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About the client perspective

A participatory study evaluating the quality of long-term care relationships

Aukelien Scheffelaar
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About the client perspective

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Chapter 1

General introduction
The three largest client groups to whom long-term care and assistance is provided in the Netherlands are physically or mentally frail older adults, people with mental health problems, and people with intellectual disabilities. 291,360 clients were receiving long-term care in the Netherlands in 2017 (1). As clients receive long-term care for lengthy periods – indeed often for the rest of their lives – the quality of care relationships with care professionals is felt to be very important by clients. At the same time, long-term care makes clients dependent on the care they need and thereby also on the professionals providing that care. No-one can better understand what it really means to be in such situations than the clients themselves. Actively engaging clients in quality improvement initiatives as co-researchers might therefore be a promising way of evaluating the quality of care relationships from a client perspective.

This thesis was set up to develop qualitative instruments for determining and improving the quality of care relationships from clients’ perspectives, with the active involvement of clients as co-researchers applying qualitative instruments in long-term care. This PhD dissertation aims to answer the following research questions:

A. What are determinants of the quality of a care relationship in long-term care for the various client groups, according to both clients and care professionals?

B. What qualitative instruments can be used by co-researchers for measuring the care relationship between clients and care professionals from a client’s perspective across client groups in long-term care?

C. What lessons can be learned from our collaboration with clients involved as co-researchers in three participatory teams in long-term care?

As will be explained in the following paragraphs, a need has been noted both in practice and in previous academic literature to discover what the quality of a care relationship actually entails and determines, in order to be able to measure and improve the quality of a relationship. Care organisations are looking for appropriate ways to evaluate clients’ experiences of the quality of care relationships in order to unravel areas for improvement. It is worthwhile exploring whether clients could be actively involved as interviewers as this might lower the threshold for other clients to share their
experiences. It is not yet known what roles clients could have and what interviewing methods are most appropriate in this respect.

1.1 Person-centred care

The individualisation of Western societies has increased the attention being paid to the person behind the patient and as a result has led to more attention for the individual needs and preferences of people receiving care (2). Furthermore, there is a growing movement in healthcare referred to as the ‘humanising of healthcare’ in which the significance of the person as a holistic being is the basis for decision-making, engagement and practice. The widely recognised and widely used frameworks of person-centred care and relationship-centred care are used in healthcare to emphasise the fact that the person is at the centre, followed by redesigning services and research towards ones that focus upon the needs of people. Person-centred care can be seen as a counter-movement in reaction to modern developments in medicine that focus on reductionism, attention to diseases, and commercialism (1).

“Person-centeredness is an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development.” P. 3 (3)

In person-centred care, relationships between people are at the core, including those receiving care and providing care. The relationship is one of the core components of person-centred care, underlining the importance of relationships and interpersonal processes, allowing the development and continuance of relationships in care that have therapeutic benefit (4). In person-centred care, being in a relationship and an ongoing “web of relationships” is seen as a fundamental part of being (and staying) a person (5). The goal of care is conceptualised more broadly than the narrow concept of healthcare, by emphasising that the main aim of person-centred care is that all those involved should benefit (6).

Person-centred care is not just about doing the right thing but doing it the right way (7). One way of including the clients’ perspective in research on
quality improvement is by inviting them to take on a role that contributes to the study actively. Participatory research and other relatively new approaches to the active involvement of clients in research and quality initiatives are promoted in person-centred research (8). It could be argued that if researchers are truly person-centred, then both their own voice and that of the clients should be equally represented (8). One way to achieve this is to carry out the research together with co-researchers and choose a participatory method.

### 1.2 Care relationships as foundation of long-term care

The quality of care relationships between clients and professionals is known to be important for a number of reasons. A high-quality care relationship is a cornerstone for providing appropriate care, support and assistance and is therefore an important element of the ‘process’ of providing care (9-12). The quality and continuity of care relationships affect the technical care that clients receive (13). Moreover, clients stated that their care relationships were also important for overall mental recovery and wellbeing (12, 14). A good care relationship also increases the willingness of clients to share useful information about their needs and wishes (12). Furthermore, the assessments by clients of care quality are often embedded in the perceived quality of the care relationship they have with the provider: clients report greater satisfaction with the care received when the quality of the care relationships is high (13, 15). The quality of care relationships is therefore related to the quality clients perceive of the care provided and their overall lives.

The value of the quality of the care relationship between a client and a professional has been recognised for decades now by various disciplines. Peplau, an influential early scholar in nursing, was already stressing the importance of the nurse-patient relationship for successful outcomes of broad nursing care back in 1952. Professional competences such as respecting, acceptance, being yourself and nondirective listening were listed as being instrumental in establishing a therapeutic and educational relationship with a client. A professional might help a client get through their illness as an experience that strengthens positive forces in their personality. A relationship between a nurse and a client should encourage greater independence in the client, and increase participation in wider society (16, 17).
An influential early scholar in the philosophy, Buber, wrote back in 1958 in his work ‘I and Thou’ about the relational nature of a man “through the Thou a man becomes I”. The central argument in this work is that a person defines himself through relationships and is able to develop and grow. When a person enters into a relationship, the Thou and the I are interconnected which makes personal development possible (18). From a humanistic perspective, the ability to communicate interpersonally - from one person to another – in a humanizing way has been underlined, centralizing the content and process of client-professional interaction regardless of labels or the status of participants (19).

The basic characteristics of a relationship are described in the literature of communication (20). From a dialogical approach, a conjoint reality is created by two people in relation to each other. The interdependent nature of a relationship makes the self and the other almost inseparable, as they influence each other. In line with this, someone’s ‘self’ can best be understood as being embedded within these webs of relationships and views of these connections. A core characteristic of a relationship is the continually changing, ever-growing and re-emerging state. Relationships can therefore never be seen as static or ‘finished’. Relationships are created through verbal and non-verbal interactions between two individuals. Furthermore, the context in which the communication takes place is essential for interpreting a relationship between two or more people. The subjective ideas and appreciations of people also influence a relationship, as it becomes real when people develop thoughts and make stories about their relationships (20).

Later publications embedded in person-centred care theories state that high-quality care relationships could lead, under ideal conditions, to flourishing of all people involved, including both the client and the professional (3, 21). However, the quality of care relationships is not always optimal yet, according to clients receiving long-term care. Previous literature spoke of clients who felt they were not being respected or listened to (22). Others felt ignored, not worth the interest, unseen or unheard (23). One client described a care relationship which did not work well as if there was a ‘wall’ between themselves and the care professional (12). More evidence is needed about the factors determining the quality of a care relationship, as it is not yet clear what is enhancing or diminishing the perceived quality of care relationships. Working effectively on improving low-quality care relationships will only be achievable when a clear picture is obtained of the aspects that determine the quality of care relationships.
1.3 Care dependency

One typical characteristic of care relationships between clients and professionals in long-term care is the dependency of clients on the care and professionals providing the care needed for a lengthy period. For example, physically or mentally frail older adults living in nursing homes are “remarkably dependent” as they often need assistance with basic activities such as dressing, bathing or eating (24). It is important to acknowledge the significance of these dependency relationships, as it affects the amount and the quality of care clients receive (21). The formal power in these care relationships resides with the professionals, who may not be able to spend enough time with clients (25). In a recent Dutch study, the dependency of clients with intellectual disabilities was extensively investigated. When there is friction in a care relationship, dependency is experienced negatively by clients with intellectual disabilities. This friction has far-reaching effects on the daily lives and emotional lives of clients. Three negative consequences were described as a result: 1) invisibility, where the needs of a person are not seen or recognised or worked on; 2) powerlessness, when the client has the feeling of having no control over the situation and actions; and 3) inequality, when the client does not feel acknowledged as a person (26). Care relationships can also be seen as a vehicle for returning to greater independence and may therefore change over time from a very dependent relationship to a more shared relationship (27).

At the same time, it is useful to put the uniqueness of dependency into perspective as well, as being dependent is an essential and unavoidable feature of human existence. As all human beings depend on others at some stage during our lives, the issue of care dependence is not totally unique; but it is however singularly manifested in the lives of clients receiving long-term care (24). The broad refusal to be labelled as ‘dependent’ could be mainly based on the fear of becoming an infantilised object of paternalistic concern and the presumption that the source of dependency is internal to the individual (28). Paradoxically, true independence and self-sufficiency only emerge when an individual is able to depend on others in times of need (29). As care dependency is an essential feature of care relationships between the clients and care professionals in long-term care, it permeates the positioning, interactions and behaviour patterns of clients and care professionals towards each other. As a consequence, clients do not always feel free to share feedback because it could negatively affect the relationship. They might be
balancing two different interests, i.e. aiming for the optimum care relationship and sharing their wishes (15, 30). So even when care professionals explicitly ask for feedback, clients may be inclined to give socially desirable answers, especially when sensitive topics such as experiences with care relationships are concerned.

1.4 Why client perspectives matter

The client perspective is increasingly being taken into account in healthcare in general and in long-term care specifically. What makes the perspective of clients so important to focus on? There is broad recognition that clients should be legitimised to make decisions about the care they receive and how the care is delivered. Given their first-hand experiences, clients are legitimately positioned to evaluate the care they receive, in terms of whether their needs and preferences are being met (31). Other studies have shown that what clients value most is not necessarily the same as what professionals value in care (32-34). The power of client experiences is that it gives services cases and evidence for focusing on what is truly right and what truly matters according to clients (35). Insights into clients’ experiences let care organisations identify shortcomings in care provision, which can be used to redesign and optimise care (36).

However, measuring client perspectives is not straightforward because it is a complex, ambiguous concept for which no common definition is yet available. Moreover, many different terms have been used in measuring client perspectives, such as satisfaction, perceptions and preferences (36, 37). On top of that, there is no consensus on what ‘quality’ entails, and for a long time it was defined from the perspective of care professionals. Attention to defining quality of care from a client perspective is increasingly seen as crucial in making it possible to improve care from a client perspective (38).

1.5 The need for qualitative instruments

In long-term care and healthcare more broadly, client experiences of the quality of care have long been operationalised and studied in quantitatively, reductively and numerically. More and more scholars are making the case for shifting the focus away from numbers and reductive processes of
measurement towards qualitative quality information, including story and description (39). Nowadays, in both care and research, it is acknowledged that objective data does not provide the complete picture. Although objective measures are important and useful as bare legal minimums, they are also insufficient for defining what matters for clients or consumers from an insider’s perspective (40). It is increasingly being recognised that qualitative methods are useful for asking what clients experience, feel and believe at a particular moment. Especially for a dynamically, continually changing and complex construct such as the experienced quality of a care relationship, qualitative, momentary and individual information is expected to provide valuable insights.

Qualitative research can elicit a lot of information about client experiences. Clients’ care experiences comprise the most important modes of access to what is important to them. Narratives, anecdotes or client stories can indicate what people value most and show who they are (24). As stated earlier, patients do not necessarily value the same things as professionals (32, 33). Qualitative methods allow professionals to combine their own perceptions with those of their clients (41). Qualitative descriptions of client stories and experiences are an accessible and memorable source for professionals for reflection on their actions and behaviour, and often provide direct insights in areas for improvement (42). Using qualitative methods is an important way of enhancing understanding of clients’ experiences and wishes and facilitating qualitative improvements (43). Qualitative statements from clients about care represent an essential missing link for professionals aiming to learn from their clients in order to improve quality, and they also offer the necessary detail (34).

1.6 Participation of clients in quality improvement

A promising way of including client perspectives in quality measurement and improvement might be by actively involving them in quality improvement processes, in the role of co-researcher. Participatory research is “a collaborative effort in which people whose lives are affected by the issues being researched are partners in designing, undertaking and disseminating research to influence socially just change. The process aims to be democratic, participatory, empowering and educational” (44). Participatory research is community-based, as the key stakeholders share a common identity or
interest. It is also value-based, with central principles such as mutual respect, collaboration, equality and social justice (44). It is covered by the transdisciplinary principle, by focusing on the improvement of real-world situations and the integration of scientific and experiential knowledge into research (45).

Participatory research can be used for identifying improvement areas in clients’ experiences. Three core arguments are frequently made for choosing a participatory research design. The substantive argument is that actively involving clients in several research stages is expected to increase the quality of a study by reflecting clients’ ideas, needs and priorities in various research stages, which increases the (content) validity and relevance of the study (46-49). The ontological and normative argument reasons that clients have the democratic right to be involved in decisions regarding the care they receive (50, 51). Specifically, clients receiving long-term care depend on the care provided for a long time. Participation in research may be an opportunity to construct a positive social identity and build up their self-esteem (50, 52). The instrumental argument applies in particular to quality improvement initiatives, as involving co-researchers yields more effective quality improvement and enhancement of support for the findings (46, 47). It could bring refreshing perspectives to light that can be used to improve the quality of care (46).

There are many synonyms in the literature for participatory research, such as ‘inclusive research’, ‘emancipatory research’, ‘participatory action research’, ‘patient and public involvement’ and ‘patient participation’ (50). Such terms are used interchangeably, although some have specific connotations and meanings. The term ‘participatory research’ was chosen to describe the process of collaboration and participation of co-researchers in this research, which focuses on quality improvement.

Participation in research can take many different forms and co-researchers can perform various tasks, e.g. advising in steering groups (49), agenda setting (53), performing research activities in all research stages (49, 54-58) and presenting and disseminating the study results (57). In general, three main roles for co-researchers in research can be distinguished. The advisory role means that co-researchers give advice about research priorities, the design and data collection methods in an advisory group but exert little control over their manner of involvement. A leading and controlling role suggests that co-researchers initiate, lead and carry out their own research. A third way of involving co-researchers in research is in collaboration or
partnership with researchers, in which contributions are equally valued and co-researchers and researchers work together, albeit with shared and distinct aspirations (59).

In addition to participation in research, clients are also involved in care and quality improvement of care in a number of ways. In mental healthcare, individual and group support is provided by experts with a wide range of experience, including in their profiles of competencies and education (60). Across client groups receiving long-term care, clients are increasingly being involved in decisions made by care organisations by becoming members of client councils. The extent to which client councils are using their legal voices to influence decision making by the organisation in terms of policy and quality of care differs substantially, however (61). A lot of roles are also possible within quality improvement research, from being a member of the steering group, an executive role by collecting data or contributing to culture change, through to being involved in the interpretation of the collected data. Only a few examples were found in which clients were actively involved in quality improvement (62-66).

Some risks or threats for meaningful roles of co-researchers in participatory research and care can be uncovered in the literature as well; four of these are frequently mentioned. Firstly, the question is raised of how to ensure that co-researchers perspectives and contributions are not sidelined or undermined (48). This lack of actual influence is often called ‘tokenism’ (64, 67). The contrast would be sharp if client participation was used to legitimise professional decisions that would have been made anyway (48). Participatory research demands reinterpretation of the existing power dynamics in both research and care settings (44). Secondly, friction between the ‘system’ world and the ‘life-world’ could arise, as co-researchers are entering a world full of structures, schedules and formal or academic language which they are not familiar with. For co-researchers, the system world is often not easily accessible (44). A researcher or project leader therefore needs to be able to present the research in such a way that co-researchers are able to participate; this affects aspects ranging from accessibility of the meetings to translating academic texts and structures into a more understandable format in lay language (67) (55). Thirdly, the blurred boundaries between the subject of the study and the co-researcher carrying out a study demand reinterpretation regarding privacy issues and other research ethics (44). For example, co-researchers hear very personal experiences of clients during interviews, with concomitant responsibility
keeping what is told confidential. Furthermore, co-researchers might be emotionally affected by an interview, so they need support and guidance how to deal with such moments. Fourthly, who is invited to join the research team also has an effect. For example, not all clients with intellectual disabilities are able to read and write (57). Participatory research often includes the co-researchers with the most abilities, those in stable health and those who are most literate. This has consequences for the representation of those whose voices are not included (44, 50, 59).

Very recently, a consensus statement was developed by international experts with and without intellectual disabilities on inclusive research. Several attributes of inclusive health research were defined, under themes such as ethos, recruiting researchers, designing the study, facilitating the process, dealing with practicalities, generating data, analysing data and using results. Potential outcomes were also described and suggestions were made for future participatory research (68).

Although participatory research is recognized as promising, clients are often only included in quality measurement and improvement as respondents or subjects, and leaving little room for clients to be more structurally and actively involved (62, 64). There is still a lack of practical knowledge about how active client involvement can best be designed and performed in quality measurement and improvement, in order to tackle the risks described earlier. Moreover, it is not yet known what roles clients could have and what support they need to perform these roles. Some interviewing methods might fit the abilities of co-researchers better, but no evidence is available about which instruments are most feasible. This thesis concentrates on generating knowledge that will diminish these gaps so that clients will be able to participate actively in quality research.

1.7 Research context

In the Netherlands, the Long-Term Care Act was introduced in 2015 for a number of reasons, such as promoting the quality of the care provided, encouraging an integrated approach and keeping care affordable in times of an ageing population and in which many people suffer from chronic diseases. Long-term care concerns care and assistance for people with chronic limitations resulting from permanent physical, intellectual or mental health conditions. The foundations of the Long-Term Care Act are the capabilities
of people rather than their shortcomings. According to the Ministry of Health, Welfare and Sport, long-term care concerns the following domains (69):

- Stay in a care facility is about long-term stay, being placed in a nursing home, or designated placement for people receiving mental healthcare.
- Personal care, including assistance with washing, dressing, using the toilet, and eating and drinking.
- Care that increases self-reliance, for example assistance in structuring the day, gaining greater control over your life and learning to perform household duties.
- Nursing care including medical assistance, personal care in daily activities and psychosocial care.
- Medical, paramedical or behavioural treatment that helps the recovery or improvement of a specific condition.
- Arranged transport to and from day programmes and day treatment for those who cannot travel independently due to medical conditions (69).

These domains and client groups show the wide variety of conditions among clients receiving long-term care. In the Netherlands, the providers of long-term care can be typically divided into three client groups to which care and assistance is provided: physically or mentally frail older adults receiving elderly care, people with mental health problems receiving mental healthcare, and people with intellectual, physical and/or sensory disabilities receiving disability care. Long-term care is provided in both inpatient care settings when a client is institutionalised or living within a care residency, and outpatient care where a client lives on their own and receives home care or when fixed recurring appointments are made.

Older adults who are becoming physically or mentally frail due to advancing age are starting to receive long-term care from that point onwards, often after a reasonably stable and healthy life. This is quite a different position to be in than clients with mild to moderate intellectual disability from birth, who often rely on support for daily needs throughout their lives. Between these two extremes, a large diversity of clients (e.g. people with mental health problems or people with non-congenital brain injuries) rely on care from a certain moment in their lives onwards, with major individual variability. The care for these three largest client-groups is organised differently in the Netherlands; often provided by various private non-profit care organisations, each with their own characteristics and dynamics. Intellectual disability care is often provided for the individual by a few
permanent personal supporters, care aides or registered nurses, supplemented with daily support for those living in a residency and supervision at work or daytime activities. Older adults typically receive personal care and medical assistance from many different care professionals; however, clients receiving outpatient care do occasionally meet the same professionals more frequently in comparison with inpatient care. In mental healthcare, inpatient clients receive multiple forms of care, assistance and therapy from professionals with different job functions, such as registered nurses, psychiatric nurses and psychologists. The psychiatrist is responsible for overseeing the whole and drafts the individual care plan and provides medication. Outpatient mental healthcare is often organised and provided at someone’s home by one or two professionals who are part of what is referred to as a ‘FACT team’. In addition to the great variability of care and assistance provided to these three client groups, there is also a great deal of variety in health status and support needs within each of the three client groups.

Although there is a broad variety of clients receiving long-term care, all long-term care clients have some things in common: their care dependency, the search for a balance between self-reliance and reliance on care professionals, and the complex issue of being a person and a client.

From 1970 onwards, a process of de-institutionalisation has been proceeding in which long-term care is provided closer to the homes and living worlds of clients, instead of separating their care out into isolated institutions (70). Recent changes in the national laws have driven this development even further by emphasizing the abilities and responsibilities of a client and their relatives, customisation, and informal care giving. These legislative changes have partly been proposed and implemented with an eye on cost reduction (71).

1.8 Outline of the thesis

Figure 1.1 gives a graphical overview of the sections of this thesis. A short outline of each chapter is given in this paragraph.
Chapter 2 starts by describing the study design and the methodology of the study in more detail. The study protocol was written to provide a structured working plan for the study on beforehand, thereby making high-quality research possible. A study protocol offered other advantages as well, as it encourages researchers to adequately consider and plan the research project in detail before the start of the study and it served as a blueprint for conducting the study when the research progressed. Publishing a study protocol gave other researchers the opportunity to review it early, before the completion of the study (72).

Chapter 3 reports on a systematic review that was conducted to gather research evidence on determinants of the quality of a care relationship between clients and professionals in long-term care. This review focused on three client groups receiving long-term care: physically or mentally frail older adults, people with mental health problems and people with disabilities. The chapter provides an overview of the large number of determinants studied of the quality of care relationships, sorted into the client level, professional level, the level of interaction between client and professional, and the contextual level. A substantial number of the
determinants of the quality of care relationships were found to apply to more than one of the client groups studied.

Chapter 4 elaborates further on Chapter 3 by focusing on the question of what determines the quality of a care relationship according to clients and professionals in long-term care. This chapter reports on a qualitative study that was carried out by co-researchers and researchers in three research teams. There was explored how generic or specific the determinants of the quality of a care relationship are among the three client groups included by conducting semi-structured interviews. The perspectives of both clients and professionals were included, as clients and professionals have been found to use different definitions and have different perspectives on care relationships.

Chapter 5 answers the question of which qualitative instruments are best feasible and most useful for evaluating the quality of a care relationship in each client group and across the three client groups receiving long-term care. A process evaluation was carried out to evaluate five qualitative instruments that were adapted to measure the quality of the care relationship with co-researchers taking the lead in the role of interviewer. The qualitative instruments were carried out by co-researchers in one specific client group at first; thereafter, the most promising instruments were applied in the other client groups to study which instruments were useful and most feasible for them to perform.

Chapter 6 focuses on the participatory research approach that was central in carrying out the empirical research. The study performed yielded lessons learned from conducting research in collaboration with co-researchers who have experience themselves of how it is to be dependent on long-term care or assistance in daily life. The lessons learned in the three research teams are described using a multiple case study design. The chapter also revealed a wide diversity between the abilities of individual co-researchers and between the three research teams. This chapter shows that a flexible approach is important in participatory research: One size does not fit all.

Chapter 7 contains the final discussion and conclusions of this thesis. Strengths and limitations are described and elaborated upon, implications for practice discussed and suggestions for further research made.

As an additional chapter, Chapter 8 gives a reflection on conducting this PhD research from a researcher’s and a co-researcher’s perspective.

After the Dutch summary, an additional summary is included in chapter 9 which was composed with five co-researchers.
Literature


Chapter 2

Protocol for a participatory study for developing qualitative instruments measuring the quality of long-term care relationships

Published as:
Abstract

**Introduction:** In long-term care (LTC), it is unclear which qualitative instruments are most effective and useful for monitoring the quality of the care relationship from the client’s perspective. In this paper we describe the research design for a study aimed at finding and optimising the most suitable and useful qualitative instruments for monitoring the care relationship in long-term care.

**Methods and analysis:** The study will be performed in three organisations providing care to the following client groups: physically or mentally frail elderly, people with mental health problems and people with intellectual disabilities. Using a participatory research method, we will determine which determinants influence the quality of a care relationship and we will evaluate up to six instruments in cooperation with client-researchers. We will also determine whether the instruments (or parts thereof) can be applied across different LTC settings.

**Ethics and dissemination:** This study protocol describes a participatory research design for evaluating the quality of the care relationship in long-term care. The Medical Ethics Committee of the Radboud University Nijmegen Medical Centre decided that formal approval was not needed under the Dutch Medical Research Involving Human Subjects Act. This research project will result in a toolbox and implementation plan, which can be used by clients and care professionals to measure and improve the care relationship from the client’s perspective. The results will also be published in international peer-reviewed journals.
2.1 Introduction

In long-term care, the relationship between clients and care professionals is seen as fundamental for the delivery of high-quality care. This importance is related to the longer period of care provision and the chronic health conditions of clients (1). Long-term care consists of ‘a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with their daily living activities and/or need permanent nursing care’ (2). A good care relationship between a client and a professional requires an equal relationship in which the professional provides care with dignity and sensitivity to the client’s wishes (3). It allows clients to express any questions or complaints they may have about the care given. This open environment has not yet been achieved in all organisations, according to a recent Dutch study (3). Another study shows that care professionals believe they listen to the needs of clients and offer care in a person-centred manner, but entrenched habits and time pressure mean that opportunities for person-centred communication are often missed (4). Worldwide, there is a drive to redress the imbalance in care from an ethos that is medically dominated, disease orientated and often fragmented, to one that is relationship focused (5).

Monitoring the quality of the care relationship between a client and a professional should be set up from the client’s perspective. Clients have unique experiential knowledge providing valuable insights into the quality of everyday care and care relationships that are missed otherwise. Care providers, clients and family perceive different determinants as influencing the closeness of the care relationship between the client and care professional. McGilton and Boscart (2006) showed that care professionals in elderly care felt that close relationships were primarily about feeling connected with the resident. Family members focused primarily on the actions staff took to present a caring attitude. Residents on the other hand felt that close relationships included staff acting as their confidants (1). By focusing on client experiences, a more comprehensive evaluation of clients’ experiences of the care provided and areas for improvement is generated (6). However, little research in long-term care has focused on the client’s perspective on these relationships (1).

An excellent way to include the clients’ perspective is by carrying out participatory research. In participatory research, clients are invited to become part of a research team (7-10). This empowers the clients and
improves the validity and relevance of the research project (11). Clients’ involvement can also lead to broader support for the outcomes of the research project and related quality improvement initiatives among clients and care professionals (12). Clients can be involved in several stages of a research project: in preparatory activities, or in data collection by actively helping conduct interviews or focus groups (13, 14). Client-researchers can also be involved in the data analysis (14) or have an advisory role, for example from the design phase onwards, by constructing the research design, a topic list or by attending steering group meetings (10, 13).

Clients’ experiences with the quality of a care relationship can be explored using qualitative instruments (15). One advantage of qualitative research is that it aims to understand social phenomena in natural settings, giving due emphasis to the meanings, experiences and wishes of people (16). Qualitative procedures give clients freedom to respond, allowing direct expression of their own concerns rather than those of the researchers (17). As a result, qualitative research can tackle aspects of complex behaviours, attitudes and interactions that are not amenable to quantitative research (16). It has also been shown that care organisations can translate qualitative results more easily into improvement actions, as such results are capable of including the nuances and complexity of care practices (18, 19).

In Western countries, a shift can be seen in long-term care practice from focusing on solely quantitative instruments to using qualitative instruments for measuring quality (17). For example, interview instruments such as narrative sensibility and storytelling (20, 21), focus groups (22-24), (25) and observational instruments (26-29) are used to improve the relationship between client and care professional and to encourage clients or their relatives to provide feedback. Corresponding to this trend, there is a call for qualitative instruments in the Netherlands that can be used in daily practice to hear clients’ experiences of their care relationship. However, it is not clear whether existing qualitative instruments are useful and effective for monitoring and improving the care relationship from a client’s perspective in long-term care and whether they focus on the important determinants of a good care relationship. Some determinants of a good care relationship might differ between client groups, as may the preferred instrument for evaluating the relationship. At the same time, we expect that there will also be general determinants that influence the quality of a care relationship in all LTC settings, such as trust or communications skills.
2.2 Aim

The aim of the present chapter is to describe the research design of the study. It is a participatory study aimed at finding and optimising qualitative instruments for evaluating care relationships in long-term care from the client’s perspective. This project seeks to answer the following research questions:

1. *What determinants influence the quality of the care relationship in long-term care for the various client groups, according to both clients and care professionals?*
2. *What qualitative instruments can be used for monitoring and improving the relationship between clients and care professionals from a client’s perspective?*
3. *Which qualitative instruments or parts thereof can be used across client groups and how?*
4. *How can the most suitable qualitative instruments be used by the various user groups (such as care professionals, care organisations, client councils and health insurance companies) to improve the quality of the care relationship?*

The purpose of the first research question is to understand the determinants that influence the quality of the care relationship in long-term care. The second and third research questions are aimed at evaluating qualitative instruments to ascertain whether they are useful for evaluating the quality of individual care relationships in long-term care across client groups. This research project will result in a toolbox that can be used by professionals and clients to measure and improve the quality of the care relationships in long-term care. The results of this study will be published in peer-reviewed international journals and presented at several congresses, preferably at the annual conference of the international Collaboration for Participatory Health Research and the International Conference on Communication in Healthcare.
2.3 Methods and analysis

Setting and participants
The study will take place in the Netherlands. In the Netherlands, long-term care is provided primarily to three client groups: 1) physically or mentally frail older adults, 2) people with mental health problems and 3) people with an intellectual, physical or sensory disability. Our study focuses on these three client groups. However, as regards the third group (people with a disability), we only aim to include clients with intellectual disabilities, as this is by far the largest group of clients with a disability receiving long-term care in the Netherlands. Three Dutch care organisations are willing to be involved in this multicentre study. Each of the three care organisations delivers care to one of the three client groups: one care organisation provides care to physically or mentally frail older adults, another care organisation provides mental health care, and the third organisation focuses on people with an intellectual disability. A convenience sampling technique was used. To make sure that we can reach a diverse group of clients, we have selected care organisations that provide care to a large client population with a diversity of recurring care needs, that deliver both inpatient and outpatient care and that comprise multiple locations. The three care organisations provide care to more than 2000 clients, and have more than 2000 care employees. If one of the care organisations withdraws later on, we will invite another care organisation to become part of the research project.

Respondents and client-researchers
Clients will be involved as client-researchers and respondents in the different phases. Inclusion criteria for both groups are described in table 2.1. Clients who have at least weekly recurring contact with a care professional and receive care for at least three months in/from long-term care organisations will be included. Physically or mentally frail older adults are clients who may need assistance due to somatic complaints or may suffer from mental decline because of dementia. Persons with mental health problems are clients who may suffer from a personality disorder, schizophrenia or an anxiety disorder. An intellectual disability may be caused by chromosome abnormalities or by a brain injury. We will focus on care relationships between clients and care professionals who take care of clients directly, those who see clients most often to provide assistance, supporting care and physical care, for instance, care aides, personal carers and different categories of
nurses. Clients will be included if they receive care at least once a week. We will not focus on professionals who are further removed from providing recurrent physical and supporting care, such as clinicians, psychiatrists and general practitioners. Also, clients receiving acute health care are outside the scope of this study. Moreover, caregivers who provide informal care will not be included.

Table 2.1  Inclusion criteria for clients as respondents and client-researchers

<table>
<thead>
<tr>
<th>criterion</th>
<th>Respondents</th>
<th>Client-researchers</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 or older (no upper limit)</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Currently a client of residential elderly care and home care, mental healthcare or disabled care</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Receiving care for at least three months</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Receiving care at least once a week</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Able to communicate verbally in Dutch</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Able to generalise from their own experiences</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Able to hold a conversation without the assistance of a close relative or friend</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Able to read and write at a basic level</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Has a fairly stable health situation</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Able to travel short distances</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

Different inclusion criteria will apply for clients as respondents and client-researchers, as participating client-researchers need to have more skills for active participation. It is important to realise that the client-researchers may not be fully representative of the target group of respondents.

Patient and public involvement

This study is participatory research: having clients participate in this study as client-researchers will help us counteract the social distance between clients and researchers. Gradations of client participation are often described using a participation ladder (see figure 2.1).

The participation levels in Arnstein’s frequently used Participation Ladder are manipulation, therapy, informing, consultation, placation, partnership, delegated power and client control (30). In this study, we are aiming for the ‘partnership’ participation level. Client-researchers will be asked to be
involved in preparation activities such as developing the design of the study, formulating a definition of a high-quality care relationship, and drafting the topic list for interviews and focus groups and selection of the qualitative instruments that will be tested. Moreover, client-researchers will help in the interviews, focus groups and instrument testing. Some of the client-researchers will also be involved in the selection and invitation of respondents. As members of the research team, client-researchers will be involved in the analysis stage as well: in work meetings, the results of interviews, focus groups and instrument evaluation will be summarised and discussed.

Figure 2.1 Ladder of Participation, Arnstein (2015) (30)

At the end of the research, client-researchers can help in the dissemination phase of the research. Earlier studies show there are several barriers for participatory research (10), and sharing responsibilities is not always easy for researchers (31). Studies underline the importance of starting the research process in a really open and flexible way to enable true client participation, empowerment and a valuable collaboration process (10, 32). The intensity
and manner of participation will be agreed in a group meeting with the client-researchers of each client group. To ensure meaningful cooperation between client-researchers and researchers, we will provide training and an introduction at the start of the research, create a safe working environment, and make basic agreements for our cooperation with the client-researchers at the start. During the research phases, we will regularly discuss the conditions for cooperation within the research team. Furthermore, we will communicate in a clear manner, tailored to the literacy and coping level of the client-researchers. Moreover, we will have a researcher available for questions continuously, and we will take the availability of client-researchers into account when planning meetings. Client-researchers will receive an allowance for their contribution, depending on the amount of time invested, not exceeding the maximum payment allowed for those receiving long-term care benefit. Client-researchers will always be able to quit or call off participation during the research process. We added a step halfway through the study in which we will evaluate the process so far with client-researchers and ask them whether they want to continue.

**Five phases of selection and development of a qualitative instrument**

This research consists of five different phases that will take place during the period 2016-2019 (see figure 2.2):

1. **Preparation**: inviting and selecting client-researchers and a literature study.
2. **Consultation**: individual interviews and focus groups on the determinants of the quality of the care relationship according to clients and care professionals;
3. **Selection** of the most promising qualitative instruments.
4. **Evaluation**: selected qualitative instruments will be tested and evaluated within one client group, with the best qualitative instruments then being tested and evaluated in the other two groups.
5. **Dissemination**: formulating an implementation plan for the most suitable qualitative instruments.

**Figure 2.2  Phases of the study**
Supervisory committee
A supervisory committee will supervise the research project from start to finish. A delegation consisting of several stakeholders in long-term care will be invited to be on the supervisory committee. The stakeholders involved are representatives of care providers and branch organisations, client (council) organisations with a nationwide scope, contact persons at the care organisations in the study, and health insurers. The committee will monitor the research process according to the project plan and give advice on the content of the study related to national developments. Eight meetings are planned and members of the supervisory committee can be asked for further input by e-mail if needed. The researchers, including two professors, will attend the meetings.

Preparation
The first phase of this study is the two-part preparation of the research.

a. Inviting and selecting client-researchers
The invitation of client-researchers will start on a small scale from a personal approach, in cooperation with client council members and care professionals. An individual acquaintance meeting will be held with every client who shows interest in participating. We aim to have three or four client-researchers from each client group. See table 2.1 for the inclusion criteria. The selected client-researchers will be offered training to prepare for and practice the qualitative interview technique. The training will be provided by the NIVEL researchers in two interactive workshops. The topics covered by the training will be tuned to the needs and literacy of client-researchers. In the training, the distribution of tasks and responsibilities will be discussed and established. Tasks and responsibilities will depend on someone’s capacities, capabilities and wishes.

b. Literature review
Three literature reviews will be conducted:
1. A systematic review to gain an understanding of determinants influencing the quality of the care relationship.
2. A scoping review to identify existing qualitative instruments that measure the quality of the relationship between clients and care professionals in the Netherlands.
3. A scoping review to collect best practices of client participation in long-term care research to determine a participation strategy for client-researchers.

The literature review will include scientific databases such as Medline, Embase, CINAHL and PsycINFO, and grey literature. For the first review (A), a systematic search strategy will be drawn up. If necessary, a librarian will be consulted during this process. Eligible articles need to be written in English and published in the last twelve years (between 2006 and 2018) due to time constraints. A preselection will be made by one researcher who will screen the titles of all articles. All abstracts then will be screened and assessed by two researchers. If they rate an abstract differently, consensus will be reached in a discussion between the two researchers. If necessary, a third researcher will be involved. Subsequently, two researchers will assess the included articles by reading the full texts. Again, consensus will be reached in a discussion between them if they rate papers differently. If necessary, a third researcher will be involved. The quality of the paper will be rated for all articles included using the criteria of the Mixed Methods Appraisal Tool (MMAT) (33, 34).

For the second and third review (B and C), we will also carry out a grey literature search in addition to the scientific literature search. Articles eligible for selection need to be written in English or Dutch and published between 2006 and 2018.

Products of the preparation phase:
- established cooperation with three care organisations and cooperation with three or four client-researchers in each organisation;
- a systematic review article of the literature regarding determinants influencing the quality of the care relationship (chapter 3);
- an overview of existing qualitative instruments in long-term care in the Netherlands.

**Consultation**

In the consultation phase, the results from the first (systematic) literature search into determinants of the quality of the care relationship will be supplemented with information from clients involved as respondents and care professionals. In each care organisation, clients will be interviewed individually in semi-structured, face-to-face interviews until saturation occurs. It is expected that saturation will occur when we have interviewed...
eight to ten clients in each care organisation, but it is difficult to determine the saturation point in advance as one size does not fit all in qualitative research (35). Clients who meet the inclusion criteria (see table 2.1) will be approached by the client-researchers together with the researcher. We will work with a convenience sample to include clients who are willing and able to participate. Even so, we will aim for as much variation as possible in terms of relevant client characteristics such as gender, age, ethnicity and whether they receive care as an inpatient or outpatient.

Interviews will take place in the client’s home or in a meeting room at the care organisation. Depending on the concentration span of each client, interviews will take approximately 30 minutes. Clients will be asked to give informed consent prior to the start of the interview. In some instances the legal representatives of persons with intellectual disabilities will be asked for permission first. It will be the responsibility of the researcher to make sure the informed consent form is signed. In interviews we will adopt a ‘process consent’ approach, meaning that we constantly observe during the interview whether consent is still present by paying attention to verbal and nonverbal indications of reluctance or hesitation to participate (36).

Additionally, four to six care professionals from each organisation will be invited for a focus group meeting. As with client respondents, we will work with a convenience sample to include professionals who are willing and able to participate. The care professionals will be selected and invited in close cooperation with the care organisation. The focus groups will take about two hours and will take place in a meeting room at the care organisation. A topic list will be drawn up in advance to guide the group discussions in a semi-structured manner.

The data collection and analysis will be conducted by the research team, consisting of one researcher and three or four client-researchers from each care organisation. The focus groups and interviews will be audio-recorded, transcribed verbatim by an independent transcription agency and analysed in three phases: open coding, axial coding and selective coding (15). The data analysis method is inspired by Interpretative Phenomenological Analysis, which places the clients’ experiences and the meaning they assign to those experiences at the core (37). A portion of the interviews will be analysed by two researchers. If these researchers disagree on the interpretation of a fragment, they will try to reach consensus by discussion. If they do not reach consensus, a third researcher will be consulted. After the construction of the final coding tree, the remaining interviews will be analysed by the first
author. The main findings will be discussed by the entire research team in work meetings. The transcripts will be analysed using the qualitative software programme MAXQDA.

Product of consultation:
- Overview of determinants influencing the quality of the care relationship in the three client groups (chapter 4)

**Selection of up to six instruments**
Based on the overview of existing qualitative instruments in the Netherlands, the research teams and supervisory committee will select the two most promising qualitative instruments for each client group. The selection will be based on the available information about issues such as corroboration, the fit of the purposes for which the information provided can be used, clear structure, usability of instruments in various client groups, validity and reliability, implementation information and the extent to which clients are involved in applying instruments. The supervisory committee will have input in the formulation of criteria for the assessment and selection of the qualitative instruments. The instruments may include individual interviews, observations, focus groups, or combinations thereof. This information will be presented to the supervisory committee using the Delphi method (38). For the selection of instruments, the supervisory committee may be supplemented with other stakeholders, such as representatives of the cooperating care organisations.

Products of the selection:
- Overview of assessed qualitative instruments for evaluating the care relationship.
- Two instruments per client group that will be evaluated.

**Evaluation of qualitative instruments**
The purpose of the systematic review and consultation phase is to understand the determinants that influence the quality of the care relationship in long-term care. In the evaluation phase, the selected instruments will be reviewed to ascertain whether they are useful for evaluating the quality of individual care relationships in long-term care. This evaluation phase will consist of three parts.
a. *Adapting the items in the selected instruments*

The selected qualitative instruments might need some adaptations in order to be useful for the purpose of this study: to create insight into the experienced quality of the care relationship from a client perspective. Some instruments may have a broader focus on quality of life and quality of care. Therefore, the determinants of the care relationship quality that emerge from the consultation of clients and professionals and the systematic review will be incorporated in additional items if the instrument does not yet cover all relevant determinants of the quality of care relationships. The instrument might also need to be adjusted to be suitable for the participation of client-researchers. For example, the instructions may need to be rewritten using easier words, and the training might have to be adapted to their level of literacy. Furthermore, the selected instruments will be adjusted to suit the specific client group if the instrument is normally used for another client group.

b. *Evaluation of the instruments in one client group*

Each instrument will be tested with at least ten clients and an expected maximum of thirteen clients from one of the client groups (see figure 2.3).

*Figure 2.3 Research respondents*
It is expected that saturation will occur after this number of clients. The respondents in the evaluation phase will not necessarily be the same respondents as in the consultation phase; it is likely that most respondents will only participate in one phase of this study. We will use the same evaluation criteria as used in the selection phase, supplemented by criteria such as generalisability to other client groups, and information needed for applying the instrument as a client and care professional.

c. **Evaluation of the instruments in other client groups**

Next, the most promising instrument for each client group will be cross-tested in the other two client groups with six to eight clients. If no instrument appears to be suitable for all three client groups, we will investigate whether there are common elements in the qualitative instruments that can be used in more than one client group. In the case of equal suitability, instruments with generic elements will be preferred over instruments that are solely applicable to one specific client group. This evaluation will lead to a new ranking based on a summary judgement of each qualitative instrument in which the advantages and disadvantages are listed as well as the conditions necessary for successful implementation. These results will be presented to the supervisory committee.

The qualitative instruments will be applied and evaluated with the help of six client-researchers from each client group. In addition, we will include at least 32 clients from each care organisation as respondents in the whole evaluation. They will be approached by their daily care professionals, client-researcher or the client council, who will ask them to take part in the study. A convenience sample technique will be used to include clients who meet the inclusion criteria and are willing and able to participate. Nevertheless, we will aim for as much variation as possible with regard to relevant client characteristics such as gender, age, ethnicity, and inpatient or outpatient care.

Products of the evaluation:
- Selection of the qualitative instruments that were evaluated as best (chapter 5)
**Dissemination**

In close cooperation with the client-researchers and participating care organisations, we will develop a toolbox including an implementation plan and the (adjusted) qualitative instruments for measuring and improving the quality of the care relationship for each client group in long-term care. The implementation plan will focus on implementing the qualitative instruments that were selected at the end of the evaluation phase. The toolbox will include a training module to let clients and healthcare providers apply the instrument, plus guidance for the analysis and use of results for improving the care relationship. The toolbox will also describe the levels at which the results of the instrument are expected to be useful, such as the individual care relationship, reflection at the team level, or at the organisational level of a care organisation.

We will also examine whether the results of the qualitative instruments can be used for other purposes, such as healthcare procurement by health insurers and monitoring for external accountability on quality measurement and improvement, primarily by the National Health Care Institute. Several meetings will be held with stakeholders, the research team and care organisations in order to disseminate and discuss the results of the project and the implementation plan. Moreover, we will look for opportunities to present the research findings and research products such as the toolbox to interested care organisations and client councils. Client-researchers will be asked to share their experiences by co-presenting at various platforms. In this way they will have an essential role in the implementation and application of the qualitative instruments. The owner of the qualitative instrument will remain responsible for further implementation and dissemination. The National Health Care Institute may also play a role in the dissemination of the instrument.

Product of the dissemination phase:

- Toolbox including the optimised qualitative instruments to measure and improve the quality of the care relationship for each client group in long-term care, and the implementation plan.
- Recommendations based on external verification of the toolbox.
2.4 Ethics

Participants will receive verbal and written information about the research. Participants will provide written informed consent and process consent will also be used in the interviews with clients (36). The Medical Ethics Committee of the Radboud University Nijmegen Medical Centre was asked whether their approval of the study was required under the Dutch Medical Research Involving Human Subjects Act. The Committee decided that formal approval was not needed.

2.5 Discussion and conclusion

Discussion

Prior work has documented the importance of the care relationship for clients in long-term care (1, 4, 39). In practice, there is a lack of qualitative instruments for evaluating or monitoring the care relationship. We will carry out a study to find and optimise the most suitable qualitative instruments for monitoring the quality of care relationships in long-term care from a client’s perspective. The aim of the present paper is to describe the research design of this study. Due to the differences between client groups in long-term care, it is possible that different instruments will fit each group best. This study will result in a toolbox containing an implementation plan and the optimised qualitative instruments.

Clients will participate in this participatory study as client-researchers. We are therefore working closely with client-researchers in activities such as conducting interviews, preparation activities and analysis. According to Roberts (2012), participatory research is more time-consuming than conventional research methods. It takes time to achieve the desired level of trust in a community, and extra time is also needed for the joint process for thinking about the research results. This extra time will be taken into account in the time schedule of this study. In order to create support in the environment and thereby increase the probability of participation by clients, client-researchers, care organisations, client councils and client organisations will cooperate in this study (40). Their willingness to join is an important prerequisite for the performance of this research. The study depends on the close cooperation of client-researchers, and it is therefore important to work together in an equal, respectful, attentive and open way (40, 41). Lessons
learned in previous participatory research will be used to prevent repetition of avoidable errors, such as tokenism, client-researchers facing difficult situations, experienced workload, and proto-professionalisation (32, 42). A scoping review will be conducted for this purpose. In order to make the project practically feasible, we will exclude some specific groups in long-term care, such as people with physical or sensory disabilities or people receiving palliative care.

If client-researchers in care organisations carry out one of the optimised instruments from the toolbox, it will provide useful information and feedback for clients and care professionals on the care relationship in long-term care. This makes the research project practically relevant. Nevertheless, this study risks being overshadowed by the everyday demands that care organisations face, which precludes implementation of the selected instrument on a large scale. The likelihood of successful implementation will depend on the willingness of organisations to change their instruments for measuring the quality of the care relationship, and the degree of support from national stakeholders. Moreover, the willingness and enthusiasm of client-researchers to be involved in the performance of the instruments will be essential for the implementation and application of the qualitative instruments. The participatory research design and involvement of the supervisory committee will increase the probability that the most preferred instruments will be implemented and disseminated in the field.

The qualitative and participatory research method was chosen to study the experiences of participants and interactions between respondents and client-researchers in natural settings. The research relies heavily on the observational and interviewing skills of researchers and client-researchers and reflectivity on ‘our’ perspectives on the findings. In qualitative research, studying the perspectives of multiple stakeholders and interpreting the results with different client-researchers and researchers is likely to result in an increased understanding of complex phenomena such as care relationships between clients and professionals. This will diminish possible limitations inherently attached to the qualitative research method (16) (43). Also, this research takes place on a small scale in three care organisations focused on three client groups within their own contexts. The generalisability to other client groups in other care settings, such as clients with a severe intellectual disability or dementia, may be limited.

From a quantitative design point of view, this study protocol may be interpreted as limited because some details are still left open. To make client
participation meaningful, we feel it is not good to define every detail on beforehand to be able to make decisions during the process as well. Therefore, the global structure and decision moments of the research process are described, but at the same time space is left open so that some aspects can be filled in later on. This is not unusual in qualitative research.

**Conclusion**

In long-term care, care relationships are seen as a fundamental element in the delivery of high quality care (4, 44-46). But good care relationships have not yet been set up everywhere. It is therefore important that clients, client-researchers, care professionals, client councils and care organisations determine areas in which improvement of the care relationship is possible. As far as we are aware, this will be the first study to use a participatory research design to represent the client perspective in the selection and optimisation of qualitative instruments for monitoring care relationships. Scientific articles will be published to expand scientific knowledge on care relationships in long-term care. This approach allows participatory research to link the practical and scientific purposes. Support for the set of qualitative instruments developed will be generated through the meetings of the supervisory committee, and the involvement of client-researchers and care organisations.

2.6 **Practice Implications**

The study will result in a toolbox with qualitative instruments that can be used for effective evaluation of the quality of a care relationship. Clients, client councils and care organisations can use the toolbox to monitor the care relationship in a structured way from a client perspective. More generally, the content of this paper may serve as a guideline for developing other studies with the combined purpose of practical outcomes and sharing empirical evidence.
2.7 **Strengths and limitations of this study**

- The study will result in useful optimised instruments for care organisations and client councils to collect information and feedback from clients on care relationships in long-term care.
- The participation of client-researchers in the research teams will improve the validity and relevance of the research project and support for it.
- The success of the study will depend on the willingness of client-researchers and care organisations to be involved in and contribute to the study.
- The success of the implementation will depend on the willingness of care organisations to use the optimised qualitative instruments, and the degree of support from national stakeholders.
Literature


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Chapter 3

Determinants of the quality of care relationships in long-term care - a systematic review

Published as:
Abstract

**Background:** The quality of a care relationship between a client and a care professional is seen as fundamental if high-quality care is to be delivered. This study reviews studies about the determinants of the quality of the client-professional relationship in long-term care.

**Methods:** A systematic review was performed using the electronic databases of Medline, Psycinfo, CINAHL and Embase. The review focused on three client groups receiving long-term care: physically or mentally frail elderly, people with mental health problems and people with physical or intellectual disabilities. Included studies concern clients receiving inpatient or outpatient care and care professionals who provided recurring physical and supporting care for a long period of time. The studies we included contained primary empirical data, were written in English and were published in peer-reviewed journals. Data extraction was carried out by two researchers independently.

**Results:** 32 studies out of 11,339 initial hits met the inclusion criteria. In total, 27 determinants were revealed, six at the client level, twelve at the professional level, six between the client and care professional levels and three at the contextual level. The data analysis showed that most determinants were relevant in more than one client group.

**Conclusions:** This is the first review that looked at determinants of the quality of the care relationship for three large client groups receiving long-term care. It suggests that the current client group-specific focus in research and quality improvement initiatives for care relationships might not be needed. Care organisations can use the findings of this review as guidance on determinants to look for when mapping the quality of a care relationship in order to get a picture of specific points of attention for quality improvement.
3.1 Background

Care relationships between clients and care professionals have received considerable attention in research in recent years. Worldwide, there is a drive to redress the imbalance in care from an ethos that is medically dominated, disease orientated and often fragmented to one that focuses on relationships and people (1). Relationships are perhaps the most visible feature of the enactment of person-centred care (2). Especially in long-term care, relationships between clients and care professionals are seen as a fundamental determinant for providing high-quality care, because these relationships are maintained for long periods of time (3). Long-term care consists of ‘a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of permanent nursing care’ (4). Furthermore, the variable and fluctuating nature of care relationships makes care relationship experiences very singular (5).

Theories focusing on relationships in general are based on several assumptions (6). Firstly, relationships are never static, but continually changing, growing, re-examined and reinterpreted by both the actors in the relationship and outsiders. Secondly, relationships are inextricably bound with social interactions: relationships are created primarily through social interaction between two people. Thirdly, each relationship must be examined within its cultural context and the overall patterns of other relationships. Finally, the self and the other party plus the relationship between the two are inextricably bound, not fully separable and influencing each other (6).

Determinants of the quality of a care relationship can be distinguished at four levels: 1) client; 2) care professional; 3) interaction between client and care professional, and 4) context. These levels can be illustrated by the following examples of determinants. At the client level, open attitudes from clients towards care professionals influences care relationships positively (7). At the professional level, the listening skills of a professional and tailoring the provision of care to the individual needs have a positive effect (8). At the level of the interaction, reciprocity comes to the fore (9). Concerning context, lack of time and the workloads of care professionals have been suggested as negatively influencing the development and maintenance of a care relationship (10).
In spite of the available studies carried out on this topic, there is as yet no systematic overview of determinants influencing the quality of client-care professional relationships in long-term care. Moreover, nothing is known about the differences or commonalities between client groups in long-term care. Previous research has focused on specific client groups: older adults who are physically or mentally frail, people with mental health problems or with physical and/or intellectual disabilities. In the Netherlands, these three client groups are the largest groups in long-term care. It is unclear to what extent empirical findings support the focus on one specific client group when studying the client-care professional relationship in long-term care.

This systematic review provides an overview of determinants of the quality of the care relationship in long-term care. The main question in this chapter is:

**What are determinants of a client-care professional relationship in long-term care according to clients and care professionals?**

In answering this question, we will examine the similarities and differences in determinants between different client groups of long-term care. Because high-quality relationships between clients and professionals are a fundamental element of the quality of care, the findings of this review can provide input for quality improvement initiatives for long-term care relationships. This systematic review is part of a larger study that focuses on improving the existing qualitative instruments for monitoring the quality of the care relationship between a client and a care professional. Determining the quality of individual care relationships can show care professionals ways of improving their working processes, which can help improve performance (11).

### 3.2 Methods

**Study design**

To examine what is known about the determinants of the quality of care relationships in long-term care, a systematic review was performed using the electronic databases of Medline, Psycinfo, CINAHL and Embase.

**Search strategy**

Search strategies were developed for each database with the assistance of an experienced librarian. So that we could focus on recent evidence, we searched for studies published since 2006. Broad strategies were chosen in order to include as many relevant articles as possible. The search strategies
included terms identifying client-professional relationships, long-term care and quality. Only EU countries and non-EU G7 countries were included to ascertain the inclusion of those countries that most likely have similarities in the organisational features in the care provision system. See appendix 1 for the search string used in Embase. The date of the last search was 6 August 2018.

Inclusion criteria were:

a. The topic focused on determinants of the quality of care relationships between clients and care professionals in long-term care.

b. The study looked at one or more of the following adult client groups receiving long-term care: physically or mentally frail older adults, clients with mental health problems and clients with a physical and/or intellectual disability. Studies that were included concern clients receiving permanent care and/or assistance with daily living activities.

c. Clients received care from care professionals providing recurring physical and supporting care for a long period of time, such as various types of nurses, care assistants, personal carers and paid caregivers. This could be inpatient or outpatient care.

d. The article contains primary empirical data and was published in a peer-reviewed journal.

e. The study was carried out in EU-27 countries and/or non-EU G7 countries (USA, Canada, Australia, New Zealand, Japan).

f. The article was written in English.

We excluded studies that did not meet the inclusion criteria:

a. Topic not relevant: studies were excluded that focused on the working relationships between care professionals, between clients, or between clients and their families.

b. Studies that focused on unrelated settings such as short-term and specialist units of hospitals or palliative services or irrelevant patient groups (patients receiving acute or short term care, hospital patients, people under 18, oncology patients, clients receiving palliative care, patients with explicitly physical care needs such as diabetes, and patients with urological disorders). We also excluded studies that focused on clients of primary care if clients of long-term care were not clearly distinguished as a subgroup.
c. Study that focused on professions less directly involved in giving recurring physical and supporting care, e.g. psychiatrists, medical specialists, dentists, medical students and general practitioners. Moreover, studies focusing on care provided on a voluntary basis were also excluded.

d. Articles that were non-empirical or not peer reviewed; for instance systematic reviews, theoretical or conceptual frameworks, editorials, abstract overviews, dissertations, letters and comments.

**Study selection**

All search results were transferred to a reference database (ENDNOTE) and duplicates were removed. Firstly, titles and abstracts of the retrieved papers were screened and assessed by one researcher (AS). References that clearly did not meet the inclusion criteria were excluded, all others were retained for the abstract screening, including those references of which the researcher had some hesitations whether the reference fitted all inclusion criteria. Secondly, the abstracts of included papers were screened by two researchers independently (AS and NB). In cases where the two researchers rated an abstract differently, consensus was reached by discussion between the two researchers and a third reviewer (MH) was consulted if necessary to make a final decision. At the start of the abstract screening phase, the five authors reviewed and discussed a selection of 15 abstracts to increase inter-researcher reliability. Thirdly, the full texts of the studies included were assessed by two researchers (AS and NB). In cases where the two researchers rated the full text differently, consensus was reached by discussion and the other authors (MH, KL, SvD) were consulted if necessary to make a final decision. Additionally, the reference lists of included articles and some relevant but excluded dissertations (exclusion criterion d) were screened to identify additional relevant studies.

**Data extraction**

Articles meeting all the inclusion criteria were retained for data extraction using a data extraction file that contained the following variables: author, title, year of publication, period of data collection, study population (client group, type of care professionals included, study population size), care setting, whose perspective the study focuses on (client, professional or both), country in which the study was carried out, study type (qualitative, quantitative, mixed method), type of data collection (open, semi-structured
or structured interviews, observations, focus groups, questionnaires), aim of study, definition of the care relationship, journal, abstract, main results.

**Quality assessment**
Two researchers (AS and MH or NB) independently rated the quality of the included studies, using the Mixed Methods Assessment Tool [MMAT] (13). This tool has been designed for reviewing mixed studies. For each type of study (qualitative and quantitative studies), four items were used to assess the quality. For each item, response categories were ‘yes’, ‘no’ or ‘can’t tell’. Each study received a score ranging from one star (25% of the criteria were met) to four stars (all the criteria were met). For mixed-method studies, three additional mixed-method items were assessed on top of the four items concerning the qualitative part and the four items concerning the quantitative part. No study was excluded on the basis of the quality assessment because we were interested in collecting all possible determinants that have been identified as important for the care relationship.

**Data synthesis**
The results were analysed and categorized by the first two authors (AS and NB) independently in the qualitative data analysis program MAXQDA. First, AS and NB separately explored the available determinants in the included manuscripts. This was comparable to an open coding phase in qualitative research: the exploration of included articles provided a long list with determinants. AS and NB made a categorization and subdivision of the determinants in two meetings. This categorization was discussed with all authors. Thereafter, all articles were ‘coded’ using the created list of determinants. Two-thirds of the articles were coded double by two researchers (AS and NB or MH). Next, differences and doubtful cases were compared and discussed until consensus was reached. The remaining articles were coded by one researcher. All determinants had to have been noted in at least one high-quality study (i.e. that met at least 75% of the quality criteria of the Mixed Methods Assessment Tool) in order to be included in the results section.
### 3.3 Results

**Study selection**

The numbers of articles retrieved from the databases that were screened by title, abstract and full text are shown in figure 3.1. The searches resulted in 9,662 unique titles. A total of 32 studies were included eventually. A summary of the study characteristics and main results of these 32 studies can be found in table 3.2.

*Figure 3.1  Flow chart of the numbers of articles excluded at each stage*
<table>
<thead>
<tr>
<th>Authors (year)</th>
<th>Aim</th>
<th>Data collection</th>
<th>Study population</th>
<th>1</th>
<th>2</th>
<th>Determinants described (level)</th>
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</thead>
<tbody>
<tr>
<td>Abma et al. (2009)</td>
<td>To understand tensions in the care relationship between professional and client due to different expectations from a care ethics perspective.</td>
<td>Open interviews</td>
<td>3 women with multiple sclerosis, chosen out of 15 case studies. The women were receiving care in both inpatient and outpatient settings and reported their experiences with these settings. One case study about a client Jane living in a nursing home was relevant for our study.</td>
<td>C</td>
<td>D</td>
<td>Client: - Attitude (acceptance of situation and complaining or not) Professional: - Attitude (respectful) - Encouragement (encouraging autonomy of client) - Focus on individual client - Take time - Professional competences (technical competences) Between client and professional: - Equality Contextual: - Time</td>
</tr>
<tr>
<td>Ahlström and Wadensten (2009)</td>
<td>To explore the encounters in greater depth in close care relationships between personal assistants and disabled people of working age, as well as the prerequisites for and obstacles to the success of such encounters.</td>
<td>Open interviews</td>
<td>32 personal assistants who worked for 32 people with serious neurological diseases living at home.</td>
<td>P</td>
<td>D</td>
<td>Client: - Professional: - Attitude (respectful) - Availability (flexibility) - Encouragement (helpful, being positive and encouraging autonomy of client) - Extra effort (take initiative) - Focus on individual client - Take time Between client and professional: - Closeness versus professional distance (professional attitude and informal relationship or friendship) - Reciprocity (personal chemistry) - Trust Other: - Family</td>
</tr>
<tr>
<td>Andersen and Spiers (2016)</td>
<td>Exploring the complexities of care, working environments, and knowledge, skills, and efforts of care aides who work in nursing homes</td>
<td>Individual or paired interviews</td>
<td>22 care aides caring for nursing homes residents</td>
<td>P</td>
<td>O</td>
<td>Client: - Abilities - Attitude (open to professional) - Emotional state - Previous life experience Professional: - Attitude (open to client) - Emotional investment or caring - Extra effort (doing more than expected) - Focus on individual client - Professional competences (experience and timing) - Take time</td>
</tr>
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<td>Authors (year)</td>
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| Bäck-Pettersson et al. (2014) | To describe patients’ experiences of supportive conversation as long-term treatment in a psychiatric outpatient context. | Focus group interview    | 6 female patients receiving mental healthcare in an outpatient setting for more than 2.5 years. Clients with: emotional unstable personality disorder (n=1), severe depression, without symptoms of psychosis (n=1), dysthymia (n=1), general anxiety disorder (n=1), and bipolar disorder (n=2). The contact was mostly a qualified nurse. | C  | M                                      | Working in a team  
Between client and professional: - Continuity (development of relationship)  
Context: - Hierarchy - Time (workload)  
Other: - Family  
Client: - Ask for help  
Professional: - Attitude (respectful) - Availability - Dependable (confidentiality) - Encouragement (creating roles outside of being patient and being helpful) - Extra effort - Focus on individual client - Listen - Professional competences (technical competences)  
Between client and professional: - Closeness versus professional distance (informal relationship or friendship) - Continuity (development of the relationship) - Equality (collaboration) - Social interaction (open communication) |
| Bangerter et al. (2016)  | Exploring the specific way that a person defines eight key care preferences. | Individual interviews    | 337 Cognitively capable nursing home residents recruited from 35 Nursing Homes. | C  | O                                      | Client: -  
Professional: - Attitude (friendly and kind, respectful, etiquettes) - Emotional investment or caring - Focus on individual client (interest, genuine concern for client) - Listen - Professional competences (communication) - Take time  
Between client and professional: - Closeness versus professional distance (professional attitude) - Equality - Reciprocity - Social interaction (use of touch)  
Context: - |
<table>
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<tr>
<th>Authors (year)</th>
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<tbody>
<tr>
<td>Berggren and Gunnarsson (2010)</td>
<td>To describe the characteristics of the Swedish Personligt Ombud (personal ombudsman; PO) through actual experiences of the service users and more particularly what they find to be significant and helpful features of their relationships with their PO.</td>
</tr>
<tr>
<td>Bourgault et al. (2010)</td>
<td>To examine the role of immigrant care workers in the home and long-term care sectors in Canada, with a particular focus on the relationships with older adults and the implications for quality of care.</td>
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<td>Authors (year)</td>
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<tr>
<td>Broer et al. (2010)</td>
<td>To explore how mental healthcare professionals initiate, improve, and maintain client autonomy while improving other aspects of quality of care.</td>
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<tr>
<td>Cook and Brown-Wilson (2010)</td>
<td>To describe residents' narratives of their experiences of interacting with staff and making suggestions for practice development.</td>
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<tr>
<td>Day et al. (2017)</td>
<td>To explore consumer concerns, issues and Preferences relating to hcp before the introduction of CDC On the 1 July 2015.</td>
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<tr>
<td>Denhov and Topor (2012)</td>
<td>Exploring the components of helping relationships and the characteristics of helping professionals as described by users who are in various stages of recovery while still undergoing some form of psychiatric care.</td>
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<tr>
<td>Dziopa and Ahern (2009)</td>
<td>To explore the attributes of a therapeutic relationship in mental health nursing to determine if there are different ways mental health nurses develop therapeutic relationships.</td>
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<td>Authors (year)</td>
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<tr>
<td>Eriksen et al. (2013)</td>
<td>To reveal and express knowledge about the meanings of recognition of clients’ person-hood and intrinsic value as human beings, based on mental health workers’ lived experiences of long-term relationships with clients.</td>
</tr>
<tr>
<td></td>
<td><em>&quot;We are All Fellow Human Beings&quot;</em></td>
</tr>
<tr>
<td>Eriksen et al. (2013)</td>
<td>To describe service users’ understanding of being in relationships with professionals, and how these relationships may limit or enhance recovery.</td>
</tr>
<tr>
<td>Challenges in relating to mental health professionals</td>
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<tr>
<td>Forsgren et al. (2015)</td>
<td>To explore how nurses experience their everyday interactions with nursing home residents, with a particular focus on interactions with residents with communicative disabilities.</td>
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<td>Huxley et al. (2009)</td>
<td>Exploring what the worker did with and for the user, what the most important actions were, which made the greatest difference, what else could or should be done, and how could the local Support, Time and Recovery (19) service could be improved.</td>
</tr>
<tr>
<td>Jones and Moyle (2016)</td>
<td>To explore the nature of relationships in elderly care services from the perspective of staff.</td>
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<tr>
<td>Ljungberg et al. (2017)</td>
<td>To investigate the experience-based Knowledge of professionals in outpatient psychiatric services with regard to being personal in their relationships with users.</td>
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<td>Authors (year)</td>
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<tr>
<td>McCloughen et al. (2011)</td>
<td>To identify whether consumers and nurses in a mental health rehabilitation setting shared common understandings, attitudes, values, and experiences of nurse–consumer collaboration.</td>
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<tr>
<td>McGarry (2008)</td>
<td>To provide a clear, in-depth account of the nature of the relationships between nurses and older people within their own home, from the perspective of both nurses and older patients.</td>
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<td>Authors (year)</td>
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<tr>
<td>McGilton and Boscart (2006)</td>
<td>To analyse the perceptions of residents, family members and care providers with regard to close care provider–resident relationships in a LTC setting.</td>
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<tr>
<td>Petriwskyj et al. (2015)</td>
<td>To examine how client engagement is enacted within the context of a large Australian elderly care provider, Blue Care.</td>
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<td>Authors (year)</td>
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</table>
| Roberts and Bowers (2014) | To develop a conceptual model that explains how residents develop relationships with peers and staff in nursing homes. | Unstructured interviews and field observations       | 15 cognitively intact nursing home residents from 2 nursing homes receiving care from staff (among others nurses) | C  | O       | Client: - Attitude (acceptance of situation, open to professional) - Previous life experiences - Strategic adapting behaviour  
Professional: - Attitude (friendly and kind) - Encouragement (encouraging autonomy of client) - Take time  
Between client and professional: - Closeness versus professional distance (being part of a community) - Reciprocity - Social interaction (having a sense of fun, humour)  
Contextual: - Time  |
| Rugkåsa, et al. (2014) | To investigate how influencing behaviours were conceptualized by professionals. | Structured interviews, in-depth interviews, focus groups | 417 patients of community health services took part in structured interviews, 39 patients were additionally interviewed in depth. 48 care professionals (including nurses, psychiatrists, social workers, community support workers, occupational therapists, students and an office manager) | C+P| M       | Client: - Professional: - Attitude - Dependable - Encouragement - Extra effort (doing more than expected) - Focus on individual client (interest, genuine concern for client) - Listen - Professional competences (communication)  
Between client and professional: - Closeness versus professional distance (professional relationship) - Continuity (development of relationship, perceiving stability in the relationship) - Equality (collaboration, dependency, power) - Reciprocity - Trust  
Contextual: - |
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<tr>
<th>Authors (year)</th>
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<th>1</th>
<th>2</th>
<th>Determinants described (level)</th>
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<tbody>
<tr>
<td>Scanlon (2006)</td>
<td>To ascertain the nature and comprehension psychiatric nurses assign to the development of a therapeutic relationship.</td>
<td>Semi-structured interviews</td>
<td>Six psychiatric nurses (client group not specified).</td>
<td>P</td>
<td>M</td>
<td>Client: - Professional: - Non-judgemental - Emotional investment or caring - Focus on individual client (interest, genuine concern for client) - Professional competences (communication, timing) - Working in a team Between client and professional: - Closeness versus professional distance (professional boundaries) - Continuity (development of relationship) - Equality (dependency, power) - Reciprocity (sensing close contact and togetherness) - Social interaction (open communication, having a sense of fun or humour) - Trust Contextual: - Time</td>
</tr>
<tr>
<td>Schroeder (2012)</td>
<td>To give voice to the lived experiences of older adults with serious mental illness and their perceptions of the healthcare provider relationship</td>
<td>Open interviews</td>
<td>8 older adults with a serious mental illness receiving outpatient care from healthcare providers such as a GP, psychiatrist or therapist.</td>
<td>C</td>
<td>O+M</td>
<td>Client: - Professional: - Attitude (Non-judgemental attitude, respectful) - Closeness versus professional distance (being part of a community) - Dependable - Emotional investment (caring) - Encouragement (creating roles outside of being patient, helpful or being supportive, encouraging autonomy of client) - Focus on individual client - Listen Between client and professional: - Closeness versus professional distance (informal relationship or friendship, professional distance) - Continuity (perceiving stability in the relationship) - Equality (dependency, power) - Trust Contextual: -</td>
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<td>Authors (year)</td>
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<tr>
<td>Sellevold et al. (2013)</td>
<td>To describe healthcare providers’ experience with the ethical challenges and possibilities in the relationship with patients suffering from dementia and their impact on quality care.</td>
<td>In-depth narrative interviews</td>
<td>12 professionals from two different nursing homes providing care to clients suffering from dementia. 4 registered and 8 assistant nurses.</td>
<td>P</td>
<td>O</td>
<td>Client: - Attitude (open to professional) – Emotional state &lt;br&gt; Professional: - Attitude (open to client) – Focus on individual client – Professional competences (communication) &lt;br&gt; Between client and professional: Equality (collaboration) – Reciprocity – Social interaction (use of touch, open communication) - Trust &lt;br&gt; Contextual: -</td>
</tr>
<tr>
<td>Shattell et al. (2006)</td>
<td>To examine mentally ill patients’ experiences of what it is like to be understood.</td>
<td>Open interviews</td>
<td>20 mentally ill clients. Clients self-identified as having a mental illness.</td>
<td>C</td>
<td>M</td>
<td>Client: - &lt;br&gt; Professional: - Take time – Attitude (non-judgmental, open to client, respectful) – Encouragement – Focus on individual client – Listen – Professional competences (communication) &lt;br&gt; Between client and professional: - Closeness versus professional distance – Continuity (development of relationship) – Equality – Social interaction (use of touch, open interaction) &lt;br&gt; Contextual: -</td>
</tr>
<tr>
<td>Shattell et al. (2007)</td>
<td>To describe mental health service recipients’ experience of the therapeutic relationship.</td>
<td>Open interviews</td>
<td>20 mentally ill clients. Clients self-identified as having a mental illness.</td>
<td>C</td>
<td>M</td>
<td>Client: - &lt;br&gt; Professional: - Attitude (non-judgmental, open to client) – Emotional investment – Encouragement (being positive, helpful) – Extra effort (doing more than expected) - Focus on individual client – Listen – Professional competences (communication) - Take time &lt;br&gt; Between client and professional: - Closeness versus professional distance – Continuity – Equality – Social interaction (use of touch) &lt;br&gt; Contextual: - Time</td>
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<td>Authors (year)</td>
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<td>Study population</td>
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<tr>
<td>Westin and Danielson (2007)</td>
<td>To illuminate and interpret the meaning of residents’ experiences of encounters with nurses in nursing homes.</td>
<td>Open interviews</td>
<td>12 residents from 3 nursing homes receiving care for at least 6 months. These residents received care from nurses.</td>
<td>C</td>
<td>O</td>
<td>Client: - Professional: - Attitude (respectful) – Encouragement (being positive, creating roles outside of being patient) – Focus on individual client - Take time Between client and professional: - Closeness versus professional distance (being part of a community) - Social interaction (having a sense of fun, humour, open communication) Contextual: - Time</td>
</tr>
<tr>
<td>Brown Wilson (2009)</td>
<td>To help understanding the factors that may be significant in forming relationships in care homes and how this may help the community’s development.</td>
<td>Participant observation, focus groups and interviews</td>
<td>Interviews with 16 residents, 25 staff members and 18 family members. 8 focus groups of which 3 were held with residents, 2 with family members and 3 with staff members. 256 hours of observation. Many residents of one nursing had a degree of cognitive impairment and residents of another nursing home suffered from enduring mental health problems. Staff were unspecified.</td>
<td>C+P+F</td>
<td>O</td>
<td>Client: - Previous life experiences – Being part of a community Professional: - Attitude (respectful) – Dependable – Focus on individual client – Listen – Task centred – Working in a team Between client and professional: - Closeness versus professional distance (informal relationship or friendship) – Continuity – Reciprocity – Social interaction (having a sense of fun, humour) Contextual: - Hierarchy – Setting – Time (workload) Other: - family</td>
</tr>
<tr>
<td>Brown Wilson and Davies (2009)</td>
<td>How these relationships are developed and the contribution that staff make to this process through the routines of care.</td>
<td>Participant observation and interviews with residents</td>
<td>256 hours of participant observation and interviews with 10 residents of three nursing homes, 25 staff members and 18 family members. Residents of the first nursing home had complex physical healthcare needs and some were</td>
<td>C+P+F</td>
<td>O</td>
<td>Client: - Previous life experiences Professional: - Encouragement (creating roles outside of being patient) – Extra effort – Focus on individual client – Task centred – Take time Between client and professional: - Continuity (development of relationship) – Closeness versus professional distance (being part of a community) - Reciprocity – Social interaction (having a sense of fun, humour, open communication)</td>
</tr>
<tr>
<td>Authors (year)</td>
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<td>Study population</td>
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<td>Determinants described (level)</td>
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<td>cognitively impaired. Residents of the second nursing home had long-term mental health issues and complex healthcare needs. Residents of the third nursing home had complex health needs including mental health problems. Staff were unspecified.</td>
<td></td>
<td></td>
<td>Contextual: - Time (workload)</td>
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</table>
Most of the studies included were qualitative studies (n=30), plus two mixed-method studies (n=2). The qualitative studies included several study types: ethnographies (n=3), phenomenological studies (n=9), studies based on grounded theory (n=3), case studies (n=3), and qualitative descriptions (n=12). Both mixed-method studies had a sequential exploratory design in which the qualitative component was followed by the quantitative component. The studies were carried out in Sweden (n=7), the United Kingdom (n=7), Australia (n=5), the United States (n=5), Norway (n=3), Canada (n=3), and the Netherlands (n=2). Fifteen studies focused on physically or mentally frail older people, fourteen on people with mental health problems and two on adults with disabilities. The study population of one study concerned older adults with serious mentally illness, and is within the scope of both older adults and people with mental health problems (14).

Of the studies included, twelve focused on the client perspective, eleven on the professional perspective, and nine on both. Furthermore, four studies that focused on both perspectives also included the family perspective, however the family perspective results were not included in this review. Two articles by Shattell are based on one common data sample (8, 15). Likewise, three articles by Wilson are based partly on one common data sample (16-18). These study articles were all included in the data extraction because their results sections focused partly on different topics within the results.

Quality assessment

Of the 30 qualitative studies, ten met all four quality criteria and ten met three of the four quality criteria (see Appendix 2). These studies appeared to be of good quality. Eight studies met two of the four quality criteria, one study met one criterion and one study met no criteria. Of the two mixed-method studies, McCloughen et al. (2011) met four of the eleven quality criteria and Dziopa and Ahern (2009) met five. Sixteen qualitative studies lacked information on the interaction between the researcher and participants, this information was also not included in the qualitative part of either mixed-method study. Six qualitative studies and both mixed-method studies had no information on how the findings relate to the context in which the data was collected.
3.4 Data summary

The determinants of the quality of care relationships were distinguished at four levels: client, care professional, interaction between client and care professional, and contextual. The essence of the key determinants is described below. It appeared that most were mentioned in two or all three client groups. We have therefore discussed the determinants collectively and only specifically reported when a determinant was found in only one client group (7). For each level, determinants are described in order from the most often mentioned to the least often. The perspectives included for a study were not related to the levels at which determinants were noted. For example, the study by Roberts and Bowers focused on the client perspective and the findings include determinants of all four levels (7) (see table 3.2). Interestingly, determinants at the client level were scarcely described in studies in which only a professional perspective was included.

Client level

The studies included described determinants at the client level less frequently and extensively than determinants at the professional level. Six determinants of the care relationship were found at the client level, of which two (previous life experiences and emotional state) were only described in studies concerning older adults who were physically or mentally frail.

- Attitude
The studies described various aspects of the desired attitude of clients (3, 7, 10, 18, 20-26). Care professionals suggested it is easier to develop close relationships with clients who have open attitudes to care professionals: clients who are willing to interact (10), show interest in a close care relationship (10) and act friendly (7, 10, 24). Some clients have an accepting attitude, or simply do as they are told (3, 7, 25). Instances of clients who did not show interest (10) or discriminated against care professionals based on the latter’s skin colour (21) were stated as hindering the development of a care relationship.

- Previous life experiences
The personal history of a client was mentioned in seven studies focusing on physically or mentally frail older adults (7, 16-18, 20, 25, 27). Care professionals gather details about clients’ lives so that they can recognise
their life experiences (20, 27). When a care professional knows and recognises the importance of the personal history of a client, this can improve the quality of the care relationship.

- **Client in the lead**
  Some studies described clients who are ‘in the lead’ in terms of their lives or care, meaning that they make their own decisions and take charge in the relationship (18, 22, 23, 27-29). A care relationship sometimes seems to serve as a safe learning environment for clients for taking the lead (22, 28). If a client is in the lead, this adds to the quality of a care relationship.

- **Abilities**
  Clients’ abilities were described as a determinant of care relationships as well (10, 18, 20, 22, 24, 30, 31). On the one hand, clients’ lack of social interactional skills and communicative disabilities such as hearing, speaking or visual impairments could reduce the possibilities for developing and continuing a good care relationship (10, 18, 22, 30). On the other hand, clients’ ability to communicate their wishes could add to a good care relationship (20, 31).

- **Strategic adapting behaviour**
  Two studies described how clients strategically adapted their behaviour to a certain situation or care professional. Residents determined the right amount and timing of active and passive approaches for receiving care according to their wishes. For example, an active approach could involve a client making specific requests, a more passive approach involved clients allowing staff to provide direct care. These clients adapted in order to avoid negative interactions with staff and maintain a good care relationship (7, 24). As a result, clients use several strategies to improve the quality of a care relationship.

- **Emotional state**
  Two studies focusing on physically or mentally frail older adults described the emotional state (specifically anger, frustration and anxiety) of clients as a determinant of care relationships (20, 26). Negative emotions in a client did not necessarily lead to a negative attitude by the care professional. Professionals tried to understand a client’s bad mood by finding the source or
reason (26). The emotional state of clients might hinder or help the quality of a care relationship.

**Professional level**
The studies included described determinants at the professional level extensively. We distilled twelve main determinants. The ones described most often, are focus on the individual client, attitude, and encouragement.

- **Focus on the individual client**
  Focus on an individual client (the person) was seen as a core determinant of a good relationship in a majority of the studies included (3, 8-10, 14-24, 26-38). Seeing and knowing the individual needs and priorities of clients are essential for responding to those needs at the right time (9, 17, 19, 20, 24, 27, 28, 35). It can mean for instance that a care professional simply remembers the client's name and introduces themselves to the client (34), or knocking before entering and using a formal approach such as ‘Mr. [last name]’ (37). Ideally, care professionals are interested in a client and their views (9, 10, 15, 24, 29-31, 33, 36-38). Care professionals need to be capable of understanding the situation of the client by feeling and thinking as though they were the other person (14, 19, 22). This focus on individual clients might result in clients feeling they are treated like human beings instead of numbers (15).

- **Attitude**
The studies described various aspects of the desired attitude by care professionals (3, 5, 7-9, 14, 15, 17-20, 22-24, 26, 28, 31, 33-37). Clients value care professionals with open or non-judgemental attitudes those who do not have a predetermined image of a client and who hold back their own opinions and prejudices (5, 14, 15, 20, 22, 24, 26, 28, 33-35). Respect and dignity for clients are also part of a desirable attitude from care professionals, because clients then feel treated as a person who is worth something in their own right (3, 5, 14-16, 18, 19, 23, 31, 34, 36). Other attitude aspects mentioned are friendliness (7, 33, 37), honesty (8, 15), being easy to talk to (34), etiquettes (37) empathy (8, 9, 15) being realistic (8) and patience (15). And vice versa: care professionals with unfriendly, disrespectful attitudes were not valued by clients (3, 36) and such attitudes do not add to the quality of a care relationship.
• **Encouragement**

The studies described encouragement as a determinant of the care relationship (5, 8, 9, 14, 17, 19, 22, 27, 28, 30-34, 36). Encouraging care professionals underline the capabilities of a client, not their disabilities (32). Especially when clients have a negative self-image or have received negative feedback from people in their environment, instilling hope, being a positive force and promoting independence were described as important (5). Encouragement also involves care professionals being positive and optimistic in contacts with clients (19, 30, 32, 36). Clients were encouraged by care professionals to explore their possibilities and make a contribution to the environment and others, for example helping the wellbeing of other clients (14, 17, 32). Moreover, care professionals try to encourage the autonomy of clients (3, 7, 14, 19, 23, 25, 28, 32) by removing constraints on client autonomy (32) and encouraging clients to be independent and to make their own choices (23, 28).

• **Take time**

Several studies describe the importance of professionals taking time and spending time with clients (3, 10, 18-21, 23, 25, 29, 33, 37). Clients felt ignored by care professionals who did not take time to interact with them (10, 27) (17) (36).

• **Listen**

Listening skills and a good ear for a client’s problems, feelings and questions are an important quality of professionals (8-10, 14-16, 21-24, 29, 31, 33, 37), e.g. care professionals who asked or checked whether their understanding was in agreement with the client’s view (15). When care professionals did not listen to clients, this could result in clients feeling ignored (14). Corresponding, when care professionals listened to clients, this improved the quality of the care relationships.

• **Professional competences**

A number of studies described professional competences (3, 5, 8-10, 15, 20, 21, 23, 24, 26-31, 33, 35, 37). Care professionals’ competences and expertise comprise technical competences (10) and training (21), non-verbal and verbal communications kills (8, 9, 23, 26, 29, 30, 35, 37), timing of actions, codes of conduct and duty of care (35), work experience (20, 27) and cultural
competencies (21). It follows that these competences add to the quality of a care relationship.

- **Availability**
  Care professionals need to be flexible and available for clients, which means that they are accessible and reachable for clients when they need them (19, 21-23, 28, 31-33).

- **Extra effort**
  Extra effort by a care professional contributes to the quality of a care relationship. Extra effort means that care professionals were doing extra things for clients that they did not expect (8-10, 17-20, 27, 28, 31, 33, 38). Taking initiative (10, 19), letting clients feel special (8), surprising a client with a small present (18, 38) and performing extra tasks besides the usual work such as dog-sitting while a client was in inpatient care (27, 38) were mentioned.

- **Dependable**
  Clients want care professionals who are dependable and can be relied on (9, 10, 14, 16, 18, 21-24, 31, 33). Unreliable care professionals did not show up at all when they were called or failed to follow up on promises (10, 14, 18). Confidentiality is also essential; clients said it was important that some private issues told to a care professional should not be disclosed to others (23, 31).

- **Working in a team**
  Care professionals need to be willing to work in a team. This requires good communication between care professionals. Cooperation in a team is suggested as affecting care relationships positively, as care professionals complement and back up each other’s tasks (16, 20, 21, 24, 35).

- **Emotional investment**
  Emotional investment and caring are a key characteristic of a care professional. It expresses the importance for care professionals of investing in a client’s well-being, having a unselfish and committed attitude, and showing genuine concern (8, 14, 15, 20, 21, 27, 33, 35, 37).
• **Task centered**
Some care professionals of physically or mentally frail older adults were described as solely focusing on routine tasks (16-18, 30, 39). A task-centred focus was often related to time shortage and high workload; as a result, these care professionals did not have time to talk to clients (39). Focusing solely on routine tasks might therefore hinder the quality of a care relationship.

**Interaction between client and care professional level**
Six determinants were found between clients and care professionals. The studies included described the determinants on this level extensively and frequently. The determinants equality and closeness versus professional distances were described most often.

• **Equality**
Equality is a determinant described in the majority of the studies included (3, 19-21, 28, 31, 32) (8-10, 14-18, 22-27, 30, 33-37). Because the client depends on the care professional’s care and assistance, truly equal relationships seem difficult to achieve (10, 27, 30). Keeping this in mind, interacting in an equal and collaborative manner is valued by clients and (some) care professionals (3, 9, 14, 22, 24, 25, 34). Examples were care professionals who provided complete information and treatment options (32), treating a client as an equal (14) and valuing clients’ expert knowledge (24).

• **Closeness versus professional distance**
The determinant of closeness versus professional distance is described in a substantial number of the studies included (5, 8-10, 14-16, 18, 19, 21, 23, 25, 28, 29, 31-35, 37-39). Some care professionals struggle with the borderline area between professional distance and a close relationship, others take a clear position one way or the other (19, 21, 34). Professional distance includes sticking strictly to professional boundaries and keeping an emotional distance (5, 14, 19, 25, 28, 33-35, 37-39). Closeness is about friendliness, engagement, sharing personal stories, and professional friendship (10, 16, 18, 19, 21, 23, 25, 28, 29, 31-33, 38). Care relationships were often compared to friendships, yet at the same time differed clearly. The client need not be concerned with the professional’s own problems and the client can lay more on the shoulders of the care professional. The care professional must maintain professional confidentiality, have unending patience, and not be personally involved in the client’s social network (33).
Moreover, close care relationships seem to be beneficial for clients’ feeling of belonging and being part of a community in which they are valued and accepted (7, 16-18, 23, 28, 36). This feeling of belonging reduces loneliness and isolation of clients (18, 28, 36). In short, different clients and care professionals may prefer either greater closeness or more professional distance in the care relationship, and matching these preferences can improve the quality of a care relationship.

- **Continuity**
  Continuity of a care relationship is experienced as important by clients and care professionals, as was described in fourteen studies (8, 9, 14, 15, 17, 18, 20, 23, 27, 29-31, 33-35). Developing a care relationship requires time and a relationship is continually being built and transformed through interpersonal processes in and outside care routines (29, 30). Policies of rotating staff or changing primary care professionals led to less continuity in care relationships (17, 18, 31). Some clients felt anxious that a care professional would quit or would not be assigned to them anymore (33).

- **Reciprocity**
  Reciprocity between a client and care professional improves the quality of care relationships. Reciprocity means mutual togetherness, personal chemistry, emotional engagement and connection in a care relationship (7, 9, 10, 16-19, 22, 23, 26-29, 33, 35, 37). Possibilities for reciprocity are created when a client is able to do something for the care professional, such as offering them a drink, or when the client and care professional have similar life experiences, for example the experience of being mothers with children of the same age (27, 28).

- **Trust**
  Trust was described in several studies as a determinant of care relationships (9, 14, 18, 19, 23, 24, 26, 27, 29, 33-35). Developing mutual trust takes time and fosters continued contact with clients (9). Trust also involves a tremendous emotional investment (33). Some clients only accepted care from the care professionals they trusted and refused care from others (26).

- **Social interaction**
  Several forms of social interaction were described in the studies that were included (7, 8, 10, 15-18, 21, 22, 24, 26, 30, 31, 33-37). Social interaction
means open, two-way communication and an ongoing dialogue (18, 24, 36). To achieve such social interaction, the ability of care professionals to communicate on the same wavelength as their clients is underlined (31). Furthermore, having a sense of fun or humour and non-verbal communication skills such as the use of touch were mentioned as components of social interaction (7, 10, 26). Open two-way social interaction adds to the quality of a care relationship.

**Contextual level**

Three determinants were found at the contextual level. The determinant hierarchy was only described in studies concerning physically or mentally frail older adults.

- **Time**
  Time constraints, workload or work pressure, inadequate staffing and a lack of backup were found to obstruct the development and retention of care relationships (3, 7, 8, 10, 16-18, 20, 21, 24, 25, 29, 30, 35, 36, 39).

- **Setting**
  Two studies focusing on care for physically or mentally frail older adults made a distinction between a home care setting and inpatient setting. Home care settings are described as giving clients a higher degree of control over their care and more individual undisturbed care time (21, 25). A study focusing on persons with mental health problems described differences between particular contexts of inpatient locations or units (38). In this regard, the care setting can help or hinder the quality of a care relationship.

- **Hierarchy**
  In two studies focusing on care for physically or mentally frail older adults, lack of decision-making authority and the hierarchy of care professionals with different positions were mentioned (20, 24). For example, a lack of nurses’ decision-making authority is been described as a practical obstacle to working collaboratively with clients (24). In a third study, the type of leadership in a care organisation was mentioned as determining the type of care relationships (task-oriented, resident-centred or relationship-centred) (16).
3.5 Discussion

The aim of this review was to provide insights into determinants of the quality of care relationships in long-term care. A systematic review design was chosen to identifying, appraising, and synthesizing all relevant studies on this specific topic. In contrary to a scoping review, a systematic review design is characterized by the predefined search strategy and by the fixed inclusion and exclusion criteria that are defined on beforehand (40, 41). Determinants were categorised at four levels: client, professional, between client and professional, and contextual. Most determinants were described for two or all three client groups of this study, which were physically or mentally frail older adults, clients with mental health problems and clients with physical and/or intellectual disabilities. The most frequently described determinants were found at the care professional level and between clients and care professionals. At the care professional level, these were ‘focus on the individual client’, ‘encouragement by a care professional’ and ‘attitude of the professional’. At the level between clients and care professionals, these were ‘equality’ and ‘closeness versus professional distance’. Four determinants were found solely for the client group of physically or mentally frail older adults. For this client group only, task-centeredness of care professionals, previous life experiences, emotional state of clients and hierarchy on the work floor came to the fore as determinants of the quality of the care relationship.

Studies focusing on people with physical and/or intellectual disabilities were scarce, resulting in fewer findings for the determinants of the quality of care relationships for this client group. Perhaps for this specific client group, more information is covered by ‘grey’ literature including practice-oriented journals for client group-specific professions. A grey literature study could provide a clearer picture of whether this is the case. Furthermore, this review shows that determinants at the client level are studied less often than determinants at the care professional level. One possible explanation for this might be that care professionals are seen as having more responsibility to make efforts for a good care relationship, given their educational background, their choice of a caring profession and their expected expertise. The responsibility of clients in long-term care relationships might be emphasized less often due to expected shortcomings in the abilities of clients regarding their need for care or assistance. Nonetheless, given the
importance of equal care relationships and empowerment of clients, it is important to focus on determinants at the client level as well.

To our knowledge, this is the first review that provides an overview of determinants of the care relationship in long-term care for three client groups. Each of the studies included focused on one specific client group. This review shows that a substantial number of determinants apply to more than one client group. At the moment, it is not clear which determinants are specific to client groups and which have just not been studied in all client groups yet. More research is needed on determinants of the quality of care relationships in more than one client group in order to explore the generalizability of determinants of care relationships. This might expand knowledge of determinants that are specific to client groups as well. Moreover, this finding might suggest that the current client group-specific focus in research into care relationships in long-term care is not necessarily needed. This implication and the findings regarding determinants of the quality of care relationships can provide input for quality improvement initiatives for long-term care relationships.

The studies included in our review were mainly qualitative studies, plus two mixed-method studies. The qualitative studies were primarily exploratory and focused on getting a picture of the wide variety of experiences of clients and/or care professionals. One limitation of qualitative studies is that the external validity of findings is often limited, due to the nature of the methods used. It is also not clear which determinants have the most influence on the quality of a care relationship according to clients and care professionals and what are least likely to be met in existing care relationships, as no weightings are assigned. Moreover, we included all studies regardless of the results of the quality assessment because we were interested in collecting all possible determinants that have been identified as important for the client-care professional relationship. Consequently, the results do not reveal which determinants are most important or have most effect on the quality of care relationships. More research is needed to determine priorities for quality improvement. The current review provides care organisations guidance about what determinants they can look for when examining the quality of the care relationship. The mapping will then give care professionals a picture of specific points of attention for quality improvement. Issues that are specific to the care organisation and care relationship could thereby be taken into account.
Some of the determinants of the quality of care relationships reflect current views on relationships in general in western societies or might be interpreted within contemporary developments in healthcare. For example the focus on the individual client in a care relationship can be placed in the trend towards person-centred care and individualisation. Determinants such as equality, closeness versus professional distance, and clients in the lead can be seen in the light of reducing the social distance between clients and care professionals and the authority of care professionals and broad emphasis on equality in societies. ‘Taking time’ and ‘time and workload’ might illustrate the incompatibilities between providing high-quality, individualised care and cost reduction strategies by national governments.

One limitation of this review may be the broad search string on determinants of care relationships. As a result, we might have missed studies that focused on one specific determinant. For example, it is possible that we have missed studies focusing on reciprocity or another determinant, because the care relationship between client and care professional was not explicitly stated and included. Another limitation is that we did not include ‘grey’ literature in this study, even though these sources may also include relevant knowledge about care relationship determinants. Furthermore, the fact that the title screening was carried out by a single researcher could be seen as a limitation of the study selection process. Besides this, although the classification and grouping of the determinants were carried out by two researchers independently, the classification remains to some extent limited to their interpretations. The interrelatedness of determinants should also be taken into account, both in the interpretation of the findings and in future research.

The influence of clients’ families on the client-professional relationship was outside the scope of this review and therefore not included. Future researchers might look at the studies listed and examine whether the clients’ families also have an effect as another level. Furthermore, in some of the studies that were included, broader concepts such as resident-centred and relationship-centred care were described (16, 17). These concepts were too broad and abstract to be included as determinants in this review. Future research might look for evidence for a more precise connection between these concepts and individual client-professional relationships.
3.6 Conclusions

This systematic review provides an overview of determinants of the quality of the care relationship in long-term care on four levels: client, professional, between client and professional, and contextual. The studies included each focused on one specific client group in long-term care, specifically physically or mentally frail older adults, people with mental health problems or those with physical and/or intellectual disabilities. This review shows that there is a substantial number of determinants that apply to more than one client group. This might suggest that the current client group-specific focus in research concerning care relationships in long-term care is not necessarily needed. This implication and the findings regarding the determinants of quality for care relationships can provide input for quality improvement initiatives for long-term care relationships. Care organisations can use the findings as a guidance for the determinants to look for when mapping the quality of the care relationship, in order to get clear picture of specific points of attention in quality improvement.
Literature


## Appendix 1  Search string used in Embase, which was adapted for other databases

### Professional-patient relationship

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49. 21 and 35 and 48
50. Limit 49 to yr = “2006-current”


Appendix 2  Scores on the Mixed Methods Appraisal Tool (MMAT)

Scores of qualitative studies

Screening questions:
0.1 Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question?
0.2 Does the collected data allow the research question to be addressed?

Qualitative questions:
1.1 Are the sources of qualitative data relevant for addressing the research question?
1.2 Is the process for analysing qualitative data relevant for addressing the research question?
1.3 Is appropriate consideration given to how the findings relate to the context in which the data was collected?
1.4 Is appropriate consideration given to how the findings relate to the researchers’ influence, e.g. through their interactions with participants?

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<tr>
<td>Cook and Brown-Wilson (2010)</td>
<td>-</td>
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</tr>
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<tr>
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<td>****</td>
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<td>Yes</td>
</tr>
<tr>
<td>&quot;We are All Fellow Human Beings&quot;</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Eriksen et al. (2013)</td>
<td>**</td>
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</tr>
<tr>
<td>Challenges in relating to mental health professionals</td>
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<tr>
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<tr>
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<td>Total score (1.1-1.4)</td>
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<td>---------------------</td>
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<td></td>
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<td>0.1</td>
<td>0.2</td>
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<td>Jones and Moyle (2016)</td>
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<tr>
<td>Ljungberg et al. (2017)</td>
<td>*</td>
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<tr>
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<tr>
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<td>Yes</td>
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<tr>
<td>Shattell et al. (2006)</td>
<td>**</td>
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<td>Yes</td>
</tr>
<tr>
<td>She Took the Time to Make Sure She Understood</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shattell et al. (2007)</td>
<td>**</td>
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<td>Yes</td>
</tr>
<tr>
<td>“Take my hand, help me out”</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Westin and Danielson (2007)</td>
<td>****</td>
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<td>Yes</td>
</tr>
<tr>
<td>Brown Wilson (2009)</td>
<td>***</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Developing community in care homes through a relationship centred approach</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brown Wilson and Davies (2009)</td>
<td>**</td>
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</tr>
</tbody>
</table>

The number of asterisks (*) shows the extent to which the quality indicators were met based on the scores for the four qualitative questions, ranging from one star (one criterion was met) to four stars (all criteria were met).
Scores of mixed-method studies

Screening questions:
0.1 Is there a clear mixed methods question?
0.2 Does the collected data allow the research question to be addressed?

Qualitative questions:
1.1 Are the sources of qualitative data relevant for addressing the research question?
1.2 Is the process for analysing qualitative data relevant for addressing the research question?
1.3 Is appropriate consideration given to how the findings relate to the context in which the data was collected?
1.4 Is appropriate consideration given to how the findings relate to the researchers’ influence, e.g. through their interactions with participants?

Quantitative questions:
4.1 Is the sampling strategy relevant for addressing the quantitative research question?
4.2 Is the sample representative of the population being studied?
4.3 Are measurements appropriate?
4.4 Is there an acceptable response rate (60% or above)?

Mixed-method questions:
5.1 Is the mixed-methods research design relevant for addressing the qualitative and quantitative research questions or aspects of the mixed-methods question?
5.2 Is the integration of qualitative and quantitative data relevant for addressing the research question?
5.3 Is appropriate consideration given to the limitations associated with this integration, e.g. the divergence of qualitative and quantitative data?

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Total score (1.1-5.3)</th>
<th>Screening questions</th>
<th>Qualitative questions</th>
<th>Quantitative questions</th>
<th>Mixed-method questions</th>
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<tbody>
<tr>
<td>Dziopa and Ahern (2009)</td>
<td>*(36% of total)</td>
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<td>Yes</td>
</tr>
<tr>
<td>McCloughen et al. (2011)</td>
<td>*(36% of total)</td>
<td>No</td>
<td>Yes</td>
<td>Can’t tell</td>
<td>No</td>
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</table>

The number of asterisks (*) shows the extent to which the quality indicators were met based on the scores for the four qualitative, quantitative and mixed method questions, ranging from one star (3-4 of the 11 criteria were met) to four stars (all criteria were met).
Chapter 4

Determinants of the quality of care relationships in long-term care - a participatory study

Published as:
Abstract

Background: The quality of the care relationship between a client and a professional is important in long-term care, as most clients depend on support for a lengthy period. The three largest client groups who receive long-term care in the Netherlands are older adults who are physically or mentally frail, people with mental health problems and people with intellectual disabilities. There is little clarity about how generic and variable the determinants of the quality of care relationships are across these client groups. The aim of this study is to explore and compare the determinants of the quality of care relationships in these three client groups in long-term care.

Methods: This participatory study involving clients as co-researchers was held in three healthcare organizations, each providing long-term care to one client group. The research was conducted by three teams consisting of researchers and co-researchers. We interviewed clients individually and professionals in focus groups. The focus was on care relationships with professionals where there is weekly recurring contact for at least three months. Clients and professionals were selected using a convenience sample. The interviews were coded in open, axial and selective coding. The outcomes were compared between the client groups.

Results: The study sample consisted of 30 clients and 29 professionals. Determinants were categorized into four levels: client, professional, between client and professional, and context. The findings show that the majority of the determinants apply to the care relationships within all three client groups. At the professional level, eleven generic determinants were found. Eight determinants emerged at the client level of which two were found in two client groups only. At the level between a client and a professional, six determinants were found of which one applied to mental healthcare and disability care only. Five determinants were found at the contextual level of which two were specific for two client groups.

Conclusions: The study yielded a variety of determinants that came to the fore in all three client groups in long-term care. This suggests that including a homogenous client group from a single care setting is not necessary when studying the quality of long-term care relationships.
4.1 Background

The importance of the quality of care relationships between professionals and clients in long-term care, where clients depend on support for their basic needs in daily life for longer periods, is well documented (1-3). The care relationship is seen as serving several purposes. A good quality of a care relationship correlates with greater life satisfaction for clients (4). A care relationship can also provide opportunities for growth and development for a client as well as a professional, and can help clients in their progression towards independence (5, 6). Moreover, a care relationship offers clients recognition, created by the awareness and acknowledgment of sharing a fundamental likeness as human beings (5).

Although the quality of the care relationship is clearly important for both clients and professionals, there is little clarity as yet about the nature of these relationships (2). And with good reason: the variable and fluctuating nature of care relationships makes them hard to define and study (5). Some authors have defined care relationships within current theories such as care ethics (7), relational ethics (8) or relationship-centred care (9). Other authors have addressed a single aspect of the care relationship, such as professional friendship (3), therapeutic relationship (10, 11), autonomy (12), client engagement (13), power dynamics (13) or communicative barriers (14). Given these multiple components of a relationship, a care relationship should be seen as a multidimensional construct (10, 15).

Research findings show that the quality of care relationships is not yet optimal for all those involved. Multiple reasons are reported for the low quality of care relationships; stigmatization (6, 7), discontinued relationships with professionals who are leaving, professionals lacking time, and the negative impact of heavy workloads (6, 10, 16-20). Clients also mentioned untrustworthy professionals, and staff who rejected clients’ opinions and discouraged them, resulting in clients feeling dismissed and ignored (6). In a study by Eriksen (2013), clients with mental health problems reported feeling detachment in care relationships, experiencing a lack of interest, unwillingness to be understood and indifference or even hostility from professionals (21). Moreover, discrimination and language barriers diminished the quality of care relationships between care workers and older, physically or mentally frail people (22).

Determining the quality of care relationships from clients’ perspectives gives clients and professionals insights into areas for improvement. This can
help professionals improve their performance and aim to achieve high-quality care relationships (2, 18, 23). We recently carried out a systematic review to map out the determinants of the quality of care relationships between clients and professionals in long-term care (24). This review focused on three client groups: physically or mentally frail older adults, people with mental health problems and people with intellectual disabilities. The review suggested a substantial number of determinants that may apply to more than one client group. Until now, all studies have, however, focused on one single client group in long-term care. As the majority of determinants may be expected to be generic and not client-group specific, such a focus on specific client groups might not necessarily be needed for identifying gaps in the quality of care relationships in long-term care (24).

There is, however, no instrument available for monitoring and evaluating the quality of care relationships that can be used within various client groups in long-term care. Such a generic instrument can make it easier for care organizations to learn from good practices in other care organizations and to improve the exchange of knowledge. Insight is needed into the generic determinants of the quality of care relationships before such a generic method can be compiled.

The aim of this study is therefore to explore the determinants of the quality of the care relationship between a client and a professional in long-term care and how generic these determinants are among different client groups. The central question of this article is: What are determinants of the quality of a care relationship in long-term care according to clients and care professionals? The client groups included are physically or mentally frail older adults, people with mental health problems and people with intellectual disabilities, i.e. the largest client groups in the Netherlands receiving long-term care. We looked at the perspectives of both clients and professionals, as clients and professionals have been found to use different definitions and have different perspectives on care relationships (2).

Clients have unique experiential knowledge derived from personal experiences and their perceptions on receiving care (25, 26). Therefore, the clients’ perspective was included in this research by performing participatory research. In participatory research, clients are invited to join the research team as co-researchers and contribute by participating in several stages of a research project (27-29).
4.2 Methods

**Study design and setting**
The participatory study took place in three organizations providing long-term care to three distinct client groups. One care organization provided care to physically or mentally frail older adults, the second organization provided care to people with mental health problems and the third provided care to people with intellectual disabilities. All three care organizations provided care in both inpatient and outpatient care settings. The three care organisations serve a large client population with a diversity of recurring care needs. Their client population entails more than 2000 clients, and more than 2000 care professionals are employed at each care organisation. The three large care organisations were selected to increase the transferability of the findings to other care organisations, as these organisations were largely representative for the client populations of long-term care in the Netherlands. The study employed an exploratory qualitative design in order to make the contributions of co-researchers meaningful and to let them use terminology according to their preferences. The data collection method involved individual semi-structured interviews with clients and semi-structured focus groups with professionals in each care organization. A protocol paper for the overall study has been published elsewhere (30).

**Participatory research method**
Participatory research is known to improve the quality, the relevance and usefulness of the findings, for democratizing research and for empowering the clients who participate (25, 31). The quality of the research is expected to improve because co-researchers are involved in the formulation of the questions, the data collection and the analysis of the data which enhances the (content) validity and relevance of the results. For example, when co-researchers formulate their questions in interviews on care relationships, they are likely to use plain language and use questions that resonate a client perspective. The contributions of co-researchers are likely to improve the understanding of clients, and make clients feel more comfortable during the interviews.

A research team was composed in each care organization consisting of three to four co-researchers and two researchers. Co-researchers had care experience with the specific care organization in which the research took place. Co-researchers followed a training course consisting of three meetings
about qualitative research, practicing semi-structured interviewing and making agreements about confidentiality and support. The topics covered by the training were tailored to the needs and wishes of the co-researchers. The three research teams were involved from the beginning of the study until the end. First, we created a topic list with the research team and carried out preparatory activities such as setting up the invitation for respondents. Co-researchers helped recruit the participants. Each interview was conducted by one co-researcher and one researcher and the division of roles was decided upon before each interview took place. The research team gathered at work meetings during which we talked about the initial experiences with interviewing and cooperation. In later work meetings, we spoke about the interview results. We also discussed the summary of findings we sent to the respondents. See figure 4.1 for an overview of the activities.

Figure 4.1 Design of the research teams activities

Preparations
- Forming the research teams
- Preparing the activities

Data collection
- Interviews with clients
- Group interviews with professionals
- Progress meetings

Data analysis
- Discussing results
- Setting up summary of results for clients
Recruitment of respondents

The study focused on relationships between clients and professionals having weekly recurring contact in long-term care for at least three months. Clients received care in their own home (outpatient) or within the care organization in which they reside (inpatient). Most clients received care at least once every week, but the assistance for some outpatient clients with long-term mental healthcare was more loosely planned. The study focused on care relationships with professionals who see clients most often to provide assistance, supporting care and physical care, e.g. care aides, personal carers and various types of nurses.

Clients and professionals were selected using a convenience sample. Clients who met our inclusion criteria were selected by the research team in consultation with client councils and the contact person of each care organization and invited to take part by the research team. There was aimed for variation in terms of client characteristics such as type and intensity of care, sex, age, and whether the care was intramural or extramural. All clients were eighteen years or older (no upper limit), and able to communicate verbally in Dutch. Clients received a verbal and written invitation for an interview. In some instances clients were informed by their personal professional at first and asked if they could be contacted before the research team invited them. This was only done when the professionals preferred to inform the client themselves first. In some other instances the legal representatives of people with intellectual disabilities were asked for permission first.

Variation between professionals was aimed at as well, in variables such as years of work experience, sex, working in an inpatient or outpatient setting, and type of function (e.g. care aides, personal assistants, different types of nurses and activity supervisors). Professionals providing more remote physical and supporting care were not included, such as clinicians, psychiatrists and general practitioners. Caregivers who provide informal care were also not included. The professionals were selected and invited by the researcher (AS) in close cooperation with the contact person for each care organization. Professionals received an invitation for a focus group by e-mail.

Individual interviews with clients

Clients were interviewed face-to-face by a pair consisting of one co-researcher and one researcher (AS, NB or field researcher) in the residence of a client or a meeting room of the care organization, depending on the
preference of the client. The interviews involved questions about clients’ experiences with their care relationship with one or more professionals. The interviewers followed up on the broader opening questions by asking clients additional questions in order to probe more deeply on the experiences a client tells about and to provide as much detail as possible. In this way, a client was able to determine what topics related to the care relationship he or she told about. The topic list is included in the Appendix. Depending on the concentration span of each client, the interview lasted between 30 and 60 minutes. Data collection of the interviews ended when saturation was reached and no new themes emerged from the data.

**Focus groups with professionals**

In every care organization, one or two focus groups were held with professionals. The focus groups took about 2 hours. One researcher (AS) and one or two co-researchers had the role of moderator. First, a poster assignment was done in pairs of two professionals. Professionals discussed and indicated what affects a care relationship, either positively or negatively. Professionals also wrote down opportunities they saw for improving care relationships and other ideas they had. This was followed by a group discussion based on the ideas and experiences the professionals had noted in pairs. The moderators asked probing questions and ensured that all professionals had the opportunity to speak. They also asked other respondents about their experiences and reactions when a determinant was mentioned by one care professional. All interviews and focus groups were audio recorded with the permission of the respondents.

**Definition of “determinant”**

This study is focused on determinants of the quality of a care relationship, by exploring what might influence the quality of care relationships from the viewpoints of clients and professionals. A determinant is therefore defined as an aspect related to the quality of a care relationship which might determine a care relationship in a positive or negative manner. Since every care relationship is developed and maintained in its own unique way, a determinant might have a variable and context specific elaboration on different care relationships. Two determinants might be also conflicting or incompatible to one another.
**Data analysis**

The focus groups and interviews were transcribed verbatim and analysed in three phases: open coding, axial coding and selective coding (32). The data analysis method was inspired by Interpretative Phenomenological Analysis, which is centred on the respondents’ experiences and the meaning they assign to those experiences (33). The analysis process was carried out for each care organization separately at first.

**Open coding**

Each research team discussed research findings in a work meeting. Co-researchers shared their own experiences and interpretations in the research team and the most important themes they heard in interviews. The topics discussed by the research team were written on a flip chart that was the start of the open coding process. Two researchers (AS and MH) then read the interviews collected so far and identified themes that emerged from the interviews. They used the themes identified in the work meetings as inductive codes. In a meeting, the two researchers (AS and MH) composed a list of open codes and reached consensus on the formulation of themes. AS is employed as a PhD student and has a background in interdisciplinary social sciences. MH is educated in psychology and has eighteen years of work experience in the field of health services research. Her research mainly focuses on patient’s experiences with health care.

**Axial coding**

Two researchers (AS and MH) independently analysed three interviews of each client group in MAXQDA. They worked from the codes to the data and determined whether the codes adequately covered the collected data. They created new codes when new themes emerged. In a meeting, the researchers (AS and MH) discussed differences in interpretations. In addition, they categorized interrelationships between themes that distinguished master codes from subcodes and adjusted the code tree.

**Selective coding**

The same two researchers analysed and discussed two interviews of each client group in MAXQDA independently using the adjusted code tree. When they disagreed on the interpretation of a fragment, they tried to reach consensus by discussion. In a meeting, the researchers adapted the code tree further and compared the three code trees of each sub-study. Formulations
and interrelationships between codes were made uniform where possible. The main findings were discussed with two other researchers involved in performing the interviews (NB and a field researcher), paying specific attention to differences and similarities between the three client groups in long-term care and the interrelationships between the determinants. All authors were informed about and involved in the broad picture obtained from the analysis during two discussion meetings. Finally, the interviews were checked again with the final code trees by AS.

**Ethical considerations**
The study was submitted to the Medical Ethics Committee of the Radboud university medical centre to decide whether the study needed formal approval. Given the Dutch Medical Research Involving Human Subjects Act, the Ethics Committee decided that extensive formal approval was not needed for this study.

All participants were given both written and verbal information about the study, including the purpose and procedures, confidentiality of individual interviews or focus groups, the voluntary nature of participation and the opportunity to withdraw at any time. Interested clients and professionals participated after completing a consent form. In the interviews with clients, we also adopted a ‘process consent’ approach, meaning that we constantly observed whether consent was still present by paying attention to verbal and nonverbal indications of reluctance or hesitation to participate (35).

To ensure a meaningful participation of co-researchers, support was provided in several ways and basic agreements for cooperation and confidentiality were drawn up by the research team.

### 4.3 Results

The sample for the study consisted of a total of 30 clients and 29 professionals. The clients interviewed varied with respect to the intensity of care, client group, care setting (inpatient or outpatient) and background characteristics such as age and sex. Professionals were employed in various professions and varied in sex. See table 4.1 for an overview of the respondents per client group.
Table 4.1  Respondents of the study

<table>
<thead>
<tr>
<th>Type of care</th>
<th>Clients</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental healthcare</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Intellectual disability care</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Elderly care</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Sex (female/male)</td>
<td>13/17</td>
<td>21/8</td>
</tr>
<tr>
<td>Care setting (inpatient/outpatient)</td>
<td>16/14</td>
<td>16/8</td>
</tr>
</tbody>
</table>

* 5 professionals worked for an inpatient and as well as an outpatient setting in disability care.

Based on the qualitative data, the determinants could be broken down into four levels: client, professional, between a client and professional, and contextual. Each level makes clear which actor is influencing these determinants of the quality of care relationships to the utmost extent. The data analysis showed that most determinants came to the fore in all three client groups. We will therefore discuss the generic determinants first, followed by the determinants that emerged in one or two client groups only. We define a determinant as generic when a determinant was mentioned in all client groups, by clients and/or professionals. The determinants are not all generic in the sense that both clients and professionals of each client group discussed a determinant. Only a few determinants were mentioned solely by either clients or professionals; most of these were at the contextual level. An overview of determinants is given in table 4.2.

**Generic determinants**

**Client level**

At the client level, six generic determinants were described by clients and/or professionals: help request, feedback supply, open attitude, respect, self-determination and strategic adapting behaviour.

- **Help request**

Clients and professionals suggested it is important that clients ask for help when they need it, in order to get appropriate support and care. Professionals explained that it is easier for them to provide the required support when clients tell them what they want. However, some clients found it difficult to ask a professional for assistance. Client 4, with an intellectual disability: “That’s what he [professional] always says too: you must come to me if there are any problems. Well, I find that difficult sometimes.”
Table 4.2 Determinants of the quality of a care relationship

<table>
<thead>
<tr>
<th></th>
<th>Mental healthcare</th>
<th>Disability care</th>
<th>Elderly care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>c</td>
<td>p</td>
<td>c</td>
</tr>
<tr>
<td><strong>Client level</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Help request</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Feedback supply</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Open attitude</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Respect</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Self-determination</td>
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<td>X</td>
</tr>
<tr>
<td>Strategic adapting behaviour</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Function of the relationship</td>
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<td></td>
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</tr>
<tr>
<td>Cognitive capabilities *</td>
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<td>X</td>
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<tr>
<td><strong>Professional level</strong></td>
<td></td>
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<tr>
<td>Listen</td>
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</tr>
<tr>
<td>Empathy</td>
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<tr>
<td>Conduct</td>
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<tr>
<td>Encouragement</td>
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<tr>
<td><strong>Between client and professional</strong></td>
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</tr>
<tr>
<td>Relationship building</td>
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</tr>
<tr>
<td>Trust</td>
<td>X</td>
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<td><strong>Contextual level</strong></td>
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<td>Limitations by laws and regulations *</td>
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c = determinant mentioned by clients; p = determinant mentioned by professionals
An asterisk (*) has been added to determinants that appeared to be specific for one or two client groups only.
• **Feedback supply**
Several clients and professionals mentioned that it is important that clients tell professionals what they appreciate and what can be improved in a care relationship. Some clients said that they share suggestions and express disapproval; others explicitly stated that they do not. One professional saw a tendency for older clients to increasingly provide feedback to professionals in comparison to some years earlier. Some other professionals explicitly ask for feedback to make it easier for clients to share their suggestions.

• **Open attitude**
Clients and professionals felt that an accessible and open attitude from the clients is very important as well. Client 30, receiving mental healthcare: “How open you yourself are matters too, of course. Like, if you think ‘Uh-oh, here’s another new one’ and ‘Ooh, that’s scary’ then it’s going to be a barrier.” According to the professionals, care relationships are negatively influenced by clients who distance themselves and who try to avoid contact. Less open attitudes on the part of clients could be related to negative experiences with care in the past, lack of language proficiency, emotional state, or coercive measures.

• **Respect**
Clients and professionals stated that a respectful approach from clients to professionals influences the quality of a care relationship positively. Clients referred to respect using phrases such as ‘decency’, ‘no insulting or name-calling’, ‘being polite’ and ‘taking the opinion and suggestions of a professional seriously’. One professional spoke about a client who acted unhelpfully and showed no respect at all, whom she asked to communicate in a more friendly way. A professional providing care for the elderly: “You get the occasional client who absolutely snaps at you [...] and then I tell them that you can say whatever you want, but you can say it nicely. And he accepted that.”

• **Self-determination**
Self-determination is about the control that a client has in a care relationship and the provision of care. Clients described the importance of having control over social aspects of life such as freedom to leave the care institution by themselves. Other clients had to get used to the fact that they had to play an
active role in treatment or care, whereas they had expected that the professional would solve their problems for them.

- **Strategic adapting behaviour**
  Clients mentioned they are trying to adapt their communication and wishes to the professionals and their capabilities at that moment. Client 16, receiving elderly care: “You read the body language too, of course. You know, she’s feeling good today, or he’s had a tough time, or that one’s been busy. And if you respond to that a bit, it does make the communication a little easier.” The majority of elderly clients said that they desire to be perceived as untroublesome and uncomplicated by professionals. Client 17, receiving elderly care: “Well, I’ve not really got much to complain about. I don’t think I’m much trouble.” Professionals of all client groups described clients varying from easy-going to some who are overly demanding.

**Professional level**

Eleven generic determinants came to the fore at the professional level: listening, empathy, dependable, availability, support, focus on the individual client, conduct, characteristics of the professional, professional competences, privacy and confidentiality, and encouragement.

- **Listen**
  Clients and professionals stated that listening is an essential ability for professionals. Clients found it easier to tell a listening professional what bothers them, how they are feeling, and how their day was. Client 6, who has an intellectual disability: “It’s nice to have someone I can get things off my chest with – what happened at work, or what annoyed me.” According to clients, a listening care professional was better able to understand a client. By remembering important events or people in the life of a client, professionals can demonstrate that they have been listening.

- **Empathy**
  Some professionals immediately sense the mood of a client. Clients appreciated these watchful professionals. Client 23, receiving mental healthcare: “She comes in and she can tell from my face how I’m feeling.” Empathic professionals sense the state of a client very well and can also respond appropriately. Professionals said that they use their intuition to sense the mood of a client, and ask questions to verify the current mood or feelings
of a client. A professional providing mental healthcare: “Then you confirm it. ‘I reckon I can see or sense this – is that right?’”

- **Dependable**
  Being dependable is another essential characteristic of professionals. Dependable professionals fulfil their promises and meet the agreements that are made. Some clients described a trustworthy professional as someone who communicates completed decisions and progress made, transparently. Moreover, a dependable professional is truthful and does not deny what has been said or done. Client 6, intellectually disabled: “If a professional makes a mistake, or denies something and says that she didn’t say it.” A professional providing mental healthcare used the term ‘fairness’ in her description, and described dependable as “Do what you say, and say what you’re doing.”

- **Availability**
  Availability comprises three related aspects: accessibility, quick responses and taking time for a client. Professionals said that they try to respond quickly when something happens or when a client calls for help. Accessibility is about clients feeling that they can reach a professional when they need help. Some clients said they felt they can go to a professional whenever needed. Many clients stated it was important that they felt a professional took time for them. This is something different from having time: a professional can take time for the care for a client while they are actually behind schedule.

- **Support**
  Clients and professionals stated that support from professionals influences the quality of the relationship as well. Client 13, receiving elderly care: “Those people [the professionals] give comfort, encouragement and support. That’s very important.” Support can be expressed in different ways, like being the clients’ adviser, accompanying a client to a stressful appointment, giving useful advice or helping to find a solution for a client’s problem.

- **Focus on the individual client**
  Clients and professionals underlined the importance of an individualised approach. It means that a client’s wishes and needs are taken into account. It also means that the timing and speed of care is adapted to a client. Instances described by professionals were time preferences, preferences for physical
care and group activities, individually tailored conversations or in short: going the extra mile. A professional providing mental healthcare: “That you can play it by ear, respond by doing whatever might help the patient at that moment.” According to clients, showing interest for a client is key, chatting about the experiences, hobbies or the private situation of a client. Professionals reported various examples in which they paid personal attention: by greeting a client, small talk, or putting a hand on a clients’ shoulder to comfort them in their grief.

- **Conduct**

The way clients are treated was felt to be positive when the professional took a client seriously, had no prejudices towards the client, the manner and tone in which things were expressed felt right, or when a professional was kind and spontaneous towards a client. Professionals said that positive treatment includes transparency, authenticity, respect and a hospitable, cheerful and spontaneous attitude. Clients characterised negative attitudes as ignoring their wishes, detached, being rude or providing care in a domineering and unequal manner. Professionals referred to prejudices, arrogance and using unnecessary force. A professional providing disability care: “Assessment, judging and pre-judging are all about not being open to the other person’s views and not picking up on them. That also applies to the ‘I know better’ attitude, because I’m your professional. And, well, then it all goes pear-shaped.”

- **Characteristics of the professional**

Several characteristics of professionals were mentioned by clients, such as sex, age, years of work experience, and having similar features to the client or a relative. Professionals mentioned features such as self-reflection, job satisfaction, work experience and age difference. Some clients had a specific preference for one or a combination of individual characteristics, for example for a professional of the same age or the same sex. Client 3, intellectually disabled: “Then you’re on the same wavelength.” Other clients described having no such preferences.

- **Professional competences**

Clients valued proper, careful and high-quality care, support and assistance. Professionals underlined the importance of communication skills and knowing their own limits, as well as knowledge and skills specific to the
client group. Clients with intellectual disabilities also referred to clear communication skills of professionals, including explanations and understandable words.

- **Privacy and confidentiality**

  According to the clients, confidentiality and privacy included keeping client information confidential from other clients, their relatives or other professionals. Client 16, receiving elderly care: “I know that I can tell them things and it will remain between us.” Clients said that information was sometimes not written in their personal file when they asked their professional not to. Professionals distinguished between clients who had a formal representative and those who did not. When clients did have a formal representative, they were obliged to provide information to the representative, while in the other instances they provided information to family according to clients’ wishes.

- **Encouragement**

  Encouragement was mentioned by several clients and professionals. Professionals were sometimes supporting a client to think of possible solutions of an issue or asked critical questions to encourage them to think things through from different viewpoints. Client 24, in mental healthcare: Then you get X’s critical questions again pretty often... She sometimes holds up a mirror so that you can take a look at yourself."

**Between client and professional**

Five generic determinants were mentioned at the level between a client and professional: relationship building, trust, match, equality and closeness versus professional distance.

- **Relationship building**

  According to both clients and professionals, building a relationship with a professional takes time, as professionals gradually get to know the client and their wishes. Some clients related relationship building to the development of trust in a care professional. After a while, clients started to share more delicate issues when they got to know and trust a professional. Professionals underlined the importance of the first contact with a client, they want to be hospitable and look for clients’ needs directly. They also felt that relationship
building requires regular contact and investments in a care relationship by organising informal activities and doing something extra for clients.

- **Trust**
  Trust was described as important by a fair number of clients, as a prerequisite for sharing thoughts and experiences with a professional. This determinant is related to the trustworthiness described for the professional level. Professionals believed trust will arise when there is mutual respect, they (as professionals) are trustworthy and reliable for clients because they keep promises and stick to the agreements that are made, and they book successes jointly with the clients. Professionals also related the determinant ‘trust’ to continuity created by the fixed assignment of a small number of professionals to each client.

- **Match**
  Some clients felt a match with a professional from the first moment. A match means a client feels they can tell anything to a professional, trust the professional, and feels calm when the professional is present. When clients did not feel there was a match, they often did not like the professional and did not have a feeling that they could trust them. Client 5, intellectually disabled: “There was a click right away, and that doesn’t then go away. And, well, if I don’t get that with someone straight off, then it takes ages before I trust the professional enough to say things to them.” Professionals suggested that a match is not necessary for the care relationship with a client, but can indeed encourage relationship building and continuation of a care relationship.

- **Equality**
  For several clients and professionals, equal positioning is important. Client 29, receiving mental healthcare: “She didn’t act like she was above me. She was standing next to me. Close by, if you like.” The examples provided include giving clients space to say what they prefer instead of interrupting immediately, making decisions together, professionals giving suggestions instead of orders. Professionals tried to achieve an equal position by sharing personal experiences and making decisions together with a client. In mental healthcare, professionals believed coercive measures are counterproductive for equal positioning, because clients do not have the power to decide where to go and what they want anymore. There were some instances mentioned in
which disagreement between a client and professional occurred, but was not seen as a problem due to the equal positioning. A professional providing mental healthcare: “If someone disagrees [...] I don’t say that they should see it my way. I try to let them understand why I think like I do. You mostly then find a compromise or you can at least agree to disagree.”

• **Closeness versus professional distance**
Some clients mentioned establishing more informal relationships with a professional. Clients shared information about their children or grandchildren, and professionals shared information about their private lives, such as holiday plans or major events such as a wedding. Client 29, receiving mental healthcare: “She remained professional, but also... well... she did get that little bit closer to you.” Some clients said that a professional felt like a sister or a friend. Some clients appreciated physical contact with professionals. Clients talked about instances such as a professional touching a client’s cheek, placing an arm around the client’s shoulder, a hug to comfort, and a hand on the clients’ knee as support at a stressful dentist meeting. Professionals also described the added value of physical contact for support. Other clients or care professionals preferred keeping a distance. Client 7, intellectually disabled: “It’s not right, because that’s simply getting a touch too close.” One professional described a client who systematically came physically too close, into his comfort zone; the professional therefore adopted a more distant and careful position with this specific client.

**Contextual level**
Three generic determinants of a care relationship were mentioned at the contextual level: continuity, lack of time, and limited financial budget and facilities.

• **Continuity**
For continuity at the contextual level, clients and professionals described several aspects. Changes in primary professional, temporary professionals and rotation policies of staff decreased the sense of continuity in care relationships. Professionals explained that a fixed designation of one professional to one client will make it easier for clients to show feelings and preferences. Some clients felt anxious that a professional would quit or would not be assigned to them anymore. Second, cooperation between professionals was related to continuity, which involved good communication and
availability of backup for primary professionals. Client 5, intellectually disabled: “If there’s anything, she writes it down. If X is on holiday, she just writes everything in the app. When X comes back, everything that’s happened is all nicely written down.”

- **Lack of time and limited financial budget**
  Some professionals felt there was a lack of time for paying real personal attention to every client. Limited budgets were also mentioned, for example when a client is temporarily in a hospital or dies, the finance ends immediately while assistance to family members might still be desirable. There were experiences in which there was no budget for uncalculated relaxing activities. Waiting lists were also mentioned by professionals as hindering care relationships.

- **Facilities**
  Professionals described facilities as both a promoting and a restricting determinant of care relationships. Facilities that help are training opportunities and home automation devices. Facilities that hinder are old buildings without individual facilities such as a private bedroom, bathroom and television, a poor atmosphere in the building, malfunctioning electronic devices and Wi-Fi, limiting electronic medical record systems (EMR systems), and a lack of training opportunities for professionals.

**Other actor: Family of clients**
Family was another actor or level that appeared in all focus groups with professionals as influencing the individual relationship between a client and a professional. As family is often part of a client’s social network, often provides informal care for a client, and is the legal representative of a client in some cases: a professional needs to stay on good terms with family members of clients. A professional described family as the third point of a triangle that includes clients and professionals as well. Family members can facilitate a client in a care relationship, but can also have a hindering role. One example given concerned family members who had excessive demands that could not be met, while the client had alternative wishes but did not want to insist. When the interests of clients and their families are in conflict, this can put the professional in a difficult bridging or in-between position. Specifically the professionals who provided care to older people who are
mentally or physically frail said that they feel that family members are sometimes 'inspecting' them.

**Determinants specific to one client group**
Five determinants did not come to the fore in all three client groups, but only in one or two. Determinants on contextual level were only mentioned by professionals.

**Client level**
- *Function of the care relationship*
The older clients who were mentally or physically frail described several functions of a care relationship. For example, a professional can serve as a welcome interruption, increase sociable conversations, give comfort in grief after losing a loved person, serve as a link to the world outside the care organization, and help people feel at home in the care organization. On the other hand, some clients preferred to have a task-focused relationship, without small talk or exchanging personal experiences. A professional providing mental healthcare had the feeling that the function required from the care relationship has changed to being more task-focused.

- *Cognitive capabilities*
Some clients with intellectual disabilities mentioned that it is important that they can understand a professional’s expressions and vocabulary. Professionals providing mental healthcare felt that some clients with intellectual disabilities comprehend what a professional tries to communicate less easily. A professional providing mental healthcare: “*There are clients, in particular people with some degree of learning disability, where you have to watch how you formulate things very carefully. With autistic people too: you’ve got to be very careful how you phrase things and you may have to watch your step with humour too.*”

**Between client and professional**
- *Humour*
Professionals in mental healthcare and clients with intellectual disabilities or mental health issues believed humour, having fun and laughing relate to a good care relationship. A professional providing mental healthcare: “[…] *We’d laugh a bit together at times to keep it all a bit lighter or to put things into a different perspective.*” However, jokes could also hinder a good care
relationship. In one instance, a client’s jokes were not appreciated by the professional. In another example, a professional was laughing the whole time, which led to the client feeling that she was not being taken seriously.

**Contextual level**
At the contextual level, support from management, clear communication and accountability, and limitation by laws and regulations were found for one or two client groups only.

- **Support from management**
  Professionals in mental healthcare and disability care suggested the support and commitment of their direct manager and the board of management are needed if they are to perform their duties properly. A professional providing mental healthcare: “If something isn’t going smoothly, if you’re in a conflict situation or can’t resolve issues, you need support from your own manager and you need them to be able to escalate it if necessary.”

- **Limitations by laws and regulations**
  The professionals in mental healthcare and disability care believed that the administrative workload for fulfilling the requirements prescribed by Dutch law is limiting direct contact time. Strictly following the rules made within a care organization was also suggested to be a hindrance.

### 4.4 Discussion

The aim of this qualitative study was to explore the determinants of the quality of the care relationship between clients and professionals in long-term care, which is one aspect of the quality of care. A determinant was defined in an open and inductive manner, as an aspect related to the quality of a care relationship which might determine a care relationship in a positive or negative manner. The study focused on three client groups receiving long-term care, namely clients with mental health problems, physically or mentally frail older adults, and clients with intellectual disabilities. Respondents receiving both inpatient and outpatient care were included. Based on the qualitative data, determinants were categorized at four levels: client, professional, between client and professional, and context.
There was a large amount of overlap between the three client groups in the determinants of the quality of care relationships. This suggests that the current focus in research on care relationships in long-term care, which tends to be specific to a client group, is not needed. This might have implications for the approach of both quality improvement initiatives and future research focusing on the quality of care relationships. It confirms the result of a recent systematic review of the determinants of the quality of care relationships in long-term care: that a substantial number of determinants apply to multiple client groups in long-term care (24).

Although none of the preceding studies included three distinct client groups when studying the quality of care relationships in long-term care, most results are in line with studies focused on one client group (1, 2, 3, 6, 18, 21, 34, 36). This overlap with earlier findings provides confirmatory evidence for the quality of the study findings. The qualitative and inductive approach of the current study made it possible to confirm previously found determinants and identify unknown determinants at the same time. New determinants found in this study at the client level were 'help request' and 'feedback supply'. At the contextual level, 'facilities' was added as a new generic determinant for all three client groups, and 'support from management' and 'limitation by laws and regulations' came to the fore in two client groups.

Determinants described in this study fit in well with current views on relational aspects of care, specifically within the theoretical framework of person-centred care (37, 38) and its core principle of humaneness. Recognition as a human being and being valued by others is essential to all people, it promotes individual dignity (39). Determinants such as self-determination of a client, a professional's focus on an individual client and all determinants at the level between client and professional reflect this core value clearly.

The dependency of clients characterizes care relationships in long-term care. It is therefore useful to reflect further on this aspect. A recent publication describes friction in the care relationship as the moment on which dependency is *experienced* as such by clients (40). The dependency experienced by clients on care provided by professionals sometimes makes it difficult for clients to speak openly about improvement opportunities (41). This open conversation has to take place in a very safe way in order to encourage a client to provide truthful feedback, in this case on the quality of a care relationship. Clients differ in the degree of feedback they provide to
professionals, as was described at the determinant ‘feedback supply’. A more developed care relationship can make it easier for clients to feel open and have their say, as was described by the determinant ‘relationship building’. Determinants on the professional level might also influence the degree to which a client feels invited to share their ideas (e.g. whether a professional is available, takes time, listens well). In this sense, a care relationship is essentially mutual in the manner it is formed and shaped, as it depends on the unique interactions between a client and a professional and their behaviours.

The determinants of the quality of a care relationship as presented in this chapter can serve as guidance for care professionals to work towards good quality care relationships and prevent negative consequences of dependency. As care relationships are not fixed, but rather variable and fluctuating, they are inherently individually constructed and need to be personalized between each client and professional. Professionals can use the findings as a starting point for a conversation with an individual client to hear what determinants matter to him/her, in order to fine-tune and improve the quality of their care relationship. Moreover, evaluating the quality of an individual care relationship will help care professionals get a clearer picture of specific areas for improvement. The findings can be used to focus quality improvement initiatives on determinants of the quality of a care relationship. This will help focus on issues that matter from the client’s perspective, as is intended if value-based healthcare is to be achieved (42).

This study was performed by three research teams composed of researchers and co-researchers. The contributions of and cooperation with clients as co-researchers was expected to improve the quality of the findings and to lead to recognition among involved co-researchers (25, 31). During the study, we observed that co-researchers understood and spoke the language of other clients very well, and were able to ask questions and summarize findings in a way that remained close to the understanding and phrasing of the clients interviewed. Moreover, the clients wanted to participate and were willing to tell their experiences in an interview to co-researchers. In interviews, clients were very open. This corresponds to earlier experiences with participatory research (28). These aspects are likely to improve the internal validity and therefore the quality of the findings. Co-researchers also felt it was meaningful to be able to contribute to the research and to interview other clients. Their involvement created feelings of being useful and working towards a greater goal. This acknowledged co-
researchers, as team members empowered themselves and each other (40, 43).

A strength of this study is the relatively large number of clients interviewed. This resulted in a variety of determinants being found in all three client groups. Another strength is that both client and professional perspectives were included in the study. However, we did not aim at saturation within each care organization in terms of the professional perspective due to the focus on the client perspective, which is a potential limitation of the study. Nevertheless, the results for the professional perspective are in line with the results of our systematic review of this topic and some new determinants were found. This indicates that most fundamental determinants were found in the focus groups.

Regarding client participation, we decided to counteract pseudo-participation by sticking to the tasks and activities that co-researchers were really good at and interested in. This article was written by the researchers without consulting the co-researchers. The article was based on reflections upon the results as discussed in the research teams. The co-researchers focused primarily on the findings of their client group, and the intergroup comparison between the sub-studies was carried out by two researchers. The co-researchers took a training course to learn and practice the basic skills needed for semi-structured interviewing. There were still some moments where a co-researcher asked a closed question that directed a client towards a particular answer, potentially reducing the quality of the interviews. Due to the fact that interviews were conducted by pairs consisting of one co-researcher and one researcher, the researcher was able to reformulate questions or ask for more clarification or examples in these occasions.

One limitation of this study concerns the respondents selected for the interviews. This study focused on clients who were able to speak about their care relationship experiences. This means that some groups in long-term care were not interviewed and excluded from the target group on beforehand, i.e. people with a severe disability or severe forms of dementia. The consequence is limited generalizability of the determinants found to the least articulate client groups who also receive long-term care. Furthermore, the respondents received or provided care within three care organisations. The results from the present study do not attempt to portray a general opinion on satisfaction on care relationships within the care organisations but instead were an exploration of determinants related to the quality of care relationships from a client perspective and a professional perspective.
Although organisation cultures may differ, it is likely that the determinants of care relationships are transferable for this study purpose to other care organisations providing long-term care as saturation was achieved in the interviews with clients. Also the variation of client characteristics increased the transferability of the findings, such as type and intensity of care, sex, age, and care setting.

The study findings give four directions for future research. The main findings of this study expand the knowledge of determinants of the quality of a care relationship between client and professional in long-term care. A follow-up study might give a better picture of the use of these determinants for improving the quality of individual care relationships. Furthermore, it is not possible on the basis of this qualitative, inductive study to provide insights into which determinants are most influential on the quality of a care relationship, according to clients and professionals. It is also not yet known what determinants are most and least often met in existing care relationships. Future (quantitative) research might provide more insights into these issues. Lastly, the influence of the families of clients on the client-professional relationship was only described briefly in this study. Future researchers might look more closely at this triangle between client, professional and family in order to examine in what ways a client’s family also influences the quality of care relationships.

4.5 Conclusion

The results of this study show that the majority of determinants of the quality of care relationships are similar for all three client groups of long-term care that were studied: clients with mental health problems, physically or mentally frail older adults, and clients with intellectual disabilities. This finding suggests that a specific focus on a single client group is not needed when studying, monitoring and improving the quality of care relationships. The determinants discovered can be used by care professionals, client councils and other people involved in quality improvement initiatives or when evaluating the quality of an individual care relationship.
Literature

Appendix: Topic list interview

Part A
1. Which professional from (care organization) do you deal with most?
2. What does this professional (name) help you with?
3. What is the care relationship with this professional (name) like?
4. Why is the relationship (good or not so good)?
5. What else can you say about the relationship?
[Ask questions 4 and 5 two or three times and keep following them up. You can stop when the client has nothing further to add.]

- Any more questions? Have a look at the crib sheet.

Part B
[If the positive points have been described first, we now move on to the less positive aspects.]
[If the negative points have been described first, we now move on to the positive aspects.]

First positive, now negative:
You’ve told us a lot about how pleasant your relationship with your professional is.
6. Are there also things about the relationship with your professional that aren’t so nice for you?
7. What other aspects make the relationship less pleasant?
- Any more questions? Have a look at the crib sheet.

First negative, now positive:
You’ve told us a lot about what you don’t like about your relationship with your professional.
6. Are there also things about the relationship with your professional that are nice?
7. What other aspects make the relationship pleasant?
- Any more questions? Have a look at the crib sheet.

9. Is there anything else in your relationship with (name of professional) that you’d like to mention?

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Go/no-go point for the researcher to decide if we’re going to ask questions about a second relationship. Rounding off the interview? => Go to “Completion”. Ask about a second professional? => Go to Part C.

Part C
You’ve told us about the care relationship with (name). We’d also like to hear about your experiences with another professional, where the care relationship is different (If a good care relationship has been described first, we now move on to a care relationship that is experienced as not so good, and vice versa).

10. Do you have a professional from (care organization) with whom you have a (good/less good) care relationship?
11. What does this person guide you in?
12. What is your relationship with this professional (name) like?
13. What makes this relationship different from the relationship with the first professional?
14. What else would you like to say about this relationship?

First positive, now negative:
You’ve told us a lot about how pleasant your relationship with your professional is.
15. Are there also things about the relationship with your professional that aren’t so nice for you?
16. What other aspects make the relationship less pleasant?
• Any more questions? Have a look at the crib sheet.

First negative, now positive:
You’ve told us a lot about what you don’t like about your relationship with your professional.
15. Are there also things about the relationship with your professional that are nice?
16. What other aspects make the relationship pleasant?
• Any more questions? Have a look at the crib sheet.

17. Is there anything else that you’d like to tell us about the relationships?

Crib sheet – probing deeper
...for explanation
• What do you think is the reason for that?
• What causes that?
• How can you tell?
• Why (or why not)?
• What did you think then?
• How did that make you feel?
• Why do you think that’s needed?
• At what point do you notice that?
• From what moment does that happen?
• Why is that so important for you?
• How did that happen, exactly?
• Can you say a bit more about that?

…for examples
• Do you have an example of that?
• Can you give an example of that?

Positive
• What makes that so nice?
• Why does that make you feel good?

Negative
• What makes that so awkward?
• Why is that so annoying?

Extra questions – pick a few
• When did you start to feel a bond with your professional?
• Do you get the feeling that your professional listens to you?
• Do you trust your professional?
• Can you go to your professional if you have problems?
• If there are things that you don’t like, can you say that to your professional?
• Could you describe a moment when you did (or did not) understand your professional properly?
• Do you get the feeling that your professional sticks to what the two of you have agreed upon?
• How do the discussions about the personal plan affect the bond with your professional?
• Does your professional help you to achieve what you want to achieve?
• How does having several professionals at the same time feel for you?
• Do you think it’s important that you have fixed, designated professionals?
• You live (in your own accommodation/at a care organization). Do you think that this affects your relationship with (name of professional)?
Chapter 5

Qualitative instruments involving clients as co-researchers to assess and improve the quality of care relationships in long-term care: an evaluation of instruments to enhance client participation in quality research

Currently invited for a revise and resubmission:
Scheffelaar A, Bos N, Triemstra M, de Jong M, Luijkx K, Van Dulmen S.
Qualitative instruments involving clients as co-researchers to assess and improve the quality of care relationships in long-term care: An evaluation of instruments to enhance client participation in quality research.
Abstract

Background: Enhancing the active involvement of clients as co-researchers is seen as a promising innovation in quality research. This study assessed the feasibility and usability of five qualitative instruments applied by co-researchers for assessing the quality of care relationships in long-term care.

Methods: A qualitative evaluation was performed in three client groups: frail older adults, people with mental health problems and people with intellectual disabilities. The data comprised observations by researchers and experiences from co-researchers, clients and professionals.

Results: Two instruments scored best on feasibility and usability and can therefore both be applied by co-researchers to monitor the quality of care relationships from the client perspective in long-term care.

Conclusions: The selected instruments let co-researchers interview other clients about their experiences with care relationships. The study findings are useful for long-term care organisations and client councils who are willing to give clients an active role in quality improvement.
5.1 Introduction

Clients in long-term care receive care, support or assistance for a long time or indeed permanently, and are typically people with an intellectual and/or physical disability, a mental illness, or physical or mental frailty due to old age. The quality of care relationships between these clients and their care professionals is important, as clients depend on professionals who provide the needed support for a substantial period. Positively experienced care relationships benefit the perceived quality of care and quality of life of clients (1). But the quality of the care relationship is not always satisfactory for clients receiving long-term care (2-5). A care relationship is dynamic and several factors are likely to affect it, such as trust (6-8), continuity (9, 10), the listening skills of the professional (11, 12), and equality (3, 7, 13). As the client’s experience of a care relationship is continuously changing, there are often opportunities for improving the quality of a care relationship (13, 14). Clients in long-term care may therefore raise several points of improvement (2, 5, 11, 15, 16).

Qualitative research provides rich and meaningful information about client experiences. Qualitative descriptions of the experiences and perceptions of clients are an accessible and valuable source to help professionals reflect on their actions and behaviour, as well as often providing an immediate picture of areas for improvement (17). Qualitative information also lets professionals complement their own perceptions with those of clients (18) and may derive a deeper understanding of the clients’ perceptions and corresponding meanings by offering concrete and detailed examples (19-22). Care organisations that rely solely on large-scale survey data may overlook important nuances in how individual clients experience care (17). Professionals have suggested that quality improvement needs to give useful handles for reflecting on their own practice and actions (23). Qualitative research is therefore useful for professionals in helping them become more aware of the perspective of a client and attuning them to the needs of individual clients (24).

A growing number of quality improvement initiatives focus on client or user experiences (25). Evaluating care from the client’s perspective is essential for quality improvement as clients are in a legitimately position for deciding to what extent their needs and preferences are being met (26). A promising way of including the clients’ perspective in quality improvement is through their active involvement in quality improvement processes.
Participatory research methods, as they are known, are useful in identifying improvement areas from real-life client experiences and fostering a sense of partnership between the client interviewers and clients as respondents (19). Client involvement is seen as essential for improving the quality of care and changes the substantive outcomes (26, 27). As users of services themselves and because of their own experiential knowledge, clients may find it easier to interpret comments from other clients and extract the most relevant themes from a unique ‘insider’ perspective (28). When participating clients are positioned at the interface between clients and professionals, they also may offer a genuine client perspective for understanding the data collected (29). Client involvement in quality improvement can thus lead to useful areas to work on, empowerment of the clients involved and an open climate in care organisations letting clients express their preferences (30). Nevertheless, client involvement in quality improvement still remains rather rare, due to a lack of experience with client participation (28). No qualitative instruments have yet been developed that clients can easily apply themselves. Giving clients an active role in the application of generic quality instruments will increase their influence on healthcare in general and is likely to benefit quality improvement from a client perspective.

Until now, qualitative instruments for improving the quality of care relationships have been developed and applied solely for specific client groups and care settings. Recently, however, two studies showed that the quality of the care relationship between clients and professionals is influenced mainly by generic determinants that are broadly applicable to all client groups in long-term care (31, 32). These recent findings suggest that generic qualitative instruments for measuring the quality of care relationships may serve the various client groups and settings in long-term care well. Using a generic instrument may potentially facilitate the exchange of quality improvement information between care settings and encourage reflection and learning among care professionals serving various client groups.

This chapter examines the feasibility and usability of qualitative instruments with the aim of finding the qualitative instruments that can be applied by co-researchers for measuring the quality of care relationships in various long-term care settings. The instruments will be evaluated across the three main client groups in long-term care: physically or mentally frail older adults [OA], people with mental health problems [MH] and people with intellectual disabilities [ID]. In this study, we evaluate existing qualitative
instruments that have been adjusted to measure the quality of care relationships with co-researchers among long-term care client groups. As the feasibility and usability of the qualitative instruments depends on the interplay of several factors and actors involved, the process of evaluation includes the perspectives of all actors (i.e. clients, co-researchers and professionals) in order to determine which of the qualitative instruments work best, how, and when (under what conditions and for whom) (33, 34). The most feasible and useful instruments can be applied by co-researchers in long-term care, permitting clients themselves to take an active position in monitoring the quality of care relationships and giving professionals an overview of improvement areas as seen from the client perspective.

5.2 Methods

This study concerns a process evaluation aiming to evaluate the feasibility and usability of five qualitative instruments that can be used by co-researchers to assess and improve the quality of care relationships in long-term care (35). A process evaluation describing the implementation process and the context is useful for indicating whether the interventions were performed as planned, by assessing the experiences of the researchers and co-researchers, clients and care professionals involved (36). Co-researchers applied the instruments, independently or with assistance of a supporting interviewer. The five instruments were first tested and evaluated for the selected client-group. The instruments that scored highest were then cross-tested in the other two client groups in a smaller sample to investigate whether these instruments could be applied in the other two client groups as well.

Study design and setting

Data were collected between March and November 2018 in three large long-term care organisations in the Netherlands selected by a convenience sampling technique. To make sure a diverse group of clients would be included, care organisations were selected that provide care to large client populations with a diversity of recurring care needs, that deliver both inpatient and outpatient care and that comprise multiple locations (35). The participating organisation for mental healthcare [MH] treats about 30,000 clients with long-term psychological and/or addiction problems annually.
This care organisation has 58 locations in the urban area around Amsterdam, including 12 clinics for both inpatient and outpatient care, and 3,500 employees. The care organisation for physically and mentally frail older adults [OA] provides home care and residential care at 35 locations in the province of Noord-Brabant (a rural area in the Netherlands) for about 9,900 unique clients per year, of which 40% receive inpatient care and 65% outpatient support (e.g. cleaning, home care, day care and case management). The care organisation providing care for people with an intellectual disability [ID] assists 2,375 clients a year spread over 100 locations in the south-east of Noord-Brabant. The support provided covers a wide range of care, from 24/7 intensive care to occasional support (e.g. for living, working, leisure time or day care).

**Profile and activities of co-researchers**
The co-researchers of the research teams were involved in the preparations, utilisation and evaluation of the qualitative instruments. The qualitative instruments were applied by five to six co-researchers from each client group; their experiences were an important part of the evaluation. Three research teams were formed with co-researchers and researchers from every client group. Co-researchers were current or former clients of the care organisation in which the research took place. All were adults with a fairly stable health status, able to travel short distances, able to hold a conversation, read and write at a basic level, and open to experiences different from their own. Co-researchers were given training in interviewing techniques that was tuned to the needs and wishes of the co-researchers. Regarding the preparations, the research team, including co-researchers and two researchers (AS and NB or AB), discussed and adjusted the care relationship questions that were based on an earlier study and carried out preparatory activities such as setting up the invitations for respondents. Each co-researcher participated in a training on the interviewing techniques and structure of one type of qualitative instrument. Appointments for interviews and focus groups were made by the researcher and the co-researchers started interviewing respondents in the predesigned way. Some fundamental support with interviewing or reporting was arranged if necessary, particularly for the co-researchers of the ID and OA teams. These co-researchers preferred to interview clients with the help of a supporting interviewer or an experienced co-researcher from the mental health team. The research team gathered at work meetings in order to share initial experiences about interviewing and
cooperation. In later work meetings, interview results, the summary of findings and the final evaluation of instruments were discussed and evaluated. For the analysis of the results, co-researchers were expected to share their experiences, give advice and participate in the discussions of the work meetings. Results were summarised by the team and communicated to the respondents to provide them with general information on the study findings.

**Qualitative instruments**

Five qualitative instruments were evaluated in this study to assess whether they are useful for evaluating the quality of individual care relationships between a client and a professional in long-term care (see table 5.1 and Appendix 1 for a more detailed description of the instruments). The WIEK instrument was selected and evaluated for two client groups. The qualitative instruments were selected out of a total of 23 qualitative instruments inventoried by several stakeholders of the sectors using a Delphi method (36, 38, 39). Stakeholders included representatives of care providers and branch organisations, co-researchers, client or client council organisations with a nationwide scope and care organisations. These stakeholders assessed the available qualitative instruments on several criteria: corroboration, providing recommendations for improving a care relationship, clarity and structure, applicability of instruments in various client groups, validity and reliability, and the extent to which clients are or could be actively involved in applying the instruments.

Each of the qualitative instruments has its own unique properties. In two qualitative instruments, data were collected through open interviews with one client each time. One qualitative instrument concerns focus groups with clients, professionals and the manager of a ward, followed by follow up meetings after one month. Two qualitative instruments are mixed methods, including individual interviews with clients and a focus group. Three instruments provide improvement information for individual care relationships, while the results of other instruments can be used for improvement opportunities at a more aggregated group level (i.e. team, ward or organisation level). For some instruments, the co-researchers were also involved in converting the results into recommendations for quality improvement.

The five qualitative instruments selected were already being applied in some care organisations, but they were initially aimed at measuring the
quality of life or quality of care more generally. The instruments needed some adaptations in order to correspond to the purpose of the current study, i.e. to provide a picture of the quality of the care relationship as experienced from a client perspective. The questions in each instrument were narrowed down to determinants of the quality of a care relationship based on the earlier findings of a systematic review and qualitative research (31, 32). Some instruments were modified in advance to allow client participation by co-researchers using the instrument.

*Table 5.1 Descriptive information about the qualitative instruments*

<table>
<thead>
<tr>
<th>Name of instrument</th>
<th>Research methods</th>
<th>Measurement results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Am I satisfied? (39-41)</td>
<td>Open interview combined with general ratings (Likert scores)</td>
<td>Individual feedback on the care relationship for a specific professional, including individual scores for one professional. Professionals discuss their new insights in a team reflection meeting</td>
</tr>
<tr>
<td>Clients about quality (42, 43)</td>
<td>a) Semi-structured interviews b) Mirroring focus group</td>
<td>Individual feedback on the care relationship for a specific professional; scores and supportive information</td>
</tr>
<tr>
<td>WIEK interview (44)</td>
<td>Open interview</td>
<td>Individual feedback on the care relationship for a specific professional</td>
</tr>
<tr>
<td>Feedback consultation</td>
<td>a) Focus group b) Follow up meeting (one month later)</td>
<td>Feedback consultation, resulting in two formulated action points for the ward</td>
</tr>
<tr>
<td>Participatory narrative inquiry (45)</td>
<td>a) Narrative interview b) Storytelling meeting</td>
<td>Anonymous stories used in a meeting with a group of professionals, co-researchers and the client council to identify areas for improvement</td>
</tr>
</tbody>
</table>

*Evaluation of the instruments*

The evaluation concerned two phases, as shown in figure 5.1. The first phase concerns the evaluation of two instruments per client group, for which the instruments were originally chosen in a Delphi study. In the second phase, the instruments that scored best were cross-tested in the other two client groups to examine whether these instruments could be applied in the other two client groups as well.
The qualitative instruments were evaluated on two core aspects: feasibility of the instrument and usability of the instrument outcomes.

- **Feasibility** concerns whether or not those involved (co-researcher, respondent and care professional) can apply the instrument appropriately. Two main topics were addressed regarding feasibility:
  - Is it possible for co-researchers, clients and professionals to perform the intended roles? Are co-researchers able to perform the described process of the instrument?
  - Does the instrument fit the specific client group (i.e. physically or mental frail older adults, mental health clients or people with an intellectual disability)? Does the manner of questioning of the instrument fit the respondents; i.e. are respondents comfortable answering the questions asked, do they understand the questions and are respondents not too exhausted afterwards? Is it possible for clients to relate their experiences in the designated way?

- **Usability** is defined as how well users (clients, professionals and managers) can use the instrument outcomes. Questions that were answered were:
  - Does applying the instrument result in useful information about the experienced quality of a care relationship from a client perspective?

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**Figure 5.1 Evaluation phases of the instruments**

<table>
<thead>
<tr>
<th>Phase 1</th>
<th>Instruments phase 1</th>
<th>Intellectual disability care (ID)</th>
<th>Mental health care (MH)</th>
<th>Elderly care (ID)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Client about quality</td>
<td>Feedback consultation</td>
<td>Am I satisfied</td>
</tr>
<tr>
<td></td>
<td></td>
<td>WIEK interview</td>
<td>WIEK interview</td>
<td>Participatory narrative inquiry</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Phase 2</th>
<th>Instruments phase 2</th>
<th>Best instrument MH</th>
<th>Best instrument ID</th>
<th>Best instrument OA</th>
<th>Best instrument OA</th>
<th>Best instrument ID</th>
<th>Best instrument MH</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cross-evaluation of best instruments in 2 other client-groups</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Do the results of the instrument lead to concrete areas for improvement, and are these improvement areas clear so that professionals can make the changes needed?

Specific suggestions for modifications of instruments that came to the fore in the evaluation relating to feasibility or usability were also included in the results section.

The evaluation is based on two primary sources: the experiences and perspectives of the stakeholders, and the observations of researchers. Experiences and perspectives of the following stakeholder groups were involved in the evaluation of the qualitative instruments: co-researchers, clients, professionals and supporting interviewers. Moreover, all interviews and group discussions were observed by a researcher (AS, NB, AB) using an observation list applicable to the type of instrument (individual interview or group interview).

This process evaluation was inspired by a realistic evaluation approach, based on the argument that evaluations need to indicate what works, how, under what conditions and for whom (33, 34). Both actors and programmes are rooted in a stratified social reality, resulting from an interplay between individuals and institutions with their own interests and objectives. Realistic evaluation helps find out in which specific conditions the intervention works and how. The accumulation of insights helps us to assess whether interventions that proved successful in one setting may also succeed in another setting and how. In this project, however, it was difficult to build up a theoretical basis as most of the instruments were practically oriented. Nevertheless, the assumptions about the mechanisms of each instrument were defined for each of them beforehand (33).

The three field researchers developed a common interpretation framework by listening to the first two audio recordings individually, filling in the observation list, and discussing similarities and differences between their interpretations. Based on the points discussed, the observation lists were adjusted to create a final version for broader use. The completed observation lists were analysed by the first author in working meetings with the research teams and in a number of reflection and discussion meetings among the three field researchers (AS, NB, and AB). Eighteen audio recordings were listened to and interpreted by a second researcher to check the written notes made by the first researcher and to see if they reached the same conclusions. Eleven of these recordings of various qualitative
instruments were listened to and interpreted individually by the three researchers and discussed thereafter in six discussion meetings. The additions and notable differences in the observations were used as feedback for the researcher concerned and increased the inter-researcher reliability. The modified observation list is presented in Appendix 2.

The evaluation data was collected and analysed in an iterative process. Written materials including the experiences of co-researchers, respondents and care professionals and the completed observation lists were analysed in MAXQDA in sub-themes for the core aspects of feasibility and usability. The data collected by applying each instrument was summarised for one client group, based primarily on the experiences of stakeholders and observations of the researchers. The findings were then discussed by the three field researchers (AS, NB, AB). The final decision on the instruments was based on the totality of the advice given by the co-researchers, experiences of respondents, experiences of care professionals and the participant observations made by the researcher.

**Participants and recruitment**

The instruments were applied in three client groups in long-term care: people with mental health problems [MH], physically or mentally frail older adults [OA] and people with intellectual disabilities [ID]. Clients were selected from a convenience sample by their care professional on the basis of the inclusion criteria and invited by letter to take part in an interview or focus group. Nevertheless, we aimed for variation with regard to relevant client characteristics such as age, sex, ethnicity and inpatient or outpatient care. We focused on clients who have had weekly recurring contact with care professionals for at least three months. Clients received care in their own home (outpatient) or within the care organisation in which they reside (inpatient). Most clients received care at least once every week, but the assistance for some outpatient clients with long-term mental healthcare was more loosely planned. Clients were aged 18 or older, physically and mentally able to take part, and able to communicate verbally in Dutch. The instruments focused on the professionals clients speak to most often for assistance and supporting or physical care (e.g. care workers, personal carers and nurses). We excluded other types of professionals, such as psychiatrists, medical specialists, general practitioners, or those who provide care on a voluntary basis. Participating departments were appointed by the contact person of each care organisation, and information was provided to
professionals about the research project and research aims. If required, the legal representatives of people with intellectual disabilities were asked for permission first.

**Ethical considerations**

This study was submitted to the Medical Ethics Committee of the Radboud University Medical Centre to decide whether the study needed formal ethical approval. In the light of the Dutch Medical Research Involving Human Subjects Act, the MEC decided that extensive formal approval was not needed for this study. Respondents received information about the scope of the research project and gave verbal and written consent for their participation. Respondents and co-researchers were told they could always quit their involvement without having to state a reason.

### 5.3 Results

After the first evaluation phase, three out of five instruments were selected for further evaluation in all three client groups: “WIEK interview”, “Feedback consultation” and “Participatory Narrative Inquiry”. The results for these three instruments are reported comprehensively below, starting with a short summary of the general findings for each instrument.

The two instruments that did not pass the first evaluation phase (“Am I satisfied?” and “Clients about Quality”) were excluded because of their lower performance in terms of feasibility and usability. In short, “Am I satisfied?” was not selected for the second evaluation phase for three main reasons: 1) collaboration between professionals and co-researchers generally did not work out well, 2) co-researchers and professionals had difficulties performing their roles, and 3) few areas for improvement were yielded due to people giving socially desirable answers.

“Clients about Quality” was not selected because of 1) contradiction regarding the content of the instrument (e.g. multiple choice questionnaire versus open manner of interviewing) and 2) the imbalance between the time investment needed from clients (participating in the interviews and the 2-hour mirror conversation) and the lower usability of findings (as clients did not bring forward new points for improvement in the mirror conversation, possibly due to the presence of professionals). Detailed results for these two instruments are included in Appendix 3.
A summary of the evaluation findings for the five qualitative instruments is shown in table 5.2. Examples of the results of the instruments that were further tested in phase 2 are included in the Appendix 4.

**Table 5.2  Summary of findings**

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Final selection</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Client group</td>
<td>Feasibility</td>
<td>Usability</td>
</tr>
<tr>
<td>Am I Satisfied?</td>
<td>OA</td>
<td>Low</td>
<td>Low</td>
</tr>
<tr>
<td>Clients about quality</td>
<td>ID</td>
<td>Low</td>
<td>Low</td>
</tr>
<tr>
<td>WIEK</td>
<td>MH, ID</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td>Feedback consultation</td>
<td>MH</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td>Particpatory narrative inquiry</td>
<td>OA</td>
<td>Moderate</td>
<td>High</td>
</tr>
</tbody>
</table>

* OA=elderly care; MH=mental healthcare; ID=intellectual disability care

**WIEK interview**

**General findings in various client groups**

The WIEK instrument proved to be feasible for all three client groups. In mental healthcare, the WIEK interview was carried out independently by a co-researcher. The co-researchers asked the questions and sometimes explained the questions to the client. In the ID and OA teams, an experienced co-researcher from the MH team helped the co-researcher by asking questions and asking probing questions, summarising the answers and drafting a report. Fixed duos should preferably be used so that the co-researcher and supporting co-researcher get used to each other’s way of doing things. The results of the WIEK instrument provide insights into the
experiences of clients about the care relationship with a particular care professional and the areas of improvement identified can be used for working on this individual care relationship. The WIEK theme cards proved to be useful for clients in choosing the topics to discuss and at the same time provided assistance for the co-researchers in asking questions regarding the chosen topics. The researchers and co-researchers had the impression that the topics on the theme cards were related and sometimes overlapped; the examples and stories that clients wanted to share fitted multiple theme cards. The individual approach of the WIEK instrument suited all three client groups. An improvement for the older adults would be that the questions could better be focused on the whole care team instead of on a single care professional. General descriptive statistics are shown in table 5.3.

<table>
<thead>
<tr>
<th>Client group</th>
<th>No. co-researchers and supporting interviewers involved</th>
<th>Respondents (n)</th>
<th>Duration (mean, min.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental healthcare</td>
<td>3</td>
<td>10</td>
<td>37</td>
</tr>
<tr>
<td>Intellectual disability care</td>
<td>3 + 1 supporter (MH team)</td>
<td>10</td>
<td>42</td>
</tr>
<tr>
<td>Elderly care</td>
<td>2 + 2 supporters (MH team)</td>
<td>7</td>
<td>53</td>
</tr>
</tbody>
</table>

**WIEK – Mental healthcare**

*Feasibility*

The WIEK interview scored well on feasibility from the perspective of co-researchers, clients and researchers. Co-researchers were satisfied about their role and were able to ask the questions, drill deeper and summarise the answers. Making a report was felt to be challenging at first, as co-researchers had to develop these skills gradually. To facilitate this learning process, the first reports were read by the observing researcher and debriefed and supplemented as necessary. The majority of clients were able to answer the questions. From the observations, it appeared that clients were well able to choose two theme cards and talk about these topics, and most respondents enjoyed the opportunity to choose. One client said at the end of the interview that she did not understand two themes and therefore did not pick those cards. The length of the interviews was tailored to the concentration span of the client; if an interview did not take long and the client still looked
energetic, co-researchers asked whether a client wanted to discuss an extra theme card.

**Usability**

In seven interviews, the interview resulted in one or more improvement areas. In six interviews, these improvement areas focused on the professional and one focused solely on the role of the client themselves. Co-researchers stated that the WIEK theme cards worked well for discussing the themes a client wanted to discuss. Professionals indicated that the results were recognisable for them. The interviews that did not reveal any improvement areas could nevertheless contain important information, for example when the results confirmed the view of a professional regarding the client’s wishes.

**WIEK – Intellectual disability care**

**Feasibility**

The WIEK interview was judged to be feasible for clients with an intellectual disability. The observations showed that co-researchers were able to perform their role with assistance of the supporter. The co-researcher asked the questions and sometimes explained the questions to the client. Co-researchers appreciated the cooperation and role division with the supporter. Co-researchers found the theme cards with questions easy to use, and noted that the layout and icons appealed to clients. In three initial interviews, there was little coordination between the co-researcher and assisting supporter, whereas in the following interviews the coordination between the interviewers went well. Clients liked to take part in an interview, understood the questions and the length of the interview was not felt to be too long. Sometimes a question was difficult to answer for a client. The professionals indicated that applying the instrument did not take much of their time and that expectations were clear from the beginning.

**Usability**

In eight of the ten interviews, an area for improvement for the care relationship with the professional was discussed. In four interviews, the improvement concerned the professional and in two other interviews the improvement concerned the client. Two interviews resulted in the improvement that trust needed to develop. Most professionals described the results as useful. Some interview reports did not yield new insights or showed areas for improvement that were already known.
WIEK – Physically or mentally frail older adults

Feasibility

Co-researchers in the older adult team were able to perform their role if they received appropriate support from an experienced co-researcher. Co-researchers felt that the cards gave them guidance in the interview. Clients were positive about the length of the interview and appreciated it because they liked to share their experiences. However, one main modification was needed to let the cards fit well with the client group. The current questions on the cards were focused on one care professional, but in practice clients have contact with many care professionals. Clients found it difficult to talk about a single care professional and spoke almost automatically about the entire care team. The recommendation is that the cards should be changed from questions focusing on a single care professional to questions concerning the plural form 'care professionals', with feedback results for the entire team. Another prerequisite is the support of an experienced co-researcher who can properly ask questions, summarise and simultaneously give the co-researcher space for input and assist where necessary. According to co-researchers, poor hearing on the part of respondents made interviewing harder. Interviewing a couple was also experienced as more difficult than interviewing an individual.

Usability

Four interviews resulted in one or more areas for improvement for the care relationships. In three interviews, no improvement areas were mentioned. Two clients mentioned another point of improvement that did not concern contact with caregivers but quality of care in general. According to the care professionals, the presence of the co-researchers encouraged clients to say what bothers them.

Feedback consultation

General findings in various client groups

The feedback consultation helps understand the experiences of a group of clients, and initiates a group process in which clients and employees work on the two action points formulated by clients. In mental healthcare, feedback consultations were carried out independently by a co-researcher. In the ID and OA teams, an assisting team member from the mental health team helped the co-researcher keep to the structure to the meetings, ask probing questions, let all clients have a say and summarise the answers. The feedback
consultation has proven to be feasible for clients receiving mental healthcare, and to a moderate extent for those with a mild intellectual disability. Feedback consultation was not feasible in elderly care. The group-oriented approach did not suit the client group well due to reluctance to discuss areas for improvement in the presence of professionals and the manager, as well as because of hearing impairments. The co-researchers could not perform the intended role and did not have enough guidance from the open instructions and lacked the experience to lead a group discussion. Moreover, the action points were not perceived as useful by professionals in the elderly care. In contrast, the action points formulated were felt to be useful by care professionals in mental healthcare and by a majority of the professionals in intellectual disability care. A recommendation for the writing task of the manager was to write down (anonymous) examples under each action point to give absent professionals a clearer picture of what exactly was meant. General descriptive statistics are shown in table 5.4.

Table 5.4 Descriptive data for the “Feedback consultation” instrument

<table>
<thead>
<tr>
<th>Client group</th>
<th>No. co-researchers involved</th>
<th>No. of feedback consultations</th>
<th>Total number of respondents</th>
<th>Duration (mean, min.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental healthcare</td>
<td>2 - having experience with leading group discussions</td>
<td>4</td>
<td>34 clients 12 professionals 3 managers</td>
<td>9 clients 6 professionals 3 managers</td>
</tr>
<tr>
<td>Intellectual disability care</td>
<td>3 co-researchers + 1 supporter of MH team</td>
<td>3</td>
<td>13 clients 5 professionals</td>
<td>3 clients 3 professionals</td>
</tr>
<tr>
<td>Elderly care</td>
<td>2 co-researchers + 2 supporters of MH team</td>
<td>2</td>
<td>8 clients 1 member client council 3 professionals 2 managers</td>
<td>2 clients 2 professionals 2 managers</td>
</tr>
</tbody>
</table>
**Feedback consultation – Mental healthcare**

**Feasibility**

The feedback consultation was assessed as being feasible in mental healthcare. Co-researchers conducted the group discussions and follow-up meetings according to the designated structure, asked questions, let all clients have a say, clarified the questions when necessary and summarised the experiences of clients. Co-researchers felt that the group discussion worked best when a maximum of eight clients participated, so that attention could be paid to all clients attending. Prioritising the discussion topics was adapted to the group size. Clients were positive about their participation. The observations showed that the attention span and understanding of clients differed considerably between clients and wards. As a result, the group discussions differed in length and interaction dynamics. Professionals stated that the time investment was in proportion to the returns and they appreciated the clear structure and the inclusive manner in which all clients were involved by co-researchers.

**Usability**

Each feedback consultation provided, as intended, two general action points focused on the entire ward. In addition, several individual points for improvement were discussed in each group discussion. After 4 weeks, some professionals reported they were still working on changes and they needed more time, which explained why some clients noticed little change concerning the action points in the follow-up meeting. Two professionals stated that periodic recurring feedback consultations could help the continuous improvement cycle. One hindering factor was that two managers cancelled the follow-up at the last minute; some clients and co-researchers saw this absence as a lack of interest and perceived importance. In addition, one professional had difficulty in reporting the improvement points to employees as they were absent during the feedback consultation.

**Feedback consultation – Elderly care**

**Feasibility**

The feedback consultation was not feasible in elderly care. Although the respondents felt at ease and understood most questions, the group-oriented approach did not fit this client group. A number of clients found it hard to discuss areas for improvement because they preferred to see themselves as satisfied people and were not used to thinking critically about the care they
received. Similarly, some clients had difficulties in prioritising themes, partly because the themes concerned areas for improvement. The focus on improvement areas and sharing issues in a group seemed to raise the threshold for sharing improvement suggestions and led to socially desirable answers. The hearing impairments of some clients also appeared to be a major barrier to having a smooth conversation. In both feedback consultations, the co-researcher did not have the intended role, i.e. asking questions. One co-researcher was steering by talking a lot about his own experiences, whereas others were listening quietly. The co-researchers did not have enough guidance from the open instruction and did not have enough experience in leading a group discussion. The collaboration between the co-researcher and the supporting co-researcher (from the mental health team) was not entirely satisfactory in the two feedback consultations, because the co-researchers still needed to get to know each other’s characters.

**Usability**
Each feedback consultation resulted in two action points, but care staff deemed these to be not really useful as all four action points were already known before the feedback consultation took place. Two action points were already passed on by clients and had been worked on by professionals. The other two action points were more about attention for clients by professionals if more money or time was available, but professionals did not think this was realistic. The co-researchers noticed that many of the clients were totally satisfied with the care contact with professionals. Moreover, co-researchers noticed that professionals did not change anything in response to the points for improvement, nor were the action points made clear for the clients.

**Feedback consultation – Intellectual disability care**

**Feasibility**
For clients with an intellectual disability, the feedback consultation was assessed as being moderately feasible. In two feedback consultations, the collaboration and roles of co-researcher and supporter worked well. In one feedback consultation, the collaboration and role division did not work well as the supporting interviewer helped too little with interviewing and co-researchers became stressed and therefore contributed little. Moreover, the internal communication between professionals was insufficient, as the
professionals on duty did not know that the feedback consultation would take place. In general, clients liked to talk about their experiences and appreciated the possibility of choosing the themes for discussion. Most clients felt positive about the duration of the feedback consultation, although two clients thought it took too long. Only a small group of clients could participate in this instrument, as it is only appropriate for people with a mild intellectual disability, and relatively high intellectual and communication skills for interacting in groups.

**Usability**
Each feedback consultation resulted in two action points. The professionals in two feedback consultations thought that all action points were worth working on. In the feedback consultation that went less well, two action points did not concern the care relationship or were too generally formulated (according to the professionals). The follow-up meetings showed that professionals and clients worked on the action points in a very different way: from very active – weekly work on the group during mealtimes – to only discussing in the team and no further changes made. Presenting the action points on a visible site encouraged active follow-up of action points.

**Participatory narrative inquiry**
*General findings in various client groups*
Participatory narrative inquiry proved to be feasible for all three client groups. The combination of individual interviews and a story meeting allows different client groups to participate. Co-researchers noticed that the theme of the interview was left open and clients could choose which story they wanted to share. Due to the anonymous nature of the stories collected, the results are useful for reflection and learning by a large group of employees of a care organisation. The active contributions of co-researchers increased the commitment of professionals to work on the findings. Co-researchers also noticed that the stories created awareness among employees. However, interest and time are mentioned as conditions for letting professionals join in the reflection meeting. Some clients had difficulties answering some additional closed questions for interpreting the shared experience. One possibility for making the interview more easily accessible would be to remove these questions and write the answers after the interview by co-researchers. General descriptive statistics are shown in table 5.5.
<table>
<thead>
<tr>
<th>Client group</th>
<th>Total number of respondents</th>
<th>Duration (mean, min.)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Interviews</td>
<td>Group meeting</td>
</tr>
<tr>
<td>Elderly care</td>
<td>3</td>
<td>9 clients</td>
</tr>
<tr>
<td>Mental healthcare</td>
<td>4</td>
<td>6 clients</td>
</tr>
<tr>
<td>Intellectual disability care</td>
<td>3 + 2 supporting co-researchers from MH team</td>
<td>6 clients</td>
</tr>
</tbody>
</table>

**Participatory narrative inquiry – Elderly care**

**Feasibility**

Co-researchers asked most of the questions, but it was difficult for them to ask more probing questions to clarify the open story of the client. In some interviews, they used a number of directing questions, for example by making comparisons between the situation of the client and their own. The role division in the workshop and the story meeting led by a moderator was adjusted so that co-researchers performed the roles as they wished. Most co-researchers used the audio recording option and did not write down the narrative of a client themselves. Clients had difficulties in answering four of the nine additional questions. The instrument was evaluated as feasible if two modifications to the instrument were taken into account. Firstly, based on the observation and the co-researchers, the recommendation was to change the four additional questions. Secondly, some co-researchers need assistance in formulating and asking drill-down questions. In the interviews, the researcher performed this role several times, without this being intended in advance. It would be helpful if a supporting interviewer could help the co-researcher ask more in-depth questions and report on the answers.
Usability
After the story meeting, professionals indicated that useful points for improvement emerged from the client stories, including some that were previously unknown to them. The rich and personal description in a narrative worked well to show the clients’ perspectives on the care relationships with professionals. A total of thirteen narratives showing improvement areas were selected from a total of twenty narratives. In four interviews, one or more narratives with improvement areas were collected; six narratives with areas for improvement were discussed in the group meeting. Commitment among professionals for the improvement areas as formulated in the meeting was seen as a precondition for real change.

Participatory narrative inquiry – Mental healthcare
Feasibility
The interviews and storytelling were easily feasible for co-researchers in mental healthcare. They developed their skills and techniques during the interviews. Co-researchers also had an active role at the reflection meeting. Clients felt that the length of the interviews was fine, and they favoured being interviewed by a co-researcher who understood them well. Some of the additional questions were modified based on the results of the evaluation in elderly care. For two clients receiving mental healthcare, it was still difficult to give a specific example in the open part of the interview, and four of the six clients found it difficult to give a name or add a theme to their story.

Usability
Co-researchers selected nine useful stories from the interviews and stories meeting for the reflection meeting from the 17 stories collected. The other stories contained positive experiences or ambiguities. According to the professionals, the improvement themes were useful and recognisable, and showed a cross-section of the client population. They also indicated that the stories highlighted care relationships from a different angle, i.e. from the perspectives of clients. The active contributions of co-researchers increased the commitment of professionals to work on the findings. Co-researchers noted that the stories created awareness among employees.
**Participatory narrative inquiry – Intellectual disability**

**Feasibility**

The interviews and storytelling group meeting are well feasible for co-researchers with intellectual disabilities when assisted by another co-researcher. The supporting co-researcher from mental healthcare was partly responsible for asking probing questions, for assisting the co-researcher when necessary and for summarising and writing down the answers. Clients were positive about the interviews and their length. Even if a story became less concrete, it sometimes contained an area for improvement for professionals. Three clients of the six found it difficult to come up with a title for the story, and some clients have difficulties with one of the questions.

**Usability**

A total of 11 out of 17 stories were selected by the co-researchers for the reflection meeting to reflect on. Professionals found the stories recognisable and useful to reflect on, and they stated that professionals need both interest and time if they are to come to the reflection meeting in which concrete improvement actions are formulated.

### 5.4 Discussion

This study aimed to select qualitative instruments that can be used by clients as co-researchers to measure the quality of care relationships in long-term care. Five qualitative instruments were evaluated for three large client groups in long-term care. Two instruments (“WIEK interview” and “Participatory Narrative Inquiry”) can both be broadly applied by co-researchers in long-term care to monitor the quality of care relationships from a client perspective. For the study purposes, existing instruments were modified to make it possible for clients as co-researchers to interview other clients about their experiences with a care relationship. The two instruments may serve the aims of care organisations to give clients an active role (in quality improvement initiatives) in monitoring the quality of care relationships. Both instruments have their own characteristics and aim to map out the quality of the care relationship from a client perspective. The WIEK interview is meant for evaluating or monitoring the quality of an individual care relationship, and reflecting on the individual client-professional relationship and aspects that can be improved. Participatory Narrative
Inquiry, on the other hand, provides a collection of anonymous stories that show areas for improvement that are important to most clients. A group of professionals can reflect on the themes emerging from the client stories, and may formulate actions for their own team or organisation. This instrument targets the client-professional relationship at the team level. The two instruments are therefore complementary and care organisations may choose the instrument that best corresponds to their need for quality assessment and the level of results (i.e. the individual or group level). The common success factors for application are the clarity and easy-to-use structure for co-researchers, the open and in-depth approach to addressing client experiences, and the small-scale, personal setting. Both instruments are comprehensively described in a toolbox to enable broader use in the future.

In this study, co-researchers with different strengths, skills and characters performed the qualitative instruments. To make their participation meaningful, roles and task divisions in the qualitative instruments need to be adjusted to the capacities of individual co-researchers. This was achieved by providing co-researchers with an option to conduct the interviews with a supporting interviewer who helped asking probing questions, summarised the results, made notes of the experiences and wrote a small report afterwards. Consequently, a variety of co-researchers was able to perform the instruments. At the same time, not all clients will be able to perform the role of interviewer in the selected qualitative instruments. Selective recruitment of co-researchers with the necessary skills and providing interview training is therefore needed to safeguard clients against bad interview experiences and to yield useful outcomes. Moreover, coordination and support during interviews requires a substantial amount of time.

Working with clients as co-researchers showed the following benefits. Firstly, clients are more willing and able to express and share their experiences, wishes and needs with a co-researcher. Secondly, client participation in quality improvement is hereby made obtainable for a relatively large and diverse group, not only the client group in which client participation is most advanced at the moment. Thirdly, it permits and encourages the interchange between co-researchers of different client groups, with the advantage that co-researchers can use each other’s experiences and even provide each other with practical support in applying the instruments.

Regarding the study design, it could be questioned whether the client group setting in which an instrument was applied during the first evaluation
phase influenced the selection of instruments for the second phase. We tried
to diminish this chance by not strictly retaining the criterion of selecting one
instrument in one client group. In the mental health setting, two instruments
showed promising results; both instruments were therefore selected for the
second evaluation phase. The main reasons for not selecting the instruments
“Am I Satisfied?” and “Clients about Quality” for the second evaluation phase
concerned the design characteristics of the instruments, such as the presence
of care professionals during data collection or the structured nature of the
instrument, rather than client group characteristics.

An important issue regarding the implementation of the instruments is
whether care professionals will regard the quality improvement suggestions
brought forward by co-researchers as useful and supplementary to their own
perspectives. Initial reactions from professionals showed that they were in
fond of an active role for clients in quality improvement initiatives pursued
by the instruments evaluated in this research. At the same time, a recent
study focusing on client participation in inspectorate supervision in long-
term elderly care homes showed that inspectors eventually ignored the
information from ‘experts by experience’. The inspectors only illustrated
their own report findings with notes made by the people with practical
experience, but they did not use new experiential knowledge if it was not
reflected in other data (46). It was hard for the inspectors to value the
experiential knowledge that clients brought in as equal to their own. It is an
interesting topic for future research if care professionals intend to take the
areas for improvement seriously and if they want to work on improving the
situation in practice.

Another attempt at quality improvement does not guarantee that the
desired changes are actually achieved. Success depends not only on
performing the instrument as intended but also on a number of general
conditions that must be met, such as endorsement and commitment to the
instrument application and outcomes by clients, professionals and
management. Moreover, the instrument is not applied in isolation: the
context reshapes and affects the instrument outcomes as well. And “even
where an intervention itself is relatively simple, its interaction with its
context may still be highly complex” (47). Whether change is achieved by
the instrument or not is related to these kinds of general conditions and
contextual factors. It makes measuring real effects and changes in
professional behaviour after the application of a qualitative instrument hard
to get a grip on.
An important factor regarding the context of care that requires specific attention is the national quality frameworks for specific client groups, i.e. disability care (48), home care (49), and nursing home care (50). The quality frameworks underline the importance of reflection on quality improvement regarding client experiences and the involvement of clients in quality improvement. However, quality frameworks often provide quantitative sets of criteria and put high demands on quality instruments that can be hardly accomplished by qualitative instruments carried out by co-researchers. For example, the quality framework for intellectual disability care requires that all clients of a care organisation are questioned with the preferred instrument, and content validity and reliability requirements are operationalised quantitatively. In a Dutch essay entitled “About the new rules, obedience and prudence”, Baart criticises the way in which the complex reality is reduced into simplified, inflexible and uncompromising protocols and quality frameworks. He argues that professionals need to make independent reflections and moral judgements if they are to be able to provide high-quality care. Professionals must be permanently assisted and helped to freely perceive, critically interpret and substantiate how care can be best provided. This could best be done on the spot and in the moment (51). The two instruments selected by this study could help professionals to reflect open-mindedly on the everyday and complex realities by providing in-depth quality information from a client perspective.

**Strengths and limitations**

Some strengths and limitations can be identified regarding the study design and content. One strength is the data triangulation achieved by including multiple perspectives in the evaluation. The perspectives of co-researchers, clients and professionals were gathered and supplemented with observations of the researchers to make an accurate and comprehensive evaluation of the studied instruments possible. Another strength of the study was the active collaboration between co-researchers and researchers in carrying out the study, which made it possible to conduct this study and select the most promising instruments. Moreover, existing instruments were modified and then used in this study to take advantage of instruments that were already developed and utilised. Unfortunately, however, the quality and utility of most instruments had not been previously investigated or published in academic literature.
The instruments can be used for clients who are able to talk about their own experiences. In long-term care, clients’ capabilities are diverse. A qualitative instrument based on observations by family members could be employable for those clients who cannot express themselves, such as clients with severe intellectual disability or advanced dementia. For the study purposes, existing instruments were adjusted to enable clients as co-researchers to interview other clients about their experiences with their care relationships. Although the co-researchers participating in the three teams were quite diverse, the number of co-researchers was limited which might possibly influence the generalisability of the study findings. The role division must always be decided together with the co-researchers involved. For purposes other than measuring care relationships and with other actors such as care professionals carrying out instruments, alternative instruments may be more appropriate. Furthermore, the number of improvement areas mentioned in the interviews of each instrument was described as an indicator of the usability but needs to be interpreted with some caution as these are related not only to the characteristics of the instrument but also to the satisfaction levels of the clients interviewed.

The instruments were conducted and evaluated in three care organisations. The selected care organisations were large and provided care to various client groups. A total of 140 respondents participated in this study, with a minimum of 10 respondents for each instrument. Although clients in long-term care are diverse and each person and interview was unique, specific strengths and restrictions appeared regarding the feasibility and usability of the instruments evaluated, and saturation of the instrument findings was reached. Future research might show the dynamics of organisational features and cultures of other care organisations and their influence on the implementation, results and contributions of the instruments.

5.5 Conclusion

Based on this process evaluation, two out of five qualitative instruments evaluated can be performed by co-researchers to measure the quality of care relationships in long-term care: the WIEK interview and Participatory Narrative Inquiry. These two instruments scored well on both the feasibility and usability of the results. The selected instruments allow clients as co-
researchers to interview other clients about their experiences with care relationships. The study findings are useful for long-term care organisations and client councils who are willing to involve clients actively in quality improvement, thus making the client perspective visible in both the content and the process of quality improvement.
Literature


Appendix 1  Description of the qualitative instruments

Am I Satisfied?
The "Am I Satisfied?" instrument concerned two ways of collecting data: 1) interviews and 2) impressions. In the original version of the instrument, a familiar professional from the client conducts the interview. For this research, we evaluated whether interviewing together with a co-researcher added any value. The interviews were conducted by both a co-researcher and a professional who was familiar to the client, and the topic of the interview was preferably the relationship with that professional. For clients who could not express themselves, the second manner applies: discuss the client's impressions made by a care professional and client representative. The impressions were discussed by a client representative (proxy) and a professional known to the client. Co-researchers and professionals followed a training session provided by two trainers of Praktikon (an independent organisation for research and development and one of the owners of the instrument). Professionals reflected after the data collection on cases from client experiences in a team reflection meeting. The first reflection meeting was supervised by Praktikon.

Clients about Quality
This instrument consisted of four steps: 1) interviews, 2) a mirror group conversation, 3) writing a report and 4) drawing up an improvement plan based on the report. The instrument has been developed by LSR, a Dutch client council organisation with a nationwide scope. Clients were interviewed by one co-researcher and an LSR quality employee on the basis of a structured questionnaire with space for open answers. Important outcomes from the interviews were then discussed with a group of clients and their professionals in a mirror conversation. Then a report was written by the LSR, which was used by the care organisation for drawing up an improvement plan. The client council, the research team (client researchers and a researcher), a few employees, the location manager and executive officer made the plan together in a meeting, resulting in a shortlist of SMART formulated goals for improvement for the organisation and locations.
WIEK
Co-researchers interviewed clients about the quality of a care relationship with their professional. Ten cards are the core of this instrument, each describing one care relationship theme on the one side and open questions on the other side. The client chose 2 theme cards they are willing to talk about and the co-researcher asked questions about these chosen themes. Notes were made during the interview to make an individual traceable client report afterwards to send to the professional. The professional read and reflected on the improvement suggestions, and discussed the results with the client when needed. The WIEK cards were formulated by the research team.

Feedback consultation
This instrument focused on clients and professionals of a single ward and the experiences and improvement areas as mentioned by clients. The instrument consisted of two meetings:
1. Group discussion: Under the guidance of one or two co-researchers, clients exchanged experiences about their care relationships with professionals. Clients first jointly chose 2 themes to discuss, focused on positive experiences, negative experiences and areas for improvement. Four basic rules were followed and monitored by the co-researchers: speak from your own experiences, let each other talk freely, respect each other, and give everyone a chance to provide input. Everyone was allowed to respond to each other’s input. The feedback could address both the client’s own role and the roles of care professionals. The feedback consultation results in 2 action points for the ward, placed visibly on a large sheet of paper in the ward.
2. Follow-up meeting: After one month, the progress of the issues was discussed with a delegation of the attendees at the group discussion: 1 client, 1 professional, the manager and the co-researcher.

Participatory narrative inquiry
This instrument included three aspects: a workshop, data collection with interviews and storytelling, and a reflective meeting. First a workshop was organised in which clients, family and care professionals determine the content of the questions and answer categories. Data collection consisted of individual interviews and a group meeting. Clients were interviewed by co-researchers. An interview consisted of an open narrative and some additional questions by which the client interprets their own story. Co-researchers were given the option to make an audio recording so that the results can
subsequently be transcribed and they did not have to do this themselves. In the group meeting of about 90 minutes, 6-15 clients shared their stories with each other and interpreted these stories. After the data collection, a meeting was held with professionals, the manager, the research team (co-researchers), and possibly a representative of the client council. Central themes were discussed and areas for improvement determined based on anonymous stories from the interviews and stories meeting.
Appendix 2  Evaluation materials

A. Observation list – for interview
Date and time
Instrument:
Interview number:
Co-researcher:
Family/relative:
Support role:
Researcher:

Content of the conversation (in keywords) and/or notes in a text field
Role of the interviewer: co-researcher and (where applicable) the support role
1. Does the interviewer put the client at ease?
2. Does the interviewer ask the questions clearly and in the agreed way?
3. Does the interviewer listen to the client’s answers and do they drill down from there?
4. Does the client (helped by the person in the supporting role) come up with points for improvement for the staff?
   See also question 22.
5. Does the interviewer stick to the process as described in the instrument?
   See also question 19.
6. Extent to which the interviewer steers the conversation
7. Does the interviewer summarise the answers clearly?
8. What does the interviewer find difficult (researcher’s interpretation)?
   See also question 21.

Cooperation between the co-researcher and the support role (if applicable)
9. Attitude, interaction and any agreement between the co-researcher and supporting researcher takes place between equals and in a natural way, before the test activity
10. Co-operation, attitude, interaction and any agreement between the co-researcher and supporting researcher takes place between equals and in a natural way, during the test activity
11. Ratio between the times the co-researcher and supporting researcher are speaking
12. Co-operation, attitude, interaction and any agreement between the co-researcher and supporting researcher takes place between equals and in a natural way, after the test activity

**Client/respondent**
13. Does the client understand the questions?
14. Which questions does the client answer easily? Which questions does the client find difficult?
15. Does the client feel at ease? Or does the client seem tense?
16. Does the client appeared to be tired; does the test activity require a lot of concentration?
17. Extent to which the client understands the subject matter and purpose of the investigation
18. Is there anything worth noting about how the client responds to the co-researcher and support research?

**General**
19. Were all parts of the instrument conducted? Which parts of the instrument went as intended and which did not?
20. What is typical for this interview?
21. Was the co-researcher able to carry out their role?

**Researcher**
22. Reflection on the role of the researcher presents during the test activity: Did you remain neutral during the test activity, only observing and not interviewing?

**Answers to the assessment questions that the researcher asked the client at the end of the test activity**
In the presence of the co-researcher and any support interviewer
- How did you think this conversation went?
- What did you think of the fact that (a) another client, (b) a familiar professional, (c) a researcher was present during the interview?
- Do you have any tips you would like to give us?
- Would you be ready to take part in another interview?
- Have all the points for improvement in the relationship been discussed?
- Is it clear to you what we will be doing with the results? What do you think of that?
Do you think that the point is that improvement will actually be implemented? Why (or why not)?

What did you think of the duration/length of the interview?

Notes on the conversation afterwards with the co-researcher and any support interviewer
- How did you think this conversation went?
- How do you think your role went?
- What did you think of the client’s answers? Do you now know what they think of their relationship?
- What did you think of the cooperation/division of tasks with the other person (care professional/co-interviewer)?
- What would you do differently next time?
- Did the amount of time you spent match what you expected beforehand?

After conducting the instrument
- Length of interview
- Number of questions asked
- Elements conducted as planned
- Were the results and points for improvement written down clearly?
- Can differences be seen between the interviewers?
- Can a learning effect be seen in the kind researcher or support interviewer? (Does it get easier, within single interviews as well?)
- Do you think that the co-researcher could perform their role outside the research setting?

B. Evaluation with care professionals (e.g. by phone)
- What do you think of the results of the instrument? Are they recognisable? Did the instrument yield new insights?
- Have you discussed the results with the client?
- Has the instrument yielded specific points for improvement? Based on the results, do you know what you can do to improve the care relationship with the clients who took part in the study?
- Can you identify moments or processes in the approach and during its implementation (planning, conditions, etc.) that played a role in the success or failure of the instrument?
- What do you think of the co-researcher role?
- What have you noticed about the implementation of the instrument?
• What did you think of your role in the instrument?
• Was it clear to you what was expected of you?
• Did the amount of time you spent match what you expected beforehand?
• What do you think of the length of time it takes?
• Did implementing the instrument affect your other work activities? If so, what effect did it have?
• Did carrying out the instrument set undesirable or indeed desirable unforeseen processes in motion?
• Did it reach the intended target group of clients?
• What groups of clients were missing and what were the consequences?
• What has to be arranged within the organisation if the implementation is to be successful? What are the key preconditions?
• Would you want to be involved in implementing the instrument in the future as well? Why (or why not)?
Appendix 3  Findings regarding the two instruments that did not pass the first phase

Am I satisfied? – Elderly care

Table A3.1 Descriptive data for the “Am I satisfied?” instrument

<table>
<thead>
<tr>
<th>Client group</th>
<th>No. co-researchers and professionals involved</th>
<th>Total number of respondents (n)</th>
<th>Duration (mean, min.)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Interviews</td>
<td>Impression</td>
</tr>
<tr>
<td>Elderly care</td>
<td>2 co-researchers 4 professionals</td>
<td>9 clients</td>
<td>1 client *</td>
</tr>
</tbody>
</table>

* At the impression, no co-researcher was involved

Feasibility
Researchers and professionals found that the feasibility of the “Am I Satisfied?” interviews was low. The collaboration between professionals and co-researchers generally did not work out well. Professionals gave little support to the co-researchers and they reported confusion about the roles that made it hard for them to intervene when a co-researcher forgot something or asked a leading question. Professionals were generally not critical and very directive, for example in asking questions that prompted for positive answers and by filling in answers based on their own interpretations instead of the actual answers of the client. Co-researchers also found it difficult to perform their role, specifically in asking neutral open questions or probing questions to clarify the answer of a client. The impression was with one client insufficiently tested. In the care environment, almost all clients were able to discuss the care relationship themselves. General descriptive statistics are shown in table A3.1.

Usability
The instrument yielded few areas for improvement for professionals. In two interviews, areas for improvement came to the fore that were useful for improving the contact with the professional present. The clients who were interviewed often gave socially desirable answers, which was explained by
co-researchers by the presence of the professional involved. According to professionals, the setting was too formal and unnatural.

**Clients about Quality – Intellectual disability care**

<table>
<thead>
<tr>
<th>Client group</th>
<th>No. co-researchers and supporting interviewers involved</th>
<th>Total number of respondents (n)</th>
<th>Duration (mean, min.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual disability care</td>
<td>3 co-researchers + 2 professional interviewers</td>
<td>10 clients + 6 clients*</td>
<td>57 + 75 + 105</td>
</tr>
<tr>
<td></td>
<td>2 co-researchers + 1 quality employee + 1 professional</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* The clients taking part in the mirror meeting were also interviewed.

**Feasibility**

Interviews and mirror conversations were applicable according to co-researchers, but the feasibility was low with respect to the amount of time the instrument takes for the clients who participate and the content of the instrument. Co-researchers were able to ask the questions with the support provided and satisfied with the collaboration. Concerning the questionnaire, some clients found certain questions difficult, for example those including broad or vague terms like 'respect' or 'match'. The smileys were useful for some clients in helping them answer the closed questions of the questionnaire. The interviewers reported overlap between various questions and felt that the ordered questionnaire was too long for clients. Specifically, the manner of interviewing was very open, whereas the questionnaire consisted of multiple choice questions, which resulted in time-consuming interviews and overlapping topics. Two hours were scheduled for the mirror conversations, but this was too long for the concentration spans and energy levels of clients and difficult to fit in the work schedules of the professionals. Furthermore, some professionals reported that the questions in the mirror conversations were too difficult. General descriptive statistics are shown in table A3.2.
Usability
The observations showed that an improvement area for the professional was mentioned by a client in half the interviews. The mirror conversations did not yield any additional points for improvement. The presence of the professionals may possibly have inhibited clients from sharing areas for improvement in the mirror conversation. According to the professional interviewers of LSR, the co-researchers and the observations, a more open approach in the interviews (without closed questions) would have matched the clients’ wishes and the purpose of the interview better.
Appendix 4  Examples of the results of the instruments that were tested in phase 2

Participatory Narrative Inquiry
Two narratives of older adults with a physical or mental frailty

Hygiene
“I had lived here for a while and I noticed several times that the shower chair had not been cleaned after it was used. Once there was even bath foam on it! The chair was not really cleaned or disinfected. I complained about this to the manager. The care professional did not apologise and insisted it wasn’t true. Then I said that I no longer wanted to be helped by this care professional, because he simply wasn’t honest. In general, hands are also washed far too infrequently, whereas the protocol is that the care professionals must disinfect after every client before they take care of me. It really doesn’t happen enough.”

Sympathy
“If I feel bad when I have flu, I occasionally need a helping hand from someone. Then it’s very nice if a nurse wants to talk to me. And asks if she can do anything for me. I’m not here for fun: it’s my body forcing me into it. Some care professionals don’t even greet me and they remember for a long time if I give negative feedback even once. They don’t always have attention and time for me. Don’t ask simple questions to show interest. Then I feel so unnecessary.”

Feedback consultation
Goals formulated for professionals of a mental health ward.

Goal 1: The professionals are aware of the following points regarding respecting each other:
• Don’t touch other people’s property
• When entering an apartment, first ring or knock and wait for a response.
• Actively listening to the client
Goal 2: The professionals make more time to get in touch with clients (both on request and spontaneously). In particular also approaching clients who never ask for help:
- Doing things together is progress!
- Tip: give each other compliments and feedback
- Also mention what has gone well

<table>
<thead>
<tr>
<th><strong>WIEK</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>The report on two WIEK theme cards discussed in an interview with a person with an intellectual disability.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Building a relationship</strong></th>
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</thead>
<tbody>
<tr>
<td>[Name of client] clicks well with [name of professional]. [Name of professional] is now one of the supervisors of [name of client] for one year. They are building a better relationship together. [Name of client] is gradually able to tell him more and more. This is because [name of client] is getting to know [name of professional] better and better.</td>
</tr>
<tr>
<td>What are points for improvement for the topic: Continue to supervise this client for a longer time.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Trust</strong></th>
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</thead>
<tbody>
<tr>
<td>[Name of client] trusts that [name of professional] will not tell anything to others. The professional could sometimes be a little more on time, but this is actually true for all professionals. The client would also appreciate it if the professional were to send a message when he’s running late to say how much later he will be coming. If an appointment has been made, [name of client] will stay at home for it and he is therefore reliable for the professionals. The longer [name of client] knows [name of professional], the more he feels at ease with him.</td>
</tr>
<tr>
<td>What are points for improvement for the topic: That the professional arrives on time and sends a message if he will be arriving late.</td>
</tr>
</tbody>
</table>
Chapter 6

Lessons learned from participatory research to enhance client participation in long-term care research: a multiple case study

Currently under review:
Scheffelaar A, Bos N, de Jong M, Triemstra M, Van Dulmen S, Luijlkx K
Lessons learned from participatory research to enhance client participation in long-term care research: a multiple case study.
Abstract

Background: Although participatory research is known to have advantages, it is unclear how participatory research can best be performed. This study aims to report on lessons learned in collaboration with clients involved as co-researchers in three participatory teams in long-term care.

Method: A multiple case study design was chosen to explore the collaboration in three teams, each covering one specific client group receiving long-term care: physically or mentally frail elderly people, people with mental health problems or people with intellectual disabilities.

Results: A good working environment and a good collaboration were found to be crucial requirements for participatory research, of which the consisting elements were described extensively in the result section. The motivations and unique contributions of the co-researchers and differences between the teams were reported.

Discussion: These results can be used by researchers for designing and shaping future research projects in long-term care in collaboration with clients as co-researchers.
6.1 Introduction

In recent years, clients receiving long-term care have become more actively involved in research and quality improvement through adopting a role as co-researchers. Consequently, participatory research is being conducted ‘with’ or ‘by’ clients as co-researchers, rather than ‘to’, ‘about’ or ‘for’ clients as is usual (1). This development is being driven by three core arguments. Firstly, putting the client perspective at the centre by actively involving clients in several research stages is expected to increase the quality of studies, as the research better reflects clients’ ideas, needs and priorities and as such enhances the (content) validity and relevance (2-5). Secondly, the active role of co-researchers yields to more effective quality improvements and enhances the support for the findings and proposed changes by clients and professionals (2, 3). Thirdly, the ontological and normative argument concerns the rights of clients as care users and humans to influence decisions regarding their lives and specifically their care (2, 4, 6). In this argument, clients have the democratic right to become involved (7, 8). This is especially relevant for clients in long-term care, who depend on the provided care for a long time. For these clients, participation in research may be an opportunity to construct a positive social identity and build up their self-esteem (7, 9).

There is a growing amount of literature about client participation. Participation in research can take many different forms, as clients can perform various tasks depending on their roles and levels of participation. Some co-researchers are advisors in steering groups (5, 10) or involved in agenda setting (11, 12). Other co-researchers perform research activities themselves (13). They can be involved in preparatory activities in research, such as formulating research topics and recruiting participants (7, 14). Co-researchers can also be involved in data collection; they can observe and record what strikes them, or conduct interviews or focus group discussions (1, 5, 14-17). Furthermore, co-researchers have been involved in analysing the outcomes (14, 15, 18). In order to become experienced and well prepared, co-researchers may attend formal training, learn while performing the research, or a mixture of the two (19).

Arnstein’s (1969) ladder of participation is probably the best-known conceptualisation of variations in participation ‘levels’. The ladder distinguishes five levels of participation, ranging from informing to citizen control (20). Some academics criticised the oversimplification of reality and the underlying assumption that higher steps on the participation ladder are
deemed better while this is not always the case (2). More recently, Bigby et al. (2014) distinguished three main roles for co-researchers, which overlap with the levels on the ladder. The *advisory role* is the commonest form of inclusion and corresponds to the consultation level. Co-researchers give advice about research priorities, the design and data collection methods in an advisory group and exert little control over how their input is used (21). A *leading and controlling role* suggests that co-researchers initiate, lead and carry out research on their own terms (examples are (22) and (17)). A third way of involving co-researchers in research is in *collaboration or partnership* with researchers, with the initiation and leading roles not necessarily held solely by co-researchers. The position of the co-researchers is then not privileged or subordinate but equal (14) (15). Important conditions for collaboration are time, trusting relationships, money and commitment from several parties (21).

Existing literature addresses the required competencies of researchers and co-researchers, and conditions and potential barriers for participatory research (7, 8, 23-26). Biomedical researchers often believe that partnership in research is complex, time-consuming, and incomprehensible with the objectiveness principle (14). Moreover, researchers judge experiential knowledge often as inferior, they tend to invite the most accessible clients to join the research, and travel support and financial compensations are not always arranged (7). When the required circumstances and individual needs and capacities are not taken into account, well-mentioned attempts can result in pseudo-participation and tokenism (23). The study of Brown et al. provided some examples of practical difficulties, as researchers tended to share an overload of written information which was not always needed, and small talk was viewed as a waste of time by researchers although it was viewed as essential for developing a bond (27). There is still a lack of practical knowledge about *how* participatory research can best be designed and performed (28). What are the requirements for participatory research, and how can they be applied in practice? To avoid tokenism and bad practices in attempts to achieve participatory research, a better picture of these ‘how’ issues is needed (15, 21, 29) (28). This can be most effectively constructed from experience of what actually happens in research that aims to be participatory (15).

We recently conducted three participatory research projects in long-term care which are used for exploring the collaboration process and what motivates co-researchers to participate (30). The aim of this chapter is to
report on lessons learned about collaboration between researchers and co-researchers that can be derived from the three projects. Each project involved a research team of researchers and co-researchers. The co-researchers of one team concerned physically or mentally frail elderly people, the second involved people with mental health problems and the third involved people with intellectual disabilities. This chapter provides insight into team members’ experiences and the requirements for collaboration in a team of researchers and co-researchers in long-term care research that focused on the quality of care relationships between clients and professionals. The three distinct research teams from different client groups make it also possible to explore differences and similarities in client participation opportunities in three long-term care settings.

In this chapter, the term ‘participatory research’ is used to describe the process of collaboration between researchers and co-researchers in three research teams focused on quality improvement. The definition of Frankena et al. (2015) was followed that “participatory research strives for a partnership between patients and researchers, meaning that control is shared between both parties” (7). The term “co-researchers” is chosen for those clients actively involved in the research, to emphasize the joint collaborative research process.

### 6.2 Methods

**Setting the scene: the broader context**

This paper presents three projects performed by three teams including co-researchers and researchers in long-term care in the Netherlands. A three-year study from 2016 to 2019 was conducted to find and optimise the most suitable and useful qualitative instruments for monitoring care relationships in long-term care by co-researchers, as these relationships are a major determinant of the perceived quality of care (30). A Delphi method was used to select five qualitative instruments by co-researchers and stakeholders such as representatives of care providers and branch organisations, nationwide client (council) organisations, staff from the care organisations involved, and health insurers. The content of the instruments was adapted for the research context with input from the co-researchers by adding questions about the quality of a care relationship, based on the findings of a systematic review and a qualitative research (31, 32). The guidelines of the instruments were
also adapted to give co-researchers a central participatory role in using the instruments. Co-researchers were trained to conduct interviews or focus group discussions. The central focus of this study was to find out which qualitative instrument applied by co-researchers was most useful for evaluating the quality of care relationships between clients and professionals in long-term care. The three research teams applied and evaluated all five qualitative instruments: Am I Satisfied, Client about quality, Feedback consultation, WIEK and Participatory narrative inquiry. The specific findings regarding the contents of the five qualitative instruments and the performed process evaluation are reported elsewhere (Scheffelaar, Bos, de Jong, Bons, Triemstra, Luijksx. Dulmen. An evaluation of qualitative instruments for measuring the quality of a care relationship with co-researchers in long-term care. Submitted).

**Case study design**

For the design of this study, a multiple case study was chosen to explore the co-researchers’ and researchers’ role in this participatory research in long-term care. Case study research involves a ‘how’ or ‘why’ question about a contemporary set of events over which a researcher has little or no control (33). It is an empirical inquiry that investigates a contemporary phenomenon (the ‘case’) in depth and within its context. This is especially useful when the boundaries between phenomenon and context may not be evident (33). The essence of a case study is that it tries to illuminate a decision or set of decisions: why they were taken, how they were implemented, and with what result (33, 34). Therefore, the orientation of the study was towards pragmatism.

The cases in this study are defined as the participation and collaboration of three teams of co-researchers and researchers in three long-term care settings. Each team consisted of two researchers and five or six co-researchers. The first team consisted of physically or mentally frail older adults (the OA team), the second of people with mental health problems (the MH team) and the third of people with an intellectual disability (the ID team). The basic characteristics and minimum capabilities needed for inclusion in a research team are described in table 6.1. The reason for drawing up this profile was the intended active role in the performance of the qualitative instruments and within the research as a whole. The capabilities were also based on earlier participatory studies that came to the fore in a scoping review (8, 24, 35-38).
Multiple case study

Table 6.1  Inclusion criteria for co-researchers

- 18 or older (no upper limit)
- Experience as a client of long-term elderly care (residential or home care), mental health care, or care for intellectual disabilities
- Receiving care for at least three months
- Able to communicate verbally in Dutch
- Able to generalise from their own experiences
- Able to hold a conversation
- Able to read and write at a basic level
- A fairly stable health situation
- Able to travel short distances

Research process
The joint research process consisted of three phases: 1) preparatory activities, 2) application of the instruments, and 3) evaluation of the instruments (see figure 6.1).

Figure 6.1 Phases of research process and data collection

The preparatory activities involved drawing up the invitation letter for respondents, formulating basic agreements, and training sessions. The use of the instruments by co-researchers consisted of individual interviews, group
interviews, the corresponding preparation meetings and debriefings, and work meetings. The evaluation of the instruments and collaboration was carried out in work meetings by the research team.

To recruit co-researchers, invitations were sent via the contacts in the care organisations to care professionals, client councils and activity supervisors at the learning centres. Clients who were willing to join the research team as a co-researcher contacted the first author, either in person or through a care professional. More information was provided when requested, and individual introductory meetings with the first author were scheduled with those showing interest.

**Data collection**
This case study draws upon evidence from the viewpoints of researchers and co-researchers collaborating in the three teams. Four sources of data were collected: direct observations, participant observations, individual and group discussions, and documentation. Two types of observations were made during the research process. Firstly, researchers carried out direct observations while interviews and focus group sessions were being held in order to assess the qualitative instruments. Secondly, participant observations were made in the training sessions and work meetings of the three research teams. The difference between direct observations and participant observation is associated with the researchers’ role: passive in the direct observations of the measurement moments, and active (as a research team member) in the training sessions and work meetings. Field notes were made of the salient features of both types of observations. The third source of data is the evaluation of individual and group discussions. Individual conversations were held before and after the instruments were applied by co-researchers in practice, and concerned in particular preparations and debriefings. Three group discussions were held by each of the research teams about the experiences and to evaluate the participation and collaboration of co-researchers and researchers. Plenary discussions were audiotaped and field notes were made. Fourthly, various outputs from the research teams were part of the documentation, such as notes made by co-researchers, analytical summaries of the work meetings and observation forms filled in by the researchers. Some co-researchers also wrote down their experiences in notebooks. Altogether, these four sources provided a variety of data for overall reflections, to create insights into the collaboration process.
**Data analysis**

Cross-case syntheses and four types of data analysis were used: categorical aggregation, direct interpretation, looking for patterns, and naturalistic generalisation (39). In categorical aggregation, the researcher looks for a collection of instances from the data to find relevant meanings. In direct interpretation, single instances are looked at. Looking for patterns between cases means that the researcher looks for similarities and differences among cases. Lastly, naturalistic generalisations can be developed. Yin (2014) described looking for patterns more thoroughly as “cross-case synthesis”. Cross-case syntheses can be performed when two or more cases are studied. Word tables can be created to display the data from the individual cases according to one or more uniform categories (33).

Direct interpretation and looking for patterns were carried out by each research team in work meetings and evaluation meetings. Each team discussed research experiences, focusing on motivations, facilitators and barriers of the collaboration. Co-researchers shared their own experiences of their roles and participation and interpretations in the research teams, and also made notes of their experiences individually. Furthermore, notes were made by the researcher of the topics discussed by the research team. The other two forms of data analysis (categorical aggregation and naturalistic generalisation) were carried out by the first author (AS), who read the raw material collected and identified similarities and cross-case patterns. The results were then discussed with other authors (NB, MdJ, SvD, KL).

With regard to the data analysis, the quality of the qualitative data was validated and increased in three ways. First, the work meetings and debriefings of co-researchers and researchers in each research team enabled the inclusion of both co-researcher and researcher perspective in the analysis, which was likely to increase the internal coherence and validity of the findings. Second, one co-researcher contributed as a co-author to the writing stage of this article to ensure that the article reflected the perspectives of co-researchers well throughout. Third, the dilemma’s and questions rising during data collection and analysis were discussed in peer debriefings with all co-authors, of which some had more distance to the practical execution of the research.

**Ethical considerations**

The study was submitted to the Medical Ethics Committee of the Radboud Uuniversity medical center to decide whether the study needed formal
approval. Given the Dutch Medical Research Involving Human Subjects Act, the Ethics Committee decided that extensive formal approval was not needed for this study.

**Informed consent**

*Co-researchers*

At the start of the study, a recruitment letter and poster was spread to search for potential co-researchers willing to join the team. All potential co-researchers were informed in an individual meeting about the study prior to their decision to join the research team. They were initially informed about the purpose and procedures, the work, the voluntary nature of participation as a co-researcher, and the option of withdrawing at any time. Co-researchers then decided whether they really wanted to join and filled in a form with individual details needed for reimbursement and contact details. To ensure a meaningful participation of co-researchers, assistance was provided in several forms and basic agreements for cooperation and confidentiality were drawn up together by the research team. All three research teams had discussions about confidentiality regarding individual client information and made agreements about privacy issues and collaboration issues that are described in the results section of this article. All co-researchers were also willing to contribute to the evaluation of the collaboration process.

*Clients*

Clients were informed by letter and verbally about the purpose for which the data collected would be used, the privacy agreements made by the research team, and the fact that they could withdraw at any time. Clients who were interviewed by co-researchers according to one of the five qualitative instruments participated after completing a consent form and agreed that an audio recording would be made. The consent form was also signed by the co-researcher who was performing the interview and by the researcher present for the observations. In the interviews with clients, a ‘process consent’ approach was adopted, meaning that we constantly observed whether consent was still present by paying attention to verbal and nonverbal indications of reluctance or hesitation to participate (40).
6.3 Results

Description of the research teams
The characteristics of members of the three research teams are described in table 6.2.

Five co-researchers and two researchers took part in the older adult research team (OA team). Co-researchers all lived in the same residential care facility in a small village. One co-researcher was a critical thinker and offered many ideas, while others were more accommodating and looked for a feeling of togetherness. The atmosphere was friendly, relaxed and low-paced. All co-researchers received some kind of support such as support with dressing and showering, cleaning, meals or medication provision. They were all able to move independently within the building. Co-researchers talked a lot about their experiences with the care provided and their lives before they entered the residential care facility.

The mental health team (MH team) comprised five co-researchers and two researchers. The atmosphere in the MH team was generally very energetic. Co-researchers were very willing to contribute and think along; they had a lot of ideas and criticisms. The co-researchers could reflect very well on the research process and expressed themselves clearly. Three of the co-researchers received outpatient support, the other two co-researchers were in a stage of their recovery process in which they no longer received care. Three co-researchers used their experiences to assisted clients with mental health issues in a paid position. Co-researchers had experience with a variety of psychological issues, among others autism, addiction, and personality disorders.

The intellectual disability team (ID team) consisted of six co-researchers and two researchers. The atmosphere in this research team was generally very cheerful. The co-researchers were eager to learn and often asked questions. Some of the co-researchers reflected on the research process actively, whereas others preferred to listen to the ideas of other co-researchers. Most of the co-researchers were open in their communication, including about what they did not like when they provide feedback. Three of the co-researchers lived in a care facility themselves and three received outpatient support at home. Five of the co-researchers were born with their intellectual disability, and one co-researcher suffered from a non-congenital brain injury.
Table 6.2  Description of the three research teams

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Older adults team - OA</th>
<th>Menthal health team - MH</th>
<th>Intellectual dissability team - ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>Co-researchers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male / Female</td>
<td>2 / 3</td>
<td>3 / 2</td>
<td>4 / 2</td>
</tr>
<tr>
<td>Living situation</td>
<td>Situated in rural area</td>
<td>Living in Amsterdam (capital of the Netherlands)</td>
<td>Situated in and around Eindhoven (city in the province of Noord-Brabant)</td>
</tr>
<tr>
<td>In- / outpatient care setting</td>
<td>5 / 0</td>
<td>0 / 5</td>
<td>3 / 3</td>
</tr>
<tr>
<td>In care for</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5 physically frail elderly</td>
<td>2 people for addictions, 1 people for personality disorders, and 2 people with autism</td>
<td>5 people with mild intellectual disability, 1 person suffering from a non-congenital brain injury</td>
</tr>
<tr>
<td>Age (years)</td>
<td>73-93</td>
<td>32-67</td>
<td>24-67</td>
</tr>
<tr>
<td>Researchers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male / Female</td>
<td>1 / 1</td>
<td>1 / 1</td>
<td>0 / 2</td>
</tr>
<tr>
<td>Age (years)</td>
<td>27 and 67</td>
<td>27 and 67</td>
<td>27 and 41</td>
</tr>
</tbody>
</table>

In total, three researchers were involved. A young female PhD student (AS) with an educational background in interdisciplinary social sciences was part of all three research teams throughout the project. One researcher is almost retired and works for a Dutch client council organisation with a nationwide scope. He was first part of the ID team only and later on part of the MH and OA team. The third researcher (NB) is a female senior researcher of 41 years old having an educational background in public health and movement sciences. She was first part of the OA team and later on part of the ID team. The researchers were eager to perform the participatory research and put into practice their theoretical knowledge based on the literature. During the facilitation of the team meetings, researchers took on slightly different roles based on the features of co-researchers of each team. In the MH team, researchers ensured that all co-researchers could have equal contributions, and facilitated the process of seeking consensus in the team. In the OA team,
researchers tried to stimulate co-researchers to think in a critical manner. In the ID team, researchers tried to hold on to a clear structure in the meetings to calm down the atmosphere.

**Main overview**
The following results section is divided into three sections. The first specifies the co-researchers’ motivations for participating. The second describes the main requirements for a good working environment and collaboration in participatory research. The third section gives a description of the differences within and between the teams. Only in the third section, the differences between research teams are described. An overview is given in table 6.3 and a summary is included in table 6.4.

<table>
<thead>
<tr>
<th>Table 6.3 Conditions and motivations for participation</th>
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<tbody>
<tr>
<td><strong>Motivations for participation</strong></td>
</tr>
<tr>
<td>Committed to quality improvement</td>
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<tr>
<td>Being of worth to other clients</td>
</tr>
<tr>
<td>Being part of a social group</td>
</tr>
<tr>
<td>Creating a new social identity</td>
</tr>
<tr>
<td>Personal development and acquiring new skills</td>
</tr>
<tr>
<td><strong>Requirements for developing a good working environment</strong></td>
</tr>
<tr>
<td>Discussing reasons for engagement and wishes</td>
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<tr>
<td>Formulating basic rules</td>
</tr>
<tr>
<td>Training sessions</td>
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<tr>
<td>Availability of researcher and travel support</td>
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<td>(Financial) appreciation</td>
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<tr>
<td><strong>Requirement for a good collaboration</strong></td>
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<tr>
<td>Development of a bond</td>
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<tr>
<td>Deciding on role division</td>
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<tr>
<td>Transparency and feedback</td>
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<tr>
<td>Need for structure</td>
</tr>
<tr>
<td>Equal positioning</td>
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<tr>
<td>Sufficient time</td>
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<tr>
<td><strong>Main feature of inclusive collaboration</strong></td>
</tr>
<tr>
<td>Individual differences in:</td>
</tr>
<tr>
<td>Personal skills and unique contributions of co-researchers</td>
</tr>
<tr>
<td>Abilities and contributions of the researchers</td>
</tr>
<tr>
<td>Differences between research teams</td>
</tr>
</tbody>
</table>

**Co-researchers’ motivations for participation**
Co-researchers gave five motivations for participation that they found to have significant importance: being committed to quality improvement, being of worth to other clients, being part of a social group, creating a new social identity, and personal development / acquiring new skills.
• Commitment to quality improvement
Co-researchers shared substantive reasons for joining participatory research. One co-researcher described the role as a co-researcher as an essential bridge that connected individual experiences of clients to the level of a care organisation. In this way, this co-researcher was meaningful for other clients: “I thought it was really useful that you could be an important link between the stories and the complaints of the people and the organisations. That you’re able to do something for people.” (co-researcher 15, OA)
Other co-researchers specifically underlined the desire to improve the quality of care relationships between clients and professionals in long-term care, which was the main aim of using the qualitative instruments: “To try and help bring a client and professional together. I’m also intrigued to see if the relationship between the clients I interviewed and their supervisors are now better.” (co-researcher 6, ID)
A couple of co-researchers told they were highly motivated right from the start to study the differences between the qualitative instruments that were evaluated in the study.

• Being of worth to other clients
For most co-researchers, it is important that they are valuable for other clients. Sometimes co-researchers heard stories of other clients who experienced problems in their relationships with care professionals. Co-researchers were motivated to help clients to improve the situation: “I think it’s really important to be able to mean something to someone else. That you’re living here and can genuinely change things for someone else.” (co-researcher 12, OA)
Aiming to improve the quality of care was not only important to clients, but the co-researchers themselves also benefited because they felt meaningful and valuable for other clients, as well as for the community at large: “It’s nice to do something like that, in the final stage of my life. To be able to do something useful. I always used to make efforts to help people in my work. And now I still can. I hope we all get something out of it. Me, the residents, staff... the whole lot.” (co-researcher 12, OA)
“I’ve got no more goals in life. This could be a goal: doing something for the world.” (co-researcher 4, MH)
• **Being part of a group**
  For some co-researchers of the three research teams, the social connections and social interactions with the research team members and social contacts with respondents were the primary reason for joining.
  "The group was a very positive experience for me. It gave me a lot of energy for being with the group." (co-researcher 2, MH)
  Multiple co-researchers mentioned the nice and cozy atmosphere in the team, and the added value of the team support for overcoming their feelings of insecurity with their interviewing techniques.

• **Creating a new social identity**
  Joining the research team presented possibilities for creating new social roles and acquiring a new social identity. For example, one co-researcher shared the experience of telling his family at a birthday party about his role as a co-researcher. The family members responded positively to the news. This reaction mattered a lot to this co-researcher. Other co-researchers were glad to join something so different from their usual day activities, and visiting places they had never been to before. Positive reactions from other people such as care professionals, clients, or friends boosted their self-esteem:
  "It’s nice that people come to me to ask how this interview went. You can really see me improving!" (co-researcher 6, ID)

• **Personal development and acquiring new skills**
  Another theme that came to the fore in discussions within the three research teams was acquiring new skills. Being part of the research team created a safe environment for learning new things and generating self-esteem. For example, some co-researchers carried out tasks which they had not thought they could. Co-researchers also referred to the training and interviewing skills that they learned as useful assets:
  "I learned to keep asking questions. I mustn’t impose opinions on others. I’ve stopped doing that." (co-researcher 8, ID)
  "Asking more questions than was usual for me in my network: I’ve learned from that." (co-researcher 13, OA)
  Being involved in research changed the perspectives and ideas of co-researchers about some topics. Co-researchers described examples in which they observed their environment more critically after joining the research team, in order to see what could be improved. Moreover, participation made co-researchers reflect on their own activities and work:
“It makes me more aware. What am I actually doing at the moment? And my own position to come. I can now make a decision about what I want to do in the future. I've now applied for a job with the municipality. The uncertainty has now gone. I know that I can listen properly and pay attention to the client. I've been able to do that a lot. [...] I knew I could, but now I’ve got confirmation of it from the interviews. It has made me a happier person.”
(co-researcher 1, MH)
Co-researchers also described how the research boosted their self-esteem:
“The aim was to get more self-confidence and stand up for myself better. I can do that now. I'm more self-assured. Life has become more interesting. I know a lot more now than I did at first. I can ask better questions. All because I took part.”
(Co-researcher 3, MH)
In particular in the MH team, co-researchers saw their participation as an opportunity to gain more work experience. Several co-researchers requested a job reference that they could use when applying for jobs.

Requirements for participatory research
The requirements for collaboration in participatory research were broken down into chronological order: for developing a good working environment and for the actual collaboration. These requirements were based on the perspectives of both researchers and co-researchers.

Requirements for developing a good working environment
One of the lessons learned from the collaboration was the importance of developing a good working environment. Five requirements were found to contribute to a good working environment, which are outlined below.

- Discussing reasons for engagement and wishes
Individual introductory meetings were held with clients who had shown an interest in joining the research team. Co-researchers then decided whether they really wanted to join. An introductory meeting was then organised in which all the members of each research team shared their reasons for becoming involved in the research (see previous section 1. Motivations) and shared personal information about their lives such as hobbies and interests. The research project and desired roles were also discussed. Discussing the reasons for involvement and sharing their wishes concerning the collaboration created a shared understanding of what each team member wanted to accomplish in performing the research together.
• **Formulating basic agreements**

Basic agreements were decided on jointly in each research team and written on a flip-over. Agreements were made about privacy issues, team cooperation, and the possibility to stop taking part. This resulted in four agreements:

1. *We do not talk about the shared experiences of clients in the research team. If it has no added value, we do not mention the names of clients in the research team.*
2. *Listen to the client: stop the interview when a client is too tired.*
3. *If you notice anything, tell the group. Or otherwise share it with the person involved or (researcher's name).*
4. *If you are sick or too busy with other things, sign out. You can also stop (or stop temporarily).*

We decided it would always be possible for a co-researcher to resign for personal reasons. Beforehand, the researchers expected that there was a chance that this would happen for these client groups, due to their long-term illness. In practice, the co-researchers were very often present, as they valued their participation highly. All team members tried to stay attentive about the first privacy agreement, giving feedback when anyone provided information without thinking. Co-researchers also reported at the end of the research they found it really helpful “to be honest to each other, and give your opinion.” *(Co-researcher 7, ID).* One co-researcher explained that she learned from the agreement to listen to respondents and increasingly left silences during interviews to encourage a respondent to explain more deliberately.

• **Training sessions**

A training course of at least five sessions was given to each research team to prepare co-researchers for their active involvement in applying the qualitative instruments and evaluation. The specific content of the training sessions has been added as an Appendix. The training was prepared by the researcher (AS) and partly by one trainer who was hired for training interview techniques, based on the planned research activities, lessons of previous participatory studies, and wishes of co-researchers. The meeting length was adapted to the concentration span of the co-researchers, lasting between 90 and 120 minutes. Lay language was used as much as possible.
Written information for the ID and OA teams was in a large font, in short sentences and simple language, and with more white space between the lines. If the co-researchers said they needed extra practice on some topics from the training, an extra meeting was planned. In all the teams, more time was taken to practice interviewing and using the qualitative instruments than scheduled. All team members completed the training. Afterwards, co-researchers said that the training had been really helpful in acquiring and developing the skills needed for interviewing. One co-researcher explained, “The training has helped me understand interviewing, and I also learned how to apply the knowledge. I sometimes tended to fill in a question for someone. I’ve learned not to do that, and not to draw premature conclusions by asking questions ending with ‘right?’ or ‘isn’t it?’ ” (Co-researcher 11, ID).

• **Availability researcher and travel support**
Throughout the research project, one researcher (AS) could be reached by telephone, e-mail, and text messages. After a while, the researcher became familiar with the various needs of individual co-researchers as well. At the start, the researcher (AS) reminded all co-researchers of scheduled meetings shortly beforehand. After a while, some co-researchers still needed this extra reminder whereas others were perfectly able to remember meeting dates. If necessary, a researcher helped co-researchers organise travel to all gatherings and interviews. For example, some co-researchers asked whether their care professional could also be told about the meetings so that these care professionals could arrange transport by a tax or bus or could reschedule daily activities. For another co-researcher, the researcher pre-planned the route and sent the co-researcher a link to the online routing map to help the co-researcher to cycle from his house to the meeting location. This communication helped the co-researcher “get a picture of what to expect and make clear where I would be going.” (Co-researcher 4, MH).

• **Financial appreciation**
A financial budget was available for paying co-researchers an allowance for their participation, but such an allowance was tied to national restrictions. As most co-researchers are either deemed unfit for the labour market or receiving a pension, they are receiving monthly payments from the Dutch government with a restricted maximum allowance for other activities. These co-researchers are only allowed to receive 1500 euros per year for their
volunteering work, otherwise the reimbursement will be deducted from their benefit resulting in extra bureaucracy. In addition, travel expenses normally require a receipt for the tax reimbursement. In some cases, arrangements were made to reduce this administrative burden.

**Requirements for collaboration**

Besides creating a positive working environment, good collaboration between team members was felt to be essential. Six requirements were identified that influenced actual collaboration in the teams. Each requirement is explained below.

- **Development of a bond**
  Developing a close bond between team members was very valuable for good collaboration. This required spending time together in training sessions and work meetings and constantly listening to each other. There was a gradual progression of opening up towards each other, showing our true selves, our ideas and starting to trust each other. Team members got to know the character, needs, and the strengths and pitfalls of every team member. This knowledge made fruitful collaboration possible as team members could better estimate what could be expected from each other and build enough trust to share ideas and give each other feedback.

- **Deciding on clear role division**
  Clear role divisions were agreed in the research teams. Before the start of the study, the exact division of roles was left open. Broadly, the researchers expected that the preparations would be done in partnership, with co-researchers and researchers both participating and deciding together. The co-researchers were expected to be in control when applying the qualitative instruments, while the researcher could support when necessary. For the analysis of the results, co-researchers were expected to share their experiences, to give advice and participate in the discussions of the work meetings. The final decision on the usability of the instruments would be based on the totality of the advice given by the co-researchers, experiences of respondents and experiences of care professionals. In this last phase, the researchers were expected to have more influence in the decision-making than the co-researchers, by having the overview of all evaluation material and making sure that the perspectives of other stakeholders such as professionals and respondents were taken into account.
The division of roles was in line with the broad expectations. The role splits were discussed from the beginning by the teams, and the choice to include multiple perspectives in the evaluation was discussed. Co-researchers accepted the role division and they found it quite logical that the perspectives of respondents and professionals also needed to be taken into account. There were no discussions raised by co-researchers stating that they ought to have had more influence in the research stages performed. Every co-researcher held at least 5 interviews, and they were in control while the tool was being used, as expected. One co-researcher from mental healthcare indicated however that being involved in writing the project proposal would have been of added value. Although each perspective placed its own emphasis on certain aspects, the findings of the various perspectives were mostly in accordance with each other and there were no major differences in judging the qualitative instruments.

The first author had the responsibility for the planning and communicating the training dates, work meetings and the interviews. She was also responsible for the research planning and the progress and quality of the research. Although all team members were accountable for proper collaboration, the researcher also checked whether everyone agreed about the way the research was done together, or whether friction had arisen. Co-researchers and researchers improved their skills by performing the research together and the tasks of each team member changed accordingly as the collaboration matured. For example, one co-researcher said, “At first I found it difficult to feel calm, and that made it difficult to keep my concentration during an interview. Now I can do this well, I reckon.” (Co-researcher 1, MH).

**Transparency and feedback**

A third facilitator for collaboration was clarity and openness of transparency about the preferred and possible degrees of participation on either side. Points of friction could only be recognised and discussed when both co-researchers and researchers talked about the difficulties. Feedback on what was noticed during the interviews and about each team member’s role, and discussing critical or delicate moments and reflecting on them together, were essential for good collaboration. The conversations took place directly after each interview and at the research teams’ work meetings to reflect on shared difficulties and achievements. Team members often provided useful solutions or suggestions to each other for handling specific situations. Open
communication and joint reflection require self-knowledge and generated a learning and development process that improved our research skills. The following example shows more clearly how this openness was achieved. One co-researcher in the ID team had little share in one interview, and left the questioning mainly to the other interviewer who was assisting in the interview. The available researcher suggested after a while that the co-researcher could take the leaflet with the questions from his bag as a reminder of possible questions to ask. Afterwards, the co-researcher told the researcher he did not like the fact that the researcher gave this suggestion, as he consciously had chosen to do the interview without leaflet. Thanks to this openness, the researcher and co-researcher were able to agree that the researcher would not make such suggestions in future interviews anymore, and would stick to the observation role as agreed beforehand.

- **Need for structure**
During the research, some co-researchers preferred more structure than was given in the beginning of the collaboration. Co-researchers needed a lot of flexibility for dealing with interview cancellations by respondents. The last-minute changes and the range of unexpected events were the main barrier to participation, stated the co-researchers in our research. The researcher involved in the planning (AS) learned that providing certainty, clear information and as many details as possible were very important. This issue was regularly discussed in work meetings. One co-researcher stated: "It did stress me a bit at times, though that’s partly down to me. I find it awkward if things aren’t clear when the interviews are being planned." (Co-researcher 6, ID). The researcher also communicated to co-researchers that it was sometimes difficult to give information in time when communication with a respondent was slow, or when there was a high workload in a busy week. Another co-researcher wanted to receive more information about the interview setting and the background characteristics of a respondent prior to an interview. Other uncertainties that were mentioned were unexpected violent emotions of a respondent in an interview, the unknown number of respondents attending a group interview, unexpected twists in a group conversation, and the waiting time before a respondent was able to start the interview.
• **Equal positioning**

Equal positioning was an important factor for our collaboration, i.e. letting every team member have an influence and a say in the way the research was performed. At the beginning of our cooperation, the researchers learned a lot about this aspect from one event in the MH team that caused friction when writing the invitation letter for respondents. Two co-researchers were quite critical of how the draft had been formulated and gave a lot of comments, but they did not make changes to the text themselves. One week later, the invitation as modified by the researcher did not meet the expectations of the co-researchers. In retrospect, the co-researchers explained that they were angered by a remark the researcher had made (“I'll make something out of it”) because they had worked it out in the meeting together. In the end, the team decided to plan an extra meeting to work on the invitation once more by sitting behind a laptop and writing the text together. This example was a good lesson for the researchers about creating new practices to counteract the traditional power imbalance and about the influence of the formulation and the use of an inclusive vocabulary. The skills of a researcher for equal positioning were summed up by the co-researchers of the OA team later on in the collaboration process: a researcher needs to be willing to cooperate, to be able to listen well, to let someone finish talking and not interrupt too soon, to accept opinions from others, and to be good at deliberation.

• **Sufficient time**

Time for collaboration was found to be an essential requirement of participatory research. Substantial time and effort is needed from all team members. For co-researchers, it was sometimes difficult to combine an interview with other planned activities: “When an interview is held in the evening, I’m tired afterwards. So I take that into account on beforehand, by planning fewer activities in the days before and after. I need time to process it.” (Co-researcher 8, ID). Specifically for the researcher who is in charge for the planning and coordination, substantial time was needed for planning the interviews with respondents, co-researchers and the extra supporting interviewer (as the activities and schedules of every individual needed to be taken into account). Communication with co-researchers and taking account of the individual situations of co-researchers also required substantial attention from the researcher coordinating the study.
Features of inclusive collaboration: individual contributions and team differences

Valuing contributions and differences at both the individual level and the team level was essential for achieving an inclusive collaboration. The skills and unique contributions of co-researchers and researchers and the differences between the teams are described in this section. The first and third aspects were mainly based on the experiences of researchers, as the first author cooperated in all three teams; this created the possibility of identifying personal skills and group differences. The second aspect is mainly based on the experiences of co-researchers.

Personal skills and unique contributions of co-researchers

The abilities and individual contributions of co-researchers differed a lot. In the OA team, one co-researcher was very critical of the quality of the care organisation and was very accessible when respondents wanted to share negative feedback. Another co-researcher was really up-to-date and knew exactly what was going on in the care organisation; she knew almost all the residents personally. One co-researcher put a lot of effort into inviting clients to a group meeting, for which it was hard to attract clients. The co-researcher “saved” the group meeting by making multiple individual invitation rounds of possible respondents in his wheelchair. Thanks to the efforts of this co-researcher, enough clients attended the group meeting in the end.

In the MH team, one co-researcher was a really quick reader and remembered the structure very easily. She therefore did not have to look closely at the written interview instructions. Another co-researcher already had experience with group conversations with clients, and she had exceptional interviewing skills. She therefore supported the ID team in their interviews by summarising, making notes and asking probing questions. Two other co-researchers independently decided to rewrite and summarise the original group interview instructions in their own words before their first focus group meeting. Afterwards, they were able to moderate the group discussions in a natural and personal way.

In the ID team, one co-researcher had a calm presence that let respondents feel at ease, but he asked probing questions less often. Another co-researcher formulated many of her own questions, was really good at holding on to the interview structure, and at providing extra explanations or examples for a question when a client did not understand it.
At the same time, there were also co-researchers who did not have a particular competency that stood out. This was especially visible when a co-researcher with less interviewing competencies interviewed a very strong client who was a quick thinker and talker. While the personal competences of some co-researchers did not stand out in terms of the value for the research itself, the personal value of participation seemed as high to them as to the others. The opportunity to contribute was also very important to them. For example, the care professional of one co-researcher told the researcher that they had spoken with pride about their experiences as a co-researcher, and the added value of their contributions to other clients.

**Abilities and contributions of the researchers**

According to the co-researchers, the key ability for researchers was being able to support co-researchers in fulfilling their tasks. Before applying an instrument, the researchers helped co-researchers prepare by reading the structure together, practising the introduction of the method together, and appraising the abilities of co-researchers. After each interview, the researchers and co-researchers took time to evaluate the interview together. Researchers always gave compliments and also shared one learning point the co-researcher could work on. The co-researchers felt it was important that the researchers were not too critical. Correspondingly, the researchers always tried to let co-researchers go home with a good feeling about their contribution. In this sense, the role of researchers could be described as coaching. Other abilities of researchers, mentioned by co-researchers, were: being easily accessible by telephone, having personal interest in co-researchers and willing to show their own personality in the collaboration.

**Team differences**

The three research teams differed a lot. In the OA team, co-researchers often related the stories they heard to their own experiences and values. This was specifically the case when their views on the interview outcomes were asked. The co-researchers were less used to abstract thinking and tended to use more common ground with their own experiences. Moreover, the cooperation and observations gradually showed (in the case of the majority of the research team) that co-researchers did learn interviewing skills less quickly, such as asking open and non-directive questions. But even after several interviews, their interviewing skills remained closer to their level at the start of the study. In the MH team, co-researchers were better able to
make the distinction between research findings and personal experiences, and were quick learners and very self-reflective. They were capable of being openly critical on several aspects, regardless of the opinions of other members of the research team, including the researchers. Co-researchers had a clear picture of participation possibilities, other than conducting the research itself. In the ID team, the ability to keep their own experiential knowledge aside was also apparent, and they were non-directive in their method of interviewing after the training. However, deeper reflections were difficult for some co-researchers, while other co-researchers could also reflect on their own role and the interview results. The ID co-researchers evaluated their roles very optimistically, without a critical attitude. These co-researchers had neither the desire nor the abilities to interview independently.

Given the team differences, different kinds of support had to be provided for holding the interviews and focus groups. On the whole, the teams agreed that every co-researcher would do one interview a day. The only deviation from this general rule was when a co-researcher wanted to try two interviews consecutively. In the MH research team, co-researchers decided to perform two qualitative instruments without extra assistance. In the ID team, an experienced co-researcher or professional interviewer assisted the co-researchers in all interviews by asking probing questions, summarising and writing answers. The OA research team held all the interviews for one qualitative instrument in cooperation with care professionals, whereas the design of the second instrument seemed easier and the team decided that co-researchers could conduct these interviews without assistance. During the interviews for the second instrument, the team found out together that the design alone did not provide sufficient support for co-researchers. The researcher, who was present for observing the interviews, stepped away from the observation role by helping and supporting co-researchers several times in interviews. In the evaluation, interviewing assistance was subsequently added as a condition for the application of this instrument.
Table 6.4  Summary of study findings and lessons learned from this participatory research

<table>
<thead>
<tr>
<th>Co-researcher level</th>
<th>Researcher level</th>
<th>Process level</th>
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<tbody>
<tr>
<td><strong>Facilitators</strong></td>
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<tr>
<td>- Individual preparation: reading the instructions, practising asking probing questions, repeating the introduction, reflecting on past interviews.</td>
<td>- Supportive attitude: support when necessary, increasing self-confidence of co-researchers, backup.</td>
<td>- Discussing reasons for engagement and sharing wishes for collaboration: this created a shared understanding of what each team member wanted to accomplish in the research.</td>
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<tr>
<td>- Being motivated for one or more of the following reasons: being committed to quality improvement, being valuable to other clients, being part of a social group, creating a new social identity, or personal development and acquiring new skills, wanting to spend time.</td>
<td>- Coordination and communication: inform co-researchers on time about the day and time an interview is planned, know what to expect, preparation of team meetings by researcher.</td>
<td>- Formulation of basic agreements: i.e. privacy issues, team cooperation and the possibility of cancelling attendance.</td>
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<tr>
<td>- Becoming experienced: doing research activities more often makes it easier.</td>
<td>- Motivated for participatory research.</td>
<td>- Training: learning to ask probing questions, learning to listen openly, practise in a realistic setting, written information in a small booklet.</td>
</tr>
<tr>
<td>- Discussing reasons for engagement and sharing wishes for collaboration: this created a shared understanding of what each team member wanted to accomplish in the research.</td>
<td>- Preparation right before the interview: Preparing the interview together: what are we going to do? Practising the introduction to an interview.</td>
<td>- Debriefing right after the interview: complimenting each other, giving suggestions, and sharing what went well, what could have gone better. Discussing the report notes of a co-researcher.</td>
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<tr>
<td>- Formulation of basic agreements: i.e. privacy issues, team cooperation and the possibility of cancelling attendance.</td>
<td>- Collaboration in team: being part of a team, joint meetings, good atmosphere, development of a bond, transparency and providing feedback, support of the team, sociability, good communication.</td>
<td>- Practice in a realistic setting: written information in a small booklet.</td>
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### Barriers

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<th>Co-researcher level</th>
<th>Researcher level</th>
<th>Process level</th>
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<tr>
<td><strong>Limited energy:</strong> interviews sometimes took a lot of energy, and a lot of stuff to think about. Schedule extra rest moments and plan one interview for one day.</td>
<td><strong>Permanent availability for questions and travel support when needed:</strong> sometimes it was not possible to answer the telephone during another interview.</td>
<td>Ambient soundings and stimuli during an interview, for example when a respondent chose an interview setting outdoors.</td>
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<tr>
<td><strong>Being a perfectionist:</strong> set too high goals for yourself, becoming too nervous.</td>
<td><strong>Coordination and collaboration takes substantial time</strong></td>
<td><strong>Clarity on preferences versus flexibility needed:</strong> interviews took place at various times which needed a lot of flexibility from co-researchers, whereas they preferred clarity beforehand, as early as possible. Some co-researchers preferred more structure.</td>
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<td><strong>Writing a report afterwards:</strong> not motivated enough to write a report of the interview directly afterwards.</td>
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<td><strong>Poor health and bad hearing:</strong> specifically in the OA team) bad hearing or poor physical health.</td>
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### Requirements for participation

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<th>Researcher level</th>
<th>Process level</th>
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<tr>
<td><strong>Knowing clients of the care residence:</strong> this makes inviting respondents easier.</td>
<td><strong>Motivation and skills for equal collaboration:</strong> willing to work with co-researchers, able to listen well, let the co-researcher have their say without interrupting, accepting opposite opinions of co-researchers, good in deliberation and open attitude in discussing themes.</td>
<td><strong>Proper training:</strong> practising together, getting to know the subject and each other.</td>
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<tr>
<td><strong>Motivation and skills:</strong> Co-researchers need to be motivated for collaboration and quality improvement, have people knowledge, be social, good communication and listening skills, be enthusiastic, be interested in others, be healthy, able to hear, open to others.</td>
<td></td>
<td><strong>Coordination:</strong> one person needs to be responsible for planning the interviews, for logistics, and for keeping an overview on the activities.</td>
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<td><strong>Courage:</strong> Be brave, willing to overcome limitations.</td>
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<td><strong>Financial appreciation for the time invested by co-researchers and a travel allowance:</strong> Pay attention to national restrictions for co-researchers receiving a pension or welfare benefit.</td>
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<tr>
<td><strong>Relax:</strong> try to stay calm and &quot;remember to keep breathing in and out&quot;.</td>
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<td><strong>Support in the care organisation at the management level:</strong> Help in recruiting respondents and informing care professionals.</td>
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### Process level

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| | | **Good collaboration:** team members fit in the team.
6.4 Discussion

This chapter describes lessons learned in the process of working with co-researchers in long-term care by reflecting on the process of participation and collaboration in participatory research. We tried to create insight into what helped and hindered co-researchers in making significant contributions. The motivations of co-researchers ranged from individual goals – such as personal development, creating a new social identity and belonging to a social group – to more external goals, such as being valuable for other clients and increasing the quality of care. Our research derived eleven requirements for participatory research for developing a good working environment and achieving a good collaboration. Moreover, an inclusive collaboration requires valuing the individual contributions of co-researchers and adjustment to team differences.

Several recent studies provide insight into participatory research with co-researchers of one specific client-group (13, 14, 26). The present study evaluated collaboration with co-researchers in various long-term care settings, in order to report on lessons learned for future research. Due to the great emphasis attached to client participation recently, care organisations are expected to involve clients increasingly in quality improvement. These care organisations can do so by starting with small local initiatives for client participation in long-term care with those clients who can be easily involved. Researchers and employees of care organisations can use the findings reported in this study to design and shape inclusive future research and quality improvement projects, if they are willing to start a participatory study themselves in long-term care.

From the perspective of the researchers, individual and team contributions were worthwhile for the quality of the study, as illustrated by the wide range of contributions made by co-researchers during the study. As was shown by the motivations of co-researchers, they attached great personal value to the collaboration, corresponding to the ontological argument for participatory research that clients have the democratic right to be involved. Once co-researchers learned interviewing skills and grew in their role, they were very much willing and able to perform a variety of tasks. The fact that no co-researchers quit the collaboration during the performance of the instruments showed the high motivation of co-researchers, as did the appraisal co-researchers assigned to their roles. Their continued involvement could also be interpreted as a sign that the coordination and collaboration
were carried out in such a way that co-researchers felt respected and appreciated, and that team members were well able to resolve the points of friction encountered during the collaboration, such as the need for structure. Taking account of the benefits and added value of client participation, there are also some major demands and substantial efforts required when considering starting a participatory study in long-term care. In line with earlier research (15, 28), this study shows that participatory research is time-consuming and labour-intensive. Although research skills can be learned and used by co-researchers, coordinating and assistance remain essential and is dynamic and rather complex. In order to prepare co-researchers properly, it is worthwhile to discuss the flexibility needed for performing research on beforehand. By overcoming these complexities of participatory research could be valuable in improving quality of care using co-researchers who represent the client perspective.

Furthermore, in line with previous studies (7, 21), this study shows the diversity of long-term care clients, both within and between the three research teams. Three cases in different long-term care settings were selected to strive for maximum variation to be able to look into variations within- and between teams. The roles and task divisions were set up together in the teams in order to include the various voices of co-researchers with different strengths. This not only let the most literate clients join the research teams, but also involved a wider variety of co-researchers. The consequence of this recruitment approach was that not all co-researchers had or needed to have a particular competency that stood out. The personal value of participating was felt to be as high for these co-researchers as for the others. A recommendation for future study is to weigh up the democratic right to become involved in research and the minimum competencies needed for a particular study prior to recruiting co-researchers for participation in the study. As Bindels (2014) points out, ongoing reflection and room for change is needed as there is no single perfect collaborative method that applies to all co-researchers. Neither should every person necessarily be involved as a co-researcher (14). Different methods and levels of client participation can be useful for achieving person-centred care in long-term care, depending on the content and goals of a participatory study (41). A related issue was that, similar to other participatory studies, co-researchers chose roles that were meaningful to them and mutually beneficial to the group, without pressure to participate in tasks that have little meaning to them such as academic writing (15). The motivation and willingness of one co-researcher to be
involved writing the academic article, is an example of how each co-researchers used their own competences and interests in their contribution. In the current study, some co-researchers, especially of the MH team, had exceptional interviewing skills. These co-researchers started to assist co-researchers of the other teams with the interviews. The question could perhaps be raised of whether these highly competent co-researchers from the MH team could conduct all the interviews, including the interviews for the other client-groups. Although this would have been practically beneficial, our study indicated the opposite based on two observations. Firstly, respondents could recognise themselves better in a co-researcher with the same care needs. This central characteristic would be lost if a MH co-researcher performed all the interviews individually. Secondly, the co-researchers of the MH team repeatedly showed a lack of knowledge of the specific situations and contexts of the other client groups, sometimes resulting in a lack of empathy for a client situation or an awkward moment. Including co-researchers with diverse backgrounds as representatives of different client groups therefore remains fundamental: as interviewing skills alone are not enough.

**Methodological considerations**

Some strengths and limitations can be identified in this study. A strength was that competences and contributions of both co-researchers and researchers were included, as both were needed to achieve an effective and fruitful collaboration. From our perspective, it is not possible to provide a complete picture of our collaboration by focusing on the value and contribution of co-researchers alone, as one of the two parties will then not be described (7, 29). Partnerships need to be reciprocal and all aspects of participatory research – from the initial training to the manner of reflecting together and reporting the findings – should contribute to this reciprocity (19). In line with this, explicitly including both the co-researchers’ and researchers’ perspectives in this manuscript could be seen as a strength. At the same time, it means that the article was written based on our own reflections on the collaboration from an insider’s perspective. As is outlined in other research, this could be seen as both a strength and a limitation at the same time (3). One limitation of the convenience sample in forming the teams is the limited possibility for making clear distinctions between the research teams that represent three client groups of long-term care within the teams. It is for instance not possible to draw conclusions on the differences between the motivations for
collaboration between the three teams as if they were typical for the distinct client-groups. With regard to abilities, there were clear differences visible between the three research teams, but other co-researchers from other client groups may show other specific strengths and capacities in future research. This has implications for the limited generalisability of the findings related to client group differences. Another limitation was that the co-researchers and researchers were included after the research proposal had been submitted and approved. Although a lot of details were left open in the proposal (choice of qualitative instruments, content of qualitative instruments, distribution of roles), this created a power and information imbalance at the beginning of the research project, resulting in less decision-making space with regard to the main goals and focus of the research project (14).

Several topics for future work arise from this study. As the current study described the collaboration in three research teams, more good practices could further increase the accumulation of knowledge about the opportunities and barriers in participatory research focused on people with intellectual disabilities, older adults and people with mental health issues. This means it would be relevant to focus on developing research skills and contributions of co-researchers in long-term research projects, thus creating insights into the learning curves and the skills of long-term care client groups. Moreover, it would be interesting to study whether care professionals are open to this new acquired role in quality improvement, and whether they are willing to reflect on the findings brought to the fore by co-researchers and if they could respect their position as equals.

### 6.5 Conclusion

This case study describes the lessons learned from the collaboration and participation of co-researchers and researchers in three research teams in long-term care. The results show the importance of developing a good working environment, the collaboration, taking individual and team differences into account, and the importance of coordination and support by a researcher or coordinator for establishing a good collaboration. The findings of the collaboration in the three research teams are deemed to be useful for researchers wanting to design and shape future participatory research projects in long-term care.
Take away points

- Developing a good working environment and achieving a good collaboration were essential for a meaningful collaboration in participatory research. This can be achieved by meeting requirements such as formulating basic agreements, deciding on a clear role division and transparency and feedback.

- There is a great diversity among long-term care clients, both within and between the three client-groups. In participatory research, researchers and co-researchers together need to decide on the roles and task divisions to include the various qualities and input of co-researchers with different strengths.

- Co-researchers have both personal motivations for participation, such as acquiring new skills, and external motivations, such as being of worth to other clients and commitment to quality improvement.
Literature


34. Schramm W. Notes on Case Studies of Instructional Media Projects. 1971.


## Appendix  
### Contents of each training session

<table>
<thead>
<tr>
<th>Training session</th>
<th>Content of the session</th>
</tr>
</thead>
</table>
| 1 (introductory meeting) | Team members introduce themselves by using association cards  
Discussing the content, aims and need for the research (i.e. added value of client participation and evaluating the quality of a care relationship)  
Sharing motivations for becoming involved  
Formulating basic agreements for cooperation  
Exchanging personal information for getting in contact and paying remunerations |
| 2 | Discussing research activities and role preferences  
Drawing up the invitation letter for respondents  
Modifying the content of the qualitative instruments: open or semi-structured questions |
| 3 | Training in individual interviewing techniques  
- asking open questions and multiple choice questions  
- techniques for encouraging a respondent to tell more  
- summarising  
Learning to present the research to respondents  
Completing an interview |
| 4 | Training in group interview techniques (optional)  
- asking open questions and multiple choice questions  
- learning to deal with group dynamics  
Practising observing nonverbal information such as emotions |
| 5 | Specific training sessions in applying one qualitative instrument, concerning individual interview and/or group interview techniques. |
Chapter 7

Summary and general discussion
A high-quality care relationship is one of the foundations of the process of providing appropriate long-term care, as it is related to the quality of the care provided as experienced by clients (1-4). Clients say their satisfaction with care is greater when the quality of the relationships is high (5-7). Furthermore, the quality and continuity of care relationships also affect the technical care the clients receive (5). Specifically for clients receiving long-term care, these relationships are seen as important due to the lengthy need and dependency on care. However, the quality of care relationships is not yet always optimum (8,9,4).

The main objective of this dissertation was to develop qualitative instruments for determining and improving the quality of care relationships in long-term care from the clients’ perspective, with active involvement of clients as the co-researchers applying these qualitative instruments. This dissertation focused on the three largest client groups receiving long-term care, i.e. people with an intellectual disability, with a mental illness, or those who are physically or mentally frail due to advanced age. Long-term care is provided by several types of professionals, such as nurses, care assistants and personal assistants.

Three research questions were answered in this thesis:

1. What are the determinants of the quality of a care relationship in long-term care for the various client groups, according to both clients and care professionals?
2. What qualitative instruments can be used by co-researchers for measuring the quality of the relationship between clients and care professionals from a client’s perspective across client-groups in long-term care?
3. What lessons can be learned from our collaboration with clients involved as co-researchers in three participatory teams in long-term care?

### 7.1 Summary of the main findings

The following section gives a short summary of the findings from answering the three main research questions.

1. What are the determinants of the quality of a care relationship in long-term care for the various client groups, according to both clients and care professionals?
As it was not yet clear what benefits or diminishes the experienced quality of care relationships, more evidence was needed about the factors determining the quality of a care relationship. It was also unknown whether the determinants are unique to specific client groups, or common to all. A systematic literature review and a qualitative study were set up to provide a clear picture of the determinants of the quality of care relationships in long-term care. The systematic review provided an overview of determinants of the quality of care relationships in long-term care based on 32 (mostly qualitative) studies. Studies focusing on people with intellectual disabilities were scarce, resulting in fewer findings for this client group. The findings of the empirical qualitative study were based on 30 interviews with clients and 4 focus groups with a total of 29 professionals.

In both studies, the determinants were categorised at four levels: client, professional, between client and professional, and contextual. The levels represent the influence of various actors on the quality of care relationships. Both studies resulted in a large number of determinants, reflecting the dynamic and multi-layered nature of the quality of care relationships (see table 7.1).

Based on both the review and qualitative study, the following determinants were found important for the care relationship. A client determines the quality of care relationships by adopting a certain attitude (e.g. openness), by their own capabilities, and by strategically adapting their behaviour to the current position of the professional. A professional determines the quality of a relationship by focusing on the needs and wishes of an individual client, listening to them, encouraging them, being available and dependable, showing empathy, by providing support and using their own professional competences. In the interaction between a client and a professional, trust, equality and closeness versus professional distance came forward as determining factors for care relationships. At a more contextual level, continuity and time (of lack thereof) and financial budgets (or limitations on them) can influence the quality of care relationships.
<table>
<thead>
<tr>
<th>Client level</th>
<th>Professional level</th>
<th>Interaction between client and care professional level</th>
<th>Context level</th>
</tr>
</thead>
<tbody>
<tr>
<td>- open - attitude</td>
<td>Focus on the individual client</td>
<td>Equality</td>
<td>Continuity ¹</td>
</tr>
<tr>
<td>Client in lead / self-determination</td>
<td>Availability / take time</td>
<td>Closeness versus professional distance</td>
<td>Time / lack of time and limited financial budget</td>
</tr>
<tr>
<td>Strategic adapting behaviour</td>
<td>Listen</td>
<td>Trust</td>
<td></td>
</tr>
<tr>
<td>(Cognitive) capabilities</td>
<td>Encouragement</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Professional competences</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Emotional investment / support</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Empathy</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dependability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review &amp; qualitative study</td>
<td>Previous life experiences *</td>
<td>Attitude</td>
<td>Reciprocity</td>
</tr>
<tr>
<td></td>
<td>Emotional state *</td>
<td>Extra effort</td>
<td>Social interaction</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Working in a team *</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Task-centred *</td>
<td></td>
</tr>
<tr>
<td>Qualitative study</td>
<td>Help request</td>
<td>Conduct</td>
<td>Relationship building</td>
</tr>
<tr>
<td></td>
<td>Feedback supply</td>
<td>Characteristics of the professional</td>
<td>Match</td>
</tr>
<tr>
<td></td>
<td>Respect</td>
<td>Privacy and confidentiality</td>
<td>Humour *</td>
</tr>
<tr>
<td></td>
<td>Function of the relationship *</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* determinant was found for one or two client groups only.

¹ The determinant ‘Continuity’ was categorised in the systematic review at the interaction level.
Some new determinants were found in the qualitative study, on top of the determinants from the systematic review. At the client level, the determinants ‘help request’, ‘respect’ and ‘feedback supply’ came forward in all three client groups. At the professional level, conduct, characteristics of the professional and the determinant ‘privacy & confidentiality’ were added. ‘Relationship building’ and ‘match’ came forward at the level of interaction between the client and care professional. At the contextual level, ‘facilities’ was added as a new generic determinant for all three client groups, and ‘support from management’ and ‘limitation by laws and regulations’ came to the fore in two client groups.

Substantial overlap was found between the determinants of the quality of care relationships for the client groups in both studies, as well as determinants that came forward in one study only. This finding suggests that research focused on long-term care relationships can include multiple client groups at the same time.

2. What qualitative instruments can be used by co-researchers for monitoring the relationship between clients and care professionals from a client’s perspective across client-groups in long-term care?

For a process evaluation, five qualitative instruments for assessing the quality of care relationships in long-term care were applied by co-researchers. For each client group, two previously developed instruments were selected in a Delphi study by stakeholders (e.g. representatives of care providers and branch organisations, co-researchers, client or client council organisations with a nationwide scope and care organisations) and adjusted for evaluating the quality of care relationships. The qualitative instruments were evaluated on two core aspects: feasibility of the instrument and usability of the instrument outcomes. In each client group, two instruments were first evaluated. The three instruments that scored highest on feasibility and usability were then cross-tested in the other two client groups to examine whether these instruments could be applied in the other two client groups as well. Co-researchers applied the instruments by interviewing clients independently or with assistance of a supporting interviewer. The evaluation data comprised observations by researchers and the perceptions of the co-researchers, clients and care professionals involved.

The two qualitative instruments “WIEK interview” and “Participatory Narrative Inquiry” came forward as the most promising instruments, and
could both be applied by co-researchers in all three long-term care client
groups. Both interview instruments have a clear and easy structure, an open
and in-depth approach to questioning the client’s experiences, and an easily
accessible individual interview setting.

The WIEK interview focuses on evaluating the quality of an individual
care relationship. Clients are invited to choose two theme cards out of ten to
discuss and focus on during the interview. The results of the WIEK
instrument provide insights into the experiences of clients with a particular
care professional and the areas of improvement that it identifies can be used
for working on this individual care relationship. The individual interview
method made the WIEK instrument individually adaptable and therefore
applicable for the three client groups. Clients found the WIEK theme cards
attractive and clear when choosing the topics to discuss; at the same time, the
cards helped the co-researchers in asking questions about the topics chosen
by a client.

Participatory Narrative Inquiry, on the other hand, provides a collection
of anonymous stories that reveal areas for improvement that are informative
for a wider group of care professionals. The combination of individual
interviews and a story meeting allowed different client groups to participate.
As the theme of the interview was left open, clients could choose which
experiences they wanted to share. Due to the anonymous nature of the
experiences collected, the results are useful for reflection and learning by a
large group of employees of a care organisation.

3. What lessons can be learned from our collaboration with clients involved
as co-researchers in three participatory teams in long-term care?

Although clients receiving long-term care have become more actively
involved over recent decades in research and quality improvement through
adopting a role as co-researchers, more practical knowledge is needed about
how participatory research can best be designed and carried out. A multiple
case study design was chosen to explore the collaboration in three research
teams, consisting of two researchers and co-researchers from one specific
client group receiving long-term care. A suitable working environment and
good collaboration were seen as the two crucial elements for participatory
research. Five requirements were found for setting up a good working
environment at the start: 1) discussing co-researchers’ wishes and their
reasons for engagement, 2) formulating basic agreements for cooperation at
Six requirements were identified that influenced the actual collaboration during the research: 1) development of a bond between team members, 2) a clear role division between co-researchers and researchers, 3) transparency and room for feedback, 4) a need for structure, 5) equal positioning, and 6) sufficient time for planning and communication while applying the instrument.

The study revealed large differences in the abilities and support needs between co-researchers from the various client groups. In the mental health research team, co-researchers were very self-reflective and some co-researchers had well-developed interview skills based on their work as experts by experience. These co-researchers helped their counterparts in the other research teams by providing interview assistance. In the intellectual disability team, co-researchers evaluated their roles very optimistically but had neither the desire nor the ability to hold interviews independently. In the older adults team, co-researchers often related the stories they heard to their own experiences and values. The co-researchers were pleased with the help of the interview supporters in asking open and non-directive questions. Co-researchers could choose roles that were meaningful to them and they received the backing they needed from the researcher and supporting interviewer to perform their roles well. The assistance provided was the result of a continual process of alignment and therefore differed between individual co-researchers and teams, and sometimes changed gradually over time as well. Regarding the motivations of co-researchers, it appeared that they attached great personal value to the collaboration, corresponding to the ontological argument for participatory research that clients have the democratic right to be involved.

### 7.2 General discussion

The general discussion is divided into various parts. First, there is a description of what the thesis contributes. There is then further detail addressing long-term care relationships, the active role of clients as co-researchers, the evaluation of qualitative instruments, and future implementation of the instruments. Methodological reflections are subsequently given regarding the designs of the studies carried out and the start, 3) training in open interview techniques, 4) availability of the researcher and travel support, and 5) financial appreciation.
described in this thesis. Suggestions for future research and implications for long-term care practice are presented at the end of the discussion.

**Contribution of the thesis**

This thesis contributes to scientific literature and clinical practice in multiple ways. Firstly, this is the first study that provides a comprehensive and systematic overview of the determinants of the quality of care relationships in long-term care. Bringing together the findings of the relevant studies that have been published has produced a synopsis of determinants associated with the quality of care relationships. This overview shows the relevant determinants for care professionals and gives academics a baseline for their studies in the future. Moreover, the systematic review findings were subsequently confirmed and supplemented in a qualitative study, for example by including new determinants concerning the influence of clients.

Secondly, the thesis is unique as it included three distinct long-term care settings in which the overlap and differences in determinants of the quality of care relationships were studied. There appeared to be a lot of determinants that were common to all the care settings included. This finding implies that there is no need for a focus that is specific to the client group when studying the quality of care relationships. For both clinical and scientific practice, multiple client groups can be included when studying or evaluating the quality of care relationships in long-term care.

Thirdly, the most relevant determinants described in the systematic review and qualitative study were used to formulate questions for adapting existing qualitative instruments for evaluating the quality of care relationships to let them be used by co-researchers. Five qualitative tools were (re)developed and adjusted based on the findings of the systematic review and qualitative study. The qualitative instruments were assessed to find out which instrument was the most feasible and useful for letting care professionals and clients work on the areas of improvement found regarding care relationships. This step of developing and evaluating qualitative instruments for practical use will help use the study findings in practice and is likely to facilitate change.

Fourthly, another asset of this thesis is the participatory approach and the active contribution of clients as co-researchers. Only a small number of studies were available in which clients were actively involved in long-term care quality research or improvement initiatives (10-14). Of these, only one actively involved clients as interviewers in open or semi-structured
interviews with clients, in addition to making observations (10). The other studies were about quality improvement groups or steering groups, and structured interviewing with questionnaires (11-14). Collaboration of clients in research teams led to a more complete understanding of whether and how clients could be actively involved in activities such as preparations and interviewing in quality improvement research. The two selected interviewing instruments (“WIEK interview” and “Participatory Narrative Inquiry”) can be carried out by co-researchers to measure and improve the quality of care relationships in a care organisation. Co-researchers stated that they were not only getting involved due to their commitment to quality improvement but also because they were motivated by being valuable to other clients, becoming part of a social group, creating a new social identity, and being able to work on their own personal development.

**Care relationships in long-term care**

This thesis categorised the determinants of the quality of care relationships in four levels that will be explained further in the paragraphs below.

Table 7.1 gives an overview of the determinants resulting from the systematic review and the qualitative study. The results of the qualitative study confirmed the results of the systematic review and at the same time led to new insights as new determinants came forward due to the explorative nature of the qualitative study. Similarly, some determinants were described differently in the qualitative study, as another formulation fitted better with the vocabulary and experiences of co-researchers and respondents. For example, the determinant “Client in the lead” was called “Self-determination” in the qualitative study.

Determinants of the quality of care relationships at the client level included an open attitude, strategic adapting behaviour, self-determination (or ‘client in the lead’) and the abilities of clients. Interestingly, the systematic review findings show, in terms of both the amount and the frequency of determinants described, that the responsibility of care professionals for care relationships is more often emphasised and described in the literature than the responsibility of clients. This could be related to the inherently asymmetrical positioning of clients towards professionals in care relationships due to their care and support needs (15). Determinants that came forward in the qualitative study such as help requests, respect and feedback underline the skills that clients need in order to have their say and thereby influence the quality of care relationships. The determinants
operating between the client and the professional – such as equality, reciprocity, trust and social interaction – show once more that care relationships are formed and maintained by both parties. So relationships between professionals and clients must be acknowledged as mutually beneficial and grounded in the belief that the patient’s role is also equally influential (16).

Care relationships are established in an individually variable and dynamic way. Some clients may be more in favour of a personal, friendship-like and close relationship with a care professional, whereas others may prefer a more professional stance and a functional, task-centred relationship. Care relationship types may also differ due to the specific aims of a care relationship, from therapeutic to amusing and friendly. The term ‘meaningful relationship’ may fit this diversity well, as the interpretation of ‘meaningful’ depends on what is best suited for a particular client (17).

Some competences and characteristics of professionals came to the fore in both the systematic review and the qualitative study as determining the quality of care relationships, e.g. encouragement, listening, availability, focus on the individual client, trustworthiness, empathy and technical competences. From a moral point of view, these competences and characteristics illustrate what it means to ‘be a good care professional’. It has been suggested that the standard opening question of a care professional “How are you?” should be redefined in terms of “Who are you?” This question lets care professionals create more space for clients to tell stories, in turn letting professionals gather information about a client’s personality and priorities (18). A care professional should be open towards the client to understand their needs (19), to step away from the expert role in terms of directly deciding themselves what is best for a client (18). It problematizes the balance between what is done (technical care and evidence-based methods) and how it is done (based on an evolving care relationship)(20). Because the quality of a care relationship is a precondition for high-quality technical care and thorough use of evidence-based methods, it is important to spend time on developing and maintaining care relationships.

The most ideal picture is that a care relationship between client and professional has time to develop in order to achieve a trusting care relationship. In reality, however, the development and continuation of care relationships are restricted by rotating shifts of professionals, limited time for relationship-building, changing work schedules, job changes and care professionals dropping outs due to the work burden. These organisational
barriers at the contextual level were identified not only in the qualitative study but also by earlier studies; they affect care relationships negatively (21-26). The influence of contextual factors confirms that care relationships are multi-layered rather than just an individual matter between one client and one professional.

**Active role of clients in research and quality improvement**

The current study focused on instruments in which co-researchers have an active role as interviewers. Arnstein's (1969) ladder of participation is a well-known conceptualisation of variations in participation 'levels'. The ladder distinguishes five levels of participation, ranging from informing to citizen control (27). In the current study, the main role of co-researchers in conducting the research was in collaboration or partnership with researchers. The position of the co-researchers was not privileged or subordinate but equal (28) (29). Although Arnstein’s ladder is useful for a researcher at the start of a study to reflect on the desired levels of participation, it is also an oversimplification of reality (30). The ladder was found to be less useful during our study for reflecting on the role division within the teams, as the collaboration did not fit neatly into the levels and was more fluidly constructed. An extensive description of the collaboration in the three teams (serving as cases) and the conditions and requirements which are needed does more justice to the reality.

Three advantages of participatory research that were most frequently mentioned in the literature are examined in more detail here. Regarding the content of the study, the research is expected to better reflect clients’ ideas and priorities and as such enhances the validity (content validity) and relevance (30-33). During the study, the additional value of collaborating with co-researchers regarding the content was shown in the direct contact with clients, as clients found it easier to open up and tell their stories to someone who had experienced long-term care themselves. Furthermore, the interpretation of client experiences was valuable, as co-researchers noticed various aspects in the answers and asked probing questions about these issues, which would not always have been noticed by a researcher or care professional. Because the co-researchers were formulating the questions themselves, the vocabulary used matched well with the vocabulary of clients.

A second advantage of participatory research is that the active role of co-researchers is expected to enhance the support for the findings (30, 31). During the evaluation of our study, professionals and co-researchers noted...
that care professionals backed the findings and were willing to work on the areas for improvement highlighted by the qualitative instruments.

Thirdly, the ontological and normative advantage of participatory research concerns the rights of clients to influence decisions regarding their lives and their care (30, 32, 34). Given that clients depend on care for a long time, participation in research may be an opportunity to construct a positive social identity, increase self-esteem and work empowering (35, 36). In the work meetings, co-researchers said their self-esteem increased and they got an impression that they made useful contributions. Furthermore, joining the research team presented possibilities for co-researchers to create new social roles and a new social identity. Co-researchers also acquired new interviewing skills and acquired new work experience. The active role of co-researchers in the application of the qualitative instruments may perhaps have had advantages for clients, as co-researchers could serve as exemplary role models. The client involvement might have had advantages for the organisational culture within the care organisation as well, as it could generate a shift in power relationships in practice. This was however outside the scope of the study.

When quality improvement instruments are applied by co-researchers, attention shifts from the purpose of the activities to the process of co-researchers collecting the quality information. In conventional quality improvement and broader research methods, the process of data collection is of course seen as essential to the validity and reliability of the final results. Participatory research is more characterised by the process of creating a good working environment and meaningful collaboration, and safeguarding the quality of the findings by providing good support and training to co-researchers. At the start of the study, each research team made some basic agreements about privacy issues, team cooperation and the possibility of stopping taking part. In work meetings, the research teams reflected on privacy and confidentiality issues as well. Difficulties co-researchers encountered in interviews were also discussed, for example when a client became very emotional or when co-researchers became emotional themselves. Moreover, the coordinating researcher needed the soft skills for building up collegial bonds and providing support when needed, and had to be able to recognise the value of an active role of co-researchers in quality measurement.

Not only the most literate clients joined the research teams as co-researchers, but a diversity of co-researchers participated. The variations
between co-researchers were demonstrated in the ability of some co-researchers to interview clients independently while others needed more support, the number and usefulness of the ideas a co-researcher shared in the work meetings, and the amount of self-reflection. The roles and task divisions were set up together in the teams in order to include the voices of various co-researchers with differing strong points. A consequence of the diversity among co-researchers was that not all co-researchers had or needed to have a particular competency that stood out and all contributions were valued equally. It is worth noting that the personal value of participating was felt to be high by all co-researchers. Prior to the application of the qualitative instruments, the care organisation employees and client councils involved have to decide who will be asked to join the team. The support required might subsequently differ as a result. Sometimes only the more vital and educated clients were involved (see (28) for an example).

In the current study, co-researchers who participated had ‘expert experience’ by virtue of intellectual disability, mental illness, or physical or mental frailty due to advanced age. The current collaboration strategy fitted well with these different types of co-researchers, as individual variation, support needs and capabilities were taken into account. Frankena et al. stated that there are a lot of similarities in participatory research with varying client groups: “Overall, there appear to be more similarities than differences between participatory research in varying groups. Similar to the need for tailoring found in this thesis, attention must be paid to the unique features of all those involved in participatory research, whether they are people with ID, people with mental health issues, or older persons” (37). In line with Frankena et al., the current participatory study also underlines the importance of embracing individual variation and adjusting the support needs to the abilities and wishes of individual co-researchers, as there is so much diversity among co-researchers in terms of capabilities, needs and wishes.

A previous study describing a responsive evaluation carried out by researchers and older people involved as co-researchers underlined the fact that co-researchers need time to feel comfortable enough to share their experiential knowledge in the research team (38). This is in line with the findings of our study; co-researchers developed over time and creating a safe working environment was an essential precondition for our collaboration in research teams. Prolonging the collaboration is preferable in order to maximise the benefits for both the content and the co-researchers and
researchers involved. For example, the same co-researchers could use the instrument within a single care organisation periodically for a longer period of time. In addition to prolonging the learning processes and deepening the collaborative bonds, it would make it easier to start a project more inclusively, by designing the project together from the start. At the same time, the health situation of co-researchers remains vulnerable, so it could also be possible that some co-researchers might need to quit if they are involved for a longer term. Practical issues that need to be overcome include the continuation of travel expenses and allowances for co-researchers’ time and the restrictions on such allowances that might be imposed by social security legislation, as appeared to be the case in the Netherlands (39).

**Evaluation of qualitative instruments assessing care relationships**

This thesis evaluated five qualitative instruments that were already being applied in long-term care. Two main adjustments were made: the procedure was adjusted to enable the co-researchers’ role and the content of the instruments was adjusted to measure the quality of a care relationship based on the findings of the systematic review (chapter 3) and the qualitative study (chapter 4).

The evaluation explored whether co-researchers were able to apply the qualitative instruments and whether the instruments yielded useful findings. It was expected that the neutral stance of co-researchers (compared to a professional) and their ability to act naturally as equals at the same level could make it easier for clients to open up in an interview. Co-researchers know from their own experiences what depending on care and establishing care relationships with professionals feels like. During the study, researchers observed that co-researchers understood and spoke the language of other clients very well. Moreover, co-researchers were able to ask questions and summarise answers in a way that remained close to the understanding and phrasing of the clients being interviewed. Clients did open up in interviews, sometimes to an unexpected degree, and they were able to share their experiences with the co-researchers.

The two qualitative instruments that came to the fore as the most promising (WIEK interview’ and ‘Participatory Narrative Inquiry’) embraced the openness and variation of in-depth interviewing and did not employ a structured design. The topics of the interview were not imposed on clients by the interviewer, as the interviewed clients choose experiences they were willing to bring forward and are meaningful to them. The open interviewing
approach might be one of the main reasons why these qualitative instruments fitted multiple client groups. The instruments could be customised for each client and the role of the co-researcher also varied. See table 7.2 for more information about the content of the instruments.

To prevent the added value of the qualitative methodology from becoming flattened out, it is essential to hold on to certain quality conditions (40). Appropriate training of co-researchers carrying out the instruments, a central contact providing clear information to clients and professionals, and prearranged support from an assisting interviewer while applying the instruments are essential for ensuring that the instruments are used properly and yield informative outcomes. The two selected instruments balanced an open interviewing approach with sufficient guidance and aid for the co-researchers.

**Future implementation of the instruments**

In quality measurement, a growing emphasis is placed on the reflection, continual learning processes, and quality awareness of care professionals. Care professionals should develop and adopt a learning and questioning attitude, based on commitment, deliberation, reflection and argumentation (40). In doing so, care professionals are key to quality improvement. The findings of the qualitative instruments can in this respect be used by care professionals to enrich and accelerate these learning processes based on client feedback and experiences. As clients are part of the care processes themselves, their unique and specific perspectives are complementary to the improvement areas a care professional is already aware of.

Some could question whether care professionals and care organisations are ready to regard the quality improvement suggestions brought forward by co-researchers as useful and supplementary to their own perspectives. The negative impact of power relationships has been recognised in earlier participatory research (41). Although the professionals involved in this thesis were often enthusiastic about the involvement of co-researchers, it is not clear what will happen when the instruments are implemented outside a research setting. As the three participating care organisations were willing to participate in the study, their readiness to embrace active client involvement might be greater than in other care organisations. The level of endorsement and openness could vary between care professionals, and might depend on
the extent to which using expert experience is already mainstream in any given care organisation.

Table 7.2  Description of the selected instruments

<table>
<thead>
<tr>
<th>WIEK interview</th>
<th>Participatory narrative inquiry</th>
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<tr>
<td><strong>Aim of the instrument</strong></td>
<td><strong>Aim of the instrument</strong></td>
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<tr>
<td>The WIEK interview is meant for evaluating or monitoring the quality of an individual care relationship and reflecting on the individual client-professional relationship and aspects of it that can be improved.</td>
<td>Participatory Narrative Inquiry provides a collection of anonymous stories that reveal areas for improvement according to clients. A group of professionals can reflect on the themes emerging from the client stories, and may formulate actions for their own team or organisation. This instrument targets the client-professional relationship at the team level.</td>
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<tr>
<td><strong>Procedure</strong></td>
<td><strong>Procedure</strong></td>
</tr>
<tr>
<td>Co-researchers interviewed clients about the quality of a relationship with one specific care professional. Ten cards are the core of this instrument, each describing a theme on one side and with open questions on the other. The WIEK cards were formulated by the research team. The clients choose 2 theme cards they are willing to talk about and the co-researcher asks questions about these chosen themes. Notes are made during the interview to make an individual traceable client report afterwards to send to the professional. The professional reads and reflects on the improvement suggestions, and discusses the results with the client if needed.</td>
<td>This instrument comprises three parts • First, a workshop is organised in which clients, family and care professionals determine the content of the questions and answer categories. • Data collection consists of individual interviews and a group meeting. Clients are interviewed by co-researchers. An interview consists of an open narrative and some additional questions that the client uses to interpret their own story. Co-researchers were given the option of making an audio recording so that the results could subsequently be transcribed and they did not have to do this themselves. In the group meeting of about 90 minutes, 6-15 clients shared their stories with each other and interpreted these stories. • After the data collection, a meeting is held with professionals, the manager, the research team (co-researchers) and where appropriate a representative of the client council. Central themes are discussed and areas for improvement determined based on anonymous stories from the interviews and stories meeting.</td>
</tr>
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</table>

According to the publication “Diffusion of innovation” written by Roberts, willingness to innovate and change current practices and behaviour to a new mode depends on the compatibility with existing values and needs, relative advantage, simplicity and ease of use, observable results, and the degree to which it can be implemented on a small scale for trial purposes (42). Moreover, engaging user groups in the implementation from an early moment on is highlighted elsewhere as increasing the level of endorsement
and the fit with users’ wishes (43, 44). In this study, the perspectives of all stakeholders – co-researchers, clients, care professionals and managers – were included in order to increase the fit between the instrument and the wishes of the main stakeholders involved. Winters et al. have argued that improvements in work processes should be organised decentrally, close to clients in daily practice. Quality improvements are more easily adopted when operationalised as practical activities that are easy to understand (44). Both qualitative instruments can be best applied on a small scale and are closely linked to the practical work activities of professionals and the ‘life world’ of the clients involved. The toolbox of materials, training descriptions and information about implementation provides a lot of information for organisations that start with applying one of the qualitative instruments, WIEK interview or Participatory Narrative Inquiry.

Ambiguity is often considered as negative and dysfunctional in quality research and improvement, as clear, collective, and unambiguous findings are the easiest to implement. Abma suggested that it is impossible and unproductive to deny, ignore or erase ambiguity in the evaluation of care, as it is an inherent part of social lives. It is more effective to acknowledge this ambiguity and help co-researchers and care professionals to find solutions (45). The qualitative instruments ‘WIEK interview’ and ‘Participatory Narrative Inquiry’ are instrumental in helping clients give their individual, situational and time-bound feedback about their care relationship, which could also involve contradictory information from any single client or between clients. The qualitative instruments are meant to illustrate ambiguities and differences between individual clients, their relationships with professionals and between care settings.

The aims for which a quality instrument is chosen by a care organisation need to match the characteristics and capabilities of that particular instrument. There is broad recognition that the focus on quality measurement for improving care provision inside a care organisation can be separated from the quality measurement for external accountability purposes, e.g. for health insurance policies and for regulatory government agencies. These different objectives of quality measurement are sometimes conflicting and incompatible. For example, the data collected using the WIEK interview instrument is meant for reflection by a professional on their influence on the quality of one particular care relationship, which makes the client experiences gathered very private and personal. This individual quality information must be held separately from the appraisal or assessment of the
healthcare professional in question. The WIEK interview was also not developed to provide a comprehensive view of the quality of care and care relationships for future clients. The instrument Participatory Narrative Inquiry might be more suitable to use for purposes other than quality improvement. The appropriateness for consumer choice information and external accountability could be explored during application of this instrument in the future.

7.3 Methodological reflections

In qualitative research, the quality criteria and the corresponding techniques for achieving trustworthiness distinguished by Guba and Lincoln are widely used: credibility, transferability, dependability and confirmability (46, 47). These terms match with terms that are broadly used in quantitative research, e.g. credibility corresponds to ‘internal validity’, transferability to ‘external validity’, dependability to ‘reliability’, and confirmability to ‘objectivity’ (48). These four qualitative quality criteria were used to reflect on this study and evaluate its trustworthiness.

Credibility

Credibility refers to whether the research findings are representing ‘the truth’ and giving a correct interpretation of the participants’ original views (48). To ascertain whether the experiences of clients were interpreted correctly, the voices of clients were included in the setup, analysis and interpretation in four ways. Firstly, to ensure that interview topics and questions corresponded to the understanding and ‘life world’ of the clients, they were drawn up by the research teams using the input of co-researchers. As a result, the questions matched the understanding of the respondents well and the quality of care relationships was studied from authentic and genuine client perspectives. Secondly, a summary of the interview content was provided at the end of each interview, both in the qualitative study and during application of the qualitative instruments, to obtain a member check directly from the respondent. For evaluating the qualitative instruments, the clients were questioned at the end of each interview about their experiences with those instruments. Thirdly, co-researchers contributed to the analysis of the study findings by interpreting the interview content of the interviews they performed. Co-researchers shared, reported and discussed their
interpretations both individually (by discussing each interview directly after it took place) and collectively (in work meetings of the research teams). As co-researchers interpreted the findings based on their own experiences of long-term care, their perspective was complementary to the researcher’s perspective. The shared interpretations were summarised on a flip-chart in each research team. Fourthly, one co-researcher contributed as a co-author to the writing stage of two scientific articles, to ensure that the article reflected the perspectives of co-researchers as much as possible and that no harmful information could be traced back to individual co-researchers. On top of the inclusion of client perspectives at various stages of the research, the close collaboration with co-researchers and the extended time spent together had as an extra advantage the fact that the researcher developed a greater understanding of the local contexts and cultures in long-term care.

The Delphi study in which stakeholders chose the instruments that would be used in this study resulted in an overview in Dutch. This limits the replicability of that particular sub-study for an English audience. This decision was made at the start of the study due to the limited relevance of the Delphi study findings for an international readership, as most qualitative instruments were developed and used only in a Dutch context. Although the instruments were already being applied in Dutch long-term care settings, the quality of the instruments had scarcely been reported on in Dutch or English scientific literature, which limited the documentation available at the start of the evaluation.

In the evaluation study, the five selected qualitative instruments were developed further. The reasoning behind this design choice was that a lot of qualitative instruments were already developed and using the available knowledge as a starting point was seen as worthwhile. The downside of this approach was that sticking to the prescribed instrument processes restricted the options for drawing up an instrument with variants and new possibilities. Developing a totally new instrument might have therefore resulted in a different instrument and the current design limited the freedom during development and reworking.

The content of the five selected qualitative instruments was adjusted to cover the determinants of the quality of care relationships found in the systematic review and qualitative study. From a quantitative viewpoint, it might be possible to question the internal validity of this qualitative adaptation process. For example, was there no overlap between determinants, and what determinants affect care relationships most strongly? From the point of view
of a qualitative researcher, the quality of this adaptation process was likely to have been increased by the close involvement of co-researchers, researcher triangulation during the operationalisation process, and by consulting the developers of the original instruments. Moreover, the open structure of the instruments makes it possible for respondents to relate whatever they believe is important, which makes overlaps or the absence of a particular sub-question less problematic than for the content of a quantitative instrument.

Finally, multiple sources of data were combined to obtain corroborating evidence: scientific literature alongside the empirical qualitative study, care professionals' perspectives alongside clients’ perspectives, and co-researchers’ perspectives alongside researchers’ perspectives. In the last part of the study, the evaluation of the instruments was based on the sum of the direct observations made by the researchers filled in on observation forms, and the experiences of co-researchers, clients and care professionals. All the stakeholder perspectives were involved in an open way to ensure that different viewpoints were taken into account. The researchers’ observations added a perspective from a more distant viewpoint, as the researchers did not have an active role in applying the instrument.

**Transferability**

Transferability can be defined by the degree to which results can be transferred to other care contexts (46). Providing detailed descriptions of the sample and context makes reader more capable of making a substantiated judgement of whether findings are transferable to their own context (49). The samples used in this research included clients receiving long-term care who were able to speak about their care relationship experiences. The qualitative study included 30 clients and 29 professionals. A total of 140 respondents participated in the evaluation study of the qualitative instruments. The study was carried out in large long-term care organisations with multiple locations and a diverse client population to ensure transferability to other care organisations. The samples covered a broad spectrum of clients receiving long-term care: inpatient and outpatient care settings, clients with a wide variety of diseases and conditions, different care needs, and different age groups (above 18). Most clients received care at least once per week, but the assistance for some outpatient clients with long-term mental healthcare was more loosely planned. The focus was on clients’ care relationships with the care professionals who the clients see most often to provide assistance, supporting care and physical care, e.g. care assistants,
personal carers and various types of nurses. Clients were selected using a convenience sample, but we also aimed for variability in order to include a broad sample of clients. Clients from each of the following categories were therefore included in every study: inpatient and outpatient setting, male and female, different ages.

Nevertheless, the way that care organisations, clients and professionals were selected using a convenience sample limits the transferability. Care organisations were not randomly selected but instead collaborated as a result of their interest in the study. The three care organisations and their employees might therefore adopt a more open stance to active participation of clients in quality research or might already be working on the quality of care relationships within their current policies. Additionally, variation between rural and urban settings could not be taken into account, nor did we include a representative sample in terms of ethnicity. With regard to the selection of clients, all client respondents of the study were willing to participate and might therefore cause a selection effect as well. It is unlikely that the feasibility and usability of the instruments (Chapter 5) or the determinants of the quality of care relationships (Chapter 4) were directly influenced by the manner of selecting clients, as the extent to which clients share negative or positive experiences is not directly related to these study results.

Lastly, the study findings depended on the capabilities of co-researchers involved. This might to some extent be a limitation of the transferability, as other co-researchers might have other abilities and support needs. The teams were relatively large as 5-6 co-researchers collaborated in each team, and their competences varied. The variability and relative large number of co-researchers were likely to benefit transferability and gave an impression of the possible skills and abilities of the client-groups co-researchers represented.

**Dependability**

Dependability refers to the stability of findings over time, whether the research process is logical, traceable and clearly documented, so that it can be repeated by another researcher in the future (48). In each research article, the methods of the sub-study were described in detail to provide the necessary information for replication. All qualitative data and analysis material is available on reasonable request.
Several procedures were applied to increase the stability of findings over time. The study findings depended on the collaboration and abilities of researchers and co-researchers involved. The researchers and co-researchers performing the sub-studies were involved for a long time. Training sessions were organised for each research team to create a good working environment and train interviewing skills as a baseline. Two supervisors who were not involved in the practical performance and data collection helped think through the essential methodological and analytical decisions that were taken. Their contributions ensured that the decisions were logical and beneficial for the content of the study. It also helped the completeness of the documentation of the process, as they identified and made explicit aspects that were obvious for the researchers who were more closely involved. Furthermore, a larger committee supervised the research project from start to finish; it included stakeholders such as representatives of care providers and branch organisations, client organisation and client council organisations with a nationwide scope, contacts at the care organisations in the study and health insurers. The committee met on average three times a year to monitor the research process and crucial decisions from a less closely involved perspective with diminished the dependability of the researchers.

The process requirements for achieving a good working environment and good collaboration were described in detail in Chapter 6 to increase the replicability as well. For the same reason, the personal reflections of the principle researcher and two co-researchers regarding participatory research were made explicit in Chapter 8 of the thesis. These descriptions allow the influence of the researcher’s own background and perceptions to be estimated.

**Confirmability**

Confirmability refers to the degree to which the results of the thesis could be confirmed by other researchers (49). The double interpretation of interview data by two or three researchers aimed to diminish the influence of any single researcher. In all subsections of the thesis, peer debriefings and researcher triangulation were used during data collection and data analysis to increase the quality of the findings. For the evaluation, the observation topics were explained and discussed by the three researchers involved to develop a joint interpretation framework. Furthermore, dilemmas and questions that arose during data collection, analysis and writing the research articles were discussed with the research supervisors in meetings; they were able to view
issues from more distance. Discussing the researcher's dilemmas improved the reliability of the findings.

The number of co-researchers involved in each team was based on the expected number of interviews to be performed by each co-researcher and therefore largely pragmatically chosen. The number of co-researchers was also set so that it would outnumber the researchers, literally increasing their voice (50). It is debatable whether the current number of co-researchers involved did influence the results. On the one hand, fewer co-researchers in the evaluation of the instruments would have permitted a longer learning curve and further development of skills of the co-researchers involved; on the other, the individual characteristics of co-researchers would have had more influence on the results, which would have made it less clear whether co-researchers were representative of the skills and abilities of their client group, which could be a useful insight for future implementation.

7.4 Recommendations for future research

A number of ideas for further research are presented that are based on the results of this study. This thesis reveals the determinants of the quality of care relationships between clients and professionals in long-term care. However, there has been no investigation yet of which determinants are the most influential or important for the quality of a care relationship and whether there are differences between subgroups of clients in terms of determinants (for instance men/women). It is also not yet known what determinants are most and least often met in existing care relationships. Although care relationships are very variable and individually constructed, it could be interesting to look into these two questions with appropriate research designs. Additionally, there has not yet been any investigation of whether the application of the two qualitative instruments effectively resulted in higher-quality care relationships.

In this research, we focused on the quality of care relationships between clients and professionals, and we did not include family-professional relationships, relationships between clients, relationships between clients and their families, or working relationships between professionals. In the literature, specifically in person-centred care frameworks and relationship-centred care theories, the importance of relationships between all actors in the care cycle is underlined (51-54). As these relationships are expected to
have their own dynamics, they might have different, opposite or reinforcing effects on the care relationships between clients and professionals. Family members might provide an additional perspective that could be valuable in itself (17, 55). These relationships could potentially be interesting to focus on in future research.

With the current study design, it was only possible to focus on the more verbally skilled client groups that were able to talk about their experiences and ideas. It might be an interesting direction for future research to explore the determinants of the quality of care relationships for those who are not able to speak about their experiences themselves, i.e. people with severe forms of dementia or a severe intellectual disability.

Regarding client participation in research focused on quality improvement, additional research could address a more structural implementation of client participation in quality improvement projects, and eventually the long-lasting embedding in organisational structures. For this study, the qualitative instruments were applied and evaluated on a small scale. The actual implementation of the qualitative instruments in other care organisations is, however, outside the scope of this study. The implications for applying the instrument should be explored further during implementation, for example how the quality of the way the instrument is carried out is maintained, and how the coordination role is carried out in other settings.

Lastly, it could be useful to create more insights into the learning curves and the skills of co-researchers of distinct long-term care client groups, to be better able to indicate possible changes in the support needs of co-researchers. Moreover, it will be interesting to study the extent to which care professionals appreciate and embrace the active involvement of clients in quality improvement and the consequences for implementing quality instruments with help of co-researchers. Patient involvement could generate a shift in the balance of power in practice, and it might be interesting whether care professionals are willing to reflect on the findings brought to the fore by co-researchers and readjust to a position in which they are equals.
7.5 Implications for practice

Shared responsibility
It is important to stress the shared responsibility of the care professional and the client regarding the quality of their care relationship. Both parties are able to influence, contribute to and work on the dynamics of a care relationship. This reflects current views and contemporary developments in healthcare based on the active stance of clients and individual choice. Factors such as reciprocity, equality and the ability of clients to ask for help and provide feedback reflect these active roles of clients.

Shifting the balance of power through active client involvement
Actively involving clients in quality instruments could generate a shift in power relationships in practice as the clients take on new active roles. The qualitative instruments carried out by co-researchers for quality improvement could serve as a vehicle for experimenting with this new balance of power and showing the potential of actively involving clients in long-term care. When clients are actively involved, taking account of individual variability and creating a good working environment and collaboration are instrumental to the inclusive team process.

Continuous reflection and learning
Care professionals establish and maintain care relationships within an organisation-specific context. Care organisations should aim to develop a learning culture in which professionals are encouraged to reflect on their professional conduct and consequences of certain actions, in order to improve the quality of care. Including client perspectives in these reflections is crucial for optimising the quality of care relationships and facilitating change from client perspectives. The qualitative instruments ‘WIEK interview’ and ‘Participatory Narrative Inquiry’ are meant to yield useful suggestions and areas for improvement for the care process, as expressed by clients. These suggestions help professionals reflect on how they determine the quality of a care relationship, e.g. whether a client finds that a professional takes enough time or is available, takes a client’s needs and wishes into account, listens well, shows empathy, provides support when needed, and whether they are dependable.
**Organisational policy**

At a contextual level, organisational policy is needed in order to generate conditions that facilitate the development and maintenance of high-quality care relationships between clients and professionals. For example, assigning a single professional or a small number to one client helps the client get to know the professional well, lets the professional know more about the wishes, needs and personality of the client and makes it possible to develop a close bond. Moreover, a more flexible time justification policy for professionals for organising their time might let care professionals invest time in building a new care relationship with a client and responding to the varying needs of clients. Furthermore, technical facilities such as mobile phones and individual contact details of the care professional might lower the threshold experienced by clients to getting in contact with a care professional when needed. Ultimately, giving clients and professionals the option to ask for someone else when it is really not working out should not be forgotten as a last resort.

**The value of qualitative instruments**

In this study, qualitative instruments were developed or reworked for measuring the quality of care relationships and then evaluated. Qualitative instruments are characterised by the openness and variation of in-depth interviewing, and capture individual client experiences, variations, and the dynamics of a care relationship. Qualitative instruments can be customised for each client, giving the client the opportunity to choose those topics that are most relevant for them at a particular moment. The narratives give care professionals quick access to clients’ perceptions of care contacts. The aim of a qualitative instrument is not to generalise the outcomes to all clients, but rather to visualise the diversity and individuality of the experiences of some clients. The application of qualitative instruments gives professionals concrete points for improvement from the clients’ perspective.

### 7.6 Final concluding remarks

Hopefully, the results of this thesis have made clear what the opportunities and added value are of studying the quality of care relationships with the active involvement of co-researchers. The determinants of the quality of long-term care relationships were explored and showed substantial overlap
for the client groups being studied. The study resulted in two feasible and useful optimised qualitative instruments for care organisations and client councils to let them collect quality information and feedback from clients about care relationships in long-term care with the help of co-researchers. With the toolbox that was developed, co-researchers, client councils and care organisations will be able to apply the instruments “WIEK interview” and “Participatory Narrative Inquiry” on their own in the future. The toolbox is available online via www.nivel.nl/toolbox-hzs. A participatory action research design could evaluate the structural implementation of the qualitative instruments in the future.
Literature


Chapter 8
Reflections on the participatory research
During the course of this PhD research, I learned a lot about the content of the study and about the process of participatory research. I decided to include a personal reflection in this thesis, to share my personal experiences during the research. Although some topics have also been discussed in the other chapters, they were framed there more from a research perspective than from my perspective as a person. This chapter lets me state my personal values and principles more explicitly. Describing these personal values more comprehensively is likely to increase the trustworthiness of qualitative and participatory research. When researchers take a reflective stance, they will be “able to articulate and reflect on their personal values, beliefs and needs and from this act with a moral intention of doing ‘good’” p. 42 (1). The personal and professional development described in the collaboration with co-researchers is likely to be valuable for my future collaborations with colleagues, both researchers and co-researchers.

8.1 Regarding my background

From early age, I was intrigued by equality and inequality between social groups in society. I chose to study interdisciplinary social sciences as this subject focuses on current societal issues including inclusion, exclusion, the influence of policy, media and so forth. During an internship for my master’s, I focused on discrimination reports recorded by the police. Why are some people discriminated against due to their ethnicity or religion? Why do we not see a person regardless of their background characteristics, which seem to shape and colour our vision?

At my first job with Movisie, I started to notice the relevance of people who are experts thanks to their experience and the value they have in training and in providing positive examples for young adolescents. In the process evaluation of the ‘Girl Empower team’ project, for example, I helped report on the evaluation results of a project in which young women were trained as peer educators to talk with girls from secondary school classes about the negative effects of gossiping and social exclusion.

I had three main reasons for applying for this job vacancy and PhD trajectory. Firstly, I believed that care relationships between clients and care professionals in long-term care feature dependency and inequality, plus individual potential as well. Secondly, anyone in a position that is dependent on care needs a very strong personality and courage to give a care
professional personal feedback about the interactions and the relationship being constructed between them. A client who has experience of care themselves could lower the threshold for talking about the care relationship and may yield a different interpretation to what is shared and told by a client. Thirdly, I wanted to practice what I preached in my aim for a more equal society with opportunities for everyone, so I wanted to conduct this research together with co-researchers. Including clients as co-researchers enriched the study with client perspectives throughout the research process, and generating knowledge becomes democratised as it is not exclusively the task of researchers anymore. It is expected to change power dynamics as well.

At the start of the research, I was completely new in the world of healthcare. Thanks to my relatively young age and good health, my personal experiences with healthcare and long-term care are very limited. At the same time, there are people close to me who do rely on long-term care. For example, I saw from nearby when my grandmother became more frail and fragile as she became older and increasingly dependent on technical devices such as hearing aids and a rollator. She also talked about how she needed assistance at intimate moments such as showering and what a good contact with personal carers meant to her. Moreover, I learned from another person close to me about the societal stigmas that accompanied his mental health problems and his wish to be ‘normal’ and successful in life. Someone else who was diagnosed with a chronic disease felt relieved when the difficulties could be put in context. Contradictorily, the diagnosis also restricted life opportunities.

Of course, I only saw these close relatives and friends as the people they were, as we knew each other from a private setting. Interestingly, I noticed my role became more distant and studying more anonymous, abstract social groups when I started conducting the systematic review focused on long-term care. This role I took on as a researcher initially differed a lot from my role as a relative. Gradually, the role of researcher became more integrated during my involvement in participatory research, as it diminished the differences between the stances of a researcher and a human being when building up relationships with co-researchers during our collaboration in the research.
8.2 Reflection on the realisation and my guiding principles

When I started the research, I was very eager to learn and full of energy and inquisitiveness about starting empirical research together with my new, as yet unknown, colleagues with expert experience. In the first months of the study, however, my main task was developing my knowledge about the background of this scientific research in the field of person-centred care and participatory research by studying the literature. Also, thanks to my promotor Sandra van Dulmen having affiliations there, I was invited to follow the course focused on “The Science and Practice of Person-Centred Research” in Drammen, Norway. This course gave me the opportunity to reflect on the research ahead together with other PhD students who were involved in person-centred care research. As my research could easily be positioned and framed in person-centred care in terms of both the study purpose and the chosen design, I was eager to learn more about this valuable concept and framework for healthcare and my positioning within it. During the course, I reflected on questions such as, who am I, as a person-centred researcher? What values are important to me? What are the guiding principles in this research? Because qualitative research literature places a heavy emphasis on the values of the researcher and the explanation of these values (1), I needed to reconsider the principles that underpin my research practices. At the start of the current study, I therefore selected 5 central principles for my positioning in the research. These five principles had already been described by other researchers, specifically Brendan McCormack (2), Joan Cardiff and Femke van Lieshout (3). The principles showed what filters I would be looking at the subject through, what values I would put at the centre. Based on these values and principles, I was starting a journey – together with others – and I was very curious where it would lead us.

1. Informed flexibility – Facilitating decision-making through sharing information and integrating new information into established perspectives. In person-centred research and specifically participatory research, a researcher needs to be sensitive to the setting and the multiple unpredictable challenges that might arise (2). Flexibility regarding the planning and progress of the study is an asset for practice-oriented researchers. Especially in participatory research carried out in collaboration with co-researchers in a setting and towards a topic that is
constantly changing, I believed informed flexibility in terms of the stakeholders and the context in which a study takes place is an indispensable asset.

2. **Transparency** - Clarifying the intentions and motivations for action and the boundaries within which decisions are made (2). Especially when conducting research with co-researchers with democratisation as a goal, it is important that the researcher is clear about what is and is *not* possible in terms of levels of involvement and making changes in the research. At the start of the cooperation, decisions were already being made in the research proposal with regard to the products (i.e. the scientific articles) and a toolbox. Transparency was also needed during the process of participatory research. For instance when I made a mistake, this was not necessarily a problem as long as I admitted it to the research team and communicated about it with co-researchers.

3. **Being centred on others without losing yourself** - Given that I was preparing the training for co-researchers and facilitating work meetings, I saw myself as a facilitator as well. This principle meant that it is important not to lose track of your own role, by expressing clearly what I thought was important to take into account in order to balance my own ideas and the ideas of co-researchers equally. During the study, I was primarily focused on getting to know and engaging with the co-researchers. After all, mutuality and reciprocity seemed an important goal to me in establishing relationships with co-researchers in my person-centred research.

4. **Relational connectedness** - Relational connectedness means that I, in my role as a researcher, need to be a sympathetic presence, need to be engaged and in favour of shared decision-making (3). As I understand relational connectedness, it is about responding to individuals from various stances, reflecting on my own position and how this might enhance the empowerment of co-researchers and clients that were interviewed. It is about opening up to each other, and explaining what our needs are.

5. **Valuing a constant state of ‘becoming’** - The assumption here is that people in relationships create social structures that in turn influence their own condition. Consequently, subjected to this constant influencing, individuals and their relationships are in a constant state of ‘becoming’ (3). This is particularly the case for my research: I was constantly developing in this participatory research project, while relating and
communicating to co-researchers in a trusting and equal way, specialising within our collaboration and on the topics we focused on. Developing all aspects of my research competences, it would seem. At the same time, as the co-researchers were all developing too, they were in a state of ‘becoming’ as well. It is very important to celebrate this state of becoming.

These five principles were implicitly guiding me through the three years of my PhD research. Looking back, I have developed and learned a lot with regard to these five principles. Below, I aim to describe and reflect upon my personal development and role in the research.

Regarding informed flexibility, I believe my educational background in interdisciplinary social sciences shaped my views and the position I adopted as a researcher. In interdisciplinary social sciences, it is usual to start by formulating a research question or problem that comes from a practical setting in which the research will take place. Then a method is chosen that is most useful for answering the problem. Pragmatism dominates the discipline, as settings nowadays are complex and unpredictable. At the beginning of my PhD, a more structured colleague of mine encouraged me to make a detailed plan in order to let me think several steps ahead. Although this was useful for thinking the research through, while putting the plan into practice I saw also the limitations of trying to stick to a detailed structure and overview while the research process depended on so many different actors. I learned to let go of the reins to a certain extent, and kept on working – fully motivated – together with the research teams to perform the study.

My own personality and background mean that I am accustomed to and prefer goal-oriented working and being well prepared and thinking ahead, so it was a learning process for me to focus more on the research process and feel satisfied about the smaller steps. A lot of aspects took substantially more time than initially scheduled in the project proposal. I was often asked by those showing interest if I was “on schedule”, which frustrated me sometimes as this well-intentioned and interested question reflected little understanding of the research process and seemed also to imply a lack of progress on my part when I answered “no” or “it depends on which schedule you mean…”

In the beginning of the participatory research, there were moments when I found it hard not to intervene and instead let a co-researcher make their contribution in their own way. For example, four focus groups with care professionals were organised to explore the determinants of the quality of
care relationships from a care professional point of view. During the first focus group, I noticed that one co-researcher found it much harder to emphasise with care professionals than with clients. As a result, that co-researcher did not ask open questions to the professionals who were present but instead responded indignantly a couple of times based on his own client experiences. Afterwards, the co-researchers who were present told me they learned a lot about the perspectives of care professionals. As I had an interviewing role in mind for the co-researcher, I doubted whether it was better for the quality of the results to carry out the remaining focus groups in absence of co-researchers. However, I did not want to decide for the co-researchers what they could and could not do during the data collection. In the end, we decided together that co-researchers could be present at the focus groups and I asked them to try not to share their own opinions during the focus group. This allowed co-researchers to learn during focus groups, and professionals still felt free enough to speak about their experiences. Later on in the research, I became more flexible towards the contributions of co-researchers during interviews and focus groups – including those aspects a co-researcher was not really able to do from a research aim perspective – as I started to see their abilities as a part of the research findings as well. From an ethical stance, the ultimate line in the sand for intervening for me was that I had to guarantee that clients, co-researchers and care professionals were not harmed or hurt in any way.

Transparency was an important theme in the collaboration in the research teams. When first forming a research team, we talked about our wishes, the research aims and what was and was not possible regarding the role divisions. After the training sessions, we tried to construct a division of roles that everyone felt comfortable with. During the research, points of friction could only be recognised and discussed when we talked about the difficulties and gave each other feedback. For example, I was really glad about a suggestion I received from a co-researcher in the first qualitative study on my use of vocabulary. During an interview we carried out together, I referred in one of my questions to ‘people with intellectual disabilities’. The client himself used this phrase as well, so I thought it was fine to use the same term when asking a probing question. Afterwards, this co-researcher told me that the phrase felt stigmatising to her, and suggested using ‘people who receive assistance from (name of the care organisation providing assistance to people with intellectual disabilities)’ instead from then on. She taught me that it matters
who says something, and that someone who does not have a disability cannot automatically use the same words. This kind of feedback helped me to become a more informed interviewer, more attuned to the reactions of clients and better connected to the world as clients see it.

In another team, a couple of co-researchers decided in a certain meeting right before the interviews were due to start that the focus of the study on the care relationship and clients and professionals involved were not yet defined and operationalised well enough, explicitly regarding the specific care setting. The co-researchers were well-informed about the organisational structure and the types of care that distinct clients receive in mental healthcare and were eager to share their knowledge. As a researcher, I was able to tell them more about the other settings in which the research took place, the literature I had read, and the focus described in the project proposal. After discussing our definition of the respondents extensively and writing our decisions on a flip-over chart, we were able to start the interviews. I learned that discussing our views and ideas together led to a shared understanding and definition and resulted in greater self-confidence when holding the interviews.

I also learned that when I did something that did not feel right afterwards, it was not necessarily a problem as long as I discussed it with the co-researcher or team afterwards. This was the case with one co-researcher who wanted to know what was planned a long way in advance, so that she could take it into account in her planning. In reality, I found out it was not always possible to be clear about the specific time very far beforehand, as clients sometimes respond slowly through their care professionals sometimes or because of cancellations. Once, a co-researcher was quite upset by last-minute changes. In response to a phone call we had, I sent a postcard with an apology for how things had been changed, although I was also clear about the fact I could not prevent similar issues in future. Afterwards, the co-researcher felt acknowledged and recognised and the collaboration recovered.

The principles of being centred on others without losing yourself and relational connectedness are intertwined and distinctly aligned with each other. My reflections on these two principles therefore work best when combined. I recognised that it was relatively easy for me to relate to co-researchers and their situations. I believe that opening up and getting to know each other was vital for developing a bond. It meant sharing personal
information as well, for example about hobbies, joyful events and interests in a similar way to how I would with a normal Nivel colleague. During our shared travelling, waiting time and breaks, co-researchers and I often opened up and shared what was bothering us and what we had experienced lately. At the same time, it was essential to remain at the level I felt comfortable with. At the beginning of the research, it was much harder for me to explain my own preferences to co-researchers. For example, one co-researcher who had held a senior position before his retirement used to look and type on his mobile phone a lot of time during work meetings. Because he was more than twice my age, I found it hard to ask him to stop doing this and pay attention to other team members by listening to them. I see attention for all ideas and experiences of the team members who were present at work meetings as a way of showing respect to each other. Throughout our entire collaboration, I did not ask the co-researcher to put away his mobile phone and instead I concentrated on the other co-researchers who all paid attention fully in the meetings. Later on in the research process, I developed more self-confidence which made it easier to express my own needs and wishes. For example, one co-researcher reached out for close physical contact, such as hugging me and touching my arms when talking to me. As I am more the type of person who feels comfortable with physical distance to people in a work setting (and also in general), I sometimes felt uncomfortable with such proximity. I felt it was important to do justice to my own feelings in such situations by asking this person to keep a bit more physical distance. Stating my wishes meant that the co-researcher could easily take them into account without feeling offended, which solved the issue easily.

Valuing a constant state of ‘becoming’ is not typically something that comes naturally to me. I feel comfortable when I have control over the research planning and process. Furthermore, I am fairly impatient by nature, and I would ideally want to do my work as efficiently and quickly as possible. Of course, I had to become aware of these two characteristics and let my urge to control the process go if I was to make participatory research meaningful and possible. At the same time, I greatly valued the process of getting to know and trust each other, as I am quite a sensitive and social person. In the research, I developed strong personal ties with all co-researchers, and I was surprised by the amount of wisdom and kindness I received from co-researchers during our collaborations. Working intensively together let us all benefit from learning and developing, as well as our collaboration. We
praised each other’s qualities and celebrated our achievements together, which also strengthened our bond and pride in the successes we had during the project. For example, I bought sunflowers for all the co-researchers for our last work meeting before the holidays. And as a surprise, one co-researcher once gave me a flowering plant for no specific reason. At the same time, I tried to reflect on my functioning in different ways. For example, I asked two co-researchers to provide me with feedback on my functioning in the team for my performance appraisal at Nivel. I also asked for feedback in more informal ways, on specific issues such as the training contents and my functioning as facilitator, as well as more broadly on our collaboration. Conversely, I also tried to provide my colleagues with positive and negative feedback as well. Reflecting on our actions let us increase the opportunities to learn and improve during the research process.

More broadly, I discovered that doing PhD research that meets academic standards demands a lot of detail and highly structured reporting. At some times, this focus on perfection and aiming for high standards made me feel insecure about my own abilities as a researcher. Contact with co-researchers was a good way of putting this high-quality endeavour into a broader perspective. As an example, the implicit view in my research that everyone makes mistakes sometimes and this is not by definition a problem as long as you learn from it, discuss it and reflect on it, felt somewhat contradictory to the goal of making no mistakes at all in research, and quality policies that were often primarily focused more on increasing the output (high-quality scientific articles) than on the lessons learned during research processes.

Looking back, the participatory research approach did permit us as team members to learn a lot. Co-researchers upgraded their interviewing skills, finding a balance between using their experience as a long-term care recipient and taking an impartial stance during interviewing, observing proceedings in interviews, and reflecting on the work and their own and others’ roles. As a researcher, I learned to adjust my targeted and rapid tempo to the research flow and pace of the whole team. When facilitating work meetings, I learned to translate academic language from the ‘system’ world to the more lay language used in the ‘life’ worlds of co-researchers. From both perspectives, we learned from the collaboration about being honest with each other by providing feedback, and we learned from each other’s perspectives and knowledge and insights. The principle of ‘valuing a state of becoming’ created a safe learning place where all the team members could continue to develop and challenge ourselves.
**Being an all-rounder**

In this research, I had the role of academic researcher. But I sometimes felt more like an all-rounder. Tessa Frankena recently published some role divisions of participatory research, which are useful in describing the facets of my all-rounder job (4). In the training and work meetings, I often took on the role of facilitator, as I tried to make space for all team members involved to have their say and make contributions. I also kept an eye on all the diaries of the team members involved, and the amount of time available in each meeting. Throughout the research, I took on the role of organiser and HR manager to let co-researchers check and sign the declaration forms so that the reimbursements could be paid periodically. For some co-researchers, I was quite involved in the transportation planning. I even handed out money for train tickets when a co-researcher was short of cash. As a team manager, I tried to prepare and plan the training dates and data collection activities with all those involved, taking account of their schedules. As a colleague, I appreciated the personal contact and bonds with co-researchers, and laughed together with them about my researcher role and some of the regulations that I needed to safeguard in the research process. Thanks to this PhD research, I also learned to communicate with every co-researcher and team member in appropriate (sometimes simplified) language.

**8.3 Reflections of co-researchers**

As an addition to my own personal reflection on the research, the reflections of two co-researchers are added below. One of the co-researchers from the ID team reflected on his contributions to the research by writing in his notebook. At the end of his research, he shared his notes with me, and asked me to use his field notes to share our findings. Similarly, Pierre de Ries, who worked as co-researcher for the MH team, reflected on the research and presented his ideas on the concluding symposium. His presentation is also added below.

**Reflections by co-researcher B.**
We started as a team in April. We learned a lot in the training, with all the role-playing and above all about how to hold interviews. The training was
very informative for me. If I did anything wrong, it would sometimes be stopped. Fair enough, too, because I wasn’t doing it right.

Then we started with the real talks, and we held interviews. That wasn’t easy to start with. But it went a lot better later on. For the WIEK method, I had to read the questions off the cards. I thought that went well enough. We worked hard. At first, I thought I’d never learn to do it. But you did get the hang of the material. I enjoyed it, particularly when it went well. And being able to do it all together as a team. I soon found out that I had to do things for myself.

When the holidays came round, we all got a bunch of sunflowers. That was a lovely way to close things down for the holiday period, very peaceful.

In September, we started a new training course. This one was very different. But it was a good way of doing it. I thought this one was very educational too.

Personally, I had a good time doing this. I’ll miss you all. It was always fun, doing things together! I liked being able to learn so much and do so many fun things.

**Reflections by Pierre de Ries**

I read in the Amsterdam autism cafe in February 2018 that they were looking for co-researchers for a project run by the Nivel. I reckoned that might suit me, because there’s no stopping me when it comes to asking questions! I soon got a phone call to ask whether I was ready for an introductory interview. It was held at home – I don’t know why, perhaps so that it was less intimidating. They know what they’re talking about at Nivel, which makes you feel a bit more secure – even suspecting that is a help!

This woman who came in was really pleasant and friendly, asking pointed questions. Even during that chat, I realised that she liked how it was going, because I was making notes. I got a compliment for that, and when the study was finished, I had a rucksack full of those compliments. Instead of just a bag full Asperger history as the outsider on the playground or at birthday parties and so forth. Even though I wasn’t at all sure when I started whether I’d be able to keep it up.
But I did. It surprised me too, perhaps, because I saw it as a great opportunity to use my own experience to feel a link (in both directions) with the clients that the professionals maybe don’t have – or don’t have time for. I could tell that I had succeeded in that from the reactions of the clients when saying goodbye after the interview. I apparently put people at ease and – maybe for that reason – they said some unexpectedly touching things at the end, like “Animals will always love you!”

Before long, it was time for the first introduction meeting. World-class stress on the way to the training course: have you ever asked anyone on the street about how Google Maps shows north and south? Shit, you aren’t half on your own then: helpless expressions, getting lost, turning up late – a complete disaster for someone with Asperger’s! No problem, though: everyone was pleased I’d made it. This happened three times, because I got station names in the wrong order, or messaged that I was just coming as the stop rolled by, absolutely sadistically. But the rest of the research team just said, “Right – here’s Pierre,” as if they were pleased that I had turned up at my own birthday party.

Once the aim of the study had been discussed, we started drawing up the information letter for clients. I was surprised that we could do this ourselves. And I thought it was very challenging and interesting, because the talents of everyone in the team all helped make it a good letter. I was soon allowed to think up sentences that would make clients enthusiastic about taking part. Some of them may have thought this was being a bit too pernickety, and others corrected my somewhat formal use of language. (As your textbooks will undoubtedly have taught you, that’s an Asperger speciality... it's why we flourish in governmental circles.)

In the first example letter, I thought that the clients were not asked enthusiastically enough whether they wanted to take part. Even though they were invited very cordially to participate, I still thought you had to butter the client up a bit if you’re going to bring them on board. People need to be made to feel that they will be an indispensable cog in the machine, in improving the relationship between client and professional. A sentence fragment like “the relationship between you and those treating you is important, which is why we are approaching you about a study...” didn’t seem appealing enough to me. So this became “You know better than anyone
that good contacts between clients and professionals are important, so your experiences are very valuable. That’s why we are approaching you for this study.”

Throughout the study, the cooperation and the atmosphere within the team were extremely pleasant and committed. It was striking how we, as the ‘experts by experience’, were able to bounce things off each other without ego problems. We are sensitive people and we understand each other’s emotions and can press each other’s buttons. Apart from the fact that my key motivation to keep coming was the biscuits that Aukelien brought along and all that chocolate... too much... the introduction days also released some pretty heavy emotions for me. M. was superb at distilling the point out of something, in surprisingly few sentences; I was well jealous of that. There was one time when I started crying after I read my own report of a client interview, transmogrified by one of the researchers. Jeez, the structure was so clear – I’d never be able to do that? Had I put in too many observations and conclusions that weren’t relevant? And wasn’t I forgetting some of the essentials? Whether or not Aukelien was exaggerating a bit, she said it was almost the other way round: I was writing down what really mattered to the client and the study, where others would have missed it because they’d never been a client themselves and found it more awkward to estimate the impact of what were apparently peripheral matters. You couldn’t ask for more support than that. I was really able to be myself – great!

I unexpectedly found a gap to come back from the canteen with a plate of fish, which I ate during the meeting. The others looked at me and laughed about it: how does he manage it? The kitchen is closed, to everyone. (Perhaps an example of the fact that I’ve been able to sneak through the mesh of the net all my life, by thinking outside the box... the condition does have some benefits!)

We could choose which method we wanted to work with – individually or in a group – and we were also able to decide for ourselves how to implement it and put it into practice. I chose interviews rather than group discussions. One-on-one suits me better. I heard a lot of positive things during the WIEK study about the people in the room, giving you guidance. That worried me... Why? As researcher, I wanted in fact to be helping find the blind spots in the people who were doing the guiding! Even so, I’ve never gone looking for
negative experiences; I stuck to the instructions by simply keeping asking open questions. Why, how, when, how often, what was the cause? And so forth. Throughout the study, I was pleased that I stuck to it strictly. After all, the results had to be objective. Fortunately there was another method that got the person I’d interviewed to express different pain points, such as being able to see groups of assisting staff behind a glass wall all working on their bloody PCs – too long and too often – while you felt unsafe and excluded on the ward. It felt a bit like standing in a restaurant where you could see the cook working to prepare food others and... shit... where’s my wallet?

There were some surprises for me during the research. There were several occasions when the assisting staff didn’t transfer things to each other properly about what (with hindsight) was most essential for the client, for instance the atmosphere on the ward, or coming into a room where all your things had been taken away, without being told beforehand. In our last instrument, “Participatory Narrative Inquiry”, it turned out that the guiding staff had difficulty giving positive and negative criticism to each other, or didn’t always dare to do so. These seem to be the same reactions that make the client feel so small when the person treating them acts that way. The feeling that the only contribution you’re making is to their salary.

At the end of the presentation of the research, I spoke to the management, addressing them personally about this issue. And I asked if a safe method of giving feedback or staff training was being prioritised at all by the management, or whether it could be. (In my opinion, this was the biggest blind spot that I came across in terms of prioritising quality.) Once it was over, a couple of the staff came to me and said that I’d provided some great insights and that I’d embarrassed the management in a positive way. One of my favourite experiences in the project was the compliment that I got: “Pierre, we’re proud that you drew their attention to this. You’ve really put the ball in the managers’ court.” Relieved to have genuinely been useful for the study and to have tactfully pointed out a blind spot, I was able to walk away from the building and the research project, feeling and thinking: mission accomplished!
8.4 What’s in a name?

At the start of the research, we discussed in the teams what the ‘co-researchers’ should be called during our collaboration in the research teams. The term ‘client-researcher’ (or cliënt-onderzoeker in Dutch) was chosen as it was a clear statement of the expert experience of those involved, given their position as clients in care combined with the researcher role. At this stage, the term ‘co-researcher’ was deemed too abstract and too vague, with regard both to the clients who would be involved as respondents and to those actively involved. Later on in the process, some co-researchers from the mental health team (who started their collaboration at a later stage) said they favoured the term ‘co-researcher’. Some argued they did not feel like clients anymore, as they had largely recovered from their mental illnesses. The term ‘client-researcher’ felt in this respect a bit stigmatising to them, reducing their personalities to some status they did not have anymore. Others felt that the ‘co-’ prefix emphasised the team collaboration, the equal value and was therefore less stigmatising. In this research team, we all therefore started to use the term ‘co-researcher’. Similarly, we changed the term ‘client-researcher’, which had been used in the study protocol, into the term ‘co-researcher’ in later articles. Changing the term in the later research articles also felt logical because the term ‘co-researcher’ is more broadly used and recognised in academic literature than the term ‘client-researcher’. Conversely, some members of the other two research teams said they favoured the term ‘client-researcher’, as ‘co-researcher’ was less straightforward and more difficult to understand. They proudly persisted in using the term ‘client-researcher’ as some kind of a badge of honour. In the end, the two terms were both used in the research teams interchangeably, and everyone used the term they preferred. I tried to use the term most team members favoured and had adopted in each research team. With regard to “What’s in a name?”, I learned that terminology does of course matters, but differs between individuals; variation should therefore be taken into account.

8.5 Concluding remarks

Overall, this three-year research project offered me a lot of lessons and insights into the research processes, our collaborations in the research teams, and about myself and others involved. Although I made every effort to
perform this research to the best of my abilities, the research process also showed some areas in which I developed more gradually, such as my lack of patience, and the opportunities and future directions for performing research in an inclusive way. At the same time, I am grateful for our enjoyable collaboration, the lessons we learned and successes we achieved. Although it is the completion of three years of research, I am sure that I will be able to use the newly-acquired skills I learned from my collaboration with co-researchers and other researchers in the future. Performing participatory research together with those who are close to or part of the phenomenon being studied is an interesting approach that I am eager to contribute to in the near future.
Literature

Chapter 9
Nederlandse samenvatting
Binnen de gezondheidszorg is de kwaliteit van de zorgrelatie van groot belang. Dit is immers een belangrijke graadmeter voor de ervaren kwaliteit van zorg. Cliënten rapporteren een hogere mate van tevredenheid over de zorg wanneer zorgrelaties van betere kwaliteit zijn. Daarnaast beïnvloedt de kwaliteit en continuïteit van zorgrelaties de technische zorg die cliënten ontvangen. Zorgrelaties zijn specifiek van belang voor cliënten in de langdurige zorg omdat deze cliënten voor lange tijd afhankelijk zijn van de geboden ondersteuning. De kwaliteit van zorgrelaties is nog lang niet altijd optimaal. Uit onderzoek blijkt dat cliënten zich niet altijd gerespecteerd voelen. Anderen voelen zich genegeerd, of niet gehoord. Omdat het nog niet duidelijk is wat bijdraagt aan een goede zorgrelatie of wat deze juist in de weg staat, is er meer inzicht nodig in de factoren die de kwaliteit van de zorgrelatie bepalen. Daarmee kunnen zorgprofessionals en cliënten bestaande zorgrelaties optimaliseren.

Het onderzoek beschreven in dit proefschrift is gericht op de drie grootste cliëntengroepen die langdurig zorg of ondersteuning ontvangen: mensen met een verstandelijke beperking, mensen met psychische problemen, en mensen met een fysieke of mentale kwetsbaarheid vanwege hogere leeftijd. De focus ligt op zorgrelaties met zorgprofessionals die cliënten het vaakste zien en hen ondersteuning, begeleiding en/of fysieke zorg verlenen, waaronder verpleegkundigen, verzorgenden, en persoonlijk begeleiders.

Niemand kan beter begrijpen wat het betekent om zorg te ontvangen dan een cliënt zelf. Daarom lijkt het actief betrekken van cliënten als co-onderrzoekers in onderzoek naar kwaliteitsverbetering een veelbelovende manier om de zorgrelatie vanuit cliëntperspectief te evalueren. Drie kernargumenten worden vaak genoemd voor het actief betrekken van cliënten bij (kwaliteits)onderzoek. Het inhoudelijke argument houdt in dat het actief betrekken van cliënten de kwaliteit van het onderzoek kan verhogen doordat de ideeën, behoeften en prioriteiten van cliënten in verschillende fasen van het onderzoek worden meegenomen, wat de (inhouds-) validiteit en relevantie van het onderzoek vergroot. Vanuit het ontologische en normatieve argument hebben cliënten het democratische recht om betrokken te zijn bij beslissingen over zorg die zij ontvangen. Het instrumentele argument is in het bijzonder van toepassing op initiatieven voor kwaliteitsverbetering, doordat de inbreng van co-onderrzoekers draagvlak creëert voor de bevindingen. De bijdrage van cliënten kan nieuwe, verhelderende perspectieven aan het licht brengen die kunnen worden
gebruikt om de kwaliteit van de zorgrelaties en daarmee de kwaliteit van zorg te verbeteren.

In de langdurige zorg zijn de ervaringen van cliënten over de kwaliteit van zorg lange tijd kwantitatief onderzocht om algemeen geldende uitkomsten op organisatie- of locatieniveau te genereren. In de praktijk en op beleidsniveau is een groeiende interesse en behoefte zichtbaar voor kwalitatieve kwaliteitsinformatie waarin cliëntervaringen meer individueel en diepgaand in beeld wordt gebracht gebaseerd op wat cliënten zelf belangrijk vinden. Kwalitatieve kwaliteitsinformatie biedt zorgprofessionals inzicht in concrete en gedetailleerde ervaringen van cliënten en bijbehorende verbeterpunten.

Het doel van dit onderzoek was om kwalitatieve instrumenten te ontwikkelen die cliënten als co-onderzoekers kunnen toepassen om de kwaliteit van de zorgrelaties in de langdurige zorg vanuit cliëntperspectief in beeld te brengen en te verbeteren.

Vanuit de doelstelling zijn drie onderzoeksvragen geformuleerd:

1. *Wat zijn determinanten van de kwaliteit van de zorgrelatie in de langdurige zorg voor verschillende cliëntengroepen, volgens cliënten en zorgprofessionals?* (Hoofdstuk 3 en 4)

2. *Welke kwalitatieve instrumenten kunnen gebruikt worden door co-onderzoekers om de kwaliteit van de zorgrelatie in beeld te brengen vanuit cliëntperspectief overstijgend aan verschillende cliëntengroepen in de langdurige zorg?* (Hoofdstuk 5)

3. *Welke lessen kunnen worden getrokken uit de samenwerking met cliënten die betrokken waren als co-onderzoekers in drie participatieve teams in de langdurige zorg?* (Hoofdstuk 6)

De onderzoeksvragen worden in de onderstaande samenvattingen van de hoofdstukken beantwoord.

**Hoofdstuk 2**

In hoofdstuk 2 staat het onderzoeksprotocol van de studie beschreven. De studie is uitgevoerd in drie zorgorganisaties in Nederland. Elke zorgorganisatie biedt zorg aan één van de drie grootste cliëntengroepen uit de langdurige zorg: fysiek of mentaal kwetsbare ouderen, mensen met
psychische problemen, of mensen met een verstandelijke beperking. Het onderzoek bestond uit vijf fasen: voorbereiding, consultatie, selectie, evaluatie en disseminatie van de instrumenten.

- **Voorbereiding:** In de voorbereidende fase werden co-onderzoekers uitgenodigd om een actieve bijdrage te leveren in de onderzoeksteams. Daarnaast werden drie literatuurstudies uitgevoerd, waaronder één systematische review en twee scoping reviews. Voor de systematische review (zie hoofdstuk 3) zijn Engelstalige artikelen geselecteerd naar de determinanten van de zorgrelaties in de langdurige zorg. Met de scoping reviews werd de benodigde informatie verzameld over twee thema’s: cliëntparticipatie en bestaande kwalitatieve instrumenten. Eén scoping review is uitgevoerd om goede voorbeelden van cliëntparticipatie in de langdurige zorg te verzamelen om een participatiestrategie voor het onderzoek te kunnen formuleren. Met de andere scoping review en bijbehorende grijze literatuurstudie zijn bestaande kwalitatieve instrumenten geïnventariseerd waarmee de kwaliteit van leven en/of kwaliteit van zorg in de langdurige zorg in beeld werden gebracht vanuit cliëntperspectief.

- **Consultatie:** In de consultatiefase zijn cliënten en zorgprofessionals in de langdurige zorg geïnterviewd om de determinanten van de kwaliteit van de zorgrelatie in beeld te brengen vanuit beide perspectieven (zie hoofdstuk 4).

- **Selectie:** Vervolgens zijn belanghebbenden en experts gevraagd om de meest veelbelovende kwalitatieve instrumenten met een Delphi studie te selecteren door in drie rondes tot overeenstemming te komen. Per sector selecteerden zij twee kwalitatieve instrumenten, op basis van criteria zoals een duidelijke structuur, bruikbaarheid van de uitkomsten voor het in beeld brengen van de ervaringen van cliënten met de zorg(relatie) en mogelijke verbeterpunten, geschiktheid van het instrument in verschillende cliëntengroepen, en in hoeverre cliënten betrokken zijn of kunnen worden bij het toepassen van de instrumenten.

- **Evaluatie:** Gedurende de evaluatie werden de twee geselecteerde kwalitatieve instrumenten uitgetest en geëvalueerd binnen één sector van de langdurige zorg (gehandicaptenzorg, geestelijke gezondheidszorg, ouderenzorg). De beste kwalitatieve instrumenten zijn vervolgens uitgevoerd en geëvalueerd in de andere twee sectoren, om te onderzoeken of deze instrumenten sectoroverstijgend kunnen worden ingezet (zie hoofdstuk 5 en 6).
• **Disseminatie:** In de disseminatiefase is een toolbox ontwikkeld voor de toepassing van de geselecteerde kwalitatieve instrumenten. In de toolbox staat ook beschreven voor welke doeleinden de geselecteerde kwalitatieve instrumenten kunnen worden ingezet.

**Hoofdstuk 3**

Wat bepaalt de kwaliteit van de zorgrelatie tussen cliënten en zorgprofessionals in de langdurige zorg? Met een systematische literatuurstudie is inzichtelijk gemaakt welke factoren - oftewel determinanten - bijdragen aan de kwaliteit van een betekenisvolle zorgrelatie tussen cliënten en zorgprofessionals in de langdurige zorg. Voor de literatuurstudie zijn de elektronische zoeksystemen Medline, Psycinfo, CINAHL en Embase systematisch doorzocht op publicaties vanaf 2006 tot 6 augustus 2018. Er werden artikelen geselecteerd die voldeden aan de volgende criteria:

a. Het onderwerp is gericht op determinanten van de kwaliteit van zorgrelaties tussen cliënten en zorgprofessionals in de langdurige zorg.
c. Het gaat om professionals waarvan cliënten terugkerende fysieke of ondersteunende zorg ontvangen voor een langdurige periode, zowel in een intramurale of ambulante setting. Bijvoorbeeld verpleegkundigen, verzorgenden, en persoonlijk begeleiders.
d. Artikelen bevatten primair empirische data en zijn gepubliceerd in een peer-reviewed tijdschrift.
e. De studie is uitgevoerd in Europa (EU-27) of één van de G7 landen (de VS, Canada, Australië, Nieuw Zeeland of Japan).
f. Het artikel is geschreven in het Engels.

Na een eerste selectie op basis van titel en samenvatting zijn de mogelijken relevante artikelen volledig gelezen. Er zijn 32 artikelen uit een totaal van 11.339 geselecteerd. Vooral artikelen over kwalitatieve studies voldeden aan de inclusiecriteria. In totaal bleken 27 determinanten beschreven die gecategoriseerd werden op vier niveaus: vanuit de cliënt, vanuit de professional, in de interactie tussen de cliënt en professional, en vanuit de context waarin het contact plaatsvindt. Een overzicht van de determinanten staat weergegeven in tabel 9.1.
De uitkomsten van de systematische review laten zien dat een meerderheid van de determinanten gelden voor meer dan één cliëntengroep uit de langdurige zorg: de meeste determinanten gelden voor twee of alle drie de cliëntengroepen en blijken daarmee sectoroverstijgend te zijn. Dit impliceert dat wetenschappelijk onderzoek en kwaliteitsonderzoek dat gericht is op de langdurige zorgrelatie niet noodzakelijk op één specifieke cliëntgroep gericht hoeft te zijn. Artikelen gericht op mensen met een verstandelijke beperking waren schaars, wat in minder bevindingen voor deze groep resulteerde. De meeste determinanten zijn gevonden op het niveau van de zorgprofessional en op dat van de interactie tussen cliënt en zorgprofessional.

**Tabel 9.1 Determinanten uit de systematische review**

<table>
<thead>
<tr>
<th>Cliënt</th>
<th>Professional</th>
<th>Interactie tussen cliënt en professional</th>
<th>Context</th>
</tr>
</thead>
<tbody>
<tr>
<td>Houding</td>
<td>Luisteren **</td>
<td>Gelijkwaardigheid</td>
<td>Tijd</td>
</tr>
<tr>
<td>Cliënt aan zet **</td>
<td>Betrouwbaar **</td>
<td>Vertrouwen</td>
<td>Setting **</td>
</tr>
<tr>
<td>Vaardigheden **</td>
<td>Focus op individuele cliënt</td>
<td>Nabijheid versus professionele afstand</td>
<td>Hiërarchie *</td>
</tr>
<tr>
<td>Aanpassen **</td>
<td>Zorgzaam **</td>
<td>Continuïteit **</td>
<td></td>
</tr>
<tr>
<td>Eerdere levenservaringen *</td>
<td>Beschikbaar zijn</td>
<td>Wederkerigheid</td>
<td></td>
</tr>
<tr>
<td>Emotionele staat *</td>
<td>Tijd nemen</td>
<td>Sociale interactie **</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Professionele competenties</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Aanmoediging</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Iets extra's doen</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Houding</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Samenwerking in team **</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Taakgerichtheid *</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Een sterretje (*) staat achter de determinanten die naar voren kwamen in 1 cliëntengroep/sector.
Twee sterretjes (**) staan achter de determinanten die naar voren kwamen in 2 cliëntengroepen/sectoren.
Hoofdstuk 4

Wat maakt de relatie tussen cliënt en zorgprofessional betekenisvol en prettig, en wat juist niet? En in hoeverre verschillen deze determinanten tussen cliëntgroepen van de drie langdurige zorg sectoren? Naast de systematische literatuurstudie is een aanvullend kwalitatief participatief onderzoek uitgevoerd om antwoord op deze twee vragen te vinden. Het doel van dit onderzoek was om a) de determinanten te vinden van de kwaliteit van de zorgrelatie tussen een cliënt en professional in de langdurige zorg en b) na te gaan in hoeverre de determinanten sectorspecifiek of juist sectoroverstijgend – en langdurige zorg breed – gelden. Voor het onderzoek zijn 30 cliënten individueel geïnterviewd en 29 zorgprofessionals bevraagd in vier focusgroepen. Het onderzoek was gericht op ouderen met een fysieke of mentale kwetsbaarheid (verpleging, verzorging en thuiszorg), mensen met psychische problemen (geestelijke gezondheidszorg) en mensen met een lichte tot matige verstandelijke beperking (gehandicaptenzorg). Doordat cliënten zowel intramuraal als ambulant zorg ontvingen werd een verscheidenheid aan cliënten geïnterviewd. De geïnterviewde cliënten ontvingen minimaal wekelijks terugkerende zorg in de afgelopen drie maanden.

Het onderzoek werd uitgevoerd in drie zorgorganisaties door drie onderzoeksteams bestaande uit 3-4 co-onderzoekers (mensen met ervaringskennis als zorgontvanger) en twee onderzoekers. In elk onderzoeksteam bereidden we het onderzoek eerst voor door een topiclijst en een uitnodiging op te stellen voor de respondenten van elke zorgorganisatie. Ook oefenden we in trainingsbijeenkomsten met interviewen. Daarna werden cliënten uitgenodigd voor een interview door een co-onderzoeker of onderzoeker. Elk interview werd uitgevoerd door een duo van één co-onderzoeker en één onderzoeker waarbij de rolverdeling onderling werd bepaald. Gedurende het onderzoek kwamen de onderzoeksteams bij elkaar in werkbijeenkomsten om over de opgedane ervaringen te praten en de resultaten te bespreken. De posters waarop de uitkomsten werden opgeschreven, vormden de open codes die gebruikt werden bij het schriftelijke analyseproces. Vervolgens analyserden twee onderzoekers alle woordelijk uitgeschreven interviews en focusgroepen door deze achtereenvolgens open, axiaal en selectief te coderen.

De gevonden determinanten zijn weergegeven in tabel 9.2. Overeenkomstig met de systematische literatuurstudie bleken veel
determinanten van de zorgrelatie voor alle drie de sectoren van de langdurige zorg te gelden. In totaal werden 25 sectoroverstijgende determinanten gevonden; 5 andere determinanten goldendel enkel in één of twee sectoren. De reeds bekende determinanten werden aangevuld door enkele nieuwe determinanten, waaronder enkele over de inbreng van cliënten in een zorgrelatie: hulp vragen, feedback vragen en respect tonen. Dit kwalitatieve onderzoek resulteerde daarnaast in nieuwe inzichten in determinanten van de kwaliteit van de zorgrelatie voor cliënten met een verstandelijke beperking, waarover nog weinig bekend was.

Tabel 9.2 Determinanten uit de kwalitatieve studie

<table>
<thead>
<tr>
<th>Client</th>
<th>Professional</th>
<th>Interactie tussen cliënt en professional</th>
<th>Context</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hulp vragen</td>
<td>Luisteren</td>
<td>Gelijkwaardigheid</td>
<td>Continuïteit</td>
</tr>
<tr>
<td>Feedback geven</td>
<td>Betrouwbaar</td>
<td>Vertrouwen</td>
<td>Gebrek aan tijd en beperkte financiële middelen</td>
</tr>
<tr>
<td>Open houding</td>
<td>Focus op de individuele cliënt</td>
<td>Nabijheid versus professionele afstand</td>
<td>Faciliteiten</td>
</tr>
<tr>
<td>Respect</td>
<td>Steun</td>
<td>Klik</td>
<td>Steun van management **</td>
</tr>
<tr>
<td>Zelfregie</td>
<td>Beschikbaar zijn</td>
<td>Relatie opbouwen</td>
<td>Beperkingen door wet- en regelgeving **</td>
</tr>
<tr>
<td>Aanpassen</td>
<td>Professionele competenties</td>
<td>Humor **</td>
<td></td>
</tr>
<tr>
<td>Functie van de relatie **</td>
<td>Aanmoedigen</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitieve vaardigheden **</td>
<td>Kenmerken van de professional</td>
<td>Empathisch vermogen</td>
<td></td>
</tr>
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<td></td>
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</tr>
</tbody>
</table>

Een sterretje (*) staat achter de determinanten die voren kwamen in 1 cliëntengroep/sector. Twee sterretjes (**) staan achter de determinanten die naar voren kwamen in 2 cliëntengroepen/sectoren.
Hoofdstuk 5

In de vervolgstudie werden vijf kwalitatieve meetinstrumenten geëvalueerd die de zorgrelatie vanuit cliëntperspectief in beeld brengen. Innovatief hierbij was de inbreng van ervaringsdeskundige cliënten, die zelf als co-onderzoekers de kwalitatieve instrumenten toepassen door andere cliënten te interviewen of groepsgesprekken te leiden. Met een Delphi studie selecteerden experts en belanghebbenden (onder andere vertegenwoordigers van zorgorganisaties en brancheorganisaties, co-onderzoekers, landelijke cliëntenkoepelorganisaties) twee instrumenten per sector in de langdurige zorg uit een totaal van 23 geïnventariseerde instrumenten. Vervolgens werden de instrumenten inhoudelijk aangepast zodat co-onderzoekers de instrumenten konden uitvoeren en inhoudelijk toegesplitst om de kwaliteit van de zorgrelatie te evalueren. De drie geïncludeerde doelgroepen zijn: ouderen met een fysieke of mentale kwetsbaarheid, mensen met psychische problemen en mensen met een lichte tot matige verstandelijke beperking. Co-onderzoekers pasten in drie onderzoeksteams de kwalitatieve instrumenten per zorgorganisatie toe. De kwalitatieve instrumenten werden geëvalueerd op twee kernpunten: uitvoerbaarheid van het instrument en bruikbaarheid van de uitkomsten. Nadat in elke sector twee instrumenten waren geëvalueerd, zijn de drie instrumenten die het hoogste scoorden sectoroverstijgend geëvalueerd om na te gaan of instrumenten ook in verschillende cliëntengroepen kunnen worden toegepast. Aangezien de uitvoerbaarheid en bruikbaarheid afhingen van de wisselwerking tussen een cliënt, co-onderzoeker en interviewondersteuner, omvatte de evaluatie directe observaties van alle betrokkenen en werden daarnaast de ervaringen van co-onderzoekers, cliënten, zorgprofessionals en de ondersteuners van de interviews meegenomen.

De co-onderzoekers pasten de instrumenten toe door ofwel cliënten zelfstandig te interviewen of met ondersteuning van een interviewondersteuner. De co-onderzoeker en interviewondersteuner verdeelden de taken onderling op basis van de individuele vaardigheden van co-onderzoekers. De interviewondersteuner hielp meestal met doorvragen, samenvatten, het maken van aantekeningen en het opstellen van een verslag naderhand. De twee kwalitatieve instrumenten ‘WIEK interview’ en ‘Luister

1 De interviewondersteuner was een ervaren co-onderzoeker of iemand anders met interviewvaardigheden.
naar mijn verhaal’ (in het Engels: participatory narrative inquiry) bleken geschikt te zijn om door co-onderzoekers in de langdurige zorg breed te worden toegepast. Kenmerkend aan beide instrumenten is de duidelijke en gemakkelijke structuur, de open kwalitatieve en diepgaande benadering, en de persoonlijke interview setting.

**WIEK interview**

“WIEK-interview” is ontwikkeld om de kwaliteit van de individuele zorgrelatie te evalueren tussen één specifieke cliënt en zijn/haar zorgprofessional. Cliënten worden uitgenodigd om uit tien themakaarten twee kaarten te kiezen waarover zij willen vertellen in het interview. De resultaten van het WIEK-instrument bieden de betreffende zorgprofessional inzicht in de ervaringen van de cliënt en mogelijke verbeterpunten. Dankzij de individuele benadering is het WIEK-interview geschikt voor alle drie de sectoren in de langdurige zorg. Cliënten vonden de WIEK kaarten aantrekkelijk en handig om onderwerpen te kiezen die zij wilden bespreken. Tegelijkertijd boden de kaarten co-onderzoekers handvatten om vragen te stellen over de gekozen thema’s.

**Luister naar mijn verhaal**


**Hoofdstuk 6**

Hoewel cliënten die langdurig zorg ontvangen de afgelopen decennia actiever betrokken worden in onderzoek en kwaliteitsverbetering, is er nog een tekort aan praktische kennis hoe participatief onderzoek optimaal kan worden vormgegeven. Met een multiple case study design werd de
samenwerking tussen onderzoekers en co-onderzoekers in de drie onderzoeksteams verkend. Twee elementen bleken cruciaal voor de samenwerking: het creëren van een geschikte werkomgeving en het opbouwen van een goede samenwerking.

Vijf randvoorwaarden voor het creëren van een geschikte werkomgeving bij aanvang van participatief onderzoek kwamen uit dit onderzoek naar voren: 1) bespreken van de wensen van co-onderzoekers en hun motivatie om mee te doen, 2) basisafspraken maken voor de samenwerking, 3) training in open interviewvaardigheden, 4) beschikbaarheid van de onderzoeker voor het bieden van (reis)ondersteuning, 5) financiële waardering.

Zes randvoorwaarden bleken van invloed op de daadwerkelijke samenwerking: 1) ontwikkeling van een band tussen teamleden, 2) een duidelijke rolverdeling tussen co-onderzoekers en onderzoekers, 3) transparantie en ruimte voor feedback, 4) behoefte aan structuur, 5) gelijke positionering, 6) voldoende tijd voor de coördinatie en communicatie.

Qua motivaties vertelden co-onderzoekers dat ze niet alleen betrokken waren vanwege hun bijdrage aan kwaliteitsverbetering. Zij vond het ook fijn om van waarde te zijn voor andere cliënten, deel uit te maken van een sociale groep als teamlid en een nieuwe sociale identiteit te creëren. Ook vertelden co-onderzoekers dat ze het leuk vonden om nieuwe vaardigheden te leren en te werken aan hun persoonlijke ontwikkeling.

De studie laat grote verschillen zien in de vaardigheden en ondersteuningsbehoeften tussen co-onderzoekers uit verschillende sectoren van de langdurige zorg. In het GGZ-team hadden sommige co-onderzoekers hun interviewervaringen reeds ontwikkeld vanwege hun werk als ervaringsdeskundige. Deze co-onderzoekers gaven de co-onderzoekers uit de andere onderzoeksteam interviewondersteuning en ondersteunden waar nodig bij het doorvragen, samenvatten en aantekeningen maken. In het GZ-team waren de co-onderzoekers zeer optimistisch over hun rol, maar zij hadden geen behoefte om cliënten onafhankelijk te interviewen. In het ouderen-team relateerden co-onderzoekers de ervaringen van cliënten vaak aan hun eigen ervaringen en waarden. Deze co-onderzoekers vonden het fijn om hulp te krijgen van interviewondersteuners bij o.a. het stellen van open, niet-sturende vragen. De geboden ondersteuning van interviewondersteuners en de coördinerende onderzoeker waren het resultaat van een continu proces van afstemming en verschilde daarom tussen individuele co-onderzoekers en teams, en veranderde soms ook in de loop van de tijd. Bij de samenwerking blijkt een individuele benadering van belang om bij de
individuele mogelijkheden en behoeften van elke co-onderzoeker aan te sluiten. Ongeacht de individuele vaardigheden van co-onderzoekers hechtten vrijwel alle co-onderzoekers een grote persoonlijke waarde aan de samenwerking en hun bijdrage.

**Meerwaarde van dit onderzoek**

Dit proefschrift heeft op meerdere manieren meerwaarde voor de wetenschappelijke literatuur en langdurige zorgverlening in de praktijk. Ten eerste is dit de eerste studie waarin een uitgebreid en systematisch overzicht geboden wordt van de determinanten van de kwaliteit van zorgrelaties tussen cliënten en professionals in de langdurige zorg. Ten tweede is het proefschrift uniek doordat het gericht is op drie verschillende cliëntengroepen uit de langdurige zorg waardoor de overeenkomsten en verschillen in determinanten van de kwaliteit van zorgrelaties konden worden bestudeerd. Er bleken veel sectoroverstijgende determinanten voor de kwaliteit van zorgrelaties te zijn wat impliceert dat een sectorspecifieke focus niet noodzakelijk is bij het onderzoeken of evalueren van de kwaliteit van zorgrelaties. Ten derde werden vijf kwalitatieve instrumenten geëvalueerd om erachter te komen welk instrument het best uitvoerbaar was en bruikbare resultaten opleverde. Het ontwikkelen en evalueren van kwalitatieve instrumenten voor praktisch gebruik vergemakkelijkt het gebruik van de onderzoeksresultaten in de praktijk. Ten vierde bieden de geleerde lessen over de participatieve samenwerking tussen co-onderzoekers en onderzoekers in de drie onderzoeksteams inzicht in de manier waarop participatief onderzoek in de toekomst kan worden vormgegeven. De kwalitatieve instrumenten "WIEK-interview" en "Luister naar mijn verhaal" kunnen in alle drie de sectoren door co-onderzoekers worden toegepast om de kwaliteit van zorgrelaties in een zorgorganisatie in beeld te brengen.

**Methodologische reflectie**

Op verschillende aspecten van de methoden wordt in deze paragraaf gereflecteerd, omdat ze hebben bijgedragen aan de kwaliteit van de onderzoeksuitkomsten of de kwaliteit juist hebben verminderd.

Allereerst is het belangrijk dat in het onderzoek een correcte interpretatie van de perspectieven van respondenten wordt weergegeven. De betrokkenheid van co-onderzoekers vergrootte de inbreng en bijdrage van
cliënten aan de onderzoeksopzet, de uitvoering van het onderzoek, en de analyse en interpretatie van de bevindingen. Daarnaast werd na elk interview of na iedere focusgroep in hoofdpunten een samenvatting gegeven van het verhaal van een cliënt als directe member check bij de respondenten. Daarnaast kan men zich afvragen of de interne validiteit gewaarborgd is na aanpassing van de instrumenten. De inbreng van co-onderzoekers, de onderzoekers triangulatie, en de consultatie van de ontwikkelaar van elk instrument hebben bijgedragen aan passende formuleringen van de interviewvragen. Daarnaast biedt de open structuur van de instrumenten cliënten de mogelijkheid om te vertellen wat zij zelf belangrijk vinden.

Een tweede kwestie is in hoeverre de resultaten overdraagbaar zijn naar andere zorgcontexten. In de beschrijving van de methoden van elk artikel staat gedetailleerd beschreven wat de doelgroep is en op welke wijze de steekproef is getrokken, zodat lezers een goede inschatting van de overdraagbaarheid naar de eigen context kunnen maken. De manier van selectie van de zorgorganisaties door convenience sampling beperkt de overdraagbaarheid. Zorgorganisaties besloten zelf of ze aan de studie wilden deelnemen. Daarnaast hadden de betrokken co-onderzoekers mogelijk andere vaardigheden en ondersteuningsbehoeften dan de co-onderzoekers die in de toekomst instrumenten gaan toepassen. Doordat de teams relatief variabel en groot waren (5-6 co-onderzoekers per team), geven de teams wel een goede impressie van de mogelijke vaardigheden van toekomstige co-onderzoekers.

Een derde kwestie is of de uitkomsten logisch, herleidbaar en goed gedocumenteerd zijn, zodat het onderzoek in de toekomst door een andere onderzoeker kan worden herhaald. Voor dit doel zijn de methoden van elke deelstudie gedetailleerd beschreven. Ook werd het proces van de participatieve samenwerking in hoofdstuk 6 uitgebreid beschreven om de repliceerbaarheid te vergroten. Bovendien is een persoonlijke reflectie op het participatieve onderzoek toegevoegd van de onderzoeker en twee co-onderzoekers in hoofdstuk 8 om ook inzicht te bieden in onze persoonlijke ervaringen. Alle kwalitatieve data, zowel ruwe als bewerkte data, zijn op verzoek beschikbaar.

Er werd gekozen voor de doorontwikkeling van bestaande kwalitatieve instrumenten, die met een Delphi studie werden geselecteerd door belanghebbenden en experts. Doordat het proces en de uitkomsten van deze
Delphi studie staan beschreven in een Nederlands overzicht, is de inzichtelijkheid en replicaerbaarheid voor een Engelstalig publiek beperkt. Daarnaast heeft het vasthouden aan de structuur van bestaande instrumenten als consequentie dat er niet vrijuit nieuwe mogelijkheden konden worden toegevoegd. Het ontwikkelen van een nieuw instrument had daarom mogelijk in een ander instrument geresulteerd.

Een vijfde kwestie is of de resultaten bevestigd kunnen worden door andere onderzoekers. De dubbele interpretatie van de interviewgegevens door twee of drie onderzoekers had als doel om de invloed van een enkele onderzoeker te verminderen. In de hele studie werden peer debriefings en onderzoekerstriangulatie gebruikt tijdens de dataverzameling en data analyse om betrouwbaarheid van de bevindingen te vergroten. Dilemma’s en vragen die gedurende het onderzoek naar voren kwamen, werden bediscussieerd in het promotieteam zodat onderzoekers met wat meer afstand tot de dataverzameling mee konden denken wat de onderzoekers betrouwbaarheid ten goede kwam.

Het aantal co- onderzoekers van elk team was pragmatisch gekozen. Het is de vraag of het huidige aantal co- onderzoekers de resultaten heeft beïnvloed. Aan de ene kant zou een kleiner aantal co- onderzoekers tot een langere leercurve hebben geleid doordat er per persoon meer interviews zouden zijn uitgevoerd. Aan de andere kant zouden individuele kenmerken van co- onderzoekers meer invloed op de resultaten hebben gehad wat minder duidelijk zou hebben gemaakt wat de vaardigheden van elke cliëntengroep zijn terwijl dit nuttige informatie biedt voor toekomstige implementatie.

**Aanbevelingen voor toekomstig onderzoek**

Op basis van de uitkomsten van deze studie kunnen een aantal mogelijkheden voor toekomstig onderzoek worden geformuleerd. Dit proefschrift leidde tot inzicht in de determinanten van de kwaliteit van zorgrelaties in de langdurige zorg. Het is echter nog niet onderzocht welke determinanten het meest invloedrijk of belangrijk zijn voor de kwaliteit van de zorgrelatie en of er verschillen zijn tussen subgroepen van cliënten (bijvoorbeeld sekse). Het is ook nog niet duidelijk aan welke determinanten van de zorgrelatie het meest of minst vaak wordt voldaan. Tenslotte is nog niet onderzocht of de toepassing van de twee geselecteerde instrumenten daadwerkelijk leidt tot een hogere kwaliteit van de zorgrelaties.
Dit onderzoek is enkel gericht op zorgrelaties tussen cliënten en zorgprofessionals; andere relaties zijn niet onderzocht zoals de relatie tussen cliënten en hun familieleden, familieleden en professionals, tussen cliënten onderling, en werkrelaties tussen zorgprofessionals. Deze relaties zijn mogelijk interessant om in toekomstig onderzoek te bestuderen. Ook is onbekend wat de determinanten van de zorgrelaties zijn van degenen die niet zelf over hun ervaringen kunnen praten, zoals mensen met vergevorderde dementie of een ernstige verstandelijke beperking.

Tenslotte kan de structurele implementatie van co-onderzoekers in kwaliteitsverbetering worden onderzocht, en wat voor invloed actieve cliëntbetrokkenheid heeft op de bestaande machtsverhoudingen tussen cliënten en professionals. Ook kan meer inzicht worden verkregen in de leercurves en vaardigheden van co-onderzoekers van verschillende cliëntengroepen.

**Implicaties voor de praktijk**

**Gedeelde verantwoordelijkheid**

Vanuit de resultaten wordt de gedeelde verantwoordelijkheid van zorgprofessionals en cliënten met betrekking tot de kwaliteit van hun zorgrelatie benadrukt. Beide partijen zijn in staat invloed uit te oefenen en te werken aan de zorgrelatie. Determinanten zoals wederkerigheid, gelijkheid en het vermogen van cliënten om hulp te vragen en feedback te geven weerspiegelen de actieve rol van cliënten. Met de actieve betrokkenheid van co-onderzoekers bij kwaliteitsinstrumenten wordt deze gedeelde verantwoordelijkheid onderkend en zichtbaar gemaakt.

**Continue reflectie en leren**

Zorgprofessionals ontwikkelen en onderhouden zorgrelaties met cliënten in een organisatie specifieke context. Als zorgorganisaties streven naar een lerende cultuur worden professionals aangemoedigd na te denken over de gevolgen van bepaalde acties en interacties. Het opnemen van het cliëntperspectief in deze reflecties is cruciaal om de kwaliteit van zorgrelaties te optimaliseren en verandering vanuit cliëntperspectief mogelijk te maken. De kwalitatieve instrumenten 'WIEK-interview' en 'Luister naar mijn verhaal' zijn bedoeld om te resulteren in bruikbare verbetersuggesties van cliënten. Deze suggesties helpen professionals na te denken over de manier
waarop ze de kwaliteit van een zorgrelatie bepalen en verder kunnen verbeteren.

**Organisatiebeleid**
Op organisatieniveau is beleid nodig om de ontwikkeling en het onderhouden van kwalitatief hoogwaardige zorgrelaties met cliënten te faciliteren. Door bijvoorbeeld een klein aantal professionals de zorg te laten verlenen aan één cliënt, kunnen cliënt en professional elkaar goed leren kennen en een band opbouwen. Daarnaast leert een professional op deze manier beter de wensen en behoeften van een cliënt kennen en kan hij/zij daarop inspelen. Een meer flexibel verantwoordingsbeleid van de gemaakte uren kan professionals de mogelijkheid geven om variërende zorgbehoeften in acht te nemen en bijvoorbeeld meer tijd te besteden aan een nieuwe cliënt. Technische faciliteiten voor professionals zoals mobiele telefoons verlagen de drempel voor cliënten om contact op te nemen. Als laatste redmiddel kan cliënten en professionals de mogelijkheid worden geboden om een andere persoon te vragen wanneer het echt niet werkt in een bepaalde zorgrelatie.

**De waarde van kwalitatieve instrumenten**
In deze studie werden kwalitatieve instrumenten (door)ontwikkeld en geëvalueerd voor het in beeld brengen van de kwaliteit van zorgrelaties. Kwalitatieve instrumenten worden gekenmerkt door openheid en diepgaand interviewen, waarmee de individuele cliëntervaringen, variatie en de dynamiek van een zorgrelatie in beeld wordt gebracht. De geselecteerde kwalitatieve instrumenten bleken in deze studie aan individuele cliënten te kunnen worden aangepast en gaven een cliënt de mogelijkheid om de onderwerpen te kiezen die voor hem of haar op een bepaald moment het meest relevant waren. Het doel van een kwalitatief instrument was hierbij niet om de uitkomsten te generaliseren naar alle cliënten, maar om de diversiteit en individualiteit van de ervaringen van sommige klanten in beeld te brengen. De toepassing van kwalitatieve instrumenten bleek professionals concrete informatie en inzicht in verbeterpunten vanuit cliëntperspectief te bieden.
**Tot slot**

Met de resultaten van dit proefschrift wordt duidelijk gemaakt wat de toegevoegde waarde is van het in beeld brengen van de kwaliteit van zorgrelaties met behulp van kwalitatieve meetinstrumenten die worden toegepast door co-onderzoekers. De determinanten van de kwaliteit van langdurige zorgrelaties toonden aanzienlijke overeenkomsten voor de verschillende sectoren in de langdurige zorg. De studie resulteerde in twee kwalitatieve instrumenten voor zorgorganisaties en cliëntenraden om kwaliteitsinformatie en feedback van cliënten over zorgrelaties in de langdurige zorg te verzamelen met de hulp van co-onderzoekers. Met de ontwikkelde toolbox kunnen co-onderzoekers, cliëntenraden en zorgorganisaties de instrumenten "WIEK-interview" en "Luister naar mijn verhaal" in de toekomst zelfstandig toepassen. Beide instrumenten zijn uitgebreid beschreven in een online toolbox die beschikbaar is via www.nivel.nl/toolbox-hzs.
Samenvatting door co-onderzoekers
Deze samenvatting is geschreven samen met vijf co-onderzoekers die aan het onderzoek hebben meegewerkt.

Het doel van dit onderzoek is het in beeld brengen van de zorgrelatie tussen cliënt en medewerker en als het nodig is deze relatie te verbeteren.

Met de zorgrelatie bedoelen we de opgebouwde vertrouwensband of omgang tussen cliënt en medewerker.

Het onderzoek gaat over cliënten die langdurig zorg krijgen. Dit zijn mensen met een psychische kwetsbaarheid, ouderen en mensen met een verstandelijke beperking.

De medewerker is degene die de cliënt het vaakst ziet: bijvoorbeeld de persoonlijk begeleider, verpleegkundige of verzorgende.

Voor en door cliënten met ervaringskennis

Dit onderzoek is uitgevoerd samen met mensen die zelf langdurige zorg krijgen of kregen, ook wel co-onderzoekers genoemd. We hebben gemerkt dat mensen het makkelijker vinden om met ons als co-onderzoekers te praten, omdat we zelf ook in een soortgelijke situatie hebben gezeten.

Er zijn drie teams gemaakt met 4 tot 6 co-onderzoekers en 2 onderzoekers van het Nivel. De drie teams werkten elk aan het onderzoek bij 1 zorgorganisatie.

We hebben samen de uitnodiging geschreven voor cliënten, waarbij we zoveel mogelijk wilden aansluiten bij de beleving van de cliënten, zodat zij mee wilden doen.

Ook bedachten we zelf de vragen voor de interviews in de teams, en we waren vrij om zelf te kiezen welke woorden we wilden gebruiken en welke vragen het beste waren om te stellen.

In elk team hebben we afspraken gemaakt. Bijvoorbeeld dat we de namen van cliënten niet zouden noemen. Daarnaast konden wij en ook de cliënten altijd afzeggen als er iets was.
We hebben in een training geoefend met interview vragen die uitnodigen om te vertellen. Zo kregen we zelfvertrouwen en wisten we wat we gingen doen.
Daarna begon het onderzoek, waarin we mensen gingen interviewen. Het onderzoek bestond uit verschillende delen.

1. **Wat beïnvloedt de zorgrelatie?**

In het eerste onderzoek hebben we gekeken naar wat de zorgrelatie tussen een cliënt en een medewerker beïnvloedt. Wat maakt een zorgrelatie fijn, wat niet? Dit is op 2 manieren onderzocht:

- We hebben zelf 30 cliënten apart geïnterviewd en 29 medewerkers geïnterviewd in vier groepsgesprekken. Dit deden we in tweetallen van 1 co-onderzoeker en 1 onderzoeker.
- Daarnaast hebben de onderzoekers eerdere onderzoeken opgezocht en gelezen. Dit heet een literatuurstudie.

We zagen dat verschillende factoren de zorgrelatie beïnvloeden:

- factoren die gaan over de rol van de cliënt;
- factoren die gaan over de rol van de medewerker;
- factoren die gaan over het contact tussen cliënt en medewerker;
- factoren die gaan over de organisatie.

De uitkomsten staan hieronder. Als iets uit onze interviews kwam, staat er dit plaatje van een interview achter. Als iets uit de literatuurstudie komt, staat er een plaatje van een boek achter.
Wat doen cliënten zelf voor een prettige relatie met de medewerker?
• De cliënt vraagt om hulp.
• De cliënt geeft feedback en zegt wat hij/zij wil.
• De cliënt staat open voor contact.
• De cliënt neemt de medewerker serieus en heeft respect.
• De cliënt heeft zelf inbreng en controle.
• De cliënt past zich aan en werkt mee.

Wat zorgt vanuit cliënten voor een minder fijne relatie met de medewerker?
• Een cliënt hoort slecht of vindt praten lastig.
• Boosheid, frustratie of angst.

Wat doen medewerkers voor een fijne relatie?
• De medewerker luistert naar de cliënt.
• De medewerker ziet aan de cliënt hoe diegene zich voelt.
• De medewerker kijkt naar wat de cliënt nodig heeft.
• De medewerker heeft aandacht en toont interesse.
• De medewerker neemt de cliënt serieus.
• De medewerker vertelt privé informatie van cliënten niet door.
• De medewerker doet extra moeite voor de cliënt.
• De medewerker kent de cliënt en zijn/haar wensen.
• De medewerker steunt en helpt de cliënt.
• De medewerker neemt de tijd voor de cliënt.
• De medewerker is bereikbaar als de cliënt iemand nodig heeft.
• De medewerker reageert snel.

Wat zorgt vanuit de medewerker voor een minder fijne relatie?
• De medewerker begrijpt de cliënt niet.
• De medewerker helpt de cliënt niet.
• De medewerker vertelt de cliënt niet genoeg over wat er gebeurt.
• De medewerker behandelt de cliënt niet met respect, en lacht de cliënt bijvoorbeeld uit.

Wat zorgt tussen cliënt en medewerker voor een goede relatie?

• De cliënt en medewerker kunnen elkaar vertrouwen.

• Er is een klik tussen de cliënt en de medewerker.

• De medewerker staat niet boven, maar naast de cliënt.

• De cliënt en medewerker kunnen dingen delen over wat ze meemaken, maar ook dingen voor zichzelf houden als ze dat fijner vinden.

• De cliënt en medewerker dragen allebei bij aan de relatie.

• De cliënt en medewerker bouwen een relatie op en werken eraan.

• De cliënt en medewerker kunnen samen lachen.
Wat maakt de zorgrelatie minder goed tussen cliënt en medewerker?

- De medewerker plaatst de cliënt in een hokje.
- De medewerker is bazig.
- Er is geen klik tussen de cliënt en de medewerker.

Wat zorgt vanuit de organisatie voor een prettige relatie?

- Een klein team met vaste medewerkers.
- Medewerkers werken goed met elkaar samen.
- De organisatie regelt dingen goed in het gebouw en voor het contact.

Wat maakt vanuit de organisatie de zorgrelatie minder goed?

- Medewerkers hebben niet genoeg tijd voor de cliënt.
- Medewerkers gaan weg.
- De organisatie en wetten zorgen soms voor veel regels en administratie.

Er kwamen veel dezelfde factoren uit de onderzoeken voor ouderen, mensen met een beperking en mensen met een psychische kwetsbaarheid. Voordat we aan dit onderzoek begonnen, was dit nog niet duidelijk.
2. **Onderzoeken interviewmethoden**

Hierna hebben we verschillende manieren van interviewen uitgetest. Co-onderzoekers interviewden cliënten op verschillende manieren over hoe zij de zorgrelatie met hun medewerker vonden. Zo hebben we onderzocht of de manieren goed werken en verbeterpunten voor medewerkers opleveren.

Het waren allemaal “kwalitatieve methoden”, dat betekent dat mensen hun eigen verhaal mogen vertellen. Wij stelden als co-onderzoekers vragen over de zorgrelatie. Cliënten kozen zelf of ze thuis of in een vergaderruimte van de organisatie wilden worden geïnterviewd. De interviews duurden zo lang als nodig was.

Er zijn 5 manieren van interviewen onderzocht.

1. **Bij het WIEK interview** koos de cliënt 2 kaarten uit een totaal van 10 kaarten waar hij/zij over wilde praten. Over de twee thema’s van deze gekozen kaarten ging het interview.

2. **Bij het Feedbackgesprek** werd een groepsgesprek gevoerd met een groep cliënten met de medewerkers erbij. Hieruit kwamen 2 verbeterpunten voor de afdeling.

3. **Bij Luister naar mijn verhaal** kon iemand een zelfgekozen ervaringsverhaal over een gebeurtenis vertellen die indruk had gemaakt.

4. **Bij Ben ik tevreden** interviewden een co-onderzoeker en de persoonlijke medewerker een cliënt over de zorgrelatie met de aanwezige medewerker, zodat de uitkomsten meteen gebruikt konden worden door deze medewerker.

5. **Bij Cliënt over kwaliteit** interviewden een co-onderzoeker en iemand van het LSR2 (de ontwikkelaar van het instrument) een cliënt met vragen waarbij cliënten met een smiley konden antwoorden. Daarna was er een gesprek met begeleiders en cliënten zodat zij elkaars ervaringen en ideeën hoorden bij de uitkomsten.

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2 Het LSR is het landelijk steunpunt (mede)zeggenschap
Uitkomsten

Twee methoden kwamen als beste uit ons onderzoek naar voren: Wiek interview en Luister naar mijn verhaal. Cliënten konden met deze methoden echt hun persoonlijke ervaringen vertellen. Ook voor ons als interviewers waren deze methoden goed uit te voeren, door de duidelijke vragen en een makkelijke structuur. Ook bleken de uitkomsten voor medewerkers bruikbaar, treffend en duidelijk.

Het feedbackgesprek bleek niet passend voor ouderen en mensen met een verstandelijke beperking, vanwege de groepsbenadering. Veel mensen durfden niet hun ervaringen in een groep te vertellen. Sommige ouderen konden elkaar niet goed verstaan. Ook was het voor ons als co-onderzoekers lastiger om het gesprek in een groep goed te leiden.

De methode ‘Ben ik tevreden’ verliep moeizaam doordat cliënten het lastig vonden om direct aan de aanwezige medewerker te vertellen wat zij van de zorgrelatie vonden. Ook was het soms lastig afstemmen tussen de co-onderzoeker en de medewerker die samen interviewden.

‘Cliënt over kwaliteit’ bleek niet goed te werken omdat het interview te lang duurde. Dat kwam door de vele vaststaande vragen en het doorvragen op de gegeven antwoorden. Het spiegelgesprek leverde weinig nieuwe uitkomsten op, en cliënten vonden dit best spannend in het begin. Ook vonden cliënten het lastig om over één zorgrelatie te praten met de begeleiders en cliënten erbij.

Wat vonden we opvallend?

De gesprekken waren heel herkenbaar voor ons. We vonden het heel interessant om te doen. We waren ook geraakt door de verhalen van de cliënten. Cliënten waren open naar ons, en we voelden aan het eind van een gesprek al een band. Dat komt volgens ons doordat we ook cliënt zijn of zijn geweest. We merkten dat cliënten vrijuit konden praten zonder medewerkers erbij.
Onze ervaring met interviewen

- Het was heel leerzaam om mee te doen. We hebben onttzettend veel ervaring opgedaan.
- Onze ervaringskennis werd gewaardeerd. Hierdoor konden we cliënten op een speciale manier interviewen.
- We voelden ons welkom bij cliënten.

De ervaringen van twee co-onderzoekers staan in het verslag dat als bijlage is toegevoegd aan deze samenvatting.

Zelf hiermee aan de slag? Kijk op de website

Er is een website gemaakt over de twee interviewmethoden die als beste uit dit onderzoek kwamen: WIEK interview en Luister naar mijn verhaal. Op de website staat alles wat je nodig hebt om de interviews uit te voeren. Ook staan er korte filmpjes op de website waarin co-onderzoekers, de onderzoeker en medewerkers over hun ervaringen vertellen. Je kunt de website bezoeken via www.nivel.nl/hzs-toolbox.
Bijlage: Verslag van twee co-onderzoekers over het onderzoek.

Verslag Pierre de Ries, co-onderzoeker
Februari 2018 las ik in het Amsterdamse autisme café dat er co-onderzoekers gevraagd werden voor een onderzoek door het Nivel. Ik dacht, daar ben ik geknipt voor, want vragen stellen kan ik als de beste. Ik werd al snel gebeld of ik toestemde in een kennismakingsgesprek. Het gebeurde bij mij thuis, waarom weet ik niet meer, wellicht, om t prikkelvrij te houden. Men kent zn pappenheimers bij t Nivel, en dat gaf ook een stuk veiligheid, dat alleen al te vermoeden alleen al is fijn!

Er kwam een uiterst gezellige, vriendelijke, gericht vragen stellende dame binnen. Gedurende het gesprek merkte ik al, dat ik haar ingepakt had, omdat ik ook aantekeningen maakte. Daar kreeg ik een compliment om, en na het onderzoek had ik daar een rugzak vol van, i.p.v. alleen een ransel vol Asperger verleden als buitenstaander van t schoolplein de verjaardags bla bla. Ook al ben ik vol onzekerheid begonnen of ik wel kon en vol zou houden.

Dat heb ik inderdaad. Verrassend ook voor mij misschien, omdat ik het als een buitenkans zag mn eigen ervaring in te zetten om die band met de cliënten te voelen die professionals wellicht niet hebben, of daar geen tijd voor krijgen, en omgekeerd. Dat ik hierin slaagde merkte ik aan reacties van cliënten tijdens het afscheid nemen na het interview. Ik stelde blijkbaar mensen op hun gemak en kreeg daarom (?) bij het afscheid onverwacht ontroerende woorden mee, zoals “Dieren zullen altijd van je houden!”

Al snel was de eerste inwerkvergadering. Een wereldreis vol stress, op weg naar de training. Heeft U wel eens op straat diverse mensen gevraagd hoe google maps noord en zuid aangeeft interpreteert? Shit, wat eenzaam ben je dan, hulpeloze gezichten, ik verdwaalde en kwam later op locatie, wat moord is voor een Asperger! Nix aan de hand, iedereen was blij dat ik er was. Dit zou 3 keer gebeuren omdat ik stationsnamen verwisselde in volgorde, of appte dat ik er aan kwam, terwijl de halte gewoon sadistisch voorbij schoof. Maar de anderen uit het onderzoeksteam zeiden telkens “Ha daar is Pierre” alsof ze blij waren dat ik toch nog op mijn eigen verjaardag verscheen.

Nadat het doel v het onderzoek besproken was, gingen we samen de info brief voor cliënten opstellen. Verbazend dat we dit zelf mochten doen. Wat ik wel weer erg uitdagend vond en interessant, omdat
ieders talenten in het team bijdroegen aan een goede brief. Ik mocht al snel zinnen opstellen die cliënten zouden enthousiasmeren om mee te doen. Dit leek misschien zout op slakken leggen voor de anderen. Anderen corrigeerden mijn wat vormelijke taal. (zoals U heeft gelezen in uw leerboeken is dat een Asperger specialiteit....daarom floreren we bij de overheid).

In de eerste voorbeeld brief werden de cliënten naar mijn mening nog niet enthousiast genoeg gevraagd of ze mee wilden doen. Al werden ze wel van harte uitgenodigd zich te melden, maar ik vond toch, dat je de cliënt groot moet maken om hem of haar te vangen voor deelname. Men moet zich aangesproken voelen onmisbaar onderdeel te zijn, bij het verbeteren van de betrokkenheid cliënt behandelaar. Zo een zin als “ de relatie tussen U en de behandelaar is belangrijk, daarom benaderen we U voor een onderzoek”.....vond ik niet uitdagend genoeg. Dit werd dus ... “u weet als geen ander dat een goed contact tussen cliënt en begeleider belangrijk is, uw ervaringen zijn daarom erg waardevol, dáárom benaderen we U voor dit onderzoek.”

Gedurende het onderzoek was de samenwerking en sfeer in het team heel fijn en betrokken. Opmerkelijk hoe wij als ervaringsdeskundigen elkaar de bal konden toespelen, zonder ego problemen. We zijn gevoelige mensen en snappen elkaars emoties of gebruiksaanwijzingen. Afgezien dat mijn belangrijkste motivatie om te blijven komen de koekjes waren die Aukelien meenam en rijkelijk chocola ...t kon niet op.....waren er ook voor mij zwaar voelende emoties tijdens de inwerkdagen. M. kon zo goed beknopt de pointe uit iets halen, met weinig zinnen dat ik verbluft was en ook best jaloers. Ook moest ik eens huilen nadat ik mijn eigen verslag van een cliënten interview, vertaald door een van de cursus leiders las. Allemachtig wat duidelijk van structuur, dit kon ik niet of niet meer? Haalde ik er niet teveel observaties en conclusies bij die er niet toe deden? En vergat ik niet t wezenlijke? Of t nou overdreven was van Aukelien of niet, t was volgens haar bijna omgekeerd, Ik zou juist opschrijven wat er zeker toe deed voor de cliënt en het onderzoek, waar een ander dat laat liggen omdat die zelf nooit cliënt was, en de inpakt van ook schijnbaar bijzaken lastiger kan inschatten. Beter ruggensteunje kan je niet krijgen. Ik kon zo lekker mezelf zijn.
Zo had ik ruimte om onverwacht met een bordje vis uit de kantine te komen, en op te eten tijdens de vergadering. Anderen keken me verbaasd toe en lachten erom: hoe krijgt ie ’t voor elkaar?! De keuken is dicht voor iedereen. (misschien een voorbeeld van dat ik al mijn hele leven door de mazen van t net weet te kruijpen, door buiten t raamwerk te denken ........ heerlijk die ziekte winst!

We mochten kiezen aan welke methodes we zouden meewerken, individueel of met een groep, en ook de uitvoering en uitwerking daarvan, hebben we zelf mogen componeren. Ik koos voor interviews en niet voor groepsgesprekken. 1 op 1 ligt me beter. Ik hoorde veel positiefs tijdens het Wiek onderzoek over de U in de zaal als begeleiders. Dat baarde me zorgen...waarom? Als onderzoeker wou ik nou juist blinde vlekken bij begeleiders helpen boven water krijgen. Toch heb ik nooit gevist naar negatieve ervaringen, ik hield me aan de instructie om alleen door te vragen via open vragen. Waarom, hoe dan, wanneer, hoe vaak, waar ligt dat aan? enz. Gedurende het onderzoek was ik daar ook trots op dat ik me er strikt aan hield. T resultaat moest immers objectief zijn. Gelukkig zouden er bij een andere methode, bij de door mij geïnterviewde wat meer stekels boven komen, zoals het wel achter een glas wand kunnen zien werken van groepjes hulpverleners aan hun verdomde P.C, en nog veel te vaak en te lang terwijl je je niet veilig voelt en dat op de afdeling en buitengesloten voelt, en daar even melding van maken. Dit voelt wellicht als in een restaurant staan waar je de kok kan zien werken aan eten voor anderen en shit....waar is je portemonnee nou?!

Gedurende het onderzoek waren er verrassingen voor mij. Meerdere keren bleek dat hulpverleners onderling geen juiste of geen overdracht geven naar elkaar, over wat voor de cliënt achteraf meest wezenlijk was b.v. sfeer op de afdeling, of in een al van je spullen leeggehaalde kamer komen, zonder aankondiging vooraf. Bij onze laatste methode “Luister naar mijn verhaal” bleek dat de begeleiders moeite hadden positieve en negatieve kritiek op elkaar te geven of dat niet altijd durven. Dit lijkt op de zelfde reacties die cliënten zo klein maken als ze van een behandelaar komen. En t gevoel krijgen alleen aan t salaris bijgedragen te hebben.

Aan het eind van de presentatie van het onderzoek sprak ik het management aan tafel, op persoonlijke titel hierop aan. En vroeg of een veilige feedback
methode dan wel training van het personeel daarvoor überhaupt prioriteit heeft voor het management, of nog kan krijgen. (In mijn ogen de grootste blinde vlek, qua prioriteit kwaliteit die ik tegenkwam). Na afloop kwamen er een paar medewerkers naar me toe dat ik zulke mooie inzichten had gebracht, en het management positief in verlegenheid had gebracht. Een van de voor mij mooiste ervaringen in het project was het compliment dat ik kreeg. “Pierre, we zijn trots op je dat je dit onder hun aandacht bracht. Dat heb je t management mooi voor de voeten gelegd!” Opgelucht echt iets bij gedragen te hebben via het onderzoek zelf en mijn vinger tactvol op een blinde vlek te hebben kunnen leggen, ging ik de deur van het gebouw, en het onderzoeksproject uit. Ik voelde en dacht: missie geslaagd!

Verslag van B., co-onderzoeker
In april zijn we als team begonnen. In de training hebben we veel geleerd met rollenspellen en vooral gespreksvoeren. De trainingen waren voor mij leerzaam. Als wat ik fout deed werd het soms afgebroken. Terecht want dat deed ik niet goed.

Daarna zijn we begonnen met de echte gesprekken, en voerden we interviews. In het begin viel dat niet mee. Maar later ging dat een stuk beter. Voor de WIEK methode ging ik vragen van kaartjes voorlezen. Dat vond ik prima gaan. We hebben hard gewerkt. In het begin dacht ik: dat leer ik nooit! Maar de stof werd wel eigen. Ik had er plezier in, vooral als het goed ging. En om dit als team werken samen te doen. Ik kwam er al snel achter dat ik het zelf moest doen.

Bij de vakantietijd kregen we allemaal een bos zonnebloemen. Dat was een mooie afsluiting voor de vakantie met heerlijke rust. In september zijn we begonnen met een nieuwe training. Dit was weer heel anders. Maar was toch een goede manier. Dit vond ik ook leerzaam.

Zelf vond ik dit een fijne tijd. Ik zal jullie missen. Het was altijd gezellig onder elkaar! Ik vond het fijn om veel te leren en leuke dingen mogen doen.

Groet, B.
Appendices

- Dankwoord
- Research Data Management
- About the author
- PhD Portfolio
Dankwoord
Doordat dit onderzoek met veel verschillende mensen is uitgevoerd, hebben veel personen aan deze thesis bijgedragen, die ik graag op deze plek wil bedanken.


Goede begeleiding is onmisbaar bij het uitvoeren van dit promotieonderzoek. Mede dankzij mijn promotieteam is het onderzoek goed verlopen en afgerond, ontzettend bedankt voor jullie fijne begeleiding. Jullie vragen, suggesties en ideeën gaven me de mogelijkheid om steeds kritisch na te denken en mijn analytisch vermogen verder te ontwikkelen. Ik vind het bijzonder hoe jullie mij stimuleerden en het vertrouwen gaven om zelf weloverwogen keuzes te maken gedurende de uitvoering van dit onderzoek. Ik heb ontzettend veel van jullie geleerd, elk op een eigen unieke manier. Nanne en Michelle, jullie hebben me vanaf het begin wekelijks geholpen bij het opzetten, uitvoeren en analyseren van het onderzoek. Bedankt voor jullie betrokkenheid, steun en het intensieve contact. Sandra en Katrien: fijnere promotoren kan ik me niet wensen. Van een afstand stonden jullie altijd klaar.

Daarnaast wil ik André Bons van het LSR hartelijk bedanken voor de prettige samenwerking en de manier waarop je buiten de structuren meedacht en het onderzoek plaatste in de relevante ontwikkelingen. Mattanja, bedankt voor je betrokkenheid bij de afrondende fase van het onderzoek. Dank aan de betrokken personen bij Lunet zorg, Arkin, GGZ Centraal en Brabantzorg voor de prettige samenwerking. Anne Geesink wil ik graag bedanken voor het maken van de mooie passende cover en je persoonlijke betrokkenheid bij het ontwerpproces. En tenslotte dank aan Christel en Doortje voor de tekstuele opmaak van het proefschrift.
Mijn kamergenoten maakten mijn werkperiode bij het Nivel tot een leuke tijd: Chantal, Charlotte, Paul, Karlijn, Kim, Marjon, Femke en Marlon, heel erg bedankt voor jullie humor, quotes-van de dag, beweging stimulans en pauzewandelingen. Ook buiten mijn kamer heb ik het contact met Nivel-collega’s gewaardeerd.

Bij Movisie kreeg ik als pas afgestudeerde de kans om mij verder te ontwikkelen. Mooi vond ik het hoe ik door mijn Movisie collega’s uitgenodigd werd om met een frisse en open blik mee te denken. Na mijn promotieonderzoek ben ik warm verwelkomd door mijn nieuwe collega’s op de Vrije Universiteit in Amsterdam, waar ik met veel plezier werk.

Daarnaast wil ik graag degenen bedanken die me buiten mijn werk hebben gesteund. Mijn lieve vriendinnen, voor de fijne afleiding met onder andere samen eten, theeleuten, lachen, sporten, kamperen, wandelen en fietsen. Mijn lieve ouders, voor jullie onvoorwaardelijke steun. Jullie hebben het vermogen om doorzettingsvermogen en hard werken te combineren met rust en het genieten van kleine dingen. Marjolein, als tweelingzus ken jij me door en door, sta je altijd voor me klaar, en houd je me af en toe een spiegel voor. En natuurlijk Bart-Jan, voor je liefde en vertrouwen. Samen hebben we tijdens dit onderzoek ons huis gekocht en grondig verbouwd, dat was zonder de deskundige hulp van onze ouders niet mogelijk geweest. Ook hier leerde ik dat niet alleen het resultaat telt, maar juist het (verbouw)proces ernaartoe en het bouwplezier. Ik ben dankbaar dat we samen ons levensavontuur vervolgen.
Research Data Management
Aukelien Scheffelaar was employed as an external PhD candidate at the Radboudumc. The thesis is primarily the product of a study conducted at the Netherlands Institute for Health Services Research (Nivel). Research conducted at Nivel is and has to be performed and assessed according to the prevailing scientific standards and procedures relating to project management, data collection, archiving of data and confidentiality requirements. The scientific standards and procedures that apply to Nivel research are described extensively in the Nivel Quality Handbook (ISO-9001 certified). The results and conclusions of research projects, as well as the working methods followed, are always made public (= our statutory obligation to publish).

At the beginning of the thesis, the study was submitted to the Medical Ethics Committee of the Radboud university medical centre to decide whether the study needed formal approval. In the light of the Dutch Medical Research Involving Human Subjects Act, the Ethics Committee decided that extensive formal approval was not needed for this study.

The data was stored in the project folder at Nivel (P:\VRA\VRA-125). At Nivel, project members work for a certain research project in a shared project folder (P:) that is accessible to the project members and backed up daily. This folder contained the logbook of the entire study including all relevant information, data and analyses. After completion of a project, the files are archived in the archive folder (Q:). Following the guidelines applicable at Nivel, a readme.txt file was drawn up describing the contents of that archive folder. Data and analyses are stored for a minimum of 10 years.

Contact information for respondents was obtained from contacts at each care organisation who transferred the clients’ contact details in secured files. The clients’ contact details and traceable information were stored in the secured privacy folder (P:\VRA\VRA-125\privacy), to which only two people (as few as possible) had access: Aukelien Scheffelaar and the secretary. The clients’ contact details were deleted within six months after finishing the study.

The interview transcripts were typed out by an external secretarial agency and adhered to the quality requirements of Nivel as agreed in a formal contract. The written transcripts were also checked for traceable contact details and such details were removed as necessary. During the data analysis and the report stage, the privacy of the participants in this study was guaranteed by using encrypted and unique individual subject codes.
The study was carried out in collaboration with external partners, including LSR (a Dutch client council organisation with a nationwide scope) and the co-researchers. All parties agreed to adhere to the quality procedures including Nivel’s confidentiality requirements.

Informed consent forms from the clients and professionals were stored in a locked documentation cabinet while the study was being carried out. After the study was finished, these forms were stored at the Nivel archive where they will be retained for at least ten years.

The encrypted MAXQDA datasets are available from Nivel on reasonable request.
About the author
Aukelien Scheffelaar was born in Utrecht in the Netherlands on 11 September 1991. She completed secondary school (VWO) at the Montessori Lyceum Herman Jordan in Zeist and obtained her bachelor’s degree in Interdisciplinary Social Sciences at Utrecht University with honours in 2013. During her bachelor course, she studied abroad in Southampton (UK) for one semester. Her interdisciplinary master’s degree focused on Ethnic Diversity and Multiculturalism in the Netherlands, completed in 2014 and again with honours. Aukelien received the NIP Scheherazade prize for her master’s thesis focused on explaining regional differences in discriminatory incidents registered by the Dutch police. From 2014-2016, Aukelien worked at Movisie, the Netherlands Centre for Social Development which aims to offer a comprehensive approach to societal issues. At Movisie, she focused on implementation and dissemination by converting research findings into practical tools, guides and instruments. In May 2016, she started the three-year PhD study that has resulted in this thesis at Nivel, the Netherlands Institute for Health Services Research. Aukelien was attached as an external PhD candidate to the Department of Primary and Community Care of the Radboud university medical center. She has currently just started a new position as a post-doctoral researcher at the Athena Institute (VU), focusing on Community Service Learning.
PhD Portfolio
**TRAIING ACTIVITIES**

<table>
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<th>Year(s)</th>
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<td>- The Science and Practice of Person-Centred Research</td>
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### TEACHING ACTIVITIES

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**TOTAL** 36.5