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Good care in group home living for people with dementia. Experiences of residents, family and nursing staff

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Aims and objectives: To investigate experiences of residents, their family caregivers and nursing staff in group living homes for older people with dementia and their perception of the care process.

Background: Traditional nursing homes for people with dementia have several shortcomings related to depersonalisation, passivity, loss of skills and use of physical restraints. Group living homes are seen as an alternative to regular nursing homes, but experiences with this new care setting have rarely been investigated.

Design: The study followed a naturalistic design. Qualitative data were collected over a period of 6 months in two group living homes located in the southern part of the Netherlands.

Methods: Systematic participatory observations were carried out during daily life, care and activities in both homes. In addition, semi-structured interviews were held with residents, their family and nursing staff. These data were inductively analysed and related to Tronto's care ethical framework.

Results: According to all parties, group living homes create structural opportunities for individualised care and attention to the residents' personal needs. The increased attentiveness and responsiveness for residents' well-being was seen as a sign of good care and fits with the phases of caring about and receiving care of Tronto's care ethical model. However, tensions occurred relating to the phases of taking responsibility and carrying out care. Not all residents and family members want or are able to take responsibility and perform self-care.

Conclusions: Group living homes create conditions for good care and stimulate attentiveness and responsiveness. Tensions in these homes may relate to the new division of responsibilities and tasks.

Relevance to clinical practice: Values of attention to needs and responsiveness are of high importance for nursing staff to provide good care for people with dementia in a nursing home setting.

Key words: care ethics, dementia, group living, nursing home, quality of care, qualitative research

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Introduction

Many people suffer from dementia, with estimations of 80 million people worldwide by 2040 (Ferri *et al.* 2005). Health statistics indicate that dementia, specifically Alzheimer's disease, is currently rising dramatically as a cause of death, whereas other major causes of death are decreasing (Alzheimer's Association 2009). Dementia is a progressive syndrome including a variety of symptoms such as cognitive decline, functional impairment and disturbing behaviour. Although the majority of people with dementia live at home, nursing home care is often inevitable as the disease progresses. Traditionally, nursing home care is based on a medical-somatic model of care and organised in large, hospital-like settings. Several shortcomings related to these settings have been reported such as loss of autonomy, depersonalisation, passivity, lack of personal integrity and use of restraints (e.g. Bolmsjö *et al.* 2006, Teeri *et al.* 2006).

During the past decade, we see a shift towards person-centred care aimed at individual well-being of people with dementia (Finnema *et al.* 2000, Verbeek *et al.* 2009, Edvardsson *et al.* 2010). Values such as autonomy, individualisation, personhood and well-being are emphasised. This change involves a shift in philosophy towards resident-directed care and quality of life (Foy White-Chu *et al.* 2009). Kitwood and Bredin (1992) state that the key task in dementia care is enabling personhood for residents. Personhood is a sense of self-identity or self-esteem and is preserved by relationships. Nursing staff have a responsibility in maintaining these relationships (Kitwood & Bredin 1992). McCormack (2004) argues that four concepts are at the heart of person-centred nursing: being in relation, being in social world, being in place and being with self.

New visions on dementia care are accompanied with a trend towards deinstitutionalisation of nursing home care (e.g. Kane *et al.* 2007, Verbeek *et al.* 2009). Care is increasingly organised in small-scale and homelike environments, where normalisation of daily life is emphasised. In many countries, similar concepts have been developed, such as group living in the Netherlands (te Boekhorst *et al.* 2009, Verbeek *et al.* 2010a) and Sweden (Annerstedt 1993), group homes in Japan, (Funaki *et al.* 2005) and Wohngruppen in Germany (Reggentin & Dettbarn-Reggentin 2004). These concepts support a social model of care, emphasising residents' (psychosocial) well-being and social context. Usually, a small number of residents live together and form a household with nursing staff. The physical environment resembles an archetypical house and residents are stimulated to participate in meaningful, domestic activities. Nursing staff have integrated tasks: they are not only responsible for personal and medical care, but also perform household chores such as cooking and organising activities (Verbeek *et al.* 2009).

Only a limited number of studies have been conducted, mainly focusing on effects of small-scale living facilities. Some studies suggest a positive effect on residents' quality of life (e.g. Kane *et al.* 2007, te Boekhorst *et al.* 2009), socio-psychological well-being of residents (Zingmark *et al.* 2002) and staff's job satisfaction and burn-out symptoms (Alfredson & Annerstedt 1994, te Boekhorst *et al.* 2008), while other studies found no convincing effects (e.g. Verbeek *et al.* 2010a). A study by Norbergh *et al.* (2002) found that residents in a group living unit spent more time with nursing staff and were more involved in passive interaction. However, research into experiences of participants is very scarce and few studies have directly involved residents with dementia.

This study, therefore, investigates experiences of residents with dementia, their family and nursing staff with group living for people with dementia. A care ethical framework (Tronto 1993) is used to deepen the understanding of the recurring themes in the experiences of these groups. This theory, which has not been used in previous literature on group living for people with dementia, reveals new insights about the ethical quality ('goodness') of care in such settings.

Method

Research design and methods

This study used a naturalistic inquiry (Lincoln & Guba 1985). Naturalistic inquiry aims to understand the particularities of a phenomenon in its natural setting and from the perspective of those involved. Our study focused on the meaning of experiences of daily life in two group living homes. The data were collected via participant observations and interviews over a period of 6 months (September 2008–March 2009).

Setting

The study took place in two group living units, established for approximately 30 months and located on the grounds of a traditional large-scale non-profit nursing home in an urban area in the southern Netherlands. These sites were chosen because they provided a typical example of group living. Each unit has a living room with an open kitchen, located in the corner of the room. A large wooden table is situated in the kitchen, which serves as the central part of the house. Residents are able to bring their own furniture and all spaces were decorated to create a homelike feeling. Eight residents

have a private bedroom with their own furniture, 12 share a bedroom with someone else. Each unit has a separate laundry area.

Each home housed 10 residents with dementia (nine women and one man per unit). It is unknown why there is such a high ratio of women to men, although this is consistent with previous literature (te Boekhorst *et al.* 2009, Verbeek *et al.* 2010b). All residents required nursing home level of care, determined by a standardised assessment procedure carried out by a governmental agency. Nursing staff consisted of nine (7.2 full-time equivalents) and worked in day and night shifts. Their age varied from 20–60 years; all had experience in geriatric care, with varying degrees of formal education.

Nursing staff perform several household activities like washing, cleaning and preparing daily meals in the kitchen, together with the residents. They also organise various activities like walking, exercises, singing and talking. A multidisciplinary team consisting of a nursing home physician, psychologist, physiotherapist and occupational therapist are involved on a consultation basis. The physician visits each unit once a week. Both units adhere to a 'home for life' principle, meaning that residents stay until the end of their lives.

Participants

All residents, their family and nursing staff in these two group living units were eligible for this study; inclusion was based on informed consent. Interviews were conducted with five residents with dementia (age 68–93 years). The Mini Mental State Examination (MMSE) (Folstein *et al.* 1975) was used to determine their level of dementia (score 0–30). MMSE scores varied from 0–14, with a mean of 10, indicating moderate to severe dementia. Furthermore, four family caregivers were interviewed and five nursing staff members.

Procedures

Participant observations

Participant observations were conducted during daily life in both units (spread over 8 days, totalling 32 hours). The observer's role consisted of watching, listening, assisting with activities and having conversations. Participants could also initiate conversations. Observations followed residents, family and nursing staff in different situations (having coffee, at dinner time, helping with preparations and cleaning up afterwards) and sitting in the living room, watching, listening and discussing what was going on. Also informal conversations were held with participants separately. Field notes were written immediately after each observation, consisting of systematic notations and records of behaviours, expressions and group dynamics. The fieldwork was performed by the first author (EvZ).

Box 1 Topic list for interview

Topics
Opening question: how do you like working (staff), living (resident) and visiting (family) this group living home (for nursing staff: in comparison with a traditional setting.
- Expectations of group home living
- Experiences related to daily life and activities
- Contact and communication with and among resident(s)
- Contact and communication between caregivers-residents
- Contact and communication between caregivers and family
- Resident–family relation
- Possibility to continue family habits and rituals
- Possibility to hold on to former identity (personhood)

Interviews

In-depth interviews were conducted with nursing staff ($n = 5$), residents ($n = 5$) and family members ($n = 4$), using a topic list (Box 1) to gather information on their experiences with group living. The interviews started with an open question: how is living/working in group living? Topics included well-being of residents, contacts between residents, staff-family-resident interactions, working environment and housing conditions. Methodological considerations especially relevant in interviewing people with dementia were taken into account (Hellstrom *et al.* 2007). Ensuring the agenda is led by the person with dementia is central in creating a 'safe context' and to ensure informed consent and assent. After the opening question the interviewer followed the conversation of the respondent to make sure that the resident could express his/her own story instead of responding to predefined questions. Furthermore, the interview's pace was relaxed. The interviewer specifically looked for signs of fatigue or potential stress. The interviews with residents lasted approximately 30 minutes; interviews with family members and nursing staff about 1 hour. After consent all interviews were tape recorded and transcribed.

Analysis

The transcripts were analysed by means of open coding, in two steps. First, an inductive analysis was performed, focusing on recurring themes, to stay near to the experiences of residents, family and nurses. Observation notes and interview transcripts read line by line and analysed by selecting and labelling recurring themes. Data were analyzed by the first author (EvZ), together with the last (TA) and the third author (GW). All have extensive experience with qualitative research in care for older people. During the research, the importance of the different themes and interpretations

were discussed in the research team. The results were presented to the staff and family for a check and feedback. Since residents had significant memory problems, direct checks were not possible. We checked reliability of data during participatory observation, especially by paying attention to whether residents acted differently than found in the data. In the second theoretical analysis, the themes which had emerged from the first analysis were related to and interpreted using Tronto's (1993) care ethical framework to enhance understanding and deepen empirical insights in the meaning of good care in group living.

Quality procedures

Various qualitative research methods were combined, such as participant observations and interviews. This triangulation is one of the quality procedures in naturalistic inquiry. It helps to broaden the scope of data (Greene *et al.* 1995). In this study, the interviews and informal conversations with individuals provided an understanding of personal expectations and (learning) experiences. Participant observations helped to illuminate the group dynamics. Other quality procedures included the prolonged engagement in the setting and persistent observation. The credibility of the analysis of the interviews was checked with the respondents (member checks) and the coding process was part of discussion within the author team (check coding) (Meadows & Morse 2001).

Ethical considerations

The study and its protocols were approved by the ethical committee of the participating nursing home and group living units. Written informed consent was obtained from legal guardians of the residents. Furthermore, assent was obtained by residents for their participation, which is defined as the willingness to participate even without full understanding of the complexity and the aims of the study. Finally, relatives and nursing staff provided informed consent for the interviews.

Results

An example of a typical day in the group living unit, based on this study's results is presented in Box 2. The most important themes, indicated by the respondents during the interviews and the observations, are described per group: that is residents, family and nursing staff (Table 1).

Residents

Being at home

Residents express regularly that they feel at home in their group living unit. Facial expressions support this impression: residents feel comfortable, both in the living room and in their private bed and living room. A homelike feeling was also perceived during participant observation. Mostly residents are gathered together in the living room during the day. They talk with one another, drink coffee or read a magazine. They are settled, at ease, restful and accepting the situation and life as it is. Only once in a while a resident is restless, but mostly the recurring of everyday activities provides stability and clarity and contributes to a sense of coherence for the residents.

Box 2 Observation of a typical day of a group living unit

I (EvZ, first author) am walking towards the porta cabins, where two group living units are situated. The door is open and I enter a small hallway with another door. I ring the doorbell and Mr. Harolds (all names are pseudonyms) opens; he is the husband of Mrs. Harolds and is present every day from 9.00 am–1.30 pm to help around in the group living unit.

Maria and Angelique, two nurses who work at the unit, give me a warm welcome. 'Would you like some coffee?' they ask. Together with the residents and Maria and Angelique, I drink a cup of coffee. In total, there are 10 residents: 9 women and a man. Some residents sit at the table or near the window. Two women have just come back from the hairdresser. Another woman walks around a bit restlessly with her walker. In the basket, many personal belongings are packed and the handlebars hold several purses. Three residents are watching television.

A pleasant smell spreads through the room. They are making spaghetti. Some residents set the table together with Maria. They use colourful placemats, nice plates and cutlery. 'Would you like to join for dinner?'a woman asks me. 'You shouldn't turn down the offer. There is always enough for everybody.' A residents asks: 'What's for dinner?' Maria answers: 'Spaghetti'.

'What is that?' 'Strings of pasta with red meat sauce,' Maria replies. There is also cucumber salad and shredded cheese.

I am helping pouring some drinks. Various drink cartons are placed on the table: Fruit orange and apple juice. 'What would you like to drink?' A residents answers: 'Well, I do not like this at all.' 'Would you like some apple juice?' 'Yes, that is much better. Thank you.'

It is quiet during dinner. Mr. Harolds has written a riddle on a piece of paper. He asks Maria: 'Do you know what is says?' She looks at it and thinks. 'I don't know,' she says. 'I am not that good at solving puzzles.' 'Maybe the lady from the University knows,' Mr. Harolds says and he shows me the piece of paper. The riddle is a song and I sing it. Residents look up and smile, some begin to sing along. Mr Harolds smiles, 'Yes that is correct.'

After dinner I help cleaning up, together with a resident. Maria does some ironing. The atmosphere is nice and calm. Five residents sit at the table and drink tea and coffee. Some are reading a magazine. Then I decide it is time to go.

Table 1 Description of main themes

Respondent	Themes	Description of theme
Residents	Being at home	Maintenance of personal characteristics
	Being together	Feeling connected and united
	Rhythm of everyday activities	Continue the life and habits that they had
Family members	Being part of taking responsibility	Staying/being part of the lives of their family members
	Personalised attention well-being	Possibility for their family.
		Some concern about their role
		Preferences of residents are point of departure
		Peaceful environment and attentiveness
Nursing staff	Individualised care	Respecting preferences of the residents
	Contact and communication	Eye for specific needs
	Solidarity	Personal contact
		Feelings of friendship

Being together

Group living implies a focus on group activities. Many activities are performed together like cooking meals and eating. Residents react differently to this. Most of them join the group, adapt and feel comfortable. One resident stresses the harmony and solidarity in the group, explaining how being with others helps her to maintain her identity as helper:

Everything happens in harmony. Everybody is always together and I like that. 'I will help you', that is what I usually say.

Yet, a minority likes to be on their own, preferring privacy and a separate room. One of them expresses feeling sad and sorry about her loss of privacy:

I prefer to have my private living and my privacy. I would like to have my own house.

Another resident says she had to adjust. For her it is important to have the possibility to retire to her room. Other residents may watch television in their own room or have visitors. Having the possibility to withdraw is often enough:

I can go to my room when I like. But I don't often do so, I prefer to stay in the living room with the others. At home I stayed with other people as well.

Rhythm of everyday activities

Residents do housekeeping and various other activities together. Residents don't feel obliged to participate. Most respondents like to join home-like activities, such as setting the table and folding linen. It seems that doing what they have always done helps them to stay in control of the situation and maintain their identity. Doing everyday activities enables residents to reconnect to their previous lives and memories, giving them a sense of continuity and feeling of wellness. This was confirmed during participant observations: most residents actively engaged in meaningful activities:

I always do the washing here, I always did this at home as well, I know how to do it

One respondent, however, is clear in stating that she does not want to participate in joint household work: she felt having done this kind of work long enough.

Family

Being part of

Family members feel more involved in the group life than in a traditional nursing home. They are treated as group members (instead of visitors) and have the unit's key. Some family members actually help their relative with daily care and carry out everyday activities in the unit. One residents' wife irons all of his shirts on a regular basis. These activities increase the feeling of being a member of the group.

Furthermore, family frequently joins dinner and drinks coffee or tea. Family members say they visit their relatives more frequently than they used to do in the traditional nursing home, mainly because of the pleasant atmosphere:

Sometimes we bring food and make coffee for all of us. It is like being at home. For the visitors this is far more pleasant.

The group living home thus enables mutually beneficial relationships between nurses, family and residents.

Taking responsibility

Family members take more responsibility for their relatives than they did in the traditional nursing home. This is also

expected of them. Family members sometimes experience tensions concerning the expected responsibilities and concern about their role. Nursing staff make it clear that they expect an active family role in the care taking process. They expect, for example, that family help with transportation of their relative (to church, hairdresser or hospital) or make coffee for the group. These issues are discussed with family members before admission. Generally it gives no problems, although sometimes concerns are expressed (e.g. too burdensome).

Personalised attention

Family feels that nursing staff can spend more time with individual residents in a relaxed way. They know the residents' preferences and take this into account in the relationship and contact with them. A family member gives an example of the empathetic understanding and positive attitude:

> My relative and other residents are respected by the nurses. They do not think: it is only a resident with Alzheimer's disease. We can laugh with them instead of about them.

They appreciate that staff approach residents as unique people with a specific history, individual qualities, values, culture, needs and rights, including the right to dignity.

Since nursing staff follow residents' needs and preferences, there is more harmony in the group; they can spend enough time interacting with the residents. An improved atmosphere compared with traditional nursing home care is noticeable. Staff's approach is based on respect for personhood, with warmth, trust, openness, hospitality, care and honesty, both in contact with residents and family members:

> When the nurses feel comfortable, this influences the unit's atmosphere. It is cozy and nice.

Well-being

Family members also notice that their relatives' well-being has improved, which comforts them also:

> I am satisfied. My mother is at home here. In the traditional unit there were many people, who did not know each other. Here she knows everybody, is familiar.

The atmosphere in group living makes residents feel like at home. Meals are prepared in the unit's kitchen. This creates domestic circumstances and feelings.

Residents make a positive contribution to their situation: they can help with meaningful activities. According to family, residents gain weight:

> It smelled very good when I arrived here. We have just had dinner, they replied. We ate meat and potatoes. And every weekend we eat cake and pie. One of the ladies, she prepares cake.

In addition, family share activities which the residents used to do, for example watching a DVD of a favourite singer.

Nursing staff

Individualised care

Nursing staff indicate that they can pay more attention to each individual resident, because of the small case load. They have time to talk and communicate with residents, look them in the eyes and often make physical contact by touching the residents, for instance, by holding their arm. The setting creates possibilities for a therapeutic alliance, genuine empathy and positive regard. Moreover, nursing staff consider residents' choices and preferences, for example, regarding bed times and leisure activities. At all times, residents' wishes and needs take precedence. Tuning to the needs is possible due to the fact that there is no institutional regime. A staff member puts it as follows:

> There [in traditional settings] the rules reign, here we follow the preferences of the individual resident.

Staff members told that some nurses left group living. They liked the nurse aid related work more than the kind of care mentioned above. Those who have stayed are satisfied:

> It gives me rest, I can now give energy to residents and I really looked forward to that.

Contact and communication

In small groups, nursing staff know their residents well, as the span of control is much smaller than in traditional settings. They know how the residents used to live and their personal biography. Nursing staff have a better understanding of residents' behaviour and this improves the interaction; they can better respond to the residents. Dialogical communication, expression of emotions and needs and attentive listening are enhanced:

> Personal attention is essential. We talk equally as human beings and they tell you a lot.

Residents tell (verbally and non-verbally) what they want in terms of care. Nursing staff adapt to the residents and listen very carefully to what they like and dislike. Through this way of working, residents have more control over their own lives and well-being. Nurses indicated this personal connection also increased their job satisfaction:

We are as a family, involved with one another, it is a small group. Residents tell us what they like.

Solidarity

According to nursing staff, their relation with the residents is closer, more intimate:

As a staff-member I feel that there is more engagement compared with regular care. When something is the matter with a resident, I feel more involved, more close.

Nursing staff are more perceptive and talk more about their private life than in a regular setting. The professional brings her own social context, experiences and emotions. For example, they share stories about activities during their weekend:

I sometimes tell them about my weekend. And I tell my neighbours about my work. Last week my neighbour brought me a basket full of apples: for the group at my work. In the group we prepared apple sauce and ate heartily.

Additionally, they spend a part of their free time organising and joining activities. This makes the connection with residents and the group more intimate than in a regular setting. The small group, family-life structure and presence of fewer colleagues facilitates a sense of belonging and shared language:

People get along well with each other, experience the group as a household, we live as a family.

At the same time, this solidarity may cause tensions between emotional engagement and clinical or professional distance.

Theoretical analysis

Tronto's care ethical framework was used to deepen the understanding of good care in small group living and to shed more light on the positive experiences as well as the tensions. Tronto's care ethics stems from the idea that all human beings are vulnerable at certain moments in their lives. People are thus mutually dependent and take care of each other. Care is a fundamental human act. According to Tronto (1993), care is a continuous and interactive process. Caring does not stop when needs have been identified and fulfiled, as needs change over time and as care-receivers may not always be open to care. Care is intersubjective as the needs can only be identified through observation and communication with the care receiver. Tronto (1993) distinguishes four phases in the process of care: (1) caring about, recognising the necessity of care and identifying needs; (2) taking care of, assuming some responsibility for the identified needs and determining how to respond to it; (3) care giving, directly meeting of needs of care and (4) care receiving, the subject of the care responds to the care that the person receives. According to Tronto each of these phases in the caring process requires certain virtues. The first virtue is 'attentiveness' to the particular needs of this specific person. The second virtue is 'responsibility'. One can only take care for someone if one *feels* responsible to improve the well-being of this person (as opposed to being functionally responsible given one's role. The third virtue is 'competence'. Without specific expertise one cannot provide good care. The fourth virtue is 'responsiveness'. The care receiver should be open to care. In sum, Tronto urges us to see care as an ongoing process of giving an answer to a question of another person. This requires mutual dialogue, even if the other person is completely dependent. Table 2 highlights the most important themes based on the analysis with the concepts of Tronto.

Caring about

Good care starts with 'caring about' (Tronto 1993). What matters is acknowledging a situation that needs good care. This phase is related to the virtues of attentiveness and watchfulness. Nurses have chosen for a career in healthcare

Table 2 Theme analyses by Tronto's framework

Tronto phase	Nursing staff	Residents	Family members
1. Caring about	Able to give individual care, well informed individual needs and to find out what is important for the individual resident		
2. Taking care of	Giving care together with residents and family-members	Being involved in needs of care and in daily activities	Active role for family members. Taking responsibility
3. Giving care	Work from holistic model Family and nursing staff disagree on aspects of taking responsibility of care		
4. Receiving care	Notice whether care is accepted	Open to the care provided	

(geriatric care), but that doesn't mean that they have and use the virtue of attentiveness. The setting of group living homes creates the conditions for nursing staff to be alert to residents' needs and preferences. The case load is small, with possibility for therapeutic alliance, genuine contact and respect for individuality and personal values. Nurses are enabled to be well informed and to recognise the importance of valuing people as individuals with awareness of differences, unique strengths and life paths. Residents are seen and approached as social beings with a social context and mutual interdependent relations. Hence, the family and their needs and the importance of maintaining family relations are recognised as well.

The quiet atmosphere creates rest and time for staff, enabling them to better attend to residents. Finding out what is important for others, how the identity of residents can be maintained can be quite complicated (Abma *et al.* 2011) since people with dementia cannot always express themselves verbally. Intensive interactions are needed to observe and interpret facial expression and postures. Tuning to the situation and personal needs is also easier, since there are fewer rules than in a regular setting. This creates flexibility and stimulates creativity among staff.

Taking care of

Characteristic for the second phase of good care is the active organisation of help, which Tronto refers to as 'taking care'. This phase is linked with the virtue of responsibility. In group living homes, nurses are willing to take on responsibilities to take care of the residents. These tasks are broader than the usual repertoire and also include domestic activities. Some nurses were unhappy with these additional tasks and left the setting. Those who stayed do accept and appreciate this broader responsibility, as they work from an inclusive, holistic model of health and well-being.

However, there are also some tensions among caregivers, family and residents, related to the more active role that is expected from family members and residents. Group living starts from the fundamental idea that everyday activities create stability and rest and that carrying out everyday activities will help residents to maintain their identity as long as possible (Dahlberg *et al.* 2009). The expectation is that residents will keep a sense of vitality being involved in such activities and in most situations this seems to work fine for the residents. They do indeed join, help and take care of domestic tasks and nurses only little motivate and stimulate residents to get involved. Occasionally someone may protest, referring to the right to be taken care of by others. The staff leave room for such exceptions. This is somewhat more complicated when it concerns family. Staff stimulate them to share responsibilities and control. Family appreciate this involvement. Some family members do, however, express serious concerns about their role. Not all of them are able or willing to accept the new responsibilities. This requires adaptation and communication.

Giving care

This phase emphasises the competence to perform physical or mental work for the one who needs care in the contact that the receiver of care needs. Here, we see again some tensions, because this phase is related with ideas about professional expertise and care content. Not all nurses are willing to work from an holistic model and carry out domestic tasks. They have left the setting. Those who stayed act with care, but are sometimes confronted with families who are not available to share tasks. They experience tensions concerning their responsibilities. Taking care in group home living is not just a matter of typical nursing activities, but also includes comfort, attachment, maintaining the life history and identity and quality of life.

Receiving care

Phase four of Tronto's model is receiving care. The moral virtue involved is responsiveness. Good care should include an evaluation of how care was received to adjust care to the needs of the client. Central questions are: Was the client open to the care provided? Did the care provided help to cope with the vulnerabilities, dependency and needs? Our findings indicate that in group living the conditions for feedback and adaptation are good. Due to intensive personal contact and interactive communication it is relatively easy for staff to notice if care does not fit with the needs and adjustments can be made within short time frames.

From our theoretical analysis, we conclude that the conditions in group living are positive for the first (Caring about) and last (Receiving care) phases of good care. There is time, patience and calm to attend to personal needs and to check whether care matches the needs of residents. The conditions are less favourable for phases of Caring for and Giving care, as group living implies a new division of responsibilities among residents, staff and family, which is grounded in the persuasion that sharing and carrying out everyday activities are essential elements to create stability, maintain identity, social relations and involvement. Dialogue among all parties is needed to tune expectations.

Discussion

This study has investigated experiences of residents, their family and nursing staff with group living care and has

related their perception of the care process to a theoretical framework on good care. Positive experiences are expressed, especially related to the individualised care approach, personal attention and the feeling of home sense of self and well-being. These results are in line with the core concept of group living in providing person centred care (e.g. Zingmark *et al.* 2002, Verbeek *et al.* 2009) and the notion of lifeworld-led care (Dahlberg *et al.* 2009) which stresses the importance of finding a rhythmic balance between stillness (rest, piece, being at home) and movement (vitality). However, some difficulties are reported as well. Nursing staff feel more emotional engagement towards residents which increases solidarity, although this also may cause tension with their clinical or professional distance. Additionally, family members feel more involved with the care process in group living, but some expressed that they cannot fulfil the active part expected from them.

Person-centred care is increasingly regarded as synonymous with best quality care. The findings of this study indicate that the core category of person centred care entailed promoting a continuation of self and normality: knowing the person, welcoming the family, providing meaningful activities, being in a personalised environment and experiencing flexibility and continuity (Edvardsson *et al.* 2010). We see many similarities with the themes in our study, especially knowing the person, welcoming the family and being in a personalised environment.

The theoretical analysis showed that Tronto's ethical framework (1993) is a useful tool to discuss the care process in dementia care. The focus on daily life in group living units, however, may cause tension with the professional and medical care residents which severe dementia require (Annerstedt 1993). Therefore, phases two (taking care of) and three (giving care) should not be neglected or underestimated in group living care. Appropriate staff training and education as well as communication with the family and residents is crucial in this process.

Some limitations concerning this study must be considered. Generalisation of outcomes from this study is limited, due to the small sample size. Yet, we do believe that our description provides readers with a vicarious experience of what group living is alike. Insights from the study context may be translated to other contexts by the readers, a process known as naturalistic generalisation (Abma & Stake 2001). Moreover, our interviewees (nursing staff, family and residents) were motivated to participate in this study. These respondents, especially family members, are probably more involved with the care process and may have different opinions than other families. In addition, nursing staff working in these units have deliberately chosen to work in group living. Therefore, they are not representative for all nursing staff working in dementia care.

Future research is needed to explore the experiences of respondents in further detail. Since residents with severe dementia have limited verbal communication skills, other non-verbal ways to communicate must be considered like hermeneutic photography (Sitvast *et al.* 2008).

Conclusion

Good care implies attentiveness, responsibility, professionalism and responsiveness (Tronto 1993). Group living for people with dementia creates an environment which facilitates the values of attentiveness and responsiveness. The small number of residents, the homelike environment and the emphasis on daily life contribute to this. However, family and nursing staff may disagree on aspects concerning taking responsibility of care and performing care giving activities. This requires competence of nursing staff in engaging in dialogue.

Relevance to clinical practice

Dementia care is increasingly organised in small-scale and homelike settings, also referred to as group living. These settings imply person-centred care with emphasis on residents' wellbeing and involvement in everyday activities as vehicles to create rest, stability and maintaining identity. The possibilities for a therapeutic alliance, authentic contact and empathic understanding are valued and beneficial for all involved. The role of nursing staff is changing, emphasising caring about and receiving care.

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Contributions

Study design: EvZ, GW, EvR, TA; data collection and analysis: EvZ, HV, GW, TA and manuscript preparation: EvZ, HV, GW, EvR, TA.

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