

Dutch community nursing care, experiences of persons with dementia and informal caregivers

a multiple-case study

Student	Corinda Rijfers (CR)
Student number	3181308
Student for second encoding	Milou Velthuis (MV)
State	Final
Date	June 29 th 2016
Course	Clinical Health Science, program Nursing Science, Utrecht University
Supervisor	Dr. C.H.M. Smits (CS) University of Applied Sciences Windesheim, Zwolle
Lecturer University	Dr. H. van Os - Medendorp
Targeted journal of publication	Journal of Advanced Nursing
Requirements targeted journal	max. 5,000 words
Number of words	3,791
Number of words Dutch abstract	300
Number of words English abstract	300
Reference style	Vancouver
Criteria for transparent reporting	COREQ

Dutch abstract

Achtergrond. Dementie is een ernstig en chronisch syndroom dat voorkomt bij 270.000 mensen in Nederland. Bijna 70% van de personen met dementie is thuiswonend en wordt ondersteund door mantelzorgers, casemanagers dementie en wijkverpleegkundigen. Door overheidsbeleid in de chronische zorg, ingezet sinds 2015, vindt er een transitie plaats van casemanagement met specialisatie dementie naar de generalistische wijkverpleging. Wat in dit onderzoek wordt omschreven als geïntegreerde wijkverpleegkundige zorg. Naast positieve gevolgen, zijn er twijfels over deze transitie en is het onduidelijk hoe personen met dementie en hun mantelzorgers de geïntegreerde wijkverpleegkundige zorg ervaren.

Doel. Inzicht verkrijgen in de ervaringen van personen met dementie en hun mantelzorgers met geïntegreerde wijkverpleegkundige zorg in Nederland.

Methode. Een explorerend multiple-case studie werd uitgevoerd van januari tot en met april 2016. Casussen bestonden uit koppels van thuiswonende personen met dementie (≥ 65 jaar) en hun mantelzorgers, die geïntegreerde wijkverpleegkundige zorg ontvangen in Nederland. Er werden twaalf semi-gestructureerde interviews gehouden met zes koppels. Daarnaast werd data verzameld uit de zorgplannen van de personen met dementie. Analyse van de data werd uitgevoerd met de QUAGOL, within-case en cross-case analyse.

Resultaten. Zes koppels werden geïnterviewd, bestaande uit zeven mantelzorgers en vijf personen met dementie. Gebaseerd op hun ervaringen met geïntegreerde wijkverpleegkundige zorg werden de volgende drie thema's geïdentificeerd: 1) een goede zorgrelatie; 2) communicatie, informatie en besluitvorming; 3) ondersteuning en flexibele zorg. Communicatie, informatie, besluitvorming en ondersteuning komen overeen met casemanagement dementie.

Conclusie en aanbevelingen. De geïnterviewde personen met dementie en mantelzorgers bleken tevreden te zijn met de geïntegreerde wijkverpleegkundige zorg die ze ontvangen. Echter, meer aandacht is nodig voor het thema communicatie, informatie en besluitvorming door wijkverpleegkundigen. Verder is er meer onderzoek nodig om inzicht te krijgen in de ervaringen van wijkverpleegkundigen met het verlenen van geïntegreerde wijkverpleegkundige zorg.

Trefwoorden. Dementie, mantelzorger, casemanagement, multiple-case studie, geïntegreerde wijkverpleegkundige zorg.

Abstract

Rationale. Dementia, a severe and chronic syndrome, affects 270,000 people in the Netherlands. Nearly 70% of these people are community-dwelling and are supported by informal caregivers, external case managers dementia and community nurses. Since 2015 a government policy on chronic care has decentralized specialized case management care to general community nursing care. This enlargement of responsibilities of community nurses is therefore described as integrated community nursing care. Despite positive effects, there are doubts about this decentralization and it is unclear how persons with dementia and their informal caregivers experience integrated community nursing care.

Aim. To gain insight into experiences of community-dwelling persons with dementia and their informal caregivers with integrated community nursing care in the Netherlands.

Methods. An exploratory multiple-case study was conducted from January until April 2016. Cases consisted of dyads of community-dwelling persons (≥ 65 years) with dementia and their informal caregivers, who receive integrated community nursing care in the Netherlands. Data was collected through twelve semi-structured interviews, within six dyads. Documentary data was collected from personal care plans of persons with dementia. Data analysis was performed with the QUAGOL, within-case and cross-case analysis.

Results. Seven informal caregivers and five persons with dementia were interviewed, within six cases. Based on their experiences with integrated community nursing care three themes were identified: a good care relationship; communication, information and decision-making; support and flexible care. Communication, information, decision-making and support were linked to case management dementia.

Conclusion and implications. Persons with dementia and informal caregivers have good experiences with integrated community nursing care. However, more attention from community nurses is needed on the theme of communication, information and decision-making. Furthermore, additional research with community nurses is needed to explore how they experience providing integrated community nursing care.

Key words. Dementia [Mesh], informal caregiver, case study, case management, community nursing care.

Introduction

Dementia is a severe and chronic syndrome, caused by a brain disorder which affects memory, thinking and behavior and the capacity to perform activities of daily living (ADL)^{1,2}. Dementia is usually diagnosed in people ≥ 65 years, except for people with young onset dementia². In the Netherlands, the prevalence of dementia in 2016 was estimated at 270,000³, and nearly 70% of these people lived at home⁴. Dementia has a major impact on affected persons and their families; dementia leads to increased dependence, which results in an increased burden on informal caregivers^{4,5}. Informal caregivers are spouses, other family members or friends who care for the person with dementia (PwD)^{6,7}. This caring role is demanding for informal caregivers, who are vulnerable to becoming overburdened⁶. Therefore, support of professional caregivers is needed. In the last decade most PwDs and informal caregivers in the Netherlands were supported by external case managers specialized in dementia^{4,8-10}.

Case managers support PwDs and their informal caregivers by assessing care needs, coordinating care and by offering informational and emotional support in a collaborative relationship¹¹. The case manager refers to and monitors other healthcare providers and services^{12,13}. MacNeil Vroomen et al. investigated the clinical effectiveness of two often-used case management care models in the Netherlands: 1) the intensive case management model (ICMM), 2) the linkage model. These two models were compared with usual care and a control group without case management^{1,4}. The mental health of the informal caregivers of PwDs was worse in the control group when compared with ICMM. However, results showed no significant difference between the two models and control group and these pragmatic study' results should be interpreted carefully because a non-randomized design was used¹.

Since 2015, the Dutch government policy has changed. The Dutch community nurse has to be a key person in community care¹⁴. This policy aims to allow elderly persons to live longer independently at home, to reduce costs, to minimize the number of healthcare providers and gives the community nurse the ability to provide integrated care within a prolonged and trusted relationship¹⁴⁻¹⁶. The community nurse works in a community care team, which consists of up to twelve professional nurses and nurse assistants¹⁷. Every client has one or two personal community nurses, who visit the client frequently¹⁸. The responsibility of community nurses consists of a wide range of activities: coordinating of care, encouraging the clients' self-management, providing nursing care and prevention¹⁶. As a result of the decentralization, specialized case management in dementia is performed by community nurses^{9,15,16}. Therefore, we described the enhanced responsibility of community nurses as integrated community nursing care.

Due to their enhanced responsibility, community nurses have to meet the needs of PwDs and informal caregivers. The needs of PwDs relate to information, communication, collaboration, adaptation to their care needs¹⁹ and psychological distress²⁰. Afram et al. described the needs of informal caregivers in the domains of 'emotional concerns', 'information and knowledge' and 'support'²¹. However, this systematic review of qualitative studies on the needs of informal caregivers of PwDs during a care-transition period did not describe certain needs clearly; for example, 'support' was not explained through statements²¹.

It is unclear if, in this new position, the community nurse meets the needs of PwDs and informal caregivers. So far, no evidence is available. Therefore, insight into the experiences of PwDs and their informal caregivers with integrated community nursing care is needed to determine if the community nurse is able to fulfil the needs of PwDs and their informal caregivers.

Aim

The aim of this study is to gain insight into the experiences of community-dwelling persons with dementia and their informal caregivers with integrated community nursing care in the Netherlands.

Method

Design

This qualitative research was an exploratory multiple-case study. Cases consisted of dyads of community-dwelling PwDs and their informal caregivers, who receive integrated community nursing care. Multiple-case designs are suitable for in-depth investigation of cases within their current real-life context²². Therefore, the choice of multiple-case design gave strength and certainty to the conclusions and increased external validity²². Exploratory design was chosen because this was the first study with integrated community nursing care. The study was executed in the community care setting in the Netherlands, from January until April 2016. Transparent reporting of this study was performed by using the consolidated criteria for reporting qualitative studies (COREQ)²³.

Participants

This study was conducted with twelve participants. Sample size was determined by data saturation, which is reached during analysis when no new information is acquired²⁴. Literature showed that saturation was reached between twelve and seventeen interviews^{25,26}. Creswell mentioned that four or five cases within a single study are sufficient to identify

themes and perform a cross-case synthesis²⁷. Therefore, a sample size of twelve participants within six cases was sufficient for conducting this study.

Purposeful sampling was performed. People were included if they could give rich and detailed information about their experiences with integrated community nursing care²⁸. The maximum variation of sampling ensures variation in perspectives²⁷. Variation was sought in the duration and intensity of integrated community nursing care, the work experience of the personal community nurses, the gender of the PwD, the relationship between the persons of a dyad, in dyads who live in different regions in the Netherlands and in the age of the personal community nurses.

PwDs were included in the study if they met all the following inclusion criteria: 1) were community-dwelling; 2) had a diagnosis of dementia; 3) were ≥ 65 years; 4) received community nursing care for at least a half year; 5) had a personal community nurse with a bachelor's-level degree, which is in line with the governmental policy of decentralization in chronic care^{9,15}; 6) were able to understand and sign informed consent; and 7) speak and understand Dutch. Informal caregivers of PwDs were included if they were a spouse, son or daughter and sufficiently involved in the care for PwD. Participants were excluded when they were terminally ill or experienced care provided by an external case manager.

Participants were recruited by the researcher (CR) of one large community care organization. Recruitment was performed by e-mail contact with the dementia network of this organization, telephone contact with teams and posting messages on the digital community page. Community nurses of the teams asked eligible persons to participate and, if they were willing, they received an information letter and informed consent form. Appointments were made in consultation with the personal community nurse or by telephone with the informal caregiver.

Data collection

Semi-structured interviews were conducted at the participants' home and individually with each participant, because both PwD and informal caregiver had different interests. Interviews were guided by a topic list (Appendix A), in order to enhance the reliability of the study. The topics included were general experiences with community nurses and experiences with community nursing process¹⁵, communication¹⁹, information, support and counseling, coordination of care provided by others, provision of practical help²⁹, relationship with the professional caregiver and the postponing of nursing home admission³⁰. These topics were based on case management of dementia, community nursing care and needs of PwDs and informal caregivers. Moreover, participants had the opportunity to discuss their own experiences with integrated community nursing care. Documentary information was collected from the PwDs' personal care plan. Background information was obtained for each case

consisting of age of participants, marital status, duration and intensity of community nursing care, diagnosis of dementia, and age and training of the personal community nurse on case management of dementia. The first case was a pilot case, which resulted in small refinements to the interview guide.

Data analysis

Analysis of the experiences with integrated community nursing care was performed by the researcher (CR) by using qualitative data analysis software Nvivo 11 and a modified version of the Qualitative Analysis Guide of Leuven (QUAGOL)³¹. The interviews were audio-taped, transcribed verbatim in an active process and data was read and reread thoroughly, in order to become familiar with it. Text fragments relevant to the experiences with integrated community nursing care were marked and codes were created. The PwDs' personal care plans were also read and the codes created for the interviews were used. Codes in relation to integrated community nursing care were compared in a within-case analysis²². Cross-case synthesis was performed by comparing the data of all cases²². Based on the conclusions of these analyses, concepts were formulated which emerged from clustering the codes. Subsequently, these concepts were merged into themes which described the essential meaning of achieving the aim of this study³¹.

During analysis, memos were written which assisted critical thinking²⁷. Investigator triangulation was performed by encoding the first two interviews independently with two researchers (CR, MV). The created codes were discussed and agreement was reached by consensus. Bracketing was performed to reflect on the investigator's experiences²⁷, because the investigator's (CR) profession corresponds with the study setting. Peer review was conducted to do justice to participants' experiences in meetings with master students and supervisors, where procedures and analyses were discussed.

Ethical considerations

This study was conducted according to the principles of the Declaration of Helsinki³². A declaration of non-being subject to the Medical Research Involving Human Subjects Act was obtained from the Medical Research Ethics Committee of the Isala Clinics in Zwolle, The Netherlands (16.0107/1). All participants gave written informed consent for their participation in this study, in advance. All informal caregivers also allowed the PwDs' study participation.

Results

Participants

Interviews were conducted with seven informal caregivers and five PwDs, within six cases. PwDs had received community nursing care for between one and six (mean 3.5) year(s).

PwDs were visited by the community care team variously between one and five time(s) a day. The ages of personal community nurses varied between 26-54 (mean 43) years old. Participants were recruited from several regions of the Netherlands. Participant characteristics and results of the within-case analysis are shown in Table 1. Variation of participant characteristics was found between the cases in the relationship between PwD and informal caregiver, in the ages of personal community nurses and participants who were living in different regions, which contributed to the diversity of the participant experiences with integrated community nursing care. Data saturation was not reached because in the last case new information was obtained.

<Insert Table 1>

In two cases, the PwDs were not able to be interviewed due to the progress of their dementia syndrome. Therefore, the two involved informal caregivers of these cases were merged into one case. Furthermore, the characteristics of these informal caregivers correspond with each other (Table 1). Six other cases were invited, but were non-participating because: they did not agree to participate (two cases), the PwD was admitted to a nursing home (two cases), an unstable emotional situation of the PwD (one case) or the PwD was unable to be interviewed (one case) and it was not possible to combine this case with another.

Findings interviews

Interviews took between 20-45 (mean 30) minutes with PwDs, and between 35-75 (mean 55) minutes with informal caregivers. After performing QUAGOL and cross-case synthesis, the following themes, in relation to integrated community nursing care, were found: 1) a good care relationship; 2) communication, information and decision-making; 3) support and flexible care. Overall, participants stated that they had good experiences with integrated community nursing care. Interviews with informal caregivers provided more detailed and meaningful experiences, in comparison to the interviews with PwDs. Therefore, the experiences of informal caregivers provided a larger contribution to the themes. The code tree is shown in Table 2. Themes are described below and related quotes are shown in Table 3.

<Insert Table 2>

<Insert Table 3>

A good care relationship. The relationship between the participants and community care team was considered to be sympathetic and attentive, and consisted of the concepts contact and trust.

Contact. All PwDs and informal caregivers experienced personal contact with the personal community nurse. They experienced the community care team as friendly, open

and sociable. Participants stated that PwDs were approached with respect. Due to their dementia syndrome, PwDs can frequently ask the same questions; they stated the community care team deals with this in a good way (Quote 1, 2). However, some PwDs experienced varied contact with team members; one PwD said he had a better relationship with some team members than with others and he felt free to tell things to them, and another PwD remembered faces of team members better than names (Quote 3).

Trust. Most participants experienced the community care team as trustworthy. They work with small groups of between six and thirteen team members, often visit the PwD for years, they know each other well and the community nurses know where to find everything in the house (Quote 4). Another participant experienced a close relationship with the team members because of their interest in each other.

Communication, information and decision-making. This theme is especially focused on the informal caregivers, who receive help from the personal community nurse in providing care to the PwD. This included the concepts dialogue, and knowledge and experience.

Dialogue. In some cases, informal caregivers stated that they were kept informed by telephone or email about the PwDs' situation which they experienced as very pleasant (Quote 5). Furthermore, some informal caregivers regularly had conversations with personal community nurses. Conversation topics were introduced by both informal caregivers and personal community nurses, and practical problems were discussed (Quote 6). The safety and future of the PwD was discussed, and the provided care was evaluated. PwDs were often not involved in these conversations (Quote 7). In other cases, evaluation of care was carried out during care and not in conversations. However, suggestions and ideas introduced by the community care team were discussed and informal caregivers had time to think about them. Participants said they were satisfied with this way of evaluating care (Quote 8). Some informal caregivers stated that they provided care to the PwD in collaboration with the community care team (Quote 9). In one case, both participants stated that they never talked about the future with the community care team, for example what to do if it were no longer possible to live at home, and the informal caregiver was worried about this.

Knowledge and experience. Participants stated that the community care team knows where to get help and they think along with you. They know addresses in the neighborhood, for example for the hairdresser or meal services. One informal caregiver said the personal community nurse knows everybody, thereby referring to the pharmacist and the general practitioner (GP). Other informal caregivers stated that the community nurses come up with ideas (Quote 10). Furthermore, informal caregivers said the personal community nurses have an expert role in the field of dementia. They can discuss practical problems caused by dementia, and they give advice on how to deal with it (Quote 11, 12).

Support and flexible care. This theme consisted of counseling of informal caregivers, being available for the involved participants and providing primary care to the PwD by the community nursing team. This included the concepts attention and presence, and adaptation of care to needs and wishes.

Attention and presence. Participants experienced support as the quality of 'being there' of the team members. Participants said the personal community nurse is always accessible for questions. Participants could discuss anything and team members were empathetic, for example when the nights with the PwD are difficult. They are also willing to take anything with them, and they offer help when needed (Quote 13). Furthermore, informal caregivers stated that the personal community nurse pays attention to them. An informal caregiver experienced the personal community nurse as her informal caregiver, and in another case, team members stayed with the PwD, so that the informal caregiver could do some necessary shopping (Quote 14).

Adaptation of care to needs and wishes. Participants talked about what the community care organization will primarily do. They help with ADL, intake of medication, giving injections, and checking the body weight. Almost all informal caregivers stated that they found it important that team members notice changes in the PwDs' health and well-being (Quote 15). This primary care was adapted to the needs and wishes of the dyad. In two cases, the informal caregivers, both spouses of the PwD, experienced privacy as important. Therefore, it was agreed with the community care team that no help was needed at the weekend. In other cases, more help was provided when needed (Quote 16). One informal caregiver stated that care for the PwD was slowly increased, as the PwD needed more help. However, one informal caregiver experienced that the community care team could not do everything, and had limited roles as a result of rules established by the government. Therefore, the informal caregiver experienced caring for her mother as burdensome. She stated that she would like for the personal community nurse to arranged a volunteer for her mother and bring urine to the GP when needed (Quote 17).

Findings personal care plans

Most of the interventions in the personal care plans described the primary care provided by the community care team. This corresponded with the concept adaptation of care to needs and wishes. In nearly all personal care plans, interventions were found to approach the PwD, which was related to the theme of a good care relationship. In some personal care plans, interventions were focused on the attention of informal caregivers, dialogue, knowledge and experience. These concepts were related to case management of dementia. Two personal community nurses followed training in case management of dementia (Table 2). However, it

cannot be stated that trained community nurses paid more attention to concepts related to case management of dementia.

Discussion

The aim of this study is to gain insight into the experiences of the participants with integrated community nursing care. All PwDs and informal caregivers had good experiences with integrated community nursing care. Based on the experiences of twelve participants within six cases, consisting of seven informal caregivers and five PwDs, the following themes were found to be meaningful: 1) a good care relationship; 2) communication, information and decision-making; and 3) support and flexible care.

A good care relationship between the participants and community nursing team consisted of personal contact and trust. Karlsson et al. described a trusted relationship between the professional, and the PwD and informal caregiver. They stated that within this relationship a dyadic approach is needed, because the informal caregiver will increasingly take care of the PwD when the process of dementia syndrome advances¹⁹. In comparison with our study results, a dyadic approach to the PwD and informal caregiver by the personal community nurse is confirmed. Moreover, informal caregivers, who were not living with the PwD, also experienced good and regular contact.

The theme communication, information and decision-making is related to case management tasks^{13,29}. Verkade et al. described providing information as the most important component of case management of dementia²⁹. Furthermore, having time to think about ideas and solutions to problems in care is also in line with the literature of case management³³. However, few interventions in the personal care plans were focused on this part of case management. Also conversations about the care for PwDs did not always take place. Therefore, community nurses have to pay more attention to interventions related to communication, information and decision-making.

The concept attention and presence, part of the theme support and flexible care, is identified as being a case management task²⁹. In literature, support was described as emotional support and counseling of informal caregivers, and being present for the involved persons²⁹, which is in line with the found results. Furthermore flexible care, which consists of primary care adapted to the needs and wishes of the PwD and informal caregivers, is provided most by community nurses. This is confirmed by the interventions in the personal care plans of the PwDs.

In literature, the coordination of care provided by others is also a main component of case management of dementia²⁹. However, coordination of care was not an emerging theme of the participant experiences in this study. A reason for this could be that participants are not

familiar with this community care component. Therefore, based on the participants' experiences it is unclear how community nurses deal with coordination of care.

Interviews with informal caregivers provided more detailed and meaningful experiences in comparison with the PwDs' interviews. This can be explained by the fact that PwDs are often not involved in all the care provided by the community care team, for example, the conversations between informal caregivers and personal community nurses. Another reason is that it was challenging to interview PwDs. They are easily diverted from the conversation subject, are living in the moment, and quickly forget what is being discussed.

A strength of this study is the rigor data collection and analysis, which enhanced the credibility of the study results. This was performed by data triangulation using interviews and personal care plans, and investigator triangulation by analyzing a selection of the interviews with two investigators. Another strength is the variation between the cases: variation was found in the relationships between PwDs and informal caregivers, in the ages of personal community nurses, and participants living in different regions. This enhances the generalizability of the study' results²⁸. A limitation of this study is that data saturation was not fully achieved because new information was obtained in the last case. This may be explained by the difficulty of obtaining rich data in the interviews with PwDs, which has implications for the reliability of the data. Another limitation is that the study setting corresponds to the investigators' (CR) profession, which could have resulted in bias in conducting this study. However, bracketing was performed by the investigator (CR) and study procedures and analyses are regularly discussed with other master's students and the supervisor (CS).

In clinical practice, more attention from community nurses is needed for conversations, because these are often performed during the care and not in conversations. Furthermore, more attention can be paid to themes related to case management of dementia. However, further research is needed to confirm the results found and to explore how community nurses deal with other components of case management, including coordination of care. The same study could be conducted with a larger group of participants and with community nurses.

In conclusion it can be stated that, to our knowledge, this is the first investigation into integrated community nursing care. In this study, a good care relationship; communication, information and decision-making; support and flexible care were found to be themes of integrated community nursing care. Participants had good experiences with integrated community nursing care. However, community nurses should pay more attention to communication, information and decision-making. The findings of this study, on integrated community nursing care provided by community nurses, may be useful in the discussion in the Netherlands about providing case management by community nurses or external case managers specialized in dementia.

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Table 1. Participant characteristics

Case number	Gender	Age	Diagnosis of dementia of PwD	Year of diagnosis	Marital status	Relation of informal caregiver	Personal community nurse followed a training case management of dementia (Yes/No)	Main topic(s) within cases based on within-case analysis
1 PwD IC	Women	88 88	Alzheimer	2010	Married	Husband	No	<ul style="list-style-type: none"> • Support of daughters
2 PwD IC	Women	91 66	Alzheimer	2014	Widow	Son	No	<ul style="list-style-type: none"> • Living together • IC overburden
3 PwD IC	Man	85 83	Alzheimer	unknown	Married	Wife	No	<ul style="list-style-type: none"> • Support of neighbors • Having dementia was no topic during interviews
4*PwD IC 1 PwD IC 2	Man Women Man Women	89 83 85 85	Vascular dementia Vascular dementia	2013 2010	Married Married	Wife Wife	Yes No	<ul style="list-style-type: none"> • Support of children • IC overburden • Be used to the community care for PwD
5 PwD IC	Women	83 51	Alzheimer	2010	Widow	Daughter	No	<ul style="list-style-type: none"> • PwD experienced loneliness
6 PwD IC	Women	81 41	Alzheimer	2010	Widow	Daughter	Yes	<ul style="list-style-type: none"> • Inadequate care as result of government policy

PwD = person with dementia; IC = informal caregiver

*In case 4 only the two informal caregivers were interviewed.

Table 2. Code tree

Themes	Concepts	Codes
A good care relationship	Contact	Personal contact
		Approached with respect
		Varied contact with team members
	Trust	Community care team consist of small groups
		Community care team is trustworthy
Communication, information and decision-making	Dialogue	Caring together for the PwD
		To be kept informed
	Knowledge and experience	Community nursing team know where to get help and think along with you
		Team members are experts on dementia
Support and flexible care	Attention and presence	Attention for informal caregivers
		Being there
	Adaptation of care to needs and wishes	Receiving community nursing care you need
		Varied adaptation of nursing care to wishes

Table 3. Quotes of the participants

Quote number	Quotes	Related codes
1	They still find you valuable, which I find enjoyable. (Case 1, PwD)	Approached with respect
2	And we often make a joke about my husband, because he is somewhat stubborn. He remains a teacher. When they measure the glucose, he says, for example: 8.5, did you write it down? (...) He asks that all the time. (...) And then they also laugh themselves. (Case 3, informal caregiver)	Approached with respect
3	Look, every day there is someone else, I cannot remember that anymore. (...) They think I know them, but I know their faces. But all names, no I cannot remember it. (Case 5, PwD)	Varied contact with team members
4	It is a small group, everyone knows us and I know the persons by name. (...) This feels more trustworthy. (Case 4, informal caregiver 1)	Community care team is trustworthy
5	If something happened, then they call me. (Case 6, informal caregiver)	To be kept informed
6	We regularly have conversations at their office, with the two personal community nurses. (...) And then they have an agenda with items that we discuss, about hygiene, nutrition, health and self-reliance. And yes, these conversations are actually meant for us to ask questions and to share our experiences and they can also ask their questions. Every time they make a report, which they also send to us. (Case 5, informal caregiver)	Caring together for the PwD
7	Those conversations are without my mother. In the beginning we talked about it, but yes, the nature of the talks, say, I think it could make my mother unhappy. (...) But I do say, I think that the conversation would take three times longer and that we could not openly discuss certain things. No, I think it's good that we have these conversations without my mother. (Case 5, informal caregiver)	Caring together for the PwD
8	Well, no, they actually never ask it. Apparently they think it goes well. (...) But more so, it goes well. Yes. (Case 3, PwD)	Caring together for the PwD
9	We have been busy for a while, so he is diabetic, he had quite a lot of pills and he switched to injections, insulin. (...) All those things together, so that was a whole process and we did it together. (Case 4, informal caregiver 1)	Caring together for the PwD
10	And also the fact of thinking along with you, about a welfare organization for example. (...) Because in the last conversation, I indeed mentioned that my mother indicated that she felt lonely. That she was sorry that she just did not have so many friends. (...) So the fact that they think along with you, come up with ideas and that we can undertake action ourselves, yes very good. (Case 5, informal caregiver)	Community nursing team know where to get help and think along with you

11	<p>We are very happy with this community care team, they are just experts to us. And of course they have more demented patients, they go there and see how such a process goes. And, once again, we are laymen. So for us it's just great that we can discuss: is it going well? Can she still live on her own or not? What do you think?</p> <p>(Case 5, informal caregiver)</p>	Team members are experts on dementia
12	<p>We asked about sleeping in the afternoon of my mother. She says (the personal community nurse), look on the Internet for a lazy boy chair, where you can sleep on. The personal community nurse says I'm not really happy that people go to bed in the afternoon. That is not an issue now, but of course there comes a time when, (...) she changes her day and night rhythm. (...) That was also a very good idea of her. So now we are looking for a lazy boy chair.</p> <p>(Case 6, informal caregiver)</p>	Team members are experts on dementia
13	<p>They help you, give advice and sometimes they bring something with them. If you need something, oh we will bring it along for you next time. Especially the personal community nurse is a sweetheart though.</p> <p>(Case 2, PwD)</p>	Being there
14	<p>Sometimes I go to the store in the afternoon, when my husband is in bed. Then the community nurse says (...) we know about it, we are close and we stay here with your husband (...) just as long as necessary.</p> <p>(Case 4, informal caregiver 2)</p>	Attention of informal caregivers
15	<p>And that is this community care organization: (...) they notice everything, if there is a small wound ... he is also diabetic. (...) So that all is very important. They are very alert. And that is very nice.</p> <p>(Case 4, informal caregiver 1)</p>	Receiving community nursing care you need
16	<p>They come with a frequency of once a day, but if they see it does not go well with my mother, (...) they come an extra time.</p> <p>(Case 5, informal caregiver)</p>	Receiving community nursing care you need
17	<p>For example my sister had asked: collect urine of my mother. If they could bring it to the GP, but they are not allowed to do such things. (...) They are only allowed to do particular tasks.</p> <p>(Case 6, informal caregiver)</p>	Varied adaptation of nursing care to wishes

Appendix A Interview guide

Interview guide PwD

Main question: You receive community nursing care. How do you experience that?	
Topics	Mogelijk vragen te stellen aan deelnemers
Community nursing process	Kunt u vertellen hoe het in zijn werk gaat als uw wijkverpleegkundige komt?
Trusting relationship	<ul style="list-style-type: none"> • Hoe ervaart u de band met de wijkverpleegkundige/het team? • Hoe ervaart u de begeleiding door de wijkverpleegkundigen?
Information and knowledge	<ul style="list-style-type: none"> • Hoe gaat het met maken van afspraken? Hoe is dat voor u? • Heeft u de afgelopen tijd meer kennis gekregen over dementie en de gevolgen, voorzieningen etc.? Zo ja, welke rol speelt uw wijkverpleegkundig daarin?
Support and counseling Psychological distress	<ul style="list-style-type: none"> • Kunt u iets vertellen over hoe u de begeleiding van uw wijkverpleegkundige (evvers) ervaart? Hoe is dat voor u?
Coordination and monitoring of care provided by others	<ul style="list-style-type: none"> • Hoe sluit de ondersteuning van bijv. huisarts, specialist, dagbesteding op elkaar aan en wat vindt u daarvan? • Vraagt de zuster wel eens hoe u het vindt gaan met de zorg?
To postpone an nursing home admission	<ul style="list-style-type: none"> • Hoe ziet u de toekomst voor zich? • Hoe staat u tegenover een verhuizing naar een verpleeghuis ? Bespreekt u dat met uw wijkverpleegkundige (evver) en hoe is dat voor u?
Providing of practical help and ADL	<ul style="list-style-type: none"> • U krijgt hulp bij wassen en aankleden etc. Kunt u daar wat mee over vertellen en hoe is dat voor u?
Afsluiting: Heeft u nog vragen? Zijn er dingen die u graag nog wilt bespreken?	

Interview guide informal caregiver

Main question: Your partner/parent receives community nursing care. How do you experience that?	
Community nursing process	Main question
Support and counseling Emotional concerns	<ul style="list-style-type: none"> • Kunt u iets vertellen over hoe u de begeleiding van uw wijkverpleegkundige (evvers) ervaart? Waar bestaat het uit? • Hoe is het voor u om de zorg te hebben voor uw partner/ouder? • Ziet u zich als mantelzorger? • Hoe is het voor u om samen met de wijkverpleegkundige voor uw partner/ouder te zorgen? • Wat gaat daarbij goed en wat kan beter? • Het is bekend dat er soms ook spanningen kunnen zijn tussen wat de wijkverpleegkundige wil en wat u wilt. Hoe ervaart u dat?
Information and knowledge	<ul style="list-style-type: none"> • Hoe gaat het met maken van afspraken? Hoe is dat voor u? • Heeft u de afgelopen tijd meer kennis gekregen over dementie en de gevolgen? Zo ja, welke rol speelt uw wijkverpleegkundig daarin? • Hoe ervaart u de timing en het tempo waarmee uw wijkvpk zaken met u en uw naaste aan de orde stelt? Is dit te snel of te langzaam?
To postpone a nursing home admission	<ul style="list-style-type: none"> • Hoe ziet u de toekomst als mantelzorger voor zich? • Hoe staat u tegenover een verhuizing naar een verpleeghuis? Bespreekt u dat met uw wijkverpleegkundige (evver) en hoe is dat voor u?
Coordination and monitoring of care provided by others	<ul style="list-style-type: none"> • Hoe sluit de ondersteuning van bijv. huisarts, specialist, dagbesteding op elkaar aan en hoe is dat voor u? • Kunt u iets vertellen over hoe u hierbij wordt betrokken? Hoe ervaart u dat?
Communication Relationship Community nursing process	<ul style="list-style-type: none"> • Hoe ervaart u de begeleiding door de wijkverpleegkundigen? • Wordt er tijd en ruimte genomen voor evaluatie van de zorg? Hoe ervaart u dat?
Afsluiting: Heeft u nog vragen? Zijn er dingen die u graag nog wilt bespreken?	