Chapter 1

General introduction

1.1   Introduction

Backgrounds and context of the influence of older people

In the sixties and seventies of the 20th century, sociologists and philosophers brought forward their unsettling perspectives on the power of institutions over the quality of life of vulnerable and powerless people.[1-3] They claimed that the impact of the 'total institution', 'system', control, observation and disciplining social norms on the individual was devastating, leaving no room for individual self-development. In this view, health care institutions, such as hospitals, nursing and residential care homes and psychiatric care units, are totalitarian, hierarchical and repressive environments. In later decades, empirical research in the field of elderly care and sociology has shown that long-term elderly care institutions pave the way to structural dependency, depersonalization, disengagement and frailty.[4-9] Thus, the impact of institutional environments is seen as an important barrier for older people living in long-term care institutions to have a voice in the issues that are affecting them. Further, negative ageist stereotyping hamper their chances of being an equal conversation partner for care professionals. Ageism is defined as any prejudice or discrimination against or in favor of a particular age group, and especially the elderly.[10] These taken for granted images refer to dependency, passivity, progressive physical and mental decline, social isolation, asexual behavior, lack of creativity, and economic and familial burden.[11] Since these stereotypes permeate organizations, inform policy and act as social determinants of health, they stand in the way of more tolerant and differentiated responses to older people.[12] Also, it is argued that people aged over 65 experience a loss of social position after leaving their employed life, being confronted with a 'roleless role'.[13] This societal rolelessness (or this way of stereotyping this particular group of people) may hamper older people to take up an active role once they come to live in an elderly care institution.[14] Empirical studies indicate that older people who live in institutional care settings can experience a lack of influence on the rules, routines and decision-making processes of the organization.[8, 14-16]

Parallel to the recognition of the problematic context of health care institutions with regards to patients having a voice, since the seventies of the 20th century new developments have been described in Western societies, such as individualization and the rise of a negotiation

culture.[17-19] As part of this trend, patient movements (representing and advocating the interests of patients, trying to fight negative stereotyping) increasingly have become an established party for policymakers, researchers and health care professionals.[20-23] These advocacy groups are especially strong in the disability field, and claim more control over decision-making processes affecting their lives, expressed in the phrase *'Nothing about us, without us'*.[20] Also other groups increasingly have been involved in research and policymaking, such as mental health service users,[24] persons with intellectual disabilities,[25,26] but also other groups that are liable to social exclusion and inequality (for example migrants, refugees, women, people with a low income, etc.).[27,28]

Experiential knowledge of patients is increasingly being acknowledged and brought to the fore in policymaking and research.[22,23,29,30] In health care practice, care organizations are working hard to develop client centered care, in order to give patients (who have now become 'clients' and 'consumers' in this new discourse) a voice in the care and services they receive.[31,32] Professional associations (*e.g.* Vilans, www.vilans.nl; Vereniging Verpleegkundigen & Verzorgenden Nederland, www.venvn.nl) support the development of demand-driven and client centered care in Dutch health care organizations by providing information and training for care workers and managers.

Consumers and citizens

Besides the rise of patient organizations and the growing attention for the voice of patients in research, policymaking and health care practice, the liberalization of the national health care policy has strongly influenced the trend towards demand-driven care. In this context, care services have become products and patients are considered to be critical consumers.[33] The patient has become a *third party* with regard to the two more established market players; care providers and health insurers. In this role, patients are supposed to independently make rationally informed choices. The reorganization of health care on a free-market basis has created more room for patients to chose the best available services and care providers. Consequently, health care providers have been challenged to increasingly take into account the opinions and experiences of their patients in order to improve and maximize the quality of their care and services.[23] Against this background, the rise of the free-market system in

health care can be seen as a positive development, providing more freedom and more quality. A pitfall of this consumerist approach is that the individual patient can become a claiming and demanding party, blind to the interests of others. As such, the consumerist approach can be at odds with the possibility of patients acting from a sense of citizenship, with an eye for others, solidarity and contributing something to society.

At the intersection of the consumerist and citizenship approach towards patients, legislation can be found to support both these patient roles (consumer and citizen roles). In the Netherlands, a legal act has been instituted in 1996 (*WMCZ; Wet Medezeggenschap Cliënten Zorgsector*), obliging every care organization to commission a client or resident council; a committee of people who receive care and services from the organizations, with legal rights and duties to represent the interests of fellow clients. The development of this legal act can be seen as part of the increased political and societal attention for supporting vulnerable groups, such as patients, to determine their own lives despite the vulnerable situation (physically, mentally and/or socially) they find themselves in. At the same time, resident councils can be seen as an instrument for voicing the consumerist side of care. They can claim good quality of care and act as a sounding board as well as a watchdog for managers. However, empirical studies of resident councils indicate that the influence of resident councils is limited.[34-36]

Organization of care for older people in the Netherlands

In the Netherlands, arrangements for care for older people consist of long-term care, social services and housing for older people.[37] Long-term health care for older people generally refers to home care and institutional care. Institutional care is provided in nursing homes and residential care homes. In the Netherlands, approximately 150,000 older people live in institutional care institutions.[38] Almost 1700 nursing homes and residential care homes exist in the Netherlands. The distinction between nursing homes and residential care homes is not always clear, due to the overlapping of some forms and gradations of care services. In general, residential care homes are institutions providing living conditions for older people who are unable to live independently on their own, but who usually require little more nursing care than what can be given by a visiting nurse.[37] Nursing homes provide more intensive nursing care and 24-hour supervision. Developments towards the disentanglement of living and care

facilities, the provision of tailored care, and living as long as possible independently in the own living environment have led to the fading of clear borders between diverse forms of care services.[38-40] Nowadays, residential care homes can be environments in which older people rent their apartment from a housing company and where they buy in care services of the residential care home. Often, besides these sheltered housing environments, special care units for people with more specific and intensive nursing care needs can be found in the same building, for example departments where people live who are dependent on somatic and/or psycho geriatric care.

Shifting power of older people in health care: micro, meso and macro level

We distinguish three levels or areas in which the power and influence of people in the context of health care have been shifting from being subjected to the expert status of others toward becoming more involved in decision-making processes. These are the level of health care and social policy (macro), the level of the individual client/patient (micro) and in-between these two levels the level of institutions/organizations (meso). The macro level of patients' influence in health care relates to the endeavor of bringing together government authorities, professionals and their institutions, advocacy organizations, and community members for interactive decision-making and collaboration.[41,42] For example, in the Netherlands partnerships between care receivers and professionals can be found in the National Program for Elderly Care, commissioned by the Ministry of Health Care. In this program, diverse organizations work together regionally and nationally in order to meet the challenges the elderly care sector is confronted with. The perspectives of older people are given special attention in this program, for example by workshops and trainings provided by CSO (the umbrella organization for senior citizens' leagues) in collaboration with academic and professional knowledge partners.[43] In the United Kingdom particularly, a central premise in the Labour Government's 'Third Way' is the participation of consumers in policy-making as a way of managing the public sector and creating opportunities for (care) consumers' influence.[42,44] At this macro-level, the collective interests of patients/clients/consumers are being represented by smaller representative groups (panels, networks, patient organizations, etc.).

The micro-level of power of care receivers in health care refers to the individual relationship between a patient/client and a professional caregiver. According to Gallant et al. (2002), the relationship between patient and professional involves a shift in the role of the professional from being an expert care provider to being a partner with the client in order to improve the client's capabilities.[45] Important attributes of this partnership relation are power-sharing, shared decision-making, patient autonomy, shared knowledge, participation, communication and professional competence.[46] These are concepts that represent the development of more dialogical care relations.

In this thesis, we focus on the collective influence of older people who live in residential care homes on collective issues that affect their life in the institutional context. We call this the meso-level of client participation. It refers to the community life in residential care homes and the area in which collective services, activities and projects are being organized. For example, the work of resident councils who advise managers on issues that affect the common good of residents (such as the meals, activity programs, division of resources, etc.) relates to the meso-level of participation and influence of patients/older people who live in residential care homes. In general, this meso-level of client participation concerns the relationships between groups of clients and groups of care workers, volunteers and/or management professionals, dealing with collective issues of clients (as opposed to individual issues of clients). Representation is an important feature of the meso-level of influence of older people in residential care homes. It presupposes that a smaller group of residents represents the collective interests of all residents who live in the residential care home. Representation can be organized either formally through mandates given to a smaller group, such as in the case of resident councils, or in a more informal manner via deliberation among residents.

On all levels (micro, meso and macro) of influence of people in health care, we see a shift from having little influence to developments that create more room for influence of patients/clients/consumers. This can be seen as a culture change that takes place in society as a whole and that is reflected in the institutional context of long-term care too. This has led to a raised awareness of policymakers and managers in health care organizations to take the client perspective into account and to turn care homes into more humane communities.[23,47] However, practice is often more complicated than theory. The extent to which developments

towards more influence for clients in the institutional context of health care (meso-level), effectively leads to the feeling of clients that they are taken seriously and that they have real influence, has to be investigated. Thus, in this thesis, we will describe how existing forms of client participation in residential care homes are experienced by those who are involved and how the influence of older people in residential care homes can be developed to further strengthen the position of residents.

Degrees of influence of older people in residential care homes

The influence of older people who live in residential care homes on issues that affect their life can be related to several degrees of power. Arnstein (1969) critically assessed forms of citizen power in order to distinguish between real power and an 'empty ritual of participation'.[48] She developed a participation ladder to make visible the diverse levels of citizen participation (and thus of power), ranging from nonparticipation (manipulation, therapy) to tokenism (informing, consultation, placation) to citizen power (partnership, delegated power, citizen power). Arnstein refers to power of citizens in political and economic processes in hierarchical societies. Yet, the ladder can be translated to the context of residential care homes given the hierarchy between professionals and residents. Based on Arnstein's ladder, we use a client participation ladder with five levels of influence of older people in residential care homes (see figure 1).

It should be noted that this ladder does not represent the complexity and multidimensional nature of client participation. Also, it presents the outcome/type of participation and not the different ways and processes that can be involved. However, as a starting point for thinking about client participation this ladder can be helpful. The higher on the ladder, the more influence for older people in residential care homes. On the lowest rung, they are being informed (by managers and professionals) about the policy agenda that is set by the organization, without having a say in these issues. Clients are listeners. They can also be asked to provide information, for example through surveys. This information will be used by managers and professionals. Clients have no say in the way their information is being used. On the rung of consultation, the policy agenda is defined by managers and professionals, but they see clients as conversation partners. However, managers and professionals do not commit themselves to the outcomes of the conversations with clients. Advice is another step

Figure 1 Ladder of client participation in residential care homes, based on Arnstein (1969)

higher on the participation ladder. Managers and professionals set the agenda, but clients are given the opportunity to bring up problems, ideas and solutions, which play a full role in the policymaking process. In principle, managers and professionals commit themselves to the results, but they can still deviate from it. Partnership refers to the situation in which clients, managers and professionals develop a joint agenda and develop solutions issues together. Managers commit themselves fully to the outcomes of the partnership process, and clients, managers and professionals are partners who collaborate on an equal basis. On the highest rung of the participation ladder, clients take the initiative to develop services and policy plans on their own. Managers and professionals are not involved.

The question arises where existing forms of participation of older people in residential care homes, such as resident councils, can be situated on this ladder. Moreover, we are interested in the possibilities for developing forms of client participation higher on the participation ladder, in order to strengthen the position of residents in the context of long-term care facilities.

1.2   Research questions

The general question that underlies this thesis can be formulated as follows:

How can older people who live in residential care homes influence collective issues that affect their life in the institutional context?

The research questions that will be answered in this thesis are:

1. To what extent does the formal structure for client participation by resident councils support the influence of residents in the residential care home and how can this situation be improved?

2. What alternative ways and processes for client participation in residential care homes can be developed in order to strengthen the position of residents and their influence on issues affecting their lives?

3. What are barriers for alternative ways for client participation in residential care homes and how can these barriers be explained?

4. What are success factors for alternative ways for client participation in residential care homes?

5. How can insights about barriers and success factors for client participation be used in residential care homes?

1.3   Core concepts

1.3.1   *Older people*

In this thesis, we write about the influence and participation of older people who live in residential care homes. We are aware of the fact that by defining a whole group of people as 'older people who live in residential care homes', the rich diversity of these persons runs short. Therefore, in the following chapters we carefully pay attention to presenting the individual older persons we worked with. These persons are all unique individuals, whose personality, character and background greatly influenced and defined the outcomes of the research. Generally, people who are aged over 65 are defined as 'older people'. Another operational age limit for 'older people' is 55. However, both age limits hardly represent the experiences of these supposedly 'older people' themselves and a counterbalance can be found in numerous initiatives that focus on the life experience, talents, power and vitality of this older age group, such as elders councils (*e.g.* www.elderscouncil.org.uk), corporations (*e.g.* www.gilde-nederland.nl; www.ouderenorganisaties.nl) and initiatives that break through the negative stereotypes connected to old age (*e.g.* www.zilverenkracht.nl; The Eden Alternative, www.edenalternative.org). Almost 90 % of the people who live in long-term care facilities is aged over 75.[37] Therefore, a general distinction is made between the 'third generation' of vital older people, aged 55-75, and a 'fourth generation' of older people with a higher risk of frailty, aged over 75.[49] Most of the older persons who were actively involved in our studies were aged 76-92 at the time of participation. They all live in residential care homes and have varying degrees of care needs. Older people in residential care homes can be defined as patients, consumers, service users, clients, residents citizens. Each reference defines the underlying values of these diverse views. When people are defined merely as patients, the focus lies on their frailty, passivity and medical deficits. Labeling older people as consumers, service users and clients implies that medical and social services are commodities to be managed in a market.[50] In this role, older people are supposed to make rationally informed choices about the services they use and they have the power of exit and voice. Reference to older people as residents or citizens reveals dimensions of accountability, rights, belonging to a community and participation.[51] This definition presupposes a very active (or even activist) role of older people in standing up for social justice and making positive contributions to society and their own community.

The older people who were involved in our studies were approached in the first place as individual persons who find themselves in a similar situation or position (for example, being a resident council member and/or a resident, living in a residential care home). We do not want to generalize or limit these persons by defining them either as patients, consumers, service users, clients or citizens. In this thesis, we use diverse references, depending on the context and content of the separate studies that were conducted. We call the persons we worked with 'older people who live in residential care homes', 'clients', or 'residents'. In all instances, we refer to a very *diverse* group of people, who all have unique knowledge, life experience, health status, personalities and characters. They may be confronted with the challenges of growing older, its physical, mental, spiritual and social consequences, and a certain degree of vulnerability or frailty. At the same time they may be strong, powerful, resilient and wise. All stereotypes that exist about older people may (temporarily) apply to them, or -equally- none of the stereotypes may apply to them, and everything in-between. Who they are cannot be caught in a static definition, and who they appear to be and become in the relationships with others and with us researchers is strongly context-bound and constantly changing over time. Notwithstanding this diversity and dynamic nature of older people who live in residential care homes, common ground, mutual understanding, shared experiences, hopes and dreams can be found. By referring to 'older people who live in residential care homes', residents and clients in residential care homes we denote existing diversity as well as communality.

1.3.2 Participation

On the meso-level of client participation (collective influence of older people in the institutional context), several dimensions can be distinguished. One of these dimensions is *social participation* which generally refers to the participation of people in social and societal activities, such as paid work, volunteering, social contacts, social support and recreational and cultural activities.[52,53] Chronic diseases and functional disabilities form a threat to social participation of older people, and a reverse causal relation is also acknowledged.[51] Social participation contributes positively to health and quality of life.[54,55] In residential care homes, the social participation of older people can refer to their taking part in (leisure) activities organized in the care home, volunteering, having social contacts with other residents as well as with people 'from outside' the residential care home. Social interaction is considered to

have an important influence on the way older people in residential care homes view their quality of life, on their satisfaction with life, self-esteem, well-being, continued functioning and health.[56]

Another dimension of participation of older people in residential care homes concerns their *role in democratic policymaking processes.* This form of client participation consists of the work of resident councils, and is supported by the Dutch legal act *WMCZ*. It relates to the meso-level of influence of older people in health care, because resident councils act in the institutional context, representing the interests of the residents. Yet another dimension refers to the involvement of older people *in the process of improving care provision and services.* An examples of this dimension is the involvement of residents in care improvement programs (concerning quality of life and care) that are being implemented in residential care homes (www.zorgvoorbeter.nl). The first example relates to the participation of individuals and the second example refers to participation of groups of residents, who work together with professionals on a certain topic that is to be improved. In this thesis, we write about the latter two dimensions of client participation in residential care homes. We investigate the status quo of democratic participation (through resident councils) and some initiatives in which residents participate in processes to improve care and services. We draw a distinction between social participation and these other forms of participation: unlike democratic participation and participation in improvements, social participation of residents does not concern the realization of influence on the institutional context in which they live.

1.4   Methodological framework

In our studies, we used responsive evaluation and action research to respond to the dynamics in practice, to monitor and facilitate the process, and to investigate the newly gained insights in the furtherance of the overall study. We chose qualitative research methods because these offer opportunities for people to participate in the development of knowledge, due to the open, emergent design. Also, we wanted to develop alternative ways for client participation and gain insight in what this means for clients and professionals (instead of measuring effectiveness). In this section, we describe these qualitative designs and connect them to a transformative research paradigm.

1.4.1   Responsive evaluation

The roots of responsive evaluation lie in the 1970s. Calling for a wider scope for evaluation than mere goal-oriented evaluation, Stake (1975) introduced a responsive approach as part of his vision for educational research and evaluation.[57] Central to this vision is the broadening of evaluation criteria to as many stakeholder issues as possible, unlike evaluation models which merely include the goals and intentions of policymakers. In responsive evaluation, processes, backgrounds and judgments are included as well, rather than a focus on simply measuring outcomes.[58,59] These ideas have been further developed by others. Guba and Lincoln (1989), for example, built on Stake's work, proposing an interactive approach in which stakeholder issues are a departure point for negotiation to enhance mutual understanding and consensus.[60]

In our evaluation study (project with resident councils and managers) we used a particular version of responsive evaluation, linking the traditional responsive evaluation [57-60] to insights about narratives, storytelling and ongoing dialogues in evaluation.[61-67] The latter approach uses hermeneutic dialogue to engage stakeholders in a learning process to help them better understand themselves and each other, and hence place their own viewpoints in perspective. Stakeholders thus gain a better understanding of a given practice through the combination and amalgamation of various perspectives.

From a hermeneutic perspective, human life is essentially a process of interpretive understanding.[66] Through stories, people make sense of their world and are interconnected with each other.[67,68] Hermeneutic dialogue takes the complexity of human life (embedded in their stories and experiences) as a starting point for mutual learning processes in which all stakeholders change by way of interaction with one another. Change and learning processes occur when people extend their horizons by appropriating new perspectives. Dialogue in this hermeneutic sense is an ongoing and cyclical process among stakeholders, aiming at reciprocal understanding and acceptance.[64] Consensus is not the ultimate goal of this kind of evaluation, as it is never an absolute value—conditions change over time and a lack of consensus and ambiguities, expressed through the narratives of stakeholders, generate reasons to interact and continue ongoing dialogues.

Responsive evaluation involves four steps: (1) creating social conditions, (2) generating stakeholder issues, (3) conducting homogeneous focus groups to discuss issues among those with converging interests, and (4) conducting heterogeneous focus groups to bring perspectives together to enhance mutual understanding and learning.[65] Responsive evaluation is an iterative way of working: outcomes of former steps are used for next steps to validate, refine and integrate the various stakeholder issues. This approach to evaluation is very suitable to use in contexts where ambiguity, complexity, conflict or power asymmetries exist, since it takes into account the various experiences and values of stakeholders by first giving room for empowerment in the context of their own group (enclave deliberation) and then by facilitating dialogue and mutual understanding between stakeholders who start to develop a joint action agenda.[68-71]

1.4.2   Action Research

Action research is not easy to define, since it can be considered more as a dynamic umbrella term than as a static and clearly bordered approach to research. Reason and Bradbury (2008) describe action research as

'(…) a family of practices of living inquiry that aims, in a great variety of ways, to link practice and ideas in the service of human flourishing. It is not so much a methodology as an orientation to inquiry that seeks to create participative communities of inquiry in which qualities of engagement, curiosity and question posing are brought to bear on significant practical issues.' (p.1)[72]

In order to investigate and develop good ways for supporting and developing client participation, we needed a methodological framework that gives room for action and learning via collaboration with the people who live and work in residential care homes. Action research offers this framework, with its focus on engagement with people in collaborative relationships, its value-oriented approach of and its living, emergent process of designing, and the acknowledgement that 'we are embodied beings part of a social and ecological order, and radically interconnected with all other beings'.[72] Action research is not a specific research methodology, but a methodological framework and design in which planning, action and fact-finding about the result of the action form a cyclical process.[73] Reason and Bradbury

(2008) emphasize that action research is full of choices and that the exact way action research takes place is strongly context-bound and connected to the particular inquiry circumstances.[72] Therefore, in the description of the studies in which we worked with action research we will describe the methods we used in more detail.

We were particularly informed by appreciative inquiry as an action research methodology. Appreciative inquiry is seen as a way to counterbalance a focus on deficits and problem-solving. Instead of asking what problems people experience, an appreciative researcher focuses on causes for success, sources of what gives 'life' to organizations and people, dreams and visions on positive change. Ludema & Fry (2008) describe almost poetically what underlies this approach:

'It is based on the assumption that every living system has a hidden and underutilized core of strengths—its positive core—which, when revealed and tapped, provides a sustainable source of positive energy for both personal and organizational transformation.' (p.282)[74]

The 4-D cycle[74,75] inspired us to enter a search process with the participants in our studies by 1) discovery of the best what is, 2) dream to imagine what could be, 3) design what will be, and 4) destiny – to enact change and learning to become what the participants most hope for.[74] However, we did not only focus on the positive but gave room to frustrations and feelings of discontent as well. Otherwise these experiences would be suppressed instead of becoming driving forces for social activism.[76]

Responsive evaluation and action research are closely related and have many similar features (emerging design, collaboration with stakeholders, researcher as facilitator) and both aim for practice improvements, emancipatory change and involvement of all stakeholders. Responsive evaluation can even be seen as a form of action research as well. However, action research and responsive evaluation can be distinguished on the basis of their focus and utilization. Responsive evaluation is particularly suited for evaluating the status quo. Diverse perspectives are being investigated and dialogue is being facilitated in order to discover the values underlying the practice that is being evaluated. New practices follow from the basis of the joint action agenda that is created as last step of the evaluation, based on mutual

understanding of values. Action research focuses more on developing new practices and experimenting: it gives a central place to the creation of new situations or practices and further developing these throughout the research process. This is why we used responsive evaluation in our first research project (evaluating the status quo of the influence of clients by resident councils) and action research in the following research projects in order to develop new ways for enlarging the power position of residents.

1.4.3   Transformative research paradigm

Responsive evaluation and action research can be embedded in what is called a transformative paradigm in research and evaluation.[77] This paradigm reflects a value-committed stance on the part of researchers, working for social justice, equality, empowerment and emancipation. It focuses on:

'(1) the tensions that arise when unequal power relationships surround the investigation of what seem to be intransigent social problems and (2) the strength found in communities when their rights are respected and honored.' (p.10)[77]

The rationale for transformative research is to further social justice and human rights. It is argued that this form of research, combining an activist agenda for social justice and human rights with the assets of scientific research, is needed to address the inequities that push people to the margins of society.[77] Transformative research is about exploring what possibilities there are to break through asymmetric power relations and transform the social position of marginalized groups. Not by thinking about these possibilities from an 'ivory tower' but by developing them in real life, *together* with these groups. Thus, activism and science go hand in hand in this paradigm. Since this paradigm is very broad (as is every paradigm), we summarize the aspects of this way of thinking about and doing research that have most inspired our work. Within the transformative research paradigm, researchers try to foster social change, human rights and the improvement of quality of life of marginalized groups. They do this by taking an appreciative approach, asking positive questions that focus on the life-giving and life-sustaining aspects of people and communities. Further, transformative researchers try to enhance social relations between people and to stimulate collaboration and

mutual understanding between all those involved in order for power imbalances between them to become more balanced.[77,78]

Then, the research process itself is participatory, empowering and responsive to power inequalities. In transformative research, the researcher is not a distant 'expert' who empirically describes a practice and formulates recommendations for those in the 'field' to put into practice, nor is the researcher an external judge who criticizes practices based on normative frameworks and legal rights. Transformative researchers try to find suitable ways for working together with people and communities to define the issues, investigate the depth of their experiences and values, and to start to change practice immediately during and by the research project. By doing so they perform 'multiple partiality', which is a different attitude than being a neutral and external party. On the contrary, transformative researchers explicitly work to create good social conditions with all participants in the research that allow for trust and mutual understanding to develop. The relationship between the researcher and the participants is grounded in epistemological, axiological and ontological assumptions. Transformative research is based on the epistemological assumption that all knowledge is socially constructed. As such, the relational location of the researcher matters to what knowledge is generated and is subject of critical scrutiny.[76] The underlying axiological (normative) assumption relates to an ethic of care perspective, in which the relational quality between researcher and participants should be based on reciprocity and the balancing of normative expectations of all those involved (researcher and participants).[61] The researcher should strive for research outcomes that contribute to social justice and ownership of participants. This axiological framework closely relates to the ontological assumption that human beings are fundamentally relational and storytellers who give meaning to our social world as a product of social interactions and relations. Working from these assumptions, the transformative researcher is never a distant expert, but always engages with the participants in diverse roles, for example in the role of facilitator (enhancing dialogue between groups), educator (learning people to see diverse perspectives), and/or Socratic guide (probing into the already existing but sometimes latently present experiential knowledge of people). Which role(s) a transformative researcher plays depends on the personal characteristics of the researcher, the context, aims and backgrounds of the study, and the characteristics and needs of the group of participants. This is an emergent and flexible process in which the researcher
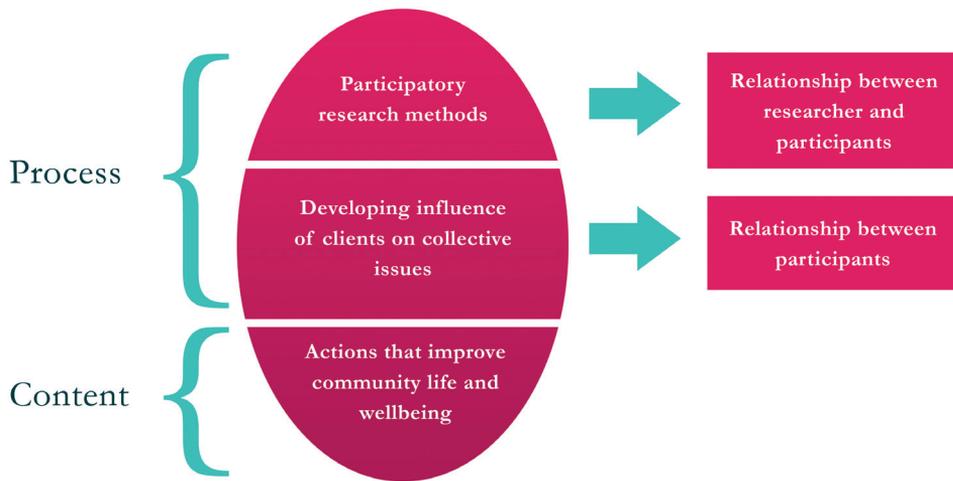
Figure 2 Transformative paradigm in our research

should be self-reflexive and enter a high-quality awareness to understand the psychological state of themselves and others.[77]

In figure 2 below we visualize how the transformative research paradigm interweaves the three core features of our research. The ellipse shows that the focus of our research is on the middle part: developing influence of clients on collective issues that affect their life in residential care homes. The relationship between researcher and participants will be addressed by the 'Reflection on Self-in-Relation' sections in this thesis.

Thus, this study is not merely a description of the current state of affairs concerning the influence of clients in residential care homes. We have the explicit aim to strengthen, improve and develop client participation in residential care homes. The research projects we conducted are transformative in nature. With our study we aim to contribute to the democratizing of elderly care institutions, by experimentally developing forms of client participation together with residents to see in what ways they could influence the collective issues that affect their life in the institutional context. By taking qualitative, participative and action-oriented research approaches (responsive evaluation and action research) groups that had felt marginalized became actively involved in improving collective issues in the institutional context and thus their influence and empowerment already developed during the research projects.

Therefore, all projects that are described in this thesis are double-layered, as is visualized in figure 2. There is the *content* of the actions that improve community life and wellbeing of clients (the interactions between resident councils and managers; the personal care files; the quality of the meals; the social interaction between residents) and there is the *process* of how these actions have come about through dialogue among and between the groups that were involved. It is this process that we focus on, since the facilitation of resident participation shows the way towards creating care organizations that give room to the voice of residents.

Responsive evaluation and action research fit with the transformative research paradigm in several ways. Responsive evaluation provides a systematic methodology for exploring all stakeholders' issues and to enhance mutual understanding of values between interest groups. Further, in responsive evaluation dialogue has a central place as a vehicle for social change and practice improvements. In our study in which we used responsive evaluation, we strived for social change (improvements in the interactions between and practices of resident councils and managers) and ownership, based on the experiential knowledge and involvement of multiple stakeholders. Also in action research, contributing to social change and ownership of participants is an important driving force. In the research projects in which we used action research we focused on developing the influence of clients in residential care homes, which is a profoundly transformative goal in itself.

1.5   Description of studies and methodology

1.5.1   *Evaluating resident councils*

The first study was funded by a provider of care services for older people and people with a chronic disease. The occasion for commissioning this study was the fact that resident councils rung the alarm about the lack of influence they experienced. Thus, the study aimed to evaluate the status quo of client participation in residential care homes through resident councils by investigating the experiences of all stakeholders (resident councils and managers). Also, responsive evaluation was explicitly used in this study as a vehicle for change and practice improvements as the resident councils and managers developed a joint action agenda to

further strengthen their collaboration and communication. This is a transformative research goal.

Our research activities consisted of participant observation of council gatherings and group interviews with the resident councils (one per location; eight in total); participant observation of one central resident council gathering; fourteen in-depth interviews with various stakeholders (resident council members, managers); a homogeneous storytelling workshop with resident council members; a homogeneous focus group with managers; and a heterogeneous storytelling workshop with resident councils and managers. The interviews took between 1.5 and 2 hours and were recorded, following approval. The interview reports were sent to the respondents for member check.[60] Field notes were taken during the participant observations and were used in the analysis of the issues together with the analysis of the interviews that had been accorded by the respondents after member check. These findings were further validated by the homogeneous groups with resident councils and managers separately. We used the format of a storytelling workshop for the homogeneous meeting with the resident councils as well as for the heterogeneous meeting with all stakeholders together, because this is a suitable way for enhancing deliberation and mutual understanding.[66,67,69] Finally, we integrated our empirical data with existing theory on system and lifeworld[3] in order to develop insights about the tensions that were experienced by resident councils and managers in their collaboration and to gain a better understanding of possibilities to change these tensions into learning opportunities and improvements relating to their interaction.

The study resulted in 2 articles (chapter 2 and 3). Both chapters will provide insights concerning barriers and success factors for client participation through the formal structure of resident councils (research questions 1 and 2).

1.5.2   *Collaboration between one client and seven professionals*

Our second study (as well as our third and fourth study) was funded by Mosae Zorggroep, an elderly care organization with five residential care homes with diverse services (ranging from home care to more specialized psycho geriatric care). The study took place in one of these locations, a residential care home. A team of professionals was established to plan

the implementation of the new care files in this residential care home. The overall aim of implementing new, more personalized and holistic care files was to improve residents' involvement in the care they receive. Since Mosae Zorggroep's aim was to support the development of new ways for client participation, the manager was open to our suggestion to create room for client participation in the planning and implementation of the new care files. He decided to involve one client in the project team. In this study we closely followed the interactions between this client and the professionals in the project team with the aim to investigate the barriers and success factors of this specific form of client participation. We also had the transformative research aim to support the client participation where needed in this specific context of the team.

We used a combination of qualitative research methods: participant observations of all team meetings (13 meetings, 26 hours in total); informal conversations with team members were held regularly; 6 in-depth interviews were conducted with five team members by the time the project concerning the care files ended (the client was interviewed twice; at the start of the project and on conclusion of the project); 2 evaluation meetings were organized to enhance joint reflection on the collaboration between the team members (one evaluation meeting took place after the first half year of the project, the other evaluation meeting half a year after the project on the care files had ended). Field notes were taken during the participant observations. The interviews were recorded and a written summary was sent to the respondents for member check. The evaluation meetings were recorded and summarized as well, and sent to the respondents for member check. Also the draft research report was sent to the participants, and their reflections on the report were part of the last evaluation meeting. This way, the analysis of the data was validated. Moreover, the preliminary analysis in the draft report turned out to be a catalyst for the joint reflection, as it helped the participants to place their experiences in a broader, theoretical framework.

This study resulted in 1 article (chapter 4). This chapter will particularly contribute to answering research questions 2 and 3.

1.5.3   Collective action of clients to improve the meals

On the basis of gained insights about barriers for client participation and influence, we conducted the third study with the aim to find ways for resident participation supplementary to resident councils. The study took place at the same location of Mosae Zorggroep where we conducted our previous study on the participation of one client in a team of professionals. The status quo of client participation in residential care homes and the barriers we found in our previous studies made action research suitable for our transformative research goal to experiment with new forms of participation.

Insights from responsive evaluation and dialogical patient participation in research (the Dialogue Model)[79], influenced our choice to globally design the action research in two phases: first homogeneous consultation and then integration of perspectives. This way, we could address asymmetric power relations and pay attention to the empowerment of clients in a safe setting before going into dialogue with other stakeholders. We started with an exploration of experiences of clients with their life in the residential care home and their experiences with participation. We did this by organizing a group conversation with clients of this location about their experiences and values in life. After this meeting, seven of these clients (all female) were enthusiastic about the idea of having more group conversations like this and participating in our research to develop client participation. It turned out quickly that their main concern and topic of interest was dinner time and the quality of the meals. In total, this group of clients (calling themselves the Taste Buddies) gathered eight times over a period of seven months. An appreciative approach was taken to respond to the dynamics of the group. The integration of perspectives took place by organizing four dialogue meetings in which the Taste Buddies deliberated with other stakeholders (managers, kitchen staff). This led to the formulation of a joint action agenda and actions that relate to improving the meals.

Field notes were taken during the meetings and summarized in short report that was shared with the clients every time. This was part of the collaborative analytical process in which the researcher and the participants reflected on the interactions within the group, the subject of the desired actions to improve the wellbeing of residents and the actions to be taken. Every step of this action research was deliberated on together with the action group of clients. We

also shared with them the draft research report and deliberated with them about the question whether they recognized the process as it was described.

This study resulted in 1 article (chapter 5). This chapter will address research question 3.

1.5.4   Evaluation of the process and perceived effects of the PARTNER intervention

Based on theoretical insights and our study with the Taste Buddies we developed an intervention for resident participation. We call this procedure the PARTNER intervention. This intervention was used in another location of Mosae Zorggroep than the location where the previous two studies were conducted so that the development of client participation could be spread further into the organization. The clients who were involved in the intervention wanted to strengthen the social interaction between residents. This became the driving force for these clients to follow the steps of the intervention. The fourth study of this thesis aimed to evaluate the process and perceived effects of the intervention. We conducted 16 qualitative interviews with residents, volunteers and professionals, three focus groups and participant observations. This study shed light on the significance and impact of the PARTNER intervention on enlarging the influence of residents on improving collective issues. This part of our study led to 1 article (chapter 6) in which the PARTNER intervention and its qualitative evaluation are presented respectively. This article relates to research question 4.

1.6   Outline of this thesis

This thesis is divided in two main parts. The first part, *'Resident Councils'*, describes the status quo and the (limited) room for improvement of formal participation of resident councils in policymaking processes and developing actions that contribute to community life and wellbeing of clients in residential care homes. This part consists of chapter 2 and 3. In chapter 2 we will describe the tensions between resident councils and managers and analyze these against Habermas' theory on the friction between lifeworld and system. The pitfalls and possibilities for bringing the worlds and perspectives of resident councils and managers closer together will be explored and described in this chapter as well as in chapter 3. Furthermore,

in chapter 3 we will relate the practice of resident councils and managers to insights from responsive evaluation concerning hermeneutic dialogue.

The second part of this thesis concerns *'Alternative ways for resident participation'*. In this part we investigate the possibilities for developing alternative ways of participation and influence of residents on collective issues that affect their life in the institutional context. This part consists of chapter 4, 5, and 6. In chapter 4 we will address a specific form of client participation in which one client worked together with professionals in a care improvement team. We will explore the dynamics and interactions between these team members in presenting an ethnodrama. In chapter 5 we describe the coming into existence of a new way for client participation: the case of the Taste Buddies. Chapter 6 will describe the outcomes of the qualitative evaluation of the process and perceived effects of the PARTNER intervention in the context of the case of the Social Interaction Group.

The chapters 3, 4, 5 and 6 will each be followed by a section of 'Reflections on Self-in-Relation' concerning the researcher's role in relation to the research participants. In transformative research, critical self-reflection is needed to understand the psychological state of self and others so that the development of dialectical relationships are enabled. [76] The 'Reflections on Self-in-Relation' also reveal the learning process of the researcher

Finally, in chapter 7 we will bring the insights from the distinct studies in the two parts of this thesis together. We will answer the research questions by summarizing and discussing our main findings and new insights. Further, we will reflect on the transformative research paradigm (including the meaning of the 'Reflections on Self in Relation'), methodological issues and implications for further research and practice. We will conclude this chapter with a general conclusion.

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