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Needs in Early Onset Dementia: A Qualitative Case From the NeedYD Study

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American Journal of Alzheimer's
Disease & Other Dementias[®]
000(00) 1-7
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DOI: 10.1177/1533317510385811
<http://ajadd.sagepub.com>



Abstract

Objectives: The aim was to explore the experiences of a caregiver of a patient with early onset dementia (EOD) and the needs of patient and caregiver. **Methods:** A single case study design was used to explore (1) unmet needs of patient and caregiver and (2) caregiver's experiences of transitions in care and health care services. A qualitative analysis was used to examine the data. **Results:** This study shows that a patient with EOD and the caregiver were confronted with specific issues during the care process, namely (1) prolonged time to diagnosis, (2) a lack of fit between needs and services, (3) the strain of dedication to care versus the caregiver's own future perspective, (4) the need for response of health care services to changing individual preferences. **Conclusion:** This study illustrates specific issues related to early onset dementia that require specialized EOD care such as the differential and changing needs of patients and caregivers.

Keywords

caregiver, needs, early onset dementia, qualitative study

Introduction

Dementia is typically regarded as a disease of old age, but in 3% to 5% of the patients, onset of the disease occurs before the age of 65.¹⁻⁴ When dementia occurs at an early age, the psychosocial implications for both the patient and family are numerous. Patient with early onset dementia (EOD) are in a life phase in which they often play an active role in society and may have young children. The loss of roles and responsibilities is, therefore, greater than that of older people. They must also deal with specific issues such as difficulties in obtaining a proper diagnosis, marital problems, family conflict, unemployment, and financial issues.⁵⁻⁷ Furthermore, many patients with EOD of the postwar generation grew up in a society that is quite different from that of the older generation. The needs of EOD patients may as a result differ from the needs of patients with late onset dementia and demand a different approach. A need is defined here as a situation in which an individual experiences a significant problem that impedes functioning.

Despite these differences, the availability of specialized health care services remains limited in most countries. This forces patients with EOD and their family members to use services that are designed for the elderly individuals and are less likely to meet their needs. At present, there is no agreement among researchers regarding whether specific guidelines and services should be developed to meet the needs of these younger individuals and their families or whether existing health care services must be more responsive to these specific

needs.⁸ This stresses the importance of gaining insight into all possible needs of patients with EOD and their families.

From research on needs of older people with dementia in residential care,⁹ it is known that unmet needs are associated with an increase in behavioral problems and that younger age is associated with a higher number of unmet needs. Roest et al¹⁰ found that the needs of older patients with dementia and their caregivers are less related to instrumental needs but more associated with how they cope with the disease and well-being. It is, to our knowledge, unclear whether this is also true for patients with EOD and their caregivers. Furthermore, domains that influence the quality of life of the patients with dementia and his/her primary caregiver are subject to change as the

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disease progresses and, with that, needs are also likely to change. Transitions in care, for example when daycare begins or the patient is admitted into a nursing home, especially lead to a shift in the hierarchy of the domains that influence the perception of quality of life.¹¹

Most of the current research on needs and services for patients with dementia and their caregivers focuses on elderly sufferers. Specific knowledge on the characteristics and needs of patients with EOD and their families is lacking, but this knowledge is an important prerequisite for the development of suitable health care services. Adequate diagnosis, informal support and services such as support groups, daycare facilities, and respite care may help patients and their families cope with the situation and may even postpone institutionalization.¹² Especially in early onset dementia, there is a need to understand the effect of the disease on both patients' and family members' functioning and family roles with regard to their specific life phase.

In the current case report, we explored the experiences of a spouse of a young person with dementia and studied how the needs of both the patient and his wife developed and changed over time from the perspective of the spouse. Furthermore, we explored experiences and views concerning provided health care services.

Method

We used a single case study design. Cognitive functioning of the patient, disease state, and neuropsychiatric symptoms were assessed with validated measures. Qualitative interviews with the caregiver were used to explore how the caregiver perceived met and unmet needs of both the patient and caregiver and how she experienced transitions in care and health care services provided. We used qualitative methods because they are especially suitable to study complex topics and allowed us to thoroughly explore experiences and needs.¹³ A patient who underwent transitions in care was randomly selected from a sample of 217 cases of a 2-year follow-up study on Needs in Young Onset Dementia (NeedYD).¹² Data were collected at time of inclusion and after 6 and 12 months. Written informed consent was obtained for both the patient and caregiver.

Cognitive functioning of the patient at baseline was assessed with the Mini Mental State Examination.¹⁴ This is a widely used screening instrument in dementia. In addition, the Short Severe Impairment Battery (SIB)^{15,16} was used because it is especially suitable for assessing cognitive functioning in severely impaired patients with dementia.

Severity of the dementia was assessed with the Global Deterioration Scale¹⁷ using a 7-point scale (1-7), ranging from "no global impairment" (1) to "very severe global impairment" (7). Neuropsychiatric symptoms and caregiver burden were assessed at baseline, 6 and 12 months using the Neuropsychiatric Inventory (NPI).¹⁸ Depressive symptoms of the caregiver were measured at baseline and after 12 months using the Montgomery Asberg Depression Rating Scale (MADRS), which has adequate interrater reliability and exhibits construct and concurrent validity.¹⁹

Table 1. Interview Guide

Period prior to diagnosis
Diagnosis
Period after diagnosis
Caring
Transitions in care
Future perspective

A trained researcher (CB) held semistructured interviews at baseline and after 12 months according to an interview guide (see topics listed in Table 1) with topics derived from clinical practice and the relevant literature. In the NeedYD study, the Camberwell Assessment of Needs in the Elderly (CANE)²⁰ is used to assess needs of patient and caregiver. Because of the explorative character of this case study to gain new insights into the complex experiences and evolving needs of the caregiver, we used the narratives as a result of the administration of the CANE, for the qualitative analysis in addition to the data of the semistructured interviews.

The audiotapes of the semistructured interviews were fully transcribed. An inductive content analysis²¹ was used by the first author (CB) to compare similarities and differences to understand relationships in the data concerning problems met, perceived needs of both the patient and his wife, and experiences with health services. Quotes of the caregiver were coded. Codes referring to the same phenomenon were grouped into categories and the categories were grouped into themes. A second researcher (MdV) independently applied the same procedure. After thorough discussion, consensus was reached about categories, subcategories, and the major themes.

Results

Case Description

The patient was a 59-year-old male with early onset Alzheimer's disease. The first problems retrospectively occurred when the patient was 50 years old. At that time, he often forgot appointments, experienced difficulties in managing finances, and also lost his job as a salesman because he was not able to function properly. He attempted to obtain other jobs, but without success. At the time of the first symptoms of the disease, his wife was 46 and she still worked full-time. She noticed that her husband showed less initiative, experienced difficulties executing simple household tasks, and began drinking excessively. She also noticed that her husband became irritated when she confronted him with these things. During the 5 years that followed, both these functional problems and behavioral problems became more severe and she sent her husband to the general practitioner (GP). The GP and a psychologist both thought that her husband was not suffering from a serious problem and suggested a minor concentration problem as well as marital difficulties. Nearly another year passed and symptoms worsened. When the patient's wife forced a referral to a memory clinic, a diagnosis of early onset Alzheimer's disease was established within 3 weeks. The patient was included in the NeedYD study at the age

Table 2. Baseline Characteristics of the Patient

Gender	Male
Diagnosis	Alzheimer's disease
Age at onset	50
Age at diagnosis	56
Age at inclusion in the NeedYD study	59
Disease state	
Global deterioration scale–score	5/7
Cognitive functioning	
Mini mental state examination score	4/30
Short impairment battery score	24/37

Abbreviation: NeedYD, needs in young onset dementia.

of 59 (patient's baseline characteristics are summarized in Table 2). At that time, he was still living at home and visited a specialized daycare centre 5 days a week.

At the time of inclusion, the cognitive functioning of the patient was severely impaired (Table 2). Furthermore, the caregiver reported delusions, hallucinations, agitation, depression, anxiety, euphoria, disinhibition, irritability, aberrant motor behavior, and nighttime disturbances on the NPI (NPI frequency \times severity total score: 39). The caregiver found these behavioral problems to be quite distressing (NPI-D total score: 33). At that time, she also reported minor feelings of tension and lassitude, but no other depressive symptoms (MADRS total score: 4/60). In the first month after inclusion, the severity of behavioral problems and especially anxiety and aggressive behavior worsened according to the caregiver and the patient was admitted into a nursing home at a dementia special care unit for the elderly people. In spite of the prescription of psychotropic medication, behavioral problems continued, and apathy/indifference was also observed as a new behavioral problem at that time.

Two months after admission, the patient was transferred to a special care unit for patients with EOD. We visited the patient a second time and it appeared that the frequency and severity of behavioral problems had decreased (NPI total score: 15). However, at time of the third assessment, agitation/aggression and irritability reappeared, especially when the nursing staff offered help with activities of daily living. Furthermore, apathy and aberrant motor behavior continued (NPI total score: 20). The behavioral problems present still were experienced by the caregiver as moderately distressing (NPI-D total score: 13). The caregiver experienced no depressive symptoms at that time (MADRS total score: 1/60).

Qualitative Results

Analysis of the qualitative data resulted in 3 major themes in the caregiver's experiences of the care process: (1) Making choices in the care situation, (2) Conditions for the use of care, and (3) Involvement in care. An overview of codes, categories, and themes is provided in Table 3.

Making choices in the care situation. Throughout the course of the disease, the caregiver encountered a range of emotional and moral dilemmas in which the decision making *process* was an

important issue, leading to an increase in experienced caregiver burden. The *reciprocity* in the relationship gradually diminished and, in the end, the caregiver was forced to make all of the decisions concerning work, finances, the household, and the care of her husband.

Cg: I really felt abandoned. At that time, I really thought: I am going to take care of things myself because managing all these things together with my husband is not going to work.

(...) 'I had all these things on my mind, and my husband just sat there all day doing nothing.'

A proper and timely diagnosis was perceived as an important prerequisite for (1) being able to perceive the (behavioral) problems that occurred such as aggression, irritability, and excessive drinking of her husband as a symptom caused by the disease and (2) obtaining appropriate care in time. The patient denied that he had a problem.

Cg: At that time, I did not know that he was ill. He did not want to see a doctor. I thought: If you are not ill, I will leave you ... it could have ended in a divorce.

Furthermore, the GP and the psychologist that she and her husband visited did not recognize the disease. This resulted in a delay of the caregiver's search for appropriate support and in feelings of guilt.

Cg: My husband went three times and the psychologist was more or less angry with me. I had to give my husband more space; there was no dementia, no brain tumor, only a minor concentration problem. I left and thought: maybe I am interfering with his life too much. I blamed myself.

Only after the diagnosis was established, the caregiver was able to *change her perspective* on the situation and to seek appropriate support such as daycare and a support group. However difficult, the diagnosis was an important marking point and led the caregiver to decide to stay in the marriage and care for her husband. It also allowed her to begin *grieving*.

Cg: Finally, I had the answer to what had gone wrong in the past four, five years.

Cg: When my husband was asleep, I was in the living room, crying and thinking, not knowing what the future might bring. (...) I was only just 50 years old. (...) How devastating for him ...

Furthermore, the *duality* in the caring situation, combining continuing care with maintaining a life of her own, was an important issue from the perspective of the caregiver. The caregiver gradually realized (with the support she received from the coordinator at the daycare centre) that to remain able to care for her husband, she also had to meet her own needs.

Cg: I would like to be able to enjoy myself again, but I am not sure that I really can. (...) But I will have to try. Imagine that

Table 3. Overview of Codes, Categories and Major Themes

Themes	Categories	Codes
Making choices in the care situation	Decision-making process	Making decisions without the patient, ambivalence, combining (new) roles, fear of diagnosis, financial and legal issues, patients' approval, social consequences.
	Diminishing reciprocity	Loss of roles, feelings of abandonment, loneliness, giving and taking, quality of the relationship, communication.
	Changing perspectives	Diagnostic issues, changing symptoms of the disease, grief, burden of care
	The duality in the caring situation	Entanglement, maintaining a life of your own.
	Adjusting to change	Dealing with loss, dependency, coping with behavioral changes.
Conditions for the use of care	Need for information	Questions about symptoms of the disease, the course of the disease, practical issues, availability of services, legal/financial issues.
	Changing needs	Practical needs, functional needs, activity, being among peers.
	Confirmation	need for reassurance, guidance, comprehension.
	Availability of (in)formal support	Safety net, practical aid, someone to talk to, social support.
Involvement in care	Continuity in care	Understanding EOD, burden of transitions in care, access to the same professionals.
	Commitment and dedication to care	Feelings of guilt, concern for the patients' future, fear of harm, comfort patient, changing relationship.
	The process of letting go	Retain control, adjusting to change, personal growth, ambivalence, emotional problems, practical boundaries.
	Trust	Experiences with informal care, referral to appropriate services, image of health care services, medical care.
	The fit between needs and services	Ability of services to meet the patients' needs, patients' personal needs, selfhood and self-esteem, resisting care.

Abbreviation: EOD, early onset dementia.

he will be at home for two more years. No vacation for two or three years with continuing care. When he's at home I constantly have to be on my guard. If I do something wrong, he gets angry, thus I do everything to keep him happy.

In terms of respite care, she expressed:

Cg: It is very difficult, but I do know, and I approach this rationally, he has to be there for a few nights. As a result, I will be able to care for him at home much longer, he has got to get used to being here. This will become his future home eventually. (...) The fact that he has daycare and sleeps at the nursing home two days a week, makes that I have been given back a piece of my life.'

Conditions for the use of care. As the disease progressed and especially during transitions in care, such as the start of daycare or the admission of the patient into the nursing home, needs *changed*. At times, there was a need for specific information about the course of the disease, dealing with behavioral problems, psychosocial problems of the patient, or practical information about addressing the personal or instrumental needs of the patient. This information, for example, was provided by the coordinator of the daycare centre and partially by a caregiver support group that she infrequently visited:

Cg: When my husband gets in a different stage, I just want to know how others deal with that. I don't have to go every month, which would be too much. (...) I do not want to listen to their stories; I have enough on my mind as is.

There was also a need for *confirmation* from health care professionals of the decisions that the caregiver made, such as planning a vacation and admitting her husband into the nursing home.

Cg: I thought I will not take that vacation, but then I talked to the coordinator of the daycare centre and she said, "If you never take a few days off, you will not be able to manage." And that is true. (...) "I am glad that she said that."

Cg: Maybe I can talk to a psychologist who can alter my way of thinking. Maybe he can take away the guilt.

As needs changed, the *availability* of supportive professional caregivers was mentioned as another important prerequisite throughout the caring process.

Cg: You have to grow into each stage of the disease. But I do need the support of others, who you can call, whenever you need to. I have that now here at the daycare centre, I can call them. (...) We have a fine GP and neurologist, I can always call them.

Furthermore, there was also a need for *continuity* in care, meaning the availability of support throughout the course of the disease for both the patient and caregiver from the same health care professionals. This was important, for example, when talking about the fact that she had met another man and that this fact troubled her:

Cg: Friends do understand. I do know friends I can talk to about these things, but they are not professionals. (...) What I do

need now is a professional I can talk to about the changes in my life. (...) You would think that would be possible at the nursing home where my husband is staying. Especially for partners of young patients with dementia who want to pick up their own lives again. They should be much more able to understand these kinds of issues.

Involvement in care. The great commitment to the care of her husband resulted in little room for other things in the caregiver's life, such as a personal job, social contacts, and relaxing.

Cg: The most important issue for me is that he is comfortable. I hope, in spite of everything, that he is happy. (...) I spent so much time caring for him. My life revolves around Alzheimer's disease.

Despite the caregiver's dedication during the caring process, it became clear that (1) the caregiver and her husband needed additional help from others, such as friends and professionals and (2) the caregiver *had to let go* and allow others to gradually take over.

Cg: I just want to know how we can get through this together. You have to accept practical help. I saw people who did not want help for their partner, wanted to do everything themselves. But then, you are not going to cope. I do not want to listen to them. I want to do it my way. That is better for me.

Regarding the decision to admit her husband into the nursing home, she stated:

Cg: My biggest concern is that I will not be able to let go. I don't want to let go. I hope I will not have the urge to go see him every day. I hope that I can let go, let go of caring. I suppose I have to grow into that as well.

In this respect, *trust* was also an important issue that influenced the caregiver's ability to allow others to tend to the needs of her husband. Especially when there was not a good *fit* between support, services, and the needs of her husband, this was particularly distressing for both the patient and caregiver. When talking about the first weeks of admission into a dementia special care unit for the elderly people in the nursing home, the caregiver expressed:

Cg: At first, he was very rebellious; he did not want people helping him. (...) He was among older people with dementia with fewer activities and he just walked around there, lost. (...) It was very difficult for him. (...) He was in distress during that period. He said: I'll jump of that roof.

The importance of a good fit between needs and services is illustrated by the transfer of the patient to a special care unit for patients with EOD. A few months after the transfer, the patient's behavioral problems decreased and well-being improved. This also enabled the caregiver to reduce her share in the care for her husband.

Cg: This unit is right for him. (...) Now I let them take care of him. I also have confidence in them now. Before, I constantly had the feeling I had to visit him. I can somewhat let go now because I can see there is more personal attention from people working at this unit. (...) I think the way they approach people in this unit is different. I think it is less patronizing, more direct, more personal.

Although the care environment seemed to be an improvement for the patient, the caregiver noticed that the personal needs of her husband were not fully met by the nurses. This influenced her perception of her role in the caring process while her husband was residing at the nursing home. When talking about his incontinence, she stated:

Cg: I already told them before; you have to change his incontinence material (diapers) regularly. I already noticed several times that he is wet, just because they don't replace the incontinence material in time. (...) I wonder what happens when I am not there.

Discussion

This case study revealed 3 major themes in the care process of a patient with EOD. First, the caregiver perceived the decision-making process as complicated and stressful. The decision-making process was complicated by problems related to the specific life phase of the patient and his caregiver. Second, the fit between the needs of both the patient and caregiver and the characteristics of the available support and services was a main concern for the caregiver. As the disease progressed, and especially when there were transitions in care, the expectations toward health care services and informal support changed. Third, the involvement of the caregiver during the care giving process was influenced by the caregiver's perception of the changing needs of her husband, the quality and availability of support and health care services, as well as the dilemma between the dedication to caring for her husband by herself and her own changing future perspectives.

In the process of caring for a patient with EOD, it appears as though the caregiver is confronted with difficulties and issues that are specifically related to their younger age and life phase. Besides the care for her husband, the caregiver was confronted with issues concerning work, financial difficulties, and the household, while her husband became increasingly unable to fulfill his roles as husband and financial provider. These conflicting roles are much more likely to occur in a younger, active life phase than in late life. Furthermore, the caregiver had to deal with severe behavioral problems that remained distressing throughout the caring process. Behavioral problems are known to have important adverse effects on the psychological and physical health of informal caregivers²² and are suggested to be an especially important caregiver issue in EOD.²³ Moreover, this case strikingly showed the dilemma of a younger caregiver dedicated to the care of her family member versus her own future perspective. This complicated the decision-making

process while caring and led to an increase in perceived caregiver burden.

Additionally, obtaining a diagnosis is especially problematic for people with EOD, prolonging the period of uncertainty and adversely affecting the relationship between the patient and his family members. As illustrated by this case, EOD is often not recognized as such by health care professionals. This is likely due to the fact that early onset dementia is not as prevalent as late onset dementia, has a different clinical manifestation (ie, predominant behavioral changes such as those of our patient), and has different cognitive symptoms compared to late onset dementia. This is consistent with the available literature that addresses this issue in EOD.²⁴⁻²⁷ The timely diagnosis of early onset Alzheimer's disease was an important prerequisite for the caregiver in our case to change her perspective on their situation, start grieving, and to seek the appropriate support and health care services, such as specialized daycare, a support group for caregivers of patients with EOD, individual support and assistance with behavioral problems, and intermittent stays at the nursing home. In this case, the availability of these services and support enabled the caregiver to prolong the period that she could care for her husband at home.

As the disease progressed, the needs of both the patient and caregiver were subject to change. This case suggests that this is a dynamic process that is influenced by the cognitive and psychological state of the patient as well as by the presence of behavioral problems and the ability of both the patient and caregiver to cope with the consequences of the disease. From this case, it is also clear that a good fit between the developing needs and the support and health care services available is important. When these services were responsive to the individual needs of the patient and his caregiver, the patient's behavioral problems decreased. This also enabled the caregiver to entrust others with the care of her husband and eventually led to an increase in both the patient's and caregiver's well-being.

Services designed for the elderly people, like the unit where the patient first resided after admission to the nursing home, did not adequately address the needs of the patient. It is likely that services designed for the elderly people have more difficulty recognizing the specific needs of these younger people and have less resources to meet those needs.²⁸ In our case, the overall combination of services specifically designed for patients with EOD seemed beneficial for both patient and caregiver. The caregiver perceived that these EOD services did better fit her and her husband's needs, but still had difficulty addressing the functional and ADL needs of the patient and her need for individual support. Thus, also EOD services can be improved by further integrating care throughout the different stages of the dementia process and by offering the possibility for both patient and caregiver to receive care and support from the same health care professionals, for instance a case manager during the course of the disease. It is likely that health care professionals are able to be more responsive to the individual wishes and preferences when they are involved throughout the course of the disease and are aware of the issues of both the patient and caregiver.

Conclusion

This study shows that a patients with EOD and caregiver were confronted with specific issues during the caring process, namely (1) the prolonged time to diagnosis, (2) the fit between the patient and caregiver needs and the available health services, (3) the strain of dedication to care versus the caregiver's own future perspective, and (4) the need for response of health care services to the changing individual wishes and preferences during the course of the disease. This study illustrates that there is a need to develop specific care and care programs for younger people with dementia and their families. Based on this study, we suggest that these care programs should include the monitoring of changes in patient and caregivers' needs and address the issue of continuity in care. We believe that these younger patients and their families would benefit from the support of a case manager that has specific knowledge on the issues in EOD and has insight in which EOD services are available.

This explorative study also has provided important insights into the domains that should be addressed in future (longitudinal) research. This research is needed to further explore the themes found in this case study in a larger group and to more closely examine the effect of a good fit with health care services on the functioning and well-being of both patients with EOD and their caregivers.

Authors' Note

CB designed the study, collected and analyzed the data, and wrote the article. MdV co-designed the study, analyzed the data and assisted with writing the article. MVD advised on the methods for analyzing the data and reviewed the article. DvV reviewed the article. FV reviewed the article. RK assisted with writing the article.

Acknowledgments

We wish to thank both the patient and caregiver for their time and effort and entrusting us with their experiences. We would also like to thank Yvette Daniëls for transcribing the audiotapes.

Declaration of Conflicting Interests

The author(s) declared no conflicts of interest with respect to the authorship and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research and/or authorship of this article: Grant from the Dutch Alzheimer Society and a grant from Florence Care Group in the Netherlands.

References

1. Harvey R, Skelton-Robinson M, Rossor M. The Prevalence and causes of dementia in people under the age of 65 years. *J Neurol Neurosurg Psychiatr.* 2003;74(9):1206-1209.
2. Fujihara S, Brucki S, Carvalho A, Piccolo A. Prevalence of pre-senile dementia in a tertiary outpatient clinic. *Arq Neuropsiquiatr.* 2004;62(3A):592-595.

3. Panegyres P, Frencham K. Course and causes of suspected dementia in young adults: a longitudinal study. *Am J Alzheimers Dis Other Dement*. 2007;22(1):48-56.
4. Shinagawa S, Ikeda M, Toyota Y, et al. Frequency and clinical characteristics of early-onset dementia in consecutive patients in a memory clinic. *Dementia Geriatr Cogn Disord*. 2007; 24(1):42-47.
5. Harris P, Keady J. Living with early onset dementia: exploring the experience and developing evidence-based guidelines for practice. *Alzheim Care Q*. 2004;5(2):111-122.
6. Kaiser S, Panegyres P. The Psychosocial Impact of Young Onset Dementia on Spouses. *Am J Alzheimers Dis Other Dement*. 2006;21(6):398-402.
7. Van Vliet D, De Vugt M, Bakker C, Koopmans R, Verhey F. Impact of early onset dementia on caregivers: a review. *Int J Geriatr Psychiatry*. 2010. In press.
8. Harris P. The subjective experience of early-onset dementia: voices of the persons. Paper presented at: The 55th Gerontological Society of America Annual Meeting;. November 26, 2002; Boston, MA.
9. Hancock G, Woods B, Challis D, Orrell M. The needs of older people with dementia in residential care. *Int J Geriatr Psychiatry*. 2006;21(1):43-49.
10. Roest van der H, Meiland F, Maroccini R, Comijs H, Jonker C, Droës R. Subjective needs of people with dementia: a review of the literature. *Int Psychogeriatr*. 2007;19(3):559-592.
11. Droës R, Boelens-Van der Knoop E, Bos J, et al. Quality of life in dementia in perspective: an explorative study of variations in opinions among people with dementia and their professional caregivers, and in literature. *Dementia*. 2006;5(4):533-558.
12. Van Vliet D, Bakker C, Koopmans R, Vernooij-Dassen M, Verhey F, De Vugt M. Research protocol of the NeedYD-study (Needs in Young onset Dementia): a prospective cohort study on the needs and course of early onset dementia. *BMC Geriatr*. 2010;10:13.
13. Baarda D, de Goede M, Teunissen J. Basisboek Kwalitatief onderzoek. Handleiding voor het opzetten en uitvoeren van kwalitatief onderzoek. Stenfert Kroese; 2005.
14. Folstein M, Folstein S, McHugh P. Mini-mental state: a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975;12(3):189-198.
15. Saxton J, Kastango KB, Hugonot-Diener L, et al. Development of a short form of the severe impairment battery. *Am J Geriatr Psychiatry*. 2005;13(11):999-1005.
16. Jonghe de JF, Wetzels RB, Mulders A, Zuidema SU, Koopmans RT. Validity of the severe impairment battery short version. *J Neurol Neurosurg Psychiatry*. 2009;80(9):954-959.
17. Reisberg B, Ferris S, de Leon M, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry*. 1982;139(9):1136-1139.
18. Cummings J, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J. The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology*. 1994;44(12):2308-2314.
19. Davidson J, Turnbull C, Strickland R, Miller R, Graves K. The Montgomery-Asberg Depression Scale: reliability and validity. *Acta Psychiatr Scand*. 1986;73(5):544-548.
20. Reynolds T, Thornicroft G, Abas M, et al. Camberwell assessment of needs for the elderly. *Br J Psychiatry*. 2000;176:444-452.
21. Elo S, Kyngas H. The qualitative content analysis process. *J Adv Nurs*. 2008;62(1):107-15.
22. Vugt de M, Nicolson N, Aalten P, Lousberg R, Jolles J, Verhey F. Behavioral problems in dementia patients and salivary cortisol patterns in caregivers. *J Neuropsychiatry Clin Neurosci*. 2005; 17(2):201-207.
23. Arai A, Matsumoto T, Ikeda M, Arai Y. Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia? *Int J Geriatr Psychiatry*. 2007;22(12):1255-1261.
24. Mendez M. The accurate diagnosis of early-onset dementia. *Int J Psychiatry Med*. 2006;36(4):401-412.
25. McMurtray A, Clark D, Christine D, Mendez M. Early-onset dementia: frequency and causes compared to late-onset dementia. *Dement Geriatr Cogn Disord*. 2006;21(2):59-64.
26. Licht EA, McMurtray AM, Saul RE, Mendez MF. Cognitive differences between Early- and Late-Onset Alzheimer's Disease. *Am J Alzheimers Dis Other Dement*. 2007;22(3):218-222.
27. Sampson E, Brayne C, Dawson K, Hodges J. Young onset dementia. *Postgrad Med*. 2008;80:125-139.
28. Luscombe G, Brodaty H, Freeth S. Younger people with dementia: diagnostic issues, effects on carers and use of services. *Int J Geriatr Psychiatry*. 1998;13(5):323-330.