Chapter 7

Discussion and general conclusion

8.1 Introduction

Enlarging the influence of older people who live in residential care homes on collective issues that affect their life in the institutional context is a development that can be placed within broader societal trends and values. Client-centered care, inclusion of 'lay' voices in public decision-making and research, the rise of a liberal healthcare market and legislative support for resident councils are all trends in our Western society that focus on strengthening the position of patients. [1-7] In the context of residential care homes for older people these developments are reflected in practice as well. However, institutional and personal barriers, such as asymmetric power relations, dependency, depersonalization, disengagement and frailty hamper the influence of people who live in residential care homes. [8-15]

The aim of this study was to investigate how older people who live in residential care homes can have influence on the collective issues that affect their life in the institutional context. Besides the aim to generate knowledge on barriers, success factors and prerequisites for influence of older people on collective issues in residential care homes, we had the transformative aim to improve this practice. Departing from these aims, we formulated five research questions:

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 collective 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?

In this chapter we will answer these questions by summarizing and discussing our main findings and new insights. Further, we will reflect on the transformative research paradigm, methodological issues and implications for further research and practice. We will conclude this chapter with a general conclusion.

8.2 Main findings

8.2.1 The practice of resident councils

In this section we will answer the first research question:

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?

In chapter 2 and 3 we have described the responsive evaluation of the practice of resident councils in a large resident care organization with ten locations in the South of The Netherlands. In this organization, ten local resident councils existed and one central resident council (consisting of two representative resident council members from the local councils). In this care organization, the resident councils had rung the alarm about the lack of influence they experienced. Responsive evaluation was chosen as a research design in order to include multiple perspectives and to enhance dialogue and mutual understanding of underlying values between resident councils and managers. This led to learning processes for resident councils and managers as a fundament for improving their interactions.

Issues of resident councils and managers

The interviews and focus groups shed light on the experiences of resident council members and managers. Resident councils felt they had no real influence on decision making processes. They expressed difficulties with reading and understanding difficult and bulky policy reports,

that were given to them in a (often too) late stage of the policy-making process so that the resident councils' advices were not relevant anymore. Further, resident councils often had the experience that managers set the agenda (top-down communication) and that there was little room for deliberation on issues the councils thought to be important.

Managers expressed their doubts about the capabilities of the resident council members to be effectively involved in decision making and to have a say. Some managers saw the resident councils as a hurdle to be taken, since it takes extra time to explain the complicated policy plans in understandable language. They critiqued the resident council members for holding on to their own personal issues and not being able to expand these personal issues to a well-founded vision on the general well-being of residents. Contact between the resident councils and the residents they represented was scarce. Another critical remark related to the fact that only few actual clients participated in resident councils; resident councils mostly consist of family members and volunteers and only few people who live in the residential care homes. Other managers wanted the resident council to be more critical and activist, so that the resident council could be a sounding board for them.

Moreover, managers and resident councils held different scopes on what matters to them most. Resident councils mainly focused on the daily lives and well-being of residents in the location they represented, whereas managers had to combine the policy interests of the organization as a whole with their attempt to protect and enhance the well-being of the current and future residents in the location they managed.

Friction between lifeworld and system

We explained these arising issues against the background of Habermas' theory on lifeworld and system. [16] Habermas (1987) describes how in modern western society, a process of rationalization has led to a divergence between lifeworld and system. The system relates to material reproduction in society and is driven by the economy and the state. The system is characterized by instrumental action, directed at profit, the regulation and rationalization of relations between citizens, and the strengthening of one's own position within the system through strategic action. People fulfill different, rather circumscribed, social roles in the

system, for example as professionals. This social role gives them power in certain domains, they acquire identities that go with such a role, and when communicating they use specific (e.g. professional) rationalities. Power in the system is power over people, and authority is not granted but related to position. The lifeworld refers to the symbolic reproduction of meanings in of society and is characterized by values that are intrinsically cultural and personal (for example solidarity and social justice), and by communicative action. The lifeworld can be seen as a coherent set of cultural and social values and identity structures that form the unproblematic horizon for human interaction. Communicative action is directed at finding agreement and shared understanding. Power in the life world is power with others, and power to realize communal values. Members of a community produce meaning, identity and solidarity by acting communicatively. In an ideal communicative situation (which according to Habermas can never be fully realized) communication proceeds in power free settings, with room for communicative rationalities (which are not in the first place instrumental) and reflexive identities.

Both worlds are intrinsically valuable, and originally they are interdependently connected. However, according to Habermas, system and lifeworld have become uncoupled and problems arise when the system in the words of Habermas 'colonizes' the lifeworld. This means that the mechanisms of the system penetrate the lifeworld to such an extent that the lifeworld is overshadowed and dominated by system values. Meaning, identity and solidarity become undervalued, leading to alienation, frustration, and unrest.

In elderly care institutions residents and professionals meet each other in a shared environment that has different meanings for them. Residents *live* in the residential care home. They are there day and night, it is the context of their lifeworld, their meaningful interactions and quality of life. For clients, the actual 'here and now' issues are most important to them, since this relates to the lifeworld values they represent and with which they are continuously being confronted. It is the task of professionals to ensure that residents feel comfortable in their environment and that they receive the care they need. Professionals thereby enter the living environment of the residents and simultaneously also take with them their own lifeworld: their backgrounds, their own 'codes', values and personal identity.

Managers' identity, rationality and power position can be placed in the dominance of the system, where strategic action (driven by the forces of money, market, bureaucracy, etc.) is central to their framework of thinking and acting. This strategic action collides with the identity, rationality and power position of resident councils, that focus on lifeworld values (*e.g.* quality of meals, having a garden to walk in) and communicative action. Even though these lifeworld values are indeed part of managers' outlook on maintaining the quality of care and services in the residential care homes, managers experienced a tension related to their position in the organization. Managers felt they had to think strategically about the continued existence of the organization in the light of scarcity of means c.q. restructuring of care services and at the same time they had to watch the well-being of residents and feel connected to the lifeworld experiences of resident councils. This made them feel like they were torn two ways. Resident councils, in their turn, felt frustrated as well. They had the feeling they could not get across their lifeworld values in order to really make a difference in the policy processes they were confronted with. They felt overwhelmed by the reports and difficult issues that were set on the agenda by managers (which they are obliged to do, as laid down in the legal act concerning resident councils' rights and duties).

Improving the situation

Our responsive evaluation not only shed light on these issues, but was also a means to start to improve the interactions between resident councils and managers. By first developing voice and sharing experiences in their own (homogeneous) group, resident councils and managers were prepared to enter a dialogue about their experiences and values. A shared learning process developed in a heterogeneous storytelling workshop, based on the mutual understanding and acknowledgment of the values that underlie both resident councils' and managers' aims and wishes. Special attention was paid to the perspective of resident councils, by starting with their story. This was a conscious decision in the evaluation, since resident councils were in a less powerful position towards managers. In this heterogeneous dialogue, resident councils and managers discovered that, despite their differences and communication difficulties, they shared common ground in valuing and prioritizing the well-being of residents. From this basis of common ground and mutual understanding, a joint action agenda was developed in order to further improve the interactions between resident councils and managers in practice.

Thus, to answer our first research question we conclude that the formal structure and legal existence of resident councils does not automatically guarantee a powerful position of resident councils and equal relations between clients and professionals. On the contrary, in practice it turns out that resident councils mostly feel disempowered. Often, they do not feel heard. We also see that these frustrations not only exist for resident councils, but for managers as well. The managers in our study were relatively receptive to taking the resident council seriously, but they experienced several hindrances in their collaboration with resident councils.

We explained these tensions with Habermas' theory on lifeworld and system. And although practical problems regarding representativeness and capabilities of resident council members and the top-down agenda setting by managers may exist, we learned there is room for improvement. In the responsive evaluation project, resident councils and managers came closer together and created a space for communicative action during the heterogeneous dialogue. They found common ground and shared values (well-being of residents) from which they could build actions to improve their collaboration. By communicative action, identity, power and rationality in the system can start to shift, leading to a better balance between lifeworld and system. Identity that used to be mainly derived from position and function can become more personalized. Power becomes more relational and develops as collaboration and mutual understanding. Rationality becomes broader, giving space to emotions and passionate expressions.

8.2.2 Alternative ways and processes for client participation

The insights in the tensions and barriers that are experienced by resident council members and managers concerning this formal structure for client participation, led to the following research question:

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?

The research we conducted resulted in three case studies in which alternative ways for client participation were developed and evaluated: a) the case of one client in a project team of professionals, b) the Taste Buddies, and c) the Social Interaction Group. The first one is a form of individual client participation (one client who is asked to represent the interests, experiences and perspectives of other clients), the other two are forms of collective client participation (a group of clients who represent the interests, experiences and perspectives of other clients). We will describe here by what processes these forms of client participation, as developed in these case studies, are characterized.

One client in a project team of professionals

In a residential care home, a team of professionals was established to plan the implementation of the new care files. The overall aim of implementing new, more personalized and holistic care files was to improve residents' individual involvement in the care they receive on a micro-level. In order to create room for client participation in the planning and implementation of the new care files, the management decided to ask a client to become involved as a member of the project team. This client participated in the project by attending the meetings of the project team and sharing his thoughts, experiences and ideas with the other team members. This process was featured by direct interactions between this client and the professionals. This form of client participation was a new undertaking in this residential care home, both for the resident who became involved in the project team and the professionals.

In this case, the participation of this client was added to the normal routine of the professionals concerning attending team meetings and managing projects. From the start of this project team, client participation seemed to be something that could easily be fitted in the project work of the professionals. It turned out to be more complicated, and the dominance of system over lifeworld became visible through the confrontations between the perspectives of the client and the professionals in this team. This made the client feel he was standing alone. The professionals felt confused, looking for the right balance between the lifeworld stories of this client and their own lifeworld values on the one hand and their professional agenda and consumer rights, driven by system values, on the other hand. However, the process of this form of client participation was also featured by reflection and learning when the

participants were invited by the responsive evaluator to share experiences. This form of client participation shows that it can stir up the normal routines and roles of professionals and thus gives way for learning processes and insights about each others' roles, functions and the relationships to one another. In the responsive evaluation, room was created deliberately for systematic reflection on various stakeholder issues concerning the process and outcomes. The team members learned that issues of power and identity were underlying their interactions. The professionals and the client learned that differences between people can be valuable, if only their existence is acknowledged in the first place. Professionals learned that their own lifeworld values are important to be shared with others, including clients, in order to create more equal and open deliberation and relationships.

The Taste Buddies and the Social Interaction Group

Contrary to the case of one individual client joining a predetermined project and becoming a member of a project team of professionals, in these two case studies *collective* client participation was developed around issues put forward by residents. The process of the Taste Buddies was characterized by an open and experimental start by organizing a conversation between a group of diverse residents about how they experience living in the residential care home. This led to recognition of these residents that they had shared experiences. They decided they wanted to come together more often together with the action researcher, because they enjoyed speaking with each other about their experiences. One particular topic turned out to be extremely important to them: the quality of the meals. This client participation project then started to develop from the basis of this shared topic. Residents started to explore shared experiences concerning their influence (feeling disappointed and powerless to change something about the meals).

Initially these residents felt that complaining was not done, and emphasized their gratitude for the care and services they received in the residential care home. The turning point in this process came when one of these residents shared a story with the others about a situation in which she refused to pay for the meals. This act of civil disobedience stimulated the others in the group to see that they have a choice and that they can actually have influence on things in the residential care homes. It made them decide that they really wanted the meals to be

improved. Relational empowerment started to develop: the residents acknowledged that they were not on their own and they supported each other to trust their own experiences and opinions. However, this process started to stagnate during the meetings, because the sharing of negative experiences and complaints seemed to become a negative spiral. Therefore, the researcher stimulated the group to envision their ideal meals by making a collage together. This brought new energy in the group and they learned how to transform their complaints into a constructive advice for the management and professionals of the residential care home to improve the meals. This group of residents proudly started to call themselves 'the Taste Buddies' and showed a sense of responsibility and ownership concerning the improvements of the meals they proposed. They spoke with other residents, managers, volunteers and kitchen personnel and developed collaboration and partnership with them by creating a joint action agenda for improving the meals.

Ultimately, this led to the realization of many improvements with regards to the meals and the organization of dinner time in this residential care home (for example the re-opening of the kitchen at location with two cooks). The manager of the location also sees a relation between the dialogue among stakeholders developed in this location and practice improvements in general. The location received two awards (Het Goede Gesprek) from the Ministry of Health, Welfare and Sport for good dialogue in 2010 and the location is in the top 10 of best residential care homes in The Netherlands. [17]

This experimental form of client participation, that resulted in improvements of the meals and more general practice improvements and the continued existence of the Taste Buddies, was translated into a practical work format (the PARTNER intervention which has been described in chapter 6 and further in this chapter 7 in detail) and was then used in another residential care home of Mosae Zorggroep to evaluate how this process was experienced by residents, volunteers and professionals, and what effects they perceived. In this new project, the residents wanted to strengthen the social interaction between residents. We call this group the Social Interaction Group.

The process of the Social Interaction Group developed around the urgency that was experienced in this residential care home concerning the social interactions between

residents. Not only residents, but also professionals and volunteers were concerned about the way residents interacted with each other (exclusion, gossiping, formation of cliques) and at the same time they all felt rather powerless to change something about it. A group of residents, who had expressed concerns about the social interactions in other project groups in the residential care home, was brought together to speak about this topic. One resident in the group had experienced feelings of exclusion herself, and she shared her disappointed feelings in the resident group. Some other residents in this group had seen similar patterns of interaction with other residents, and thus understood the feeling of this particular resident, even though they did not experience exclusion themselves (or took an indifferent position towards what other residents thought of them). Two other residents in the group, a married couple who lived at the department for Indonesian people in this residential home, had not experienced or seen exclusion of residents. On the contrary, at their department they experienced strong social ties and friendship between residents. However, they were touched by the stories of the other residents and felt the urgency to improve the interactions because they wished for other residents to have the same positive experience as they had themselves.

The Social Interaction Group started to develop their ideas about strengthening the social interaction between residents. The different experiences of the residents in this group turned out to be a source of inspiration for them: the positive experiences of the residents in the Indonesian department led to the idea of the resident group to think of something that would bring other residents closer together as well. They spoke about how most of them did not really know their neighbours, and they also exchanged experiences of how new friendships were being build in the residential care home and examples of mutual support between residents. Also in the group itself, residents started to support each other. For example, the resident who was very troubled about her experiences of being gossiped about, was stimulated by the others to have more self-confidence and to look for good contacts instead of focusing on the people who were excluding her. This support has helped her a lot, as she herself and the others, who saw her change, emphasized.

The group decided to take an appreciative approach to the topic of social interactions, by not merely focusing on the problems of exclusion but by looking at the good examples that were already present. From that basis, they came up with the idea to organize ‘gallery parties’

for residents who were neighbours at their floor in order to get to know each other and to strengthen social interaction, friendship and mutual support. The organization of the gallery parties became the collective action and dream of this group of residents. They organized a pilot gallery party together with the activity leader and some volunteers. Also, they wrote together a newspaper article, in which they protested against the stereotyping way the media paid attention to bullying and negative interactions between older people in residential care homes and nursing homes.

During this process, also volunteers, professionals and managers were asked about their experiences and ideas concerning the interaction between residents. Hearing the experiences of residents, represented through a narrative in which these experiences were summarized, helped to relate to the issues concerning social interaction between residents. They recognized the tensions that were described. Volunteers, professionals and managers developed their ideas about supporting residents who felt lonely and excluded, resulting in the plan to re-institute the buddy project in which individual residents can get in touch with a volunteer who accompanies them in activities.

In a dialogue between the residents from the Social Interaction Group, volunteers, professionals and managers, the success of the pilot gallery party was discussed as well as the underlying ideas and values. Also, the idea to re-institute the buddy project was being discussed. The result of this dialogue was the joint agreement to have a monthly gallery party, organized by residents themselves, with some practical support from volunteers. Also, they decided to compile a small working group of some residents, volunteers and the activity leader, to speak about ways to re-institute the buddy project.

8.2.3 Barriers for alternative ways for client participation

Based on our own empirical data concerning the participation of one client in a team of professionals, in this section we will answer our second research question:

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

Our study on the interactions between a client and professionals in a project team with the joint remit to plan the implementation of a new personal care file for residents (described in chapter 4), brings some barriers for the influence of clients to the fore, related to process and structure. In order to give way to more direct influence of clients on the policymaking process, the management of the location where we conducted this study was very receptive to our idea to include the client perspective in the personal care files project. The management invited one client to become involved as a member in the project team. The developments with regards to this mixed team with one client and seven professionals show that even when all parties have sincere intensions to collaborate as equal partners, the different perspectives and identities of clients on the one hand and professionals on the other can be difficult to unite. The data from this study provide some answers to this research question about barriers for client participation in residential care homes.

Again friction between lifeworld and system

The first barrier we distinguish relates to insufficient acknowledgment of differences between people. With the intention to work together as equals, clients and professionals can easily overlook their divergent identities, rationalities and power positions, which may even only become manifest when they start working together. This barrier is connected to the friction between lifeworld and system, as we saw occurring in the relationship between resident councils and managers as well. The professionals, who were used to acting instrumentally within the system world of the organization, were confronted with the lifeworld of the client in this team. His personal stories and attempts to discuss with the professionals what he experienced to be core issues of living in a residential care home (such as 'what does it mean to be ill', 'what is good care', etc.), confused the professionals as it was alien to their usual way of communicating and functioning. The client appealed to the lifeworld values of the professionals, to their presence as human beings rather than as bare representatives of the organization they work for. At the same time, the professionals tried to give the client a place in the system world. This tension confronted the members of this project team with differences concerning power, identity and rationality. When these differences between residents and professionals are not being acknowledged and scrutinized in residential care homes, client participation will be hindered.

Narrow notion of deliberative legitimacy

Another insight we gained from this case study is that a focus on dispassionate and disembodied expressions as defining good deliberative quality forms a barrier for client participation. This leads to exclusion of those who express themselves in an emotional way, using figurative language, wide gestures and so on. Deliberation with its claims to democratic legitimacy based on rational arguments and its demands for reason, consensus and the common good runs short in acknowledging differences, emotive language and emotional engagement. [18-22] In this narrow notion of rationality and deliberative legitimacy, marginalized groups may not get the opportunity to bring their views to the fore. [22] In the context of residential care homes, a narrow notion of what is an authoritative knower and conversation partner, what is legitimate input in deliberations and policymaking processes and of what is a legitimate style of communication can form a serious barrier for client participation.

Deliberative quality runs short when the norms of deliberation (inclusion, equality, reasonableness, and publicity) are not met. [21] When there is none or insufficient interaction between representatives and those who are represented, at least two norms are not realized, namely inclusion and publicity. This was the case with the situation in which only one client was involved in a team of professionals. Further, deliberative quality runs short if only a limited view of deliberative democracy is taken into account, excluding people who express themselves differently (emotionally, passionately) than the mainstream deliberative standard implies. [21-23] This became visible in this case study as well: the resident expressed himself emotionally, telling stories and sharing personal anecdotes.

Individual client participation

Connected to this latter insight about a narrow notion of deliberative legitimacy, is the insight that individual client participation (one client who becomes involved in a team of professionals) is not an ideal form of client participation. Our study shows that the client who was involved in the team of professionals felt he was standing alone. This feeling stemmed from not being understood and/or being acknowledged as an equal partner by the professionals (due to the differences concerning identity, rationality and power). The dominance of system over lifeworld may lead to disempowerment of residents if they feel

unable to bring their message across to the professionals or if their issues are not represented on the policy agenda. The dominance of the system over lifeworld was already present from the very start of the collaboration between the client and professionals in this team because the project design was predetermined by the professionals. Further, the fact that this client was indeed the only client in the team increased his feelings of disempowerment. Moreover, he had little contact with other residents and hardly engaged in deliberations with other residents about their shared experiences. This complicated his (informal) role as being a representative for other clients in the project team.

8.2.4 Success factors for alternative ways for client participation

Based on our studies, we can now answer the third research question:

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

The three case studies in which alternative ways for client participation were developed and investigated, show several aspects that can be described as success factors that foster client participation. In the case study with one client in a project team of professionals, the reflection meetings of the responsive evaluation ultimately led to more mutual understanding between the client and professionals. This process showed the importance of joint learning processes as a success factor for client participation. In the other two case studies (the Taste Buddies and the Social Interaction Group), the process of client participation was featured by agenda setting and collective action of residents, relational empowerment between residents, and dialogue between residents ('enclave deliberation') before dialogue between residents and other stakeholders ('proportional dialogue'). The dialogue between residents and other stakeholders led to mutual understanding of the underlying values as the basis for joint action and collective empowerment. In both cases, residents and professionals developed a joint action agenda and started to work as partners. These are all success factors that we will now further explain.

Collective agenda setting and action by residents

The Taste Buddies and the Social Interaction Group consisted of residents who developed collective action together on a topic that really mattered to them. Collective action requires three conditions: a shared dissatisfaction, group solidarity and a longed-for future. [24] The sharing of experiences through storytelling can lead to emotional recognition and feelings of solidarity when people discover that they are not alone in their dissatisfaction or discomfort. By coming together as a group, they started to exchange stories. Stories play an important role in the meaning-making process. [25] According to Rappaport, the support of a collectivity can provide a new communal narrative that sustains the personal life stories of people in positive ways. [25] In turn, individuals create, change, and sustain the group narrative.

We have seen this with the individuals who participated in the Taste Buddies: at first they all thought they were the only one with dissatisfactions about the meals, but through exchanging their experiences they discovered that they shared feelings of disappointment and sadness concerning the meals. The residents in the Social Interaction Group discovered a shared concern with the way residents interacted. The individual stories helped to construct the communal narrative. For example, in the Social Interaction Group, the female resident who felt frustrated and vulnerable because of gossiping, contributed to the communal narrative of the group by a sense of urgency, solidarity, altruism (wanting to support her), and satisfaction (when the others started to see a positive change in this resident). The story of the individual 'Taste Buddy' who refused to pay for a meal contributed to the communal narrative of the Taste Buddies confidence and pugnacity. Their new, communal narrative became one of empowerment because they added the possibility of influencing, or at least resisting, the status quo. The joint longed-for future they envisioned (with good meals and good social interactions between residents) became an important driving force for the Taste Buddies and the Social Interaction Group to keep coming to the meetings and formulating their ideas and plans for improvements.

Good meals and good social interactions are what political philosopher Melucci calls the 'love objects' of these residents, which have a high motivational value. [24] The emotional recognition these residents found in these two groups, constructed their collective identity,

based on their sense of solidarity. Collective identity is needed for a collective actor to come into existence. The collective identity of the Taste Buddies is illustrated by the name they thought of for themselves. In the Social Interaction Group, the collective identity can be found in what they referred to as a 'belonging to a family'.

Thus, a success factor for client participation is fostering the prerequisites for collective action by bringing residents together for exchanging their stories and developing their own agenda and actorship.

Enclave deliberation first

This is the principle to first bring together persons from the 'marginalized' group(s) in order to develop voice and empowerment in their safe group of peers before organizing dialogue between diverse groups. [26-29] This relates to what Karpowitz et al. (2009) call 'enclave deliberation', which is the development of an intimate and political voice of marginalized groups within a 'protected enclave' in which people with the same interests can explore their ideas in an environment of mutual encouragement. [22] Exclusion of people and discourses that do not fit with the focus on rational discourse (adjusted to democratic legitimacy), can be prevented by enclave deliberation. Enclave deliberation can stimulate participation of marginalized groups, develop their critical awareness, knowledge and skills, help them discover common interests, and it can contribute to the inclusion of a broader range of arguments in the democratic process. [22] However, enclave deliberation needs to be followed by exposure to and dialogue with the larger, heterogeneous public sphere. [22] We have seen the benefits of this approach with the Taste Buddies and the Social Interaction Group. In their homogeneous (enclave deliberation) meetings, they developed collective action and empowerment. This process laid the fundaments for dialogue and collaboration with professionals (heterogeneous meetings).

The lack of enclave deliberation in the case in which one client was involved in a team of professionals led to representational problems as well as to problems due to power asymmetries. The cases of the Taste Buddies and the Social Interaction Group on the contrary show the value of enclave deliberation. We learn from these three cases that residents need enclave

deliberation with each other in order to develop their own agenda, discover their shared experiences and values, to create a joint mission and to connect to other residents. Without this first basic step, it is particularly difficult for residents to develop a more powerful position as a basis to go into dialogue with professionals in residential care homes.

We thus conclude that enclave deliberation of residents is a success factor for client participation.

Relational empowerment

We connect the notion of enclave deliberation to the notion of relational empowerment, which stresses that people can become more autonomous as together they develop a feeling of trust in their own opinion, are able to acknowledge criticism, and appreciate the feasibility of change. [30,31] In community psychology, empowerment is defined as the psychological aspects of processes by which people gain greater control over their lives, experience a positive identity, participate in democratic decision-making, and develop critical awareness of their sociopolitical environments. [32, 33] It is argued that the relational aspect of empowerment should be acknowledged. [34] In this relational understanding of empowerment, power is suffusing all interpersonal interactions and discourses [35] and is not a static entity but a process that involves the development of collaborative competence, the bridging of social divisions, the facilitation of others' empowerment, network mobilization and passing on the legacy of empowerment. [34]

The notion of relational empowerment is based on an ethics of care perspective and stresses that people can become more autonomous as together they develop a feeling of trust in their own opinion, are able to acknowledge criticism, and appreciate the feasibility of change. [31,36,37] This notion of relational empowerment is based on the idea that when power is given from one (powerful) party to another (less powerful) party, or taken from the powerful by the less powerful party, empowerment is imbalanced. Rather empowerment can be seen as a dialogical learning process in which all who are involved will change.

Taking these insights from community psychology and feminist ethics into account, we formulate our definition of relational empowerment as follows. Relational empowerment is based upon the recognition that every human being can be in a vulnerable position as well as in a powerful position, and that power is not a static attribute that can be given to another person or group by another person/group. Neither can power be taken by one person/group from the other. Relational empowerment as we define it is the dynamic process by which people learn from their differences, find common ground and inspiration for developing their own life and for contributing positively to the life of others. Relational empowerment refers to the interdependency and connectedness between people, and it exemplifies the deeper meaning of the Aristotelian saying that 'the sum is bigger than its parts'. We saw relational empowerment of residents occurring in the case of the Taste Buddies as well as in the case of the Social Interaction Group.

Thus, relational empowerment is a success factor for client participation.

Communicative democracy

In these case studies we see how dialogue about values and the creation of mutual understanding became fundaments for partnership and relational empowerment. In the study about the participation of one client in a team of professionals, we saw how difficult it was to find this common ground of values and mutual understanding. The client felt he stood alone in his mission to contribute something to the wellbeing of the residents. The deliberations in the mixed team were dominated by system rationality and there was little room for the lifeworld values of the client, as well as of the professionals. The reflection meetings that were organized with this project team led to their insight that the differences between the team members had not gained enough attention from the start of the project. They also learned about how important it is for the success of client participation that residents and professionals engage in open dialogue with each other, acknowledging differences and allowing diverse styles of communication. Thus, a success factor for client participation is to facilitate regular reflection and open deliberation about the *process* of client participation in every particular case in which residents and professionals try to work together.

Differences between people should not be ignored in client participation and collaboration between residents and professionals. On the contrary, reality is always constructed, fragmented and dynamic, as well as the relations between people. Feminist theory concerning the importance of difference, community, relationships and an ethic of care results in a vision of communicative democracy. [21,23,37] Storytelling, embodied experiences and emotions have a place in communicative deliberation, whereas in deliberative democracy reason and unity are considered as proofs of the legitimacy of parties and thus lead to exclusion of those who are different. [21,23,38,39] Where differences and asymmetric power relations exist, storytelling can be a successful approach to foster understanding across difference without ignoring or assimilating those who are different. [40-43] Moreover, a continuous search for connections and understanding between people can take place in processes of greeting, meeting and interacting. [40] Communicative democracy recognizes the value of a plurality of perspectives, speaking styles, and ways of expressing [40]. The differences between the individual residents who together formed the Taste Buddies, led to their collective action and inspiration. Also in the Social Interaction Group, the residents learned from each other because of their differences. And in both cases we saw how professionals and residents learned from their different perspectives and were able to build partnership from the basis of this mutual understanding. Thus, the principles of communicative democracy are important for the success of client participation.

Facilitation

Further, our studies show that a facilitator who is relatively external to the existing power structures in the residential care home, is needed to foster the process of building partnership relations and relational empowerment. In the evaluation of resident councils, we were evaluators who facilitated dialogue and learning between the stakeholder groups. In the studies concerning the Taste Buddies and the Social Interaction Group, the relational empowerment in these groups of residents was fostered by the supportive, reflective and critical role of the researcher who acted as a process facilitator. The interaction in the mixed team with one client and seven professionals was turned into a joint learning process by the active intermediating role of the researcher. Resident empowerment and client participation in residential care homes, requires a profound change of attitudes and actions (of residents and professionals). A

facilitator who can guide residents and professionals in this joint learning process is a success factor for client participation.

8.2.5 Translating insights into practical use: the PARTNER intervention

Having answered the prior research questions, we can now address the last research question:

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

We see an iterative and emergent development of insights throughout the diverse studies we conducted over the last six years. Every study built on the insights of the prior study/studies. As such, the insights about process, barriers and success factors for client participation formed the basis for ultimately constructing a practical work format for enhancing the influence of residents on collective issues that affect their life in the institutional context. Core to these insights is the overall conclusion that influence of residents can be enlarged by developing client participation as *partnership* between residents and professionals. We developed the PARTNER intervention which is based on the conceptual principles of Participation, Action, Relations, Trust, Negotiation, Empowerment, and Responsiveness. By including the success factors for client participation and taking into account the insights about barriers for client participation, the PARTNER intervention fosters resident empowerment and partnership relations (amongst residents and between residents and professionals). This intervention is described in detail in chapter 6 of this thesis and is visualized in the next figure.

Five steps

The PARTNER intervention exists of five steps that occur in chronological order but also overlap sometimes. The steps of the intervention are 1) agenda setting by residents, 2) homogeneous groups, 3) heterogeneous group, 4) formulating ideas and plans, and 5) action in practice. Step 4 also partially happens during the homogeneous groups (step 2) and during the heterogeneous group (step 3).

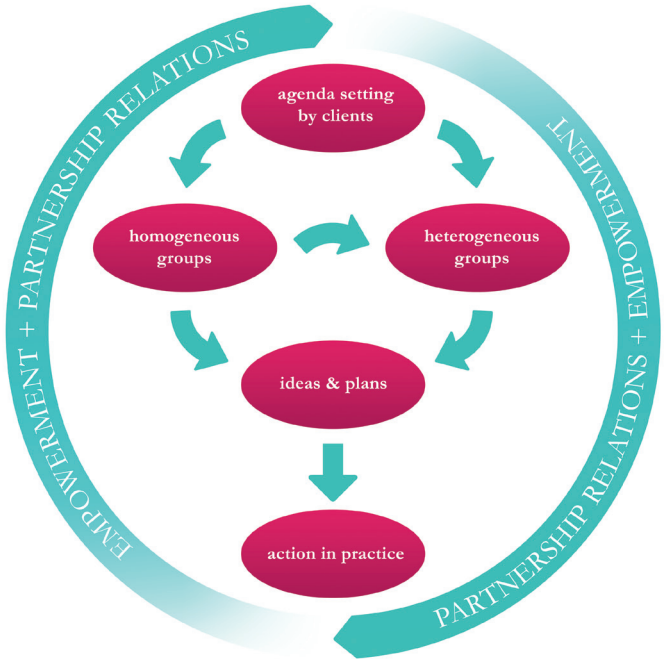

Figure 1 The PARTNER intervention

During step 1, the agenda setting phase, a group of residents starts to exchange their experiences with life in the residential care home. They are given free space to discuss the 'here and now' topics they relate to, placing their own lifeworld issues at the centre of their conversations. The discovery of shared experiences leads to their choice for one of these issues they want to discuss further (for example, the meals or social interaction). This is how the practice improvements are being formed from the very start of the intervention as a bottom-up development, rooted in the experiences of residents. Group conversations about topics that really matter to them are an attractive way of starting to participate for many people who live in residential care homes.

Then, with step 2, the residents meet several times (approximately 8-11 times) to develop their agenda for practice improvements. During these meetings, relational empowerment between the participating residents will occur. This is reflected in a sense of 'standing strong together' and interpersonal support and recognition. This is not a straight-forward development, but can be a complicated dynamical process in which persons develop

voice, start to utter complaints, may stagnate in negative accounts, and can be lifted up by creative methods and an appreciative approach in order to develop ideas and plans for practice improvements that reflect their deepest needs, dreams and wishes. The group of residents becomes an action group with a strong group identity, which is particularly fueled by their interactions with other residents from outside the action group. The facilitator of the PARTNER intervention will organize, together with the action group, a meeting for all residents. During that meeting the preliminary ideas and issues of the action group will be presented and a dialogue takes place. This is important for the action group to find support for their ideas and to make their ideas and agenda fit the common good of the other residents as well. If other residents have different opinions and experiences, this is the phase in which the action group searches for ways to develop action ideas and plans that do justice to this diversity. Here, communicative democracy amongst the people who live in residential care homes takes place. It raises awareness of a common good and the value of being able to help others, to contribute something to the community of residents. This sense of community is an important added value of collective participation compared to the individual participation of residents in practice improvement projects.

During step 2 of the intervention, also the other people who are involved in the residential care home, especially in relation to the subject that was set on the agenda by the residents, are brought together by the facilitator as well, one meeting per group of parties concerned (for example, one group meeting with only with volunteers or only with care workers). During this meeting, they develop their own agenda, based on an exchange of their experiences with the topic at hand. At the same time, the facilitator communicates the experiences and agenda of the action group of residents to the other parties, so that they are invited to reflect on it already. This is seen as a preparation for the next step in the intervention, in which the action group of residents engages in dialogue with professionals. This does not mean that the professionals have to set aside their own experiences and perspectives. From a hermeneutic view on understanding, this is a process by which people open up their own horizon and learn from each other, a process that can ultimately lead to a fusion of horizons. [44]

Step 3 entails dialogue meetings between the action group of residents and others. The facilitator of the PARTNER intervention will organize, together with the action group, a

meeting for all residents. During that meeting the preliminary ideas and issues of the action group will be presented and a dialogue takes place. This is important for the action group to find support for their ideas and to make their ideas and agenda fit the common good of the other residents as well. If other residents have different opinions and experiences, this is the phase in which the action group searches for ways to develop action ideas and plans that do justice to this diversity. Here, communicative democracy amongst the people who live in residential care homes takes place. It raises awareness of a common good and the value of being able to help others, to contribute something to the community of residents. This sense of community is an important added value of collective participation compared to the individual participation of residents in practice improvement projects.

The final heterogeneous group is the phase in which the joint learning process and development of partnership between residents and professionals takes place through the exchange of the ideas and plans by all parties (step 4). It requests from the side of the professionals an open attitude towards the residents, not only towards the concrete contents of their ideas and plans, but also to their specific way of communicating. It is the facilitator's task to make sure that everyone has an equal share in the dialogue and that everyone is being respected and understood. Again, this does not mean that everyone has to assimilate to the views of the residents, but there is striving for understanding the underlying values. This is a mutual process, since also the residents are challenged to understand the values that underlie the ideas and plans of the other groups.

The format of a storytelling workshop can help to bring these underlying values across. From the basis of mutual understanding, the action group of residents and the professionals who are involved, develop a joint action plan in which the values of all parties are brought together in practice improvements. This involves a negotiation of what is possible (in terms of money, people, organization, etc.). However, the starting point is dialogical understanding (not a vice versa defense of interests) and the ideas and plans for practice improvements as developed by the action group are the starting point of the dialogue, not the agenda of the professionals. This is needed in order to create more balanced power relations and to enhance the empowerment of the residents who are involved.

Finally, as step 5 of the intervention, the joint agenda for action in brought in practice. These actions are based on a shared responsibility of residents and professionals, and where possible, residents will play an active role in the realization of the practice improvements. This further enhances their sense of empowerment, through ownership. These practical results can have an inspiring effect on other residents as well, since they see that participation of residents actually matters. At this stage of the intervention a shift in the work of professionals has taken place from improving practice *for* residents towards improving practice *with* residents. A certain period after the practice improvements have been brought in practice, the residents and professionals will evaluate the actions together. As such, new partnerships and/or practice improvements can come into existence by this joint evaluation.

Perceived effects on residents

In the qualitative evaluation of the process and the perceived effects of the PARTNER intervention (chapter 6), we found that the intervention helped residents to develop actions (gallery parties) that met their needs for social interaction. Furthermore, the intervention led to resident empowerment. The participating residents supported each other on a personal level, respected each others' differences and developed a group identity they referred to as a 'family feeling'. Also, the residents described how the results of the project exceeded their expectations and how they learned from this project that they can actually contribute something valuable (the organization of gallery parties) to the community of residents. By the PARTNER intervention, older people who live in residential care homes may enlarge their influence on collective issues in the institutional context by creating actions together that are valuable for community life and wellbeing. This is an empowering experience for residents and enlarges their influence on their environment.

Perceived effects on professionals

The professionals who had been involved described that the research and the PARTNER intervention had raised their awareness about the value of bringing diverse perspectives together. Even though staff members emphasize that resident participation still needs attention, staff members stated that they had become more aware of resident participation

and increasingly tried to integrate this in their work. Thus, the PARTNER intervention was a learning experience for professionals, creating critical awareness about resident involvement and their own role in this, and making them feel more supported and understood by residents. This can contribute to making the residential care home into a more open environment where resident involvement and empowerment is fostered.

Manual

We developed a manual in which practical questions concerning the PARTNER intervention (for example concerning the role of the facilitator, the time investment of residents, facilitator and other parties, what topics are suited for the PARTNER intervention, etc.) are answered. This manual will be further refined in collaboration with the current facilitators who work with the PARTNER intervention in residential care homes. Attention will be paid not only to the practical sides of the intervention but also to the care ethical implications for working with the PARTNER intervention (for example, concerning the partnership between facilitators and the action group, how to deal with power asymmetries, and how to find a balance between the appreciative approach of the intervention and the need for solving problems).

In sum, the answer to the fourth research question in this thesis is that the insights about the barriers and success factors for client participation are translated into the PARTNER intervention. In residential care homes, residents, professionals and others (like volunteers and family members) can use this intervention to foster resident empowerment and partnership relations between residents and professionals.

8.3 General discussion

8.3.1 New insights

Throughout the studies we conducted, we distinguish several insights that overarch the research questions.

Climbing the participation ladder toward partnership

In the introduction chapter of this thesis we presented the participation ladder, based on Arnsteins ladder for representing varying levels of citizen power. We translated this ladder to the context of residential care homes and asked ourselves where the existing form of participation of older people in residential care homes (resident councils) can be situated on this ladder. Further, we wanted to investigate what the possibilities are for developing resident participation in a way that promotes more power and influence for older people who live in residential care homes.

We have investigated diverse forms of client participation and can now place these on the participation ladder (see figure 2). The evaluation project concerning the resident councils showed the pitfalls of client participation and the lack of influence as experienced by resident council members (chapter 2 and 3). This is a form of participation that can be placed on the participation ladder on the lower rungs of informing and consultation. Formally, resident councils have the right to give advice on issues that affect the day-to-day affairs and future life of residents. So resident councils could be placed on the rung of 'advice' as well. However, in practice, the resident councils we worked with did not feel they had much influence. They felt that their advice was not always taken seriously. Therefore, we reckon that the lower rungs of the participation ladder represent the influence of the resident councils best, the way it is felt and expressed by themselves. The insights concerning the status quo of these resident councils, paved the way for focusing our research aim on developing alternative ways for client participation that would foster more power and influence for residents.

The form of client participation in which one client participated in a team of professionals (chapter 4) should be placed on the participation ladder somewhere in-between consultation and advice, even though the initial aim and intention of the client and professionals who were involved was to create partnership (the level above advice). The pitfalls and barriers of this form of individual client participation influenced our subsequent action research project with the Taste Buddies. In that project we could now consciously and cautiously take into consideration the insights about the challenges of client participation, in order to prevent them and to transform them into insights about possible success factors.

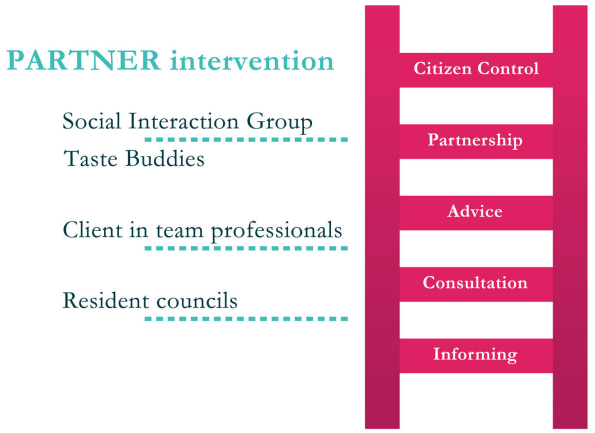

Figure 2 Case studies on the participation ladder

The participation of the Taste Buddies as it took shape in this action research project (chapter 5) can be placed on the 'partnership' rung of the participation ladder, relating to the process of relational empowerment within the action group of clients and relating to the development of partnership between this group of clients and the professionals who were involved in the project. The same partnership development was distinguished in the project in which the PARTNER intervention was applied and residents organized gallery parties to strengthen the social interaction between residents (chapter 6).

Thus, over time and throughout the diverse research projects, we developed client participation by climbing up the participation ladder from little influence to more power in the form of partnership. Our definition of partnership between residents and professionals in residential care homes is influenced by insights on partnership as co-production, [45,46] an ethics of care perspective on relationships in the context of health care [23,37,47] and a philosophical hermeneutical perspective. [44,48] As such, we define partnership at the level of institutions/organizations as a collaborative relationship between *groups* of residents, professionals, volunteers, and family members in residential care homes, with the joint goal to improve or strengthen (a certain aspect) of the institutional community life, taking into account the personal and collective enrichment of bringing together different experiences, ideas and forms of knowledge. Partnership in this definition requires a process of relational empowerment (within and between groups). Partnership as we envision it, is built on the bottom-up agenda

setting and collective action of residents, enclave deliberation, communicative democracy, and relational empowerment (within and between groups). Client participation that is constructed as partnership development may lead to mutual learning about values, the creation of common ground, dreams and inspired aspirations, and consequently the realization of collective action, shared power, shared responsibilities, and ownership. We developed the PARTNER intervention as a practical work format to contribute to residential care homes in which the influence of residents on their environment is increased by creating meaningful actions (contributing to community life and wellbeing of residents) in collaboration and partnership with other groups (professionals, volunteers, family members).

Using a model like this participation ladder easily leads to over-simplification. This ladder might give the impression that enlarging the influence of clients should be the sole aim of client participation and that only the higher rungs of the ladder are desirable. However, for individuals and groups of residents, every rung of the ladder can be an empowering experience to their participation and involvement, even when according to the participation ladder their actual influence (as an outcome of the participation process) is low. The crux lies in the recognition that clients should be given the opportunity to be involved just the way they wish to be involved. Furthermore, diverse stages of projects or developments may trigger clients to be involved on diverse rungs of the ladder. The most preferred form of involvement and influence is not an invariable. For some (stages of) projects or developments, 'information' might be considered as the most preferred rung of the participation ladder, and this can also differ from person to person. Most important is that clients and professionals, at every occasion, come to a mutual understanding and (renegotiable) agreement concerning what form of participation is most appropriate, possible and desired for clients in that specific situation.

Notwithstanding the acknowledgment of the value of all rungs of the participation ladder, we make the case here for client participation as partnership. In our research settings, the starting point was that this particular form of influence of clients had been lacking, and that resident councils, individual residents as well as professionals wished for a more powerful position of residents. Partnership turned out to be a form of influence and collaboration between clients and professionals that showed its merits. From a care ethical and hermeneutical perspective,

we argue that delegated power and 'citizen control' (client control) are less desirable forms of power relations in residential care homes. We see power as a relational concept, that should be balanced. Further, the combination and amalgamation of diverse perspectives lead to hermeneutical learning and mutual understanding of people. In the case of delegated power for clients or full control by clients in residential care homes (if that would even be possible or desired by residents), professionals and others would become powerless. The intrinsic value of diverse perspectives and the broadening of horizons would be lacking. Thus, striving for full citizen power of residents (they take the initiative to develop services and policy plans on their own, without managers, professionals or others being involved), would only mean a turning around of power position, leaving no room for hermeneutical learning, communicative democracy and the value of relational empowerment.

Alternative ways for client participation, such as initiatives that are based in the PARTNER intervention, are not a substitution for resident councils. We consider the PARTNER intervention as a form of client participation that is complementary to the work of resident councils. Resident councils can use the PARTNER intervention to get in touch with the residents they represent and to develop their own agenda setting process and influence. Resident councils may feel that their agenda is filled with management issues, and that day-to-day issues of residents are left over. By the PARTNER intervention, resident council members can actively involve other residents and form an action group connected to a certain topic they want to work on. We also see resident councils that take up an active role in the residential care home and that have been organizing working groups or committees to deal with specific matters (such as renovations of the building, safety, leisure activities, etc.). The PARTNER intervention offers a work format to take on these working groups in a structured way. Furthermore, we think that resident councils have the important task to be involved in far-reaching strategic decisions of care organizations, and to use their formal rights and duties to make sure that the resident perspective does not disappear from the policy agenda.

A call for enclave deliberation and communicative democracy in residential care homes

Overall, the studies that we conducted for this thesis deal with democratizing care institutions by gaining insights in and enlarging the influence of residents. One of the biggest challenges of democracy is to balance the voice of lay people with the voices of experts and elites. [22] Dealing constructively with inequality and difference is a central task of democratic endeavors. Those with more education and higher status speak more frequently and tend to have more influence, differing points of views tend to be silenced by the insistence on consensus and dominant groups can bring forward generalized terms of common goods that do not take into account experiences of marginalized groups. [22] These tendencies can be found in the context of state democracy as well as in institutional contexts such as residential care homes, where marginalized voices of clients can easily be overlooked or even silenced by professionals—despite good intentions for example concerning the institution of resident councils.

The issue of representation is therefore important in developing insights about the influence of older people on collective issues by creating practice improvements in residential care homes. Resident councils are instituted on the fundaments of what is called an interest-based model of democracy. [40] Resident council members are chosen by the other residents to represent their interests. Communicative democracy, however, entails a different form of representation. Here, the inclusive deliberations between people lead to a mutual understanding of issues and values and from this basis, joint decisions are made. It also allows room for different ways of expressions and communication, that might differ from the rational discourse of deliberative democracy.[21-23] In the communicative model of democracy, differences between people are seen as a resource for transformation. [40] Young states that this transformation occurs in the confrontation with different perspectives and meanings and teaches people the partiality of their own. Further, knowing that one is in a situation of collective problem solving with others make people transform their expressions of self-interest and desire into appeals to justice. Finally, expressing, questioning, and challenging differently situated knowledge adds to the social knowledge of all participants, an insight in the ways proposals and claims affect others who are in a different position.[40] Enclave deliberation (deliberation and exchange

of experiences, emotions, and opinions in a small group) before dialogue and deliberation within a broader forum (heterogeneous) is a structure that fosters the development of voice and empowerment of marginalized groups. [22] This model of communicative democracy and enclave deliberation is reflected in the PARTNER intervention.

We thus propose a form of representation of residents which is grounded in enclave deliberation amongst groups of people and, after that, proportional dialogue between diverse groups of people, acknowledging and appreciating differences so that hermeneutical learning can occur. This is a different form of representation than in the interest-based democratic model, where a minority of people is chosen by voting to represent others. The action group of residents that is formed in the PARTNER intervention is a small group indeed, but they engage in deliberations with other residents (included in the homogeneous phase of the intervention) in order to further develop their views as to take into account the diversity of experiences of residents. After all, 'older people who live in residential care homes' are not a homogeneous group.

We envision the creation of communicative democratic residential care homes. This basis for democratizing residential care homes can be a valuable addition to the interest-based model of resident councils because it stimulates resident councils to come out of the board room and to interact and deliberate with the residents they represent.

8.3.2 Transformative research

As described in the methodological framework of this thesis (chapter 1), we worked from the backgrounds of a transformative research paradigm. Residential care homes are hierarchical institutions in which the influence of the residents asks for attention. As we have seen, transformative research can help to change the asymmetric power relations by bringing to light the experiences and issues of those who feel they lack voice. Also, by actively participating in transformative research, residents and professionals become aware of their shared responsibility and the possibilities to change their joint environment and their relations for the better. This is an empowering aspect of transformative research.

Conducting transformative research has several implications for the role of the researcher. Instead of being a 'distant' expert who describes a certain practice and formulates recommendations, the transformative researcher closely engages with the practice to be evaluated or investigated. We distinguish the following four main characteristics that define the kind of engagement of the transformative researcher:

1) Developing partnership relations with participants (multiple partiality)

2) Fostering reflection and learning processes among people

3) Making sure the research process and results contribute to social justice

4) Being self-reflective and open to personal transformation

In the studies we conducted, the first three forms of engagement are reflected in the design and implementation of the research. These forms of engagement of the transformative researcher have consequences for the roles and tasks the researcher has during projects. Several roles can be distinguished such as facilitator, teacher, and Socratic guide.[49] For example: I* played the role of facilitator when I brought the resident councils and managers together in a dialogue during the responsive evaluation. I played the role of teacher when I explicated each others' experiences towards one another during the reflection meetings of the mixed team with one client and seven professionals. I played the role of Socratic guide when I kept asking the Taste Buddies about their dreams about the meals and their -first latently present- ideas for improvements. These roles are dynamic and constantly changing, also within a single project, flowing with (or sometimes against) the dynamics of the participant groups. These can be called 'contradictory skills' because of the polarities that together form a whole spectrum of skills for transformative research.[50] There are movements between taking control and following, between questioning and directing, nurturing and challenging, between offering structure boundaries and flex boundaries. In order to know when to play what role, researchers should be 'in the moment' and work with the energy flows and group dynamics. [50,51]

Transformative research is a paradigm, not a specific research design or method. This creates opportunities and the obligation for the transformative researcher to seek for designs and methods that are attuned to the specific context and participants in the study. We chose responsive evaluation and action research, because these designs fitted with the challenges (multiple perspectives and underlying tensions related to a complex set of factors) encountered in practice. Transformative research should take into account the extent to which people can and want to be involved in the research process itself. Therefore, we discussed with the participants in our studies in what way they wanted to be involved in research activities. The residents and professionals we worked with were mainly interested in the improvements concerning power issues (resident councils and managers; one client in team of professionals), meals (the Taste Buddies), and social interaction (gallery parties project). Their focus was not on being involved in the design, data collection and analysis. Even though being involved in research was not their first focus, the participants in all studies were very willing to reflect on the research process and the analysis of data (which is also part of responsive evaluation and action research).

The fourth form of engagement, self-reflexivity and personal transformation, asks for a more detailed description which can be found in sections 'Reflection on Self-in-Relation' in-between the chapters of this thesis. In this study, we started with responsive evaluation, followed by the conscious choice to start action research. Both these designs are embedded in a transformative paradigm. Over time, we learned more about the transformative research paradigm and discovered how our work fits with this paradigm. The main lesson we learned from conducting transformative research is that it not only aims at transformations in the practice that is the topic of the research, but that it also requires (and contributes to) transformation of the researcher herself.

The main transformation I experienced is a changed perspective on my feeling of responsibility, from feeling too responsible for helping create successful partnership relations between clients and professionals to creating more room for shared responsibilities and partnership between myself and the research participants. Whereas in the beginning of this study I felt I was responsible for creating successful social change in the practice of resident councils and the collaboration between a client and professionals, over time I learned that, as a transformative

researcher, I can and should only be the catalyst for social change, facilitating learning processes, asking appreciative questions and stimulating people to share their experiences and knowledge with others and to work together. This development was not straightforward, but a search process by which I learned about my own role, in interaction with the research participants. In the first project (the responsive evaluation with resident councils and managers), I discovered that I could make a positive contribution to the process by 'me being myself'. During the next project (collaboration between a client and professionals), I experienced that this could also be problematic: I brought with me my personal 'backpack' that made me feel very responsible for making the collaboration between the client and professionals succeed. The project with the Taste Buddies taught me that I could share with the research participants my doubts (showing them 'me being myself'). This openness turned out to be very helpful in the process and created room for partnership between us and shared responsibilities. During the following project, with the Social Interaction Group, I felt I could draw from my lessons learnt and implement it in developing partnership and shared responsibilities with research participants, at the same time 'me being myself' and me being a professional researcher.

Another transformation relates to my shifting perspective on residential care homes. Prejudices cannot simply be put aside. From a hermeneutical perspective, this would not be productive either. By being aware of these prejudices, and investigating them by reflecting on my actual experiences working with older people in residential care homes, I was able to connect new experiences to these stereotypes in my head. I learned that elderly care institutions can be places for human flourishing, learning, empowerment, inspiration and partnership.

8.3.3 Methodological issues

We want to reflect here on the overall methodological rigor of our study. Every scientific paradigm has its own basic ontological, epistemological, methodological and axiological beliefs. For example, different basic beliefs can be distinguished between positivism, postpositivism, ciritical theory, and constructivism.[52] These differences are reflected in the formulation of different quality criteria. In the qualitative research paradigm, the nature of reality is featured by the assertion that there is no single reality on which research may

converge, but that there are multiple realities that are socially constructed. However, we do not take a relativist perspective that leaves no room for assessing the quality of truth claims. Criteria for evaluating qualitative research as developed by Lincoln and Guba (1985) can be adapted for use concerning transformative research and evaluation studies. [53,54] These criteria are credibility, dependability, confirmability, and transferability. By these criteria, the rigor of scientific research is assessed in terms of trustworthiness. [55]

Credibility

Credibility as an equivalent of internal validity refers to the absence of systematic errors and the trustworthiness of the research. We have used several techniques to optimize the credibility of our studies, namely prolonged engagement and persistent observations, triangulation and respondent validation or member checks. In every study, the importance of prolonged engagement and persistent observations was taken into account by making time schedules that allowed enough time for data collection and analysis, but also for building rapport and trust with the participants. For example, we attended resident council meetings, presented ourselves in team gatherings of professionals, we participated in informal activities of residents, we went with care workers on their daily rounds visiting residents, we had dinner with residents, we had informal talks with professionals and residents, and we took part in festivities and special occasions in the residential care homes where we conducted the studies. This way, we could familiarize ourselves with the people and their routines, events and developments.

Triangulation refers to the use of multiple data sources and methods. [56] This was applied in our studies by combining individual interviews, focus groups and participant observations, as part of the responsive evaluation study as well as part of the action research studies. Responsive evaluation is particularly suited for involving multiple stakeholders and perspectives in the evaluation of the status quo of client participation. Action research was chosen as an approach for developing alternative ways for client participation. These methods complement each other, from a focus on multiple perspectives and values (responsive evaluation), we moved to developing new ways for client participation by experimental actions and reflections on these actions, in which residents, professionals and others in the residential care homes participated.

The combination of designs (responsive evaluation and action research) and the combination of various methods in this thesis offers a broad scope and breadth of findings concerning client participation in residential care homes. Further, the analysis and interpretation of data was fed back to the participants as a form of respondent validation or member checking, [54,55] for example by draft reports that we discussed with the participants. Member checks are meant to give participants the opportunity to check whether they recognize the analysis and interpretation of the data. Member checks are particularly relevant in the context of transformative research were researchers work with participants on an ongoing basis to facilitate change. Asking for feedback is then also a way to foster engagement and co-ownership. [57] In the case studies, interview reports and written accounts of group meetings/ focus groups were given to the respondents to check whether they recognized the findings. Responses of the participants were taken into consideration (not just accepted), and were part of an ongoing dialogue with participants.

Dependability

Dependability as an equivalent of reliability refers to the absence of a-systematic errors. In qualitative research the researcher is the main instrument for data gathering and analysis. In response to the charge of subjectivity in qualitative research, an equivalent of inter-rater reliability is developed. Dependability refers to the idea that the findings are not dominated by the frames of the researcher. Therefore, the collection, analysis and interpretation of data is done by more than one person, and codes are discussed (multiple coding). What is important in this process of multiple coding is the content of disagreements and the insights that follow from the discussion leading to refining the coding schemes. As Barbour indicates: "The greatest potential of multiple coding lies in its capacity to furnish alternative interpretations and thereby to act as the 'devils' advocate' (...) in alerting researchers to all potentially competing explanations." (p. 1116). [57] In this study all data collection was done by the author of this thesis. However, the analysis and interpretation of data was done by the author of this thesis together with the supervisor and other co-authors of the articles that are presented as chapters in this thesis. The data of all studies we conducted were analyzed by inductive content analysis. [58,59] Yet, comparison of the analysis of the interviews in the evaluation study concerning the process and the perceived effects of the PARTNER intervention, was done

by three researchers. These transcripts and field notes were read line-by-line and analysed independently for repeating themes and sub-themes. These analyses were subsequently brought together by these three researchers who discussed each separate analysis and reached consensus.

Researcher dependability also refers to the extent to which the research has been self-reflective throughout the research projects to stay alert and minimize the influence of the researchers' frames. Researchers should be aware of the role and influence of their own personal characteristics and personal and intellectual biases. During every research project we had regular team meetings in which we critically reflected on our own role and behavior during interviews, group meetings/focus groups and participant observations. We also discussed sensitive issues such as how to find a balance between taking an active problem-solving approach (feeling too much responsibility for social just outcomes of the research) on the one hand and 'simply' describing barriers and realistic hampering factors in practice on the other hand. Further, during the action research projects we used reflexive journals in which we described the steps and decisions we took during the projects but also our own emotions, hypotheses, feelings. We revisited these minutes when writing research reports and academic publications and this helped us to interpret the data from an integrated and self-reflective view.

Authenticity

Authenticity means that researchers present a fair and balanced view of the research, and that participants are able to use the information for the furtherance of social justice. [54] This is also referred to as 'fairness'.[60,61] Participation and voice of all parties was important in all our research projects, and thus in our publications we made sure that all perspectives were represented. Also conflicts and value differences are presented as they occurred in reality (for example concerning the tensions between resident councils and managers, and concerning the dynamics in the mixed team with one client and seven professionals). By discussing and sharing the research reports with the participants, the information became theirs. As such, the research helped the participants to develop their personal understanding of resident participation, which is ontological authenticity. Furthermore, in all studies, enhancing mutual

understanding between participants was a central focus. This relates to educative authenticity: resident council members, managers, residents, professionals and others were stimulated to appreciate viewpoints of people other than themselves. Also, participants fed back to us that the information and insights from the projects helped them to continue working on the participation of residents. This is an example of catalytic authenticity (stimulating action) as well as tactical authenticity, which means that participants feel empowered to act. Furthermore, the practical results of the projects (a joint action agenda for resident councils and managers, improvements with regards to the meals, gallery parties to strengthen social interaction) all are in line with enhancing social justice, citizenship and quality of life.

Confirmability

This refers to the extent to which the interpretations and conclusions of the research are plausible and based on the data. As described in detail in the introduction chapter of this thesis, we have taken a value-committed stance by explicitly working from the backgrounds of the transformative research paradigm. However, this does not mean that these values should influence the way we interpret the data. Therefore, we engaged in self-reflection through discussions in team meetings and writing reflexive journals to learn about our own starting points, values and possible bias. The discussions of findings with participants further helped us to analyze the raw data and present the insights and results in a way that was recognized as representing the reality of the participants. Moreover, our research data are structurally ordered and stored.

Transferability

Transferability as an equivalent of external validity refers to the ability of the researcher to present the findings to readers in such manner that they can assess the transferability of the results to another situation. [62] By providing 'thick descriptions' (sufficient details of context and meaning) that provide readers with a vicarious experience, readers can make a judgment as to the transferability of the information from the specific case to his/her own circumstances. We consciously described our studies in detail, offering quotes and descriptions of context, persons and developments. We also presented our findings and lessons learned

at international and national conferences, in presentations and workshops, and in learning community meetings. At these occasions, people from diverse backgrounds, localities, care organizations and disciplines were introduced to our work and the results of our studies. From the interactions with these people we learned that they highly recognized the issues around participation of older people in residential care homes as we described them, and that the outcomes of our projects inspired them to look differently at their own practice because they saw so many resemblances with the barriers for participation they were confronted with in their own context. This does not automatically mean that the insights from our studies can easily be transferred to other settings. In qualitative research, knowledge can be transferred by enhancing 'vicarious experience' (substituted experience). This means that detailed, thick descriptions from research studies can generate new knowledge in the reader, who can weigh the given data against her/his experience, confront previous interpretations and temper convictions formerly held. [63]

8.3.4 Suggestions for further research

Applicability and prerequisites

In the PARTNER intervention the insights about barriers, success factors and prerequisites for participation of older people in creating practice improvements in residential care homes are brought together. However, more research is needed to gain insight in the applicability and prerequisites of the PARTNER intervention for organizations to use it successfully. First steps are taken in nine long-term care organizations in the Netherlands by facilitators who work in the organizations to implement the PARTNER intervention. Six of these organizations are elderly care organizations (including higher levels of care needs), the other three consist of diverse client populations (psychiatrics, rehabilitation, physically disabled). A research team of four researchers are conducting qualitative process evaluation in order to answer questions such as 'what are organizational barriers and success factors for the implementation of this intervention?', 'what do facilitators need as to be able to guide participants through the steps of the intervention?', 'for what population groups is the PARTNER intervention a suitable instrument for participation?' Moreover, with these studies, we hope to find more qualitative evidence for the occurrence of empowerment, partnership development, and actions that

improve community life and wellbeing of residents. By these studies we will also further investigate the relationship between empowerment and collective action in the context of residential care homes. Furthermore, we developed a manual that is being refined and we are developing training for facilitators who work with the PARTNER intervention.

Outcome measurements

Furthermore, after the feasibility studies as described above, there is a need for outcome measurements of the PARTNER intervention. We have seen some qualitative evidence for relational empowerment and improvement of wellbeing and community life, as described in this thesis. However, this has not been tested on a bigger scale yet through an a randomized controlled trial (RCT). In order to do so, first an instrument (questionnaire) should be developed by a participatory process together with clients and professionals of long-term care institutions. Currently, to our knowledge there are no instruments for measuring collective empowerment. Quantitative research on this topic can then further complement and strengthen the qualitative research we have conducted thus far. We propose a study with a mixed methods design, combining a qualitative intervention study with RCT to measure the effects of participation by the PARTNER intervention on their (individual and collective) empowerment. A theoretical study should focus on further conceptualizing how participation leads to empowerment.

Culture change

Besides these feasibility and effect studies, we argue that more research is needed to develop empirical and theoretical insights concerning culture change in long-term care facilities. This culture change refers to a move from a medical, institutionalized model to person-centered care, and a more humane and resident-focused community in care homes. [64-66] We propose to take a relational approach to the organizational learning that is involved in this culture change in the context of long-term care. [67-69] Bate argues that successful small-scale pilots do not normally spread systems-wide. [67] The system has to be mobilized through movements in which change is viewed as a releasing of energy that is largely self-directing, as 'moving' people, driven by informal systems, and fed by peer to peer changing interaction between

people. [67] We see opportunities for putting our methodological, theoretical and empirical lessons learned into practice by developing participatory action research that involves and mobilizes people (residents, professionals, managers, volunteers, family members, etc.) in residential care homes. By this participatory action research, a movement, an active learning community, can be formed in which people learn from each other, collaborate and develop a shared vision *and* practice that enhances a culture of relational empowerment, partnership, communicative democracy, and real influence of residents. This way, a context will be created that is receptive to the values of client participation as partnership development, and the PARTNER intervention. Through niche experiments a system change can be fostered.

8.4 General conclusion

The influence of older people on collective issues that affect their life in the institutional context is featured by several barriers in practice. Due to diverse factors related to the tension between system and lifeworld in residential care homes, communicative action and communicative democracy can be hampered in this institutional context. However, also success factors were found in our studies, which shed light on a more optimistic view on the possibilities for enlarging the influence of residents and fostering communicative democracy in residential care homes. In collaboration with participants in our studies we translated these insights into a practical work format for developing partnership and relational empowerment between residents and professionals in residential care homes. This co-constructed PARTNER intervention fosters relational empowerment, learning processes of residents and professionals leading to mutual understanding, and actions that meet the needs, dreams and wishes of residents. This concerns an ongoing process. The first steps have been made, showing us that also in the context of old age and institutional life, room for transformation, learning and human flourishing can be found.

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