EXPERIENCES WITH CARE IN GROUP LIVING HOMES FOR PEOPLE WITH DEMENTIA: A CASE-STUDY

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1. INTRODUCTION AND RATIONALE

Dementia is a major problem worldwide as it is increasingly becoming a cause of death among elders[1]. In 2013 the amount of people with dementia (PWD) was estimated to be 44.4 million worldwide and this number is expected to double every 20 years[2]. In 2050, the number of PWD in the Netherlands is expected to increase to 565,000[3].

People increasingly value social contacts and enjoyment of activities, acceptance and respect of who they are and staying home as long as possible[4]. Basic principles of the standards about dementia care in the Netherlands reflect these needs. Some of these principles are that care is characterized by dignity and respect in the relationship between PWD and the caregivers, and that PWD stay home as long as possible[5]. Even though often dementia care is provided at home[6,7], residential care is required in a progressed stage of dementia-.

Residential care institutions offer medical care and are hospital-like with large wards and a big number of residents, which makes difficult to meet the unique needs of PWD. To improve this situation, dementia care is increasingly provided in Group Living Homes (GLH)[8]. GLH, in contrast to residential care institutions, is referred to as the “housing”-care model. Characteristics of GLH are i.a. that they provide six to eight residents per unit with housing and care[9,10], there is a regular nursing staff and staff is capable of creating a home-ambience[8] (box 1).

Since the emergence of GLH, a significant amount of research has focused primarily on the effects of care in GLH on PWD, the informal caregivers[9,11-16] and staff members[12]. Positive findings are such as having something to do and are being more involved in household activities; acceptance of the admission and the illness of the relatives of informal caregivers; and a higher motivation to work. However, there is less research on detailed residents’ experiences of their unique needs, choices and preferences being respected and of being personally involved with the care[17].

This research therefore focuses on residents’ experiences with GLH-care. GLH-care aims to provide person-centered care[10] (PCC), as the PCC approach concentrates on the values, preferences and choices of the resident regardless of cognitive abilities[18]. The framework of

Person-centered Nursing (PCN)[19] gives insights in how PCC could be offered. Therefore, this framework is used for this study.

PCN consists of four constructs[20]: prerequisites for nurses, the care-environment, PCN processes and PCN outcomes (table 1). PCN outcomes are the results (satisfaction with care, involvement with care, feelings of well-being and a therapeutic culture) expected from working in accordance with the three other constructs[20]. This study uses the constructs to understand how PWD experience GLH-care.

2. PROBLEM STATEMENT, AIM AND RESEARCH QUESTIONS

Currently it has not been reported whether PWD in GLH experience care that meets their unique needs, choices and preferences. Therefore, the aim of this study is to provide a thorough description of the experiences of a person with dementia, her informal caregivers and staff with care in GLH. Gained insights can be used to optimize quality of care for PWD. PCN's framework is used to fit in with these experiences.

Research question:

"How do a person with dementia, her informal caregivers and staff experience care in a group living home?"

Sub-questions:

- How do a person with dementia, her informal caregivers and staff experience satisfaction with care?
- How do a person with dementia, her informal caregivers and staff experience involvement with care?
- How do a person with dementia, her informal caregivers and staff experience feelings of well- being?
- How do a person with dementia, her informal caregiver and staff experience the therapeutic culture?

3. METHOD

Design

A single embedded case-study was conducted. A single embedded case-study concentrates on a representative case and involves more than one sub-unit[21] -in this case the resident, her informal caregivers and staff. A case-study makes it possible to describe in detail how one person experiences the care provided in GLH, including the complexity of her real-life situation. Therefore, a case-study design has been found as appropriate for this study.
Ethical approval was provided by the Human Research Ethics of the Isalac Clinics, Zwolle, Netherlands. The criteria for medical research with humans (WMO) did not apply for this study.

Sample

WZH Oosterheem is a GLH facility which meets the ten statements mentioned by te Boekhorst[8](box 1). The selection of the participants was based on inclusion criteria. The resident has lived more than three months in the GLH, has reached a mild or moderate stage of dementia and speaks Dutch. The informal caregiver is involved in the basic care the resident is provided with, participates in the activities of daily living, participates in the activities offered to the residents, and speaks, writes and reads Dutch. The staff member is involved in the basic and daily care of the resident and speaks, reads and writes Dutch. Therefore, the research population is purposive sampled. The intention of purposive sampling is to have access to people from whom rich data can be obtained[22].
The manager of the facility WZH Oosterheem approached the legal representative of the resident to participate. Two of her informal caregivers and eleven staff members that formed a team for the resident were approached.
The researcher distributed an information letter and asked to give written informed consent to the two family members, the legal representative and staff. The resident gave assent to participate in the study.

Data collection

Data was collected from January to May 2014. This study employed a triangulation of methods: participant observation, semi-structured interviews and document analysis (table 2). Methodological triangulation confirms data and ensures data are complete, increasing the credibility of the findings[23,24]. The researcher developed an observation protocol and a topic list for the interviews (box 3), both based on the three first constructs of PCN's framework.

In total twelve semi-structured interviews were conducted with two informal caregivers and ten staff members. The topic-list consisting of open questions was used to guide the interviews. After conducting four interviews, the researcher used findings to adapt the topic list for interviewing the staff, applying constant comparison. The interviews were verbatim transcribed.
The observation protocol was used to observe the situation, including every person present, at specific moments. Furthermore, participant observations included unofficial conversations with the resident and staff, which were reported in the observation summaries. The researcher chose to be a participant as observer during the observations. As a participant the researcher could build a relation of trust with the resident, which was essential to ensure she felt comfortable to act and speak as usual. To increase reliability and confirmability[24], the researcher asked an independent colleague to make observations at the same time with the researcher, making use of the observation protocol.

For the document analysis documents were gathered from the digital-file of the resident. Furthermore, the researcher wrote memo's during the observation, in order to reflect on her preconceptions of the facility.

Data analysis

For the qualitative data analysis a method was developed based on Quagol[26] and Boeije[27] (appendix 1). The researcher analyzed across all data (document, observations and interviews). After coding all data, resulting codes were categorized in emerging core-codes (table 3). These core-codes were used to describe the results according to the PCN outcomes. QDA-miner[25] was used as support software for coding data.

Of the twelve interviews conducted, two were coded independently by the researcher and one co-researcher to increase trustworthiness. Furthermore, data was analyzed through iterative review by the research team.

4. RESULTS

The resident is a woman aged 89. Her informal caregivers are both women, on average aged 60. The legal representative of the resident is one of her informal caregivers, and the person most involved with her care. All staff members are women. A complete demographic description of the participants is given in table 4.

The experiences of the resident, the informal caregiver and staff are presented and described per each of the PCN outcomes, which are: satisfaction with care, involvement with care, feelings of well-being and creating a therapeutic culture[20].
A conversation between the researcher and the resident about her feelings is presented in Box 2 to give an idea about her living in the GLH.

Satisfaction with care

Emerged core-codes that are related to satisfaction with care are: emotional engagement, resident feeling safe and at ease, physical environment, tools and systems, professional competence, appropriate skill-mix and staff relations (table 5).

Resident

The resident (P0) expresses enjoying company of her family and staff and recognizing nurses from the regular staff. During observations, facial expressions confirm these feelings: P0 familiarly talked to regular staff. Presence or non-presence of family was reported in her digital-file as determining her mood: feeling happy when family was there and feeling sad when not.

P0 gives the impression of feeling safe and at ease by the presence of known staff, but still uncomfortable and scared when being cared, which was observed as well as reported in her digital-file. Furthermore, the atmosphere is enjoyable for P0 when regular staff works, which is perceptible in her talking and laughing. In conversations during the observations, P0 said to be glad having her own things, but did not mention feeling at home.

Informal caregiver

One informal caregiver (P1) expresses being surprised that her relative (P0) recognizes some staff members. Both informal caregivers (P1,P2) consider nursing staff being kind and cordial to the family. P1 and P2 sense delightful homely smells of cooking, and find the design of the GLH being like P0 desires for her own home, giving the feeling of being at home.

P1 and P2 experience concerns about the lack of recognition of care-demand of the nursing staff; and struggles because of the presence of nurses with a low qualification, especially in the evenings. Moreover, they express some concerns about the few possibilities to go

outdoors; the differences in dementia-stages of residents in the GLH; and dirty laundry not being well-collected.

"[...] *Sometimes one person is working and sometimes another one- just to give a practical example- then sometimes there is a lot of dirty laundry, and the other time you think, well, after five days you can give her some clean cloths*, *you know?*"
Issues about the dirty laundry were reported as well in the digital-file of P0.
Dissatisfaction and concerns of P1 about how care was going was reported in the daily reports of March 2014. During an encounter with the researcher in May, P1 mentioned having concerns about the physical care of P0.
Nevertheless, P1 and P2 stated more than once during the interviews being satisfied with the provided care:
"[…] *I believe I come over as negative [laughing] but I'm overall very satisfied…*"

Staff
Staff experiences being recognized by P0. During the observations, P0 said warm words to some regular staff members, such as: *"she's always that lovely to me"*. Staff indicates that the regular nursing staff is competent; has good intentions providing care; and takes the time to care for P0. Staff finds the atmosphere peaceful, familiarly and enjoyable. During observations, this was experienced when regular nursing staff was working.
Staff is aware P0 is sensitive to their mood; and consider that their mental condition influences the care they provide to her.

Staff expresses feelings of discontent when flexi-workers are unknown with the life-care plan of P0 and when they don't make proper use of the digital-file, causing delay in their own duties. Not reading the digital-file causes non-attendance for (medical or nursing) care-interventions. During observations, lack of information about P0 especially among flexi-workers was noticed.

Staff reported frequent change of personnel of the regular nursing staff, making it difficult to become familiar with each other. Employing flexi-workers and the differences in the atmosphere when they worked was observed.

Involvement with care

Emerged core-codes that are related to involvement with care are: sharing of power, feeling engaged, commitment to job, sharing decision-making, providing physical and emotional needs and interpersonal-skills (table 5).

Resident

P0 is free to indicate by herself what she wants to do regarding her care. Information in her digital-file confirms this point: staff allows her to choose whether or not to take a shower and whether or not to enjoy company in the living-room. P0 participates to the activities offered to her, after informing about what the activity is about, which was noticed during observations. However, having a cigarette whenever she desires seems to be a problem. This was observed: P0 usually waited until somebody asked her if she wanted to have a cigarette. In her digital-file was reported she felt upset and confused because she was not allowed to keep cigarettes in her private room.

Informal caregivers

P1 and P2 experience an open communication with and being understood by staff. P1 and P2 feel free to take other residents besides P0 to activities inside the building or outdoors for a walk. Informal caregivers, especially P1, experience having to pay attention to get all things done well regarding the care of P0.

Staff

Regular nursing staff works orderly and steadily, while flexi-workers works rushed and untidily. This was observed. Staff expresses struggling with a lack of communication among colleagues, especially because of unwillingness to listen to each other and to report and read reports from the digital-file. Staff mentioned that particularly flexi-workers show this behavior.

Staff experiences difficulties when combining care-tasks with other tasks, such as housekeeping and activities. Differences in being motivated to do more than required and regular staff being committed to their job were expressed. The observations show that however nursing staff works individually in the different GLH, they are willing to help each other, especially when the regular nursing staff works.

Feelings of well- being

Emerged core-codes that are related to feelings of well-being are: physical and mental conditions of resident, preferences and rejections of resident, relations resident, feelings of well-being, being reflective and innovative, barriers for good care and knowing the resident (table 5).

Resident

By the presence of regular staff, P0 looks well-cared and lively. During one observation moment in the morning, P0 was left behind by a flexi-worker in the bathroom, alone, with no help and no alarm. P0 enjoys having a talk, smoking a cigarette and taking care of her hair. This was perceived during the observations, and confirmed by reports in her digital-file. P0 expresses dissatisfaction of co-residents sleeping during the day. Staff manages to pacify her feelings about her co-residents.

P0 talks mainly to staff or family, and has poor but sympathetic response to talks and actions of co-residents. Being helpful and doing things with her co-residents was reported in her digital-file. "(11-12-2013) *[P0] was helpful to her neighbor when sitting at the dinner-table*"

Informal caregivers

P1 mentioned to be able to let go of thoughts about the care of P0 when leaving the GLH, and feel calm by leaving her behind. Though her co-residents are in a further stage of dementia, both P1 and P2 find the process of dementia decline going slower than expected.

Staff

Medical- and paramedical staff see the nursing staff becoming more and more one team, probably because of organized teambuilding activities and the moments during the day planned to reflect about the teamwork. Nursing staff has divergent feelings about having a moment for reflection and considers still not being one team. Nevertheless, during the observations regular nursing staff worked together as one team instead of separately.
Other staff except nurses considers that nursing staff makes little use of the self-reliance of P0. During the observations, most of the time, P0 was independent in preparing her own breakfast and washing herself.

Staff considers missing a helping hand in the living-room and flexi-workers not knowing P0 or her routine being impediments to good care. Furthermore, staff experiences work-pressure

and disquiet among nursing staff because of the multiple tasks, even to the extent of nurses quitting their jobs. Some staff members have to get used to the concept of GLH:
"*I notice some colleagues work steadier than I do. I actually have to get use to the small group of residents and to the fact that you can take your time"*
Nursing staff expresses having the possibility to make jokes and talks with P0, which was noticed as well during the observations.

Creating a therapeutic culture

Emerged core-codes that are related to the therapeutic environment are: structure for the resident, working with values and beliefs of resident, having something to do, accountable staff, providing for physical and emotional needs and offering activities (table 5).

Resident

P0 seems to enjoy herself most when smoking a cigarette, having company or a talk and participating to offered activities. These moments are offered to P0 as often as possible.
In her digital-file was reported enjoyment of offered activities and helping with the housekeeping now and then. She withdraws from the living-room when she sits, not doing anything; and when she has to wait a long time for smoking a cigarette.

Informal caregivers

P1 and P2 stated two main disappointments: the offered activities to P0 and an unattended living room, especially in the evenings. Both points were supported by observations: activities were mainly offered somewhere else in the building, not in the living-room of the GLH; and there was no professional caregiver present in the living-room sometimes for an hour while residents were sitting there.

"[…] *in the evenings when I bring her back and she needs her medication, then I have to look for someone in other GLH's for assistance*"

Staff

Staff mentioned difficulties in finding a balance between self-reliance of P0 and supporting her. This was only observed when flexi-workers worked. Staff admits that nurse-apprentices fulfill an important role in offering activities in the living-room to the residents; and find difficult to combine housekeeping activities with entertaining P0. The medical and paramedical staff

describes this as a lack of creativity, while the nursing staff thinks this is because of a lack of time and missing a helping hand in the GLH.
"*It is easy to make her [P0] happy, but the barrier is, as I said, the difficult thing is time*"

5. DISCUSSION

This case-study presents the experiences with care in a GLH of one person with dementia and her informal caregivers and staff, which were interpreted with the PCN's framework [20]. Positive experiences are expressed; particularly that regular nursing staff knows the resident and has respect for her unique needs, choices and preferences; and a safe and peaceful atmosphere for the resident when regular nursing staff works. These findings are strongly related to description van der Cingel[28] gives about the constructs of the framework: the uniqueness of the resident, the care-environment and the competence of staff. According to her, McCormack and McCance see providing PCC as[28] "to see the other as the human-being he or she is" and having the competencies required to provide care.

However, concerns are about the unattended living-room and the competence of the nursing staff as struggling combining tasks. Furthermore, difficulties with (outdoors) activities are reported, as well as worries about the negative influence of flexi-workers on the mood of the resident and the atmosphere. Though, a regular staff and the offer of (personalized) activities are characteristics for GLH-care[8].

Comparable results are showed in other studies. GLH-care is reported to provide personal attention and individualized care[20], but also concerns about nursing staff working alone during a large part of the day and vulnerability to staff shortages[29].

These findings offer a thorough description and particularization of the experiences with care provided at GLH, and show in which way individualized and personalized care can be provided. The use of data triangulation supplied diversity in data and enhanced the trustworthiness of the study.

Some limitations of this study must be considered. The results of this study may not be generalized to a broader population, due to the design[30]. Furthermore, the researcher chose not to interview the resident, while this could have provided more personal insights about her experiences.

This study implies that a regular nursing staff influences the way care in GLH is experienced. The care regular nursing staff provides is personalized and concentrates on the unique needs, choices and preferences of the resident.

6. CONCLUSION

This case-study shows that this specific person with dementia, her informal caregivers and staff positively experience satisfaction with care, involvement with care, feelings of well-being and a therapeutic culture when care is provided by a regular nursing staff; as well as concerns about the skills of the nursing staff to combine the different tasks.

7. RECOMMENDATIONS

GLH-care should be provided by a regular nursing staff that has the demanded skills to combine the different tasks. Accordingly, feelings of safety can be safeguarded when providing care in GLH. More research could be conducted about the perceptions and experiences with PCC in GLH, interviewing residents at a moderate stage of dementia.

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9. TABELS

Box 1: Statements describing GLH (Traduced from Te Boekhorst, 2007)

1. There is a regular nursing staff;
2. staff or family does the cooking;
3. people can get up, go to the toilet and go back to bed whenever they like;
4. people can stay till they die;
5. residents determine the look of the interior of their room;
6. residents, family and staff can decide what happens on a daily basis;
7. there is a clear vision on providing dementia care based on the needs of the resident;
8. there is no staff uniform;
9. the institution furnishes in housekeeping;
10. Staff is capable of create a home ambience.

Box 2: Interaction moment between the researcher and the resident

I ask the resident if she is happy here "well, I'm not a difficult person, you know? It wasn't easy at the beginning, but o well, you get used to it" I keep asking if she feels happy "well, happy… I prefer not to be here. These are my furniture, my closet... this is a beautiful room, but I get tired of this place! I… I get tired of things very fast. But it is okay, you know? I look at her and see 'conformism'. "Do you remember when you came here?" I ask her "Sure I remember" "And? How was it?" "h'm, you know. I'm here alone. There is no so much to do. But well, I don't want to be troublesome. It's fine here"... "My children are very lovely. They come to visit me..." "You have a daughter, haven't you? [...]" "Yes, do you know her?" [...] "And you have two sons... how many children do you have?" she counts… "Two boys...- she looks away- well, one daughter passed away when she was 6 years old" "oh, really? 6 years?", I ask. "Yes... she was lovely, so sweet. She laughed the whole time..." She tells a story about her deceased daughter "ah well, nobody asks for this to happen, right? It just happens. Nobody asks... My husband also passed away, a darling man he was, you know? And he was crazy about her" She points at a picture of a girl in a dress above a table, next to it a picture of an older man. "That is why I have them next to each other". She sighs. "But I don't want to cause troubles. I don't want to be boring, you know? I don't want to bother people with my sadness" She sighs again…

[...]

"I love to talk and be busy, and people talk to me, while my heart aches. It hurts […] well, and you just end up here alone. I have lovely children, you know?

[...]

Box 3: Main topics for interviews and observations

Interviews:

Professional competence of nursing staff: how competent do you think staff is?

Developed inter-personal skills: how do you experience the behavior of staff?

Dedication to work: How motivated do you think staff is to come to work?

Clarity in beliefs and values: How do you experience the values of WZH (openness/ safety/ being together)?

Knowing self: how emotional engaged are you with the care provided here?

Skill-mix: What can you tell me about the educational level of the nursing staff?

Shared decision-making systems: How is the interaction among staff?

Power sharing and effective staff relations: how do you experience the teamwork? What kind of conflicts have you experienced?

Physical environment: How do you experience what you smell/ see/ hear/ feel at the atmosphere?

Working with values and perceptions of the patient: How do you experience staff takes into account the uniqueness of the resident?

Share decision-making: how to facilitate it? How does staff makes choices about the care of the resident?

Commitment: How is the interaction between resident and staff?

Observations:

Everybody working that day is observed: resident, co-occupants, family, staff.

- Competence and skill (mix) of staff
- Interpersonal-skills and commitment
- Sharing decision-making and sharing of power
- Experiences with values of WZH (openness/ safety/ being together)

Table 1: Core concepts of PCC (McCormack and McCance, 2006)

McCormack's framework(2006)	Components of each construct
Pre- requisites of nurses	Professionally competent Developed interpersonal skills Commitment to the job Clarity of beliefs and values Knowing self
The Care environment	Appropriate Skill mix Shared decision making systems Effective staff relationships Supportive organisational systems Power sharing Potential for innovation and risk taking The physical environment
PCN care process	Working with the patient's beliefs and values Engagement Shared decision making Having sympathetic presence Providing holistic care
PCN outcomes and evaluation	Satisfaction with care Involvement with care Feeling of well- being Creating a therapeutic culture

Table 2: Data collection methods

Document analysis	The most recent life-care plan; Four resume-cards of the life-plan (which contains all specific information about the resident); The most recent nursing-care (description of which care the resident should receive during all day); and The daily reports from 01-11-2013 till 31-03-2013
Participant Observation of the daily routine	during three mornings (from 8:00 till 12:00) and two afternoons (from 12:00 to 16:00)
Semi-structured interviews	With informal caregivers and professional caregivers for no longer than 60 minutes per interview

Table 3: Codebook

Core-codes	Codes
Accountable professional caregiver	Presence of staff in the GLH
	Feelings of accountancy of staff
Appropriate skill mix	Differences in educational levels of staff
	Differences in duties and responsibilities
Barriers for good care	Hindering for providing care
	Not knowing residents of the GLH
	Organizational hindrance
Being reflective and innovative	Receiving and giving feedback
	What's improving
	What have to be improved
	What is expected of staff
	Introspection
Commitment to job	(inner) motivation of staff
	Experiencing teamwork/ being a team (staff)
	Executing/ keeping to (organizational) appointments
	Following (care)appointments about the resident
	Following medical interventions
Emotional engagement of resident	Understanding staff
	Engagement of resident
	Knowing boundaries
	Working with passion
Feeling engaged (informal caregiver)	Experiencing being together
	Being satisfied
	Expectations of informal caregiver
Feelings of well-being informal caregiver	Distress of informal caregiver
	Feelings of the informal caregiver
	Irritation points of resident and family
Feelings of well-being of professional	(un)quiet among staff
	Feelings of staff
	Experiencing work-pressure
	Feeling in one's niche
Having something to do	Having something to do
	Enjoying activities
Interpersonal skills	Communication between informal caregiver and staff
	Communication between staff and resident
	Communication among staff
	Working in own way
	Guarding own boundaries

	Daring to the human-being he/ she is
Knowing the resident	Making use of the possibilities of the resident for own care
	Transferring knowledge of resident
Offering activities for residents	Creatively managing activities
	Creating a therapeutic atmosphere
	Conducting activities for the resident
	Taking initiatives
Organizational systems	Safeguard the continuity
	Setting in apprentices in the GLH
	Composition of the staff
Physical and mental conditions of resident	Physical and mental decline
	Physical well-being
	Feeling comfortable
	Mental well-being
	Being satisfied
	Feeling home
	Self-reliance of resident
	Feeling appreciated
Preferences and rejections of resident	Enjoys of resident
	Life-history of resident
	Interests of resident
	Whishes and preferences of resident
Professional competence	Treatment
	Competencies of staff
	Looking through the behavior of the resident
	Recognition of care-demand
	Attitude of staff
	Managing changes in the care
	Keeping order and overview at work
	Prioritizing tasks
Providing for physical and emotional needs	Giving attention to
	Participation of informal caregiver
	Care-routine of resident
Relations resident	Communications among residents
	Behavior of the resident
	Interaction among residents
Resident feeling safe and ease	Feeling safe
	Influence on the resident
	Safety of resident
Sharing decision making	Contribution of informal caregiver
Sharing of power	Irritations in the team

	Positions of power in the team Experiencing openness (family) Experiencing openness (staff) Distribution of tasks in the team Resident indicating
Staff relations	Being one team Helping each other as a team Getting alone together Being satisfied (staff) Trusting each other Work-culture
Structure for the resident	Resident experiences structure Offering structure to the resident
Tools and systems	Approach-form for people with dementia Client-agenda Digital-file (DZD) Life-narrative form Caregiver-agenda Life-care plan
Working with beliefs and values of resident	Managing whishes and preferences of resident Taking into account whishes, preferences and needs of resident Empathizing with (emotions of) resident

Table 4: Demographic data of participants

	Gender (number)	Average Age	Occupation/ educational level (number)
Resident	Woman (1)	89	Unknown
Informal caregivers	Woman (2)	60	Unemployed Unknown
Professional caregivers	Woman (10)	34	Nurse-assistant L2 (2) Nurse with / or having a secondary educational level (L3) (2) Registered nurse (L4) (2) Paramedical (3) Medical (1)

Table 5: PCN Theme's, core-concepts and quotes.

Themes (Outcomes of PCN)	Sub-unit	Core-codes	Quotes
Being satisfied with care:	Resident	Emotional engagement	Observation: <P0 is sitting in the living-room. It seems that P0 doesn't like it sitting there, alone. "all these dozing people" she keeps saying this the whole time.>
		Resident feeling safe and ease	
		Physical environment	
	Informal caregivers	Emotional engagement of resident	P1: [...] when they are cooking, every time again I say when I arrive Oh it smells so tastily!
		Tools and systems	
		Professional competence	
		Physical environment	
		Appropriate skill mix	
	Staff	Emotional engagement of resident	P4: at first, she reacts well, making jokes. So, most of the time she is happy. Sometime she says: Oh I'm so happy to see you again! Finally! A known face!
		Resident feeling safe and ease	
		Tools and systems	
		Organizational systems	
		Staff relations	
		Professional competence	
		Physical environment	
		Appropriate skill mix	
Being involved with care:	Resident	Sharing op power	Observation: < It's 10h20. I'm pouting out coffee to other residents but P0. "What about me? I haven't had anaything yet!" P0 says to me. "would you like to have coffee, then? Do you like it?" "Sure I like it! Yes, please"
	Informal caregivers	Feeling engaged (informal caregiver)	P1: [...] well, that kind of things happen, and it take so long to get it well done, no matter how simple it can be. They could write these things on a board,
		Sharing of power	

		Commitment to the job (of staff)	like: this person has to go to bed. During the swift of shifts or you start working you just have to watch the board Oh! What dot I have to do today? I can imagine you do that.
		Sharing decision making	
		Providing for physical and emotional needs	
	Staff	Interpersonal skills	P4: [...] For example, if you have technical problems with the iPad, if you are from the regular staff then you at least write something about the day on the communication-form. Flexi-workers don't do that. But, we always say: it doesn't matter if you are from the regular staff or a flexi-worker, you have to do what you have to do.
		Commitment to the job	
		Sharing of power	
Having feelings of well-being:	Resident	Physical and mental conditions of resident	Digital-file: In the afternoon, ma'am went to walk and to drink a cup of coffee enjoying the company of B6.
		Preferences and rejections of resident	
		Relations resident	
	Informal caregivers	Feelings of well-being (informal caregiver)	P1: [...] I trust everything goes well, I just have to think so, otherwise I would be thinking about it all the time. When I'm here I'm here, when I go home I let go of thoughts about here. I think I manage to do so.
		Physical and mental conditions of resident	
		Interpersonal skills (of staff)	
	Staff	Being reflective and innovative	R: How dot you think that infleunces the client? P4: well, sometime she says: "Is everything all right with you? You know? On that way. So, I say: "no ma'am,everything is all right." "really? I don't think so,
		Barriers for good care	
		Knowing the resident	
		Feelings of well-being (staff)	

		Relations resident	something is wrong" You know? On that way. She she can't explain it, but she can see in my eyes something is bothering me. So she says "is everything all right?" R: You mean P0? Or somebody else? P4: yes, P0 en another woman. They are very sensitive. […] because, just like I said, I'm always moving around and talking [...] and making jokes [...] but then, she notices, she notices anyway.
Experiencing/ creating a therapeutic culture:	Resident	Structure for the resident Working with values and beliefs of resident Having something to do	Observation: < Who is knitting?" I ask while B3, B1, B2, B6 and P0 were sitting in the living-room. "Me" answers P0 "They made me to. I get the assignment to knit. I have to make a scarf" P0 smiles. "And who made you to" I ask. P0 points to Pr13 "over there" Pr13 looks up and smile. P0 and Pr13 grin "but it is nice, isn't it?" I say to P0 "Oh sure. They make me to peel potatoes and to fold cloths and to knit. But that's all right, you know?">
	Informal caregiver	Having something to do (resident) Accountable professional caregiver	P2: [...] but regarding activities? Well, I think... there are… no, I find it disappointing. There were few outdoors activities at the beginning, but they never asked her, when they knew that she really wanted to go, a day outdoors. But, you know? They bring it up very nicely, but there is no time and no money. Most of the time (sigh) … and only a limited number of people can enjoy the activity, so, she can't always enjoy it.
	Staff	Accountable professional caregiver Working with beliefs and values of resident	P5: Sometime I see someone only sitting there, so I ask "Is something wrong?" [...] "No, nothing, so blablabla, but then a couple of minutes later you

	Providing for physical and emotional needs	notice there is actually something wrong. And then you see them look at you very often, so you sit next to them and talk to them and, as long as you keep making contact with them, it comes at some moment out.
	Offering activities for residents	

10. SUMMARY

Title: Experiences with care in group living home for people with dementia: A case study.
Background: The increasingly demand for individualized and homelike care of people with dementia and their family and recent standards about dementia care forces residential care institutions to provide more personalized care. Group living homes are a result of these changes in dementia care. Group living homes concentrate in the individual needs and preferences of the resident. Resident experiences of being involved with the care and own values and choices being respected are not reported, despite earlier research.
Aim and research question: to provide a thorough description of the experiences of a person with dementia, her informal caregivers and staff with care in a GLH facility. The research question is: how do a person with dementia, her informal caregivers and staff experience care in a group living home?
Method: Document analysis, participatory observations of the daily routine and semi-structures interviews were conducted from January to May 2014. A method for analysis of qualitative data was used. Codes and core-codes were described and categorized in themes.
Results: The resident, informal caregivers and staff experiences positively that regular nursing staff knows the resident and has respect for her own choices and preferences, and that the atmosphere feels safe and peaceful for the resident. Concerns were also reported, such as struggles with combining tasks, an unattended living-room and the few offered (outdoors) activities were reported as difficulties.
Conclusion: a person with dementia, her informal caregivers and staff experienced the care in GLH positively, though some improvements which have to be made, especially working with a regular nursing staff and having the appropriate skills to combine the different tasks.
Recommendations: Care at GLH should be provided by a regular nursing staff. Staff must have the appropriate skill-mix to work in a GLH. More research interviewing the resident could be conducted at a moderate stage of dementia.

Keywords: Person-centered care, group living home, homelike-care, dementia-care, case-study.

11. SAMENVATTING

Titel: Ervaringen van mensen met dementia met de zorg in kleinschalig wonen: een case-study.

Inleiding: De stijgende vraag van mensen met dementia en hun familie voor geïndividualiseerde and huiselijke zorg en de recente zorgstandaarden voor dementiezorg, dwingen verpleeghuizen om persoonlijke zorg te bieden. Kleinschalig woonsettings zijn een resultaat van deze veranderingen in de dementiezorg. Kleinschalig woonsettings biede zorg aan een kleine groep bewoners en concentreert zich in de individuele behoeften en voorkeuren van de bewoner. Ondanks eerder onderzoek, zij de ervaringen van bewoners over het zich betrokken voelen bij hun eigen zorg, en dat hun waarden en keuzes gerespecteerd worden zijn niet gerapporteerd.

Doel en onderzoeksvraag: de study oogt een diepgaande beschrijving te geven over de ervaringen van een persoon met dementia, haar mantelzorgers en zorgverleners over de zorg in kleinschalig wonen. De onderzoeksvraag is: hoe ervaren een persoon met dementia, haar mantelzorgers en zorgverleners de zorg in kleinschalig wonen?

Methode: data is verzameld van januari tot mei 2014 door middel van document analyse, participerende observaties en semi-gestructureerde interviews. Voor de analyse werd een methode gebruikt gebaseerd op Quagol en Boeije. Codes en hoofdcodes werden gecategoriseerd in thema's.

Resultaten: De bewoner, mantelzorgers en zorgverleners ervaren op een positieve manier dat het vaste personeel respect heft voor de eigen keuzes en voorkeuren van de bewoner en dat de sfeer uistraalt rust en geborgenheid. Zorgen over het niet (kunnen) combineren van de verschillende taken, de onbemande huiskamer en de weinig activiteiten, vooral buitenshuis, werden ook vermeld.

Conclusie: een persoon met dementie, haar mantelzorgers en zorgverleners ervaren op een positieve manier de zorg in kleinschalig wonen. Echter, sommige aspecten behoren aandacht te krijgen, zoals het werken met een vast zorgteam en het hebben van de geschikte vaardigheden om de verschillende taken te kunnen combineren.

Aanbevelingen: Zorg in kleinschalig wonen zou verleend moeten worden door een vast zorgteam, dat beschikt over de vereist vaardigheden. Meer onderzoek kan verricht worden, waarbij de persoon met dementie geïnterviewd wordt wanneer dit mogelijk is.

Trefwoorden: Persoonsgerichte-zorg, kleinschalig-wonen, huiselijk-wonen, dementiezorg, case-study.

Appendix 1: method for analysis

1. Make transcript(s) of the qualitative data (of observations and non-verbal signs)
2. Read and reread data, an amount of interviews (or other qualitative data: focus group, documents). Shade quotes that could be relevant and report quotes that strikes in memo's:

- First time coding with noting/ reflection in memos;
- Short report about characteristics and context of interviewees (in data software by participants)
- Make first coding by two researchers independently

3. The two researchers together discuss the coding and end up with one code scheme:

- Assess/ discuss coding
- Scrap, complete and reformulate codes until consensus
- First description of codes
- Coding in a temporal scheme of two levels

4. Develop a code list with description of codes/ concepts per interview (make pronouncements); in each interview add codes/ adjust code list.
5. Analyze back and forth the rest of the data; make a final concept of the first code list in relation to the pronouncements; develop memos with hypothesis.
6. Discuss and determine code list with all codes without any hierarchy in the research team
7. Reread interview with code list, if needed, adjust and re-code critically the code list; discuss questions and reflections reported in memos in the research team; develop code in a second level: codebook with core-codes.
8. Describe core-codes in own words based on cross-data analysis; discuss and determine description of codebook in the research team.
9. Determine connections and relations between core-concept in a conceptual model; discuss and determine this in the research team.
10. Describe findings in terms of the research question