

MASTER

The effect of case-management on informal caregivers' desire to institutionalize dementia patients

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Eindhoven, August 2009

**The effect of case-management
on informal caregivers' desire to
institutionalize dementia patients**

by
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BSc Industrial Engineering and Management Science — TU/e 2007
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in partial fulfilment of the requirements for the degree of

**Master of Science
in Operations Management and Logistics**

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Abstract

This master thesis project investigates the effect of case-management on informal caregivers' desire to institutionalize dementia patients. The study was carried out in the region of Eindhoven and aimed to address the following questions: '(1) Which factors are related to the informal caregivers' desire to institutionalize dementia patients?' and '(2) Which aspects of case-management as implemented in the region of Eindhoven, contribute to reduced desire to institutionalize?'.

This study tried to answer these questions by developing and testing a model with relationships between various factors and the desire to institutionalize. No support was found for the relation between the extent to which caregivers received case-management services and the desire to institutionalize. Instead, effects were mainly found for background variables.

Preface

This master thesis project marks the end of my master degree program ‘Operations Management and Logistics’ at the Eindhoven University of Technology. The project was carried out for the sub department ‘Human Performance Management’ of the faculty Industrial Engineering & Innovation Sciences. I am pleased to end my studies at this sub department under supervision of my first and second mentor, as I found the project challenging and a rewarding experience from which I learned a lot.

The results of this master thesis could not be accomplished without the support of a number of people. I would like to take this opportunity to show my gratitude to these people. First, I would like to thank Dr.ir. P.A.M. Kleingeld for his guidance, enthusiastic support and critical reviewing of the project. Next, I would like to thank Dr. H.F.J.M. van Tuijl for looking at the project from a broader perspective. In addition, I would like to thank my company supervisors for their support and commitment to the project and for providing me the opportunity to conduct scientific research in a real-life environment.

Finally I would like to thank my family and friends for showing their interest and their provision of the necessary distraction when needed.

René Steur

August 2009

Management summary

Context

For Dutch people it is self-evident that they take care of a relative who is ill or a relative with disabilities (Timmermans, 2003). ‘Informal care’ (Mantelzorg in Dutch) is a term to describe the voluntary, unpaid care provided by people (De Boer et al., 1994). Providing care for people with dementia is a challenging responsibility. Numerous support programs are developed to support the informal caregivers during the process and are often presented under the heading ‘case-management’.

In this study, case-management is evaluated as implemented in the region of Eindhoven. The vision of the organization which implemented case-management is to facilitate that dementia patients could stay at home as long as possible (if beneficial to their quality of life), with adequate professional care. Case-management is provided to sustain informal care, which consists of the following activities: (1) brokering by providing linking patient needs to services, (2) arranging these services when necessary, (3) providing social support, (4) providing information how to cope with behaviour problems of a dementia patient, (5) explaining and educating caregivers about dementia, and (6) advocacy (e.g., defending the interests of the caregiver in problem situations).

Research objectives

Case-management, as a provision, is formerly not financed by the public insurance of the ‘Algemene Wet Bijzondere Ziektekosten’. The organization would like more structural financial investment in case-management. The organization contacted the Eindhoven University of Technology because it wanted to evaluate the effectiveness of case-management in the region of Eindhoven with respect to the length of care an informal caregiver wants to provide. If informal caregivers want and are able to provide informal care for a longer period, this could lead to a lower use of nursing homes, which would lead to cost savings. These cost savings could, e.g., be used to increase the capacity of nursing homes to deal with the high demand of nursing home placement or to lower to overall costs of the health care system in general. This would make investment in case-management financially attractive.

To gain insight into the effectiveness of case-management, this study tries to answer to following questions: (1) ‘Which factors are related to the informal caregivers’ desire to institutionalize dementia patients?’ and (2) ‘Which aspects of case-management as

implemented in the region of Eindhoven, contribute to reduced desire to institutionalize?'. The study included 'caregiver burden' as an alternative dependent variable. This could give more insight into the overall effect of case-management and if 'desire to institutionalize' would be inappropriately measured with respect to validity or reliability, it would enable an alternative analysis.

Methodology

Although the first intention was to use a pre-experimental setup for this study (a static group comparison), difficulties acquiring enough participants for the control group within the time available for this study led to within-group study, where all subjects respond to the intervention of case-management. The extent to which they received case-management services is investigated whether to be related to a lower desire to institutionalize.

A survey was developed for testing the relationships hypothesized in this study. In total, 266 out of 520 questionnaires (response rate 51%) were analyzed using multiple regression analysis.

Results

Significant effects were mainly found for background variables. The following factors were found related to the desire to institutionalize: the education of the caregiver; the relationship between the caregiver and the dementia patient; the physical health of the caregiver; the trade-offs a caregivers is willing to make with respect to his/her job, hobbies, or interests; and the stage of dementia of the dementia patient. The following factors were found related to caregiver burden: time-based trade-offs, domestic care, involvement, and the mental health of the caregiver. The relationship between the caregiver and the dementia patient was found the strongest predictor for the desire to institutionalize, whereas it was not found related to caregiver burden. Time-based trade-offs was found the strongest predictor for caregiver burden, but the effect on desire to institutionalize was considerably smaller.

With respect to case-management, the following services were investigated: (1) brokering services, (2) arranging and follow-up services, (3) providing social support, and (4) providing coping strategies for dealing with behaviour problems. Advocacy and arranging services were found strongly related and were further conceptualized as arrange and follow-up services. Explaining and educating caregivers about dementia could not be investigated due to insufficient validity. The extent to which caregivers received services of case-management

was not found related to the desire to institutionalize. Only social support given by friends was found to have an indirect effect on caregiver burden, via an increased mental health of a caregiver. An overview of the results is given in Figure 1a and Figure 1b.

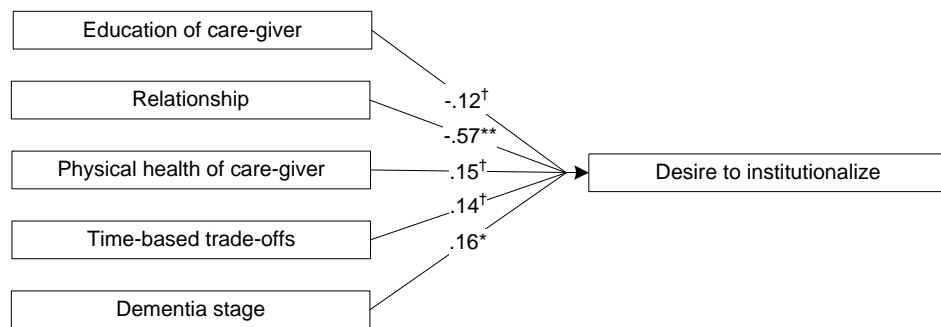
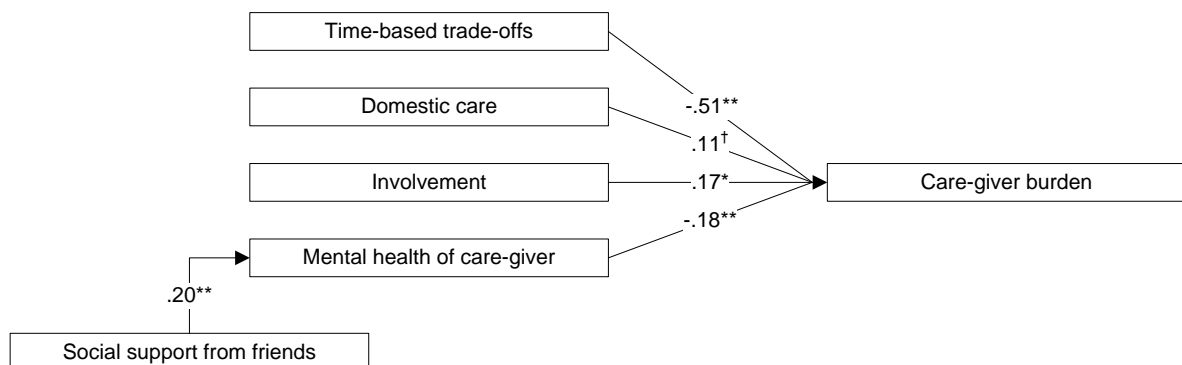


Figure 1a An overview of the relations found for desire to institutionalize



Beta coefficients are shown, ** = $p < 0.01$; * = $p < 0.05$; † = $p < 0.10$

Figure 1b An overview of the relations found for caregiver burden

Discussion

The findings in this study did not confirm expected positive effects of case-management as implemented in this specific context. However, current findings do not mean that case-management could not be effective at lowering institutionalization rates. In the context of community-based long term care, results from research were dominantly not found to provide evidence for case-management to lead to lower institutionalization rates. However, a relative small amount of studies using experimental setups, have found statistical significant effects on nursing home use (Weissert et al., 1988). These effects were also practically meaningful:

Decreases of 10% were reported. Weissert et al. (1988) furthermore found that studies that reported higher effectiveness are frequently those where the case-management intervention did a comparatively better job of targeting. Targeting can be described as selecting people to which case-management should be given, based upon the potential case-management could have. Many interventions, as well as the case-management implementation in the current study are directed at all informal caregivers known to exist, identified in the earliest phase as possible, i.e. no targeting is used. The lack of targeting could well be an explanation for the lack of extensive support for the effectiveness of case-management. If too many caregivers in a sample at which case-management could not be effective to begin with, this will show up in the overall effect.

It is important to realize that case-management could have multiple high-level outcomes. Increased service linking, lower nursing home use, decreased overall health costs, a better quality of life of the caregivers are all possible outcomes of case-management. However, to reach maximum effectiveness on one or a set of these outcome variables is likely to demand a different implementation of case-management. This will be illustrated with case-management viewed from an overall cost-perspective contrasted with a view that values the quality of life of a caregiver. With respect to overall health care costs, case-management could lead to cost savings, but case-management itself should also be seen as a cost. To be cost-effective, the costs of case-management should at least, be offset by the savings due to delayed institutionalization of dementia patients. This would further stress the importance of targeting, e.g., if case-management is given to caregivers of which their institutionalization rate is not positively delayed, case-management could even lead to an increase in overall costs. Ideally, case-management should be directed at caregivers of dementia patients who would have entered nursing homes for a long period of time (Weissert et al., 1988).

On the other side, if the quality of life of an informal caregiver is the main objective, this could lead to a different ideal strategy. Factors like the amount of sleep the person can get, how well a caregiver is able to deal with behaviour problems, and the amount of time the informal caregiver could spend relaxing could be related to the quality of life. Case-management could positively affect these factors. From the perspective of the quality of life of informal caregivers, it may seem interesting to provide case-management to all informal caregivers identified in the earliest point in time. However, one must understand the implications this could have in terms of cost-effectiveness. The question should then be raised how much increased quality of life of caregivers is worth and how much the government or

the society is willing to pay for this. This could then be taken into account with respect to the financing of case-management.

Limitations and further research

To gain a better understanding of the effect of case-management, this study relied on the variation with respect to the extent to which different case-management services were received. Therefore, the effect of (levels of) case-management compared to no support from case-management could not be established in this study.

Furthermore, the setup of this study does not provide evidence for relationships to be causal, because all variables were measured at the same time, i.e., the time sequence is not accounted for. Another limitation is the use of 'desire to institutionalize' instead of the actual institutional rate. How well the desire to institutionalize at one point relates to an actual decision to institutionalize a dementia patient is not known. Furthermore, one aspect of case-management, namely explaining and educating caregivers about dementia, could not be included in the current study, due to the underlying structure of the study variables.

To deal with the limitations discussed, it is recommended to extend this study with a static group comparison. This involves comparing an intervention group with a control group. Other regions could be used where case-management is not implemented yet. With respect to the research field in general, it may be interesting to do additional research whether case-management could be more beneficial if caregivers are carefully selected based upon characteristics related to an increased potential of case-management. Further research could be directed at clarifying these characteristics.

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1. Introduction

1.1 Case-management to support informal care

As the world population ages, a growing number of people is serving as caregivers for family members with dementia. Dementia is the progressive and long-term decline in cognitive function due to damage or disease in the body beyond what might be expected from normal aging (Berrios, 1987). Dementia prevalence increases with increasing age. Prevalence doubles approximately for every 5-year interval, from 1% among people of 60-64 years of age to about 40% among those aged 90 (Jorm et al., 1987). Since the proportion of the oldest people is rising and will continue to rise during the forthcoming decades (Centraal Bureau voor Statistiek, 2008), the number of dementia patients will also increase. The prevalence of people with dementia in the Netherlands is estimated to double between 2000 and 2050 (Health council of the Netherlands, 2002). Moreover, the costs of dementia care constitute a substantial part of the total costs of care for elderly (Wimo et al., 1997). Therefore, it is safe to say that dementia is a major public health problem.

In the period in which people with dementia live at home, they receive regular care (e.g., from a family doctor), home-care, and they make use of community services facilities. Increasingly important is the role of the informal caregivers (mostly relatives), who also take part in providing care in the total process. For Dutch people it is self-evident that they take care of a relative who is ill or a relative with disabilities (Timmermans, 2003). Informal care or ‘Mantelzorg’ in Dutch is a term to describe the voluntary, unpaid care provided by non-professionals (De Boer et al., 1994). Since the amount of professional care is limited, the length-of-care provided by informal caregivers is of importance. The future demand of care might only be fulfilled with the addition of care provided by informal caregivers.

Dementia can affect many areas of cognition such as memory, attention, language, and problem solving and could have serious impact on the quality of life of a person with dementia. It is important to highlight that dementia is not only difficult for the patient; the process of dementia is also difficult for the family and relatives who live with the patient. Providing care for people with dementia is a challenging responsibility, whereby informal caregivers could experience adverse psychological, physical, social, and financial consequences (Huckle, 1994). Numerous programs were developed to support the informal caregivers during the process and are often presented under the heading ‘case-management’.

Though case-management programs can vary widely, there appears to be some consensus about the key functions of case-management (Noelker, 2002). These key functions include assessment, planning, linking to services, monitoring, and advocacy (Mueser et al., 1991). How these functions are performed varies by contextual characteristics such as the type of the provider organization, characteristics of the case-managers, the way services are financed, and the case management model used (Noelker, 2002).

The context of the current study is discussed in the next section. After that, the research objectives are explained. Then the theoretical model used in this study is described, followed by sections describing parts of this model into more detail. Finally, another outcome of providing care (caregiver burden) is introduced that is also included in this study.

1.2 Context

Today in the Netherlands, case-management is a widely accepted solution for dementia patients who have an informal caregiver (Perenboom et al., 1996). The specific region of interest of this study is the region of Eindhoven. In this region, providers of professional care have formed a new organization to organize and implement case-management. This organization holds the responsibility for the organization and implementation of case-management. Case-management provided by this organization is individual based: Each caregiver is assigned to one case-manager throughout the process. The point of contact is mostly at the homes of either the dementia patient or caregiver. The intensity of contact is moderate and varying with respect to the client needs and typically varies between once per 2 months to multiple times per week. Budgetary control for patient services is centralized and outside the control of the case-managers.

Case-managers are either full-time or partially assigned from people who worked at these participating health care suppliers in the region of Eindhoven. This means that all case-managers have a background in health care, but could have had different specializations prior to their assignment and education as case-manager. The caseload is around 50 caregivers per full time job.

Case-managers are paid by the participating health care organizations, but work for the organization responsible for case-management. Case-management is currently financed by project funds from various sources.

Having discussed the organization, the case-managers, and financing, the particular implementation of case-management further defines the context. Mueser et al. (1998) provided a brief description of case-management models that have generated most discussion and research. They distinguished six main case-management models: the broker service model, the clinical case management model, the assertive community treatment model, the intensive case management model, the strengths model, and the rehabilitation model. These models often were used in research of the previous decade. The broker model and the clinical case management model will be briefly discussed below, as they are most relevant for the current study.

The broker model relates to the key functions of case-management. The case manager's primary role is to arrange the services needed and to coordinate between service providers. The functions include assessment, planning, linking to services, monitoring, and advocacy. Case-managers are expected to identify the needs of a patient and then arrange the services. This model aims to address many patients' problems in finding their way in the confusing community health system.

The clinical case management model extends the previous model with some inclusion of clinical services provided by the case-manager. Examples of these clinical interventions are psychotherapy, psycho-education, and crisis intervention. Psychotherapy and psycho-education are activities that aim to increase the informal caregiver's ability to cope with the situation. In addition, this model explicitly states that the case managers have a clinical background and have skills in psycho-education and psychotherapy.

An important difference between the broker model and clinical case-management model and the other forms of case-managements, is the intensity of contact and that these forms of case-management are delivered by a multi-disciplinary team. Both models discussed have a relative low intensity of contact between a case-manager and informal caregivers and frequently have a relative high caregiver to case-manager ratio.

The case-management model used in the region of Eindhoven corresponds to the clinical case management model, where case managers have a background in health care and extend the key functions of the brokerage model by providing psychosocial interventions. The service provided can be summarized as follows: (1) brokering by providing linking patient needs to services, (2) arranging these services when necessary, (3) providing social support, (4) providing information how to cope with behaviour problems of a dementia patient, (5)

explaining and educating caregivers about dementia, and (6) advocacy (e.g., defending the interests of the caregiver in problem situations). These dimensions were established by a series of 25 interviews with caregivers. These descriptions are used in the upcoming sections of this report.

1.3 Research objectives

The vision of the organization is to facilitate that dementia patients could stay at home as long as possible (if beneficial to their quality of life), with adequate professional care. In the Netherlands, health care is organized by demand. For some groups such as dementia patients and their caregivers, this demand-organized care could lead to problems (Ligthart, 2006): They are less able to find information sources, are not informed about support sources, and are less able to recognize and organize support. Increasing competition in support sources leads to even less transparency. By providing case-management to support the informal caregivers throughout the dementia process, informal caregivers are supposed to be better able and longer willing to provide informal care.

Case-management, as a provision, is formerly not financed by the public insurance of the ‘Algemene Wet Bijzondere Ziektekosten (AWBZ)’. The AWBZ is an obligatory, collective health care insurance for health care risks that are not covered by the basic health care insurance (Ministerie van Volksgezondheid, Welzijn en Sport, 2009). The organization would like more structural financial investment in case-management. If informal caregivers want and are able to provide informal care for a longer period, this could lead to a lower use of nursing homes, which would lead to cost savings. These cost savings could, e.g. be used to increase the capacity of nursing homes to deal with the high demand of nursing home placement or to lower the overall costs of the health care system in general. This would make investment in case-management financially attractive.

The organization would like to evaluate the effectiveness of case-management in the region of Eindhoven with respect to the length of care an informal caregiver wants to provide. Due to practical limitations, it is not possible to measure the actual length of care of multiple informal caregivers in this study. Therefore, an alternative measure will be used, namely the ‘desire to institutionalize’, which can be defined as the extent to which the informal caregiver would like to institutionalize the dementia patient (Morycz, 1985).

To gain a better understanding of the effectiveness of case-management in Eindhoven, the current study aimed to answer the following research questions: ‘(1) Which factors are

related to the informal caregivers' desire to institutionalize dementia patients?' and '(2) Which aspects of case-management as implemented in the region of Eindhoven, contribute to reduced desire to institutionalize?'

This study tried to answer these questions by developing and testing a model containing relationships between various factors and the desire to institutionalize. This model will be discussed in depth in the upcoming sections. This model served as the foundation to develop the survey, which was used to test the relationships present in the model. The survey is sent to a number of dementia-caregivers in the region of Eindhoven. Results were analyzed and based upon the results implications are finally discussed to the organization and for the research field of case-management in general.

1.4 The Demand-Induced Strain Compensation model

To explain a caregiver's desire to institutionalize, the concept of the Demand-Induced Strain Compensation (DISC) model developed by De Jonge & Dormann (2003) was used in this study. The model consists of three primary elements: job demands, job resources, and job outcomes. Job demands refer to the degree to which the work environment requires cognitive, emotional, and/or physical effort. Job resources could be conceptualized as a kind of energetic reservoir that could be utilized in order to perform the specific job well. As far as job demands are concerned, three types can be distinguished (De Jonge, 2009): (1) cognitive demands that primarily rely on information processing in the brain, (2) emotional demands which refer to the effort needed to deal with emotions during interpersonal transactions, and (3) physical demands that are primarily associated with the motoric and physical aspects of behaviour. Job resources can be divided into three similar dimensions (De Jonge, 2009): (1) It may have a cognitive-informational component (e.g., colleagues providing information), (2) an emotional component (e.g., colleagues providing sympathy and affection), and (3) a physical component such as instrumental help of colleagues. Job related outcomes can be both positive (e.g., motivation and creativity) or negative (e.g., adverse health or stress).

To a certain extent, providing informal care could be seen as a voluntary job. Therefore, this model could be well transferred to the context of this study. Providing care may have physical demands (e.g., preparing a meal, bathing a dementia patient), cognitive demands (e.g., finding professional care, dealing with various administration processes), and emotional demands (e.g., dealing with behaviour problems of the dementia patient and accepting that the relative has dementia). Physical support resources are available if the dementia patient

meets certain criteria and these resources could include domestic care, personal maintenance care, and nursing care provided by health care organizations at the home of a dementia patient. Case-management was implemented to supply the informal caregivers with emotional resources (e.g., providing social support and coping strategies to deal with behaviour problems) and cognitive resources (e.g., providing information about local services and arrange services).

In the context of this study, it is theorized that if there is a balance between the task demands and task resources of an informal caregiver (see Figure 2a), the caregiver would like to provide informal care for a longer period, i.e. the desire to institutionalize will be lower, than in a case where there are insufficient support resources available relative to the task demands (see Figure 2b).

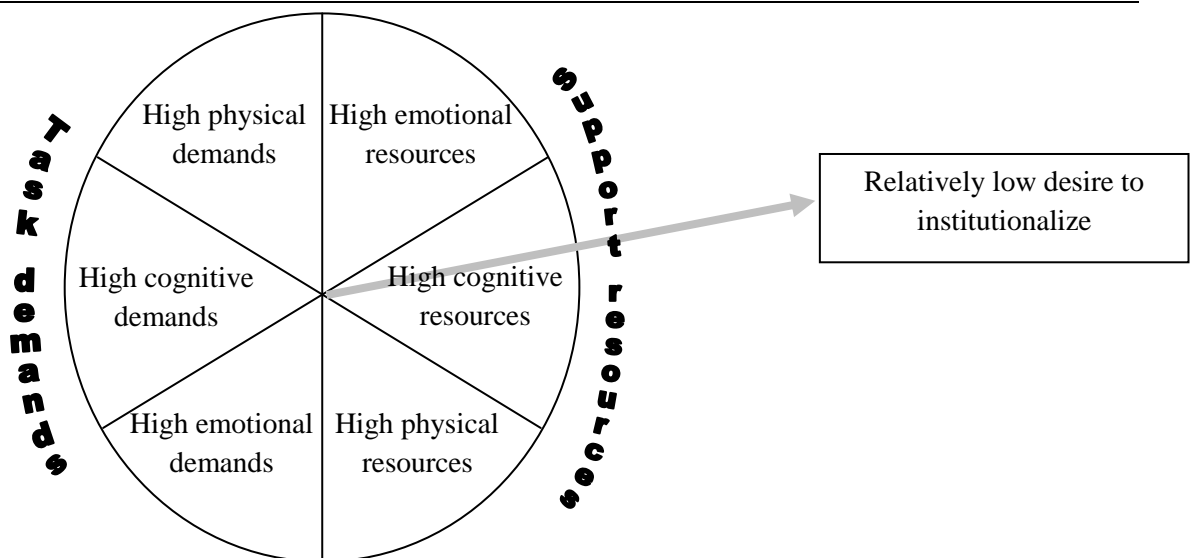


Figure 2a Match between task demands and resources

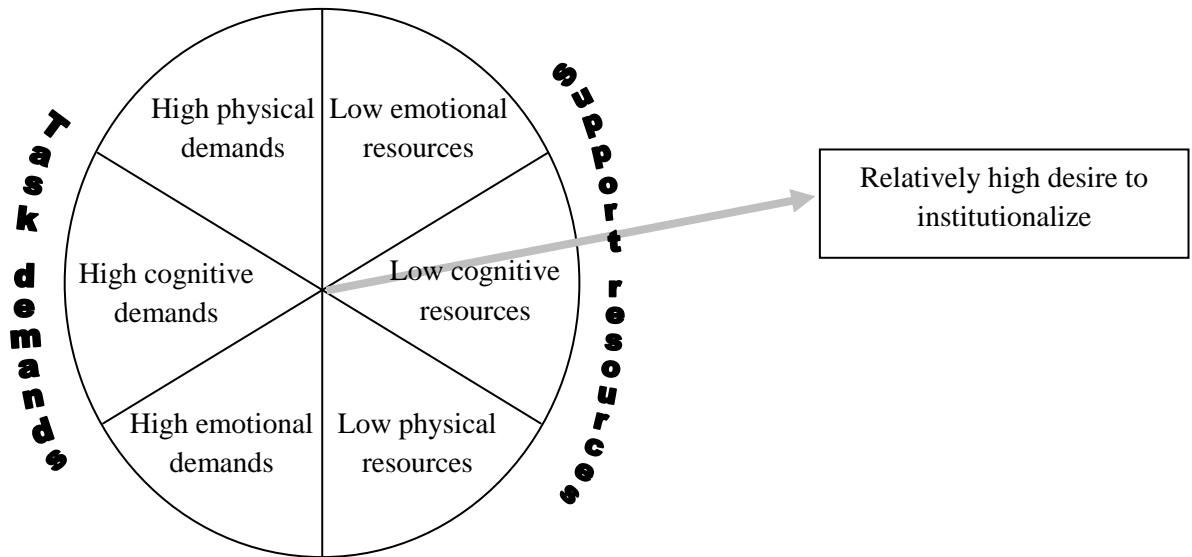


Figure 2b Mis-match between task demands and resources

1.5 Task demands of providing informal care

In the previous section, a theoretical model is provided in which three dimensions, namely physical, emotional, and cognitive, were identified. Two of these (emotional and cognitive) are of specific interest, since case-management operates on these dimensions. In the upcoming section, variables related to mental task demands and cognitive task demands are discussed. After discussing variables related to these two domains, general background variables are investigated that could affect the desire to institutionalize.

1.5.1 Variables related to emotional demands

Mental health of caregiver. Multiple studies have included the effect of the mental health of a caregiver on the rate of institutionalization. Although the general expectation is that institutionalization rate will be higher when caregivers experience a decrease in mental health, the effect of mental health on the institutionalization rate was mainly found insignificant (Kim et al., 2002; Pot et al., 2001; Spitznagel et al., 2008).

Dementia stage. This variable relates to the severity of dementia, in the research field often expressed using a stage model. It is expected that the higher the stage of dementia of a patient, it will become more mentally difficult for caregivers to continue providing care. It could also lead to higher physical demands, but other factors like impairment in activities of daily living might better represent physical demands. A widely accepted clinical rating of dementia severity is the Global Deterioration Scale (GDS) (Reisberg et al., 1982). This stage-model emphasizes the memory function and the ability to complete activities of daily living. Although initially developed for primary degenerative dementia like Alzheimer, Paul et al. (2002) have provided support for the validity of the stage model for secondary Vascular Dementia. Alzheimer and Vascular dementia constitute the largest part of all dementias (Katzmann, 1986; Plassman et al., 2007).

Behaviour problems: severity and distress. Neuropsychiatric symptoms such as apathy, aggression, depression, psychosis, aggression, and agitation are common during cognitive and functional decline in a disease like dementia (Kaufer, et al., 2000). The severity of behaviour problems is defined as the extent to which these neuropsychiatric symptoms are present. The resulting caregiver distress could affect the caregiver's desire to institutionalization. Results from different studies (Hope et al., 1998; Mittleman et al., 1996; Spitznagel et al., 2008) seems to be mixed as to whether the severity of problematic behaviours would be associated with institutionalization. Spitznagel et al. (2008) have

included both the severity of behaviour problems and the resulting distress in their study and did not find either significantly related to the desire to institutionalize.

1.5.2 Variables related to cognitive demands

Find information about services & Arrange services. Caregivers do not only have to provide care, they also have to find and arrange support services in the community to supplement their own given care. These services are being offered by multiple organizations. Getting to know the organizations and the services they offer could be seen as a cognitive task for caregivers. It could affect the desire to institutionalize, since caregivers that are better able to find and arrange support services obtain better support, therefore being longer able to provide informal care.

Knowledge about dementia. Interesting are the results of the study of Spitznagel et al. (2008), who found that the knowledge of the caregiver about dementia is related positively to the desire to institutionalize. They argued that it is possible that caregivers who are more informed about dementia more fully appreciate the eventuality of severe cognitive decline. This makes the group possibly more willing to consider institutionalization of the care recipient. The authors therefore suggest that interventions should include components aimed at reducing caregiver burden, because these may be more effective at delaying institutionalization than educational programs.

1.5.3 Background variables

Although in this study, variables related to task demands and support resources are of main interest, many background variables could also lead to the desire to institutionalize available in the literature. It should be noted that the predictive variables are neither exhaustive nor generally accepted (Kim et al., 2002) and the authors highlighted the importance of considering culture-specific elements when results are generalized to other populations.

Age and gender of both caregiver and dementia patient. Hope et al. (1988) found that younger carers were less committed to provide care. They argued that this could be because younger caregivers may have jobs or greater demands from other members of the family. Gender will also be taken into account as a general context factor.

Educational level. The educational level corresponds to the highest educational level attained by the caregiver. Pot et al. (2001) found the educational level of caregivers positively associated with time until institutionalization. They argued that higher educated caregivers

have probably more knowledge of alternatives, may discuss the difficulties of providing care, and ask for professional help more easily, get more easily an indication for placement.

Relationship. One important factor that leads to the willingness to provide care could be the relationship between the patient and the caregiver. Pot et al. (2001) claim that spouses, compared to non-spouses are likely more strongly committed to providing care. This is also suggested by Hope et al. (1998) and Spitznagel et al. (2008), who found that spouses having a higher commitment to providing care. Hope et al. (1998) furthermore found that this is true at both the point of entry into the study and at time of institutionalization.

Physical health. The physical health of the caregiver could be thought of as a caregivers' capacity to do physical or motoric tasks related to providing care, e.g., bathing a dementia patient might be physical demanding for many elderly, because of their own health. Physical health of the caregiver is not often included as a variable in previous studies. Therefore, little is known about the effect of the physical health on the rate of institutionalization. Gaugler et al. (2008) found that the physical health was not significantly related to institutionalization. However, Hope et al. (1998) found a very marked decrease in the caregiver's physical ability to cope by the time the patient entered an institution.

ADL and IADL impairment of dementia patient. Because of dementia, patients need assistance in their daily living. Activities of daily living (ADL) are functions which are essential for an individual's self-care (e.g., washing or dressing oneself) (Spector et al., 1987). Instrumental activities of daily living (IADL) are functions concerned with self-reliant functioning in a given environment (e.g., shopping, preparing meals) (Spector et al., 1987). Results from Pot et al. (2001) are interesting for this study, since their study also used a Dutch sample. Their results show that IADL dependency was significantly related to the rate of institutionalization, whereas ADL dependency was not.

Type(s) of care giving. As previously discussed, Timmermans (2003) defined four types of informal care: domestic care, personal care, nursing care, and supervision. Although no research is found that relates these types of care to the desire to institutionalize, it could well be that different types of caregiving put less or more strain on the caregiver.

Amount of care given & length of care given. Although ADL and IADL show to what extent a dementia patient might need help in their daily lives, they do not show how much time actually is spent on providing care by an informal caregiver. They also do not show how long

the caregiver was providing care. Because this is likely to vary between caregivers, it might be important to include these variables.

Time-based trade-offs. Duijnste (1992) suggested that providing care might have implications for an informal caregiver with respect to the time that is available for work, his or her own family, hobbies, social contacts, and holidays. This may lead to trade-offs that have to be made in order to be able to provide care. Time-based trade-offs could be defined as the extent that a caregiver is willing to make these trade-offs.

Involvement. Job involvement can be defined as a degree to which a person's total job situation is an important part of his life or central to the person and his identity (Lawler & Hall, 1970). People probably differ as a function of their background and personal situation in the degree to which they become involved in this particular 'job' of giving care. It could be that people who are more involved want to provide care for a longer period.

1.6 Support resources of providing informal care

As previously discussed, physical support resources are available if the dementia patient meets certain criteria and could include domestic care, personal maintenance care, and nursing care. This study aims specifically at the effects of case-management and therefore physical support resources are outside the scope of this study. Case-management can be split up into mental resources and cognitive resources. In the upcoming section the hypothesized effect of each support activity will be elaborated on.

The dementia stage of the patient was previously discussed as a factor related to the emotional task demands of providing informal care that is likely related to the desire to institutionalize. Case-management could be seen as an emotional resource for this task demand, since case-managers provide 'social support' to deal with emotions that arise when dealing for a relative with dementia. Results from the study of Chu et al. (2000) have shown that case-management could have beneficial to patients with severe dementia. No such result was found for people with mild dementia. The authors argued that case-management may only be effective in cases where dementia of the patient is further developed, e.g., when people do not have to deal with any stressful situation, they are unlikely to benefit from social support given by a case-manager, whereas caregivers of severe dementia patients are likely to benefit from social support. Social support could not only be given by a case-manager, but could also be given by family, friends, or people met at the 'Alzheimer cafe'. The Alzheimer

café is a place where informal caregivers can voluntarily come together to share their thoughts and discuss providing informal care.

González-Salvador et al. (1999) have shown that family caregivers of Alzheimer's disease patients have a worse mental health compared to family caregivers of aged non-demented chronically ill patients. It is likely that increasing stages of dementia will result in a worse mental health of a caregiver. Furthermore, Uchino et al. (1996) have reviewed evidence for linking social support to health and provided multiple sources which show that both the quantity and quality of social relationships are reliably related to various mental health factors. They also state that in general, stronger associations may be obtained with interventions focusing on familial social support. Based upon the results of these studies, mental health is proposed as a (partial) mediator of the effect of social support on the desire to institutionalize.

The particular relationship where the effect of one independent variable on a dependent variable is dependent on another independent variable is called a moderating relationship. A hypothesized moderating effect of social support given by a case-manager on the relationship between dementia stage of a caregiver and mental health is illustrated in Figure 3. The moderation effect is visible, because the two lines are unparallel to each other.

Note that values in this particular example are chosen such to illustrate to moderating effect and have no meaning.

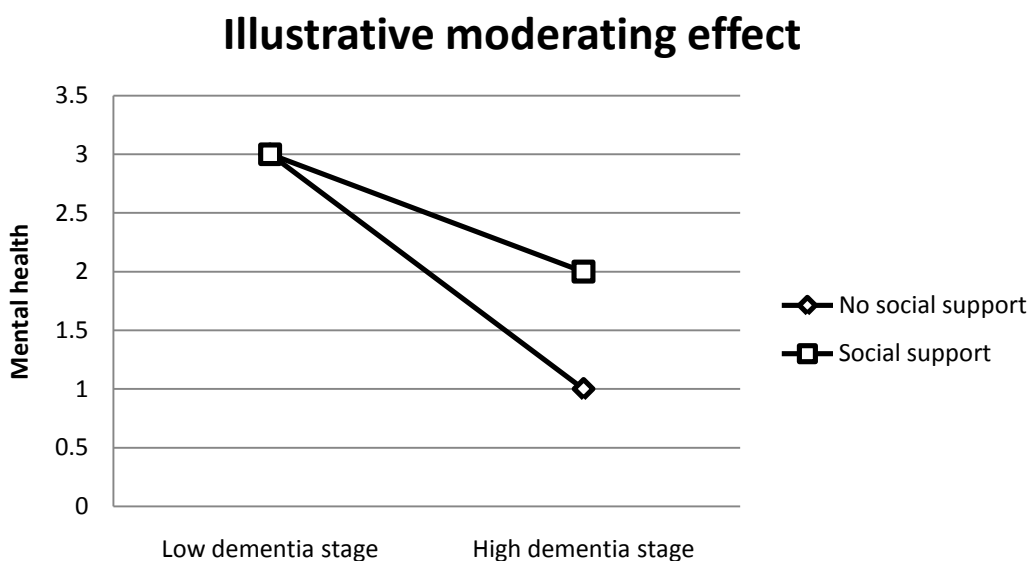


Figure 3 Moderating effect of social support given by a case-manager on the relationship between psychological stress of the caregiver and the desire to institutionalize

Based upon the preceding discussion, the following hypotheses are derived:

Hypothesis 1: The dementia stage of the patient is positively related to the desire to institutionalize.

Hypothesis 2: Mental health (partially) mediates the effect of dementia stage on the desire to institutionalize.

Hypothesis 3: Social support given by case-management (3a), by family and friends (3b) and by the Alzheimer cafe (3c) moderates the relationship between dementia stage and mental health, such that the relationship will be weaker for higher values of the moderator.

The severity of behaviour problems was also previously discussed as an emotional task demand, which could be related to the desire to institutionalize. Case-managers provide ‘coping strategies’ to deal with behaviour problems of the dementia patient. This in turn could lead to less distress resulting from these behaviour problems. Therefore, providing coping strategies can be seen as a moderator of the effect of behaviour problems on the resulting distress. The following hypothesis are derived:

Hypothesis 4: The severity of behaviour problems is positively related to the desire to institutionalize.

Hypothesis 5: Distress due to behaviour problems (partially) mediates the effect of behaviour problems on the desire to institutionalize.

Hypothesis 6: Coping strategies provided by a case-manager moderates the relationship between the severity of behaviour problems and the resulting distress, such that the relationship will be weaker for higher values of the moderator.

Finding information about support services and arranging these services were defined as cognitive task demands. Case-management can be thought of as a cognitive resource with respect to these demands, since they offer a ‘brokering’ service by giving advice about local support services. This should help people to better find services that suit their needs, especially when they do not know much about the support services themselves. Furthermore, a case-manager could ‘arrange’ these services or assist the caregiver arranging these services when caregivers experience difficulties arranging services themselves. Finally, a case-manager provides an advocacy role. All these activities could lead to a lower desire to institutionalize. This could be because these activities results in adequate support services for the dementia patients, such they are longer able to provide informal care themselves.

With respect to providing information of support services and arranging support services, there should be a need for information or administration of support services in the first place. Therefore, it is important to take into account whether there is such a need or not. This is accounted for in this current study. However, the strength of this particular need for information or administration was not included in the study, due to conceptual changes during the project. With respect to providing information, arranging services, and advocacy, only cases were included where there was a need for these respective services. Therefore only direct relationships are hypothesized:

Hypothesis 7: Providing information about local services is negatively associated with desire to institutionalize (for caregivers who reported a need for information).

Hypothesis 8: Arranging services to support caregivers is negatively associated with the desire to institutionalize (for caregivers who reported a need for support with arranging services).

Hypothesis 9: Monitoring services with respect to the client's needs is negatively associated with the desire to institutionalize (for caregivers who reported a need for services to be monitored).

Case-managers furthermore educate caregivers about dementia in general. This should lead to an increased knowledge of dementia of the caregivers. It is believed by the organization that creating understanding could have a beneficial effect by preparing them for what is going to come. This is contrary to the results found by Spitznagel et al. (2008), who found that the knowledge of the caregiver about dementia is related positively to the desire to institutionalize, as discussed earlier. Again the initial need for general information about dementia is accounted for whether present or not and only cases where such a need was present are included. Given the results from the study of Spitznagel et al. (2008) a negative effect of caregiver knowledge on the desire to institutionalize is hypothesized:

Hypothesis 10: Educating caregivers about dementia leads to an increased knowledge of dementia of caregivers (for caregiver who reported a need for education about dementia).

Hypothesis 11: An increased knowledge of dementia is positively related to the desire to institutionalize.

1.7 Burden

It should be noted that literature about case-management outcomes often investigates both the desire to institutionalize and caregiver burden. How the term care-giving burden is conceptualized in literature varies widely (Duijnste, 1992; Braithwaite, 1992). George and Gwyther (1986) defined caregiver burden as the physical, psychological or emotional, social, and financial problems that can be experienced by family members fulfilling their caregiving functions. Poulshock and Deimling (1984) argued for a narrower definition of burden. The authors proposed that burden should refer to caregivers' distress arising from dealing with physical dependence and mental incapacity. Hoenig and Hamilton (1966) distinguished objective from subjective burden. Objective burden refers to events associated with negative caregiving experience and subjective burden refers to feelings aroused in caregivers as provided informal care. In this study, caregiving burden is conceptualized as the extent to which a caregiver perceives providing care as a difficult responsibility to bear. Note that burden in this study therefore is subjective.

This concept is included as a dependent variable as a lower caregiver burden could be an alternative outcome of case-management. Furthermore, if the scale of 'desire to institutionalize' would be inappropriate due to validity or reliability problems, this would enable an alternative analysis. Although this outcome is not the main interest of this study, it might be interesting to see differences in underlying factors predicting these outcome variables. Perhaps, these differences would also lead to a better understanding of the desire to institutionalize.

An overview of the initial conceptual model with all the constructs and relationships hypothesized in this chapter is shown in Appendix A.

2. Methodology

2.1 Procedure and participants

Although the primary intention was to use a static group comparison for this study, which involves a comparison of an intervention and control group (Campbell & Stanley, 1996), difficulties acquiring enough participants for the control group within the time available for this study project led to a within-group study, in which all subjects responded to the intervention of case-management. A requirement with respect to this analysis is that there should be variability with respect to the extent that multiple activities of case-management were executed by case-managers and this variability should be practically meaningful. When this requirement is met, it is useful to analyze the effect of the extent to which case-management services are perceived by the caregiver. A discussion whether this requirement was met will follow later.

Case-management started in the region of Eindhoven in 2005. It has started in several areas of the region around Eindhoven, but not all areas are covered yet. The population of interest contains 784 caregivers in the region of Eindhoven, who have case-managers assigned. Each caregiver is assigned to one of 33 case-managers. The relationship between a caregiver and dementia patient is fixed. It must be noted though that many case-managers work part-time. The current caseload per FTE is approximately 50:1. From the population, 520 participants were selected for whom contact details were available in a database used by the organization. A questionnaire survey was conducted to test the hypotheses stated in Chapter 1. Participants of the intervention group received the questionnaire by mail and they were asked to return it with a pre-paid envelope.

In total, 266 out of 520 questionnaires (response rate 51%) were returned. Six questionnaires were excluded due to too high overall missing data (>30%) and twelve questionnaires were excluded due to missing values for the dependent variables, resulting in a final sample size of $n = 248$.

Most caregivers were female (69%) and the age ranged from 33 to 94 ($M=62.8$, $SD = 13.7$). Dementia patients were also mostly female (61%) and the age ranged from 34 to 98 ($M=80$, $SD = 8.5$). The contact time with a case-manager during last month ranged from 0 to 11.5 hours ($M = 1.4$, $SD = 1.8$). The relationship between the caregiver and dementia patient constituted for a large part of mother/father relationships (47%) and partner

relationships (41%). The living arrangements of the dementia patients were mostly independent (86%). The remainder reported to live in an institution where they either received partial care (9.4%) or full-time care (4.5%). It should be noted however, that in case of recent institutionalization, respondents were asked to fill in the questionnaire as they would have done just before the moment of institutionalization. Therefore, they could be included in the study sample.

2.2 Measures

2.2.1 Dependent variables

Desire to institutionalize. The desire to institutionalize was measured with a 6-item scale developed by Morycz (1985) that quantifies stages in considering nursing home placement, ranging from discussion with family about nursing home placement to actually have taken steps towards nursing home placement. All items are scored using a 3-point Likert scale using the following categories: yes; often (3), yes, now and then (2); no (1). Examples of questions are: ‘Did you ever discuss placement in a nursing home with your family members?’ and ‘Did you ever feel that the dementia patient would be better off in a nursing or boarding home?’.

Burden. In research papers investigated in this current study, burden is often measured using established scales like the Caregiving Difficulty Scale (McCallion et al., 2005) or the Zarit Burden Interview (Zarit, 1980). However, these scales include multiple different concepts already included in this study and would be more suitable for a broader conceptualization of burden. Therefore, burden is measured using a 2-item self defined scale. Two questions were asked related to one’s overall judgement of perceived burden. Items are scored using a 5-point Likert scale. The questions that were used are: ‘Providing care is very hard’ and ‘I feel bearing a load by providing care’. The correlation between the two items was 0.83.

2.2.2 Independent variables

Gender. Male was coded 1 and female was coded 0. This information is necessary to interpret the direction of the effect in subsequent analyses.

Education. Education level was categorized as proposed by ‘Rijksinstituut voor Volksgezondheid en Milieu’ (Verweij, 2008). Four levels of education were used. To give an idea this would roughly correspond to the following to the following categories: (1) primary

education, (2) low secondary education, (3) high secondary education, and (4) higher (tertiary) education.

Relationship. The following categories were used: partner, father or mother, father or mother in law, son or daughter, son or daughter in law, brother or sister, friend, and other.

Type(s) of caregiving. For different types of caregiving the four categories proposed by Timmermans (2003) were used: domestic care, personal maintenance care, nursing care, and supervision. For each type of care the respondent was asked whether the type of care was given.

Physical health and mental health. Physical health and mental health were measured using Dutch translation of subscales of the MOS Short-form General Health Survey (Kempen et al., 1995). Answers for physical health were scored using a 5-point Likert scale instead of the 3-point Likert scale originally suggested by the authors, to enhance the precision of the instrument. Sample questions are: ‘Do you experience difficulties climbing several flights?’ and ‘Do you experience difficulties bending, kneeling, or stooping?’ Answers for mental health are scored using a 5-point Likert scale. Sample questions are: ‘How often have you been a very nervous person lately?’ and ‘How often have you felt calm and peaceful lately?’

Activities of daily living (ADL) and instrumental activities of daily living (IADL). Impairment of ADL and IADL was measured using the measurement instrument proposed by Suurmeijer et al. (1994), which uses 11 items to assess impairment of ADL and 7 items to assess impairment of IADL. Answers were based upon 3-point Likert scales. Sample questions are: ‘Can you, fully independently, dress yourself?’ and ‘Can you, fully independently, do the shopping?’.

Time-based trade-offs. Caregiver trade-offs were measured using multiple items selected from the scale for time-based work interference, provided by Carlson (2000). These items were adapted to fit the context of this study. Four items were selected, using a 5-point Likert scale. Sample questions are: ‘Because I have to spend time providing care, I do not have enough time to fulfil other responsibilities’ and ‘Because I have to provide care, I am able to spend less time on other activities than I would like’.

Involvement. Caregiver involvement was measured using 4 items, inspired by the job involvement scale provided by Lawler & Hall (1970), with answers were based upon a 5-point Likert scale. Sample questions are: ‘I am very much involved personally in the situation

at hand' and 'A large part of my overall satisfaction is being influenced by the situation at hand'.

Dementia stage. The Functional Assessment Staging (FAST) scale (Sclan & Reisberg, 1992) was used to determine the dementia stage. This scale was developed to allow professionals but also caregivers to chart the decline of people with dementia. This instrument is closely related to the original Global Deterioration Scale (GDS) as discussed earlier.

Behaviour problems: severity and stress. To measure the severity of behaviour problems present and the resulting psychological distress of the caregiver, a Dutch translation of the NPI-Q was used (Jonghe et al., 2003). This instrument covers 12 neuropsychiatric symptom domains: delusions, hallucinations, agitation/aggression, dysphoria/depression, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviours, nighttime behavioural disturbances and appetite/eating disturbances. Twelve separate questions were asked, where the participant first needs to confirm whether he/she recognized the symptom to be present in his/her situation. If positive, they were asked to report the severity using a 3 point Likert scale and to report the resulting distress using a 5 point Likert scale.

Knowledge about dementia. To measure caregivers' knowledge about dementia, a dementia quiz from Alzheimer Nederland was used (Alzheimer Nederland, 2008), using 10 true or false questions. Examples of questions are: 'Is dementia curable? (false)' and 'Mr. de Graaf had Dementia at age of 74. Does the daughter of Mr. de Graaf have a high risk to get dementia as well? (false)'.

Activities of case-management. For each of the six main case management activities discussed on page 7, several questions were developed and scored on a 5 point Likert scale. Example questions are given for each activity. Brokering: 'My case-manager has told me about different providers of support for informal caregivers'. Arranging: 'My case-manager did provide assistance arranging support services'. Advocacy: 'My case-manager defends my interests when things go wrong'. Coping strategies: 'Thanks to my case-manager, I can better cope with some behaviour problems'. Educating: 'My case-manager has provided enough information about dementia in general'. Social support: 'I can share my worries with my case-manager'.

As noted before, there should be an initial need for these activities in the first place. Therefore, an additional answer category was introduced: 'not applicable'. Before the

questions were introduced, the respondents were told that if the respective support service was not applicable yet due to their situation, they should check the 'not applicable box'. Only data from cases at which a need for the respective activity was present, were included in the analysis.

Other measures (e.g., duration of dementia, other mental or physical illness, gender) are relative straightforward to measure and are not discussed here.

2.3 Data preparation

2.3.1 Missing data, outliers and exploration of data

First, the data were checked for missing data. When missing data was evident on summated scales and at least 70% of the items were filled in correctly, the missing data was estimated using other items from the corresponding scale by taking the mean of these items. In case of missing data over 30%, all items of the corresponding scale were discarded. Missing data on all other variables was estimated by mean substitution. List-wise exclusion was not an option, due to the large amount of variables. Even a small extent of missing data would lead to the exclusion of many cases, which would drastically reduce the sample size. The results were compared with a pair-wise exclusion of missing variables and would not lead to different conclusions. Note that the regression analyses were executed with a pair-wise deletion of missing data. This was necessary, because not all respondents reported a need for a number of case-management activities and only these who reported a need for these services were included in this study with respect to these variables.

Next, the univariate outliers were investigated. The number of univariate outliers was small and were mainly found on variables like 'Alzheimer Cafe' and the 'Length of care given'. Because the frequency with which people generally visit the Alzheimer cafe is very low, people that reported to go to each session were found as outliers. Furthermore, one multivariate outlier was found with a significant Mahalanobis D^2 ($P < 0.001$). Overall, inspection of the outliers raised no reason to doubt the outliers. Therefore, the outliers were retained in the analysis.

Upon exploration of the data, two variables were identified that showed some problems. For the 'relationship' between the caregiver and the dementia patient, eight categories were used in the questionnaire. Because respondents were mainly found in two categories (88%), namely father/mother and partner relationships, the other categories had too few respondents

to be included in the analysis as a separate category. To be able to generalize the results to the study of Pot et al. (2001), which was also related to a Dutch sample size, this variable was recoded to partner (coded 1) vs non-partner (coded 0). Another variable which raised some concern was ‘care intensity’. Some caregivers reported to spend a maximum of 168 hours per week at providing care for the dementia patient. It is likely that they wanted to show that they are there for their relatives at all times. To get a more meaningful distribution, the variable were recoded using categories of an increment of 5 hours per week with the final category to be 20 hours or more, containing 23% of the respondents.

2.3.2 Underlying structure of the variables

Factor analysis was used to investigate the factor structure used in this study. Principal axis factoring (common factor analysis) was used as the method. According to Hair et al. (2006), principal axis factoring is most appropriate when the primary objective is to identify the latent dimensions or constructs, that are represented in the original variables and the researcher has little knowledge about the amount of specific and error variance. Component factor analysis is most appropriate when data reduction is the primary concern. Principal axis factoring was therefore most appropriate in this case. Furthermore, an oblique rotation was used, because this is the preferred method when the research goal is to obtain several theoretically meaningful factors or constructs (Hair et al., 2006). In an orthogonal rotation extracted factors do not correlate, whereas in an oblique rotation factors are allowed to correlate. In this study it was expected that multiple constructs are correlated, justifying the oblique rotation.

The scales included for factor analysis were all the scales that were either self-defined or modified from literature-based scales and the scales for the dependent variables. Variables included were: Physical health, Mental health, Social support of friends, Time-based trade-offs, Involvement, Desire to institutionalize, Burden, case-management (CM): social support, CM: education, CM: coping strategies, CM: Brokering, CM: Arrange, CM: advocacy.

A factor analysis was run using 13 components. Investigating the results of the factor analysis, the Barlett’s test of sphericity was found significant ($p < 0.05$), which indicates there is likely enough correlation among at least a selection of variables included at the factor analysis. Another measure of the degree of correlations among variables is the Kaiser-Meyer-Olkin Measure of Sampling Adequacy. This measure was also sufficient at 0.85, which can be interpreted as meritorious (Hair et al, 2006). The diagonal of the anti-image correlation

matrix was investigated for measures of sampling adequacy for individual items. The measure of sampling adequacy values exceeded 0.50 for each individual variable. All assumptions necessary to proceed with a factor analysis thus were met.

The pattern matrix (see Appendix B) showed that there were multiple issues. According to Hair et al. (2006), a factor loading of 0.40 is statistically significant with a sample size of about 200. This was used as a guideline throughout the factor analysis. Investigation of the scree plot and the total variance explained by the factor solution show that there are likely 11 different components. Second, item three from “CM: providing information” did not load significantly on any component. Therefore, this item was deleted from the analysis. Third, item six from physical health had a low loading on its intending component and instead loaded on a different component. This could be because too many factors were extracted. The pattern matrix with 11 components extracted indeed solved this issue (see Appendix C). More interesting, ‘CM: Coping strategies’ and ‘CM: Knowledge of dementia’ load well on a single component. ‘CM: Coping strategies’ seem to load stronger on the component than ‘CM: Knowledge of dementia’. Furthermore, ‘CM: Arrange’ and ‘CM: advocacy’ load well on one single dimension. Clearly, people interpret ‘defending their interests’ as related to arranging care when needed. These two activities of case-management were further conceptualized as ‘CM: Arrange and follow-up’ in subsequent analyses.

To get a better understanding of the factor structure of ‘CM: Coping strategies’ and ‘CM: Dementia knowledge’, a confirmatory factor analysis was conducted using LISREL 8.50 (Jöreskog & Sörbom, 2001). Fit indexes of a one-factor model were compared with fit indexes of a two-factor model. The Chi-Square goodness of fit statistics of both models showed a significant Chi-Square test ($p < 0.05$) indicating that there were significant differences between the observed sample covariance matrix and the SEM estimated covariance matrix. Comparing the Chi-Square values, the two-factor model was likely to fit better, as there was a significant decrease in the chi-square statistic value ($\Delta\chi^2 = 143.46$, $\Delta df = 1$, $p < 0.01$). The Root Mean Square Error of Approximation (RMSEA) showed values above 0.10 for both models, which indicate a poor fit. Other fit indexes like GFI, AGFI and NNFI showed a poor fit of a one-factor model, but showed adequate values for a two-factor model (0.95, 0.86, 0.96 respectively). A correlation of 0.85 between the two components and taken into account the results from all fit indexes, led to the conclusion that neither a one-factor nor a two-factor model fits the data well. Therefore, one variable was deleted from the analysis. Because providing coping strategies is more of a core activity of case-management

than providing information of dementia in general, providing knowledge about dementia was excluded in further analyses. Summarizing, four activities of case-management were included in the final model, namely: (1) providing social support, (2) providing coping strategies, (3) brokering, and (4) arrange services and follow-up.

2.3.3 Reliability of the scales

All scales were checked for reliability using Cronbachs α test, which provides a measure for the internal consistency of a scale. Most scales were found internally consistent with alpha's ranging from 0.73 to 0.92, exceeding the generally accepted lower limit of 0.70 (Hair et al., 2006). The exception was the scale of the caregiver's amount of knowledge of dementia (alpha = 0.18). Deletion of items would not lead to a substantially more reliable scale. Therefore, this construct was not used in further analysis, leading to an omission of caregiver's dementia knowledge from the analysis. Item 6 of the physical health scale showed a low loading on its intended component during the factor analysis. The scale of physical health shows a Cronbachs α of 0.88. Furthermore, item 6 had an item-to-total correlation of 0.5 and four out of five inter-item correlations were above 0.3. Deletion of this item would only increase alpha with 0.01. Therefore, this item was retained.

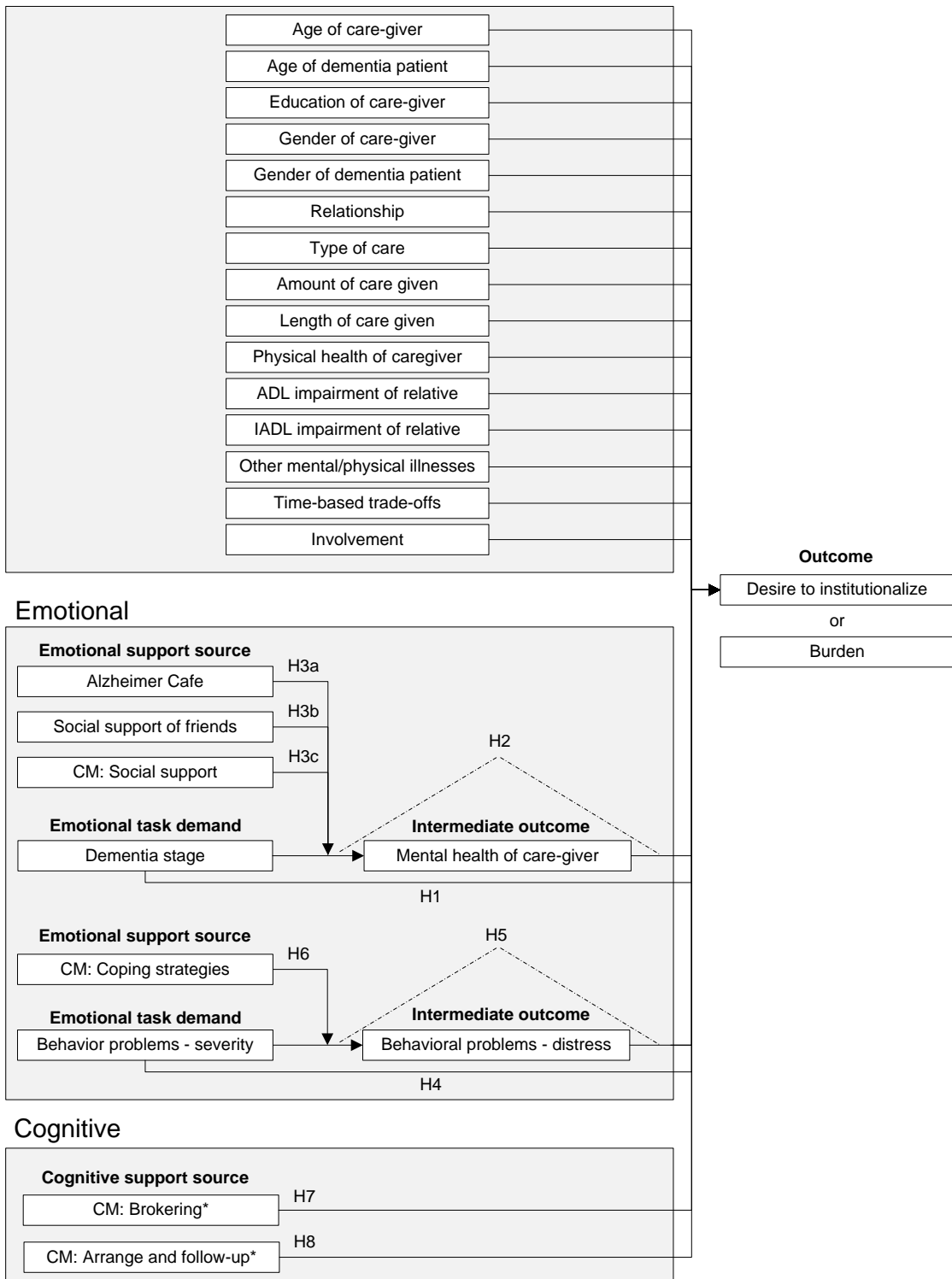
2.4 Conceptual model

From the data preparation phase, it was evident that two actions had to be taken. First, the arranging services and advocacy role are combined into a new factor called: CM: arrange and follow-up. Second, educating the caregiver about dementia and caregiver's dementia knowledge was omitted from the analysis. Therefore, hypothesis 10 'Educating caregivers about dementia leads to an increased knowledge of dementia of caregivers' and hypothesis 11 'An increased knowledge of dementia is positively related to the desire to institutionalize' were dropped from the study. Hypothesis 8 and 9 were reformulated as:

Hypothesis 8: 'Arrange and follow-up services to support caregivers' is negatively associated with the desire to institutionalize.

Given the discussion in the introduction chapter, this led to the conceptual model with the predicted relationships given in Figure 4.

Background variables



* = only for caregivers who reported a need for these services

Figure 4 Conceptual model

2.5 Data analysis

In order to proceed with multivariate analysis, first some assumptions should be checked to justify the use of these techniques. These assumptions are discussed in the upcoming paragraph. The multivariate analyses used in this study, are described after that.

2.5.1 Exploring assumptions

Assumptions of normality and linearity should be checked for the appropriateness of multivariate data techniques. The survey made quite some use of Likert scales and some variables were category based. Needless to say, data on variables with these scales were not normal distributed. Because of the use of Likert-scales, departure from normality is always evident in the tails of the distributions. Therefore, this assumption was not met. However, when the sample size is large (>200), multivariate techniques become less sensitive to departures from non-normality (Hair et al., 2006). Nevertheless, variables were investigated for serious departure from normality and for possible remedies.

P-P plots were used to investigate normality in the regions of high probability density of a distribution (Cary, 2008). No serious departures from normality in the high regions of probability were found. Therefore, no variables were transformed. Taking into account the sample size and a reasonable fit of the distributions in the regions of higher probability density, multivariate analysis was considered appropriate.

Linearity was analyzed by creating plots with the independent variables on one axis and the dependent variable on the other axis. No curvilinear relations were found. Therefore, no transformations due to non-linearity were necessary.

Another requirement that should be met for the within-subject analysis is that there should be enough variance on the case-management variables, such that variability in the extent to which caregivers receive casemanagement services is practically meaningful. All activities of case-management had summated scores ranging from 1 to 5. Mean scores varied between 3.5 and 4.1 and standard deviations vary between 0.85 and 1.03. Considering that a 5-point Likert scale was used, with a score of 3 being neutral, it was assumed that enough variance was present for the variables that measure the activities of case-management to justify a within-group analysis.

2.5.2 Analytical strategy

In order to explain what factors predict the caregivers' desire to institutionalize, multiple regression analysis was used. Multiple regression is the appropriate method of analysis when the research problem involves a single metric dependent variable that is related to multiple metric independent variables (Hair et al., 2006). The main objective of the multiple regression analysis in this case was to determine the relative importance of each independent variable in the prediction of the dependent measure. The specific type of multiple regression that was used, is a stepwise block regression. The first step adds the background variables and the second step adds the variables of interest. This analysis was done for both 'desire to institutionalize' and 'burden' as dependent variables. Hair et al., (2006) recommend a sample size of at least 5 observations per independent variable, however the desired level is between 15 and 20 observations per independent variable. This study used a model with 24 independent variables related to the desire to institutionalize. After the data preparation phase, 248 cases have been selected for multiple regression analysis. This would lead to a ratio of approximately 10 observations per independent variable. The sample size thus meets the minimum requirements but is somewhat below the desired level.

In Figure 4 the 'emotional' dimension of the model is the most complex. A separate multivariate regression was used to investigate the moderating effects of the case-management intervention. To determine the interaction effect, the product of the corresponding two variables was computed. This however could lead to problems of multicollinearity unless these variables are centered (Tabachnick & Fidell, 2007). Centering could be done by subtracting the mean (mean centering) or by standardization. Preacher (2006) advocates that significance should be assessed using unstandardized coefficients. To attain a 'correct' standardized solution with an analysis including products of variables, manual standardization of the variables before the analysis should be used. However, this would only be necessary if significant moderating effects were found. Again, a blockwise regression was used, in which the first step included all main effects and the second step will included the moderating effects.

With respect to the mediating hypotheses, an investigation of partial or full mediation could be carried out based upon the method provided by Hair et al. (2006). A new model must be analyzed relating the independent variable to the dependent variable. If the relationship of the independent variable is significant and unchanged when the mediating variable is included in the model, there will be no mediation. When it stays significant if the mediating variable is

included, but is reduced, then there is support for partial mediation. When the independent variable is non-significant upon introducing the mediating variable into the model, there is support for full mediation, i.e. no direct effect.

A third possibility would be an indirect effect instead of a mediation effect. An indirect effect implies that the only significant relationship observed is the combined effect (Mathieu & Taylor, 2006). The authors explain that this means that significant relationships are found between the independent variable and the mediating variable, and between the mediating variable and the dependent variable. The relationship between the independent variable and the dependent variable should be absent. The combined effect could be investigated by a Sobel test (Baron & Kenny, 1986).

3. Results

3.1 Correlational analysis

Table 1 shows the Pearson zero-order correlations among the study variables and the Cronbach's Alpha's on the diagonal of the axis between brackets if applicable. A first inspection of the Pearson zero-order correlations shows that the desire to institutionalize and caregiver burden were not associated with each other ($r=0.04$, ns). It is therefore likely that some associated variables would be different as well. This appears to be the case, e.g., whereas the age of a caregiver was negatively associated with desire to institutionalize, it was positively associated with burden, and whereas gender type 'female' was positively associated with desire to institutionalize, it was negatively associated with burden.

Inspection of the strongest associations for the dependent variables shows that relationship was most strongly associated with desire to institutionalize in a negative direction ($r=-0.52$, $p<0.01$). Relationship was however positively associated with burden ($r=0.31$, $p<0.01$). Time-based trade-offs was most strongly associated with caregiver burden in a positive direction ($r=0.68$, $p<0.01$). However, time-based trade-offs was uncorrelated with desire to institutionalize ($r=-0.01$, ns). Other strong associations of burden were care-intensity ($r=0.39$, $p<0.01$) and mental health of caregiver ($r=-0.47$, $p<0.01$) and involvement ($r=0.52$, $p<0.01$). Involvement had a more moderate association with the desire to institutionalize ($r=-0.29$, $p<0.01$).

The variables included to measure the different activities of case-management were weakly correlated with both desire to institutionalize and caregiver burden. The variables were also weakly correlated to other variables such as mental health and distress due to behaviour problems. The variables measuring case-management activities were moderately correlated with each other ($0.59<r<0.70$). This is expected, because if one receives one support-service, it is likely that one receives other support services as well.

Overall, many significant ($p<0.01$) associations were found between background variables and both the desire to institutionalize and caregiver burden and it is surprising that many of these associations are not in the same direction.

	Mean	SD	N	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1 Desire to institutionalize #	1.76	0.67	248	(0,92)														
2 Burden	3.34	1.03	248	0.04	(0,90)													
3 Age care-giver	62.77	13.66	248	-0.26 **	0.25 **	-												
4 Age of relative	80.40	8.44	248	0.25 **	-0.01	0.15 *	-											
5 Sex of care-giver	1.69	0.46	248	0.04	-0.03	-0.17 **	0.12	-										
6 Sex of relative	1.61	0.49	248	0.19 **	-0.16 **	-0.23 **	0.06	-0.40 **	-									
7 Education of care-giver	2.70	0.97	248	0.14 *	-0.05	-0.31 **	0.05	-0.20 **	0.16 *	-								
8 Relationship	1.41	0.49	248	-0.52 **	0.31 **	0.68 **	-0.29 **	-0.15 *	-0.36 **	-0.33 **	-							
9 Type of care: Domestic care	1.24	0.43	248	0.14 *	-0.12	-0.12	0.11	0.03	0.06	0.21 **	-0.25 **	-						
10 Type of care: Personal	1.75	0.43	248	0.10	-0.22 **	-0.23 **	0.01	-0.01	0.06	0.12	-0.33 **	0.24 **	-					
11 Type of care: Nursing care	1.54	0.49	248	0.26 **	-0.23 **	-0.33 **	0.03	0.02	0.17 **	0.20 **	-0.45 **	0.29 **	0.38 **	-				
12 Type of care: Supervision	1.09	0.28	248	0.04	-0.05	0.10	0.03	-0.17 **	0.00	-0.04	-0.01	0.17 **	-0.03	0.17 **	-			
13 Care intensity: heures/week	2.76	1.52	248	-0.20 **	0.39 **	0.40 **	-0.14 *	-0.01	-0.16 *	-0.23 **	0.49 **	-0.30 **	-0.34 **	-0.38 **	-0.11	-		
14 Length of care: total months	26.63	19.68	248	0.10	0.02	-0.03	0.07	0.12	0.12	-0.11	-0.08	-0.23 **	-0.13 *	-0.07	-0.11	0.07	-	
15 Physical health of care-giver #	2.54	0.53	248	0.25 **	-0.24 **	-0.53 **	-0.02	0.07	0.14 *	0.32 **	-0.46 **	0.13 *	0.19 **	0.22 **	-0.12	-0.32 **	-0.04	(0,88)
16 Dementia stage	4.69	1.34	248	0.32 **	0.21 **	-0.02	0.19 **	0.02	-0.04	0.19 **	-0.15 *	-0.04	-0.14 *	-0.05	0.00	0.06	0.07	-0.02
17 Time-based trade-offs	3.20	1.05	248	-0.01	0.68 **	0.19 **	0.01	0.00	-0.09	0.00	0.31 **	-0.28 **	-0.23 **	-0.27 **	-0.15 *	0.45 **	0.11	-0.19 **
18 Involvement	3.59	0.92	248	-0.29 **	0.52 **	0.41 **	-0.11	-0.05	-0.24 **	-0.25 **	0.62 **	-0.32 **	-0.27 **	-0.38 **	-0.09	0.53 **	0.03	-0.35 **
19 ADL impairment of relative #	1.67	0.51	248	0.18 **	0.22 **	0.02	0.20 **	-0.06	0.06	0.02	-0.01	-0.10	-0.27 **	-0.01	0.04	0.18 **	0.12	-0.09
20 IADL impairment of relative #	2.37	0.57	248	0.18 **	0.24 **	0.13 *	0.18 **	0.08	-0.15 *	0.00	0.05	-0.12	-0.32 **	-0.20 **	-0.10	0.29 **	0.12	-0.02
21 Other physical or mental	2.44	1.03	248	0.17 **	0.21 **	-0.07	0.04	0.07	-0.06	0.02	-0.04	-0.19 **	-0.18 **	-0.05	-0.07	0.20 **	0.17 **	-0.13 *
22 Mental health of care-giver	3.67	0.79	248	0.09	-0.47 **	-0.28 **	0.10	-0.07	0.25 **	0.21 **	-0.36 **	0.08	0.06	0.11	0.05	-0.34 **	-0.05	0.33 **
23 Behavioral problems: severity #	0.86	0.63	248	0.21 **	0.21 **	-0.09	-0.02	0.03	0.00	0.12	-0.11	-0.05	-0.01	0.06	-0.05	0.14 *	0.09	0.06
24 Behavioral problems: distress	1.02	0.89	248	0.14 *	0.29 **	-0.03	-0.06	0.08	-0.07	0.06	0.03	-0.08	-0.05	0.01	-0.01	0.16 *	0.07	0.02
25 Alzheimer cafe	4.68	0.85	248	0.21 **	-0.09	-0.16 *	0.20 **	0.04	0.07	0.17 **	-0.26 **	0.07	0.03	0.22 **	0.04	-0.06	0.11	0.17 **
26 Social support of friends	4.24	0.84	248	0.14 *	-0.15 *	-0.18 **	0.10	0.19 **	0.00	0.12	-0.23 **	0.02	0.00	0.09	-0.05	-0.19 **	0.08	0.17 **
27 CM: Social support	4.12	0.85	216	-0.08	-0.01	0.20 **	-0.04	0.07	-0.17 *	-0.11	0.22 **	-0.08	-0.12	-0.20 **	-0.01	0.17 *	0.11	-0.15 *
28 CM: Coping strategies	3.52	1.03	194	0.00	0.01	0.11	0.07	0.16 *	-0.15 *	-0.09	0.07	0.02	-0.10	-0.11	0.08	0.12	0.09	-0.10
29 CM: Brokering	4.09	0.86	208	0.05	-0.04	0.03	0.03	0.15 *	-0.11	0.08	0.00	0.06	-0.01	-0.02	-0.05	0.01	0.07	0.00
30 CM: Arrange and follow-up	3.84	1.01	196	-0.04	0.05	0.23 **	0.02	0.03	-0.15 *	-0.10	0.25 **	0.00	-0.15 *	-0.15 *	-0.02	0.16 *	0.01	-0.22 **

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

These variables have been measured using 3-point instead of 5-point likert scales

Table 1 (part I) Coefficient alpha (between brackets) and Pearson intercorrelations of the study variables

	Mean	SD	N	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
1 Desire to institutionalize #	1.76	0.67	248															
2 Burden	3.34	1.03	248															
3 Age care-giver	62.77	13.66	248															
4 Age of relative	80.40	8.44	248															
5 Sex of care-giver	1.69	0.46	248															
6 Sex of relative	1.61	0.49	248															
7 Education of care-giver	2.70	0.97	248															
8 Relationship	1.41	0.49	248															
9 Type of care: Domestic care	1.24	0.43	248															
10 Type of care: Personal	1.75	0.43	248															
11 Type of care: Nursing care	1.54	0.49	248															
12 Type of care: Supervision	1.09	0.28	248															
13 Care intensity: heures/week	2.76	1.52	248															
14 Length of care: total months	26.63	19.68	248															
15 Physical health of care-giver #	2.54	0.53	248															
16 Dementia stage	4.69	1.34	248	1.00														
17 Time-based trade-offs	3.20	1.05	248	0.17 **	1.00													
18 Involvement	3.59	0.92	248	-0.01	0.52 **	1.00												
19 ADL impairment of relative #	1.67	0.51	248	0.38 **	0.23 **	0.11	1.00											
20 IADL impairment of relative #	2.37	0.57	248	0.45 **	0.22 **	0.14 *	0.61 **	1.00										
21 Other physical or mental	2.44	1.03	248	0.19 **	0.21 **	0.16 *	0.46 **	0.31 **	1.00									
22 Mental health of care-giver	3.67	0.79	248	0.00	-0.36 **	-0.53 **	-0.08	-0.04	-0.15 *	1.00								
23 Behavioral problems: severity #	0.86	0.63	248	0.26 **	0.24 **	0.05	0.17 **	0.17 **	0.27 **	-0.07	1.00							
24 Behavioral problems: distress	1.02	0.89	248	0.18 **	0.29 **	0.17 **	0.14 *	0.13 *	0.28 **	-0.19 **	0.87 **	1.00						
25 Alzheimer care	4.68	0.85	248	0.05	-0.05	-0.12	0.14 *	0.08	0.12	0.01	0.17 **	0.11	1.00					
26 Social support of friends	4.24	0.84	248	0.12	-0.18 **	-0.24 **	0.04	0.06	0.04	0.19 **	0.06	0.01	0.07	1.00				
27 CM: Social support	4.12	0.85	216	0.08	0.01	0.07	-0.01	0.02	-0.04	-0.01	0.00	-0.01	-0.06	0.14 *	1.00			
28 CM: Coping strategies	3.52	1.03	194	0.02	-0.03	0.11	0.03	0.06	0.08	-0.01	-0.03	-0.03	-0.07	0.15 *	0.70 **	1.00		
29 CM: Brokering	4.09	0.86	208	0.07	-0.02	-0.03	-0.06	0.00	0.00	0.10	0.00	-0.05	-0.01	0.11	0.66 **	0.67 **	1.00	
30 CM: Arrange and follow-up	3.84	1.01	196	0.03	0.03	0.11	0.01	0.07	0.01	-0.01	-0.14	-0.11	-0.04	0.07	0.70 **	0.59 **	0.61 **	1.00

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

These variables have been measured using 3-point in stead of 5-point likert scales

Table 1 (part II) Coefficient alpha (between brackets) and Pearson intercorrelations of the study variables

3.2 Predictors of desire to institutionalize and burden

Table 2 shows the results from the multiple regression analyses for desire to institutionalize and burden. Contrary to the expectations, severity of behaviour problems, distress due to behaviour problems, brokering by case-management, and arranging and follow-up services by case-management show very small standardized effect sizes ($\beta < 0.15$) and all did not reach significance ($P < 0.05$ or $P < 0.10$) at predicting the desire to institutionalize. Therefore, hypotheses 4, 5, 7 and 8 are rejected. Dementia stage was significantly related to the desire to institutionalize ($\beta = 0.16$, $P < 0.01$), therefore hypothesis 1 is confirmed. Mental health was not significantly related to the desire to institutionalize ($\beta = -0.09$, ns). Therefore, mental health could not mediate the effect of dementia stage on the desire to institutionalize and hypothesis 2 is rejected. Mental health was significantly, negatively related to caregiver burden ($\beta = -0.18$, $P < 0.01$). Dementia stage is uncorrelated ($r = 0.00$, ns) with mental health and therefore mental health could not be seen as mediator of the effect of dementia stage on burden.

Statistically significant predictors were mainly found in the background variables (see step 2 in table 2). Relationship was significantly related to the desire to institutionalize ($\beta = -0.57$, $P < 0.01$) and clearly appeared to be the strongest predictor. This means that partners versus non-partners had less desire to institutionalize. Dementia stage was found the second strongest predictor of the desire to institutionalize ($\beta = 0.16$, $P < 0.05$). This means the higher the dementia stage, the more likely people had a high desire to institutionalize. The highest level of education acquired by the caregiver is marginally significantly, negatively related to the desire to institutionalize ($\beta = -0.12$, $P < 0.10$). Physical health and time-based trade-offs were marginally significantly, positively related to the desire to institutionalize ($\beta = 0.15$, $P < 0.10$ and $\beta = 0.14$, $P < 0.10$ respectively).

The results were quite different for caregiver burden. Whereas the strongest predictor for desire to institutionalize was relationship, this variable was not significantly related to caregiver burden ($\beta = -0.12$, ns). Instead, the strongest predictor for caregiver burden was time-based trade-offs ($\beta = 0.51$, $p < 0.01$), which was significantly related to caregiver burden. This indicates the more trade-offs a caregiver had to make with respect to his/her job/family/interests, the more burden was perceived. The second strongest predictor was the mental health of a caregiver, which was significantly, negatively related ($\beta = -0.18$, $P < 0.01$) to caregiver burden. Other significant predictors were involvement and domestic care, which both were significantly, positively related to caregiver burden ($\beta = 0.17$, $P < 0.05$ and $\beta = 0.11$,

$p < 0.10$ respectively). This means that the desire to institutionalize and caregiver burden have only one predictor in common and the strongest two predictors are not shared.

The coefficient of determination (R^2) show the amount of variance in the data that is explained by the model. For desire to institutionalize the amount of variance explained is 43% and for burden this is 58%.

Model		Dependent variables						
		Desire to Institutionalize			Burden			
		B	SE	Beta	B	SE	Beta	
Step 1	Sex of care-giver	-0,11	0,11	-0,08	-0,12	0,15	-0,05	
	Age care-giver	0,01 †	0,01	0,19	0,01	0,01	0,09	
	Education of care-giver	-0,07	0,05	-0,09	-0,01	0,07	-0,01	
	Sex of relative	-0,01	0,11	-0,01	-0,19	0,14	-0,09	
	Age of relative	0,00	0,01	0,01	-0,01	0,01	-0,07	
	Relationship	-0,82 **	0,17	-0,60	-0,31	0,23	-0,15	
	Other physical or mental diseases	0,08	0,05	0,12	0,04	0,06	0,04	
	Type of care: Domestic	0,10	0,11	0,06	0,33 *	0,15	0,13	
	Personal maintenance	-0,03	0,11	-0,02	-0,08	0,15	-0,03	
	Nursing care	0,12	0,10	0,09	-0,01	0,14	-0,01	
	Supervision	0,08	0,16	0,03	0,05	0,21	0,01	
	Care intensity: heures/week	-0,02	0,04	-0,05	0,00	0,05	0,00	
	Length of care: total months	0,00	0,00	0,03	0,00	0,00	-0,03	
	Physical health of care-giver	0,15	0,10	0,12	-0,10	0,13	-0,05	
	ADL impairment of relative	-0,01	0,12	-0,01	0,06	0,16	0,03	
	IADL impairment of relative	0,19 †	0,10	0,16	0,11	0,13	0,06	
	Time-based trade-offs	0,12 *	0,05	0,19	0,55 **	0,07	0,56	
	Involvement	-0,04	0,07	-0,05	0,29 **	0,09	0,26	
	Step 2	Sex of care-giver	-0,13	0,11	-0,09	-0,15	0,15	-0,07
		Age care-giver	0,01	0,01	0,17	0,01	0,01	0,07
Education of care-giver		-0,08 †	0,05	-0,12	-0,01	0,07	-0,01	
Sex of relative		0,04	0,11	0,03	-0,12	0,14	-0,05	
Age of relative		0,00	0,01	0,01	-0,01	0,01	-0,05	
Relationship		-0,78 **	0,18	-0,57	-0,26	0,23	-0,12	
Other physical or mental diseases		0,07	0,05	0,10	0,02	0,06	0,02	
Type of care: Domestic care		0,07	0,11	0,05	0,28 †	0,15	0,11	
Personal maintenance		-0,03	0,11	-0,02	-0,12	0,15	-0,05	
Nursing care		0,11	0,10	0,08	-0,05	0,13	-0,02	
Supervision		0,07	0,16	0,03	0,03	0,21	0,01	
Care intensity: heures/week		-0,03	0,04	-0,06	0,00	0,05	0,00	
Length of care: total months		0,00	0,00	0,02	0,00	0,00	-0,04	
Physical health of care-giver		0,19 †	0,10	0,15	-0,04	0,13	-0,02	
ADL impairment of relative		-0,04	0,12	-0,03	0,01	0,15	0,01	
IADL impairment of relative		0,13	0,10	0,11	0,09	0,14	0,05	
Time-based trade-offs		0,09 †	0,05	0,14	0,50 **	0,07	0,51	
Involvement		-0,07	0,07	-0,09	0,19 *	0,09	0,17	
Dementia stage		0,08 *	0,04	0,16	0,08	0,05	0,10	
Mental health of care-giver		-0,08	0,07	-0,09	-0,24 **	0,09	-0,18	
Behaviour problems: severity	-0,03	0,14	-0,02	-0,17	0,19	-0,10		
Behaviour problems: reaction	0,08	0,10	0,11	0,18	0,13	0,15		
CM: Brokering	0,01	0,06	0,01	0,00	0,08	0,00		
CM: Arrange and follow-up	0,07	0,06	0,10	0,00	0,07	0,00		

Full model

$R^2 = 0.43$

$F(18,169) = 5.035; P < 0.001$

$R^2 = 0.58$

$F(24,163) = 9.25; P < 0.001$

** = $p < 0.01$; * = $p < 0.05$; † = $p < 0.10$; N = 248

Table 2 Hierarchical regression models of desire to institutionalize and burden

3.3 The moderating effect of social support

Table 3 shows the results from the regression models of mental health with the moderating terms. The results show that only social support given by family or friends was significantly, positively related to mental health ($\beta=0.20$, $p<0.01$). No such results were found for social support given by case-management or the Alzheimer cafe ($\beta=-0.04$, ns and $\beta=0.00$, ns respectively). No significant moderating effect was found of social support on the effect of dementia stage on mental health from either case-managers, friends, or the Alzheimer cafe ($\beta=-0.09$, ns, $\beta=-0.04$, ns and $\beta=-0.00$, ns respectively). Therefore, hypothesis 3a, 3b, and 3c are rejected.

Model		Dependent variables		
		Mental health		
		B	SE	Beta
Step 1	Alzheimer cafe (m)	0.00	0.06	0.00
	Social support from friends (m)	0.19 **	0.07	0.20
	CM: Social support (m)	-0.03	0.06	-0.03
	Dementia stage (m)	-0.01	0.04	-0.02
Step 2	Alzheimer cafe (m)	0.00	0.07	0.00
	Social support from friends (m)	0.19 **	0.07	0.20
	CM: Social support (m)	-0.03	0.06	-0.04
	Dementia stage (m)	-0.02	0.04	-0.03
	Alzheimer cafe * Dementia stage (m)	0.00	0.06	0.00
	Social support from friends * Dementia stage (m)	-0.03	0.05	-0.04
	CM: Social support * Dementia stage (m)	-0.05	0.05	-0.08

m = mean centered

Table 3 Hierarchical regression models of mental health with moderating terms

For illustrative purposes, the interaction effect is graphically represented in Figure 5 according to the method described by Aiken and West (1991). Values of the predictor variables were chosen one standard deviation above and below the mean. The regression lines are representing respondents, which received low social support and high social support respectively. Figure 5 confirms that there is no main or moderating effect present.

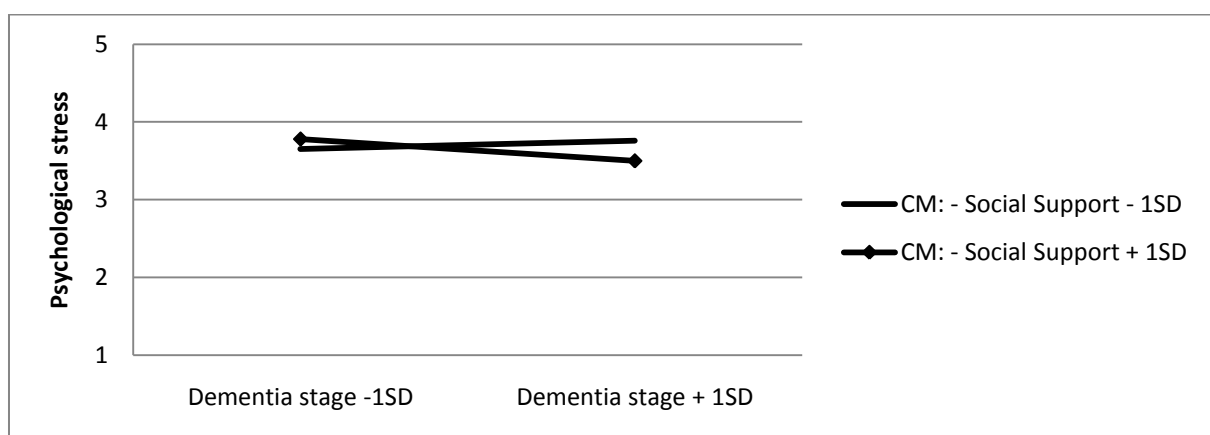
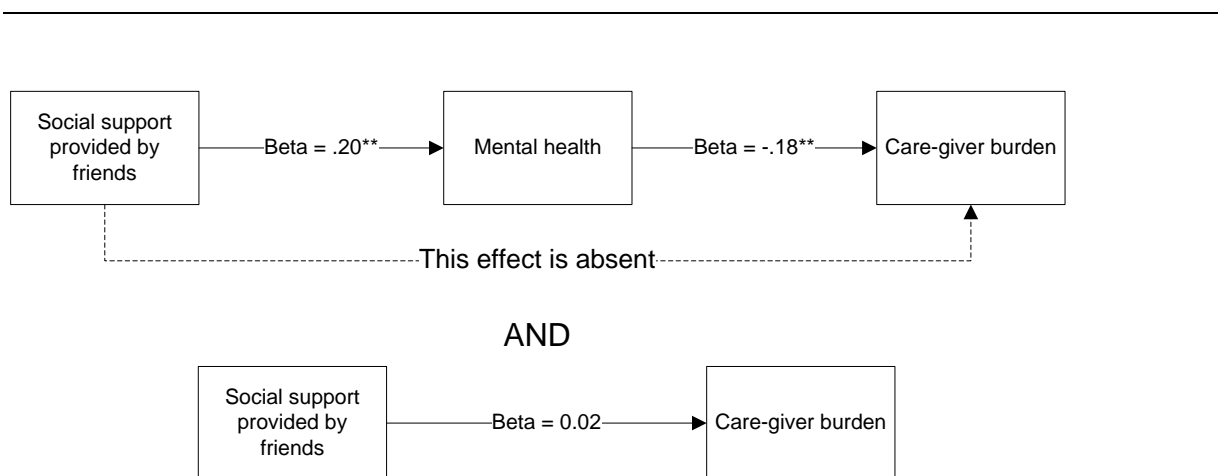


Figure 5 Interaction effect of dementia stage and social support at predicting mental health

3.4 The indirect effect of social support provided by friends on burden

So far, there appeared to be a direct relation between social support provided by friends and mental health. In section 3.2, a direct relation was found between mental health and caregiver burden. Further analysis could be done whether there is a partial or full mediation effect, or an indirect effect. An additional regression analysis is run, first including the background variables and secondly including the social support provided by friends. No significant effect of social support provided by friends on caregiver burden was found ($\beta=-0.02$, ns). This is an indication that there might be an indirect effect of social support on caregiver burden via mental health. A Sobel test (Baron & Kenny, 1986) was used to confirm the combined effect. A sobel test requires four parameters, namely: (1) the unstandardized regression coefficient for the association between social support provided by friends and mental health (table 3, $B=0.185$), (2) the standard error of the regression coefficient for the association between social support provided by friends and mental health (table 3, $SE=0.065$), (3) the unstandardized regression coefficient for the association between mental health and caregiver burden (table 2, $B=-0.238$), and (4) the standard error of the regression coefficient for the association between mental health and caregiver burden (table 2, $SE=0.087$). The sobel test was conducted using the sobel calculator provided by Preacher & Leonardelli (2001). The sobel test was significant (Sobel test statistic = -1.98 , $P<0.05$), further providing support for an indirect effect. Figure 6 illustrates the indirect effect using standerdized effects.



** = significant at $p<0.01$

Figure 6 Illustration of the indirect effect of social support provided by friends on caregiver burden

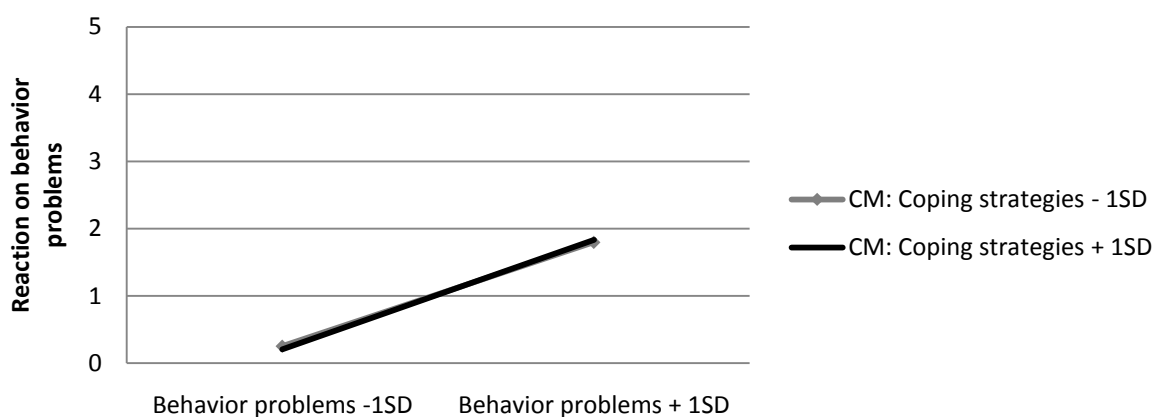
3.5 The moderating effect of coping strategies

Table 4 shows the results from the hierarchical regression models of distress due to behaviour problems with the moderating terms. The results show that the severity of behaviour problems was significantly, positively related to resulting distress ($\beta=0.87$, $p<0.01$). Furthermore, the moderating effect of coping strategies on the effect of the severity of behaviour problems on the resulting distress was not found significant ($\beta=0.03$, ns). Therefore, hypothesis 6 is rejected. Coping strategies provided by case-managers also did not have a significant main effect ($\beta=-0.00$, ns) on distress due to behaviour problems.

Model	Dependent variables		
	Distress due to behavior problems		
	B	SE	Beta
Step 1			
CM: Coping strategies (m)	0,00	0,03	0,00
Behavior problems (m)	1,22 **	0,05	0,87
Step 2			
CM: Coping strategies (m)	-0,01	0,03	-0,01
Behavior problems (m)	1,22 **	0,05	0,87
CM: Coping strategies * Behavior problems (m)	0,04	0,04	0,03

Table 4 Hierarchical regression models of distress due to behaviour problems with moderating terms

For illustrative purposes, again the interaction effect is graphically represented in Figure 7, using the same method as at the previous section. The two regression lines show whether caregivers receive a high amount of coping strategies versus a low amount respectively. Figure 7 confirms that there was no main effect or interaction effect of coping strategies provided by case-managers.



BP = Behaviour problems

Figure 7 Interaction effect of the severity of behavior problems and coping strategies on caregiver distress due to behavior problems

4. Discussion

In this chapter, first an overview and discussion is given of the relationships that were found for both the desire to institutionalize and caregiver burden. Then the practical implications are discussed for the organization and theoretical implications are discussed for the research field. Finally, the limitations of this study are discussed, followed by recommendations for further research.

4.1 An overview of the results

An overview of the relations found for desire to institutionalize and caregiver burden is given Figure 8a and Figure 8b respectively.

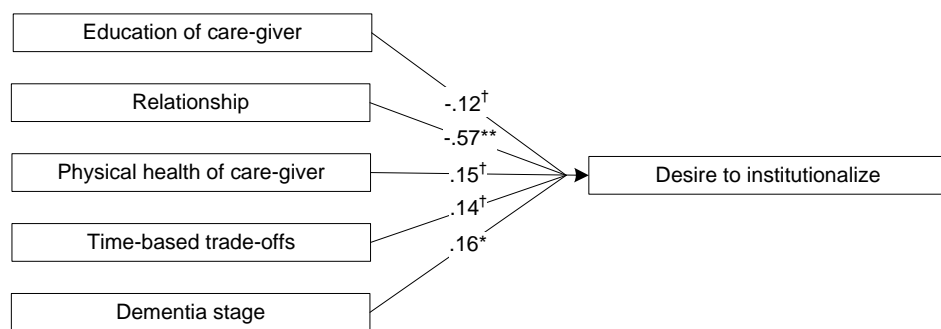
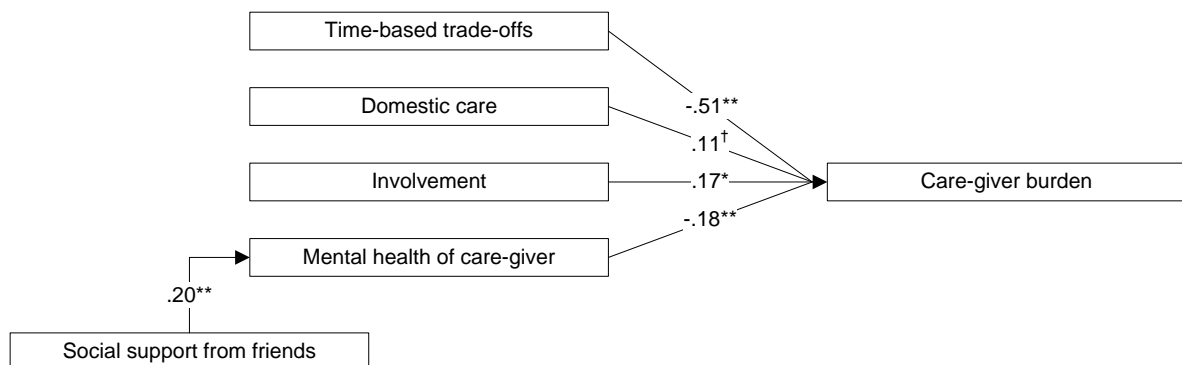


Figure 8a An overview of the relations found for desire to institutionalize



Beta coefficients are shown, ** = $p < 0.01$; * = $p < 0.05$; † = $p < 0.10$

Figure 8b An overview of the relations found for caregiver burden

The objectives of this study were to answer the questions ‘Which factors are related to the informal caregivers’ desire to institutionalize dementia patients?’ and the question ‘Which aspects of case-management as implemented in the region of Eindhoven, contribute to reduced desire to institutionalize?’ The results of this current study show significant effects on

desire to institutionalize were mainly found for background variables. The relationship between the caregiver and dementia patient was the strongest predictor. Remember that in this study relationship finally was operationalized as partners versus non-partners. Partners might be more willing to support each other through good and bad times. Other predictors had substantially smaller effect sizes. Characteristics that were found related are education of the caregiver, the caregiver's physical health, the trade-offs he/she was confronted with and the stage of dementia of the patient. Contrary to the expectations, activities of case-management were not related to a lower desire to institutionalize. It should also be noted that all variables found related to the desire to institutionalize are variables that case-managers cannot influence, e.g., case-managers are not able to change the stage of dementia or the relationship between the caregiver and dementia patient.

An interesting finding is that mental health was negatively related to caregiver burden. Only social support was found related to mental health of a caregiver. Social support provided by case-managers was not found related. This is an interesting finding and is in line with the evidence shown in the study of Uchino et al. (1996) for linking social support to health. Here the authors also suggested that social support might be more effective when given by family members. This study seems to provide support for this suggestion. (Note that social support from friends is operationalized as social support given from friends or family.) Spitznagel et al. (2008) also found social support from family members to be a significant predictor of the desire to institutionalize dementia patients. The effect was not found for social support from other sources than family. A possible explanation for these findings is that friends and family members are likely to spend more time with the caregivers, than others or case-managers do.

Social support from friends indirectly led to a lower caregiver burden. This is contrary to the hypothesis that social support would act like a moderator variable on an existing relationship between dementia stage and mental health. This might indicate that caregivers might already experience stress from the day they are confronted with the fact that they have to provide care for a relative with dementia and that social support could increase mental health from the early stages on. This is in line with the findings of Zwaanswijk et al. (2009a), who found no significant difference in the emotional support requested by caregivers for patients in an early stage compared to a late stage of dementia. This is not contrary to the DISC theory used in this current study. It is likely that there still should be an initial need for emotional support, but this need for support might not increase at increasing stages of dementia.

Contrary to the findings of Pot et al. (2001), education was found negatively related to the desire to institutionalize. A possible explanation is that in their study the authors have not included trade-offs which could be made due to work, hobbies, or other interests. Higher educated people might hold more responsible or demanding jobs. Because of more demanding jobs, they would have less time available to provide care. However, in the current study both concepts are taken into account. Correcting for the trade-offs one has to make education could become negatively related. This may be because higher educated people are more willing to discuss problems and might ask earlier for help from the right sources.

4.2 Comparing the results to other research or findings

Because the null findings are unexpected, the results from this study will be compared to results from other studies. First, research from studies conducted outside the Netherlands focusing on case-management and its relation to outcome variables will be discussed. Second, recent descriptive studies from the Netherlands will be discussed.

Eloniemi-Sulkava et al. (2001) have reviewed an intervention of case-management similar to the intervention in the current study. The intervention included advocacy, support, counselling, training courses, and assistance with arrangements for social and healthcare services. Case-managers were also available by mobile phone 24 hours per day. The authors measured the actual time until institutionalization took place. After 1 year no significant difference was found between an intervention and control group. After 2 years also no significant difference was found in the proportion of institutionalized patients. The authors estimated the survival curves for patients at different stages of dementia and these curves seemed to suggest that the intervention might be more effective with patients with a higher dementia stage. However, as the authors confirm as well, this should only be interpreted as a suggestion, due to the low sample size (intervention group = 53 and control group 47).

Mittelman et al. (1996) have studied the effectiveness of comprehensive support and counseling for spouse-caregivers and families in postponing or preventing nursing home placement of people with Alzheimer Disease. They found that a program of counseling and support can substantially increase the time spouse-caregivers are able to care for dementia patients at home. Firstly, the intervention was family based. The counseling sessions were task oriented, promoting communication among family members, teaching techniques how to cope with behavior problems and improving emotional and instrumental support for the primary caregiver. After a series of counseling sessions, caregivers were required to join

support groups that met weekly and continued indefinitely. These groups provided a continuous emotional support and education. Thirdly, counselors to caregivers and families were available continuously for support if necessary. The authors show the most frequent reason for requests for help were for additional emotional support (88%), advice about services (21%), problems with patient behaviours (18%). Overall this intervention is quite different from the intervention in this study, mainly because it was more oriented towards building up a network of support, by increasing family function and building support groups that would be a continuous source of information and social support. The differences described might explain why alternative results were found.

In the field of case-management in general, Mueser et al. (1998) argue that controlled research indicates that other models of case-management like the assertive community treatment and intensive case management model, reduce time in hospitals. They argue that research on other models remains inconclusive. Case-management, based upon assertive community treatment and the intensive case management model, were not found with respect to sustaining informal caregivers of dementia patients. Mueser et al. (1998) note that these models were often adapted to meet the unique needs of specific patient populations and that these models were developed for high service users. These models are therefore less suited for sustaining informal caregivers. Quinlivan et al. (1995) provide an example where an intensive case-management model had significant benefits over a traditional case-management model. However, this study was related to frequent users of inpatient services and therefore the results cannot be generalized to contexts like in this study.

Still, one could argue that a lower case-manager to patient ratio might yield in effects that are more beneficial. Fox et al. (2000) studied the effect of intensity and different case-managers to patient ratio (1:30 compared to 1:100). The case-management program in this study is comparable to the case-management program in this study and furthermore, it was also directed at caregivers for dementia patients. Both interventions failed to show significant results with respect to the rate of institutionalization. The 1:30 case-manager to caregiver ratio did not have any significant advantage over the less-expensive 1:100 case-manager to caregiver ratio.

The most extensive investigation of case-management research that was found is the study of Weissert et al. (1988), who reviewed three decades of studies related to case-management interventions to sustain home care. Results of 27 rigorous studies with experimental designs show that only four studies have shown significant results with respect to a decrease in

nursing home use. Furthermore, these studies also showed practical, meaningful reduction in nursing home use (a decrease of at least 10%). Weissert et al. (1988) also found that the effective interventions were frequently those that did a comparatively better job of targeting. Targeting means that a selection is made of caregivers that could have most beneficial effects of case-management. This will be discussed in more detail in the next section.

Recent research from Zwaanswijk et al. (2009a) has shown that a relative high amount of informal-caregivers (59%) would like to receive additional support. Additional support was mainly required with respect to advice on how to cope with behavior problems and information about support sources and about dementia in general, although some would like to receive additional emotional or practical support. These results of their study suggest that the need of this information and advice is likely to be independent of the stage of dementia of the patient. The authors furthermore stated that these forms of support could be essential for caregivers to learn how to cope with dementia of their relative, to make dementia patients able to longer live at home or to make caregivers better able to provide care. The authors conclude that the results provided in their study highlight the importance of providing support for informal caregivers, to reduce elevated levels of caregiver burden. Thus, the authors assume that providing advice, information, emotional or practical support would lead to a lower caregiver burden. However, no evidence is provided for this. In fact, elsewhere the same authors (Zwaanswijk et al., 2009b) argue that although there was an increase in case-management, caregiver burden was not found to be reduced compared to earlier measurements of 2006.

From case-managers of the organization that was studied in this project it is often reported that people are satisfied and happy receiving case-management. Reasons provided include that case-managers provide answers for different requests for information or provide advice about how to deal with behaviour problems. However in this study, the severity of behaviour problems and the resulting caregiver distress were not found related to the desire to institutionalize. But apparently, people are happy that they receive this advice or information. A possible explanation for this is that these factors are outweighed by more important factors, like the trade-offs one is willing to make or whether one is a partner or not. An example will be given as illustration. A spouse caregiver might experience multiple behavior problems of his/her dementia patient. But since they are partners with a long history, the caregiver is very committed to providing care. The caregiver is also willing to accept the behaviour problems as

a result. However, this does not mean that the caregiver would not be more happy or satisfied if she would be effectively able to deal with the behaviour problems present.

Overall, the results from other studies and other findings are in line with the results found in the current study. Only intensive case-management interventions (aimed at specific patient populations) and case-management interventions that included targeting were found to report positive effects with respect to a delay in nursing home use. Studies where no targeting was used, like in this current study, could not provide evidence for a delay in nursing home use.

4.3 Practical and theoretical implications

The results of this study could not support that the extent to which caregivers receive services of case-management is related to the desire to institutionalize or caregiver burden. However, current findings do not mean that case-management could not be effective at lowering institutionalization rates. As discussed, positive results were found for case-management interventions that included targeting. Would this be interesting for the context of this study? This question is not easily answered. It is important to realize that case-management could have multiple high-level outcomes. Furthermore, case-management could be viewed from the perspective of the organization and from a perspective from the stakeholders. Different stakeholders may value different outcomes of case-management. Increased service linking, lower nursing home use, decreased overall health costs, a better quality of life of the caregivers are all possible outcomes of case-management. However, to reach maximum effectiveness on one or a set of these outcome variables is likely to demand a different implementation of case-management. This will be illustrated with a discussion of case-management viewed from an overall cost-perspective contrasted with a view that values the quality of life of a caregiver.

If case-management is to be structurally financed by the government or health care insurances, it is assumed that a reduction in the overall costs of the health care system is desired. This overall cost of health care could be decreased by case-management, because due to a desired delay in institutionalization people would stay shorter in permanent nursing homes, leading to lower costs. However, it must not be forgotten that case-management should also be seen as a cost. To reduce overall costs, the costs of case-management should be at least, offset by the savings due to delayed institutionalization of dementia patients. As long as increasing investment would lead to increased savings due to delayed institutionalization, the government or health care insurances should be willing to increase the investment in case-

management. This is important to realize and should be kept in mind when defining the company's strategy towards the implementation of case-management.

This brings us to the question how case-management could be organized such, to be most effective reducing the overall costs. If home and community care programs are to avoid raising overall costs, these programs should be directed at caregivers of dementia patients who would have entered nursing homes for a long period of time (Weissert et al., 1988). This is what the authors mean with targeting. Furthermore, case-management should be able to delay the institutionalization in these cases without diminishing the quality of life of the caregiver or dementia patient. In these cases, investment in case-management could generate savings that would at least be higher than the investment itself. Case-management should not be directed at people who would not institutionalize their dementia patients, whether they would receive case-management or not. In fact, this would only lead to increased overall costs; a reason to stop financing case-management.

Given these lines of reasoning, it seems interesting to provide case-management for only a selection of informal caregivers. This selection should be based upon the risk for institutionalization and the expected stay in a nursing home. In the current implementation of case-management in Eindhoven, all informal caregivers are given case-management and no selection is made. The organization especially strives to supply case-management as soon as possible and therefore tries to target people in very early phases.

Because selecting a subset of caregivers at the time they are identified would not only be very difficult, but also ethically doubtful, it could therefore be interesting to implement case-management reactive instead of proactive. If case-management should aim at caregivers with a high risk at institutionalization, it could be interesting to select caregivers at the time they apply for nursing homes. Instead of screening from the moment caregivers are known, screening thus takes place at the time of application for nursing home use. These cases could then be investigated whether a delay in institutionalization would be desired and beneficial for the quality of life of both the caregiver and dementia patient. Furthermore, the current difficulties could be discussed and the motivations for admission could be investigated. Then, case-management could be considered whether it could sustain these caregivers with respect to the needs identified to delay institutionalization. This approach would have two major advantages and one major disadvantage. The first advantage would be that no case-management would be given to caregivers who would not have institutionalized their dementia patients, irrespective of whether they received case-management. Second, at the

point of admission it is likely easier to identify if a delay in institutionalization would be desired and beneficial for the quality of life of both the caregiver and the dementia patient. Thus, this approach would likely better target caregivers where beneficial effects could be achieved. The major disadvantage is that the effect of case-management given from the time of admission forward, could be less as it would have been if case-management was given from the time the caregiver was identified, i.e., the preventive effect from case-management is not present anymore. This could probably lead to a smaller number of caregivers that would qualify for case-management, however the overall cost-effectiveness of the intervention could be increased. No research was found with respect to reactive case-management in the context of this study.

On the other side, if the quality of life of an informal caregiver is the main objective, this could lead to a different ideal strategy. Factors like the amount of sleep the person can get, how well a caregiver could deal with behaviour problems, and the amount of time the informal caregiver could spend relaxing could be related to the quality of life. Case-management could positively affect these factors. This would then be interesting for a large number of informal caregivers. Again, a previously discussed example could be used to illustrate the difference between the two perspectives. A spouse caregiver is very committed to providing care, due to their long shared history. The amount of behaviour problems and resulting distress would not be important for this particular caregiver with respect to the desire to institutionalize. However, the caregiver could be more happy or satisfied if she would be effectively able to deal with the behaviour problems present. Although this caregiver would not be an ideal caregiver seen from a cost-perspective view, positive results could be achieved with respect to factors relating to the quality of life.

In the end, case-management still has to be financed. From the perspective of the quality of life of informal caregivers, it may seem interesting to provide case-management to all informal caregivers identified in the earliest point in time. However, one must understand the implications this could have in terms of cost-effectiveness. The question should then be raised how much increased quality of life of caregivers or service linking is worth and how much the government is willing to pay for this. This could then be taken into account with respect to the financing of case-management.

4.4 Limitations

One limitation of this study is that only an intervention group was studied. This means that all subjects received some amount of case-management. To gain a better understanding of the effect of case-management, this study relied on the variation with respect to the extent to which different case-management services were received. Inherent in this setup of the study, is the fact that most respondents received at least some case-management services. Therefore, the difference between no case-management at all and some level of case-management intervention could not be established in this study.

A second limitation of this study is that the design of the study does not allow establishing causality with respect to the relationships found in this study. Hair et al. (2006) describes types of evidence needed to establish causality. First, covariation should be established between two constructs. An additional requirement for causation is the temporal sequence of events. This is problematic in the design used for this study, because the time sequence cannot be accounted for. An example will be given for the relationship between social support of friends and mental health. Although it is expected that social support would lead to an improved mental health this relationship could be reversed. If a family member perceives a decreased mental health of the primary caregiver, they might be stimulated to provide more social support.

Another drawback of the study is that due to practical limitations, the actual time to institutionalization could not be recorded. In this study the desire to institutionalization is used, which is most likely a good predictor of the actual time to institutionalization, however no studies were found that investigated the relation between these two factors.

This study also could not control for the effect different case-managers might have. As discussed earlier, case-managers had different backgrounds. It could well be that the intervention is differently implemented by each case-manager. It may be that some case-managers were more effective than others were. Although the case-mangers for each respondent were known, this variable was not accounted for, because there was too much variation in the number of cases per case-manager and division by case-manager would lead to small subgroups, inappropriate to draw conclusions on.

Educating caregivers about dementia and caregiver knowledge could not be analyzed in this study due to cross-loading in the factor structure and unreliability of the scale of caregiver knowledge. The effect of this particular dimension is therefore unknown.

4.5 Further research

First directions for further research will be given related to the current study. After that, directions will be given for the research field in general.

The current study could not investigate the effect of the intervention compared no intervention at all. In order to do so, a comparison should be made with an equivalent non-treatment group. It is recommended to extend this study with a static group comparison study. In a static group comparison study, two groups are used. One group receives the intervention of case-management and one group does not. Results from both groups could then be compared with respect to the outcome variables. A possibility would be to use other regions where case-management has not been implemented yet as the non-treatment group. Care should be taken to control for variables, which could be different with respect to the intervention group and the non-treatment group, such as age and social support from friends. These characteristics could be different for a city compared to a town. A static group comparison is not without limitations either. Since this setup does not include any pre-testing, differences between the two groups prior to the study are unknown and cannot be accounted for. However, results from this study could provide substantial additional insight.

The establishment of causal relationships was another limitation of this current study. To provide support for causal relationships, a research design must involve either an experimental or a longitudinal design (Hair et al., 2006). An experimental design provides evidence since the design allows control of the causal variable through manipulations. A longitudinal data could provide evidence, since the time sequence of events is accounted for. Extension of the current study with a comparison to a control group would therefore deal in some extent with the limitations in this current study.

After exploring research on case-management and this current study, it remains questionable as to whether case-management could lead to delayed institutionalization. It might therefore be interesting to do additional research whether case-management could be more beneficial if caregivers are carefully selected based upon characteristics related to an increased potential of case-management as discussed. Further research could be directed at clarifying these characteristics. Furthermore, research could be dedicated to reactive case-management as discussed in this study, with respect to its potential to decrease institutionalization.

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Appendix A

Background variables

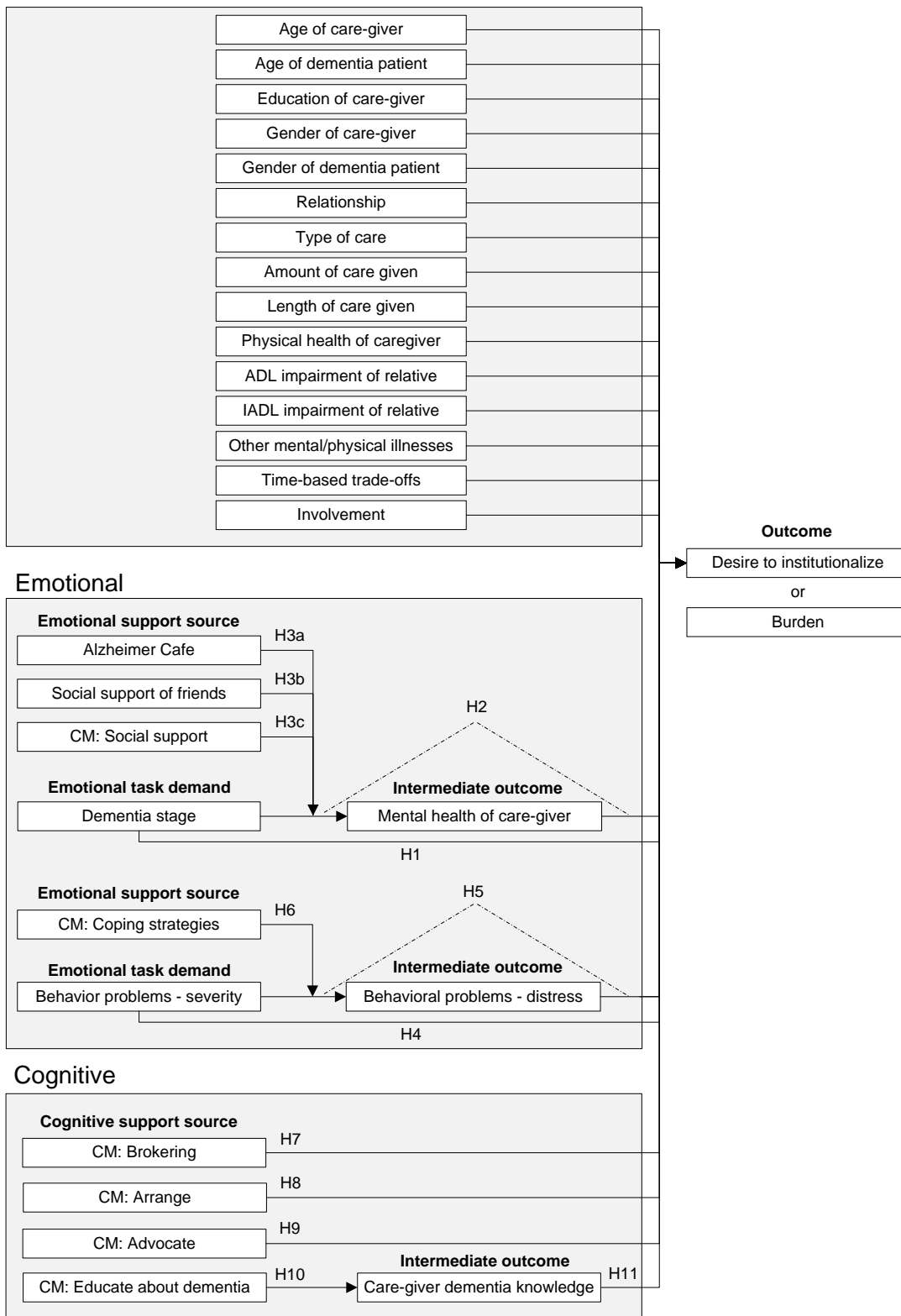


Figure A 1 Initial conceptual model

Appendix B

	Factor												
	1	2	3	4	5	6	7	8	9	10	11	12	13
Physical health of care-giver 1				0.82									
Physical health of care-giver 2				0.71									
Physical health of care-giver 3				0.66									
Physical health of care-giver 4				0.69									
Physical health of care-giver 5				0.42								-0.61	
Physical health of care-giver 6												-0.62	
Mental health 1						0.71							
Mental health 2						0.61							
Mental health 3						0.86							
Mental health 4						0.67							
Mental health 5						0.79							
Social support of friends 1					0.90								
Social support of friends 2					0.87								
Social support of friends 3					0.69								
Social support of friends 4					0.86								
Time-based trade-offs 1		-0.80											
Time-based trade-offs 2		-0.85											
Time-based trade-offs 3		-0.75											
Time-based trade-offs 4		-0.79											
Involvement 1								0.49					
Involvement 2								0.84					
Involvement 3								0.52					
Involvement 4								0.68					
Desire to institutionalize 1			0.86										
Desire to institutionalize 2			0.90										
Desire to institutionalize 3			0.64										
Desire to institutionalize 4			0.68										
Desire to institutionalize 5			0.88										
Desire to institutionalize 6			0.83										
Burden 1												-0.69	
Burden 2												-0.67	
CM: Social support 1	0.84												
CM: Social support 2	0.91												
CM: Social support 3	0.53												
CM: Social support 4	0.63												
CM: Dementia knowledge 1									-0.79				
CM: Dementia knowledge 2									-0.86				
CM: Dementia knowledge 3									-0.78				
CM: Coping strategies 1									-0.69				
CM: Coping strategies 2									-0.54				
CM: Coping strategies 3									-0.60				
CM: Brokering 1										-0.74			
CM: Brokering 2										-0.88			
CM: Brokering 3													
CM: Arrange 1							-0.64						
CM: Arrange 2							-0.70						
CM: Follow-up 1							-0.63						
CM: Follow-up 2							-0.57						

Extraction Method: Principal Axis Factoring. Rotation Method: Oblimin with Kaiser Normalization.

a. Rotation converged in 20 iterations.

Figure B 1 Pattern matrix of a factor analysis with 13 factors extracted

Appendix C

	Factor											
	1	2	3	4	5	6	7	8	9	10	11	
Physical health of care-giver 1				0.68								
Physical health of care-giver 2				0.76								
Physical health of care-giver 3				0.80								
Physical health of care-giver 4				0.71								
Physical health of care-giver 5				0.83								
Physical health of care-giver 6				0.60								
Mental health 1						0.77						
Mental health 2						0.66						
Mental health 3						0.82						
Mental health 4						0.66						
Mental health 5						0.81						
Social support of friends 1					0.88							
Social support of friends 2					0.85							
Social support of friends 3					0.71							
Social support of friends 4					0.87							
Time-based trade-offs 1		-0.81										
Time-based trade-offs 2		-0.84										
Time-based trade-offs 3		-0.74										
Time-based trade-offs 4		-0.84										
Involvement 1								0.44				
Involvement 2								0.67				
Involvement 3								0.57				
Involvement 4								0.69				
Desire to institutionalize 1			0.87									
Desire to institutionalize 2			0.91									
Desire to institutionalize 3			0.63									
Desire to institutionalize 4			0.69									
Desire to institutionalize 5			0.90									
Desire to institutionalize 6			0.81									
Burden 1											-0.61	
Burden 2											-0.58	
CM: Social support 1	0.70											
CM: Social support 2	0.78											
CM: Social support 3	0.48											
CM: Social support 4	0.54											
CM: Dementia knowledge 1							0.83					
CM: Dementia knowledge 2							0.89					
CM: Dementia knowledge 3							0.81					
CM: Coping strategies 1							0.73					
CM: Coping strategies 2							0.58					
CM: Coping strategies 3							0.60					
CM: Brokering 1										-0.62		
CM: Brokering 2										-0.73		
CM: Arrange 1									-0.72			
CM: Arrange 2									-0.77			
CM: Follow-up 1									-0.68			
CM: Follow-up 2									-0.66			

Extraction Method: Principal Axis Factoring. Rotation Method: Oblimin with Kaiser Normalization.

a. Rotation converged in 15 iterations.

Figure C 1 Pattern matrix of a factor analysis with 11 factors extracted