Definition and design of client profiles for dementia clients in the Dutch home care sector

Benchmarking performance of home care providers in order to better estimate healthcare costs

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Abstract

Objective: Develop client profiles based on a set of determinants which predict the costs of home care services for dementia patients.

Study design: We developed client profiles on the basis of a literature review and workshops with representatives of nine home care providers. Client profiles are meant to characterize groups of clients based on determinants with predictable health services efforts and costs. The scope was limited to dementia as main disease. Within the main group of dementia clients eight client profiles are initially defined based on possible values of three determinants. Subsequently, the home care providers gathered and delivered effort and cost data of clients distributed over the client profiles. These data were analyzed together with the results of five additional determinants which were abstracted from the literature and recognized by the representatives. Successively a data analysis has been performed to analyze which determinants – out of the total selected group of eight - are valuable to include in the client profiles for better estimation of efforts and costs according this data set.

Results: We have examined eight determinants. The representatives of the involved home care providers included three of these determinants (*informal support system, formal support system and comorbidity*) for the eight client profiles, because they assume these determinants have the biggest impact on the demand for care and associated healthcare costs. The other five candidate determinants identified were: age, gender, living situation, phase of dementia and the home care provider. Client data including the values of all eight determinants are collected (N=652), and multiple analyses and tests are performed. The data analyses show that the four determinants organizations, comorbidity, age and phase of dementia are the best determinants for predicting home care costs for dementia clients for our data set. These four determinants explain 17.3% of the variation in costs. The initial determinants (informal support system, formal support system and comorbidity) explain only 1.7% of the variation, so 15.6% less. There are also several side-results. One of these results is that we find indirect proof that a strong informal support system ensures that a person can live longer at home and/or become older, and need less formal care. Another result is that the costs of care significantly increases with age and per phase of dementia.

Conclusion: Based on our data set, the eight client profiles based on three determinants defined with the representatives of major home care providers are not the best profiles for cost prediction. The data analyses shows that another set of four determinants out of the researched set of eight are more representative for health care service costs in the defined group of dementia clients. The determinant which explains the biggest part of the variation, is the organizations (8.3% of the 17.3%). This means

that the difference in health care costs between clients (partly) can be explained by the organization where the client receives home care. More research on organization specific characteristics is for this reason advised. Besides of this, before being able to define usable client profiles, additional discriminating determinants must be isolated. Possible candidates may be the income of the client (household) and binary things like smoking/non-smoking. Also more comprehensive data sets needs to be gathered; more clients and a longer period of which data is collected. With identifying representative determinants, useful client profiles which are broadly recognized and accepted in the field can probably be defined in order to predict healthcare costs.

Key Words: Home care, dementia, client profiles, determinants, healthcare costs, benchmarking

Introduction

In 2012, around 630,000 Dutch inhabitants aged 18 years and older received home care (i.e. long term care provided in the home setting). The average amount of service hours per client is 165 hours per year (1). Due to the aging of the population and the shifts currently taking place in the Netherlands from inpatient care to outpatient care, it is expected these figures will significantly rise in the near future and the coming decades. Policymakers, clients, and their families are facing the challenge how to implement cost-effective care for the growing numbers of home care clients (2-5).

Home care providers show large differences in the number of hours of care supplied to customers and the duration of care efforts. Comparisons carried out by the Dutch healthcare insurer Menzis of twelve (major) home care providers showed that the lowest average cost per client of one home care organization is €3,938 per month and the highest average costs €7,090 per month (standard deviation (SD) is €1,024). For hours of care per month provided, these averages are 73 hours and 137 hours (SD 20.74). In conclusion, the costs and hours of care provided by the most expensive home care providers is almost twice as much as of the least expensive home care provider. Such large differences cannot be explained easily, for instance by different client bases.

Currently healthcare insurers have little to no insight into profiles in the home care customer base and the diversity and cost drivers within these profiles. Such profiles would give better understanding as typology will be introduced. Hence, healthcare insurers do not have grip on the average cost of care per kind of customer (6). A literature study has shown that very limited research has been performed on client profiles in the healthcare sector. There are a few studies related to this subject carried out abroad, but none have been carried out in the Netherlands (7-14). In conclusion, currently there is lack of knowledge about this practically relevant topic. This study aims to provide more insights into the characteristics of the home care sector, its clients, and the distribution of costs in this sector for a specific disease.

In order to achieve this objective, two research questions are formulated, related to the two research parts in which the study has been divided:

‘What are appropriate client profiles for long term care provided in the home setting according to representatives of home care providers?’;

and

‘What determinants best predict the demand and costs for home care services, which potentially can form the basis of broadly recognized and accepted standardized client profiles?’.

In this study, we focus on the target group dementia. Dementia is one of the most common diseases among the elderly in the Netherlands (15-17). Because a lot of the people who receive home care are elderly, it is expected that dementia is a common condition in home care.

The study exists of two main research parts. In the first part, together with field workers from nine home care providers out of the north-east of The Netherlands, the characteristics of clients in their working field has been gathered. Out of these insights, the typical elements of a client type has been listed and described. We call them 'determinants'. A set of combination of values of determinants is the foundation for a certain type of clients; a 'client profile'. We aimed to create and define eight profiles. The reason why is chosen for eight profiles, is to limit the scope of the research and enhance the ability of the representatives of the home care providers to collect enough clients for the study. When more client profiles would be compiled, more client date would have to be gathered in the study to draw valid conclusions about the validity of all client profiles. This was not feasible because of time limitations of the study.

In part two of the study, we investigated client profile costs in the home care sector in the north-east of the Netherlands. Each participating home care provider has delivered cost data of approximately 80 clients distributed over the eight profiles. These data were analyzed and compared to identify cost patterns for each client profile and each determinant. The data gathering was implicitly also a proof-of-principle for the usability of the newly generated profiles.

In this article, we first review the relevant literature. Next, the methods of this study are described, followed by the results. The methods and results sections of the article are divided in two parts, accordingly to the two research parts of this study. Finally, the discussion and conclusion are provided.

Literature review

The literature review section consists of four parts. In the first part, the Dutch home care sector is described in order to explain the context of this study. Secondly, a brief overview is given on similar studies which have been carried out abroad. In addition, some possible healthcare payment models will be described. These healthcare payment models give an overview about which healthcare payment model is currently used in the Dutch home care sector and which model is advised to use in the future. Finally, the selected determinants in the client profiles will be further explored and explained in order to be able to develop standardized client profiles.

The literature search has been performed on the databases PubMed, Google Scholar, and Cochrane. Used search terms are *home care, client profiles, dementia, informal care, formal care, comorbidity, case rate financing,* and *comprehensive care payment*.

The Dutch home care sector

In the Dutch home care sector, there are four types of home care, namely counseling, personal care, household help and nursing (18). Counseling involves informing, guiding, recommending, thinking along, and arranging care for the client. In the Netherlands, counseling is often performed by a so-called case manager. For example, people diagnosed with dementia or suspected to have dementia may have a specialized case manager assigned. A case manager monitors and controls at three levels: the client itself, the client system (the client and his relatives together), and the professional and informal care system around the client system (19). Personal care includes for example help with showering or bathing, dressing, mobility support, meal preparation, and eating (20). Household help is a form of home care with professional caregivers to help clients in performing various household tasks, such as cleaning and doing laundry, and with moving in and around the house (18). Finally, nursing includes medical care such as wound care, providing of subcutaneous and intramuscular injections, the insertion of a gastric tube and giving advice for handling with illness (21).

In 2011, around 1397 healthcare providers were operating in the home care setting. Totally, they provided 70.1 million rural care hours, including personal care, counseling, nursing, and household help (1).

Previous studies on the subject
Literature shows that several studies similar to our study have been performed abroad. These studies have only been performed in the inpatient care for elderly and in the hospital setting, and not in the home care sector. Nevertheless, they are still relevant for our study as there are similarities between home care and inpatient care and hospital care as we show later on in this section. There are also differences, such as the higher importance of informal support systems in the home care setting.

Several of the earlier studies are focused on so-called evidence-informed case rates (7, 8). An evidence-informed case rate (ECR) is a single, risk-adjusted, prospective payment given to providers across inpatient and outpatient settings to care for a patient diagnosed with a specific condition. Payment amounts are based on the resources required to provide care as recommended in well-accepted clinical guidelines. The goals of ECRs are (7, 8):

- To limit both underuse and overuse of healthcare;
- Eliminate unwarranted variation;
- Reduce risk selection problems that occur when providers receive the same payment to treat different types of patients;
- Promote clinical integration between providers across disparate settings; and
- Deliver recommended, high-quality care.

De Brantes and Camillus (7) selected ten disorders for ECR development, such as colon cancer and diabetes mellitus type 2. Client profile factors that may require increased services, like age, comorbidity, and gender[1], are taken into account and are considered later on in this article for use in our study. Previous studies have shown that it is possible to create a working set of ECRs (7, 8). ECRs have successfully achieved a limitation on physician-induced demand, a reduction in risk selection problems, the promotion of clinical integration, and the delivery of recommended, high quality care (7-9).

Some other studies focus on the so-called clinical risk-groups (CRGs) (10, 11). CRG is a claims-based classification system for risk adjustment that assigns each individual to a single mutually exclusive risk group based on historical, clinical and demographic characteristics to predict future use of healthcare resources. CRGs incorporate the effect of multiple coexisting and interacting chronic diseases and allow adjustment for severity of illness. CRGs have the potential to provide risk adjustment for capitated payment systems and management systems that support care pathways and case management (10, 11).

In conclusion, previously performed studies show the use of client profiles on the prediction of use of healthcare resources and demand for care. The studies show that for both the ECRs and CRGs, the average costs of care can be determined. These studies can be used for our study, as an example of how a client profile can be drawn and what factors should be taken into account (7-11).

Healthcare payment models
Several studies indicate that it is important to understand and have an overview of the used healthcare payment model in the healthcare sector/organization where the research will be performed (7, 8, 12). Four common globally used payment systems are the fee-for-service system, episode-of-care payment, full-risk capitation, and comprehensive care payment, also called condition-adjusted capitation (12-14). These four models are shortly described in *Table 1.*

Currently, a fee-for-service system is used in the Dutch healthcare sector, including the home care sector (22, 23). This system does not account for the quality of care and the amount of episodes of care provided, which can have a negative impact on the care provided and the associated costs.

[1] The other factors are acute cardiac dysrhythmias requiring mechanical intervention (e.g. pacemaker), acute pump failure requiring mechanical intervention (e.g. intra-aortic balloon pump), chronic cardiac dysrhythmias, chronic heart failure, diabetes, dyslipidemia, hypertension, obesity, and pulmonary disease/respiratory failure.

These disadvantages do not apply to a comprehensive care payment model. This study examines whether a comprehensive care payment model is possible in the Dutch home care sector. This is sought by discerning client profiles and associated costs. When it appears that the cost per client in each profile are clearly recognizable, and the costs for all clients in a profile are about the same, it could be possible to determine fixed amounts of money that can be paid for the care for clients within these profiles.

Healthcare payment model	Description	Main pros and cons
Fee-for-service system	Predetermined amount is paid for each discrete service provided	- Puts the provider at risk for the number and cost of processes within each service - No limit on the number of services, providers get paid regardless of quality or outcomes
Episode-of-care payment	Paying a single price for all of the services needed by a patient during an entire episode-of-care	- Gives the provider responsibility for the number and types of services within an episode - Not create any constraint on the number of episodes of care
Capitation models	A single payment to cover all of the services a patients need during a specific period of time, regardless of how many or few episodes of care the patients experience	- Control the number of episodes of care as well as the cost of individual episodes - not taking into account the severity of the condition / how sick the client is
Comprehensive care payment (or condition adjusted capitation)	A provider or group of providers would receive a single payment to cover all of the services their patients need during a specific period of time	- A provider gets paid more for taking care of sicker patients but not for providing more services to the same patients - Gives providers responsibility for performance risk, whereas traditional, no-condition-adjusted, capitation systems transfer all of the cost risk to the provider

Table 1: Healthcare payment models

Determinants for client profiles

In this study, we have chosen for the target group dementia. Literature revealed some possible determinants, namely informal care, formal care, comorbidity, phase of dementia, age and gender. The literature states that these determinants can have major influence on the demand for care and the associated healthcare costs (1, 2, 7, 8, 10, 11, 24-28). In the remainder of this section, the determinants are further explained.

Dementia

Dementia is a common brain disorder. In the Netherlands, one in five people is likely to get some form of dementia in their lifetime (15-17). An estimated 235,000 persons in the Netherlands have dementia, of which 12,000 are young demented. Young demented is defined as persons suffering from dementia aged younger than 60 (26). In 2040 it is expected that the amount of people with dementia will be doubled to at least half a million, and worldwide to 115 million (26, 27). Because a relatively small group of people is young demented, this group is not included in this study.

Age is a major risk factor for dementia (29). The risk of dementia increases sharply with the age, namely:

- More than 10% of people over 65 years old have dementia;
- More than 20% of people over 80 years old have dementia;

- More than 40% of people over 90 years old have dementia (29).

Already known is that the demand and use of care increases by age (30). In 2011, in the Netherlands 37.1 billion (41.5% of the total) is paid for healthcare to people in the age group 25-64 years and 33.3 billion (37.3%) is paid for healthcare of people aged 65 and older (30). So, almost the same amount of money is paid, during about half of the years of life of the group of 25-64 years old in the group aged 65 years or older. Besides age, gender also affects healthcare costs and possibly suffering from dementia. The prevalence of persons with dementia in the Netherlands on January 1st 2007, was 14.05 per 1,000 inhabitants in men older than 65 years, contrast to 24.91 per 1,000 inhabitants in women older than 65 years (28). In conclusion, there are at least 75 percent more women than men diagnosed with dementia over 65 years old. However, in 2012, the remaining life expectancy at age 65 was 18.3 years for men and 21.2 for women. This means that women live about three years longer than men. Consequently, it is expected that for this reason more women suffer from dementia. Because of the influence of age, the influence of gender on suffering from dementia is unclear (31).

Three commonly recognizable phases of dementia can be distinguished, based on symptoms and behavior of persons diagnosed with dementia (32). Nurses and other (medical) staff in the home care sector experience these symptoms daily, and for this reason the phases are clearly identifiable. Phase one is the early phase of dementia. Characteristics of individuals in this stage may be small changes in behavior, loss of memory for recent events, anxiety and restlessness, confusion and speaking less fluently. In phase two characteristics become worse. Examples of characteristics in this phase are difficulty in recognizing people or confusing people, easily getting upset, angriness, suspiciousness, disturbed sleep-wake rhythm and loss of inhibitions. Lastly, characteristics of phase three could be pronounced loss of memory, running away or getting lost, bedridden, compulsive actions and having problems with perception, such as hallucination (32). A full description of the three stages is provided in *Appendix 1*.

Informal support system

One of the determinants that is included in this study is informal care, or informal support system. The amount of informal home care used increase with disability, as well as with other measures of need for care (2, 24). Informal care includes lay care (‘mantelzorg’) and volunteer care (‘vrijwillige zorg’) (33). Lay care is defined as the voluntary and unpaid additional care, more than a personal relationship, by relatives, friends, acquaintances and neighbors to people in their family, household or social network severe physical, mental or psychological limitations (34, 35). In 2010, the Netherlands counted 3.5 million lay care givers, meaning that one in four adults granted lay care. Of these, 2.6 million persons provided longer than three months lay care of which 1.1 million persons provided this more than eight hours a week. Lay care is stated as long-term when it is provided longer than three months, and intensive when it is provided more than eight hours a week (34, 36, 37). The difference between lay care and volunteer care, is that lay care arises directly from the social relationship (33). Volunteer care is the intensive, volunteer care at people in a vulnerable situation, often driven by an organization. Central is the participation in society and personal support. Volunteer care could for example include buddy care, organized neighborly assistance and voluntary home care (33, 38, 39).

The availability of immediate family increases reliance on informal care and reduces reliance on formal care (2, 24). The living situation of the clients have a positive influence on the amount of informal care the client receives (40, 41). People living in a multi-persons household receive more informal care than persons living in a single-persons household. Both the amount of informal care givers as the amount of informal care received are higher for persons in a multi-persons household compared to persons in a single persons household (40, 41).

Formal support system

Besides of informal care, formal care is included as a determinant in this study. Formal care is defined as community care paid for directly by public programs, agencies or private individuals (38). Examples of formal care are household help, external meal service (‘*tafeltje-dek-je*’) and counseling (39).

Counseling includes the (repeated) practice of skills and behavior learned during treatment to apply in practice (42). Counseling involves promoting, maintaining and compensating the ability to cope. For performing the counseling, no specific skills are required of the caregiver. Counseling may focus on learning and applying knowledge, communication, mobility and interpersonal interactions and relationships. The counseling can be delivered individually or in groups (42). The Dutch Healthcare Authority ('NZA') makes also a distinction between these two types of counseling in the home care sector in the declaration and financing of the counseling (42-46). Individual counseling is delivered personally for each client. Group counseling can be designated when the client due to the nature, extent and/or duration of its limitations is not able to achieve structuring a day. Daycare is an example of group counseling (42-46).

Comorbidity
The final determinant which is included in this study is comorbidity. In earlier performed research in the healthcare sector, comorbidity was an important determinant (7-11). Comorbidity is the general term for the occurrence of more than one (chronic) disease in an individual at a time. It assumes an additional condition in people who already have a disease, a so called index-disease (25). An example of an index-disease is dementia. Examples of other diseases could be diabetes mellitus, cardiac failure, coronary heart disease, hypertension, osteoarthritis, vision impairment, noise and hearing impairment, neck and back complaints, osteoporosis, stroke, asthma, COPD, Parkinson's disease and rheumatoid arthritis. These examples are based on the most common diseases in general and among the elderly in the Netherlands in 2007 and 2011 (47, 48).

Methods

The study is divided in two parts. In the first part, as mentioned before, together with the representatives of the involved home-care providers possible client profiles are determined. After that, for all determinants and client profiles (cost) data are collected. This data is analyzed, and cost patterns were identified.

Part 1: establishment of client profiles
The first stage in this study was to investigate determinants for the client profiles based on the results of the literature review. For the determinants found, we created subdivisions. We chose for a two component subdivision to limit the final number of client profiles, to keep overview, and to ensure the data collection remains manageable for employees of the home care providers. The choice for the first set of determinants and subdivision was based on the importance and justification of these determinants and groups described in the literature (see the literature review section for further explanation).

Subsequently, this investigation proposal was discussed during three meetings with representatives of nine home care providers – the field workers. In total, fourteen home nurses, three dementia case managers and three other representatives were present during one of the three meetings. With their practical experience, they had a good view on which determinants and subdivisions of the determinants are feasible in practice, and which client profiles can be composed. Additionally, during the meetings there was a check if sufficient data / clients would be available within these profiles. During the meetings the determinants where modified. We explain these modifications in further detail in the results section.

Besides of the determinants, multiple inclusion and exclusion criteria are described for the client profiles. The goal of these criteria is to ensure that data could be clearly and properly collected by the representatives of the home care providers during the data collection, and that the data is homogeneous. The inclusion and exclusion criteria are:

- The client has been diagnosed with dementia;

- The client is 60 years or older[2];
- The client receives for at least six months home care at one of the involved home care organizations[3];
- When the client is comorbid, the required care for this condition should not be more/heavier than the dementia care[4].

Part 2: data collection and analysis
When the client profiles has been initially defined, all nine home care providers have been requested to deliver (cost) data of approximately 80 clients spread over the eight profiles. The anonymity of all clients was guaranteed, as client names and birth dates were not known by the researchers. The delivered data was collected over a period of six months (September 1st 2013 to February 28th 2014). Data over a period of six months gives a sufficient reflection of the reality from which a valid and reliable conclusion can be drawn. The following data of all clients selected for the study was requested from the home care providers:

- Age;
- Gender;
- Living situation (single or multi-person households);
- Client profile number;
- Phase of dementia (one, two or three);
- Total number of hours of personal care;
- Total number of hours of nursing;
- Total number of hours of individual counseling;
- Totally declared costs (in Euro).

The choice for these types of data is further explained in the results section.

After all data was collected, the data was analyzed. The mean and standard deviation per client profile, per home care provider, and per home care provider per client profile was calculated. The means and standard deviations are compared, what gives an overview of the differences between organizations and client profiles. Next, further analyses per determinant were performed. On the basis of the amount of people and the average hours of care, age and healthcare costs per client profile, phase of dementia, type of gender and living situation, several notable results were observed. This will be further explained in the research section.

The ultimate goal of the data analysis was to determine which determinants will be useful to include in the client profiles in the future, based on how well these determinants can estimate the total healthcare costs. We examined whether this set of determinants corresponds to the set of determinants that emerged from the interviews with the staff of the home care providers. To test how much influence the various determinants have on the total health care costs, multiple variation tests are carried out.

For testing the variance in costs of determinants with two groups, like gender and living situation, a T-test is used. For testing determinants with more than two groups, for example the three phases of dementia and the eight client profiles, we performed an Analysis of Variance (ANOVA) test. For all variation tests we performed, we used the null-hypothesis ‘means/variance are equal’, and the alternative hypothesis ‘means/variance are unequal’. All tests are two-sided with an α of 0.05. Besides

[2] Because a relatively small group of people is young demented, it is decided not to include this group in this study.
[3] The client should obtain a minimum of a half year home care at one of the involved home care providers in this study, to be sure sufficient cost data is available.
[4] When the client has a condition requiring more care than care needed for the dementia, it is expected that this will have a major influence on the healthcare costs. This could have a bias effect on the costs in this study. That is why it is excluded.

of the variation tests, a multiple linear regression analysis with all determinants is performed. Herewith is calculated which determinants can explain a part of the variation in the total declared cost. The variables which can explain the variation in costs of care the best ($P<0.05$ with the highest R square value), will be included in the client profiles.

For all variation tests performed, the assumptions for that specific test are checked (49, 50). All tests performed meet these assumptions. A T-test is based on the following assumptions:

- The sample is randomly collected;
- The dependent variable (for our tests this is the total declared costs) have an interval/ratio scale;
- The sample is normally distributed and/or is large enough (at least 30 cases).

For an ANOVA test the assumptions are:

- All samples are independent and collected at random;
- All groups are normally distributed and/or is large enough (at least 30 cases);
- The variation is the same for all groups (Test of Homogeneity-of-Variance).

Finally, the assumptions for a multiple regression analysis are:

- The dependent variable (total declared costs) has an interval/ratio scale. The independent variables could have interval/ratio scales or could be categorical variables (Dummies);
- The model is linear;
- There are no independent variables which measure approximately the same;
- The residues/outliers are checked by determining whether all outliers are normally distributed (49).

Results

The results section is divided in two parts. In the first part, research question one is answered. The results of the meetings with the representatives of the home care providers are described. This section also describes which set of determinants should be included in the client profiles, according to the representatives of the home care providers. In part two of the result section, the most important outcomes of the data analysis are provided. Herewith is also calculated which determinants have the most impact on the need and cost of care according to this data analysis, which allows us to answer the second research question.

Part 1: establishment of client profiles

After the literature review was completed, three meetings with representatives of the involved home care providers took place. During these meetings the client profiles and associated determinants identified from the literature were discussed. The representatives examined which determinants found in the literature should be included in the client profiles.

All representatives who were present during one of the meetings confirmed that dementia is a common disease among clients in the home care sector. They also confirmed unanimously that all determinants found in the literature, so informal care, formal care, comorbidity, phase of dementia, age and gender, have (major) influence on the demand for care and the associated healthcare costs. The participants stated that they assume that living situation has a significant influence on the amount of informal- and formal care the client receive. They indicate that persons living in a multi-person household often receive many (informal) care by their housemates. For this reason, persons in a multi-person household receive more informal care compared to persons in a single-person household, requiring less formal care. Therefore the participants assume that living situation should be included as an individual determinant, to measure the exact influence of living situation on the informal- and formal care received.

All participants stated that less than these seven determinants should be included in the client profiles, to limit the number of client profiles. Given our data set, we have to limit the number of client profiles up to eight profiles. Using more than eight profiles would lead to a small number of clients per profile, which would hamper our analysis possibilities. Together with the participants we decided that a maximum of three determinants with two possible groups each (e.g., weak or strong) should be included in the client profiles, which leads to eight client profiles. We first discussed all seven possible determinants to decide at the end of the meetings collectively which three determinants should be included in the final client profiles. These three determinants should have the biggest impact of all seven determinants on the demand for care and associated healthcare costs. During the discussion, it became clear that all participants of the meetings expect that the determinants formal care, informal care and comorbidity have the biggest impact on the demand and costs of care, based on their professional knowledge and expertise.

Based on the meeting outcomes, we decided to make a distinction between two levels of an informal support system, based on the duration, amount and assessment of informal care obtained by the client. The distinction is made in a weak/insufficient and strong/sufficient informal support system. All participants have confirmed that obtaining informal care has direct impact on the demand of formal care. All care that is provided by the informal caregivers does not have to be provided by the formal caregivers. Hence, the less formal care a client receives, the lower the healthcare costs. To make it easier for representatives of the home care providers to determine which client belongs to which group of an informal support system, several guidelines for a strong/sufficient informal support system have been developed during the meetings. These guidelines are used as a guidance and not to definitively determine whether the informal support system is strong or weak. The guidelines for a strong/sufficient informal support system are:

- The informal care should on average be more than eight hours a week (intensive), longer than three months (long-term) granted;
- There should be a backup person(s) present for providing the informal care when the permanent informal caregiver is not able to provide informal care;
- The communication between the informal care givers mutually, and with the formal caregivers should be progressing well;
- There resides a volunteer with the client at home;
- The burden, capacity and ability of the informal caregiver(s) are evenly distributed. The informal care giver should not be or become overloaded.

In this study, we made a similar distinction for formal support systems as for informal support systems. There are two levels of formal support system, namely a weak/insufficient and strong/sufficient formal support system. For the determinant formal support system, we chose that the nursing, personal care and individual counseling delivered by the home care provider are not included, because this is already known for the study. This determinant involves the additional care. Participants of the meetings gave multiple examples of types of formal care, such as day-care, external meal service (*'tafeltje-dek-je'*), household help, social psychiatric nursing ('*SPVer'*) and psychiatric intensive home care (*'PIT-verpleegkundige"*).

For both informal and formal support systems, we decided to use an existing measurement instrument to determine whether the support system is strong/sufficient or weak/insufficient, namely the Visual Analogue Scale (VAS) (51, 52). The participants of the meetings stated that the use of such a measurement scale will make it easier for them to determine whether a client has a weak/insufficient or strong/sufficient (in)formal support system. The VAS is designed to present the respondent a rating scale with minimum constraints. It is an often used scale in healthcare, usually to measure pain. However, it can also be used for the measurement of other purposes, because it uses general numbers what can be used for a variety of purposes. Respondents mark the outcome on a ten-point scale. The VAS gives clients freedom to choose an exact intensity. It gives each respondent the maximum opportunity to express a personal response style (51, 52). In case of this study we used an ten-point scale, where one means no to a very poor (in)formal care system, and ten means a perfect

(in)formal care system. All representatives can decide the scores for each client individually. A score of five or lower means a weak/insufficient (in)formal care system and a score of six or higher means a strong/sufficient (in)formal support system.

For the determinant comorbidity, we have chosen to make an allocation based on the effect of comorbidity on the demand for care. The participants of the meetings indicated that a distinction can be made between *no to slight effect* on demand for care, and *moderate to heavy effect* on demand for care. All participants agreed upon the fact that all involved representatives of their home care organization, can decide for their own if a possible comorbidity have no to slight or moderate to heavy effect on the demand for care. In conclusion, eight client profiles can be composed of the three determinants identified with the corresponding groups. An overview of the eight client profiles is provided in *Table 2.*

During the three meetings with the representatives of the home care providers, we also discussed which data can be provided by the home care providers for the second part of the study, in order to test which determinants are the best predictors of costs and care. We chose to collect data about age, gender, phase of dementia and living situation, in addition to data about the three fixed determinants, in order to measure the influence of all possible determinants individually and to measure the effect of all determinants together. Beside of these determinants we decided to include type of organization as an individual determinant. We received the data from each organization individually, why we can compare the organizations. Totally we have eight determinants. Because we analyze the data of all possible determinants we can also examine if the determinants for the client profiles emerged from the meetings with the representatives of the home care providers corresponds with the set of determinants following from the data analysis.

Together with the participants of the meetings we decided that over a period of six months the total hours of personal care, nursing and individual counseling, and the total declared costs will be provided per client for the data collection. We chose for these four components, because we think these components together are likely to give a reliable and realistic overview and reflection of the total provided care (costs) by all included home care providers. We chose for a period of six months, because we expected a sufficient amount of clients would be available by the home care providers who receive home care during this period of time.

	Formal support system		**Informal support system**		**Comorbidity: demand for care on the basis of other (chronic) disorders**	
	Weak/insufficient	Strong/ sufficient	Weak/insufficient	Strong/sufficient	No to slight effect on demand for care	moderate to heavy effect on demand for care
Client profile 1	**X**		**X**		**X**	
Client profile 2	**X**			**X**	**X**	
Client profile 3		**X**	**X**		**X**	
Client profile 4		**X**		**X**	**X**	
Client profile 5	**X**		**X**			**X**
Client profile 6	**X**			**X**		**X**
Client profile 7		**X**	**X**			**X**
Client profile 8		**X**		**X**		**X**

Table 2: final basic client profiles according the representatives of the home care providers

Part 2: data collection and analysis
For the data collection all home care providers provided the data on the basis of a standardized spreadsheet format. In total the homecare providers provided data of 678 clients. From these clients, 26 clients could not participate in further investigation, because the data of these clients was not complete. Fourteen of these clients did not receive any type of care during the study period. Eleven persons did not receive care by one of the involved home care providers during the whole period of six months, and one person was younger than 60 years old. Four of the remaining 652 clients did also receive specialized medical care at home (''*Medisch Specialistische Verpleging in de Thuissituatie, MSVT")*. The data of these clients are included in the data analyses, only the specialized medical care is excluded from the data analyses.

The rest of part 2 is divided in several subsections. These subsections are subsequently used in the discussion section. Firstly, the general outcomes of the client profiles with the three determinants informal care, formal care and comorbidity, compiled during the meetings with the representatives of the home care providers, are described. After this the general outcomes for the remaining determinants are discussed individually. Finally, the outcomes of the variation analyzes and the multiple regression analysis are described. The most interesting outcomes of this study are shown in this chapter. The outcomes of the comparison of the organizations could be found in *Appendix 2*.

General outcomes client profiles
It is remarkable to see how all clients are spread over the client profiles. As shown in *Table 3*, client profiles 3 and 4, followed by client profiles 7 and 8, are the most common client profiles (81.90% of all clients). In all of these four profiles, clients have a strong formal support system. On average occur the client profiles 1, 2, 3 and 4 more frequently than the client profiles 5, 6, 7 and 8 (62.27% in contrast to 37.73%). To better clarify all outcomes according the client profiles, in *Table 4* is stated which group of each determinant applies to each client profile.

Client profile	Amount of clients	Average total declared costs	SD of total declared costs	SD in % of average
1	44	5921,31	5207,56	87,95
2	28	10738,56	7110,32	66,21
3	145	8128,70	6039,46	74,30
4	189	8526,02	7048,13	82,67
5	30	7025,76	6640,00	94,51
6	16	17346,77	25600,49	147,58
7	97	12158,28	9402,81	77,34
8	103	13308,61	14132,42	106,19
Total	**652**	**9800,24**	**9714,80**	**99,13**

Table 3: Amounts of clients client profiles

Client profile	Formal support system	Informal support system	Comorbidity
1	Weak	Weak	Slight effect
2	Weak	Strong	Slight effect
3	Strong	Weak	Slight effect
4	Strong	Strong	Slight effect
5	Weak	Weak	Heavy effect
6	Weak	Strong	Heavy effect
7	Strong	Weak	Heavy effect
8	Strong	Strong	Heavy effect

Table 4: determinants per client profile

As shown in *Table 3 and 5* the average amount of hours of care, for both personal care (SD 35.29), nursing (SD 45.94) and individual counseling (SD 12.44), and the average declared costs (SD €3,536.21) are the highest for client profiles 6, 7 and 8. This is probably due to comorbidity. In client profiles 6, 7 and 8 people have comorbidity that have a moderate to heavy effect on the demand of

care. However, the standard deviation for these three client profiles is also higher than for the other client profiles. Beside of this, it is remarkable that these higher costs and hours of care do not apply to client profile 5, whereby persons also have comorbidity with a moderate to heavy effect on the demand of care. These differences will be further explained in the discussion section.

Client profile	Average hours of PC	Average hours of nursing	Average hours of IC	Average total hours of care
1	88,63	17,40	1,04	107,07
2	176,93	10,02	9,60	196,54
3	137,42	10,19	8,27	154,93
4	142,77	14,39	5,06	160,72
5	110,64	18,61	2,30	131,55
6	117,71	144,08	40,34	302,13
7	186,64	25,30	11,88	223,83
8	174,54	59,19	9,69	243,33
Total	**148,88**	**25,55**	**8,18**	**181,92**

Table 5: hours of care per client profile

Age

As shown in *Table 6*, most clients in this study are between the 76 and 90 years old (total 77.62% of the clients; SD 6.37 years). The average age of the clients is the highest for client profiles 2 and 6 (see *Table 7*). Clients in both profiles 2 and 6 have a strong/sufficient informal support system and a weak/insufficient formal support system. However, notable is that there is a low amount of clients included in client profile 6 (16 clients) and that the standard deviation for client profile 6 is the highest of all standard deviations of the client profiles.

Amount	Client profiles									
Age	1	2	3	4	5	6	7	8	Total	Total in %
61-65	1		1	3	1	1	3	2	12	1,84%
66-70	1		5	2			2		10	1,53%
71-75	4	1	10	11	3		12	4	45	6,90%
76-80	10	3	27	43	5	2	16	20	126	19,33%
81-85	15	7	49	57	9	4	32	36	209	32,06%
86-90	6	11	40	52	7	5	23	27	171	26,23%
91-95	6	5	13	21	3	3	7	13	71	10,89%
96-100	1	1			2	1	2	1	8	1,23%
Total	**44**	**28**	**145**	**189**	**30**	**16**	**97**	**103**	**652**	**100,00%**

Table 6: age per client profile

Client profile	Average age	SD age
1	82,55	6,85
2	86,68	5,57
3	83,05	5,92
4	83,30	6,16
5	83,80	7,30
6	85,13	7,51
7	82,12	6,96
8	84,17	6,10
Total	**83,37**	**6,38**

Table 7: average age

The hours of care used and the associated costs of care increase with age (see *Table 8*). Remarkable is that the group of 61-65 years old differs in comparison to the other age groups. The hours and costs of care is higher for clients in the group 61-65 years old, compared to the group of 66-70 years old. These differences will be further explained in the discussion section.

Age	Average of total hours of care	SD of total hours of care	Average of total declared costs	SD of total declared costs
61-65	137,85	148,80	7482,74	8597,39
66-70	90,09	64,97	4961,39	3148,63
71-75	143,02	100,31	7825,86	5923,96
76-80	146,71	130,27	8047,89	7148,62
81-85	174,83	135,78	9278,49	7503,33
86-90	201,78	214,68	10695,20	12285,55
91-95	246,36	191,03	13582,61	11495,52
96-100	324,92	325,56	18962,94	21526,07
Total	**181,92**	**169,39**	**9800,24**	**9714,80**

Table 8: age and costs and hours of care

Gender

As shown in *Table 9* and *10*, there are more women (69.02%) than men (30.98%) included in this study. You can see that in all client profiles, except for client profile 6, women are older than men. On average women are approximately two years older than men. Besides of this, the costs of care are on average higher for women than for men. However, remarkable is that this is not the case in client profiles 3, 5 and 6, where men have higher costs than women. An explanation for these differences is given in the discussion section.

	Men			
Client profile	**Amount of clients**	**Average age**	**Average of total declared costs**	**SD of total declared costs**
1	15	79,60	4084,36	2986,30
2	6	84,17	10272,44	9443,33
3	42	82,21	8459,13	7164,43
4	52	82,71	7015,49	6113,23
5	6	80,33	7936,08	5246,77
6	2	86,50	30726,97	43340,29
7	38	80,29	9930,75	6010,37
8	41	82,51	10307,81	10476,72
Total	**202**	**81,89**	**8673,50**	**8329,63**

Table 9: outcome for men

	Women			
Client profile	**Amount of clients**	**Average age**	**Average of total declared costs**	**SD of total declared costs**
1	29	84,07	6871,45	5868,97
2	22	87,36	10865,69	6609,83
3	103	83,39	7993,96	5549,65
4	137	83,53	9099,36	7311,09
5	24	84,67	6798,18	7024,00
6	14	84,93	15435,31	24088,27
7	59	83,31	13592,96	10860,42
8	62	85,26	15293,01	15872,53
Total	**450**	**84,03**	**10306,02**	**10244,46**

Table 10: outcomes for women

Phase of dementia

Dementia phase two is clearly the most common phase, with 48.31% of the total amount of clients. Remarkable is that client profiles 1, 2, 5 and 6 are relatively the least common profiles in dementia phase three (8.89% of all clients in phase three; see *Table 11*). In client profiles 1, 2, 5 and 6 clients have a weak formal support system.

Amount	**Phase of dementia**		
Client profile	**1**	**2**	**3**
1	52%	43%	5%
2	21%	64%	14%
3	28%	49%	23%
4	28%	47%	26%
5	20%	60%	20%
6	31%	56%	13%
7	29%	49%	22%
8	17%	43%	40%
Total	**27%**	**48%**	**24%**

Table 11: amount of clients per phase of dementia

As showed in *Table 12*, the average hours of care increases with the phases of dementia. On average, clients with dementia phase three receive totally 49.80% more care than clients with dementia phase one. Both the provision of personal care (PC), nursing (N) and individual counseling (IC) increases at the higher phases of dementia. Beside of the hours of care, the average declared costs of care increase per phase of dementia. As shows in *Table 13* the average declared costs of care increase per phase of dementia approximately €2,000 per person. This is probably due to the previously mentioned increase in use of care. For further explanation, see the discussion section.

Phase of dementia	Average hours of PC	Average hours of N	Average hours of IC	Average total hours of care
1	126,97	16,33	3,40	145,29
2	152,39	23,40	9,06	184,82
3	166,55	40,29	11,85	217,64
Total	**148,88**	**25,55**	**8,18**	**181,92**

Table 12: hours of care per phase of dementia

Client profile	Average of total declared costs	SD of total declared costs
1	7764,33	6680,00
2	9954,11	9657,92
3	11799,98	12058,01
Total	**9800,24**	**9714,80**

Table 13: Average costs per phase of dementia

Living situation

As shown in *Table 14* and *15* there are more clients living in a single-person household (62.58%) than in a multi-person household (37.42%). Clients in a single-person household are approximately two years older than clients in a multi-person household. In addition, the total declared costs of care are also higher for clients in a single-person household than for clients in a multi-person household, with a difference of approximately €900. However, in client profiles 1 and 6 have clients in a multi-persons household higher costs of care instead of clients in a single-person household. Further explanation about the differences between a single-person household and multi-persons household is provided in the discussion section.

	Single-person household			
Client profiles	**Amount of clients**	**Average age**	**Average of total declared costs**	**SD of total declared costs**
1	30	82,43	5747,78	4156,24
2	21	86,95	10685,59	7876,03
3	100	83,62	8400,31	6326,49
4	122	83,80	9359,77	7721,56
5	16	86,63	9109,64	8296,06
6	9	85,56	7996,06	5316,95
7	58	83,93	12708,71	10524,38
8	52	85,27	15333,33	16770,23
Total	**408**	**84,17**	**10124,78**	**9616,60**

Table 14: Outcomes for single-person household

	Multi-person household			
Client profile	**Amount of clients**	**Average age**	**Average of total declared costs**	**SD of total declared costs**
1	14	82,79	6293,16	7137,70
2	7	85,86	10897,49	4548,94
3	45	81,78	7525,12	5364,47
4	67	82,39	7007,86	5345,02
5	14	80,57	4644,18	2736,40
6	7	84,57	29369,12	36069,23
7	39	79,44	11339,68	7487,64
8	51	83,04	11244,19	10581,29
Total	**244**	**82,02**	**9257,57**	**9872,82**

Table 15: Outcomes for multi-persons household

Variation analysis

As described in the method section, we performed some tests to measure witch determinants affect the costs of care. We have chosen to analyze the effect of all determinants on total declared costs only, and not on the received hours of care. All the above analyses demonstrated that there is a clear relationship between the received hours of care and the total declared costs of care.

Firstly, we performed several T-tests, for determinants consisting of two groups, and ANOVA tests, for determinants consisting of more than two groups, to test if there are variations in costs between the groups in all determinants individually. For these analyses we have chosen to release the client profiles, which are determined during the meetings with the representatives of the involved home care providers, in three individual determinants again, namely comorbidity, formal support system and informal support system. Consequently we have a better overview on the influence of each determinant individually on the total declared costs. This will be helpful to estimate witch determinants are potentially useful to include in the client profiles according to our data analysis. For the formal- and informal support system we know if the systems are weak or strong. For comorbidity we know if the comorbidity has a small or major impact on the demand for care. Besides of these determinants, we included the organizations as an individual, eighth, determinant during this analysis. The purpose is to measure the effect of the organizations on the costs of care. Because the organizations are a categorical variable, we made dummy variables of the organizations for the multiple regression analysis. In conclusion, now we have eight determinants, namely age, living situation, gender, phase of dementia, formal support system, informal support system, comorbidity and the organizations.

For the determinants gender, living situation, comorbidity, formal support system and informal support system, we performed T-tests. The outcomes of these tests can be found in *Table 16.* As can been seen, for the determinants gender, comorbidity and informal support system P (sig.) is smaller than 0.05. For this reason we reject the null-hypothesis for these tree determinants. This means that the total declared costs of the two groups in these determinants are significantly different from each other. For example, the total declared costs of men significantly differ from the total declared costs of women. For the determinants living situation and formal support system there are no difference in costs between the groups shown.

For the remaining three determinants we performed an ANOVA test. As shown in *Table 17*, for both age, phase of dementia and the organizations the costs significantly differ between the groups in each determinant, because P (sig.) is smaller than 0.05. This means, for example, there is a significant difference in total declared costs between the nine organizations participating in this study.

	T-test					
	Levence test for equality of variance					
Determinant	**F**	**Sig.**	**Equal variance**	**f**	**df**	**Sig. (two tailed)**
Gender	1.582	0.209	assumed	-1.989	650	0.047
Living situation	0.001	0.975	assumed	1.103	650	0.270
Comorbidity	25.146	0.000	not assumed	-4.603	322.504	0.000
Formal support system	0.176	0.675	assumed	-1.119	650	0.263
Informal support system	6.923	0.009	not assumed	-2.190	584.816	0.029

Table 16: outcomes T-tests

	ANOVA	
Determinant	**F**	**Sig.**
Age	2.819	0.000
Phase of dementia	7.464	0.001
Organisations	7.287	0.000

Table 17: outcomes ANOVA tests

After for all determinants a separate variation test was carried out, we performed a Multiple Regression Analysis including all determinants. The model summary of this analysis can be found in *Table 18.* In *Table 19*, the combinations of determinants in each model are shown. The determinants included in this model significantly explain a part of the variation in total declared costs between clients (P<0.05). As can be seen, this applies for the determinants organizations, comorbidity, age and phase of dementia. The determinant which explains the biggest part of the variation (8.3%) in total declared costs is the organizations. Subsequently, the determinant phase of dementia adds an explanation of (12.7-8.3) 4.4% of this variation, followed by age, which adds (15.6-12.7) 2.9%, and the determinant comorbidity, which explains (17.3-15.6) 1.7% of the total variation. In conclusion, these four variables explain 17.3% of the variation in total declared costs between clients. The determinants formal support system, informal support system, living situation and gender do not add a significant explanation of the variation in total declared costs between clients. The outcomes of the variation tests and the Multiple Regression Analysis will be further explained in the discussion section.

Model	R	R square	Adjusted R square	Standard error of the estimate
1	0,288	0,083	0,072	9.359,97611
2	0,356	0,127	0,114	9.141,88926
3	0,396	0,156	0,143	8.995,75456
4	0,416	0,173	0,158	8.911,74746

Table 18: Model summary multiple regression analysis

Model / Determinants	1	2	3	4
Organizations	X	X	X	X
Phase of dementia		X	X	X
Age			X	X
Comorbidity				X

Table 19: coefficients multiple regression analysis

Discussion

In the discussion section, we further analyze and substantiate all results. For this we use the same structure as in the second part of the results section. After this we describe the limitations of the study, followed by a short explanation of the expected future changes in home care. Finally, some recommendations for further research are presented.

General outcomes client profiles

As stated in the results section, client profiles 3, 4, 7 and 8 are the most frequently appearing client profiles. In these four client profiles, clients have a strong formal support system. This could be explained by the fact that in our study dementia patients often have/need a strong formal support system to live (longer) at home. Beside of this, there are more clients in profiles 1, 2, 3 and 4 than in profiles 5, 6, 7 and 8. In the first four client profiles, comorbidity has little to no effect on the demand

for care, in contrast to the last four client profiles, where comorbidity has a moderate to heavy impact on the demand for care. In conclusion, in our data set, dementia clients have more frequently comorbidity that has little to no effect on the demand for care. Dementia is often the most prominent disease, whereby other diseases are less ‘’noticeable’’.

In the results section is described that client profiles 6, 7 and 8 are the client profiles with the highest demand for care and costs of care. In client profiles 6, 7 and 8 people have comorbidity that have a moderate to heavy effect on the demand of care. The care and associated costs provided for the other diseases are also included in these data, what could explain the higher demand and costs of care in client profiles 6, 7 and 8. However, remarkable is that the total declared costs for client profiles 6, 7 and 8 have a high standard deviation. This means that there is a large difference in total declared costs between clients in these three profiles. Client profile 6 also has only 16 clients included. This is a relative small number. Two of these clients have extremely high total declared costs, namely €96,6620.50 and €61,373.18. A common used line for determining outliers is that the value of the outlier should be greater than three times the standard deviation associated with that analysis. This applies for the costs of one of these two clients (3 x 25,600.43= 76,801.47). It means that the costs of one client is an outlier, and this could give a biased effect on the average costs for clients in profile 6. Client profile 8 also have two outliers. The earlier stated conclusion about client profiles 6, 7 and 8 in this study could be biased because of these reasons.

Remarkable is that the higher demand and costs of care is not the case at client profile 5, whereby persons also have comorbidity with a moderate to heavy effect on the demand for care. These differences could not be explained by differences between the determinants and between the organizations. All organizations have one or more clients in client profile 5 (see *Appendix 2*). Notable is that there are just 30 clients included in client profile 5. It is possible that this relative small amount of clients explains the difference between client profile 5 and the following three profiles in our study. Client profile 5 also have one outlier. Because of the low amount of clients and this outlier, no good conclusions can be given about client profile 5.

Age

As stated in the result section, clients in profiles 2 and 6 have on average a higher age, compared to the other client profiles. Clients in both profiles 2 and 6 have a strong/sufficient informal support system and a weak/insufficient formal support system. Therefore we conclude that, in our data set, a strong informal support system ensures that a person can live longer at home and/or become older, and need less formal care. The P-value of 0.031 of the performed ANOVA test for the average age between the client profiles, also confirmed that there are significant differences in the average age between the client profiles. However, remarkable is that the standard deviation of the average age of client profile 6 is the highest standard deviation of all client profiles. This reason, together with the fact that there are just sixteen clients included in client profile 6, limits the above stated conclusion of client profile 6.

In the results section is shown that in our study the demand for care and associated costs for care increases with age. How older the person, the more care is required. Remarkable is that the group of 61-65 years old differs in comparison to the other age groups in this study. The hours and costs of care is higher for clients in the group 61-65 years old, compared to the group of 66-70 years old. This can probably be explained by the relatively few clients that belong to these two groups (10 and 12 of the total 652 clients). This few clients could give a bias effect. Besides of this, the standard deviations for both the total hours of care received and the total declared costs for the final three age groups (>85 years old) are higher compared to the other age groups in this study. This means that there are many differences in the amount of care received and the total declared costs between clients in these three groups. These three groups also includes a few outliers. The age group 61-65 years old includes for example one outlier. These differences can influence our conclusion above about the age groups in this study in a negative way.

Gender

In the results section has been described that there are differences between men and women in the amount of clients and costs of care. Women have approximately €2,000 higher costs than men. However, these differences could be explained by age. As stated in the results section, women are approximately two years older than men. As described before, costs of care increases with age. This could explain that women have higher costs than men in our study. Remarkable are the differences in costs between men and women in the client profiles. In client profiles 3, 5 and 6, men have higher costs than women, instead of women having higher costs than men, what applies for the other client profiles. However, client profile 5 and 6 have a low amount of men included (6 and 2 clients), which might explain this unexpected outcome.

Phase of dementia

As stated in the results section, dementia phase two is clearly the most phase of dementia in our study. This is in line with our ideas and the ideas of the representatives of the home care providers. It is possible that people in the first phase of dementia not always receive home care, because the need for care is often low and the symptoms of dementia are sometimes not clear yet, and people in phase three are more often receiving intramural care instead of home care, because of the high demand for care and the (continuous) observation required. Client profiles 1, 2, 5 and 6 are relatively the least common profiles in dementia phase three. In client profiles 1, 2, 5 and 6 clients have a weak formal support system. This could explain the minor amount of clients in these profiles. It seems that, in our data set, persons in phase three dementia need a strong formal support system. When this is not the case, the client probably (needs to) receive intramural care instead of home care, which means they cannot be included in these four client profiles in this study.

As shown in the results section, in this study the average hours of care and associated healthcare costs increase with the phase of dementia. The associated standard deviations increase approximately equal with the phases of dementia. This result is consistent with the findings in the literature section.

Living situation

In the results section we described that, in our data set, there are more clients living in a single-person household, than in a multi-person household. The total declared costs of care are approximately €900 higher for clients in a single-person household than for clients in a multi-person household. However, this difference in costs is relative small, given the fact that the total declared annual costs of all clients in this study are on average €9,800.24 with a standard deviation of €9,707.34. In addition, in client profiles 2 and 6, clients in a multi-persons household have higher costs of care instead of clients in a single-person household. This is the opposite of the other client profiles in our study. This result may be biased, because a low amount of clients are included in these two client profiles (28 and 16 clients) and the average age of clients in both profiles is higher compared to the other profiles. Finally, clients in a single-person household are approximately two years older than clients in a multi-person household. For this reason, the small differences in costs between a single-person household and multi-persons household in our study could possibly be explained by age instead of the living situation.

Variation analysis

Out of the tests performed to measure the influence of all determinants on the variation in total declared costs between clients, some remarkable outcomes emerged. For all determinants, except from the determinants formal support system and living situation, we found that there are significant differences in total declared costs between the groups in each determinant in this study. For example, in the determinant gender there are significant differences in total declared costs between men and women. Remarkable is that this is not the case for the determinants formal support system and living situation. In our study there is no significant difference in total declared costs between a strong formal support system and a weak formal support system, and between a single-person household and a multi-persons household. For the determinant formal support system, this could be explained by the fact that the personal care, nursing and individual counseling received from the home care provider is not included in this determinant. This determinant only considers the received formal care in addition

to the regular home care, because this study assumes that all clients included in the study receive regular home care. However, in this study only the costs for the regular home care are included, and not the remaining cost for the additionally received formal care. In this study, we hoped to show that a person receiving a lot of additional formal care (so having a strong formal support system) needs less regular home care, why the total declared costs for regular home care is lower. However, the data does not indicate this.

For the determinant living situation there are also no differences in total declared costs between the two groups. Several representatives of the home care providers who were present during the meetings stated that they expect there are differences in total declared costs between a single-person household and multi-persons household, which was further explained in the first part of the result section. However, our data have not indicated this for our study. This could be explained by the determinant informal support system. As shown in *Table 20,* there are more-or-less no differences in the amount of persons with a weak and strong informal support system between a single-person household and multi-persons household. It was expected that persons in a multi-persons household have more often a strong informal support system, why less formal care is required, resulting in less home care costs. This is not the case for our data set.

Amount	**Informal suport system**		
living situation	**Weak**	**Strong**	**Total**
Single-persons household	204	204	408
multi-persons household	112	132	244
Total	**316**	**336**	**652**

Table 20: living situation and informal support system

The multiple regression analysis has shown that the determinants organizations, comorbidity, age and phase of dementia could significantly explain some of the variation in total declared costs between clients. For this reason, we conclude that, based on our study results, these four determinants could be useful for estimating the home care costs for dementia clients. Remarkable is that the three determinants comorbidity, age and phase of dementia explain only 9.0% of the variation in costs. In other words, the remaining 91.0% could not be explained by the original determinants for the client profiles. 8.3% of this remaining 91.0% variation can be explained by the organization. This means that the difference in home care costs between clients (partly) can be explained by the organization where the client receives home care. There are (major) differences in costs between clients of different home care organizations in our study, which means there are differences in received home care and tariffs for this care for approximately the same clients (the same characteristics) between organizations, according our data.

In order to explain more variation in costs between the clients in our study, we performed some multiple regression analyzes (MRA) based on other subsets of data, compiled from our original data set. For example, one data set only included clients with less than €20,000 total declared costs. In *Table 21* is for each tested data set shown what percentage each determinant individually and the total data set (significant) explains of the variation in the total declared cost between dementia clients. In the bottom of the table is described how many clients in each data set are included. As shown in *Table 21,* all other tested data sets do not explain approximately more variation in the total declared costs compared to the originally data set of our study (20.6% to 13.0% compared to 17.3%). For this reason, we cannot advice to exclude a certain group of clients in any follow-up investigation.

Limitations of the study

Although the home care sector is usually labeled as divers and heterogeneous, we were able to generate useful client profiles within the main group of dementia clients. Also costs gathering was possible for the profiles. Of course, our exclusive choice for a homogeneous subgroup dementia added a lot, but the approach of this study has also contributed to being able to create client profiles.

Analyzed data set / Determinant	Clients of the three most expensive organizations	Clients in the age group 76-90 years old	Clients with total declared costs <20,000 euro	Clients with phase two dementia	Clients with comorbidity with no to slight effect
Phase of dementia	6.3	3.3	4.9	-	8.4
Age	4.0	0.8	1.8	1.6	4.0
Comorbidity	2.0	1.9	1.0	2.6	-
Gender	-	0.9	0.6	-	-
Living situation	-	-	-	-	1.0
Formal support system	-	-	0.9	-	-
Organizations	3.1	6.1	5.8	10.2	7.2
Total	15.4	13.0	15.0	14.4	20.6
Amount of clients included	230	506	594	315	406

Table 21: Outcomes MRA (percentages %) of the alternative tested data sets

The study has some limitations. The duration of the study is the first limitation. During a period of half a year the study had to be performed, making the scope of the study limited. The home care providers had to gather and structure data in a short time – four weeks – using structures which were not directly present in their systems. When more time would have been available for the study, more determinants could be gathered why more client profiles could be designed and more data over a longer period of time could have been gathered. Examples of new determinants could be the income of the client (household), the educational level of the client, whether the client use care support tools (e.g. wheelchair or walking frame), religion and culture of the client, the demography in where the clients live (rural/urban), and if the client does or does not smoke.

The study has been limited to clients of nine major home care providers out of the north-east of the Netherlands. To draw a more valid and reliable conclusion over the entire Dutch home care sector, home care providers from all parts of the Netherlands should be included in follow-up research. As a result, possible differences between homecare providers from, for example, the north and south of the Netherlands can be observed and the results can be adapted to this. In addition, the study was limited to clients with dementia. Other diseases and reasons for receiving home care were not included in the study. Examples of these are terminal care, chronic diseases such as diabetes and muscular diseases, and home care after hospitalization. These groups could be included in further research to better understand differences between different types of care. The same line of reasoning applies to young demented people, who were also not included in this study.

Another limitation of this study is that the data is provided by the home care providers themselves without auditor control. The representatives of the involved home care providers collected all client data and delivered this anonymously to us. To achieve this, there is both orally and in writing a clear description and explanation of the required data and the data collection provided to all involved representatives of the home care providers. We had to rely on them to provide the correct data, and that all clients are assigned to the appropriate client profiles. For this reason, it is possible the used data was not always correct. It was possible to use data from the database of the Dutch healthcare insurer Menzis. This could provide more reliable data. However, this manner would have two major limitations. To select the appropriate clients from the database, the names and/or birthdates of the clients need to be known. This will harm anonymity of the clients, and for this reason all involved clients must sign to participate in the study. Because people with dementia are not always self-capable and authorized to sign for participation, this needs to be asked to empowered relatives. This could lead to a biased sample selection. Also, the home care nurses and case managers still have to select the clients for the study and indicate in which client profile the client belongs, which still makes us to rely on the providers. Because of these two limitations, we chose to not use this alternative manner of data collection.

A final limitation was the inclusion of outliers in the data analysis. A frequently used method for determining outliers is that the value of the outlier should be greater than three times the standard

deviation associated with that analysis. If you look for example at the analysis of the total declared costs per client profile, 38 outliers stand out (5.83% of the total data set). Noticeable is that 13 of these outliers belong to one organization. However, the outliers are checked in order to perform the Multiple Regression Analysis. This revealed that the model is linear and the outliers are normally distributed, which means that the outliers (almost) not influence the outcomes of our study. Beside of this, we performed an extra Multiple Regression Analysis with only clients included with total declared costs lower that €20,000, so the outliers are implicitly excluded. This test explained no more variation is costs. Because of these two reasons we decided not to exclude the outliers from the analysis.

Future changes in the home care sector

It is expected that home care will significantly change in the coming decades (53-55). Extensive automation of care, remote care, robotics and shifting the caring to people themselves, are required to keep health care affordable and to make health care less dependent of care personnel. Healthcare professionals will support more clients and their families in what they can do themselves, and must prepare to work more with technology and remote care. Remote care, or any care that is not physically provided at the client at home, is in full development (53-55).

Information technology discloses medical knowledge for laymen and creates better consumer information on care on an international scale. People can make more often choices by their own and perform care related activities themselves. This results in a radical different way of care. The request for healthcare and social services could often be handled digitally. Elderly, disabled and dementia clients regulate their daily lives and their own care at home, using their social network, robots, automation (''domotica''), digital coaching products, and private care. The use of technology becomes more and more part of the healthcare culture and vision (53-55).

Healthcare organizations, including home care organizations, must prepare for these shifts in care. Home care will probably not be supplied through the current way. Healthcare insurers probably will purchase their care in a different way, for example by the currently used personal budget system (*''persoonsgebonden budget, PGB'')*. However, a mandatory collective insurance for high, unforeseen medical expenses remains necessary. For these reasons, we have the opinion our client profile system still will remain useful. For each client profile you can determine a fixed amount of money (like a *PGB*). If a person belongs to a particular client profile, they can spend this amount of money to purchase care. In this situation, people can determine themselves what care, from whom and when they purchase it. For this reason, the client profile system connects well with the expected changes in (home) care in the future. However, for this financing purpose it has to be examined if for example a minimum or maximum amount of clients per client profile is required, to be sure this system is profitable/workable.

Recommendations for further research

For the drawing of a final conclusion if the implementation of client profiles in the Dutch home care sector to determine the need for care and the care budget is possible, further research is required. This study can be used as the basis for further research. As described above, in further research we recommend a broader and larger approach. When it is possible, there should be more home care providers spread across the whole country participate in the study. Also, we recommend that more different diseases and/or reasons for receiving home care are included in the study. Beside of this, we recommend that more clients with data over a longer period of time should be included in the study. The data collection can be better supported, and could be collected on a different, more directed manner. Doing so, other determinants (e.g. income of the client (household) and if the client do/do not smoke) which influence the costs of care for dementia clients could be tested, and this may better explain the differences in costs between dementia clients. Performing a time study could be a possibility to get more insight where the costs actually originate.

As stated earlier in the discussion, there are differences in received home care and costs of care for approximately the same clients (the same characteristics) between organizations, according our data. This could mean two things: We do not have enough insight into the characteristics (of the

client and his or her environment) which do matter, and/or it is possible that some organizations by definition committed more care than others, independent of the characteristics of the client and his/her environment. In the last case, we just seem to have relatively more expensive home care organizations that others (quality not taken into account). Besides of this, it is possible that not the organization specific, but other factors on the supply side have impact on the provided care. You have, for example, one home care provider which is a monopolist in his working area, and another organization must compete with this organization. This could have an effect on the amount of provided care. To compete, it is possible that the other organization have to provide more care. For this reason, we recommend that in the future more specific research have to be performed on this type of supply factors, instead of only ‘’demand factors’’. Besides of this, we recommend to investigate the influence of quality on the provided care. Does a client receiving care of a more expensive home care organization, experience a higher quality of care?

Finally, we recommend monitoring the current changes in the (home) care sector closely, and anticipating the study on these potential changes.

Conclusion

Literature research shows that seven determinants can be predictive for demand and costs of dementia patients in the health care sector. Three of these determinants, namely informal support system, formal support system and co-morbidity, were recognized by field workers as the determinants which have the most influence on the demand and cost of care. Eight clients profile have been defined based on these three determinants.

The analysis of the collected data of 652 clients shows that the three determinants are not representative for demand and costs of care. Only the determinant comorbidity explains just 1.7% of the total costs. Regression analyses with the original eight determinants (now the organizations are included as an individual –eighth– determinant) has been conducted. The four determinants comorbidity, age, phase of dementia and the organizations are slightly representative for demand and costs off care. The three determinants comorbidity, age and phase of dementia can only explain 9.0% of the total variation in costs of care between clients (7.3% more than the original three determinants for the client profiles). In addition to this, the organizations explains 8.3% of the total variation of costs. This means that a part of the variation in health care costs between clients can be explained by the organization where the client receives home care. For further investigations we advise to perform more research on the organization specific supply factors. Besides of this, more research with comprehensive data sets is needed on the client profile system; more clients, longer period of which data is collected and more determinants (e.g. the income of the client (household) and if the client do/do not smoke). With identifying more representative determinants, more variation in total declared costs can be explained. After that, it is more likely that useful client profiles which are broadly recognized and accepted in the home care field can be defined.

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Appendix 1: Full description of the three stages of dementia

Description of the symptoms and behavior included in the three phases of dementia, described by Alzheimer Nederland (2013):

Phase 1→ early stage:
Dementia usually begins gradually with very small changes. These characteristics are often mistakenly attributed to stress, a shocking event or the normal aging process. Many people realize afterwards that this where the first signs of dementia. Multiple characteristics of the early stage could be:

- Small changes in behavior or ability of the person;
- Loss of memory from recent events, such as forgetting recent conversations or events, repeating, slowly understanding new ideas, and losing the thread of a story;
- Losing interest in other people and activities;
- Sometimes anxious and restless;
- Having difficulties with making decisions;
- Other symptoms such as confusion and speaking less fluently.

Phase 2→ middle stage:
When the dementia progresses, the changes become larger. Increased support is needed with daily activities, such as regular recall or help with eating, washing, dressing and going to the toilet. Characteristics of the middle phase are:

- Difficulty with recognizing people or confusing people;
- Forgetting more and more things and sometimes keep repeating the same sentence;
- Often easily become upset, angry, aggressive and/or suspicious;
- Loss of inhibitions;
- Confusion in time, place and environment, such as run away or get lost and disturbed sleep-wake rhythm;
- Putting themselves or others at risk by their forgetfulness, for example, igniting the gas of the stove;
- Behaving in an unusual way, for example, going outside in nightwear;
- Sometimes having problems with the perception, like hallucination.

Phase 3→ late stage:
In this phase, the person need more and more help, and gradually become completely dependent of others. Possible characteristics of this phase are:

- Often pronounced loss of memory, with no recognition, or sometimes just flashes of recognition, of familiar objects, people or environment;
- Difficulty with expressing themselves;
- Physical decline, including walking unsteadily, shuffling, and eventually bedridden;
- Sometimes compulsive actions;
- Restless, often seem to look for something or someone;
- Incontinence of urine or feces;
- Gradual loss of speech, sometimes few words keep repeating or yelling;
- Difficulty with chewing and swallowing, significant weight loss (despite overeating);
- Sad or aggressive when the person feels threatened, sometimes anger outbursts during personal care.

Appendix 2: Remaining outcomes of the data analyses

Because the data in this appendix is confidential, appendix two is only available to the researchers of this study