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

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

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Abstract

Introduction In long-term care (LTC), it is unclear which qualitative instrument or 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 organizations 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 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 a client's perspective. Results will also be published via international peer-reviewed journals.

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 of clients on care relationships in long-term care.
- The participation of client-researchers in the research teams will improve the validity, relevance and support of the research project.
- The success of the study will depend on the willingness of client-researchers and care organisations to be involved 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.

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 professional requires an equal relationship in which professionals provide care with dignity and sensitivity to the clients’ 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 should be set up from a 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 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 [6]. By focusing on client experiences, a more comprehensive evaluation of clients’ experiences of the care provided and areas for improvement is generated [7]. However, little research in long-term care has focused on the client’s perspective on these relationships [6].

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 [8-11]. This empowers the clients and improves the validity and relevance of the research project [12]. 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 [13]. Clients can be involved in several stages of a research project. In data collection, by actively helping conduct interviews or focus groups [14, 15]. Client-researchers can also be involved in the data analysis [15] 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 [11, 14].

Clients' experiences with the care relationship can be explored using qualitative instruments [16]. 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 [17]. Qualitative procedures give clients freedom to respond, allowing direct expression of their own concerns rather than those of the researchers [18]. As a result, qualitative research can tackle aspects of complex behaviours, attitudes and interactions that are not amenable to quantitative research [17]. 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 [19, 20].

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 [18]. For example, interview instruments such as narrative sensibility and storytelling [21, 22], focus groups [23-25],[26] and observational instruments [27-30] 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 client 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 of evaluating the relationship. At the same time, we expect that there are also general determinants that influence the quality of a care relationship in all LTC settings, such as trust or communications skills. In this study, we have attempted to find both specific and more generic determinants of care relationship.

Aim

The aim of the present paper is to describe the research design of the study. It is a participatory study to find and optimise qualitative instruments for evaluating care relationships in long-term care from the client's perspective. This project seeks to answer the following research questions:

A. 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?

B. What qualitative instruments can be used for monitoring and improving the relationship between clients and care professionals from a client's perspective?

C. Which qualitative instruments or parts thereof can be used across client groups and how?

D. 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?

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. Methods and analysis

Setting

The study will take place in the Netherlands. In the Netherlands, long-term care consists of three client groups: physically or mentally frail older adults, people with mental health problems and people with an intellectual, physical or audio-visual disability. For this research, we focus within the client group of people with a disability solely on clients with intellectual disabilities. Three Dutch care organisations will be involved in this multicentre study, one delivering care to one client group. To make sure that we can reach a diverse group of clients, we will select care organisations that provide care to a large client population with a diversity of recurring care needs and receiving both intramural and extramural care and that comprise multiple locations.

Respondents

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 are included. Physically or mentally frail older adults may need assistance due to somatic complaints or suffer from mental decline because of dementia. Persons with mental health problems 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. Clients receiving acute health care are outside the scope of this study. 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. The focus is not on professionals who are further removed from providing recurrent physical and supporting care, such as clinicians, psychiatrists and general practitioners. Moreover, caregivers who provide informal care are not included. Clients will be involved as client-researchers and respondents in the different phases. Inclusion criteria for both groups are described in Table 1.

Table 1 Inclusion criteria for clients as respondents and client-researchers

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

Figure 1 Ladder of Participation, Arnstein (2015) [31]

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 1). The participation levels in Arnstein's frequently used Participation Ladder are manipulation, therapy, informing, consultation, placation, partnership, delegated power and client control [32]. 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 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. At the end of the research, client-researchers can optionally help in the dissemination phase of the research. Earlier studies show there are several barriers for participatory research [11] and sharing responsibilities is not always easy for researchers [33]. Studies underline the importance to start the research process really open and flexible to make true client participation, empowerment and a valuable collaboration process possible [11, 34]. 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 a training and introduction at the start of the research, create an safe working environment, and make basic agreements for our cooperation with the client-researchers at the start. During the research phases, we will discuss the conditions for cooperation of the research team regularly. Furthermore, we will communicate on 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 take availability of client-researchers into account when meetings will be planned.

Five phases of selection and development of a qualitative instrument

This research contains five different phases that will take place during the timespan 2016-2019 (see Figure 2): 1) Preparation: recruitment of care organisations & 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 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, client organisations and health insurers. The committee will monitor the research process according to the project plan and give advice on the content of the study. Eight meetings are planned and members of the supervisory committee can be asked for further input by e-mail if needed.

2.1 Preparation

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

a. *Inviting three care organisations*

Three care organisations and their client councils are invited to participate in the consultation and instrument selection phase. The care organisations invited provide care to one of the three different client groups.

b. *Inviting and selecting client-researchers*

The invitation of client-researchers starts on a small scale from a personal approach, in cooperation with members of client councils and care professionals. We aim to have three or four client-researchers from each client group. Because the participating clients need to have sufficient skills for participating so actively in the study, it is important to realise that the client-researchers may not be fully representative of the target group. See Table 1 for the inclusion criteria. The selected client-researchers will be offered a training to prepare 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 are tuned to the needs of client-researchers. In the training, the distribution of tasks and responsibilities will be discussed and established. Tasks and responsibilities can depend on someone's capacities and wishes.

c. Literature study

Three literature studies will be conducted:

A. A systematic review to gain an understanding of determinants influencing the quality of the care relationship
B. A scoping review to identify existing qualitative instruments that measure the quality of the relationship between clients and care professionals in the Netherlands
C. 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 studies will include scientific databases such as Medline, Embase, Cinahl and PsycINFO, and grey literature. For the first study (A), a systematic search strategy will be drawn up. Eligible articles need to be written in English and published in the last ten years (between 2006 and 2016) 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) [35, 36].

For the second and third studies (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 2016.

Products of the preparation phase:

- established cooperation with 3 care organisations and cooperation with 3 to 4 client-researchers in each organisation
- a systematic review article on determinants influencing the quality of the care relationship

- an overview of existing qualitative instruments in long-term care in the Netherlands

2.2 Consultation

In the consultation phase, the results from the first (systematic) literature search into determinants of the quality of the care relationship will be verified amongst clients and care professionals. In every care organisation, clients will be interviewed individually face-to-face until saturation occurs. It is expected that saturation will occur when we have interviewed 8-10 clients, but it is difficult to determine the saturation point in advance as one size does not fit all in qualitative research [37]. Additionally, 4-6 care professionals from each organisation will be invited for a focus group meeting. Clients who meet the inclusion criteria (see Table 1) will be approached by the client-researchers. We will work with a convenience sample to include clients who are willing and available 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 the care is intramural or extramural. The care professionals will be selected and invited in close cooperation with the care organisation.

The data collection and analysis will be conducted by the research team, consisting of 1 researcher and 3 to 4 client-researchers from each care organisation. The focus groups will take about 2 hours and will take place in a meeting room of the care organisation. Interviews will take place in the residency of a client or in a meeting room of 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 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 [38]. The focus groups and interviews will be audio-recorded, transcribed verbatim and analysed in three phases: open coding, axial coding and selective coding [16]. The data analysis method is inspired by the Interpretative Phenomenological Analysis, which places the clients’ experiences and the meaning they assign to those experiences at the core [39]. 25% 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. 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

2.3 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 instruments may include (a combination of) individual interviews, observations, and/or focus groups. This information will be presented to the supervisory committee using the Delphi method [40]. For the selection of instruments, the supervisory committee may be supplemented with other stakeholders.

Products of the selection:

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

2.4 Evaluation of qualitative instruments

During the fourth phase of this study, 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 3). It is expected that saturation will occur in between this quantity. The respondents of the evaluation phase are not necessarily the same as respondents of the consultation phase and it is likely that most respondents will only participate in one phase of this study. If necessary we will adjust the selected qualitative instruments to the specific client group. We 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. Next, the most promising instrument from 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 are preferred over instruments that are solely applicable to one specific client group. This evaluation leads 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 this phase. They will be approached by their daily care professionals, client-researcher or the client council to 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 available to participate. Nevertheless, we will aim for as much variation as possible with regard to relevant client characteristics such as gender, age, ethnicity, and intramural or extramural care.

Products of the evaluation:

- Selection of the qualitative instruments that were evaluated as best

Figure 3 Research respondents

2.5 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 focuses 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.

We will also examine whether the results of the qualitative instruments can be used for other purposes, such as healthcare procurement and monitoring for external accountability. 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.

Product of the dissemination phase:

- Toolbox including the qualitative instruments (adjusted if necessary) to measure and improve the quality of the care relationship for each client group in long-term care. The implementation plan is part of the toolbox.
- Recommendations based on external verification of the toolbox.

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 [38]. 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.

3. Discussion and conclusion

3.1. Discussion

Prior work has documented the importance of the care relationship for clients in long-term care [1, 4, 41]. 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 likely that different instruments will fit each group best. This study will therefore 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 backing in the environment and thereby increase the probability of participation of clients, client-researchers, care organisations, client councils and client organisations are cooperating in this study [42]. Their willingness to join is an important prerequisite to perform 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 [42, 43]. 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 [44] [45]. 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.

When organisations use 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 everyday demands that care organisations face, which precludes implementation of the selected instrument on large scale. The likelihood of successful implementation depends 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. 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.

3.2. Conclusion

In long-term care, care relationships are seen as a fundamental element in the delivery of high quality care [4, 46-48]. But good care relationships have not been set up everywhere yet. It is therefore important that 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. Backing will be generated for the set of qualitative instruments developed through the meetings of the supervisory committee, the involvement of client-researchers and the creation of a LinkedIn group to share the findings and issues.

3.3 Practice Implications

The study will result in a toolbox with qualitative instruments that can be used for effective monitoring 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 could serve as guideline for developing other studies with the combined purpose of practical outcomes and sharing empirical evidence.

4. Declarations

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Author’s contributions

All authors contributed to, reviewed and approved the article drafts and final manuscript. AS was responsible for writing the manuscript. MH, NB, KL and SvD read several versions of the manuscript and provided their feedback and suggestions regularly.

Competing interests

The authors declare that they have no competing interests.

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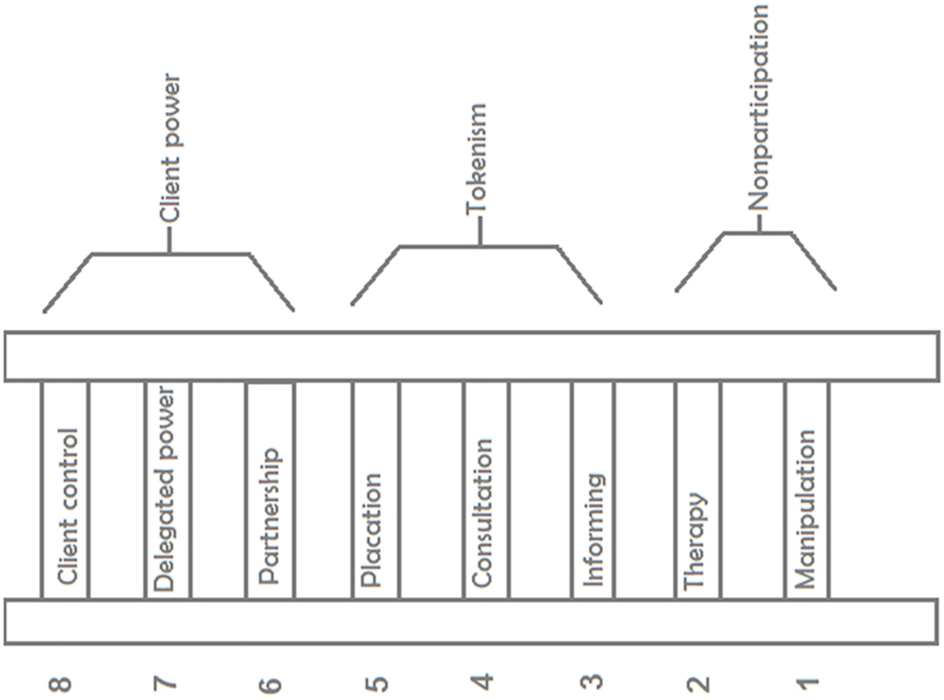

Figure 1 Ladder of Participation, inspired on Arnstein (2015)

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Figure 2 Phases of the study

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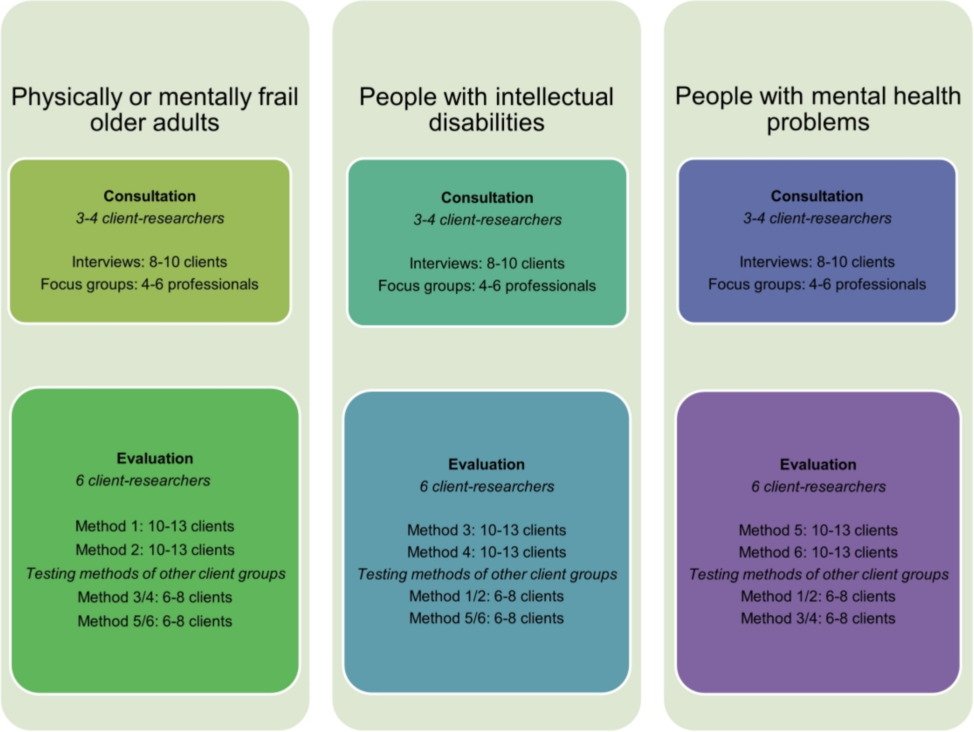

Figure 3 Research respondents

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

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

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Abstract

Introduction In long-term care (LTC), it is unclear which qualitative instrument or 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 organizations 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 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 a client's perspective. Results will also be published via international peer-reviewed journals.

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 of clients on care relationships in long-term care.
- The participation of client-researchers in the research teams will improve the validity, relevance and support of the research project.
- The success of the study will depend on the willingness of client-researchers and care organisations to be involved 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.

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 professional requires an equal relationship in which professionals provide care with dignity and sensitivity to the clients' 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 should be set up from a 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 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 [6]. By focusing on client experiences, a more comprehensive evaluation of clients' experiences of the care provided and areas for improvement is generated [7]. However, little research in long-term care has focused on the client's perspective on these relationships [6].

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 [8-11]. This empowers the clients and improves the validity and relevance of the research project [12]. 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 [13]. Clients can be involved in several stages of a research project. In preparation activities, or in data collection by actively helping conduct interviews or focus groups [14, 15]. Client-researchers can also be involved in the data analysis [15] 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 [11, 14].

Clients' experiences with the quality of a care relationship can be explored using qualitative instruments [16]. 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 [17]. Qualitative procedures give clients freedom to respond, allowing direct expression of their own concerns rather than those of the researchers [18]. As a result, qualitative research can tackle aspects of complex behaviours, attitudes and interactions that are not amenable to quantitative research [17]. 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 [19, 20].

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 [18]. For example, interview instruments such as narrative sensibility and storytelling [21, 22], focus groups [23-25],[26] and observational instruments [27-30] 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 client 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 of evaluating the relationship. At the same time, we expect that there are also general determinants that influence the quality of a care relationship in all LTC settings, such as trust or communications skills. In this study, we have attempted to find both specific and more generic determinants of care relationship.

Aim

The aim of the present paper is to describe the research design of the study. It is a participatory study to find and optimise qualitative instruments for evaluating care relationships in long-term care from the client's perspective. This project seeks to answer the following research questions:

A. 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?
B. What qualitative instruments can be used for monitoring and improving the relationship between clients and care professionals from a client's perspective?
C. Which qualitative instruments or parts thereof can be used across client groups and how?
D. 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 question are aimed to evaluate qualitative instruments to know 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. Methods and analysis

Setting and participants

The study will take place in the Netherlands. In the Netherlands, long-term care consists of three client groups: physically or mentally frail older adults, people with mental health problems and people with an intellectual, physical or audio-visual disability. For this research, we focus within the last client group of people with a disability solely on clients with intellectual disabilities. Three Dutch care organisations are willing to be involved in this multicentre study, each of the three care organisations serves care to one client group. A convenience sample technique was used. To make sure that we can reach a diverse group of clients, we selected care organisations that provide care to a large client population with a diversity of recurring care needs and receiving 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 a care organisation will withdraw 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 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 are included. Physically or mentally frail older adults may need assistance due to somatic complaints or suffer from mental decline because of dementia. Persons with mental health problems 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 aids, personal carers, and different types of nurses. Clients receive care for at least once a week. The focus is not 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 are not included.

Table 1 Inclusion criteria for clients as respondents and client-researchers

	Respondents	Client-researchers
18 or older (no upper limit)	X	X
Currently a client of residential elderly care and home care, mental healthcare or disabled care	X	X
Receiving care for at least three months	X	X
Receiving care at least once every week	X	
Able to communicate verbally in Dutch	X	X
Able to generalise from their own experiences		X

Able to hold a conversation without assistance of a close relative or friend		X
Able to read and write at a basic level		X
Has a fairly stable health situation		X
Able to travel short distances		X

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

Figure 1 Ladder of Participation, Arnstein (2015) [31]

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 1). The participation levels in Arnstein's frequently used Participation Ladder are manipulation, therapy, informing, consultation, placation, partnership, delegated power and client control [32]. 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, compose 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. At the end of the research, client-researchers can optionally help in the dissemination phase of the research. Earlier studies show there are several barriers for participatory research [11] and sharing responsibilities is not always easy for researchers [33]. Studies underline the importance to start the research process really open and flexible to make true client participation, empowerment and a valuable collaboration process possible [11, 34]. 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 a training and introduction at the start of the research, create an safe working environment, and make basic agreements for our cooperation with the client-researchers at the start. During the research phases, we will discuss the conditions for cooperation of the research team regularly. Furthermore, we will communicate on 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 take availability of client-researchers into account when meetings will be planned. Client-researchers receive a small allowance for their contribution, depending on the invested amount of time. Client-researchers can always quit or call off participation during the research process. Halfway, we added a moment to evaluate the process so far with client-researchers and to ask them whether they want to continue.

Five phases of selection and development of a qualitative instrument

This research contains five different phases that will take place during the timespan 2016-2019 (see Figure 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 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 of the involved care organisations, and health insurers. The committee will monitor the research process according to the project plan and give advice on the content of the study. Eight meetings are planned and members of the supervisory committee can be asked for further input by e-mail if needed. The whole research team will be present at the meetings, including two professors.

2.1 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 starts on a small scale from a personal approach, in cooperation with members of client councils and care professionals. An individual acquaintance meeting is held with every client who shows interest to participate. We aim to have three or four client-researchers from each client group. Because the participating clients need to have sufficient skills for participating so actively in the study, it is important to realise that the client-researchers may not be fully representative of the target group. See Table 1 for the inclusion criteria. The selected client-researchers will be offered a training to prepare 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 are 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 can depend on someone's capacities, capabilities and wishes.

b. Literature review

Three literature studies will be conducted:

A. A systematic review to gain an understanding of determinants influencing the quality of the care relationship

B. A scoping review to identify existing qualitative instruments that measure the quality of the relationship between clients and care professionals in the Netherlands

C. 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 study (A), a systematic search strategy will be drawn up. When necessary, a librarian will be consulted during this process. Eligible articles need to be written in

English and published in the last ten years (between 2006 and 2016) 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) [35, 36].

For the second and third studies (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 2016.

Products of the preparation phase:

- established cooperation with 3 care organisations and cooperation with 3 to 4 client-researchers in each organisation
- a systematic review article of the literature regarding determinants influencing the quality of the care relationship
- an overview of existing qualitative instruments in long-term care in the Netherlands

2.2 Consultation

In the consultation phase, the results from the first (systematic) literature search into determinants of the quality of the care relationship will be complemented amongst clients involved as respondents and care professionals. In every 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 8-10 clients of each care organisation, but it is difficult to determine the saturation point in advance as one size does not fit all in qualitative research [37]. Clients who meet the inclusion criteria (see Table 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 available 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 the care is inpatient or outpatient.

Interviews will take place in the residency of a client or in a meeting room of 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 is the responsibility of the researcher that the inform 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 [38].

Additionally, 4-6 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 available to participate. The care professionals will be selected and invited in close cooperation with the care organisation. The focus groups will take about 2 hours and will take place in a meeting room of the care organisation. A topic list will be made in advance to lead the group conversations on a semi-structured manner.

The data collection and analysis will be conducted by the research team, consisting of 1 researcher and 3 to 4 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 [16]. The data analysis method is inspired by the Interpretative Phenomenological Analysis, which places the clients' experiences and the meaning they assign to those experiences at the core [39]. 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. The remaining interviews will be observed by one of the researchers. 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

2.3 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 on which the qualitative instruments will be assessed and selected. The instruments may include (a combination of) individual interviews, observations, and/or focus groups. This information will be presented to the supervisory committee using the Delphi method [40]. For the selection of instruments, the supervisory committee may be supplemented with other stakeholders, such as representatives of 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

2.4 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 know whether they are useful for evaluating the quality of individual care relationships in long-term care. This evaluation phase consist of three parts.

A. (If necessary) supplementing questions of selected instruments

The selected qualitative instruments might need some adaptions in order to be useful for the purpose of this study: to create insight in the experienced quality of the care relationship from a client perspective. Some instruments cover a broader focus on quality of life and quality of care. Therefore, the determinants of the care relationship quality coming forward in the consultation of clients and professionals and the systematic review, will be used to supplement the questions whenever the instrument does not cover all relevant determinants of the quality of care relationships yet. The instrument might also be adjusted to be suitable for client participation of client-researchers. For example, the instructions may be rewritten in easier words, and the training might be adapted to their literacy. Furthermore, the selected instruments will be adjusted to 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 3). It is expected that saturation will occur in between this quantity. The respondents of the evaluation phase are not necessarily the same as respondents of the consultation phase and it is likely that most respondents will only participate in one phase of this study. We 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 from 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 are preferred over instruments that are solely applicable to one specific client group. This evaluation leads 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 to 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 available 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

Figure 3 Research respondents

2.5 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 focuses 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.

We will also examine whether the results of the qualitative instruments can be used for other purposes, such as healthcare procurement of health insurances and monitoring for external accountability on quality measurement and improvement, primarily to the National Health Care Institute (In Dutch: Het Zorginstituut). 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. The owner of the qualitative instrument will stay responsible for further implementation and dissemination. The National Health Care Institute might also play a role in the dissemination of the instrument.

Product of the dissemination phase:

- Toolbox including the qualitative instruments (adjusted if necessary) to measure and improve the quality of the care relationship for each client group in long-term care. The implementation plan is part of the toolbox.
- Recommendations based on external verification of the toolbox.

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 [38]. 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.

3. Discussion and conclusion

3.1. Discussion

Prior work has documented the importance of the care relationship for clients in long-term care [1, 4, 41]. 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 likely that different instruments will fit each group best. This study will therefore 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 backing in the environment and thereby increase the probability of participation of clients, client-researchers, care organisations, client councils and client organisations are cooperating in this study [42]. Their willingness to join is an important prerequisite to perform 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 [42, 43]. 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 [44] [45]. 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.

When organisations use 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 everyday demands that care organisations face, which precludes implementation of the selected instrument on large scale. The likelihood of successful implementation depends 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. 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.

From a quantitative point of view, this study protocol might be interpreted as limited as some details are still left open. To make client participation meaningful, we feel it is not good to define every detail on beforehand and make decisions during the process as well. Therefore, the global structure and decision moments of the research process are described while there is still space left open to fill in aspects later on. This is not unusual in qualitative research.

3.2. Conclusion

In long-term care, care relationships are seen as a fundamental element in the delivery of high quality care [4, 46-48]. But good care relationships have not been set up everywhere yet. It is therefore important that 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. Backing will be generated for the set of qualitative instruments developed through the meetings of the supervisory committee, and the involvement of client-researchers and care organisations.

3.3 Practice Implications

The study will result in a toolbox with qualitative instruments that can be used for effective monitoring 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 could serve as guideline for developing other studies with the combined purpose of practical outcomes and sharing empirical evidence.

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 of clients on care relationships in long-term care.
- The participation of client-researchers in the research teams will improve the validity, relevance and support of the research project.
- The success of the study will depend on the willingness of client-researchers and care organisations to be involved 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.

4. Declarations

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Author's contributions

All authors contributed to, reviewed and approved the article drafts and final manuscript. AS was responsible for writing the manuscript. MH, NB, KL and SvD read several versions of the manuscript and provided their feedback and suggestions regularly.

Competing interests

The authors declare that they have no competing interests.

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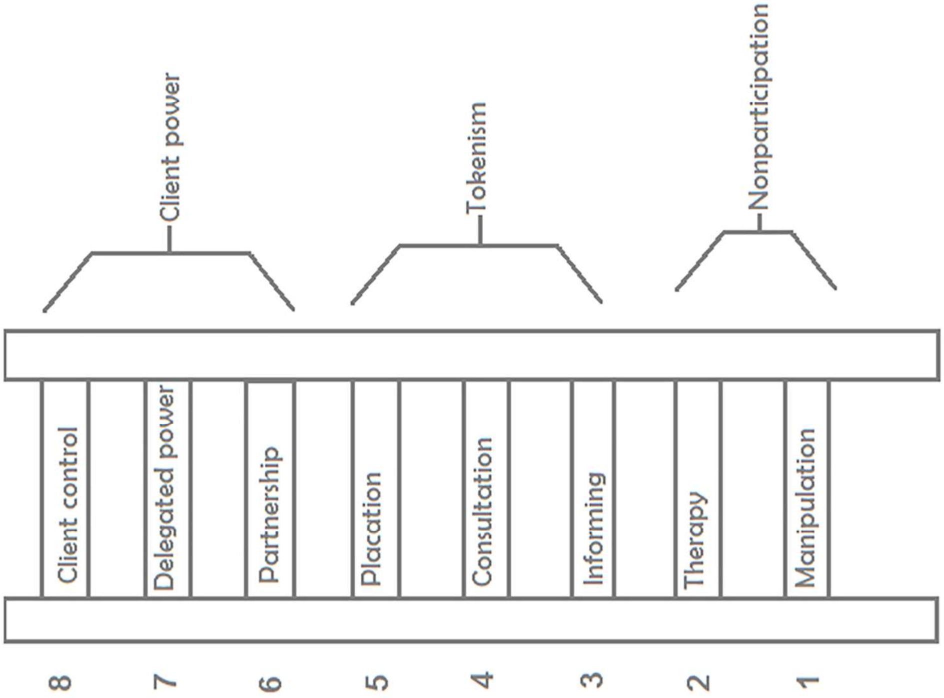

Figure 1 Ladder of Participation, inspired on Arnstein (2015)

254x190mm (300 x 300 DPI)

Figure 2 Phases of the study

253x20mm (300 x 300 DPI)

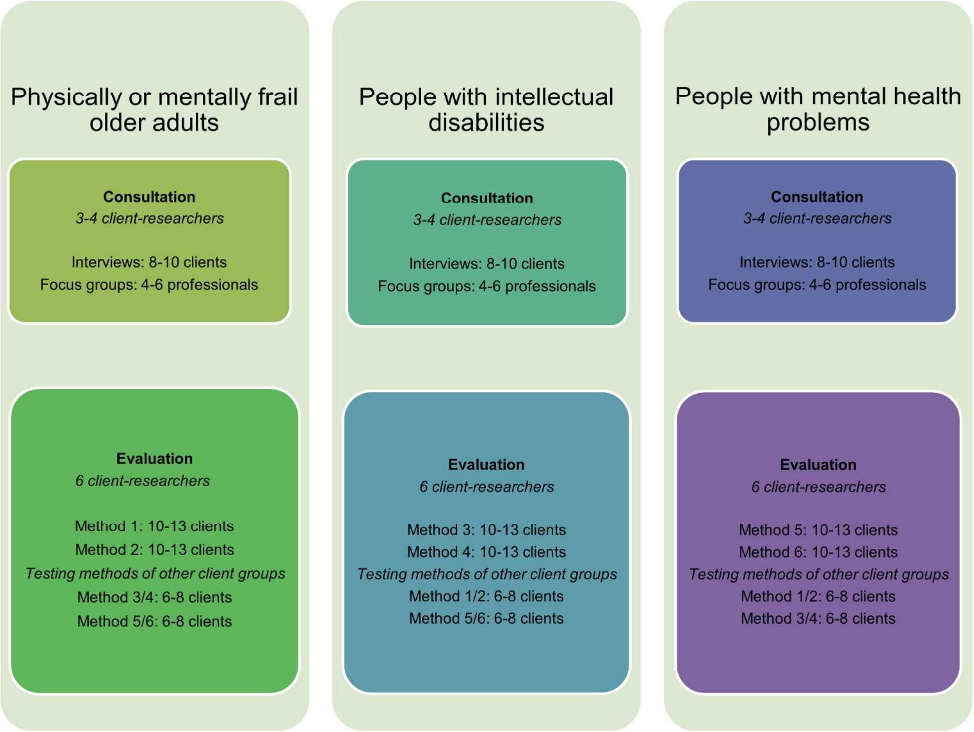

Figure 3 Research respondents

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

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

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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.

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.

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.

Aim

The aim of the present paper 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:

A. 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?

B. What qualitative instruments can be used for monitoring and improving the relationship between clients and care professionals from a client's perspective?

C. Which qualitative instruments or parts thereof can be used across client groups and how?

D. 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. 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 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 1 Inclusion criteria for clients as respondents and client-researchers

	Respondents	Client-researchers
18 or older (no upper limit)	X	X
Currently a client of residential elderly care and home care, mental healthcare or disabled care	X	X

Receiving care for at least three months	X	X
Receiving care at least once a week	X	
Able to communicate verbally in Dutch	X	X
Able to generalise from their own experiences		X
Able to hold a conversation without the assistance of a close relative or friend		X
Able to read and write at a basic level		X
Has a fairly stable health situation		X
Able to travel short distances		X

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.

Figure 1 Ladder of Participation, Arnstein (2015) [30]

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 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. 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): 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 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.

2.1 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 councilmembers 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 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 studies will be conducted:

A. A systematic review to gain an understanding of determinants influencing the quality of the care relationship

B. A scoping review to identify existing qualitative instruments that measure the quality of the relationship between clients and care professionals in the Netherlands

C. 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 study (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 studies (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 2016.

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
- an overview of existing qualitative instruments in long-term care in the Netherlands

2.2 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 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

2.3 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

2.4 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 consist of three parts.

A. (If necessary) adapting the questions in the selected instruments

The selected qualitative instruments might need some adaptions 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 have a broader focus on quality of life and quality of care. Therefore, the determinants of the care relationship quality that emerge in the consultation of clients and professionals and the systematic review will be incorporated in additional questions 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 3). 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 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 from 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 are 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

Figure 3 Research respondents

2.5 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 stay responsible for further implementation and dissemination. The National Health Care Institute might also play a role in the dissemination of the instrument.

Product of the dissemination phase:

- Toolbox including the qualitative instruments (adjusted if necessary) to measure and improve the quality of the care relationship for each client group in long-term care. The implementation plan is part of the toolbox.
- Recommendations based on external verification of the toolbox.

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.

3. Discussion and conclusion

3.1. 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 backing 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 use 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 depends 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, might be limited.

From a quantitative point of view, this study protocol might 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 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.

3.2. 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 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. Backing will be generated for the set of qualitative instruments developed through the meetings of the supervisory committee, and the involvement of client-researchers and care organisations.

3.3 Practice Implications

The study will result in a toolbox with qualitative instruments that can be used for effective monitoring 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 could serve as a guideline for developing other studies with the combined purpose of practical outcomes and sharing empirical evidence.

4. Declarations

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Author's contributions

All authors contributed to, reviewed and approved the article drafts and final manuscript. AS was responsible for writing the manuscript and MH, NB, KL and SvD read several versions of the manuscript and provided their feedback and suggestions regularly.

Competing interests

The authors declare that they have no competing interests.

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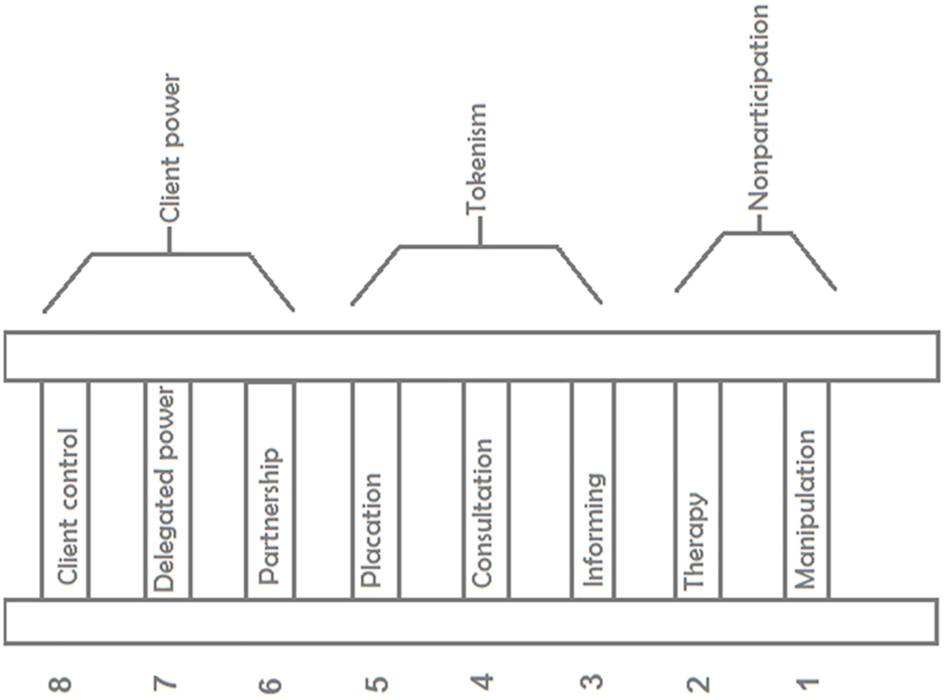

Figure 1 Ladder of Participation, inspired on Arnstein (2015)

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Figure 2 Phases of the study

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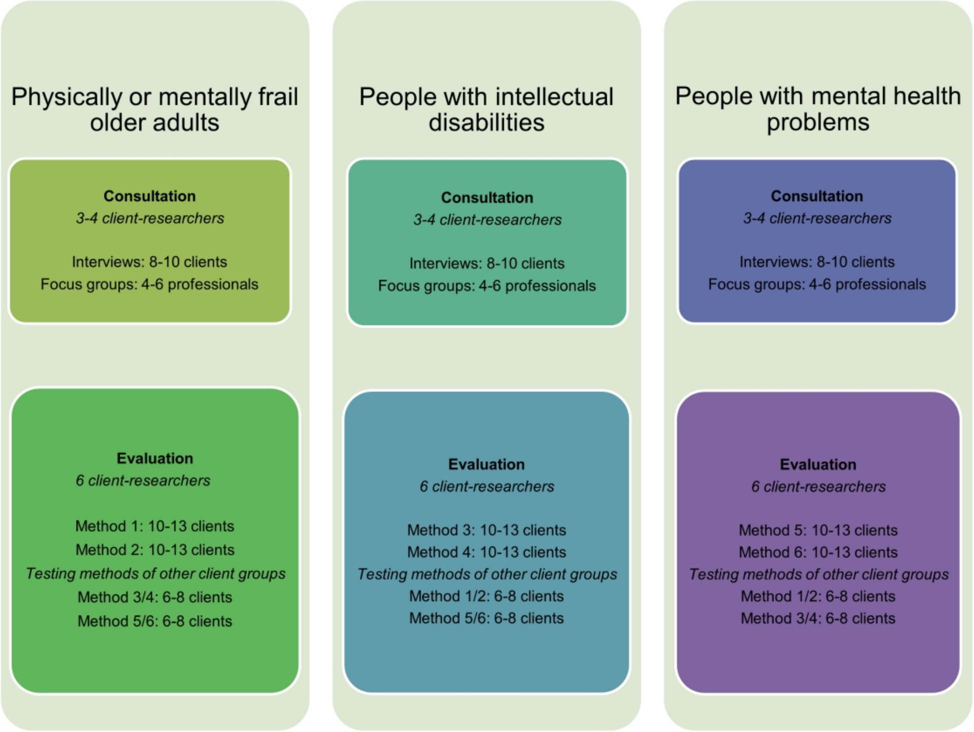

Figure 3 Research respondents

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

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

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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.

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.

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.

Aim

The aim of the present paper 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:

A. 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?
B. What qualitative instruments can be used for monitoring and improving the relationship between clients and care professionals from a client's perspective?
C. Which qualitative instruments or parts thereof can be used across client groups and how?
D. 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. 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 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 1 Inclusion criteria for clients as respondents and client-researchers

	Respondents	Client-researchers
18 or older (no upper limit)	X	X
Currently a client of residential elderly care and home care, mental healthcare or disabled care	X	X

Receiving care for at least three months	X	X
Receiving care at least once a week	X	
Able to communicate verbally in Dutch	X	X
Able to generalise from their own experiences		X
Able to hold a conversation without the assistance of a close relative or friend		X
Able to read and write at a basic level		X
Has a fairly stable health situation		X
Able to travel short distances		X

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.

Figure 1 Ladder of Participation, Arnstein (2015) [30]

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 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. 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): 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 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.

2.1 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 councilmembers 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 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:

A. A systematic review to gain an understanding of determinants influencing the quality of the care relationship

B. A scoping review to identify existing qualitative instruments that measure the quality of the relationship between clients and care professionals in the Netherlands

C. 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
- an overview of existing qualitative instruments in long-term care in the Netherlands

2.2 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 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

2.3 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

2.4 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 adaptions 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 3). 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

Figure 3 Research respondents

2.5 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.

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.

3. Discussion and conclusion

3.1. 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 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.

3.2. 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.

3.3 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.

4. Declarations

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Author’s contributions

All authors contributed to, reviewed and approved the article drafts and final manuscript. AS was responsible for writing the manuscript and MH, NB, KL and SvD read several versions of the manuscript and provided their feedback and suggestions regularly.

Competing interests

The authors declare that they have no competing interests.

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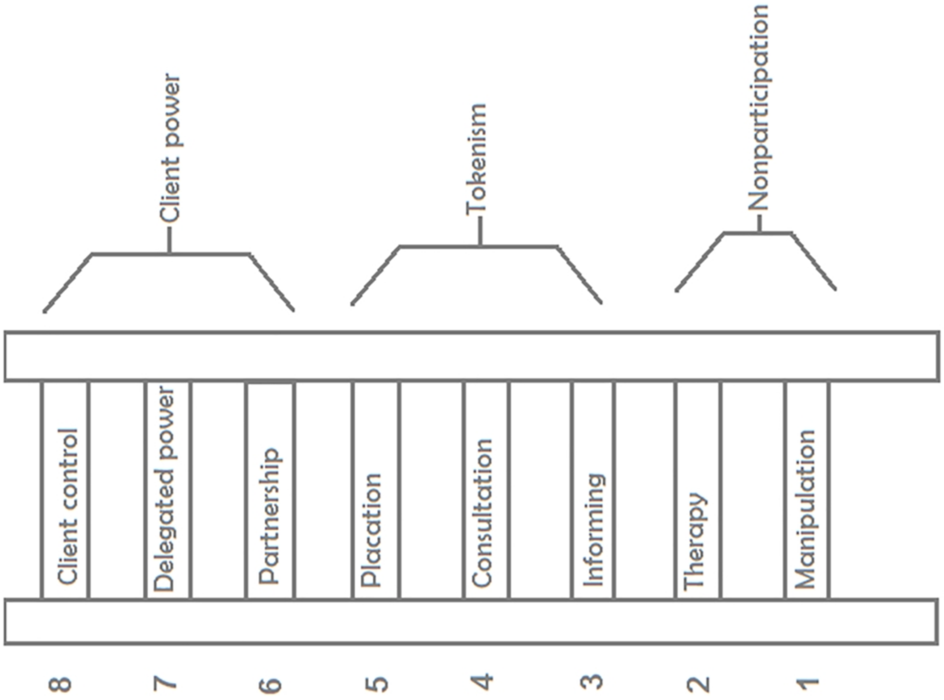

Figure 1 Ladder of Participation, inspired on Arnstein (2015)

254x190mm (300 x 300 DPI)

Figure 2 Phases of the study

253x20mm (300 x 300 DPI)

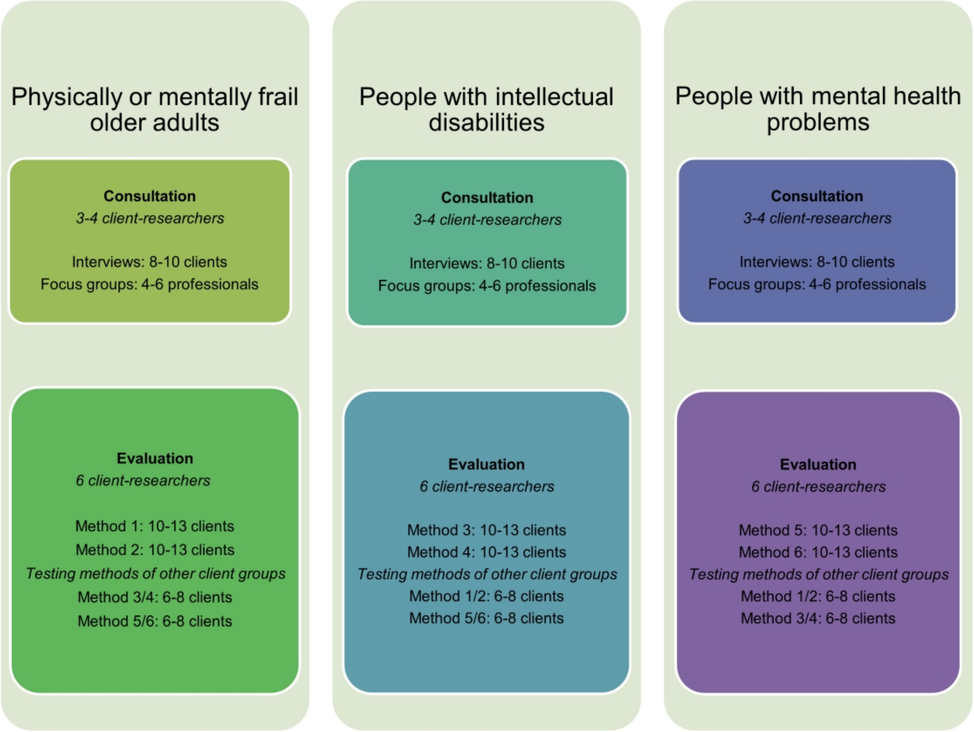

Figure 3 Research respondents

254x190mm (300 x 300 DPI)