Care assessment process of dementia clients by community nurses

A qualitative study

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Nederlandse samenvatting

Achtergrond: Cliënten met dementie hebben een intensieve zorgvraag. Deze zorg wordt meestal geleverd door mantelzorgers met ondersteuning van professionals. De groeiende populatie ouderen was reden voor een wijziging in het beleid rondom zorgverlening en dat heeft geleid tot een transitie in zorg in Januari 2015. Gespecialiseerde dementie zorg wordt sinds Januari 2015 geleverd door wijkverpleegkundigen en wijkverpleegkundigen indiceren sindsdien het gehele zorgproces. Recent onderzoek heeft aangetoond dat sinds deze overgang, er sprake is van een daling van het aantal indicaties voor gespecialiseerde dementie zorg.

Doel: Het doel van deze studie is enerzijds om te beschrijven hoe wijkverpleegkundigen de zorg bij mensen met dementie indiceren in de thuiszorg en anderzijds om te onderzoeken hoe wijkverpleegkundigen het indiceren van mensen met dementie in de thuiszorg ervaren.

Methode: In deze studie is een kwalitatief onderzoeksdesign gebruikt. De populatie bestond uit vijftien wijkverpleegkundigen werkzaam in de thuiszorg in Nederland. Dataverzameling en data-analyse zijn uitgevoerd tussen Januari 2016 en April 2016. Dataverzameling bestond uit observaties en semigestructureerde interviews met wijkverpleegkundigen. Observaties en interviews zijn geanalyseerd met behulp van de QUAGOL methode.

Resultaten: Tijdens de analyse werden vijf hoofdthema's ontdekt; zorgbehoefte, proces van dementie en symptomen, wijkverpleegkundigen en gespecialiseerde dementie zorg, gestructureerde lijst en scholing.

Conclusie: Verschillende classificatiemethoden die door wijkverpleegkundigen worden gebruikt om de zorg te indiceren zijn uitsluitend gericht op de beperkingen in dagelijkse activiteiten van cliënten. Verder hebben wijkverpleegkundigen niet de kennis en de tools om het hele spectrum van zorgbehoeften van cliënten met dementie te indiceren.

Aanbevelingen: Verder onderzoek is nodig om een instrument met een bredere scope te ontwikkelen voor de indicatiestelling bij mensen met dementie. Wijkverpleegkundigen zouden geschoold moeten worden om ze in staat te stellen om gespecialiseerde dementie zorg te indiceren.

Sleutelwoorden: wijkverpleegkundigen, dementie, indicatiestelling, thuiszorg

Abstract

Background: People with dementia require a high level of care and this care is mostly provided by informal caregivers with support from professionals. The growing population of elderly people was reason for a policy change that has led to a transition in care since January 2015. Specialized dementia care is now performed by community nurses and community nurses also assess care for clients with dementia since January 2015. Recent research shows that since the transition took place, there has been a decrease in assessments and prescriptions in specialized dementia care.

Aim: The purpose of this study is to describe how community nurses shape the care assessment process for dementia clients in primary care and to identify the experience of community nurses with care assessments for dementia clients in primary care.

Methods: A qualitative approach was chosen. The research sample consists of fifteen community nurses working in primary care in the Netherlands. Data collection and analysis were carried out between January 2016 and April 2016. Data collection consists of observations and interviews with community nurses. Observations and interviews were analysed using the QUAGOL method.

Results: In the analysis, five main topics were discovered; care needs, dementia process and symptoms, community nurses and specialized dementia care, structured list and education.

Conclusion: Classification methods used by community nurses are only focussed on activities of daily living. Community nurses do not have the knowledge and tools to assess the full spectrum of care needs of clients with dementia.

Recommendations: Research is needed to develop a dementia tool for care assessments, which embodies the full spectrum of dementia care. Community nurses need education to be able to assess specialized dementia care.

Keywords: Community nurses, dementia, care assessment, primary care

Introduction and rationale

In the Netherlands, 260.000 people are diagnosed with dementia and 70 percent of these people live at home[1]. An increasing client population in homecare consists of people with dementia[1,2] who encounter diverse functional, cognitive, behavioral and psychological problems[3-9]. Dementia is the leading cause of disability and dependency in elderly people[10,11], which results in stigmatization, barriers to diagnoses and care, and impacts informal caregivers mentally and physically[11,12]. People with dementia require a high level of care and this care is mostly provided by informal caregivers with the support of professionals[10,13]. Informal caregivers are very important in dementia care because they provide guidance and support[14-16]. The care of a dementia patient can be a heavy load for informal caregivers and often affects their own well-being. Informal care givers cannot always provide 24-hour care, thus support of home care professionals is essential to provide adequate care for people with dementia. To support this care, professional guidance of case managers in dementia helps to decrease the burden on informal caregivers[16,17].

The growing population of elderly people was cause for a policy change that has led to a transition in care since January 2015. Specialized dementia care performed by case managers is no longer included in dementia care since then[18]. Case managers in dementia are counselors for clients with dementia who live at home and focus on coordinating the entire process of dementia care[17,18]. Specialized dementia care focuses on diagnostics, coordination, treatment and guidance of the client and care provider, emotional support and crisis intervention[19]. It is a continuous process in which the informal caregiver is supported and the quality of care is ensured[17]. Although evidence is weak, the use of case managers in dementia is described as a key component in dementia care[18]. The use of case managers in dementia care enables people suffering from dementia to live at home independently for a longer period of time[16-18,20,21]. However, tasks of case managers in dementia are now performed by general community nurses[18,22,23].

The Dutch government has also changed its policy regarding care assessment in primary care in recent years. Due to this transition, community nurses have been assigned to assess the care needs of clients and this was expected to result in tailored care for clients suffering from dementia[22,24]. The process of care assessment consists of anamnesis, diagnosis, planning of interventions, implementation and evaluation of care[25]. However, in the process of care assessment in dementia care it is not only the treatment of the client that is important. Coordination as well as emotional support and crisis intervention have to be considered.

Additionally, recent research shows that since the transition took place, there has been a decrease in assessments and prescriptions in specialized dementia care[22,26]. In care assessments, community nurses are guided by classification methods such as OMAHA, NIC, NOC and NANDA[(24)]. Each of these methods has its own characteristics and focus on different aspects (e.g. outcomes or interventions) of care assessments. Recent research shows that community nurses focus on direct care needs (bathing, dressing and medication intake) of clients during care assessments[3,5]. Components of specialized dementia care such as coordination and emotional support are often not considered. It is unknown whether and to what extent this is caused by the aforementioned classification methods.

A trend is noticed, in which there is a reduction of support in dementia care[18]. This may have negative consequences for the quality of life of clients and the duration of participation in the community. Although it is unclear what causes this decline, the assessment and decision-making processes of community nurses may have an influence[18,27]. The purpose of this study is to describe how community nurses shape the care assessment process for dementia clients in primary care and to identify the experience of community nurses with care assessments for dementia clients in primary care.

Primary research question:
How do community nurses shape the care assessment process for dementia clients in primary care?

Secondary research question:

How do community nurses experience care assessments for clients with dementia in primary care?

Method

Design

To explore the role of nurses during the process of assessments in dementia care, a generic qualitative study was conducted[28,29]. A qualitative design was chosen to draw conclusions based on experiences reported by community nurses and their opinions, without being inhibited by external influences, to ascertain a detailed understanding of care assessments[29] of clients suffering from dementia. The guidelines for reporting qualitative studies established by the Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed[30].

Participants

The population of interest consisted of community nurses working with dementia clients in primary care in the Netherlands. The study was conducted between January 2016 and July 2016. Purposeful sampling was used during this study to ensure a broad variety of participants. The study sample should consist of community nurses working in the Netherlands who were eligible for inclusion and had the willingness to participate in the study. Eligibility for inclusion required that nurses were able to communicate in Dutch, community nurses had to carry out dementia care, assess clients with dementia and have had experience with assessments. Community nurses were contacted in seven different organizations by e-mail or via social media. Eligible community nurses were provided information about the study by e-mail and an informed consent. Community nurses who participated in this study gave consent. Clients only participated in this study during care assessment, performed by community nurses. Clients with dementia were chosen by the participating community nurses. Clients and informal caregiver also gave consent to observe the care assessment.

Data collection

Data was collected from observations of community nurses during the assessment of clients with dementia and from semi-structured interviews with community nurses. When all of the observations were conducted, some additional community nurses were interviewed. To structure the observations and interviews and increase internal reliability[29], an observation form and topic list were used. These were based on literature and experiences from community nurses with care assessments and dementia care. The main topics within observations were: introduction, dementia process, informal caregivers and timing of

professional guidance[19,22-26] (table 1). The main topics within the topic list were care assessment, specialized dementia care and facilities and barriers[19,23-25] (table 2).

Observations

To see how community nurses work and to see the interaction between community nurses and clients with dementia, data was collected from observations[29]. The observations took place at the residences of clients with dementia. All observations were audio recorded and memos were made from the interaction and non-verbal communication between community nurse and client with dementia[28,29]. To prevent errors in interpretation, bracketing was applied[31,32]. Data saturation was assumed after ten observations, because no new themes were mentioned after the sixth observation[31].

Interviews

The interviews were used to explore the perspectives of community nurses regarding care assessments of clients with dementia[29]. All questions were open ended, so community nurses were not directed towards a certain response[31]. The interviews were taken in a room by choice of the community nurse to create a comfortable setting[29]. The interviews were audio recorded. Similar to the observations, bracketing was applied[31,32]. Data saturation was assumed after five interviews, because no new themes were mentioned after the fourth interview[31].

Analysis

For the analysis of data, the analytical process of a modified version of the Qualitative Analysis Guide of Leuven[33] (QUAGOL) was used. This version combines the original QUAGOL with the spiral of analysis as described by Boeije[29], which results in a clear and structured model for data analysis. The systematic procedure consists of ten phases which are presented in table 3**.** All data were analysed using computer assisted qualitative data analysis (CAQDAS) software: NVivo version 11. Three interviews and three observations were coded by two researches separately (MV,CR). Based on this analysis, no modifications were applied to the observation form or interview guide.

All observations were analysed before interviews were conducted. Further interviews and observations were coded by one researcher (MV). Themes within the interviews were discussed between the researchers (MV,CR) to reach consensus about the contents of themes and interpretations[29]. During data collection observational memos were made to describe notable events during observations. During data analysis observational, theoretical

and reflective memos provided insight in the process of reflexivity of the investigator[29,32]. Memos were made to increase theoretical thinking and to increase the quality of the study[29,32].

Ethical considerations

The research proposal was presented to the Medical Ethics Committee (METC) of Isala in Zwolle, which declared that this research was not part of the Medical Research Involving Human Subjects Act (WMO)[34]. This study was conducted according to the principles of the Declaration of Helsinki[35]. Clients with dementia and/or informal caregiver gave written informed consent before they participated in the study because clients with dementia are vulnerable clients.

Results

Participants

In total, 24 community nurses from seven different organizations were invited to participate. Fifteen community nurses from five different organizations were included. The other nine community nurses refused to participate. Reasons for community nurses to decline participation were lack of time and the fear to violate the trust between community nurse and clients. Duration of observations ranged from 38 minutes to 71 minutes with a mean duration of 58 minutes. Duration of the interviews ranged from 21 to 36 minutes with a mean duration of 27 minutes. Community nurse characteristics are presented in table 4.

**table 4*

Assessment procedures

In this study all community nurses worked with either the NANDA or the OMAHA classification method. In both classification methods, there is no specific focus on dementia care. In three out of ten observations, the community nurse indicated specialized dementia care for dementia for the client. In all other cases, community nurses did not focus on specialized dementia care during care assessments.

Findings

Results of observations and interviews are presented separately. During observations, the following themes emerged from the data: care needs and the dementia process and symptoms. These themes provide insight in the shape of care assessments performed by community nurses. During interviews, the following themes emerged from the data: a

structured list, specialized dementia care and community nurses and education. These themes provide insight in the experiences from community nurses in care assessments.

Findings observations

Care needs

Community nurses were focussed on the care needs of the clients. Their primary focus was on personal care and the use of medication. Community nurses continuously considered what clients could do themselves, what the role of the informal caregiver was and which type of care was needed.

''What can you do on your own when it comes to bathing and dressing'' (CN 1)
''What type of support do you get from your daughter'' (CN 3)
''Besides the support from your daughter and sons, what care do you need from community nurses'' (CN 7)
'*'What do you expect from healthcare'' (CN 8)*
''Why are we not allowed to help you'' (CN 10)

The care needs of the client were a substantial part of the intake. Questions from community nurses were mainly about care needs and especially about bathing, dressing and medication. Community nurses asked the client which care was needed and form their own opinion about those care needs. If informal care givers were present, they were involved and consulted in the assessment. Community nurses payed attention to body language, such as the way clients walked, their behavior, their personality and the nature of contact with informal caregivers.

The dementia process and symptoms

During the assessment, the focus was primarily on activities that clients could no longer do themselves due to their condition. Most community nurses asked about the diagnosis, forgetfulness and housekeeping activities. Also, they seemed to reflect on the client's behaviour. Attitude and the ability to cope with the process of dementia were part of the final assessment. Although this information was not directly gathered by questions, these indirect observations often provided insight in the stage of dementia the client was in.

'' You indicate that you sometimes forget things and that you have amnesia. Is it clear to you what happened to your memory?'' (CN 4)
''Your daughter mentioned that you forget to shower regularly. Do you agree'' (CN 6)
''Do you sometimes forget to take your medication'' (CN 9)

''Do you ever feel hungry and do you always eat three times every day'' (CN 7)

Findings interviews

Structured list

Many community nurses declared that their assessment was guided by a structured list. Community nurses were allowed to deviate from the structured list but there was often not enough space to note findings from questions that were not on the list. They stated that the list may not be suitable for dementia care, because dementia is a complex condition that manifests differently in each client. They would have rather seen a list that is developed specifically for use in the assessment of clients with dementia.

''We only have to ask for subjects that are on the list. There is little room for additional findings in the assessment of clients.'' (CN 11)
''We use a predefined list, which is not focused on the individual needs of clients with dementia'' (CN 11)
''The classification system we work with is very structured'' (CN 13)
''If we have the tools to bring dementia care under attention, perhaps we can better apply the assessment for clients with dementia'' (CN 12)

Specialized dementia care and community nurses

Community nurses stated that it was unclear what was expected of them regarding the assessment of specialized dementia care. Furthermore, community nurses were often not aware that they had to perform tasks that were performed by case managers in recent history. As a consequence, community nurses did not provide specialized dementia care for dementia in their organization. Some organizations still used case managers, even though guidelines state that community nurses are responsible for specialized dementia care.

''We do not provide specialized dementia care'' (CN 14)
''Case managers monitor the entire process of dementia care, but as a community nurse, I am not aware of the entire process'' (CN 15)

Community nurses also stated that they regret that special case managers in dementia care are no longer present. They expected that quality of care will be reduced and that it takes time for community nurses to provide the same quality of care as case managers did.

''Actually, I don't think that case managers should be phased out. They are all specialized in their field and have specific knowledge and skills'' (CN 11)

''So basically, I think that specialized dementia care cannot be performed by community nurses, because they are generalists.'' (CN 12)

Education

Community nurses indicated that training is needed before they can assess specialized dementia care in primary care. They did not know what tasks are associated with special dementia care. Furthermore, they have had no experience with the tasks of specialized dementia care and community nurses mentioned that it would help to review some specialized dementia care assessments.

'' I think that community nurses definitely need training to develop knowledge about specialized dementia care'' (CN 13)
''I cannot assess specialized dementia care, because I don't know which tasks are associated with specialized dementia care'' (CN 14)

Discussion

The aim of this study was to examine the process of care assessments of clients with dementia and the experience of community nurses in this process. The observations provided insight in the decision-making process of community nurses in care assessments. Subsequently, the interviews provided in-depth information regarding the motivation of community nurses in the process of care assessments. The observations show that community nurses are focussed on care needs of the client, especially bathing, dressing and medication. It became clear that most community nurses do not pay enough attention to the full spectrum of care needs of clients with dementia.

In the interviews, most community nurses indicated that they assess care needs using a structured list, which provides guidelines for questions about care needs. Additionally, most community nurses indicated that they find it hard to assess specialized dementia care because they are limited in their knowledge regarding care assessments of clients with dementia. With this information it is understandable that community nurses only assess part of the spectrum of care needs.

There is little literature available about the topic of research. However, some discrepancies between literature and results in this study were found. Literature suggests that community nurses are generalists and that is why they are suited to perform specialized dementia care[14,15]. Additionally, it is stated that by empowering community nurses, care for clients with

dementia can be coordinated by a single care provider instead of multiple care providers[10,20,36]. In this study, it became clear that in fact, community nurses themselves disagree that specialized dementia care should be carried out by them. They argue that case managers in dementia care provide specialized care and acknowledge their own limitations. These limitations are caused mostly by lack of knowledge regarding care assessment in dementia care and the use of predefined lists, which only cover part of the potential care needs.

Case managers are rarely deployed for care assessments of clients with dementia anymore[19,22,26]. It was shown that none of the community nurses, deployed by the different organizations, provided specialized dementia care. Some organizations still have case managers for dementia care. None of the community nurses were offered training in specialized dementia care. However, several studies and protocols indicate that all community nurses in the Netherlands should be trained in specialized dementia care[22,23,25]. Included community nurses only had training in assessing care, but this is a general training, which does not cover the full capacities needed to provide specialized dementia care.

Health insurers oblige community nurses to use special classification methods for assessing dementia care[23]. However, these classification methods are not uniform and differ, making it difficult to deviate from predefined methods. This leads to different approaches in organizations in the Netherlands. None of the available methods are geared towards the process of dementia.

Ketelaar et al[18] state that community nurses know the importance of specialized dementia care, but special tasks of dementia care are often not assessed. This statement is confirmed by results found in this study.

This study contains a number of strengths and limitations. A limitation to this study is that results are based on ten observations and five interviews. However, after six observations and four interviews, data saturation was assumed, because no new information was gathered. Another limitation is that interviews were conducted with nurses who were not observed. It was therefore assumed that observed nurses had the same motivation for their decision-making process as the nurses that were interviewed, but not observed. Not all of the observations and interviews were analysed by two persons. Only the first three observations and the first three interviews were analysed by two persons separately. However, when new codes were found in observations or interviews, they were discussed with the other researcher (CR) to ensure a transparent analysis. The last limitation to this study was that no member check was done by community nurses.

This study distinguishes itself from available literature because of the rigour analysis and combination of observations an interviews. This combination provided insight in limitations of community nurses as well as the cause of these limitations. All codes of the observations and interviews were discussed in detail with an experienced researcher (CS). To ensure unbiased observations and interviews, bracketing was applied.

Recommendations

Several clinical implications and recommendations emerge from these results. To provide more freedom for community nurses in the assessment of dementia care, a universal classification method should be used. Also, community nurses should use these methods as a guideline, rather than a set of mandatory questions. This gives them freedom to answer to client-specific care needs. Also, community nurses lack knowledge regarding the theme of specialized dementia care. Community nurses should therefore follow extensive and in-depth training before they assume the role that case managers previously fulfilled, to be able to deliver a better quality of coordinated care for clients with dementia.

Conclusion

Community nurses shape the care assessment process of dementia clients with support of a structured list in a special classification method. During care assessment, community nurses are expected to focus on the full spectrum of care needs of each client specifically. However, community nurses do not have the knowledge and tools (classification methods) to live up to this expectation. Furthermore, they are inhibited by governance from health insurers. These results are supported by statements of community nurses, acknowledging their limitations and lack of knowledge of care assessments for clients with dementia. It seems that the assumption that community nurses can assess clients that were previously assigned to case managers, was made without regarding all implications. To enable community nurses to assess the full needs of clients with dementia and provide an acceptable quality of specialized dementia care, the classification methods should be reconsidered and extensive and in-depth training should be made available.

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Tables

Table 1: observation form

Observation protocol	
	Descriptive and Reflective Notes
Introduction	
Dementia process	
Information about informal care givers	
Timing professional guidance	

Table 2: topic list for interviews

Main topics	Questions
Care assessment	What barriers do you experience to undertaking a care assessment? Where you pay attention to during care assessments? What role does your experience play in care assessment?
Specialized dementia care	What is specialized dementia care What does care assessment by dementia clients mean
Facilities and barriers	What helps to facilitate care assessment Which facilities are important in dementia care

Table 3: systematic procedure consist of ten phases, QUAGOL(33)

1. Transcript maken van kwalitatieve data (pm. Observaties en non-verbale signalen)
2. Leze en herlezen ruwe data 1e aantal interviews, arceren van de citaten die opvallen: 1e codering, aantekeningen/reflecties in memo's; kort verslag karakteristieken en context van geïnterviewde bijvoegen. 1e codering van aantal interviews onafhankelijk door minimaal 2 verschillende onderzoekers
3. Na aantal interviews bespreken coderingen in duo's onderzoekers: beoordelen coderingen schema; schrappen, aanvullen en herformuleren en 1e beschrijving codes
4. Ontwikkelen van codelijst met beschrijving van codes/begrippen per interview in ruwe data van volgend aantal interviews; in elk interview coderingen toevoegen, codelijst aanpassen/aanvullen
5. Heen- en weer analyse in resterende interviews; definitief voorstel maken 1e codelijst tot de uitspraken; memo's met hypothesen ontwikkelen
6. Codelijst met alle codes zonder hiërarchie bespreken en vaststellen in onderzoekersbijeenkomst.
7. Herlezen interviews met codelijst, zo nodig aanpassen en her-coderen op basis kritisch gebruik van de lijst vragen en reflecties over codelijst in memo's bespreken in onderzoeksgroep ontwikkelen codes 2e niveau: codeboom met hoofdcodes
8. Beschrijven hoofdcodes in eigen woorden in concepten op basis cross-interview analyse, beschrijvingen codeboom met onderzoeksteam bespreken en vaststellen
9. Relaties en onderlinge verbanden tussen de hoofdconcepten vastleggen in conceptueel model; bespreken en vaststellen in onderzoeksteam
10. Beschrijven van bevindingen in antwoord op de onderzoeksvraag

Table 4: characteristics community nurses (N=15)

Mean age (years)	38,3
Standard deviation (years)	8,2
Sex	
Male	-
Female	15
Function	
Community nurse	10
Community nurse, dementia care	3
Community nurse, wound care	2
Community nurse, lung disease	1
Mean experience (years)	11,9
Standard deviation (years)	5,9
Organization	
North	1
South	-
East	2
West	1
Training specialized dementia care	
Yes	3
No	12
Training in assessments in primary care	
Yes	15
No	-