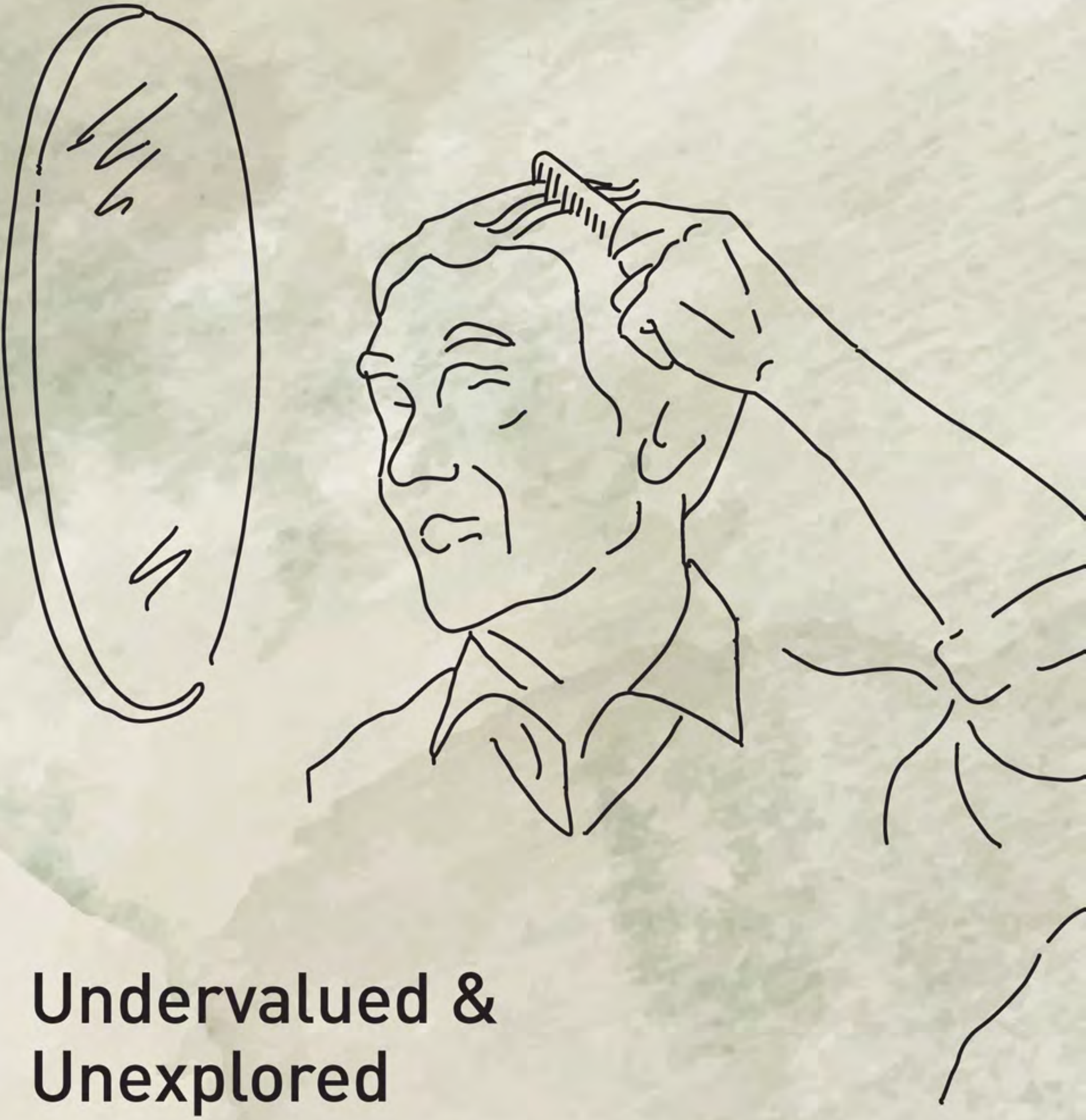

# Undervalued & Unexplored

## Underpinning and Guiding Nursing Care in Activities of Daily Living

**Svenja Cremer**

Stellingen behorende bij het proefschrift

# Undervalued & Unexplored

*Underpinning and Guiding Nursing Care in Activities of Daily Living*

Svenja Cremer

1. Simpele ADL zorg bestaat niet. (dit proefschrift)
2. De wetenschap biedt onvoldoende handvaten voor het verlenen van ADL zorg. (dit proefschrift)
3. Zonder fundament geen huis. Zonder betrokken zorgvrager geen persoonsgerichte ADL zorg. (dit proefschrift)
4. Soms begint ADL zorg niet in de badkamer, maar buiten in de modder. (dit proefschrift)
5. Taakgericht werken sluit de deur voor buitengewone kansen. (dit proefschrift)
6. Huidige richtlijnen falen in het overbruggen van de kloof tussen wetenschap en praktijk.
7. In elke verpleegkundige of verzorgende moet een mini ergotherapeut verborgen zitten.
8. Op automatische piloot zorg verlenen verander je alleen door regelmatig in de spiegel te kijken.
9. Coloring outside the lines makes the bigger picture. (unknown)
10. That will all make sense when I am older. So there’s no need to be terrified or tense. I’ll just dream about a time, when I’m in my aged prime, ‘Cause when you’re older, absolutely everything makes sense. (Olaf, Frozen)

# Undervalued & Unexplored

## Underpinning and Guiding Nursing Care in Activities of Daily Living

Svenja Cremer

The research presented in this thesis was conducted at CAPHRI Care and Public Health Research Institute, Department of Health Services Research, of Maastricht University. CAPHRI participates in the Netherlands School of Public Health and Care Research CaRe. This research was supported by funding from the Netherlands Organization for Health Research and Development (ZonMw), Grant ID: 516004014.

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## Underpinning and Guiding Nursing Care in Activities of Daily Living

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Prof. Dr. W. Paans, Hanze Hogeschool Groningen

# Contents

**Part I: Underpinning ADL Nursing Care**

**Part II: Providing and Pilot- Implementing Practical Guidance**

**Addenda**

*Für Opa Peter – Machet joot.*

# Reader’s Guide

The underlying product of this dissertation is a clinical practice guideline (CPG) for nursing professionals on care for Activities of Daily Living (ADL) (Figure 1). The CPG itself can be found in the guideline database of the Dutch Association for Nursing Professionals (V&VN) and is considered part of this dissertation. This reader's guide explains the structure of this dissertation, and how it relates to the CPG (Figure 2). The development process of the CPG is divided into several phases. First, **Chapter 2** of the dissertation presents the results of the analysis of challenges in ADL nursing care. Next, the questions intended for inclusion in the CPG were formulated. **Chapter 3** answers one of these questions, namely the question which ADL nursing interventions effectively improve ADL independence or comfort. However, due to the diverse and multifaceted nature of these questions, not all of them could be addressed within the scope of the CPG. Hence, **Chapter 4** presents an exploratory study for a question that ultimately did not find its place within the CPG. This chapter explores the use of a green care environment to facilitate ADL performance. **Chapter 5** outlines the process of guideline development and explains how other questions were addressed in light of sparse scientific evidence. Furthermore, the process of transforming accessible information into practical recommendations for nursing professionals in real-world scenarios is explained. Additionally, in **Chapter 6** the CPG's key recommendations were pilot-implemented to support nursing staff in providing ADL care. This pilot implementation demonstrates the application of the key recommendations in different nursing teams, as well as the perceptions of factors influencing their use in practice.

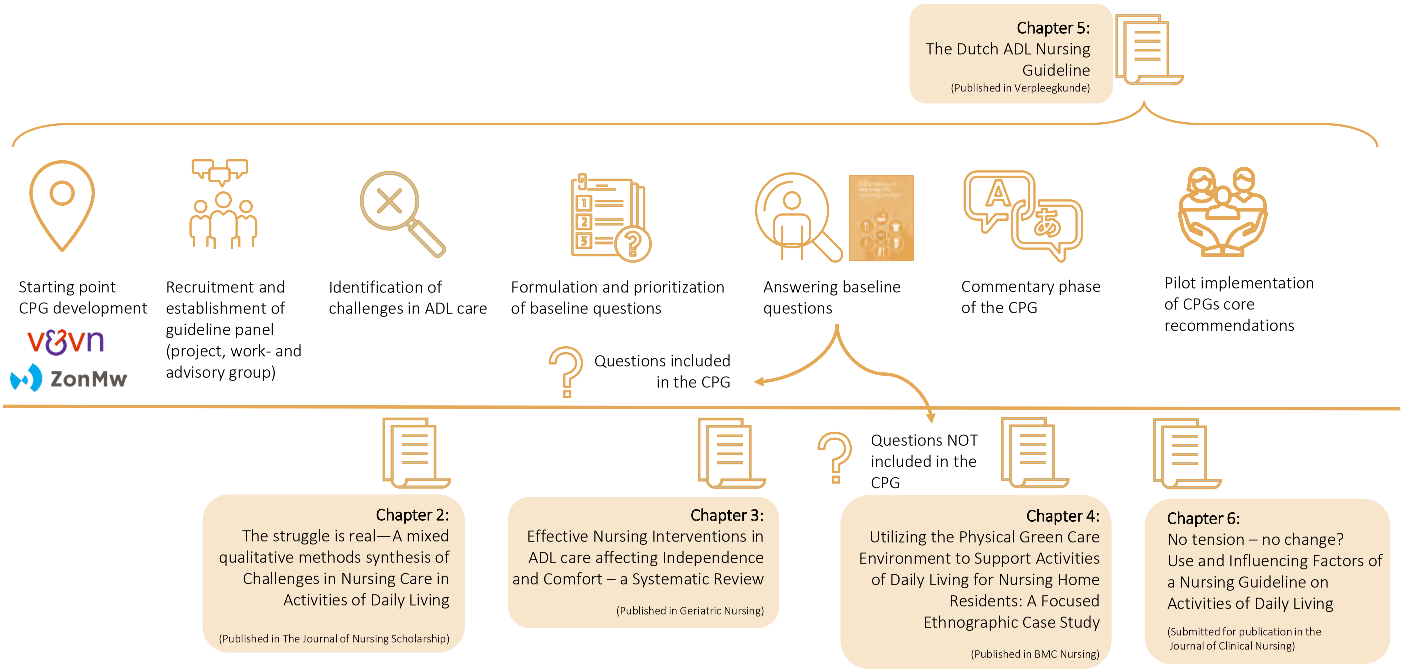

**Figure 1** Guideline Development Process and Chapters included in this Dissertation.

The initiative for the development of the CPG, was undertaken by the Dutch Association for Nursing Professionals V&VN and the project was funded by the Netherlands Organization for Health Research and Development (ZonMw)

# General Introduction

*"The alarm goes off. You wake up and take a stretch. A bright new day lies ahead of you. You stand up because you need to go to the toilet. Then, you take a shower and brush your teeth. Maybe you need to put on some makeup. Why not? Who knows whom you will meet today? So, get dressed, put on your favorite shoes, and you are ready to start the day.*

*But what if your plans are stuck at the moment, you can't get out of bed, and you really need to use the toilet? What if you don't remember how to put on a shirt? And what is this weird thing with brushes at the end of a stick? Come on, it's only washing and dressing, right? How hard can it be?"*

(Extracted from "Pitch your PhD, CAPHRI Research Day, 2021", awarded with the CAPHRI audience award)

## The Call for Nursing Professionals in Meeting Care Needs in Activities of Daily Living

Globally, healthcare systems face substantial challenges in providing consistent, high-quality care for a growing number of older persons across different care settings. However, the number of people using its services has been gradually rising. The main causes of this increased use, including an aging population, rising welfare, and technological advancements, are all anticipated to continue in the ensuing decades [2]. The increasing demand for healthcare is driven by the impending "age quake," which will see the population of individuals aged 65 and above more than double by the year 2050 [4]. Moreover, the number of people suffering from one or more chronic conditions such as dementia, stroke, or chronic obstructive pulmonary disease is increasing globally [5, 6]. Hence, more people are living longer with chronic conditions, which can lead to functional limitations. Simultaneously, acute conditions (such as transient ischemic attacks (TIA) or fractures) can result in temporary functional limitations that necessitate immediate care but show improvement following treatment and attention [5, 6]. Functional limitations often manifest themselves in a need for support in activities of daily living (ADL) [7]. Especially among older individuals, there is a high demand for care in ADL. Research shows that 50% of people over the age of 85 require support in their daily activities [8].

Nursing professionals play a crucial role in meeting the ADL care needs of individuals facing disease or disability. As described by Virginia Henderson [9], it is the unique function of nursing professionals to "*assist them [care receivers] in the performance of those activities contributing to their health or recovery […] that they would perform unaided if they had the necessary strength, will, or knowledge and to […] help them gain full or partial independence as rapidly as possible.*". Hence, nursing professionals spend a significant amount of their shifts providing direct care activities, including ADL care. The exact amount depends on the care setting and varies between 25% of the observed shift time in hospitals [10] and 30% in nursing homes [11]. More specifically in home care, registered nurses (RNs) spend 32% of their time on direct patient work, while 48% of direct care is performed by certified nursing assistants (CNA's) and 70% health workers [12].

From a care receiver perspective, ADL nursing care carries the potential to improve outcomes that are central to care receivers, including mobility [13], independence, and resistance to care [14]. It is not surprising that ADL is one of the most commonly assessed nurse-sensitive outcomes in the nursing profession [15]. On the other hand, when ADL nursing care is missed or left incomplete, it can lead to lower overall quality and safety risks, increasing the likelihood of adverse events such as falls or pressure ulcers [16].

## The Definition of ADLs and Their Attributed Meaning

Waking up, going to the toilet, taking a shower, and getting dressed are activities that are often performed routinely and taken for granted on a daily basis. These and other daily activities are summarized in the concept of ADL, which encompasses one's essential personal self-care needs deemed necessary for independent living, health, and well-being [17]. For this dissertation, we use the term ADL to refer to the six daily activities, including washing, (un)dressing, toileting, grooming, indoor mobility, and eating and drinking, which are further elaborated on in Table 1. These activities are the core concepts frequently incorporated in ADL assessment tools (e.g., Katz, Barthel).

**Table 1** Operationalization of ADL

| Aspect of ADL | Associated (sub-)activities |
|---|---|
| 1. Washing | Washing at a sink or on the bed with a washcloth, for example, bathing, showering, drying (parts of the body). |
| 2. (Un) dressing | Dressing and undressing garments and/or compression stockings. |
| 3. Toileting | Going to and safely using the toilet: undressing, sitting down on the toilet, defecating (urine and feces), cleaning oneself after use, flushing the toilet, getting up, dressing, using and handling incontinence materials, and menstrual hygiene. Use of toilet alternatives: toilet chair (shower or post chair), bedpan, urinal, and menstrual hygiene. |
| 4. Grooming | Taking care of own appearance, including brushing teeth or caring for teeth, usual care of fingers and toenails (nail clipping), care of hair (combing, drying, use of products), skin care (use of lotions or creams), and use of makeup or other products. |
| 5. Indoor mobility | Moving around the home, transfers, positioning in bed or (wheel) chair, climbing stairs, and use of walking aids. |
| 6. Eating and drinking | Bringing (prepared) food or drink to the mouth and handling (adapted) cutlery or cups. |

ADLs strongly give meaning to how a person spends their day and contribute to one's sense of self [18]. Hence, experiencing difficulty in one or more of these activities while relying heavily on others greatly impacts one personhood, as this intimate form of care encompasses one’s personal self-care needs [17]. Choosing if or when to shower, what to wear, or when to go to the toilet and subsequently performing these activities independently might seem trivial. At the same time, independent functioning in daily activities, from a cultural-historical perspective, represents a core value of independence and self-determination in Western culture [19]. Being independent means being self-determined and serves as a desirable model of the kind of freedom that individuals can achieve [20].

Over time, factors such as age [21], sex, neighborhood, and income [22, 23] may affect an individual’s ability to independently perform ADLs. This can lead to dependency, which can evoke feelings of powerlessness and negativity when relying on others in society [20]. However, it is important to note that care dependency does not automatically imply a negative state of being. Care dependency, when managed with respect for autonomy, leads to satisfaction and empowerment for care receivers. It can foster acceptance, adaptation, and individual integrity [24]. Perceived levels of dependency rely on the perspectives of both caregivers and care receivers, as well as their goals and how caregivers engage in behaviors that support independence [25]. This leaves nursing professionals with an opportunity to provide holistic support for the needs of care receivers, going beyond their physical well-being and considering their need for control and independence in decision-making.

## The Fundamentals of ADL Nursing Care

Fundamental care also known as essential nursing care lies at the heart of the nursing profession and includes, but is not limited to, ADL. It also comprises other essential aspects such as rest and sleep, as well as medication management [26]. Nursing professionals support individuals in performing their ADLs, regardless of their diagnosis or the level of care they require [27]. Despite its frequent provision, ADL nursing care is often taken for granted in society and perceived as “common sense” [28] or “low-status work,” especially when involving bodily care and the risk of being exposed to, for example, incontinence [29]. Care activities related to ADLs are typically carried out primarily by vocationally trained nurses or nursing aides [30]. Registered nurses tend to gravitate towards more specialized, technically demanding, or “prestigious” forms of care, often placing less emphasis on ADL care [27]. In contrast to viewing fundamental nursing as straightforward or common-sense tasks, prior theoretical research provides a more nuanced understanding of this type of care. From a conceptual point of view, Kitson [31] established “The Fundamentals of Care (FoC) framework,” which highlights the complex interplay and co-dependency between the care receiver and provider. The FoC also emphasizes the relationship within the wider care system, including the healthcare organization or setting, and the policy and system context (Figure 1).

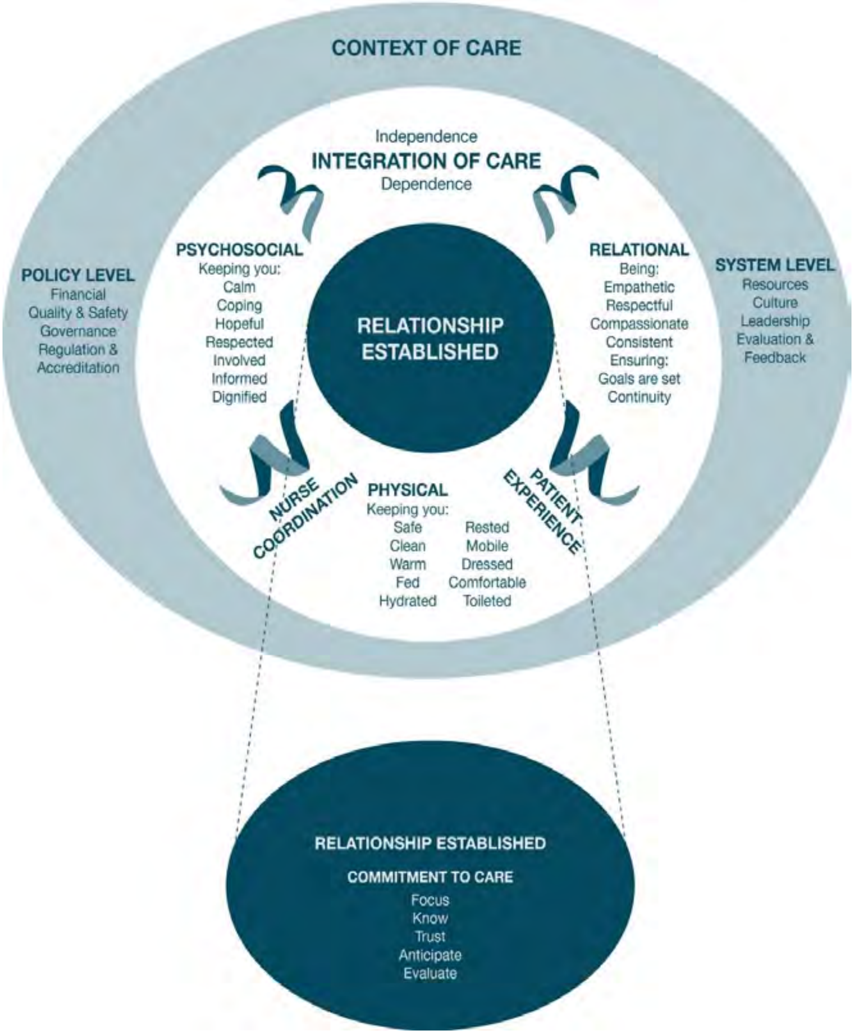

**Figure 1** The Fundamentals of Care Framework from Feo et al. [1] used with permission as presented in Rey et al. [3]

Fundamental nursing care is defined by the actions of nursing professionals addressing a person's fundamental needs and desired outcomes. These needs include physical needs (e.g., hygiene, mobility, and safety), psychosocial needs (e.g., dignity, privacy, and involvement in decision-making), and relational needs (e.g., being heard and supported by caregivers and working together to achieve goals) [17]. In essence, the FoC advocates for the integration of the physical, psychosocial, and relational dimensions of the care encounter within the care environment and its context. The integration of physical, psychosocial, and relational needs of a person while working with (and sometimes against) the care context is complex and requires a sophisticated combination of activities [26]. As described by Feo et al. [28], *"Whilst it might be 'common sense' to provide* *someone a bedpan when they require toileting and are unable to walk, recognizing when someone requires assistance and attending to this need in a way that is safe, both culturally and physically; maintains the person's dignity and privacy; and fosters a relationship of mutual trust and respect is hardly a simple matter, nor something that anyone can do by default." (p.83).* Hence, this type of care, when aiming to provide well, goes beyond common sense and offers significant opportunities to integrate and meet the diverse needs of an individual to achieve person-centered quality care delivery in the given context. Consequently, ADL nursing care as part of fundamental nursing should be person-centered, and the goal of the encounter between nursing professionals and care receivers, where the aim is to maximize a person's independence while ensuring their safety and security in the given context of care [31].

## The Context of ADL Nursing Care

The context of care is considered a "challenging macroscopic puzzle," which includes but is not limited to observable features such as space, place, people, or things [32]. Contexts also refer to the political, social, and economic structures [33] that influence ADL nursing care. The FoC framework acknowledges several contextual elements at the system and policy levels that impact the provider's ability to develop a caring relationship and integrate a person's fundamental care needs [26]. Examples of contextual elements at the organizational level include resources such as staff and equipment (e.g., the presence of lifting equipment and assistive devices) as well as leadership (e.g., prioritizing ADL nursing care and providing continuous feedback by management).

As part of the context, social, organizational, and physical elements are considered important perquisites for ADL nursing. Social elements such as the relationship with an informal caregiver can greatly impact the functional self-care abilities of care recipients [34]. Additionally, the relationship between a formal caregiver and the care receiver may also affect the quality of care provided [35]. Similarly, a strong organizational culture is a resource that can promote improved nurse professionalism [36] and indirectly affect the quality of patient care [37].

One contextual element that particularly shapes ADL nursing care while interacting with other elements is the physical environment (space and place) in which care is provided. The living and care environment of a person greatly determines what activities can be performed and how they can be performed [38, 39]. For nursing home residents with dementia, central elements of the physical environment that influence their daily lives have been identified by Chaudhury et al. [40]. These elements include unit size, spatial layout, homelike character, sensory stimulation, and specific spaces (such as dining, bathing, and outdoor areas). Also, within the home care setting, it is widely theorized that the ability to age in place is correlated with the extent to which their environment aligns with their cognitive and physical abilities [41].

Whether or not the environment is a person's home not only determines the extent to which ADLs can be performed independently but also influences one's perception of freedom to manage one's life as autonomously as possible [42]. At the same time, a poor environmental fit additionally affects the quality and safety of care provided for both nursing professionals and care receivers [43]. Hence, the physical environment largely determines whether and how ADLs can be performed by individuals receiving care and supported by caregivers. Research has emerged on how the environment and its use can either facilitate therapeutic progress in cognition or hinder independent functioning and high quality of life [44, 45]. Moreover, the scientific literature has established how the environment can be utilized to enhance person-centered care [46], which includes the active participation of care receivers [47] and their families [48]. Contextually, the environment significantly impacts the quality and safety of care. Understanding this interaction is vital for providing person-centered ADL nursing care.

### The "Evidence" in Evidence-Based Nursing Practice

Integrating scientific evidence into nursing practice holds a prominent place on the agenda for clinical governance [49]. The understanding of evidence in nursing care evolves with the implementation of evidence-based practice (EBP). When it comes to the term "evidence" in EBP, there are numerous conceptual interpretations that coexist and vie for legitimacy [50]. The scientific discourse on evidence in nursing research is divided between two viewpoints. The first group of primarily positivist-oriented researchers only anticipates evidence to come from quantitative research, primarily from systematic reviews of randomized control trials (RCTs) [51, 52]. Over the past few decades, the evidence supporting ADL nursing care has faced criticism for its insufficient basis. [53-55]. This criticism relates in particular to the absence of (quasi) experimental studies, which represent only 13% of all studies published in nursing journals [56]. Moreover, the quality of experimental studies conducted in fundamental nursing is often prone to bias and low quality due to poor study reporting, as indicated by established standards [57]. Hence, in ADL nursing care, there is a need for conducting and publishing more high-quality, well-documented experimental research, as well as systematic reviews, meta-synthesis, and meta-analysis, to generate evidence for daily practice [56].

The second group of researchers acknowledges other types of evidence, such as qualitative studies, professional experience, and clinical experience [58]. Qualitative research and its benefit are increasingly acknowledged in evidence-based nursing [59], as it contributes to a comprehensive understanding of the complexity and entirety of human experiences [60]. This understanding is crucial in providing nursing care for ADLs. At the same time, it has been discussed that different forms of evidence should mutually support each other instead of being competitive, to strengthen the quality and continuity of nursing practice and its outcomes [50, 61]. Qualitative research, literature reviews, and theoretical work have emerged on concepts closely related to ADL nursing. Nursing literature has seen an increase in topics aimed at providing evidence for practice, including shared decision-making [62, 63], person-centered (fundamental) nursing [64-67], and the involvement of care receivers [68, 69]. Having presented two ends of the scientific approaches for nursing sciences have been presented, it raises the possibility of investigating how both perspectives can complement and strengthen each other to generate practical and applicable recommendations for nursing professionals.

## Challenges and Considerations in ADL Nursing Practice: Balancing Intuition and Routines

In daily practice, nursing professionals often rely heavily on experience, intuition, and tradition when providing ADL care due to a lack of evidence [55]. The literature debates the validity of intuition in nursing, with some dismissing it as an irrational “gut feeling,” while others consider it crucial to nursing expertise [70, 71]. It is suggested that intuition should be used as a supplementary tool in clinical decision-making processes [71]. Additionally, routines play a significant role in ADL care due to their frequent and regular occurrence. While routines can provide comfort and well-being, they are also noted to potentially hinder the delivery of quality care [72, 73]. This is because routines may limit the progress of care receivers and cause nursing professionals to act “mechanically” and lose their flexibility to respond to a person’s needs in a person-centered way [74]. This “mechanic and task-focused approach is well known,” especially in fundamental nursing, such as ADL care [75].

When ADL care is mainly based on intuition and routines, the quality of care is susceptible to unwarranted practice variation due to intuition and a lack of uniformity in the provision and reporting of care [76, 77]. More importantly, nursing professionals, depending on their level of self-awareness, tend to provide care based on their own values and may potentially overlook the values of the care receivers [78]. When personal values, intuition, and routines dominate care provision, there is a risk of unwanted variation in care, which endangers the continuity of ADL care delivery. ADL nursing care offers a unique opportunity for nursing professionals to improve their clinical reasoning skills while considering the viewpoints of care receivers and informal caregivers in making ADL-related care decisions. Insights into the underlying challenges and practical issues specific to ADL nursing are therefore necessary to guide nursing professionals on core aspects of ADL nursing, including clinical reasoning and person-centeredness.

## A Quest for Implementing Evidence-Based Practice in Nursing

Overall, the aforementioned paragraphs emphasize the importance of integrating evidence-based principles into ADL nursing practice, taking into account the needs and experiences of nursing professionals and care receivers. Despite existing efforts to increase EPB in nursing, further developments are needed to integrate existing evidence into education and practice [79]. These efforts are especially needed in light of global evidence emphasizing the inconsistent and often inadequate quality of fundamental care, which can lead to instances of risky and dehumanizing patient experiences [80, 81]. These developments, while concerning, make it even more important to ensure that the correct evidence is in the right place. Implementing evidence into practice, however, can be complex and is met with a range of obstacles, including system-level barriers, organizational barriers, or individual barriers [82, 83].

Moreover, the effectiveness of integrating evidence into practice relies on the successful incorporation of the innovation or product into staff routines. One way of integrating evidence into practice is through clinical practice guidelines (CPGs). When unwanted variability in practice jeopardizes the quality, safety, and continuity of care, it becomes particularly challenging for nursing professionals to maintain a standardized approach and adapt care to evolving patient needs [84]. Delivering guidance for nursing professionals through a CPG might be a way to support nursing professionals in substantiating and tailoring the ADL care provided to the changing needs of care receivers. CPGs empower nursing professionals to make informed clinical decisions, effectively bridging the evidence-practice gap [85, 86]. However, implementing CPGs in practice is considered a complex undertaking [87]. CPGs require active implementation, and the research supporting this process does not offer easy solutions. What proves effective in one context may not be equally successful in another. In summary, implementing guidelines and making practice changes can be complicated and challenging to navigate.

## Aim and Outline of the Dissertation

The overall aim of this dissertation was twofold.

Part I of this dissertation aimed to scientifically underpin ADL nursing care.

In addressing this aim, three sub-objectives were formulated as follows:

(1) Identify challenges that arise in ADL nursing care (Chapter 2);
(2) Gain insight into the effects of ADL nursing interventions on independence and comfort (Chapter 3); and
(3) Understand how a green care environment can be used to support ADL performance (Chapter 4).

Part II of this dissertation aimed to provide and pilot-implement practical guidance for nursing professionals in various care settings relevant to ADL.

The sub-aims of this part were twofold, aiming to:

(1) Provide practical recommendations for nursing professionals on ADL nursing care in a CPG (Chapter 5); and
(2) Measure the use of key recommendations (KRs) from the CPG and identify factors that influence their implementation (Chapter 6).

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# Part I

# Underpinning ADL Nursing Care

# Chapter 2

# The Struggle is Real – A Mixed Qualitative Methods Synthesis of Challenges in Nursing Care in Activities of Daily Living

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## Abstract

**Introduction:** Supporting care receivers in Activities of Daily Living (ADL), irrespective of diagnosis, setting, or cultural background, lies at the heart of fundamental nursing care. The pursuit of quality ADL care becomes increasingly challenging with the changing complexity of care needs. ADL care delivery is often undervalued and is considered a low-status task despite its crucial importance to care receivers. This study aims to synthesize challenges in ADL care irrespective of the care setting.

**Methods:** In the mixed qualitative methods study, we used expert panel consultations, world café sessions, and a rapid literature review. For data analysis, we simultaneously analyzed the three data sets using inductive and deductive inquiry.

**Results:** These challenges reveal the complexity of ADL care and how its paradoxical narrative relates to the conditions in which nursing professionals struggle to create opportunities, for reflective clinical reasoning and shared ADL decisions, by facing organizational and environmental barriers.

**Conclusions:** These challenges reveal the complexity of ADL care and how its paradoxical narrative relates to the conditions in which nursing professionals struggle to create opportunities, for reflective clinical reasoning and shared ADL decisions, by facing organizational and environmental barriers.

**Clinical Relevance:** This study is relevant to nursing professionals, care organizations, policymakers, and researchers aiming to improve ADL care and provide insights into challenges in ADL care. This study forms the starting point for a changing narrative on ADL nursing care and subsequent quality improvements in the form of, for example, guidelines for nursing professionals.

## Introduction

Nursing professionals play a critical role in supporting a person's ability to perform Activities of Daily Living (ADL) irrespective of the disease, disability, or healthcare setting [1]. ADL comprises activities such as washing, dressing, toileting, grooming, mobility inside the home, and eating and drinking, which are deemed necessary for (independent) living, health, and well-being [2]. Care receivers themselves perceive ADL care as critically important and indispensable since this intimate form of care encompasses one's self-care needs [3]. At the same time, the care needs of, for example, nursing home residents [4] and palliative care receivers [5] are increasing in complexity. The consequences of these developments also affect the social environment of care receivers where informal caregivers play an important role in providing ADL care. Given that the need for providing ADL care may exist 24 hours a day, informal caregivers can feel ADL care is an overwhelming burden [6].

Nevertheless, ADL care is undervalued by nursing professionals [7] and is almost invisible, especially in bachelor of nursing education programs [8]. In daily practice, ADL care is often considered a simple, executive task, performed exclusively by vocationally trained nurses or nursing aides [9], and registered nurses prefer to engage in more "prestigious", highly specialized, and technical forms of care while giving little attention to ADL care [2]. Despite the image of ADL care as being "simple", research has criticized current methods of ADL care as being poorly administered and directly affecting the quality of care [10, 11].

Poor ADL care comprises care that is delayed (e.g. delayed feedings or toileting), partially completed (e.g. tasks from the previous shift not completed by a nurse in the next shift), unnecessarily performed [12], or not completed at all (e.g. missed care/ ambulation) [13]. Consequently, missed nursing care might also be unsafe and lead to adverse physical and psychosocial events such as falls or other negative consequences for receivers. The physical consequences may include infections or pressure ulcers due to missed ambulation or suboptimal hygiene [14]. The psychosocial consequences are loss of dignity, and respect or feeling of lack of safety or experienced lack of autonomy when ADL are taken over unnecessarily [15-17].

From a research perspective, ADL care—as part of essential nursing care—has started to receive scholarly attention. Central developments in research on ADL care revolve around exploring and establishing an evidence base around effective interventions [18] or theory development and the multifactorial complexity of the ADL provision. Theory development by Conroy et al. [19] and Thompson et al. [20] resulted in frameworks or models highlighting a complex interplay and co-dependency of the care receiver/care provider (micro level) in the wider healthcare contexts, such as the healthcare organization or setting (Meso level), as well as the policy and system context (macro level). Challenges on different interacting levels arise within the complex interplay of factors, which have been identified by Kitson et al. [1]. However, to date, there is no coherent overview of identified challenges from an ADL care perspective. Current literature, in general, either focuses on essential nursing care, including other aspects such as sleep, temperature control, sexuality, and medication [1], or focuses on only one specific aspect of ADL care, such as eating [21] or toileting [22], in a specific care setting. This results in an either too general or too fragmented impression of challenges in ADL care. Understanding the challenges of providing ADL care, emerging from different relevant perspectives (e.g., care receivers, nursing staff, informal caregivers, and other stakeholders like occupational therapists or physiotherapists), can further inform the development of practical implications or guidelines within ADL care. As a starting point for improving ADL care, this study is a synthesis of the challenges arising in ADL care in relevant care settings like the community, hospitals, rehabilitation and/or nursing homes, and care homes for people with intellectual disabilities.

## Design

We conducted a mixed qualitative methods study [23] using different methods of data collection, like expert panel consultations, world café sessions, and a rapid review, to ensure data triangulation (see Figure 1). This type of intra-paradigm research allows for a deeper, richer, and more comprehensive insight into the perspectives of stakeholders, current practices, processes, and dynamics of care [24].

## Materials & methods

### Expert Panel Consultation

To explore the first impression of challenges, as perceived by experts in the field, we created an expert panel of care receivers and care providers who are familiar with providing, receiving, or advising on ADL care.

*Recruitment and Selection*

We approached two national care receiver organizations and a national informal caregiver organization. Patients and informal caregivers were eligible if they had experienced ADL care themselves or had been involved directly as caregivers or advocates. We reached out to the Dutch National Council of nurses and Nursing Assistants to recruit nursing care professionals. Nursing professional caregivers, whose work largely involved ADL care (at least 20 hours per week), were eligible. We aimed to include at least one nursing professional from home care, hospitals, rehabilitation and/or nursing homes, and care homes for people with intellectual disabilities. Once selected, the experts received the mandate of the relevant professional or patient organization; they represented the perspective of that organization based on a regular exchange.

*Data Collection*

Before data collection, all experts received a mandate from the respective organization, and they consented to participate by signing a declaration of conflict of interest. We asked the experts, via e-mail, to answer the open-ended question: “What are your top five challenges in ADL care?”

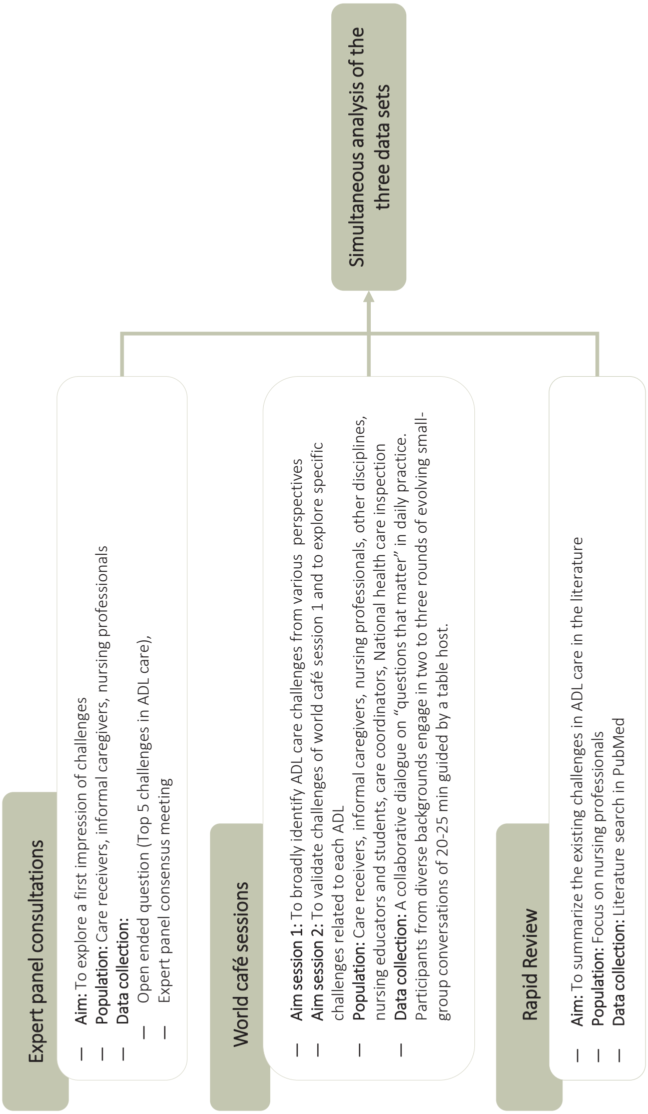

**Figure 1** Overview of Qualitative Methods

The answers were summarized and presented in an expert panel meeting where we facilitated a discussion among experts to reach a consensus on the first overview of challenges in ADL. This overview was written down on a flipchart. During the meeting, we took minutes of the discussion to capture the course of the discussion. After the session, we distributed the minutes among the experts for them to discuss and member-check the challenges within the organizations they represent.

*Participants*

An overview of participants in the expert panel can be found in Table 1.

**Table 1** Overview of Participants in the Expert Panel

| **Expert panel** | |
|---|---|
| Care receivers (or representatives) | n=4 |
| Informal caregiver representative | n=1 |
| Nursing professionals[1] | n=10 |
| Therapists | n=0 |

[1] Representing one department of the Dutch National Association of nursing professionals: Palliative nursing (n=1), Oncology nursing (n=1), Geriatric and gerontology nursing (n=1), Neurology nursing and neurological rehabilitation (n=2), Nursing care for people with intellectual disabilities (n=2), Community nursing (n=1) and Certified nursing assistants (n=2).

### World Café Sessions

To explore a broader view of the challenges experienced by a variety of stakeholders, we hosted two world café (WC) sessions. A world café stimulates a collaborative dialogue on “questions that matter” in daily practice [25], assuming that all participants are wise and creative enough for collective contribution. Participants from diverse backgrounds engage in rounds of evolving small-group conversations in a welcoming, “café-like” setting. Then, they move between tables to build on previously expressed thoughts and concepts to create a new understanding of the matter at hand. This “cross-pollination” ultimately results in collective knowledge and opportunities for further action [25].

*Recruitment*

To recruit care providers, we invited a broad range of organizations, via e-mail, which included national patient and professional organizations involved in receiving, organizing, and providing ADL care. We approached organizations representing care receivers (n = 2) and informal caregivers (n = 2). We reached out to the Dutch national councils of nurses and nursing assistants (n = 1), occupational therapists (n = 1), physiotherapists (n = 1), and speech-language therapists (n = 1). Additionally, to represent the organizational perspective, we recruited care professionals from the seven nursing home organizations within the Living Lab in Ageing & Long-Term Care, Limburg (The Netherlands), representatives of the Dutch healthcare authority, and care coordinators from other care organizations (n = 7) as well as representatives of organizations for nursing education (n

= 1) and vocational education for nursing assistants (n = 1). Participants were invited, by e-mail, to attend the world café activity at one of the two locations in the Netherlands (South and Central).

### *Data Collection*

### Developing questions that matter

Before the World café sessions, we formulated questions guided by the World café manual of Vogt et al. [26] (see Table 2). The first World café session aimed to obtain a broad perspective on the problems that arise in ADL care. During the second session, we aimed to reach a deeper understanding of the challenges that arise in direct ADL care. Therefore, the questions specified different aspects of ADL care. Each question represents the topic discussed at one table.

### Conduct of the Sessions

We organized the sessions with guidance from the manual of Vogt et al. [26]. Both world café sessions were held at public venues, where participants were offered food and beverages, to create a welcoming space.

**Table 2** Questions for the First and Second World Café Session

| **World café session 1:** Central question: What problems do you experience when receiving, providing, or organizing ADL care? |
|---|
| Sub questions:<br>1. What makes ADL care difficult, and what are the underlying challenges?<br>2. I have a dream! What is my vision of ideal ADL care?<br>3. What are my personal experiences with ADL care?<br>4. How can ADL care be improved? |
| **World café session 2:** |
| 1. (To what extent) Do you recognize the identified challenges in WC session 1?<br>2. What practical problems arise when providing care for (1) Washing, bathing, or showering; (2) Toileting, (3) Mobility or transfers; (4) Un-dressing (5) Grooming (6) Eating or drinking |

To guarantee heterogeneity throughout the sessions, participants received a nametag, which included the table numbers for each round, in a color that represented their background as care-receiver, informal caregiver, nurse, or other. Participants also received a pamphlet with the “house rules” stating the core principles of the world café session (e.g., facilitating oneself and others, connecting ideas, focusing on what matters, etc.). We added an informed written consent form, to this pamphlet, for audio recording.

During an introductory presentation, we informed the participants about the operationalizing of ADL and the goal of the session. In the second session, we added the preliminary results of the first session to the presentation where participants confirmed the previously identified challenges.

The discussion, in both café sessions, was held in three consecutive rounds of 25 minutes each and guided and documented by a table host who was familiar with both the process and the allocated questions and who received a manual, including questions, to promote discussion and a one-hour briefing on the aim, procedure, and the way to guide and document the conversation. The table host remained seated at the same table, during the rounds, to introduce the topic and elaborate on the previous conversation to the next group. Graphic documentation was an essential part of the conversation that allowed participants to visualize their ideas by writing down or doodling their thoughts, interconnecting the assigned colored post-its, and arranging them on a paper tablecloth. To inspire the conversation for Question 2 in WC 1, "Vision of ideal ADL care", we also used photo-elicitation with the My Home Life Scotland© images. After the three table sessions, the participants returned to their first table and each group plenary presented their main results and insights. The sessions ended with a summary of the overall findings.

### *Participants*

An overview of participants in the expert panel and World café sessions can be found in Table 3.

**Table 3** Characteristics of World café Participants

| **Meeting 1 (n=38)** | | **Meeting 2 (n=13)** | |
|---|---|---|---|
| Care receivers | n=7 | Care receivers: | n=2 |
| Informal caregivers | n=6 | Informal caregivers | n=1 |
| Nursing professionals | n=10 | Nursing professionals | n=6 |
| Occupational therapist | n=3 | Occupational therapist | n=1 |
| Physiotherapist | n=5 | Physiotherapist | n=0 |
| Speech-language therapist | n=1 | Speech-language therapist | n=0 |
| Other[1] | n=6 | Other[2] | n=3 |

[1] Hospital care coordinator (n=1); Chief of bachelor of nursing education (n=1), students (Bachelor nursing n=2; Health education and promotion: n=1)

[2] Consultant of the Dutch national health-care inspection (n=1), students (Bachelor nursing n=1; Healthy Ageing Professional n=1)

## Rapid Review

To identify the existing challenges in ADL care, in the literature, we performed a rapid review (RR) of the literature, which was guided by the recommendations of the Cochrane Rapid Reviews Methods Group (RRMG) [27].

### *Search*

We conducted a literature search in January 2020, using the PubMed database, by using a combination of Medical Subject Heading [MeSH] terms and free terms. The search consisted of four search strings: (1) nursing (e.g., nurses, nursing, professional care provider); (2) activities of daily living (e.g., Activities of Daily Living (ADL), self-care, dressing, bathing, washing, mobility, transferring); (3) challenges (e.g., problem, challenge, dilemma, issue, difficulties); and (4) excluding topics irrelevant to the research question (e.g., reproductive health, pediatric health, or pharmacological interventions) (see appendix 1). The search focused on publications in English, German, French, or Dutch language, which were published between April 2009 and January 2020. After the full-text screening, we hand-searched the reference lists of selected studies.

*Study Selection*

Studies were eligible if the publication focused and reported on challenges, as perceived by nurses, nursing assistants, or other professionals, directly involved with providing ADL care to all adult patient populations. ADL care was defined as care occurring during washing/bathing, (un-) dressing, moving inside the house, toileting (or continence), eating and drinking, and grooming, as described in commonly used assessment instruments, e.g. Katz [28], the Barthel index [29], and the Groningen Activities Restriction Scale [GARS] [30]. After completing the search, two authors (SC & JW) first selected the studies based on titles and abstracts. The study selection is portrayed in the flowchart (see Figure 2). Both authors screened the titles, abstracts, and full texts separately. Discrepancies and articles categorized as doubtful were discussed until a consensus was reached between the two authors. In the case of disagreement, a third reviewer was consulted (MB). The flowchart in Figure 2 outlines the selection process and reasons for exclusion. 2639 articles were identified, of which 2605 were rejected during the screening of the titles and abstracts, and 34 articles were assessed on a full-text basis. Additionally, 5 articles were included, after checking the references, resulting in the inclusion of 19 articles.

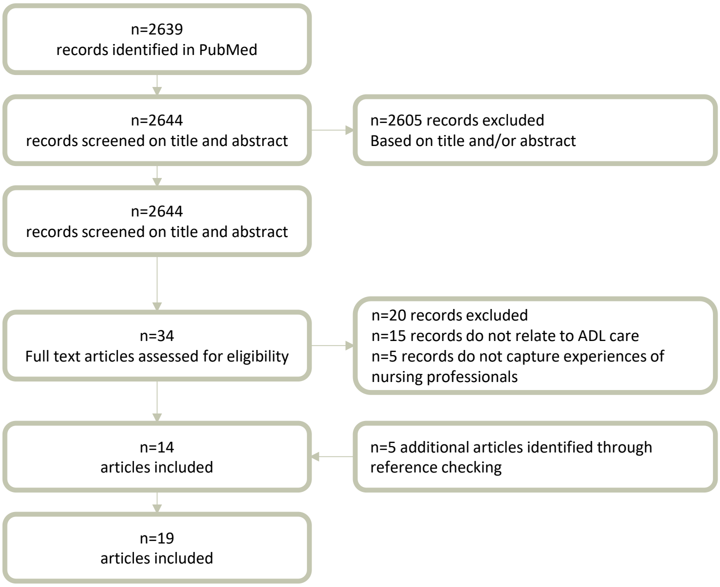

**Figure 2** Flowchart Selection Process Rapid Review

### *Data Extraction*

The first and second authors extracted and summarized the data, from the included studies, including the following information: authors, year of publication, country, the aim of the study, study design, and participants, according to the aspects of ADL and textual information related to possible challenges in ADL care.

### *Characteristics of Included Studies*

An overview of the characteristics and references of the 19 included studies can be found in Appendix 1. We included 15 qualitative studies, 2 quantitative studies [31, 32], and 2 mixed-method studies [14, 33]. Out of the different aspects of ADL, we found six studies on eating and drinking [33-38], five studies on mobility care [31, 39-42], three studies on oral care [32, 43, 44], three studies on continence care [14, 45, 46], and two studies on two or more aspects of ADL care [47, 48]. In addition to the perspectives of nursing professionals, we used the perspectives of care receivers, informal caregivers, or other disciplines as sources of information [14, 33, 35, 37, 38, 40, 42, 45, 47, 48].

### *Analysis*

In analyzing the data, inductive and deductive inquiry were integrated, as described by O'Reilly et al. [24], which allowed simultaneous analysis of the three data sets (expert panel, world café, and rapid review). We dynamically moved between the data sources to inductively identify key messages while deductively looking for similar patterns in other data sources. In the planning and conduct of the analysis, a thematic analytical approach was chosen, using the 15-point checklist of criteria for good thematic analysis [49], to increase the dependability of the results and maximize rigor. At the beginning of the analysis, the first author familiarized herself with the data. This phase included 1) reading and summarizing the written overview of challenges by the expert panel, 2) reviewing and re-listening to the material from the world café sessions, and 3) reading the graphic recordings, transcribing the table hosts' summaries and extracting the data from the included studies. Subsequently, she systematically generated separate initial codes for the datasets. After coding, she searched for themes and key messages in the datasets starting with the data from the literature and moving back and forth between other data sources [24]. As part of the analysis, the first author generated thematic maps to create overarching themes and subthemes. During this process, she presented and discussed different versions of these maps, including the themes and their naming, with the co-authors, in the monthly meetings. Consequently, she adapted the map until it accurately reflected the meaning of the data.

## Results

Based on the data collected through the expert panel (EP), world cafés (WC), and the rapid review (RR), we synthesized four main challenges that arise in ADL care: (1) The ADL care paradox that undervalued common sense work vs. complex, high-skilled care provision; (2) Limitations in professional reflective clinical decision-making; (3) Missed opportunities for shared ADL decisions, and (4) Meeting ADL care needs in a high-throughput system. In the following sections, we elaborate on these four main challenges, including their subthemes (see Figure 3).

### Challenge 1: Undervalued Common-Sense Work vs. Complex, High-Skilled Care Provision

Two contradicting narratives were identified in ADL care, in two subthemes *(1.1), Undervalued, unpleasant, common-sense work* versus *(1.2) Complex, never-finished, high-skilled care provision.* The image of common sense expresses itself in the perception of ADL care being “normal and simple” and always being part of “the daily businesses” (EP, WC, RR).

*“People often assume that washing and dressing, that's a piece of cake, right? It’s ingrained in the process of everything.”* [WC1, Nursing professional]

Hence, ADL care is often considered “non-technical”, “taken-for-granted”, and a “low-status task” in, for example, mealtime care [38] and consequently not considered a priority in nursing care (WC, RR). Additionally, unpleasant experiences during ADL care provision add to its challenging narrative; for example, nausea for nursing professionals results in avoidance of oral care activities (RR). This unpleasant experience, during ADL care provision, exacerbates the image of “dirty” and “low status” work that generally appears to be an undervalued form of care within the nursing profession. On the contrary, results show that the narrative of ADL care changes due to the emerging complexity of care needs (see: challenge 2) within an organizational context (see: challenge 3). As the following quote represents, ADL care emerges as an increasingly complex form of care where nursing professionals handle complex and risky care situations demanding multitasking, personalized approaches, and highly skilled, technical care provision (WC, RR):

*“ For example, assistance with movement and stability during bathing in the home care setting, when care receivers are naked and often wet, making them more difficult to hold […] or providing support for client stability means that care providers are effectively doing two physically demanding activities simultaneously in transfer situations: providing care and supporting client stability.”[48]*.

Hence, ADL care can be physically and socially demanding, especially when aiming to meet a person’s emotional and relational needs in intimate care provision (see: 2.1).

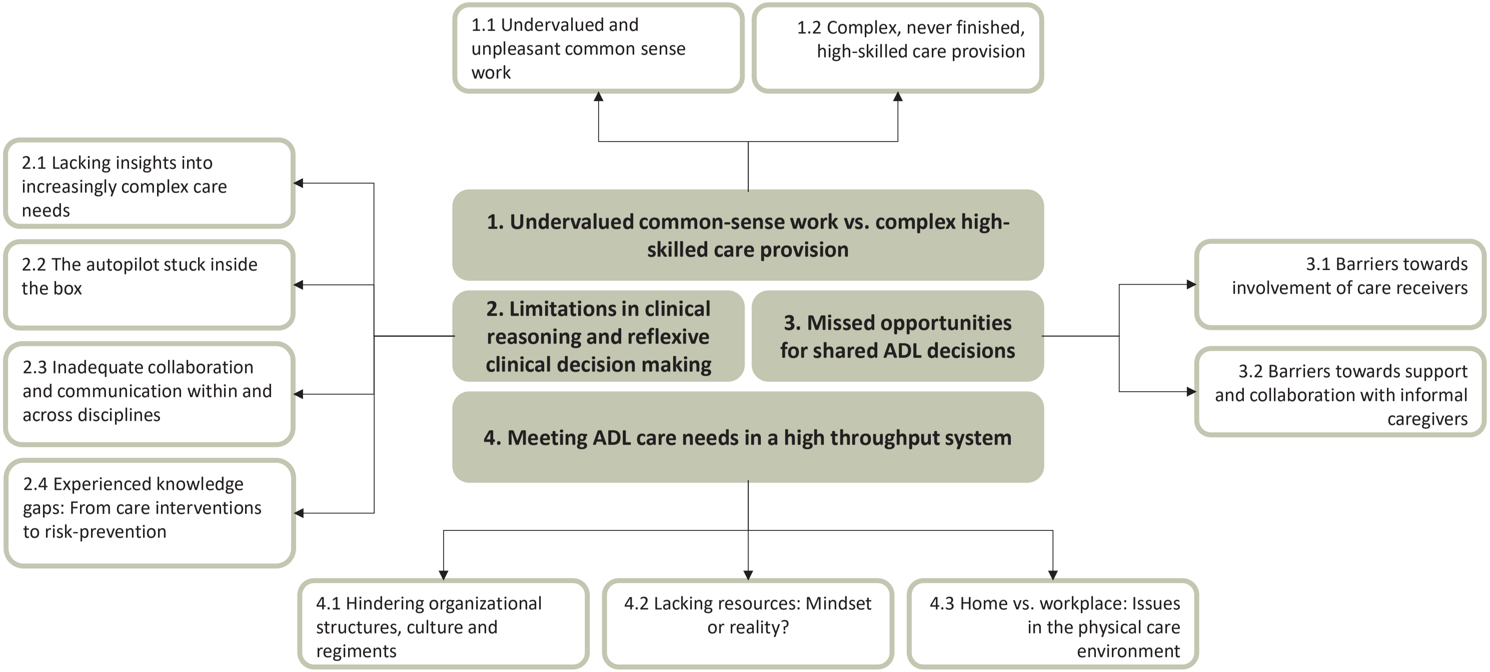

**Figure 3** Concept-Map of Challenges in ADL care and their Subthemes

### Challenge 2: Limitations in Professional Reflective Clinical Decision-Making

This second challenge is characterized by four sub-themes illustrating the challenges arising when gaps occur in clinical reasoning in ADL care provision.

Theme 2.1 *Lacking insight into increasingly complex care needs* shows that care needs in ADL care are increasing in complexity and diversity, and it is changing frequently (EP, WC). Part of this complexity becomes visible in ADL when nursing professionals need to adapt their approaches to the individuality of care receivers, as one informal caregiver illustrates.

*"I quite understand that if you go to the toilet with a stroke survivor it's a thousand times different. They just have some common characteristics. […] at the same time the variation is greater than the similarity." [WC2, Informal caregiver]*

Specific care receiver characteristics, that add to the complexity of ADL care needs, were identified, which may influence clinical reasoning, increasing age and age-related risk factors in, for example, malnutrition and bed sores (RR); overestimation of abilities (EP, WC, RR); tiredness and fatigue affecting ADL performance (RR); cognitive impairments (WC, RR); or unsteady, unpredictable, unwilling, or uncooperative care receivers (WC, RR).

Additionally, the analysis reveals gaps and challenges in identifying and assessing those ADL care needs. ADL care needs contain several domains that are not limited to physical support in activities. The results show that the emotional needs of care receivers are not always seen. Nursing professionals often appear unaware of the emotional impact on care receivers when receiving ADL care (RR). Care receivers and professionals emphasize that ADL care provision is a matter of preserving humanity and dignity since ADL care can provoke feelings of vulnerability, fear, frustration, or feeling overwhelmed (RR).

*"ADL care is such a personal thing. It's such a personal thing that people also really value. It's about whether people are recognized for their humanity. There is so much more involved and people feel ashamed."* [WC2, Nursing professional]

Also, ADL functioning and personal preferences are inadequately or often not assessed at intake due to the unavailability of assessment tools (RR) or lack of confidence among nursing professionals in, for example, assessing ambulating ability without therapist input [39], poor interviewing skills, lack of competencies (WC; EP) or not seeing the necessity for a formal assessment (WC).

Theme 2.2 *The autopilot stuck inside the box* describes how hanging on to "old habits or values" and "fixes structures" of providers, in particular, hinders critical reflection and change towards quality ADL care provision (EP, WC, RR), resulting in "blind", routine daily care provision in which the autopilot seems to take over control.

*"They [other colleagues] even follow protocols blindly that they don't even start thinking"* [WC2, Nursing professional].

When ADL care becomes "business as usual" for nursing professionals, they will find themselves in a situation where the ways of caring are transformed into habits, which limits one's ability to critically reflect (WC, RR) and see the person behind the care receiver, and the "Why" question is no longer asked (WC) (see challenge 3). In some cases, elements of ADL care, such as oral care, are even missed without professionals giving it *'a moment's thought'* [44].

Theme 2.3 *Inadequate collaboration and communication within and across disciplines* illustrate how collaboration challenges hinder continuous ADL care provision (EP, WC, RR). This includes an issue of responsibility within intra- and interdisciplinary work settings where task perceptions of "who is responsible for what" differ among nursing professionals in, for example, mobility care (pressure ulcer prevention) or between professions in, for example, continence care (RR).

In interdisciplinary work, in particular, the mutual dependence of nursing professionals and other disciplines arises in two ways: First, nursing professionals often depend on the judgment of physical or occupational therapy staff before they can mobilize a care receiver, but limited availability does not allow for timely assessment (RR). Second, other disciplines often depend on nursing professionals following up on their advice in daily care provision, which is experienced as risky and problematic when nursing professionals do not adhere to therapeutic advice, as this speech and language therapist explains:

*"Officially, I would have to file a formal error every time someone does not read or follow my advice on for example thickening drinks for residents. But then, on a bad day, the commission would do nothing else except read my complaints"* [WC1, speech-language therapists]

Adding to the challenges related to collaboration, within and across disciplines, is poor communication (EP, WC, RR), especially when written handovers are inadequate or lacking or when discharge information is simply not read by nursing professionals, for example, in case of eating ability in stroke survivors [34]. Moreover, information within care settings tends to get lost due to high staff turnover (WC, RR), a high number of part-time workers (RR) (see challenge 4), or simply not routinely discussing oral care approaches (RR).

Theme 2.4 relates to *Knowledge gaps experienced by care providers in daily practice*. Within the different data sources, we recognized knowledge gaps among nursing professionals, in ADL-related fields, in daily practice, and nursing education (EP, WC, RR). Most of these were related to the use of interventions to effectively improve ADL care-related outcomes, such as independence or comfort, as illustrated by the following quote.

*"If someone has no idea how to wash themselves, I can think that someone needs to get as independent as possible, but how do I get there?"* [WC2, Nursing professional]

Another knowledge gap relates to the role of risk detection and prevention and insufficient awareness and knowledge about the use of care in ADL, as early detection of health problems and prevention, for example, lacking awareness of stimulating independence and physical activity are a proactive way to prevent health risks and problems (EP, WC).

In education and training, nursing professionals identify gaps in almost all elements of ADL, including continence care [14, 46], eating and drinking [35], oral care [44], and mobility [41] as well as safe handling of care receivers [39] and the use of assistive devices [31].

### Challenge 3: Missed Opportunities for Shared ADL Decisions

The third challenge of missed opportunities for shared decisions revolves around two subthemes: 3.1 Barriers to the involvement of care receivers and 3.2 Barriers towards support and collaboration with informal caregivers.

In subtheme *3.1, Barriers to the involvement of care receivers,* we describe the perspective of care receivers who lack involvement in decisions regarding the way their ADL care is provided and the direction in which their ADL care is headed (EP, WC, RR). It appears that ADL goals are often not discussed with care receivers, for example, incontinence care [14]. Additionally, care receivers feel frustrated when not involved in care plans and agreements, e.g. nutritional care [37], or are left uninformed on ADL-relevant care aspects such as why it is important to stay physically active or strive towards ADL independence or where to apply for assistive devices or care from other disciplines (WC).

*"We should move towards care that is completely tailored to the client's experience."* [EP, Care receiver]

Moreover, we found that the attitudes of nursing professionals might also be a barrier to shared decisions. For example, when nursing professionals are unable to balance their own personal or professional values and those of the care receiver (EP, RR), they might underestimate the ability and willingness of care receivers to be involved in decisions (WC, RR). Similarly, the perception of nursing professionals that providing the information is equal to shared decisions, while offering very limited opportunities for shared decisions, is problematic.

*"The only nursing action [...] was to instruct the older persons to drink supplemental nutrition drinks, and the older person's only involvement was to be allowed to 'pick the flavor you like.'"* [37]

On the other hand, certain care receiver characteristics pose a challenge for nursing professionals when it comes to involvement in decisions, e.g. lacking insight into their illness (WC), struggling to communicate verbally, due to a dementia diagnosis or their own (oral care) abilities [44], refusing care (WC, RR), or having values, that are at *odds with the policies of nursing professionals,* in terms of mobility in ulcer prevention [41]. Balancing care receiver needs and preferences and determining the "right" choice in ADL care provision is a challenge for nursing care professionals who struggle to decide when to encourage independence or take over tasks or support taking into account a person's and the professionals' capacity and comfort (WC). As a result, in ADL care, missed opportunities for shared decisions arise, especially when nursing professionals do not stand still, struggle to balance care receivers' preferences and abilities (WC) (See challenge 2.1), or do not seize moments to discuss experiences and preferences while offering information and advice.

In theme 3.2, we describe the *Barriers to supporting, involving, and collaborating with informal caregivers* who often perceive that their needs are unseen by care professionals. The ADL care-related needs of informal care consist of adapting to a new care role and a need for respite care, especially due to the never-ending nature of ADL care, which can result in a higher burden for informal caregivers.

*"The informal caregiver occasionally needs a break from ADL care to take a breath. Sometimes the informal caregiver can barely leave the house, and never go on holiday, because the ADL care for the loved one always continues."* [EP, consultant of the Dutch Association of informal caregivers].

In addition to directly providing ADL care, informal caregivers often plan and organize care for their loved ones, where they perceive the need for a single point of contact for questions (EP, WC) and the need to be informed on the situation of the loved one in hospital care [33].

Challenges of involving and collaborating with informal caregivers arise especially when norms and values do not align in the triad of informal caregiver, nursing professional, and care receiver (e.g. when there is disagreement about the necessity of care or how care should be provided effectively and safely) (EP, WC, RR).

The way the expertise of informal caregivers is used also adds to the tension. While informal caregivers value the use of their expertise, balancing values and expectations poses challenges for nursing professionals to contemplate how to handle differing views and expectations [38].

*"Sometimes I experience pressure from informal caregivers in terms of safety. When going to the bathroom they [informal caregiver] want me to let him [the care receiver] sit in the*

*wheelchair anyway then, while I would prefer him to ask him to walk a few more steps to be more active."* [WC2, Nursing professional]

### Challenge 4: Meeting ADL Needs in a High-Throughput System

The fourth theme takes an organizational perspective illustrating the ADL care challenges arising in the health care system including three subthemes: 4.1 Hindering organizational structures, culture, and regiments; 4.2 Lack of resources: mindset or reality? and 4.3 Home vs. workplace: issues in the physical care environment.

In theme 4.1, *Hindering organizational structures, culture, and regiments*, we display how organizational structures hinder the personalization of ADL care provision. Nursing professionals struggle to balance within the organizational structures (EP, WC), that are often defined by mealtime [35] or medication schedules [36], especially in institutionalized care. Schedules and planning are perceived as major issues in-home care, that hinder personalized solutions, especially in *ad hoc* situations:

*"It's hard for example, if you were wetting your trousers at 2 p.m. you'd have to wait until the evening for someone to help you [community care setting]"* [WC1, Care receiver]

Adding to this challenge are hierarchical and cultural aspects of care provision distinguished by a blame culture associated with, for example, a lack of confidence in the ability of nursing home staff to reposition care receivers to prevent or manage pressure ulcers (RR) or being blamed for falls (WC):

*"If someone falls, you haven't done your job properly, I find that difficult. If, for example, I have to mop the floor and someone stumbles into the room I thought was safe and falls, then theoretically I haven't done my job properly."* [WC2, Nursing professional]

In theme 4.2, *Lack of resources: Mind-set or reality?,* we discuss different experiences of lacking resources where we see tension, especially among nursing professionals experiencing time constraints, as the major challenge for adequate care provision and promoting ADL independence (WC, EP, RR). However, some participants address the fact that promoting ADL independence even saves time in the long run and that time pressure is a construct that does not exist when time is properly managed and communicated, as illustrated by a former nursing professional.

*"Time pressure does not exist, you should not project that. I had a colleague who was always busy, busy, busy, which is sometimes so individual in how you experience it. I was never time-pressured in my job all those years."* [WC1, Former nursing professional].

Another scarce resource is the nursing workforce. We found the lack of nursing professionals to be an important issue, including high staff turnover and a high number of part-time workers endangering the continuity of ADL care provision (EP, WC, RR).

Moreover, the experienced workload is perceived as a substantial challenge in meeting care receiver needs, which results in missed ADL care, like not performing oral care at the weekends [44], or potentially unsafe ADL care, for example, by not using mechanical lifting equipment [31].

Theme 4.3, *Home vs. workplace: issues in the physical care environment,* illustrate the tension in an environment where people reside or live and work at the same time. Nursing professionals mainly report the unavailability of assistive devices, variation in layouts and geometry of care rooms, and poorly equipped environments as challenging (EP, WC, RR). With ADL care often taking place in (small) bathrooms, the physical environment can hinder safe practices and impact care providers and receivers; while professionals are often aware of ergonomic rules and principles, the physical environment and/or patient's needs do not always allow for adhering to them (EP, WC, RR).

The transformation of a home into a caring environment brings unique challenges, such as the feeling that care professionals are invading your home, privacy being lost at times when care is provided (WC), care receivers refusing to install environmental modifications to not project a narrative of disability (RR), or nursing professionals finding themselves in an inferior position compared to an inpatient setting (WC).

*"In the home environment, it's the home of the care receiver, so they are in charge and it's not your business. In the hospital you're the boss, but not in-home care."* [WC1, Nursing professional].

## Discussion

In our study, we aimed to synthesize the challenges that arise in ADL care irrespective of the care setting. We identified four challenges based on three different data sources: (1) Undervalued common-sense work vs. complex, high-skilled care provision; (2) Limitations in professional reflective clinical decision-making; (3) Missed opportunities for shared ADL decisions, and (4) Meeting ADL care needs in a high-throughput system. These challenges reveal the complexity of ADL care and how its paradoxical narrative interrelates with opportunities for shared decision-making and reflective clinical reasoning and how it influences the (organizational) ADL care environment and care system.

Even though each theme illustrates a different challenge, a certain level of interrelatedness cannot be unseen. Challenge 1 clearly shows the tension between, on the one hand, a simple form of care that is easily overlooked and, on the other hand, a form of care that, depending on the circumstances, can also involve complex forms of care provision. When the narrative of ADL care being "simple" is a dominant one, nursing professionals appear to be limited in the quality of reflective clinical reasoning (challenge 2) throughout the whole nursing process, especially when insights into the ADL care needs of a person are limited due to an insufficient ADL intake (including a conversation and assessment). The way nursing professionals act, within the respective ADL narrative, influences the extent to which shared ADL-related care choices (challenge 3) are possible in goal-setting or care agreements. At the same time, increasing complexity in care needs and care provision requires additional knowledge or complementary collaborations within and beyond the nursing profession, accompanied by unique challenges, for example, insufficient handover and unclear responsibilities. How ADL care is received and provided is highly related to the system (challenge 4), including the environmental and organizational context, which, based on the narrative, hinders or facilitates the way ADL care is received and provided. Within that context, resources are provided not only in terms of staffing or time but also in assistive equipment and the way it fits the environment. These resources again influence the way opportunities for shared decisions (challenge 2) and reflective clinical reasoning (challenge 3) arise.

When taking a closer look at our findings, within the broader scope of the literature on (essential) nursing care, we see the themes of synthesized challenges confirmed. In our first theme, we identified discrepancies in the image of ADL care as being simple and undervalued on the one hand and increasingly complex and highly skilled on the other hand. On the one hand, the undervalued image of ADL care becomes visible within a broader scope of essential nursing being perceived as "common sense work" [50]. On the other hand, the complexity of fundamental nursing care is very much acknowledged in the scientific literature, which is described as "anything but basic" by Kitson et al. [1]. This complexity lies in the integration of the physical, psychosocial, and relational elements of the care experience while embedding them in professional clinical decision-making, assessment procedures, and reflection of daily practice [1]. In line with our results, the expectations of integrating these elements into daily behavior often remain unmet; for example, hospital nursing professionals adhere to routines and "task-focused approaches" that hinder the efforts of nursing professionals to integrate the physical, relational, and physical elements of care [51]. This observation also resonates with our findings in theme 2, where we described the struggle of nursing professionals in clinical decision-making in ADL care. Clinical reasoning is at risk in ADL care when nursing professionals lack insights into ADL care needs. Gaps in the comprehensive assessment of ADL care needs prevent nursing professionals from moving forward from data collection into the following steps of clinical reasoning [51] and also stand in the way of building a meaningful care relationship [52]. This latter aspect also relates to our results in theme 3, which showed that care receivers often feel uninvolved in steps and decisions within the nursing process (for example goal setting, choice of interventions, and everyday decisions during care delivery). The literature shows that shared decision-making is often limited to cure-related medical or direct health decisions—for example, medication decisions in end-of-life care [53] or chronic care [54]. However, shared decisions should not be neglected in ADL care, which is prone to a lack of personal control, including emotional distress, for example, feeling exposed, embarrassed, or vulnerable [55]. This leaves care receivers uninformed and limits the opportunities for person-centered care provision in ADL care.

On top of that, the organizational and system-level challenges, identified in theme 4, hinder the efforts of nursing professionals to meet care receivers' needs, which adds to the complexity of ADL care provision. This observation raises the question of how we generally view and value ADL nursing care in society and how we consequently allocate resources and processes. Our results suggest that the paradoxical narrative of ADL nursing care as "undervalued common sense work" and "highly skilled care provision" is problematic, especially when it translates to inadequate allocation of (staffing-) resources on a system level, resulting in nursing professionals struggling to meet patient needs and/or documentation needs in a high-throughput system. Similar paradoxes emerge when looking from a health system perspective, where one aims towards cost-effective approaches and standardized tools [56] on the one hand and a holistic and relationship-centered approach on the other hand. In the latter, care receivers are engaged as active partners within the nursing care process [57, 58]. Unfortunately, these paradoxical paradigms are accompanied or even exacerbated by several global challenges such as the nursing workforce crisis that potentially lead to missed essential nursing care if not adequately addressed [59].

In moving forward, one may ask how to create an enabling environment and preconditions for nursing professionals to tackle the challenges of clinical reasoning and shared decision-making while meeting ADL care needs. As a first step, we, therefore, propose to foster a narrative that acknowledges the complexity of ADL care delivery and eventually translates into facilitating quality ADL care. These changes would include (1) changing the way we look at essential nursing care, including ADL care, from a theoretical perspective (for example, fundamentals of care framework [60] and acknowledging the complexity of meeting (complex) ADL needs; (2) advancing research to develop ADL interventions and future nursing research (to develop effective interventions (e.g. Basic Care Revisited I+II [61]); (3) developing policies and quality frameworks dedicated to the importance of the care relationship [62] that facilitate the creation of a supportive environment for nursing professionals that embraces a safe culture in which mutual reflection on current practices is stimulated while simultaneously striving towards adequate resource allocation in terms of staffing and time. Eventually, these changes could result in mutual understanding between nursing professionals and organizations on how one can achieve quality ADL care while doing justice to the system paradigms of cost-effective yet relationship-centered ADL care, and (4) developing clinical practice guidelines and advising nursing professionals on relevant elements of ADL care, including a meaningful care relationship, identifying ADL care needs, and working towards shared ADL decisions.

### Strengths and Limitations

During our study, we undertook several measures to increase the study quality guided by the quality indicators described in Korstjens and Moser [63]. First, we used triangulation via different methods (expert panel, world cafés, and literature) to increase the credibility of the data. Additionally, we member-checked our data by providing the expert panel minutes and overview of challenges to the participating experts and the organizations they represent. To retrieve credible results from the original graphic recording data, we took time, in the first phase of the analysis, to re-listen to the audio recordings of the World café session while following the reasoning on the graphic recordings. Second, we aimed to increase the transferability of the results by providing descriptive data on the different settings, sample sizes, and inclusion and exclusion criteria as well as the iterative research process and by guiding world café questions. Third, we used a 15-point checklist of the criteria for good thematic analysis [49] to plan and check ours to increase the dependability of the results and maximize rigor during analysis. Fourth, to increase the confirmability of the results, we kept minutes of the research meetings in which study decisions were made, and emerging concept maps of the analysis were discussed. Fifth, reflexivity was increased by the first author, who kept reflective notes, before and after data collection, on their own biases, preferences, and preconceptions.

This study is subject to the following limitations. While focusing on the challenges encountered in this study, we did not look at enabling factors in ADL nursing care. This might have resulted in a one-sided picture of ADL care. In conducting our study, however, we specifically invited participants in the World café sessions to not only focus on the negative side of ADL care but also share positive experiences (see World café questions). During data collection, we chose to first conduct the expert panel and world café sessions to ensure that our perceptions as researchers were not additionally influenced by the research results. Thus, we were able to focus on the participants' experiences. The open way in which we phrased the questions on challenges, in the world café session, could have compromised the depth of the discussion and sharing of real ADL-specific experiences. However, we aimed to address this limitation by rephrasing the questions, for the second world café session, into ADL-specific questions.

Furthermore, by choosing articles for a RR, from a single database, and limiting it to studies published in the last 10 years, we might have missed studies relevant to our research question. However, since we were able to confirm our results in the broader scientific body of evidence, we are confident that we did not miss essential challenges.

## Conclusion

We identified four core challenges that reveal the complexity of meeting care receiver needs in ADL care and how its paradoxical narrative relates to the conditions in which nursing professionals struggle to create opportunities for reflective clinical reasoning and shared ADL decisions by facing organizational and environmental barriers. This overview of challenges forms a starting point for future changes contributing to the quality of ADL nursing care, possibly including changes in policy organizational structures and guidelines for nursing professionals.

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# Appendicies

Appendix 1: Search strategy PubMed

Appendix 2: Characteristics of Included Studies

## Appendix 1: Search Strategy PubMed

((Nurse[title/abstract]) OR (Nurses[title/abstract]) OR (nursing[title/abstract]) OR (Nurses[Mesh]) OR (professional care provider*[title/abstract])) **AND** ((Activities of daily living[title/abstract]) OR (ADL[title/abstract]) OR (Activities of Daily Living[Mesh]) OR (Self-care[title/abstract]) OR (dressing[title/abstract]) OR (bathing[title/abstract]) OR (showering[title/abstract]) OR (washing[title/abstract]) OR (mobility[title/abstract]) OR (transferring[title/abstract]) OR (personal hygiene[title/abstract]) OR (grooming[title/abstract]) OR (eating[title/abstract]) OR (maintaining continence[title/abstract]) OR (toileting[title/abstract])) **AND** ((problem[title/abstract]) OR (insight[title/abstract]) OR (problems[title/abstract]) OR (challenge[title/abstract]) OR (challenges[title/abstract]) OR (dilemma[title/abstract]) OR (dilemmas[title/abstract]) OR (issue[title/abstract]) OR (issues[title/abstract]) OR (barrier[title/abstract]) OR (barriers[title/abstract]) OR (experience[title/abstract]) OR (difficult*[Title/abstract])) **NOT** ((child[mesh]) OR (child[title/abstract]) OR (infant[title/abstract]) OR (infant[mesh]) OR (adolescent[Mesh]) OR (toddler[title/abstract]) OR (adolescent[title/abstract]) OR (pediatric*[title/abstract]) OR (parent[title/abstract]) OR (midwife[title/abstract]) OR (midwive*[title/abstract]) OR (postpartum[title/abstract]) OR (birth[title/abstract]) OR (sleep quality[title/abstract] OR (young people[title/abstract]) OR (reproductive health[title/abstract]) OR (maternal[title/abstract]) OR (sexual health[title/abstract]) OR (eating disorder[title/abstract]) OR (HIV[title/abstract]) OR (Randomized controlled trial[title/abstract]) OR (sexual[title/abstract]) OR (pharma[title/abstract])))Filters: published in the last 10 years; Dutch; English; French; German

## Appendix 2: Characteristics of Included Studies

**Table 1** Characteristics of Included Studies in the Rapid Review

| **Author(s), Year of publishing & Country** | **Study design** | **Care setting** | **Population** | **Aim** |
|---|---|---|---|---|
| **Two or more ADL's (n=2)** | | | | |
| Liebel, Powers, Friedman, and Watson (2012)<br>USA | Qualitative descriptive design | Home care | Older persons with disability (n=19)<br>RNs (n=11) | To understand the results of the nurse home visit in terms of facilitators and barriers to disability improvement/maintenance as compared with disability worsening. |
| King, Holliday, and Andrews (2018)<br>Canada | Qualitative descriptive design | Home care | Personal support worker<br>Physical therapist<br>Shift nurses | To understand, from a care provider perspective, the specific ways in which providing assistance with bathing and toileting is difficult and dangerous |
| **Continence care (n=3)** | | | | |
| Brady et al. (2016)<br>Scotland | Mixed methods design | A mixed acute/rehabilitation stroke ward in a Scottish hospital | Nurses (n=14) & Nursing assistants (n= 9)<br>Stroke patients (n=15) | To investigate the perspectives of patients and nursing staff on the implementation of an augmented continence care intervention after stroke. |
| Helewa et al. (2017)<br>Canada | Cross-sectional, qualitative study | Colorectal Surgery Clinic | Patients with Fecal Incontinence [FI] (n=6)<br>Nurses (n=3)<br>Physical therapists (n=3)<br>Physicians (n=4) | To better define successful outcomes and to identify barriers for [continence] program sustainability. |
| Borglin, Hew Thach, Jeppsson, and Sjögren Forss (2020)<br>Sweden | Qualitative descriptive study | Home care | Registered Nurses (n=11) | To illuminate nurses' experience of continence care for older people receiving home care, either in their own homes or in an assisted living facility. |

| Author(s), Year of publishing & Country | Study design | Care setting | Population | Aim |
|---|---|---|---|---|
| **Eating and drinking (n=6)** | | | | |
| Carlsson, Ehnfors, Eldh, and Ehrenberg (2012)<br>Sweden | Qualitative descriptive study | Transitional care (Hospital-Home) | Registered Nurses: n=15<br>Licensed Practice Nurses: n=15 | To explore the perceptions of RNs and licensed practical nurses (LPNs) in elderly care of the accuracy and adequacy of web-based discharge information for stroke patients in the transfer from hospital to municipality care. |
| Lea, Goldberg, Price, Tierney, and McInerney (2017)<br>United States | Qualitative descriptive study | Nursing home | Care workers (n=2),<br>Enrolled nurses (n=2)<br>RNs (n = 2),<br>Diversional therapy assistants (lifestyle and leisure staff) (n = 2)<br>Hospitality (management and chefs) (n = 3) | To examine awareness of aged care home staff regarding daily food and fluid care needs of older people with dementia. |
| Forss, Nilsson, and Borglin (2018)<br>Sweden | Qualitative descriptive study | Nursing home | Older people (n=4)<br>RNs (n= 8) | To illuminate the experience of participating in nutritional care from the perspectives of older people and registered nurses. A further aim is to illuminate the latter's experience of nutritional care per se. |
| Heaven, Bamford, May, and Moynihan (2013)<br>United Kingdom | Qualitative descriptive study | Hospital care | Catering managers (n=4)<br>Catering staff n=5);<br>Consultants (n=6)<br>Senior nursing (13)<br>Healthcare assistant (n=7);Housekeeper (n=1)<br>Staff nurse (n=2);<br>Occupational therapist (n=4); Physical Therapist (n=1); Dietitian (n=3)<br>Speech and Language Therapist (n=10<br>Stakeholder representative (n=6)<br>Former patients (n=2)<br>Carers (n=3) | To understand and describe processes that promote or inhibit nutrition in hospital. |

| Author(s), Year of publishing & Country | Study design | Care setting | Population | Aim |
|---|---|---|---|---|
| Robison et al. (2015)<br>United Kingdom | Qualitative descriptive study | Hospital care | Healthcare assistant (n=2)<br>Staff nurse (n=2)<br>Ward sister (n=3)<br>Matron (n=2)<br>Patients (n=10)<br>Relatives (n=5) | To obtain multiple perspectives on nutritional care of older inpatients, acceptability of trained volunteers and identify important elements of their assistance. |
| Liu, Tripp-Reimer, Williams, and Shaw (2018)<br>United States | Qualitative descriptive study | Nursing home | Nursing Assistants (n=23) | To identify nursing assistants' perceptions of barriers and facilitators to engaging residents in eating will provide important experientially based foundation for developing and testing evidence-driven interventions to promote mealtime care. |
| **Mobility (n=5)** | | | | |
| Kanaskie and Snyder (2018)<br>United States | Qualitative descriptive study | Hospital care | RNs (n=14)<br>NA's (n=11) | To explore decision-making regarding use of safe patient handling and mobility (SPHM) technology among registered nurses (RN) and nursing assistants (NA). |
| Kuipers et al. (2016)<br>The Netherlands | Qualitative descriptive study | Nursing home care | Occupational Therapists (n = 4),<br>Nurses (n = 10)<br>Caregivers (n = 12) | To define the problem space, use context and user context of the iLift project. |
| Noble and Sweeney (2018)<br>United States | Mixed method design | Hospital care | Nursing staff (n=107) | To assess barriers to the use of assistive devices in safe patient handling and mobility (SPHM) that contribute to health care worker injuries. |
| Lavallée, Gray, Dumville, and Cullum (2018)<br>United Kingdom | Qualitative descriptive study | Nursing home | Healthcare assistants (n=7)<br>RNs (n=11)<br>Nurse managers (n=2)<br>Community based tissue Nurses (n=4)<br>Community nurse managers (n=1) | To understand the context of pressure ulcer prevention in nursing homes and to explore the potential barriers and facilitators to evidence-informed practices. |

| Author(s), Year of publishing & Country | Study design | Care setting | Population | Aim |
|---|---|---|---|---|
| Taylor, Sims, and Haines (2014)<br>Sweden | A focused ethnography. | Nursing home | Nurses (n=18) | To explore mobility care as provided by care staff in nursing homes. |
| **Personal hygiene (oral care) (n=3)** | | | | |
| Odgaard and Kothari (2019)<br>Denmark | Cross-sectional web-based survey | Rehabilitation | Nursing care professionals (n=157) comprised of:<br>Registered Nurses (66%)<br>Social and Healthcare Assistants (34%) | To gain knowledge on nursing care professionals´ attitude, belief, knowledge and practice towards oral care in a neuro-rehabilitation setting. |
| Sonde, Emami, Kiljunen, and Nordenram (2011)<br>Sweden | Qualitative descriptive study | Nursing home | Enrolled Nurse (n=7)<br>Nursing assistant (n=2) | To describe care providers' perception of and reasoning for the oral care for nursing home residents with dementia and to describe registered nurses' reasoning in relation to their responsibility for monitoring oral care interventions within the regular caregiving routines for nursing home residents with dementia. |
| De Visschere et al. (2015)<br>The Netherlands | Qualitative descriptive study | Nursing homes | Nurses (n=66) | To explore barriers and enabling factors to the implementation of an oral hygiene protocol in nursing homes. |

# Chapter 3

# Effective Nursing Interventions Affecting Independence and Comfort – A Systematic Review

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## Abstract

Despite its frequent provision, evidence of nursing interventions in Activities of Daily Living (ADL) remains unclear. Hence, we addressed the research question: What are the effects of ADL nursing interventions on independence and comfort in adults across all care settings? We conducted a systematic review of randomized controlled trials and quasi-experimental studies described in systematic reviews. In three databases, we searched for systematic reviews that we used as a portal to select (quasi-) experimental studies. After narratively summarizing the studies on characteristics, effects, and interventions, we assessed the risk of bias. Among the 31 included studies, 14 studies evaluated independence, 14 studies measured comfort, and three studies assessed both outcomes. Seven interventions significantly improved independence and seven interventions significantly improved comfort. The studies varied highly in intervention components, outcome measures, and quality. Evidence on ADL nursing interventions affecting independence and comfort remains fragmented and inconclusive, limiting guidance for nursing professionals.

## Introduction

Necessary for independent living and caring for oneself persons perform activities of daily living (ADL) including washing, dressing, toileting, grooming, eating and drinking, and in-home mobility. Over time, a person's ability to perform ADL independently can change due to multiple factors, especially with increasing age being a risk factor for developing limitations in ADL [1], next to socio-economic factors (e.g. gender, neighborhood, or income) [2, 3]. Furthermore, the ability to perform ADL independently is determined by the way a person acts or copes within the environment, meaning that a highly supportive environment (i.e. physical or social) can result in greater independence [4]. When a person experiences difficulties in performing ADL and appears to be unable to cope within their environment, a self-care deficit emerges, which results in the need for compensatory actions. The nature of these compensatory actions for (in)formal care depends on the (perceived) degree of dependence and on the different goals to be pursued in the process of care, such as improving or maintaining functional status or level of comfort [5]. One form of compensatory action is the delivery of nursing care in ADL, which is often targeted towards two central goals and outcomes: (1) achieving optimum independence and (2) maximizing comfort by primarily meeting a person's physical and emotional needs.

Sustaining ADL independence as one goal remains central to the quality of life and dignity of a person, and their perception of their own identity [6]. Previous research established that a loss of ADL independence relates to feelings of worthlessness and low self-esteem [7], hospitalization [8], institutionalization [9], and increased risk of mortality [10]. Nursing professionals fulfill a crucial role in supporting and respecting a person's ability to manage their ADL, regardless of diagnosis, cultural background, or healthcare setting [11]. Nursing professionals assist care receivers in their essential daily activities when they lack the strength, knowledge, or will, to carry them out unaided and to achieve healthy independence [12]. Hence, nursing professionals aim to actively encourage ADL independence in daily care.

The second goal of providing ADL care, i.e., maximizing a person's comfort when ADL care is provided, also represents a fundamental aspect of ADL care [13]. Comfort is emerging as a multidimensional concept central to the personal care experience not limited to (temporary) relief of physical discomfort but a matter of integrating positive emotions (i.e., having a sense of personal control, feeling cared for, valued, or safe) [14] which is highly relevant to nursing care at any stage [15]. ADL care involves a high level of intimacy and is therefore prone to a potentially humiliating experience, commonly associated with emotional or physical distress. Emotional distress in ADL care can manifest itself in feeling exposed, embarrassed, or vulnerable [16]. In severe cases, ADL care can provoke behavioral symptoms such as agitation and aggression that are distressing and potentially unsafe to both the person and the nursing professional [17]. Due to the intense nature of

ADL care, physical distress in daily care can be expressed in pain, physical exhaustion, feeling cold and uncovered, bowel regimen-associated problems (i.e., constipation, uncomfortable supplies, and seats), or unpleasant environmental factors (i.e., noise, limited privacy) [18]. Hence, nursing professionals fulfill an important role when it comes to understanding and integrating a person's physical and emotional comfort-related needs in ADL care.

Improving or maintaining ADL independence and comfort whilst meeting the personal ADL care needs of individuals in daily practice can be complex and challenging. Adding to the complexity is the insufficient guidance as to how nursing interventions in ADL care can effectively improve care receiver outcomes [19]. Hence, the existing scientific literature has been criticized for an absence of evidence in core areas of ADL care such as hygiene, mobility, or toileting [19]. In the last decade, however, several systematic reviews (SRs) on the topic of ADL care have been published. In terms of ADL independence, systematic reviews on ADL care yet often focus on solely one of the six ADLs, i.e. mobility [20], washing [21], or bathing [22], and include multidisciplinary interventions such as 'reablement' [22, 23]. While a multidisciplinary approach might be considered beneficial in general, SRs lack information on the specific role and implications of the crucial role of the nursing profession in ADL care.

Similarly, in SRs on comfort, the implications for nursing professionals remain limited when including studies whose interventions are performed by informal caregivers or research staff [17] and, including environmental interventions (e.g. light or music) where the role of the nursing professional is unclear [24]. Hence, in daily practice, nursing professionals largely rely on experience, intuition, and tradition [25] and are in need of integral scientific knowledge and guidelines on the delivery of ADL care [26]. Despite heightened awareness and efforts to establish evidence-based nursing practice, guidance for nursing professionals as to how to provide effective ADL nursing care is lacking. To address this need for guidance, we aim to address the following research question: What are the effects of ADL nursing interventions on independence and comfort in adults across all care settings?

## Materials and Methods

We conducted a systematic review of the randomized controlled trials and quasi-experimental studies described in published systematic reviews (SRs) in two phases.

### Phase 1: Identification of Eligible Systematic Reviews

*Search*

We built our search for SRs in collaboration with an information specialist from the Maastricht University Library using the Patient, Intervention, Comparison, and Outcome, Study Design ( PI(C)OS) -structure [27] (Table 1). We chose to limit the period for the search since the literature on ADL care has been emerging for the past two decades resulting in a time-limited search from 25th March 2000 to 25th October 2021. The reason for this time limitation was twofold. First, when developing our search we discovered that reviews on this matter appear to not have been published before 2000. Second, we saw that health systems, patient characteristics, and the way we provide care are rapidly changing. The following electronic databases were searched: PubMed, CINAHL, and the Cochrane Database of Systematic Reviews. We conducted this review according to the methodological recommendations of the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) protocol [28]. The present SR has been registered in the International Prospective Register of Systematic Reviews (PROSPERO) (registration No. CRD42021218051).

**Table 1** Keywords and Search based on the Patient, Intervention, Comparison, and Outcome, Study Design (PI(C)OS) -structure

| | Keywords[a] |
|---|---|
| P | **Adults in all ADL relevant health care settings:** adult[b], or humans[b] or disabled persons[b] or adult or adults or patients or care recipients OR care receivers or clients or residents or inpatients or older people or older adults or community dwelling or patient or patients or elderly or elders |
| I | **Nursing care:** evidence-based nursing[b] or nursing service, hospital[b] or home Nursing[b] or home health nursing[b] or critical care nursing[b] or geriatric nursing[b] or geriatrics/methods[b] or hospice and palliative care nursing[b] or neuroscience nursing[b] or rehabilitation nursing[b] or ambulatory care[b] or long-term care[b] or primary care nursing[b] OR home care services[b] or rehabilitation/methods[b] or rehabilitation/nursing[b] or rehabilitation/standards[b] or nursing care/standards[b] or self-help devices[b] or bathroom Equipment[b] or personal care services or restorative homecare or fundamental care or nursing approach or nursing process or nursing or nursing intervention or basic nursing care] **AND ADL:** [activities of daily Living[b] or baths/methods[b] or baths/standards[b] or baths/nursing"[Mesh] or hygiene/methods[b] or hygiene/nursing[b] or hygiene/standards or sanitation/methods[b] or Soaps[b] or health Promotion/methods[b] or personal activities of daily living or bathing or baths or bed bath or hygiene or reablement or re-ablement or self-care or dressing or showering or shower* or washing or mobility or transferring or ambulating or personal hygiene or eating or maintaining continence or toileting or toilet use or daily activities or Everyday activities or personal activities |
| O | ADL-independence and comfort know various definitions and operationalizations within the literature. Taking the diversity of the outcomes of interest into account we chose to not further limit the scope of the search strategy by adding a string of outcomes. This resulted in a broader starting point, while also offering the full scope of relevant outcomes. The following outcomes were applied as inclusion criteria during the screening phases.<br>**(1) ADL-independence** as the degree of independence from any help, physical or verbal [29] measured by general ADL instruments i.e. Barthel Index, Functional independence Measure (FIM), or instruments measuring independence in one of the six ADLs.<br>**(2) Level of physical or emotional comfort,** a multidimensional concept central not limited to (temporary) relief of physical discomfort but a matter of integrating positive emotions (i.e. having a sense of personal control, feeling cared for, valued, or safe) measured by e.g. the resident discomfort scale or the Cohen-Mansfield Agitation Inventory (CMAI), emotional comfort scales Patient Evaluation of Emotional Comfort Experienced (PEECE) pain scales, behavioral pain scale (BPS). |
| S | The study design was limited to systematic reviews. We used a search filter of the National Library of Medicine [30] for PubMed and the UT Health School of Public Health [31] filter for Cinahl |

Abbreviation: MeSH, Medical Subject Headings.

[a] Keywords were searched in title and/or abstracts (PubMed); in abstract (CINAHL); and title, abstract, or keywords (Cochrane) by combining Population AND Intervention AND Outcome. Truncation was not used to prevent the exploding of results; in Cochrane word variations have been searched.

[b] Keywords which were MeSH terms in PubMed.

*Eligibility Criteria*

SRs were eligible when describing interventions undertaken by nursing professionals primarily, such as nursing aides, nursing assistants, and registered nurses, during one or more of the six predefined ADLs, aiming to affect the level of ADL independence or the level of comfort. Studies including other professionals (i.e. occupational or physiotherapists) fulfilling only an advisory role for nursing professionals were included. Hence, studies were not considered when other professionals, such as therapists or interdisciplinary teams, had an active role in carrying out the intervention. All studies conducted in all types of healthcare settings in which ADL care is provided (i.e. home, nursing home, hospital, rehabilitation settings) were eligible. Additionally, SR was eligible when including randomized controlled trials (RCTs), and/or quasi-experimental research designs with and without a control group. Studies published in English, French, Dutch, or German were eligible for inclusion. Interventions included in the SR were excluded when investigating medical devices or products such as nutritional supplements, washing products, incontinence materials, and devices. Moreover, we excluded interventions that solely aimed to improve the movement of limbs or enhance exercise capacity.

*Selection*

After we imported all identified records into the citation management system (EndNote), we removed duplicates. Before performing the screening process in two phases (see Figure 1), we used the online screening tool RAYYAN QCRI. First, two authors (SC and SV) independently reviewed the SR records in two steps by first screening on titles, and abstracts, and subsequently screening the full-text articles. After the full-text screening, we identified 11 reviews including a subset of (quasi-) experimental studies potentially matching the eligibility criteria of our study (see appendix 1 for reasons for partial in- and exclusion of SRs). Discrepancies were discussed throughout the screening process. Conflicts and discussions were solved by consulting the third author (MB). The co-authors SM, JMG, and SZ were updated throughout the entire screening process by the first author during monthly meetings in which methodological considerations and the relevance of the selected studies to the research aim were confirmed.

## Phase 2: Identification of Eligible (Quasi-) Experimental studies

In phase two we screened all individual (quasi-)experimental studies included in the 11 identified reviews by importing those into the online screening tool RAYYAN QCRI. Again, the same two authors (SC and SV) independently reviewed the (quasi-)experimental records based on the same eligibility criteria and processes as described in phase 1. Additionally, we screened the references of the selected studies for additional studies. Finally, we assessed the risk of bias using the checklists of the Joanna Briggs Institute [32].

*Data extraction and Data Synthesis*

After the screening process, the first author performed the data extraction of the (quasi-) experimental studies using a data extraction spreadsheet in Microsoft Excel 2016 (Microsoft Corporation, Redmond, WA, USA). Descriptive data on study characteristics (bibliographical details, countries, aims, study design, settings, participants, and intervention) were extracted and categorized guided by the 'Characteristics of included studies table' of the Cochrane Handbook [33]. Relevant analytical data based on the pre-selected outcomes, i.e. mean differences of ADL independence and comfort, were collected in a summary of findings table following the outcome-centered approach of the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) [34]. Since included studies varied in terms of most characteristics, we described the findings narratively guided by Popay et al. [35] by tabulating, grouping, and clustering the data as far as possible according to the outcome, ADL, and interventions.

*Risk of Bias Assessment*

To assess the quality of the quasi-experimental studies, we used the Joanna Briggs Institute (JBI) guidelines for RCTs and quasi-experimental studies [32]. The risk of bias assessment tools consists of different quality criteria depending on the design. After assessing the studies, we calculated the proportion of the criteria that the study achieved to determine a total quality score. We determined the cut-off scores for the different levels prior to the assessment, as advised in the JBI Manual. The following cut-off points were applied: >70% 'yes' equals high quality, 50-69.9% moderate quality, 20-49. low quality, and <20% very low quality. To present the full spectrum of studies, studies of all quality levels are displayed in this review. We divided the studies among three authors (SC, SV, and JMG) in which one study was always assessed by a minimum of two authors, and discrepancies in judgment were resolved by discussion.

## Results

### Study Selection

The flowchart in Figure 1 outlines the selection process and provides reasons for exclusion. We identified 1,483 potential SR after removing duplicates (n=135). During the title abstract review, we excluded 1,226 SR. After screening 257 SR on a full-text basis, we found 11 SR that were in line with the eligibility criteria containing potentially relevant (quasi-) experimental studies [17, 19, 20, 24, 36-42]. Consequently, we extracted 366 (quasi-) experimental studies from these 11 reviews. In phase 2, we removed duplicates and screened (quasi-) experimental studies based on title and abstract full-text, and consequently we included 28 (quasi-) experimental studies in our review.

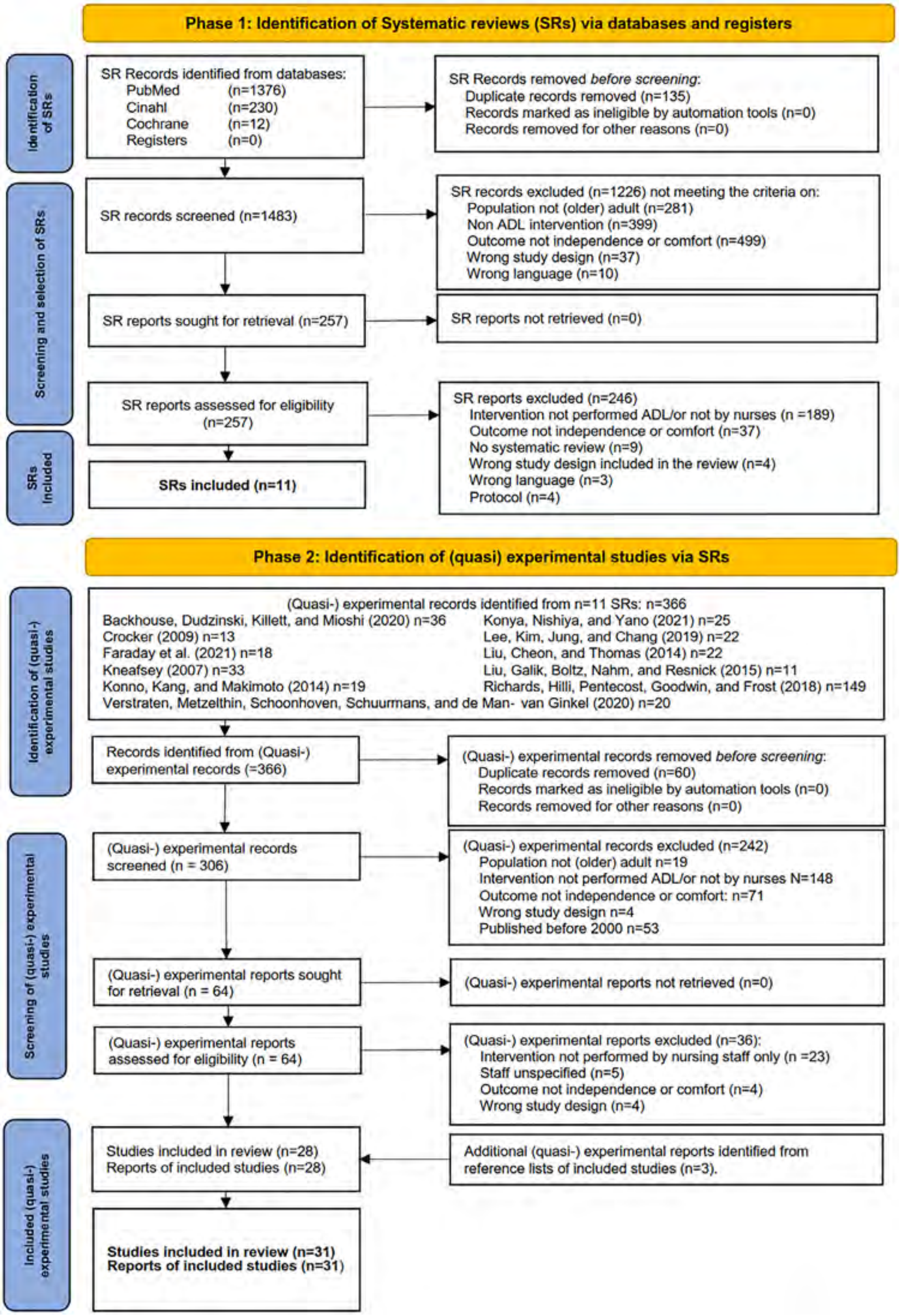

**Figure 1** Adapted PRISMA 2021 Flowchart Selection Process in Two Phases

After performing a reference check, an additional three studies appeared to be relevant, resulting in the total inclusion of 31 studies.

## General Study Characteristics

In total, we identified eight randomized controlled studies and 23 (quasi-) experimental studies, published between 2000 and 2018. Fourteen studies assessed ADL independence and 14 studies targeted comfort as the outcome. Additionally, we found three studies including both outcomes. Twenty-six studies (84%) were conducted in long-term care facilities such as nursing homes, while five studies were carried out in the hospital setting [43-47]. The majority of studies (n=26; 87%) focused on nursing home residents with dementia [48-66] without dementia [67-71] or with cognitive impairment [72, 73]. The other studies were targeted at persons admitted to the hospital[43-47]. Concerning the content of the interventions presented in the studies, 12 interventions (39%) were aimed at general ADL, whereas the other studies focused on specific ADL activities such as bathing (n=7), mobility (n=6), eating (n=3), toileting (n=1), dressing (n=1), and grooming (n=1). The characteristics of the included 31 studies are displayed in Table 2.1, Table 2.2, and Table 2.3.

## Studies Targeting ADL Independence

### *Study Characteristics*

Among the seventeen studies targeting ADL independence, we found four randomized controlled studies [48, 65, 67, 68] and 14 quasi-experimental studies, among which seven studies included a control group. [44, 45, 47, 49, 53, 54, 69]

Interventions described in six studies aimed to increase independence in a broader scope and aimed to increase ADL independence in personal care activities (i.e. bathing, dressing, grooming) [48, 65-67, 69, 73]. Six interventions focused on mobility activities, such as stimulating additional physical activity during daily activities, i.e., walking, transferring [44, 47, 68], sit-to-stand activity [52, 53], and early bed mobilization in intensive care patients [45]. Interventions to increase independence in eating and drinking were described in three studies [49, 51, 54]. One intervention aimed to improve independence in dressing [50] and one in grooming [72]. We describe the included interventions in Appendix 2.

In terms of outcomes measures, we found that all the studies that evaluated ADL independence used an observational scale assessed by a care professional or research assistant evaluating general ADL performance (i.e., the Barthel Index), or activity-specific performance in, for example, eating (e.g., Edinburgh Feeding Evaluation in Dementia) or mobility (e.g. the 30-second sit-to-stand test).

**Table 2.1** Characteristics of Included Studies Targeting Independence (n=14)

**Studies targeting Independence (n=14)**

| **Author (Year)**<br>**Country** | **Design** | **Study aim** | **Aspect of ADL** | **Study population and setting** | **Sample** | **Measured outcome(s) of interest** |
|---|---|---|---|---|---|---|
| **RCT's (n=3)** | | | | | | |
| **Henskens, Nauta, Drost, and Scherder (2018)**<br>The Netherlands | Double parallel randomized controlled trial | To evaluate the effect of three movement-stimulating interventions including an exercise or social activity (control) intervention, resulting in four groups: 1) PADL: physical activity and ADL training,<br>2) SADL: social activity and ADL training,<br>3) PCO: physical activity and care-as-usual, and 4) SCO: social activity and care-as-usual on Quality of Life and ADL performance in NH residents with dementia. | General ADL | Residents with dementia<br>Nursing home | Total: n=87<br>Age: 85.7 (5.96)<br>Female:77.2%<br>PADL: n=22<br>SADL: n=21<br>PCO: n=22<br>SCO: n=22 | Care Dependency Scale (CDS)<br>E-ADL test |
| **Resnick et al. (2009)**<br>USA | Randomized controlled repeated-measure design | To test the effectiveness of a restorative care (Res-Care) intervention on function, muscle strength, contractures, and quality of life of nursing home residents, with secondary aims focused on strengthening self-efficacy and outcome expectations. | General ADL | Residents<br>Nursing home | Total: n=486<br>Age: 83.8 (8.2)<br>Female: 76.9<br>IG: n=255<br>CG: n=231 | Barthel Index |
| **Peri et al. (2008)**<br>New Zeeland | Cluster randomized controlled trial | To determine whether a repetitive activity of daily living (ADL) activity program improves health status, life satisfaction, and mobility for older people living in residential care. | Mobility | Residents<br>Nursing home | Total: n=149<br>Age: 85.7 (6.1)<br>Female: 84.0%<br>IG: n=73<br>CG: n=76 | Elderly Mobility Scale (EMS)<br>Timed-up-and-go test (TUG) |

| Author (Year) Country | Design | Study aim | Aspect of ADL | Study population and setting | Sample | Measured outcome(s) of interest |
|---|---|---|---|---|---|---|
| Quasi-experimental studies (n=11) | | | | | | |
| **Blair, Glaister, Brown, and Phillips (2007)**<br>USA | Quasi-experimental, repeated measure design | To determine how consistently intact nursing home residents would perform selected morning ADLs after the NAs who provided their care attended one of the following four educational conditions: (1) a combination of Orem's system of nursing care (OSNC) and applied behavior analysis (ABA), (2) ABA only, (3) OSNC only, and (4) regular in-service education (RISE). | General ADL | Residents<br>Nursing home | Total: n= 84<br>Age: 79.5<br>Female: 68.9%<br>IG: n=63<br>OSNC & ABA: n=19<br>ABA only: n=19<br>ONSC only: n=25<br>CG: n=21<br>RISE n=21 | Barthel Index |
| **Chang and Lin (2005)**<br>Taiwan | Quasi-experimental design | To develop a comprehensive feeding skills training program for nursing assistants and to test the effects of this training program on their knowledge, attitude, and behavior and the outcome of dementia patients including total eating time, food intake, and feeding difficulty. | Eating | Residents with dementia<br>Nursing home | Total: n=67<br>Age: N/R<br>IG: n=31<br>CG: n=36 | Edinburgh Feeding Evaluation in Dementia (EdFED) |
| **Engelman, Mathews, and Altus (2002)**<br>USA | Pilot study | To assess the impact of teaching certified nursing assistants to use a graduated prompting procedure to increase the dressing independence of persons with dementia. | Dressing | Residents with dementia<br>Special dementia care facility | Total: n=3<br>Age 84 (7)<br>Female: 100% | ADL Independence (coded in four categories)<br>(a) independent (no assistance);<br>(b) minimally intrusive assistance (verbal prompts, gestural prompts, and modeling);<br>(c) intrusive assistance (physical guidance);<br>(d) complete assistance |

| Author (Year) Country | Design | Study aim | Aspect of ADL | Study population and setting | Sample | Measured outcome(s) of interest |
|---|---|---|---|---|---|---|
| **Killey and Watt (2006)**<br>USA | A quasi-experimental design | To examine the effect of two extra walks per day on mobility, independence, and exercise self-efficacy. | Mobility | Older adults<br>Hospital | Total: n=55<br>Age: 83,3 (6,8)<br>Female: N/A<br>IG: n=28<br>CG: n=27 | Barthel Index |
| **Klein, Mulkey, Bena, and Albert (2015)**<br>USA | Prospective, two-group pre/post-comparative design | To determine if an early mobilization protocol increased mobility and improved clinical and psychological outcomes. | Mobility | Critically ill patients with primary neurologic injury admitted to the neurologic ICU<br>Hospital | Total: n=637<br>Age: 61,9 (16,5)<br>Female 50,1%<br>Pre-intervention: n=260<br>Post-intervention: n=377 | Mobility: 16 levels of progressive mobility |
| **Lim (2003)**<br>Korea | quasi-experimental time series design | To explore the effectiveness of nursing interventions for the grooming performance of individuals with mild dementia. | Grooming | Residents with mild cognitive impairments<br>Special dementia care facility | Total: n=4<br>Age: 78.6 (NR)<br>Female: 50% | Performance of Grooming Tasks (PGT) |
| **Lin, Huang, Watson, Wu, and Lee (2011)**<br>China | Experimental crossover design | To investigate the efficacy of applying a Montessori intervention to improve eating ability and nutritional status. | Eating | Residents with dementia<br>Nursing home | Total: n=29<br>Age: 82.9 (5.95)<br>Female: 41.4% | Edinburgh Feeding Evaluation in Dementia (EdFED) |
| **Padula, Hughes, and Baumhover (2009)**<br>USA | Non-equivalent control group design | To determine the impact of a nurse-driven mobility protocol on functional decline. | Mobility | Older adults<br>Hospital | Total: n=50<br>Age: 84 (35)<br>Female: 54%;<br>IG: n=25<br>CG: n=25 | Barthel Index |

| Author (Year) Country | Design | Study aim | Aspect of ADL | Study population and setting | Sample | Measured outcome(s) of interest |
|---|---|---|---|---|---|---|
| **Slaughter and Estabrooks (2013)**<br>Canada | Quasi-experimental pilot study | To assess (1) the effect of the sit-to-stand activity on mobility outcomes of nursing home residents, (2) the effect of an audit-and-feedback intervention on uptake of the sit-to-stand activity by healthcare aides, and (3) the contextual factors influencing uptake of the sit-to-stand activity by healthcare aides. | Mobility | Residents with dementia<br>Nursing home | Total: n=22<br>Age: 85,7 (5.1)<br>Female: NR<br>Site 1: n=11<br>Site 2: n=11 | 30-second sit-to-stand outcome |
| **Slaughter et al. (2015)**<br>Canada | Longitudinal quasi-experimental intervention study with intervention and control groups. | To assess the effect of the sit-to-stand activity on the mobility, function, and health-related quality of life of nursing home residents with dementia. | Mobility | Residents with dementia<br>Nursing home | Total: n=111<br>Age: 86.0 (6.9)<br>Female: 73,4%<br>IG: n=56<br>CG: n=55 | Functional Independence Measure (FIM)<br>30-second sit-to-stand test |
| **Wu, Lin, Wu, Lin, and Liu (2014)**<br>Taiwan | A single-blinded and quasi-experimental design with repeated measures (3 group comparisons) | To explore the long-term effects of standardized and individualized spaced retrieval combined with Montessori-based activities on the eating ability of residents with dementia. | Eating | Residents with dementia<br>Nursing home | Total: n=90<br>Age: 82,5 (5,9)<br>Female: N/R<br>IG: n=63<br>Standardized: n=25<br>Individualized: n=38<br>CG: n=27 | Edinburgh Feeding Evaluation in Dementia (EdFED) |

### *Effects on Independence*

We reported the effects on of all included independence-related studies in Table 3.1. Seven studies targeting ADL independence reported significant effects. Three studies used the Barthel Index (total scores range from 0 to 100, with 100 being the independent). First, the 'Function Focused Care' (FFC) intervention of Galik et al. [65] reported significant results in the intervention group compared to the control group at three months (p=0.01). This multi-component intervention targeted at nursing home residents with dementia comprised (a) an evaluation of barriers to the implementation of an FFC approach, (b) the education of nursing home staff and families about FFC, (c) individualized goal setting through assessment, and discussion, and (d) additional mentoring. Second, the 'extra walks per day' intervention by Killey and Watt [44] showed statistically significant improvement in hospitalized persons on the Barthel Index after 7 days (p=0.03). This intervention consisted of two assisted or supervised walks a day, seven days a week, in which participants decided the maximum comfortably walkable distance at that time. Nursing staff were instructed to encourage and enable a longer walk on each occasion. Third, the Geriatric Friendly Environment through Nursing Evaluation and Specific Interventions for Successful Healing (GENESIS) intervention [47] showed statistically significant improvement in hospitalized persons on the Barthel Index comparing admission and discharge scores (p=0.05). Nursing professionals performed different parts of the intervention according to their role in which Registered Nurses (RN) evaluated the necessity for bed rest as well as obstacles to mobility, such as urinary catheters. Certified Nursing Assistants (CNAs) walked with participants 3 to 4 times per day and assisted them in walking to meals or the bathroom.

Significant improvements in specific ADL activities were found in the overall reduction of eating difficulty and increased mobility levels. We found two of three studies reporting significantly reduced levels of eating difficulty in nursing home residents with dementia measured on the Edinburgh Feeding Evaluation in Dementia scale and/or the Eating Behaviour Scale. First, a Montessori intervention [51] showed significant results after two months between the intervention group and control group for a reduction of eating difficulty on the Edinburgh Feeding Evaluation in Dementia (p=0.008) and improved levels of eating performance on the Eating Behaviour Scale (p=0.025). The Montessori intervention divided eating-related activities into continuous chronological procedures, training residents to actively practice and repeat the procedures.

Second, this Montessori-based intervention was extended with elements of spaced retrieval where residents learn procedures related to eating and are asked to recall them at increasing time intervals. [54] Both a standardized and individualized approach to this intervention showed a statistically significant reduction on the Edinburgh Feeding Evaluation in Dementia scale over time after six months in the intervention group compared to the control group (p=0.007).

In terms of mobility outcomes, significant improvements in the 30-second sit-to-stand outcome in nursing home residents with dementia were observed in the ‘sit-to-stand activity intervention’ [52] after 3 months in the high dose group (>120) compared to the group receiving the low dose treatment (<120) after adjustment for age (p=0.046). During this intervention, nursing aides encouraged participants to slowly stand up and sit down as many times as possible twice a day during usual ADL care.

Improved levels of mobility in critically ill patients with primary neurologic injury admitted to the neurologic Intensive Care Unit (ICU) were observed in the ‘early mobility protocol’ [45] after 4 months (p< 0.001). This early mobility protocol included written orders for four progressive mobility milestones from 16 mobility levels. No statistically significant improvements were found for dressing or grooming interventions.

### *Risk of Bias in Studies Targeting Independence*

We present our risk of bias assessment tables in appendix 3. In the 17 studies targeting ADL independence, we found one quasi-experimental study of high quality [54]; 10 studies were of moderate quality, four were RCTs [48, 65, 67, 68] and six were quasi-experimental studies [44, 50, 53, 66, 69, 73]. Six quasi-experimental studies were of low quality [45, 47, 49, 51, 52, 72].

**Table 3.1** Summary of Findings Table of Studies Targeting Independence

| Outcome measure | Author (year) | ADL-domain | Intervention | Population | Effect on patient discomfort | |
|---|---|---|---|---|---|---|
| | | | | | Follow-up | Results |
| **Overall ADL-functioning (n=8)** | | | | | | |
| **Barthel index**<br>*(Range 0-100)*<br>*Higher scores = favorable outcome* | Resnick et al. (2009) | General ADL | Restorative care intervention | Nursing Home Residents | 4 months | No significant differences emerged in mean Barthel scores between the groups on either baseline or after 4 or 12 months. |
| | | | | | 12 months | No significant differences emerged in mean Barthel scores between the groups on either baseline or after 4 or 12 months. |
| | Blair et al. (2007) | General ADL | Applied behavior Analysis | Nursing Home Residents | 2 months | No significant differences in mean scores in Conditions 1, 2, 3, and 4 at 2 months post-intervention. |
| | | | Orem's System of Nursing Care | | 4 months | No significant differences in mean scores in Conditions 1, 2, 3, and 4 at 4 months post-intervention. |
| | | | Combined | | 6 months | No significant differences in mean scores in Conditions 1, 2, 3, and 4 at 6 months post-intervention. |
| | Galik et al. (2008) | General ADL | Restorative care intervention | Nursing Home Residents with dementia | 4 months | No significant differences in overall mean scores between baseline and 4-month post-intervention. |
| | | | | | 6 months | No significant differences in overall mean scores between baseline and 4-month post-intervention. |
| | E. Galik et al. (2014) | General ADL | Restorative care intervention | Nursing Home Residents with dementia | 3 months | Significant differences in mean scores were found in the intervention group compared to the control group at three months.<br>CG: 44.32 (SD:2.92) vs. IG: 55.20 (SD:3.16), p:0.01 |
| | | | | | 6 months | No significant differences in overall agitation mean scores between the groups at 6 months post-intervention. |
| | Killey and Watt (2006) | Mobility | Mobility intervention (extra walks) | Hospital in-patients | 7 days | Significantly improved levels of ADL-functioning were found for the intervention group after 7 days.<br>CG: 55.18 (SD:31.78) vs. IG: 70.81 (SD:24.33), p:0.03 |
| | Padula et al. (2009) | Mobility | Nurse-driven mobility protocol | Older hospitalized adults | Admission | No significant differences in ADL functioning between pre-admission and admission. |
| | | | | | Discharge | Significant differences in ADL functioning mean scores were found in the intervention group compared to the admission scores.<br>Difference in mean scores: IG:+11.5 (P = 0.05); IG: Admission: 69.10 vs. discharge: 80.60 |

| Outcome measure | Author (year) | ADL-domain | Intervention | Population | Effect on patient discomfort | |
|---|---|---|---|---|---|---|
| | | | | | Follow-up | Results |
| **Functional Independence Measure (FIM)**<br>*(Range 18 – 126)*<br>*Higher scores = favorable outcome* | Slaughter et al. (2015) | Mobility | Sit-to-stand activity | Nursing Home Residents with dementia | 6 months | No significant differences in mean FIM scores between the groups at 6 months post-intervention. |
| **The sum of the z-scores of the CDS and E-ADL**<br>*(Range N/R)*<br>*Higher scores = favorable outcome* | Henskens et al. (2018) | General ADL | ADL-training | Nursing Home Residents with dementia | 6 months | No significant main effect or group-by-time emerged of ADL training on ADL performance after 6 months. |
| **Refined ADL Assessment (RADL)**<br>*(Range 13-78)*<br>*Higher scores = favorable outcome* | Sidani et al. (2012) | General ADL | Abilities-focused approach to morning care (AFMC) | Nursing Home Residents with dementia | 1 month | No significant differences in overall mean scores between baseline and 1-month post-intervention. |
| **Eating performance (n=3)** | | | | | | |
| **Eating behavior scale (EBS)**<br>*(Range 0-18)*<br>*Higher scores = favorable outcome* | Lin et al. (2011) | Eating | Montessori intervention | Nursing Home Residents with dementia | 2 months | Significantly improved levels of eating dependence were found for the intervention compared to the control group in favor of the intervention.<br>CG: Pre: 15.61 (SD:3.50) vs. Post: 14.68 (SD:4.80)<br>Difference Pre-Post: -0.96 (SD: 2.99); p=0.054<br>IG: Pre: 16.18 (SD:2.78) vs. Post: 16.79 (SD:1.85)<br>Difference Pre-Post: 0.63 (SD:2.84); p=0.130<br>Difference of difference between groups: p=0.025 |

| Outcome measure | Author (year) | ADL-domain | Intervention | Population | Effect on patient discomfort | |
|---|---|---|---|---|---|---|
| | | | | | Follow-up | Results |
| **Edinburgh Feeding Evaluation in Dementia (EdFED)**<br>*(Range 0-20) Lower scores = favorable outcome* | Chang and Lin (2005) | Eating | Feeding skills program | Nursing Home Residents with dementia | Post-intervention | Significantly increased levels of feeding difficulty were found in the intervention group compared to the control group at the post-test (p < 0.05).<br>CG: Pre: 7.8 (SD: 3.1) vs. Post: 8 (SD: 7.8)<br>IG: Pre: 7.4 (SD: 2.3) vs. Post: 10.3 (SD:7.4) |
| | Lin et al. (2011) | Eating | Montessori intervention | Nursing Home Residents with dementia | 2 months | Significantly reduced levels of overall feeding difficulty were found for the intervention group between pre and post-test and compared to the control group in favor of the intervention.<br>CG: Pre: 3.98 (SD:2.87) vs. Post: 4.61 (SD:2.64)<br>Difference Pre-Post: 0.71 (SD: 2.43); p=0.058<br>IG: Pre: 5.11 (SD:3.31) vs. Post: 3.54 (SD:1.77)<br>Difference Pre-Post: -1.57 (SD:3.41); p=0.011<br>Difference of difference between groups: p=0.008 |
| | Wu et al. (2014) | Eating | Spaced retrieval and standardized or individualized Montessori Intervention | Nursing Home Residents with dementia | 1 month | No significant differences in overall mean scores between the control group and both interventions (standardized, individualized) |
| | | | | | 3 months | No significant differences in overall mean scores between the control group and both interventions (standardized, individualized) |
| | | | | | 6 months | Significantly reduced levels of overall feeding difficulty were found for the standardized and individualized intervention vs. the control group.<br>Standardized: Mean change from the post-test to the 6-month follow-up between the standardized and control groups: -0.37 p=0.007;<br>Individualized: Mean change from the post-test to the 6-month follow-up between the individualized and control groups: - 0.30, p=0.02 |
| **Mobility performance (n=4)** | | | | | | |
| **Elderly Mobility Scale (EMS)**<br>*(Range 0-20) Higher scores = favorable outcome* | Peri et al. (2008) | Mobility | An activity program delivered in 4 phases | Nursing Home Residents | 3 months | No significant difference in EMS mean scores emerged between the groups after 3 months. |
| | | | | | 6 months | No significant difference in EMS mean scores emerged between the groups after 6 months. |

| Outcome measure | Author (year) | ADL-domain | Intervention | Population | Effect on patient discomfort | |
|---|---|---|---|---|---|---|
| | | | | | Follow-up | Results |
| **Timed-up-and-go score (TUG)**<br>*(Range: Depending on patient's condition. Max. 240 secs)* | Peri et al. (2008) | Mobility | An activity program delivered in 4 phases | Nursing Home Residents | 3 months | No significant difference in TUG mean scores emerged between the groups after 3 months. |
| | | | | | 6 months | No significant difference in TUG mean scores emerged between the groups after 6 months. |
| **30 seconds sit to stand outcome:**<br>*(Range: Based on age and sex-related averages)*<br>*Higher scores = favorable outcome* | Slaughter and Estabrooks (2013) | Mobility | Sit-to-stand activity | Nursing Home Residents with dementia | 3 months | Statistically significant differences in improved mobility were found in the intervention group receiving the high dose (>120) compared to the group receiving the low dose treatment (<120) after adjustment for age. Difference between the pre-post mean scores between groups: 2.00: F=4.46; p=0.046. |
| | Slaughter et al. (2015) | Mobility | Sit-to-stand activity | Nursing Home Residents with dementia | 6 months | No significant differences in mobility mean scores between the groups at 6 months post-intervention. |
| **16 levels of progressive mobility**<br>(Range 1-16)<br>*Higher scores = favorable outcome* | Klein et al. (2015) | Mobility | Early mobility protocol | Critically ill patients admitted to the neurologic ICU | 4 months | The intervention group presented with significant differences in improvements highest level of mobility during the NICU stay up to 13 days.<br>Pre: 25 (9.6) vs. post: 44 (11.7), p< 0.001 |
| **Dressing performance (n=1)** | | | | | | |
| **Level of dressing independence**<br>*(Range: N/R)*<br>*Higher scores = favorable outcome* | Engelman et al. (2002) | Dressing | System of least prompts (SLP) during residents' dressing routines | Nursing Home Residents with dementia | Observations one to four times each day for six months | Two residents' level of dressing independence increased from complete assistance (median = 0) during the baseline condition with each CNA to a mixture of minimally intrusive assistance (median = 2) and intrusive assistance (median = 3) after each CNA completed the workshop on how to use the SLP procedures. One resident's level of dressing independence increased from complete assistance (median = 0) to dressing independently (median = 3). |

| Outcome measure | Author (year) | ADL-domain | Intervention | Population | Effect on patient discomfort | |
|---|---|---|---|---|---|---|
| | | | | | Follow-up | Results |
| Grooming performance (n=1) | | | | | | |
| Performance of Grooming Tasks (PGT)<br>*(Range: N/R)*<br>*Lower scores = favorable outcome* | Lim (2003) | Grooming | Systematic prompting and social reinforcement to guide their grooming. | Residents with mild cognitive impairments | 6 weeks | No significant differences in mean PGT mean scores emerged over time. |

## Studies Targeting Comfort

### *Characteristics of Studies Targeting Comfort*

In total, 17 studies evaluated the effect on comfort comprising five RCTs [55-57, 65, 70] and 12 quasi-experimental studies, among which three studies had a control group [43, 64, 71] and nine studies took place without a control group [46, 58-63, 66, 73, 74]. Almost all studies targeting comfort took place in a nursing home, except for two studies, which were conducted in a hospital [43, 46]. Twelve studies evaluated the impact on comfort in nursing home residents with dementia [55-66] and one evaluated the impact on residents with moderate to severe cognitive impairment [73]. Other comfort-related interventions were evaluated in the general population of nursing home residents[70] or hospitalized persons who were mechanically ventilated [43] or had cardiovascular diseases [46].

Most interventions targeting comfort (n=9) aimed to increase comfort in terms of reducing discomfort-related behaviors (i.e. agitation, resistance to care, apathy) in general performance of ADLs [55, 58, 59, 61, 63-66, 73], followed by seven on bathing [43, 56, 57, 60, 62, 70] and one on toileting [71].

In terms of the comfort-related outcomes, most studies assessed ‘disruptive’ resident behavior including physical or verbal agitation, aggression, and/or resistance to care using a variety of observational measurements (e.g. Care Recipient Behavior Assessment) Cohen-Mansfield Agitation Inventory). One of the 17 studies evaluated observable pain [43] by administrating the Behavioral Pain Scale. Another study [46] evaluated a person’s anxiety using physiological measures including systolic blood pressure, diastolic blood pressure, respiratory frequency, and cardiac frequency.

**Table 2.2** Characteristics of Included Studies Targeting Comfort (n=14)

| **Author (Year) Country** | **Design** | **Study aim** | **Aspect of ADL** | **Setting and study population** | **Sample Mean age: (SD) % Female** | **Measured outcome(s) of interest** |
|---|---|---|---|---|---|---|
| RCT's (n=4) | | | | | | |
| **Beck et al. (2002)**<br>USA | Randomized Controlled Trial (RCT) | To test two interventions—an activities of daily living (ADL), a psychosocial activity intervention (PSA)—, and a combination of the two (CB) to determine their efficacy in reducing disruptive behaviors and improving affect in nursing home residents with dementia. | General ADL | Residents with dementia<br>Nursing home | Total: n=127<br>Age: 83.6 (7.97)<br>Female: 81.0%<br>IG (n=79):<br>ADL n=28<br>PSA n=29<br>CB n=22<br>CG (n=48):<br>Placebo: n=29<br>No intervention: n=19 | Disruptive Behavior Scale (DBS) |
| **Gozalo, Prakash, Qato, Sloane, and Mor (2014)**<br>USA | Randomized crossover diffusion study | To evaluate the effectiveness of the Bathing Without a Battle intervention in reducing physical and verbal aggressive behaviors for nursing home residents with dementia. | Bathing | Residents with dementia<br>Nursing home | Total: n=240<br>Age 84.7 (11.2)<br>Female: 65.8%<br>Group 1 Intervention: n=134<br>Group 2 Delayed intervention: n=106 | The modified version of the Care Recipient Behavior Assessment (CAREBA) |
| **Schoonhoven et al. (2015)**<br>The Netherlands | Cluster randomized trial | To compare bed baths for effects on skin integrity and resistance against bathing and costs. | Bathing | Residents<br>Nursing home | Total: n=500<br>Age: 82.4<br>Female: 71.1%<br>IG: n=290<br>CG: n=210 | Occurrence of resistance to care behaviors: warding the nurse off with hands, trying to avoid the nurse's touch, being restless, turning away, or struggling with the nurse, or protesting verbally, e.g., by screaming or cursing in %. |

| Author (Year) Country | Design | Study aim | Aspect of ADL | Setting and study population | Sample Mean age: (SD) % Female | Measured outcome(s) of interest |
|---|---|---|---|---|---|---|
| **Sloane et al. [57]**<br>USA | Randomized controlled trial (RCT) | To evaluate the efficacy of two non-pharmacological techniques in reducing agitation, aggression, and discomfort in nursing home residents with dementia. | Bathing | Residents with dementia<br>Nursing home | Total: n=69<br>Age: 83.6 (7.6)<br>Female: 84.8%<br>IG: n=46<br>CG: n=23 | Care Recipient Behavior Assessment (CAREBA)<br>Modification of the discomfort scale for dementia of the Alzheimer's type. |
| Quasi-experimental studies (n=10) | | | | | | |
| **Bowles, Griffiths, Quirk, Brownrigg, and Croot (2002)**<br>Canada | Quasi-experimental design | To evaluate whether gentle touch using the essential oil cream would reduce the occurrence of resistance to nursing care and other dementia-related behaviors more than touch with the aqueous cream alone. | General ADL | Residents with dementia<br>Nursing home | Total: n=8<br>Age: N/R<br>Female: N/R | Daily frequency x severity scores for other dementia-related behaviors (adapted from the CMAI). |
| **Chou, Waszynski, Kessler, Chiang, and Clarkson (2016)**<br>United Kingdom | Crossover pilot study | To test if deliberately eliciting positive affect in nursing home residents with dementia could decrease their behavioral problems during dressing/toileting activities | Dressing & Toileting | Residents with dementia<br>Nursing home | Total: n=4<br>Age: 94.50 (5.51)<br>Female: 100% | The Agitated Behavior Scale (ABS) |
| **Dunn, Thiru-Chelvam, and Beck (2002)**<br>Canada | Quasi-experimental design | To detect different bathing methods, the conventional tub bath and a modification of the bed bath, known as the Thermal bath. | Bathing | Residents with dementia<br>Nursing home | Total: n=16<br>Age: 81 (7)<br>Female: 38% | Frequency of 14 observable behaviors formulated from a combination of the Agitation levels Cohen-Mansfield Agitation Inventory (CMAI) and the Ryden Aggression Scale (RAS) |

| Author (Year) Country | Design | Study aim | Aspect of ADL | Setting and study population | Sample<br>Mean age: (SD)<br>% Female | Measured outcome(s) of interest |
|---|---|---|---|---|---|---|
| **Engst, Chhokar, Robinson, Earthy, and Yassi (2004)**<br>USA | Quasi-experimental design | To evaluate the impact of a scheduled toileting program on the risk of injury to care providers and resident agitation or aggressive behaviors. | Toileting | Residents<br>Nursing home | Total: n=62<br>Age: N/R<br>Female: N/R<br>IG: n=34<br>CG: n=28 | Cohen-Mansfield Agitation Inventory (CMAI) |
| **Hammar, Emami, Götell, and Engström (2011)**<br>Sweden | Pre-post-test design | To describe expressions of resistiveness to care of persons with dementia and expressions of emotions, while being cared for by their caregivers during morning care situations without and with music therapeutic caregiving. | General ADL | Residents with dementia<br>Nursing home | Total: n=10<br>Age: 81.3 (N/A)<br>Female: 60% | Observed emotion rating scale (OERS)'<br>Resistiveness to care scale (RTCS) |
| **Jacq et al. (2018)**<br>France | Pilot Study | To assess the effect of music on pain experienced by mechanically ventilated patients during morning bed bathing. | Bathing | Mechanically ventilated patients<br>Hospital | Total: n=60<br>Age (Median): 69 (N/A)<br>Female:<br>IG: n=30<br>CG: n=30 | The Behavioral Pain Scale (BPS) |
| **Lopes Jde, Nogueira-Martins, Gonçalves, and de Barros (2010)**<br>Portugal | Randomized crossover study | To compare levels of anxiety generated during AMI patients' bed and shower baths hospitalized in Coronary Care Units (CCU); | Bathing | Patients with cardiovascular Diseases<br>Coronary Care Units (CCU), Hospital | Total: n=71<br>Age: 58.8 (8)<br>Female: 43.7 | Generalized Estimating Equations for state-anxiety according to systolic blood pressure, diastolic blood pressure, respiratory frequency, and cardiac frequency in the types of bath and evaluations. |
| **Mickus et al. (2002)**<br>USA | Repeated measures design | To describe the impact of a psycho-educational intervention with Nursing Assistants upon behavioral disturbances of patients with dementia. | Bathing | Residents with dementia<br>Nursing home | Total n=27<br>Age: 77.1 (19.5)<br>Female: 74% | Behavior (Neuropsychiatric Inventory (NPI)) |

| Author (Year) Country | Design | Study aim | Aspect of ADL | Setting and study population | Sample<br>Mean age: (SD)<br>% Female | Measured outcome(s) of interest |
|---|---|---|---|---|---|---|
| **O'Connor, Smith, Nott, Lorang, and Mathews (2011)**<br>Australia | Single-system ABA withdrawal design | To investigate the effect of video-simulated presence (VSP) on decreasing RTC and increasing participation in ADLs to improve basic care of people with dementia. | General ADL | Residents with dementia<br>Nursing home | <u>Total: n=1</u><br>Age: 83<br>Female: 100% | Adapted version of the positive response schedule (PRS) for severe dementia |
| **Wells, Dawson, Sidani, Craig, and Pringle (2000)**<br>Canada | Quasi-experimental, repeated measures design | To conduct a controlled investigation to examine the effects of an abilities-focused program of morning care on the interaction behaviors and functioning of residents with dementia and caregivers' interaction behaviors and perceptions of caregiving. | General ADL | Residents with dementia<br>Nursing home | <u>Total: n=40</u><br>Age: 88,6 (5.7)<br>Female: 84.0%<br>IG: n=20<br>CG: n=20 | The Pittsburgh Agitation Scale (PAS) |

**Table 2.3** Characteristics of Studies Targeting Comfort and Independence (n=3)

| Author (Year) Country | Design | Study aim | Aspect of ADL | Setting and study population | Sample Mean age: (SD) % Female | Measured outcome(s) of interest |
|---|---|---|---|---|---|---|
| **RCT (n=1)** | | | | | | |
| **Galik, Resnick, Hammersla, and Brightwater (2014)**<br>USA | Cluster-randomized controlled | To test the impact of Function-Focused Care for the Cognitively Impaired Intervention on nursing home residents with dementia and the nursing assistants who care for them. | General ADL | Residents with dementia<br>Nursing home | Total: n=103<br>Age: 83.7 (9.9)<br>Female: 77%<br>IG: n=53<br>CG: n=50 | Barthel Index<br>Cohen-Mansfield Agitation Inventory, Short Form (CMAI) |
| **Quasi-experimental studies (n=2)** | | | | | | |
| **Galik et al. (2008)**<br>USA | Single-group repeated measures study | To test the feasibility and impact of a 2-tiered motivational intervention, the Restorative Care Intervention for the Cognitively Impaired (Res-Care-CI), on nursing home residents with moderate to severe cognitive impairment. | General ADL | Residents with moderate to severe cognitive impairment<br>Nursing home | Total: n=46<br>Age: 82,6 (8,8)<br>Female: 82,6% | Barthel Index<br>Cohen-Mansfield Agitation Inventory, Short Form (CMAI)<br>Apathy Inventory |
| **Sidani, Streiner, and LeClerc (2012)**<br>USA | Single-group pre–post-test design | To examine changes in resident outcomes before and after nursing staff's implementation of the abilities-focused approach and the contribution of this approach to resident outcomes. | General ADL | Residents with dementia<br>Nursing home | Total: n=65<br>Age:83 (8)<br>Female: 45.8% | Pittsburgh Agitation Scale (PAS)<br>Refined ADL Assessment (RADL) |

N/R= not reported

* Only the participant's age was reported

*Effects on Comfort*

We reported the effects on of all included comfort-related studies in Table 3.2. In terms of comfort, we found seven of the 17 interventions to be effective in affecting comfort. The hospital bed bath intervention [43] significantly reduced the proportions of total bath time spent with a pain score ≥5 and with the maximum pain on Behavioral Pain Scale in the music group compared to the control group (p <.0001). In the music group, mechanically ventilated patients were exposed to the music of Mozart during a bed bath. Furthermore, we found five interventions that effectively reduced overall mean agitation in nursing home residents with dementia, First, the ‘restorative care intervention (ResCare)[73] reduced levels of overall agitation in nursing home residents with cognitive impairment on the Cohen-Mansfield Agitation Inventory at 4 months post-intervention (p=-0.04). In the ResCare intervention, Nursing assistants (NAs) participated in a program to engage nursing home residents in restorative care activities in all care interactions. Second, the ‘thermal bath intervention’[60]significantly reduced the frequency of aggressive or agitated behaviors in nursing home residents with dementia after 8 weeks compared to the control group (p<0.001). In this intervention, washcloths soaked in non-rinse soap were used during a bed bath. Third, the two bath interventions comprising the ‘towel bath’ and the ‘person-centered showering’ interventions[57] reduced agitation on the agitated and aggressive behaviors scale after 6 weeks compared to the control group (shower: p=0.02; towel: p=0.01). The towel bath is a bed bath technique in which moist towels are used in combination with gentle massages, while the person-centered showering intervention applies communication techniques to meet preferences and needs and applies problem-solving approaches to identify causes and possible solutions to maximize comfort. Fourth, the ‘abilities-focused morning care’ intervention[64] reduced agitation in nursing home residents with dementia on the Pittsburgh Agitation Scale after 6 months compared to the control group (p=0.041). This intervention trained nursing professionals in dementia-specific social abilities and self-care abilities. Fifth, the ‘bathing without a battle’ intervention[56] reduced physical and verbal agitation in nursing home residents on a modified version of the agitation on the agitated and aggressive behaviors scale after 4 months (p=0.004). Nursing professionals in the intervention group employed resident appropriate communication techniques, respected preferences, and regulated the physical environment to maximize comfort during bathing. Finally, another ‘bed bath intervention’[46] significantly reduced the anxiety of hospital patients with acute myocardial infarction compared to a shower bath (p<.0001). During the bath intervention, participants reclined in the bath while being assisted by a nursing professional.

**Table 3.2** Summary of Findings of Studies Targeting Comfort

| Outcome measure | Author (year) | ADL-domain | Intervention | Population | Effect on patient discomfort | |
|---|---|---|---|---|---|---|
| | | | | | Follow-up | Results |
| Agitation (n=9) | | | | | | |
| **Agitated and aggressive behaviors (CAREBA)**<br>*(Range N/R)*<br>*Lower scores = favorable outcome* | Sloane et al. (2004) | Bathing | Shower bath<br>Towel bath | Nursing Home Residents with dementia | Observations during a 6-week intervention period | Significantly reduced levels of agitation in the combined score "any physically or verbally aggressive behavior" were found in both intervention groups (Shower intervention difference compared to the control group in favor of the intervention.)<br>CG: Pre:38.85 (SD:24.75) vs. Post:35.65 (SD:27.46)<br>Shower: Pre: 37.93 (25.16) vs. Post: 25.84 (SD:24.12); Shower vs. Control: p=0.02;<br>Towel: Pre: 37.93 (25.16) vs. Post 23.51 (SD:20.53); Towel vs. Control: p=0.01 |
| | Gozalo et al. (2014) | Bathing | Bathing Without a Battle | Nursing Home Residents with dementia | round of observations: 2 to 4 months | Statistically significant reduced in levels of agitation were found in any verbal behavior of 17.8% (p = .008) and any physical or verbal behavior of 18.6% (p = 0.004). |
| **Agitated Behavior Scale (ABS)**<br>*(Range 14-56)*<br>*Lower scores = favorable outcome* | Chou et al. (2016) | General ADL | International Affective Pictures System (IAPS) | Nursing Home Residents with dementia | N/A | No statistically significant reduced levels in overall mean scores of the ABS were found over time. |
| **Cohen-Mansfield Agitation Inventory (CMAI)**<br>(Range N/R)<br>*Lower scores = favorable outcome* | Engst et al. (2004) | Toileting | Scheduled toileting program | Nursing Home Residents | 8 months | No statistically significant differences in means were found for emotional agitation between the intervention and control groups. |
| | Galik et al. (2008) | General ADL | Restorative care intervention | Nursing Home Residents with dementia | 4 months | Significantly reduced levels in overall agitation mean scores in favor of the intervention were found in the intervention group at 4 months post-intervention.<br>IG: Pre: 24.29 (SD: 8.54) vs. 4 months: 22.02 (SD: 7.00); F=3.2; p=-0.04. |
| | | | | | 6 months | No statistically significant differences in overall agitation mean scores between baseline and 6 months post-intervention. |

| Outcome measure | Author (year) | ADL-domain | Intervention | Population | Effect on patient discomfort | |
|---|---|---|---|---|---|---|
| | | | | | Follow-up | Results |
| **Cohen-Mansfield Agitation Inventory (CMAI)**<br>(Range N/R)<br>*Lower scores = favorable outcome* | Galik et al. (2014) | General ADL | Restorative care intervention | Nursing Home Residents with dementia | 3 months | No significant differences in overall agitation mean scores between the groups at 3 months post-intervention. |
| | | | | | 6 months | No significant differences in overall agitation mean scores between the groups at 6 months post-intervention. |
| **Pittsburgh Agitation Scale (PAS)**<br>*(Range 0.01- 1.0)*<br>*Lower scores = favorable outcome* | Sidani et al. (2012) | General ADL | Abilities-focused morning care | Nursing Home Residents with dementia | 1 month | No significant differences in overall mean scores between baseline and 1-month post-intervention. |
| | Wells et al. (2000) | General ADL | Abilities-focused morning care | Nursing Home Residents with dementia | 3 months | No significant differences in overall mean scores between the groups. |
| | | | | | 6 months | Significant reductions in overall mean agitation scores were found in the intervention group compared to the control group in favor of the intervention<br>IG: Pre: 0.35 (SD: 0.33) vs. 6 months: 0.17 (SD:0.24); CG:Pre:0.29 (0.38) vs. 6 months:0.33 (0.38); F:4.43; p= 0.041 |
| **Frequency of 14 observable behaviors formulated from a combination of the Agitation levels Cohen-Mansfield Agitation Inventory (CMAI) and the Ryden Aggression Scale (RAS)**<br>*(Range N/R)*<br>*Lower scores = favorable outcome* | Dunn et al. (2002) | Bathing | Thermal bath | Nursing Home Residents with dementia | 8 weeks | Significantly reduced levels of observed agitated behaviors were found in the thermal bath intervention group compared to the tub bath control group during 8 weeks.<br>IG: 49.47 (33.72) vs. CG: 98.00 (49.13), p<0.001 |

| Outcome measure | Author (year) | ADL-domain | Intervention | Population | Effect on patient discomfort | |
|---|---|---|---|---|---|---|
| | | | | | Follow-up | Results |
| Positive emotions (n=2) | | | | | | |
| **Observed emotion rating scale (OERS)**<br>*(Range N/R)*<br>*Higher scores = favorable outcome* | Hammar et al. (2011) | Morning care situations | Music therapeutic caregiving | Nursing Home Residents with dementia | 4 weeks | No statistically significant differences in overall mean scores between the 4-week baseline and 4-week intervention period. |
| **Adapted version of the positive response schedule (PRS) for severe dementia**<br>*(Range N/R)*<br>*Lower scores = favorable outcome* | O'Connor et al. (2011) | Eating and taking medication | Video-stimulated presence (VSP) | Nursing Home Residents with dementia | 15 days | No statistically significant differences in overall mean scores emerged over time between the A and B phases. |
| Discomfort (n=2) | | | | | | |
| **Discomfort Scale**<br>*(Range N/R)*<br>*Lower scores = favorable outcome* | Sloane et al. (2004) | Bathing | Person-centered showering<br>Towel Bath | Nursing Home Residents with dementia | 6-week intervention period | Significantly lower levels of discomfort were found for the shower intervention group and towel bath intervention group compared to the control group.<br>CG: Pre:2.12 (SD:0.35) vs. Post:2.14 (SD:0.35)<br>Shower: Pre: 2.11 (SD: 0.42) vs. Post: 1.86 (SD: 0.46); Shower vs. Control: p=0.001<br>Towel: Pre: 2.11 (SD: 0.42 vs. Post 1.57 (SD:0.58); Towel vs. Control: p= <0.001 |
| **Disruptive behavior scale (DBS)**<br>*(Range N/R)*<br>*Lower scores = favorable outcome* | Beck et al. (2002) | General ADL | Behavioral-interventions | Nursing Home Residents with dementia | Week 4-10 | No statistically significant differences in overall mean scores between the groups. |
| | | | | | Week 11-12 | No statistically significant differences in overall mean scores between the groups. |
| | | | | | Week 16 | No statistically significant differences in overall mean scores between the groups. |
| | | | | | Week 20 | No statistically significant differences in overall mean scores between the groups. |

| Outcome measure | Author (year) | ADL-domain | Intervention | Population | Effect on patient discomfort | |
|---|---|---|---|---|---|---|
| | | | | | Follow-up | Results |
| Resistance to care (n=2) | | | | | | |
| **Occurrence of resistance to care behaviors**<br>*(Range N/R)*<br>*Lower scores = favorable outcome* | Schoonhoven et al. (2015) | Bathing | Bed bath | Nursing Home Residents | 6 weeks | No statistically significant differences in overall mean resistance to care were found between both groups 6 weeks post-intervention. |
| **Restiveness to care scale (RTCS)**<br>*(Range N/R)*<br>*Lower scores = favorable outcome* | Hammar et al. (2011) | General ADL | Music Therapeutic Caregiving (MTC) | Nursing Home Residents with dementia | 4 weeks | No statistically significant differences in overall mean scores between the 4-week baseline and 4-week intervention period. |
| Pain (n=1) | | | | | | |
| **Behavioral Pain Scale (BPS)**<br>*(Range N/R)*<br>*Lower scores = favorable outcome* | Jacq et al. (2018) | Bathing | Music for pain relief | Mechanically ventilated patients | 8 months | Significantly lower proportions of total bath time spent with BPS≥5 and with the maximum BPS scores emerged over time in the music group compared to the control group.<br>IG: 1.5 [0;3.0] vs. 3.5 [2.0;6.0]; p = 0.005<br>CG: 2.0 [0.3;4.0] vs. 10 [4.3;18.0]; p<0.0001 |
| Dementia-related behaviors (n=1) | | | | | | |
| **Daily frequency x severity scores for other dementia-related behaviors**<br>*(Range N/R)*<br>*Lower scores = favorable outcome* | Bowles et al. (2002) | Bathing | Essential oil treatment | Nursing Home Residents with dementia | 4 weeks | No statistically significant differences in both groups emerged between the essential oil treatment and the 'no oils' treatment in the frequency x severity scores. |
| Neuropsychiatric symptoms (n=1) | | | | | | |
| **Neuropsychiatric Inventory (NPI)**<br>*(Range N/R)*<br>*Lower scores = favorable outcome* | Mickus et al. (2002) | Bathing | PRIDE | Nursing Home Residents with dementia | 1-2 months | No statistically significant differences in overall mean scores between baseline and post-intervention. |

| Outcome measure | Author (year) | ADL-domain | Intervention | Population | Effect on patient discomfort | |
|---|---|---|---|---|---|---|
| | | | | | Follow-up | Results |
| Anxiety | | | | | | |
| **State-Trait Anxiety Inventory (STAI)**<br>*(Range N/R)*<br>*Lower scores = favorable outcome* | Lopes et al. (2010) | Bathing | Bed bath | Hospital Patients with acute myocardial infarction | Before bath, after bath, 20 min after bath | Significant increases in anxiety mean scores were found in the bed bath before and 20 min after bathing ($p < 0.0001$) compared to the shower bath. |

$^{\$}$ Statistically significant based on the Bonferroni-Holm method of adjusting for multiple tests

*Risk of Bias in Studies Targeting Comfort*

We present our risk of bias assessment tables in appendix 3. In the 17 studies assessing comfort, we found three quasi-experimental studies of high quality [43, 60, 61], and nine studies of moderate quality, among which four were randomized controlled studies [55, 56, 65, 70] and five were quasi-experimental studies. [46, 58, 66, 73] Five studies were found to be of low quality comprising one RCT [57] and four quasi-experimental studies. [59, 62, 64, 71]

## Discussion

For this review, we aimed to address the following research question: What are the effects of ADL nursing interventions on independence and comfort in adults across all care settings? Overall, the included ADL nursing interventions focused on all ADL domains as a whole or one of the six domains separately. Most studies (n=22) focused on only one specific ADL domain, such as mobility, bathing, or eating. For both outcomes, we found seven studies effectively improving either ADL independence [44, 45, 47, 51, 52, 54, 65] or comfort [43, 46, 56, 57, 60, 64, 65]. Despite the overall low to moderate quality of the studies, the quality of the effective comfort-related interventions is slightly higher than the quality of the ADL independence-related studies with one RCT [56] and one quasi-experiment of moderate quality [46] and one quasi-experiment of high quality by Jacq et al. [43]. Based on these findings, we state that the guidance for nursing professionals on improving ADL independence and/or comfort during ADL care remains inconclusive in general.

Additionally, the effects of ADL nursing interventions are inconsistent. Moreover, with the majority of the interventions focusing on solely one of the six ADLs, our review shows that current research has not yet found a way to look at ADL nursing care in an integrated way. This finding also contributes to the findings that ADL nursing interventions are barely comparable, yet provide unambiguity about effective ADL care delivery. Nevertheless, the results of our current review in the light of independence and comfort could provide an initial direction for the further development of ADL care interventions.

When looking for patterns in the ‘most promising’ independence-related interventions, we see that two interventions based on Montessori-based activities (MOBA) effectively reduced eating difficulty in Taiwanese nursing home residents with dementia [51, 54]. MOBA was originally designed for school-aged children; it simplifies tasks, provides immediate feedback, and promotes individualized supervision and learning [75]. In more recent research, nursing professionals apply MOBA to promote choice and independence by tailoring eating support while striving towards more respectful and dignified mealtime care [76]. Hence, the underlying principles of MOBA, such as simplification of activities while allowing for individual tailoring, might include promising elements in reducing eating difficulty and moving towards personalized care provision to be explored in further research.

When looking for patterns in effective comfort-related interventions, we see that the majority of the interventions aimed to enhance comfort in bathing. Five bathing interventions aimed to increase comfort either in nursing home residents with dementia [56, 57, 60] or hospital patients [43, 46]. Effective bathing interventions consisted of bed baths with [43] and without music [46, 57, 60], or person-centered approaches to bathing or showering [56, 57]. When taking a closer look at bathing methods within the literature, it becomes apparent that nursing professionals consider bed baths the most effective measures of comfort provision during bathing especially in bedridden patients [77]. Additionally, patient preferences in terms of bed baths largely determine whether comfort can be improved in bed baths. Our results indicate that more than half of the effective interventions targeting comfort in bathing include elements of identifying preferences in bathing while taking them into account during care delivery. In addition to recent efforts to study patient preferences for bed baths [78], in daily practice, nursing professionals should ask regarding personal preferences in daily care to offer different bathing options accordingly.

Additionally, the way comfort was measured within these studies was highly varied, ranging from agitation and aggression [56, 57, 60, 64, 65] to anxiety [46], or pain [43]. Comfort is, however, considered a multidimensional concept that is not limited to end-of-life care or pain management, but is also highly relevant to nursing care at any stage [15]. Our results indicate that the multidimensional concept of comfort has to date been inadequately used as a nurse-sensitive outcome. In our results, comfort measurements are limited to either pain or neuropsychiatric symptoms (e.g. agitation or aggression) and were not represented as a holistic conceptual outcome. Moreover, emotional aspects of comfort such as ' a sense of personal control' or feelings of safety in these intimate care activities were not addressed in the studies found. Current literature on comfort assessments mainly focuses on physical discomfort [79], emotional comfort [80], and behavioral symptoms [81] setting implications for future research.

Effective interventions for both outcomes, i.e., ADL independence and comfort, suggest that ‘function’ or ‘ability-focused’ interventions where nursing professionals stimulate physical activity might be an important component. However, for almost every effective intervention, we also find a similar non-effective intervention. This observation applies to both central outcomes independence and comfort as well as to both single-component and multicomponent interventions. In terms of independence, single component interventions are, i.e. sit-to-stand activity showing statistically significant [52] or non-significant results [53]. The multi-component ‘function-focused care’ intervention of Galik et al. [65], however, reports effective results in terms of ADL independence and comfort-related outcomes. In addition to an ability- or function-focused approach, the intervention included additional components, i.e., policy, family, goal-setting, assessment, and mentoring Galik et al. [65]. Despite the reported effects on ADL independence, we found similar interventions, i.e. those of Resnick et al. [67] and Henskens et al. [48], to be non-effective for nursing home residents. Similarly for comfort-related outcomes, we found varying effects in ability-focused interventions in terms of reducing agitation in nursing home residents with two similar effective [64, 65] and two non-effective interventions [66, 73]. Ability-focused interventions often include comprehensive assessments and allow for individual tailoring and modification of activities, which are considered effective elements when aiming to reduce agitation [82]. Also, the importance and effectiveness of physical activity have been well-established when aiming to improve ADL dependence [83]. However, our findings remain inconsistent for both outcomes.

These inconsistencies might be explained by the complexity of implementing these multi-component interventions. Hence, the type of, often multicomponent, interventions included in this review are often complex, highly variable, and context-dependent. This complex interplay of factors in combination with varying reporting on the intervention content and context adds to the ‘black box’ phenomenon in nursing intervention research [84]. Information on the interventions within this review was often brief, limiting the possibility of comparing them across studies, since information on setting-specific factors such as staffing, environment (bathrooms, materials), or other factors limiting comfort or ADL independence (i.e. noise, temperature) were left unreported. Detailed descriptions of the components and context of nursing interventions are necessary for research and practice to avoid research waste and to foster the implementation of effective interventions in daily practice [84]. Since the current review focused on effectiveness, we cannot determine whether the interventions were completed as intended and described by the available protocols. Process evaluations are therefore necessary to unravel the underlying factors possibly impacting the effectiveness of interventions.

Within this review, ADL independence and comfort were selected as central outcomes of ADL nursing care. However, the operationalization of these outcomes was highly variable among the included studies. ADL independence-related outcomes range from general ADL observational scales (i.e. Barthel Index, functional independence measure) to specific mobility tests (timed up and go, 30-second sit-to-stand test). Within the comfort-related measures, the range of outcomes assessed was even broader, ranging from observational scales to assess agitation (CMAI, CAREBA) up to pain scales or anxiety measured by vital parameters (i.e. heart frequency, hypertension, and respiratory frequency). All studies reported performance-based and/or observational data, not data originating from persons who receive care themselves or their proxies (i.e. self- or proxy-reported functioning). Hence, there is an opportunity for subjective measures, especially within this type of care close to the care-receiver.

Another element explaining the variety of our results may lie in the complexity and context-dependency of the care relationship within ADL nursing care. Within this review, most interventions build on the behavior of nursing professionals in ADL care in interaction and collaboration with the care receiver either to address the care receiver's behavior or to encourage physical activity in ADL. Within the nursing literature, this increasingly collaborative relationship is positioned at the center of essential nursing care delivery [11], largely determining the care experience of care receivers and nursing professionals [85]. Despite the importance of the interactional component, the fundamental aspect of the (existing) care relationship was left unaddressed. The results from other forms of collaborative care relationships, i.e., therapeutic alliances between patients and therapists, suggest that this relationship positively impacts the care receiver’s health outcomes (i.e. blood pressure, and pain scores) [86], and also relates to the experienced quality of care [87]. Future research should increasingly reflect on the context of the intervention and what role it played in its design and evaluation. Additionally, transparent documentation of the relationship between nursing professionals is needed to provide clarity on how this might have impacted the experiment.

## Strengths and Limitations

The strengths of this review rely upon the systematic and comprehensive approach, including a predefined search strategy applied in multiple databases with an additional manual search from reference lists of retrieved studies, however, the risk of not having identified all relevant systematic reviews remains.

In the reporting of this review, we adhered to the requirements of the PRISMA statement. We increased the transparency and the reliability of the results by double screening during the selection phase double assessing the quality of the studies and resolving disagreements by discussion involving a third investigator. Also, the risk of bias assessment was performed in a way in which each study was assessed by two investigators. However, the generalizability of these results is subject to certain limitations. By choosing systematic reviews as a starting point, we might have missed relevant (quasi-) experimental studies that have not been included and published in recent systematic reviews. With assessing the risk of bias of the (quasi-) experimental studies as our final unit of analysis, we chose not to assess the risk of bias of the originating reviews which might have influenced the sort and amount of studies included in this review.

Moreover, our search was restricted to interventions that were (primarily) performed by nursing professionals. Despite the fact that ADL care lies at the very heart of the nursing profession, knowledge or lessons learned from effective multidisciplinary interventions such as ‘reablement’ [88] might also be relevant to nursing professionals. However, we aimed to partially tackle this issue by including studies in which therapists fulfilled an advisory role for nursing professionals.

### Implications for Further Research

The results of this review show a high level of variability of targeted ADL, intervention components, and outcomes leading to a fragmentation of ADL nursing interventions. However, we see the following possibilities for future research:

Across care settings interventions maximizing independence and comfort are crucial so we would suggest first identifying and then synthesizing intervention components and their outcomes To identify and synthesize promising components of ADL nursing interventions future RCTs or quasi-experimental studies need to improve in reporting the content and context of the intervention provided. Then, a synthesis of promising intervention components can take place. Within this synthesis, one should consider a holistic approach to include multiple components, allowing for adaptation to contextual differences and the care relationship between the nursing professional and the care receiver. For example, within the scope of function-focused care interventions, and Vluggen, Heinen (13) suggest preserving four themes in future programs, consisting of policy and environment, education, goal setting, and coaching. Finally, further experimental research across health care settings, if well-documented, might contribute to unraveling the black box of nursing interventions to be applied in ADL care.

In terms of synthesizing outcomes in ADL nursing care, we propose the integration of instruments assessing comfort that represent the multidimensionality of the concept. Future experimental research should find ways to holistically assess comfort by integrating scales on physical and emotional comfort targeted to ADL nursing care situations. Moreover, future research should consider the opportunity to assess positive emotional aspects of comfort in experimental research by for example the Patient Evaluation of Emotional Comfort Experienced (PEECE) scale [80].

*Relevance to Clinical Practice*

The results of this review do not allow for clear practical recommendations for nursing professionals as to how ADL care in general can effectively improve independence and comfort. However, the added value of Montessori-based eating interventions, ability-focused programs, and bed bath methods might be beneficial to explore in daily practice. However, more research is needed to determine the effectiveness of these interventions in daily ADL care provision. Nursing professionals should therefore at all times be enabled to critically reflect on the way they routinely provide ADL care.

## Conclusion

For this review, we aimed to determine the effectiveness of nursing interventions on ADL independence and comfort. This systematic review identified 31 studies describing nursing interventions that aimed to increase ADL independence (n=14), comfort (n=14), or both (n=3). In terms of effectiveness, seven of the independence-related interventions and seven of the comfort-related interventions reported significant results. Interventions were highly variable due to intervention characteristics and components, as well as outcome measures. In light of the overall low to moderate quality of the included studies, guidance for nursing professionals on ADL interventions remains a challenge for future research.

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# Appendices

Appendix 1: Overview of Partially Included Systematic Reviews

Appendix 2: Descriptions of Interventions Targeting Independence and Comfort

Appendix 3: Risk of Bias Assessment

# Appendix 1: Overview of Partially Included Systematic Reviews

**Table 1** Overview of Reasons for Partial Inclusion of Systematic Reviews as a Portal for the Identification of (Quasi-) Experimental Studies

| Review | | Reasons for partial inclusion | | Reasons for partial exclusion | |
|---|---|---|---|---|---|
| 1 | Backhouse, T., et al. (2020). "Strategies and interventions to reduce or manage refusals in personal care in dementia: A systematic review." Int J Nurs Stud **109**: 103640. | P | participants living with dementia | P | |
| | | I | N=8 interventions on general or mixed care activities,<br>N=8 bathing, N=4 mealtimes,<br>N=2 mouth care. | I | N=2 interventions on medication administration (Not ADL)<br>N=1 Intervention performed by informal caregivers<br>N=4 intervention performed by research staff |
| | | C | | C | |
| | | O | refusals of care | O | |
| | | S | N=19 quasi-experimental designs<br>N=5 randomized controlled trials (RCTs),<br>N=3 cross-sectional studies,<br>N=1 case report, one case-control study | S | N=1 qualitative study |
| 2 | Crocker, T., Young, J., Forster, A., Brown, L., Ozer, S., & Greenwood, D. C. (2013). The effect of physical rehabilitation on activities of daily living in older residents of long-term care facilities: systematic review with meta-analysis. Age Ageing, 42(6), 682-688. | P | older people (over 60 years) living in long-term care facilities | P | |
| | | I | N=2 interventions involved encouraging residents to take a more active part in routine activities such as transferring, bathing, or dressing, delivered by nurses and assistants following assessment and goal-setting | I | N=7 interventions were exercise interventions<br>N=2 group interventions<br>N=4 interventions delivered by OT or PT or both |
| | | C | either no intervention or an alternative intervention | C | |
| | | O | Independence in ADL (measured by BI, FIM, PSMS, MDS) | O | |
| | | S | Systematic review and meta-analysis of RCTs | S | |

| Review | | Reasons for partial inclusion | | Reasons for partial exclusion | |
|---|---|---|---|---|---|
| 3 | Faraday, J., et al. (2021). "How do we provide good mealtime care for people with dementia living in care homes? A systematic review of carer-resident interactions." Dementia (London): | P | People with dementia | P | |
| | | I | N=3 studies assessed the effectiveness of a nursing care staff<br>intervention at mealtimes | I | N=2 studies investigated the association between quantity of oral intake and possible influencing factors. |
| | | C | | C | |
| | | O | Edinburgh Feeding Evaluation in Dementia scale<br>Level of<br>Eating Independence scale. | O | Oral Intake & Weight |
| | | S | N=3 (quasi-) experimental studies | S | N=11 Qualitative studies<br>N=2 crossectional studies |
| 4 | Kneafsey, R. (2007). A systematic review of nursing contributions to mobility rehabilitation: examining the quality and content of the evidence. J Clin Nurs, 16(11), 325-340. | P | Older people | P | |
| | | I | identify nursing approaches to promoting improvements in patients’ mobility | I | Contains multidisciplinary interventions<br><br>Exercise interventions |
| | | C | | C | |
| | | O | mobility and<br>preventing immobility; walking | O | |
| | | S | No purely qualitative<br>studies were included | S | Included Informational papers consisting (case studies, expert opinion, educational papers, and reports on service innovations)<br>n=12 studies published before 2000<br>n=3 research papers, not experimental studies |

| | Review | | Reasons for partial inclusion | | Reasons for partial exclusion |
|---|---|---|---|---|---|
| 5 | Konno, R., Kang, H. S., & Makimoto, K. (2014). A best-evidence review of intervention studies for minimizing resistance-to-care behaviors for older adults with dementia in nursing homes. J Adv Nurs, 70(10), 2167-2180. | P | nursing home residents with dementia | P | |
| | | I | Interventions apply in a personal-care context. | I | N=1 intervention performed by research therapist<br>N=10 environmental interventions where the involvement of nurse is unclear |
| | | C | | C | |
| | | O | resistance-to-care behaviors | O | |
| | | S | N=3 RCTs<br>N=16 quasi-experimental. | S | |
| 6 | Konya, I., et al. (2021). "Effectiveness of bed bath methods for skin integrity, skin cleanliness, and comfort enhancement in adults: A systematic review." Nurs Open 8(5): 2284-2300. | P | Adults | P | |
| | | I | Bed bath methods | I | Persons who perform the intervention are not always reported in the table |
| | | C | Standard practice, alternative intervention, and no comparator | C | |
| | | O | N=9 studies measured outcomes for comfort enhancement. | O | N=9 studies measured outcomes for skin integrity.<br>N=10 studies measured outcomes for skin cleanliness |
| | | S | Published, peer-reviewed, systematic reviews of quantitative studies, randomized clinical trials, quasi-experimental studies, and observational studies | S | |
| 7 | Lee, S. J., Kim, M. S., Jung, Y. J., & Chang, S. O. (2019). The Effectiveness of Function-Focused Care Interventions in Nursing Homes: A Systematic Review. J Nurs Res, 27(1), 1-13. | P | Nursing home residents | P | |
| | | I | FFC interventions | I | Exercise interventions included |
| | | C | | C | |
| | | O | Physical outcomes | O | Psychosocial and cognitive functions. |
| | | S | N= 13 quasi-experimental designs<br>N=9 RCTs | S | |

| Review | | | Reasons for partial inclusion | | Reasons for partial exclusion |
|---|---|---|---|---|---|
| 8 | Liu, W., Cheon, J., & Thomas, S. A. (2014). Interventions on mealtime difficulties in older adults with dementia: a systematic review. Int J Nurs Stud, 51(1), 14-27 | P | Older adults with dementia. | P | |
| | | I | interventions on mealtime difficulties | I | N=8 nutritional supplements<br>Interventions also for physicians, therapists, |
| | | C | | C | |
| | | O | Eating difficulty, eating ability | O | Energy intake, weight, mid-arm circumference, BMI |
| | | S | N=9 RCTs, n=5 Controlled<br>Clinical Trials (CCTs), n=6 interrupted time series and n=2 cohort studies | S | |
| 9 | Liu, W., Galik, E., Boltz, M., Nahm, E.-S., & Resnick, B. (2015). Optimizing Eating Performance for Older Adults With Dementia Living in Long-term Care: A Systematic Review. Worldviews on Evidence-Based Nursing, 12(4), 228-235. | P | Older adults (≥ 65 years old) with dementia who were involved in oral eating or feeding | P | |
| | | I | Any behavioral or environmental intervention on optimizing oral feeding or eating performance or behavior | I | N=3 staff unspecified<br>N=4 intervention performed by research staff |
| | | C | Any comparator, or none at all (e.g., placebo, no therapy, another active therapy, or no control therapy). | C | |
| | | O | Self-feeding or eating performance (e.g., eating independence, eating frequency, eating task participation and assistance, self-feeding ability, feeding difficulty). | O | |
| | | S | Eleven intervention studies (five randomized controlled trials [RCTs]) | S | |

| | Review | Reasons for partial inclusion | | Reasons for partial exclusion | |
|---|---|---|---|---|---|
| 10 | Richards, D. A., Hilli, A., Pentecost, C., Goodwin, V. A., & Frost, J. (2018). Fundamental nursing care: A systematic review of the evidence on the effect of nursing care interventions for nutrition, elimination, mobility, and hygiene. J Clin Nurs, 27(11-12), 2179-2188. doi:10.1111/jocn.14150 | P | People in hospital and residents in care homes | P | |
| | | I | nursing interventions that address the nutrition, elimination, mobility, and hygiene needs | I | N=17 Multidisciplinary interventions<br>N=48 Staff unspecified<br>N=25 Intervention performed by researchers |
| | | C | | C | |
| | | O | Most studies focused their outcomes on observational or physiological measures, with very few collecting patient-reported outcomes, such as quality of life, experience, or self-reported symptoms. | O | N=18 Outcome not ADL-functioning or comfort |
| | | S | experimental studies n=67 randomized controlled trials, n=32 non-randomized controlled trials and n=50 uncontrolled trials) | S | |
| 11 | Verstraten, C., et al. (2020). "Optimizing patients' functional status during daily nursing care interventions: A systematic review." Res Nurs Health | P | Participants: adult patients (>18years) within any care setting | P | |
| | | I | interventions that are embedded in daily nursing care (irrespective of care setting) | I | N=5 multidisciplinary interventions |
| | | C | | C | |
| | | O | functional status of patients by increasing their physical activity | O | |
| | | S | Randomized experimental studies, quasi- and nonrandomized studies. Included different types of experimental studies because daily nursing care interventions are not often studied with a robust design. | S | Systematic reviews were used for snowball sampling |

# Appendix 2: Descriptions of Interventions Targeting Independence and Comfort

**Table 1** Description of Interventions Targeting Independence (n=14)

| Author (Year) | Aim | Name of the intervention | Intervention type | Duration of the training | Time/ frequency of the intervention | Participants |
|---|---|---|---|---|---|---|
| **General ADL (n=3)** | | | | | | |
| Blair, Glaister, Brown, and Phillips (2007) | To provide nursing assistants with the ability to produce a therapeutic milieu supportive of intact residents' activities of daily living, positive self-esteem, and mood: | Applied Behavioural Analysis (ABA) | Educational intervention | 4-hour session on ABA. | N/R | NAs. |
| | | **Intervention Content:** ABA provides a systematic approach to promoting and maintaining desired behaviors in intact persons. Operant learning emphasizes reciprocal interactions between the individual and his or her social environment. It suggests that voluntary behaviors, whether sick or healthy, are learned behaviors and are supported by the social environment in which they occur | | | | |
| | | Orem's Systems of Nursing Care (OSNC) | Educational intervention | 4-hour session on OSNC | N/R | NAs. |
| | | **Intervention Content:** Orem's theory provides guidelines as to whether the staff or the client should perform the client's ADLs. It suggests three systems of care to guide nursing actions depending on the client's self-care abilities: the wholly compensatory system (WCSC), the partly compensatory system (PCSC), and the educative-supportive system (ESSC). | | | | |
| | | Combination of OSNC and ABA | Educational intervention | 4-hour OSNC session<br>4-hour ABA.session | N/R | NAs |
| Henskens et al. (2018) | To stimulate movement during daily care tasks by encouraging residents to perform as much of their self-care as independently as possible throughout the day. | ADL-Training | Educational intervention | three 3-hour educational sessions by physio- and occupational therapists | 3 sessions, 6 months | Nursing staff |
| | | **Intervention Content:** In individually based intervention, nursing staff were asked to stimulate movement during daily care tasks by encouraging residents to perform as much of their self-care as independently as possible throughout the day. Examples are encouraging a resident to participate in bathing or dressing, or having a resident set the table Nursing staff could provide verbal cues to assist the resident. By encouraging independence during daily (care) tasks, it was possible to focus on improving specific ADL functions and to stimulate movement throughout the whole day. For each ward per ADL location, ambassadors (consisting of one physio- or occupational therapist and two nursing staff) were appointed to receive three 3-hour educational sessions by qualified physio- and occupational therapists. Consequently, ambassadors were responsible for sharing their knowledge about ADL stimulation with the other nursing staff. The individual nature of the intervention allowed for variance in training between participants based on their capabilities and limitations. Individually based goals, plans, capabilities, and activities were reported in four domains of the health care plan: 1) living conditions, 2) participation, 3) mental well-being and autonomy, and 4) physical well-being and health. Participants in the control locations received care as usual and completed all outcome measures at the same time as the intervention group. | | | | |

| Author (Year) | Aim | Name of the intervention | Intervention type | Duration of the training | Time/ frequency of the intervention | Participants |
|---|---|---|---|---|---|---|
| Resnick et al. (2009) | To motivate NAs and residents to engage in functional and physical activities. | Res-Care Intervention | Educational intervention | 6-week in-service program | N/R | NAs |
| | | 1st class: Philosophy of restorative care and stressed the contrast between this philosophy and the more traditional designated restorative care programs.<br>2nd class: Motivation of residents and taught the NAs useful self-efficacy-based interventions to encourage residents who resisted performing personal care activities to participate in these tasks (i.e. verbal encouragement, physiological feedback, cueing with self-modeling)<br>3rd class: Incorporating restorative care into daily personal care activities (bathing, dressing, and feeding).<br>4th class: integrating restorative care activities during transfers and ambulation and by engaging residents in simple exercise activities.<br>5th class: documenting the time providing restorative care<br>6th class: discussion about how to overcome the many challenges faced in providing restorative care in real-world settings (i.e. how to address family and resident expectations of care and innovative ways to motivate residents) | | | | |
| **Eating and drinking (n=3)** | | | | | | |
| Chang and Lin (2005) | N/R | Feeding skills training program | Educational intervention & hands-on training | 3 hours classes<br>1-hour training | 1 hour | NAs |
| | | **Intervention Content:** The content of the classes included the purpose of this training program, an overview of dementia, the etiology and behaviors of feeding among dementia patients and protocol for feeding dementia patients regarding how to manage feeding problems of dementia patients. The protocol contained the preparation for the mealtime environment, interactions between caregivers, dementia patients, and feeding skills to deal with food refusal.<br>Hands-on training was provided using one to- one teaching and provided nursing assistants opportunities to practice and give feedback. The content of the hands-on training followed the instruction guideline that was developed based on the feeding protocol. The nursing assistants had opportunities to feed several dementia patients at one mealtime and deal with different feeding problems of dementia patients. | | | | |

| Author (Year) | Aim | Name of the intervention | Intervention type | Duration of the training | Time/ frequency of the intervention | Participants |
|---|---|---|---|---|---|---|
| Lin, Huang, Watson, Wu, and Lee (2011) | To improve the eating ability and nutritional status of residents | Montessori intervention | Educational intervention | N/R | 30-min sessions once every day, three days per week, for eight weeks | Nurses |
| | | **Intervention Content:** The protocol for the Montessori intervention for eating difficulty of persons with dementia was based on the studies of Camp (2001) and Lin et al. (2010), but only hand–eye coordination, scooping, pouring, and squeezing were adopted.<br>The foods used during training sessions were served as snacks rather than as a regular meal setting. Food types used consisted of those that subjects would be familiar with, but which were rarely served by the long-term care facilities, such as cookies, candy, fruits, and desserts. This study added the matching and differentiating of edible and non-edible items to the program.<br>1. The Montessori intervention was standardized, but it also had vertical extension based on individual ability. For example, if the resident had difficulty grasping black beans, the trainer would instead ask them to grasp a small tomato (downward extension) and vice versa. The intervention included five domains of activities such as hand–eye coordination, scooping, pouring, squeezing, and matching. Each domain of activity had 4–5 specific activities, with a total of 24 specific activities. For example, the activities for hand–eye coordination included five fingers grasping black beans and three fingers grasping cookies. The activities of scooping consisted of scooping small tomatoes, grapefruit scooping, etc. In pouring activities, bean pouring, juice pouring and soybean milk pouring were used. The activities geared toward squeezing included picking up candy with chopsticks, and using chopsticks to pick up rice, cookies, etc. As to matching, the subjects were asked to match healthy food, 'Do you eat lunch yet?', stone vs. bread, etc. The protocol included the following:<br>2. Sensory stimulation, where music by Mozart was played to remind participants that an activity session was about to begin. After the music, the activity leader introduced the time, place, and the content of activities.<br>3. Procedural movements, which included hand–eye coordination, scooping, pouring, squeezing and matching were, employed. Typically, the procedure began with the trainer having the subject touch an object, which is called 'association of sense-perception with the name'. The subject then said the name of the object, which is 'recognition of the object corresponding to the name'. The subject was then asked 'what is it?', which is 'remembering the name corresponding to the object'. If they could not remember the name, the trainer told them the name of the object.<br>4. The extension and conclusion portion of the protocol consisted of the activity leader reviewing the day's activities, materials being put away and an announcement of the activity to be carried out at the next scheduled meeting. The routine activities group did not receive the above protocol, but followed the typical daily routine of the long-term care facility. | | | | |

| Author (Year) | Aim | Name of the intervention | Intervention type | Duration of the training | Time/ frequency of the intervention | Participants |
|---|---|---|---|---|---|---|
| Wu et al. (2014) | To improve the eating difficulty of residents with dementia | Spaced retrieval combined with Montessori-based activities | Educational intervention | 16-hour training course covering dementia and related assessment tools and a 7-day clinical practicum | N/R | Nurses |
| | | **Intervention content:** Spaced retrieval (SR): SR trained the participants to recall eight learning items in 32-minute time interval trials. An example of the application of the SR process is presented here using the second learning item. First, the trainer said to the participant: 'Today we are going to practice eating procedures. The first thing we are going to practice is to pick up a bowl and spoon (Note: said with an actual bowl and spoon on the dining table in front of them). What will you do after seeing a bowl and spoon on the dining table?' The desired response from the participant is saying: 'Pick up a bowl and spoon', and performing this action concurrently. If the /desired responses occur, the participant would be asked again after the next time interval had passed. In the case of an incorrect or no response, the participant would be told the right answer and asked again after the previous correctly answered time interval had lapsed. If the participant could recall each item correctly after the 32-minute interval, it was assumed that the eight learning items had been successfully stored in long-term memory.<br>Montessori-based activities related to eating, such as scooping, pouring, squeezing, and matching were used. An example of the application of the Montessori-based activities is presented here using golf ball scooping. In the initial shorter time intervals (i.e. 1 and 2 minutes), the trainer placed the needed materials (i.e. twelve golf balls with three different colors, a tablespoon, and a baking dish with twelve grooves of three different colors) in front of the participant and then introduced each material and its usage. For the longer intervals (i.e. 4 and 8 minutes), the trainer slowly and sequentially demonstrated the basic procedure of the activity (scooping a golf ball into a groove using a tablespoon) and invited the participant to practice the procedure in the same way. If the participant was able to complete the basic procedure, vertical (upward) extensions (e.g. the color of the golf ball scooped and the groove needs to be consistent) were used to accommodate his ability and provide appropriate challenges. Moreover, horizontal extensions (e.g. golf balls were replaced by table tennis balls or circular fruits) were used to increase the participant's interest by replacing the familiar objects in an activity. | | | | |
| **Mobility (n=6)** | | | | | | |
| Killey and Watt (2006) | To enhance mobility, increase independence and exercise self-efficacy | Extra walks per day | Educational intervention | a short education session | N/R | Nursing staff |
| | | **Intervention Content:** The intervention group was supervised or assisted as necessary to go for a walk twice a day, seven days a week. The distance walked twice a day was the maximum distance able to be comfortably walked as decided by that individual at that time. Jirovec's (1991) technique was followed in determining their comfortable limit. This consisted of providing a chair to rest on at their first request, and then after resting, walking back to the bed area. The nursing staff in the units involved in the study were encouraged to attend a short education session that covered the intent of the research and how the walking program was to be implemented. They were instructed that the general intent was to encourage and enable a longer walk on each occasion. | | | | |

| Author (Year) | Aim | Name of the intervention | Intervention type | Duration of the training | Time/ frequency of the intervention | Participants |
|---|---|---|---|---|---|---|
| Klein et al. (2015) | To increase mobility and improved clinical and psychological outcomes | Early progressive mobility protocol | Protocol and staff advocacy | N/R | N/R | Nursing staff |
| | | **Intervention Content:** An early mobility program included a progressive mobility protocol, written orders, and staff (clinical nurse specialist clinical technician) who advocated for and assisted with mobility. The protocol provided criteria for 1) excluding patients from the progressive protocol, 2) evaluating patient readiness for and tolerance of mobility progression, 3) advancing patient mobility (steps), 4) documenting mobility status, and 5) consulting with physical therapy. Progressive mobilization was initiated on the day of admission, unless patients were physiologically unstable, for example, had high intracranial pressure, preventing movement. In addition to the protocol, nurses were encouraged to use ICU bed features and a mobile patient lift with the sling. ICU bed features and the mobile lift device were standard in the NICU, yet rarely used before the initiation of the study. | | | | |
| Padula, Hughes, and Baumhover (2009) | To maintain or improve functional status from admission to discharge and reduce length of stay. | Geriatric Friendly Environment through Nursing Evaluation and Specific Interventions for Successful Healing (GENESIS) | Educational intervention | 3-day continuing education units<br>4-hour refresher on the mobility protocol | N/R | Nursing staff and CNAs |
| | | **Intervention Content:** As part of the mobility protocol, the registered nurse is directed to question orders for bed rest as well as to routinely evaluate the necessity of obstacles to mobility such as urinary catheters. It is a priority of certified nurse assistants to walk GENESIS patients 3 to 4 times per day and also to assist patients to the chair for meals and the bathroom or commode for toileting | | | | |
| Peri et al. (2008) | To implement the program into the daily activities of residents to improve resident health status, life satisfaction, and mobility. | The Promoting Independent Living Study (PILS) | Educational intervention | Comprehensive activity program in 4 phases | N/R | Nursing staff |
| | | **Intervention Content:** An activity program delivered in 4 phases<br>i) Goal-setting phase: The gerontology research nurse visited each resident twice during the goal-setting phase. The first visit facilitated setting a goal volunteered by, and significant to, the resident. The second visit ensured the resident's set goal encompassed physical functionality.<br>ii) Gerontological nursing assessment: The gerontology research nurse completed a comprehensive functional assessment of each resident using a health assessment tool. Occupational therapist and physiotherapist assessments were available to support the gerontological nurse only if the allied health professional was part of the usual staff at the home.<br>iii) Development of Promoting Independent Plan (PIP): A prescriptive activity program was developed and tailored to meet the identified goal. The activities were designed to increase the resident's strength, balance, and endurance by increasing the usual level of activity by repeating ADL. The repetitive activities included bed mobility, sitting to standing, and transfers to various surfaces and heights. This meant that a resident transferred from bed to chair several times instead of once, completed a series of sit-to-stands in the resident's bedroom, the dining room, and the lounge, and increased walking distances by taking a longer route to the dining room and incremental walking distances outside. | | | | |

<table>
<tr><td></td><td></td><td colspan="5"><b>Intervention content PILS continued:</b> The emphasis throughout was resident-centered and followed the principle that incrementally increasing repetitions of exercises will increase activity tolerance and support goal attainment.<br>iv) Health care assistant training: The individualized programme was explained to both the resident and health care assistant by the research gerontology nurse with an emphasis on how the activities would support the resident in achieving their goal. The prescriptive care plan was prominently displayed in the resident’s room and included in the medical record. The health care assistant was responsible on a daily basis for ensuring that residents carried out their activity programme.</td></tr>
<tr><td><b>Author (Year)</b></td><td><b>Aim</b></td><td><b>Name of the intervention</b></td><td><b>Intervention type</b></td><td><b>Duration of the training</b></td><td><b>Time/ frequency of the intervention</b></td><td><b>Participants</b></td></tr>
<tr><td rowspan="2">Slaughter and Estabrooks (2013)</td><td rowspan="2">To affect resident mobility outcomes</td><td>sit-to-stand activity</td><td>Educational intervention</td><td>15-minute education sessions</td><td>4 times each day: twice on the day shift and twice on the evening shift.</td><td>Healthcare aides (HCA’s)</td></tr>
<tr><td colspan="5"><b>Intervention Content:</b> The sit-to-stand activity involved a cooperative effort between the healthcare aides and the residents. Healthcare aides encouraged residents to slowly stand up and sit down as many times as possible on two occasions each day and evening shift. The sit-to-stand activity was carried out as part of the resident’s usual activities of daily living such as toileting or dressing. No time limit was placed on the duration of the activity. The number of sit-to-stand repetitions on a given occasion was individualized according to the resident’s abilities and fatigue.</td></tr>
<tr><td rowspan="2">Slaughter et al. (2015)</td><td rowspan="2">To affect resident mobility outcomes</td><td>sit-to-stand activity is</td><td>Educational intervention</td><td>N/R</td><td>4 times each day: twice on the day shift and twice on the evening shift.</td><td>HCA’s</td></tr>
<tr><td colspan="5"><b>Intervention Content:</b> The sit-to-stand activity is repeating the action of standing up from a seated position and sitting down in a controlled manner. HCAs prompted and encouraged residents to repeat the sit-to-stand activity during their daily care routines (e.g. during dressing or toileting). The timing and location of the activity was at the discretion of the HCAs. The HCAs had a target number of repetitions for each participating resident to complete on each of the 4 occasions; however, the actual number of repetitions completed depended on resident ability, fatigue, and motivation.</td></tr>
</table>

| Author (Year) | Aim | Name of the intervention | Intervention type | Duration of the training | Time/ frequency of the intervention | Participants |
|---|---|---|---|---|---|---|
| **Dressing (n=1)** | | | | | | |
| Engelman, Mathews, and Altus (2002) | To teach the CNAs to implement the system of least prompts (SLP) during residents' morning dressing routines | System of least prompts training | Educational intervention | 45-minute in-service training workshop | N/R | CNAs |
| | | **Intervention Content:** SLP was taught using the following directives:<br>1. Knock on the door before entering the resident's room;<br>2. Greet the resident, using the resident's name (e.g., "Good morning, Lila.");<br>3. Introduce yourself (e.g., "It's Lisa!");<br>4. Prepare the area by eliminating disturbances and ensuring that all necessary materials (e.g., clothing) are available for skill step completion;<br>5. Identify the task to be completed (e.g., "It's time to get dressed.");<br>6. Use at least two less intrusive prompts before using physical guidance. Less intrusive prompts include verbal prompts, gestural prompts, and modeling;<br>7. Time prompts correctly. The CNA should wait five seconds between each prompt to give the resident sufficient time to respond to the instruction or prompt;<br>8. Use physical guidance correctly. As a last resort (e.g., after offering at least two less intrusive prompts), the CNAs should gently assist residents in completing the current dressing step;<br>9. Provide praise. The CNA should provide approval or praise within five seconds of the resident completing a step (with or without assistance).<br>CNAs watched two researchers role-play how to conduct the SLP procedure when helping a resident to dress. Three additional roleplaying situations were conducted in which one of the researchers played the role of the resident and the CNA assisted her in dressing. During these role-plays, the researchers provided the CNA with feedback regarding her performance using the SLP procedure. During her regular work shift the day after the training, the CNA practiced using the SLP procedure with residents in the DCU. On this day, the CNA was provided with immediate feedback regarding her implementation of the SLP. | | | | |

| Author (Year) | Aim | Name of the intervention | Intervention type | Duration of the training | Time/ frequency of the intervention | Participants |
|---|---|---|---|---|---|---|
| **Grooming (n=1)** | | | | | | |
| Lim (2003) | To improve the grooming performance of elders with cognitive impairments in Korea. | behavioral nursing intervention strategies | Educational intervention | 3 sessions | N/R | Nurses |
| | | **Intervention Content:** The behavioral nursing strategies were derived from preliminary studies on improving the grooming behavior of elders with cognitive impairments in the special dementia unit of a long-term care facility.3-6 The intervention consisted of systematic prompting and social reinforcement to give residents a series of 1-step commands to guide their face-washing, tooth brushing, and hair-combing.<br>At the beginning of each intervention session, the resident was given an orientation to grooming. Lewis' protocol for reality orientation was used as follows. "Good morning, Mrs Kim (a polite greeting giving time and personal information). My name is Carol (caregiver's name). It's 8:30 Monday morning (time). Did you like your breakfast this morning (general conversation)? It's a good time to clean your hands and face after breakfast (behavioral expectation). I'm here to help you get ready to wash your hands and face (ongoing activity). Let's go to the bathroom (ongoing activity). Here is the bathroom (place). Here are your soap and towel to wash your face (behavioral expectation)." Residents were asked to wash their faces, brush their teeth, and comb their hair. Each resident was allowed to do as much of each task as he or she could. The intervener assisted the resident in performing correctly and independently the sequence of steps necessary to complete each task. Prompts were graduated in strength from verbal to manual guidance, depending on the resident's responses. Social reinforcements included verbal praise and positive nonverbal behavior. At the end of each task, the resident was verbally praised, acknowledged, and encouraged to express feelings, such as, "Thank you," "You did a very nice job," "Do you feel good?" or "How do you feel now?" While giving verbal approval, the intervener made eye contact with the resident, smiled, or delivered physical approval in the form of a friendly touch on the shoulder. Another type of social reinforcement was given at the end of the grooming task when lotion was provided for the hands and face.<br>The intervener used prompts as sparingly as possible because the goal of the nursing intervention was to maintain or improve the resident's functional ability. For example, a resident combed the back of her hair when prompted with verbal instruction. After several sessions, it was not necessary to prompt her to initiate the combing behavior. | | | | |

**Table 2** Description of Interventions Targeting Comfort (n=14)

| Author (Year) | Aim | Name of the intervention | Intervention type | Duration | Time/ frequency of the intervention | Participants |
|---|---|---|---|---|---|---|
| **General ADL (n=6)** | | | | | | |
| Beck et al. (2002) | To meet residents' psychosocial needs for territoriality, communication, autonomy, and self-esteem, to promote their sense of safety and security, and to respect their cognitive and physical abilities | Activities of daily living | Educational intervention | N/A | 45–60 minutes a day during various ADL. They implemented the interventions Monday–Friday for 12 weeks. | CNAs |
| | | **Intervention content**: Intervention during bathing, grooming, dressing, and the noon meal based on successful protocols that improved functional status in dressing (Beck, Heacock et al., 1997).<br>3 types of strategies<br>(1) Strategies to complete an ADL address specific cognitive deficits. For example, a person with ideomotor apraxia needs touch or physical guidance to start movements<br>(2) Standard strategies are behaviors and communication techniques that work for almost everyone with dementia. For example, the caregiver gives a series of one-step commands to guide the resident to put on her shoe.<br>(3) Problem-oriented strategies address particular disabilities such as fine motor impairment, physical limitations, or perseveration. For example, a subject who rubs his hand back and forth on his leg continually and without apparent reason needs redirection | | | | |
| | | Psycho-social activity (PSA) | Educational intervention | N/A | Initially, many participants tolerated less than 15 min. of the activity but eventually habituated and participated for 30 min. | CNAs |
| | | **Intervention content:** 25 standardized modules<br>Each module contained five psychosocial areas of content (expression of feelings, expression of thoughts, memory/recall, recreation, and education) and stimulated five sensory modalities (verbal, visual, auditory, tactile, and gustatory/olfactory). For instance, Activity Module I involved life review, communicating ideas visually (identifying and making drawings), clapping to different rhythms, massaging one's face, and eating a snack. Intervention provided a systematic plan for the project nursing assistants (PNA) to address some of the participants' basic psychosocial needs; Intervention presented clinical interventions that many long-term care facilities routinely used but had not been formalized into a research protocol or systematically tested. | | | | |
| | | Combined | A combination of the PSA and ADL intervention was provided. | | | |

| Author (Year) | Aim | Name of the intervention | Intervention type | Duration of the training | Time/ frequency of the intervention | Participants |
|---|---|---|---|---|---|---|
| Bowles et al. (2002) | To reduce the occurrence of resistance to nursing care and other dementia-related behaviors in nursing care. | Essential oils and touch | Environmental intervention | 4 weeks | 2 treatments per day (morning and before night) | Nurses |
| | | **Intervention content**; Individually labeled 250 ml pump bottle for each stage of the trial. The cream was lightly massaged onto the back, shoulders, neck, and arms of each participant following their morning shower and during the routine toileting and pressure care rounds each day. The final treatment was administered while each participant was being put to bed for the night. Each treatment consisted of no more than 5 min. of light effleurage strokes using approximately 5 ml (one pump) of the cream. The touch was administered both to allow the cream to be absorbed into the skin and to provide a sense of care and nurture. Each participant had their own individually labeled 250 ml pump bottle for each stage of the trial. | | | | |
| Chou et al. (2016) | To avoid the possibility that residents display behavioral symptoms. | International Affective Pictures System (IAPS) | Environmental intervention | N/A | During personal care in dressing and toileting | CNAs |
| | | **Intervention content**: During the intervention/control trials, after the resident resisted care and exhibited combative behavior, the CNA showed the stimulus to the resident. The CNA was encouraged to begin a short conversation with the resident (e.g., “Look at this!”) and resumed providing personal care. The resident was allowed to continually hold the stimulus if desired. However, during the process of personal care, there were times when the CNA needed to take the stimulus away from the participant (e.g., transferring). After the task was completed, the CNA was encouraged to return the stimulus to the participant. | | | | |
| Hammar et al. (2011) | N/R | Music Therapeutic Caregiving (MTC) | Educational intervention | Course in MTC | Morning care situation, 4 weeks | Direct-care staff |
| | | **Intervention content**: The caregivers were offered a course in preparation for the intervention offered by the first author who was certified in MTC. The caregivers sang songs and hymns that the older ordinarily would recognize from their past, such as children’s songs, sing-along songs, and popular songs from the early part of the 20th century. The caregivers themselves chose songs they preferred to sing. Some spoke between the songs, but only to instruct or explain something to the PWD. They sang most of the time and for the duration of the morning care situations | | | | |
| O'Connor et al. (2011) | To encourage participation during the basic care tasks | Video-stimulated presence | Environmental intervention | N/A | During care tasks of feeding and medication intake | Nursing staff |
| | | **Intervention content**: The family member who agreed to participate in the study was asked to make individual 30- to 60-second videos in which the family member spoke directly to the participant asking them to comply with staff requests and prompting them to participate in specific tasks. The family members targeted tasks based on the nurse's report and their knowledge of their relative’s participation restrictions. Videos prompted the participant to comply with medications, meals, and drinks and also included a general video to promote social reassurance and thus compliance with general care tasks such as transfers or mobility. The VSP recordings were played according to the task at hand and were played in situ using an iPad which permitted ease of application during a range of tasks within the setting. Prior to playing the VSP, verbal permission was always gained from the participant by the researcher asking ‘‘would you like to watch a video of your daughter?’’. The VSP was played immediately prior to staff attempting normal procedures to facilitate occupational participation. During longer tasks such as eating a meal, the VSP intervention was replayed up to 3 times throughout the task. | | | | |

| Author (Year) | Aim | Name of the intervention | Intervention type | Duration of the training | Time/ frequency of the intervention | Participants |
|---|---|---|---|---|---|---|
| Wells, Dawson, Sidani, Craig, and Pringle (2000) | To assist an individual in using her or his abilities. | Abilities-focused morning care | Educational intervention | 5-session educational program (20-30 minutes per session) reinforcement sessions lasting 20 to 30 minutes were provided every second week for 3 months | Morning care is defined as the period of time between 7:00 and 12:00 a.m. when caregivers are engaged with residents in activities related to bathing, grooming, dressing, and toileting. | Caregivers |
| | | **Intervention content**: Participants were educated on the effects of dementia on the social abilities of (a) giving and receiving attention; (b) social accessibility; (c) engaging in conversation; Participants were educated on self-care abilities of (a) Spatial orientation; (b) voluntary movements; and (c) purposeful movements. Twelve interventions within social abilities and 17 interventions within self-care abilities were taught. I.e. how bathing and dressing an individual with dementia may be affected by the appearance of the grasp reflex was demonstrated based on research about primitive reflexes. Related interventions of avoiding stimulation of the palm during bathing and of moving the hand by holding the top of it were taught. One-page summaries of each of the research studies covered in the sessions were provided. | | | | |
| Gozalo et al. (2014) | To make showering, tub bathing, in-room bathing, and hair washing safe and comfortable for the persons receiving and giving care. | Bathing Without a Battle | Educational intervention train-the-trainer | Trainers in the facility group attended a 2-day training session | N/R | Direct-care staff |
| | | **Intervention content**: Tools used during the training included video examples followed by practice (role-playing) and a discussion with video illustrations of how to match the intervention to different stages of dementia and resident preferences to make bathing safe and comfortable for the persons receiving and giving care. The strategy employs communication techniques appropriate for the resident's impairment level, views behavioral symptoms as expressions of unmet need, respects the preferences of the resident, and regulates the physical environment to maximize resident comfort. | | | | |
| Dunn et al. (2002) | To reduce discomfort in bathing use the "thermal bath" as a bathing alternative. | Thermal bath | Bathing alternative | N/R | 4 sessions of tub bath and thermal bath over 8 weeks | Staff attendants |
| | | **Intervention content**: Thermal bath procedure: A cap full of Sproam (Coloplast, Mississauga, Ontario), a non-rinse skin cleanser, is placed in the thermal container. Very hot water (300ml) is passed. Enough washcloths for the bath (nine) are placed in the water until just moistened. The container is then taken to the bedside and the washcloths are removed one by one at a time to bathe each body part. There is no rinsing required and the skin dries in approximately 30 seconds. | | | | |

<table>
<tr><th>Author (Year)</th><th>Aim</th><th>Name of the intervention</th><th>Intervention type</th><th>Duration of the training</th><th>Time/ frequency of the intervention</th><th>Participants</th></tr>
<tr><td rowspan="2">Jacq et al. (2018)</td><td rowspan="2">To reduce pain during the morning bed bath</td><td>Music for pain relief</td><td>Bed bath</td><td>N/R</td><td>N/R</td><td>Nurse and nursing assistant</td></tr>
<tr><td colspan="5"><b>Intervention content</b>: In the intervention group, patients were exposed to music during the morning bed bath, using headphones connected to an MP3 converter via a Bluetooth connection. The same selection of passages by Mozart was used in all patients. The music was started at the same time as the bed bath and continued throughout the bath and for 30 minutes after the end of the bath. The music amplitude was 60 decibels</td></tr>
<tr><td rowspan="2">Lopes et al. (2010)</td><td rowspan="2">To evaluate the influence of several variables on patients' anxiety in view of bed and shower baths.</td><td>Shower and bed bath</td><td>Bed bath</td><td>Nursing professionals did not receive any type of additional training concerning</td><td>N/R</td><td>Nursing professional</td></tr>
<tr><td colspan="5"><b>Intervention content</b>: The patients remained reclined during the bed bath and were assisted by a nursing professional. For the shower bath, a shower chair was used and patients took their bath without direct assistance, though they were under supervision. These procedures were carried out according to the unit's normal routine and by professionals who were responsible for the patients at the point of data collection. However, aiming to diminish the influence of interpersonal conversation during the procedures, the professionals were instructed to keep to a neutral and superficial conversation.</td></tr>
<tr><td rowspan="2">Schoonhoven et al. (2015)</td><td rowspan="2">To clean the client's body for the purpose of cleanliness, performed by the nurse while the patient is lying in bed.</td><td>Bed bath</td><td>Bathing alternative</td><td>N/R</td><td>N/R</td><td>Nursing professional</td></tr>
<tr><td colspan="5"><b>Intervention content</b>: A bed bath is defined as cleaning of the client's body for the purpose of cleanliness, performed by the nurse while the patient is lying in bed. The experimental condition was bed baths with disposable washing gloves made of soft waffled non- woven fibers, impregnated with a no-rinse, quickly vaporizing skin cleaning and caring lotion, so named 'washing without water'. A package of washing gloves contains eight disposable gloves to be used for one bed bath. The package was heated in a microwave.</td></tr>
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| Author (Year) | Aim | Name of the intervention | Intervention type | Duration of the training | Time/ frequency of the intervention | Participants |
|---|---|---|---|---|---|---|
| Sloane et al. (2004) | To individualize the experience for the resident | Person-centered bathing | Educational intervention | A clinical nurse specialist or psychologist working alongside the CNAs 2 days a week for 4 weeks introduced the interventions | ± 8 hours per study subject per intervention | CNAs |
| | | **Intervention content**: Person-centred bathing focused on resident comfort and preferences, viewed behavioral symptoms as expressions of unmet need, and employed communication techniques appropriate for the resident’s level of disease severity. A variety of techniques were used: providing choices, covering with towels to maintain resident warmth, distracting attention (e.g., by providing food), using bathing products recommended by family and staff, using no-rinse soap, and modifying the shower spray. | | | | |
| | | Towel bath | Educational intervention | N/R | N/R | CNAs |
| | | **Intervention content**: The towel bath is an in-bed method in which the caregiver uses two bath blankets, two bath towels, a no-rinse soap, and 2 quarts of warm water; keeps the resident covered at all times; and cleanses the body using a gentle massage. | | | | |
| Mickus et al. (2002) | To minimize problematic behavior during bathing | PRIDE (Privacy, reassurance, information, distraction, and evaluation) intervention | Educational intervention | 30-minute interactive seminar | N/R | NAs |
| | | The interventions consist of an interactive seminar with NAs<br>10-minute tape followed by discussion and reinforcement of the PRIDE principles.<br>Tape offered two scenarios (1) “bad bath” (NA delivering a bath without the use of appropriate behavior strategies); (2) “good bath” (a similar scenario demonstrating useful behavioral approaches)<br>Examples of useful approach principles:<br>- encouraging privacy: closing the bathroom door or not undressing the patient before the necessary<br>- reassuring the patient by repeatedly reminding the patient that he/she is safe and not alone<br>- sharing information before and during the bath given the short-term recall and confusion problems<br>- distracting patients who became agitated during the process by bringing up a pleasant topic<br>- being constantly aware of how the patient was responding, in extreme cases evaluating whether the timing for the bath was appropriate | | | | |

| Author (Year) | Aim | Name of the intervention | Intervention type | Duration of the training | Time/ frequency of the intervention | Participants |
|---|---|---|---|---|---|---|
| **Toileting (n=1)** | | | | | | |
| Engst et al. (2004)<br>**USA** | N/R | scheduled toileting program | Educational intervention | N/R | N/R | Care aids<br>RNs |
| | | **Intervention content:** Residents were placed on individualized toileting schedules. The toileting program was phased in by assessing the bowel and continence routines using a voiding diary and documented bowel interventions and frequency on the medication administration record. Residents whose voiding patterns were deemed consistent enough to benefit from scheduled toileting were put on a personalized toileting schedule. An interdisciplinary team assisted with the assessment of resident transfer and seating, appropriate use of medications, and review of resident fluid intake and diet. To manage the increased demand for lifting and transferring residents during toileting, 10 mechanical lifts (5 sit-stand lifts and 5 seated lifts) were purchased to provide a ratio of at least I lift per 8 residents. Staff was educated on the use of the mechanical lifts and the clinical practice guidelines.<br>Staff was educated on identifying agitated behaviors. Agitation awareness education promoted early recognition of emotional, verbal, or physical cues of resident agitation and an awareness that attention to contributing factors could alleviate the agitation and prevent escalation to more intense agitation such as physical aggression. | | | | |

**Table 3** Description of Interventions Targeting Comfort and Independence (n=3)

| Author (Year) | Aim | Name of the intervention | Intervention type | Duration of the training | Time | Participants |
|---|---|---|---|---|---|---|
| **General ADL (n=3)** | | | | | | |
| Galik et al. (2008) | To engage cognitively impaired residents in restorative care activities, and motivating NAs to provide restorative care in all care interactions | Restorative Care Intervention | Education and coaching | 4-week educational<br>4 different 20- to 30-min. classes<br>Coaching 20 hours a week for 4 months | N/R | NAs<br>Restorative Care Nurse (RCN) |
| | | **Intervention content**: Classes covered:<br>(1) the philosophy of restorative care,<br>(2) motivating cognitively impaired residents to participate in functional activities and exercise,<br>(3) incorporating restorative care interventions into the resident's daily life<br>(4) documentation and coordination of restorative care<br>The Res-Care-CI Intervention also consisted of the mentoring and monitoring of the nursing assistants by the Restorative Care Nurse (RCN), an advanced practice nurse with experience in restorative care, rehabilitation nursing, and dementia care. The RCN completed the following activities:<br>(1) Working with NAs to develop and re-evaluate restorative care goals for each resident;<br>(2) Coaching and mentoring NAs related to the implementation of restorative care activities;<br>(3) Providing weekly ongoing encouragement and support to NAs related to the implementation of the intervention. | | | | |
| Galik, Resnick, Hammersla, and Brightwater (2014) | To engage cognitively impaired residents in function and physical activity, and to incorporate Function-Focused Care (FFC) into routine daily care. | Function-Focused Care (FFC) | Educational intervention | 30-min in-service and handouts that covered resident and staff benefits of FFC, strategies | 10 hr per week for 6 months | FFC nurses |
| | | **Intervention content**: Component I: Environment & Policy Assessment: Evaluation of the environment and nursing home policy and procedures to determine whether they presented barriers to implementation of an FFC approach.<br>Component II: Education of nursing home staff and families about FFC<br>Component III: Development of Function-Focused Care Goals: Individual resident goals were initiated through assessment and discussions with the FFC Nurse, resident, family, staff, and facility champions<br>Component IV: Mentoring and Motivating: Ongoing education and motivation of staff by FFC Nurse and facility champion | | | | |

| Author (Year) | Aim | Name of the intervention | Intervention type | Duration of the training | Time | Participants |
|---|---|---|---|---|---|---|
| Sidani, Streiner, and LeClerc (2012) | To enable nurses to implement the abilities-focused approach to morning care (AFMC) components in their day-to-day practice | Abilities-focused approach to morning care (AFMC) | Educational intervention | 1.5- to 2.0-hour session | N/R | Nurses |
| | | Each of the six AFMC components comprises specific interventions implemented throughout the morning care episode. (1) Introduction to resident consists of strategies to greet residents before giving morning care. (2) Conversation with residents involves interacting with residents during morning care. (3) Caregiver approach focuses on strategies to promote relaxation. (4) Orientation to resident includes breaking a task into smaller steps to facilitate residents' involvement in morning care. (5) Use of tools contains strategies that assist residents in using tools needed for morning care. (6) Bathing, dressing and grooming involve strategies to promote residents' actual participation in morning care.<br>The education program focused on instructing nurses in the effects of dementia on social and self-care activities with an emphasis on the fact that some abilities are retained: the AFMC components; the principles for selecting appropriate AFMC interventions; and the advantages of the abilities-focused approach to care to residents and nurses. Because of contextual constraints (Sidani et al., 2010b), the program was given in. Nursing staff members were given a list of the strategies and instructed to consult trained advanced practice nurses (APNs), available on site, to discuss issues with the implementation of strategies. Trained APNs delivered the educational sessions to nursing staff. | | | | |

# Appendix 3: Risk of Bias Assessment

**Table 1** Assessment of Risk of Bias of randomized controlled studies (n=8)

| JBI Critical appraisal checklist for randomized controlled trials | Beck et al. (2002)$^{C}$ | Galik et al. (2014)$^{IC}$ | Gozalo et al. (2014) $^{C}$ | Henskens et al. (2018)$^{I}$ | Resnick et al. (2009)$^{I}$ | Schoonhoven et al. (2015)$^{C}$ | Sloane et al. (2004)$^{C}$ | Peri et al. (2008)$^{I}$ |
|---|---|---|---|---|---|---|---|---|
| 1. True randomization for assignment to treatment groups | N | N | Y | Y | Y | Y | N | Y |
| 2. Concealed allocation to treatment groups | U | N | U | Y | U | Y | U | N |
| 3. Similarity of groups at baseline | N | Y | U | N | N | N | N | Y |
| 4. Participants blind to treatment assignment | N | N | N | N | N | N | U | B |
| 5. Treatment providers blind to allocation | N | N | N | N | N | N | N | B |
| 6. Outcome assessors blind to allocation | N | Y | N | U | N | U | Y | Y |
| 7. Groups treated identically except for intervention | Y | Y | Y | Y | Y | U | U | U |
| 8. Follow-up complete and analyzed? | Y | N | Y | Y | Y | Y | U | U |
| 9. Participants were analyzed in allocated groups. | Y | Y | Y | Y | Y | Y | U | Y |
| 10. Outcomes were measured the same way in both groups | Y | Y | Y | Y | Y | Y | U | Y |
| 11. Outcomes measured in a reliable way | Y | Y | Y | Y | Y | Y | U | Y |
| 12. Appropriate statistical analysis | Y | N | Y | Y | Y | Y | Y | Y |
| 13. Trial design appropriate | Y | Y | Y | Y | Y | Y | Y | Y |
| Yes in (%) | 54% | 54% | 54% | 63% | 63% | 63% | 23% | 63% |
| Total quality score | Moderate | Moderate | Moderate | Moderate | Moderate | Moderate | Low | Moderate |

$^{I}$= Outcome of interest: ADL independence; $^{C}$ = Outcome of interest: Comfort; $^{IC}$= Outcome of interest Independence and Comfort

**Table 2** Assessment of Risk of Bias in included quasi-experimental studies (part 1)

| **JBI Critical appraisal checklist for quasi-experimental studies** | **Blair et al. (2007)$^{I}$** | **Bowles et al. (2002)$^{C}$** | **Chang and Lin (2005)$^{I}$** | **Chou et al. (2016)$^{C}$** | **Dunn et al. (2002)$^{C}$** | **Engelman et al. (2002)$^{I}$** | **Engst et al. (2004)$^{C}$** | **Galik et al. (2008)$^{IC}$** | **Hammar et al. (2011)⍰** | **Jacq et al. (2018)$^{C}$** | **Killey and Watt (2006)$^{I}$** |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Clear cause and effect | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 2. Similar participants included in the comparison | N | Y | U | Y | Y | U | U | Y | Y | N | U |
| 3. Receiving similar treatment except for intervention | U | Y | N | U | Y | U | U | N | Y | Y | U |
| 4. Control group | Y | N | N | N | N | N | Y | N | N | Y | Y |
| 5. Multiple measurement of outcomes pre and post-exposure | Y | Y | Y | N | N | Y | Y | N | Y | Y | Y |
| 6. Follow up complete and analyzed | N | N | N | Y | Y | U | U | Y | Y | U | Y |
| 7. Outcomes measured in the same way | Y | Y | U | U | Y | Y | Y | U | Y | Y | Y |
| 8. Outcomes measured in a reliable way | U | N | Y | U | Y | Y | U | Y | Y | Y | U |
| 9. Appropriate statistical analysis | Y | U | N | Y | Y | Y | U | Y | U | Y | Y |
| Yes (in %) | 55% | 55% | 33% | 44% | 77% | 55% | 44% | 55% | 77% | 77% | 66% |
| Total quality score | Moderate | Moderate | Low | Low | High | Moderate | Low | Moderate | High | High | Moderate |

$^{I}$= Outcome of interest: ADL independence; $^{C}$ = Outcome of interest: Comfort; $^{IC}$= Outcome of interest Independence and Comfort

**Table 2** Assessment of Risk of Bias in included quasi-experimental studies (part 2)

| **JBI Checklist for Quasi-experimental Studies** | **Klein et al. (2015)$^{I}$** | **Lim (2003)$^{I}$** | **Lin, et. Al (2011)$^{I}$** | **Lopes Jde et al. (2013)$^{C}$** | **Mickus et al. (2002)$^{C}$** | **O'Connor et al. (2011)$^{C}$** | **Padula et al. (2009)$^{I}$** | **Sidani et al. (2012)$^{I}$** | **Slaughter and Estabrooks (2013)$^{I}$** | **Slaughter et al. (2015)$^{I}$** | **Wells et al. (2000)$^{C}$** | **Wu et al. (2014)$^{I}$** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Clear cause and effect | Y | Y | Y | U | Y | Y | Y | Y | U | Y | Y | Y |
| 2. Similar participants included in the comparison | N | U | U | Y | U | Y | U | U | N | N | U | N |
| 3. Receiving similar treatment except for intervention | U | U | U | Y | U | U | U | U | U | Y | U | Y |
| 4. Control group | Y | N | N | N | N | N | Y | N | Y | N | Y | Y |
| 5. Multiple measurement of outcomes pre and post-exposure | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | U |
| 6. Follow up complete and analyzed | U | U | U | Y | U | U | U | U | U | U | N | Y |
| 7. Outcomes measured in the same way | U | Y | U | Y | N | Y | U | Y | U | Y | Y | Y |
| 8. Outcomes measured in a reliable way | U | Y | Y | Y | Y | Y | U | Y | U | Y | U | Y |
| 9. Appropriate statistical analysis | Y | U | Y | U | N | U | U | Y | U | Y | U | Y |
| Yes (%) | 44% | 44% | 44% | 66% | 33% | 55% | 33% | 55% | 22% | 66% | 44% | 77% |
| Total score | Low | Low | Low | Moderate | Low | Moderate | Low | Moderate | Low | Moderate | Low | High |

# Chapter 4

# Utilizing the Physical Green Care Environment to Support Activities of Daily Living for Nursing Home Residents: A Focused Ethnographic Case Study

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## Abstract

**Background:** The nursing home residents' ability to carry out Activities of Daily Living (ADLs) is influenced by the physical care environment. One emerging area of interest in scientific research is the green care environment within nursing home care, where agricultural activities such as gardening and animal care are integrated alongside daily care. Surprisingly, previous research has neglected to explore how these environments can be employed to enhance ADL performance. This study, therefore, explores how a green care environment, specifically one with an animal shelter, can be used to support nursing home residents in their ADLs.

**Methods:** A focused ethnographic case study was conducted in one nursing home. Data was collected employing participatory observations, informal conversations, and semi-structured interviews, which we analyzed by employing a thematic analysis.

**Results:** Overall, 25 residents were observed for a total time of 89 hours, and interviews were conducted with 10 staff members. The nursing home integrates activities in the green care environment into daily care for a broad scope of residents. The analysis revealed four themes: Theme 1: The (in)visibility of ADL, Theme 2: Reciprocal care dynamics: Fostering ADL performance through connection and teamwork, (3) Theme 3: Seized and missed opportunities for meaningful integration of ADL in the physical green care environment, and Theme 4: Professional fulfillment and ADL task obligation: Views from staff and management.

**Conclusions:** This physical green care environment has the potential to enhance the residents' daily activities and foster better staff-resident relationships. Yet, there are varying views among staff and management regarding its integration into the residents' lives and care.

## Background

Due to the progression of their disease, residents with dementia and related diseases increasingly depend on their environment when performing activities of daily living (ADL) [1, 2]. ADLs collectively refer to essential skills necessary for self-care and independence, encompassing activities like eating, bathing, and mobility which has first been described as a concept by Katz et al. [3]. With nursing professionals supporting a person's ability to perform ADLs, they lie conceptually at the heart of the nursing profession as the fundamentals of care framework illustrates [4]. As part of fundamental nursing, ADL care has received increased scholarly attention in the past decades focusing on the challenges and pre-conceptions [5, 6] as well as its importance for those who receive care. [7]. Hence, it is not surprising that the World Health Organization (WHO) prioritizes the maintenance of underlying abilities to perform these activities, as essential to healthy aging [8].

The extent to which people are or are made capable of healthy aging depends in part on the environment they inhabit [9]. The physical environment should be carefully considered to assist in meeting a person's needs and optimizing care routines [10-12]. The physical environment in dementia care encompasses various elements, such as unit size, residential ambiance, sensory stimuli, dining spaces, resident rooms, bathing and toilet facilities, and outdoor areas. These factors collectively contribute to the overall care environment for individuals with dementia [13]. Within nursing homes, the physical care environment can significantly impact the health and behaviors of residents [14] but its promising potential has not been sufficiently recognized within the scientific literature yet [15]. Inside spaces include, for example, the bathroom layout, orientation cues, more homelike character or noise, and light adaptations to the residents' needs [15]. The outside environment and its natural elements including gardens, plants, and animals are often underestimated and overlooked opportunities for improving resident outcomes. For nursing home residents, access to the outdoors may be entirely restricted, and opportunities for outdoor experiences may be solely determined by facility personnel [16]. A care environment receiving recent scholarly attention, especially in Europe is the green care environment [17] in which nursing home care offers agricultural activities (e.g. gardening and animal care) combined with care for people with dementia [18]. In the Netherlands, for example, nursing homes increasingly aim to integrate natural elements into daily care practices, recognizing the value of the presence of nature and animals and the activities associated with them [19].

As demonstrated by a recent review by Speckemeier et al. [20], innovative changes in the living environment such as smaller scales or opportunities for involvement in meaningful activities might be reasons why residents with dementia could better maintain their abilities in ADL functioning. Specifically for the outdoor environment a different review indicated positive effects on mental health, physical activity, structure, and meaningfulness in residents being involved in activities around animals and plants [21].

Research has shown that environments including activities with animals contribute to a general increase in ADL performance in, for example, stroke survivors [22] as well as to ADL-related outcomes such as food and fluid intake in community-dwelling older people with dementia [23]. These findings hold particular importance for nursing professionals as they play a crucial role in providing ADL nursing care for residents in nursing homes [7]. However, it remains unclear whether and how this environment is used to facilitate ADL performance.

It appears that the purposeful use and integration of the physical green care environment in ADL care remains challenging as up until now they mainly serve recreational purposes [19]. It remains unclear how the physical green care environment can be used to facilitate ADL performance. In fact, a review by Woodbridge et al. [24] emphasizes the gap in the literature as to how the environment can support ADLs in the living environment of older people with dementia. They furthermore emphasize the need to enhance insights into the interactions between older persons with dementia and their surroundings while integrating their perspectives. Therefore, this study aims to answer the following research question: How can a physical green care environment be used to facilitate ADL performance in residents of a nursing home?

## Methods

A focused ethnographic case study was conducted [25] adhering to the Standard for Reporting Qualitative Research (SRQR) [26]. Aligned with the exploratory nature of our research, ethnography presented a suitable approach as it allows an immersion into real-life situations to identify patterns, relationships, and meanings within the entire environmental context [27]. This approach was chosen in line with this study's aim since it allows the researchers to get insights into the living world of how this environment is used to facilitate ADL functioning in this particular setting. It not only permits the observation of residents and staff behavior within the environment during activities but also facilitates the observation of interactions and relational aspects as they unfold. A focused ethnography, as opposed to prolonged immersion, employs concentrated data gathering to investigate a specific topic. In health services research, this approach proves beneficial for rapidly gaining a thorough understanding of a particular topic involving short-term and targeted data collection [25].

### Setting

Despite Dutch policies that encourage individuals to reside in their own homes as long as possible, nursing homes in the Netherlands are primarily an option for the most vulnerable individuals in society, such as people living with dementia [28]. In 2017, 38% of the people living with dementia resided in Dutch nursing homes. The case for this study was a nursing home (n ~ 200 residents) for residents with psychogeriatric diagnoses including early-onset dementia, other forms of dementia, Korsakoff's, and Parkinson's disease. All residents living in the nursing home were in need of 24-hour care. However, depending on the residents' needs and diagnosis, ADL care needs varied greatly. This nursing home combines large- and small-scale living, ranging from 11–24 residents per ward. To meet the different interests of the residents, the nursing home offers different activities for residents including carpeting, painting, musical activities, and swimming or other physical exercise. Additional descriptions of the setting and its physical green care elements are described in the results section.

### Sampling

For the observations, we used a convenience sample of residents and nursing, activity staff, and managers, based on their presence during the observed activities with and around animals (Table 1). Moreover, we selected ward managers who were responsible for the residents we observed. The selection of staff members for interviews strived towards selecting a variety of professionals including Registered Nurses (RNs), Certified Nursing Assistants (CNAs), activity staff, and ward managers with different roles and experiences in using the environment including animals.

**Table 1** Characteristics of Nursing Home Wards, the Resident's Main Diagnosis, and the Frequency of Participation in the Outside Environment

| Ward | Residents participating/Residents living in the ward* | Residents' main diagnosis | Weekly frequency of organized activities per ward (total time spent per week) |
|---|---|---|---|
| A | 8/24 | Geriatric psychiatry | 1x per week (1.5h) |
| B | 2/11 | Geriatric psychiatry | 2x per week (1h) |
| C | 1/27 | Korsakoff's disease | 1x per week (1h) |
| D | 5/20 | Early onset dementia (early and advanced stages) | 5x per week (3h) |
| E | 0/20 | Parkinson's disease | 3x per week (4.5h) |
| F | 5/15 | Advanced dementia | 2x per week (1.5h) |
| G | 2/14 | Korsakoff's disease | 8x per week (7h) |
| H | 2/14 | Korsakoff's disease | 6x per week (7.5h) |

* The number of residents living in the ward is not equal to the number participating in the activities. Out of the 28 residents who took part, three legal representatives of those involved in the outdoor environment opted not to provide consent for participation in this study.

### Data Collection

All data, including participatory observations, informal conversations, and interviews, were collected from January 2022 to September 2022.

### *Resident and Staff Characteristics*

We used a short questionnaire to collect general resident demographics (name, age in years, main diagnoses as reported in the electronic resident records, and name and type of ward they live in). Data was collected by the social worker of the care organization who had access to the electronic resident records. During the interviews, staff, data was collected including name, age, profession, and the ward they work on.

### *Participatory Observations and Informal Conversations*

To explore the interplay between the physical green care environment and the performance of ADLs of residents, participatory observations were conducted. This allowed the researchers to immerse in the setting and engage with the residents and staff [29]. The unit of observations centered around the activities taking place in the physical green care environment. Observations took place before, during, and after the scheduled activities. This meant that researchers accompanied residents from their ward to the outside environment. Following this, the planned activities at the animal shelter took place. Afterward, the researchers, along with the staff, escorted the residents back to their ward, concluding the session. The approach involved open and flexible observations and capturing the natural flow of activities and interactions, providing a more authentic and contextually rich understanding [30]. When conducting the observations we took a stepwise approach of descriptive, focused, and selective observations inspired by Spradley [31] and Whitehead [32] in which we gradually added structure as we moved further along in this iterative process.

In the descriptive phase, we first entered the field aiming to “naturally inquire” as much information as possible on the context guided by questions such as *what* is happening as well as *who, where*, *when,* and *why*. In line with our research questions, this also meant that we paid particular attention to elements of the physical environment including space and objects To pay particular attention to the environment we devoted our observations to the green care environment, such as the spatial layout, objects, animals, distances between the outside environment and wards. In this phase, the researcher’s participation in the activities was limited accompanying residents and staff to the activities and being there. Hence, we also got a general impression of the kind of activities taking place in that environment (including ADLs) as well as the residents and staff members participating in these.

In the focused part of our observations, we moved from general observations to exploring specific behaviors of and interactions between residents, staff, and environment within the activity context. This meant gradually increasing our participation to experience firsthand how for example staff prompts or animals stimulate ADL performance. Leading for the selection of observation moments were six predefined ADL categories based on the Barthel index which assesses ADLs including (1) washing (2) mobility (3) (un)-dressing

(4) grooming (5) toileting, and (6) eating and drinking) [33]. This means that the researchers were especially mindful of events related to these ADL categories during the activities.

In the selective phase of our observations, we were looking at patterns of interactions, their meaning as well as the goals and motivations of those involved in the activities. Throughout this phase, as active participants, we used naturally occurring informal conversations to understand how participants attributed meaning to the activities and their environmental context. In the case of residents not being able to engage in conversations, we specifically focused on the non-verbal reactions and behavior of residents.

The first author performed most of the observations; the second author joined in one-third of the observations for purposes of mutual reflection and additional perspectives. After each observation, the authors briefly 'jotted' or sketched a record of the observed events in keywords into a journal they kept with them at all times. These were then processed into extensive and descriptive field notes as described by Emerson et al. [27].

For illustrative purposes, photos of some residents engaging in activities were taken with consent for publication from the residents or their formal representatives. Participatory observations took place in January and February 2022. Overall, we observed the residents for a total time of 89 hours.

*Semi-structured Interviews*

The perspective of nursing and activity staff as well as ward managers was explored in semi-structured interviews, enabling them to share their views, attitudes, interpretations, and opinions on the use of this environment. A topic guide was developed to guide the interviews which included questions targeted to the role of the participant, his or her experiences, and perceptions of the green care environment and its use. In relation to ADL, questions about the purpose of using this environment were asked, followed by questions on what this environment in return means for the daily life and ADLs of the residents. Questions were openly formulated leaving room for what the participants deemed important on how the environment is used to facilitate ADL. For instance, what is your view on the activities that take place in the green care environment? To what extent does the environment and the activities relate to daily care? Do you see a connection between the activities in the green care environment and the daily activities of the residents (washing, dressing, eating, drinking, mobility)? Moreover, we used examples of the observations to illustrate situations and to gather the interviewee's in-depth perspectives on these examples. We conducted two pilot interviews to get acquainted with the guide and adapt it where necessary. The interviews were conducted between June and September 2022. In total, ten interviews were conducted, which on average lasted 31 minutes ranging from 22 minutes to 40 minutes.

## Analysis

We inductively used our data using the thematic analytical approach by Clarke et al. [34]. We were furthermore guided by their 15-point checklist of criteria for good thematic analysis to increase the dependability of the results and maximize rigor (31). As a tool for coding our data, we used MAXQDA 2022 (VERBI Software, 2021). In our analysis, we used a stepwise approach was used starting with the field notes which were read in-depth and given a preliminary initial open coding layer. As examples from the field notes were used in the interviews, this step was necessary to get familiar with the data, to form an initial impression, and distill illustrative examples for deeper insights.

As a second step, we indicatively coded the interviews as well by generating initial open codes to the interview transcripts. We methodically examined the complete dataset, dedicating thorough attention to elements relevant to the research question. Once field notes and interviews were foreseen of an initial coding layer we proceeded to the third phase in which we shifted our focus to generating themes. We began by merging and matching codes to bring together all the important data extracts to identify overarching themes. As we understood relations between overarching themes, we concluded this phase with a set of potential themes and sub-themes, along with all the coded data extracts related to them. In the final phase of analysis, we reviewed and refined our themes by reviewing all codes based on their coherence and meaningfulness to the generated theme as well as judging whether the theme itself adequately represents the coded data. This included that in some instances we moved segments to other (sub) themes or new sub-themes were created until we were satisfied that themes adequately captured the contours of the coded data. Finally, we looked at the accuracy of our themes in relation to the data set as a whole and adjusted where necessary. We added a code tree describing our themes, subthemes, and examples of codes to Appendix 1.

To ensure accuracy in interpreting the data, a combination of consensus coding and split coding [35] was used. The same two pages of field notes and two interviews were openly coded by the first two authors, and the results were compared on a one-to-one basis. Once consensus was achieved on the initial data, the remaining data was divided equally between the first two authors to streamline the process. Furthermore, weekly meetings were held by the first two authors to continually compare new data with previously coded information. The codes and themes were collectively discussed by the research team in monthly meetings.

Attaining data saturation in ethnographic research can pose challenges, given the extensive data collected throughout the limited study period [36]. ). Moreover, the concept of data saturation has encountered increased criticism in qualitative research due to its inherent vagueness [37]. Consequently, the focus of this study was directed towards obtaining rich, contextualized data for the research setting

### Reflexivity

Reflexivity was increased by the first two authors, who kept reflective notes, before and after data collection, on their preferences and preconceptions. Especially rapid ethnography reflexivity can enhance team relationships and the caliber of the research output [38]. All members of the research team have a background in nursing home care with additional backgrounds in occupational therapy (SC), health economics (KR), nursing (SZ), psychology (HV, BdB), and physiotherapy (MB). Moreover, a part of the research team holds expertise in innovative care environments for persons living with dementia, for example, Green Care Farms (KR, HV, BdB). It is precisely this composition of backgrounds that has ensured an examination of identical data from various perspectives, identifying variations in interpretations through discussions. Regular research team meetings increased mutual reflection on the research background and previous work in clinical practice as well as own pre-conceptions on the use of the physical environment and affinity with animals and nature.

Looking at how the cultural background of researchers could have influenced the results, we consider the influence of language, and geographical region minimal since researchers and participants lived in a similar geographical region in the south of the Netherlands and or Germany. Regarding cultural values linked to the research question, we were aware of differing values of good care. For example, traditional care approaches might value safety and taking over activities over stimulating independence. However, since regular reflection on potential cultural influences was incorporated in the research meetings we consider this influence on our results minimal.

### Ethics

Ethical approval was gained from the Research Ethics Committee of Zuyderland (approval number METCZ20210138). In order to conduct the observations, we obtained written informed consent from the legal representatives of the residents, as the residents themselves were unable to provide formal consent due to cognitive limitations. For the interviews, the participating staff members signed informed consent during the interview. To prevent ethical issues for nursing home staff during observations, the presence of the researchers during the activities was communicated by mail within the nursing home, and the researchers introduced themselves and the studies’ aim to the staff members In addition, residents were always treated with respect and dignity by having the observers being integrated into the social context as much as possible.

## Results

The results section consists of three parts: 1) characteristics of the participants, 2) a consideration of the setting, and 3) identified themes from the thematic data analysis.

### Participants

Characteristics of participating residents who were mostly males are displayed in Table 2. These characteristics describe the variety in both diagnosis and age.

**Table 2** Characteristics of Participating Residents

| | Residents' main diagnosis in the wards | Residents participating | Mean age [range] | Gender (Male %) |
|---|---|---|---|---|
| Ward A | Geriatric psychiatric diagnoses* | 8 | 80.1 [73–92] | 33 |
| Ward B | Geriatric psychiatry diagnoses* | 2 | 57.5 [53–62] | 100 |
| Ward C | Korsakoff's disease | 1 | 76 | 0 |
| Ward D | Early-onset dementia (early and advanced stages) | 5 | 57.2 [50–68] | 80 |
| Ward F | Advanced dementia | 5 | 80.6 [75–91] | 40 |
| Ward G | Korsakoff's disease | 2 | 61 | 100 |
| Ward H | Korsakoff's disease | 2 | 65 [68–74] | 100 |
| Total | | 25 | 68,2 [50–91] | 57 |

* Common diagnoses found in these wards included schizophrenia, intellectual disabilities, various types of dementia, or bipolar disorder.

Staff characteristics are displayed in Table 3.

### Considering the Setting

#### *A Description of the Residents' ADL Care Needs and the Context*

Where residents with Korsakoff's disease were often younger and able to perform their ADLs with prompts and structural support, other residents, for instance, with severe dementia, fully depend on support in ADL. During the observations, differences in mobility among the 25 observed residents were noted. Where most residents were able to walk independently (n=11), a significant proportion used either a walker (n=4) or a wheelchair (n=8) or depended on physical assistance (n=2). Residents using a wheelchair were not able to use it themselves and depended on staff to be mobile. Depending on the ward, the residents used a shared bathroom. A toilet was present in each resident's single room. In each ward, residents share a dining- and living room, and a kitchen where residents share meals with and without support. Additionally, the facility includes a restaurant open for residents, staff, and visitors. Staff members regularly visited with residents after the scheduled activities outside.

Residents were allowed to move around inside the nursing home. To access the outside environment, residents depended on staff. Some residents were in possession of a key that opened the doors to the outside.

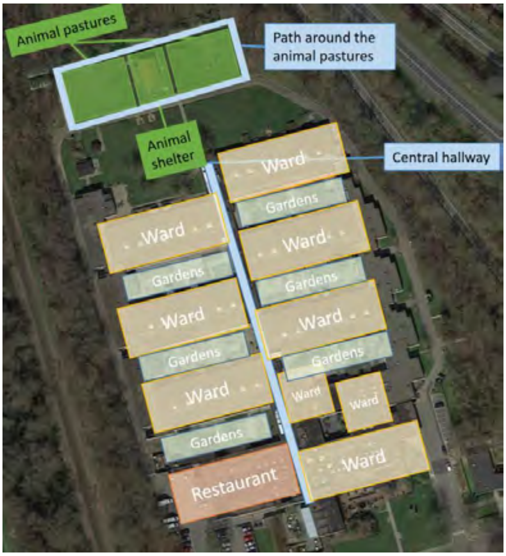
**Table 3** Characteristics of Care Staff Participating in Interviews (n=10)

| Participant * | Age | Gender | Position | Ward | How their position relates to the environment |
|---|---|---|---|---|---|
| **Nursing professionals** | | | | | |
| Gabrielle | 51 | Female | NA | F | Responsible for meal-time care |
| John | 28 | Male | CNA | D | Responsible CNA for two residents participating in activities |
| Liza | 47 | Female | CNA | G | Responsible CNA for two residents participating in the activities |
| Rose | 38 | Female | RN | F | Delivery and coordination of nursing care and identifying the residents' preferences |
| **Activity staff** | | | | | |
| Emma | 44 | Female | Activity staff | D | Cares for residents with advanced dementia using the environment |
| Jennifer | 24 | Female | Activity staff | F | Cares for residents with advanced dementia using the environment, participates in activities |
| **Other professions** | | | | | |
| Jess | 27 | Female | Social worker | - | Responsible for managing and coordinating the environment and activities with and around animals |
| **Managers** | | | | | |
| Ava | 49 | Female | Ward manager | A, F | Responsible for care delivered in wards |
| Monica | 63 | Female | Ward manager | D | Responsible for care delivered in wards' coordination volunteers and central coordination of activities throughout the LTRC home |
| Shelly | 59 | Female | Ward manager | G, H | Responsible for care delivered in wards and the creative workshop |

* Pseudonyms; NA: Nurse assistant, CNA: Certified Nursing Assistant, RN: Registered  Nurse

### *The Physical Green Care Environment*

The nursing home was entirely situated at ground floor level. Each ward had access to a small garden area where some residents grew flowers or vegetables. Additionally, a large park was shared by the entire nursing home. Here, an animal shelter was built a few years ago. The animals present included deer (n=4), goats (n=2), chickens (n=12), and geese (n=2). The animals lived in a fenced area of ca. 1600m$^2$ behind the nursing home to be reached by a paved path of ca. 80 meters (Figure 1). At the heart of this space stands a wooden house,



environment. Adapted from Map data ©2023 Google housing stables for chickens and goats, as well as storage for their feed. Encircling the fenced area, a path beckons residents, staff, and visitors for a leisurely stroll. Beyond the animal enclosure lies a gated forest. The wooden house and stable are also secured, with select employees and residents having access via a key. Figure 2 provides a visual representation of the physical components of this green care environment and its associated activities. With the goal of integrating the green care environment into the residents' daily routines, a variety of activities centered around the animal shelter was planned for each ward. An illustrative example of how the activities are planned is provided in Table 4. These activities were tailored to the specific ward, taking into account the residents' preferences and abilities, and included tasks such as visiting and interacting with the animals or helping with stable maintenance. The planning and execution of these activities were overseen by a social worker, with the assistance of activity staff and nursing professionals from the respective wards. The social worker was also responsible for the health and safety of the animals including vet appointments and the collaboration with local animal welfare authorities.

**Table 4** Example of Scheduled Activities With and Around Animals

| Time | Activity |
|---|---|
| 8:30 – 09:00 | Residents living with early-onset dementia feed the goats in their inside stable and let them outside to join the deer in grazing. Then residents feed hay to the deer outside, clean the water buckets, and refill them. Residents check for eggs in the chicken coop and collect them, often taking them to their ward for breakfast. |
| 10:30 – 12:00 | People living with advanced dementia engage in a 'Cuddle activity'. They first take a walk to the animals and have a drink there. Residents prepare fresh food for the animals (apples, carrots) and feed them.<br>Some residents engage in 'farm-like' activities based on their interests and use the broom to clean the premises. |
| 13:30 – 15:00 | Residents with Korsakoff's disease clean the inside pens for chickens and goats. Exchanging straw, and hay and cleaning the floor with water. Carrying the dirty straw outside with a wheelbarrow (ca. 4 wheelbarrows).<br>Cleaning the outside premises, sweeping the deer and goat manure, collecting the dirt in a wheelbarrow, and emptying the wheelbarrow in a container 85 meters away from the stables. |
| 15:00 – 16:30 | Residents with Korsakoff's disease care for plants outside the animal premises, or do construction work (e.g. fences, building hotels for insects) |
| 16:30 – 17:00 | Residents living with early-onset dementia bring the goats to their inside stables and feed them. Checking on all animals before nighttime. |

## Themes Identified Based on Thematic Analysis

The thematic data analysis revealed four themes: (1) The (in)visibility of ADL, (2) Reciprocal care dynamics: Fostering ADL performance through connection and teamwork, (3) Seized and missed opportunities for meaningful integration of ADL in the physical green care environment, and (4) Professional fulfillment and ADL task obligation: Views from staff and management.

**Picture 1: The Outside Environment Including Animals**
Inside the wooden house, there are stables and storage facilities. Beyond the confines, there's a fenced area where animals can graze. The image captures a resident tending to the animals by bringing water, a task necessitated by frozen water pipes.

**Picture 2: Feeding Apples to the Goats**
A resident in a wheelchair is offering bite-sized pieces of apples to the goats, which were prepared beforehand by residents with dementia.

**Picture 3: Filling the Hayrack Outside**
A resident, who normally relies on a walker for mobility, is replenishing the hayrack for the deer and goats.

**Picture 4: Spreading Straw in the Indoor Goat Pen**
After a different group of residents cleaned the pen, this resident spreads fresh straw in the indoor goat stable.

**Figure 2** Impressions of the Green Care Environment and Its Use (Residents and formal representatives agreed to take and publish these photos in the way they are displayed.)

### *Theme 1: The (In)visibility of ADL*

The theme (In)visibility of ADL is characterized by the tension of ADLs being visible to observers as an integral part of the organized activity within the green care environment. Subthemes include the 'Visibility of ADL and before, during, and after activities' as well as 'Invisible Aspects of ADL within and beyond activities'.

The initial theme highlighted a contrast in how ADLs were visible in the context of the physical environment. ADLs were quite noticeable prior, during, and after activities. For example, prior to the activity when residents get dressed appropriately according to the weather, putting on jackets and suitable footwear. This resulted in additional ADL care moments for those residents participating in activities. Residents diagnosed with Korsakoff's disease, who participated in the stable cleaning, were provided with specialized work clothing, which mandated a full change before engaging in the tasks. It also became evident that the frequency and scheduling of activities such as shower times were adjusted to align with the scheduled activities in the green care environment.
The findings showed how perceived benefits of the green care environment use appeared to extend themselves to periods before or after activities. In the context of ADL morning care, one of the staff members even mentioned how the animals seemed to motivate some residents to get up in the morning:

*"They always get up for the animals in the morning. […]. I've rarely experienced residents not going. Whereas to activities like the carpenter workshop or choir, they often say, 'No, I'm not coming.' […]. Of course, the animals also need to eat and that's also important and I think they have that in the back of their minds, I mean of course, the animals will still get food if they don't go with them, but I still think it's a feeling inside and they also just like it.*" [John, CNA, l.115-118]

It was observed that residents with dementia are more able to voice their ADL needs after activities, as noted by a ward manager:

*"I just saw these residents coming back from visiting the animals. And when I normally ask her [a resident] something, there's no response. Now she can indicate to me that she is thirsty after visiting the animals. And then I find it really special that she can indicate to me that she is thirsty."* [Monica, Ward manager, l.287-290]

During the activities, the green care environment also encouraged residents to prepare and eat food such as apples, drink tea or coffee, and to engage in more demanding, mobility-related ADLs. Residents who were able to walk covered significant distances during the activities, including walks from the ward to the animal shelter and back, as well as engaging in physical activity when for example cleaning the stables, getting hay, and emptying the wheelbarrow. One of the residents was very aware of the physical benefits of helping in the animal shelter and even applied advice from his therapist:

*"My physiotherapist always says how I need to avoid rotating movements because of my hip. This is why I clean the stables like this [resident moves around using small steps]."* [Fieldnote extract]

After the activities, ADLs such as washing hands or undressing were observed regularly. For example, residents were encouraged to wash their hands or to clean their shoes using a built-in shoe brush before re-entering the building. Depending on the work the residents did, they were encouraged to shower afterward.

Regardless of the number and clear presence of ADLs, the topic seemed less visible when talking to staff members, as the subtheme invisible aspects of ADL within and beyond activities' highlights. Although some staff members perceived the use of the green care environment as beneficial in terms of prevention of physical decline or being overweight, most described it solely as a valuable asset for residents to have meaningful activities, a work-life structure, or moments of relaxation. The researchers observed moments where some staff members used the animal shelter to eat together with residents and carried food and drinks to eat on a terrace in front of the stable.

*"While sitting on a bench a staff member arrives on a 'duo-bike' where she and a female resident can ride the bike next to each other. We engage in small talk on the weather and when I ask what she will be up to, she explains how she took some sandwiches for the resident to eat while watching the animals. According to her, the resident will eat more when looking at the animals. Inside the ward, they struggle to achieve a sufficient food intake for this resident. That's why they sometimes have lunch outside near the animals."* [Fieldnote extract]

Nevertheless, in the majority of cases, the perceived aim and objective of utilizing the environment were identified as 'being outdoors,', 'a sense of purpose and meaning', 'alleviating agitation,' or 'providing structure' and' social connectedness' or 'intentionally engaging residents'. Enhancing ADLs was not generally recognized as one of the purposes of utilizing the green care environment.

*Theme 2: Reciprocal Care Dynamics: Fostering ADL Performance Through Connection and Teamwork*

Theme 2 illustrates the social and relational components of the use of the green care environment especially between residents and staff. It is defined by the subthemes 'Strengthening the care relationship within and beyond green care activities' and 'Reciprocity through equality and expertise'.

As part of the subtheme 'Strengthening the care relationship within and beyond green care activities', staff described how using the environment gives them an easier entry point to have conversations with the residents about their day and their interests. This conversation starter made it easier for residents to share their concerns and preferences, which in the experience of staff members, strengthened the care relationship. In some cases, the use of the green care environment built a relationship, which had a direct influence on ADL morning care. An activity staff member described how the use of the environment allowed her to support a resident with dementia and complex care needs in ADL care activities whereas the resident refused care from other nursing professionals:

*"This lady refused all activities and care [...] she is very distrustful of everything and everyone and you then have to work towards it very slowly and try to build a bond and little by little I was able to go to the animal shelter. In the beginning, she went along grumbling reluctantly, but from the first moment she has been in there she brightens up and talks to the animals [...] the look becomes milder in the face […] and the eyes start to shine, she starts to talk to the animals she starts to pet the animals...[...]. And so I found an entrance to be able to take care of her and shower her. Each time step by step and after showering we went to the animals together and at some point, she started linking that so every time I went to groom her, she asked if we were going to see the deer again."* [Emma, activity staff, l.52-71]

The green care environment allowed for shared positive moments where there is room for humor and jokes on the one hand but also reactions of residents who enjoy being outside and around animals. In the observed activities, staff members took the time to wrap up activities by spending time together outside or in the restaurant while talking, smoking a cigarette, or enjoying a cup of coffee. In interviews, staff members explained that experiencing these moments helped them to foster a relationship beyond the intimate care environments or situations in which residents were expected to perform or behave in a certain way.

As a result, the subtheme 'Reciprocity through equality and expertise' highlights how using the green care environment and caring for animals together reduced hierarchical structures during the activities since both parties care for a third party, the animals. Observed staff members equally engaged in activities such as cleaning the chicken pen or stables next to residents as this nursing professional explains:

*"And I mean I lay on my knees just as much, maybe even worse. It does encourage them to do everything together. That's super fun though. […] And the feeling like you still belong, I think is especially important, because you may suffer from a disease, but about everything that happened in the past, I don't judge, because that's not what I'm here for. You just have to be here and now and are responsible for taking care of yourself. Now and then when we take a break, I show a picture of my children or my grandchildren or a crazy movie or a joke from Facebook to them and then we have a good laugh. They love that, because then we are equal, and I am not their boss, because that is sometimes said: 'Yes that she is the boss,' and then I say, 'A dog has a boss, you don't have a boss.'"* [Liza, CNA, l. 264-271]

Residents were observed to use their talents and expertise. Several residents participating in the activities had a background in farming and advised staff members on, for example, how to build a fence or how to best catch a chicken when they need medication. In this reciprocal relationship, ‘traditional’ gender roles appear to facilitate the use of the environment. Male residents were observed to see themselves as the persons who have to be of assistance to female care staff as described by a nursing professional:

*“You are then going to put them in a certain role anyway. That you indeed say like, ‘Tom, can help me with that?’ You know like that and that works. With men that works! And in that respect, you often have an advantage as a woman here. Sometimes you don’t, and sometimes you do. It’s just the way it is.”* [Liza, CNA, l.466-468]

Hence, the environment enhanced reciprocity in the care relationship as residents care for others instead of being cared for**.** The observations revealed how residents who gave the impression of being passive and agitated in the living room eagerly engaged in activities for the animals. Verbal reactions and facial expressions indicate joy when animals react positively to them being fed and cared for. As observed in the following field note, a resident with dementia explains how he shared his new role with his daughter.

*“The resident explains how he calls his daughter every morning at 10 a.m. and yesterday he told her that he was going to take care of the animals today. His daughter just really enjoys hearing this he tells proudly. He looks at the ladies [residents] around him and smiles.”* [Fieldnote extract]

### *Theme 3: Seized and Missed Opportunities for Meaningful Integration of ADL in the Physical Green Care Environment*

The third theme demonstrated how the green care environment was used to create a meaningful integration of the environment with resident needs and skills. It is therefore divided into the subtheme: ‘Seized opportunities by meaningful integration’ and ‘Missed opportunities for resident involvement and integration’.

Generally, how the green care environment was used by the organization depended on the needs and goals of the residents living in a particular ward. The use of the environment was tailored towards different needs including structure and work character for people with Korsakoff’s disease, a moment of rest for the agitated resident with dementia, or purposeful movement under supervision for the residents with mobility problems.

Seized opportunities for meaningful ADL performance were identified when staff members were mindful of the residents’ needs and skills as well as how the environment contributed to that as the following example illustrates:

*“A staff member asks a group of six residents with dementia sitting around a table outside the animal shelter who wants to cut an apple for the animals. The residents do not respond. A colleague grabs a cutting board, a kitchen knife, a bowl, and an apple. She puts*

*these things in front of a resident and cuts the apple in half. The resident takes an apple in one hand and the knife in the other and begins to cut off pieces. In the hand holding the knife he also holds the cut-off piece of the apple, which the resident then brings to his mouth. This brings the knife close to his mouth, but the activity looks safe and he enjoys his apple considerably."* [Fieldnote extract]

Hence, the use of the environment was directly linked to ADL performance if staff members saw and seized the opportunities.

Results showed how different staff members took different approaches in using this environment and identifying key strategies. Staff members explained how using the green care environment requires a certain amount of courage or 'guts' to experiment with how the environment works for different individual residents. Some staff members indicated how using the environment also results in positive experiences for the residents who never had any interest in nature or animals in the past. Trial and error were identified as a strategy by the staff to maximize the use of the environment, especially for residents who struggle to communicate verbally, as this nurse assistant describes:

*"Just trying. Just try it. And if the effect is nothing or you notice that it doesn't seem to be working, then try a spin on it. Because last week it had gone outside with someone. And they didn't like it at all. Then I went with her for coffee in the restaurant. And she talked so much. Yes, and then I think, look at that! It does depend. I mean, they can't say what they want themselves. So you also just have to try to figure out what would be the best thing we could do?"* [Gabrielle, nurse assistant, l. 80-83]

Trial and error as a strategy also implied that staff members take a certain risk with the residents. For instance, the risk of the residents not enjoying the activity or being afraid of the animals on the one hand, and the risk of being exposed to the potential to fall or eat the chicken feed. At the same time, staff members saw how the risk is worth taking in light of the benefits the residents experience from this environment. Staff members described situations in which agitated residents verbally and non-verbally experience joy and fulfillment from these activities or how residents tell them how this environment gives them a purpose. Other staff members observed how sometimes residents appear 'overstimulated' or change their mood quickly when they enjoy being in the green care environment.

Sometimes opportunities for resident involvement in ADLs are missed especially before and after scheduled activities where (un)dressing or washing hands was taken over by staff. These activities seemed not to be seen as part of the animal activity but rather as a necessary and quickly performed task. For instance, by using wet wipes for cleaning the hands of the residents, staff members in several observed instances choose convenience over active facilitation of ADL performance:

*"After feeding and petting the animals at the animal enclosure, a staff member discusses with her colleagues how we can best wash the residents' hands. She thinks it is more convenient to do this on the ward because people are cold. [...] Inside the living room, the other residents are still in the same places as we found them. [...] We stay in the middle of the living room and a moment later, a staff member comes with wet wipes to clean the hands of sir. For each resident who joined us, the care worker wipes their hands."* [Fieldnote extract]

*Theme 4: Professional Fulfillment and ADL Task Obligation: Views from Staff and Management*

Theme 4 described how the use of the environment was perceived by different staff members in relation to their professional fulfillment and task obligation. This theme is divided into the subthemes 'Professional fulfillment by creating shared moments of joy', 'Task-oriented view on care', and 'Management perspectives on integrating the environment in daily care'.

As part of the theme of 'Professional fulfillment by creating shared moments of joy', staff members including nursing and activity staff explained how the use of the environment contributes to their professional fulfillment, especially when resident experiences are positive. They described how creating positive and meaningful moments for residents by using this environment makes them feel satisfied when they get home from work. As the following nurse assistant illustrates, staff members enjoy seeing residents happy especially since these moments are sparse and often fade away once the residents return to the inside environment.

*"I feel that, more often than not, it [positive feeling of residents] has receded into the background. That's only very brief moment of happiness. I just call it happiness, because that is what it is. It's very short and when I'm inside, I often notice that the feeling has faded again. But did the residents enjoy it? I think so. And those small, short moments are very important. That's what you do it for. [...] That was so beautiful! Sometimes, in a moment like that, if they're happy, then I'm happy too. Then I know, I've done well and I think it's also not just effort or difficult at that moment, but you also gain so much from it!"* [Gabrielle, nurse assistant]

While the common experience of using the environment is positive among the staff members who use it, the subtheme 'Task-oriented view on care' illustrates perspectives across all interviewed staff differed on whether the use of the environment feels part of their role and task obligation. Some nursing professionals considered using the environment as part of their job to assist residents in all activities including using the green care environment. Other nursing professionals saw their role in creating 'small' meaningful or person-centered moments within the inside 'traditional ADL environment' including baths and bedrooms rather than the green care environment. This nursing professional explained that she saw a clear difference between the tasks and responsibilities of nursing professionals and those of the activity staff.

*“I think activity staff is responsible for the bigger activities where we sometimes are scheduled to participate in. I think we are responsible for those little extra moments. That one-on-one moment. It doesn’t even have to be very big activities, but yes, a glass of wine or an eggnog, you know is something already. Or indeed doing the nails for the ladies on the ward, which is just something very small because it might only take five minutes. […]. Those are just really those little moments already, which is enough for them and I think that’s often forgotten.[…] So I think the care staff are a bit more focused on that and activity staff is really more focused on the bigger things.”* [Rose, RN, l.250-258]

Moreover, the quote shows the nurses’ task-oriented view on their role in assisting residents in their daily lives. Staff members differed in perception on whether the use of the environment was viewed as a separate task or an opportunity to stimulate abilities or brighten the day of the residents appears to limit its potential in practice. Hence, other staff members observed a variety of task obligations among their colleagues. They would see more nursing professionals involved in the activities within the green care environment. With the increased engagement of nursing professionals, they hoped more residents could benefit from this environment. At the same time, activity staff at instances feel left alone with activating and encouraging residents to use green care environment, which has caused some staff members to become disheartened.

The final subtheme “Management perspectives on integrating the environment in daily care” highlights how ward managers acknowledged the different perceptions and encouraged nursing professionals to seize the opportunities of the green care environment for the benefit of the residents and their own job satisfaction, as stated in one of the interviews:

*“Activity staff are doing this now [activities with animals]. Yes, and I do see them struggling sometimes and they hope that nursing colleagues will pick this up as well. And that just has to do with your team. That’s also what I say: Make your job fun! How much fun is it? Even if you’re a CNA or a registered nurse, you can think I take three residents and I’m going to go to the animals. Come out from behind your computer and also make it fun for yourself to then go with three residents and see them enjoying themselves.”* [Monica, ward manager, l.142-150]

At the same time, staff members and managers acknowledged how the outside environment especially being in contact with animals is not for everyone. Some staff members were afraid of particular animals or simply preferred to stay inside. Managers saw how optimizing care and the use of the environment required a change in attitude and competencies in staff. These changes are especially needed to perform care and environment use in a person-centered way.

The required change is also visible in the way different wards engage in the green care environment and the responsibilities they take on and are able to manage. Results showed how some wards took responsibility for maintaining the green care environment and others did not. An often-mentioned key player in creating shared responsibility in staff across wards and ensuring quality was the social worker of the nursing home. Across wards, managers, direct care workers, and activity staff stressed how the social worker's enthusiasm and organizing skills led to an increased use of the environment. However, as one of the managers explained, it was their role to ensure continuity in using and sustaining an integrated use of this environment in collaboration with the social worker:

*"Sometimes I do think, that's also up to me, that I also said to her [the social worker] you should just join a ward meeting again, to tell about it very briefly, even if it's for 10 minutes, to get that mindset in fellow workers, huh? That's very often, we have so much to offer […] and sometimes that's just forgotten in that day-to-day grind. When reminded, staff members think to employees it's 'Oh yes, yes, of course, I can use this or that again'."* [Monica, ward manager, l.317-321]

## Discussion

This study showed how meaningful opportunities for engaging in ADL performance arise before, during, and after activities in the green care environment, and how responsibilities like caring for animals motivate engagement and activity. The environment also fosters a reciprocal care relationship between the residents and the staff. However, there are differing opinions among the staff and management on integrating this environment into daily routines. This study was, to the best of our knowledge, the first to explore how the physical green care environment is used to support the ADL performance of nursing home residents.

This study illuminated the potential of a green care environment potentially affecting the residents' abilities of ADL performance. Literature on innovative care environments indicates that opportunities for involvement in activities might be a promising element of maintaining and increasing ADL dependence [20]. Green care environments strongly advocate for resident involvement with meaningfulness as a core mechanism for empowerment [39] Meaningfulness can be achieved by a purposeful use of the physical environment [40]. The significance of outdoor activities in the green care environment, a coherent integration between these activities, and direct care activities such as ADL creates meaningful opportunities to be explored in further research. Our findings indicate that ADLs are an integrated part of the scheduled activities, within the green care environment throughout various stages (e.g. getting dressed before activity or washing hands afterward). However, they tend to be overlooked. Direct hands-on ADL care seems to become less prominent in a green care setting as the focus shifts from an indoor, care-centric setting to a more outdoor, productivity-oriented one. As an illustration, tasks like feeding the animals take center stage, while activities related to mobility or handwashing tend to recede into the background and may be at risk of being unnoticed. While this transition is not necessarily negative, this situation could potentially lead to residents missing out on opportunities to actively engage and maintain their functional ADL abilities within a unique and innovative setting.

Considering the potential benefits a green care environment and its animals might have on the residents, more and more nursing homes have integrated them into their facilities [41, 42]. This study shows how staff members play an important role in seizing opportunities within the physical green care environment to facilitate ADL. When integrating fundamental elements of nursing care such as ADLs in a specific context, it is crucial to view ADLs not solely as addressing physical necessities (such as eating, toileting, or personal hygiene) but also as recognizing the psychosocial needs of individuals with dementia (e.g. considerations of dignity, involvement, and information) in the provision of nursing care [43]. This entails that more and more nursing homes expand their definition of 'care' beyond the fulfillment of physical needs and pay attention to psychosocial elements of care provision [44, 45]. This is in line with previous research in dementia care, equally recognizing the social and organizational environment next to the often more obvious changes in the physical environment [46, 47]. For example, while most interview participants valued the animal shelter and enjoyed cleaning stables together with the residents, they also mentioned that not all colleagues had an affinity with animals. Here, staff members, as part of the social environment, substantially impact the success of the physical environment. As they play a central role in care delivery, their work environment is of crucial importance for the quality of care delivered [48, 49]. Consequently, the changes resulting from an innovation in their work environment have to be recognized as well.

With this comes an often underestimated, changed understanding of the role of staff members, for example, demonstrated in earlier studies on 'Shabazim' – the staff members in Green Houses for people with care needs [50-52]. Here, staff members are seen as companions in the daily life of residents, where the laundry, meal planning, and joint coffee breaks are an equally important part of their tasks as the care delivery. Where especially nursing staff members perceive their role as merely task-focused, specifically in ADL nursing [5], the organization might have to adapt routines nudging staff members towards integrating the activities in a desired context or change the workforce – posing difficulties in times of scarcity of qualified personnel. Qualities or competencies of staff members as described by de Boer et al. [53] aid in integrating activities for residents into daily practice while being able to take multiple responsibilities within and beyond care activities. This shows how organizational decisions to change the physical environment might not be successful without similarly acknowledging the social and also organizational environment of the organization.

### Limitations

This study has certain limitations. First, although informal conversations were held with residents during observations, their perspectives were not specifically explored in more in-depth discussions or interviews. This could potentially have led to an underrepresentation of the residents' viewpoints as to how they view the use of the environment and their ADL care experience. Second, despite striving for variety in experiences and professions, for instance in selecting staff members for the interviews, it could, of course, have been the case that there are other critical staff members we did not hear. Those who willingly participate in research and enjoy discussing it may hold a more positive outlook compared to those who may be more hesitant to engage in such discussions.

### Implications for Further Research

Given the specific focus of this study, it is recommended to explore more comprehensive qualitative ethnographic research. Further research should concentrate on various types of outdoor environments, extending the duration beyond specific animal-related activities to encompass morning care and other ADL moments throughout the day. Although some demographic characteristics were considered in the current study, this could be enhanced in future studies. Hence, certain biographical data might impact the role an environment has on an individual. For example, aspects such as having an agricultural background, or having an affinity with animals and the outdoors might facilitate the impact of the environment on ADL functioning. This is especially the case when considering the impact of the role of an outdoor environment. Moreover, it would be valuable to conduct systematic experimental research to determine whether utilizing the environment actually improves ADL functioning over time.

## Conclusions

Our findings suggest that the physical green care environment carries the potential to increase. ADL performance. We found that activities within this environment increase opportunities for ADL performance and care before, during, and after activities. Moreover, using this green care environment can motivate the residents to engage in purposeful activities and increase reciprocity in staff-resident relationships. However, there are differing opinions among staff and management on its integration into the residents' lives and care.

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# Appendix

## Appendix 1: Code Tree

## Appendix 1: Code Tree

| Data-Extracts | Code Examples | Subthemes | Themes |
|---|---|---|---|
| The activity staff member brings Mr. and Mrs.'s coats, and together we help them put on their coats. Both Mr. and Mrs. are seated in wheelchairs, so we ask both of them to lean forward in order to put on the coats. [Fieldnote extract]<br>The resident takes off his Birkenstocks and puts socks on his feet. For this, He leans forward in the chair and tries to lift his leg. Judging by his strained facial expression, this proves to be quite challenging for him, but he manages independently. After putting on both socks, he puts the Birkenstocks back on. I ask if it's not too cold for his feet. He indicates that it's fine and proceeds to put on a hat." [Fieldnote extract] | Getting dressed before going outside | Visibility of ADLs before during and after activities | Theme 1: The (In)visibility of ADL |
| As we walk to the animals, the resident and I and talk about how quiet it is on the ward and how you can see fewer and fewer people through the windows. 'They must all be lying in front of the TV,' he says 'not running around like crazy as we are out here,' he adds with a smile." [Fieldnote extract]<br>"A resident and I stand two meters away, waiting for the goats to come out. They seem a bit cautious at first but decide to leave their stable. A staff member walks ahead outside, and he follows with the walker to guide the goats outside." [Fieldnote extract] | Being physically active and mobile during activities | | |
| Right before the entrance, there is a device with brushes for cleaning shoes. The resident independently uses this to clean his shoes. To do this, he stands on one leg while wiping his shoes on the brushes with the other leg. He keeps one hand on the wall next to the entrance for support. Marco seems to take this task seriously and cleans each shoe on the brushes at least 10 times. [Fieldnote extract] | Cleaning oneself after the activity | | |
| You also have something to go to, right? I: and then it's not like, "come, let's go outside." No, but "come, let's go to the animals." That sounds very different. Or then you have a goal, you have a goal, right? A destination. [Interview transcript]<br>Aren't you going to the gym, swimming...? Indeed, when you work in a structured department, like here in the Korsakov unit, people are used to structure. If we leave people with Korsakov to themselves, they'll stay in bed all day. Simple. Yes, so you try indeed. to stimulate people to do something. [Interview transcript] | Perceived purpose and goals of using the environment | Invisible ADLs | |
| I am the responsible caregiver for two residents in [this ward], and both of them go to the animals, and spending some time there is also important. Suppose they don't feel like talking—I usually let them be. If they don't feel like it, they don't feel like it. However, I can easily find an entry point by bringing up the animals, the plants, or the birds, and then I can usually start a conversation." [Interview transcript] | Easier entry point for conversations | Strengthening the care relationship | |

| | | | |
|---|---|---|---|
| And so, I have found a way to take care of her, to take her for a shower. Every time, little by little, and after showering, we would go to the animals together. At some point, she started associating it, so every time I went to take care of her, she would ask if we were going to the deer. [Interview transcript] | The strengthened relationship within and beyond intimate ADL care | | Theme 2: Reciprocal Care Dynamics: Fostering ADL Performance Through Connection and Teamwork |
| They are not unintelligent people; they used to function just fine before. It's not like they've lost all of that," he would say to me. "I wouldn't do that yet," he said, so I responded, "Yes, you're absolutely right! How clever of you; I hadn't even thought about that. [Interview transcript] | Using residents talents and expertise | Reciprocity | |
| Especially in this setting. That's also something I observe. Residents are often taken care of a lot. And then it's precisely the other way around. [Interview transcript] | Reduced hierarchical structures | | |
| A staff member asks if he wants to do it himself or if she should lend a hand. The resident. indicates that she should help. [Fieldnote extract]<br>A staff member stands next to a resident and places the cutting board, 2 knives, 2 apples, and 1 bowl on the table in front of him, and slices the first apple in half with a kitchen knife. She then addresses him directly and asks him if he would like to cut apples for the animals. He takes an apple in one hand and the knife in the other, starting to cut pieces from it. The piece of apple ends up in the hand holding the knife, which he then brings to his mouth. This brings the knife close to his mouth, but the action appears safe, and he greatly enjoys his apple. [Fieldnote extract] | Integration of environment, purpose, and resident capabilities | Seized opportunities | Theme 3: Seized and Missed Opportunities for Meaningful Integration of ADL in the Physical Green Care Environment |
| In one corner of the room, three staff members are sitting and having a meeting. Two other staff members are in the kitchen, washing dishes. A staff member  hands me a coat and asks me to put it on a female resident while she, along with another colleague, is putting coat on a residents in wheelchairs [Fieldnote extract]<br>A staff member with moist wipes to clean the residents' hands. For each resident who has come along, the caregiver cleans their hands with the moist wipes. [Fieldnote extract] | Not involving residents in activities, taking over | Missed opportunities | |
| What do I think about it, hmm... what it means to me... well, that's what it's all about, you know. When you see them coming in from their home situation, not wanting or accepting anything, and then, with very small steps, you can ultimately achieve this, well then I think 'I'm in the right place,' and that's actually the icing on the cake. That's what you do it for. [Interview transcript]<br>Because, in the end, you're doing it all for... quality time or just for more beautiful moments or something like that.. [Interview transcript]<br>"Due to workload, but also just, you know, sometimes you just don't order something, so that even something small is actually sufficient. Just that moment, that small moment. And I think that's something we need to become more aware of. It's | That's what you do it for | Professional fulfillment by creating shared moments of joy | |

| | | | |
|---|---|---|---|
| just nice that an animal enclosure has been added, and you can just see that a resident becomes much happier because of it. And seeing themselves in the photo, last week I showed him the pictures where he's holding the chicken: 'Ah, that's me' (laughs). P: And then it's- that sense of pride, you know, just that moment back, that recognition. And then you see that, the laughter, and you think, that's what you do it for. So, yes, you definitely see the effect of activities on the behavior of residents. And if you can do just one activity and don't have to resort to medication, that's certainly an advantage as well." [Interview transcript] | | | Theme 4: Professional Fulfillment and ADL Task Obligation: Views from Staff and Management |
| And do you see the animal enclosure as something [big or small]? Is it a small addition or is it really something bigger just because it's a bit further away? We talk about those small things and big activities where the activity staff is mainly responsible. Does the animal enclosure fall somewhere in between, or do you say that it's really something big, you don't use it as easily as just painting someone's nails, for example?"<br>Yeah, it's just here, very black and white thinking, you're activity staff so you're meant for that, that's just how it is. And yes, it's ingrained, and I've advocated for it a lot, but you just can't get it out. And sometimes it's a shame [...]it's quickly said, 'Why did you go there? That's not your task, and you were needed here, and I wasn't needed here because there was nothing here.' So, yeah, new people are discouraged, and then they won't do it anymore. And that's so unfortunate. I think, I can damn well do it, you know? There are people who still see it, and then it's dismissed or like, no. I find that unfortunate. [Interview transcript]<br>How should I say it? It's all so, a bit stuck, can I say that? Stuck in a rut, that you're standing there, and for the rest, you just stay there. And no, that's not going to work. Last week, I really said, listen, I am a care assistant! I say it, the part about individual attention for people is sometimes forgotten here. And that's what I'm here for. [...] And that's what appealed to me about the job. To do that, because it's a bit of attention they don't get. To still give that, I find that very important. [Interview transcript] | Role/identity conflict staff members | Task-oriented view on care | |
| And then, of course, it was like... Okay, you know, you're admitted to the nursing home. Well, then you leave your entire identity and personality outside the door, and you get admitted. Well, that's how we do it here. And then you completely embrace the whole nursing home ideas, the clinical aspect. And now, of course, we look at it very differently. But that requires a shift for employees. We have employees here who have been working for 30 years. And that really demands a turnaround. [Interview transcript] | | Management perspectives on integrating the environment in daily care | |

# Part II

# Providing and Pilot Implementing Practical Guidance

# Chapter 5

# The ADL Nursing Guideline

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Derived from the original Dutch article, translated for this dissertation.

This article relies on the Nursing Guideline for Care in Activities of Daily Living, which can be found in Dutch on the V&VN website.

Activities of Daily Living (ADL) are routine daily tasks that are a prerequisite for being able to function independently and participate in society, for example, washing, dressing and undressing, eating and drinking, getting in and out of bed, walking, and exercising. Given the importance of ADL, it is not surprising that supporting ADL is one of the most common forms of care provided by caregivers and nurses. For example, 50% of hospitalized patients have trouble getting dressed, undressed, and washing [1]. In long-term care, the level of assistance provided by nurses and caregivers in ADL is significantly higher. During one or more episodes of assistance and/or support with ADL, more than 90% receive care at home or in a nursing home [2, 3]. A characteristic feature of ADL care is its generic nature; it is not connected to specific conditions or specific care settings. Moreover, almost everyone experiences ADL support at some point in their lives, whether it be at home, in a hospital, during rehabilitation, or in long-term residential care facilities.

Even though ADL is at the core of care receivers' needs, it is undervalued and frequently treated as "part of the job," where nursing professionals spend as little time as possible on ADL care. On the contrary, the reality is that quality ADL care aims to encourage and support the user to pick up ADLs as quickly as possible and contributes to the maintenance and restoration of physical, social, and psychological functioning. In doing so nursing professionals play a crucial role in maintaining ADL independence, preventing and restoring limitations in ADL, and promoting autonomy. Despite being at the heart of nursing practice and having a significant impact on care receivers' functioning, there is less scientific evidence of ADL care. Hence, Maastricht University began developing the guideline on ADL nursing care in 2018 on behalf of the Dutch National Association of Nursing Professionals (V&VN) and ZonMw, working closely with healthcare professionals, caregivers, and their loved ones. The guideline was created to give nurses the resources they need to deliver high-quality ADL care. The guideline is intended for all situations where (older) adults get ADL care from registered nurses and certified nursing assistants. Based on common operationalization [2-4] this guideline defines ADL care according to a set of individual activities (Table 1). These include activities such as washing, dressing and undressing, toileting, grooming, indoor mobility, and eating and drinking.

## ADL Guideline Development

Several qualitative and quantitative research methods, such as literature review, expert group meetings, and questionnaires, were utilized throughout the ADL guideline development process. The requirements of the Dutch Health Care Institute and the Guideline for Quality Standards provide a standardized methodology for drafting quality standards. This guideline was developed following the guideline of the AQUA Advisory and Expert Group of Quality Standards [5]. This AQUA methodology gives structure to the guideline development process to increase uniformity and quality of guideline development for guideline users.

**Table 1** Operationalization of Activities of Daily Living (ADLs)

| Aspect of ADL | Associated (sub-)activities |
|---|---|
| 1. Washing | Washing at a sink or on the bed with a washcloth, for example, bathing, showering, drying (parts of the body). |
| 2. Undressing | Dressing and undressing garments and/or compression stockings. |
| 3. Toileting | Going to, and safely using, the toilet: undressing, sitting down on the toilet, defecating (urine and feces), cleaning oneself after use, flushing the toilet, getting up, dressing, using and handling incontinence materials, menstrual hygiene.<br>Use of toilet alternatives: toilet chair (shower or post chair), bedpan, urinal, menstrual hygiene. |
| 4. Grooming | Taking care of own appearance, including brushing teeth or caring for teeth, usual care of finger- and toenails (nail clipping), care of hair (combing, drying, use of products), skin care (use of lotions or creams), and use of makeup or other products. |
| 5. Indoor mobility | Moving around the home, transfers, positioning in bed or (wheel) chair, climbing stairs, and use of walking aids. |
| 6. Eating and drinking | Bringing (prepared) food or drink to the mouth, handling (adapted) cutlery or cups. |

The analysis of the problem is the primary goal of the development phase. To identify what challenges in ADL care exist, discussions were held in groups of 4–5 people according to a world café method [6]. In several rounds in which the composition changed, discussions included caregivers, nurses, informal caregivers, caregivers, occupational and physical therapists, and educational experts. To identify existing bottlenecks in ADL care, literature was also consulted. The gathered data formed the central starting questions, which were then refined and prioritized in the working group consisting of mandated caregivers from different sectors and (representatives of) caregivers.

Guidelines for nursing care focus on highly practice-relevant complex care issues. Guideline questions are preferably answered based on scientific literature. Ideally, the results from the selected literature are assessed and presented for each outcome measure following the Grading of Recommendations Assessment, Development, and Evaluation methodology [7]. This is a method for weighing the evidence base of the literature and the resulting recommendations. However, nursing care in ADL is “weakly” substantiated in the scientific literature [8-10]. In the nursing field, to date, only a limited number of randomized controlled trials (RCTs) have been conducted in this research area and the emphasis is on observational and qualitative studies [8]. More than in other fields, baseline questions often cannot be answered using literature on effectiveness. Guidelines in nursing often focus on highly practice-relevant complex care problems (e.g., Overburdened Informal Care; documentation). This makes the application of the AQUA methodology less feasible for some guidelines in care such as the current guideline on ADL care. However, when effectiveness is not central to the guideline question, literature beyond classic RCTs or literature from adjacent fields needs to be used. Therefore, in addition to identifying scientific literature, the experience and expertise of members of the working group, and information from related sources (e.g., guidelines on informal care and reporting) played a crucial role in answering this type of question. The AQUA methodology leaves room for this: "For guideline questions that can be answered with knowledge other than scientific literature or where there is virtually no scientific evidence, knowledge can be collected and summarized in other ways, for example by a well-considered panel of experts. The methods and results of this knowledge gathering are also summarized transparently" [11]. However, a standardized methodology to accomplish this is not yet available. Working closely with the working group, we translated information from available sources into recommendations for ADL care using various co-creation methodologies.

Guideline questions based on the problem analysis were as follows:

1. How can the care receiver be involved in setting goals, making care arrangements, and in the provision of ADL care?
2. How can ADL care needs be identified, and what valid and reliable instruments are available for this?
3. What interventions effectively contribute to increasing ADL independence and comfort?
4. How can informal caregivers be supported in ADL care?
5. How can ADL care be used to identify possible health risks and problems?

The final guideline [12] instructs nursing professionals on providing quality ADL care through recommendations divided into five guideline modules: involving care receivers in ADL-related care choices, identifying ADL care needs, effective ADL care interventions, supporting informal caregivers in ADL care, and risk identification in ADL care. These recommendations are generically applicable to all settings in which ADL care is provided to (older) adults with various conditions. However, the applicability of the recommendation—given the broad nature of ADL care—may vary depending on the individual care receiver and care setting. For example, the informal caregiver is involved differently in care at home compared to the nursing home. As a result, recommendations on involving the informal caregiver and his/her required knowledge and skills to support the caregiver in ADL care may differ. In the next step, the most important recommendations were selected into a set of 11 core recommendations, such as using the Barthel index to objectively determine the degree of independence or applying proven effective interventions, such as Function-Focused Care (Table 2).

**Table 2** A Selection of Key Recommendations from the Care in Activities of Daily Living (ADL) Guideline.

| Module | Recommendations |
|---|---|
| Identifying ADL care needs | Use the Barthel Index (BI) to assess the degree of ADL independence of the care receiver (objective data). When interpreting the BI, be aware of possible ceiling effects. For example, if, care receivers already score high in the BI during intake, the measurable progress may be limited because the maximum attainable score is reached (ceiling effect). Record the Barthel Score in the care record. |
| Involving care receivers in ADL-related care choices | Involve the caregivers in setting ADL goals by a) identifying the care receivers' (changing) motivations on ADL; b) informing the care receivers about issues that are important from professional expertise around ADL care; and c) formulating ADL goals with the care receivers whenever possible. |
| Supporting informal caregivers in providing ADL care | In a conversation with the caregivers, explore the extent to which the informal caregivers feel competent and have the knowledge and skills to support the care receivers in ADL care. |
| Effective interventions | Consider applying the principles of the Function-Focused Care approach to increase the ADL independence of care receivers with dementia in nursing homes. |

## From the Guideline to Good Use

The key recommendations were tested for usability in a pilot implementation. To this end, care teams from ADL-relevant settings tested the core recommendations over three weeks. After all, a guideline is of value only when it is applied to practice by professionals. The purpose of the pilot implementation was twofold. On the one hand, it assessed the extent to which the core recommendations were used in practice and, on the other hand, it assessed factors that hinder or promote the use of the core recommendations by nursing professionals working in hospital care, care for adults with intellectual disabilities, community care, nursing home care, and rehabilitation care. The pilot implementation demonstrates that the core recommendations are compatible and implementable in practice. The guideline has become an extensive document. It consists of a comprehensive text outlining the methodology used and the scientific reasoning for arriving at whether certain recommendations are fully explained. An infographic will be developed to make the information and essence of the core recommendations easier to understand. The ADL guideline provides nursing professionals with a scientific basis for responsible decision-making and action. By providing guidance, unwanted variation in the actions of nurses can be reduced and excellent person-centered care in ADL becomes possible.

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# Chapter 6

## No Tension, No Change? - Use and Influencing Factors of a Nursing Guideline on Activities of Daily Living

Submitted for publication

## Abstract

**Background:** Nursing professionals often lack evidence-based guidance in supporting Activities of Daily Living (ADL). Hence, a clinical practice guideline was created, offering key recommendations (KRs) on involving care receivers and informal caregivers, identifying ADL care needs, and effective interventions. Before implementing the guideline, understanding the influencing factors is crucial. This study aimed to assess KR utilization in different care settings and explore influencing factors.

**Methods:** In a pilot implementation study, we used mixed methods in which nursing professionals (1) registered the frequency of key recommendations used for three weeks; (2) filled in a survey identifying influencing factors; and (3) participated in focus. We descriptively analyzed the registration and survey data and deductively analyzed the focus groups.

**Results:** Seven nursing care teams participated from the hospital (n=1), rehabilitation (n=2), home care (n=1), and long-term care (n=3) settings. The KR use varied between KRs and across care settings. The most frequently used KRs were on involving care receivers in care choices. KRs were least applied in assessing ADL functioning. The survey on influencing factors showed how most factors across domains and care settings were perceived as facilitating, including the inner setting, the guideline itself, and individuals. Impeding factors related to low tension for change and limited personal benefits. Additional constructs addressed in six focus groups included innovation characteristics (e.g. procedural clarity) and care receiver cooperation.

**Conclusion:** The KRs appear implementable across care settings, with limited factors hindering their use. Despite the perception of the KRs being compatible with current norms and workflows, low tension for change raises questions on the awareness of current opportunities for improvement in ADL nursing care.

**Relevance to Clinical Practice:** Results of this study help organizations and professionals understand factors related to implementing the ADL nursing guideline while facilitating the formulation of implementation strategies accounting for contextual and individual differences.

## Background

Supporting and respecting a person's ability to manage their ADL, regardless of diagnosis, cultural background, or healthcare is seen as the most indispensable care provided by nursing professionals [1, 2]. However, evidence on how to provide ADL care adequately and effectively is insufficient [3]. As a result, nursing professionals need integral scientific knowledge and guidelines to apply in the delivery of ADL nursing care [4].

Despite a growing number of clinical practice guidelines (CPGs) being developed, the actual success of these CPGs hinges on their actual use by healthcare professionals in practice. Implementing guidelines and changing practices are considered difficult and complex processes [5, 6]. Many factors that are regarded as either barriers or facilitators often play a role in the success or failure of the implementation of CPGs [7]. Influencing factors might relate to the innovation itself (e.g. the guideline), the individuals using the guideline (e.g. their competencies, attitudes), the inner setting (e.g. care organization or team), or the outer setting (e.g. health system) [8]. Also, other aspects of the actual procedure and actions taken to implement a guideline into practice, such as the planning, execution, and procedures, are equally important [9]. On the individual level, influencing factors include the nursing professionals' attitudes, knowledge, and beliefs about the CPG [6, 10] and learning through social processes such as group interactions, collaboration, and teamwork [6]. Influencing factors on an external level, for example, comprise the level of integration of guideline recommendations into organizational structures and processes [6, 11], organizational leadership and culture [6, 12] education and training [11], resources, and leadership (time/staffing/workload) [6, 10, 11]. These factors often lay beyond the control of the nursing professional.

Guideline recommendations that are easily implemented in one environment might not work in another. Therefore, insight into the potential influencing factors in different settings is necessary before the actual implementation. A recommended approach for evaluating the factors affecting implementation is through pilot implementation studies [13] as, these studies contribute valuable insights to the development of "implementation strategies," enhancing the implementation and sustainable utilization of innovations [14]. Hence, the implementation of a CPG should be well-designed, well-prepared, and preferably tested before use to increase adherence to guidelines in daily nursing practice.

ADL nursing care is being provided to a diverse patient population in a broader scope of care settings. Hence, it is crucial to understand and address diverse influencing factors for the successful implementation of CPGs in nursing, advocating for the need and importance of pilot implementation studies to inform robust "implementation strategies" that enhance the sustainable use of innovations, with specific relevance to the nursing profession.

In the Netherlands, the Dutch Nursing Association prioritized the development of a clinical practice ADL guideline for nursing professionals [15]. A CPG on ADL nursing care has been developed (see 2.2) according to national and international standards for guideline development [16, 17]. This study's significance lies in its potential to enhance the practical application of evidence-based ADL care by measuring guideline utilization, and identifying factors influencing the use of the CPG influencing factors, ultimately contributing to the development of effective implementation strategies for nursing professionals.

## The Study

### Aims

This study aims to

(1) Measure utilization of the key recommendations of the ADL Clinical Practice Guideline relevant care settings.
(2) Identify and explore impeding and facilitating factors that influence the use of the key recommendations from the ADL clinical practice guideline.

## Methods

### Design

We conducted a pilot implementation study guided by Pearson et al. [13] in which we used a mixed methods approach. Reporting was guided by the Mixed Methods Reporting in Rehabilitation & Health Sciences (MMR-RHS) [18]. In conducting our approach corresponded with a deductive-sequential design (QUAN → qual) where the core component is quantitative and the supplemental component is qualitative by (1) tracking the use of recommendations and (2) surveying the factors that promote or hinder recommendation use. Followed by a qualitative approach using (3) focus group interviews which allowed us to gain an in-depth insight into the use of key recommendations and their influencing factors. A mixed methods approach was deemed necessary for this study to comprehensively assess the implementation of KRs. This involved tracking their utilization, surveying factors influencing their use, and conducting focus groups for a deeper understanding and exploration. The incorporation of both quantitative and qualitative methods provided a more holistic perspective on the effectiveness and influencing factors of the key recommendations.

### The Clinical Practice Guideline on ADL Nursing Care

With ADL nursing care being scarcely informed by scientific evidence, relying on professional intuition and experience results in an unwarranted variation in care provision. To support nursing professionals in providing and underpinning ADL care provision, we developed a CPG on ADL nursing care. according to national and international standards [16, 17]. More information on the development process can be found in Cremer et al. [15]. The CPG on ADL nursing care comprises five guideline modules on (1) involving care receivers and informal caregivers in ADL-related care choices (2) identifying ADL care needs; (3) effective ADL interventions targeting independence and comfort; (4) supporting and collaborating with informal caregivers, and (5) using ADL care for the detection of health risks. We summarized the most important recommendations of the CPG in 11 key recommendations (KRs). These KRs were organized according to the steps of the nursing process that guide nursing professionals from assessing ADL care needs to planning and evaluating the care provided (Table 1). This overview of KRs is displayed in the first part of the guideline as a summary for nursing professionals, including references to the modules where more information on the KRs is provided. The KRs of this guideline were tested in this pilot implementation.

After development a ‘commentary phase’ took place. In this phase, different stakeholders (caregivers and or care providers and/or representatives, policymakers, or educators) provided feedback on the entire guideline document, including procedural clarity, correctness, completeness, complexity, and relevance for the client regarding the recommendations. Based on the received feedback and comments, we adapted the guideline accordingly before the pilot implementation.

### Participants and Recruitment

For our study, we recruited existing nursing teams from various Dutch care settings relevant to ADL care, including hospitals (n=2), rehabilitation (n=2), intuitional long-term care facilities (nursing homes, care for intellectually disabled adults) (n=4), and home care (n=1). The care teams' organizations were located in various regions across the Netherlands, encompassing Zeeland (n=1), North Holland (n=2), South Holland (n=2), Gelderland (n=1), and Limburg (n=1). The teams consisted of registered nurses (RNs) and (certified) nursing assistants ((C)NAs). We also recruited the manager from one care team, as they played a crucial role in translating the KRs into ADL care processes. We then distributed a call for participation within the Dutch Nursing Association and the author’s network to recruit participating teams. We planned online meetings to discuss the purpose and mutual expectations of the pilot implementation with interested nursing professionals and/or managers who responded to the call.

Additionally, we sent an information letter describing the study's aim data collection processes, and consent forms, which we received back prior to the start of the implementation. All teams that signed up were able to participate, and the nursing professionals were asked to implement the KRs in a group of at least eight care receivers.

**Table 1** Key Recommendation (KR) of the CPG on ADL Nursing Care in the Nursing Process

| | |
|---|---|
| **Nursing process phase 1-3**<br>(1) Data collection, (2) Identification of ADL preferences, needs, and problems (3) Goal setting | |
| KR 1<br>Care relationship | In all moments of contact with the care receiver, strive to establish a care relationship based on trust, respect, equality, and shared responsibility. |
| KR 2<br>Subjective data | During an intake, identify the ADL-related habits and experienced complaints of the care receiver (subjective data), and document these in the care file. |
| KR 3<br>Objective data | Use the Barthel Index (BI) to assess the degree of ADL independence of the care receiver (objective data). When interpreting the BI, be aware of possible ceiling effects. For example, if, care recipients already score high in the BI during intake, the measurable progress may be limited because the maximum attainable score is reached (ceiling effect). Record the Barthel Score in the care record. |
| KR 4<br>Contextual data | Map out the social and physical environment of the care receiver (contextual data) through a conversation with the care receiver and targeted observations of the living environment, and record them in the file. |
| KR 5<br>Shared goal-setting | Involve the caregivers in setting ADL goals by a) identifying the care receivers' (changing) motivations on ADL; b) informing the care receivers about issues that are important from professional expertise around ADL care; and c) formulating ADL goals with the care receivers whenever possible. |
| KR 6<br>Informal caregiver skills | In a conversation with the caregivers, explore the extent to which the informal caregivers feel competent and have the knowledge and skills to support the care receivers in ADL care. |
| **Nursing care process phase 4-6**<br>(4) Identification and Planning of Care Actions and Intervention; (5) Carrying out Activities and Interventions; and (6) Evaluating and, if necessary, Adjusting Care and Support. | |
| KR7<br>Shared care agreements | Involve the care receiver in agreeing on care actions and interventions by a) emphasizing that the care receiver had a voice in choices around ADL and b) discussing these ADL care options and collaboratively making these care agreements and documenting them. |
| KR8<br>Involvement in intervention and evaluation | Involve the care receiver in planning and evaluating the care actions and interventions performed. |
| KR9<br>Bathing interventions | Consider applying the principles of the interventions "Person Centered Bathing" and "Bathing Without a Battle" to reduce agitation and discomfort in persons living with dementia in nursing homes. |
| KR10<br>Function Focused Care | Consider applying the principles of the Function Focused Care interventions (FFC) to increase the level of ADL independence of people living with dementia in a nursing home. |
| KR11<br>Informal caregiver support | Support the informal caregiver during ADL care moments in collaboration with the care receiver. |

## Data collection

At the time of data collection (January 2022 until April 2022), the Netherlands was affected by COVID-19 and in lockdown. Therefore, all contact with the participants and instruction exclusively took place online. Before implementation, we sent a summary version of the guideline with the 11 KRs and included a summary of the guideline modules to the team manager. We instructed the manager to embed the processes of the pilot implementation in day-to-day operations. This includes putting the pilot implementation on the agenda of team meetings and drawing attention to and reminding them of the key recommendations. The researchers did not interfere with the processes of how the manager chose to introduce the KRs within the care teams.

*Weekly Registration of Used KRs*

Nursing professionals self-reported the use of KRs in three weeks and received this list prior to implementation from their manager who distributed and collected these lists after each week of implementation. After each week, we asked nursing professionals to register which KR they applied in the past 7 days for each care receiver in a registration list (example in Table 2). Care receiver data were anonymized in the lists.

*Survey on Influencing Factors*

After three weeks, participants completed a self-developed survey on the facilitating and impeding factors based on a selection of the Consolidated Framework for Implementation Research (CFIR) [19] and the Dutch Measurement Instrument for Determinants of Innovations (MIDI) [20]. The CFIR consists of 39 underlying components and sub-constructs that are divided into five domains (intervention features, outer setting, inner setting, characteristics of individuals, and process) that may influence change in practice [19]. Similarly, the MIDI questionnaire comprises 29 items divided into four domains related to 1) the innovation, 2) the potential user of the innovation, 3) the organization where the potential user works, and 4) the socio-political context. We selected this questionnaire since it overlaps as well as adds construct to the CFIR constructs, and its questions were translated and tested in the Dutch setting [20]. We selected constructs that we considered close to the daily work reality of nursing professionals, relevant to using the KRs in practice while accounting for the length of the survey. The constructs mainly originated from the

**Table 2** Example of the Weekly Registration Matrix to Poll the Use of Key Recommendations (KR) per Care Receiver (CR)

| **W1** | **Name** | | | **Nursing qualification** | | | | **Date:** | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | KR 1 care relationship | KR 2 subjective data | KR 3 objective data: Barthel index | KR 4 contextual data | KR 5 shared goal setting | KR 6 informal caregiver skills | KR 7 shared care agreements | KR 8 shared care actions | KR 9 bathing intervention | KR 10 function focused care | KR 11 informal caregiver support |
| **CR Nr.** | | | | | | | | | | | |

CR Nr: Care Receiver Number; W: Week; KR: Key Recommendation domains concerning the innovation itself, the inner setting, and the individuals using the KRs. The selection of relevant constructs was made after several discussions among the authors until a consensus was reached. Eventually, we selected 18 constructs, of which nine constructs overlap in both sources, seven originate from the MIDI, and two are described in the CFIR. We displayed the selected constructs in Table 5 in the results secti. Nursing professionals who used the specific KRs during the pilot implementation were able to fill in the questions. We used a five-point Likert scale ranging from (1) totally disagree to (5) totally agree as options to answer the questions about the influencing factors. The survey was built and distributed in Castor EDC using the mail addresses of the participating nursing professionals. We asked them to complete the survey within seven days after the final registration in the third week to limit recall bias in the following focus groups. We also sent a reminder after five days.

#### *Focus Group Sessions*

After receiving the weekly registration forms and surveys from the teams, we scheduled focus group meetings with each participating team to discuss the results with the participants and to gain more insight into why some factors worked in a facilitating or impeding way. In addition, we used the focus group to obtain additional information about the context of the ADL care in question. Prior to conducting the focus groups, we built a topic guide for each individual care team comprising general open questions on the experience of pilot testing the guideline and questions related to the results of the weekly registration forms. For this purpose, the first and the last authors reviewed the results of the weekly registration forms and surveys of each care team to add context-specific questions to the developed topic guide. Due to COVID-19, we used ZOOM (Zoom Video Communications Inc.) to conduct the focus group sessions online, which were then audio-recorded by a manual voice recorder.

### Data analysis

#### *Weekly Registration*

Before analyzing the data, we transferred the polled used KRs into Microsoft Excel to digitalize all registration matrixes manually. For data processing, we used codes for nursing professionals and care receivers to guarantee anonymity throughout the process of analysis. In creating the codes, we indicated the setting and organization of the person in question. To analyze the data, we calculated descriptive data in Excel, including totals and average use per organization, setting, and total.

#### *Survey on Influencing Factors*

After exporting the survey responses from Castor EDC and importing them into IBM SPSS Statistics v.27, we used descriptive statistics to describe the general study population and the total and mean responses from the participants. We did not include partially completed surveys in our analysis. To further analyze the data, we merged the five-point Likert scale into a three-point scale by calculating sum scores of the categories (1) Strongly disagree and (2) Disagree, as well as (4) Agree and (5) Strongly agree into new categories. Category (3) ‘neither impeding nor facilitating’ remained the same. This step resulted in an overview of scores indicating the extent to which a factor was perceived as impeding, neither impeding nor facilitating, or facilitating.

#### *Focus Groups*

Prior to analysis, we transcribed the audio recordings of the six focus groups and extracted data from the open-ended survey questions. We then analyzed the transcripts by applying techniques of qualitative content analysis, guided by a deductive approach [21], as we aimed to analyze our data in light of an existing framework. Hence, we created a codebook inspired by the CFIR codebook template, in which we imported operationalizations of constructs from CFIR and MIDI into MAXQDA as a deductive template for content analysis. As a first step, the first author familiarized herself with the data to gain a deeper understanding. Subsequently, she systematically generated initial codes of the data using MAXQDA. From initial coding, she moved forward to descriptive categories and subcategories that were, where applicable, assigned to existing constructs. During the process of analyzing the data, she kept an open mind to possible other constructs and categories that were then added to the predefined constructs in the codebook. Throughout the whole process, weekly meetings were held by the first and the last author to continually compare new data with previously coded information. The codes and themes were collectively discussed by the research team in monthly meetings.

### Ethics

Before commencing the study, we obtained ethical approval from the internal ethics board of the Faculty of Health Medicine and Life Sciences (FHML) of Maastricht University (Approval number: FHML-REC/2022/017). Staff received both written and oral information about the study's aim and methodology. Written informed consent was signed before data collection and participants could withdraw from the study at any time. The research team had no pre-existing connection with the participants before undertaking this study.

### Rigor and Reflexivity

#### *Researchers Background*

All members of the research team have a background in care across different care settings with additional backgrounds in occupational therapy (SC, SM), nursing (SZ JdM), and physiotherapy (MB). Moreover, a part of the research team holds expertise in guideline development and implementation. It is precisely this composition of backgrounds that has ensured an examination of the data from various perspectives, identifying variations in interpretations through discussions. Regular research team meetings increased mutual reflection on the research background and previous work in clinical practice as well as own pre-conceptions on the use and implementation of CPGs.

*Methodological Rigor*

Given the differences between quantitative and qualitative research methods, rigor is assessed in different ways.

For the quantitative part, the survey on influencing factors originated from established concepts of the CFIR framework [19] as well as questions from the MIDI questionnaire [20]. Despite the concepts being established as well as being judged as generic by experts, the psychometric properties of the MIDI as well as the questions posed based on the CFIR are yet to be established.

To ensure the credibility and trustworthiness of the qualitative data and findings, we implemented various strategies following the recommendations of Creswell and Poth [22]. The first and last author collaborated in analyzing the data comparing and discussing codes and themes until agreement was reached. The first author kept reflective notes before and after data collection, on their preferences and pre-conceptions to increase reflexivity. Establishing confirmability involved debriefing with team members to discuss decisions made during data analysis and verifying the data analysis processes.

## Results

### Participants

In total, 62 participants took part in the pilot implementation. We displayed further specifications on the participants per phase of data collection in Table 3.

**Table 3** Overview of Participants per Setting and Phase of Data Collection.

| Setting | Organization | Occupation[1] | Total number of participants[2] n=62 | Participants of registration (n=46) | Survey participants (n=44) | Focus group participants (n=25) |
|---|---|---|---|---|---|---|
| All settings | | Team manager | 6 | 1 | 3 | 4 |
| | | RN | 24 | 16 | 14 | 5 |
| | | CNA | 11 | 12 | 10 | 7 |
| | | NA | 2 | 2 | 1 | 1 |
| | | RN Intern/student | 10 | 10 | 9 | 5 |
| | | Personal support worker | 8 | 4 | 2 | 2 |
| Home care | | Team manager | 1 | 0 | 1 | 1 |
| | | RN | 1 | 1 | 1 | 1 |
| | | CNA | 1 | 1 | 1 | 1 |
| | | NA | 1 | 1 | 1 | 1 |
| | | RN Student/intern | 1 | 2 | 2 | 2 |
| Acute and subacute care | Geriatric rehabilitation | Team manager | 1 | 0 | 0 | 1 |
| | | RN | 4 | 4 | 4 | 1 |
| | | CNA | 2 | 2 | 1 | 2 |
| | Stroke rehabilitation | Team manager | 1 | 0 | 0 | 0 |
| | | RN | 5 | 0 | 5 | 0 |
| | | RN student/intern | 3 | 3 | 3 | 3 |
| | Hospital care (Mixed ward) | RN | 8 | 8 | 4 | 0 |
| | | RN student/intern | 3 | 3 | 3 | 0 |
| Long term care | Nursing Home 1 | Team manager | 1 | 1 | 1 | 1 |
| | | RN | 1 | 1 | 0 | 1 |
| | | CNA | 5 | 5 | 5 | 2 |
| | | RN Student/intern | 1 | 1 | 1 | 0 |
| | Nursing Home 2 | Team manager | 1 | 0 | 1 | 1 |
| | | RN | 4 | 1 | 4 | 1 |
| | | CNA | 4 | 4 | 3 | 2 |
| | | NA | 1 | 1 | 0 | 0 |
| | | RN Student/intern | 2 | 2 | 0 | 0 |
| | Care for intellectually disabled adults | Team manager | 1 | 0 | 0 | 0 |
| | | RN | 1 | 1 | 1 | 1 |
| | | Personal support worker | 8 | 4 | 2 | 3 |

[1] Registered Nurse (RN); Certified Nursing Assistant (CNA), Nurse Assistant (NA)

[2] The number of participants per data collection may overlap so these numbers are not a cumulative summation of the number of participants per point of data collection.

### Weekly Registrations

We presented an overview of the applied KRs within and across care settings in Table 4. During the three-week period, 46 participants applied in a total of 2565 KRs. The number of applied KRs varies widely, ranging from 111 to 393 times. Generally, the use of KRs varies significantly across all KRs. The KRs on involving care receivers in ADL-related care choices were applied most often across care settings.

Four out of the five most applied KRs were KRs on involving care receivers in ADL care, including working (1) towards an equal collaborative relationship (KR1: 619); (2) involving care receivers in care actions (KR8: 435); (3) Shared goal setting (KR5: 272); Shared care agreements (KR7: 264). Additionally, the KR on Function Focused Care (FFC) belonged to the top three of the most applied KRs (KR10: 273). Focus group sessions added information on how involving care receivers in ADL-related care choices largely aligns with current norms, values, workflows, and organizational developments (see compatibility). The KRs that were used the least were those on identifying the level of ADL independence using the Barthel Index (KR3: 66 [0-26]) and identifying the capacity of informal caregivers to support the care receiver in ADLs (KR6: 48 [0-18]). Focus group discussions revealed that ADL functioning is often not routinely assessed, especially in community or long-term care settings. In hospital or rehabilitation settings, Dutch health insurance requires periodic assessment of ADL functioning. Whereas community or long-term care organizations did not choose to assess and consequently did not provide either assessment forms or digital infrastructure. In some cases, the ADL assessment is taken over by other disciplines, e.g., occupational physiotherapists.

**Table 4** Overview of Registered Use of KRs Within and Across Care Settings and Organizations

| **Setting** | **Organization** | **N** | | KR 1 | KR 2 | KR 3 | KR 4 | KR 5 | KR 6 | KR 7 | KR 8 | KR 9 | KR 10 | KR 11 | **Total** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Care relation-ship | Subjective data | Objective data: Barthel index | Contextual data | Shared goal setting | In-formal care-giver skills | Shared care agree-ments | Shared care actions | Bathing intervention | Function focused care | Informal caregiver support | |
| All settings | All organizations | 42 | Total | 619 | 200 | 66 | 79 | 272 | 48 | 264 | 435 | 258 | 273 | 71 | 2565 |
| | | | %* | 24,1 | 7,8 | 2,6 | 3,1 | 10,6 | 1,9 | 10,3 | 17,0 | 10,1 | 10,6 | 2,8 | 100 |
| Home care | | 5 | Total | 122 | 2 | 0 | 0 | 9 | 0 | 7 | 120 | 3 | 0 | 0 | 263 |
| | | | %* | 46,4 | 0,8 | 0 | 0 | 3,4 | 0 | 2,7 | 45,6 | 1,1 | 0 | 0 | 100 |
| Acute and subacute care | Hospital | 11 | Total | 57 | 27 | 14 | 26 | 60 | 13 | 56 | 55 | 32 | 50 | 3 | 393 |
| | | | %* | 14,5 | 6,9 | 3,6 | 6,6 | 15,3 | 3,3 | 14,2 | 14 | 8,1 | 12,7 | 0,8 | 100 |
| | Neuro-rehabilitation | 3 | Total | 41 | 14 | 3 | 4 | 13 | 2 | 12 | 9 | 3 | 9 | 1 | 111 |
| | | | % * | 36,9 | 12,6 | 2,7 | 3,6 | 11,7 | 1,8 | 10,8 | 8,1 | 2,7 | 8,1 | 0,9 | 100 |
| | Geriatric rehabilitation | 6 | Total | 55 | 28 | 22 | 8 | 40 | 6 | 40 | 45 | 20 | 20 | 0 | 284 |
| | | | %* | 19,4 | 9,9 | 7,7 | 2,8 | 14,1 | 2,1 | 14,1 | 15,8 | 7 | 7 | 0 | 100 |
| Long-term care | Nursing home 1+2 | 16 | Total | 186 | 46 | 26 | 30 | 49,0 | 18,0 | 52,0 | 167,0 | 43,0 | 42,0 | 21,0 | 577 |
| | | | %* | 32,2 | 8,0 | 4,5 | 5,2 | 8,5 | 3,1 | 9,0 | 28,9 | 7,5 | 7,3 | 3,6 | 100 |
| | Care for intellectually disabled adults | 5 | Total | 82 | 17 | 0 | 1 | 5 | 0 | 12 | 45 | 42 | 30 | 0 | 234 |
| | | | %* | 35 | 7,3 | 0 | 0,4 | 2,1 | 0 | 5,1 | 19,2 | 17,9 | 12,8 | 0 | 100 |

*% of total KRs used

**Table 5** Facilitating and Impeding Factors of KR Use Based on the Survey and Focus Group Sessions

| Characteristics of the Inner Setting | | | |
|---|---|---|---|
| | | N | N % |
| Tension for Change[1] | Facilitating | 6 | 15.8 |
| | Impeding | 24 | 63.2 |
| | Neither/nor* | 8 | 21.1 |
| Social Support Management[2] | Facilitating | 26 | 68.4 |
| | Impeding | 4 | 10.5 |
| | Neither/nor* | 8 | 21.1 |
| Social Support colleagues [2] | Facilitating | 28 | 73.7 |
| | Impeding | 4 | 10.5 |
| | Neither/nor* | 6 | 15.8 |
| Subjective Norm Management [1,2] | Facilitating | 26 | 68.4 |
| | Impeding | 1 | 2.6 |
| | Neither/nor* | 11 | 28.9 |
| Subjective Norm Colleagues [1,2] | Facilitating | 20 | 52.6 |
| | Impeding | 2 | 5.3 |
| | Neither/nor* | 16 | 42.1 |
| Time [1,2] | Facilitating | 136 | 67.3 |
| | Impeding | 26 | 12.9 |
| | Neither/nor* | 40 | 19.8 |
| Staff capacity [1,2] | Facilitating | 123 | 60.9 |
| | Impeding | 24 | 11.9 |
| | Both | 55 | 27.2 |
| Compatibility [1,2] | Facilitating | 165 | 81.7 |
| | Impeding | 9 | 4.5 |
| | Neither/nor* | 28 | 13.9 |
| **Total Inner Setting** | **Facilitating** | **365** | **61.4** |
| | **Impeding** | **85** | **14.3** |
| | **Neither/nor*** | **144** | **24.2** |
| **Constructs added based on Focus Groups** | | | |
| Characteristics of the Innovation | | | |
| • Procedural clarity<br>• Completeness<br>• Design Quality and Packaging | | | |
| Characteristics of the Individual | | | |
| • Client/patient cooperation<br>• Knowledge and Beliefs | | | |

| Characteristics of the Innovation | | | |
|---|---|---|---|
| | | N | N % |
| Relative Advantage [1] | Facilitating | 153 | 75.7 |
| | Impeding | 8 | 4.0 |
| | Neither/nor* | 41 | 20.3 |
| Adaptability [1,2] | Facilitating | 180 | 89.1 |
| | Impeding | 7 | 3.5 |
| | Both | 15 | 7.4 |
| Complexity [1,2] | Facilitating | 161 | 79.7 |
| | Impeding | 16 | 7.9 |
| | Neither/nor* | 25 | 12.4 |
| **Total Innovation** | **Facilitating** | **659** | **81.6** |
| | **Impeding** | **40** | **5.0** |
| | **Neither/nor*** | **109** | **13.5** |
| **Characteristics of the Individual** | | | |
| Knowledge [1,2] | Facilitating | 177 | 87.6 |
| | Impeding | 4 | 2.0 |
| | Neither/nor* | 21 | 10.4 |
| Outcome expectations (Probability) [2] | Facilitating | 181 | 89,6 |
| | Impeding | 5 | 2.5 |
| | Neither/nor* | 16 | 7.9 |
| Outcome expectations (Importance) [2] | Facilitating | 187 | 92.6 |
| | Impeding | 3 | 1.5 |
| | Neither/nor* | 12 | 5.9 |
| Self-Efficacy [1,2] | Facilitating | 174 | 86.1 |
| | Impeding | 1 | 0.5 |
| | Neither/nor* | 27 | 13.4 |
| Professional obligation [2] | Facilitating | 189 | 93.6 |
| | Impeding | 3 | 1.5 |
| | Neither/nor* | 10 | 5,0 |
| Personal benefit [2] | Facilitating | 140 | 69.3 |
| | Impeding | 62 | 30.7 |
| Personal drawback [2] | Facilitating | 187 | 92.6 |
| | Impeding | 15 | 7.4 |
| **Total Individual** | **Facilitating** | **1235** | **87.3** |
| | **Impeding** | **93** | **6.6** |
| | **Neither/nor*** | **86** | **6.1** |
| **Total** | | | |
| **Total all Factors** | **Facilitating** | **2259** | **80,2** |
| | **Impeding** | **218** | **7,7** |
| | **Neither/nor*** | **339** | **12,0** |

* Neither facilitating nor impeding

[1] Based on the Consolidated Framework for Implementation Research (CFIR) [19]

[2] Based on the Measurement Instrument for Determinants of Innovations (MIDI) [20]

## Facilitating and Impeding Factors of KR Use

In our survey, we identified the factors influencing the use of KRs regarding the inner setting (i.e., the care organization or team), the innovation (i.e. the KRs), and the individuals (nursing professionals) applying the KRs. Overall, our results show that the majority of factors influencing the KR use are perceived as facilitating with 80.2% (n=2259). More specifically, characteristics regarding the individuals were perceived as the most facilitating with 87.3 % (n=1235), followed by characteristics of the innovation with 81.6% (n=659). Inner setting characteristics scored the least facilitating with 61.4% (n=365). In the section below, we illustrate the results of the factors we surveyed, as well as the additional factors participants addressed in the focus group sessions. In Table 5 we present an overview of the facilitating and impeding factors of KR use based on the survey and focus group sessions.

### *Characteristics of the Inner Setting*

#### General Inner Setting

The constructs that stand out the most in the inner setting domain are the low tension for change and the high degree of compatibility. Tension for change appears to be most impeding since 63.2% (n=24) of the participants do not feel the urgency for the ADL care situation to change, in contrast to the 15.8% (n=6) who do. This result might align with the perceived high-level compatibility scored as the most facilitating with 81.7% (n=165). The focus group sessions confirmed the impression of the KRs being close to the norms and values of person-centered ADL care. Participants express how the vision of care evolved towards person-centered care and in line with the KRs as the following nursing professional explains:

*“I also see a development in the care we provide. Because I've been working in healthcare since 1985. […] And I've noticed that in the past, as soon as you walked in the door of a nursing home, the control was within the nursing home, and as a resident or client, or whatever you want to call it, you had very little insight into what one could or could not do. Much more attention was paid to the structure of a ward, and what fitted in. And now we have to look the other way around"* [CNA, Nursing home care].

In terms of workflow, we see that depending on the KR, nursing professionals generally feel that the KRs are *‘not being anything new’* and in line with *‘what one does on a daily basis anyways.’* They were largely perceived to be in line with their daily work when it comes to involving the care receiver in ADL-related care choices or stimulating independence in ADL care.

On a different note, focus group sessions revealed how, depending on the care setting, KRs were less compatible regarding assessing ADL functioning or involving informal caregivers in the actual care. Whether or not nursing professionals assess ADL functioning seems to depend on organizational choice, especially in long-term care settings, where an ADL assessment is not a requirement from an insurance company, for example. Moreover, reporting subjective, objective, and contextual data depends on the structure of electronic patient dossiers (EPDs), which can differ per organization.

### KR-specific Inner Setting Characteristics

We separately surveyed other constructs such as ‘time’ and ‘staff capacity’ as part of the inner setting for each KR. The responses showed that time was generally perceived as facilitating, with a score of 67.3% (n=136) across all KRs. KR8 was the only KR where time was perceived as more impeding, with a score of 21.7% (n=5). The focus group sessions revealed a tension between the perception of involving caregivers in actions and encouraging autonomy, which takes more time. However, it could save time in the long term if colleagues act consistently, as this nursing professional explains:

*“Well, I also think you need to be on the same page with colleagues. For example, if I ask a resident, who can still do a lot of things independently, to wash their face, I expect my colleagues to do the same the next day. Otherwise, you end up with a ‘wait-and-see attitude,’ like, hello, yesterday Johnny did everything for me and now you want me to wash my face. So you don't gain any time. But if you can get a resident to do it themselves, I think you can save some time”* [CNA, Nursing Home care].

Staff capacity was generally perceived as less facilitating, with a score of 60.9% (n=123), and was also addressed as a major issue in the focus group sessions. Issues raised by focus group participants mainly evolved around workload due to staff shortages that even have been exacerbated by COVID-19. One nursing professional expresses the hope of being able to change ADL care when the team is complete again:

*“We all have good ideas all in us, and we would like to change. But, right now we have four instead of eight colleagues. And we've all just had COVID. It's all not going the way we want, actually. So, at the moment, we can't do very much yet. But, I think when we will soon have the team complete again, we will find the turn well for certain things. Just keep going, and you'll get the good things out of it. But, you need a good team for that, indeed”* [RN, Care for Adults with Intellectual Disabilities].

### *Characteristics of the Innovation*

In our study, the characteristics of the innovation scored relatively high, with a total score of 81.6% (n=695) facilitating. This result might create the impression that the innovation is generally well-adaptable, not too complex, and has an advantage over alternatives. However, focus group sessions revealed additional constructs related to the innovation, among which procedural clarity was highlighted. Despite the KRs’ procedural clarity generally being perceived as facilitating, hindering aspects included wording and sentence structures in some instances. Nursing professionals recognized the challenge of being complete and clear in the formulation of KRs while also being concise, as this nursing intern illustrates:

*“In itself, I found what was written clearly understandable. Now it takes, say, so much time […]... So I can imagine if it is perhaps even more concise ... We had also received a summary per KR, which is again a bit too concise, but somewhere in the middle, you can find some extra explanation, I can imagine. But in itself, how it was written down, I thought it was pretty clear”* [RN intern, Neuro rehabilitation].

*Other Characteristics of the Innovation Addressed in the Focus Group Sessions*

Additionally, based on the focus group data, we added the construct of completeness, which was especially perceived as hindering in KRs on interventions lacking a clear and complete description of the steps to be taken to be performed (KR9, 10).

*"If this core task can provide calmness to the care receiver, then I think this is a good one to apply. Yet, I also find it difficult and would like to know more about it"* [CNA, nursing home].

In terms of the design and packaging of the KRs, nursing professionals found the perceived overlap of information in the KRs to be hindering. For example, an overlap of information on involving care receivers in different steps of the nursing process came at the expense of readability.

*"‘I also spent quite a long time reading it because a lot of things were similar. I don't know if you had that too, that there were repetitions, maybe in it, well, not really repetitions, but overlap, that key recommendation especially the first few, are quite similar.”* [Community Nurse].

Moreover, the presentation of KRs did not allow all nursing professionals to locate the information they were looking for immediately.

*Characteristics of the Individual*

Nursing professionals generally attribute the most facilitating factors to their individual characteristics with a mean of 87.3% facilitating (n=1235). Of all the individual characteristics we surveyed, the professional obligation was perceived as most facilitating with 93.6% (n=189); (impeding: 1.5%, n=3). Despite providing ADL care, including observing and documenting changes, is perceived as part of the profession, focus group results show that certain roles within the nursing profession perceive a different obligation towards certain KRs. Nursing professionals fulfilling additional roles in intake processes or supporting during a transition from home to nursing home adhering to KRs on identifying and monitoring ADL care needs contributes to the professional obligation. Additionally, the role of other disciplines was discussed in focus groups. Nursing professionals explained that occupational or physical therapists routinely assess ADL functioning or investigate the living environment. This limits the contribution of nursing professionals, as this nursing professional explains:

*"Our occupational therapist does know the Barthel Index. But, she was also like, 'Yes, that's my area, and you don't have to do anything with that'"* [RN, Care for adults with intellectual disabilities]

In terms of personal benefits and drawbacks, results show that personal drawbacks were not perceived as an issue with a score of 92.6% (n=187) facilitating (7.4%; n=15). Personal benefit scores were comparatively low with 69.3% (n=140) facilitating (impeding: 30.7%; n=62). However, the open-ended questions in the survey and focus group sessions indicate that nursing professionals report beneficial experiences on three levels: (1) the care relationship indicating that working towards a care relationship based on trust, respect, equality, and shared responsibility results in, for example, care receivers sharing their concerns and emotions more easily; (2) care delivery and working climate where nursing professionals experience their care as more person and goal-centered since they feel empowered in clinical reasoning when assessing ADL functioning and using these results to set goals. Regarding the working climate, nursing professionals report that when care receivers feel seen and heard in their ADL care needs, nursing professionals feel less stressed since they don't have to engage in discussions with care receivers. Additionally, clear documentation results in clear care arrangements among nursing professionals, who can work consistently according to those arrangements. Nursing professionals also report benefits in their (3) Professional development, especially through mutual evaluation and reflection with care receivers on the provided care, which leads to points of improvement for the professionals.

*"The KRs contribute to my growth process in being a Certified Nursing Assistant is not taking over too much from the care receivers. My lesson is that autonomy is important for the client's self-esteem"* [Nursing professional, Nursing Home Care].

Personal drawbacks were reported by some nursing professionals, indicating struggle with frustration or disappointments when they feel unable to address the care receiver's needs. Additionally, they mention that being too close to a care receiver can limit the professional 'objective' view of the care receiver's process.

### Other Characteristics of the Individual Addressed in the Focus Group Sessions

The cooperation of care receivers and informal caregivers was a construct that was added after the focus group sessions. This construct was generally perceived as facilitating, especially when applying KR1 and working towards improving the care relationship, or letting care receivers make their own ADL choices (KR 5, 7, 8). Participants perceive this to increase the level of cooperation of care receivers resulting in ‘smoother’ care delivery. A hindering aspect of the cooperation with care receivers or informal caregivers arises when generational gaps or attitudes clash with the care paradigm of younger care professionals who aim to encourage independence.

*“But of course, there are different ages of employees. And some find it more difficult to say to an older resident: ‘Well, you'd better try it yourself.’ The resident then thinks, ‘Well, I'm not going to enter into that whole discussion, […] you young thing, you can't do that.’ […] They just outplay each other. And then they [the younger employees] think, I'm not going to have that whole discussion, I'll do it. Because then I'll be done faster”* [Community Nurse].

Especially professionals working with intellectually disabled adults highlight that difficulties in collaboration with care receivers due to insecurity of care receivers and old traditions are a hindering factor:

*“Well,[…] our residents have also never been […] asked: ‘What do you think is important?" We just had another client who just can't choose what color nail polish she wants because she was never asked, "What do you like?" From back home, huh? So, I think asking: ‘How do you want to be cared for?’ That's a question that goes all over them. I mean, I can ask: "Do you want to take a bath or do you want to shower?" They then sometimes say, ‘What would you do?’ […]”* [RN, care for intellectually disabled adults].

Cooperating with informal caregivers was perceived as delicate when aiming to involve them in ADL care (KRX). Nursing professionals reported a fine line between voluntary involvement and obligation. Nursing professionals appreciate the involvement, while not wanting to increase the burden of informal caregivers. In fact, ADL care by nursing professionals in-home care, for example, was reported as a moment in which informal caregivers have time for themselves, as this nurse describes:

*"However, many informal caregivers also choose to retreat the moment the nursing professional comes. They are then just happy, like okay, you can take over for a while, I can do something for myself, even if it's a cup of coffee or just take a shower, etc."* [Community nurse].

Knowledge and beliefs of nursing professionals were perceived as a facilitating factor when their previous education was in line with the KRs, especially involving care receivers or stimulating independence. Additionally, the KRs helped nursing professionals realize the depth of ADL care and how it contributes to the personhood of the care receiver, as this CNA explains:

*"I'm caring for persons with severe dementia, and then you quickly take control yourself. But just then, when I think about this, I see, "This care receiver has special body lotion or she likes to brush her teeth before or after something." […] I became much more aware that it has a lot more depth, and not just that person at that time and that time in this room"* [CNA, nursing home care].

Hindering attitudes were mainly characterized by being ‘stuck in old patterns and routines’ and ‘less motivated’ to change their ways of providing ADL care.

## Discussion

In this pilot implementation, we aimed to first measure the utilization of the key recommendations of the CPG on ADL in relevant care settings and second to identify impeding and facilitating factors that influence the use of the selected key recommendations from CPG on ADL. Overall, our integrated results highlight the general feasibility of using the KRs in practice while also emphasizing high contextual variability in terms of KR use and its influencing factors.

Our results showed that the use of KRs varies across KRs and settings. The most frequently used KRs were on involving care receivers in ADL-related care choices. KRs were the least applied in using the Barthel Index to assess ADL functioning and supporting informal caregivers in ADL care. Factors influencing the implementation of KRs were generally perceived as facilitating, including the inner setting, characteristics of the innovation, and individuals. However, impeding factors mostly comprise a low tension for change and limited personal benefits. Focus group sessions revealed additional explanations and additional impeding and facilitating factors such as procedural clarity or collaboration with care receivers and informal caregivers.

When taking a closer look at which KRs were applied, we see KRs on involving care receivers in ADL care are applied the most, especially the KR on working towards a care relationship based on trust, respect, equality, and shared responsibility. This result is consistent with the literature on ADL care as part of fundamental nursing, stressing the importance of the care relationship as foundation for person-centered [23] and quality nursing care [24]. At the same time, nursing professionals appear to be challenged by their own routines, task-focused, and time driven approaches [25], limiting their ability to maintain an authentic connection and use a variety of professional knowledge and skills to manage the care. Hence, despite its importance confirmed by our results and literature, establishment this care relationship might remain challenging.

Another crucial part of quality ADL nursing care relates to the clinical reasoning of nursing professionals, specifically the assessment of ADL functioning. Assessing ADL functioning is the least-used KR and appears to be mostly restricted to acute clinical care settings (rehabilitation or hospital care), where organizations and insurance companies require periodic assessments of function. However, in community or long-term care, functional assessments do not seem integrated into the nursing processes, since organizations did not ‘choose for this assessment’ or ‘the EPD does not allow for reporting an ADL assessment.’ Based on the literature, different factors can account for a proper ADL needs assessment, which accounts for a vital aspect of ADL care. Within the guideline implementation literature, defining organizational barriers related to organizational choices are well recognized, including lacking organizational readiness [26] or lacking administrative support or technology [27]. Without the right infrastructure embedded in daily processes, nursing professionals are not enabled to assess ADL functioning. In the Netherlands, requirements of health insurance in (sub) acute care might be the most determining incentive for organizations to regularly assess ADL functioning. In other settings, skilled nursing professionals often intuitively interpret, recognize, and judge symptoms or patterns while bypassing the stages of obtaining relevant information and clinical reasoning [28]. While intuitively assessing function often happens unconsciously, some nursing professionals experience a lack of knowledge and skills for completing assessments [29] as part of the nursing process. This potentially hinders recognizing the individuality of care receivers [30] and hinders nursing care, as required care may be left undone. This observation highlights the need for functional assessment, even in long-term care settings, to improve clinical reasoning and ultimately achieve quality and person-centered ADL care.

Our findings on facilitating and impeding factors influencing the use of KRs partially align with those in the literature on guideline implementation and extend them in numerous ways. Similar influencing factors are described in literature reviews, where the attitude of care professionals is both impeding and facilitating, depending on the professional or the general lack of personal benefits in nursing professionals [10]. In other studies, nursing professionals mainly report external barriers (up to 91% of sampled nurses), which were mainly organization-based with time, staffing, and workload up to 21% [11]. Surprisingly, in our study, the perception of external barriers overall remained relatively low with time being reported as 12.9% impeding and staff capacity as 11.9%. These findings might be explained by the overall perception of nursing professionals acting in line with the CPG already, as shown by the high levels of compatibility (81.7% facilitating) and low tension for change (15.8% facilitating), and the focus group sessions confirming this result.

Our results reveal that nursing professionals, overall, do not feel that the way that ADL care is currently provided needs to change and that KRs are largely compatible with current norms and workflows. However, given the current literature on fundamental nursing care, this result has to be interpreted with caution. As this type of nursing care is undervalued and largely taken for granted [25], the question arises, whether nursing professionals are sufficiently aware of their own practice in considering the complex underlying processes of ADL nursing care. Studies observing nursing professionals’ behavior in ADL show how nursing professionals struggle to actually pay attention to care receiver needs and integrate them into their care processes [31]. With ADL being a routine-based and repetitive form of care, there is a risk that nursing professionals are not sufficiently aware of their actions. Literature on self-reflection shows that nursing professionals perceive difficulties in ending the cycle of repetitive, circular thinking through self-questioning [32]. Therefore, future research on implementing this CPG on a larger scale should pay specific attention to the implementation process, specifically the process of reflecting and evaluating by involving stakeholders' own views on their behavior [33] and providing feedback on progress towards objectives as a key behavior change technique [34].

Moving forward to possible strategies for implementation, our results point in the following direction: First, we suggest improving the KRs in a way in which nursing professionals can easily find the right information, such as by using an infographic. Second, future implementation should focus on creating tension for change by getting insight into the current ADL care and contrasting the aspects that can be improved, announcing a change, and cultivating commitment [35].

### Strengths and Limitations

Our study's strength lies in its breadth of settings, as we conducted it across all settings in which ADL care is provided, including care for intellectually disabled adults. The overall picture we captured is unique since most studies tend to focus on one or at most two settings at a time. Nonetheless, this approach has enabled us to shed light on implementation-related knowledge and issues of ADL nursing across care settings, taking into account contextual factors. Moreover, choosing a mixed methods approach allowed us not only to capture the number of KRs used and the factors influencing the KR use but also to gain additional information on underlying reasons based on our focus group sessions. This approach allowed us to validate the quantitative findings while understanding how additional factors influence KR use.

However, this study is subject to certain limitations: The use of KRs in practice and their influencing factors relies on the self-judgment of nursing professionals, which comes with a certain level of subjectivity when it comes to the numbers of whether or not a KR was applied or how care receivers were actually involved in decisions. With varying perceptions of actual involvement that differ between care receivers and nursing professionals, it would have been valuable to either include care receivers or to directly observe nursing professionals when applying the KRs. This would have contributed to the picture of the actual number of KR applications.

We designed our survey on influencing factors in a way that allowed participants to answer questions on a specific KR when nursing professionals indicated that they actually used the KR in the last weeks. Consequently, nursing professionals who may have found KRs, for example, too complex to apply, did not assess these KRs in the questionnaire which might have increased the positive picture of influencing factors. However, in focus group sessions, we included the perspective of all nursing professionals, allowing us to identify additional points for improvement in terms of readability and design.

Moreover, the COVID-19 lockdown in the Netherlands during data collection limited our study in two ways. Firstly, the ability of nursing teams to prioritize the registration of KRs was limited in one nursing home, limiting the accuracy of the reported numbers of week two. Secondly, it was not possible to conduct a focus group with the hospital nursing team since the care for COVID-19-infected patients was prioritized. Additionally, COVID-19 has limited the possibilities for involving informal caregivers in ADL care, for example, rehabilitation or nursing home care, through the application of KRs. At the same time, there could be a certain selection bias, considering that those organizations participating during a pandemic already consider themselves progressive while prioritizing their ADL care. Additionally, the small sample of this pilot implementation study limited the generalizability of the findings.

In our study, we used the CFIR framework of Damschroder et al. [19], which was updated after our data collection and first analysis [8]. A central change in this updated framework revolves around an improved centering of the innovation recipients (e.g., care receivers) and their values, beliefs, and needs, as well as allowing them to participate in implementation [8]. Reflecting on our results, our CPG already advocates for considering the needs of care receivers and involving them in decisions. Moreover, the cooperation of care receivers and nursing professionals emerged as an additional influencing factor from the focus group discussions. This central role of care receivers within the innovations should, hence, also be considered during future implementation processes.

## Conclusion

Our study makes an important contribution to the literature by describing nursing professionals' perceptions and experiences of factors that influenced the implementation of the CPG on care for ADL across relevant care settings and organizations. Our results show how KRs involving care receivers in ADL-related care choices are frequently used, while clinical reasoning, more specifically assessing ADL functioning, may contain room for improvement. Despite the impression that the KRs are generally perceived as highly compatible with current norms and workflows, a low tension for change raises questions on the awareness of current opportunities for improvement in ADL nursing care. Moreover, the future implementation should account for contextual differences regarding the assessment of ADL functioning. Future research and implementation should stimulate awareness and critical reflection in routine processes for successful implementation and quality ADL nursing care.

## Relevance for Clinical Practice

This study shows that the guidelines KR are perceived as relevant and applicable for nursing professionals in clinical practice. Furthermore, understanding the factors influencing the implementation of this guideline helps in formulating implementation strategies that consider the contextual and individual variations among nursing professionals. These might include increased reflection of professionals and organizations on the ADL care provided as well as promoting the adaptability of the guideline. When implementing the guideline accounting for the influencing factors holds the promise of improving the overall quality of ADL care and fostering a culture of ongoing improvement in healthcare settings.

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# General Discussion

## Main Findings

### Part I: A Quest for Evidence on ADL Nursing Care

Part I of this dissertation aimed to scientifically underpin ADL nursing care. **Chapter 2** demonstrated how ADL nursing care is still defined by a paradoxical narrative torn between undervalued common-sense work and the provision of complex, highly skilled care. The ambivalence is evident in the inconsistent quality of clinical decision-making and the lack of involvement of care receivers and their informal caregivers in these decisions. Additionally, gaps in knowledge regarding effective interventions impede the delivery of efficient ADL care. At the same time, nursing professionals face system-level and environmental barriers that make it challenging to meet and integrate the needs of care receivers in their daily care situations. This identification of challenges led to the formulation of questions to be addressed in a Clinical Practice Guideline (CPG).

Within the scope of the CPG, **Chapter 3** describes how knowledge gaps related to effective ADL nursing interventions remain difficult to address. Interventions that effectively improve ADL independence (n=7) or comfort (n=7) vary greatly in terms of intervention components, outcome measures, and quality. Evidence on interventions, therefore, remains fragmented and inconclusive, leaving nursing professionals with insufficient guidance on effective care provision.

Recognizing the significance of the physical environment in both performing and delivering ADL care, the scope of the CPG was exceeded in **Chapter 4**. The conducted highlighted how a specific green care environment offers opportunities for meaningful ADL performance while fostering reciprocity in care dynamics between nursing home residents and staff members. This chapter challenges current perceptions of nursing professionals regarding their task obligations by expanding the environmental context of ADL nursing care. An integrated use of this environment, however, still requires a change in the level of care providers and organizations. Conclusively, the scientific underpinning ADL nursing care remains an unsolved puzzle in light of the complex multifactorial challenges and an inconclusive evidence base. Nevertheless, there is promise in exploring the potential benefits of incorporating green care environments into ADL nursing practices.

### Part II: Providing and Pilot Implementing Practical Guidance

Part II of this dissertation aimed to provide and pilot-implement practical guidance for nursing professionals across ADL-relevant care settings.

**Chapter 5** showed how the best available evidence was translated into a CPG for nursing professionals. Translating practical guidance involved summarizing the best available evidence into actionable recommendations for both care professionals. They prioritized the following five aspects of ADL nursing, for which recommendations were developed: (1) identifying ADL care needs, (2) involving the care receiver in ADL-related care choices, (3) providing effective interventions, (4) involving the informal caregiver, and (5) using ADL care to detect health risks. The expertise and experience of care receivers and providers, along with relevant (gray) literature, greatly contributed to the development of this CPG, considering the limited scientific evidence available. The CPG is published and authorized by the Dutch Association of Nursing Professionals (V&VN) as well as the Dutch Patient Organization. It is included in this dissertation through a provided web link.

Since the success of CPGs depends on their actual implementation in practice, a pilot implementation study was conducted in **Chapter 6**. This study aimed to measure the utilization of the CPGs' key recommendations (KRs) and to identify factors that either facilitate or hinder their use across different care settings. Seven nursing care teams from various ADL-relevant care settings who registered the use of the KRs showed that the usage of KRs varies among recommendations and across care settings. The most frequently used KRs were those involving care receivers in making ADL-related care choices. KRs were least applied to assessing ADL functioning. Although most factors supported the utilization of KRs, a lack of tension for change was identified as a hindering factor. Combining and translating scientific evidence, gray literature, and practical expertise into CPG modules on core areas of ADL nursing resulted in a comprehensive CPG. The KRs of the CPG were overall well received and applied in practice.

## Methodological Considerations

### Navigating Methodological Challenges in CPG Development and Its Research Designs—Coloring Outside the Lines?

This section will describe and reflect on the overall methodological considerations of this dissertation regarding the gaps in established methods of CPG development and the employed study designs. Aiming to scientifically underpin ADL care and provide practical guidance, a CPG for ADL nursing was developed. Internationally, CPGs are developed using the Appraisal of Guidelines, Research and Evaluation (AGREE) criteria [4]. The Advisory and Expert Group on Quality Standards (AQUA) guideline of the Dutch Care Institute offers additional guidance for the development and implementation of CPGs as a cornerstone of evidence-based medicine [5]. Both, AGREE and AQUA, specify that the initiation of CPG development should involve defining the scope and objectives. This implies that the questions to be addressed can indeed be resolved based on scientific literature. Furthermore, a panel of experts and stakeholders has been constituted including care professionals, care receivers, and methodological experts. Once the guideline panel and preparatory measures are in place, the actual CPG development starts with an analysis of challenges. For the CPG on ADL nursing, this analysis is described in

**Chapter 2** serving as the basis for formulating questions. These inquiries formed the starting point for the process of developing the CPG on ADL, primarily focused on synthesizing the most robust evidence that is currently available. Additional guidance in the process of searching, synthesizing, and appraising the quality of the best available evidence, as well as formulating recommendations, is provided by the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) Working Group (Figure 1) [6]. Standardized methods based on GRADE are used to formulate a "focused and sensible healthcare question" to summarize and grade the best available evidence [6, 7]. For a question to be focused and sensible, it is recommended to apply the PICO framework. As described in the GRADE handbook, a PICO question contains four components: the Patient (the patients or population to whom the recommendations are meant to apply); the Intervention (the therapeutic, diagnostic, or other intervention under investigation, such as the experimental intervention or, in observational studies, the exposure factor); the Comparison (the alternative intervention or intervention in the control group); and the Outcome (the outcome(s) of interest) [6].

### *Searching for Appropriate Methods in Light of Complex Yet Practical Challenges in ADL Nursing Care*

Our analysis of challenges in **Chapter 2** revealed that not all challenges could be formulated as questions that fit into the PICO structure and the processes recommended by GRADE. This was due to two reasons: First, the questions that were relevant to nursing professionals were mostly "non-interventional" in nature, as they focused more on the practical application of principles (such as shared decision-making or person-centeredness) instead of the effectiveness of interventions. In this transfer, the emphasis lies on how to integrate these principles into daily care processes and the soft skills and competencies required to accomplish this. While primarily designed for assessing the effectiveness of interventions, its application to non-interventional questions relevant to the ADL CPG is less straightforward. Secondly, the topic of ADL nursing care is understudied in scientific research, which limits its overall evidence base. GRADE strongly relies on the availability and quality of data, making it difficult to provide clear instructions on formulating a recommendation when there is limited or no scientific evidence available. Consequently, GRADE was found to be unsuitable for most types of clinical questions or situations. In fact, the only question that closely aligns with the suggested CPG structures and review methods is the question of effective ADL nursing interventions. Hence, our starting point for scientifically underpinning ADL care within the framework of a CPG was to identify effective nursing interventions for ADL that promote independence and comfort in **Chapter 3**. This was achieved through a systematic literature review using the PICO format. However, this methodological choice presented its own challenges.

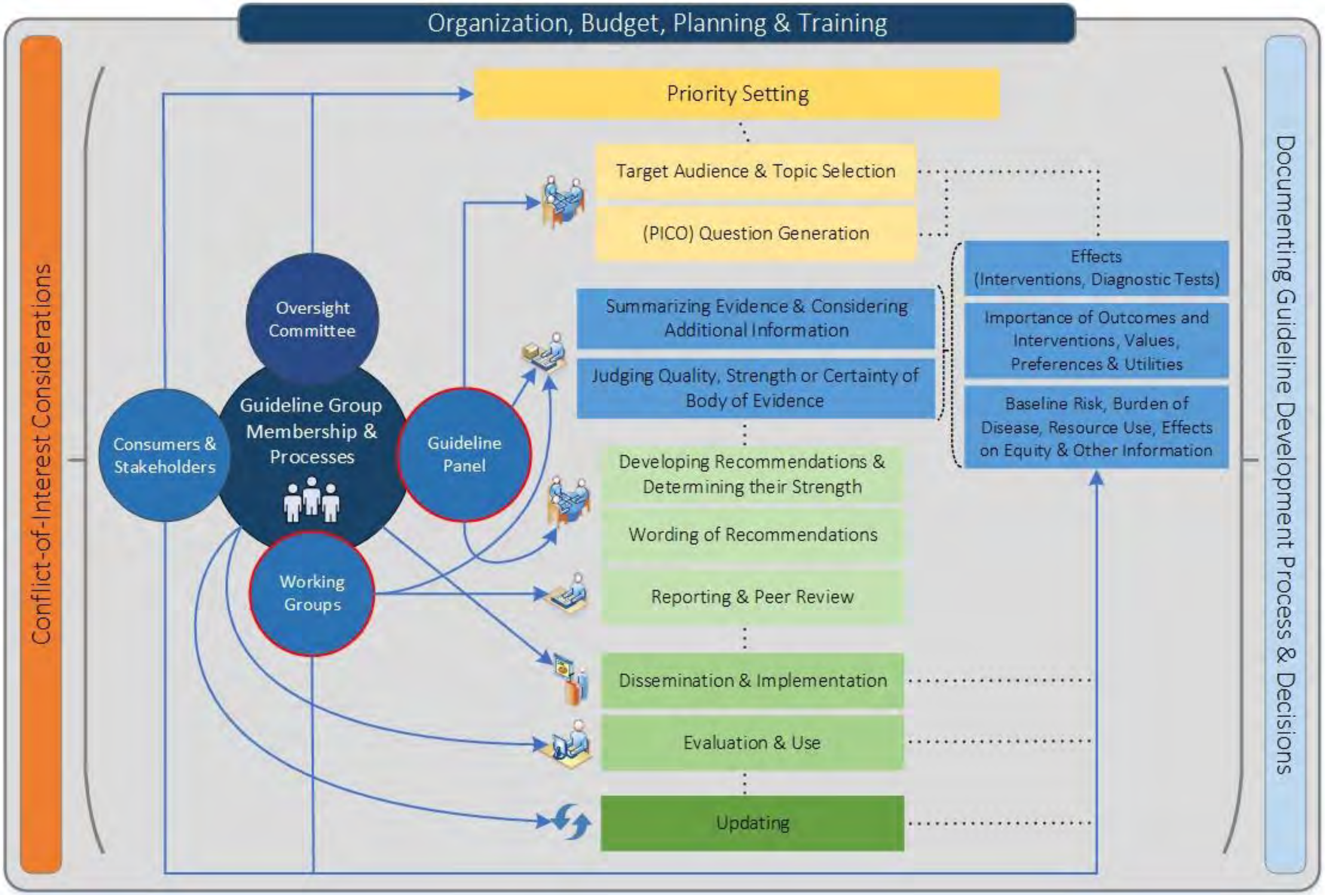

**Figure 1** The steps and involvement in a guideline development process as published in by Schünemann et al. [1]

ADL nursing care entails a wide range of interventions, whether they are focused on all aspects of ADLs or merely one specific activity like bathing or toileting. This type of care is provided irrespective of the care setting or diagnosis. Consequently, the PICO for this review was not specifically set for any particular group or intervention. Looking at the fragmented and ambiguous results and the available evidence, the question arises as to whether this was the right decision in hindsight. Current methodologies fall short in synthesizing outcome effects across diverse populations and interventions, particularly for broad topics and target groups as in ADL nursing care. While the PICO and GRADE approaches have proven to be beneficial for searching, summarizing, and evaluating evidence for a specific intervention in a particular setting, target group, and outcome, the question of the effects of different ADL nursing interventions across various care settings and populations goes beyond the scope of the conventional PICO structure.

When strictly adhering to GRADE and the recommended PICO structure, one is actually pre-sorting questions that leave little to no room for relevant issues beyond the effectiveness of the intervention. This observation meant that other methodological guidance had to be sought to develop an approach that properly incorporated the experience and expertise of the guideline panel, as well as the best available scientific evidence. AQUA and AGREE offer a certain margin for alternative methods, especially when there is a lack or insufficiency of evidence to summarize. However, these methods are often limited to the opinions, expertise, and experience of the guideline panel, which are identified based on consensus-based methods. The scientific literature describes a wide variety of consensus methods that range from explicit or formal methods (e.g., Delphi or Nominal Group Techniques) to more implicit or informal methods (e.g., unstructured consensus, majority votes) [8]. However, information on which method to use, and more specifically, how, is lacking in the common guidance documents, including AQUA, AGREE, and GRADE. In addition, while the process of searching for and selecting can be described transparently, establishing consensus informally in CPG development is often considered pragmatic and situation-dependent [9].

Given the scarcity of existing scientific literature, specifically on ADL nursing care as described in **Chapter 5**, recommendations mainly relied on indirect evidence, including adjacent literature from general nursing science or gray literature. For example, to address the question of how nursing professionals can involve care receivers in ADL-related care choices, evidence was synthesized from existing literature reviews, which often consisted of narrative studies. These findings were then summarized, interpreted, and presented to the guideline panel. In doing so, however, the most relevant evidence and its implications were summarized and selected while also adapting the language to conceptual recommendations or practice statements. The guideline panel then validated and specified the study results for ADL nursing care until reaching an informal consensus. Especially in light of the scarcity of evidence, informal consensus methods are considered appropriate when transparently documented [8]. Hence, all changes made in collaboration with the guideline panel were documented and distributed to all members and their constituents.

While this approach may have been unique in CPG development at the time, other methodological approaches are known in the scientific literature that encounter similar problems and follow similar steps. For example, Weiss et al. [10] describe challenges encountered in addressing “non-interventional” questions relating to ethical, legal, or implementation questions. Adhering to the GRADE criteria of good practice statements as described in [11] they found ways to make good practice statements largely informed by indirect evidence [10]. Moreover, Downe et al. [12] describe how the synthesis of qualitative evidence provides valuable insights into the concerns of various groups that may be affected by a CPG. They outline how qualitative evidence can shape the direction and scope of CPG development and provide crucial criteria for decision-making in the realm of CPGs. Besides, GRADE offers a system called GRADE-Cerqual [13] to systematically grade qualitative evidence. While their system holds promise for utilizing qualitative research in CPG development, it seems to be restricted to informing decisions on the acceptability, feasibility, advantages, and drawbacks of interventions. It might be worth exploring how qualitative research and indirect evidence can be used to answer complex yet practical questions close to the reality of nursing professionals and the individuals they care for.

Furthermore, current methods for developing CPGs based on the GRADE framework have a notable limitation in accounting for context-specific factors that can influence CPG recommendations. Considerations such as local healthcare resources, patient populations, and local clinical practices are not always fully addressed by GRADE. In response, this dissertation opted to employ an ethnographic approach in **Chapter 4** to address a question beyond the scope of the CPG. It investigated how the physical environment impacts ADL performance in nursing home residents. This ethnographic approach allowed for a comprehensive examination of how healthcare professionals, among others, utilize outdoor spaces and the potential benefits of integrating the physical environment with the abilities and competencies of care receivers. This broader methodological perspective provided valuable insights, serving as a foundation for a more comprehensive understanding of the contextual relevance of care. It includes the interplay and complexity of ADLs and their interventions, extending beyond a specific PICO question.

Consequently, when dealing with unique non-interventional questions, the possibilities to provide reliable recommendations within the framework were limited. An alternative approach could involve the development of additional guidelines from the GRADE working group tailored to handling pragmatic, yet complex and context-dependent questions. These guidelines could assist panel members in formulating recommendations for issues closely aligned with the practical aspects of care professionals' day-to-day responsibilities. Additionally, there is a call for further research to explore optimal approaches for creating recommendations and broadening the scope of questions within the scope of non-interventional questions.

### *The Role of the Guideline Panel: Prone to Bias?*

The aforementioned processes of selecting, summarizing, and interpreting evidence were necessary for the guideline panel to understand and process research findings. This allowed representatives of nursing professionals, occupational therapists, physiotherapists, and care receivers with varying educational backgrounds to comprehend the information.

Even though all panel members were offered training on CPG development, which included the grading of the available evidence, a significant responsibility rested on the developers to present the information accurately and appropriately. At the same time, without formal guidance, there is a certain level of subjectivity involved in processing and presenting scientific non-experimental evidence to guideline panels. Nonetheless, the guideline panel played a crucial role in translating the research findings into practical recommendations. Within the CPG literature, the importance of the guideline panel is well acknowledged, as well as its contribution towards increasing the acceptability and credibility of evidence-based recommendations [14]. Despite their importance, the role and value of the guideline panel and their opinions are debated in the literature. In both their 2015 and subsequent 2016 publications, Guyatt and colleagues emphatically advised against the excessive reliance on so-called ‘’good practice statements” (GPS) [11, 15]. GPSs when considered CPG recommendations should not be framed as a GRADEd. Guyatt et al. [15] voiced concerns that guideline panel members might perceive GPS as a shortcut to issuing a robust recommendation, even when faced with limited-quality evidence, potentially allowing them to bypass the rigorous and time-intensive process of conducting a thorough literature review and formal GRADE assessment. They point out that panels have faced criticism for misusing or misinterpreting formal GRADEd recommendations by relying on indirect or alternative evidence. Hence, several measures were implemented to ensure widespread support for both the translation of the evidence and the consensus-based adaptation of the draft recommendations. In addition to signing a conflict-of-interest statement, all members of the guideline panel were required to represent a professional or patient organization and advocate for their respective constituencies.

As mentioned before, the guideline panel, consisting of representatives of care professionals and care receivers, is of essential value to the development of CPGs since the panel members are considered experts in their respective fields. Moreover, the involvement of care receivers and their representatives played a vital role. While the CPG primarily targeted nursing professionals, the participation of care receivers ensured that the recommendations took into account the perspectives of care receivers in all modules. Additionally, the inclusion of occupational and physiotherapists enriched the CPG with valuable multidisciplinary expertise. However, the selection of panel members was primarily based on their experience with ADL care, their willingness to participate in the panel, and their additional training on guideline development. No mechanism was included in the selection of panel members to test their expertise on ADL-relevant topics, shared decision-making, or prior knowledge of reviewing scientific literature. The actual selection of panel members also depended on the responses from patient and professional organizations, as well as the developers' network, which may have increased the risk of selection bias.

Given that the ADL nursing CPG primarily relied on indirect evidence, it was crucial for both care professionals and care receivers to offer valuable and practical guidance based on their expertise and experience. Here, it may be clearly stated that a practice statement or recommendation can be considered "good" regardless of the underlying evidence. A good practice statement is particularly concerned with the clarity, necessity, and accessibility of the recommendation and its underlying evidence. In our opinion, professionals in the nursing field are in the best position to do this. These practice statements or recommendations were, therefore, neither formally GRADEd nor of high evidential value. At the same time, the significant role of the guideline panel ensured that the recommendations made were perceived as highly applicable as demonstrated in **Chapter 6.**

## Theoretical Considerations

### Examining ADL Nursing Care Through the Lens of the Fundamentals of Care Framework: A Theoretical Perspective

*The Role of Theoretical Frameworks in Nursing Practice*

While the nursing profession is grounded in theory and practice, nursing theories help shape values and person-centered approaches to care [16]. They are as significant as EBP, providing insight into the roles of nurses in healthcare settings. Both EBP and nursing practice guided by theory are essential for knowledge development and improving the quality of care [17]. When theories inform nursing care, nursing professionals are supported in reflection, critical thinking, and decision-making [17]. In terms of fundamental aspects of nursing, such as ADL care, there has been a lack of theoretical developments. This has led to a shortage of insights grounded in theory and subsequent initiatives to enhance both the delivery of ADL nursing care to patients and the management of the nursing workforce [18]. Kitson [18] was the first to develop a theoretical framework that provides guidance and predicts nursing interactions at the point of care. This framework, known as the FoC framework (Figure 2), helps nurses navigate and balance the various influences [19]. The FoC framework outlines three core dimensions for delivering high-quality fundamental care: (1) Establishing a trusting therapeutic relationship between the care receiver and the care provider, (2) Addressing the physical, psychosocial, and relational needs of individuals, and (3) Creating a supportive context of care that promotes relationship development and care integration [19]. This section of the dissertation presents the findings in relation to the framework.

### *A Trusting Therapeutic Care Relationship*

As an important prerequisite for addressing both physical and psychosocial care needs, the FoC framework, along with other research on nursing theories [20-22], emphasizes the central role of the care relationship [18]. This relationship is regarded as a precondition for effective nursing interventions [22] to moderate risk and optimize recovery, well-being, and independence [23], and it is a major part of nursing practice [24]. The challenges outlined in **Chapter 2**, which include a limited understanding of ADL care needs and a task-oriented care approach, are closely linked to the absence of a therapeutic and trusting care relationship.

Upon examining interventions aimed at optimizing care receiver outcomes, it is evident that the majority of these interventions rely on the behavior of nursing professionals in ADL care. These interventions emphasize the importance of interaction and collaboration with the care receiver, either in response to their behavior or to promote physical activity. The interventions discussed in **Chapter 3** involved various interactions, including reciprocity with the social environment [25], verbal encouragement and cues, self-modeling [26-28], and positive gestures like greetings or praise [29]. Moreover, when ADLs are performed in a setting that is not directly associated with caregiving, such as a green care environment outside, it creates opportunities to foster a therapeutic care relationship. This approach also recognizes and utilizes the expertise, knowledge, and skills of the individuals receiving care. **Chapter 4** explored how dynamics within the relationship change in a different care context while also strengthening reciprocity. These opportunities are then used to enhance performance in ADL and promote physical activity. The collaborative relationship is also included as a central recommendation in the CPG, as described in **Chapter 5.** This recommendation involves actions such as ensuring privacy, collaborating on an equal basis, respecting the care receiver’s preferences in ADLs, and being aware of one’s communication style. n practical application, as demonstrated in **Chapter 6** of this dissertation, it was observed that the nursing professionals most frequently implemented the KR to enhance the care relationship. his dissertation emphasizes the fundamental importance of fostering an equal caregiving relationship within high-quality ADL care and intervention development. It illustrates how the dynamics of this relationship evolve in distinct contexts. Moreover, this dissertation highlights that establishing a trusting care relationship is a primary focus when implementing CPG recommendations in practice.

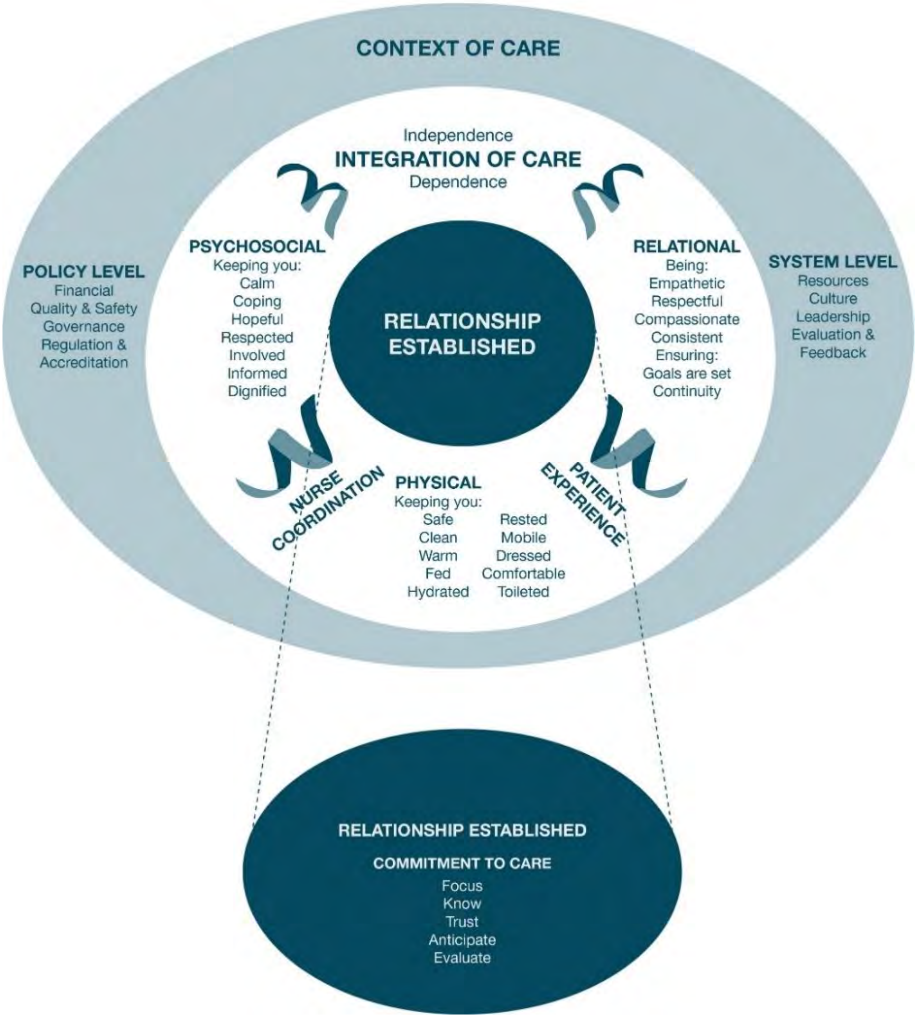

**Figure 1** The fundamentals of care framework from Feo et al. [2] used with permission presented in Rey et al. [3]

*Integrating and Meeting a Person's Physical, Psychosocial, and Relational Care Needs*

The FoC framework offers a nuanced understanding of care dynamics necessary for integrating different ADL care needs [30]. It comprises three dimensions of care, including the relationship, the integration of care needs, and the context of care. Within this framework, fundamental nursing care is committed to respecting individuals' essential needs, which include physical needs (e.g., ADLs, safety, and rest), psychosocial needs (e.g., dignity, privacy, engagement, and access to information), and relational needs (e.g., attentive listening, support, and collaborative goal attainment with care providers). The FoC framework underscores the imperative of integrating these dimensions—physical, psychosocial, and relational—within the care environment and its contextual setting [19]. This dissertation contributed to transforming elements of this framework into actionable guidance, striving to integrate care needs. Initiating the CPG development by defining the scope of ADL care initially seemed to focus primarily on addressing physical needs, such as toileting, feeding, and other bodily care activities. However, the synthesis of challenges in **Chapter 2** highlights issues in recognizing and evaluating various aspects of ADL care needs, extending beyond physical assistance. Notably, nursing professionals sometimes overlook the emotional needs of receivers. Both, care receivers as well as nursing professionals stress the importance of maintaining dignity and humanity in ADL care, as it can evoke emotions of vulnerability, fear, frustration, and being overwhelmed. Moreover, the psychosocial and relational aspects of ADL care are easily neglected in routine and task-oriented approaches, which can potentially compromise the person-centeredness of care [31]. In line with the FoC framework, this dissertation advocates for an integrated view of ADL nursing care that includes a comprehensive assessment of care needs. This is why the CPG, as described in **Chapter 4**, recommends assessing both functional ADL performance and subjective experiences (e.g., perceived complaints, feelings, and habits) related to ADLs, as well as contextual components (e.g., built and social environment).

Furthermore, the FoC framework emphasizes the significance of “being informed” and “being involved” in addressing psychosocial care needs. This is evident in the deliberate inclusion of shared decision-making principles as stated in **Chapter 5** of the CPG. Especially in ADL care, a variety of opportunities arise in which care receivers can be involved in choices that are closely related to their daily life and personal identity. For example, they can be involved in setting ADL goals (such as choosing which aspects they aim to re-gain (partial) independence in) or in making care agreements (such as deciding what they can do for themselves? Where does one prefers to wash oneself? In the bed, shower, or sink? Which products are used?). This dissertation emphasizes the responsibility of nursing professionals to inform care receivers about the possible advantages or drawbacks of not actively participating in care tasks while honoring their decisions, even if they diverge from personal or professional beliefs. Moreover, this dissertation addressed and recognized the psychosocial aspects of care needs for ADL by choosing the outcomes when searching for effective ADL nursing interventions in **Chapter 3.** Instead of limiting the selected outcomes to ADL independence, comfort was deliberately added as a crucial outcome of ADL nursing care. Comfort was understood and defined as a multidimensional concept that encompasses both physical and emotional well-being.

### *The Context of Care*

The final dimension of the FoC framework acknowledges the significant influence of the systems and organizations within which nursing professionals provide care. The FoC delineates important system and policy prerequisites essential for enabling effective fundamental care delivery [15]. These prerequisites encompass various elements such as resources (both physical and human), organizational culture, leadership practices, and evaluation mechanisms. Additionally, policy-related necessities involve financial allocations, an emphasis on quality and safety, robust governance procedures, and regulatory adherence.

This dissertation acknowledges the importance of context in ADL nursing in different ways. While contextual barriers are not uncommon in nursing in general, we described those relevant to ADL nursing in **Chapter 2**. Contextual barriers can include hindering organizational structures, culture, and regiments, as well as a lack of resources and limitations of the physical environment. These contextual challenges are complex, and addressing them would require a comprehensive approach, potentially including system-level changes (e.g., policies, regulatory standards, or resource allocation), organizational restructuring (e.g., hierarchies and workflows), or cultural transformation (e.g., fostering patient-centered care, open communication, and mutual reflection and collaboration).

Therefore, when addressing the contextual aspect of ADL nursing care, our focus was directed toward environmental factors that fall within the sphere of influence of nursing professionals. **Chapter 4**, demonstrated how a different context and environment enable care professionals to purposefully integrate the physical, psychosocial, and relational dimensions of care. For example, activities in a physical green care environment motivate nursing home residents to get out of bed and ready to engage in physical activity, while their participation fosters reciprocity in the caregiver-resident relationship.

Moreover, this study specified the definition of context in the FoC framework. In terms of the physical care environment, it was initially limited to *“physical resources in terms of environment, equipment, infrastructure […]”* [30]. Focusing specifically on the outdoor spaces of a care environment was considered a unique approach to illuminating how nursing professionals support care receivers in their ADLs. This was achieved by integrating their abilities and preferences within the overall context of care.

## Future Directions

This dissertation's results highlighted several implications for policy, practice, and research.

### Policy

The findings in this dissertation clearly illustrate the complexity of ADL nursing care and its associated challenges in **Chapter 2**. Policymakers play an important role in addressing these challenges, for example by fostering a sociocultural shift within society. This shift should be targeted toward recognizing and acknowledging the complexity and value of ADL nursing. Policymakers can use this dissertation to provide information on ADL nursing care by e.g. national campaigns or by paying special attention to quality ADL care by honoring care organizations integrating the CPG in daily processes.

The content of this dissertation and the CPG result in further efforts of policymakers in dissemination activities. These efforts include regularly assessing policy frameworks and the positioning of ADL nursing care ensuring that the narrative matches the importance for care receivers as well as the complexity for care nursing professionals. Moreover, efforts should be directed toward minimizing system-level and environmental barriers (e.g. gaps in education, unfitting ADL work and care environments, and electronic patient record systems) that limit the quality of ADL care provided. Policymakers might promote the standardization of electronic patient record systems and improve comprehensive ADL handovers within and between care settings.

Furthermore, policymakers should allocate funding for further research underpinning ADL nursing care by using these dissertation findings to prioritize research in the field of ADL nursing care and by supporting research grants for academic institutions, and healthcare organizations to collaboratively conduct further research on ADL nursing care. In doing so, policymakers should put continuous efforts into involving nursing professionals and ADL care receivers in decision-making.

### Practice

In addressing the challenges identified in **Chapter 3**, care organizations and managers play a crucial role in future improvements of ADL nursing. Quality ADL nursing should be integrated into organizational visions and policies informing their staff and putting the importance and value of quality ADL nursing high on the agenda of meetings of multi and monodisciplinary staff and meetings with management. Improving the quality of ADL nursing care could be achieved by fostering mechanisms to implement and monitor adherence to the CPGs, particularly the CPG on ADL nursing care described in **Chapter 5.** To empower nursing professionals to integrate the CPG recommendations, healthcare management should grant them the flexibility to customize CPG-based ADL nursing care according to the care receiver's preferences. This entails ensuring that nursing professionals e.g. have access to a different set of bathing materials to offer choices, or to plan care activities irrespective of meal-time care or other organizational processes (e.g. fixed shower moments).

Moreover, care organizations should work towards establishing a continuous culture of learning to break circles of routine-based care and facilitate a needed tension for change as explained in **Chapter 6**. Organizations therefore should work towards a workplace atmosphere in which nursing professionals can comfortably engage in reflective practice, feeling both secure and motivated to assess their work without apprehension of negative consequences. This entails cultivating a culture that welcomes the opportunity to learn from errors.

Care organizations could furthermore benefit from insights from **Chapter 4** by understanding the potential of the outside environment. Organizations might want to explore the presence of purpose- and meaningful activities outside the regular care environment (e.g. caring for plants or animals). These efforts might strengthen the care relationship and increase a more purposeful ADL performance.

While acknowledging the importance of policymakers and organizations in establishing conditions and contexts that adequately address challenges in ADL care, it is essential to emphasize the major implications this dissertation has for nursing professionals. Firstly, nursing professionals need to incorporate the recommendations outlined in the CPG into their daily care routines as described in **Chapter 5.** Additionally, nursing professionals should look for opportunities for meaningful engagement in ADL care provision within and beyond the traditional care environment such as explored in Chapter 4. Moreover, nursing professionals should feel encouraged to reflect on their day-to-day care provision and to ask why care is provided a certain way. Furthermore, nursing professionals can challenge themselves to further incorporate the perspectives of care receivers and informal caregivers in daily care provision.

### Education

The findings of this dissertation are also significant for nursing educators, who hold substantial influence in shaping the beliefs, skills, and competencies of nursing students – the future generation of nursing professionals. As fundamental aspects of nursing such as ADL nursing care seem overall invisible in education [32], ADL care, its complexity, and value should be more explicitly emphasized in nursing curricula. An integrating the ADL nursing CPG into nursing curricula in applied sciences as well as vocational education, future nursing professionals can be better prepared to navigate the complexities of ADL nursing care and provide high-quality, person-centered care. Within this integration, special attention should be paid to the complexity and the value of ADL nursing care beyond established, task-based protocols (e.g. Vilans Kick-Protocollen).

## Research

There is a need to conduct more research on ADL nursing care. Chapter 3 advocates for the further conduct of high-quality experimental studies to further underpin the effectiveness of interventions in ADL care. However,  given the complexity and context-dependency of ADL care, it is crucial not only to ascertain *whether* an intervention works, but especially to understand what works for whom, under what circumstances, and most importantly *why*. [33]. Our findings emphasize the need for increased focus and a reevaluation of ADL nursing as a fundamental aspect of nursing care. Future research should put continuous efforts into addressing the challenge of underpinning ADL nursing care. Realist evaluations offer a promising approach to understanding these complexities, delving into underlying mechanisms and their interaction with context [33-36]. Having established how a different context changes the way ADLs are performed in **Chapter 4,** calls for a closer look at the environments in which mechanisms function and the conditions under which they can be successfully implemented [36].

Furthermore, **Chapter 6** has provided initial insights into influencing factors and the extent of CPG usage. Considering the importance of guidelines for evidence-based nursing, especially in essential care such as ADL care, it emphasizes the significance of further research on the sustainable use of guidelines. Additionally, in translating evidence into guidance for nursing professionals, researchers should refine and validate CPG development methods to effectively address the complexities of ADL nursing. With this dissertation demonstrating limitations and opportunities in answering relevant questions with limited evidence, further research is needed to support future CPG developers in guiding care professionals.

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# Addenda

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# Summary

## Summary

The overall aim of this dissertation was to scientifically underpin ADL nursing care and provide guidance for nursing professionals. This dissertation is therefore divided into two parts. As a starting point, challenges in ADL nursing care were identified through a mixed qualitative design in Chapter 2. This study demonstrated how ADL nursing care is still defined by a paradoxical narrative torn between undervalued common-sense work and complex, highly skilled care provision. This ambivalence is also reflected in the varying quality of clinical decision-making in ADL care by nursing professionals and the inconsistent involvement of care receivers and their informal caregivers in those decisions. At the same time, nursing professionals face system-level and environmental barriers that make it challenging to meet and integrate the needs of care receivers in their daily care situations.

To tackle one of these challenges, a systematic literature review was conducted in **Chapter 3**. The aim was to gain valuable insights into the impact of ADL interventions. These insights could then be used by nursing professionals to maximize care receivers' ADL independence and comfort. We found seven interventions that effectively improve independence and another seven that effectively improve comfort. However, studies varied greatly in terms of intervention components, outcome measures, and quality. Hence, the fragmented and inconclusive evidence base on interventions affecting independence and comfort has previously left nursing professionals with insufficient guidance on effective care provision, which exacerbates the challenges that have been identified.

In **Chapter 4**, we conducted a rapid ethnographic case study to understand how the physical (green) care environment is used to facilitate ADL performance. This study highlights the opportunities for meaningful performance of ADL in this environment, as well as the potential for strengthening the care relationship between nursing home residents and staff members. This chapter challenges current perceptions of nursing professionals regarding their task obligations by expanding the environmental context of ADL nursing care. An integrated use of this environment, however, still requires a change in the level of care providers and organizations.

Part II of this dissertation aimed to translate the evidence on ADL care into practical guidance. As a next step, the best available evidence was summarized in a Dutch CPG on ADL nursing care for nursing professionals and care receivers across various care settings in **Chapter 5**. The expertise and experience of care receivers and providers, along with relevant (gray) literature, greatly contributed to the development of this CPG, considering the limited evidence available. This CPG consists of five modules: (1) identifying ADL care needs, (2) involving the care receiver in ADL-related care choices, (3) providing effective interventions, (4) involving the informal caregiver, and (5) using ADL care to detect health risks.

Since the success of the CPGs relies on their actual implementation in practice, a pilot implantation study was conducted in **Chapter 6** to measure the use of the CPGs' KRs and to identify factors that either facilitate or hinder their use across different care settings. Seven nursing care teams from various ADL-relevant care settings who registered the use of the KRs showed that the usage of KRs varies among recommendations and across care settings. The most frequently used KRs were those involving care receivers in making ADL-related care choices. KRs were least applied to assessing ADL functioning. Although most factors supported the utilization of KRs, we pinpointed a lack of tension for change as a hindering factor. The main findings and implications of this dissertation's results are discussed in **Chapter 7**. Methodological considerations are also addressed, encompassing an examination of existing techniques for CPG development along with their limitations. On a theoretical level, the findings of this dissertation are viewed through the lens of the Fundamentals of Care Framework, thereby providing a conceptual backdrop for ADL nursing care. This dissertation is a valuable resource for elevating the quality and continuity of ADL nursing care and enhancing the daily lives of individuals who receive such care.

# Samenvatting

## Samenvatting

Het overkoepelende doel van dit proefschrift was het om zorg bij Algemene Dagelijkse Levensverrichtingen (ADL) wetenschappelijk te onderbouwen, handvaten te bieden en deze te testen. Dit proefschrift is opgedeeld in twee delen:

Als vertrekpunt voor de wetenschappelijke onderbouwing van de verpleegkundige zorg voor ADL, hebben we eerst de knelpunten geïdentificeerd in een ons kwalitatieve mixed-methods onderzoek in **Hoofdstuk 2.** Dit onderzoek toonde aan hoe de verpleegkundige zorg voor ADL nog steeds wordt beïnvloed door een paradoxale vertelling, verscheurd tussen ondergewaardeerd gezond verstandswerk en complexe, hooggeschoolde zorgverlening. Deze ambivalentie wordt ook weerspiegeld in de wisselende kwaliteit van de klinische besluitvorming in de verpleegkundige zorg voor ADL en de fluctuerende manier waarop zorgontvangers en hun informele zorgverleners bij deze beslissingen worden betrokken. Tegelijkertijd dagen systeemniveau- en omgevingsbarrières verpleegkundige professionals uit om aan de behoeften van de zorgontvangers te voldoen en deze te integreren in de dagelijkse zorgsituaties.

Om een van deze uitdagingen te beantwoorden, voerden we een systematische literatuurreview uit die beschreven is in **Hoofdstuk 3.** We wilden inzicht krijgen in de effecten van ADL-interventies die door verpleegkundigen of verzorgenden kunnen worden ingezet om de onafhankelijkheid en het comfort van de zorgvragers te maximaliseren. We vonden zeven interventies die de onafhankelijkheid effectief verbeterden en nog eens zeven die het comfort effectief verbeterden. Echter, verschilden de studies sterk in interventiecomponenten, uitkomstmaten en kwaliteit. Eerder geïdentificeerde uitdagingen worden dus versterkt door een gefragmenteerde en niet overtuigende bewijslast over interventies die van invloed zijn op onafhankelijkheid en comfort, waardoor verpleegkundigen en verzorgenden onvoldoende handvaten hebben voor effectieve ADL-zorgverlening.

In **Hoofdstuk 4** voerden we een ‘rapid etnografische casestudy’ uit om te begrijpen hoe de fysieke (groene) zorgomgeving wordt gebruikt om het ADL functioneren te bevorderen. Ons onderzoek benadrukt hoe deze omgeving kansen biedt voor een betekenisvolle ADL-uitvoering en tegelijkertijd de zorgrelatie versterkt tussen verschillende bewoners van het verpleeghuis en medewerkers. Dit hoofdstuk daagt het beeld van zorgverleners uit over hun rollen en taken in deze omgevingscontext. Een geïntegreerd gebruik van deze omgeving vraagt om een verandering op het niveau van zorgverleners en organisaties.

Deel II van dit proefschrift had als doel om het bewijs van ADL-zorg te vertalen naar praktische richtlijnen, die samengevat is in **Hoofdstuk 5**. Als volgende stap hebben we het beste beschikbare bewijs samengevat in een Klinische Praktijkrichtlijn (CPG) voor ADL-verpleegkundige zorg voor verpleegkundige professionals en zorgontvangers in verschillende zorginstellingen (Hoofdstuk 5). Deze CPG bestaat uit vijf modules: (1) het identificeren van ADL-zorgbehoeften, (2) de zorgontvanger betrekken bij ADL-gerelateerde zorgkeuzes, (3) effectieve interventies bieden, (4) de informele zorgverlener betrekken en (5) ADL-zorg gebruiken om gezondheidsrisico's op te sporen. De expertise en ervaring van zorgontvangers en zorgverleners, evenals gerelateerde (grijze) literatuur, hebben aanzienlijk bijgedragen aan de ontwikkeling van deze richtlijn gezien het beperkte bewijsmateriaal.

Aangezien het succes van de richtlijn afhangt van het daadwerkelijke gebruik in de praktijk, hebben we een proefimplementatiestudie uitgevoerd zoals beschreven in **Hoofdstuk 6.** Hierin hebben we het gebruik van de kernaanbevelingen gemeten en factoren geïdentificeerd die het gebruik van de kernaanbevelingen beïnvloeden. Zeven zorgteams uit alle relevante ADL-zorginstellingen registreerden het gebruik van de kernaanbevelingen en vulden een enquête in over beïnvloedende factoren. In een focusgroep ontvingen we aanvullende informatie over de uitvoerbaarheid van de kernaanbevelingen in de praktijk. Hoe de werden gebruikt, varieerde tussen de aanbevelingen zelf en de verschillende zorginstellingen. Ondanks de meeste factoren het gebruik van de kernaanbevelingen leken te ondersteunen, moet er speciale aandacht worden besteed aan een lage ervaren noodzaak tot verandering.

De belangrijkste bevindingen en implicaties van de resultaten van dit proefschrift worden besproken in **Hoofdstuk 7.** We behandelden tevens ook methodologische overwegingen, door bestaande technieken voor de ontwikkeling van richtlijnen samen met hun beperkingen te bediscussiëren. Op theoretisch niveau worden de bevindingen van deze dissertatie bekeken door de lens van het Fundamentals of Care Framework, waardoor een conceptueel kader wordt geboden voor ADL zorg door verpleegkundigen en verzorgenden.

Deze dissertatie is een waardevolle bron voor het verhogen van de kwaliteit en continuïteit van ADL-verpleegkundige zorg en het verbeteren van het dagelijks leven van individuen die dergelijke zorg ontvangen.

# Zusammenfassung

## Zusammenfassung

Das übergeordnete Ziel dieser Dissertation war es, die Pflege bei den Aktivitäten des täglichen Lebens (ATL) wissenschaftlich zu untermauern, Richtlinien bereitzustellen und diese zu testen. Diese Dissertation ist darum in zwei Teile unterteilt:

Als Ausgangspunkt für das wissenschaftliche Fundament der ATL Pflege haben wir zunächst die Herausforderungen in einer qualitativen Mixed-Methods-Studie identifiziert, die wir in **Kapitel 2** beschreiben. Diese Studie zeigte, wie die ATL Pflege immer noch von einem paradoxen Narrativ beeinflusst wird, zerrissen zwischen Arbeit basierend auf unterbewertetem gesundem Verstand und komplexer, hochqualifizierter Pflege. Diese Ambivalenz spiegelt sich auch in der variablen Qualität der klinischen Entscheidungsfindung und der schwankenden Art und Weise wider, wie Pflegeempfänger*innen und pflegende Angehörige in diese miteinbezogen werden. Gleichzeitig fordern Hindernisse auf Systemebene und in der Umgebung Pflegefachkräfte heraus, den Bedürfnissen der Pflegeempfänger*innen gerecht zu werden und diese in den täglichen Pflegesituationen zu integrieren.

Um einer dieser Herausforderungen zu begegnen, führten wir in **Kapitel 3** eine systematische Literaturstudie durch. Wir wollten Einblicke in die Auswirkungen von ATL-Interventionen erhalten, die von Pflegefachkräften oder Pflegehilfskräften eingesetzt werden können, um die Unabhängigkeit und den Komfort der Pflegeempfänger*innen zu maximieren. Wir fanden sieben Interventionen, die die Unabhängigkeit effektiv verbesserten, und weitere sieben, die den Komfort effektiv verbesserten. Die Studien unterschieden sich jedoch stark in den Interventionskomponenten, den Ergebnismessungen und der Qualität. Früher identifizierte Herausforderungen werden somit durch eine fragmentierte und nicht überzeugende Beweislage über Interventionen, die die Unabhängigkeit und den Komfort beeinflussen, verstärkt, was den Pflegefachkräften und Pflegehilfskräften unzureichende Richtlinien für eine effektive ATL-Pflege bietet.

In **Kapitel 4** führten wir eine schnelle ethnografische Fallstudie durch, um zu verstehen, wie die physische (grüne) Pflegeumgebung genutzt wird, um die ATL-Funktionalität zu fördern. Unsere Forschung betont, wie diese Umgebung Möglichkeiten für eine sinnvolle ATL Ausführung bietet und gleichzeitig die Pflegebeziehung zwischen verschiedenen Bewohner*innen des Pflegeheims und Mitarbeitenden stärkt. Dieses Kapitel fordert das Bild der Pflegefachkräfte über ihre Rollen und Aufgaben in diesem Umgebungskontext heraus. Eine integrierte Nutzung dieser Umgebung erfordert eine Veränderung auf der Ebene der Rollenbilder der Pflegekräfte unterstützt durch die Organisationen.

Teil II dieser Dissertation hatte zum Ziel, die Beweise für ATL-Pflege in praktische Leitlinien zu übersetzen. Als nächsten Schritt haben wir das beste verfügbare Beweismaterial in einer Klinischen Leitlinie für ATL-Pflege für Pflegefachkräfte in verschiedenen

Pflegeeinrichtungen zusammengefasst, die wir in **Kapitel 5** beschreiben. Diese Leitlinie besteht aus fünf Modulen: (1) Identifizierung der ATL-Pflegebedürfnisse, (2) Einbeziehung von Pflegeempfänger*innen in ATL-bezogene Pflegeentscheidungen, (3) Bereitstellung effektiver Interventionen, (4) Einbindung und Zusammenarbeit pflegender Angehörigen und (5) Nutzung der ATL-Pflege zur Früherkennung von Gesundheitsrisiken. Die Expertise und Erfahrung der Pflegeempfänger*innen und Pflegefachkräfte sowie die verwandte (graue) Literatur haben erheblich zur Entwicklung dieser Richtlinie beigetragen, da das Beweismaterial begrenzt ist.

Da der Erfolg der Leitlinie von ihrer tatsächlichen Anwendung in der Praxis abhängt, führten wir in **Kapitel 6** eine Pilotimplementationsstudie durch. Hier haben wir die Anwendung der Kernempfehlungen aus der Leitlinie gemessen und Faktoren identifiziert, die die Anwendung der Kernempfehlungen beeinflussen. Sieben Pflegeteams aus allen relevanten ATL-Pflegeeinrichtungen dokumentierten die Anwendung der Kernempfehlungen und füllten einen Fragebogen zu beeinflussenden Faktoren aus. In einer Fokusgruppe erhielten wir zusätzliche Informationen zur Umsetzbarkeit der Kernempfehlungen in der Praxis. Wie die Empfehlungen verwendet wurden, variierte zwischen den Empfehlungen selbst und den verschiedenen Pflegeeinrichtungen. Obwohl die meisten Faktoren die Anwendung der Kernempfehlungen zu unterstützen schienen, muss besondere Aufmerksamkeit auf eine geringe wahrgenommene Notwendigkeit zur Veränderung gelegt werden.

Die wichtigsten Ergebnisse und Implikationen der Ergebnisse dieser Dissertation werden in **Kapitel 7** diskutiert. Wir behandeln zudem auch methodologische Überlegungen, indem wir bestehende Techniken für die Entwicklung von Leitlinien sowie ihre Einschränkungen diskutieren. Auf theoretischer Ebene werden die Ergebnisse dieser Dissertation durch die Linse des Fundamentals of Care Framework betrachtet, wodurch ein konzeptioneller Hintergrund für die ATL-Pflege durch Pflegefachkräfte und Pflegehilfskräfte geboten wird. Diese Dissertation ist eine wertvolle Ressource zur Verbesserung der Qualität und Kontinuität der ATL-Pflege und zur Verbesserung des täglichen Lebens von Personen, die solche Pflege erhalten.

# Impact

## A Transformative Journey: From Challenges to Guidance in Improving ADL Nursing Care

### Introduction

Meet Emilia, a passionate certified nursing assistant (CNA) dedicated to improving how she supports persons in ADL. Her journey uncovers a series of challenges, leading to insights that promise to empower the way she and her colleagues approach ADL care. Join us as we discover Emilia’s notable findings, shaping the future of ADL nursing care.

### Part I: Discovering Challenges in ADL Nursing

In the first leg of her journey, Emilia dives deep into the world of ADL nursing care. She engages in conversations with her colleagues and the persons she cares for, and she also reads different studies to understand the challenges that come with ADL care in **Chapter 2**. Emilia encounters paradoxes: She discovers that ADL care is somewhat similar to a seesaw. On one side, it seems like everyday tasks that we might not think much about. But looking closer, it turns out there’s a whole layer of complexity to it. It's like a puzzle – sometimes straightforward, sometimes surprisingly detailed!” Through her work, she sees that sometimes, care decisions can be a bit uncertain, and the people receiving care and their families might not always be as involved as they should be. Alongside, she encounters barriers in the environment and the healthcare system, which makes it harder to provide quality care.

Emilia also notices that there’s a lot we still don’t know about what works best when it comes to ADL care in **Chapter 3.** Emilia learns that some ways to care can really make a big difference in how independent and comfortable people feel. She discovered that there are many different ways to help people with their daily activities. It’s like putting together a puzzle with lots of different pieces, all different in how they measured effect and how good they were. Some effective ways of caring to make people more independent include setting goals and encouraging them to perform activities as independently as possible. Other ways are about assisting people with eating while having them remember and perform various steps with longer and longer gaps in between. Emilia also discovers that there are a lot of different ways to make people feel comfortable during care activities. One approach that makes the experience of bathing less stressful is customizing the whole experience to a person's likes and dislikes. So, finding the best way to help isn’t always easy. Sometimes, the evidence about what works best for whom is like a big question mark.

Then, Emilia found something special. She learned that being in a natural, green environment might make a difference in **Chapter 4.** Emilia realizes that even activities outdoors with animals have a close relation to ADLs and that there are a lot of opportunities to involve a person in them.  And, it’s not just about getting things done but about creating a special connection between herself and the people she cares for. This was a big change, and Emily knew it would take effort from everyone involved.

### Part II: From Evidence to Action – A Tapestry of Knowledge

Emilia’s journey takes an exciting turn as she turns her findings into practical advice. She carefully puts together a Clinical Practice Guideline for ADL care in **Chapter 5.** This CPG covers important things like understanding what the people she cares for really need, how to involve them or their families, and what she can do to help people become more independent and comfortable during ADL care. As Emilia puts her ideas into action, she learns that being open to change is really important in **Chapter 6**. Emilia noticed that her coworkers often believe they are following the guidelines, but she isn't so sure about it. When she visited other healthcare facilities, she saw that most of her colleagues there were trying hard to include the people receiving care in the decisions about their care, which made her happy. However, she also noticed that in some places they weren't properly assessing how well the people receiving care could perform these activities on their own. However, Emilia realized that to make the new care guidelines effective in real healthcare settings, certain things needed to be considered. For instance, the recommendations should be easy to incorporate into the way she and her colleagues actually work, and she and her co-workers like to feel supported in applying the recommendations in care.

Emilia’s journey has paved the way for a brighter future in ADL nursing care. She skillfully blends what we know works best with her own real-life experience, creating a set of recommendations that will serve as a solid foundation for both herself and her colleagues. Emilia’s journey helped her realize the importance of improving everyday care. Even though it’s not always easy, she is eager to keep learning!

## Societal Impact

### The Impact of Co-Creation on Providing Practical Guidance

The CPG, which is a central part of this dissertation, directly impacts nursing professionals who provide ADL care and the individuals who receive it. This work highlights how both parties played a crucial role in shaping the CPG. In different phases, the expertise and experience of different stakeholders were integrated, including formally mandated care receivers (Dutch Patient Federation, Burgerkracht Limburg) and care providers (Nursing professionals (V&VN), physiotherapists (KNGF), and occupational therapists (EN)). Their expertise and experiences ensured that the CPG reflected real-world needs and was patient-centered, relevant, and practical. This approach also encourages better acceptance and adherence to recommended practices. The CPG and related documents offer practical advice for nurses, emphasizing the importance of involving care recipients in decisions regarding their ADL care. Throughout the development process, a diverse group of professionals and care receivers provided valuable insights and feedback on the recommendations. This approach resulted in nursing professionals experiencing their voice being heard and being eager to contribute towards future CPG development as CNA stated in an interview with the Dutch Journal for CNAs

*"It's interesting and you can learn a lot, and you get to connect with people from other fields. On top of that, I received a reimbursement […] for each meeting. It's leaving me hungry for more – I'm going to start helping write CPGs for dealing with challenging behavior at home, and I'm also chipping in on the CPGs for dealing with itching. I think it's important for us CNAs to speak up because we're the biggest group in our profession, and lots of issues affect what we do. And, to be honest, it's actually really enjoyable!"*

[CNA who participate in the CPG panel, as stated in the interview published in Kragt [1]]

Similarly, the voice of care receivers was heard in the CPG development process. It was especially valuable to maximize the person-centered nature of the CPG in that not only representatives of care receivers participated in the panel but actual ADL care receivers shared their experiences with the care provision and their ideas for improvement.

*"It's so important to me that care professionals see me as a person. We should move towards ADL care that is completely tailored to the experience of the person."*

[Care receiver and representative of care receivers in the CPG panel]

### Practice and Education

This dissertation and the CPG contribute to improvements in practice and education. Understanding the challenges in ADL nursing care can help us see it in a new light, recognizing that ADL nursing care is not always easy and has many different aspects to consider. The knowledge gained within this dissertation is relevant and beneficial for every level of the nursing profession. Registered nurses often oversee the whole process of ADL nursing and provide support to certified nursing assistants who perform daily care regularly. Hence, the practical impact of this dissertation could potentially result in improved quality of care and better outcomes for care recipients. This dissertation shows that ADL care encompasses more than simply assisting with or taking over everyday activities. It provides direct and practical insights into how the care receiver can participate in goal-setting, making agreements, and carrying out ADL care. It also explains how to assess ADL care, which interventions increase independence and comfort in performing ADLs, how to involve informal caregivers, and how to detect health risks. This dissertation suggests that nurses should be encouraged to rethink the way they provide care. It is important to question why things are done in a certain way. By recognizing the complexities of ADL nursing care, one can start to understand that it involves different challenges. In their daily work, nurses can make a significant impact by considering the genuine needs and priorities of the individuals they are caring for. It is, therefore, crucial for nursing professionals to consider their own values and beliefs. The CPG provides nurses with a method to make ADL care more personal and meaningful, utilizing the best evidence available. This dissertation advocates for the integration of ADL nursing care into nursing education for both registered nurses and nursing assistants. This is important because ADL nursing care is often overlooked in nursing education [2]. Quality ADL nursing care necessitates skills in relationship building, communication, and professional reflection. Therefore, education on ADL nursing care should extend beyond current protocols for functional assistance (e.g., Vilans KICK – protocols). Additionally, understanding the crucial role that the physical environment plays in providing care may change how nurses perceive their role in ADL care and the setting where it happens. This could lead to a different perspective on their roles and responsibilities.

Consequently, several websites relevant to the nursing profession have taken notice of the significance of the publication of the CPG. For instance, nursing.nl [2] has highlighted the importance of utilizing appropriate assessment tools for evaluating ADL functioning. The Dutch Knowledge Network for care for people with intellectual disabilities, on the other hand, emphasizes that the CPG fosters communication and dialogue between care recipients and care providers [3]. More broadly, implications of the CPG have been incorporated in the updated Dutch “Beter doen/Beter laten lijst 2023” [4]. This list contains nursing procedures that have been demonstrated to be (in)effective or even cause harm. Furthermore, the Dutch Journal for CNAs has highlighted the importance of active involvement by the largest professional group in the field of CPG development. Moreover, on a more practical level, it has been observed that nursing professionals both within and beyond the CPG panel have organized sessions and workshops to educate their peers about the CPG. For example, one member of the CPG panel presented a conference contribution on how the CPG be applied in geriatric rehabilitation [5].

## Care Organizations

Organizational decisions shape daily practices. Close collaboration with care organizations, particularly during CPG implementation, emphasizes the vital role of key stakeholders in prioritizing and sustaining CPG recommendations in care routines. Care organizations, therefore, have an important role in prioritizing ADL care, for example, through improvements in decision-making and clinical reasoning. This might mean making some changes in how care is organized. The way care information is collected and organized in electronic files is also significant. This affects how well nurses understand and meet the needs of care recipients. Additionally, this research offers practical advice for healthcare leaders to ensure that care is consistent and person-centered across teams. It encourages a culture of reflecting on how care is performed, which can improve its quality. In short, this study provides practical tools and ideas for healthcare organizations to enhance the quality of ADL nursing care.

## Policy

The findings in this dissertation were developed in collaboration with the Dutch Association for Nursing Professionals (V&VN), the largest professional association in the Netherlands. V&VN serves as a liaison between nursing professionals and the government, providing advice on legislative and policy matters. The involvement of key stakeholders, including the Dutch Patient Federation, the Royal Dutch Society for Physical Therapy (KNGF), the Dutch Occupational Therapy Association (EN), and the Organization for Dutch Health Insurers (ZN), supported by formal authorization from V&VN and the Patient Federation, lays a solid groundwork for widespread improvements in ADL care. This research could influence the agenda-setting for ADL care at a macro level, benefiting multiple stakeholders. Looking at the current developments of the Integral Care Agreement (Integraal Zorgakkoord) in the Netherlands, the Ministry of Health, Welfare, and Sport has established agreements to ensure the delivery of suitable care. It is imperative that all stakeholders, including the government, citizens, and organizations, effectively execute their respective roles. Its implications, therefore, stimulate the development and use of CPGs for nursing professionals.

With ADL nursing care often being invisible or taken for granted, this dissertation invites stakeholders at a macro-level to engage in a conversation about reevaluating the narrative surrounding ADL nursing care and the necessary steps to improve and sustain ADL nursing care in daily practice. Highlighting the significance of ADL nursing might involve giving priority to ADL as a nurse-sensitive aspect and quality indicator of care as one of the most commonly assessed nurse-sensitive outcomes in nursing interventions, for example in home care [6].

## Scientific Impact

The scientific impact of this dissertation lies in the comprehensive approach to underpinning and guiding ADL nursing care. This dissertation demonstrated how current challenges foster a paradoxical narrative on ADL care, nurturing misconceptions and generalizations about the value of ADL nursing care in science and society in **Chapter 2**. In doing so, it contributes to the understanding of challenges in fundamental nursing [7, 8] from the perspective of ADL nursing care. Insights into these challenges imply that the scientific acknowledgment of ADL nursing care and its complexity is necessary for all research activities, including but not limited to intervention development, theory advancement, and implementation research.

Moreover, this dissertation brings attention to a critical issue within the field of nursing research: the ambiguity and fragmentation of evidence regarding central outcomes in **Chapter 3**. While these results contribute to the existing image of the limited evidence on fundamental nursing [9-11], existing evidence was summarized for two important outcomes: independence and comfort. These outcomes are highly relevant to care recipients.

The exploration of the physical care environment's role in facilitating ADL performance reveals how the environment can enhance meaningful ADL performance and strengthen the care relationship between residents and staff in nursing homes in **Chapter 4**. This insight has the potential to inform and transform the design and implementation of ADL care interventions. It further encourages additional research and innovation in this area, with the ultimate goal of optimizing care environments for the benefit of both care providers and recipients.

However, the challenges of translating and implementing these findings are acknowledged. In light of a scarce evidence base, alternative methods were employed to integrate the most reliable evidence with practical expertise in **Chapter 5.** This approach calls for further exploration of CPG development methods on themes where evidence is lacking, and questions are complex yet practical.

In terms of implementation, **Chapter 6** contributes to ongoing scientific efforts aimed at identifying factors influencing CPG implementation. For future research, however, it is important to continue focusing on investigating and addressing the barriers to effectively implementing these findings, especially in addressing barriers such as a lack of tension for change to foster successful implementation of CPGs in healthcare settings.

## Dissemination

This dissertation has and will be actively used to discuss the transformation of ADL nursing care. In the past, findings were widely disseminated, specifically targeting nursing professionals as a key audience through the CPG on ADL nursing care. This CPG is publicly accessible on the V&VN website. During the development of this CPG, results were communicated through CPG panel meetings, where members were continuously informed from different sub-departments of V&VN. Additionally, nursing professionals were reached by publishing the results of this dissertation in the national journal “Verpleegkunde” [12].

Furthermore, findings were presented at different symposia, including the annual symposium of the Living Lab of Ageing and Long-term Care and the National Symposium of Cardiovascular Accidents (CVA) in collaboration with nursing professionals from the CPG panel. The presentation at the Dutch CVA network published the presentation on their website [13]. Moreover ZonMw paid considerably attention to the CPG and its related research by holding and publishing an interview on the CPG development process and the innovative methods used which can be read on their website [14]. ZonMw furthermore provided the opportunity to display the findings of this dissertation at the ZonMw Network at the “innovation market” meeting for nursing professionals, policymakers, and educators.

To facilitate dissemination among a scientific audience, **Chapter 2**, **Chapter 3,** and **Chapter 4** were published in renowned scientific journals while **Chapter 6** is currently under review. Moreover, findings were presented at several (inter)national scientific conferences in the Netherlands, the United States of America, Switzerland, and Belgium. A pitch for the Care And Public Health Research Institute (CAPHRI) Research Day 2021, which was awarded the audience award, further strengthened the scientific dissemination of this thesis. This pitch is still available online and is one of the most-viewed pitches of this symposium.

This dissertation is embedded in the Living Lab in Ageing and Long-Term Care Limburg, where policymakers, experts, and client councils of home care organizations are regularly informed and involved. A factsheet and this dissertation will be publicly available on the website of the Living Lab.

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# List of Publications

## Publications

### Scientific Articles in International Journals

**Cremer, S**., Rosteius, K., Zwakhalen, S. M. G., Verbeek, H., Bleijlevens, M. H. C., & de Boer, B. (2024). Utilizing the physical green care environment to support activities of daily living for nursing home residents: a focused ethnographic case study. BMC Nursing, 23(1), 160. doi:10.1186/s12912-024-01782-7

**Cremer, S.,** de Man-van Ginkel, J. M., Zwakhalen, S. M. G., Willems, J., Metzelthin, S. F., Veenstra, M. Y., & Bleijlevens, M. H. C. (2023). The struggle is real - A mixed qualitative methods synthesis of challenges in nursing care in activities of daily living. J Nurs Scholarsh. doi:10.1111/jnu.12921

**Cremer, S.,** Vluggen, S., de Man-Van-Ginkel, J. M., Metzelthin, S. F., Zwakhalen, S. M., & Bleijlevens, M. H. C. (2023). Effective nursing interventions in ADL care affecting independence and comfort – a systematic review. Geriatric Nursing, 52, 73-90. doi:https://doi.org/10.1016/j.gerinurse.2023.04.015

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### Submitted Articles

**Cremer, S.,** Bleijlevens, M., de Man-van Ginkel, J. M., Metzelthin, S., & Zwakhalen, S. No Tension, No Change? Use and Influencing Factors of a Nursing Guideline on Activities of Daily Living; Submitted for publication

### National Publications

Verpleegkundige Richtlijn Zorg bij Algemene Dagelijkse Levensverrichtingen (ADL). (2022), Beroepsvereniging van Verpleegkundigen en Verzorgenden (V&VN), https://www.venvn.nl/richtlijnen/alle-richtlijnen/richtlijn-zorg-bij-algemene-dagelijkse-levensverrichtingen-adl/23

Zwakhalen, S. M. G., **Cremer, S**., Bleijlevens, M. H. C., Metzelthin, S. F., & de Man-Van-Ginkel, J. M., (2022). Richtlijn Algemene Dagelijkse Levensverrichtingen. Verpleegkunde 4, 4-6.

## Conference Contributions

### International Scientific Conference Contributions

**Cremer, S.**, Bleijlevens, M.H.C., Metzelthin, S. F., de Man - Van- Ginkel, J. M., & Zwakhalen. S. M.G., Results of a Pilot Implementation of an ADL Guideline for Nursing Professionals in the Netherlands (2022) Innovation in Aging, 6(Suppl 1), 533.; Gerontological Society of America (GSA) Annual Scientific Meeting in Indianapolis, Indiana (VS) 2-6 November 2022, (poster presentation)

van der Sande, R., **Cremer, S.**, Toering, J., Development of Nursing Quality Standards: Insights from a unique nursing guideline program in NL;, European Nursing Congress, online, 4-7 October 2022 (oral presentation)

**Cremer, S.**, Vluggen, S., Bleijlevens, M.H.C., Metzelthin, S.F., de Man-van-Ginkel, J.M., Zwakhalen, S.M.G, Fragmentation in ADL-nursing care – a systematic review on ADL-nursing interventions targeting ADL-independence and comfort; Heilberufe Science (2022) 13 (Suppl 1):S1–S25, https://doi.org/10.1007/s16024-022-00377-z, European Doctoral Conference of Nursing Science, Bern 9 –10 September 2022 (oral presentation)

**Cremer, S.**, Bleijlevens, M.H.C., Metzelthin, S. F., de Man-van-Ginkel, J. M., & Zwakhalen. S. M.G., Guiding nursing professionals in choosing and providing ADL-care - The development of a nursing guideline on ADL care, CARE4 conference (online), 9 - 10 February 2022 (poster presentation)

**Cremer, S.**, Bleijlevens, M.H.C., Metzelthin, S. F., de Man-van-Ginkel, J. M., & Zwakhalen. S. M.G., Development of an ADL-practice guideline: The next step towards guidance in essential nursing care activities, (2021). Innovation in Aging, 5(Supplement_1), 934-935; Gerontological Society of America Annual Scientific Meeting, online, 10- 14 November 2021 (poster presentation)

**Cremer, S.**, Bleijlevens, M.H.C., Metzelthin, S. F., de Man-van-Ginkel, J. M., & Zwakhalen. S. M.G., Challenges in receiving, organizing and providing care in activities of daily Living – a world café dialogue. (2019). Innovation in Aging, 3(Supplement_1), S493-S494. Gerontological Society of America Annual Scientific Meeting, Austin, Texas, 13-17 November 2019, (Poster Presentation)

### National Conference Contributions

**Cremer, S.**, Bleijlevens, M.H.C., Metzelthin, S. F., de Man-van-Ginkel, J. M., & Zwakhalen. S. M.G., Resultaten van de proefimplementatie van een verpleegkundige ADL-richtlijn – een mixed methods studie; Sano Wetenschapsdag, Leiden, 22 september 2022, (oral presentation)

**Cremer, S.** Pitch your PhD, https://www.youtube.com/watch?v=iy_3FT4Z9Mo, CAPHRI Research Day in Maastricht & Online, 23 September 2021 (oral presentation)

**Cremer, S**., Bleijlevens, M.H.C., Metzelthin, S. F., de Man-van-Ginkel, J. M., & Zwakhalen. S. M.G., Identifying barriers and facilitators during the implementation of an ADL-guideline for nursing professionals, CARE Days, Eindhoven, 11 May 2022, (oral presentation)

**Cremer, S**., Bleijlevens, M.H.C., Metzelthin, S. F., de Man-van-Ginkel, J. M., & Zwakhalen. S. M.G., Challenges in ADL-care - Results of a world café dialogue, Care Days, online, 26 May 2021, (oral presentation)

## Invited Talks and Lectures

**Cremer, S.** Quick and Dirty? – Lessons learned from a rapid ethnographic case study in a green nursing home environment, At the Maastricht - Graz - Bern Doctoral Program Nursing Science, Maastricht, 28 February 2024, (oral presentation & workshop)

**Cremer S**., Beyond the bathroom: Geleerde lessen uit een rapid etnografisch onderzoek, Lecture at the Module: Practice-Based Research at ZUYD University of Applied Sciences, 26, January, 2024, (Guest lecture)

**Cremer, S**., van Gameren, B., Zorg bij ADL – een open deur? – geleerde lessen uit het richtlijnontwikkeltraject, Sympoisum van het CVA/NAH Kennisnetwerk, Utrecht & online, 03 december 2021 (oral presentation)

**Cremer, S**., Ervaringen ontwikkeling kwaliteitsstandaard – “Zorg bij ADL”, V&VN Congresstival in Utrecht, 27 november 2019, (oral presentation)

# Dankwoord

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*En nu echt het dankwoord*

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*Nu maken we langzaam de overstap naar de mensen nog dichter bij mijn hart. U zult zien dat het aandeel aan verschillende talen hier niet minder gaat worden. Bare with me.*

**Nicilein**, ja, woran hattet jelegen? Dat fragste disch am Ende immer woran et jelegen hat? Und dieses Mal kann ich mit relativer Sicherheit behaupten dattet an dir jelegen hat. Ich bin unglaublich dankbar für unsere Freundschaft! Die Podcastsprachnachrichten und Abendteuer mit und ohne Pferd sind so besonders. Ob wir Kaffeetrinken oder uns bei einer gepflegten Dosis Metal das Herz auf einem Festival aus dem Leib tanzen, ich weiss dass ich immer auf dich verlassen kann! Ohne dein offenes Ohr und deinen weisen Rat wäre ich bestimmt nicht die Frau die ich jetzt bin. Ganz arg schlimm dankbar bin ich dafür!

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Wenn wir schon bei back to the roots sind, auch ein grosses Danke an meine Nepal Ergo-Ladies **Lisa, Hannah und Dorothee**. Unsere gemeinsame Zeit in Nepal inspiriert mich noch heute in der Forschung und bin ich um so dankbarer dass wir uns nicht aus den Augen verlieren. #comegoodhome. Ebenso **Mareike,** als GlobalHealth Ergo teilen wir die Nepal 2.0 experience wofür ich heute noch sehr dankbar bin.

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*Nu de overstap van vrienden en vriendinnen naar de familie.*

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Geheimnis daraus gemacht viel stolz du auf mich bist und obwohl ich das wahrscheinlich nicht oft genug sage, bin ich dafür sehr dankbar. Wenn sich unsere Telefongespräche auf den Flachwitz des Tages beschränken und wir anschließend geschlagene 15 Minuten nur lachen und nicht mehr reden fühle ich mich verbunden. Ich hab dich lieb Dr. Papa.

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*Beste lezer, u heeft het einde van het dankwoord bereikt. Proficiat met deze prestatie en veel dank voor uw geduld!*

# About the Author

Svenja Cremer was born on February 19, 1992, in Mönchengladbach, where she attended secondary education at the Gymnasium Am Geroweiher. Following her graduation in 2011, she pursued her studies in Occupational Therapy in Heerlen, the Netherlands. In 2015, Svenja travelled to Kathmandu, Nepal, for her Bachelor Thesis. During this time, she developed a program aimed at training and supporting professionals working at a school for children with disabilities in Kathmandu. The program's goal was to empower these professionals to assist the children in their daily activities while promoting their independence.

After completing her bachelor's degree, Svenja continued her academic journey within the Master of Global Health program. In 2016, she took the opportunity to return to Kathmandu to explore the perspectives of a different group for her Master's Thesis. Her research focused on understanding the Quality of Life perceptions of older Tibetan refugees living in a nursing home in Kathmandu.

Upon returning to the Netherlands, Svenja worked as a project officer for a Dutch care organization (Cicero Zorggroep). In this role, worked on several projects aimed at improving the quality of life for nursing home residents. These projects included promoting person-centered leisure activities for residents, developing future-oriented volunteer work and policies, and enhancing the utilization of the natural environment for residents, their families, and staff.

In 2018, Svenja started her a PhD position at the Department of Health Services Research (HSR) within the Living Lab of Aging and Long-term Care. Her research focused on underpinning and guiding nursing care in Activities of Daily Living (ADL). As part of her doctoral work, she developed the first Dutch Clinical Practice Guideline on ADL nursing care. Throughout her PhD journey, Svenja presented her research findings at various national and international conferences. Within the HSR department, Svenja engaged in several educational roles within the Bachelor of Health Sciences, as a tutor, trainer, and member of the planning group. Svenja also assumed the role of Junior Chair in 2018. In this capacity, she primarily focused on the mental well-being of PhD candidates and team dynamics. Her efforts led to the establishment of a departmental working group called "Team Dynamics," which aimed to enhance collaboration within research teams. Svenja's participation in this group contributed to the implementation of measures designed to foster psychological safety, a culture of reciprocity, and equitable dialogues between members of a research team including PhD candidates and their supervisors.

Starting in October 2023, Svenja continued her work at the HSR department as a post-doctoral researcher. Her research focuses on exploring organizational aspects of care and in particular the role of middle managers in the transforming care environment.

# The Living Lab in Ageing and Long-Term Care

## Living Lab in Ageing and Long-Term Care

This thesis is part of the Living Lab in Ageing and Long-Term Care, a formal and structural multidisciplinary network consisting of Maastricht University, nine long-term care organizations (MeanderGroep Zuid-Limburg, Sevagram, Envida, Cicero Zorggroep, Zuyderland, Vivantes, De Zorggroep, Land van Horne & Proteion), Intermediate Vocational Training Institutes Gilde and VISTA college and Zuyd University of Applied Sciences, all located in the southern part of the Netherlands. In the Living Lab, we aim to improve the quality of care and life for older people and the quality of work for staff employed in long-term care via a structural multidisciplinary collaboration between research, policy, education, and practice. Practitioners (such as nurses, physicians, psychologists, physio- and occupational therapists), work together with managers, researchers, students, teachers, and older people themselves to develop and test innovations in long-term care.

## Academische Werkplaats Ouderenzorg Limburg

Dit proefschrift is onderdeel van de Academische Werkplaats Ouderenzorg Limburg, een structureel, multidisciplinair samenwerkingsverband tussen de Universiteit Maastricht, negen zorgorganisaties (MeanderGroep Zuid-Limburg, Sevagram, Envida, Cicero Zorggroep, Zuyderland, Vivantes, De Zorggroep, Land van Horne & Proteion), Gilde Zorgcollege, VISTA college en Zuyd Hogeschool. In de werkplaats draait het om het verbeteren van de kwaliteit van leven en zorg voor ouderen en de kwaliteit van werk voor iedereen die in de ouderenzorg werkt. Zorgverleners (zoals verpleegkundigen, verzorgenden, artsen, psychologen, fysio- en ergotherapeuten), beleidsmakers, onderzoekers, studenten en ouderen zelf wisselen kennis en ervaring uit. Daarnaast evalueren we vernieuwingen in de dagelijkse zorg. Praktijk, beleid, onderzoek en onderwijs gaan hierbij hand in hand.

## PhD-Theses Living Lab in Ageing and Long-Term Care

Svenja Cremer. Undervalued & Unexplored. Underpinning and Guiding Nursing Care in Activities of Daily Living. 2024.

Katinka Pani – Harreman. The place to be. Guiding the activation of a community to facilitate ageing in place. 2024.

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