

Master Thesis

Case managers' roles in the decision-making process within care networks of people with dementia living alone: *a multi-perspective qualitative study*

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ABSTRACT

Background: People with dementia and their care network have to make several decisions in daily life. Because of population ageing and replacement of institutionalized care to home care, more people with dementia are living alone. Decision-making in dementia concerns: multiple decisions, with several stakeholders, over a long-term period, in an ever-changing situation. Case managers are the important link in the care network of persons with dementia to involve them in decision-making. It is unclear what roles this professional uses in the facilitation of (shared) decision-making.

Aim: Gain insight into the roles of case managers in the decision making process within care networks of people with dementia living alone in order to investigate how this can be facilitated in shared decision-making.

Method: A multi perspective study using already available qualitative data for a secondary analysis. 71 semi-structured longitudinal interviews from five dementia care networks with people with dementia, informal caregivers and professional caregivers, were coded according to the principles of Grounded theory.

Results: The different roles in decision-making can be explained by five themes who are used by all case managers during decision-making. Core theme of connecting shows an interactive process with the roles: expert, monitor and stimulator. Advocate's role runs simultaneously through the process.

Conclusions: The case manager uses different roles during decision-making to facilitate the decision-making process. These roles will be applied in greater or lesser extent in different dementia care networks and can be used as a first step in professionalization of case management and in the facilitation of shared decision-making in dementia care.

Recommendations: Care professionals, care networks and care programs should be aware of the diverse roles of case managers' that exist for involvement in dementia care networks for facilitation of shared-decision making.

Keywords: Decision-making; case manager; dementia; living alone; Shared-decision making

INTRODUCTION

Dementia is a chronic disease among older people characterized by cognitive memory disorders, and receives much attention over the past few decades^{1, 2}. Population ageing increases the number of Dutch people with dementia (PWD)³. In 2011, 110.000 people were diagnosed with dementia in the Netherlands. An additional 120.000 patients are estimated to be undiagnosed with dementia. Of these 230.000, 35% live alone⁴. Since government's elderly policy has changed over the past years, care at home increasingly replaces institutionalized care⁵. Reduced funding for nursing homes, recession, and financial well being of elderly, are the most important factors⁶.

This replacement results in a long-term illness trajectory for PWD at home where they receive care from relatives, professionals and case managers (CM). These care networks are confronted with a complex and heavy trajectory where many decisions regarding issues in well being and daily life for the PWD have to be taken⁷. For providing the feeling of autonomy the PWD should be supported and be involved in making decisions for as long as possible^{7, 8}, especially when they are living alone. However, this is difficult due to progressive cognitive decline of PWD.

Over time, decision-making call for changes in decision-making roles from the PWD, informal caregiver and CM, from 'supported decision-making' to 'substituted decision-making' in a non-linear process⁹. Decision-making in dementia care networks concerns: multiple decisions, with several stakeholders, over a long-term period, in an ever-changing situation¹⁰. Decisions are based on practical considerations, personal preferences and values, however, are their various perspectives from the care network on interests^{11, 12}. For family it is a challenge considering a carefully balance between these potentially conflicting interests and involving the PWD in the decision-making process¹⁰.

The CM plays an important coherence, coordinating and continuity role in this challenge and is the crucial link in the chain of dementia care¹³. This profession is actually derived from the nursing profession and is still in development. Already a number of minimum requirements of the CM's profession are formulated: main point of contact, knowledge of dementia- and informal care-issues as well as satisfying needs. However, these requirements are free for interpretation and do not cover any requirement about their role in decision-making¹⁴.

According to the CanMEDS roles, which the Netherlands has adopted as competence framework for specialist education, other professions such as the CM, expressing interest in harmonizing their roles on facilitating the decision-making process in dementia care¹⁵. Therefore CanMEDS roles (Figure 1) can be powerful resource for development of CM's profession¹⁶. This can be taken into account to CM's because they are

becoming increasingly popular as a strategy in collaborating PWD and their informal caregivers in decision-making¹³.

For collaborating within dementia care networks in the decision-making process, patient centred care is an essential part of the health care system¹⁷. A widely promoted approach in decision-making that supports patient centred care is shared decision-making (SDM), what means sharing the responsibility for decisions between patient and professional¹⁸. Research suggests that SDM in general leads to higher levels of satisfaction with decisions, higher quality of life and better caring relationships¹⁹.

SDM in relation to dementia is different from typical SDM-situations due to cognitive disabilities of PWD (legal incapacity), types of decisions (well-being instead of medical issues), and multiple participants involved in this process²⁰.

A previous study of Groen-van de Ven²¹ investigated SDM in dementia but no focus on decision-making in home-dwelled PWD who live alone is known. For SDM in care networks of PWD this means that CM's need to facilitate and acknowledge the way the care network collaborate in making decisions and should be anticipate in such a way that it helps reaching agreement within the care network in the decision-making process. Investigation which roles the CM use in this process is needed.

Problem statement

The increase number of PWD living alone and their changing involvement in decision-making asks for an appropriate support of the CM. The CM plays an important and decisive role in decision-making. Therefore it is necessary to get insight into roles the CM use in decision-making within dementia care networks. Investigating these roles will help in the development of the CM's profession in decision-making and for facilitating SDM in dementia care networks.

AIM

The following research aim is designed:

Gain insight into roles the case manager use in the decision-making process within care networks of people with dementia living alone in order to investigate how these roles can be facilitated in SDM in dementia care networks.

METHOD

Design

A qualitative multi-perspective exploratory design was selected to capture the roles of the CM on everyday decision-making among PWD within care networks. Data was selected from a larger on going longitudinal research programme on SDM in care networks of PWD¹⁵.

Population

In the original study 23 care networks, consisting of the PWD, two informal caregivers and two professional caregivers, were purposely selected²². In the current study, care networks that are eligible for inclusion must meet the following criteria: a person diagnosed with any form of dementia, living alone and a CM involved. Semi-structured interviews were conducted with individual care network participants three times with six-month intervals (T0, T1, T2). Five care networks (71 interviews) met the inclusion criteria and were used for secondary analysis (Table 1). In two networks the CM did not participate at T2, because the PWD was already moved to a nursing home. Figure 2 presents a flowchart of the inclusion and exclusion from the overall and current study. Table 2 shows care network characteristics.

<Insert Figure 2>

<Insert Tables 1, 2>

Data collection

The original data collection took place between July 2010-August 2012. Semi-structured face-to-face interviews were conducted by using an interview guide. Topic guides were based on existing topics from the original study and included: decisions made, participants in decision-making and communication about decisions (Box 1). Amongst the interviewers were eight bachelor students (Nursing or Applied Gerontology) who were trained in qualitative interviewing and knowledge about dementia by the three researchers of the overall study. The 11 interviewers were trained to build up rapport for maximum responses from all participants. The interviews lasted around one hour and were written out verbatim using tape recording prior to analysis.

<Insert Box 1>

Data analysis

Principles of Grounded theory were used that interprets the data²³. This process defined an integrated set of concepts explaining a social phenomenon²⁴. It consists of three elements:

open, axial and selective coding. A research team of three members (MH, LG and LB) was involved in the entire process of data analysis. For open coding MH and LB independently read the first three care network transcripts (44 interviews). They were consistently analyzed to make a codebook and clarify homogeneity of both researchers. Double coding was used for constant comparison. The last two care networks were coded as check for the existing codes and for reaching theoretical saturation, however, data saturation was not reached. During joint meetings, newfound codes were discussed towards consensus about interpretation. This method constituted researcher triangulation and increasing reliability. Nvivo 10.1.3²⁵ supported the analysis.

Through axial coding the codes were clustered and labeled, and categories were defined. Workshop using affinity diagramming between MH, LG and LB was conducted as a tool for axial coding to include multiple perspectives in the analysis. The affinity diagram, created within the anthropology, organized a large number of categories into their natural relationships²⁶.

The conditional relationship guide was used for identifying relations between the categories, following the procedure of selective coding²⁷. To provide more structure in order categories questions were asked: what, when, where, why, how and consequence²⁸. This method helps to find the dimension of a process and selecting or defining a core theme²⁷. All codes, categories, themes and quotations had been translated into English.

Ethical considerations

It can be stated that this study was conducted according to Declaration of Helsinki²⁹ and in accordance with Medical Research Involving Human Subjects Act (WMO). The regional ethical board of Isala Klinieken approved the overall study.

All participants received oral and written information about the overall study. When the PWD and the primary informal caregiver decided to participate in the study all participants of the care networks signed informed consent.

The handling of personal data is confidentially according to the Dutch Personal Data Protection Act (WBP). Transcripts are stored for fifteen years.

RESULTS

Five themes about CMs' roles are developed and explain what different roles the CM uses in the decision-making process within care networks of PWD living alone. A multi-perspective view was provided, however, only responses from CM and informal caregivers appeared relevant for reaching the aim of this study.

Table 3 presents the coding process and Table 4 shows quotations. Appendix 1 provides definitions of the categories and themes.

<Insert Tables 3, 4>

Connecting

This role is based on CM's awareness of stakeholders' interactions, interconnected relationships and finding a balance between potential conflicts between stakeholders. Connecting is the important start for a sustainable relationship in decision-making, also to put effort in the relationship between the PWD and informal caregivers. In some care networks the communication is clear and open whereas other care networks ensures conflicts between informal caregivers.

This theme consists of: 1) Being aware of what is going on in the network and 2) Building relationship with care networks.

Being aware of what is going on in the care network

CM knows what interests all stakeholders have and identifies physical and emotional problems and evaluates decisions. Exchanging information between CM and other members involved the process of sharing knowledge, interests and considerations in decision-making. The CM expresses ideas, offers a listening ear, identifies limitations and expresses concerns. Because of multiple perspectives of the stakeholders, the CM tries to reach agreement (quote 1). All CM's of the care networks invest in developing sustainable relationships with all stakeholders.

Building (long-term) relationship with care network

The CM is clear about his role in this process and about future prospects at the start of the involvement in the dementia care network, for building a balanced, trusted and fair relationship during accompany and involvement of the care process (quote 2). The CM participate as main contact point. Building a relationship with the care network provides in better collaboration between stakeholders of the care network. Interviews show that every participant is responding in building a relationship in the care network.

Expert

This theme is defined as role of using own expertise and relying on the professional network, which means that sharing their own experience, knowledge and information is used for providing insights into illness trajectory. Not every informal caregiver accepts involvement of the CM, what means the interrelationship between both was not present. Three categories relates to the role of expert: 1) Using own expertise, 2) Using own professional network, 3) Advising and informing.

Using one's own expertise

The CM's use of own expertise varies between the different networks. The use of own expertise, for instance knowledge, skills and experience, seems to depend on the need for this expertise from the informal caregiver (quote 3). The CM appears to interests of the informal caregiver. One informal caregiver already has experience with and knows the course of the disease. In another care network the informal caregiver does not want involvement in the decision-making process because they make all further arrangements, with regards to make decisions themselves. In generally, care networks are satisfied when CM's using their own expertise.

Using own professional network

CM's use deliberation with and feedback from the professional network for making or evaluating decisions (quote 4). This illustrates that CM's look for confirmation and feedback from their peers to provide the best accompaniment in decision-making. In two care networks the CM did not consult their professional network. This relates to the care networks the CM's are less involved during decision-making.

Advising and informing

CM is: giving advice, educates, and present solutions in the decision-making process (quotes 5 and 6). The CM tries to give insight into the disease and how decision-making during this illness trajectory takes place, only when there is a sharing need from the care network for receiving advice.

Informing and giving options or alternatives put the CM into an informational role to receive access and apply relevant information to informal caregivers to understand the illness trajectory of dementia in combination with making decisions (quote 7). One care network does not express this category. The CM is little involved in the decision-making process in this network. The other four care networks uses the CM for advice and information.

Monitoring

Monitoring include the way that the CM moves actively with the preferences of the care network in a watching position from the background to manage decisions. It is a conscious choice, because the network can handle the situation at that moment. The CM keeps an eye on the situation. This theme contains: 1) Awaiting and 2) Participating in the background.

Awaiting

The CM encourages contact with the informal caregivers and decides to wait for a moment that an intervention is necessary and/or safety cannot be guaranteed (quote 8). The CM stays in the present and does not want to anticipate what is coming. Sometimes waiting for a crisis is the best way of involvement to provide PWD's autonomy. This does not mean that no other decisions are made, because making no decision may lead to another problem for which decisions are necessary.

Also possible is a 'wait-and-see' attitude whereby a decision would fall into place. Not every CM uses waiting due to that decisions have already been made or safety could not be provided.

Participating in the background

This category differs from the previous category in the way that the CM has no directly contact with the care network and is not involvement in decision-making. From CM's perspective they stay involved in the care process and received information from other professional caregivers but plays no decisive role.

In two networks the CM participate in the background. The informal caregiver(s) did not involve the CM (quote 9).

Stimulating

Stimulating in the decision-making process means that the CM has a steering function in the moment of deliberation about making decisions to the PWD and informal caregivers. The aim of the CM being a stimulator is to let the care network think and collaborate about making choices and decisions and 'push' them to decide which decisions have to be made. The CM is more noticeable and present in this function. This theme consists of: 1) Taking the lead in timing and content of decision and 2) Preparing for the future

Taking the lead in timing and content of decision

The CM provides safety and has a supportive role in decision-making. Timing means looking for and knowing the right moment at the right time to make decisions. Informal caregivers

are often ready for making decisions (quote 10). The PWD cannot always make a decision, because of the cognitive disability, to oversee the content of the decision, or is not aware of future decisions. The informal caregiver looks after the interests of the PWD and cannot always make the decision, when there is no agreement and/or collaboration with the PWD. Therefore, the CM has a motivating role to the PWD and the informal caregiver in order to reach this agreement. During the first stage of this study, most CM's took the lead in timing and content of the decision. This can be linked to the fact that the care network asked for more steering in the decision-making process at the start of this study.

Preparing for the future

The CM makes future plans and gives information about future prospects. Preparing care networks for the future is something that must come from the CM. Most of the informal caregivers are worrying about the future, but focus on the present to stay more in line with the interests of the PWD depending on cognitive decline of dementia. PWD cannot oversee the impact of making decisions, let alone that oversee prospects for the future.

The care network is less focussed on making decisions for the future (quote 11). At the start of the research the CM spoke about future prospects. Interviews after half a year and a year show no future plans were discussed within the network.

Advocate

Decisions should be made to reach the best way of alignment for the PWD. This can be with or without involving the PWD. The primary consideration is that decisions will be made for the PWD's best interests. All CM's use this role, but the decision should also be in line with interests of the informal caregiver(s). This role is applied during the entire decision-making process, because it puts the PWD as central focus. Making the right decision for PWD, that is where it is all about.

This theme includes: 1) Ensuring calm for PWD and 2) Supporting autonomy.

Ensuring calm for PWD

CM tries to make decisions in the right way (with or without involving PWD) for providing unnecessary anxiety and/or agitation for the PWD (quote 12). Informal caregivers and CM discuss about decisions for a best fit with the character of the PWD.

Supporting autonomy

For making the right decision the CM can deliberate with PWD about decisions to provide more control over their lives. Listening to the preferences of the PWD, recognize them as

unique individuals and making efforts to elicit their own perspectives can help in the decision-making. The CM feels the responsibility for involving the PWD in the decision-making process to provide the right (shared) decisions and giving the feeling of autonomy. (quote 13).

Construction of interrelationships

After analysing interrelationships a core theme shows up: connecting. Investing in a building (care) relationship, with all stakeholders involved in the care network, to connect with each other, is the basis of becoming involved in the decision-making process. It all starts with being clear and express expectations (quote 2). When the CM is involved at the start of the care process in dementia care networks, they become more involved during the care trajectory. It is the beginning of an interactive process between the roles of connecting, expert, monitoring and stimulating. The role of advocate is provided during the entire process of decision-making because it ensures the PWD as central focus during the entire decision-making process (Figure 3).

<Insert Figure 3>

DISCUSSION

The findings of this study suggest five different roles during the decision-making process within care networks of PWD living alone. Connecting is the core theme as and will be followed by expert, stimulator, monitor and advocate.

Prior work has documented that the role of the CM in decision-making is becoming increasingly popular. Publications published significant positive effects about the role of the CM, for example: reduction in distress, caregiver burden and depression^{30, 31, 32}. However, studies conducted great variations in terms of CM. Verkade¹³, for example, reports that components of case management are essential, but that there should be awareness of the various forms of CM's that exists, not mentioning which forms. The results of the current study confirm that CM uses different roles in the decision-making process of PWD who live alone by mentioning the specific five roles and their interrelationships.

A previous study of Groen-van de Ven²¹ confirms that CM supports decision-making by giving advice, stimulating decisions, taking the lead by making a decision and giving their own perception. Another conclusion from that study²¹ is that the role of the CM emphasises an important supportive role to the informal caregiver. This study shows this supportive role, but is comprehensive to the other participants of the care network, what means they also need to recognize when en who needs to be involved in supporting SDM.

The role of connector shows many similarities with the phase of constructive engagement in the collaborative deliberation model of Elwyn¹⁸. This model, existing of five elements, is used in SDM and relates to deliberation and collaboration in the decision-making process.

Because connector is the core theme of this study this will provide a new perspective in SDM related to dementia care networks where the PWD lives alone.

According to the professionalization of the CM there are similarities between the CanMEDS roles^{15, 16} and the investigated roles in this current study. Matches are found between the roles of expert and advocate. The investigated role of connector in the current study contains both roles of communicator and collaborator from the CanMEDS and the role of monitor shows agreement with the role of manager. Only the role of stimulator, found in the current study, appears as newfound role. This means for the development of the CM's profession that a first step has been taken towards acknowledgement for the professionalization of case management in dementia care networks where PWD lives alone.

In this study the characteristics of the PWD, the CM's role and the informal caregivers are not taken into account in every care network. Some roles are more present and/or will be used more during decision-making to the different care networks. The suspicion is that the

functions and attitude of the CM in decision-making can be related to typologies. Nonetheless, there is no evidence based on this number of CM's due to the fact that no saturation is reached. To make a statement to these preliminary results, further research is needed.

Limitations and strengths

One of the strengths of this study was that already available data provides more time for data analysis and reanalysis of multi-perspective rich data offer new interpretations.

Interviews were double coded, which contributes to the reliability of the findings.

This study has several limitations. First, conducting a secondary analysis with already available data stated dependency of the existing data and the questions were asked during the interviews. Besides that, there is a lack of familiarity with the data. Second, different interviewers collected data and did not receive all relevant information for answering the aim of this study. Third, CM's were not involved during the complete data recruitment, since the PWD received institutional care in a nursing home. Finally, the multi-perspective view can be questioned because only responses from CM's and informal caregivers were useful.

CONCLUSION

Notably, this is the first study in which CM's roles in decision-making process within care networks of PWD living alone are investigated and gives a detailed insight into five roles that represent CM's involvement in decision-making as an interactive process with core theme connecting, followed by expert, stimulating, monitoring and advocate.

RECOMMENDATIONS

Professionals, care networks and care programs should be aware of the diverse roles CM's use in dementia care networks. Building awareness is necessary for facilitating these roles into SDM and further development of CM's profession.

There is an important need for further international multi-perspective research into CM's profession development in the decision-making process within care networks of PWD living alone.

REFERENCES

1. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*. 5th ed. San Francisco 2013.
2. Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-5) (2013). *American Psychiatric Association*, San Francisco
3. Smit D, de Lange J, Willemse B, Pot AM. The relationship between small-scale care and activity involvement of residents with dementia. *Int Psychogeriatr*. 2012;24(5):722-732. doi: 10.1017/S1041610211002377 [doi].
4. Alzheimer Nederland. Wat is dementie. http://www.alzheimer-nederland.nl/media/438873/infopdf_wat_is_dementie.pdf. Updated 2014. Accessed 07,
5. Centraal Bureau voor de Statistiek. More elderly people living alone. <http://www.cbs.nl/NR/rdonlyres/1590CBAF-B153-4BCB-9D12-A3D787746576/0/pb01e112.pdf>. Updated 2012. Accessed 05/29, 2001.
6. Smits CH, van den Beld HK, Aartsen MJ, Schroots JJ. Aging in the Netherlands: State of the art and science. *Gerontologist*. 2014;54(3):335-343. doi: 10.1093/geront/gnt096 [doi].
7. Livingston G, Leavey G, Manela M, et al. Making decisions for people with dementia who lack capacity: Qualitative study of family carers in UK. *BMJ*. 2010;341:c4184. doi: 10.1136/bmj.c4184 [doi].
8. Mitoku K, Shimanouchi S. The decision-making and communication capacities of older adults with dementia: A population-based study. *Open Nurs J*. 2014;8:17-24. doi: 10.2174/1874434620140512001 [doi].
9. Samsi K, Manthorpe J, Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. *Int Psychogeriatrics*. (2013) 25(6), 949-961
10. Groen – van de Ven L, Nijman E, Smits C, Family participation and informal caregivers: Shared decision making in dementia care networks *Research group elderly care innovations, Centre of expertise in Health care en social work*. (2012) Windesheim University of applied sciences
11. Smeybe KL, Kirkevold M, Engedal K. How do persons with dementia participate in decision making related to health and daily care? A multi-case study. *BMC Health services research*. (2012) 12;241
12. Hirschman KB, Joyce CM, James BD, Xie SX, Karlawish JHT. Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them? *Gerontologist*. (2005) 45; 381-388
13. Verkade PJ, van Meijel B, Brink C, van Os-Medendorp H, Koekkoek B, Francke AL. Delphi research exploring essential components and preconditions for case management in people with dementia. *BMC Geriatr*. 2010;10:54-2318-10-54. doi: 10.1186/1471-2318-10-54 [doi].
14. Peeters JM, Francke AL, Pot AM. Organisatie en invulling van "casemanagement dementie" in Nederland. Verslaglegging van een landelijke peiling onder regionale projectleiders *Nivel/Trimbos-instituut* 2011
15. Ringsted C, Hansen T, Davis D, Scherpbier A. Are some of the challenging aspects of the CanMEDS roles valid outside Canada? *Medical Education* (2006) 40: 807-815
16. Frank J.R. The CanMEDS 2005 physician competency framework. Better standards. Better physicians. Better care. *Ottawa: The Royal College of Physicians and Surgeons Canada*.
17. Barry MJ, Edgman-Levitan S. Shared decision making-pinnacle of patient-centered care. *New England Journal of Medicine*. 366(9); 780-781

18. Elwyn G, Lloyd A, May C, van der Weijden T, Stiggelbout A, Edwards A, Frosch DL, Rapley T, Barr P, Walsh T, et al. Collaborative deliberation: a model of patient care. *Patient Education and Counseling* 2014
19. Stiggelbout AM, Van der Weijden T, De Wit MP, et al. Shared decision making: Really putting patients at the centre of healthcare. *BMJ*. 2012;344:e256. doi: 10.1136/bmj.e256 [doi].
20. Wolfs CA, de Vugt ME, Verkaaik M, et al. Rational decision-making about treatment and care in dementia: A contradiction in terms? *Patient Educ Couns*. 2012;87(1):43-48. doi: 10.1016/j.pec.2011.07.023 [doi].
21. Groen – van de Ven, L.: Smits, C.: Span, M.: Jukema, J.: Coppoolse, K.: de Lange, J.: Eefsting, J.: Vernooij-Dassen, M. Living in the present and preparing for the future: The dynamic, temporal and collaborative process of shared decision-making in dementia care networks. Accepted 2014.
22. Coyne IT. Sampling in qualitative research. purposeful and theoretical sampling; merging or clear boundaries? *J Adv Nurs*. 1997;26(3):623-630.
23. Charmaz K (2006) Constructing grounded theory: a practical guide through qualitative analysis. SAGE, London
24. Corbin J, & Strauss A, Grounded theory research: procedures, canons, and evaluative criteria. *Qualitative Sociology*, 1990 13(1), 3-22
25. NVivo [computer program] (2014) Version 10. QSR International, Doncaster Victoria
26. Nancy R. Tague's *The Quality Toolbox*, Second Edition, ASQ Quality Press, 2004, pages 96–99.
27. Scott KW, Relating categories in grounded theory analysis: Using a conditional relationship guide and reflective coding matrix. *The Qual report*, 9(1), 113-126.
28. Strauss A, Corbin J, Basics of qualitative research: Techniques and procedures for developing grounded theory (2nd ed) Newbury Park, CA: sage
29. World Medical Association Declaration of Helsinki. Ethical principles for medical research. *Journal of the American Medical Association*. 2013;2191(4):310-20
30. Callahan CM, Boustani MA, Unverzagt FW, Autstrom MG, Damush TM, Perkins AJ, Fultz BA, Hui SL, Counsell SR, Hendrie HC. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. *JAMA* 2006, 295(18):2148-2157
31. Chu P, Edwards J, Levin R, Thomson J. The use of clinical care management for early stage Alzheimer's patients and their families. *American Journal of Alzheimer's Disease* 2000, 15(5):284-290
32. Newcomer R, Yordi C, DuNah R, Fox P, Wilkinson A. Effects of the Medicare Alzheimer's Disease Demonstration on caregiver burden and depression. *Health Serv Res* 1999, 34(3):669-689