural personalized feedback module *Intervention 2*: Relational motivational interviewing without directive elements consisting of the non-directive elements of motivational interviewing, including therapist stance (warmth, genuineness, egalitarianism), emphasis on client responsibility	*Intervention 1*: Not studied *Intervention 2*: Not studied	The change in therapeutic bond (E) and empathic resonance (M) from Week 1 to Week 8 was → significant in predicting drinking outcomes (O) → and decreased alcohol use at the end of treatment for participants in both conditions (O)	2

A. Context (C) [1]: Therapist—In-Person—Individual

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) [2] and Outcome (O) [4]	Mechanisms (M) [3] and Outcome (O) [4]	Study Quality (MMAT)
			for change and avoidance of MI-inconsistent behaviors, such as advising and confronting			
B. Context: Therapist—Not-in-Person—Individual						
Best et al. (2015); USA [62]	N = 22; >18+ Mean age 43.1 (12.9)	Quantitative descriptive	*Intervention*: A 24-h, 7-days-a-week, free, anonymous state-wide telephone counselling, information and referral service for people who use alcohol and other drugs	*Intervention*: (1) Over the telephone; (2) practice elements were presented in the manual alongside a spatial representation through a cognitive (node-link) mapping exercise. After the initial session, the participants were posted a copy of the workbook containing node-link maps, drink diaries and information connected to each of the relevant modules (E) → reduction in drinking (O)	Not studied Not studied Not studied Not studied	3
Bischof et al. (2008); DE [63]	N = 408; 18–64 years Intervention 1: mean age 36.8 (13.2) Intervention 2: mean age 36.8 (13.5) Control mean age 35.9 (13.7)	Quantitative randomized controlled trial	*Intervention 1*: Stepped-care participants received computerized feedback and a maximum of three brief counselling sessions based on motivational interviewing and behavioral change counselling. All counselling sessions were conducted by telephone *Intervention 2*: Full-care participants received computerized feedback and simultaneously received brief counselling sessions conducted	*Both interventions*: (1) Received computerized feedback (E) and (2) a maximum of three brief counselling sessions based on motivational interviewing and behavioral change counselling. (3) All counselling sessions were conducted by telephone (E) → reduction in drinking (O) *Control group*: No significant effect	Not studied	3

			by trained psychologists based on motivational interviewing and containing structured elements of behavioral change counselling. Counselling sessions were conducted by telephone *Control group*: Participants received roughly half of the number of intervention in minutes compared with full-care participants			
Blankers et al. (2011); NL [64]	N = 205; 18–65 years Mean age 42.2 (9.7)	Quantitative randomized controlled trial	*Intervention 1*: No-therapist-involved web-based intervention: fully automated, self-guided treatment programme *Intervention 2*: Therapist-involved web-based intervention: synchronous online therapy including up to seven synchronous text-based chat therapy sessions. Before each chat session, the participant worked on a homework assignment. There was no other kind of contact between participants and therapists	*Intervention 1*: (1) Feedback about alcohol consumption is provided with interactive graphs and table (E) → reducing alcohol (O) *Intervention 2*: (1) Online therapy (E); (2) seven synchronous text-based chat therapy sessions (E). (3) Before each chat session, the participant worked on a homework assignment (E) → reduction of alcohol consumption (O)	Not studied	4
Brown et al. (2007); USA [65]	N = 897; 21–59 years Mean age not specified	Quantitative randomized controlled trial	*Intervention*: Motivational telephone calls: an adaptation of motivational interviewing administered over up to six telephone sessions *Control*: Received a four-page pamphlet on healthy lifestyles. One page was devoted to each of four	*Intervention*: (1) Motivational telephone calls bolstered with summary letters (E) → significantly reduced drinking for male primary-care patients with alcohol abuse or dependence who are not necessarily seeking assistance for	Not studied	4

B. Context: Therapist—Not-in-Person—Individual

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) ^{2} and Outcome (O) ^{4}	Mechanisms (M) ^{3} and Outcome (O) ^{4}	Study Quality (MMAT)
			topics: tobacco, diet, exercise and alcohol	their drinking (O) *Control*: Four-page information pamphlet on healthy lifestyles (E) → reduction in alcohol consumption in women (O)		
Clifford et al. (2007); USA [66]	N = 235; >18+ years Mean age 40.01 (10.00)	Quantitative randomized controlled trial	*Intervention 1*: Frequent comprehensive (FC) quarterly in-person follow-up interviews interspersed with monthly telephone interviews for a period of 12 months after participants' treatment programme intake interview session. The content of the FC interviews covered the following areas: drinking and drug-taking behaviors; alcohol- and other drug-related negative consequences; medical and psychiatric status; psychological, social and cohabitation/marital relationships; and occupational functioning *Intervention 2*: Frequent brief (FB) quarterly in-person follow-up interviews interspersed with monthly telephone interviews for a period of 12 months after respondents' treatment programme	*For all interventions*: Follow-up contact after treatment with the study participants, even if brief in nature (E) → less alcohol consumption (O) *FC and IC*: (1) More follow-up contact after treatment for study participants (2) in-person (E) (3) or by telephone (E) → less alcohol consumption (O)	Not studied	5

			intake interview session. However, before the final 12-month, in-person interview, interviews were limited to addressing alcohol and other drug-taking behaviors *Intervention 3*: Infrequent comprehensive (IC) interviews only at the baseline and 6- and 12-month research assessment interviews. The content of the assessment battery was identical to that of the FC condition *Intervention 4*: Infrequent brief (IB) in-person follow-up interviews (i.e., only two, at 6 and 12 months) and a 6-month interview limited to the assessment of alcohol and other drug-taking behaviors			
Ettner et al. (2014); USA [39]	N = 1168; Age above 60 years Mean age 71	Quantitative randomized controlled trial	*Intervention*: Project SHARE (Senior Health and Alcohol Risk Education), which included personalized reports, educational materials, drinking diaries, physician advice during office visits and telephone counselling *Control group*: Care as usual	*Intervention*: (1) Mailed a personalized patient report (E); (2) an educational booklet on alcohol and aging (E); (3) via telephone, a health educator contacted intervention patients three times. During these calls, the health educator answered questions about the written materials and gave feedback → at-risk drinkers reduced (O) → less alcohol consumption (O) → older adults were more likely to have discussed their alcohol use with a physician (O)	Not studied	5

B. Context: Therapist—Not-in-Person—Individual

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) ^{2} and Outcome (O) ^{4}	Mechanisms (M) ^{3} and Outcome (O) ^{4}	Study Quality (MMAT)
Postel et al. (2015); NL [67]	N = 144; >18+ 22–66 years Mean age 45.8	Quantitative non-randomized	*Intervention*: A 3-month web-based alcohol treatment programme using intensive, asynchronous (non-simultaneous) therapeutic support at a 9-month follow-up assessment Intervention or Aim	*Intervention*: The web-based treatment programme consisted of (1) a structured two-part online treatment programme (E); (2) the participant and the therapist communicated asynchronously via the Internet (intensive asynchronous therapeutic) (E) → reduction in the number of drinks per week (O)	Not studied	4
C. Context: Therapist—In-Person—Relatives						
Doyle et al. (2003); IE [68]	N = 67; Age not specified Mean not specified	Quantitative non-randomized	*Intervention*: Community-based 10-week programme involved weekly separate and conjoint group therapy for problem drinkers and their families	(1) Clients and their families attended psychoeducational lectures (E) and (2) films on addiction and recovery (E) → abstinent (O) or drinking moderately (O)	Not studied	4
McCrady et al. (2002); USA [69]	N = 68; Age not specified Mean age 39.4 (10.3)	Quantitative non-randomized	*Intervention*: Alcohol behavioral couple therapy (ABCT) model; three primary domains are assumed to be related to alcohol consumption: (a) individual factors related to the drinker's alcohol consumption, (b) the quality and nature of the spouse's responses to alcohol-related situations and (c) the nature and quality of the couple's marital interactions	*Intervention*: Greater spousal use of problem solving and social support to deal with problems and less use of self-blame, wishful thinking and avoidance → less intense drinking during treatment (O)	*Intervention*: (1) The quality of the pre-treatment marital relationship (M) → men's ability to remain abstinent (O) (2) The degree of the respondents' marital happiness immediately after treatment (M) → predicted the intensity of their drinking (O)	4

McCrady et al. (2009); USA [70]	N = 102; Age not specified Intervention 1: mean age 44.78 (9.14) Intervention 2: mean age 45.31 (9.31)	Quantitative randomized controlled trial	*Intervention 1*: Alcohol behavioral couple therapy (ABCT) manual-guided, 20-session outpatient cognitive behavioral therapies with an explicit goal of abstinence from alcohol; all sessions included both partners	*Intervention 1*: (1) Sessions included both partners in all sessions (E) and (2) included self-monitoring, functional analysis of drinking and coping skills to avoid alcohol and deal with other life problems (E) resulting in more days abstinent (O) → fewer days heavy drinking (O)	*Intervention 1*: Interventions to teach the partner to support abstinence and to decrease attention to drinking and interventions to improve the couple's relationship, including reciprocity enhancement, communication and problem solving (M) → more days abstinent (O) → fewer days heavy drinking (O)	4
Rentscher et al. (2017); USA [71]	N = 33; Age not specified Mean age 39.2 (10.2)	Quantitative non-randomized	*Aim*: Investigating pronoun use prior to and during two couple-focused interventions for problematic alcohol use: cognitive behavioral therapy and family systems therapy	*Intervention*: Not studied	Spouse we-talk (M) → associated with successful treatment outcomes (O)	3
Schumm et al. (2014); USA [72]	N = 105; 18–65 years Mean age women 44.42 (8.08) men 47.68 (8.40)	Quantitative randomized controlled trial	*Intervention 1*: BCT (behavioral couple therapy) sessions attended together by the woman and her partner *Control*: IBT (individually-based therapy) for women	*Intervention*: (1) 13 BCT sessions attended together by the woman and her partner (E) (2) to build support for abstinence and improve relationship functioning (E); (3) completion of a daily "trust discussion" in which the patient states an intent to stay abstinent that day and the spouse expresses support for the patient's efforts (E) → more abstinent days during treatment and during the 12-month follow-up (O)	*Intervention*: (1) Teaching partners to decrease behaviors that may trigger or enable substance use (M); and (2) helping the couple to decrease the patient's exposure to alcohol and drugs by removing alcohol from the home and avoiding or managing alcohol-related family and social gatherings (M) → more abstinent days during treatment and during the 12-month follow-up (O)	3
Vedel et al. (2008); NL [73]	N = 64; Age not specified Mean age 45.5 (11.34)	Quantitative randomized controlled trial	*Intervention 1*: Behavioral couples therapy *Intervention 2*: Cognitive behavioral therapy	*Intervention 1*: (1) Individual couple sessions (E); (2) 10 sessions (E); (3) 90 min (E) → reduction in drinking (O) *Intervention 2*: Cognitive behavioral	Not studied	4

C. Context: Therapist—In-Person—Relatives

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) [2] and Outcome (O) [4]	Mechanisms (M) [3] and Outcome (O) [4]	Study Quality (MMAT)
				therapy (1) emphasizes overcoming skill deficits and aims to increase the person's ability to detect and cope with high-risk situations that commonly precipitate relapse (E) → reduction of drinking (O)		
*** Walitzer and Dermen (2004); USA [61]**	N = 64; Age not specified Male clients mean age 42.0 (11.3); Spouses mean age of 39.3 (9.6).	Quantitative randomized controlled trial	*Intervention 1*: Treatment for problem drinkers only (PDO) *Intervention 2*: Couples' alcohol-focused treatment; subjects were presented with specific strategies for changing drinking patterns; informational lectures on current alcohol and other health-related topics *Intervention 3*: Couples' alcohol-focused treatment + behavioral couple therapy; subjects were presented with specific strategies for changing drinking patterns	*Intervention 1*: Not applicable see **A.Context (C) [1]: therapist—in-person—individual** *Interventions 2 + 3* (not specified): A significant increase was obtained in the frequency of drinking days (O)	*Intervention 2*: Treatment material for the alcohol-focused spouse involvement component, presented in conjunction with the client's drinking reduction strategies, consisted of specific strategies designed to increase spouse behaviors supportive of drinking reduction and to support the problem drinker's independence and autonomy (M) → reduction in alcohol use (absent and light drinking days) (O) → reduction in heavy drinking days (O) *Intervention 3*: BCT consisted of a series of treatment components designed to equip each couple with a variety of skills and techniques (a) to increase cohesion and the positive aspects of their marriage and (b) to enhance communication and conflict resolution skills (M) →	4

C. Context: Therapist—In-Person—Relatives						
					reduction in alcohol use (absent and light drinking days) (O) → reduction in heavy drinking days (O)	
D. Context: Therapist—In-Person—Group Component						
Bamford et al. (2003); UK [74]	N = 124; 21–64 years Mean age 41	Quantitative non-randomized	*Intervention*: Short 6-week intervention that focused on psycho-educational materials on physical and mental complications	*Intervention*: (1) Focused on psycho-educational materials on physical and mental complications (E); (2) coping with family problems and mistrust (E); (3) visitors' groups, in which patients who had made positive changes to their drinking described their experiences (E) and positive influences (E) and (4) spent less time on problem solving and managing low mood and anxiety → reduced drinking behavior (O)	Not studied	4
Brown (2007); CA [75]	N = 76; Age not specified Intervention: mean age 41.0 (9.9) Control: mean age 33.2 (8.7)	Quantitative non-randomized	*Intervention*: Brief, four-session group-adapted motivational interviewing (GAMI) *Control*: Standard care (SC)	*Intervention*: (1) Standardized, four-session group treatment (E) (2) in a brief, four-session GAMI intervention (E) → alcohol reduction (O)	*Intervention*: (1) Targeting rapid internally motivated change (M); (2) all sessions were conducted using the specific communication style and strategies associated with motivational interviewing (M) → alcohol reduction (O)	5
Gómez-Recasens et al. (2018) ES [76]	N = 1103; >18+ years Mean age 42.48 (10.44)	Quantitative non-randomized	*Intervention*: To promote health and prevent alcohol and drug consumption in the workplace, emphasizing (1) health promotion and health monitoring, which included (a) alcohol and drug awareness and (b) the evaluation	(1) Awareness (E), (2) information (E), (3) training (E), (4) participation in a workshop outside work (E), (5) evaluation and health surveillance (E), (6) medical examination (E), (7) brief intervention (E), (8) personalized advice (E), (9)	Not studied	4

D. Context: Therapist—In-Person—Group Component

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) [2] and Outcome (O) [4]	Mechanisms (M) [3] and Outcome (O) [4]	Study Quality (MMAT)
			and monitoring of alcohol and drug consumption through a semi-structured interview designed to assess risky consumption; urine tests aimed at detecting alcohol, cannabis and cocaine use; an Alcotest based on expired air to test for the recent consumption of alcohol and a saliva exam to test for the recent consumption of six drugs; and (2) secondary prevention if risky consumption was identified	personalized follow-up (E), referral to the centre for the attention and monitoring of drug addictions (E) → reduced risky alcohol consumption (O)		
Hagger et al. (2011); UK [77]	N = 281; 18–65 years Mean age 35.65, (12.44)	Quantitative randomized controlled trial	*Intervention*: Mental simulation manipulation in pen-and-paper form after receiving information about reducing alcohol consumption and questionnaire measures *Control*: Received identical measures and information about alcohol consumption	*Intervention*: (1) Mental simulation exercise (E) (2) about alcohol intake (E) and (3) health benefits of keeping alcohol intake within guidelines limits (E) → consuming fewer unit of alcohol during the 4-week follow-up period (O) *Control*: Effect not studied	Not studied	4
Reynolds and Bennett (2015); USA [78]	N = 1510; >18+ years Mean age not specified	Quantitative randomized controlled trial	*Intervention 1*: The Team Awareness Program: (1) peer referral and (2) team building: 4-h on-the-job classroom training sessions that encouraged healthy lifestyles and the seeking of professional help *Intervention 2*: The Choices in	Intervention 1: (1) Relevance (E); (2) team ownership of policy (E); (3) understanding tolerance (E); (4) communication (E); (5) support and encourage help (E) → reduced monthly alcohol intake (O) *Intervention 2*: (1) 4-hour	Not studied	3

			Health Promotion Program delivered various health topics based on a needs assessment: 4-h on-the-job classroom training sessions that encouraged healthy lifestyles and the seeking of professional help	programme developed based on needs assessment (E), (2) goal setting (E) and (3) choice components (E) → reduced monthly alcohol intake (O)		
Toft et al. (2009); DK [79]	N = 9.415; 30, 35, 40, 45, 50, 55 and 60 years Majority of individuals at the age of 40 to 50 years	Quantitative randomized controlled trial	*Intervention 1* (Low risk): Each participant had a lifestyle consultation focusing on smoking, physical activity, diet and alcohol *Intervention 2* (High risk): Each participant had a lifestyle consultation focusing on smoking, physical activity, diet and alcohol. The individually counselled high-risk individuals were offered group counselling on diet and exercise or smoking	*Intervention 1*: (1) Each participant had a lifestyle consultation focusing on smoking, physical activity, diet and alcohol (E) → men decreased their alcohol intake (O) → less binge drinking in both men and woman (O) *Intervention 2*: (1) Each participant had a lifestyle consultation focusing on smoking, physical activity, diet and alcohol (E); (2) the individual counselling high-risk individuals were offered group counselling on diet and exercise or smoking; (3) the relatives of the participants were offered the chance to participate in one of the meetings (E) → men decreased their alcohol intake (O) → less binge drinking in both men and women (O)	Not studied	4
E. Context: No Therapist—Not In-Person—Individual						
Augsburger et al., (2021); EE [80]	N = 589 >18+ years Mean age: 37.86 (11.16)	Randomized controlled trial	*Intervention*: To estimate the efficacy of an on-line self-help intervention to reduce problem drinking at thepopulation level	*Intervention*: 10 modules based on principles of cognitive–behavioral therapy and motivational interviewing (E). Access to a website with a self-test including	Not studied	3

E. Context: No Therapist—Not In-Person—Individual

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) [2] and Outcome (O) [4]	Mechanisms (M) [3] and Outcome (O) [4]	Study Quality (MMAT)
				personalized normative feedback (E) and information for standard alcohol treatment. Control: access to a help-page received PNF on a self-test for alcohol consumption (E) and further information together with contact details for treatment options → reduction of alcohol consumption (O)		
Baumann et al. (2017); DE [81]	N = 1282; 18–64 years Mean age 30.1 (11.1)	Quantitative randomized controlled trial	*Intervention 1*: Brief intervention tailored to the motivational stage (ST) *Intervention 2*: Brief non-stage tailored intervention (NST) *Control*: Assessment only (AO)	*Intervention 1*: (1) Individualized computer-generated feedback letters in comparison to other persons at the same stage of change and feedback on intrapersonal changes by comparing the participant's current and previous data (E); (2) the letters referred to particular pages in the accompanying stage-matched manual for further information) → only persons with daily low use benefitted from intervention (O) → more change of being abstinent after 15 months (O) *Intervention 2*: Individualized computer-generated feedback letters in comparison to other persons at the same stage of change and feedback on intrapersonal changes	Not studied	4

				by comparing the participant's current and previous data (E) → only persons with daily low use benefitted from intervention (O) → more chance of being abstinent after 15 months (O) *Control*: No effect given		
Bagnardi et al. (2011); I [82]	N = 6026; >15+ Mean age not specified	Quantitative non-randomized	*Intervention* (coordinated community-based intervention): Informing residents about and committing them to the project, brochures, alcohol-free parties, public events promoting a healthy lifestyle, news about the project in local newspapers educating at schools, religious and sporting facilities, meetings with parents/teachers, driving schools, physicians, police forces and volunteers and meetings and alcohol-free events at centres for older adults	*Intervention*: (1) Informing residents about and committing them to the project (E), brochures (E), alcohol-free parties (E), public events promoting a healthy lifestyle (E), news about the project in local newspapers (E); (2) educating at schools, religious and sporting facilities (E), meetings with parents/teachers, driving schools, physicians, police forces and volunteers (E) and meetings and alcohol-free events at centres for older adults (E) → reduced alcohol consumption (O)	Not studied	3
Blankers et al. (2011); NL [64]	N = 205; 18–65 years Mean age 42.2 (9.7).	Quantitative randomized controlled trial	*Intervention 1*: No-therapist-involved web-based intervention: fully automated, self-guided treatment programme *Intervention 2*: Therapist-involved web-based intervention: synchronous online therapy including up to seven synchronous text-based chat therapy sessions. Before each chat session, the participant	*Intervention 1*: Feedback about alcohol consumption was provided with interactive graphs and table (E) → reducing alcohol conspumtion (O) *Intervention 2*: (1) Online therapy (E), (2) seven synchronous text-based chat therapy sessions (E), (3) before each chat session, the participant worked on a homework	Not studied	4

E. Context: No Therapist—Not In-Person—Individual

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) [2] and Outcome (O) [4]	Mechanisms (M) [3] and Outcome (O) [4]	Study Quality (MMAT)
			worked on a homework assignment. There was no other kind of contact between participants and therapists	assignment (E) → reduction of alcohol consumption (O)		
Connors et al. (2017); USA [83]	N = 111; Age not specified Woman: mean age 46.99 (11.79) Men: mean age 15.54 (2.70)	Quantitative randomized controlled trial	*Intervention 1*: Bibliotherapy (a self-directed manual) alone *Intervention 2*: Bibliotherapy with one telephone-administered motivational interview *Intervention 3*: Bibliotherapy with one telephone-administered motivational interview and six biweekly telephone (50 min) therapy sessions	*Intervention 1*: (1) 122-page self-directed manual (E) (2) focused on self-awareness of drinking behavior, identifying danger signals regarding problem drinking situations, developing strategies for reducing alcohol intake and reducing risks associated with drinking that does occur → fewer heavy drinking days (O) → increased abstinent and light drinking days (O) *Intervention 2*: Bibliotherapy with one telephone-administered motivational interview of 60 min (E) → increased abstinent and light drinking days (O) *Intervention 3*: Bibliotherapy (E) with one telephone-administered motivational interview (E) and six biweekly telephone (50 min) therapy sessions (E) → increased abstinent and light drinking days (O)	Not studied	4
Cunningham et al. (2001);	N = 449; Age not specified	Quantitative non-randomized	*Intervention*: Brief self-help booklet provided at assessment for alcohol	*Intervention*: (1) Self-help booklet (E); (2) perspective of encouraging	Not studied	4

CA [84]	Intervention: mean age 41.0 (10.8) Control group: 38.8 (10.5)		treatment	the individuals to consider the costs of their drinking, to motivate them to want to change and to take the next step towards change (E) → drinking on fewer days (O) → and drinking less on each occasion (O)		
Cunningham et al. (2009); CA [85]	N = 185; Age not specified Mean age 40.1 (13.4)	Quantitative randomized controlled trial	*Intervention* (internet personalized alcohol feedback): After completing a brief online assessment, participants received a 'Personalized Drinking Profile' *Control*: Sent a list of the informational components that could be included in a computerized summary for drinkers	*Intervention*: (1) Participants received a 'Personalized Drinking Profile' (E); the core element was normative feedback pie charts that compare the participant's drinking with that of others of the same age, sex and country of origin (E) → less alcohol consumption (O)	Not studied	4
Cunningham et al. (2014); CA [86]	N = 741; >19+ years Mean age 29.8 (9.7)	Quantitative randomized controlled trial	*Intervention 1*: The normative feedback component of the Check Your Drinking Screener (a personalized feedback intervention) *Intervention 2*: Personalized feedback information of the Check Your Drinking Screener *Intervention 3*: The full Check Your Drinking Screener intervention, both the normative feedback and other personalized feedback components. *Control*: No intervention	*Intervention 1*: No significant effect *Intervention 2*: (1) Personalized feedback information (E) → reduction in the number of drinks in a typical week (O) *Intervention 3*: (1) Both the normative feedback (E) and other personalized feedback components (E) → reduction in the number of drinks in a typical week (O)	Not studied	4
Dulin et al. (2014); USA [87]	N = 28; 18–45 years Mean age 33.6	Quantitative descriptive	Intervention: Smartphone-based intervention: stepwise approach to providing the information	*Intervention*: (1) Enhancement of motivation for change by providing assessment feedback (E);	*Intervention*: (1) Enhanced awareness, i.e., "it helped me to keep track" and "the reports made	4

E. Context: No Therapist—Not In-Person—Individual

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) ^{2} and Outcome (O) ^{4}	Mechanisms (M) ^{3} and Outcome (O) ^{4}	Study Quality (MMAT)
	years, (6.5)		and interventions to the client; enhancement of motivation for change by providing assessment feedback and immediate coping strategies	fewer heavy drinking days (O) → fewer drinks per day (O)	me realize how much I was drinking and what were my triggers" → fewer heavy drinking days (O) → fewer drinks per day (O)	
Fink et al. (2005); USA [40]	N = 711; >65+ Mean age 75.6	Quantitative randomized controlled trial	*Intervention 1*: Combined report intervention: participants and their GPs received a personalized report of their drinking risks and education Intervention 2: Patient report intervention: only participants received a personalized report of their drinking, risk and education *Control*: Minimal assessments	*Interventions 1 and 2*: (1) Personalized reports of their drinking classification (E) and (2) educational information to patients (E) → reduction alcohol (O)	Not studied	5
Freyer-Adam et al. (2014); DE [43]	N = 1243; 18–64 years Control: mean age 30.1 (10.9) Intervention 1: mean age 29.5 (10.7) Intervention 2: mean age 30.6 (11.7)	Quantitative randomized controlled trial	*Intervention 1*: The stage tailored intervention: individualized computer-generated feedback letters and self-help manuals. Each text module was dependent on the current stage of change *Intervention 2*: The non-stage tailored intervention: individualized computer-generated feedback letters and self-help manuals	*Intervention 1*: (1) individualized computer-generated feedback letters (E); (2) each text module was dependent on the current stage of change (E); (3) the participant's responses were compared with normative data of individuals at the same stage (E); (4) self-help manuals (E) → reduction of alcohol consumption in the short term (O) → reduction of alcohol consumption in the long term (O) *Intervention 2*: (1) Computer-	Not studied	2

				generated feedback letters (E); (2) feedback was accompanied by information and/or advice; (E) (3) participants were encouraged to complete a when/where/how-to-change plan, introduced by gender-specific examples (E) → reduction in alcohol consumption in the short term (O)		
Giroux et al. (2014); USA [88]	N = 28; 22–45 years Mean age 33.6 (6.5)	Qualitative interviews	*Intervention*: Smartphone-based intervention: 10 psychoeducational modules and tools for change, which provided immediate coping strategies and monitoring functions for numerous alcohol-related issues	*Intervention*: Not studied	Smartphone-based intervention (1) raising awareness about drinking (M) → motivated to change their drinking (O) (2) teaching new skills that could be transferred to other areas of their life (M) → motivated to change their drinking (O) → (3) tracking progress related to their goals → motivation to continue engaging in non-drinking behavior (O)	5
Gonzalez and Dulin (2015); USA [89]	N = 60; >18+ years Intervention 1: mean age 33.57 (6.54) Intervention 2: mean age 34.30 (6.22)	Quantitative non-randomized	*Intervention 1*: Location-Based Monitoring and Intervention for Alcohol Use Disorder (LBMI-A): participants were provided with a customized LBMI-A-enabled smartphone. The LBMI-A provided seven psychoeducation modules or steps: (1) assessment and feedback, (2) high-risk locations for drinking, (3) selecting and using supportive	Intervention 1: (1) Seven psychoeducation modules (E); weekly feedback reports (E) → less alcohol consumption (O) → fewer heavy drinking days (O) *Intervention 2*: (1) Objective and norm-based feedback (E); (2) links to other online interventions and resources (E); (3) a 16-page booklet (E); (4) an accompanying web page	Not studied	3

E. Context: No Therapist—Not In-Person—Individual

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) [2] and Outcome (O) [4]	Mechanisms (M) [3] and Outcome (O) [4]	Study Quality (MMAT)
			people for change, (4) cravings and their management, (5) problem-solving skills, (6) communication and drink refusal skills and (7) pleasurable non-drinking activities. Following the completion of a step, an associated tool became available *Intervention 2*: The online Drinker's Check-Up plus bibliotherapy (DCU+Bib): the DCU is an internet-based, brief motivation intervention that can be completed in less than one hour. It provides a comprehensive assessment of drinking and alcohol-related problems, objective and norm-based feedback, a decisional balance exercise to help resolve ambivalence about change, goal selection, brief development of a change plan and brief interventions to facilitate change	that has additional interactive worksheets and modules for handling urges, drink refusal and recovering from a slip (E) → less alcohol consumption (O) → fewer heavy drinking days (O)		
Guillemont et al. (2017); FR [90]	N = 1147; >18+ years Mean age not specified	Quantitative randomized controlled trial	*Intervention*: The Alcoometre self-help web-based intervention delivers personalized normative feedback and some general information about alcohol	*Intervention*: (1) Web-based intervention (E) delivers (2) personalized normative feedback (E) and (3) some general information about alcohol (E). (4) Participants can review their motivations and	Not studied	3

			Control: Were informed that their alcohol consumption was hazardous and were given information about hazardous drinking	fears regarding reducing their alcohol intake (E), (5) set individual goals (E) and (6) monitor their progress via a consumption diary and other tools (E) → reduction in weekly alcohol intake (O)		
*** Kiluk et al. (2016); USA [53]**	N = 68; >18+ years Mean age 42.7 (11.9)	Quantitative randomized controlled trial	*Intervention 1*: Treatment as usual plus on-site access to computerized cognitive behavioral therapy targeting alcohol use *Intervention 2*: Computerized cognitive behavioral therapy plus brief weekly clinical monitoring *Intervention 3*: On-site access to computerized cognitive behavioral therapy targeting alcohol use *Control*: Treatment as usual	*Intervention 1*: Not applicable see **C)1: therapist—_in-person—_ individual** *Intervention 2*: Not applicable see **C)1: therapist—_in-person—_ individual** *Intervention 3*: On-site access to computerized cognitive behavioral therapy targeting alcohol use → reduction of alcohol consumption (O) *Control*: Not applicable	Not studied	4
Koffanus (2018); USA [91]	N = 40; >18+ years Intervention: mean age 46.6 (12.5) Control: mean age 45.2 (11.5)	Quantitative randomized controlled trial	*Intervention*: Breathalyser that allows remote, user-verified collection of a breath alcohol sample, text messaging and reloadable debit cards for remote delivery of incentives to evaluate a contingency management treatment for alcohol use disorder that can be delivered with no in-person contact	Intervention: (1) 21 consecutive days with three remote breathalyser screens per day (E); (2) participants self-reported their previous day's alcohol use and current withdrawal symptoms daily in response to a text message and/or phone call (E); (3) participants chose these times each day with guidance from research staff (E). (4) Incentive payments (E) → less alcohol consumption per day	Not studied	5
Kuerbis et al. (2015); USA	N = 86; >50+ years	Quantitative randomized	*Intervention*: Brief mailed intervention with personalized	*Intervention*: (1) A personalized feedback report (E) and (2) two	Not studied	4

E. Context: No Therapist—Not In-Person—Individual

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) [2] and Outcome (O) [4]	Mechanisms (M) [3] and Outcome (O) [4]	Study Quality (MMAT)
[41]	Mean age 64.7 (8.4)	controlled trial	mailed feedback outlining their specific risks associated with alcohol and educational booklets *Control*: No intervention	alcohol education booklets (E) → less at-risk drinking (O)		
Lockwood et al., (2020); UK [92]	N = 3057 (questionnaires) N = 14 (interviews) Age between 45–65 years	Mixed methods questionnaires and interviews	*Aim*: evaluate the impact of a "gain-framed", multimedia campaign to encourage heavier drinking men aged 45–64 years to drink less.	*Intervention*: more aware of how much they routinely drink, and to make healthier choices. (1) Providing information about health consequences (E); providing information about emotional consequences (E); encouraging self-monitoring of behavior (E); encouraging self-monitoring of outcomes of behavior (E) and encouraging behavioral experiments (E).	Appreciated the friendly, non-threatening tone and that the message was straightforward (M), meaningful, achievable (M), and was gainframed—i.e., emphasised the benefits of drinking less rather than the harms of drinking too much (M) → reduction of alcohol consumption (O)	4
Moody et al. (2018); USA [93]	N = 36; 18–65 years Intervention: mean age 38.89 (11.58) Control: mean age 40.24 (12.91)	Quantitative non-randomized	*Intervention*: Two-week implementation intention interventions that linked high-risk situations with alternative responses *Control*: Two-week implementation intention interventions for selected situations and responses but did not link these together	*Intervention*: (1) Cut back on drinking over the following two weeks (E) (2) and fill in an "if–then" worksheet format. Response (linked high-risk situations with alternative responses) (E) → with a significant reduction in alcohol consumption when drinking was reported (O) → more abstinent days (O) *Control*: To try to cut back on drinking over the following two	Not studied	3

				weeks (E) and (3) asked to select situations and responses but did not link these together (E) → more abstinent days (O)		
Nygaard (2001); DK [94]	N = 13; 35–45 years	Qualitative interviews	*Intervention*: The participants were asked to abstain from drinking alcohol for 6 weeks, during which period they were to maintain their "normal" social behavior and obligated to keep a diary of their experiences with abstinence	*Intervention*: (1) Abstain from drinking alcohol for 6 weeks (E), during which period participants were to maintain their "normal" social behavior (E) → the participants reporting the largest decrease in consumption were the persons reporting the highest initial consumption level (O)	*Intervention*: (1) Abstain from drinking alcohol for 6 weeks (E), during which period the participants were to maintain their "normal" social behavior (E), producing increased awareness of the role of alcohol in their lives (M). (2) Participants expressed more insights into their expectations of social gatherings and how to fulfil them (M) → the participants reporting the largest decrease in consumption were the persons reporting the highest initial consumption level (O). (3) More participants reported that they now made conscious decisions about their alcohol consumption prior to participating in a social gathering and that they would feel more comfortable complying with those decisions (M) → some started to drink at a slower pace, and others started bringing their own water bottles (O)	3
Van Lettow et al. (2015); NL [95]	N = 2634; Age not specified Mean age 37.03	Quantitative randomized controlled trial	*Intervention 1*: Drinktest (online personalized feedback intervention) plus prototype alteration (feedback	*Intervention 1*: (1) Received feedback tailored to gender, drinking behavior (also including normative	Not studied	3

E. Context: No Therapist—Not In-Person—Individual

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) [2] and Outcome (O) [4]	Mechanisms (M) [3] and Outcome (O) [4]	Study Quality (MMAT)
	(15.19)		regarding prototype alteration tailored to gender, drinking behavior (also including normative feedback), intentions, and prototypical self-characterization) *Intervention 2*: Drinktest (online personalized feedback intervention) plus cue reminder *Intervention 3*: Drinktest (online personalized feedback intervention) plus prototype alteration and cue reminder *Control*: Original Drinktest (1) received feedback tailored to demographic background (gender drinking behavior (also including normative feedback), intentions, and prototypical self-characterization), alcohol consumption and intentions to reduce drinking. These messages reflected on personal drinking levels in comparison with the Dutch norm and peers' drinking behavior	feedback) (E), intentions and prototypical self-characterization; (2) the prototype message reflected on characteristics that the participants evaluated as personally desirable or undesirable by evaluating themselves on 11 characteristics (E); (3) participants were encouraged to reduce their drinking to achieve their desired characteristics and, in turn, to be positively valued by peers (E); (4) then, participants were guided in their goal setting by selecting an action plan to achieve the desired characteristics (E) → reduction of alcohol consumption (O) *Intervention 2*: (1) Received feedback tailored to demographic background (gender), alcohol consumption and intentions to reduce drinking. These messages reflected on personal drinking levels in comparison with the Dutch norm and peers' drinking behavior (E). Participants were guided in their goal setting by selecting an action plan to achieve the desired characteristics (E). (2) Feedback		

was provided that reflected on their action plans, explaining that a cue reminder may help them to remember their plans (E) (if made) and they received a free silicone bracelet by mail. If participants did not want to receive the bracelet, they were encouraged to select a piece of their own jewellery or another object of frequent use (E) → reduction of alcohol consumption (O)

Intervention 3: (1) Drinktest plus prototype alteration, cue reminder and feedback tailored to gender, drinking behavior (also including normative feedback) (E), intentions and prototypical self-characterization. (2) The prototype message reflected on characteristics that the participants evaluated as personally desirable or undesirable by evaluating themselves on 11 characteristics (E); (3) participants were encouraged to reduce their drinking to achieve their desired characteristics and, in turn, to be positively valued by their peers (E). (4) Participants were guided in their goal setting by selecting an action plan to achieve the desired characteristics (E). (5) Feedback was provided that reflected on

E. Context: No Therapist—Not In-Person—Individual

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) [2] and Outcome (O) [4]	Mechanisms (M) [3] and Outcome (O) [4]	Study Quality (MMAT)
				their action plans, explaining that a cue reminder may help them to remember their plans (E) (if made) and they received a free silicone bracelet by mail. If participants did not want to receive the bracelet, they were encouraged to select a piece of their own jewellery or another object of frequent use (E) → reduction of alcohol consumption (O) *Control group*: Original Drinktest: (1) received feedback tailored to demographic background (gender), alcohol consumption and intentions to reduce drinking. These messages reflected on personal drinking levels in comparison with the Dutch norm and peers' drinking behavior → reduction in alcohol consumption (O)		
Tait et al. (2019); AUS [96]	N = 793; >18+ years Mean age 40.1 (10.0)	Quantitative randomized controlled trial	*Intervention 1*: Daybreak is a self-guided programme, accessible via mobile app and desktop with weekly check-ins and peer support. The Daybreak programme enables participants to connect with other users of the programme through a	*Intervention 1*: (1) Weekly check-ins: the programme includes self-reported questionnaires to encourage participants to undertake self-reflection to explore their intrinsic motivators for change (E)	Not studied	3

			blog function *Intervention 2*: Daybreak + coaching: Daybreak and access to an online health coach between 7:00 and 19:00 on weekdays	(2) Peer support: the programme enables participants to connect with other users of the programme through a blog function (E) → reduction of alcohol use (O) *Intervention 2*: No effective elements		
Zill et al. (2019); DE [97]	N = 608; >18+ years Intervention: mean age 40.4 (11.2) Control: mean age 40.7 (12.1)	Quantitative randomized controlled trial	*Intervention*: Vorvida: a German Internet intervention based on cognitive behavioral therapy (CBT) methods, which automatically tailors content to match individual user characteristics	*Intervention*: (1) Internet intervention based (E) on (2) cognitive behavioral therapy (E) methods, which (3) automatically tailors content to match individual user characteristics (E) → less alcohol consumption (O) → less binge drinking (O)	Not studied	4
F. Context: No Therapist—Not In-Person—Group Component						
Black et al., (2020); AUS [98]	N = 24 Age not specified Mean age: 42.42 (8.69)	Qualitative interviews	*Aim*: to inform recruitment and retention strategies by exploring users' motivations and experiences in using a novel, Internet intervention, the Hello Sunday Morning (HSM) program.	*Intervention*: (1) Publicly set a personal goal to stop drinking or reduce consumption for a set period of time (E); (2) record their reflections and progress on blogs and social networks (E) → reduction of alcohol consumption (O)	Support and normalization: participants gained social support from other consumption (M), and their problems with alcohol and desire to seek help were normalized (M); (2b) goal setting and self-monitoring: setting goals (M) and monitoring progress provided participants with motivation and self-accountability (M) → reduction of alcohol consumption (O)	5
Haug et al., (2020); USA [99]	N = 57 Age 21–30, 31–40, 41–50, 51–60, 61 or older	Quantitative descriptive	*Intervention*: Self-guided alcohol Internet intervention that provides access to several different online social networks and is based on principles of harm reduction,	*Intervention*: Online mutual help program to change their alcohol drinking(E) cyber community (E), social networking (E), and self-help tools (E) → reduction of alcohol	Consumption of more than one online activity (e.g., Facebook group plus online chat) (M) was associated with greater reductions in self-reported alcohol consumption (O)	4

F. Context: No Therapist—Not In-Person—Group Component

Author; Country	Participants; Age Mean (SD)	Method	Intervention or Aim	Intervention Elements (E) [2] and Outcome (O) [4]	Mechanisms (M) [3] and Outcome (O) [4]	Study Quality (MMAT)
			cognitive-behavioral therapy (CBT), and relapse prevention	consumption (O)		
Kirkman et al. (2018); AUS [44]	N = 1917; Age not specified Mean age 46 (11.71).	Quantitative non-randomized	*Intervention* Hello Sunday Morning (HSM): An Australian social media health promotion "movement" that asks participants to set a personal goal publicly to stop drinking or reduce their consumption, for a set period of time, and to record their reflections and progress on blogs and social networks	*Intervention*: (1) Publicly set a personal goal to stop drinking or reduce consumption for a set period of time (E); (2) record their reflections and progress on blogs and social networks (E) → reduction of alcohol use (O)	Not studied	1

[1] Context (C): the way in which the intervention is offered to the target group. [2] Intervention elements (E): the elements from an intervention that contributed to the desired outcome. [3] Mechanisms (M): the responses of people regarding the intervention elements. [4] Outcome (O): reducing or abstaining from alcohol consumption. * The study is mentioned twice in the table because of the two different interventions. Walitzer and Dermen (2004); USA [61], Kiluk et al. (2016); USA [53].

Table 5 Summary of the results

Context	Element of Intervention (How)	Mechanism (Why)	Outcome
A. Practitioner—in-person—individual	*Paying attention to drinking behavior* (1) motivational exercises to change behavior (2) pointing out the health disadvantages of drinking behavior (3) helping to develop networks	Interventions make people think and act differently about alcohol consumption and seek help from family and friends	Less or no alcohol consumption
	The relationship between the patient and practitioner (1) Empathic behavior of therapist	Patient and practitioner collaborate in the identification of additional sessions, judged best to meet the patient's clinical needs and the relationship between the patient and the therapist improves -	Less or no alcohol consumption
B. Practitioner—not in-person—individual	*Personal contact and feedback* (1) workbook, (2) personalized feedback (3) follow-up telephone calls		Less or no alcohol consumption
	Online communication and feedback (1) assignments or modules (2) follow-up chat session	-	
C. Practitioner—in-person—relatives	*The status of the relationship*		
	Teaching the partner to deal with drinking behavior	When the non-drinking partner is taught to deal with the behavior of the drinking partner, this can lead to more understanding and support from the non-drinking partner for the drinking partner.	Less or no alcohol consumption

Context	Element of Intervention (How)	Mechanism (Why)	Outcome
D. Practitioner—in-person—group component	*Motivating to change lifestyle* (1) regarding personal relationships, nutrition and exercise (2) and coping with desires for alcohol	-	Less or no alcohol consumption
	Motivating to change lifestyle delivered in a workplace setting (1) discussion of alcohol use and its consequences (2) training element to change behavior and reduce alcohol use (3) personal advice is given on alcohol use		
E. No practitioner—not in-person—individual.	*Web based interventions* (1) personal feedback (2) comparing own results with others (same phase, age group, gender or country) (3) compared with the previous data of the participant. (4) cognitive behavioral therapy (CBT)	-	Less or no alcohol consumption
	Telephone based interventions (1) self-guided programme or modules or steps on coping strategies and control functions (2) self-help material on the consequences of alcohol use and motivating behavioral change	Mobile phone interventions could provide insight into how much someone drinks through the information provided and this leads to realization of their own drinking behavior	

Context	Element of Intervention (How)	Mechanism (Why)	Outcome
F. No practitioner—not in-person—group component	*Intervention to abstinent people* (1) Not drinking alcohol for a certain period or to drink less (2) share this experience with peers	Intervention to abstinent people (with or without problematic drinking behavior (1) from drinking alcohol for a certain period or to drink less and (2) to share this experience with peers makes people aware of their alcohol consumption and reduces alcohol consumption.	Less or no alcohol consumption

A. Practitioner—in-person—individual

Paying attention to drinking behavior

From the treatments that were delivered by a practitioner, in-person and individually, four effective elements were present: (1) motivational exercises [53,56,60]; (2) pointing out the health disadvantages of drinking behavior [51,52,79]; (3) helping to develop networks [54,57,58,60]; or a combination of these approaches [46]. Paying attention to drinking behavior yields results. Interventions make people think and act differently about alcohol consumption [57] and seek help from family and friends [57,58]. In many studies, the drinking behavior of the control group also changes, although they receive a much smaller intervention [45,53] or no intervention at all [79].

The relationship between the patient and the therapist

The relationship between the patient and the practitioner is of great importance for a successful outcome of the treatment [42,47,49,50,59]. More treatments can improve the relationship between patient and therapist [59]. If the practitioner shows certain behavior [42,47,50], such as reflective listening to the patient, the relationship also improves. There are also indications [47,50] that, if the patient and the practitioner collaborate in the identification of additional sessions judged best to meet the patient's clinical needs, the relationship improves and alcohol consumption is reduced.

B. Practitioner—not in-person—individual

Personal contact and feedback

Of the treatments that were delivered by a practitioner, via telephone or online and individually, five effective elements were present. If a counselling session is given over the phone by a practitioner and a (1) workbook is sent out afterwards on how to reduce alcohol consumption [39,61] or if (2) personalized feedback is given before or after the telephone sessions [39,62,64], then drinking behavior is reduced, also among older adults. (3) If an in-person session is followed by a phone call [65], this also helps to reduce drinking behavior.

Online communication and feedback

If treatment is given via online communication by means of (4) assignments or modules undertaken by the participant about his or her drinking behavior followed by a chat session with the practitioner about the assignments [63] or is (5) followed by feedback from the practitioner [66], then the drinking behavior is reduced. For none of these elements were the reasons why they were effective and which mechanisms they triggered found.

C. Practitioner—in-person—relatives

Regarding the treatments that were delivered by a practitioner, in person and included the involvement of relatives, two effective elements were found.

The status of the relationship

The (1) status of the relationship with (marriage) partners/family members influences the outcome of the intervention [61,68,70–73]. By influencing this status, the treatment can also lead to a successful outcome [69,71].

Teaching the partner to deal with drinking behavior

The partner can be (2) taught to deal with the drinking behavior of the partner through therapy [61,69,70,72] or through (video) information [68], which can lead to lead to alcohol reduction of the drinking partner. If the non-drinking partner is taught to deal with the behavior of the drinking partner, this can lead to more understanding and support from the non-drinking partner for the drinking partner [69]. The drinking partner is then better advised not to use alcohol or to moderate alcohol consumption.

D. Practitioner—in-person—group component

Of the treatments that were delivered by a practitioner, in-person and in a group setting or in a group setting at work, two effective elements were present.

Motivating to change lifestyle

Brief group interventions focusing on (1) motivating participants to change their lifestyles regarding personal relationships, nutrition and exercise [79] and coping with desires for alcohol [65,74] lead to alcohol reduction.

Motivating to change lifestyle delivered in a workplace setting

If an intervention is given in a work setting in which (1) alcohol use and its consequences are discussed [76–78] and/or in which a (2) training element is offered that intends to change behavior and reduce alcohol use [76–78] and/or (3) personal advice is given on alcohol use [76], this leads to lower (risky) alcohol use. For none of these elements were the reasons why they were effective given.

E. No practitioner—not in-person—individual

In relation to treatments that were not delivered by a practitioner, were not in-person and were individual, five effective elements were present.

Web-based interventions

Web-based interventions that give (1) personal feedback [43,64,81,85,86,89,90,95,97] and of which the respondents' result is also (2) compared with the results of people who are in the same phase [43,81] or have the same age group, gender or country of origin [85,89,95] or is compared with the previous data of the participant [81] ensure lower alcohol consumption. Web-based interventions based on cognitive behavioral therapy (CBT) that (3) gradually teach the participant skills for refusing drinks, dealing with cravings, etc., result in lower alcohol consumption [53]. Web-based interviews for older adults that also contain elements of personalized feedback and complement this with information on each person's own specific risks of alcohol consumption as well as information on the effects of alcohol on health, medication use and functional status and recommendations for safe drinking [40,41] lead to lower alcohol consumption.

Telephone based interventions

When a (mobile) phone intervention consist of a (1) self-guided program or modules or steps in which coping strategies and control functions for many alcohol-related issues are taught [83,87–89,96], this could lead to less alcohol consumption and less binge drinking. Mobile phone interventions provide insight into how much someone drinks and leads to realization of their own drinking behavior [87,88]. The provision of (2) self-help material on the consequences of alcohol use and motivating behavioral change in relation to alcohol use [84] during a telephone-based intervention leads to less alcohol use.

F. No practitioner—not in-person—group component

In the treatments that were not delivered by a practitioner, not in-person and in an online group setting, two effective elements were present: Intervention of abstinent people (with or without problematic drinking behavior) (1) from drinking alcohol for a certain period or to drink less [44,98,99] and (2) to share this experience with peers [44,98] makes people aware of their alcohol consumption and reduces alcohol consumption.

4. Discussion

We were interested in *how* (which elements of interventions), *in which context* and *why* (which mechanisms) interventions prevent or reduce (problematic) alcohol consumption among older adults. We found information on the functioning of alcohol interventions for the general population (which often were designed for an 18+ population and therefore also included older adults). Three effective elements of interventions were identified in several types of contexts for the general population. Two of these three effective elements were also found in the interventions especially designed for older adults.

The first element that was mentioned in almost all the contexts was the *provision of information on several alcohol-related issues:* the health disadvantages of drinking behavior [40,41,51,52,79]; coping strategies and control measures for many alcohol-related issues [39,63,76–78,83,84,87–89,96]; and changing participants' lifestyles regarding personal relationships, nutrition and exercise [82].

The second effective element was *being in contact with others and communicating with them about* (*alcohol*) *problems.* Sometimes practitioners help participants to develop (new) social networks [46,57,58,60]. Sometimes the family members or partners of the participants are taught to understand the drinking habits of their loved ones and how to support them in drinking less or abstaining from drinking [70,72]. Contact with peers and colleagues is also an important factor. Participants have to share their experience of abstinence for a period with their peers [44,94] or discuss with their colleagues, in a work setting, alcohol use and its consequences [76–78]. The importance of the role of contact with others or *social networks* on alcohol consumption has been acknowledged previously [100,101]. The A study by Robinson et al. [102] showed strong negative associations between empathic processing (the thoughts or feelings of others and responding accordingly) and social support and both the consequences of drinking and the percentage of drinking days.

Providing participants with *personalized feedback* about their drinking behavior is the third commonly found effective element across the context settings. This element leads to results in interventions that are given by a practitioner in-person [67,76] or by a practitioner via telephone [39,63,65] but also when the feedback is provided through computer-generated communication [40,41,43,64,81,85,86,89,95,97]. The effect of personalized feedback on alcohol consumption was described as important in an earlier review of online alcohol interventions [103]. The study by Riper et al. [104]

showed that single-session, individually personalized feedback without professional guidance can be effective in reducing risky alcohol consumption in young and adult problem drinkers.

The element of the *provision of information* on several-alcohol related issues was also found among one of the three interventions especially designed for older adults [39]. In addition, the element of *providing personalized feedback* was found in two of the three interventions for older adults [40,41]. The element of *contact with others* was not found in the three interventions especially designed for older adults. This is striking because contact with others is especially important for older adults since loneliness is a problem for that age group [105] and there is a relationship between the use of alcohol and loneliness [12,106,107].

We only found three studies on the prevention or reduction of alcohol consumption that were specifically designed for older adults. The reason for this low number of studies could be that the results of the aging of the population (people in general are becoming older and the absolute number of older adults is rising) have only become clear in the last few years and will increase in the years to come. The importance of research into the reduction and prevention of alcohol use in older adults has only recently become more apparent.

Limitations

We did not include grey literature in our review because our aim was to give an overview of the scientific peer-reviewed literature on interventions for older adults to reduce or prevent (problematic) alcohol use first. If we had included grey literature, we might have found more interventions designed specifically for older adults. Although we included many randomized controlled trials, we could not perform a meta-analysis because of the heterogeneity among the interventions, the study populations and the results. We chose to limit the operationalization of the context to the mode of delivery to make it easier to compare the contexts of the studies. For many studies, other information about the context was scarce or incomplete. If this information had been provided, a better comparison of contexts would have been possible. We only included Western high-income countries since problematic drinking behavior is highest among the population in these countries. Non-western countries were excluded because drinking culture, and thus also offered interventions to older adults, differs from western countries. This may limit the generalization of this study to other countries. Results can be generalized to the general (older) population, but not to specific groups (e.g., pregnant people, veterans) since drinking culture is different among these sub-groups. Future research might investigate other vulnerable subgroups. Another limitation is that not in all articles was the 'why' mechanism addressed, indicating that a complete overview of why some interventions were effective is lacking in current research reports. Future research about why interventions were effective and especially why interventions are effective for older adults is necessary. Despite the limitations, this study provides a broad overview of which elements of interventions are effective in preventing or reducing alcohol use as well as indicating why these elements are effective.

Practical implications

This literature review identified three major effective elements of interventions: (1) providing information on the consequences of alcohol consumption; (2) being in contact with others and communicating with them about (alcohol) problems; and (3) personalized feedback about drinking behavior. Two of these elements, information provision and personalized feedback, are related to creating awareness. This is also a common answer to why an intervention works. People became aware of their alcohol consumption and what it means for their bodies. For developers of new interventions concerning the reduction or prevention of alcohol consumption of (older) adults, but also for policy makers, it could be a good start to look at what creates awareness regarding alcohol consumption for that specific target group. The third effective element, contact with others and communicating about (alcohol) problems, is also an element that is important for developers of interventions and policy makers. People explain that sharing their experiences of (reducing) alcohol consumption helps them. In doing so, it is important that friends and family are supportive of the choice of the person to reduce or stop drinking and respond empathically about this choice. This could be difficult for some friends or family members as drinkers tend to seek each other out and then influence each other's use [100]. Developers of interventions and policy makers could therefore facilitate the process of helping (older) adults to develop contacts with people that are supportive of their choice to reduce or prevent their alcohol consumption.

Scientific recommendations

We only found three studies on the prevention or reduction of alcohol consumption that were specifically designed for older adults. In order to provide adequate interventions to help reduce or prevent alcohol consumption for older adults, more research is necessary on what creates awareness regarding alcohol consumption for this target group. Moreover, research on how to help older adults develop contacts with people that are supportive of their choice to reduce or prevent their alcohol consumption is necessary, because these contacts are helpful in reducing or preventing alcohol consumption.

5. Conclusions

This study provides answers to the questions of how (which elements of interventions), in which context and why (by which mechanisms), interventions prevent or reduce (problematic) alcohol consumption among older adults. Most of the studies were not especially designed for older adults but also included older adults. The findings of this study highlight three major effective elements of interventions: (1) providing information on the consequences of alcohol consumption; (2) being in contact with others and communicating with them about (alcohol) problems; and (3) personalized feedback about drinking behavior. Two of these elements were also used in the interventions especially designed for older adults. In order to provide adequate interventions to help reduce or prevent alcohol consumption for older adults, more research is necessary on what creates awareness regarding alcohol consumption for this target group.

Author Contributions: Conceptualisation, J.B., D.v.d.M., R.C., H.D., R.B. and A.R.; methodology, J.B., D.v.d.M., R.B. and A.R., investigation: J.B. and A.R.; formal analysis, J.B. and A.R.; writing—original draft preparation, J.B. D.v.d.M. and A.R.; writing—review and editing; D.v.d.M., R.C., H.D., R.B. and A.R.; supervision: D.v.d.M., R.B. and A.R. All authors have read and agreed to the published version of the manuscript.

Funding: This research was funded by the Netherlands organisation for Health Research and Development (ZonMw number: 555002003).

Institutional Review Board Statement: Not applicable.

Informed Consent Statement: Not applicable.

Data Availability Statement: Not applicable.

Conflicts of Interest: The authors declare no conflict of interest.

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CHAPTER 7

General Discussion

Discussion

In recent years, care and support for older adults has changed from a traditional medical model to a more humanistic approach by acknowledging the importance of ensuring that the care provision aligns with the preferences of the person (1-3). This model is referred to as person-centered care. Under the influence of this change to person-centered care more focus is given to the autonomy of older adults.

This focus on the autonomy of older adults can be seen in different areas of care delivery. Residential care facilities adopt and implement person-centered care (interventions) with the intention to enhance residents' autonomy (4-6). Similarly, hospitals adapt their working methods towards person-centered care in order to enhance the patients' autonomy (7-9), whilst interventions to prevent or reduce alcohol consumption implement methods to enhance patients' autonomy (10-12) However, the importance and manifestation of the autonomy of older adults depends to a large extent on the care setting (13, 14).

The general aim addressed in this dissertation is: Understanding autonomy of older adults receiving care in different care settings. This dissertation focuses on three different care settings and each setting has its own research aim tailored to the particular setting.

Setting 1 concerns older adults with dementia receiving long-term care in residential care facilities. In this setting autonomy for people with dementia is studied on the level of residential care facilities. People with dementia who are living in residential care facilities are dependent on the care provided in the physical environment and the associated use of technologies.

> The research aim for this setting is: *To understand how caregiving approaches and the physical environment influence autonomy and informal care for people with dementia living in residential care facilities.*

Setting 2 concerns older adults receiving care during contact isolation in hospital. Contact isolation in a hospital setting leads to separation from relatives, loss of freedom, and uncertainty regarding disease status (15-18). Coping strategies can help to better maintain (some form of) autonomy in this restrictive and isolated environment.

> The research aim for this setting is: *To understand how older adults cope with a contact isolation situation in a hospital setting.*

Setting 3 concerns community-dwelling older adults receiving interventions to prevent or reduce (problematic) alcohol consumption. Older adults may be sensitive to perceived threats to their personal autonomy when a healthcare professional expresses concern about their alcohol consumption. This concern is necessary because even in small amounts the consumption of alcohol can cause greater harm among older adults than their younger counterparts. Older adults metabolize and excrete alcohol more slowly (19, 20). Furthermore, alcohol can also accelerate and aggravate the onset of conditions associated with aging (e.g., falls (21), cognitive impairment (22), and/or sleep disturbance (23-25)).

> The research aim for this setting is: *To explore how (i.e., which elements of interventions), in which context, and why interventions are successful in preventing or reducing (problematic) alcohol consumption among older adults.*

In this chapter the main findings of the studies are described as well as the reflections, strengths and limitations, and possible future directions for research and practice.

Main Findings

Residential care facilities

To understand how caregiving approaches and the physical environment influence autonomy and informal care for people with dementia living in residential care facilities, a literature review, a multiple case study, and a cross-sectional survey study were established. Based on the literature review (Chapter 2) we concluded that the most important element for the continuation of autonomy for residents is the improvement of the relationship between residents, staff members, and informal caregivers. To improve the relationship between staff members and resident it is vital that formal caregivers get to know the residents. If staff members understand the preferences of the residents and act upon this knowledge this could contribute to the autonomy of the residents. For the informal care provision, staff members should have a social, flexible, and welcoming attitude towards informal caregivers; this attitude helps stimulate the relationship between staff members and informal caregivers. This is important because the informal care provided by family members to people with dementia increased when the contact between staff members and informal caregivers improved. The physical environment and the use of technology have a direct influence on the autonomy of residents in residential care facilities. Specially designed spaces, for instance, therapeutic gardens, create activities for residents which remind them of themselves and subsequently contribute to their autonomy. Similarly, technology assists residents in performing tasks and increases their sense of autonomy.

In the multiple case study (Chapter 3) we explored how, in practice, residential care facility staff enhance autonomy and improve informal care. We studied the influence of interactions (contact and approachability between residents, staff members, and informal caregivers) and the physical environment, including the use of technologies. For the enhancement of autonomy, the interaction between both (care and welfare) staff and residents proved to be of great significance. Staff members approaching residents in a respectful manner, knowing the residents, and encouraging autonomous behavior leads to more autonomy for residents. The behavior, attitude, and interaction of staff members with informal caregivers appeared to enhance informal care provision. Staff mebers who acknowledge the importance of informal caregiving for residents and also actively stimulate relatives to perform informal care could stimulate informal care provision. The physical environment can contribute to autonomy by providing more freedom of movement for people with dementia. The provision of informal care can also be improved if technology, for instance an interactive electronic record, is used to keep family and friends informed about the resident and to actively approach their social circle to remain part of the resident’s life.

The cross-sectional survey study among staff members (Chapter 4) explored the association between residential care facility staff characteristics and staff attitudes regarding perceived person-centered care provision and including informal caregivers in the caregiving process. A higher age of both the care and welfare staff was associated with a more negative attitude toward their perceived person-centered care and informal care provision. Similarly, welfare staff had a less positive attitude towards informal care provision compared to care staff. Finally, work experience and education of staff was not associated with perceived person-centered care provision or attitudes towards informal care provision.

Hospital

Coping can help to better maintain (some form of) autonomy in a restrictive contact isolation situation. Interviews were held (chapter 5) in order to try to understand how community-dwelling older adults coped with a contact isolation situation in a hospital setting during the COVID-19 pandemic. The study revealed that older adults use emotion-focused coping strategies, for instance seeking support from their social network or trying to accept the situation. Additionally, problem-focused coping strategies were used; these involve different mechanisms like acting on the environment (e.g., asking to be involved in decision making) or the self to modify the problem at hand. Staff members' activities (e.g., the way they approach older adults and the way they listened to and include older adults in decisions regarding their health or day-to-day living situation) are fundamental for older adults in order to improve their physical and psychological wellbeing during contact isolation in a hospital setting. These staff member activities include person centered care, such as a personalized approach with the patients, helping patients to understand their health condition, involving older adults in decision making, and responding to requests for older adults.

With regard to autonomy, the coping strategies presented in this study showed varied ways in which autonomy is maintained. Furthermore, it was revealed that if patients are treated with dignity and when staff members have and/or make time to pay attention to them on a personal level and provide them with information about their (health) situation, patients are better able to cope with the isolation. This ensures patients are treated as a person and feel that their personal autonomy is respected – even in the extraordinary contact isolation situation. An even clearer example is the sense of control on health, isolation, or day-to-day-living situations coping strategy used by patients. If patients are given more control or autonomy about their own situation, they are able to better cope with the contact isolation situation. Moreover, autonomy is related to emotion-focused coping strategies. For the seeking support from family, friends, and fellow patients coping strategy, patients contact others of their own accord to be supported; this is similar to the autonomous opportunities for them to get into contact and to be in control.

Alcohol consumption among older adults

To explore how (i.e., which elements of interventions), in which context and why interventions are successful in preventing or reducing (problematic) alcohol consumption among older adults, a literature review was conducted (Chapter 6). Personalized treatment and treatment via the Internet were the most common ways in which the interventions for reducing alcohol consumption for both older adults and the general population were delivered. The results of this study recommend that new interventions for older adults could make use of one or more of the three most successful elements of interventions to prevent or reduce problematic alcohol use: 1) providing information on the consequences of alcohol consumption; 2) being in contact with others and communicating with them about their (alcohol-related) problems; and 3) personalized feedback about their drinking behavior.

Successful elements of interventions to prevent or reduce (problematic) alcohol consumption relate to the autonomy of older adults. The study revealed that if information on the consequences of alcohol consumption is provided or people receive personalized feedback, some may choose to drink less or stop drinking. Being in contact with others and communicating with them about (alcohol) problems also affects their drinking behavior. If health care professionals show certain behaviour such as reflective listening and empathic resonance (warmth, genuineness, egalitarianism), the relationship improves between health care professionals and older adults. Also, when older adults and health care professional collaborate and health care professionals try to meet the needs of older adults, their relationship improves and several people autonomously choose to drink less or stop drinking. The results of the study established that well-informed older adults who feel supported by a healthcare professional or friends and family are more likely and more aware to stop or reduce their drinking behavior. This change in drinking behavior is then an intrinsic and autonomous personal choice. This results in autonomous older people who take matters regarding their drinking behavior into their own hands.

Reflections

There is a considerable difference between the settings and the capacities of the older adults studied in this dissertation. Three of the studies in this dissertation focus on autonomy for people with dementia. Dementia seems to be at the opposite end of the spectrum concerning autonomy because it is a disease with substantial effects on cognitive, functional, and psychological capacities (26, 27). People suffering from dementia often face challenges voicing their needs and wishes, and they may need support from others to express and execute their autonomy. The other studies focus on autonomy for community dwelling older adults who often experience less challenges with voicing their needs and wishes. Therefore, the concept of autonomy is much more difficult to conceptualise and disentangle for people with dementia. Although this dissertation provides insights in how autonomy can be maintained for people with dementia living in residential care facilities, these insights are more on the pragmatic level (e.g which clothes to were and what to eat). This was also the scope of this dissertation. More philosophical and ethical topics such as type of medicine or treatment (e.g. the different side effects), as well as palliative and end-of-life care are much more complicated to study the relation with autonomy and ask for other methodologies and study perspectives.

The studies in this dissertation ascertain that, independently of the setting and the cognitive, functional, and psychological capacities of the older adult, three elements are crucial for the autonomy of older adults: personalized care, support of family and friends, and the care relationship.

Personalized care

This dissertation contributes to the evidence that personalized care is essential for older adults in different care settings to maintain their autonomy. Care can be personalized in several ways.

The studies in this dissertation indicate that for people who receive day-to-day care (i.e., residents with dementia living in residential care facilities and patients experiencing contact isolation in hospital) two ways of personalizing care were important for autonomy: personal choice and involving older adults in decision making. If staff members are aware of the choices of the residents or patients or if they include residents or patients in decision-making regarding their care, residents and patients receive care that is adjusted to their needs. This could help residents and patients to feel in control and therefore more autonomous about their (health) situation. The importance of personal choice and involving older adults in decision making is researched in several settings and the results of the studies have indicated that the quality of care and the quality of life improves for older adults when they are included in decisions regarding their care (26, 27), as in the case of people suffering from dementia (28, 29) or experiencing contact isolation in hospital (30). Though, the results of this dissertation ascertain that personal choice and involving older adults in decision making is a crucial element for older adults to maintain their autonomy independently from the setting.

This dissertation also evidences that for people trying to prevent or reduce their drinking behavior receiving personalized care in the form of personalized feedback is important. The results of this dissertation reveal that when an intervention provides people with personalized feedback on each person's own specific risks of alcohol consumption and information on the effects of alcohol on health, medication use and functional status, this could prevent or reduce their alcohol consumption. The study of Jovanovic (31) also stated that the problem of alcohol (over) consumption may be viewed at the individual level and treatment should thus be designed according to the needs of the individual. The results of this dissertation reveal that personalized feedback is a manner to approach alcohol (over) consumption on an individual level.

Support of family and friends

The results of this dissertation contribute to the knowledge how support from family and friends not only influences the quality of live older adults but also their autonomy. Other studies have also identified that the influence of family members for people with dementia living in residential care facilities involves the provision of personal and instrumental care but also contributes to preserve the identity and quality of life (32-34). Several other studies established that virtual contact with family and friends during contact isolation resulted in valuable benefits in terms of patient recovery (35-38). The study by Robinson et al. (39) showed that empathic processing (knowing the thoughts or feelings of others and responding accordingly) and social support had a positive influence on drinking behavior for males. The results of this dissertation reveal that for people with dementia living in residential care facilities, family and friends could help staff members to gain more knowledge about residents. This change in knowledge about the personal preferences of the person with dementia could lead to more (care) alternatives in accordance with their autonomous choices. For older adults experiencing contact isolation in a hospital, contact with family and friends could help them accept the situation and contacting others on their own accord to be supported is related to the autonomous opportunities for them to get into contact and to be in control.

For older adults that participated in an intervention to prevent or reduce alcohol consumption, being in contact with family and friends and communicating with them about (alcohol) problems was fundamental in helping them prevent or reduce alcohol consumption. One of empathic processing's key elements is that friends and family are supportive of the choice of the person to reduce or stop drinking and respond empathically about this choice. This could be difficult for some friends or family members as drinkers tend to seek each other out and then influence each other's use. Thus, a person may have a network of friends and family that are strongly supportive of drinking because the person has attracted similar friends and was not interested in developing friendships with individuals whose drinking habits differed to their own (40).

The care relationship

The results of this dissertation reveal that for people who receive day-to-day care as well as for older adults participating in an intervention to prevent or reduce alcohol consumption, the development of a care relationship in which older adults feel understood and seen as a person, contributes to the autonomy of older adults. Other studies concluded that because care staff have the most one-to-one contact with residents or patients, they are able to influence residents' well-being (28, 41-45). The results of this dissertation contributed to this knowledge, because the results reveal that better relationships between staff and residents or patients in a day-to-day care situation leads to staff members having more knowledge of and a better understanding of the situation of the residents or the patients. The individual needs of the residents or patients could be better considered and included in daily care and support. For residents with dementia living in a residential care facility this meant that because staff members were able to meet their needs regarding preferences for food or clothing, the residents remained autonomous within these parts of their lives. This dissertation establishes that for patients in contact isolation in a hospital setting a better relationship with staff members is supported by open and honest communication by the staff about the (health) circumstances of the patients. This form of communication gives the patients a feeling of trust in the staff and helps them to understand their health situation and would make the patients more autonomous about that part of their lives.

Other studies indicated that if the older adults and the health care professional collaborate and try to meet the patient's clinical needs, the relationship improves and alcohol consumption is reduced (46, 47). The results of this dissertation add to this knowledge. The form of contact and interactions between older adults and health care professional is an important factor for success for interventions to prevent or reduce alcohol consumption. If health care professionals exhibit certain behaviour such as reflective listening to the patient and empathic resonance (warmth, genuineness, egalitarianism), the relationship improves and a change in the drinking behaviour is more likely. If older adults are in a care relationship in which older adults feel understood and seen as a person, this contributes to their possibilities to change their drinking behaviour and therefore to their autonomy.

Strengths and limitations

In the following paragraphs, considerations of the study design, research approach, the study population used, and its strengths and limitations are outlined.

Study design

A strength of this dissertation is the use of different types of research, namely literature reviews, qualitative research (observations and interviews), and quantitative research (survey). The use of these different methods allowed us to combine information from different perspectives which resulted in a thorough understanding and a broad view on autonomy for older adults in the different care settings.

One of the residential care facilities where the research in setting 1 took place also commissioned this part of the research. The study topics and study design were discussed with the commissioning party before the research started, as well as during the research when preliminary results were available. The other residential care facility was invited to participate by the commissioning residential care facility. The advantage of this approach as that we were able to initiate regular meetings involving different types of stakeholders of both residential care facilities; staff members, board members and policy makers, to attain knowledge of current practice. The client councils of the residential care facilities were also informed. This design also allowed us to share our preliminary results which created the situation in which the residential care facilities could immediately act on the research results.

This dissertation includes three settings, though the insight gained from each setting may be limited for two reasons. First, the studies may not provide a representative picture of the setting. For the residential care facility setting, only two residential care facilities were included. Both facilities could quality as a small-scale living facility within a larger nursing home. Generalization of the findings to other types of nursing homes may thus be limited. For the hospital setting, only one hospital was included. The inclusion of multiple hospitals could provide a more generic view on the care provided during the COVID-19 pandemic and the use of coping strategies by older adults to maintain their autonomy. For the alcohol intervention setting only a literature review was performed. By including more empirical research, greater insights about alcohol interventions for older adults and autonomy could be provided.

Second, for the empirical research in both the residential care facility setting and the hospital setting, we depended on the cooperation of organizations and people. The support of the people like contact persons of the residential care facilities or the hospital or of staff member to participate in the research could have been influenced by a positive attitude regarding autonomy for residents and patients. This attitude. may have introduced selection bias and could have created a more positive outcome on how autonomy is supported within current practice.

Realist evaluation

The use of the realist evaluation approach in this dissertation was guided by the need to adequately study the autonomy of three specific client populations embedded in three specific settings. While traditional evaluation questions focus on what works, realist evaluation focuses on how it works, for whom, and the influence of the context (50). As a result, the use of the realist evaluation helped us answer questions about how, why, and for whom interventions or programs in different care settings may help maintain autonomy for older adults. The use of the realist approach strengthened the theoretical basis of our findings and confirmed that this approach retrieved new information about autonomy of three specific client populations embedded in three specific settings.

Applying realist approach also had its challenges. Realist evaluation is a relatively new research approach. This means that there is still a need for methodological guidance on how to use this research approach and how to interpret its concepts (51). Literature on realist evaluation provides a general description of the concepts used in the research approach (e.g. context, mechanism and outcome). In order to be able to apply these concepts in our studies, it was necessary to determine for each study what the definitions of the context, mechanism and outcomes were for that particular study. Multiple deliberation sessions between co-authors were necessary to establish the definitions of the concepts for each study. Sometimes this led to very broad definitions, as in setting 1 where the context was people with dementia living in a care home. And sometimes it led to very practical definitions as in setting 2 where the definition of a mechanism was a coping strategy. Like other collogues (48) the forming of CMO configurations needed some practice. We needed to ensure that the evidence was strong enough for the configuration to hold. Therefore, we held regular team meetings to check each other's assumptions and biases. For the literature reviews in Chapters 2 and 6 we accepted that not all primary studies explicitly provided all the information, especially not for the why question. We had to thus set up a process of differentiating and documenting what was explicitly identified in papers from interpretations derived through a realist analytic lens. Multiple deliberation sessions between co-authors were also required to refine the information from the primary studies. Because realist evaluation is a theory driven approach we used this knowledge to formulate our research question. Though, instead of asking: what works, we asked how it worked and for whom. Therefore, we were able to not only point out which mechanisms were at work, but sometimes also why they worked and for whom. However, because we used already existing insights, also based on our literature searches, and because not every mechanism could be explained as to why it works, some of the results only confirms the already existing knowledge.

From a practical point of view, the application of the realist methodology also helped the managers and staff members of the research facilities to see the relevance of the studies. Therefore, the use of the realist evaluation approach created more support for the studies among stakeholders.

Study population

Because the studied settings and the cognitive, functional, and psychological capacities of older adults cover a broad spectrum, this dissertation provides a wide view on aging and how autonomy is reflected in it. For two of our studies (Chapters 5 and 6) we used the chronological age of 55+ to define old age. This is consistent with current research being done on older adults. Biological researchers often start defining old age at the chronological age of 55+ because of that age changes in body systems become more present (49, 50). For the studies about people with dementia no age limit was used.

Nevertheless, the age of people with dementia living in residential care facilities in the Netherlands is often higher than 55+ (51).

Future research directions

A number of ideas for further research based on the results of this dissertation are presented. These ideas are structured into the following topics: personalized care, support of family and friends and the care relationship.

Personalized care

To personalize care, it is important to find out and understand what the people receiving the care want and need. For people with dementia voicing their needs and wishes is often difficult, which makes asking them and involving them in decision making more complicated. Though, also for older adults in a contact isolation situation in a hospital and for older adults receiving an intervention to prevent or reduce alcohol consumption it could be difficult to participate in decision making. A method to help older adults to participate in decisions could be the use of person-centered language by staff members or health care professionals. Person-centered language could be described as to communicate in ways that promote personhood, well-being, and respect (52). For interventions to prevent or reduce alcohol consumption person-centered language facilitates people who are in treatment (53). More research could be done about how person-centered language could be used to improve involvement in decision making of older adults in the different care settings.

Support of family and friends

In all the studied settings the support of family and friends was vital to maintain autonomy for older adults. One element that came to the fore in all settings was the use of electronic devices to facilitate digital contact between residents, patients, staff members, and family and friends. For contact between staff members and family and friends the use of a contact app on a mobile phone led to more involvement of family and friends in the lives of the residents. More research could be done about how to use such apps and communication methods to enhance the support of family and friends. Considering current events, related to COVID, when face to face social contact is not always possible, it may be even more important to research how electronic devices could facilitate digital contact between residents or patients and family and friends. The importance of digital contact with friends and family during contact isolation due to COVID-19 pandemic was also found among residents of residential care facilities, since digital contact was a way to remain connected with family and friends (54).

The care relationship

Because the actions of staff members and healthcare professionals play such an important role in maintaining autonomy for older adults, the emphasis should not only be on what care providers should do to maintain autonomy for their residents or patients but also on what staff members and healthcare professionals need (i.e. in terms of knowledge and/or skills) in order to practice this behavior. Therefore, more research is required about the needs of staff members and healthcare professionals regarding autonomy-stimulating behavior towards residents and patients. With this knowledge education programs and vocational training could be developed to support staff members and healthcare professionals in their tasks.

This dissertation establishes that some characteristics of staff members can influence their attitudes toward both their perceived person-centered care provision and informal care provision. However, research is necessary to deepen this association. This could help develop education programs and vocational training to support staff members in the performance of (person-centered) care activities, affecting the autonomy of older adults. Additionally, the perspective of people with dementia and staff members should be linked so that a more holistic picture of the care provided and the experiences of the people with dementia is created. This would provide more insights into whether a technique or approach of a staff member actually leads to more autonomy for people with dementia.

Implications for policy and practice

This dissertation adds to the knowledge that autonomy for older adults can be maintained in different ways. Some findings are related to the setting in question, whilst others are setting independent. Regardless, the most important implication is that older adults should be able to co-determine their autonomy as much as possible

Personalized care

The results of this dissertation conclude that for older adults in the three different healthcare settings involving older adults in decision making is fundamental in the maintenance of their autonomy. This is not a new finding but it is a reminder to include older adults in decisions. For staff members working in residential care facilities (28, 29) or hospitals several interventions regarding involving older adults in decision making already exist (26, 27). The study of Oerlemans (55) also suggest that health care professionals learn how to involve older adults in decision making through observing and copying from their peers . Therefore, it could be helpful to create a learning environment in which staff members or healthcare professionals could learn from each other how to involve older adults in decision making. For example, staff members of residential care facilities and hospitals could discuss involving older adults in decision making situations during team meetings.

Developers of new interventions to prevent or reduce alcohol consumption could include more options for involvement of older adults in decision making in their interventions, and also support healthcare professionals with guidelines and instructions how to involve people in decision making. Another element of personalized care that developers of new interventions should consider is the provision of personalized feedback. By tailoring the feedback about their alcohol consumption to the situation of the person, the person is more likely to understand the severity of their situation and could change their drinking behavior.

Support of family and friends

The results of this dissertation add to the knowledge that family and friends need to be involved in the residential care facility as more than just visitors. This can help maintain and stimulate the autonomy of residents. The management of residential care facilities having a supportive view of the involvement of family and friends could help staff to execute this. This finding has been reflected in other studies (56, 57). Staff and family and friends have to communicate constructively, share information about the resident, and ensure that the resident's social network remains a part of their life. This conclusion was also drawn by other studies like Puurveen (56) and Backhaus (58). Our dissertation contributes to this knowledge by showing that electronic devices like an app could be used to enhance communication between staff and family and friends about the resident but also for inviting family and friends to social activities.

The results of this dissertation added to the knowledge that for patients experiencing contact isolation in hospital or residential care facilities, contact with relatives was vital. Like other studies (35-38) this dissertation demonstrated that contact with relatives via text messages, telephone, or video conferences helped the patients cope with the situation. Staff members, volunteers, or hostesses could help facilitate this. Hospitals could acquire digital devices to help patients stay in contact with their friends and family in case the patients do not own or have not brought their own device. Thomas (59) recommends interventions for staff members to help them set up video conference methods to facilitate contact between family and patients. To reduce the workload of staff members, volunteers or hosts and hostesses could be trained on how to help patients or residents and their family and friends with this form of contact.

The care relationship
Because the actions of staff members and healthcare professionals play such a pivotal role in maintaining autonomy for older adults, the emphasis should not only be on what care providers should do to increase autonomy but also on what staff members and healthcare professionals need in order to practice this behavior. Based on this dissertation and other studies (60, 61) the following recommendation could be given: it would be beneficial to create a learning environment for staff to improve their autonomy supporting skills. For example, residential care facility staff could share knowledge and skills by observing each other during interactions with residents. Residential care facility and hospital staff could also have regular team meetings to share and discuss the challenges regarding the autonomy of residents or patients. Healthcare professionals within alcohol interventions could also be helped by including instructions in training manuals explaining how to maintain patient autonomy.

General conclusion

The aim of this dissertation was understanding the autonomy of older adults receiving care in three different care settings: People with dementia living in residential care facilities, older adults receiving care during contact isolation in a hospital setting, and community-dwelling older adults receiving interventions to prevent or to reduce (problematic) alcohol consumption. The studies in this dissertation show that three elements are important for the autonomy of older adults independently of the setting and of the cognitive, functional, and psychological capacities of the older adults: personalized care, involvement of family and friends, and the care relationship. Care can be personalized through the use of involving older adults in decision making and by providing personalized feedback. Family and friends could help staff members to gain more knowledge about residents or patients; having them involved in patient care could also lead to more (care) choices in accordance with the autonomous choices of residents or patients. Contact with family and friends and communicating with them about alcohol problems could help prevent or reduce alcohol consumption. The most significant element of the care relationship with staff members is the older adults being understood and seen as a person; this type of care contributes to the autonomy of older adults.

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English Summary

Background

In recent years, care and support for older adults changed from a traditional medical model to a more humanistic approach by acknowledging the importance of ensuring that the care provision aligns with the preferences of the person (1-3). This model is referred to as person-centered care. In person-centered care more attention is on maintaining the autonomy of older adults.

This focus on the autonomy of older adults is visible in different aspects of care delivery to older adults. Residential care facilities adopt and implement person-centered care (interventions) with the intention to enhance residents' autonomy (4-6). Similarly, hospitals adapt their working methods towards person-centered care in order to enhance the patients' autonomy (7-9). Furthermore, interventions to prevent or reduce alcohol consumption among older adults also focus and implement methods to enhance older adults' autonomy (10-12) However, the importance and manifestation older adults autonomy depends to a large extent on the setting of care delivery or the intervention (13, 14).

For every setting a different perspective autonomy was used. Also, for every setting a different aspect was or different aspects were researched that could facilitate autonomy of older adults**.** Table 1 provides an overview of the settings.

Table 1 Overview of the settings

Setting	Perspective on autonomy	Facilitating element(s)
1. Autonomy of people with dementia living in residential care facilities	Decisional and executive autonomy in a residential care setting	Caregiving approaches of staff Physical environment of the residential care facility Informal care
2. Older adults receiving care during contact isolation in a hospital setting	Autonomy in contact isolation	Coping strategies
3. Community-dwelling older adults receiving interventions to prevent or reduce (problematic) alcohol consumption	Autonomy regarding decisions on alcohol consumption	Elements of interventions

Setting 1: Autonomy of people with dementia living in residential care facilities

In the first setting the autonomy of people with dementia living in residential care facilities is researched by looking at how care providers, informal care providers and the care setting contribute to autonomy of people with dementia. Facilitating the autonomy of people with dementia living in residential care facilities is rather complex (15, 16). Older adults with dementia face difficulties voicing their needs and wishes, and they may need support from others to express and execute their autonomy.

Collopy (17)) and later on McCormack (18) describe the concept of autonomy for people with dementia seen in the light of self-determination and describe the difference between decisional and executive autonomy. Decisional autonomy refers to the ability and the freedom to make one's own decisions. Executive autonomy refers to the ability and the freedom to realize of those decisions. Limited executive autonomy can easily be confused with limited decisional autonomy (18). Therefore, staff of residential care facilites should be aware of the fact that although people with dementia may not have the capacity to carry out a decision, they maintain the right to be involved in the decision making itself (1, 18)

> The research aim for this setting is: *To understand how caregiving approaches and the physical environment influence autonomy and informal care for people with dementia living in residential care facilities.*

Chapter 2 entails a literature review about how caregiving approaches and physical environment in residential care facilities, including technologies, contribute to the maintenance of autonomy and informal care provision for people with dementia. Forty-nine articles were included in this literature review. From the literature it can be concluded that the most important element for the maintenance of autonomy of residents is the quality of the relationship between residents and formal/informal caregivers. A better relationship increases the knowledge (sharing) about the resident and contributes to their autonomy. To stimulate informal care provision, it is important that the formal caregivers have a social, flexible, and welcoming attitude towards informal caregivers. Such attitudes improve the relationship between formal and informal caregivers. Increased contact between formal and informal caregivers also leads to more informal care provision by family members of people with dementia.
The physical environment and the use of technology have a direct influence on the

autonomy of people with dementia. Specially designed spaces, for instance, therapeutic gardens, create activities for residents that remind them of themselves and contribute to their autonomy. Technology can assist residents in performing tasks by themselves and increases the resident's sense of autonomy. Though, elements of the physical environment and technology often support the caregiving approach. For instance, small-scale living environments (physical environment) create a situation where a steady relatively small group of formal caregivers' serves a small group of residents (e.g. 6 to 8 residents instead of 20 residents (19)). Since the formal caregivers have fewer residents to care for, they have more contact moments with these residents resulting in better and more thorough knowledge of the residents. This improves the relationship between residents and formal caregivers. The use of technologies may save caregiver's time for primary tasks, which may increase the time they have for secondary tasks such as interaction with the residents.

Chapter 3 elaborates on chapter 2 and reports on two case studies in residential care facilities. These case studies were used to explore how residential care facility staff in practice enhance autonomy and improve informal care. We studied the influence of interactions (contact and approachability between residents, staff members and informal caregivers) and the physical environment, including the use of technologies, on autonomy of people with dementia.

In this study we found that the interaction between both (care and welfare) staff and residents is important in the enhancement of autonomy of residents. When formal caregivers approach residents in a respectful manner, have knowledge about the residents and encourage autonomous behavior of residents, this leads to more autonomy for residents. The behavior, attitude and interaction of formal caregivers with informal caregivers also appeared to enhance informal care provision. Formal caregivers should acknowledge the importance of informal caregiving for residents and actively stimulate relatives to perform informal care tasks. The physical environment can contribute to autonomy of residents by providing more freedom of movement for people with dementia. The provision of informal care can also be improved if technology is used to inform family and friends about the resident's life and actively approach the family and friends to remain part of the resident's life.

Chapter 4 reports a study in which we explored the association between characteristics of staff, such as age and working experience, and staff attitudes regarding perceived person-centered care provision and informal caregivers. A convenience sample of 68 care and welfare staff members of two residential care facilities filled out a questionnaire about their characteristics and attitudes. Staff attitudes regarding person-centered care were measured with the Person-centered Care Assessment Tool (P-CAT). Staff attitudes regarding informal care provision were measured with the Attitudes Toward Families Checklist (AFC). Multiple linear regression analyses explored the association between staff characteristics, namely age, work experience, education, and function (care or welfare) and their attitudes. This study shows that the higher the age of both care and welfare staff, the more negative their attitude towards their perceived person-centered care delivery and informal care provision. Welfare staff had a less positive attitude towards informal care provision than care staff. Work experience and education were not associated with perceived person-centered care provision or informal care provision. The perceived person-centered care provision of the care and welfare staff was both positive.

Setting 2: older adults receiving care during contact isolation in a hospital setting

Older adults in contact isolation in a hospital face themselves, usually very suddenly, in a situation in which they lost a considerable amount of autonomy. The decision of placing them in contact isolation is often made for them, for instance during the COVID-19 pandemic. The results of the contact isolation are that patients are not allowed to leave the hospital room anymore and are not allowed to see their family and friends. Patients are not able to make their own decisions regarding several aspect of their life and some decisions are not freely chosen and are not instigated and fully endorsed by their conscious self (20, 21). Older adults in contact isolation in a hospital therefore often experience stress. Patients in contact isolation have reported a poor understanding of the reasons and procedures for contact isolation, resulting in a greater level of dissatisfaction with their care (22, 23).

> The research aim for this setting is: *To understand how older adults cope with a contact isolation situation in a hospital setting.*

Chapter 5 reports on a study that explores how older adults (55+) cope with contact isolation in a hospital setting to improve their physical and psychological wellbeing. We studied which elements of this care setting trigger coping strategies that impact older adults physical and psychological wellbeing. The realist evaluation approach was used to formulate initial program theories on coping strategies used by (older) adults in an isolation setting. Coping strategies are used by individuals to deal with a variety of stressful situations in order to lower the levels of stress (24). Twenty-one semi-structured interviews with older patients who were in contact isolation in a hospital were analysed. This study revealed that both emotion-focused coping strategies as well as problem-focused coping strategies were used by older adults during contact isolation. Emotion-focused coping strategies do not focus on a problem at hand but on dealing with feelings and perceptions associated with a stressful situation, such as denial and/or positive reinterpretation of events. Problem-focused coping strategies focus primarily on devising solutions to a problem at hand, such as asking others to help you solve the problem. The study also uncovered some new specific coping strategies, such as seeking support from fellow patients and acceptance and rationalization. The results have useful implications for hospital staff to improve the wellbeing of older adults in contact isolation. Problem-focused coping strategies by patient may be stimulated through staff by taking the time to listen to patients, providing sufficient information, exercising shared decision making, and by increasing the recognisability of staff by adjusting clothing or by using a photo or a name tag. Emotion-focused coping strategies are more difficult to stimulate because they are intrinsic strategies used by patients to regulate stressful emotions. Nevertheless, trust in staff is an emotion-focused coping strategy which could be stimulated by improving the relationship between patients and staff.

Setting 3: older adults receiving interventions to prevent and/or reducing (problematic) alcohol consumption.

In today’s society consuming alcoholic beverages is a routine part of the social landscape for much of the population, including for community-dwelling older adults (25). Several studies have recently indicated that older adults are drinking more than previous generations in the same age (26-29). The prevention and reduction of alcohol use for older adults is critical because even in small amounts alcohol consumption can cause greater harm to older adults than to their younger counterparts. Older adults metabolize and excrete alcohol more slowly (30, 31). Moreover, alcohol can accelerate and aggravate the onset of conditions associated with aging (e.g., falls (32), cognitive impairment (33), and/or sleep disturbance (34-36)).

Autonomy is a common ethical principle in addressing problematic alcohol consumption**.** For many older adults, the consumption of alcohol has a central role in their social lives and therefore positively contributes towards their quality of life (37, 38)**.** Additionally, for some people the deterioration of human health with age leads to the use of alcohol as a coping strategy to overcome negative changes in both physical and mental health (39-41), including loneliness and social isolation (42), unemployment, or economic downturns (43).

> The research aim for this setting was: *To explore how (i.e., which elements of interventions), in which context, and why interventions are successful in preventing or reducing (problematic) alcohol consumption among older adults.*

Chapter 6 reports our literature review about how (i.e., which elements of interventions), in which context and why interventions are successful in preventing and/or reducing (problematic) alcohol consumption among (older) adults*.* We found 61 studies studying interventions aimed at preventing or reducing (problematic) alcohol use. Three studies report about intervention which were specifically designed for older adults. These three studies focused on interventions with personalized feedback and information provision. The interventions designed for the general populations differed to a great extent. However, the majority of these intervention included therapy sessions and

often contain motivational interviews or motivational enhancement with other educational materials. Personal treatment and the Internet were the most mentioned ways in which the interventions were delivered. Based on our findings we conclude that future interventions for older adults to prevent or reduce problematic alcohol use for (older) adults use of one or more of the three most successful elements of current interventions: 1) providing information on the consequences of alcohol consumption; 2) being in contact with others and communicating with them about (alcohol) problems; and 3) personalized feedback about drinking behaviour.

Discussion

Chapter 7 presents the main findings of the studies in this dissertation. The studies in this dissertation show that three elements are important for the autonomy of older adults independently of the setting and of the cognitive, functional, and psychological capacities of the older adults: 1) personalized care; 2) involvement of family and friends; and 3) the care relationship between staff and patient.

Personalized care

First, care can be personalized through the use of involving older adults in decision making and by providing personalized feedback. For people who receive day-to-day care (i.e., residents with dementia living in residential care facilities and patients experiencing contact isolation in hospital) two ways of personalizing care were important for autonomy: personal choice and involving older adults in decision making. If staff members are aware of the choices of the residents or patients or if they include residents or patients in decision-making regarding their care, residents and patients receive care that is adjusted to their needs. This could help residents and patients to feel in control and therefore feel more autonomous about their (health) situation. For people trying to prevent or reduce their drinking behavior receiving personalized care in the form of personalized feedback is important. The results of this dissertation reveal that when an intervention provides people with personalized feedback on each person's own specific risks of alcohol consumption and information on the effects of alcohol on health, medication use and functional status, this could prevent or reduce their alcohol consumption.

Involvement of family and friends

Secondly, involvement of family and friends was shown to help staff members to gain more knowledge about residents or patients; having them involved in patient care could also lead to more (care) choices in accordance with the autonomous choices of residents or patients. For older adults experiencing contact isolation in a hospital, contact with family and friends helps them to accept the situation and contact with others on their own accord to be supported is related to the autonomous opportunities for them to get into contact and to be in control. Contact with family and friends and communicating with them about alcohol problems helps to prevent or reduce alcohol consumption.

Care relationship between staff and patient

Finally, the most important element of the care relationship with the staff is that the older adult is understood and actually seen as a person. When a staff member was able to meet the needs of older adults in terms of preferences for certain elements of their lives, the older adults remained autonomous within these parts of their lives. Also, when therapists exhibit behaviors such as reflective listening to the patient and empathic resonance (warmth, genuineness, egalitarianism), the relationship improves and a change in drinking behavior is more likely.

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Nederlandse samenvatting

Achtergrond

In de afgelopen jaren is de zorg en ondersteuning voor oudere volwassenen veranderd van een traditioneel medisch model naar een meer humanistische benadering door te erkennen dat het belangrijk is dat de zorgverlening aansluit bij de voorkeuren van de persoon (1-3). Dit model wordt persoonsgerichte zorg genoemd. Bij persoonsgerichte zorg gaat meer aandacht uit naar het behoud van de autonomie van oudere volwassenen. Deze focus op de autonomie van oudere volwassenen is zichtbaar in verschillende aspecten van zorgverlening aan oudere volwassenen. Woonzorgvoorzieningen implementeren persoonsgerichte zorg(interventies) met de bedoeling om de autonomie van bewoners te vergroten (4-6). Ook ziekenhuizen veranderen hun werkwijze richting persoonsgerichte zorg om de autonomie van de patiënt te vergroten (7-9). Verder richten interventies ter preventie of vermindering van alcoholgebruik onder oudere volwassenen zich op methoden om de autonomie van oudere volwassenen te vergroten (10-12) Het belang en de manifestatie van autonomie van oudere volwassenen kan echter verschillen door de setting van zorgverlening of de interventie (13-14).
Het algemene doel van dit proefschrift is: Het verkrijgen van Inzicht in autonomie van ouderen die zorg ontvangen in verschillende zorgsettingen. Dit proefschrift richt zich op drie verschillende zorgsettingen zoals weergegeven in tabel 1. Voor elke setting

Tabel 1 Overzicht van de settingen

Setting	Perspectief op autonomie	Faciliterend(e) element(en)
1. Autonomie van mensen met dementie die in een woonzorgcentrum wonen	Beslissende- en uitvoerende autonomie in een woonzorginstelling	Zorgbenaderingen van het personeel Fysieke omgeving van de woonzorgvoorziening Mantelzorg
2. Oudere volwassenen die zorg ontvangen tijdens contactisolatie in een ziekenhuis	Autonomie in contactisolatie	Copingstrategieën
3. In de gemeenschap wonende oudere volwassenen die interventies ontvangen om (problematisch) alcoholgebruik te voorkomen of te verminderen	Autonomie met betrekking tot beslissingen over alcoholgebruik	Elementen van interventies

wordt een ander perspectief op autonomie gebruikt. Ook wordt voor elke setting een ander aspect of andere aspecten onderzocht die de autonomie van oudere volwassenen zouden kunnen bevorderen.

Setting 1: Autonomie van mensen met dementie die in een woonzorgcentrum wonen

In de eerste setting wordt de autonomie van mensen met dementie die wonen in woonzorgvoorzieningen onderzocht door te kijken hoe zorgverleners, mantelzorgers en de zorgsetting bijdragen aan autonomie van mensen met dementie. Het faciliteren van de autonomie van mensen met dementie die in woonzorgvoorzieningen wonen is vrij complex (15-16). Oudere volwassenen met dementie kunnen moeite hebben met het verwoorden van hun behoeften en wensen, en soms hebben zij ook hulp van anderen nodig om hun autonomie te uiten en uit te voeren.
Collopy (17) en later McCormack (18) beschrijven het concept van autonomie voor mensen met dementie gezien in het licht van zelfbeschikking en beschrijven het verschil tussen beslissende en uitvoerende autonomie. Beslissingsautonomie verwijst naar het vermogen en de vrijheid om eigen beslissingen te nemen. Uitvoerende autonomie verwijst naar het vermogen en de vrijheid om die beslissingen uit te voeren. Een beperking van de uitvoerende autonomie kan gemakkelijk verward worden met een beperking in de beslissende autonomie (18). Daarom moet het personeel van woonzorgcentra zich bewust zijn van het feit dat, hoewel mensen met dementie misschien niet de capaciteit hebben om een beslissing uit te voeren, ze wel het recht behouden om betrokken te worden bij de besluitvorming zelf (1-18).

Het onderzoeksdoel voor deze setting is: *Begrijpen hoe handelingen van zorgverleners en de fysieke omgeving van invloed zijn op autonomie en mantelzorg voor mensen met dementie die in woonzorgvoorzieningen wonen.*

Hoofdstuk 2 beschrijft een literatuurstudie die onderzocht hoe handelingen van zorgverleners en de fysieke omgeving in woonzorgvoorzieningen, inclusief technologieën, bijdragen aan het behoud van autonomie en informele zorgverlening voor mensen met dementie. De studie bestond uit negenenveertig artikelen. Uit de literatuur kan geconcludeerd worden dat het belangrijkste element voor het behoud van autonomie van bewoners de kwaliteit van de relatie tussen bewoners, formele zorgverleners en mantelzorgers is. Een betere relatie met zowel de bewoner als met zijn mantelzorger vergroot de kennis van de formele zorgverlener over de bewoner en draagt bij aan diens autonomie. Om informele zorgverlening te stimuleren, is het belangrijk dat de formele zorgverleners een sociale, flexibele en gastvrije houding hebben ten opzichte van informele zorgverleners. Een dergelijke houding draagt bij aan een beter contact tussen formele en informele zorgverleners. Meer contact tussen formele zorgverleners en mantelzorgers leidt weer tot meer mantelzorg door familieleden van mensen met dementie.

De fysieke omgeving en het gebruik van technologie hebben een directe invloed op de autonomie van mensen met dementie. Speciaal ontworpen ruimten, bijvoorbeeld therapeutische tuinen, stellen bewoners in staat activiteiten uit te voeren die ze vroeger ook uitvoerden en dragen daardoor bij aan hun autonomie. Technologie kan bewoners helpen om zelf taken uit te voeren en vergroot het gevoel van autonomie van de bewoner. Elementen van de fysieke omgeving en technologie kunnen ondersteunend zijn aan de handelingen van zorgverleners. Zo creëren kleinschalige woonomgevingen (fysieke omgeving) een situatie waarin een vaste relatief kleine groep formele zorgverleners een kleine groep bewoners verzorgt (bijvoorbeeld 6 tot 8 bewoners in plaats van 20 bewoners)(19). Doordat de formele zorgverleners minder bewoners te verzorgen hebben, hebben zij meer contactmomenten met deze bewoners wat resulteert in een betere en diepgaandere kennis van de bewoners. Hierdoor verbetert de relatie tussen bewoners en formele zorgverleners. Het gebruik van technologieën kan zorgverleners tijd besparen voor primaire taken, waardoor ze meer tijd hebben voor secundaire taken zoals interactie met de bewoners.

Hoofdstuk 3 borduurt voort op hoofdstuk 2 en beschrijft twee casestudies in woonzorgcentra. Deze casestudies werden gebruikt om te onderzoeken hoe medewerkers van woonzorgvoorzieningen in de praktijk autonomie vergroten en mantelzorg verbeteren. We onderzochten de invloed van interacties (contact en aanspreekbaarheid tussen bewoners, medewerkers en mantelzorgers) en de fysieke omgeving, inclusief het gebruik van technologieën, op autonomie van mensen met dementie.

In deze studie vonden we dat de interactie tussen zowel (zorg- en welzijns)medewerkers als bewoners belangrijk is bij het vergroten van de autonomie van bewoners. Wanneer medewerkers bewoners op een respectvolle manier benaderen, kennis hebben over de bewoners en autonoom gedrag van bewoners aanmoedigen, leidt dit tot meer autonomie voor bewoners. Het gedrag, de houding en de interactie van medewerkers met mantelzorgers bleek ook de mantelzorg te bevorderen. Medewerkers dienen het belang van mantelzorg voor bewoners te erkennen en familieleden actief te stimuleren om mantelzorgtaken uit te voeren. De fysieke omgeving kan bijdragen aan de autonomie van bewoners door meer bewegingsvrijheid te bieden aan mensen met dementie. Het verlenen van mantelzorg kan ook worden verbeterd als technologie wordt gebruikt om familie en vrienden te informeren over het leven van de bewoner en de familie en vrienden actief te benaderen om deel te blijven uitmaken van het leven van de bewoner.

Hoofdstuk 4 doet verslag van een onderzoek waarin we de associatie onderzochten tussen kenmerken van medewerkers, zoals leeftijd en werkervaring, en de houding van medewerkers ten opzichte van de ervaren persoonsgerichte zorgverlening aan mantelzorgers. Een steekproef van 68 zorg- en welzijnsmedewerkers van twee woonzorgcentra vulde een vragenlijst in over hun kenmerken en attitudes. De attitudes van de medewerkers ten aanzien van hun perceptie van persoonsgerichte zorg werden gemeten met de Person-centered Care Assessment Tool (P-CAT). De attitudes van de medewerkers ten aanzien van mantelzorg werden gemeten met de Attitudes Toward Families Checklist (AFC). Meervoudige lineaire regressieanalyses onderzochten het verband tussen personeelskenmerken, namelijk leeftijd, werkervaring, opleiding, en functie (zorg of welzijn) en hun attitudes. Uit deze studie blijkt dat hoe hoger de leeftijd van zowel zorg- als welzijnsmedewerkers, hoe negatiever hun houding ten opzichte van de door hen ervaren persoonsgerichte zorgverlening en mantelzorg. Welzijnspersoneel had een minder positieve houding ten opzichte van mantelzorg dan zorgpersoneel. Werkervaring en opleiding hingen niet samen met de waargenomen persoonsgerichte zorgverlening of informele zorgverlening.

Setting 2: oudere volwassenen die zorg ontvangen tijdens contactisolatie in een ziekenhuissetting

Oudere volwassenen in contactisolatie in een ziekenhuis komen, meestal zeer plotseling, in een situatie terecht waarin zij een aanzienlijke mate van autonomie verliezen. De beslissing om hen in contactisolatie te plaatsen wordt vaak *voor* hen genomen, bijvoorbeeld tijdens de COVID-19 pandemie. Het gevolg van de contactisolatie is dat patiënten de ziekenhuiskamer niet meer mogen verlaten en hun familie en vrienden niet meer mogen zien. Patiënten zijn niet in staat om hun eigen beslissingen te nemen met betrekking tot verschillende aspecten van hun leven. Sommige beslissingen zijn niet vrij gekozen en worden niet geïnitieerd en volledig onderschreven door hun bewuste zelf (20,21). Oudere volwassenen in contactisolatie in een ziekenhuis ervaren daarom vaak stress. Patiënten in contactisolatie geven aan een slecht begrip van de redenen en procedures voor contactisolatie te hebben. Dit resulteert in een grotere mate van ontevredenheid over hun zorg (22,23).

Het onderzoeksdoel voor deze setting is: *Begrijpen hoe oudere volwassenen omgaan met een situatie van contactisolatie in een ziekenhuissetting.*

Hoofdstuk 5 doet verslag van een onderzoek dat bekijkt hoe oudere volwassenen (55+) omgaan met contactisolatie in een ziekenhuissetting om hun lichamelijk en psychisch welbevinden te verbeteren. We onderzochten welke elementen van deze zorgsetting copingstrategieën uitlokken die het fysieke en psychische welbevinden van ouderen beïnvloeden. De onderzoeksbenadering Realist Evaluation werd gebruikt om initiële programmatheorieën te formuleren over copingstrategieën die gebruikt worden door (oudere) volwassenen in een isoleersetting. Copingstrategieën worden door mensen gebruikt om met uiteenlopende stressvolle situaties om te gaan en zo het stressniveau te verlagen (24). Eenentwintig semigestructureerde interviews met oudere patiënten die in een contactisolatie in een ziekenhuis zijn verbleven werden geanalyseerd. Deze studie toonde aan dat zowel emotie-gerichte copingstrategieën als probleem-gerichte copingstrategieën werden gebruikt door oudere volwassenen tijdens contactisolatie. Emotiegerichte coping richt zich niet op een probleem dat zich voordoet maar op het omgaan met gevoelens en percepties geassocieerd met een stressvolle situatie, zoals ontkenning en/of positieve herinterpretatie van gebeurtenissen. Probleemgerichte copingstrategieën richten zich vooral op het bedenken van oplossingen voor een probleem dat zich op dat moment voordoet, zoals anderen vragen je te helpen. De studie bracht ook enkele nieuwe specifieke copingstrategieën aan het licht, zoals steun zoeken bij medepatiënten en acceptatie en rationalisatie van de situatie. De resultaten geven nuttige aanbevelingen voor ziekenhuismedewerkers om het welzijn van oudere volwassenen in contactisolatie te verbeteren. Probleemgerichte copingstrategieën van patiënten kunnen door de medewerkers gestimuleerd worden door de tijd te nemen om naar patiënten te luisteren, voldoende informatie te verstrekken, gedeelde besluitvorming uit te oefenen en door de herkenbaarheid van de medewerkers te vergroten door kleding aan te passen of door een foto of naamplaatje te gebruiken. Emotiegerichte copingstrategieën zijn moeilijker te stimuleren omdat het intrinsieke strategieën zijn die door patiënten worden gebruikt om stressvolle emoties te reguleren. Toch is vertrouwen in de medewerkers een emotiegerichte copingstrategie die gestimuleerd zou kunnen worden door de relatie tussen patiënten en personeel te verbeteren.

Setting 3: oudere volwassenen die interventies krijgen om (problematisch) alcoholgebruik te voorkomen en/of te verminderen.

In de huidige samenleving is het consumeren van alcoholische dranken onderdeel geworden van veel sociale activiteiten voor een groot deel van de bevolking, ook voor een groot deel van de thuiswonende oudere volwassenen (25). Verschillende studies hebben onlangs aangegeven dat oudere volwassenen meer drinken dan vorige generaties in dezelfde leeftijd (26-29). De preventie en vermindering van alcoholgebruik voor oudere volwassenen is van cruciaal belang omdat alcoholgebruik zelfs in kleine hoeveelheden grotere schade kan toebrengen aan ouderen dan aan jongeren. Oudere volwassenen metaboliseren en scheiden alcohol langzamer uit (30-31). Bovendien kan alcohol het ontstaan van aandoeningen die geassocieerd worden met veroudering versnellen en verergeren (bijv. vallen (32), cognitieve stoornissen (33), en/of slaapstoornissen (34-36)).

Autonomie is een ethisch principe bij de aanpak van problematisch alcoholgebruik. Voor veel oudere volwassenen heeft de consumptie van alcohol een centrale rol in hun sociale leven en draagt daarom positief bij aan hun kwaliteit van leven (37, 38). Daarnaast leidt de verslechtering van de menselijke gezondheid met de jaren voor sommige mensen tot het gebruik van alcohol als copingstrategie om negatieve veranderingen in zowel fysieke als mentale gezondheid te overwinnen (39-41), waaronder eenzaamheid en sociaal isolement (42), werkloosheid, of economische neergang (43).

Het onderzoeksdoel voor deze setting is: *Onderzoeken hoe (d.w.z. welke elementen van interventies), in welke context en waarom interventies succesvol zijn in het voorkomen of verminderen van (problematisch) alcoholgebruik onder oudere volwassenen*.

Hoofdstuk 6 rapporteert onze literatuurstudie over hoe, in welke context en waarom interventies succesvol zijn in het voorkomen en/of verminderen van (problematisch) alcoholgebruik onder (oudere) volwassenen. Wij vonden 61 studies die interventies gericht op het voorkomen of verminderen van (problematisch) alcoholgebruik bestudeerden. Drie studies rapporteren over interventies die specifiek voor oudere volwassenen waren ontwikkeld. Deze drie studies richtten zich op interventies met gepersonaliseerde feedback en informatievoorziening. De interventies ontworpen voor de algemene populaties verschilden sterk van elkaar. Het merendeel van deze interventies omvatte echter therapiesessies en bevatten vaak motiverende gesprekken of motiverende versterking met ander educatief materiaal. Persoonlijke behandeling en het internet waren de meest genoemde manieren waarop de interventies werden geleverd. Op basis van onze bevindingen concluderen wij dat toekomstige interventies voor (oudere) volwassenen om problematisch alcoholgebruik te voorkomen of te verminderen gebruik moeten maken van één of meer van de drie meest succesvolle elementen van de huidige interventies: 1) het geven van informatie over de gevolgen van alcoholgebruik; 2) het in contact staan met anderen en met hen communiceren over (alcohol)problemen; en 3) persoonlijke feedback over drinkgedrag.

Hoofdstuk 7 presenteert de belangrijkste bevindingen van de studies in dit proefschrift. De studies in dit proefschrift tonen aan dat drie elementen belangrijk zijn voor de autonomie van oudere volwassenen, onafhankelijk van de setting en van de cognitieve, functionele, en psychologische capaciteiten van de oudere volwassenen: 1) gepersonaliseerde zorg; 2) betrokkenheid van familie en vrienden; en 3) de zorgrelatie tussen medewerker en bewoner of patiënt.

Gepersonaliseerde zorg

Zorg kan worden gepersonaliseerd door de oudere volwassenen te betrekken bij de besluitvorming en door gepersonaliseerde feedback te geven. Voor mensen die dagelijkse zorg ontvangen (d.w.z. bewoners met dementie die in woonzorgcentra wonen en patiënten die contactisolatie ervaren in het ziekenhuis) waren twee manieren om de zorg te personaliseren belangrijk voor autonomie: persoonlijke keuze en betrokkenheid bij de besluitvorming. Als de medewerkers op de hoogte zijn van de keuzes van de bewoners of patiënten en/of als zij bewoners of patiënten betrekken bij de besluitvorming over hun zorg, krijgen bewoners en patiënten zorg die is afgestemd op hun behoeften. Dit kan ertoe bijdragen dat bewoners en patiënten het gevoel krijgen dat zij de regie in handen hebben en zich daardoor autonomer voelen over hun (gezondheids)situatie. Voor mensen die hun drinkgedrag proberen te veranderen is het ontvangen van gepersonaliseerde zorg in de vorm van gepersonaliseerde feedback van belang. De resultaten van dit proefschrift laten zien dat wanneer een interventie mensen gepersonaliseerde feedback geeft over ieders eigen specifieke risico's van alcoholgebruik en informatie over de effecten van alcohol op gezondheid, medicatiegebruik en functionele status, dit hun alcoholgebruik kan veranderen.

Betrokkenheid van familie en vrienden

Het betrekken van familie en vrienden kan de medewerkers helpen om meer kennis over bewoners of patiënten te verkrijgen. Als medewerkers hen betrekken bij (zorg) situaties zou dit ook kunnen leiden dat meer (zorg)keuzes in overeenstemming zijn met de keuzes van bewoners of patiënten. Voor oudere volwassenen die contactisolatie ervaren in een ziekenhuis helpt contact met familie en vrienden hen om de situatie te accepteren. Indien deze oudere volwassenen uit eigen beweging contact opnemen met anderen om ondersteund te worden oefenen zij autonomie uit. Ook helpt contact met familie en vrienden en met hen communiceren over alcoholproblemen ouderen volwassenen om alcoholgebruik te voorkomen of te verminderen.

Zorgrelatie tussen medewerker en bewoner of patiënt

De zorgrelatie tussen de medewerker en de bewoner of patiënt kan ervoor zorgen dat de bewoner of patiënt wordt begrepen en daadwerkelijk wordt gezien als een persoon. Wanneer een medewerker in staat is om tegemoet te komen aan de behoeften of voorkeuren van oudere volwassenen voor bepaalde onderdelen van hun leven dan blijven de oudere volwassenen autonoom binnen deze delen van hun leven. In het geval van ouderen volwassen die hun drinkgedrag willen veranderen kan het gedrag van medewerkers zoals reflectief luisteren naar de patiënt en empathische resonantie (warmte, echtheid) de relatie tussen medewerker en oudere volwassenen verbeteren en daardoor ook bijdragen aan een verandering in drinkgedrag.

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Dankwoord

Een proefschrift schrijven leert je vaak ook veel over jezelf. Wat ik me pas tijdens het schrijven van mijn laatste artikel besefte was dat ik altijd nieuwsgiering ben geweest naar menselijk handelen. De reden dat ik met de studie fiscaal recht ben begonnen was omdat ik wilde begrijpen waarom mensen zoveel weerstand voelen tegen het betalen van belasting. Deze nieuwsgierigheid naar menselijk gedrag heeft bijgedragen aan het proefschrift dat nu voor jullie ligt. Een proefschrift schrijf je niet alleen. Veel dank aan iedereen die hier een rol in heeft gespeeld.

Allereerst wil ik iedereen bedanken die heeft bijgedragen aan het onderzoek. Alle bewoners, patiënten, medewerkers en familieleden en vrienden van bewoners die hebben meegewerkt aan het onderzoek. In het bijzonder wil ik Walter, Corina en Anita bedanken voor jullie begeleiding in de eerste fase van mijn onderzoek. Jullie gedrevenheid voor de ouderenzorg hebben ervoor gezorgd dat ik met nog meer enthousiasme en betrokkenheid heb gewerkt aan het onderzoek.

Daarnaast wil ik de leden van de promotiecommissie, prof. dr. Verbeek, prof. dr. Schuurmans, prof. dr. Polder, prof. Dr. Hertogh en dr. Ir. De Bruin, bedanken dat u de tijd heeft genomen om mijn proefschrift te lezen en te beoordelen, en dat u bereid bent om deel te nemen aan de oppositie tijdens de verdediging.

Veel dank aan mijn begeleidingsteam promotoren Katrien Luijkx en Caroline Baan en copromotor Leonieke van Boekel. Katrien, dank dat jij die nieuwsgierigheid naar het menselijk handelen bij mij herkende en mij de kans gaf mezelf te ontplooien. Caroline, dank voor je betrokkenheid bij mij en mijn onderzoek. Dank dat ik uit jullie kennis, expertise en enthousiasme heb mogen putten. Leonieke, dank voor al je hulp bij het onderzoek, maar ook zeker voor je hulp met alles om het onderzoek heen. Ik denk dat niet veel mensen kunnen zeggen dat ze met hun copromotor carnaval hebben gevierd.

Daarnaast wil ik ook graag Aukelien, Dike en Andrea bedanken voor jullie begeleiding. Aukelien, dank je wel voor je hulp en ondersteuning in de laatste fase van het promotietraject. Jouw rustige en nauwgezette manier van werken zorgde ervoor dat ik de laatste onderzoeken goed kon afronden. En onze gezellige (wandel)afspraken zorgde voor de motivatie om dit te doen.

Dike, dank je wel dat ik ook van jouw kennis en kunde gebruik heb mogen maken voor mijn promotietraject. Onze afspraken, vaak onder het genot van goede koffie, waren erg opbouwend en waardevol.

Andrea, wat zijn we in de 8 jaar dat we bij Tranzo hebben gewerkt veel van elkaar geweest. We hebben samen de leukste teambuildingsdag van Tranzo georganiseerd. We zijn kamergenoten geweest en ik was jouw opvolger als lid van de AIO raad. De laatste twee jaar hebben we ook samen mogen werken aan onderzoeken. Dank voor het vertrouwen dat je in mij had en dank voor jouw grote enthousiasme waarmee je me wist aan te steken.

Ook ben ik veel dank verschuldigd aan het Covid team bestaande uit Lenny, Vera, en Tessel en het verslavingsteam bestaande uit Rik, Hans en Rob. Het was fijn om ondanks het gedwongen werken op afstand toch nauw met jullie samen te werken. Verder wil ik ook Marjolein, Hanneke, Remco en Nathalie erg bedanken voor hun bijdrage aan het onderzoek.

Dank aan alle Tranzo-collega's die samen hebben gezorgd voor een fijne werksfeer en gezellige momenten. Kim, Miel en mijn glutengenoot Karien. Dank voor alle gezellige werkdagen in onze bond kamer RP 007. Kim en Karien, fijn met jullie onder het genot van vele liters thee van alles te kunnen bespreken. Miel, het was erg leuk om samen met jou in de wereld van Realist Evaluation te duiken met als kers op de taart ons bezoek aan het congres in Brisbane. Tineke, dank je wel voor alle overlegmomenten maar ook dat ik als jouw paranimf al heb mogen ervaren hoe het is om op het podium te staan. Lieke en Loraine, heel erg bedankt voor onze gezellige momenten in T met als hoogtepunt het Duitse uurtje op vrijdagmiddag. 'Hoch die Hände. Wochende!'. Daarnaast wil ik Willeke, Hilde, Sanne, David, Arthur, Nathalie, Mariëlle, Annerieke, Lisette, Lieke, Meriam, Jolande, Ingrid, Bea, Rebecca, Ien, Jacqueline en Evelien en zo vele anderen bedanken voor de gezellige en inspirerende ontmoetingsplek die Tranzo is. Emely dank dat jij altijd klaar stond met thee en een luisterend oor. Ria speciale dank naar jou voor het regelen van alle afspraken. De leukste afspraak die je geregeld hebt was toch wel die in Tokio.

Lieve vrienden, dank dat ik voor de nodige ontspanningsmomenten altijd bij jullie terecht kon.

Lieve Noud en Kristy, Nancy en Dave, Patrick en Henriette, Mark en Nathalia en Bas en Vanessa. Dank je wel voor alle gezellige avondjes en (AKP) uitstapjes waarin we naast het praten over van alles en nog wat ook onze hobby, pretparken bezoeken, met jullie konden delen.

Lieve fiscalisten, Eva, Monique, Nikie, Annelou, Angela, Erwin en Ralph. Dank voor jullie steun en interesse tijdens mijn promotietraject en alle ontspannen wandelingen, etentjes, weekendjes weg, eftelingbezoekjes, karaoke- en songfestivalavondjes. Dat we maar snel weer samen een glaasje mogen drinken.

Lieve Loriane, ook na jouw vertrek bij Tranzo hebben we contact gehouden en dat heeft geresulteerd in een jaarlijks bezoek aan het mooie Heidelberg! Dank dat ik naast je gezelligheid ook nog gebruik mocht maken van jouw kennis als ‘de oudere AIO’.
Lieve Ingeborg, erg bedankt voor je gezelligheid, maar ook voor je luisterende oor tijdens mijn promotietraject. Fijn om ook deze fase van het leven met jou te kunnen delen.

Lieve Jody, ik ben erg dankbaar dat ik jou heb leren kennen. Eerst als collega en al vrij snel als vriendin. We hebben samen al veel mogen delen en ik ben heel blij dat jij mij bijstaat als paranimf.

Lieve Kristy, omdat het een klein beetje jouw ‘schuld’ is dat ik ben gaan promoveren vond ik het fijn als jij aan mijn zijde zou staan als paranimf. Dank je wel voor alle gezellige momenten en steun in de afgelopen jaren.

Lieve familie, bedankt voor jullie liefde en betrokkenheid.

Lieve oom Peter en tante Berta, dank voor uw interesse in mij en ons en voor uw grote gastvrijheid. Heel erg bedankt dat ik een schilderij van u, oom Peter, als illustratie mocht gebruiken.

Lieve tante Jo, u bent een voorbeeld van hoe je op hoge leeftijd nog altijd je eigen leven vorm kan geven. Dank u voor uw liefde en steun en dat u altijd zo betrokken bent bij mij en bij ons.

Lieve Jos en Christien, ik ben erg dankbaar dat u in mijn leven bent. Uw liefde, interesse en aandacht betekenen veel voor mij. Misschien wel meer dan ik u laat weten. Het is heel fijn te weten een thuis bij u te hebben.

Lieve Twan, zoals jij al eens mooi omscheef hebben wij qua innerlijk en uiterlijk veel verschillen. Ik blond en jij donker, ik een echte Alpha, jij een echte Bèta. Maar in de afgelopen jaren hebben we onze overeenkomsten gevonden. Dank je wel voor je steun en je liefde broer. Alexandrine, dank voor jouw rol in Twans's en ons leven.

Lieve, lieve Joris, wat fijn dat jij in mijn leven bent. Ik kan oprecht zeggen dat ik met jou alles aankan. Dank dat je me gesteund hebt in het uitvoeren van mijn promotieonderzoek maar ook in de weg die erbij hoorde. Ik hoop nog heel vaak 11 uur 11 met je te kunnen meemaken. Dank voor wie je bent.

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Empire State of mind - ALICE KEYS

About the author

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