

Master Thesis

Dementia Caregiving: the construct validity of the CarerQol instrument to measure the impact of informal care among caregivers of dementia patients.

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Table of Contents

Abstract	3
Introduction	4
Informal care	4
Dementia caregiving	6
Informal care in economic evaluations	7
The CarerQol instrument	10
Study objectives and hypothesis	13
Methods	16
Population/ data	16
Measures/Questionnaires	16
Statistical analysis	18
Convergent validity	18
Clinical validity	20
Results	22
Characteristics of caregivers, care recipients and care situations	22
CarerQol-7D	26
Convergent validity	26
Subjective burden measures on the basis of CarerQol- 7D	27
Subgroups	28
Clinical validity	29
CarerQol-VAS score	29
CarerQol-7D sum score	30
Discussion	32
Convergent validity	33
Clinical validity	35
Study Limitations	36
Conclusion	38
Appendix 1	39
Appendix 2	39

Abstract

Objectives: In recent years, informal care is not systematically included in economic evaluations, while this could lead to suboptimal decision making. The impact of caregiving on carers is often substantial and most of the times negative, especially when the care recipients suffer from mental illnesses such as dementia. Thus, valid and reliable instruments are required to measure these carer effects for inclusion in economic assessments. This study investigates the construct validity of the Care-related Quality of Life (CarerQoL)-instrument among informal caregivers of Dementia patients. The CarerQoL instrument measures and values the impact of informal care by assessing happiness (CarerQoL-VAS) and describing burden dimensions (CarerQoL-7D).

Methods: The data were gathered with written questionnaires distributed by post in a population of informal caregivers of dementia patients living at home in the Gooi and Vechtstreek region (near Amsterdam) (n = 602, net response rate = 37%). Two different types of construct validity, i.e. convergent and clinical validity have been assessed. Convergent validity was analyzed with assessing Spearman's correlation coefficients and multivariate correlation between the burden dimensions (CarerQoL-7D) and the valuation component (CarerQoL-VAS) of the CarerQoL. Additionally, the convergent validity was tested with Spearman's correlation coefficients between CarerQoL and other subjective burden measures (SRB, CSI, Pt). Further, the convergent validity was evaluated with multivariate correlation between CarerQoL-VAS and CarerQoL-7D among subgroups of caregivers. The clinical validity was assessed with multivariate correlation between CarerQoL-VAS and CarerQoL-7D, characteristics of caregivers, care recipients and care situation. Additionally, exploratory analysis was performed concerning the convergent and clinical validity of the recently developed valuation component of CarerQoL, the CarerQoL-7D sum score (CarerQoL-7D Tariff) in a similar way.

Results: The negative/positive dimensions of CarerQoL-7D were negatively/positively related to CarerQoL-VAS, and most of them had moderate strength of convergent validity. The CarerQoL-VAS was negatively associated with SRB and CSI and positively with Pt. The CarerQoL-VAS reflected differences in important background characteristics: educational level and subjective health of the caregiver, intensity of caregiving (in number of days per week) and use of professional home care. Our results largely corroborated earlier tests of the construct validity of the CarerQoL. Additionally, the CarerQoL-7D dimensions significantly explained differences in CarerQoL-VAS scores among subgroups of caregivers. The exploratory analysis concerning the construct validity of the CarerQoL-7D sum score showed that the latter was negatively associated with SRB and CSI and positively with CarerQoL-VAS and Pt. Moreover, CarerQoL-7D sum score reflected differences in certain background characteristics of the caregivers, care recipients and care situation which all together explained 35% of the variation in the CarerQoL-7D sum scores.

Conclusion: Notwithstanding the study limitations such as the selective and of modest size sample of caregivers, this study suggests that the CarerQoL is a valid tool to measure and value the impact of informal care among these special providers of care for use in economic evaluations.

Introduction

Informal care

Informal care has been described as the care provided to ill or disabled persons by non-professionals (1). Informal caregivers are the family, friends, acquaintances or neighbors of the person in need. They perform a wide range of tasks similar to those performed by professionals without being financially compensated for them. The performed activities include personal care such as bathing, eating and dressing, household work such as cleaning and cooking and emotional support to the patient (2).

Informal caregivers contribute substantially in the total health care provided to people with disabilities or those suffering from chronic diseases (3). They constitute a vital part of every health care system since they provide a great amount of services at zero cost to public administration. In the Netherlands, it has been estimated that 3.7 million people aged over 17 years (that is 29% of the Dutch population) provide informal care for a relative, friend or neighbor in need (4, 5). The relatively large number of informal caregivers is partially due to the budget constraints in the Dutch health care system in recent years, which entailed a substitution of informal care with formal care only in case of great need or inability of the caregiver to properly take care of the patient. This shift from professional to informal care has increased the pressure on informal caregivers since it has rendered the majority of them, responsible for the provision of long term and intensive care (4).

A substantial body of research devoted to the impact of caregiving on informal caregivers has identified that the latter experience a heavy burden from the tasks they perform. The duration and intensity of care as well as the usually unpleasant and uncomfortable activities it involves, render caregiving a psychologically stressful and physically exhausting procedure (6, 7). Thus, caregivers are at risk of becoming patients themselves. In addition, it has been verified that caregiving is an independent risk factor for increased psychiatric morbidity and mortality among elderly caregivers (8). Consequently, despite its great benefits to care recipients and society as a whole, informal caregiving may come at a substantial cost to carers' well-being. Typically, caregiving entails a considerable expenditure of time which could otherwise have been spent to paid work or leisure activities (4, 6). The lack of personal time is frequently accompanied with the experience of social isolation (2). Moreover, informal care can lead to financial strain because of the reduced income from limited participation in the labour market and the extra expenditures required in the context of providing care. Subsequently, the higher poverty levels observed among caregivers due to financial problems put them at risk of social exclusion (2). Even in the case of access to alternatives for informal care such as the institutionalization of the patient or the provision of formal care in the patient's home whereby the burden of caregiver is considerably lower, still there may be a negative impact on caregivers' well-being (6). The absence of the patient may cause sadness or even depression to carer, feelings which become greater when the patient prefer to stay at home, due to the often strong emotional relationship between them. Moreover, when patient and caregiver share the same household, the provision of professional care from a stranger may raise privacy considerations and feelings of discomfort (1).

However, the most frequently mentioned motives for involvement in the provision of informal care are feelings of love, affection and reciprocity towards the dependent person (9, 10). Many informal caregivers see caregiving as a natural duty within a family relationship (11). This intimates that positive and beneficial effects of caring are possible. Informal caregivers have reported that the act of caregiving is a source of satisfaction and self-accomplishment (12). Providing the best attainable care to a loved person and seeing his well-being improving, gives meaning to caregiver's life and raise feelings of fulfillment (11). Moreover, the realization of someone's desire to die at home and the preservation of his dignity and self-esteem engender appreciation between the patient and the caregiver and strengthen their relationship (12). The adversities experienced by the caregiver when caring for a severely ill or disabled person contribute to the discovery of personal strength and allow her/him to grow as a person (11). Last, informal caregiving implies personal challenges which irritate the development of new unforeseen skills and abilities (13).

Some of the aforementioned elements could be also considered within the concept of process utility that is the (dis)utility derived from the process of providing informal care. The phenomenon of process utility relates to the fact that not only the outcome is of importance to the informal caregiver in the sense that the patient is adequately cared for, but also the way of reaching this outcome (14). Process utility is defined as the difference in a caregiver's happiness between the current situation of caring for a patient her-/himself and the hypothetical situation where somebody else undertakes the process of caring under the same conditions and for free (15). Previous research has shown that process utility exists, is substantial and thus significant in the context of informal care (14). Specifically, the results have revealed that a large proportion of informal caregivers derive positive utility from the process of caring and a major part of their happiness would be lost if the caregiving tasks were taken over by someone else.

In light of all the foregoing, health care interventions may have an impact not only on the patient's health and well-being but also on the well-being of significant others. Previous research has shown that these 'spill over effects' in significant others are distinguished in the caregiving effect and the family effect (16). The caregiving effect refers to the effects of caring for people suffering from an illness. In that, the patient's degree of illness and care dependency has an indirect yet substantial influence on the welfare of informal caregivers. The family effect refers to the effects of caring about other people and their health as a result of a strong social relationship between a person and the patient (such as parents and children). It therefore implies the direct impact of the patient's health on other's well-being. By definition, the caregiving effect is present in people providing informal care regardless of their relationship to the patient while the family effect applies to a wider group of people who have a social relationship with the ill person whether or not they provide care (17). However, since informal care is commonly provided by the family or friends of the patient due to the social relationship between the two, both the caregiving and family effect may be present in informal caregivers.

Concluding, those findings demonstrate that caregivers regardless of the degree of burden may also experience several kinds of satisfaction while providing care to a person in need. Thus, burden and gratification can coexist and display different features of the caregivers' situation. The identification of the burden as well as the beneficial effects experienced by the caregivers can be useful for the development of intervention strategies that can enhance the positive aspects of this practice, relieve providers of care from the difficulties they face and hence support and maintain their involvement in their valuable work (11, 14, 18).

Dementia caregiving

The most commonly studied type of informal caregiving, throughout the extensive literature in this area, is Dementia caregiving (6). The unique and extreme challenges which characterize this specific type of care have induced many researchers to investigate its impact on informal caregivers.

Dementia is the loss of cognitive functioning caused by brain disorders that affect thinking, memory, behavior and judgment. It is a progressive and irreversible clinical syndrome which mainly appears in older people. As the condition progresses, a demented patient can present a range of complex problems such as aggressive behavior, delusions and hallucinations, restlessness and wandering, incontinence, eating problems and mobility difficulties. Alzheimer's disease is the most prevalent type of dementia accounting for the 70% of all diagnosed cases. Dementia is an especially costly disease with spending for the health and social care of demented people exceeding that for the care of people suffering from cancer, heart diseases and stroke put together (19). Specifically, the costs associated with the disease include direct medical and nonmedical costs such as nursing home care and in-home day care respectively, and indirect costs such as lost patient and caregiver productivity.

The worldwide number of persons suffering from dementia has been estimated at about 36 million persons. With the ageing population that number is expected to increase to more than 115 million by 2050 (20). Specifically in the Netherlands, the number of demented patients of age 65 and older is projected to double during the following 25-40 years (21). Moreover, it has been identified that the majority of elderly people with dementia receive care at home by informal caregivers, even those at an advanced stage of the disease (22). Thus, the increasing prevalence and incidence of dementia disease among elderly people in combination with the ageing population implies higher demand for care of people suffering from this illness, affecting both the formal and informal health care sector (2). In addition, the availability of drugs for patients with dementia or related disorders has increased the patients' survival time (i.e., 8-20 years) (1). This has rendered the provision of informal care to those people, a long term responsibility that gradually decays the caregivers' personal, financial and social resources. In fact, many researchers have conceptualized dementia caregiving as a chronic stressor (23).

Most demented adults, receive care from their spouse and in case of the spouse's inability to take care of them, adult children usually take up the provision of assistance (6). Moreover, it has been identified that although the provision of care is divided among the family members the more frequent scenario is that the majority of caregiving tasks are performed by one family member.

A number of studies focusing on the differences between dementia caregiving and the provision of care to loved persons with physical or other chronic conditions have confirmed that caregiving has greater negative effects on dementia caregivers than non-dementia ones and that the care of a demented patient is one of the most stressful kind of informal caregiving (6, 24, 25). The greater strain levels among dementia caregivers seems to be mainly due to the behavioral problems they are asked to contend such as screaming and destroying property (17). In addition, it has been established that 20%-24% of the demented

persons also suffer from depression (6, 11, 12). Thus, the combination of cognitive, behavioral and emotional problems that accompanies the illness makes the care of demented relatives more burdensome. Specifically, dementia caregivers experience increased depression and higher levels of anxiety compared to non-dementia providers of care (23, 24, 25). Moreover, compared to non-dementia caregivers, caregivers of demented patients are more involved in caregiving in terms of hours per week and are affected more negatively from their caregiving duties in terms of physical health problems, employment complications, personal time for vacations or hobbies and family disputes (6, 24, 25). Last, the caregivers' anticipation that the condition of the patient will only worsen and usually in an unpredictable and maybe uncontrollable manner, is another contributing element to the greater impact of dementia caregiving (24).

A recent study conducted in the Netherlands in respect of the burden experienced by dementia caregivers, verified the aforementioned conditions (21). The Health Council of the Netherlands has concluded that there is imbalance between the demand and supply of facilities and services for the people suffering from dementia. It, therefore, has advised the government to expand the residential capacity. However, the government has chosen instead, to encourage the collaboration between the providers of care at a regional level aiming to improvements in the care and services for demented patients and their caregivers in a non-residential setting. Given the expected increase of people with dementia in the next years and the policy the government has adopted, the tension between demand and supply of care will shift towards informal caregivers, increasing their subjective burden considerably.

An important implication of the presented information is that dementia caregivers seem to be in great need of support and formal services so as to cope with the caregiving task without impairing themselves. However, findings from previous studies have revealed that dementia caregivers and especially the more strained ones, report greater unmet service needs contrary to non-dementia caregivers (25). Some of the unmet service needs reported include areas such as 'coping with challenging behaviors', 'moving or lifting the patient', 'managing incontinence problems', 'making end-of-life decisions', 'choosing a home care professional', 'choosing a nursing home'. Given the especially challenging and stressful type of this care, the lack of support to those people may have a substantial negative impact on the general quality of their life. Consequently, by acknowledging their specific stressors, difficulties and resulting needs we can estimate the demand for long term care, respite care and support services and hence provide those (18).

Informal care in economic evaluations

Economic assessments of health care interventions are widely being undertaken so as to inform decision makers in health services around the world. It has long been acknowledged that health care as many other aspects of life, is confronted with the problem that the resources available to spend are insufficient to meet demand (26). The resources used to provide health care comprising staff, equipment and facilities, are scarce. Thus, decisions on what services will be provided to whom, where and when, have to be made. Besides resource implications, these decisions have also health consequences. The overall aim of economic evaluation is to encourage more rational decision making by comparing the costs and effects of new and existing health technologies and hence providing guidance on the overall value of these technologies to a certain population (27). That is, after efficacy and

effectiveness have been demonstrated, decision-makers can choose between competing interventions based on their relative cost-effectiveness so as to maximize the aggregate health benefits achieved (28).

The types of economic evaluation are cost-effectiveness analysis, cost-utility analysis, cost-benefit analysis and cost-consequence analysis (26). The key feature that differentiates the four types of economic assessment is the unit for measuring the benefits. Economic evaluations can take several perspectives, most frequently either a narrow health care perspective or a wider, societal perspective. (28) Most national guidelines for health technology assessment studies suggest taking a societal perspective, which entails the incorporation of all relevant costs and (health) effects regardless of who experiences them in society (27, 29).

Within this context, the consideration of informal care in economic evaluations of health technologies seems to be of pivotal importance. As presented in the previous sections the impact of informal care on caregivers can be substantial in terms of costs as well as health effects. Thus, a health intervention targeted at the treatment of conditions of patients that are associated with a substantial input of informal care, may also affect either positively or negatively the caregiver of the patient. It has been notified that albeit some positive aspects of caring for a loved one exist, informal caregivers experience mainly negative outcomes from this process such as emotional strain, feelings of isolation and health losses. Thus, even if a new treatment reduces the amount of formal health care used by a patient and hence the pressure on health care budget, it may increase the need for informal care and subsequently the caregiver burden. This increased burden may put caregiver at risk of becoming patient herself/himself if her/his health worsens with caring and may hence lead to more health care costs. Finally, even when a more restricted, health care perspective is adopted, informal care should not be ignored, since potential adverse health effects in caregivers can be a decisive factor for the choice of the intervention that will be funded (3, 30).

The incorporation of informal care in economic evaluations is also relevant for interventions directed to informal caregivers such as respite care and support services (3, 31). Assessing a caregiver's situation will help in the provision of adequate support to those special providers of care (18, 31). This will enable them to continue to perform their caring role without damaging their own health and well-being, given that they provide a service that otherwise would cost public health and social services, a huge amount of money (32). Therefore, when informal care is not considered in economic evaluations of treatments in which caregivers play a vital role, suboptimal policy decisions are possible.

The attention on informal care becomes even more necessary in light of the expected demographic trends (31). Given the ageing population and the wide range of mainly chronic diseases prevalent in older ages, the demand for both formal and informal care is projected to be higher in the future (2). At the same time, the increasing participation of women in the labor market, the lower percentage of younger people and the smaller family size, imply less potential availability or willingness of family members to be involved in informal caregiving (24). Moreover, the restricted health care budgets in most countries entail a potential decrease in the provision of professional care (2). Thus, rationing of care becomes inevitable.

Nevertheless, in recent years, informal care is not systematically included in economic evaluations, even when a societal perspective is adopted. In terms of medical decision

making, patients are treated as isolated individuals and the position, needs and preferences of significant others are usually ignored (33). This appears to be due to the lack of practical methods for the incorporation of the full impact of informal care (3). That does not mean that there are no methods but that the existing ones present limitations. Indeed, there is a wide range of methods for measurement and valuation of informal care aiming at its inclusion in economic evaluations but they differ substantially in respect to the aspect of informal care they value (3, 34).

Measurement and valuation

The measurement entails the registration of the impact of informal care in terms of objective and subjective burden experienced by the caregiver, the impact on her/his health and the general quality of her/his life or her/his well-being (1). The valuation of informal care refers to the value attached on the measured impact. In order to give informal care a more salient role in healthcare resource allocation decisions, not only the explicit measurement of its costs and effects is required but also this measurement to be done in a way informative to decision makers (31). That is, costs and effects should be expressed as such that they can be properly incorporated in economic evaluations and be comparable across samples and interventions.

Non-monetary methods, mainly subjective burden measures have been suggested to register the impact of informal care (3). The subjective burden indicates how the informal caregiver experiences the caregiving task and is associated with the objective burden (e.g. time invested in caregiving, number of performed tasks and potential financial problems), the capacity of the caregiver to fulfill the caring role and several other factors (3, 5, 15).

Examples of validated instruments for assessing subjective burden are the Caregiver Strain Index (CSI), the Caregiver Reaction Assessment (CRA) and the Sense of Competence Questionnaire (SCQ) (35, 36, 37). However, these instruments measure the level of burden on different dimensions of the perceived caregiver burden. Thus, an assessment of the overall burden is not possible. Although they are quite informative on the caregiving situation, they do not register a preference based total level of burden neither provide a valuation of the subjective burden from the caregiver side (3). Hence, the relative importance caregivers assign to the different dimensions of burden cannot be elicited. An exception constitutes the Self-Rated Burden (SRB) instrument which measures the subjective burden by asking caregivers to express the burden they experience from the caregiving task on a visual analogue scale ranging from 'not straining at all' (0) to 'much too straining' (100), providing an overall valuation of their burden (34).

Given that the results derived from these descriptive measures are not expressed in monetary terms or health-related quality of life implies that they can be included in economic evaluations only as supplementary, supporting information (1). Other possible uses of this information are in a cost-consequence or multicriteria analysis.

Available valuation techniques can generate a monetary valuation of the impact of informal care for use in economic appraisals. The most appealing and commonly used valuation methods are the market price and opportunity cost method (3, 34, 38, 39). In accordance to these techniques, the informal care is valued by multiplying the hours spent on providing care with a value per hour. In the first case, the value assigned to the time spent on caregiving is derived from the price of a close market substitute. However, by attaching the

same value to formal and informal care, this method assumes that these two are perfect substitutes, without taking into account the potential differences in quality or efficiency of the provided care. In the second case, the value of caregiver's time input equals the value of the best alternative use of that time such as paid work or leisure activities.

Both methods constitute a quite straightforward manner to include informal care in economic evaluations by incorporating the resulting estimates on the numerator of the cost-effectiveness ratio. Nevertheless, the equal valuation of all caregiving hours implies that the aforementioned techniques fail to consider the fulfillment or disutility that informal caregivers may experience from caring for a loved one after a specific period of time and from the different care activities performed (3, 39). Thus, they are deemed unsuitable to value the full impact of informal care on caregivers.

Other possible options for the monetary valuation of informal care are stated preference methods such as the contingent valuation method and conjoint measurement method. Following the contingent valuation technique, the value of informal care is obtained by asking informal caregivers the minimum amount of money they are willing to pay or accept so as to stop or continue respectively to perform their caring role (40, 41, 42, 43). However, it has been identified that many people find it difficult or inconvenient to elicit a monetary value of the time spent on the provision of care for a loved person. Further, it is possible that the stated preferences elicited through this method, to be completely different from the revealed preferences, resulting in biased valuations of informal care. The conjoint measurement method values the informal care by asking caregivers to choose or rank different care scenarios according to their preferences on the attributes of the presented alternatives (40, 44). When cost is included as an attribute, a monetary valuation of informal care is possible. A problem with this method is that the valuation of multi-attribute scenarios may be cognitively demanding for older respondents or those with limited educational attainment. Thus, although more sensitive to caregivers' preferences, the last two valuation techniques are questionable regarding the validity and consistency of the valuations they provide.

Finally, it has been argued that maybe in addition to monetary valuation of time, the impact of informal care in terms of health effects can be directly included in economic assessments using validated questionnaires such as the EuroQol-instrument (3, 45). The EuroQol-instrument consists of a descriptive system, covering five dimensions of health and a visual analog scale for the valuation of the derived health states. It measures changes in the health-related quality of life in terms of quality-adjusted life years (24). Hence, changes in health-related quality of life of the caregivers can be combined with that of the patients and can be incorporated in the denominator of cost-effectiveness ratio. However, it has been stated that informal caregiving may affect the overall well-being of the caregivers beyond their health. Thus, such an approach provides only a partial valuation of informal care since it considers only the health effects this practice may entail (1, 3).

The CarerQol instrument

In light of the limitations of the aforementioned valuation methods and their failure to measure and value the full impact of informal care so as to be properly considered in economic evaluations, the CarerQol instrument (15) and the Caregiver Experience Scale

(CES) were developed (46, 47). Both subjective burden measures combine measurement and valuation of the caregiver burden. Our study is focused on the CarerQol instrument.

The CarerQol instrument, an acronym for care-related quality of life, encompasses a description of the caring situation on seven dimensions (CarerQol-7D) and a valuation of general quality of life (CarerQol-VAS) (**Figure 1**). It describes the subjective caregiver burden on two positive dimensions: fulfillment and support and five negative dimensions: relational problems, mental health problems, problems with combining daily activities, financial problems and physical health problems. The respondents can express the level of burden they experience in their care situation, in respect of each one of the seven dimensions, by choosing one of the possible answers, 'no', 'some' or 'a lot'. In this way, 2.187 (=3⁷) potential care situations can be discerned.

Recently, a tariff has become available for the CarerQol-instrument (48) which allows the calculation of a weighted sum score of the CarerQol-7D, taking the severity of problems into consideration (Table 1). The tariff has been calculated based on Dutch preferences for different caregiving situations and hence concern Dutch national tariffs. According to the weighted sum score, the worst caregiving situation takes a score of 0, while the best takes a score of 100. The scores ranging from 0 to 100 can be calculated using the tariffs in **Table 1**.

The CarerQol-VAS measures the general well-being in terms of happiness e.g. 'the degree to which an individual judges the overall quality of his life-as-a-whole favorably' on a visual analogue scale (VAS) ranging from (0) 'completely unhappy' to (10) 'completely happy'. A broad outcome measure such as happiness is able to capture the wide range of potential consequences informal caregivers experience with caring. Thus, the CarerQol instrument could give an estimation of the overall impact of informal care and increase its consideration in economic evaluations since it combines the information density of a subjective burden measure with a comprehensive valuation method. A downside, though, is that the happiness of a caregiver may also be influenced by factors beyond care such as the level of income or the type of work and hence a happiness score may constitute an over- or underestimation of the experienced burden (49).

The results of the CarerQol can be comprised at the denominator in a cost-consequence or a multicriteria analysis. In addition, CarerQol could be considered as useful tool to conduct a cost-utility analysis in the case of the evaluation of an intervention directed specifically to caregivers (15).

Figure 1 CarerQol-instrument (and observed response in study sample)

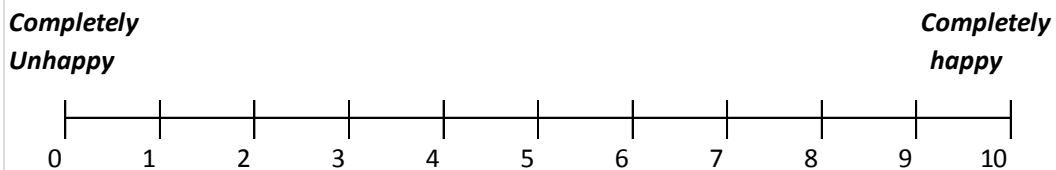
CarerQol-7D

Please draw an "X" to indicate which description best fits your current caregiving situation

	NO	SOME	A LOT	
a. I have	12.1%	54.7%	33.2%	Fulfillment with carrying out my care tasks.
b. I have	28.2%	48%	23.8%	relational problems with the care receiver (e.g., he/she is very demanding, he/she behaves differently, we have communication problems).
c. I have	32.3%	46.6%	21.1%	problems with my own mental health (e.g., stress, fear, gloominess, depression, concern about the future).
d. I have	29.1%	52.5%	18.4%	problems combining my care tasks with my daily activities (e.g., household activities, work, study, family and leisure activities).
e. I have	90.1%	6.7%	3.2%	financial problems because of my care tasks.
f. I have	17.1%	58.7%	24.2%	support with carrying out my care tasks, when need it (e.g., from family, friends, neighbors, acquaintances).
g. I have	44%	38%	18%	problems with my own physical health (e.g., more often sick, tiredness, physical stress).

CarerQol-VAS

Please draw an "X" on the scale below to indicate how happy you feel currently



[Observed score in study sample (mean; SD): 6.3 (1.9)]

Table 1 National tariff CarerQol-7D

Dimension	Tariff for score		
	no	some	a lot
Fullfilment	0.0	15.0	19.6
Relational problems	13.5	10.6	0.0
Mental Health problems	13.5	10.4	0.0
Problems with daily activities	10.2	6.1	0.0
Financial problems	15.1	11.7	0.0
Support	0.0	4.2	6.5
Physical health problems	15.0	15.6	0.0
plus: a 'bonus' for:	no	yes	
No mental health problems and no physical health problems	0.0	0.6	

Numeric Example CarerQol-7D

Suppose that the answers of a respondent on the CarerQol-7D are:

- some fulfilment
- a lot of relational problems
- no mental health problems
- some problems combining daily activities
- no financial problems
- a lot of support
- no physical health problems

The CarerQol-7D score is: $15 + 0 + 13.5 + 6.1 + 15.1 + 6.5 + 15 + 6.6 = 77.8$

It is important to keep in mind when calculating the CarerQol-7D score that respondents get a 'bonus' of 6.6 for having neither mental nor physical health problems.

Study Objectives and hypothesis

Given the growing body of evidence on the burden of caregiving and the adverse health effects it can cause to caregivers, especially those who care for a person with mental illness such as dementia, the consideration of these impacts is crucial. In that sense, feasible, valid and reliable instruments are required to measure that burden.

The concept of reliability is a fundamental way to express the amount of error, either random or systematic, which is inherent in every measurement (50). According to Joppe's (2000) definition,

the extent to which results are consistent over time and an accurate representation of the total population under study is referred to as reliability and if the results of a study can be reproduced under a similar methodology then the research is considered to be reliable (51).

The underlying idea of this citation is that of replicability or repeatability of observations. The four types of reliability mentioned in quantitative research are, the degree to which different observers give consistent estimates of the same phenomenon, the consistency of a measure from one time to another, the consistency of the results of two tests constructed in the same way from the same content domain, the consistency of results across items within a test (52). The consistency with which questionnaire parts are answered or respondents' scores remain relatively the same is referred to as stability of an instrument. The stability of an instrument can be determined using the test-retest method at two different points in time (53). A high degree of stability implies a high degree of reliability (51). Despite the fact that the researcher may be able to demonstrate the repeatability and consistency of an instrument and hence its reliability, this doesn't entail that the instrument is valid.

Validity determines whether the research instrument measures what it was supposed to measure and the veracity of the research results (51). The reason why we assess validity is that many variables measured in health sciences are not physical quantities such as height or weight and thus not readily observable. Some instances of such variables are the quality of life, happiness or social support. The measurements of these variables are based on their definitions, which may be different among persons, and the way these measurements are derived. Since such factors cannot be observed or measured directly, several questionnaires have been developed to appraise them, each of them based on a different underlying theory. Consequently, each instrument produces a different result and the arising question is which of them yields the correct one (50).

The validity in quantitative research is described as 'construct validity' (54). The construct is the primary concept, question or hypothesis that specifies which data has to be gathered and in which way. For example, we cannot see anxiety but we can observe behaviors that, according to our theory about anxiety, are the consequences of it. In that, our conclusions are hypothesized assertions in terms of the observable behaviors of the patients. Thus, the construct can be considered as a 'mini-theory' to explicate the relationships among several different behaviors or attitudes. Using the underlying theory we can develop new or better instruments in the sense that they explain a wider range of findings, give a more parsimonious explanation of them or predict more accurately the patients' behaviors (50). Different types of the construct validity are the convergent and clinical validity. It has also been stated that the researchers actively cause or influence the interaction between construct and data so as to validate their investigation, commonly by applying a test or some other process. In that, the researchers' involvement in the research process would considerably decrease the validity of a test. In summary, it is evidently necessary to perform validation studies when a new instrument is developed. Nevertheless, when a scale measures a hypothetical construct such as the aforementioned, the validation is an on-going process (50).

The CarerQol instrument seems a promising instrument to measure the burden of caregiving in a valid and reliable way. Previous studies have tested some of its psychometric properties such as, feasibility, reliability and construct validity (15, 49, 55). The results of these tests showed that CarerQol is a clear, easy to administer and comprehensible instrument. Concerning the reliability of the instrument, the obtained responses on two different measurement moments (a relatively small time interval during which differences in patient, caregiver or care situation characteristics were not likely) from the same population, gave similar CarerQol-VAS scores and the observed differences were nearly zero. The same holds for the second part of the instrument, CarerQol-7D (56). The construct validity of the

instrument, including clinical and convergent validity was also good. More specifically, increased reported burden on the CarerQol-7D was related to increased burden measured with other subjective burden instruments, such as the Self-rated Burden scale and the Caregiver Strain index. In addition, the CarerQol-VAS was positively associated with the positive dimensions of CarerQol-7D and negatively with the negative dimensions of the instrument (15, 49, 56). Thus, greater fulfillment and support was related to higher happiness scores while more relational, mental, physical or financial problems led to lower happiness scores. In respect to the clinical validity, the CareQol-instrument has been found to discriminate well between different caregivers in terms of personal characteristics, care recipient characteristics and caregiving situation. That is, CareQol-VAS was associated with the background characteristics of informal care in the expected direction e.g. elderly caregivers, those caring for a patient suffering from physical and mental health problems and those caring for someone in need of permanent surveillance had lower CareQol-VAS scores.

Two of the aforementioned studies have tested the psychometric properties of the CarerQol instrument in heterogeneous populations of informal caregivers providing informal care at home, addressed through regional informal care support centers throughout the Netherlands (15, 49). The third study assessed the feasibility, validity and reliability of the CarerQol instrument in a heterogeneous sample of informal caregivers who are long-term care users identified through a nursing home near Rotterdam (56). The aim of this study is to further investigate the construct validity of the CarerQol instrument using a Dutch population of dementia caregivers. To achieve this we will test the convergent and clinical validity of the instrument such as in the previous studies. Additionally, our research is the first to study in an explorative way the convergent and clinical validity of the new sum score of the CarerQol-7D.

We refer to convergent validation as the extent to which the construct of the CarerQol instrument resembles the construct of other instruments measuring the subjective burden of informal care. Clinical validity will be assessed by the extent to which differences in patient, caregiver and caregiving situation characteristics are reflected as anticipated in differences in CarerQol-VAS scores and CarerQol-7D sum scores. Hence, this term closely resembles construct validity in the sense that one expects a lower happiness score and a lower CarerQol-7D sum score (calculated using the CarerQol Tariff), if some of the underlying features of the caregiving situation worsen.

Given the results from the previous studies, we expect that our findings on convergent and clinical validity will be similar. That is, a positive relation between CareQol-7D and other subjective burden instruments, in terms of the burden measured. Moreover, we expect that CareQol-VAS scores will be negatively associated with more problems on the CarerQol-7D dimensions and increased burden measured with the other burden instruments. Regarding the clinical validity, we assume that differences in caregiver, patient and care situation characteristics such as the age of caregiver and care receiver, the type of the relationship between the two and the duration of provided care will be reflected in differences in happiness scores (according to the findings in the previous studies). More specifically, based on the literature regarding the dementia caregivers we anticipate that female and younger care providers as well as those with lower income will be more burdened. In addition, a lower burden is expected to be experienced by those with a better quality of life and health

status (55). Overall, a relatively lower average score of happiness is anticipated among this special group of caregivers compared to non-dementia caregivers, given the specificity of dementia disease and the considerable harder task that dementia caregivers have to perform.

Methods

Population/ data

Secondary data analysis was performed using data on dementia caregivers (57). The data were gathered with written questionnaires distributed by post in a population of informal caregivers of dementia patients living at home. The caregivers were identified by using data of the assessment agency of the Dutch Exceptional Medical Expenses Act. In this data base, diagnosed demented patients who receive formal help are registered. In September 2007, the informal caregivers of all 602 registered patients suffering from dementia in the region Gooi and Vechstreek near Amsterdam were approached so as to participate in a longitudinal study. An information package was sent to the home addresses of those patients directed to the primary informal caregiver of them. The information package included an introductory letter with a description of the background and the objective of the study, the request for participation, the questionnaires and a pre-paid reply envelope. A reminder was sent after one month.

The gross response rate was 49% (n=292). The lack of response was caused by administrative omissions in the file used. That is, the information package might be sent to people who had moved to another home or cared for demented patients already admitted to a nursing home or deceased. Another reason might be the fact that participation in the study was considered by some as too burdensome (57). The absence of an informal caregiver, loss or misunderstanding of the mail, are also possible causes of non-response (57).

In total, 223 cases were analyzed. After examining the content of the envelopes, 69 replies appeared to be inappropriate for this study. This exclusion was caused by empty or undeliverable return envelopes and response by informal caregivers of patients already admitted to a nursing home or deceased, care recipients without dementia, or barely filled in lists of questions. The net response rate was 37%.

Measures/Questionnaires

The impact of informal care was measured with the CarerQol instrument, the Caregiver Strain Index (CSI), the Self-Rated Burden scale (SRB) and the perseverance time measure (Pt). The CarerQol-instrument has been described in detail in the Introduction. The CSI and SRB are concise and simple instruments to register the impact of informal care (1). They have been established to be more feasible and of equal validity in appraising the caregiver burden compared to longer and more complex subjective burden measures such as the Caregiver Reaction Assessment (CRA) and the Sense of Competence Questionnaire (SCQ) (58).

The CSI measures the perceived strain from the caregiving task by asking the caregiver to demonstrate agreement on 13 statements concerning the consequences of informal care giving, on a dichotomous no/yes scale. Based on this, a non-weighted sum score can derive. A 'yes' receives a score of '1' for negative dimensions and a score of '-1' for positive dimensions. A 'no' receives a score of '0' for both items. The sum scores range from 0 (no burden) to 13 (problems in all 13 items) (59). A higher score implies a higher perceived burden of caregiving. The CSI makes it possible to identify caregivers at risk due to adverse (health) effects by a cut-off value which has been defined for it (60, 61). Specifically, a score of 7 or higher is indicative of substantial strain experienced by informal caregivers (35). However, as mentioned above, the summary score of the CSI is not weighted. Hence, although such a summary score in combination with a cut-off point can be a useful tool to diagnose substantial burden, it is unclear whether it generates a justifiable estimate of the burden as perceived by the caregiver. That is, not all problems are experienced as problematic or equally problematic by caregivers (58). Thus, the respondents were asked to display their experienced burden also on the SRB scale which takes this into account by producing an overall indication of subjective burden, presumably comprising all positive and negative effects of caregiving.

The SRB measures the overall subjective burden experienced by the informal caregiver with a horizontal VAS ranging from 0 (not straining at all) to 10 (much too straining). It is a generic measure and hence can be applied to different informal care populations and research settings (31). Moreover, it can be used as a screening tool for severe burden among informal caregivers (15, 49, 56, 62).

Finally, the subjective burden was also measured by the Pt. The perseverance time is defined as the period of time for which caregivers themselves denote that they can continue to provide care for their loved one in need under the current conditions (21). It is used as an indicator of how caregivers deal with their caregiving situation and the level and type of support they may need so as to be able to carry on. That is, the shorter period of time an individual states that he is able to carry on providing informal care, the more difficulties she/he may face and thus the more support she/he needs so as to continue to perform her/his caring role. More specifically, the caregivers were asked to choose between 5 different periods of time that they judge themselves able to continue to be involved in the caregiving task. These are, 'more than one week but less than one month', 'more than one month but less than six months', 'more than six months but less than one year', 'more than one year but less than two years', 'more than two years'. For our analysis we transformed the categories of perseverance time into months. Pt in months was determined in the first four answer categories by taking the middle of the category (i.e. 3.5 months for the category 'more than one month, but less than 6 months') and was set at 30 months in the (open) fifth category. 38/223 respondents didn't give an indication of the perseverance time.

In addition, the questionnaire included questions on background characteristics of the caregivers, the care recipients and the caregiving situation. Specifically, information was collected on the caregivers' age, gender, educational level, and partner status, having children under 18 in the household, health status, sufficient information on possibilities for support for dementia patients and whether they knew where to search for information in the beginning of their involvement in the caregiving role.

The information obtained on the care recipients' background characteristics included age, gender, partner status, relation to the caregiver, living situation, need for continuous

surveillance, comorbidity, the severity of the comorbidity, health status and level of care dependency.

The health status of the demented patients and informal carers was measured with a horizontal VAS, upon which informal carers could indicate how they experience their health and that of their dementia patient relative on a scale ranging from 0 (worst conceivable health) to 10 (best conceivable health). Regarding the need for continuous surveillance the caregivers were asked to choose between three different options. These are, 'yes' (i.e. there is need for continuous surveillance), 'no, but the care recipient can only be alone for one hour or less', 'no, the care recipient can stay alone for several hours'. Finally the level of care dependency was measured with a horizontal VAS ranging from 0 (completely independent) to 10 (completely dependent).

Questions on the caregiving situation comprised duration of care in years, the intensity of care in days per week and hours per week of provision of informal care, care giving activities divided up in activities of daily living (ADL), personal care and practical support. These questions aimed to register the objective burden as it was the case in previous research (5, 15, 60). In addition, information was collected on whether the caregiver and the patient share the same household, whether the demented patient receives support from other informal caregivers, the use of professional home care, personal care and nursing care, medical treatment, the use of day care outside the home of the care recipient, and the use of private help in the household of the care recipient.

Statistical analysis

Firstly, we performed descriptive analyses of all the variables using means, standard deviations and percentages (**Table 2**). For categorical variables, such as gender, educational level, we presented the number in each category, indicating the percentage of the total caregivers or care recipients. For continuous variables, we calculated the mean values. Moreover, we assessed the variability of the observations by calculating the standard deviation.

Convergent validity

The convergent validity was tested by analyzing the associations between CarerQol-7D and CarerQol-VAS using Spearman's correlation coefficients (**Table 3**). In this study we used Spearman's correlation coefficients, because we have variables measured at ordinal level (i.e. CarerQol-7D). As we know, the calculation of mean values which is the case for Pearson's correlation (parametric technique) is 'meaningless' when we have variables not measured at the interval level (63). Moreover, rank correlation has the advantage of not specifically estimating linear associations but more general associations. Hence, the researcher avoids an underestimation of the association between two variables using Pearson's correlation coefficient, in case of a curved relationship between them. In addition, the Spearman's rank correlation seems to be the preferable option since it is the only non-parametric technic which generates as much information as its parametric cousin (Pearson's correlation) rather than just a p-value. It is in general easier to be calculated than the similar

method of Kendall's coefficient and it is easy to carry out using available software programs by ranking the data and conducting the usual Pearson correlation analysis.

However, the correlation coefficient does not describe the relation between the variables but it just indicates the degree of the association between them as a single number. Hence, to assess the relation between the two components of the CarerQol instrument, we carried out multiple linear regression analysis so as to predict CarerQol-VAS scores on the basis of the CarerQol-7D dimensions (**Table 4**).

As it was notified in the section 'The CarerQol- instrument', happiness is a broad outcome measure since it can be affected by elements not necessarily related to the caregiving task. To correct for this, we related the CarerQol-7D to the more specific outcome measures: SRB, CSI, Pt, again by performing multiple linear regression analysis (**Table 4**).

In both models the CarerQol-7D dimensions were treated as continuous variables since additional analyses proved that treating them as continuous or categorical variables generates largely similar results (**Table 8, Appendix 1**). Specifically, in a manner similar to the method used in the first test for construct validation of the CarerQol instrument (15), we developed two types of models, both of which had as dependent variable the CareQol-VAS score. In the first model, each dimension was treated as continuous variable. As a result, the model had seven independent variables, one for each of the seven dimensions. In the second model, we created two dummy variables for each of the CarerQol-7D dimensions so as to correct for the fact that the results for each dimension were actually ordinal in structure. Consequently, the model had 14 independent variables.

Then, we performed a likelihood ratio test so as to compare the fit of the first model to the fit of the second. Adding predictor variables to a model will almost always make the model fit better the data i.e. a model will have higher log likelihood. However, it is necessary to test whether the observed difference in model fit is statistically significant. In our case, the difference between the log likelihoods of the two models was not statistically significant (at the level of significance $p < 0.05$) which means that both models fit the data at the same degree and thus we chose to use the first restricted model for the reason of simplicity (**Table 8, Appendix 1**).

In addition, the convergent validity was tested by the relation between CarerQol-VAS and the three other measures of subjective burden, SRB, CSI and Pt with the use of Spearman's correlation coefficients (**Table 3**). Further, the same relations were tested for the separate dimensions of the CarerQol-7D and the sum score of CarerQol -7D (**Table 3**). If all measures evaluate the similar concept, high correlations between them may be expected. There are different guidelines to assess the strength of correlation coefficients (64, 65). In line with the previous studies of the instrument (15, 49, 56), the strength of the Spearman's correlation coefficients is indicated by the guideline of Hopkins (66) : <0.1 trivial; $0.1-0.3$ small; $0.3-0.5$ moderate; $0.5-0.7$ high; $0.7-0.9$ very high; >0.9 nearly perfect, which mostly is in compliance with the other classifications (49). Correlation of small to moderate strength or higher is considered as a sign of validity, because, as it was mentioned before, happiness is a broad outcome measure and thus the CarerQol-VAS score may not only relate to caring. It may be also influenced by other factors such as merely the fact that a loved one is in a bad health condition, i.e. family effect (16, 44), the level of income, the type of job or the burden of the obligations the caregiver is asked to fulfill out of the caregiving task (49).

To further test convergent validity, the model with dependent variable the CarerQol-VAS and independent variables the CarerQol-7D dimensions, was applied in subgroups of caregivers (**Table 5**). These subgroups consisted of caregivers with low or high SRB, caregivers with low or high CSI and those with low or high Pt.

Clinical validity

We assessed the bivariate relation between CarerQol-VAS and background characteristics of caregivers, care recipients and care situation with one-way ANOVA tests (**Table 2**), such as in the previous studies of the instrument (15, 49, 56). Our aim was to examine how the changes of the values on each characteristic influence the values on the CarerQol-VAS (i.e. if there is a statistically significant relationship between two variables at a time, the strength of this relationship and if it is positive or negative). We used one-way ANOVA test, since we have categorical independent variables with two or more categories (as for the continuous variables, they were converted into categorical variables by grouping values into two categories based on the mean value calculated), the population variances in each group are equal and the dependent variable is normally distributed. The principal behind this method is to divide the total variability of a set of data into components because of different sources of variation (63). The test compares the mean CarerQol-VAS scores between the categories of the independent variables we are interested in, and determines whether any of those means are significantly different from each other. Thus, our null hypothesis is that there is no difference between the mean CarerQol-VAS scores of the groups in which we have divided our sample population based on a specific background characteristic. A statistical significant difference rejects the null hypothesis.

In addition, we performed a stepwise multiple regression analysis (backward selection, $p < 0.2$) of CarerQol- VAS and CarerQol-7D and background characteristics of informal care (**Table 6**). Our goal was to make predictions based on the relationship that exists between these variables by taking information about all of the independent variables. In this model, the choice of the reference category of categorical variables was based on the highest mean of CarerQol-VAS score. Some categories of these variables were merged because of a small number of observations in one of these categories ($< 10\%$ of observations) and also due to the similar concept of some categories (such as the categories sister/brother and sister/brother in law under the characteristic 'relationship caregiver-care recipient'). The CarerQol-7D dimensions were treated as continuous variables in the model and we included them in the model regardless of their statistical significance level.

The multivariate stepwise regression analysis has been criticized concerning the fact that it provides models that do not necessarily comprise the best subset of independent variables (56, 67). To avoid inaccuracy of our findings and due to the relatively small size of our sample ($n=223$), we used a relatively high p -value (< 0.2) as the criterion to exclude a variable from our model. In addition, we performed subsequent likelihood-ratio tests. We compared the fit of the base model (i.e. dependent variable: CarerQol-VAS and independent variables: CarerQol-7D dimensions) to the fit of the model resulted by adding variables describing the characteristics of caregiver, care recipient and caregiving situation. The level of statistical significance used to keep the added variable in the base model, was the same as in the stepwise regression model (i.e. $p < 0.2$). An observed difference of statistical significance higher than 0.2 between the two models fit entailed that both the restricted (base model) and the less restricted model fit the data the same. Hence, we excluded the

added variable because it did not improve the performance of our model. This process resulted in largely the same statistically significant explanatory variables to appear as in the stepwise regression, hence establishing the robustness of our findings to the method used.

Two additional variables emerged statistically significant in the model specified after the likelihood-ratio tests. These were the caregiver's age and the need for continuous surveillance. So as to investigate if the model resulted from the stepwise regression improves when these two variables added, we performed likelihood-ratio test by adding each time one of the variables. None of these variables appeared to improve the model and hence we did not include them in the final model (**Table 6**).

Subsequently, we performed a variance inflation factors (VIF) test in the final model so as to check for multicollinearity problems, since in data obtained from observational studies like ours, this is a usual phenomenon. Multicollinearity occurs whenever two or more predictors in a regression model are moderately or highly correlated and hence provide redundant information about the response. High multicollinearity implies that the estimated regression coefficient of any one variable depends on other predictors which are included in the model. The precision of the estimated regression coefficients, therefore, decreases as more predictors are added to the model and the standard error of estimates of the coefficients increases, decreasing the reliability of our results. VIFs exceeding 10 are signs of serious multicollinearity in the model which requires correction. Our results showed that multicollinearity did not exist.

In addition, to further test how the data fitted our model, we conducted a series of likelihood-ratio tests which concerned the linearity of the continuous variables and the probability of certain interaction effects on the variance in CareQol-VAS score. The level of statistical significance used as criterion for a change in our model (i.e. non-linear effect, interaction effects) was more restricted ($p < 0.05$). Our results confirmed the linear relationship of the continuous variables and the CarerQol-VAS score. Concerning the interaction effects among the already included variables on the CarerQol-VAS score, none of them appeared to be statistical significant.

We performed similar analysis for the new component of CarerQol, the CarerQol-7D Tariff, so as to study its clinical validity; bivariate relation was performed between CarerQol-7D sum score and background characteristics of caregivers, care recipients and care situation with one-way ANOVA tests so as to identify if there are any significant differences between the mean CarerQol-7D sum scores of the categories of each independent variable (**Table 2**). In addition, we performed a stepwise multiple regression analysis (backward selection, $p < 0.2$) of CarerQol- 7D Tariff and background characteristics of informal care so as to assess the relation between these variables (**Table 7**). In line with the aforementioned analysis, to avoid inaccuracy of our findings and due to the relatively small size of our sample ($n=223$), we used a relatively high p-value (< 0.2) as the criterion to exclude a variable from our model. In addition, we performed subsequent likelihood-ratio tests for the same reason. We compared the fit of the base model (i.e. dependent variable: CarerQol-7D sum score and independent variable: caregiver's subjective health) to the fit of the model resulted by adding variables describing the characteristics of caregiver, care recipient and caregiving situation. Subsequently, we performed a VIF test in the final model, so as to check for multicollinearity which showed that multicollinearity did not exist. Finally, linear associations were tested for all continuous variables by performing a series of likelihood-ratio tests which verified the linear relationship of the later and the CarerQol-7D sum score.

All statistical analyses were performed using Stata version 11.0 (Statistics/ Data Analysis).

Results

Characteristics of caregivers, care recipients and care situations

Table 2(a, b, c) presents the characteristics of our sample (n=223). The average age of caregivers was approximately 66 years and most of them were women with a middle or higher educational level. Caregivers most often provided care to a partner or a parent (in-law), and more than half of them shared a household with the care recipient. In addition to the responsibility for the dementia patient 11% of the informal caregivers had children living at home. The majority of caregivers reported that they had sufficient information on possibilities for support as well as knowledge on where to search for information at the beginning of their caregiving task.

The burden experienced was generally considerable with an average SRB score of 5.8 and an average CSI score of 7.7. More than half (54.7%) of the informal caregivers had CSI score ≥ 8 . The average Pt in months was 18.4 (SD 11.0). Approximately four out of ten informal carers argued they would be able to carry on providing informal care for longer than two years. However, about one out of five informal carers did not see themselves coping for longer than six months with the current caregiving situation, while five percent even no longer than one month. Overall, health and happiness were valued respectively at 7.3 and 6.3 (on a scale of 0-10).

Care recipients were predominantly women (54%) and on average, 15 years older than the caregiver. 62% of the dementia patients had a partner and 90% lived in their own home. The health of them was valued by informal carers with a mark of 5.8 (on a scale of 0-10). Approximately in three quarters of the dementia cases there was co-morbidity. The care dependency of dementia patients was valued at 7.0 (on a scale of 0-10). The largest proportion of them could easily be left alone for a few or several hours, while 22% needed continuous surveillance.

The duration of the informal care was on average 2.5 years, and the intensity amounted to an average 38 hours per week spread over, on average, 5 days per week. Most time was spent on activities of daily living, followed by assisting the patient with personal care, e.g. eating and shower, and provision of practical support, e.g. visiting friends and administrative issues. A little over four out of ten dementia patients received additional professional home care, 62% made use of day care outside home and more than half of them also received help from other informal caregivers. Last, in approximately one third of the cases, use was made of additional private help with the household activities.

Table 2a Characteristics of the **caregiver** (mean (SD) or percentages) and bivariate correlation with CarerQoL-VAS and CarerQoL-7D Tariff, n=223

	Percentage or mean	SD	Mean CarerQoL-VAS score	Mean CarerQoL-7D Tariff
Age (years)	66.4	13.4		
<66			6.63***	69.12**
>=66			6.00	74.48
Gender				
Female	65.5%		6.12*	68.69***
Male	34.5%		6.62	77.19
Educational level				
None	0.9%		5.00***	41.70**
Primary school	11.7%		6.04	65.21
Secondary school	58.7%		6.04	71.60
College/university	28.7%		6.95	75.21
Partner status				
Unmarried	7.2%		5.94	71.46
Married and/or living together	83.8%		6.35	71.44
Widow(er)	3.6%		5.62	71.80
Divorced	5.4%		6.42	74.67
household				
No	88.8%		6.20**	70.74**
Yes	11.2%		7.08	78.66
Subjective Health	7.2	1.6		
<7	26.5%		5.20***	56.91***
>=7	73.5%		6.69	76.92
Sufficient information on possibilities for support				
No	11.7%		5.42***	65.08*
Yes or a little	88.3%		6.41	72.49
Knowledge on where to search for information in the beginning				
No	39.0%		5.90***	67.49***
Yes or a little	61.0%		6.55	74.27
Self Rated Burden	5.8	2.2		
<6	43.0%		6.53	78.19***
>=6	57.0%		6.12	66.67
Caregiver Strain Index	7.7	3.0		
<8	45.3%		7.08***	81.20***
>=8	54.7%		5.65	63.70
Perseverance time in months	18.4	10.9		
<18	31.8%		5.77***	62.98***
>=18	68.2%		6.54	75.66

Note: ***p < 0.01, **p < 0.05, *p < 0.1

Table 2b Characteristics of the **care recipient** (mean (SD) or percentages) and bivariate correlation with CarerQol-VAS and CarerQol-7D Tariff, n=223

	Percentage or mean	SD	Mean CarerQol-VAS score	Mean CarerQol-7D Tariff
Age (years)	81.2	6.7		
<81			6.02*	69.69
>=81			6.50	73.04
Gender				
Female	53.8%		6.67***	77.32***
Male	46.2%		5.85	65.00
Partner status				
Unmarried	1.8%		6.75***	79.90***
Married and/or living together	62.3%		5.92	67.30
Widow(er)	33.6%		6.92	78.86
Divorced	2.3%		7.00	76.90
Relationship with caregiver				
Partner	54.2%		5.8***	65.76***
Parent (-in-law)	38.7%		6.79	77.47
Sister/brother(-in-law)	1.3%		6.00	79.87
Friend/neighbour	2.2%		7.2	86.08
Other	3.6%		8.00	85.41
Living situation				
Own home	89.7%		6.24	71.56
Residential home	10.3%		6.74	72.18
Continuous surveillance				
Yes	22.4%		6.02	72.32
No	77.6%		6.37	71.43
Comorbidity				
Yes	78.0%		6.25	70.90
No	22.0%		6.44	74.21
Severeness of comorbidity				
no	22.0%		6.45	74.21***
mild	19.7%		6.48	76.05
moderate	38.6%		6.34	72.13
severe	19.7%		5.86	63.34
Health (rated by caregiver)	5.8	1.8		
<6	41.7%		5.92***	66.97***
>=6	58.3%		6.56	74.96
Care dependency	7.0	2.4		
<7			6.45	72.28
>=7			6.20	71.23

Note: ***p < 0.01, **p < 0.05, *p < 0.1

Table 2c Characteristics of the **care situation** (mean (SD) or percentages) and bivariate correlation with CarerQol-VAS and CarerQol-7D Tariff, n=223

	Percentage or mean	SD	Mean CarerQol-VAS score	Mean CarerQol-7D Tariff
Total years care (years)	2.4	1.5		
<2			6.39	74.20
>=2			6.24	70.18
Days p/wk (days)	4.8	2.8		
<5			7.01***	77.52***
>=5			5.85	67.99
Hours p/week (h)	37.7	40.9		
<38			6.62***	75.23***
>=38			5.63	64.22
Care activities (h p/wk)				
ADL activities (h)	23.3	38.8		
<23			6.54***	73.86***
>=23			5.38	63.25
Personal care (h)	18.2	36.2		
<18			6.49***	74.02***
>=18			5.55	62.68
Practical support (h)	16.6	32.3		
<17			6.37	73.63***
>=17			6.00	63.46
Care recipient shares household				
No	42.6%		6.90***	78.70***
Yes	57.4%		5.84	66.38
Support from other informal caregivers				
No	47.0%		6.33	71.78
Yes	53.0%		6.26	71.49
Professional care				
Professional home care				
No	55.2%		5.82***	67.89***
Yes	44.8%		6.88	76.22
Personal care and nursing care				
No	62.8%		6.23	72.07
Yes	37.2%		6.40	70.87
Medical treatment				
No	85.6%		6.5	71.43
Yes	14.4%		6.17	72.81
Day care outside home				
No	37.7%		6.5	73.04
Yes	62.3%		6.17	70.77
Private help in household of recipient				
No	71.0%		6.37	72.45
Yes	29.0%		6.11	69.61

Note: ***p < 0.01, **p < 0.05, *p < 0.1

CarerQol-7D

Almost all caregivers experienced fulfillment from caring (87.9%), and the majority received support with their caregiving tasks (82.9%) (**Figure 1**). The problems most often reported were relational problems with the care receiver (71.8%) and combining care with other daily activities (70.9%). Almost two-thirds indicated physical and/or mental health problems. The problem encountered by the smallest group of caregivers (9.9%) was financial difficulties as a consequence of caring for a demented patient.

Convergent validity

The Spearman's correlation coefficients of CarerQol-VAS, SRB, CSI, Pt, CarerQol-7D Tariff and CarerQol-7D dimensions are shown in **Table 3**. CarerQol-VAS was negatively associated with SRB score, CSI score and the CarerQol-7D dimensions relational problems, mental health problems, problems with daily activities, financial problems and physical health problems and positively with the Pt score and the dimension fulfillment (range absolute values correlation coefficients 0.24-0.51).

The SRB was negatively associated with the dimension fulfillment and positively with the dimensions indicating the existence of problems, although the dimension financial problems, was not statistically significant (range absolute values correlation coefficients 0.22-0.33). The CSI was associated with CarerQol-7D dimensions in the expected way. That is, a positive association was observed with the negative dimensions and the reverse with the positive dimensions of the CarerQol-instrument (range absolute values correlation coefficients 0.13-0.47). The expected associations were also observed between Pt and the CarerQol-7D dimensions, although the dimension support was not statistically significant (range absolute values correlation coefficients 0.13-0.41).

Last, the recently developed component of CarerQol-instrument, the CarerQol-7D Tariff was positively associated with the CarerQol-VAS score, the Pt score and the CarerQol-7D dimensions fulfillment and support while a negative association was noticed with the SRB score, the CSI score and the negative CarerQol-7D dimensions (range absolute values correlation coefficients 0.17-0.80).

Table 3 Pairwise Correlation CarerQol-VAS and CarerQol-7D with measures of subjective burden, (Spearman's rho; 2-tailed), n=185 for correlations between Perseverance time and other variables, n=223 for the other correlations

	CarerQol-VAS	SRB	CSI	Pt	CarerQol Tariff
SRB	-0.25***				
CSI	-0.45***	0.55***			
Pt	0.27***	-0.57***	-0.49***		
CarerQol Tariff	0.57***	-0.39***	-0.56***	0.38***	
CarerQol-7D					
Fullfilment	0.30***	-0.25***	-0.17***	0.19***	0.52***
Relational problems	-0.41***	0.22***	0.38***	-0.24***	-0.61***
Mental health problems	-0.51***	0.33***	0.46***	-0.41***	-0.80***
Problems with daily activities	-0.31***	0.28***	0.47***	-0.30***	-0.52***
Financial problems	-0.24***	0.02	0.27***	-0.13*	-0.32***
Support	-0.05	0.00	-0.13**	0.03	0.17***
Physical health problems	-0.38***	0.33***	0.46***	-0.36***	-0.64***

Note: ***p < 0.01, **p < 0.05, *p < 0.1

Subjective burden measures on the basis of CarerQol- 7D

Table 4 presents models to explain CarerQol-VAS, SRB, CSI and Pt, all on the basis of the CarerQol-7D dimension scores. The CarerQol-VAS model displayed that relational problems, financial problems and problems with mental health were negatively associated with the CarerQol-VAS while fulfillment was positively related to CarerQol-VAS. This model accounted for 38% of the variance in CarerQol-VAS scores. The model explaining SRB showed that problems with daily activities and physical health problems were positively associated with caregiver burden, while fulfillment was negatively related to the SRB score and the model accounted for 18% of the variance in SRB. Relational problems, problems with daily activities, mental and physical health problems were positively while receiving support was negatively associated with CSI score. This model accounted for 40% of the variance in CSI. The model explaining Pt showed a negative association of mental health problems and problems with daily activities with the time period for which informal caregivers indicated they would be able to persevere with the care and the model accounted for 18% of the variance in Pt.

Table 4 Results of regression analysis of CarerQol-VAS, Self Rated Burden (SRB), Caregiver Strain Index (CSI) and Preseverance time (Pt) with CarerQol-7D as independent variables; Standardized coefficients for CarerQol-7D, n=185 for the model explaining Pt, n=223 for the other models

CarerQol-7D dimensions	CarerQol-VAS	SRB	CSI	Pt
Fullfilment	0.10*	-0.17***	0.02	0.03
Relational problems	-0.20***	0.04	0.20***	-0.06
Mental health problems	-0.32***	0.12	0.17**	-0.25***
Problems with daily activities	-0.08	0.17***	0,31***	-0.15**
Financial problems	-0.13**	-0.07	0.08	0.02
Support	0.01	0.00	-0.12**	0.02
Physical health problems	-0.08	0.19***	0.18***	-0.14
Constant	9.73	4.53	1.27	32.65
Adjusted R2	0.38	0.18	0.40	0.18

Note: ***p < 0.01, **p < 0.05, *p < 0.1

Subgroups

Table 5 presents models to explain CarerQol-VAS scores among subgroups of carers on the basis of CarerQol-7D scores (see Appendix 2 for subgroups characteristics). In all subgroups, the happiness score of caregivers was negatively associated with the experience of relational and mental health problems. For the caregivers with high SRB score and those with high CSI score, the experience of satisfaction in caring for the dementia patient was positively related to happiness scores. Last, in the subgroups of carers with high SRB, high CSI and low Pt, a statistically significant negative association was notified between the CarerQol-7D dimension financial problems and happiness scores.

Table 5 Results of regression analysis of CarerQol-VAS , standarised coefficients (see Apendix 2) for subgroups

	All caregivers (n=223)	Caregivers with low SRB (n=96)	Caregivers with high SRB (n=127)	Caregivers with low CSI (n=101)	Caregivers with high CSI (n=122)	Caregivers with low Pt (n=71)	Caregivers with high Pt (n=152)
CarerQol-7D							
Fullfilment	0.10*	0.03	0.19**	0.07	0.13*	0.08	0.09
Relational problems	-0.20***	-0.20**	-0.20***	-0.17*	-0.21***	-0.26**	-0.18***
Mental Health problems	-0.32***	-0.39***	-0.24**	-0.30***	-0.33***	-0.43***	-0.32***
Problems with daily activities	-0.08	-0.09	-0.08	-0.06	-0.03	-0.15	-0.06
Financial problems	-0.13**	-0.11	-0.15**	0.09	-0.21***	-0.20**	-0.08
Support	0.01	-0.00	0.04	0.06	-0.05	0.10	-0.02
Physical health problems	-0.08	-0.17	-0.10	-0.10	-0.03	0.07	-0.13
Constant	9.73	7.99	7.16	7.52	7.42	8.01	7.60
Adjusted R2	0.38	0.37	0.35	0.14	0.36	0.45	0.29

Note: ***p < 0.01, **p < 0.05, *p < 0.1

Clinical validity

CarerQoL-VAS score

The mean CarerQoL-VAS score was 6.3 (not presented). Further, concerning the bivariate relations (**Table 2**), it seems that happiness level was higher among male caregivers, among those younger than 66 years and among caregivers with higher educational level. In addition, caregivers having children living at home appeared to be happier than those who did not. The CarerQoL-VAS score was higher among caregivers who were sufficiently informed on possibilities for support and knew where to search for at start of their caring task. Higher CarerQoL-VAS scores were also indicated when the health of the caregiver was valued higher than 7.0 (on a scale of 0-10), when they felt less burdened (CSI score < 8) and when their Pt was longer than 18 months.

Caregivers providing care to female demented patients, patients older than 81 years and those in relatively good health (>6.0 on a scale of 0-10) had significantly greater happiness score, as did those who provided care less than 38 hours per week and less than 5 days per week. Moreover, the score was highest among those caring for a distant family or friend, a divorced or widowed demented patient and lowest among those caring for their partner or a married demented patient. In cases where caregiver and care recipient shared the same household, the caregivers indicated a lower happiness scores than in cases where they lived apart. Concerning the provision of certain care activities, caregivers indicated a higher happiness score when they provided care for fewer hours per week than the mean value calculated in each category (i.e. ADL activities < 23 h/wk, personal care < 18 h/wk). Last, when use of professional home care was made by the dementia patient the CarerQoL-VAS was higher for the carer.

The results of multivariate analysis between CarerQoL-VAS and background characteristics are presented in **Table 6**. These results were largely in agreement with the correlation coefficients presented in Table 3, with the exception of the CarerQoL-7D dimensions problems with combining daily activities and physical health problems. Moreover, secondary educational level, compared to higher education, seems to significantly decrease CarerQoL-VAS ($p = 0.05$). In addition, the CarerQoL-VAS was positively associated to the caregiver's subjective health and statistically significantly negatively associated to the intensity of care, in terms of days per week of caring ($p = 0.04$). Last, no use of professional home care seems to significantly decrease happiness score ($p = 0.1$), compared to the case whereby use of professional home care is made by the demented patient. Together all these variables explained 45% of the variation in the CarerQoL-VAS score.

Table 6 Results of multiple linear regression analysis of CarerQol-VAS with CarerQol-7D and characteristics of the caregiver, the care recipient and the care situation; Standardized coefficients for all variables; n=223

	CarerQol-VAS	
	SD coef	P value
CarerQol-7D		
Fullfilment	0.14	0.01
Relational problems	-0.18	0.00
Mental health problems	-0.24	0.00
Problems with daily activities	-0.09	0.11
Financial problems	-0.14	0.01
Support	-0.02	0.73
Physical health problems	0.01	0.90
Caregiver		
Educational level (ref. College/university)		
None	0.03	0.54
Primary school	0.05	0.36
Secondary school	-0.12	0.05
Subjective health	0.21	0.00
Sufficient information on possibilities for	-0.08	0.13
Care situation		
Days p/wk care giving	-0.11	0.06
Practical support (h)	0.08	0.12
Use of professional home care (ref. yes)	-0.10	0.07
Constant	7.69	
Adjusted R2	0.45	

CarerQol-7D sum score

The mean CarerQol-7D sum score was 71.63 (not presented). Further, concerning the bivariate relations (**Table 2**) between CarerQol-7D sum score and background characteristics, CarerQol-7D sum score emerged higher among male caregivers, among those younger than 66 years and among caregivers with higher educational level. In addition, for caregivers having children living at home a higher sum score was observed than those who did not. The CarerQol-7D sum score was higher among caregivers who were sufficiently informed on possibilities for support and knew where to search for at start of their caring task. Higher CarerQol-7D sum scores were also indicated when the health of the caregiver was valued higher than 7.0 (on a scale of 0-10), when they felt less burdened (CSI score < 8 and SRB < 6) and when their Pt was longer than 18 months.

Moreover, the CarerQol-7D sum score was highest among caregivers providing care to female demented patients, those caring for a distant family or friend and caregivers of a divorced or widowed demented patient and lowest among those caring for their partner or a married demented patient. A higher sum score, indicating a better caregiving situation was also noticed for caregivers of patients in relatively good health (>6.0 on a scale of 0-10) and among those involved in situations with no or mild comorbidity while a lower sum score was observed when there was severe comorbidity. In cases where caregiver and care recipient shared the same household, the CarerQol-7D sum score was lower than in cases where they lived apart. Concerning the total provision of care as well as that of certain care activities,

the sum score was higher when caregivers provided care for fewer hours per week than the mean value calculated in each category (i.e. total care < 38h/wk, ADL activities < 23 h/wk, personal care < 18 h/wk, practical support < 17h/wk) and less than 5 days per week. Last, when use of professional home care was made by the dementia patient the CarerQol-7D sum score was higher, implying a better caregiving situation.

The results of multivariate analysis of CarerQol-7D Tariff and background characteristics are presented in **Table 7**. These results indicated that the CarerQol-7D sum score was positively associated to the caregiver's age and subjective health. Moreover, no knowledge on where to search for information in the beginning of the caregiving task significantly decreased CarerQol-7D sum score ($p = 0.07$), compared to the case whereby caregivers knew where to look for information. Compared to caring for a female person, caring for a male patient was associated with a 0.12 decrease on CarerQol-7D sum score. In addition, caring for a partner, compared to caring for a distant family or just an acquaintance, significantly decreased CarerQol-7D sum score ($p = 0.00$) while caring for a patient living at his/her own home significantly increased CarerQol-7D sum score compared to the case whereby the patient lived in a residential home ($p = 0.04$). Furthermore, care situations with severe comorbidity seemed to significantly decrease the CarerQol-7D sum score ($p = 0.00$) compared to cases with mild comorbidity. CarerQol-7D sum score was statistically significantly negatively associated with the intensity of provision practical support to the patient in terms of hours per week ($p = 0.03$) and last the use of private help in the household of the care recipient significantly decreased the CarerQol-7D sum score ($p = 0.08$) compared to no use. Together these characteristics explained 35% of the variation in the CarerQol-7D sum scores.

Table 7 Results of multiple linear regression analysis of CarerQol-7D Tariff with characteristics of the caregiver, the care recipient and the care situation; Standardized coefficients for all variables; n=223

	CarerQol-7D Tariff	
	SD coef	P value
Caregiver		
Age	0.41	0.00
Partner Status(ref. Divorced)		
Unmarried	0.03	0.66
Married and/or living together	0.14	0.13
Widow(er)	-0.03	0.70
Subjective health	0.40	0.00
Knowledge on where to search for information in the beginning (ref.yes or a little)		
	-0.10	0.07
Care recipient		
Gender(ref.female)	-0.12	0.06
Relationship with caregiver(ref. other)		
Partner	-0.59	0.00
Parent (-in-law)	-0.11	0.47
Sister/brother(-in-law)	-0.07	0.30
Friend/neighbour	-0.02	0.76
Living situation(ref. residential home)	0.12	0.04
Continuous surveillance(ref.no)	0.08	0.13
Severeness of comorbidity(ref.mild)		
no	-0.03	0.69
moderate	-0.12	0.12
severe	-0.26	0.00
Health (rated by caregiver)	-0.12	0.11
Care situation		
Practical support (h)	-0.13	0.03
Day care outside home (ref.no)	0.08	0.17
Private help in household of recipient(ref.no)	-0.10	0.08
Constant	18.66	
Adjusted R2	0.35	

Discussion

There is increasing consensus that economic assessments of health care technologies should comprise the impact of caregiving on the informal caregivers whenever informal care constitutes a substantial part of the total care a patient receives, so as to formulate optimal policy decisions (1, 3, 16). The CarerQol has been considered in the past to be a promising instrument to measure and value those carers outcomes enhancing the consideration of informal care in economic evaluation studies (15, 49, 56). Dementia syndrome is a disease in the context of which informal care plays a substantial role (6, 22) and often causes a great burden on carers (23, 24, 25). Our study investigated the convergent and clinical validity of this instrument in a population of 223 dementia caregivers.

Our results showed that dementia caregivers often reported relational problems with the care recipient, problems with their own mental health and problems with combining daily activities. The presence of relational problems can be partially explained by the nature of the dementia syndrome. That is, the combination of cognitive, behavioral and emotional problems that comes with the illness makes the communication with and the care of demented persons quite difficult. The often reported problems with combining daily activities are reasonably explained by the relatively high level of care dependency observed among the patients of our sample and the fact that the majority of the caregivers did not use some kind of professional home care or private help in the household that could possibly free more time for other daily tasks. Hoefman et al reported comparable results concerning the problems experienced by caregivers of LTC users (56). This is well justified by similarities in the population samples of the two studies; a large proportion of the patients in the Hoefman's sample were suffering from mental health problems including Alzheimer's disease and had need for permanent surveillance. In addition, the use of either formal or informal support from other persons, were made only by a small proportion of caregivers. The two first validation studies of the instrument (15, 49) which used heterogeneous samples of caregivers, reported also often experienced problems with combining daily activities and mental health problems by the caregivers which is reasonable given the intensity and duration of care. However, the experience of relational problems with the patient was relatively less often reported, possibly due to the minor or zero proportion of care recipients with mental illnesses.

Further, we assumed that given the unique and extreme challenges of dementia caregiving, dementia caregivers would probably indicate a relatively lower level of happiness compared to non-dementia caregivers. By comparing the average level of happiness among the dementia informal caregivers with that reported among caregivers in the previous studies of the instrument, the results were varied. As we expected, the average score of happiness in our sample (6.3) was lower than that reported by Hoefman et al (7.0) (56). This is a reasonable result since caregivers of demented patients were more involved in caregiving in terms of hours per week and were affected more negatively from their caregiving duties than the caregivers of LTC users (56). However, the reverse was observed when we looked at the average happiness score among a heterogeneous population of caregivers reported by Brouwer et al (5.7) (15). Although the care recipients in Brouwer's study were not suffering from dementia, they were in relatively worse health than those in our sample. The population of caregivers was selected through support centers for informal care which entails that they were relatively burdened. Moreover, they were more involved in caregiving in terms of duration and intensity of care than the caregivers in our sample and a relatively large proportion of them cared for people who did not make use of professional home care or day care outside of the household.

Convergent validity

As anticipated, the CarerQol-VAS was negatively associated with SRB, CSI and the negative dimensions of the CarerQol-7D, and positively with Pt and the positive dimensions of the CarerQol-7D. Most of these correlations had moderate strength, although the dimension support was not statistically significantly related to CarerQol-VAS which is in line with the results of previous studies (15, 49, 56). Such an observation may imply that this dimension is less relevant in the context of informal caregiving or that support is indirectly covered by the

other CarerQol-7D dimensions. This could be considered as an indication of low content validity which requires further investigation in the future. Supportive to this conclusion is the also non-statistically significant relation of the dimension support with the less broad subjective burden measures, SRB and Pt.

Moreover, we found evidence for the validity of the CarerQol-7D. That is, the negative items of CarerQol-7D were negatively associated to Pt and positively to SRB and CSI, while the reverse was true for the positive items of CarerQol-7D. Most of these correlations had moderate strength. An exception was the positive correlation between the dimension support and the subjective burden measure SRB, though not statistically significant. Our results are in line with our hypothesis of a positive relation between CareQol-7D and other subjective burden instruments, in terms of the burden measured and almost identical to those reported by Brouwer et al and Hoefman et al (15, 49, 56).

The convergent validation of the CarerQol-7D was also established by the fact that the CarerQol-7D dimensions significantly explained the difference in CarerQol-VAS scores among the whole sample of caregivers and subgroups. Specifically, the experience of relational problems, mental health problems and financial problems by the caregiver were negatively associated with the CarerQol-VAS score while fulfillment was positively associated and all these dimensions together explained 38% of the variance in CarerQol-VAS score. Concerning the subgroup analysis, CarerQol-VAS was negatively associated with financial problems among the most burdened carers (i.e., those with high CSI, high SRB and those with low Pt). In addition, the level of happiness was positively associated with fulfillment among the highly burdened carers (i.e., those with high SRB and those with high CSI) contrary to the results reported by Hoefman (49). In the second test of the instrument, this statistically significant positive association was observed among the lower burdened caregivers (49). The divergent results may be due to the difference in the sample populations of the two studies or the different models used to investigate if CarerQol discriminated well between the different groups of carers. More specifically, Hoefman used a heterogeneous population of caregivers while our study was performed using a specific population of caregivers (e.g. carers of persons with a specific disease). Moreover, Hoefman's model, besides the CarerQol-7D dimensions, included additional variables describing background informal care characteristics as explanatory variables contrary to our model.

Another possible explanation for our results could be the following. In our sample, the majority of caregivers provided care to their demented partner which is indicative of a strong emotional relationship between the two. As established in the theoretical review on informal care, the provision of the best attainable care to a loved person gives meaning to caregiver's life and raise feelings of fulfillment (11, 12). Moreover, dementia is a progressive and irreversible clinical syndrome ending to death and thus it is possible that caregivers with high SRB and those with high CSI care for a relative, timely closer to death. This assumption is also supported by the relatively worse health of the care recipients in these subgroups of carers compared to those receiving care from less burden carers in our sample. The feeling that the life of a loved person approaches the end may encourage caregivers' perception that the experience of greater burden from caring is the only and last sacrifice they can do for their loved relative. This may explain why the positive association between satisfaction from caring and happiness score is statistically significant among high burdened carers compared to the same relation observed among less burdened caregivers. Another

supportive item to this point is that about half of the caregivers experienced high SRB(48%) and those experienced high CSI (45%), judged themselves able to cope with the informal care for longer than two years. That is, despite the high burden experienced by these caregivers, they indicated a relatively high Pt, possibly motivated by the fulfillment they receive from caring.

Additionally, given that happiness is a broad outcome measure and hence it may be influenced by elements not necessarily related to caregiving, we related CarerQol-7D to more specific outcome measures than CarerQol-VAS so as to correct for this. We observed that CarerQol-7D explained the variation in CarerQol-VAS and the less broad outcome measures of SRB, CSI and Pt not equally well. That is, the explained variance of CSI by CarerQol-7D was higher than that of CarerQol-VAS which is a reasonable result, given the broad concept of happiness. However, the reverse was noticed for the explained variance of SRB and Pt by the CarerQol-7D. Though advantageous for the CarerQol instrument, this was an unexpected result for the same reason.

Generally, given the explained variance 38%, 18%, 40% and 18% respectively, all outcome measures were not fully explained by the CarerQol-7D. Hoefman et al who reported similar results suggested the investigation of a more targeted valuation component such as care-related quality of life to measure and value the impact of informal care so as to avoid too much influence of non-care giving related items (49). Such a component is the new part of the instrument, the CarerQol-7D sum score. By examining the associations between CarerQol-7D sum score and the other subjective burden measures they emerged stronger than the associations observed between CarerQol-7D dimensions and the subjective burden measures adding to the usefulness of the CarerQol-7D sum score. Although, these are signs of good convergent validity, replication of our results using a different study population, either caregivers of people suffering from another disease or a heterogeneous population of carers, would enable us to derive more firm conclusions on the validity of this new component.

Overall, our results suggest that the CarerQol-instrument displays moderate, though not unsatisfactory, convergent validity given that happiness is a broad outcome measure. However, given the contradictory evidence above concerning the validity of CarerQol-7D (e.g. how well CarerQol-7D explains the variation in the scores derive from the subjective burden measures) and our findings regarding the convergent validity of CarerQol-7D sum score, it would be worthwhile to replicate our results in the future using a different study population so as to further examine the validity of the instrument.

Clinical validity

Concerning clinical validation, the bivariate relations assessed between CarerQol-VAS score and background characteristics, verified most of the assumptions we did in the beginning of our research based on the literature concerning dementia caregiving. Specifically, female caregivers and those with worse health status indicated lower happiness score and higher experienced burden. However, contrary to the theory, our study showed that younger

caregivers were less burdened which may be partially explained by the relatively lower proportion of those caregivers in our sample.

Moreover, differences in CarerQoL-VAS scores were observed in relevant subgroups of carers. Especially, caregivers' characteristics and caregiving situation characteristics affected the happiness among caregivers of dementia patients. Specifically, the educational level and subjective health of the caregiver, the duration of care giving and the use of professional home care by the care recipient were significantly associated with CarerQoL-VAS. Brouwer et al (15) and Hoefman et al (56) showed comparable results. In addition, they found other factors related to happiness: age and partner status of the caregiver and the use of day care by the care recipient. However, their models differed somewhat from ours in terms of the explanatory variables included. In general, as was the case in our study, these previous studies also reported a relatively modest role of care recipient characteristics on caregiver burden.

Exploratory analyses concerning the clinical validity of CarerQoL-7D Tariff showed results largely in agreement with the bivariate relations assessed between CarerQoL-VAS score and informal care characteristics. Moreover, differences in three additional background characteristics of informal care were reflected on differences in the mean CarerQoL-7D sum score; That is, CarerQoL-7D sum score emerged higher among caregivers with lower SRB score, among those who provided practical support for fewer hours per week and in cases where comorbidity was absent, indicating a better caregiving situation.

The multivariate model explaining the CarerQoL-7D sum score on the basis of background characteristics of informal care showed more characteristics to be statistically significantly associated with CarerQoL-7D Tariff, than those explaining the variance in CarerQoL-VAS scores. More specifically, the only statistically significant background characteristic in common in the two models was the subjective health of the caregiver. In addition, contrary to the CarerQoL-VAS model besides caregiver and care situation characteristics, care recipient characteristics (gender, relationship with caregiver, living situation, need for continuous surveillance and severeness of comorbidity) had also a statistically significant effect on CarerQoL-7D sum score. These findings may suggest that CarerQoL-7D sum score is a more informative outcome measure in terms of what elements affect the burden experienced from the provision of informal care, also in light of its more targeted nature compared to CarerQoL-VAS (e.g. care-related quality of life of caregiver vs well-being of the caregiver). Despite the good properties indicated, further validation study on the CarerQoL-7D sum score would be desirable in the future. Specifically, it might be worthwhile to test validity among a heterogeneous population of carers or among caregivers of people suffering from another disease so as to investigate possible similarities or differences in the results given the different population characteristics.

Study Limitations

Our sample of caregivers was of modest size and consisted only of caregivers of dementia patients. Thus, our results should be interpreted with caution; they cannot be straightforwardly generalized since our sample is not necessarily representative of the

population of Dutch informal caregivers. Moreover, our sample cannot be considered representative even of the population of dementia caregivers in the Netherlands since it included carers of demented patients living at home, omitting the population of caregivers of institutionalized demented patients.

The interpretation and generalization of our results requires caution also because of the response rate of 37%. Although, this response rate was slightly higher than in previous studies based on postal surveys (14, 56, 68), the non-response was still substantial and likely selective. For example, caregivers experiencing especially high burden may not have had the time or energy to complete the questionnaire (57). Moreover, some of them might not see direct relevance for their own tough caregiving task so as to participate in the research. It is also possible that they did not feel addressed by the questionnaire in that they do not perceive themselves as caregivers but they considered their provision of care as a natural consequence of their relationship with the patient (15, 57).

Another issue worth mentioning is that of missing values for the variable perseverance time. Missing data is a common problem in medical research and the method used for handling it depending on the reason for missingness, may affect the validity of the results (69). In our case, 38 of the 223 respondents did not give an indication of the time period they judge themselves able to continue with the provision of informal care (Pt). We could not further investigate the reason for missingness, we assumed that the data were missing completely at random or due to some unobserved characteristics of the respondents (i.e. misunderstanding of the question or personal choice of non-response) and we carried out a complete-case analysis by simply excluding the cases with missing values. Hence, our results may suffer from bias since part of the data was not used.

Since we used the CarerQol instrument to register the impact of informal care, some aspects of the instrument should also be discussed. Initially, as mentioned in the introduction section, the CarerQol-VAS is a broad outcome measure which may be affected by non-caregiving factors. To correct for this it would be helpful to know the determinants of happiness. A review of the literature devoted to the factors that influence subjective wellbeing has highlighted a series of problems in deriving firm conclusions about what causes happiness (70). The lack of a gold standard in this direction renders our results (regarding the happiness scores observed) possible over- or underestimations of the experienced burden. Hence, we comprised the more specific subjective burden measures SRB, CSI and Pt to assess the informal caregiving situation and all three scores were statistically significantly related to CarerQol-VAS scores. Specifically, the CSI score was relatively strongly related to happiness score while the other two measures appeared to have a relation of small strength with CarerQol-VAS.

Furthermore, although there is not strong and concise evidence on which are the causal factors of subjective wellbeing, findings from previous research suggest that researchers should be at least aware of the impact of income and mainly relative income, the employment status, the health status, the marital status and the personal and community relationships of people at interest (70). A limitation of our study, therefore, should be

considered the lack of information on the level of income and the employment status of caregivers, which would enable us to correct for possible influences on the happiness score.

In previous studies of the CarerQol-instrument, it has been repeatedly reported that a more targeted valuation component with a more objective outcome measure such as care-related quality of life, would be of great usefulness since it would be less sensitive to non-caregiving elements and hence it would increase the use of the instrument in economic evaluations (15, 49, 56). More precisely, standard utility scores i.e. tariffs for 'care states' defined by the CarerQol-7D would prevent the influence of other dimensions of wellbeing in that the scores would relate to caregiving only. Our study was the first to include the new component of CarerQol, the CarerQol-7D Tariff, in the investigation of the clinical and convergent validity of the instrument. Indeed, the CarerQol-7D Tariff had a higher correlation to the less broad outcome measures SRB, CSI and Pt than CarerQol-VAS did, verifying the hypotheses around the more targeted nature of this component.

In addition, coping and adaptation may have influenced the resulted CarerQol-VAS scores by underestimating the wellbeing losses because of caring for a demented patient. Studies focusing on the responses of caregivers of people suffering from cognitive impairments have revealed that carers use a range of coping strategies so as to manage the often challenging and stressful caregiving situation, to relief the emotional impact on them and to maintain their mental health (71, 72). People, in general, tend to adapt to difficult circumstances which include either their own health, the health of a close relative or a strenuous and demanding caregiving situation (16). The phenomenon of coping and adaptation, therefore, adds to the usefulness of ex ante utility scores assigned to different 'care profiles' and which preferably derive from the general public i.e. the CarerQol-7D Tariff.

Finally, the cross sectional design of the study, although appropriate for the aims of our research, did not enable the investigation of causality issues between the variables and hence nor the sensitivity of the CarerQol to changes in the caregiving situation over time. Thus, future research should focus on longitudinal analysis that would give us a better insight on the validity of the instrument.

Conclusion

Notwithstanding the study limitations, our results recommend that the CarerQol-instrument has moderate to good psychometric properties, which is in agreement with previous research (15, 49, 56). The same applies for the new valuation component of the instrument, the validity of which was tested for first time and thus should be further investigated in the future. Overall, the CarerQol-instrument adequately reflects the care-related quality of life and provides a good description of the impact of informal care on the dementia caregivers. Therefore, it seems to be a useful tool to measure and value the effect of caregiving on these special providers of care and it can facilitate an improved consideration of this impact in economic evaluations of health care.

Appendix 1

See Table 8.

Table 8

Model 1 Results of regression analysis of CarerQol-VAS; Standardized coefficients for CarerQol-7D (continuous variables), n=230

Model 2 Results of regression analysis of CarerQol-VAS; Standardized coefficients for CarerQol-7D (categorical variables), n=230

CarerQol-7D dimensions	CarerQol-VAS		CarerQol-7D dimensions	CarerQol-VAS	
	SD coef	P value		SD coef	P value
Fullfilment	0.10	0.07	Some Fullfilment	0.03	0.55
Relational problems	-0.20	0.00	A lot Fullfilment	0.05	0.34
Mental Health problems	-0.32	0.00	Some Relational problems	-0.07	0.27
Problems with daily activities	-0.08	0.14	A lot Relational problems	-0.25	0.00
Financial problems	-0.13	0.02	Some Mental Health problems	-0.11	0.09
Support	0.01	0.90	A lot Mental Health problems	-0.39	0.00
Physical health problems	-0.08	0.21	Some Problems with daily activities	-0.06	0.32
Constant	9.73		A lot Problems with daily activities	-0.10	0.13
Adjusted R2	0.38		Some Financial problems	-0.05	0.31
			A lot Financial problems	-0.09	0.12
			Some Support	-0.02	0.77
			A lot Support	0.02	0.74
			Some Physical health problems	-0.03	0.62
			A lot Physical health problems	-0.09	0.21
			Constant	7.45	
			Adjusted R2	0.38	

Likelihood-ratio test
 (Assumption: m1 nested in m2)
 LR chi2(7) = 9.63
 Prob > chi2 = 0.2107

Appendix 2

See Table 9.

Table 9 Percentages or mean(SD) of variables for subgroups in table 3

	Caregivers with low SRB (n=96)	Caregivers with high SRB (n=127)	Caregivers with low CSI (n=101)	Caregivers with high CSI (n=122)	Caregivers with low Pt (n=71)
CarerQol-7D					
Fullfilment (%)					
No	5.2	17.3	6.9	16.4	21.1

Some	52.1	56.7	54.5	54.9	52.1
A lot	42.7	26.0	38.6	28.7	26.8
Relational problems (%)					
No	31.3	26.0	43.6	15.6	21.1
Some	53.1	44.1	43.6	51.6	42.3
A lot	15.6	29.9	12.8	32.8	36.6
Mental health problems (%)					
No	46.9	21.2	49.5	18.0	14.1
Some	38.5	52.8	40.6	51.6	49.3
A lot	14.6	26.0	9.9	30.4	36.6
Problems with daily activities (%)					
No	39.6	21.2	44.5	16.4	15.5
Some	44.8	58.3	50.5	54.1	57.7
A lot	15.6	20.5	5.0	29.5	26.8
Financial Problems (%)					
No	90.6	89.8	95.0	86.1	90.2
Some	8.3	5.5	5.0	8.2	5.6
A lot	1.1	4.7	0.0	5.7	4.2
Support (%)					
No	15.6	18.1	13.9	19.7	12.7
Some	56.3	60.6	54.4	62.3	64.8
A lot	28.1	21.3	31.7	18.0	22.5
Physical health problems (%)					
No	57.3	33.9	64.3	27.0	28.2
Some	33.3	41.7	29.7	45.1	45.0
A lot	9.4	24.4	6.0	27.9	26.8
Caregiver					
Age	65.60 (14.31)	67 (12.77)	62.74 (13.74)	69.43 (12.45)	68.28 (13.54)
Gender (%)					
Female	56.3	72.4	56.4	72.9	73.2
Male	43.7	27.6	43.6	27.1	26.8
Educational level (%)					
None or Primary school	8.3	15.7	6.0	18.0	22.5
Secondary school	62.5	56.0	56.4	60.7	49.3
College/university	29.2	28.3	37.6	21.3	28.2
Partner Status (%)					
Unmarried	9.4	5.5	5.0	9.0	7.0
Married and/or living together	85.4	82.7	85.1	82.8	80.3
Widow(er)	1.0	5.5	3.0	4.1	4.2
Divorced	4.2	6.3	6.9	4.1	8.5
Children under 18 years old in household (%)					
No	84.4	92.1	79.2	96.7	91.5
Yes	15.6	7.9	20.8	3.3	8.5

Subjective health	7.48 (1.57)	7.09 (1.60)	7.84 (1.24)	6.78 (1.70)	6.82 (1.79)
Sufficient information on possibilities for support (%)					
No	13.5	10.2	11.9	11.5	12.7
Yes	86.5	89.8	88.1	88.5	87.3
Knowledge on where to search for information in the beginning (%)					
No	37.5	40.2	37.6	40.2	43.7
Yes	62.5	59.8	62.4	59.8	56.3
Care recipient					
Age	81.00 (6.43)	81.35 (6.99)	82.88 (5.69)	79.81 (7.24)	81.82 (6.65)
Gender (%)					
Female	60.4	48.8	65.4	44.3	49.3
Male	39.6	51.2	34.6	55.7	50.7
Partner status (%)					
Unmarried	3.1	0.8	3.0	0.8	1.4
Married and/or living together	57.3	66.1	43.5	77.9	66.2
Widow(er)	37.5	30.7	50.5	19.7	31.0
Divorced	2.1	2.4	3.0	1.6	1.4
Relationship with caregiver (%)					
Partner	49.0	58.2	32.6	72.2	62.0
Parent (-in-law)	40.6	37.0	54.5	25.4	31.0
Sister/brother(-in-law)	2.1	0.8	2.0	0.8	0.0
Friend/neighbour	3.1	1.6	4.0	0.8	4.2
Other	5.2	2.4	6.9	0.8	2.8
Living situation (%)					
Own home	87.5	91.3	87.1	91.8	90.1
Nursing home, non psycho-geriatric	12.5	8.7	12.9	8.2	9.9
Continuous surveillance (%)					
No	19.8	24.4	87.1	69.7	73.2
Yes	80.2	75.6	12.9	30.3	26.8
Comorbidity (%)					
No	26.0	18.9	23.8	20.5	21.1
Yes	74.0	81.1	76.2	79.5	78.9
Severeness of Comorbidity (%)					
no	26.0	18.9	23.8	20.5	21.1
mild	24.0	16.5	25.7	14.7	15.5
moderate	37.5	39.4	35.6	41.0	40.9
severe	12.5	25.2	14.9	23.8	22.5
Health (rated by caregiver)	6.02 (1.72)	5.61 (1.93)	6.05 (1.73)	5.57 (1.93)	5.51 (2.01)
Care dependency	6.35 (2.35)	7.48 (2.31)	6.45 (2.17)	7.44 (2.47)	7.32 (2.49)
Care situation					
Years of Caregiving	2.17 (1.54)	2.66 (1.51)	2.22 (1.50)	2.64 (1.55)	2.58 (1.44)
Days p/wk care giving	4.20 (3.04)	5.18 (2.48)	3.32 (2.90)	5.95 (2.00)	5.44 (2.41)
Hours p/wk care giving	31.02 (39.27)	42.68 (41.57)	11.01 (25.45)	33.5 (44.72)	20.45 (32.16)

Care recipient shares household (%)					
No	46.9	39.4	65.3	23.8	35.2
Yes	53.1	60.6	34.7	76.2	64.8
Support from other informal caregivers (%)					
No	47.9	46.5	46.5	47.5	42.2
Yes	52.1	53.5	53.5	52.5	57.8
Use of professional Home care (%)					
No	54.2	55.9	42.6	65.6	59.2
Yes	45.8	44.1	57.4	34.4	40.8
Use of day care (%)					
No	43.7	33.1	41.6	34.4	42.3
Yes	56.3	66.9	58.4	65.6	57.7
Private help in household of care recipient (%)					
No	70.8	70.9	71.3	70.5	66.2
Yes	29.2	29.1	28.7	29.5	33.8

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