Perceptions of Community Health Nurses on their role in organizing, coordinating and performing dementia care for people with dementia who live at home: A generic explorative qualitative study.

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Program: Master Clinical Health Sciences, Program Nursing Sciences

Course: Master Thesis (final version)

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Date: 30-06-2019

Criteria: Consolidated criteria for reporting qualitative research (COREQ)

Journal: Journal of Advanced Nursing (JAN)

Reference style: Vancouver

Number of words:
- Abstract: 300
- Abstract (Dutch): 298
- Content: 3798

Abstract

Background: By 2050, over one hundred million people worldwide will be diagnosed with dementia. In the Netherlands, people with dementia who live at home often receive care from Community Health Nurses (CHNs) or case managers dementia. Both professionals can play a coordinating role in organizing dementia care. The overlap in the roles and responsibilities of both professionals often creates uncertainties for CHNs.

Aim: Explore perceptions of CHNs on their role in organizing, coordinating and performing dementia care for people with dementia who live at home.

Method: A generic qualitative study was conducted using in-depth interviews. Fifteen CHNs from seven different regions in the Netherlands were interviewed. Data were analyzed with inductive content analysis.

Findings: Four themes were derived from the data. (1) Responsibility regarding the coordination and performing of dementia care. CHNs described overlap in responsibilities in for example: Having contact with general practitioners. (2) Organization of case management dementia. The variety in how case management dementia is organized leads for CHNs to different expectations regarding their responsibilities. (3) Work experience. CHNs with more than five years of work experience had less need to involve case managers dementia for advice. (4) Communication and collaboration. Overlap in responsibilities could be prevented with improved collaboration and communication between both professionals.

Conclusion: CHNs would like to be more involved in organizing, coordinating and performing dementia care. An unambiguous approach in organizing case management and improved collaboration and communication between CHNs and case managers dementia is necessary to create clarity in the responsibilities for CHNs.

Recommendations: Further research is required on the perceptions of case managers dementia and people with dementia to better understand the complete spectrum of organizing at-home dementia care. Furthermore, home care services should employ their own case manager to create an unambiguous approach and clarity in the different responsibilities.

Keywords: dementia, case management, community health nurses, perceptions

Abstract (Dutch)

Achtergrond: In 2050 zullen wereldwijd meer dan honderd miljoen mensen gediagnosticeerd zijn met dementie. In Nederland krijgen thuiswonende mensen met dementie vaak zorg van een wijkverpleegkundige of casemanager dementie. Beide professionals kunnen een coördinerende rol verzorgen in de zorg voor mensen met dementie. Deze overlap in rollen en verantwoordelijkheden van beide professionals leidt bij wijkverpleegkundigen tot onduidelijkheden.

Doel: Onderzoeken wat de perspectieven van wijkverpleegkundigen zijn op hun rol in het organiseren, coördineren en uitvoeren van dementiezorg voor mensen met dementie in de thuiszorg.

Methode: Een generiek kwalitatief onderzoek is uitgevoerd door middel van diepte-interviews. In totaal zijn er vijftien wijkverpleegkundigen uit zeven Nederlandse provincies geïnterviewd. De data zijn geanalyseerd met een inductieve content analyse.

Resultaten: Uit de data zijn vier thema's voortgekomen. (1) Verantwoordelijkheid met betrekking tot de coördinatie en uitvoering van dementie zorg. Wijkverpleegkundigen beschrijven een overlap in verantwoordelijkheden, zoals het contact onderhouden met huisartsen. (2) Organisatie van casemanagement dementie. De verscheidenheid in de organisatie van casemanagement dementie kan voor wijkverpleegkundigen leiden tot verschillende verwachtingen in hun verantwoordelijkheden. (3) Werkervaring. Wijkverpleegkundigen met meer dan vijf jaar werkervaring beschreven dat zij minder behoefte hadden aan coaching van casemanagers dementie. (4) Samenwerking en communicatie. De overlap in verantwoordelijkheden tussen beide professionals kan voorkomen worden door de samenwerking en communicatie onderling te verbeteren.

Conclusie: Wijkverpleegkundigen willen meer betrokken worden in de organisatie, de coördinatie en het uitvoeren van dementiezorg. Door meer eenduidigheid in de organisatie van dementiezorg aan te brengen en samenwerking en communicatie te verbeteren, kan duidelijkheid gecreëerd worden in de verantwoordelijkheden van wijkverpleegkundigen.

Aanbevelingen: Vervolgonderzoek naar de percepties van casemanagers dementie en mensen met dementie is noodzakelijk om een totaalbeeld te krijgen van de organisatie van dementiezorg. Daarnaast zou elke thuiszorgorganisatie een casemanager dementie moeten aanstellen om zo meer eenduidigheid en duidelijkheid te creëren in de verschillende verantwoordelijkheden.

Trefwoorden: dementie, casemanagement, wijkverpleegkundigen, percepties

Introduction and Rationale

Every three seconds, one person in the world is diagnosed with dementia[1]. Over 46 million people worldwide have a form of dementia, and due to the earth's aging population, this number is expected to increase to over hundred million people in 2050[1,2]. Dementia is a generic term for diseases and conditions characterized by a deterioration in memory and thinking skills, which affects a person's ability to participate in daily activities[2,3]. The most common types of dementia are Alzheimer Disease and Vascular Dementia[4]. In the Netherlands, an estimated 270.000 people live with dementia, and about seventy percent of them live at home[5]. It is expected that by 2055, the country will have 690.000 people with dementia who live at home[5,6].

People with dementia who live at home often receive care from a Community Health Nurse (CHN) to assist with their daily activities[7-9]. CHNs play a significant role in performing primary care for people with dementia and have three major responsibilities: Managing people with chronic diseases by using protocols, leading home care services that help to improve care and reducing healthcare costs of people with comorbidities[10-12]. Their role further focuses on performing and coordinating dementia care, which includes being a part of a multi-disciplinary team, assisting and mentoring people with daily activities, supporting self-care, and administering preventative health practices[13,14]. CHNs who were interviewed in a qualitative study of Ball et al.[14] described their role as essential in the coordination, organization and execution of care for people with an illness or in palliative care. However, research showed that their role is not always acknowledged by other healthcare professionals, such as general practitioners or case managers dementia[15-18].

In addition to CHN, case managers dementia can similarly act as primary care givers for people with dementia who live at home and their informal caregivers. The role of case managers dementia was initiated in 2002 after the Dutch Health Council concluded the quality of care for people with dementia needed to improve[19]. While there are practical variations in their daily work, the role is commonly described as a systematic delivery of coordinated care and support in treatment, health and social care for people with dementia who live at home[20,21]. Case managers dementia are often nurses who are specialized in dementia care[21,22]. The most prominent difference between case managers dementia and CHNs is that case managers dementia usually focus solely on people with dementia and have more specific knowledge about dementia, while CHNs can be seen as generalists in primary care[20,21]. Furthermore, case managers dementia are visiting people with dementia once in the eight weeks, while CHNs are visiting people with dementia once a week. Another difference is that case managers dementia do not assist people with dementia with their daily activities[20,21].

Moreover, case managers dementia advise people with dementia and their caregivers during the complete cycle of the disease, from diagnosis until institutionalization or passing away[21,22].

Based on the research of Pacala[23], CHNs and case managers dementia can both deliver the required practical elements of case management dementia in daily care[23-25]. A randomized control trial showed also no significant differences between both professionals in delivering dementia care[26,27]. In practice, thirty percent of the people with dementia receive advice from case managers dementia[9]. The remaining seventy percent are either not aware how to seek advice, or do not wish to receive advice from case managers dementia[9]. Due to the complexities which dementia presents, professionals must work closely together to complement each other and adapt their specific roles to offer qualitative integrated dementia care[10,20].

The varying organization and implementation of case management dementia must be taken into account[20]. In the Netherlands, one method that is often used in organizing case management dementia is the 'Step Model'[28], which entails that CHNs offer case management dementia and transfer people with dementia to case managers dementia in increasing complex situations[28]. In addition to the Step Model, there are other approaches to case management, such as a model where one CHN or case manager dementia coordinates everything from beginning to end[28]. While all examples of organizing case management dementia require CHNs and case managers to work closely together[10,29]. The variety in approaches can lead for CHNs to experience uncertainty in their role and responsibilities. Recent studies[27-29] have evaluated case management dementia by interviewing case managers and informal caregivers. Yet, to our knowledge, there are no studies about the perception of CHNs on their roles in primary caregiving for people with dementia. Moreover, compared to a case manager dementia, it is unclear for a CHN what their role is and where their responsibilities begin and end. Therefore, it was necessary to explore CHNs' perceptions on their role in organizing, coordinating and performing dementia care in the Netherlands.

Aim

The aim of this study was to explore the perceptions of Community Health Nurses on their role in organizing, coordinating and performing dementia care for people with dementia who live at home.

Methods

Design

In order to gain knowledge on this newly emerging subject, a qualitative study was designed and executed[30-32]. This was based on a generic explorative approach, in order to obtain insights on the perceptions of CHNs about their role in dementia care[32-34]. This study was conducted in line with the checklist of the Consolidated Criteria for Reporting Qualitative Research (COREQ)[35].

Sample

The study included CHNs from seven different regions of home care services in the Netherlands. Criteria for inclusion was: being a registered bachelor nurse, at least two years' work experience in home care services, and fluency in Dutch. Potential candidates were excluded if they had former work experience as a case manager dementia, which could influence their perceptions and work as a CHN. Participants were recruited through a convenience sample with maximum variation in age, years of work experience and location.

Data collection

In-depth face-to-face interviews were conducted with fifteen CHNs between January and April 2019. As preparation, the researcher completed an interview training and a pilot interview to test the topic list[32]. The duration of the interviews lasted between thirty and forty minutes, which began with an introduction where the CHN was asked to read an article about the topic of this study to directly come to the core of the study[36]. Next, the researcher performed an interview with the CHN until his or her perceptions were sufficiently described[30]. Topics were based on relevant literature, expert knowledge and discussions between researchers (NvdB,FS). The topic list can be found in figure 1. The interview structure was based on the river-and-channel model of Rubin&Rubin[37], which is suitable for in-depth interviews and is relevant to explore one topic. The interviews were audiotaped and later transcribed verbatim. To increase the reliability and gain information that could not be audiotaped[34,38], field notes were recorded on non-verbal behavior, such as mimicry, interrogation, nodding and/or silence in a conversation[37]. To prevent responder's bias[30,34], CHNs were asked to describe a situation that they dealt with and could remember. All CHNs were aware of the fact that the researcher who conducted the interviews is a master student and a CHN himself. One interviewed CHN was a colleague of the researcher but they were not directly working together.

Insert figure 1.

Data analysis

Data were analyzed according to the four phases of conventional content analysis: decontextualization, recontextualization, categorization, and compilation[39,40]. This type of analysis was chosen because existing theory on the investigated phenomenon is limited. All transcripts were read and re-read. During open coding meaningful units were analyzed and coded which lead to fragmentation of the data. Unmarked text was re-read to decide if it should be included or excluded[41,42]. Next, all codes were divided into categories based on the relation between the codes, and these codes were combined into important clusters[41-43]. Finally, the CHNs' own words were used to stay close to the data and describe the categories. Data analysis were performed by a student researcher and a supervising researcher who is experienced with in-depth interviews and qualitative analysis. To enhance validity of the study, the first three interviews were analyzed and coded by two researchers (NvdB,FS) independently, and discussed until consensus was reached. Analyzing and coding of the other interviews were performed by the first researcher (NvdB). The supervising researcher (FS) was consulted during each stage of the analysis and choices were discussed. Following the first three interviews and feedback of the supervising researcher, it became clear that certain topics needed to be further explored in the remainder of the interviews as part of the iterative approach[38]. Data were analyzed with Nvivo (version 11, QRS International). Interviews were transcribed within a week of the interview date, in order to enhance reliability and recall observations or non-verbal behaviors[38]. All participants received a summary of the transcribed interviews to check accuracy and interpretation[31,38]. Furthermore, participants were asked to provide their opinions about the results after analysis. Background characteristics of the CHNs were analyzed in a descriptive way, while age and years of work experience were processed as median and range.

Procedures

Participants were informed about this study in CHN platform meetings and via messages on social media. If a CHN was interested in participating, he or she could directly send a message to the researcher to provide contact information. Additional CHNs who were not participating in a platform and did not have a LinkedIn account, were reached by snowball method[38]. Subsequently, CHN who wanted to participate received written information by email. After agreeing with the interview procedures, an appointment for an interview was made. Before these took place, the informed consent was discussed, and baseline characteristics were collected including gender, age and years of work experience. Equality and safety were guaranteed by interviewing CHNs in a location of their choice, where privacy was ensured.

Ethical considerations

This study followed the principles of the Declaration of Helsinki (version 2013)[44] and the Dutch code of conduct for integrity in science[45]. It was not in the scope of the Medical Research Involving Human Subjects Acts, because CHN were not exposed to an intervention. The guidelines of Good Clinical Practice (GCP)[46] and General Data Protection Regulation[47] were followed, and informed consent was signed by all participants. Confidentiality was maintained by using identification numbers and only the first researcher had access to the data. All data was stored on a secured hard disk in the closed research environment of the NHL-Stenden University.

Findings

A total of fifteen CHNs were interviewed: one male and fourteen females. They were between 24 and 59 years old (M= 39.7, SD= 11.4), and they had between three and fifteen years of work experience (M= 8.2, SD= 3.6). The characteristics were described in table 1. The following themes arose: Responsibility regarding the coordination and performance of dementia care, organization of case management dementia, work experience, and collaboration and communication. The results were described according to these themes.

Insert table 1.

Theme 1: Responsibility regarding the coordination and performance of dementia care

Most CHNs mentioned an overlap between them and case managers dementia in the coordination of at-home dementia care. For example, both professionals have conversations with informal caregivers and general practitioners. CHNs saw themselves as generalists who care for people with care needs who live at home. All CHNs reported that case management for people with dementia is a part of their daily work. Furthermore, CHNs described that advising people with dementia and having conversations with informal caregivers is a part of their role. Most of the CHNs reported that case managers dementia often transfers people with dementia to CHNs, as CHNs have more contact with people with dementia on a day-to-day basis. Some CHNs found it comforting to involve case managers dementia, because case managers have an objective view on the situation.

'Case managers dementia stand further from the situation, which makes it easier to discuss difficult topics. As CHN, you do not want to break trust with people with dementia by having such a conversation'. (Female, ten years of work experience)

Most CHNs stated that the involvement of case managers does enhance their knowledge of the disease and their ability to coach people with dementia. CHNs also expressed their desire for increased contact with a case manager dementia to discuss responsibilities, such as contact with caregivers, legal issues and contact with general practitioners. This increased communication would also ensure that tasks are not done twice.
Almost all of the CHNs described their main responsibility as nursing and caring for people with dementia, while the responsibility of case managers dementia focuses on supporting informal caregivers. According to CHNs, informal caregivers and people with dementia say that having contact with several healthcare professionals often causes confusion. Moreover, CHNs said that in stable cases, case managers generally act in the background and the CHN performs case management him or herself.

Theme 2: Organization of case management dementia

Most of the CHNs stated that the type of organization where they work plays an important role in how the structure of at-home dementia care is organized. They described three common work structures for CHNs and case managers dementia in organizing dementia care: (1) they worked within the same organization, (2) CHNs worked within case managers dementia of overarching organizations, or (3) they worked in different organizations. CHNs who worked in the same organization as case managers dementia were, as standard protocol, involved in cases with dementia diagnosis. In this situation, some CHNs experienced negative effects on their job, as they felt their role in coordinating care for people with dementia is taken over by case managers dementia; furthermore, the CHNs say they felt that they only perform tasks in executing patient care, while case managers coordinated and organized the more significant matters of care and communication.
The group of CHNs who worked with case managers dementia from an overarching organization stated that case managers were well known in the regions and their expertise is an advantage.

'Professionals, such as case managers dementia, from an overarching had the expertise to diagnose and offer support to people with dementia, because everyone worked for the same organization'. (Female, three years of work experience)

Additionally, CHNs who worked within the same organization as case managers dementia, stated that this leads to enhanced contact and ease of communication. CHNs stated that general practitioners will refer people with dementia faster if both professionals work together within one organization. CHNs who did not work within the same organization as the case

managers dementia, said they experienced negative effects in coordinating care; they felt they were less involved, and stated that it is hard to collaborate with someone you rarely see.

Theme 3: Work experience

According to CHNs, their work experience plays a role in coordinating dementia care. CHNs with two to five years of work experience had a greater need to involve a case manager for advice or coaching.

'The backup of case managers dementia gives me a comforting feeling when difficult situations needed to be discussed, such as moving to a nursing home when people are no longer able to live at home'. (Female, two years of work experience)

CHNs with more than five years' experience felt confident enough to deliver case management dementia themselves and did not feel the need to have a case manager as backup.

Theme 4: Collaboration and communication

Collaboration between different healthcare providers was described as essential in organizing, coordinating and performing dementia care. A few CHNs experienced adequate collaboration with case managers dementia by means of daily contact and involvement. However, CHNs considered that various professionals could complement each other more. Most CHNs experienced that building trust with people with dementia and their informal caregivers was essential when the function of a case manager dementia was fulfilled. In addition, CHNs described that case managers dementia could complement CHNs more, because they visited people with dementia a few times a week.

'Together you are standing stronger…' (Female, five years of work experience)

All CHNs were familiar with their regional case manager, but most of them deemed that the collaboration does not yet work well. Some CHNs said that it was difficult to work together because the case managers are often too busy or not easy to reach. Furthermore, CHNs felt the need to be more involved to the process of organizing dementia care. Finally, CHNs stated that communication between them and case managers dementia is necessary to make use of each other their skillsets. CHNs who worked within the same organization as the case managers dementia described that communication improved when they both had access to electronic patient files.

Discussion

The aim of this study was to explore CHNs' perceptions on their role in organizing, coordinating and performing dementia care for people with dementia who live at home. Four themes were identified: Responsibility regarding the coordination and performance of dementia care, the organization of case management dementia, work experience, and communication and collaboration.

First, responsibility regarding the coordination and performance of dementia care. CHNs described an overlap between their role and the role of the case managers dementia, which is confirmed by other studies[48,49]. These studies described overlap in for example: The handling of legal issues or arranging daycare for people with dementia[48,49]. These outcomes are in line with this qualitative study. Also, the performed study implicates it is valuable for CHNs and case managers dementia to regularly discuss their different responsibilities to avoid the duplication of work.

Second, the organization of case management dementia. This qualitative study showed that if CHNs and case managers dementia work within the same organization, the collaboration between both professionals is perceived as easier. Furthermore, both professionals communicated more frequently and visited patients with dementia more often together, which are described as success factors for organizing dementia care[49-51]. These outcomes are confirmed by studies that show how various approaches to organizing case management dementia can result in uncertainties in responsibilities for professionals[48]. Additionally, Mierlo et al. described that a uniform vision has to be reached to create clarity for CHN and other professionals when they can involve a case manager dementia from an overarching organization[52]. These outcomes are in line with this qualitative study, which implicates that CHNs felt the need to communicate and collaborate with case managers dementia on a more regular basis. Therefore, an unambiguous approach in organizing case management is necessary to create clarity for CHNs and case managers dementia, regarding their respective responsibilities. This study also implicates that collaboration and communication between CHNs, and case managers dementia is stronger if both professionals work within the same organization and closely work together.

Third, work experience. This study showed that CHNs with more than five years of work experience had less need to involve case managers dementia, while CHNs with less experience felt the need to engage them for advice if situations became too complicated. Therefore, this study implicates that CHNs and case managers dementia should have regular conversations about the CHN's specifics needs for advice or coaching.

Finally, collaboration and communication. This study showed that collaboration and communication between professionals is essential in delivering primary care.

CHNs and case managers dementia could complement each other in complex situations. The following obstructive factors were described by other studies: competition and distrust between professionals in delivering care, inefficient communication between healthcare providers, and no involvement of primary care providers such as CHNs[50,53]. Therefore, a high level of case management is necessary to ensure positive clinical outcomes for people with dementia and to optimize dementia care[53]. Effective communication between primary healthcare providers is also necessary[49,50]. A systematic review showed that case managers dementia, in collaboration with general practitioners, have a fundamental role in addressing the needs of people with dementia and their caregivers[53]. Frequent communication between case managers and general practitioners is essential in the collaboration between these professionals and in the organization of dementia care[54]. However, studies performed in the Netherlands did not describe the role of CHNs[26,55] and found no benefits of case management dementia versus usual care[26]. Therefore, this study specifically focused on the perception of CHNs, and implicates that it is essential for case managers dementia and CHNs to collaborate and communicate more frequently to offer qualitative, integrated dementia care.

This study is strengthened by the number of interviewed CHNs and the maximum variation in their demographics and work experience. The participating CHN worked for twelve different home care services spread over seven regions of the Netherlands. There was also a broad variety in their years of work experience, which can be seen as a reflection of the daily practice. The results of fifteen interviews gave a realistic reflection of the CHNs' perceptions and data saturation.

However, some limitations need to be taken into account. Findings of this qualitative study are not generalizable in other countries, as only Dutch CHNs were interviewed. Another limitation is that the researcher is a CHN himself, which could have influenced the objective perception. To prevent this type of research bias, the supervising researcher analyzed three transcribed interviews and other choices were discussed. By using a convenience sample, selection bias could have occurred. There is a chance that only CHNs who were interested in case management dementia were interviewed.

Certain implications can be made for practice. This study emphasizes the importance to let CHNs and case managers dementia complement each other by having more frequent contact. First, this study showed that if CHNs and case managers dementia have frequent contact, overlap in responsibilities could be prevented. Second — due the different ways case management dementia can be organized — it is important for CHNs and case managers dementia to discuss these differences and maintain regular appointments about their responsibilities.

Finally, this study described the benefits of working within the same organization for CHNs and case managers dementia. This study implicates that every organization should employ a case manager dementia, to create more clarity for both types of professionals.

This qualitative study emphasizes the importance of involving CHNs in further research about case management dementia. Further qualitative research is required on the perceptions of case managers dementia in their collaboration and communication with CHNs. In this regard, the full spectrum of dementia care can be mapped, and every specific case can be treated in a personal way. Besides that, additional research is required to understand the opinions of people with dementia and their informal caregivers, specifically in regard to which form of case management they prefer.

Conclusion

This explorative study examined the perceptions of CHNs on their role in coordinating, performing and organizing case management dementia for people with dementia who live at home. In conclusion, CHNs described they would like to be more involved in organizing, coordinating and performing dementia care. An unambiguous approach in the organization of case management is necessary to create clarity in CHNs' roles and responsibilities. Finally, collaboration and increased contact could prevent overlap in responsibilities, and lead to qualitative integrated dementia care.

References

1. World Health Organization. Dementia [Internet]. WHO; 2019 [cited 2019Jun25]. Available from: https://www.who.int/en/news-room/fact-sheets/detail/dementia
2. Schneider JA, Arvanitakis Z, Leurgans SE, Bennett DA. The neuropathology of probable Alzheimer disease and mild cognitive impairment. Annals of Neurology. 2009;66(2):200–8.
3. Alzheimer's Association. 2017 Alzheimers disease facts and figures. Alzheimers & Dementia. 2017;13(4):325–73.
4. Riedijk S, Vugt MD, Duivenvoorden H, Niermeijer M, Swieten JV, Verhey F, et al. Caregiver Burden, Health-Related Quality of Life and Coping in Dementia Caregivers: A Comparison of Frontotemporal Dementia and Alzheimer's Disease. Dementia and Geriatric Cognitive Disorders. 2006;22(5-6):405–12.
5. Alzheimer Nederland. Factsheet cijfers en feiten over dementie [Internet]. Alzheimer Nederland. [cited 2019Jun25]. Available from: https://www.alzheimer-nederland.nl/factsheet-cijfers-en-feiten-over-dementie
6. Verbeek H, Meyer G, Leino-Kilpi H, Zabalegui A, Hallberg IR, Saks K, et al. A European study investigating patterns of transition from home care towards institutional dementia care: the protocol of a RightTimePlaceCare study. BMC Public Health. 2012;12(1).
7. Luppa M, Luck T, Weyerer S, Konig H-H, Brahler E, Riedel-Heller SG. Prediction of institutionalization in the elderly. A systematic review. Age and Ageing. 2009;39(1):31–8.
8. Bökberg C, Ahlström G, Leino-Kilpi H, Soto-Martin ME, Cabrera E, Verbeek H, et al. Care and Service at Home for Persons With Dementia in Europe. Journal of Nursing Scholarship. 2015;47(5):407–16.
9. Low L-F, Fletcher J. Models of home care services for persons with dementia: a narrative review. International Psychogeriatrics. 2015;27(10):1593–600.
10. Francke AL, Peeters JM. Ketenzorg en casemanagement bij dementie: ketenregisseurs over inkoop, uitvoering en borging in 2015. [Internet]. NIVEL. [cited 2019Jun25]. Available from: https://www.nivel.nl/nl/publicatie/ketenzorg-en-casemanagement-bij-dementie-ketenregisseurs-over-inkoop-uitvoering-en
11. Lamb G, Newhouse R, Beverly C, Toney DA, Cropley S, Weaver CA, et al. Policy agenda for nurse-led care coordination. Nursing Outlook. 2015;63(4):521–30.

12. Stuurgroep Kwaliteitskader Wijkverpleging. Kwaliteitskader wijkverpleging. [Internet]. Zorginstituut Nederland; [cited 2019Jun25]. Available from: http://www.zorginzicht.nl/bibliotheek/bestuurlijke-afspraken-kwaliteitsinformatie-wijkverpleging/RegisterKwaliteitsstandaardenDocumenten/Kwaiteitskader wijkverpleging (versie 1).pdf.
13. Johnson A. Role of district and community nurses in bereavement care: a qualitative study. British Journal of Community Nursing. 2015;20(10):494–501.
14. Peeters JM, Francke AJ. Organisatie en invulling van "casemanagement dementie" in Nederland: verslaglegging van een landelijke peiling onder regionale projectleiders. [Internet]. NIVEL. [cited 2019Jun25]. Available from:https://www.nivel.nl/nl/publicatie/organisatie-en-invulling-van-casemanagement-dementie-nederland-verslaglegging-van-een
15. Burt J, Shipman C, Addington-Hall J, White P. Nursing the dying within a generalist caseload: A focus group study of district nurses. International Journal of Nursing Studies. 2008;45(10):1470–8.
16. Griffiths J, Ewing G, Rogers M, Barclay S, Martin A, Mccabe J, et al. Supporting Cancer Patients With Palliative Care Needs. Cancer Nursing. 2007;30(2):156–62.
17. Luker K, Wilson K, Pateman B, Beaver K. The role of district nursing: perspectives of cancer patients and their carers before and after hospital discharge. European Journal of Cancer Care. 2003;12(4):308–16.
18. Shipman C, Burt J, Ream E, Beynon T, Richardson A, Addington-Hall J. Improving district nurses' confidence and knowledge in the principles and practice of palliative care. Journal of Advanced Nursing. 2008;63(5):494–505.
19. Alzheimer Nederland, Vilans. Zorgstandaard Dementie [Internet]. Alzheimer Nederland. 2013. Available from: https://www.vilans.nl/docs/vilans/publicaties/Zorgstandaard_Dementie.pdf
20. Reilly S, Miranda-Castillo C, Sandhu S, Hoe J, Challis D, Orrell M. Case/care management approaches to home support for people with dementia. Cochrane Database of Systematic Reviews. 2010;
21. Lange JD, Deusing E, Asch IFV, Peeters J, Zwaanswijk M, Pot AM, et al. Factors facilitating dementia case management: Results of online focus groups. Dementia. 2016;17(1):110–25.
22. ZonMW. Tussentijdse evaluatie Landelijk Dementie Programma [Internet]. 2013. Available from: https://www.vilans.nl/docs/producten/TussentijdseevaluatieLDP.pdf.

23. Pacala JT, Boult C, Hepburn KW, Kane RA, Kane RL, Malone JK, et al. Case Management of Older Adults in Health Maintenance Organizations. Journal of the American Geriatrics Society. 1995;43(5):538–42.
24. Mierlo LDV, Meiland FJ, Hout HPV, Dröes R-M. Towards personalized integrated dementia care: a qualitative study into the implementation of different models of case management. BMC Geriatrics. 2014;14(1).
25. Evans C, Drennan V, Roberts J. Practice nurses and older people: a case management approach to care. Journal of Advanced Nursing. 2005;51(4):343–52.
26. Jansen AP, Hout HPV, Marwijk HWV, Nijpels G, Bruijne MCD, Bosmans JE, et al. (Cost)-effectiveness of case-management by district nurses among primary informal caregivers of older adults with dementia symptoms and the older adults who receive informal care: design of a randomized controlled trial. BMC Public Health. 2005;5(1).
27. Somme D, Trouve H, Dramé M, Gagnon D, Couturier Y, Saint-Jean O. Analysis of case management programs for patients with dementia: A systematic review. Alzheimers & Dementia. 2012;8(5):426–36.
28. Huijsman R. Generalistisch en specialistisch casemanagement in de dementiezorg Duiding van een nieuw fenomeen in verschillende combinaties [Internet]. 2017 [cited 2019Jun25]. Available from: https://www.zorgnetwerkmb.nl/wp-content/uploads/2018/02/Casemanagement-dementiezorg-Huijsman-2017.pdf
29. Richters A, Nieuwboer M, Rikkert MO, Melis R, Perry M, Marck MVD. Longitudinal multiple case study on effectiveness of network-based dementia care towards more integration, quality of care, and collaboration in primary care. International Journal of Integrated Care. 2018;18(s2):60.
30. Boeije HR. Analyseren in kwalitatief onderzoek: denken en doen. 5th Edition. Amsterdam: Boom; 2016.
31. Kahlke RM. Generic Qualitative Approaches: Pitfalls and Benefits of Methodological Mixology. International Journal of Qualitative Methods. 2014;13(1):37–52.
32. Holloway I, Galvin KM. Qualitative research in nursing and healthcare. 3th Edition. Chichester, West Sussex, UK: John Wiley & Sons Inc.; 2017.
33. Caelli K, Ray L, Mill J. 'Clear as Mud': Toward Greater Clarity in Generic Qualitative Research. International Journal of Qualitative Methods. 2003;2(2):1–13.
34. Creswell JW, Poth CN. Qualitative inquiry and research design: choosing among five approaches. 10th Edition. Los Angeles: SAGE Publications; 2018.
35. Gubrium JF, Holstein JA. Handbook of interview research: context and method. 3rd Edition London: SAGE; 2002.

36. Rubin HJ, Rubin IS. Qualitative interviewing: the art of hearing data. 3rd Edition. Los Angeles: Sage; 2016.
37. Polit DF, Beck CF. Nursing Research. Generating and Assessing Evidence for Nursing Practice. 9th Edition. Wolters Kluwer. Gold Coast, Australia: Lippincott Williams & Wilkins; 2012.
38. Hsieh H-F, Shannon SE. Three Approaches to Qualitative Content Analysis. Qualitative Health Research. 2005;15(9):1277–88.
39. Kondracki NL, Wellman NS, Amundson DR. Content Analysis: Review of Methods and Their Applications in Nutrition Education. Journal of Nutrition Education and Behavior. 2002;34(4):224–30.
40. Graneheim U, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Education Today. 2004;24(2):105–12.
41. Bengtsson M. How to plan and perform a qualitative study using content analysis. NursingPlus Open. 2016;2:8–14.
42. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs. 2008;62(1):107-15.
43. Patton MQ. Enhancing the Quality and Credibility of Qualitative Analysis. Health Serv Res. 1999 Dec; 34(5 Pt 2): 1189–1208
44. World Medical Association. WMA Declaration Of Helsinki – Ethical Principles For Medical Research Involving Human Subjects. 2013.
45. Algra, K; Bouter, L; Hol, A; Kreveld van J. Nederlandse gedragscode wetenschappelijke integriteit. 2018.
46. Good Clinical Practice Network. GUIDELINE FOR GOOD CLINICAL PRACTICE - ICH Official web site [Internet]. [cited 2019Jun25]. Available from: https://www.ich.org/fileadmin/Public_Web_Site/ICH_Products/Guidelines/Efficacy/E6/E6_R1_Guideline.pdf
47. The European Parlement and The Council Of The European Union. General Data Protection Regulation (GDPR) [Internet]. Available from: https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016R0679. [Accessed 4 December 2018].
48. Inspectie voor de Gezondheidszorg (IGZ). Netwerkzorg voor thuiswonende mensen met dementie en hun mantelzorgers. [Internet]. 2013 [cited 2019Jun25]. Available from: https://www.dementiedrenthe.nl/admin/uploads/IGZ rapport netwerken dementie juli 2013.pdf

49. Minkman MMN, Ligthart SA, Huijsman R. Integrated dementia care in The Netherlands: a multiple case study of case management programmes. Health & Social Care in the Community. 2009;17(5):485–94.
50. Khanassov V, Pluye P, Vedel I. Case management for dementia in primary health care: a systematic mixed studies review based on the diffusion of innovation model. Clinical Interventions in Aging. 2014;:915.
51. Khanassov V, Vedel I, Pluye P, Bergman H. Case management for patients with dementia in primary care: Why it doesnt work—A mixed studies systematic review. Alzheimers & Dementia. 2013;9(4).
52. Mierlo LDV, Meiland FJ, Hout HPV, Dröes R-M. Towards personalized integrated dementia care: a qualitative study into the implementation of different models of case management. BMC Geriatrics. 2014;14(1).
53. Khanassov V, Vedel I. Family Physician-Case Manager Collaboration and Needs of Patients With Dementia and Their Caregivers: A Systematic Mixed Studies Review. The Annals of Family Medicine. 2016;14(2):166–77.
54. Callahan CM, Boustani MA, Unverzagt FW, et al. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. JAMA. 2006;295(18):2148-2157.
55. Laurant MG, Hermens RP, Braspenning JC, Sibbald B, Grol RP. Impact of nurse practitioners on workload of general practitioners: randomized controlled trial. BMJ. 2004;328(7445):927.

Figures and tables

1. Introduction	
• Can you tell me something about yourself? • *Age, gender, work experience, workstation, caseloads.* • The researcher asks the CHN to read the article and asks them; What is your opinion about this situation?	
2. Checklist researcher:	
• Where do the role / responsibilities of CHN begin or end - Why, how, when, can you tell me more about, can you give me an example	
• Working together with a case manager dementia - Why, how, when, can you tell me more about, can you give me an example	
• Differences in roles between CHN and case manager dementia - Why, how, when, can you tell me more about, can you give me an example	
• Opinion about the change in organization of dementia care - Why, how, when, can you tell me more about, can you give me an example	
• Check their knowledge about dementia care - Why, how, when, can you tell me more about, can you give me an example	
• Check if they have requirements to improve delivering of dementia care - Why, how, when, can you tell me more about, can you give me an example	
3. Ending	
• Do you have any other subjects you would like to discuss?	

Figure 1, interview guide.

Table 1, CHN' characteristics

Age (in years)	<25 25-40 40-55 >55	N=2 N=7 N=4 N=2
Sex	Male Female	N=1 N=14
Work experiences as CHN (in years)	2-5 5-10 >10	N=3 N=7 N=4