

# **Informal care: an economic approach**

Mantelzorg: een economische benadering

Proefschrift

ter verkrijging van de graad van doctor aan de Erasmus Universiteit  
Rotterdam

op gezag van de Rector Magnificus Prof.dr. S.W.J. Lamberts  
en volgens besluit van het College voor Promoties

De openbare verdediging zal plaatsvinden op  
vrijdag 14 januari 2005 om 13.30 uur

door

**Bernardus van den Berg**  
geboren te Sint Philipsland



## **Promotiecommissie**

Promotor: Prof.dr. F.F.H. Rutten

Overige leden: Prof.dr. B.M.S. van Praag

Prof.dr. F.T. Schut

Prof.dr. C.N. Teulings

Copromotor: Dr. M.A. Koopmanschap



# Contents

1	Introduction	15
1.1	Introduction	15
1.2	Informal care	18
1.3	The supply of informal care	18
1.4	Informal care in economic evaluations of health care	19
1.5	Cash benefits	20
1.6	Research questions	21
1.7	Approach and outline	21
2	The simultaneity between informal care and labour supply	25
	Summary	25
2.1	Introduction	25
2.2	The model	28
2.2.1	Theoretical model	28
2.2.2	Empirical analysis	31
2.3	Data	33
2.3.1	Data collection	33
2.3.2	Sample characteristics	33
2.3.3	Distribution of the dependent variables	36
2.4	Results	37
2.4.1	The effects of informal care hours on working hours	38
2.4.2	The effects of working hours on informal care hours	39
2.4.3	Simulations	41
2.5	Conclusions and discussion	42
3	Economic valuation of informal care: An overview of methods and applications	45
	Summary	45
3.1	Introduction	45
3.2	Informal care: a heterogeneous commodity	47
3.2.1	Towards a definition	49
3.3	Measurement issues	50
3.4	Valuation methods for informal care	51
3.4.1	Revealed preference methods	52
	Opportunity cost method	52
	Proxy good method	54

3.4.2	Stated preference methods	55
	Contingent valuation method	55
	Conjoint analysis	56
3.4.3	Other methods for measuring the impact of informal care	57
	Objective burden assessment	58
	Subjective burden assessment	58
	Health-related quality of life	59
	Well-being	60
3.5	Some unresolved issues	61
3.5.1	Incorporation	61
3.5.2	Partial or complete valuation	62
3.5.3	Who to ask	62
3.6	Conclusions and recommendations	63
4	Measurement of informal care: An empirical study into the reliable measurement of time spent on informal caregiving	65
	Summary	65
4.1	Introduction	66
4.2	Methods	67
4.2.1	Time measurement	67
4.2.2	The informal care diary	68
4.2.3	The informal care recall method	70
4.2.4	Diary versus recall method	70
4.2.5	Alternative approach	70
4.2.6	Test-retest reliability	71
4.2.7	Background variables	72
4.3	Data	72
4.3.1	Data collection	72
4.3.2	Study population	72
4.3.3	Characteristics of the respondents	73
4.4	Results diary versus recall method	74
4.4.1	Uncorrected diary versus recall method	74
4.4.2	Corrected diary versus recall method	76
4.4.3	Informal care and housework together	77
4.4.4	One question HDL	77
4.5	Results test-retest reliability	77

4.5.1	Test-retest for all respondents	77
4.5.2	Test-retest for respondents caring for care recipients with a stable health status	79
4.6	Discussion and conclusion	80
	Appendix 1	82
	Appendix 2	83
5	Economic valuation of informal care: Lessons from the application of the opportunity cost and proxy good methods	85
	Summary	85
5.1	Introduction	85
5.2	Opportunity cost and proxy good method	87
5.2.1	Opportunity cost method	88
5.2.2	Proxy good method	89
5.3	Applying the methods in two populations	90
5.3.1	Populations	90
Informal care for care recipients with CVA		90
Informal care for care recipients with RA		92
5.3.2	Operationalisation of the valuation methods	93
Opportunity cost method		93
Proxy good method		93
5.3.3	Results from the two valuation methods	95
Opportunity costs – measuring time forgone		95
Proxy good method – measuring time investment		98
Comparing the two methods - measurement		100
Money value using the opportunity cost method		101
Money value using the proxy good method		102
Comparing the two methods - valuation		102
5.4	Discussion	103
6	Economic valuation of informal care: The contingent valuation method applied to informal caregiving	107
	Summary	107
6.1	Introduction	107
6.2	Theoretical background: welfare economics	110
6.3	Contingent valuation method	112
6.4	CVM applied to informal caregiving	114

6.4.1	Developed survey	114
6.4.2	Hypotheses	116
6.4.3	Study sample	117
6.5	Results	118
6.5.1	Background statistics	118
6.5.2	Informal care tasks	121
6.5.3	WTA	122
6.5.4	Explaining WTA	123
6.5.5	Hypotheses	125
6.5.6	Non-response	126
6.6	Discussion and conclusions	127
7	The economic value of informal care: A study of informal caregivers' and patients' willingness to pay and willingness to accept for informal care	131
	Summary	131
7.1	Introduction	131
7.2	Theory	133
7.2.1	The Informal Caregiver	133
7.2.2	<i>The Patient</i>	137
7.3	Methods	140
7.4	Results	142
7.4.1	Sample characteristics	142
7.4.2	WTP and WTA	144
7.4.3	Estimations	145
7.5	Discussion	150
	Appendix 1	152
	Appendix 2	153
8	Economic valuation of informal care: The conjoint measurement method applied to informal caregiving	155
	Summary	155
8.1	Introduction	155
8.2	Method	158
8.2.1	The conjoint measurement method	158
8.2.2	Informal care	160
8.2.3	Survey questions	161
8.2.4	The conjoint measurement method to value informal care	161

8.2.5	Study sample	164
8.2.6	The derivation of a monetary value of informal caregiving	164
8.3	Results	166
8.3.1	Background statistics	166
8.3.2	CM Ratings	169
8.3.3	Results of the random effects ordered probit	170
8.3.4	A monetary value of informal care	171
8.3.5	Feasibility of CM	172
8.4	Discussion and conclusion	173
9	Economic valuation of informal care: A choice experiment applied to a heterogeneous population of informal caregivers	179
	Summary	179
9.1	Introduction	179
9.2	Developed vignettes	182
9.2.1	Definition	182
9.2.2	Vignette attributes	183
9.2.3	The survey and vignette questions	184
9.3	Econometric model	186
9.4	Data	188
9.4.1	Study sample	188
9.4.2	Background statistics	188
9.5	Results	191
9.5.1	Results of the random effects ordered probit	191
9.6	Informal caregivers' monetary compensation	195
9.7	Discussion and conclusion	196
10	The well-being of informal caregivers: A monetary valuation of informal care	198
	Summary	198
10.1	Introduction	198
10.2	The well-being method to value informal care	200
10.2.1	Survey questions	200
10.2.2	The well-being model	203
10.2.3	Econometric methods	204
10.3	Data	206
10.4	The well-being of informal caregivers: empirical findings	207
10.5	A monetary value of informal care	209

10.5.1	The well-being valuation method	209
10.5.2	A comparison with contingent valuation results	210
10.6	Discussion and conclusion	211
11	The economic effects of cash benefits in the long-term care sector	213
	Summary	213
11.1	Introduction	213
11.2	Institutional setting	217
11.3	Empirical model	220
11.3.1	Quantity of care in supplier regulation and demand-side subsidy	220
11.3.2	Price of care in demand-side subsidy	221
11.4	Data	222
11.4.1	Data set 1: Supply regulation and demand-side subsidy	222
11.4.2	Data set 2: Demand-side subsidy	225
11.5	Estimates	228
11.5.1	Quantity of care in supply and demand-side subsidy	228
11.5.2	Prices in demand-side subsidy	230
11.6	Conclusion	232
	Appendix A	233
12	The psychological effects of the monetarisation of informal care	235
	Summary	235
12.1	Introduction	235
12.2	Method	237
12.2.1	Survey	237
12.2.2	Econometric model	238
12.3	Data	239
12.3.1	Data collection	239
12.3.2	Descriptives	240
12.4	Results	242
12.5	Conclusion	246
13	Conclusions and discussion	247
13.1	Supply of informal care	247
13.2	Economic valuation of informal care	248
13.2.1	Measurement	248
13.2.2	Valuation	250
13.2.3	Operationalisation	251

13.2.4 Hypotheses	252
13.2.5 Results	253
13.2.6 Non-response	254
13.2.7 Unresolved issues and recommendations for future research	256
13.3 Cash benefits	257
13.4 Other areas for future research	258
13.5 Epilogue	259
References	261
Samenvatting	275
1. Inleiding	275
2. Onderzoeksvragen	276
3. Mantelzorg in relatie tot andere economische activiteiten	277
4. De economische waardering van mantelzorg	278
4.1 Meten	278
4.2 Waarderen	280
5. De (economische) effecten van het persoonsgebonden budget	283
6. Epiloog	285
Dankwoord	287



# 1 Introduction

## 1.1 Introduction

In the 1970s and 1980s health care expenditures increased excessively, both in absolute numbers and as a share of the gross domestic product (GDP). Table 1.1 shows the total expenditures on health care as percentage of the GDP in thirteen OECD countries.

**Table 1.1:** Total expenditure on health (percentage of GDP)

	1960	1970	1980	1985	1990	1995	2000	2001	2002
Australia	4,1		7	7,4	7,8	8,2	9	9,1	
Austria	4,3	5,3	7,6	6,6	7,1	8,2	7,7	7,6	7,7
Belgium		4	6,4	7,2	7,4	8,7	8,8	9	9,1
Canada	5,4	7	7,1	8,2	9	9,2	8,9	9,4	9,6
France	3,8	5,4	7,1	8,2	8,6	9,5	9,3	9,4	9,7
Germany		6,2	8,7	9	8,5	10,6	10,6	10,8	10,9
Japan	3	4,5	6,5	6,7	5,9	6,8	7,6	7,8	
Netherlands			7,5	7,4	8	8,4	8,2	8,5	9,1
Spain	1,5	3,6	5,4	5,5	6,7	7,6	7,5	7,5	7,6
Sweden		6,9	9,1	8,7	8,4	8,1	8,4	8,8	9,2
Switzerland	4,9	5,4	7,3	7,7	8,3	9,7	10,4	10,9	11,2
United Kingdom	3,9	4,5	5,6	5,9	6	7	7,3	7,5	7,7
United States	5	6,9	8,7	10	11,9	13,3	13,1	13,9	14,6

*Source: OECD Health data 2004*

Between 1980 and 2002 the percentage of the GDP spent on health care in The Netherlands increased from 7.5 to 9.1. This rise was even more explosive in countries like The United States or Switzerland. Governments in most OECD countries reacted on this so-called cost-explosion through supplier regulation. See, for instance, Zweifel and Breyer (1997) and Schut and Hassink (2002).

The combination of public regulation of health services and the sheer size of the health care sector attracted the attention of economists. Other aspects of health care that have made it an interesting area of research for economists include uncertainty about the

costs and effects of medical treatment (Arrow, 1963), the uncertainty involved in the randomness of an individual's illnesses (Arrow, 1963), and the presence of externalities (Phelps, 1997). The effects of health care, and their measurement and valuation, the externalities and the institutions that evolved, are the important topics of this thesis.

The relatively new sub-discipline of health economics has contributed to many areas of health care (see for an extensive overview Culyer and Newhouse (2000)). These contributions resulted in different, often complementary, policy recommendations aiming to increase efficiency and consumer choice in health care, given equity constraints like arrangements regarding the access to care. Policy measures taken to control health care expenditures in many countries, including The Netherlands, are a systematic positioning of economic evaluations in the assessment of new health care technologies (see Rutten (2000), Van den Berg and Rutten (2002), McDaid et al. (2003), and McDaid and Cookson (2003)), and the gradual introduction of a system of managed competition (see Schut and Hassink (2002) and (Schut, 2003)).

An economic evaluation is a systematic valuation of the relative efficiency of health care interventions. It deals with the uncertainty about the effects of health care to provide decision makers with information that can be used in decisions making regarding the implementation of new interventions or the prioritisation of different interventions, given the health care budget. Implementation involves, among other things, deciding on what interventions to include in insurance packages. In a system of regulated competition, insurance companies rather than individual consumers purchase care from health care suppliers, because individual consumers lack the necessary knowledge and bargaining power to purchase the care for the price-quality relation of their choice. However, these considerations apply to the cure sector, rather than the care sector. This is especially true for home care, which accounts for 20 percent of the long-term care expenditures, while the long-term care expenditures account for 20 percent of the total health care expenditures in The Netherlands.

Table 1.2 gives the expenditure on inpatient care as a percentage of total health care expenditures in thirteen OECD countries.

**Table 1.2:** Expenditure on inpatient care (percentage of total health care expenditure)

	1960	1970	1980	1985	1990	1995	2000	2001	2002
Australia	43		51,6	48,8	46,5	43,1	40,7	40,2	
Austria						44,7	38,3	38	38,2
Belgium		25,7	33,1	34	32,8	33,5			
Canada	43,7	52,6	53,8	51,6	49,1	44,6	30	29,1	28,8
France	38,6	40,6	50,2	48,7	45,7	45,1	42,3	41,7	41,3
Germany		30,8	33,2	34,1	34,7	36,9	36,6	36,1	36,1
Japan	34,1	26,4	30,9	32,8	33	36,8	39	38,9	
Netherlands			54,6	54,1	49,2	49,1	39,8	40,5	40,8
Spain			54,1	55,7	44,1	31	28,2	27,9	27,6
Sweden						49	46,3	31,6	31,2
Switzerland	35,7	44,4	47,5	46,7	47,9	47,9	46,8	47,3	48,1
United Kingdom									
United States	35,6	41,1	44,1	40,4	36,1	32,2	28,4	28	27,6

*Source: OECD Health data 2004*

Table 1.2 shows that over the last 40 years the expenditures on inpatient care decreased in most countries indicating a shift from inpatient care to less expensive outpatient care. This shift can partly be explained by the abovementioned policy measures that have been gradually introduced in the care sector.

The care sector has some specific characteristics compared to the cure sector and therefore not all of the abovementioned policy measures can be easily introduced easily in the care sector. For instance, because many care demanders have a chronic disease, they often have a relatively long-term relationship with their care suppliers. Home care coverage by health insurance involves moral hazard because most people cannot do without home care. The outcome and quality of the care are often difficult to measure because the health status of part of the care demanders will decline anyway due to the nature of their disease. Finally, in the care sector a lot of care is provided by informal caregivers. Research into these issues raises interesting methodological and implementation problems. This thesis discusses some of these problems focussing in particular on informal care.

An important issue in this thesis is how to prevent undesirable shifts in the financing of health care from the health care budget to the private resources of care recipients. These shifts may occur as a consequence of policy recommendations derived from economic evaluations that do not adopt a societal perspective and hence fail to take

into account all of the costs and effects of an intervention. If, for instance, informal care is not accounted for, an intervention may seem cost-effective while in fact it is not and lead to policy recommendations that shift costs from the health care sector to informal caregivers. Another important subject of this thesis is the supply and demand of informal care and their impact on institutional changes in health, social or labour policy. The demand analysis is embedded in a discussion about the introduction of cash benefits (personal budgets) in the care sector. Cash benefits are seen as a tool to attain consumer independence in the care sector, as, by analogy, in a system of managed competition in the cure sector.

## **1.2 Informal care**

Informal care is usually defined as unpaid care provided by non-professional caregivers to care recipients they have a social relation with. In The Netherlands are 750,000 informal caregivers providing care for more than three months a year and for more than eighth hours per week (Timmermans, 2003). Informal care is usually preferred by the care recipients both to formal care and to institutionalisation (Van Houtven, 2000) and (Van den Berg and Van den Berg, 2000), because most people prefer to stay at home in their own environment.

Scientists with different disciplinary backgrounds do research on distinct issues regarding informal care. Sociologists and psychologists measure and describe the burden of informal caregiving. Economists model the supply of informal care and try to value informal care. There are three unexplored issues regarding informal care, which are central in this thesis. We will discuss them in more detail below. First, the supply of informal care, second, informal care in economic evaluations and third, the demand of informal care in relation to the introduction of cash benefits in the care sector.

## **1.3 The supply of informal care**

There is a lot of information about the characteristics of informal caregivers. It is, for instance, well-known that informal care is frequently provided by women to their partner or to their parent(s) (Hughes et al., 1999) and (Schulz and Beach, 1999). Economists often stress the opportunity costs involved in terms of paid work sacrificed (Muurinen, 1986), (Carmichael and Charles, 1998) and (Carmichael and Charles, 2003). It is suggested that these opportunity costs rise due to the increasing labour market participation of women

(Carmichael and Charles, 1998). Sociologists and psychologists argue that providing informal care is often stressful and burdensome, especially when informal care is provided by caregivers who have also other responsibilities (Dautzenberg, 2000). Unfortunately, this literature fails to model the endogeneity of doing paid work and providing informal care. This means that doing paid work affects informal care supply and providing informal care affects labour market participation. Endogeneity is of importance, because it gives more precise information about the choices of informal caregivers regarding the provision of informal care. This thesis models and discusses this endogeneity.

## **1.4 Informal care in economic evaluations of health care**

As described before, due to the rising health care expenditures, economic evaluations are of increasing importance to inform policy makers about the costs and outcomes of new interventions in health care are. It is suggested that economic evaluations should adopt a societal perspective to give information on all costs and effects and to prevent the implementation of policies without knowing all consequences for the individuals' concerned (Gold et al., 1996). Adopting a societal perspective implies that the costs and effects of informal care should be incorporated in economic evaluations. However, informal care is often ignored in economic evaluations (Stone et al., 2000), because the societal perspective is not adopted or due to problems of measurement or valuation of informal care.

Measurement of informal care is a necessary condition for the valuation of informal care. However, this issue is often neglected. (An exception is, for instance, (Clipp and Moore, 1995)) This thesis tries to fill this gap in the literature. The main focus of the existing literature about the incorporation of informal care in economic evaluations is on the informal caregivers, especially on the valuation of the time inputs of informal caregivers. Two methods are recommended to value the time spent on providing informal care: the opportunity cost method and the proxy good method (Gold et al., 1996), (Drummond et al., 1997), (Posnett and Jan, 1996), and (Smith and Wright, 1994). The former values informal care at the price of the opportunities forgone due to informal caregiving, e.g., labour market participation, while the latter values informal care at the price of alternative professional home care. Some important practical and theoretical problems with these methods, however, are underexposed in the literature. For instance,

how should one measure the amount and type of time forgone when informal care is already provided for many years as is often the case in chronic disease? Or, why should one value at the price of professional care if informal caregivers choose to provide the care themselves, implicitly rejecting the professional alternative? Moreover, there is increasing evidence that providing informal care induces morbidity and in some sub-populations even mortality risks occur (Schulz and Beach, 1999). These effects of providing informal care are not included in the opportunity and proxy good methods thus neglecting significant costs and effects. This requires the development of methods that incorporate these risks. In this thesis these questions will be addressed and methods to include such items will be developed and tested.

## **1.5 Cash benefits**

In many countries, long-term home health care is financed and organised through a supplier-regulated system, in which (social) insurers pay caregivers directly. Care recipients get their care in kind. From the nineties onwards, some countries developed alternative systems in which care recipients get sums of money (cash benefits also called consumer-directed services or personal budgets) to purchase care instead of getting their care in kind. This enables recipients rather than home care agencies to choose their health care and follow their own preferences. Care recipients can now decide who provides the services and for what quality. It often enables them also to hire their informal caregivers. Countries that experimented with cash benefits include Austria, France, Germany, The Netherlands, the United Kingdom, and the United States (US). (See for detailed descriptions of the programs (Tilly et al., 2000) and (Tilly and Wiener, 2001)).

Studies that analysed the effects of the introduction of cash benefits are mainly descriptive (see Tilly et al. (2000) and Tilly and Wiener (2001) for overviews). They do not give explicit attention to the role and position of informal caregivers. This thesis tries to contribute to this literature by analysing the economic effects of the introduction of cash benefits in health care and by analysing the psychological effects of paying informal caregivers with cash benefits.

## 1.6 Research questions

This thesis deals with informal care. The adopted approach is mainly economic, but also concepts and methods from other disciplines like sociology and psychology are used. We deal with three different but related economic problems regarding informal care:

1. What is the relation between providing informal care and other economic activities like paid work?
2. How should informal care be incorporated in economic evaluations of health care?
3. What are the (economic) consequences of the introduction of cash benefits in the long-term home health care sector in general and for informal care in particular?

In trying to find answers on the research questions we will combine economic theory with econometric techniques. Therefore, we used different sources of data. First we used data collected by the Dutch Social and Cultural Planbureau (SCP) within the framework of the analysis of informal caregivers' demand for paid care leave (Timmermans, 2003). It contains information of respondents who had someone in their social environment who needs care regarding their possible care supply and all kinds of background characteristics like, for instance, labour market participation. The other four data sets we used were especially developed for this thesis. One data set contains informal caregivers caring for care recipients with Cerebrovascular Accident (CVA), also called stroke, who were identified in the context of the EDISSE study (Huijsman et al., 2001). Another data set consists of caregivers providing informal care to people with Rheumatoid Arthritis (RA). These data were collected as a supplement of the RA+ study, a panel study on health and health care utilisation among people with RA (Jacobi et al., 2001) and (Jacobi et al., 2003). Furthermore, we approached a more heterogeneous population of care recipients (in terms of disease characteristics) and their informal caregivers with the aid of Dutch regional support centres for informal caregivers, united in 'X-Zorg'. Finally, we contacted care recipients with a cash benefit and their informal caregivers through 'Per Saldo'. 'Per Saldo' is a Dutch association for people with a cash benefit. More details about the data and data collection will be provided in the chapters concerned.

## 1.7 Approach and outline

This thesis attempts to contribute to the theoretical and policy oriented economic literature on informal care. We discuss our ideas below in general and separately for each chapter. It is worth noting that all the chapters are based on existing papers. This may involve some

overlap. Besides, the terminology could differ between the chapters just like the convention of the tables and equations. But it allows reading the different chapters independently.

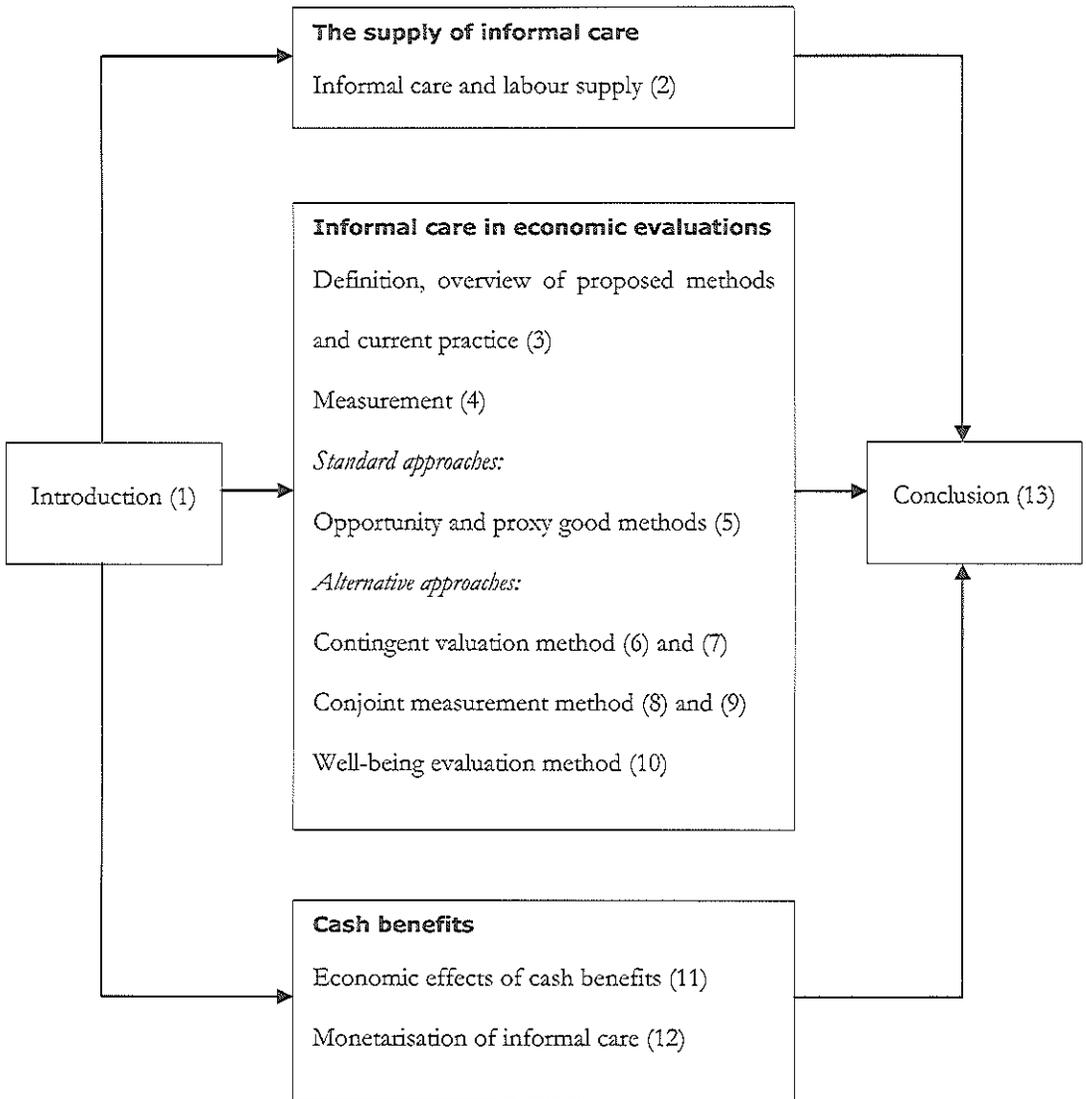
The structure of this thesis is summarised in figure 1.1 The first issue in this thesis is how the supply of informal care relates to other activities of informal caregivers, especially paid work, our first research question. *Chapter 2* analyses this theme from a standard economic point of view. It proposes a utility framework and presents an econometric model explaining the decision to do paid work on the one hand and to provide informal care on the other hand. The same model structure is used for other applications, for instance, to analyse the relation between paid work and childcare. It may help to inform policy decisions about all kinds of support services for informal caregivers, like paid care leave.

The second issue in this thesis deals with the introduction of informal care in economic evaluations. *Chapter 3* describes and discusses the current practice of incorporation of informal care in economic evaluations. It also discusses alternative methods for the incorporation of informal care in economic evaluations. Necessary conditions for the incorporation of informal care in economic evaluations are the use of a clear definition and a reliable measurement of informal care. An alternative definition of informal care is put forward that can also be used in the changing institutional environment of long-term health care due to the introduction of cash benefits. This chapter also discusses some issues in the measurement of informal care, while *chapter 4* presents the results of an empirical test for the reliable measurement of time spent on informal caregiving. The chapter compares the often used recall method in surveys regarding informal care at two moments in time (test-retest reliability) and with the gold standard of time measurement, a diary. There is some literature about the measurement of informal care time, but it does not, however, compare the results of the recall method with a diary. The opportunity cost method and the proxy good method are often suggested as tools to value informal care. They are discussed and compared in *chapter 5*. Both methods involve some measurement problems that are often overlooked. We discuss them and provide some solutions. Moreover, this chapter compares the results of both methods and shows that different methods, just like a different operationalisation of the methods, leads to different results which could bias economic evaluations. Because both methods have also important theoretical limitations, this thesis proposes the use of three other valuation methods, namely the contingent valuation (CV) method, choice experiments (CE), and the well-being valuation method (WBV). In the literature there is some suspicion towards the application of CV to value informal care. *Chapter 6* presents empirical evidence about this

issue. Moreover, this chapter shows how to frame CV questions to elicit the preferences of real informal caregivers, e.g. in the form of willingness to accept. However, chapter 6 only takes the perspective of the informal caregivers and not of their care recipients. Therefore, *chapter 7* presents an economic model of informal care that takes into account the perspectives of both the informal caregivers and their care recipients and that models the interdependencies in their preferences. We use this model to derive hypotheses about the willingness to pay and the willingness to accept for informal care of the caregiver and the care recipient and about the effect of changes in certain key variables on the valuation of informal care. These hypotheses are tested and are to a large extent confirmed, which suggests that CV may be fruitfully applied to value informal care. CE are sometimes called CV's close cousins in the family of stated preference methods. They do not have the strong welfare economic theoretical foundation as CV, but they also do not suffer from some biases, like strategic bias, as CV does. A comparison of the results of both methods in this thesis is attractive. *Chapter 8* presents the results of a relatively simple application of CE to value informal care in a homogeneous population of caregivers, while *chapter 9* presents the results of another application of CE. But the method is now applied to a larger and more heterogeneous (in terms of disease characteristics of the care recipients) sample. *Chapter 10* presents the results of the application of the WBV method to value informal care. It shows the flexibility of WBV and compares the results with CV.

The final chapters of this thesis deal with the last mentioned research question about the effects of the introduction of cash benefits in the long-term home health care sector. *Chapter 11* investigates empirically the impact of the introduction of cash benefits on the price and quantity of care purchased. The effects concern ex post static moral hazard. This means that care recipients *ceteris paribus* purchase more or more expensive care than they would buy in the absence of health insurance. These effects of the introduction of cash benefits are not yet discussed in the literature. *Chapter 12* investigates empirically the psychological consequences of paying informal caregivers through cash benefits. It is suggested that a monetarisation of informal care will involve some negative psychological effects in terms of the motivation of informal caregivers (Timmermans, 2003). However, there is no empirical evidence for this suggestion. *Chapter 12* tries to fill this gap in the literature.

Figure 1.1: Overview thesis (chapter number in parentheses)



## 2 The simultaneity between informal care and labour supply<sup>1</sup>

### Summary

*This chapter investigates the labour supply and care supply decisions of informal caregivers. We use a structural model to model the direct relationship between labour supply and informal care supply and vice versa. Moreover, we account for endogeneity and sample selection. Empirical results show that providing informal care has a negative effect on the amount of paid work performed. Conversely, having paid work has a negative effect on the amount of informal care provided, but the number of hours worked does not. There are large differences in the working and care balance between males and females and persons with and without young children.*

### 2.1 Introduction

Informal care provided by their families or friends to people with chronic diseases and terminally ill persons accounts for a substantial part of their total long-term care utilisation (Norton, 2000), (Timmermans, 2003), and Van den Berg (2004). Understanding the factors that determine informal caregivers' care and labour decisions is crucial for the development of policies to support caregivers. This chapter investigates both the labour and care supply decisions of informal caregivers.

There is a good deal of literature regarding the supply of informal care; see Van Houtven (2000) for an extensive overview. Studies that are not referred to in Van Houtven (2000) include Carmichael and Charles (1998), Carmichael and Charles (2003), and Checkovich and Stern (2002). Carmichael and Charles (2003) find that women are more likely to provide informal care than men and also that women actually do provide more informal care than men. They also find that the factors influencing the supply of informal care differ between men and women. For men, wage and income variables are the most significant factors, while other factors such as marital status, presence or absence of children and the characteristics of the care recipients (physical impairment) do not play a role. Checkovic and Stern (2002) find that the further a child lives from his or her parents, the less care he or she will provide; they also find that children who work provide less care.

---

<sup>1</sup> Based on Van den Berg, B., Woititz, I., 2004. The simultaneity between informal care and labour supply: A structural equation model. Submitted for publication.

The difference between the Checkovic and Stern paper and our chapter is that they estimate a reduced form model. Taking account of this endogeneity, Stern (1995) (Stern, 1995), argues that labour supply is statistically insignificant for the informal care decision.

Informal care is of increasing importance for health care in Western societies. It is believed that the preferences of care recipients have changed to staying at home instead of being institutionalised (Van Houtven, 2000). Van Houtven and Norton (2004) state that care recipients often prefer informal care to professional care. From a budgetary point of view, health care policymakers prefer the use of informal care because it is cheaper than professional care. In the short run, at least from a health care budget point of view, informal care is a free substitute for professional home care. However, in the medium and long run this may not necessarily be the case. It is well known that providing informal care can be stressful and may increase informal caregivers' morbidity and mortality risks (Schulz and Beach, 1999). Much work has been done to measure the impact of providing care on the health of informal caregivers, with major contributions in the fields of psychology and sociology. For examples, see Pearlin et al. (1990), Gallagher and Mechanic (1996), Kramer (1997), Hughes et al. (1999), and Schulz and Beach (1999). In economic terms, the evidence for informal caregivers' increased morbidity and mortality risks due to providing informal care implies that informal care is not free when viewed over the medium and long term. In fact, even in the short term, the provision of informal care is not free: at the very least it entails opportunity costs, for instance in terms of forgone paid work, unpaid work or leisure. See, e.g., O'Shea and Blackwell (1993), Posnett and Jan (1996), Ettner (1996), Carmichael and Charles (1998), and Carmichael and Charles (2003).

Identifying the determinants of the supply of informal care, including informal caregivers' opportunity costs, is of importance for health, social and labour policy. For health policy it is important because a decline in the supply of informal care would increase the demand for alternatives that are more costly from a health care budget perspective. Moreover, it would force some care recipients to accept institutionalised care instead of being cared for at home. In the last decade, social and labour policy has focused on facilitating the combination of work and caring for children or persons who are chronically, terminally or temporarily ill. A knowledge of the determinants of the supply of informal care is crucial for the development of effective social policy programmes, such as care leave facilities (SCP, 2001). New instruments, such as consumer-directed services (also called direct payments, cash benefits or personal budgets) in the long-term care sector, enable care recipients to buy in services, for example from informal caregivers (Tilly and Wiener,

2001). Increased use of consumer-directed services could have a major impact on the labour market participation rate of informal caregivers. Information about the determinants of informal caregivers' labour supply could make it easier to predict the labour market consequences of increased use of instruments such as consumer-directed services in the health care sector. In the long run it would probably reduce the labour supply, which is substituted into care time. On the other hand, reduced sick leave and a reduced time burden would increase the labour supply.

The policy relevance of the determinants of the supply of informal caregivers is stated above. Additionally, finding the determinants for the supply of informal caregivers is also interesting from a theoretical point of view, because there is a simultaneity between the provision of informal care and labour market participation. Providing informal care affects labour market participation and labour market participation affects the provision of informal care. For instance, Carmichael and Charles (1998) model the provision of informal care as an exogenous factor in the labour supply decision, as do Barnby and Charles (1992) and Carmichael and Charles (2003). The same holds for the related problem of simultaneity between labour supply and the demand for child care. See for examples Blau and Hagy (1998), Michalopoulos and Robins (2000), and Powell (2002). They all focus on the effects of wage and price of care on labour supply and child care demand, without modelling the direct relationship between labour supply and child care demand. In their 2003 paper, Carmichael and Charles devote explicit attention to this endogeneity problem. They state: *"Thus, while we are unable to estimate a more general allocation-of-time model that controls for the possibility that informal care responsibilities are exogenously (we think they mean endogenously) determined, there is the possibility of bias in our results. However, it is difficult to believe that for women anyway informal care is any more endogenous than child care and yet child care is generally treated as exogenous in labour supply models. Indeed, endogeneity is possibly more problematic in association with child care than with informal care. After all while contraception makes the decision to have children a genuine one, chronic illness in a close relative is something beyond the individual's control (p.797)."* Ettner (1995) uses the same kind of reasoning when she compares the concern of governments with the consequences of both child care and informal care for social and private costs. *"The argument for government intervention may be stronger in the case of eldercare than childcare. The existence of disabled parents cannot be influenced by one's behavior, as is fertility, and so cannot be regarded as a choice variable. Furthermore, caregiving needs are much more variable among the elderly than among young children (p.65)."*

In making their statements Carmichael and Charles (2003) and Ettner (1995) implicitly assume that the whole social network of an individual with impairments will provide informal care. In reality, however, the empirical literature suggests that the provision of informal care is not equally distributed over all members of society.

This chapter adds to the literature by modelling the direct relationship between labour supply and informal care supply where both labour and informal care are treated as endogenous. The supply equations are derived from a utility theory framework. Our model is tested empirically by analysing data from 1106 respondents, all of whom had someone in their social setting in need of care. Two out of three had a paid job, while three-quarters of the respondents provided informal care.

The structure of the chapter is as follows. First we present the theoretical and econometric models. Next we present the data and give the results of the estimations and present some simulations. The chapter ends with our conclusions and a discussion of our findings.

## **2.2 The model**

In this section the theoretical model is first set out, following which the empirical specification is derived.

### **2.2.1 Theoretical model**

We developed a model of the individual's supply-of-work and supply-of-informal care decisions. We propose a utility maximisation model where the individual chooses between consumption, paid work time and informal care time. Consumption and paid work time are standard elements in utility functions concerning the allocation of time. See for an overview, e.g., Gronau (1986). By including the provision of informal care as an element in the utility function, we implicitly assume that individuals derive utility from providing informal care. Others, for example Barmby and Charles (1992) assume that the reasons for providing informal care are chiefly altruistic, leading them to build a model where the welfare of the dependent enters the utility function of the informal caregiver. This implies, however, that informal caregivers do not derive direct utility from the provision of informal care. Through the assumption that the welfare of the dependent depends upon the amount of informal care provided, the welfare of the care recipient enters indirectly into our proposed utility function of the informal caregiver.

Suppose an informal caregiver maximises the following utility function subject to two constraints:

$$U^c = U^c(Q, L, C; X_1, X_2) \quad (1)$$

where: Q = consumption

L = leisure

C = hours of care

$X_1$  = exogenous variables affecting leisure, such as presence of young children and health of informal caregiver

$X_2$  = exogenous variables affecting hours of care, such as presence of young children, health of informal caregiver, and health of the care recipient.

The constraints faced by the potential caregiver are a time constraint and a budget constraint. The time constraint divides the total time T between paid work (N), leisure (L) and informal care (C):

$$T = N + L + C \quad (2)$$

T = total time available

N = working time

The budget constraint shows that total money (the sum of non-labour income and labour income) can be spent on consumption with the corresponding price p.

$$pQ = w*N + Y \quad (3)$$

where p = price of consumption

w = wage rate

Y = non-labour income

The informal caregiver's decision problem may be stated as follows:

$$\max \quad U^c(Q, L, C; X_1, X_2) \quad (4)$$

$Q, L, C$

$$\text{s.t.} \quad wT + Y = p^*Q + w^*L + w^*C \quad (5)$$

Imposing a quadratic utility function, the demand for care and leisure equations are derived by solving the first order conditions of the Langrangian:

$$\begin{aligned} \max \quad & a_1Q + a_2L + a_3C + b_{11}Q^2 + b_{22}L^2 + b_{33}C^2 + 2b_{12}QL + 2b_{12}QC + 2b_{23}CL + \\ & \lambda (wT + Y - p^*Q - w^*L - w^*C) \end{aligned} \quad (6)$$

The influence of the exogenous variables is modelled by making the preference parameters a dependent upon  $X$ , see also Pollak and Wales (1981). The solution to this problem then yields the following demand equations:

$$L_i = X_{ij1} \beta_1 + \beta_2 C_i + \beta_3 Q_i \quad (7)$$

$$C_i = X_{ij2} \gamma_1 + \gamma_2 L_i + \gamma_3 Q_i \quad (8)$$

$$Q_i = w_i T + Y_i - w_i^* L_i - p_i^* C_i \quad (\text{where } p_i \text{ is assumed to be equal to } 1) \quad (9)$$

where  $\beta_1$  and  $\gamma_1$  are vectors of parameters,

and  $\beta_1, \beta_2, \beta_3, \gamma_1, \gamma_2$  and  $\gamma_3$  are functions of  $a$  and  $b$ . \*

Variables that are typically included in the vector  $X_1$  are age, gender, the presence of young children (negative effect), wage rate, level of human capital (education) (positive correlation) and health of the informal caregiver. (See table 2.1 for an overview.) Variables that are typically included in  $X_2$  are age, gender, the presence of young children (negative effect), health of the caregiver and recipient, closeness of kinship and physical proximity.

### 2.2.2 Empirical analysis

We use a two-step procedure to estimate this system of equations. First we estimate the reduced form equations using tobit estimation, thus taking account of the specific nature of the data (Scott Long, 1997). Next we use the estimated values as instruments in the structural equations.

The data contain information on hours of work and hours of care, so that the leisure-equation (equation (7)) is translated into an hours-of-work-equation. According to this equation hours of work are related to hours of care, consumption and exogenous variables. Using budget-constraint (3) and time-constraint (2), consumption is substituted out. This yields the first structural equation of our model that will be estimated, in which hours of work are related to hours of care and various exogenous variables.

$$N_i^* = X_{ij1} *1 + *3 C_i + \varepsilon_{1i} \quad (10)$$

Analogously, a structural equation for care can be derived, relating hours of care to hours of work and various exogenous variables.

$$C_i^* = X_{ij2} *2 + *4 L_i + \varepsilon_{2i} \quad (11)$$

$N_i$	= weekly working hours of individual $i$
$C_i$	= hours of care supplied by individual $i$
$X_{ij1}, X_{ij2}$	= exogenous variables $j$ of individual $i$
$*1, *2, *3, *4$	= parameter vectors
$\varepsilon_{1i}, \varepsilon_{2i}$	= error term

Both  $N_i^*$  and  $C_i^*$  are unobservable; what we observe are a variable  $N_i$  indicating whether a person participates in the labour market or not (zero hours of work) and, if they participate, how many hours they work; and a variable  $C_i$  indicating whether a person provides care or not (zero hours of care) and, if they provide care, for how many hours:

$$\begin{aligned}
 N_i &= N_i^* && \text{if } N_i^* > 0 && \text{(works)} \\
 &= 0 && \text{otherwise} && \text{(does not work)}
 \end{aligned}
 \tag{12}$$

$$\begin{aligned}
 C_i &= C_i^* && \text{if } C_i^* > 0 && \text{(provides care)} \\
 &= 0 && \text{otherwise} && \text{(does not provide care)}
 \end{aligned}
 \tag{13}$$

Equations (10)-(13) constitute a system of simultaneous equations, which has been estimated using an instrumental variable method. The reduced form estimators are used as instruments (see equations (14) and (15)).

$$N_i^* = X_{ij1} \cdot 1 + X_{ij2} \cdot 2 + \varepsilon_{3i} \tag{14}$$

$$N_i^* = X_{ij1} \cdot 0_1 + X_{ij2} \cdot 0_2 + \varepsilon_{4i} \tag{15}$$

$\cdot 1, \cdot 2, 0_1, 0_2$  = parameter vectors

$\varepsilon_{1i}, \varepsilon_{2i}$  = error term

Assuming that  $\varepsilon_{1i}$  and  $\varepsilon_{2i}$  have an independent normal distribution, equations (14) and (15) constitute standard tobit models. The model has been estimated for every person who is a potential worker and/or a potential carer.

## **2.3 Data**

This section first describes how the data were collected, following which the sample characteristics are presented.

### **2.3.1 Data collection**

Data were collected for the Dutch care leave programme (SCP, 2001). Between September 1999 and March 2000 a random sample of households in the Netherlands were interviewed about their use of a broad range of facilities including (health) care. The next three questions, put to all respondents aged 16 year and over, are particularly relevant.

- 1) 'Is someone in your social environment (family, friends, acquaintances) chronically ill or disabled, and hence in need of help regularly?'
- 2) 'Is there someone in your social environment who has needed help during the past three years for longer than two weeks due to illness, accident or hospital admission?'
- 3) 'Has someone in your social environment been cared for and died in the past three years?'

Situations 1-3 are referred to below as chronic care, temporary care and terminal care, respectively.

Those respondents who answered in the affirmative to one of the three questions above were included in the sample. They were given another written survey, which contained questions about the general characteristics of the potential care recipient, the type of impairment, the care provided and the various caregivers involved (professional, private or informal). Ultimately 1290 people completed the survey.

### **2.3.2 Sample characteristics**

Due to missing values on one or more of the variables, 1106 of the 1290 respondents were ultimately included in the analyses. Table 2.1 thus presents the sample characteristics of the independent variables of these 1106 respondents.

Table 2.1: Sample characteristics (n=1106)

Variable	Mean	SD/ $\sqrt{n}$
<i>Dependent variables</i>		
Hours of informal care	13.63	0.69
Hours worked	20.84	0.52
<i>Company and job characteristics</i>		
Dummy service industry (other = 1)	0.58	0.01
Dummy less than 20 employees (yes = 1)	0.23	0.01
Dummy between 20 and 99 employees (yes = 1)	0.23	0.01
Dummy control own work schedule (no = 1)	0.35	0.01
Dummy shift-work (yes = 1)	0.74	0.01
Dummy works during evenings (yes = 1)	0.05	0.01
Dummy works during nights (yes = 1)	0.14	0.01
<i>Informal caregiver characteristics</i>		
Predicted hourly wage	9.52	0.21
Dummy informal caregiver's age 16-34 (yes = 1)	0.23	0.01
Dummy informal caregiver's age 35-44 (yes = 1)	0.33	0.01
Dummy informal caregiver's age >44 (yes = 1)	0.44	0.01
Dummy gender informal caregiver (female = 1)	0.64	0.01
Dummy child younger than 12 (yes = 1)	0.35	0.01
Dummy education informal caregiver low (yes = 1)	0.41	0.01
Dummy education informal caregiver middle (yes = 1)	0.38	0.01
Dummy education informal caregiver high (yes = 1)	0.22	0.01
Combination paid job and providing informal care		
Dummy has taken holiday for to provide care (yes = 1)	0.20	0.01
Dummy has taken emergency or sick leave (yes = 1)	0.08	0.01
<i>Health informal caregiver</i>		
Subjective health informal caregiver (very good = 1; very bad = 5)	1.92	0.02
Hindrance with activities due to pain (not at all = 1; very much = 5)	1.55	0.03
Dummy physical impairments (yes = 1)	0.21	0.01
<i>Care recipient characteristics</i>		
Dummy care recipient's age unknown (yes = 1)	0.01	0.00
Dummy care recipient's age 1-39 (yes = 1)	0.15	0.01
Dummy care recipient's age 40-64 (yes = 1)	0.28	0.01
Dummy care recipient's age 65-80 (yes = 1)	0.31	0.01
Dummy care recipient's age =>80 (yes = 1)	0.25	0.01
Dummy gender care recipient (female = 1)	0.65	0.01
<i>Continued on the next page</i>		

Variable	Mean	SD/ $\sqrt{n}$
Dummy education care recipient low (yes = 1)	0.36	0.01
Dummy education care recipient middle (yes = 1)	0.35	0.01
Dummy education care recipient high (yes = 1)	0.22	0.01
Dummy education care recipient unknown (yes = 1)	0.07	0.01
Dummy care recipient needs emotional support (yes = 1)	0.65	0.01
Dummy impaired can be left alone (yes = 1)	0.81	0.01
<i>Type of care situation</i>		
Dummy type of care situation: temporary (yes = 1)	0.40	0.01
Dummy type of care situation: terminal (yes = 1)	0.21	0.01
Dummy type of care situation: chronic (yes = 1)	0.39	0.01
Dummy care recipient lives with informal caregiver (yes = 1)	0.19	0.01
Dummy care recipient lives independently (yes = 1)	0.70	0.01
Dummy care recipient in nursing home (yes = 1)	0.10	0.01
<i>Other care</i>		
Dummy care recipient also receives other informal care (yes = 1)	0.66	0.01
Dummy care recipient receives professional care (yes = 1)	0.44	0.01
Dummy care recipient receives private care (yes = 1)	0.10	0.01
<i>Relationship between potential informal caregiver and care recipient</i>		
Dummy respondent is primary informal caregiver (yes = 1)	0.34	0.01
Dummy relationship partner (yes = 1)	0.12	0.01
Dummy relationship close relative (yes = 1)	0.51	0.02
Dummy relationship other (yes = 1)	0.36	0.01
<i>Travel time</i>		
Travel time informal caregiver 0 min	0.19	0.01
Travel time informal caregiver 1-15 min	0.57	0.01
Travel time informal caregiver 16-30 min	0.19	0.01
Travel time informal caregiver >30 min	0.05	0.01

Table 2.1 also shows that of the 1106 respondents, 826 (74.7%) provide care in one of the above situations 1-3, i.e. are informal caregivers. The remaining 280 respondents (25.3%) do not provide informal care despite the fact that there is someone in their social environment in need of care. In addition, 749 (67.7%) respondents have a paid job, while 357 (32.3%) do not.

It is conspicuous that the majority of informal care is provided for care recipients aged between 65 and 80 years. More than two-thirds of the care recipients cannot be left at home alone or need emotional support. Many care recipients also receive other informal care (66%) and professional care (44%), while some (10%) are also in receipt of private care. 34.4% of the care recipients receive other informal care while 12.2% receive only

professional care. About a third of the caregivers are the primary caregiver; 12% are partners, but most are close relatives. Most informal caregivers are aged over 44 years and live close to their care recipient (less than 15 minutes' travelling time).

**Table 2.2:** Informal caregivers' labour market participation

	No paid job	Paid job	Total
Number	281	545	826
<i>Percentage</i>	34.0	66.0	100

**Table 2.3:** Non-caregivers' labour market participation

	No paid job	Paid job	Total
Number	76	204	280
<i>Percentage</i>	27.1	72.9	100

Tables 2.2 and 2.3 show that non-caregivers are in employment more often than caregivers: almost 73% versus 66%. This difference is statistically significant (Pearson chi-square (1) = 4.5236; Pr = 0.033).

### 2.3.3 Distribution of the dependent variables

Table 2.4 shows the distribution of the hours of paid work performed each week, while table 2.5 presents the same information for the weekly hours of informal care provided.

**Table 2.4:** Mean hours of paid work per week in categories

Hours per week	Frequency	%	Cumulative %
0	357	32.3	32.3
1-20	191	17.3	49.6
21-40	535	48.4	97.9
> 40	23	2.1	100
Total	1,106	100	
	<i>Mean hours per week</i>		
Overall	20.8		
Without zeros	30.8		

As table 2.4 shows, a majority of the potential informal caregivers work between 21 and 40 hours per week.

**Table 2.5:** Mean hours of informal care provided per week in categories

Hours per week	Frequency	%	Cumulative %
0	280	25.3	25.3
1-20	633	57.2	82.5
21-40	99	9.0	91.5
> 40	94	8.5	100
Total	1,106	100	
	<i>Mean hours per week</i>		
Overall	13.6		
Without zeros	18.3		

Table 2.5 shows that most informal caregivers provide care for up to 20 hours a week (57%).

## 2.4 Results

This section presents the estimation results of the econometric models. The effect of informal care on labour supply is shown in section 2.4.1; this is followed in section 2.4.2 by the effect of labour supply on informal care. Finally, section 2.4.3 contains a number of simulations.

### 2.4.1 The effects of informal care hours on working hours

Table 2.6 shows the effect of providing informal care on working hours, controlled for a number of exogenous variables.

**Table 2.6:** Tobit estimations, dependent variable: paid work time

	Coefficient	T-value
<i>Informal care time</i>		
Informal care hours	-0.15	-3.53
<i>Company and job characteristics</i>		
Dummy service industry (other = 1)	-2.66	-2.00
Dummy less than 20 employees (yes = 1)	3.86	2.24
Dummy between 20 and 99 employees (yes = 1)	10.10	6.33
Dummy control own work schedule (no = 1)	9.51	6.84
Dummy shift-work (yes = 1)	-3.92	-1.99
<i>Informal caregiver characteristics</i>		
Predicted hourly wage	0.73	1.11
Dummy informal caregiver's age 35-44 (yes = 1)	-3.55	-1.52
Dummy informal caregiver's age >44 (yes = 1)	-8.12	-4.99
Dummy gender informal caregiver (female = 1)	-10.19	-1.43
Dummy child younger than 12 (yes = 1)	-6.41	-4.66
Dummy education informal caregiver middle (yes = 1)	-1.00	-0.34
Dummy education informal caregiver high (yes = 1)	-1.33	-0.17
<i>Combination paid job and providing informal care</i>		
Dummy has taken holiday to provide care (yes = 1)	13.60	-3.39
Dummy has taken emergency or sick leave (yes = 1)	10.56	7.50
<i>Health informal caregiver</i>		
Subjective health informal caregiver (very good = 1; very bad = 5)	0.13	4.07
Hindrance with activities due to pain (not at all = 1; very much = 5)	0.78	0.14
Dummy physical impairments (yes = 1)	-5.83	0.95
Intercept	22.26	2.37
Standard error	17.98	
N	1,106	

There is a statistically significant negative relation between the hours of informal care provided and the number of hours of paid work. In other words, all things being equal, the more informal care that is provided, the fewer hours of paid work the informal

caregiver provides. A correction was applied for other exogenous variables, some of which also influence the number of hours of paid work. There is a statistically significant positive relation between company size and the employee's control over their own work schedule. The larger the company, the more hours are worked, and employees who have control over their own work schedules work more hours. Shift-workers work fewer hours than other employees. Older individuals and persons with young children work fewer hours than others. Taking leave in order to provide informal care, and taking emergency or sick leave to provide informal care, has a positive effect on hours of paid work. This is partly a participation effect and partly a volume effect. Part-time workers can provide care in their free hours, while full-time workers have to take leave. Moreover, the positive relation between care leave facilities and number of hours' paid work suggests that these facilities are good institutions for ensuring informal caregivers' amount of paid work. It is worth noting that the variable 'hourly wages' is endogenous to hours of paid work. People with small or part-time jobs are less likely to have high salaries compared to their counterparts who work more hours. We therefore operationalised hourly wages using a Heckman selection model (Heckman, 1976).

#### 2.4.2 The effects of working hours on informal care hours

The effects of hours of paid work on the number of hours' informal care provided are shown in table 2.7.

Table 2.7: Tobit estimations, dependent variable: informal care time

<i>Paid work</i>	Coefficient	T-value
Hours paid work	-0.21	-2.06
Dummy works during evenings (yes = 1)	12.69	3.38
Dummy works during nights (yes = 1)	4.69	1.83
<i>Care recipient characteristics</i>		
Dummy gender care recipient (female = 1)	0.03	0.02
Dummy education care recipient middle (yes = 1)	-2.51	-1.37
Dummy education care recipient high (yes = 1)	-4.83	-2.16
Dummy education care recipient unknown (yes = 1)	4.96	1.37
Dummy care recipient's age unknown (yes = 1)	-12.39	-1.33
Dummy care recipient's age 1-39 (yes = 1)	4.63	1.65
Dummy care recipient's age 40-64 (yes = 1)	4.35	1.98
Dummy care recipient's age $\geq 80$ (yes = 1)	0.25	0.12
<i>Continued on the next page</i>		

<i>Paid work</i>	Coefficient	T-value
Dummy care recipient needs emotional support (yes = 1)	1.29	0.81
Dummy impaired can be left alone (yes = 1)	-4.79	-2.43
<i>Type of care situation</i>		
Dummy type of care situation: temporary (yes = 1)	2.30	1.39
Dummy type of care situation: terminal (yes = 1)	6.50	3.07
Dummy care recipient in nursing home (yes = 1)	0.68	0.25
Dummy care recipient lives with informal caregiver (yes = 1)	2.14	0.45
<i>Informal caregiver characteristics</i>		
Dummy informal caregiver's age 35-44 (yes = 1)	2.75	1.29
Dummy informal caregiver's age >44 (yes = 1)	3.02	1.27
Dummy gender informal caregiver (female = 1)	1.15	0.44
Dummy child younger than 12 (yes = 1)	-4.79	-2.49
Dummy education informal caregiver middle (yes = 1)	0.80	0.45
Dummy education informal caregiver high (yes = 1)	0.78	0.35
<i>Combination paid job and providing informal care</i>		
Dummy has taken holiday to provide care (yes = 1)	12.25	4.87
Dummy has taken emergency or sick leave (yes = 1)	11.07	3.29
<i>Other care</i>		
Dummy care recipient also receives other informal care (yes = 1)	-16.54	-8.51
Dummy care recipient receives professional care (yes = 1)	-0.29	-0.18
Dummy care recipient receives private care (yes = 1)	2.27	0.94
<i>Relationship between informal caregiver and care recipient</i>		
Dummy relationship: close relative (yes = 1)	-2.90	-0.73
Dummy relationship: close other (yes = 1)	-9.91	-2.36
<i>Travel time</i>		
Travel time informal caregiver more than 1-15 min	-5.99	-1.70
Travel time informal caregiver more than 16-30 min	-1.47	-0.39
<i>Health informal caregiver</i>		
Subjective health informal caregiver (very good = 1; very bad = 5)	1.56	1.29
Hindrance with activities due to pain (not at all = 1; very much = 5)	1.30	1.25
Dummy physical impairments (yes = 1)	-3.19	-1.45
Intercept	22.13	2.92
Standard error	22.69	
N	1,106	

We can derive from table 2.7 that hour spent in employment have a negative effect on the number of hours of informal care provided; the more a person works, the less

time they spend providing informal care. This could be either a participation or a volume effect. To establish which is the case, we therefore also estimated the relation between hours of work on hours of informal care where the respondent is already providing informal care, thus eliminating the participation effect. In this model, the effect of working hours is not statistically significant, indicating that there is no volume effect of work on the providing of informal care: informal caregivers appear to provide the necessary care despite their labour market responsibilities.

Table 2.7 also shows that working during the evening and at night (at the 10 percent level) has a positive effect on the amount of informal care provided. Working during the evening or at night would appear to enable informal caregivers to provide care during the day. Holiday and emergency or sick leave arrangements offer opportunities to provide care, and therefore we find a positive effect on the number of hours spent providing care. Having young children, on the other hand, reduces the opportunities to provide care, resulting in a negative effect.

Care recipients with a higher education background receive less informal care than recipients with a lower education level, perhaps because they are better able to arrange help for themselves. Terminally ill persons receive more hours of informal care than other care recipients. This is in line with the results found in (SCP, 2001). Partners provide most of the informal care, and the results show that the greater the social distance, the less care is provided.

### **2.4.3 Simulations**

The coefficient for the effect of informal care on working hours reported in table 6 tells us something about the *ceteris paribus* effects. To obtain an idea of how much the number of provided informal care hours varies between different groups, however, we have calculated the following statistics, as shown in table 2.8, in order to take account of the effect that an average person who does not work has different characteristics from one who does work.

**Table 2.8:** Simulation results

	Participation in care	Hours of care	Labour market participation	Hours of paid work
Non-caregiver	0.43	0	0.80	20
Caregiver	0.67	13	0.74	15
Non-worker	0.64	10	0.58	5
Worker	0.59	8	0.84	22
Male	0.55	5	0.92	30
Female	0.64	10	0.66	9
With young children	0.57	6	0.74	16
Without young children	0.63	10	0.76	17

Although the probability that a non-caregiver will start providing care is still 0.43, the predicted number of hours of informal care provided is zero. Males, non-workers and persons without young children not only have a smaller probability of providing informal care than females, workers and persons with young children, but if they do provide care they do so for far fewer hours.

Table 2.8 also shows the probabilities of labour market participation and hours of paid work. The table shows even more pronounced differences for the number of working hours. Although there is a difference in expected working hours between caregivers and non-caregivers, the difference is not as substantial as between males and females.

## 2.5 Conclusions and discussion

This chapter investigates the simultaneous labour supply and care supply decisions of potential informal caregivers based on a sample of 1106 Dutch respondents. We accounted for endogeneity and sample selection. Providing informal care has a negative effect on the weekly amount of paid work performed, and paid work has a negative effect on the weekly amount of informal care provided. The participation effect is responsible for the relation between paid work and providing care, whereas the amount of paid work does not influence the amount of care provided. This implies that informal caregivers provide the necessary care despite their labour market responsibilities. There are important differences between some subgroups in our sample; males, non-workers and persons without young children not only have a smaller probability of providing informal care than females, workers and persons with young children, but if they do provide care they do so for far fewer hours. On the other hand, while there is a difference between the probabilities of

labour market participation and hours of paid work of caregivers and non-caregivers, the difference is not so substantial as between males and females.

A possible weakness of our study is the measurement of the care recipient's care demands. We did not have much information about the health status of the care recipients and were therefore not able to apply a very detailed correction. Another weakness could be the measurement of informal care time. Measurement of time is difficult. We used a number of recall questions, creating the risk of lack of precision. It could be that some very specific groups were not included in our sample, for instance informal caregivers providing care to care recipients with heavy care demands. Caution therefore needs to be applied in generalising our results.

Our results have some policy implications. The amount of paid work seems to have no influence on the amount of informal care provided. This could imply that informal caregivers provide the necessary amount of care. In developing institutions to support informal caregivers, policymakers would perhaps do better to focus on participation rather than on volume.

Most papers on the supply of informal care in relation to the provision of paid work do not account for endogeneity. We have filled this gap in the theoretical literature by using a structural model to model the direct relation between labour supply and informal care supply, and vice versa.



# 3 Economic valuation of informal care: An overview of methods and applications<sup>1</sup>

## Summary

*Informal care makes up a significant part of the total amount of care provided to patients with chronic and terminal diseases. Still, informal care is often neglected in economic evaluations of health care programs. Probably this is related to the fact that the costs of informal care are to an important extent related to time inputs by relatives and friends of patients and time is not easy to value. Development of theoretically sound, yet easily applicable valuation methods is therefore important since ignoring the costs of informal care may lead to undesirable shifts between formal and informal care. Moreover, there is increasing evidence that providing informal care may lead to health problems for the caregiver, both in terms of morbidity and mortality. Up till now these health effects have not been incorporated in economic evaluations. More attention for the identification and valuation of the full costs and health effects of informal care for the informal caregiver seems needed therefore. This chapter presents a critical evaluation of the available methods to incorporate informal care in economic evaluations.*

## 3.1 Introduction

Informal care plays a substantial role in the total care provided, especially for care of people with chronic and terminal diseases. To give an indication, in The Netherlands it was estimated that around ten percent of the population of sixteen million inhabitants provides informal care (SCP, 2001). Because informal care is a less visible part of total care, in terms of costs and effects, it has often been ignored in economic evaluations and (subsequent) policymaking. At present the attention for informal care seems growing. There is increased insight in the amount of informal care provided (in different disease areas) and the tasks that caregivers provide (SCP, 2001). Moreover there is growing evidence that informal care has adverse effects on informal caregivers in terms of for example opportunity costs and quality of life (Schulz and Beach, 1999). At the same time informal care is increasingly being considered as a valuable substitute and complement of expensive formal care. Therefore, policy makers have increased their attention for the position of informal caregivers. This increased attention for informal care is especially important since the

---

<sup>1</sup> Based on Van den Berg, B. Brouwer, W.B.F., Koopmanschap, M.A., 2004. Economic valuation of informal care: An overview of methods and applications. The European Journal of Health Economics 5(1), 36-45.  
Chapter 3: Economic valuation of informal care: An overview of methods and applications

demand for informal care is likely to increase in the future, due to the ageing of the population, the wish to be cared for at home by relatives and friends, and the rationing of formal care in many countries. Changes in treatment patterns of patients, in particular substitution from inpatient to home care, may have a substantial effect on the amount and nature of informal care provided, as well as increased possibilities for monetary compensation of informal caregivers.

Parallel, economic evaluations of health care are more and more often used to inform decision-makers on the relative efficiency of the programs in terms of benefits and costs (Rutten, 1996). Despite the increasing popularity of these economic evaluations, there is a lack on consensus and uniformity of the methodology used in these evaluations. This can lead to differences in which elements are considered to be a necessary part of the analysis and how these elements should be valued. Of course such discrepancies in what to incorporate in the analysis and how to incorporate this, can lead to problems in the interpretation of results and in comparison of results of different studies. Moreover, it can lead to miscalculations and wrong policy recommendations. In this context it is argued that economic evaluations should preferably take the societal perspective (Russell et al., 1996, pp.5-7) and (Drummond et al., 1997, p.106). This means that everyone affected by an intervention under study should be considered and all significant (health) outcomes and costs that flow from the intervention should be counted regardless of who experiences the outcomes and costs. This to prevent undesirable shifts in costs within the health care sector and between the health care sector and other sectors including the informal economy. The societal perspective also has implications for the way costs and outcomes should be measured, i.e. they should be measured in such a way that the full impact on affected members is captured without double counting.

When the societal perspective is adopted, informal care needs to be incorporated in economic evaluations, as has been recognised (Luce et al., 1996) and (Drummond et al., 1997). However, presently the costs and outcomes of informal care are often ignored in economic evaluations (Stone et al., 2000). This sometimes relates to the fact that the societal perspective is not adhered to, e.g., (Gerard and Mooney, 1993), but, for instance, a health care budget perspective. More importantly probably, the methods available to measure and value informal care tend to be quite crude and the incorporation of informal care by no means uniform. More standardisation as well as improved methods appear needed, while recognising the fact that the proposed methods should be compatible with the common types of economic evaluation in health care: cost-benefit analysis (CBA), cost-

utility analysis (CUA) and cost-effectiveness analysis (CEA). The availability, development and use of such methods is a prerequisite for the incorporation of informal care in economic evaluations.

In this chapter we will discuss available methods. As the costs of informal care are to a large extent related to time inputs by informal caregivers<sup>2</sup>, identification and valuation of informal caregivers time inputs are an important focus of this chapter. The time investment may lead to impacts normally referred to as costs, e.g. opportunity costs due to forgone paid work and to impacts on health-related quality of life (morbidity and mortality risks) or well-being. We will discuss the incorporation of these different impacts in economic evaluations<sup>3</sup>.

The triad of definition, measurement and valuation is crucial for the incorporation of informal care in economic evaluations. Therefore, the structure of this chapter is as follows. First, the heterogeneity of the commodity informal care is highlighted and a definition is proposed in section 3.2. In section 3.3, some measurement issues in correctly assessing the informal caregivers input are brought under attention. In section 3.4, the different valuation methods are discussed. Some of these methods aim at valuing the time inputs of informal caregivers, while others focus on assessing the impact of providing informal care on informal caregiver's health or burden. In section 3.5, some additional problems in the valuation and incorporation of informal care are highlighted. Finally, section 3.6 concludes.

## **3.2 Informal care: a heterogeneous commodity**

A clear definition of what informal care entails is a necessary condition for a proper measurement and subsequently for the valuation of informal care in economic evaluations. However, providing such a definition is not straightforward. One might agree on the fact that informal care at least involves care provided by someone from the social environment of the care recipient. On the basis of some prior relationship between carer and patient, therefore, a caregiving situation evolves. Even though this is a good starting point, informal care is a rather heterogeneous commodity. Definitions of informal care therefore can vary greatly (Borgermans et al., 2001, p. 3), also in practical work.

---

<sup>2</sup> See Netten (1990) for an overview and discussion of other costs related to informal care.

<sup>3</sup> The effects of receiving informal care on care recipients will not be addressed in this chapter.

The heterogeneity does not only relate to differences in time investment and duration of care, which of course is an important first source of diversity. It also relates to the (number of) tasks provided, since informal care can be divided into different components, such as (1) housework, like cleaning and cooking, (2) personal care, like dressing, (3) support with mobility, (4) administrative tasks, and (5) socialising, like comforting a patient, e.g., Humbert and Van den Dungen (1994). Not all of these tasks need to be performed by one informal caregiver or needed in all caring situations. Moreover, to make it even more complicated, not all of these tasks are necessarily informal care. For instance, housework may be normal for a housewife, but when her husband falls ill, she may have to increase the number of household tasks provided, the number of hours provided etc. Only the additional part of housework and administrative tasks due to the disease of the care receiver should be seen as informal care. If the informal caregiver already used to clean the house before the care recipient became ill it should not be considered informal care. And not all housework may necessarily be solely to the benefit of the patient. Economists make a distinction between household private and household public commodities in that context. Household private commodities are consumed by one individual solely, while all members of the same household consume household public commodities jointly and therefore benefit from increased activities in this area (Bergstrom, 1997, pp. 23-24).

Another important issue is whether the caregiver and care recipient share the same household. This may have consequences in terms of time investment, travel time, tasks provided and so on. Moreover, sharing the same household may make it more difficult to separate informal care tasks from normal household activities (even for the informal caregiver). In addition, there may be differences in terms of the freedom of choice to become an informal caregiver. It is conceivable that persons outside a household (like neighbours and friends) enter a caregiving situation more voluntarily compared to people sharing the care recipients' household<sup>4</sup>. The latter may feel more obliged to care. Related to this point is the social relationship (e.g. spouse, parent, child, sister, neighbour and friend) between the patient and the informal caregiver. This can affect the way the provision of care is perceived, both by the care receiver and by the caregiver. Moreover, a person may care for a care recipient alone or together with other (informal) caregivers. Often a distinction is made between primary and other caregivers. The primary caregiver is likely to

provide most hours of informal care and to coordinate the care provided by other (informal) caregivers.

An additional source of heterogeneity is the starting point and course of a caregiving episode. The starting point of caring may be obvious (e.g. with a stroke or heart attack) or slowly evolving (e.g. with rheumatoid arthritis or dementia). In the latter situation the caregiver grows in his or her role, gradually taking on more and more tasks, with no clear distinction between before and after becoming an informal caregiver and sometimes between normal and caregiving tasks. In the former situation, the caregiving situation arises abruptly and the forgone normal activities and additional informal care efforts are clearer. This issue has also implications for the measurement of informal care and is therefore also discussed below.

### 3.2.1 Towards a definition

On the basis of the discussed heterogeneity and the starting point that informal care involves, we define informal care as:

*“a quasi or non-market composite commodity consisting of heterogeneous parts<sup>5</sup> produced (paid or unpaid) by one or more members of the social environment of the care recipient as a result of the care demand of the care recipient.”*

In this definition, we leave open the possibility for informal caregivers to be paid. It is often debated whether or not informal caregivers may receive some form of payment and still be considered informal caregivers. This question becomes increasingly relevant now that *personal budgets* become more popular, with which informal caregivers may be paid as well as formal caregivers. One possible answer is that as long as an informal caregiver does not receive a full market wage for all of his or her activities, they can be defined as informal care. Perhaps, a better answer would be to say that only when the caregiver would not want to care for someone outside of his social environment for a similar wage, it is considered to be informal care. When the caregiver would care for anyone, regardless the social relationship, it is either a volunteer –(nearly) unpaid– or a professional carer – paid.

---

<sup>4</sup> This depends for an important part on the institutional context of a society. In some societies it is usual to demand inputs of family members before one could claim support from health care professionals, while other societies are less demanding on family members.

<sup>5</sup> (1) Home keeping (the additional part), (2) personal care, (3) support with mobility, (4) administrative tasks (the additional part), and (5) to some extent socialising.

### 3.3 Measurement issues

Since the costs of informal care are to an important extent related to the time inputs of informal caregivers, valid (time-specific) ways of measuring are necessary for the valuation of informal care. We will discuss some major issues in the measurement of time spent on informal care, i.e. the choice of a measurement method, the distinction of informal care and normal housework, joint production, and several informal caregivers caring for one care recipient.<sup>6</sup>

Two frequently applied methods<sup>7</sup> of collecting time budget data are the diary method and the recall method. The diary method is normally considered to be the gold standard (Juster and Stafford, 1991, p.473). Answers typically depend on the questions<sup>8</sup> posed and the recall period used. In general, however, estimates from the diary method tend to be lower than estimates from the recall method. This is especially true for housework (Juster, 1985, p. 5). Still, a disadvantage of the diary method compared to the recall method is that it is very time consuming, which can bias the results in favour of less busy respondents.

Besides the applied method and recall period used, the assessment of time investment also entails the explicitness of questions posed. For example, one may ask: *How many hours did you spend on informal care during the last week?* Some respondents could consider certain tasks as informal care while other respondents could consider them as leisure or housework. To prevent this kind of bias, the analyst should preferably present the respondents a list of informal care tasks and ask them to indicate how much time they spent on those tasks during a certain period. Using such a list makes it necessary however, to make a distinction between normal housework and informal care. This is especially the case if the informal caregiver and care recipient share the same household or if informal care has been provided for several years. Only the additional part of housework due to the disease of the care recipient should be counted as informal care. One has to be clear about this point in a survey. Still, it may be difficult for respondents, especially in cases where informal care has been provided for many years already, to distinguish between normal tasks (i.e. those also performed if the patient had not been ill) and informal care.

---

<sup>6</sup> See Juster (1985) and Juster and Stafford (1991) for excellent methodological overviews of the measurement of time.

<sup>7</sup> Other methods are for example the 'buzzer' method and the 'outsider' method.

<sup>8</sup> "When the interviewee is asked how much time he spent on certain activities, rather than what activities he engaged in during a certain time, the results are bound to be less accurate because there is no time constraint (e.g. daily activities usually do not add up to 24 hours) (Gronau, 1986, p. 279).

Joint production, defined as doing two or more activities at the same time by one person, is another complicating factor. The more ‘joint’ activities are, the less accurate the results tend to be. The problem tends to be more complicated when for example leisure activities are combined with providing informal care, for example, watching television and supervising after a care recipient with Alzheimer. Spauwen (2002) showed that there is a positive relationship between providing informal care household activities and normal household activities at the same time. Providing informal care was, however, not combined with other activities like for instance leisure. This combination is often suggested in the literature but not supported by this data.

Another point of attention is that diaries and the recall method often, though not necessarily, relate to one informal caregiver, while in many cases more informal caregivers are involved. This can lead to an underestimation of the total amount of provided informal care and the time involved in it.

Finally, in developing the survey, one has to keep in mind the discussed measurement problems and the preferred valuation method needs to be the starting point.

### 3.4 Valuation methods for informal care

Various methods for the valuation of informal care have been discussed in the literature and have been applied in previous research. In this section we present an overview of the different methods. They can be divided into three categories: revealed preference, stated preference<sup>9</sup>, and other<sup>10</sup> (table 3.1).

**Table 3.1:** Valuation methods for informal care

Revealed preference methods	Stated preference methods	Others
Opportunity costs	Contingent valuation	Objective burden
Proxy good	Conjoint measurement	Subjective burden
		Health- related quality of life
		Well-being

<sup>9</sup> This distinction is of importance since the “difference between [the revealed and stated preference method] comes down to using uncompensated (Marshallian) demand curves in case of revealed preference valuation method, and estimating the income-compensated (Hicksian) demand curves in the case of the stated preference valuation method” (Baarsma, 2000, pp. 54-55).

<sup>10</sup> Objective and subjective burden are not valuation methods but merely an indication of the burden of caring. Moreover, the methods in the column “others” are more general concepts and involve a lot of specific methods or instruments.

The major problem in valuing informal care is that by definition no market prices exist. It is often argued that informal care in economic evaluations should be valued with the opportunity cost method (Smith and Wright, 1994, p. 139), (Posnett and Jan, 1996, p. 20), and (Drummond et al., 1997, p. 86). As an alternative the proxy good method is also proposed (Luce et al., 1996). However, there are some problems with both methods, as they will be discussed below. In addition, the pro's and con's of other available methods to value informal care are discussed below.

### **3.4.1 Revealed preference methods**

Both the opportunity cost method and the proxy good method use real life decision data to value informal care and may therefore be seen as revealed preference methods. This means that preferences of informal caregivers are deduced from informal caregivers' decisions or from decisions in the market for close substitutes of informal care. For the application of both methods, only the time forgone or spent on informal care has to be measured and valued in different states of the world: without and with the intervention under study or reference case and intervention. The advantages and disadvantages of both methods will be discussed below.

#### **Opportunity cost method**

The opportunity costs of informal care are the informal caregiver's benefits forgone due to spending time on providing informal care. In general, the forgone benefits are approximated by an individual's market wage rate. So, the value of informal care equals the market wage rate of the informal caregiver multiplied with the hours of time forgone or the hours spend on informal care.

In an optimal world this implies that from the perspective of the informal caregiver the value of all hours spent on informal care, including the last exceeds the caregiver's hourly market wage rate. Thus the opportunity cost method gives just a minimum of the value of informal care. However, informal caregiving often involves non-labour market participation, for instance for full-time housewives or retired people. As a solution to the non-labour market participation, one can use a modified opportunity cost method to find out the reservation wage rate of the informal caregiver. This is the wage rate for which an individual is willing to supply at least one hour on the labour market (Kooreman and Wunderink, 1996, p. 113). Another practical solution is the imputation of the known wage of similar people (e.g. same sex, educational level and age). To make the

valuation more complicated informal care is often at the cost of unpaid work or leisure time. The analyst needs to impute a valuation of these types of time forgone to get a value of informal care.

An advantage of the opportunity cost method compared to its close substitute, the proxy good method, is that it is not necessary to distinguish between different informal care tasks provided, which makes it easier to use. Still, distinguishing between the different types of normal time use sacrificed is necessary. As indicated, especially when informal care has been provided over longer periods of time, it may be difficult for respondents to indicate what time use has been sacrificed. An alternative approach is to ask what people would preferably want to do with their freed time if this had no longer to be spent on informal care (Chapter 5).

Despite the recommendations to use the opportunity cost method to value informal care, the method has some important disadvantages. Using the opportunity cost method to value informal care instead of just to indicate informal caregivers opportunity costs leads to different values of the same commodity informal care due to one's potential wages somewhere else in the economy. For instance, the same type and amount of informal care provided by a professor of health economics gets in the first case a higher value than informal care provided by a PhD student all other things equal (especially during paid work, but mostly valuation of leisure and unpaid activities are related to income as well – as micro-economic theory suggests). This is the so-called Hawrylyshyn paradox (Hawrylyshyn, 1977) and (Gronau, 1986). An explanation for the Hawrylyshyn paradox is that providing informal care involves different direct utilities, sometimes also called process utility, for the professor and his PhD student. It is debatable whether or not this direct utility should be incorporated in economic evaluations while traditional measures of market output do not incorporate them. Moreover, the opportunity cost method is quite general with a focus on the valuation of time forgone due to informal caregiving instead off the valuation of the full impact of providing informal care for the informal caregiver.

Double counting of other, e.g. care recipients' costs or outcomes, is not expected to pose a serious problem. The costs of informal care can be incorporated in the cost side of CBA, CUA or CEA, as they are purely monetary. The method can also be used in combination with other methods to measure the full impact of informal care, like health-related quality of life. In that case avoidance of double-counting needs more attention as well as the appropriate way of incorporating the health effects of informal caregivers in economic evaluations. The latter issue is further discussed below. Examples of the

application of the opportunity cost method to value informal care, are studies done by Ettner (1996) and O'Shea and Blackwell (1993).

### **Proxy good method**

The proxy good method or market cost method values time spent on informal care at the (labour) market prices of a close market substitute. This approach requires the availability of a market substitute for the non-market good, which is assumed to be almost perfect. The time spent on informal care is valued at the wage rate of a market substitute, which can differ for different tasks: e.g. housework is valued at the market wage of a professional house worker and personal care is valued at the market wage of a professional nurse.<sup>11</sup>

This method is also rather simple and crude. Using a list of performed activities and the time spent on these activities, it is possible to calculate some kind of formal proxy value. However, the method has also some disadvantages. First, by using wage-rates of e.g. health care professionals as the proxy value, one assumes that formal care and informal care are perfect substitutes. For instance, no differences in efficiency and quality are assumed to exist. It is also assumed that informal caregiving does not involve direct (dis)utility. This means that neither the care recipient, nor the informal caregiver enjoys the fact that the latter provides the care. Another point of concern is the used wage rates. Due to collective agreements and regulation the wages of professionals in the health care sector do not necessarily represent real labour scarcity in society.

The proxy good method poses other measurement problems than the opportunity costs method, because the analyst does not need to know the different sources of time forgone. However, the distinction between "normal" tasks and informal care tasks as discussed above is crucial. For the practical application the availability of a close market substitute in the heavily regulated health care sector or the informal sector for household services is also crucial.

The monetary costs of informal care according to the proxy good method can be incorporated in the cost side of CBA, CUA and CEA. Double counting with e.g. care recipient's outcomes or costs is not expected to be a serious problem because only the informal caregiver's perspective is used. The method can be also be used in combination with other methods, like health-related quality of life, but again the threat of double-counting needs attention.

---

<sup>11</sup> One can debate whether this should be the gross wage (the real opportunity costs to society) or the net wage (the wage rate for which the professional is willing to sacrifice leisure).

### 3.4.2 Stated preference methods

Next we discuss two stated preference methods for the valuation of informal care: the contingent valuation method (CVM) and conjoint analysis (CA). Stated preference methods are used to measure and value respondents' preferences mostly for non-market commodities through (oral or written) surveys. Often, the aim is to find a monetary valuation of a non-market commodity, such as informal care. This monetary valuation is used as a proxy for respondents' well-being because well-being is not directly measurable. However, an individual's preferences are not always a good indicator of an individual's well-being (Ng, 1983, pp.7-12). This may be the case (i) when the preferences of an individual may not only be affected by his own welfare, but also by his consideration for the welfare of others; (ii) due to ignorance and/or imperfect foresight; and (iii) when an individual exhibits irrational preferences.<sup>12</sup> One has to keep in mind those cases in the application of stated preference methods.

#### Contingent valuation method

Hicks (1939) identified two methods to express the effect of an intervention on an individual's well-being in a money metric: compensating variation (CV) and equivalent variation (EV) (see also Hausman (1981) and Boadway and Bruce (1984, pp. 39-43). These methods are commonly known as willingness to pay (WTP) and willingness to accept (WTA). One could apply CVM to value informal care e.g. by assessing the minimum amount of money an informal caregiver would need to receive to be willing to provide a certain or an additional amount of informal care.

Although the concepts of WTP and WTA are relatively easy to grasp, the practical application of CVM could be troublesome in the context of informal care, because informal caregivers often claim that money is at least low on their agenda [Smith, 1994 #36]. This could imply that informal caregivers find it unseemly to indicate that they would need a monetary compensation in order to provide informal care to somebody in their social environment they love. Moreover, economists often reject CVM because the method conflicts with the one of the central axioms in economics: revealed preference. They argue that it is just the intention of respondents that is measured in CVM instead of real

---

<sup>12</sup> "The preference of an individual is here defined irrational if he prefers  $x$  over  $y$  despite the fact that his welfare is higher in  $y$  than in  $x$ , and his preference is unaffected by considerations of the welfare of other individuals (any sentient creature can be an individual here), or by ignorance or imperfect foresight (Ng, 1983, p. 10)"

behaviour as required in the revealed preference axiom. In addition, on an applied level it is well known that CVM studies involve different types of bias<sup>15</sup>. Finally, double counting could be a major problem in the application of CVM to value informal care since informal caregivers are assumed to take the preferences and perhaps the health of their care recipient into account.

An example of the application of the CVM method to a close non-market substitute of informal care is a study done by Garbacz and Thayer (1983). They used an experiment in senior companion program services to value companionship with the CVM. In their design, respondents were placed in a hypothetical market where the current level of their services was reduced with either 25 percent or 75 percent. Then, respondents were asked either to determine their maximum WTP to prevent the reduction or their minimum WTA to be compensated for the proposed reduction in services. Finally, these results were compared to the actual costs of the program to see whether or not the reduction in the service level could be justified on the basis of CBA.

### **Conjoint analysis**

Conjoint analysis (CA) or conjoint measurement (CM) is a method for the analysis of respondents' preferences for a set of multi-attribute alternatives. It can be linked to Lancaster's attribute based utility theory (Lancaster, 1971). Lancaster's contribution was that he stressed that a commodity possesses more than one characteristic. For example, a meal will have both nutritional and aesthetic characteristics in different relative proportions for different individuals.

Green and Srinivasan (1978, p. 104) define CA as: "*any decompositional method that estimates the structure of a consumer's preferences [...], given his/her overall evaluations of a set of alternatives that are prespecified in terms of levels of different attributes.*"

Different CM techniques are available, such as ranking, rating and discrete choice or choice experiments. Respondents are for instance asked to rate different states of the world, often called vignettes, to reveal their preferences. The states of the world can differ according to dimensions, called attributes. If one attribute is a price, it is possible to derive

---

<sup>15</sup> See Mitchell and Carson (1989) for an extensive overview of these and other practical problems in assessing an individual's WTP or WTA.

implicit prices for the other attributes. Thus a value in monetary terms can be derived. One can also attain a utility outcome from the respondents' choices.

Within economic evaluation CA is of growing importance for the measurement of care recipient's preferences, see Ryan and Farrar (2000) and Ratcliffe (2000) for overviews. A Dutch study (De Groot et al. 2000) used CA to investigate to what extent people wish to spend more or less time on providing informal care given their own circumstances and what determines their choice between hiring a professional caregiver and providing informal care. The design of this study makes a distinction between providing informal care for a partner, parent (in-law), family, or friends and neighbours. In general, the researchers concluded among other things that the amount of time available and the amount of time necessary to spend on informal caregiving are important predictors of an individual's decision to be involved in the informal caregiving process as opposed to hiring another caregiver. The social relation between informal caregiver and care recipient however makes the trade-off subtler. The closer the social relationship, the more willing an informal caregiver is to provide the care himself. The less close the social relationship, the more important other considerations become. Providing informal care for a parent (in-law) for instance is more likely to be preferred when it involves more than one hour a day preferably one or two days a week. Moreover, it is in providing informal care to a parent (in-law) preferred if informal caregivers get a small monetary compensation. This finding is contrary to the before mentioned suggestion of (Smith and Wright, 1994).

Advantages compared to CVM are CA's ability to elicit respondents' preferences for different detailed scenarios and respondents' ability to express their preferences for more than one scenario. CA's complexity, in other words respondents need to consider a number of attributes at the same time, simultaneously may be a problem.

Double counting again can be a problem in the application of CA, as in CA the informal caregivers can also take the preferences of the care recipient into account.

### **3.4.3 Other methods for measuring the impact of informal care**

In this section other methods to capture the impact of informal care are presented. First, we deal with the assessment of objective and subjective burden of informal care. Although these are no valuation methods from an economic point of view, much work is done in this area by e.g. sociologists and psychologists. Next, we discuss health-related quality of life measurement in the context of informal care. Finally, we discuss direct measurements of well-being. The central problem with these methods is that their results cannot easily be

incorporated in economic evaluations. We will discuss this issue after we have discussed the methods.

### **Objective burden assessment**

Objective burden entails assessing the time invested in caring, the seriousness of the care recipients' illness, and the caring tasks performed. Problems concomitant to the measurement of time were discussed above. Two examples to measure the time spent on caring for Alzheimer patients are the Caregiver Activities Time Survey (CATS) (Clipp and Moore, 1995) and the Caregiver Activity Survey (CAS) (Davis et al., 1997). Both instruments are developed to incorporate informal care in economic evaluations. However, the underlying aim was to translate the results in monetary units with the proxy good method.

The results of objective burden assessment can be used as additional information for the decision maker. However, normally, the focus in economic evaluation lies on monetary costs and health effects solely. Additional outcomes, such as the objective burden of informal care are hard to incorporate coherently and comparably in an economic evaluation. Still, due to the practical difficulties with deriving a monetary value of informal care one could argue that it is better to present an additional outcome measure in an economic evaluation than to neglect informal care or to attach an arbitrary monetary valuation to it.

### **Subjective burden assessment**

There is abundant literature on the impact of providing informal care on informal caregivers, see for example, Kramer (1997), Hughes et al. (1999), Schulz and Beach (1999), Low et al. (1999), Leblanc et al. (1997), Gallagher and Mechanic (1996), and Pearlin et al. (1990). Often a distinction is made between the physical, emotional and social burden of informal caregiving. The assessment of subjective burden relates to the strain of care as experienced by the informal caregiver. Informal caregivers may, e.g., be asked about lack of support of others and disruption of their schedule. Many subjective burden instruments are disease-specific and focus often on the negative aspects of caring.

Three problems related to subjective burden are mentioned here. First, the concept of subjective burden is lacking a theoretical foundation leading to a lack of conceptual clarity (Kramer, 1997, pp. 227-228), (Gallagher and Mechanic, 1996) and (Hughes et al., 1999). This leads to results in differences in the elements captured in terms

of subjective burden and differences in the way these elements are made operational and measured. This makes the interpretation and comparison of the results rather troublesome. Second, the subjective burden assessment focuses mainly on the negative aspects of the caring process experienced by the informal caregivers. The positive aspects of caring are often neglected and if not, the rationale behind the choice of the included positive aspects is hardly ever indicated. Finally, existing subjective burden instruments do not value the subjective burden they 'merely' register it on some scale.

Given the informational richness of burden assessments, it has been suggested to incorporate the results of these studies in economic evaluations (Drummond et al., 1991). Moreover, the results of subjective burden assessment could, like the results of objective burden assessment, be used as a kind of additional natural units of information in CEA. However, Drummond et al. (1991, p. 171) are sceptical since subjective burden measures may not be very responsive to change while in economic evaluations it is exactly a change or difference that needs to be registered and valued.

The measurement of subjective burden may lead to fewer problems than the measurement of objective burden. To indicate the amount of time spent on caring is perhaps more difficult for informal caregivers than to express their feelings about a list of items on a certain measurement scale as in subjective burden. Still, the interpretation of objective figures may be more straightforward than the interpretation of their subjective counterparts.

### **Health-related quality of life**

It has been argued that the provision of informal care can lead to both mental and physical health problems (Hughes et al., 1999), and even to higher mortality risks (Schulz and Beach, 1999, p. 2215). These are indications that informal caring is an independent risk factor for mortality and morbidity concerning some groups of informal caregivers, e.g. elderly spousal caregivers (Schulz and Beach, 1999). In that sense, health-related quality of life measurement may be used in order to assess the impact of providing informal care on informal caregivers health, as the main goal of health care is to preserve or restore health (Mohide et al., 1988).

How to register possible health-related quality of life changes due to informal caregiving is controversial. Moreover, the causality of the relation between providing informal care and health-related quality of life losses remains unclear. E.g., does the strain of providing informal care lead to reductions in health-related quality of life or do people

with health problems who become informal caregivers find this more straining? This causality is crucial if one wishes to incorporate informal caregivers' health losses in economic evaluations because the focus of an economic evaluation is on the health effects of an intervention. Moreover, some health-related quality of life reductions reported in informal caregivers (like depression and anxiety) may be related more to the mere incidence of illness in ones social environment and less with the provision of informal care. In other words, reductions in health-related quality of life when a child falls ill may occur regardless of whether or not the parents provide informal care. This kind of health-related quality of life reductions should not be incorporated in economic evaluations.

Mohide et al. (1988) developed a Caregiver Quality of Life Instrument (CQLI). They used Torrance's time trade-off (TTO) technique to obtain utility scores for three standardised caregiver situations and utility scores for the respondent's own state. The respondents were asked to choose between being in alternative states of the world for different periods of time. The alternative states of the world differed in five dimensions: two social dimensions, i.e. amount of time to socialise with family and friends, and quality of the relationship between the caregiver and the care recipient; two physical dimensions, e.g. degree of physical wellness and energy, and adequacy of amount of sleep; and one emotional dimension, e.g. degree of happiness and freedom from anxiety and frustration. The CQLI is used to obtain utility scores from informal caregivers. The results however, have to be interpreted carefully to avoid double counting. It would be incorrect to add the utility scores of informal caregivers and care recipients simply in economic evaluations because their utility functions are expected to be interdependent. If the informal caregiver takes into account the utility of the care recipient and the care recipient does vice versa, adding their utility scores will lead to a misperception of the total utility.

Disadvantages of the CQLI are its complexity and its high costs. The method is not easy to understand thereby limiting its application and introducing possible bias. It is an expensive method because it requires face-to-face interviews by trained interviewers, which may not be feasible in many contexts.

### **Well-being**

Psychologists and sociologists have done a lot of research on the concept of well-being. A distinction is made between satisfaction with life as a whole and satisfaction with a specific domain. The main findings are that subjective variables explain individual satisfaction better than objective variables, and that domain-specific satisfaction is strongly correlated

with well-being in terms of satisfaction with life as a whole (Frijters, 1999, p.115). In (health) economics this research is uncommon, partly because the objections of economists against the measurability and comparability of well-being and partly because of the focus on health rather than well-being. Frijters' tries to remove the opposition from economist against the measurement of well-being.

We suggest that informal care could also be valued by registering changes in well-being of informal caregivers. An advantage of this method is that it allows to combine economic and non-economic factors affecting the preferences of an individual (Ng, 1980, p. 64). To our knowledge, no research has been done using this concept to value informal care. It would be interesting to measure informal caregiver's well-being to compare it with informal caregivers health-related quality of life or with the well-being of the general population. Possible, differences in reported well-being could be used as alternative measures to the so far discussed methods. Moreover, they could be incorporated in economic evaluations taking a societal perspective that is broader than a health perspective.

### **3.5 Some unresolved issues**

We have discussed different methods for the valuation of informal care. It proves that not all of those methods can be incorporated in the main types of economic evaluation. The main reason is that CEA, CUA and CBA require different kinds of information. Moreover, not all methods yield complete valuations of informal care. Finally, it is not always clear who should value informal care: the care recipient, the informal caregiver or the general public? In this section, we discuss these matters somewhat further.

#### **3.5.1 Incorporation**

The issue of incorporation is connected with yielding monetary or non-monetary results. All three types of economic evaluation can incorporate a monetary value of informal care, at the cost-side of an analysis. This implies that the valuation methods that yield monetary values can be used in all three evaluation contexts; CBA, CUA and CEA. The opportunity cost method, the proxy good method, CVM and CM. Since in CBA, all information on costs and outcomes needs to be expressed in monetary terms, the mentioned valuation techniques are also the only ones that can be used in CBA. In principle, measurement of objective burden, subjective burden, health-related quality of life and well-being will yield non-monetary outcomes. However, it is worth noting that it is possible to translate the

non-monetary outcomes in money outcomes. In the context of a CUA, one needs valuation techniques yielding preference-based or utility-based outcome measures. Utility based, health-related quality of life changes in informal caregivers could therefore in principle also be included in such an analysis. How to combine these changes with changes in health-related quality of life in care recipients is however unclear. Moreover, preference-based or utility-based CM or well-being measures may also be considered to be suitable for incorporation in CUA, as they reflect preferences or utility of informal caregivers. Meaningfully combining these with quality of life changes of patients seems however impossible, leading such CUAs to become multi-criteria analyses. Finally, in CEA, one may use the four above-mentioned techniques as well as objective burden and subjective burden measures. The latter may be seen as a measure of the impact of informal care in 'natural units' to be put on a balance sheet of pros and cons.

### **3.5.2 Partial or complete valuation**

Complete valuation methods focus on all aspects of informal care, while partial valuation methods focus only on some aspects of informal care. Especially burden measures and health-related quality of life measurement can be used to indicate only some aspects of informal care. Ideally, they should be complemented with other valuation methods, avoiding double counting. CVM and CM are normally used to create a total valuation of informal care. However, it often depends on the questions asked and the tasks considered whether such a complete valuation is reached. In CM, for instance, complete valuation would entail specifying all aspects of informal care in a vignette. This could be troublesome in practice. All the other methods do not yield a total valuation of informal care. Therefore, methods could be combined, like e.g. complementing the opportunity cost method with health-related quality of life measures.

### **3.5.3 Who to ask**

Finally, who should value informal care? This is a complicated issue in the context of the valuation of informal care. A first response could be to use actual informal caregivers as source of valuation. However, this source may come up with biased or strategic answers, just as in health state valuations. To avoid such problems, one may measure the preferences of the general public as potential, actual or former care recipients or informal caregivers. Just as for the valuation of health-related quality of life, the general public may be used as a 'more objective' though less informed source of valuation therefore.

Besides this problem, there is also the problem of whether the producer of informal care or the consumer of informal care should value this non-market commodity. Should an additional hour of informal care be valued by the producer, e.g. the value this additional hour has for the informal caregiver or rather by the consumer, e.g., the value of the additional hour to the patient. The answer to this question is a matter of perspective probably (e.g. do we wish to determine the impact of informal care on the (health or wellbeing of the) patient or do we wish to determine the impact of providing informal care on the caregiver), but also has implications for the methods chosen in the economic evaluation. In the opportunity cost method for instance, the informal caregiver is central to the valuation of informal care. His time investment and his wage rate are used. In the case of the proxy good method some kind of societal replacement value is calculated on the basis of for instance formal caregivers wage rates. For CVM, CM as well as well-being it is however more difficult to grasp who should be central to valuation. As long as the informal caregiver enters a caregiving situation voluntarily and given the focus on health outcomes in relation to costs, it appears that the valuation of informal care should be caregiver centred. Yet, this point and the interdependencies between preferences of caregivers and care recipients should receive more attention.

### **3.6 Conclusions and recommendations**

Despite its contribution to the care for chronic and terminally ill patients, informal care is often neglected in economic evaluations of health care programs. The incorporation of informal care in economic evaluations is however crucial to prevent undesirable policy recommendations. Informal care should not be treated as 'free' in economic evaluations, as this may lead to cost-ineffective care strategies from a societal perspective and even to health damage in the population at large. It is therefore crucial to incorporate the full impact of providing informal care on informal caregivers as well as on the patient. We have discussed different methods available to value and register the impact of informal caregiving on the informal caregiver.

The main message of this chapter is that to preserve undesirable shifts due to new policies on the account of informal caregivers a full valuation method of the costs and effects of providing informal care for the informal caregivers is necessary. In theory CV and CM are such methods. However, this has to be confirmed in practice. For instance, it has to be confirmed the application of CV and CM yields reliable results and that

respondents indeed can incorporate all aspects of informal care in their valuation of it. A clear advantage of both methods is that they yield monetary results and can therefore easily be incorporated on the cost side of all types of economic evaluations.

As long as no valid empirical applications of CV and CM exist, the opportunity cost and proxy good method can be used to incorporate informal care in economic evaluations. However, both methods do not cover the full costs and effects of informal care. Therefore, they should be complemented with other methods like for instance health-related quality of life measurement in informal caregiving, be it at the price of a more complex interpretation of the results of economic evaluations. Moreover, more empirical evidence is necessary to ensure that health-related quality of life methods are sensitive enough to measure changes in the health-related quality of life of informal caregivers due to the provision of informal care. It is also worth noting that a combination of for example the opportunity cost method and health-related quality of life measurement does also not necessarily cover the full impact of informal caregiving because for instance the direct utility of the informal caregiver is neglected.

More research is needed and it is recommended to combine different methods in ongoing research in order to detect the full impact of informal caregiving as well as gathering more information on the performance of different methods. We should get more serious about valuing something valuable as informal care.

# 4 Measurement of informal care: An empirical study into the reliable measurement of time spent on informal caregiving<sup>1</sup>

*“After dinner, he may find himself drinking Brazilian coffee, smoking a Dutch cigar, sipping a French cognac, reading The New York Times, listening to a Brandenburg Concerto and entertaining his Swedish wife – all at the same time, with varying degrees of success.” (Linder, 1970, p.79)*

## Summary

*Incorporation of informal care in economic evaluations of health care is troublesome. The debate focuses on the valuation of time spent on informal caregiving, while time measurement a related and may be even more important issue, tends to be neglected. Reliable time measurement is a necessary condition for the valuation of informal care.*

*In this chapter two methods of time measurement will be compared and evaluated: the diary, the gold standard and the recall method, an often-applied method. The main objective of this comparison is to explore the reliability of the measurement of time spent on providing informal care. In addition this chapter gives empirical evidence regarding the measurement of joint production and the separation between ‘normal’ housework and additional housework due to the care demands of the care recipients. Finally, a test-retest about the stability of the recall method over time was performed.*

*A total of 199 informal caregivers for care recipients in a heterogeneous population completed the diary and the recall method. Corrected for joint production, informal caregivers spent almost 5.8 hour a day on providing informal care.*

*The recall method is a reliable method to measure time spent on providing informal care compared to the gold standard, the diary, if one assumes that respondents take into account joint production when completing the recall questionnaire. Otherwise, the recall method overestimates the time spent on providing informal care. The recall method moreover proved to be unstable over time. This could be due to learning effects from completing a diary.*

---

<sup>1</sup> Based on Van den Berg, B., Spauwen, P., 2004. Measurement of informal care: An empirical study into the reliable measurement of time spent on informal caregiving. In revision Health Economics.  
Chapter 4: Measurement of informal care: An empirical study into the reliable measurement of time spent on informal caregiving 65

## 4.1 Introduction

Incorporation of informal care in economic evaluations of health care is troublesome. The debate focuses on the valuation of time spent on informal caregiving, see for instance Smith and Wright (1994), Posnett and Jan (1996), McDaid (2001) and chapter 3. A perhaps more important and related but often neglected issue is the measurement of time spent on providing informal care. Reliable measurement is a necessary condition for the valuation of informal care. This is also recognised by McDaid (2001) and in chapter 3.

In this chapter two methods of time measurement will be compared and evaluated: the diary and the recall method. The main objective of this comparison is to discuss the reliability of the measurement of time spent on providing informal care. First, we try to validate the recall method compared to the diary. The diary is the gold standard for the measurement of time use (Juster and Stafford, 1991) and (Robinson, 1985). This validation is of importance because the diary is more time consuming for respondents than the recall method and therefore less useful for applied research, especially in a context where time spent on informal caregiving is just one of the many topics of a survey. We also present empirical evidence about the measurement of joint production, a persistent problem in the measurement of time in general and also in informal caregiving. A more specific problem in the measurement of informal care is the separation between ‘normal’ housework that somebody does anyway and additional housework due to the care demands of the care recipients. We tried to solve this problem by separating ‘normal’ housework and housework due to informal caregiving in the diary. Another aim of this chapter is to present empirical evidence about the stability over time of the results of the recall method. In other words, we tested the recall method for test-retest reliability. Finally, as a spin off we give an indication about the amount of time informal caregivers spent on providing care to a heterogeneous population of care recipients.

A sample of 199 informal caregivers providing care to a population of care recipients heterogeneous in terms of disease characteristics, consisting mainly people with a chronic disease, completed the diary at one and recall method at two moments in time. This implies that we choose for within subject comparisons in our analyses.

The outline of the chapter is as follows. In the next section, we describe and discuss the developed diary and recall method, against a backdrop of available literature. The data are presented and described in section 4.3. Section 4.4 gives the results of the comparison between the diary and recall method. The results of the recall methods’ test-

retest reliability are described in section 4.5. The final section presents the discussion and conclusions.

## 4.2 Methods

Both the diary and recall method are written surveys. We introduce them in this section in more detail, against the backdrop of literature about time measurement.

### 4.2.1 Time measurement

It is not easy to measure an individual's time use. There are different methods for the measurement of time, see Juster (1985), Gronau (1986), Juster and Stafford (1991), and Kooreman and Wunderink (1996) for overviews. The most important methods are the diary, considered the gold standard, and the recall method (Juster, 1985) and (Juster and Stafford, 1991). This gold standard is however not universally accepted; see for an alternative approach for instance Homan (1988, p.77). In a diary, respondents are asked to write down all their activities during a specified period of time. The diary has an important disadvantage, in that it requires a lot of time and effort from the respondents. The method is also very costly for researchers. Therefore, measuring time with a diary is not feasible in all situations. This could well be true for the measurement of informal care time as care responsibilities put a heavy burden on informal caregivers. Therefore, a time-consuming research method like the diary might not be the appropriate choice here. A less demanding method like the recall method would be preferred.

In the recall method, respondents are asked how much time they spent on a list of activities during for example the previous day or week. Obviously, a major concern with this retrospective way of questioning is its reliability because of recall bias. Another concern is the less systematic way of questioning in a recall method compared to the diary.

Another problem in time measurement is how to measure tasks that are carried out simultaneously.<sup>2</sup> Doing several activities at the same time or a period of time is called joint production (Kooreman and Wunderink, 1996). This is an important issue in informal caregiving. Thus while looking after a person with Alzheimer, informal caregivers may perform other (informal care) tasks like cleaning or watching television. Robinson (1985, pp.46-48) suggests that respondents correct for this joint production when completing a

---

<sup>2</sup> Simultaneously does not necessarily mean at exactly at the same moment. It can also mean during the same period of time (for instance 15 minutes).

recall questionnaire. He presents some empirical evidence for this suggestion. In many recall methods, respondents reported time use that add up to more than 168 hours (7 times 24) a week. It seems that especially activities that are most often performed in combination with or as secondary to other activities, like watching television, childcare and resting, are responsible for this outcome.

Joint production can be measured with a diary. In a diary, one can ask respondents to report all their activities during a certain amount of time, for instance one quarter of an hour. However, the researcher has to decide how to allocate the time between the reported activities performed during that period. In practice most applications of the diary ask respondents only about their main activities instead of all activities (Kooreman and Wunderink, 1996).

Some instruments were developed to measure the time spent on informal caregiving, for example the CATS (Caregiver Activities Time Survey) (Clipp and Moore, 1995), the CAS (Caregiver Activity Survey) (Davis et al., 1997), and the RUD (resource utilization in dementia) (Wimo et al., 2002). The mentioned instruments are examples of the recall method. Unfortunately, they failed to validate their recall methods by comparing them with the diary. Their focus was on test-retest reliability or on the relation between the time spent on informal caregiving and the severity of the care recipient's illness. All instruments were developed to measure caregiving for people in a homogeneous sample in terms of diseases, viz. Alzheimer or Dementia.

#### **4.2.2 The informal care diary**

We developed an informal care diary to collect reliable information about the time informal caregivers spent on providing informal care during a typical 24-hour period. A 24-hours period was divided into 96 units of time (96 periods of 15 minutes). Three types of informal care tasks were distinguished: (1) support with activities of daily living (ADL), e.g. personal care, (2) support with instrumental activities of daily living (IADL), e.g. managing home adaptations, and (3) housework (HDL), e.g. cleaning the house. We added some general categories of other potential time uses, e.g. sleeping, paid work and unpaid work. To get more precise information about the time spent on informal caregiving, we divided ADL and IADL tasks each into four sub-categories, and HDL tasks into six sub-categories. In the diary, the columns contained the tasks while the rows contained the units of time. See Appendix 1 for a page from the diary.

To account for joint production, respondents could indicate two or more activities for the same quarter of an hour. This was explained in the introduction to the diary. We also gave an example of joint production in the introduction to prevent respondents from thinking that they were allowed to put only one cross in every quarter of an hour. It is worth noting that as a result of the possibility of indicating two or more activities per quarter of an hour, the total amount of provided informal care could add up to over 24-hours a day.

We corrected for joint production with equation 1:

$$\text{Corrected activity } A = (96 \text{ quarters} / \text{total number of activities per day}) * \text{activity } A \quad (1)$$

Total number of activities per day is the sum of the respondents' crosses in every quarter of an hour. Obviously, the minimum number of activities per day is 96 because a day consists of 96 quarters of an hour.

As discussed before, it is difficult to separate 'normal' HDL tasks from informal care HDL tasks. We tried to solve this problem by splitting the HDL tasks column in normal care tasks, provided in the informal caregiver's own interest and informal care HDL tasks, performed solely to meet the care demands of the care recipient. The latter column was given a blue colour to stress the difference between the two. This enables us first to compare the recall method with the diary with only the truly informal care. And second to compare the recall method with the diary where the informal care part of housework is added to the 'normal' housework to find out whether or not respondents take into account this difference when completing the recall questionnaire.

To get a representative picture of the informal care provided during a week without making too heavy demands on the respondents, we asked the informal caregivers to report their time use for only two days a week. Therefore, we took two specific days and two reserve days. Moreover, we divided our sample in 21 subgroups covering all possible combinations of two days a week. We asked the informal caregivers to fill out the diary 6 times during the day: during their breakfast, lunch, and dinner, between these meals, and before going to bed. Thus the diary involves a much shorter recall period compared to the recall method. Another advantage of the diary above the recall method is that the diary gives respondents a systematic overview of their time use during an entire day thereby forcing them to think systematically about their time allocation during that day.

### **4.2.3 The informal care recall method**

The informal care recall method was developed to collect information about the time informal caregivers spent on providing informal care during the week preceding the interview. When completing the recall questionnaire, the respondents were asked emphatically to consider the same week as in the diary.

The recall questionnaire focussed on the same informal care tasks as the diary. Respondents could choose to report their time use in minutes per day or in hours per week because some activities are perhaps routinely done everyday, while others are less of a routine. See for the exact questions Appendix 2.

The recall method questions were not presented as the central focus of the survey but as just a part of it. This to prevent respondents from becoming aware of the research aim.

### **4.2.4 Diary versus recall method**

We will compare the results of the diary and recall method in two stages. First, the diary not corrected for joint production will be compared to the recall method, in line with Robinsons' (1985) argument that respondents account for joint production when they complete the recall method. Second, the diary corrected for joint production will be compared to the recall method. This, because the objective of the measurement of informal care is the valuation of informal care to incorporate it in economic evaluations. It is therefore important to correct for joint production for one wishes to attach a monetary value to time spent on informal caregiving and providing informal care is combined with other activities, one could argue that it is not correct to attach the full monetary value. Instead of attaching part of the full monetary value, one could better measure the time spent on providing informal care corrected for joint production. We will test whether or not the recall method is successful in this respect.

Again, the diary is seen as the gold standard in both cases. Possible differences between the diary and recall method will be tested for with a t-test (Rice, 1995).

### **4.2.5 Alternative approach**

Homan (1988, p.77) suggests a complete different approach. He argues that it is better to measure time in an aggregated way instead of the disaggregated ways we discussed before. In other words, he proposes to use just one question about the aggregated time spend on a

certain task, instead of many different questions because the latter approach involves the danger of double counting. According to Homan, another advantage of this approach is that it leaves the classification of the activities performed at home up to the respondents. In case of providing informal care some respondents could indicate some tasks as informal care, while other respondents do not consider the same tasks as informal care. We also test Homan's approach as an alternative in this chapter. In the survey we therefore asked the following question:

*"How much time did you spend on housework during the last week?"*

We focussed on housework instead of informal care to prevent that respondents became aware of our research aim. We will test for possible differences between this question and the results of the diary and recall method.

#### **4.2.6 Test-retest reliability**

We also tested for consistency of the recall method over time. Five months before this study, the respondents completed the same recall method as part of another study. This makes it possible to test the recall method for test-retest reliability. For the recall method to be a reliable method to measure informal care time compared to the diary, a second condition for its application is stability over time. Moreover, critique on a within sample comparison could be that completing a recall method a few days after completing a diary would involve learning effects for respondents. Therefore, a test-retest of the recall method's reliability over time could provide useful additional information.

To test the recall method for stability over time, we also asked in our survey whether in the opinion of the informal caregivers, the health status of the care recipients had changed compared to the previous study. It is obvious that there is a strong relation between the amount of informal care provided and the care demands relative to the health status of the care recipient. The question about a probable change of the care recipients' health status, enables us to compare possible differences between informal caregivers indicating that the health status of the care recipient had remained the same over time versus caregivers indicating that the health status of the care recipient had improved or deteriorated. Again, possible difference will be tested for with a t-test (Rice, 1995).

### **4.2.7 Background variables**

To get a better and broader picture of the informal care situation, we also measured health-related quality of life of informal caregivers with the EQ-5D and the EQ VAS (Essink-Bot et al., 1993) as part of the same survey as the informal care recall method. We also measured informal caregivers' subjective burden with a visual analogue scale (VAS) ranging from 0 ("not heavy at all") to 100 ("much too heavy"). Finally, we asked the informal caregivers some general background questions.

## **4.3 Data**

### **4.3.1 Data collection**

The data were collected in April 2002. To make sure that our research would enable a comparison between the diary and recall method instead of just being an exercise in informal caregivers' mathematical skills, we tried to prevent that the information in the recall method was directly derived from the diary. Therefore, after an information letter, we first sent the diary with the specified dates. Then we sent them the survey including the recall method. The diary had to be returned before the survey was filled out. This was stressed in the first question of the survey. If the diary was not returned before respondents returned the survey, both were excluded from the analysis. As pointed out before, the recall method in the survey covered the same week as the diary.

### **4.3.2 Study population**

Our study population consists of informal caregivers who had participated in an earlier study, that is between October till December 2001, hereafter referred to as the December population. In this study, they had been asked whether they were willing to participate in a future research. Of the 568 informal caregivers who had indicated that they would be willing, 301 caregivers (53 percent) returned the diary and the survey. We lost some of them due to the quality of their response. Thus respondents who failed to indicate their time use during one or more quarters of an hour, were excluded. We also lost respondents because they did not return their diary and survey separately and thus circumvented our prevention measure as discussed above. In all, we ended up with 199 completed diaries and surveys.

We also sent a letter to ask the non-responders about their motivation not to respond. Important arguments include the diary is too difficult (11% of the entire population of 568), no time (5%), forgotten (6%), we were too late to respond on time due

to the pre-specified dates (1%), the care recipient died between the first and this second study (6%) or the informal caregiver was ill (3%). Posing that the diary is too difficult indicates a feasibility problem of the method.

### 4.3.3 Characteristics of the respondents

Table 4.1 gives the descriptive statistics of the study sample.

**Table 4.1:** Background characteristics of informal caregivers (n=199)

Sex <sup>1</sup>	70.6
Age <sup>2</sup>	57.1
Education <sup>3</sup>	
<i>Low</i>	50.9
<i>Medium</i>	24.1
<i>High</i>	25.2
Income in euro <sup>3</sup>	
<i>Less than 545</i>	19.9
<i>545-725</i>	15.3
<i>725-900</i>	8.5
<i>900-1135</i>	13.6
<i>1135-1600</i>	13.6
<i>1600-2275</i>	16.5
<i>2275-3000</i>	9.1
<i>More than 3000</i>	3.4
EQ-5D <sup>2</sup>	0.77
EQ VAS <sup>2</sup>	70.27
Subjective burden VAS <sup>2</sup>	54.30

<sup>1</sup> Percentage females

<sup>2</sup> Mean

<sup>3</sup> Percentages

The majority of informal caregivers are female with a mean age of 57.1 years (minimum of 21.0 and maximum of 83.0). This suggests that our population is quite comparable with other samples of informal caregivers. Moreover, their reported subjective burden is not that high. Some informal caregivers report very low EQ-5D scores; 5.6 percent a score below 0.3.

## 4.4 Results diary versus recall method

The results of the comparisons of the diary and recall method are presented in this section. First, the uncorrected diary and the recall method are compared. ‘Uncorrected’ means not corrected for joint production. This implies that informal caregivers could indicate that they spent over 24 hours a day on providing informal care. Then we compare the results of the corrected diary with the recall method. In both comparisons only the real informal care part of housework is included. Then we discuss a comparison between the diary including ‘normal’ housework and the recall method. To test whether or not respondents take this difference into account when completing the recall method. Finally, we present the results of the comparison between the aggregated question of time spent on housework with the diary and recall method.

### 4.4.1 Uncorrected diary versus recall method

Table 4.2 gives the results of the uncorrected diary and the recall method. Column 4 gives their mean difference, and column 5 the statistically significance of this difference.

Table 4.2: Diary versus recall method (n=199)

	Diary	Recall	Difference		Correction	Difference	
	minutes a	minutes a	Recall	Pr	Diary	Recall -	Pr > [t]
	day	day	- Diary	[t]	minutes	Joint	
					a	Prod.	
	day	day			day		
<i>HDL</i>							
Preparation of food and drinks	59.17	61.92	2.75	0.6067	39.63	22.29	0.0000
Cleaning the house	59.36	44.08	-15.28	0.0034	18.30	25.78	0.0000
Washing, ironing and sewing	16.13	24.24	8.11	0.0007	11.21	13.03	0.0000
Taking care of and playing with your children	18.20	19.76	1.56	0.8262	10.01	9.75	0.0775
Shopping	24.57	31.91	7.33	0.0507	17.88	14.03	0.0001
<i>Continued on the next page</i>							

	Diary	Recall	Difference		Correction	Difference	
	minutes a day	minutes a day	Recall - Diary	Pr > [t]	Diary minutes a day	Recall - Joint Prod.	Pr > [t]
Maintenance work, odd jobs, gardening	8.63	25.34	16.71	0.0000	5.87	19.46	0.0000
HDL Total	186.07	207.25	21.18	0.1833	102.90	104.34	<.0001
<i>ADL</i>							
Personal care	87.59	47.97	-39.62	0.0042	65.58	-17.61	0.1874
Moving around in the house	28.61	6.82	-21.79	0.0000	19.11	-12.29	0.0005
Moving or travelling outside	21.82	18.67	-3.15	0.4976	15.12	3.56	0.4068
Eating and drinking	66.97	10.60	-56.37	0.0000	44.98	-34.38	0.0000
ADL Total	204.99	84.06	-120.93	<.0001	144.78	-60.72	<.0001
<i>LADL</i>							
Making trips and visiting family	32.98	20.64	-12.34	0.0186	23.54	-2.90	0.5194
Health care contacts	11.27	0.00	-11.27	0.0000	8.62	-8.62	0.0000
Organising help, house adaptations	20.46	60.27	39.81	0.4075	14.53	45.75	0.3409
Social assistance	90.60	118.69	28.08	0.1017	54.54	64.15	0.0001
IADL Total	155.31	199.60	44.28	0.3866	101.23	98.37	0.0520
Total	546.37	490.90	-55.47	0.3376	348.91	141.9888	0.0134

We found a difference of almost an hour per day in the total time reported to have been spent on informal care between both methods, with the recall method resulting in an hour per day less than the diary. This difference is, however, limited in relative terms, only 10 percent. The difference is also not statistically significant. This suggests that on an aggregated level it is possible to measure informal care with the recall method in a reliable way. On the individual and subgroup level there are also some differences. For HDL en

IADL the recall method reports higher results than the diary. But on the individual tasks level the diary sometimes scores higher. Although some differences are statistically significant, the subgroup totals are not statistically significant. ADL tasks show the opposite pattern. The diary scores are all higher compared to the recall method and the subgroup total is statistically significant.

Table 4.2 presents the average results of the whole sample. It is worth noting that not all tasks are performed by all informal caregivers. Some tasks are performed by more informal caregivers than other tasks. For instance, only 11 percent of the respondents help the care recipient to move around the house. We also checked for differences between the first and the second day of the diary and we found no statistically significant difference. So it seems likely that as the diary project continues, the respondents do not seem to alter their answers, after their experience with the first day of the diary. Another shade is the difference between a diary on a weekday and a diary filled on a weekend day. There were two statistically significant differences in behaviour between week and weekend days. The respondents spent more time on aid in visiting and excursion in the weekends (35.1 versus 15.0 minutes a day) and they spent no time at all on escorting their care recipients on medical visits during the weekend ( $p = 0.0053$  and  $p < .0001$  respectively). The first difference seems to be fact of life and the second one is even more obvious, because one would not expect to visit a doctor or physician in the weekends unless it is an emergency.

#### **4.4.2 Corrected diary versus recall method**

We also present the results of the diary corrected for joint production in table 4.2, column six. Column seven presents the mean difference between the corrected diary and recall method, while column eight gives the results of the t-test for this difference.

A comparison between the corrected diary with the recall method shows a completely different picture. The differences in case of HDL tasks become larger, while they become smaller in case of ADL tasks. IADL tasks show a mixed pattern. The two tasks that are more easily combined with other tasks, social assistance and aid in organising and administration show even larger differences. Tasks that are less easily combined with others, like aid in visiting and excursion and aid contacting health care show smaller differences. Moreover, the recall method overestimates the provision of informal care compared with the corrected diary with more than two hours per day. This difference is especially due to the HDL and IADL tasks.

Finally, the total difference is statistically significant which suggests that the measurement of informal care with the recall method compared with the corrected diary overestimates the time spent on caregiving.

#### **4.4.3 Informal care and housework together**

Respondents may have difficulties in distinguishing between 'normal' HDL and informal care when they complete the recall method. This could be an explanation for the overestimation of HDL with the recall method in table 4.2. In the diary, informal caregivers indicate that they spent 458.56 minutes per day on 'normal' HDL. Corrected for joint production, they spent 298.69 minutes a day on 'normal' HDL. If we add the for joint production corrected 'normal' HDL to the informal care HDL, we get a time use of 505.93 minutes per day. This is over twice as high as the 207.25 minutes in the recall method. The difference is also statistically significant ( $p < .0001$ ). It is therefore not likely that respondents are not able to make a distinction between 'normal' HDL and informal care when they complete a recall method.

#### **4.4.4 One question HDL**

Informal caregivers report that they spent 169.24 minutes per day on HDL. This is much lower than the 458.56 minutes per day in the diary ( $p < .0001$ ) and the 298.69 for joint production corrected minutes per day in the diary ( $p = 0.0485$ ). Because of the statistically differences, we can conclude that asking just one aggregated question about an individual's time use leads to an underestimation.

### **4.5 Results test-retest reliability**

This section presents the results of the test-retest reliability of the recall method. First we compare the results of all respondents. Subsequently, we compare the results of respondents who indicated that the health status of their care recipient was comparable at the two measurement moments.

#### **4.5.1 Test-retest for all respondents**

Of the 199 respondents, 150 completed the recall method at both moments in time. We analysed only their results.

Table 4.3: Test-retest recall method (n=150)

	December	April	Difference	
			December - April	Pr > [t]
<i>HDL</i>				
Preparation of food and drinks	35.72	62.08	-26.36	<,0001
Cleaning the house	23.04	45.32	-22.28	<,0001
Washing, ironing and sewing	9.59	25.50	-15.91	<,0001
Taking care of and playing with your children	8.25	21.42	-13.18	0.0623
Shopping	16.74	35.38	-18.64	0.0002
Maintenance work, odd jobs, gardening	6.48	27.56	-21.09	<,0001
HDL Total	99.82	217.27	-117.45	<,0001
<i>ADL</i>				
Personal care	17.98	37.43	-19.45	<,0001
Moving around in the house or going to the toilet	6.44	15.39	-8.94	0.4619
Moving or travelling outside the house	4.65	3.39	1.27	0.4862
Eating and drinking	14.28	10.45	3.84	0.1754
ADL Total	43.36	66.65	-23.29	0.0939
<i>IADL</i>				
Making trips and visiting family or friends	10.75	19.86	-9.11	0.0837
Health care contacts	5.86	21.86	-16.00	0.0002
Organising help, aids, house adaptations or taking care of financial matters like insurance	4.23	0.00	4.23	0.0119
Social assistance	3.99	75.96	-71.97	0.2590
IADL Total	24.83	117.69	-92.85	0.1494
Total	168.01	401.61	-233.60	0.0010

Table 4.3 shows that informal caregivers report that they spent almost three hours a day more on providing informal care in April compared to December. Especially HDL tasks contribute to this difference. For ADL and IADL tasks the differences are also in favour of the April study, but these differences are smaller and not statistically significant at the 5 percent level.

#### 4.5.2 Test-retest for respondents caring for care recipients with a stable health status

From the 150 respondents analysed above, 70 respondents care for care recipients with a stable health status. It is, therefore, likely that the weekly amount of care they provided is comparable at the two moments they completed the recall method<sup>3</sup>.

**Table 4.4:** Test-retest recall method for care recipients with a stable health status (n=70)

	December	April	Difference December - April	Pr > [t]
<i>HDL</i>				
Preparation of food and drinks	40.99	53.78	-12.79	0.0705
Cleaning the house	18.21	40.33	-22.12	0.0003
Washing, ironing and sewing	7.59	20.39	-12.79	0.0001
Taking care of and playing with your children	9.99	25.21	-15.23	0.0712
Shopping	14.96	26.11	-11.16	0.0073
Maintenance work, odd jobs, gardening	5.04	21.07	-16.04	<.0001
HDL Total	96.77	186.90	-90.13	<.0001
<i>ADL</i>				
Personal care	18.36	34.58	-16.22	0.0013
Moving around in the house or going to the toilet	7.78	2.20	5.57	0.0044
Moving or travelling outside the house	6.14	4.38	1.77	0.6155
Eating and drinking	20.43	9.18	11.24	0.0193
ADL Total	52.71	50.34	2.36	0.7980
<i>IADL</i>				
Making trips and visiting family or friends	11.13	22.99	-11.86	0.2326
Health care contacts	4.67	19.69	-15.02	<.0001
Organising help, aids, house adaptations or taking care of financial matters like insurance	3.07	0.00	3.07	0.0008
Social assistance	2.88	9.18	-6.31	0.0035
IADL Total	21.75	51.86	-30.11	0.0051
Total	171.23	289.10	-117.87	<.0001

Table 4.4 shows the same pattern as table 3. However, the differences are much smaller although still statistically significant in case of HDL tasks and the total time spent.

<sup>3</sup> There can of course be many other circumstances that changed in the mean time. They include the care recipient gets now more or less other informal care or more or less professional care.

These results suggest that the recall method is not stable over time. In April informal caregivers spent much more time on providing informal care compared to December. An explanation for this difference could be that respondents learned from completing the diary and therefore indicated that they spent much more time on providing informal care after completing the diary. Empirical evidence for this learning effect is that much less respondents failed to complete the recall method in December compared to April (47 versus two respectively). This idea is supported by the fact that in particular HDL tasks contribute to the differences. If we are concerned with learning effects, then we have to be more careful in interpreting comparisons between the diary and recall method.

## 4.6 Discussion and conclusion

Incorporation of informal care in economic evaluation of health care is troublesome. Although reliable measurement is a necessary condition for a reliable valuation of informal care, the debate focuses hitherto mainly on the valuation of informal care and tends to ignore the interrelated issue of the measurement of time spent on providing informal care. This chapter tries to fill this gap.

We compared and evaluated two main methods of measuring time spent on providing informal care: the diary and the recall method. The main objective was to explore the reliability of the measurement of time. We therefore compared the recall method with the diary, the gold standard for the measurement of time use.

A total of 199 informal caregivers for care recipients in a heterogeneous population completed a diary and recall method. The recall method is a reliable method to measure time spent on providing informal care compared to the diary, the gold standard, if one assumes that respondents take into account joint production when they complete the recall method. Otherwise, the recall method overestimates the time spent on providing informal care. This is a serious problem if one wishes to incorporate informal care in economic evaluations.

In the context of informal caregiving the separation between 'normal' housework and additional housework due to the care demands of the care recipients is often neglected and asks specific attention. It is likely that respondents are not able to separate between normal HDL and informal care when they complete the recall method. We did not find any evidence that this distinction is not clear to respondents when they complete the diary.

The gold standard for time measurement is not universally accepted. An alternative approach is to use just one aggregated question to measure time spent on a

certain category of tasks. We tested for this approach. It seems to result in an underestimation of time use.

Finally, we did a test-retest about the stability of the recall method over time. The recall method proves to be unstable over time. This could be due to learning effects from completing the diary. One has to be cautious in attaching significance to results of studies applying the recall method.

A weakness of this study is that there seems to be a feasibility problem with the diary. More than a tenth of the sample indicated not to participate in our research because they found the diary too difficult to complete. Another weakness is the correction for joint production. This correction is an arbitrary choice of the researcher, but perhaps could future qualitative research provide more ideas to deal with this problem.

The application of the recall method to incorporate informal care in economic evaluations seems to involve an overestimation of the total amount of informal care provided. Future research with other designs like between subject comparisons could provide more evidence about the reliability of the recall method. Another promising area for future research is the optimal amount of tasks a diary and recall method should contain in order to get the most reliable outcomes.

Probably the recall questionnaire is a reliable method to measure informal care if one informal caregivers first exercise with a diary.

## Appendix 1: the diary

This is an example of one page of the diary. Added to the diary is a short manual with examples of how to use the diary.

Diary morning			Page 2													Informal care		Personal care for care recipient		Organisational tasks for care recipient																				
From	Till	Cycle round	At home	Sleep	Personal care	Paid work	Volunteer work	Leisure	Travelling time	Own activities		Washing, ironing and sewing		Taking care of and playing with your children		Shopping	Maintenance work, odd jobs, gardening		Personal care	Eating and drinking	Moving around in the house or going to the house		Moving or travelling outside the house		Health care contacts		Making trips and visiting family or friends		Organising help etc. or taking care of financial		Social support		From	Till						
										A1	A2	B1	B2	C1	C2	D1	D2	E1	E2	F1	F2	G	H	I	J	K	L1	L2	M1	M2	N									
6:00	6:15	Yes / No																															6:00	6:15						
6:15	6:30	Yes / No																																6:15	6:30					
6:30	6:45	Yes / No																																	6:30	6:45				
6:45	7:00	Yes / No																																	6:45	7:00				
7:00	7:15	Yes / No																																		7:00	7:15			
7:15	7:30	Yes / No																																			7:15	7:30		
7:30	7:45	Yes / No																																			7:30	7:45		
7:45	8:00	Yes / No																																			7:45	8:00		
8:00	8:15	Yes / No																																			8:00	8:15		
8:15	8:30	Yes / No																																				8:15	8:30	
8:30	8:45	Yes / No																																				8:30	8:45	
8:45	9:00	Yes / No																																				8:45	9:00	
9:00	9:15	Yes / No																																				9:00	9:15	
9:15	9:30	Yes / No																																				9:15	9:30	
9:30	9:45	Yes / No																																				9:30	9:45	
9:45	10:00	Yes / No																																				9:45	10:00	
10:00	10:15	Yes / No																																				10:00	10:15	
10:15	10:30	Yes / No																																					10:15	10:30
10:30	10:45	Yes / No																																					10:30	10:45
10:45	11:00	Yes / No																																					10:45	11:00
11:00	11:15	Yes / No																																					11:00	11:15
11:15	11:30	Yes / No																																					11:15	11:30
11:30	11:45	Yes / No																																					11:30	11:45
11:45	12:00	Yes / No																																					11:45	12:00

## Appendix 2: the recall questionnaire

*We would like to know how much time you spend on giving informal care to your care recipient. Please, consider the past week!*

1: Did you last week spend time on the activities below in your care recipients' house?

	<i>Minutes</i>		<i>Hours</i>
	<i>per day</i>		<i>per week</i>
a. Preparation of food and drinks?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>
b. Cleaning the house?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>
c. Washing, ironing and sewing?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>
d. Taking care of and playing with your children?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>
e. Shopping?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>
f. Maintenance work, odd jobs, gardening?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>

2: Did you last week spend time on assisting your care recipient with the activities below?

	<i>Minutes</i>		<i>Hours</i>
	<i>per day</i>		<i>per week</i>
a. Personal care (dressing/undressing, washing, combing, shaving)?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>
b. Moving around in the house or going to the toilet?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>
c. Eating and drinking?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>
d. Moving or travelling outside the house (aid with walking or wheelchair)?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>
e. Making trips and visiting family or friends?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>
f. Health care contacts (like visiting a doctor)?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>
g. Organising help, aids, house adaptations or taking care of financial matters like insurance?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>
h. Social assistance?	→ <input style="width: 50px; height: 20px;" type="text"/>	<i>or</i>	<input style="width: 50px; height: 20px;" type="text"/>



# 5 Economic valuation of informal care: Lessons from the application of the opportunity cost and proxy good methods<sup>1</sup>

## Summary

*This chapter reports the results of an application of the opportunity cost method and the proxy good method to determine a monetary value of informal care. We developed a survey in which we asked informal caregivers to indicate the different types of time forgone (paid work, unpaid work and leisure) in order to be able to provide informal care. Moreover, we asked informal caregivers how much time they spent on a list of sixteen informal care tasks during the week before the interview.*

*Data were obtained from surveys in two different populations: informal caregivers and their care recipients with stroke (CVA) and with rheumatoid arthritis (RA). A total of 255 care recipients with CVA and their primary informal caregivers completed a survey as well as 153 informal caregivers and 149 of their care recipients with RA.*

*The measurement of informal care according to both methods is more problematic compared to the valuation. This is especially the case for the opportunity cost method and for the housework part in the proxy good method. More precise guidelines are necessary for the operationalisation of both methods in order to ensure comparability of results and of economic evaluations of health care.*

## 5.1 Introduction

Informal care plays a substantial role in the total care provided, especially in case of care for people with chronic diseases and the terminally ill (Norton, 2000). Because informal caregivers sacrifice (amongst other resources) time to provide informal care, informal care should be incorporated in an economic evaluation taking a societal perspective (Luce et al., 1996) and (Drummond et al., 1997). Despite the recommendation to include informal care in economic evaluations, in practice informal care is often neglected in economic evaluations (Stone et al., 2000). It is quite common to consider informal care as a cost in an

---

<sup>1</sup> Based on Van den Berg, B., Brouwer, W.B.F., Van Exel, J.A.J., Koopmanschap, M.A., Van den Bos, G.A.M., Rutten, F.F.H., 2004. Economic valuation of informal care: Lessons from the application of the opportunity cost and proxy good methods. In revision Social Science and Medicine.

economic evaluation and it is therefore suggested to incorporate the changes in use of informal caregiver time as direct non-health care costs into the numerator of the cost-effectiveness ratio (Luce et al., 1996, p.177)<sup>2</sup>. This implies that informal caregiver's time should be valued in monetary terms. It is often recommended to use either the opportunity cost method or the proxy good method<sup>3</sup> to value the time investment in informal care (Posnett and Jan, 1996), (Luce et al., 1996) and (Drummond et al., 1997). Both methods have their strengths and weaknesses (McDaid, 2001) and chapter 3, and the opportunity cost method is preferred from a theoretical point of view (Posnett and Jan, 1996).

Although alternative monetary valuation methods like the contingent valuation, conjoint measurement and well-being valuation methods are proposed, discussed and applied to value informal care by Van den Berg et al. (2004) and in the chapters 6, 7, 8, 9 and 10, still the opportunity cost method and proxy good method are most commonly advocated and used. Probably an important reason for recommendations to use either one of these methods is their relatively straightforward application. In economic evaluations, where the focus is on the care recipients rather than on informal caregivers, this may be considered an advantage.

That informal care in practice is often neglected in economic evaluations where informal care is an important input may have to do with different reasons. They include (1) informal care is simply overlooked. (2) It is not overlooked but disregarded. (3) Many health technology assessment guidelines recommend conducting economic evaluations from more narrow perspectives than the societal perspective. Or (4) informal care is considered relevant but researchers may have difficulties with measuring or valuing informal care because guidelines and handbooks are quite short about these issues and recommended valuation methods are less straightforward to apply than they appear to be at first sight.

In terms of measurement of informal care as an input in health care, some important problems exist. One problem is the difficulty in measuring time forgone in order to provide informal care. Especially when providing informal care started many years ago, as is often the case in chronic diseases, the normal activities forgone are difficult to indicate for caregivers. Another problem concerns the distinction between "normal" housework and additional housework due to the health problems of the care recipient. If this distinction is not properly made it is easy to overestimate the time spent on informal care.

---

<sup>2</sup> This is not problematic unless informal care is the focus of the intervention under study in case of, for instance, respite care programs for informal caregivers. See, e.g., Mohide et al. (1988) or Drummond et al. (1991).

Regarding the valuation of informal care, it may be difficult to find appropriate opportunity cost estimates for all different time uses and groups of caregivers. Moreover, in using the proxy good method, problems may arise in finding appropriate wage rates of professional substitutes who might perform the care activities if no informal caregiver would be available.

In this chapter we discuss the application of the opportunity cost method and proxy good method in two caregiver populations – informal caregivers of care recipients with stroke (CVA) and caregivers of care recipients with rheumatoid arthritis (RA). Our aim is to indicate the costs of informal care in these two populations using both the opportunity costs and proxy good methods. Moreover, we wish to detect the major problems in using these often recommended methods. Application of these two methods in such distinct populations is useful in that context. CVA is an acute condition with a clear starting point, while RA is a slowly progressive chronic disease without a clear starting point. A starting point is important for the measurement of time forgone and time spent on informal care and has therefore important implications for the application of the opportunity cost method and proxy good method. We also propose solutions for the problems in measuring time forgone when a clear starting point is lacking and for the distinction between “normal” housework and informal care.

The structure of the chapter is as follows. First, we will discuss the opportunity cost and proxy good methods and the developed measurement instruments. Then, the data and results from the application of both methods in the two populations will be presented. Finally, some lessons will be drawn from the application of these methods in the two populations and we will compare our results with other studies.

## **5.2 2. Opportunity cost and proxy good method**

In this section, we present and discuss the opportunity cost and proxy good methods from a theoretical point of view. Moreover, some major issues in the measurement of time spent on informal caregiving are discussed, related to the measurement of time forgone (for the application of the opportunity cost method) and correct measurement of effective time spent on informal care (for the application of the proxy good method).

---

<sup>3</sup> The proxy good method is also called replacement cost method.

### 5.2.1 Opportunity cost method

Often, the opportunity cost method values informal care according to equation 1:

$$\text{Value informal care} = t_i w_i \tag{1}$$

where  $t_i$  = time spent on informal care tasks by informal caregiver  $i$ , and  $w_i$  = the net market wage rate of informal caregiver  $i$ . If the informal caregiver is unemployed some proxy for  $w_i$  is used. One could for example use a modified opportunity cost method to find out the reservation wage rate of the informal caregiver. This is the wage rate for what an individual is willing to supply at least one hour on the labour market (Kooreman and Wunderink, 1996, p.113). Another solution is the imputation of the actual wage of similar individuals (for example with the same gender, education and age).

It is worth noting that in equation (1) all time investment is valued with the same wage rate. In this approach the value of leisure and unpaid work is supposed to equal the (would be) wage rate. If one rejects this assumption because the time spent on informal care is often not just at the cost of paid work but also at the costs of unpaid work and leisure, it would be better to value informal care with equation 2:

$$\text{Value informal care} = n_i w_i + b_i s_i + l_i t_i \tag{2}$$

where  $n_i$  = informal caregiver  $i$ 's hours of forgone paid work ( $w_i$ ),  $b_i$  = informal caregiver  $i$ 's hours of forgone unpaid work,  $s_i$  = shadow price of unpaid work,  $l_i$  = informal caregiver  $i$ 's hours of forgone leisure, and  $t_i$  = shadow price of leisure. In using the opportunity cost method according to equation 2, the amount and sources of time forgone should be measured. In addition, shadow prices for unpaid work and leisure need to be determined, which poses another challenge. Often, these shadow prices are based on a(n arbitrarily adjusted) wage rate, which makes the distinction between equation 1 and 2 rather cosmetic.

To measure time forgone in order to be able to provide informal care, one would ideally use a panel data structure, comparing the normal time allocation of caregiver A to A's time allocation when engaged in informal care, all other things equal. In practice, such measurement is often not feasible and therefore sub-optimal solutions are necessary. These may involve asking respondents how their time allocation has changed since engaging in informal care or comparing their time allocation to that of a comparable sample from the general public.

### 5.2.2 Proxy good method

An alternative for the opportunity cost method is the proxy good method. The proxy good method, also called market cost method or replacement cost method, values time spent on informal care at the (labour) market prices of a close market substitute. This approach requires the availability of a market substitute for the non-market good, which is assumed to be almost perfect. The time spent on informal care is valued at the wage rate or market price of a market substitute, which can differ for different tasks: e.g. housework is valued at the market wage of a professional house worker and personal care is valued at the market wage of a professional nurse.<sup>4</sup>

The measurement of time spent on informal care instead of the time forgone in order to be able to provide informal care is the cornerstone of the application of the proxy good method. One can measure the time spent on informal care in different ways. Two important methods of collecting time budget data are the diary method and the recall method. The diary method is normally seen as the gold standard (Juster and Stafford, 1991, p.473). This method is however time consuming for respondents and costly for researchers. Therefore in practice the recall method is often applied. Respondents is asked to indicate retrospectively how much time they spent on different care tasks during a certain time period. In order to be able to compare the results between different populations and different studies it is important to standardize the concept informal care, e.g. due to the development of a standard list of informal tasks. This also helps to assist the researcher to ensure that all relevant aspects of informal care are included.

An alternative to these specific questions is to ask informal caregivers more general how many hours a week they normally spend on informal care. The drawback of this approach is that different respondents perhaps may use different definitions of informal care.

Moreover if one defines only additional housework as part of informal caregiving, as would be reasonable, it is for the proxy good method important to distinguish “normal” housework from additional housework due to informal caregiving. This is especially troublesome if the informal caregiver and care recipient share the same household or if informal care has been provided for several years already (as for instance is the case with the slowly progressing RA).

## 5.3 Applying the methods in two populations

In this section, we describe the use of both the opportunity cost method and the proxy good method in two populations of informal caregivers: one caring for care recipients after a stroke (CVA) and the other caring for care recipients with Rheumatoid Arthritis (RA). These populations were approached as part of larger studies: an evaluation of stroke units for care recipients with CVA and a study on health and health care utilisation among care recipients with RA. Some of the information gathered in the two studies was therefore not fully symmetrical, but this mainly pertains to additional information. The structure of this section is as follows. First, we describe the two populations of informal caregivers. Then, we discuss how we operationalised the two methods in this studies. Finally, we present the results from the application of the two methods in both populations.

### 5.3.1 Populations

#### **Informal care for care recipients with CVA**

The CVA data were collected as a supplement to the EDISSE study (Huijsman et al., 2001). This study evaluated three stroke service experiments in The Netherlands. Care recipients with CVA were included at hospital admission and followed for a period of six months. Data on admission in hospitals, nursing homes and rehabilitation centres was collected through medical records. Home care utilisation was measured by care recipient (or proxy) oral interviews. Care recipients were asked whether or not they received informal care. If they received informal care, we asked them to indicate their significant informal caregiver. Then, the informal caregiver was asked to fill in a written survey. If the primary informal caregiver was not present, the interviewer left a survey behind, so the informal caregiver could return it by mail.

A total of 597 CVA care recipients were included in the EDISSE study. 181 care recipients died in the period up to 6 months after stroke. 336 of the care recipients went back home within six months after CVA. A total of 255 informal caregivers completed the survey. Descriptive statistics of the informal caregivers and their care recipients are presented in table 5.1. Table 5.1 shows both the descriptive information for all caregivers as well as for partners versus other caregivers. This distinction is important because partners can differ from other carers in several respects due the fact that they often share

---

<sup>4</sup> One can debate whether this should be the gross wage (the real opportunity costs to society) or the net wage (the wage rate for which the professional is willing to sacrifice leisure).

the same household with the care recipient. The latter makes the distinction between housework and informal care more complicated.

**Table 5.1:** Characteristics informal caregivers and their care recipients

Characteristics	CVA total	CVA partner	CVA other	RA total	RA partner	RA other
<i>Informal caregivers</i>						
Age <sup>1</sup>	60.2	65.8	53.2	62.1	63.1	49.9
Female <sup>2</sup>	63.4	64.9	61.6	24.7	18.3	92.3
Partner <sup>2</sup>	54.5	100	0	91.5	100	0
<i>Education<sup>2</sup></i>						
Primary school	14.2	19.1	8.3	13.4	13.2	15.4
Lower vocational	44.6	52.7	34.9	45.6	42.6	53.8
Medium vocational	25.8	17.6	35.8	25.6	24.3	23.1
Higher vocational	11.7	9.2	14.7	9.4	9.6	7.7
University	3.8	1.5	6.4	4.0	4.4	0
Duration of care <sup>1</sup>	n / a	n / a	n / a	11.4	8.6	10.7
<i>Occupation<sup>2,3</sup></i>						
Housework	24.1	34.4	12.7	17.7	16.4	30.8
Disability	22.4	33.6	10.0	56.9	53.6	15.4
pension/retired						
Paid job	41.8	20.5	65.5	35.9	32.9	69.2
Other	11.6	11.5	11.8	4.6	10.7	15.4
Monthly income <sup>1,4</sup>	1,487.43	1,544.98	1,423.93	1,503.42	1,503.42	Unknown
<i>Care recipients</i>						
Age <sup>1</sup>	72.3	68.4	77.1	62.1	62.5	56.8
Female <sup>2</sup>	57.3	40.6	78.2	83.9	84.7	75.0
<i>Education<sup>2</sup></i>						
Primary school				19.6	19.9	16.7
Lower vocational				48.6	50.0	33.3
Medium vocational				14.2	13.2	25.0
Higher vocational				6.1	5.9	8.3
University				3.4	2.9	8.3
<i>Occupation<sup>2</sup></i>						
Housework				38.9	40.9	16.7
Disability				51.8	51.1	58.3
pension/retired						
Paid job				15.4	15.3	16.7
Other						
EQ-5D <sup>1</sup>	0.49	0.61	0.34	0.48	0.48	0.49
EQ-VAS <sup>1</sup>				55.61	55.56	56.18
<i>Continued on the next page</i>						

Characteristics	CVA total	CVA partner	CVA other	RA total	RA partner	RA other
Professional care <sup>2</sup>				26.1	25.7	30.8
Waiting list				5.9	6.4	0
professional care <sup>2</sup>						
Other informal care <sup>2</sup>				68.0	70.7	38.5
	N=255	N=139	N=116	N=153	N=140	N=13

<sup>1</sup> Mean

<sup>2</sup> Percentages

<sup>3</sup> The percentages add up to over 100 percent due to the fact that some respondents reported different occupations.

<sup>4</sup> Note that in case of CVA the net monthly income is private income, while in case of RA the net monthly income is family income.

Table 5.1 shows that the mean age of the CVA caregivers was 60.2 years, almost two thirds were women and 42 percent had a paid job. About half of the caregivers were partners of the care recipients. Partners were, compared with other informal caregivers, older, had less often paid work and their main occupation was more often housework. They had also more often a disability pension or were retired. The CVA care recipients had a mean age of over 72 years and their EQ-5D score was low: 0.49.

### **Informal care for care recipients with RA**

The data for the RA part of this study were collected as a supplement of the RA+ study, a panel study on health and health care utilisation among people with RA (Jacobi et al., 2001) and (Jacobi et al., 2003). In the 2001 wave of this panel, 365 of 683 care receivers indicated to receive informal care. We approached all care receivers and asked the 365 receiving informal care to hand over our mail survey to their primary informal caregiver. Moreover, we asked all care receivers to complete a mail survey themselves. We included a question for the 318 care recipients without informal care if they perhaps currently received informal care. If so, we also asked them to hand a mail survey over to their primary informal caregiver.

Table 5.1 also shows the characteristics of the RA informal caregivers. The average RA caregiver was with 62.1 years slightly older than the CVA caregiver and more than 90 percent of those informal caregivers were the care recipients' partner. Slightly less RA informal caregivers had a paid job compared to CVA. The duration of providing informal care for RA care recipients was 11.3 years, while the disease duration was 13.0 years. So, providing informal care starts often quickly after the diagnosis of RA. For CVA

we assume that providing informal care starts directly after the diagnosis.<sup>5</sup> The EQ-5D scores of the RA care recipients were with 0.48 similar to the CVA care recipients. RA care recipients however were younger and more often female than the CVA care recipients.

The care recipients' partners were predominantly male in case of RA, while the other caregivers were mainly female. The latter is quite common (informal caregivers are often females) and the former reflects the relatively high prevalence of RA in females.

### **5.3.2 Operationalisation of the valuation methods**

The opportunity cost and proxy good methods were both incorporated into the surveys. Here, we describe them in more detail.

#### **Opportunity cost method**

We asked informal caregiver's in retrospect what types and amount of time (paid work, unpaid work and/or leisure) they gave up in order to be able to provide informal care. The reliability of similar questions probably increases the more recent and the more well defined the informal caregiving episode started. This makes a comparison between CVA with a clear starting point and RA without one particularly interesting.

In anticipation of the absence of a clear starting point in the RA population, we also asked some additional questions. These questions also pertain to the best alternative time use, not retrospectively, but rather in terms of on what activity the respondents would preferably spend time as well as how many hours a week if they could reduce their time investment in informal care. These questions were phrased as follows:

*“Suppose, you do not have to spend time on providing informal care anymore. Would you prefer to spend this time on paid work, unpaid work or leisure?”*

#### **Proxy good method**

There are no instruments available that make a distinction between “normal” housework and additional housework due to informal care. In the existing instruments, for example the CATS (Caregiver Activities Time Survey) (Clipp and Moore, 1995), the CAS (Caregiver Activity Survey) (Davis et al., 1997) and the RUD (resource utilization in dementia) (Wimo

---

<sup>5</sup> Information about co-morbidities is lacking so we have to assume that the provision of informal care is due to CVA or RA

et al., 2002), this distinction seems to be neglected. We asked informal caregivers to report whether, and if so, how much time they spent on a list of sixteen activities (see table 3 for the complete list) in the week preceding the interview. We distinguished between (1) housework (HDL), (2) activities of daily living (ADL), (3) instrumental activities of daily living (IADL). Travel time may also be an important aspect of total time use in informal caregiving. Therefore, we added also a question about travel time due to informal caregiving. Some questions had answer categories in minutes per day, while others had answer categories in hours per week, depending on the expected time investment per week.

In order to derive the time spent on different informal care tasks, we asked the caregivers two different types of questions. The first type of question asked respondents:

*“How much time did you spend on assistance with ...”?*

These questions pertained to support activities, for example assisting the care recipient in visiting the toilet or with mobility outside. Given their nature, answers to these questions would inevitably indicate time spent on informal care (correct responses assumed for the moment). The second type of question asked the respondents:

*“How much time did you spend on ...”?*

These questions mainly pertained to time spent on different types of housework. Because our study focussed on time investment in the context of informal care, we were sceptical about the respondents' ability to separate “normal” from additional housework, particularly for informal caregivers sharing the same household as the care recipient. For caregivers not sharing the same household as the care recipient, additional housework may be estimated more easily than for caregivers sharing the same household as the care recipient. However, e.g. separating time spent on shopping due to informal caregiving or for their own purpose could also be troublesome when the informal caregiver does not share the same household as the care recipient.

Comparing the indicated time allocation on housework of informal caregivers with that of the general population could indicate whether or not caregivers are expected to have indicated ‘additional time’ spent on these tasks or rather ‘normal time’. Information on time allocation of the Dutch general public was derived from the Dutch Time-Allocation Survey 1995 (TBO'95) (SCP, 1995). These data were collected with time budget

diaries. Respondents (n=3227) reported every 15 minutes per day their time spent on a broad range of activities including HDL tasks. With the results from the TBO, we forecast the expected time spend on several HDL activities in the two populations corrected for age and gender. This forecast can be compared to the reported time in order to get some idea on the correctness of the answers provided in our sample.

Finally, one could argue that the time invested in providing informal care should equal the total time forgone due to providing informal care. A possible difference may be due to the fact that one of the two methods is easier to complete. It is also possible that this is due to the neglect of joint production in one way of questioning or because the figures do not adequately reflect that certain household tasks (e.g., house maintenance) are sacrificed to perform more urgent household tasks (cleaning or cooking). Possible differences between the two populations may also have to do with the starting point, which is clear in CVA while it is lacking in RA. This makes that for many RA informal caregivers the period of retrospect is substantial.

### **5.3.3 Results from the two valuation methods**

#### **Opportunity costs – measuring time forgone**

We distinguished three types of time forgone in order to be able to provide informal care: paid work, unpaid work and leisure. Table 5.2a presents the types and time forgone in both populations.

Table 5.2a: Informal caregivers' opportunity costs of time

	Percentage respondents performing activity before caregiving episode	Mean hours a week before	Percentage respondents having forgone activity due to informal care	Mean hours a week forgone
<b>CVA (255)</b>				
Paid work	38.0 (97)	27.7 (103)	18.5 (17)	3.0 (70)
Unpaid work	13.4 (29)	1.7 (103)	35.7 (10)	0.6 (70)
Leisure	n/a	n/a	32.2 (82)*	8.8 (70)
Total	40.4 (103)	29.4 (103)	27.5 (70)	12.4 (70)
<b>RA (153)</b>				
Paid work	35.3 (54)	15.9 (107)	16.7 (9)	2.2 (30)
Unpaid work	24.2 (37)	2.5 (107)	27.7 (10)	1.2 (30)
Leisure	58.2 (89)	7.2 (107)	30.3 (27)	6.1 (30)
Total	69.9 (107)	25.6 (107)	19.6 (30)	9.5 (30)

\* percentage based on total group (n=255)

It first shows the percentage of respondents involved in the three different categories before they became an informal caregiver, just like the mean hours per week in column 3. Next, table 5.2a gives the percentage of respondents that gave up paid work, unpaid work or leisure in order to provide informal care. This percentage is based on the number of people performing these activities before they became an informal caregiver (column 2). Column five gives the total number of hours forgone a week per activity for the total group. The columns two and four were based on dichotomous answer categories, while columns three and five were based on (less often completed) open-ended answer categories.

The results show that 18.5 percent of CVA caregivers with paid work reduced their time spent on paid work, resulting in a reduction of 3 hours paid work per week on average. The RA caregivers with paid work indicated a slightly lower amount of paid work forgone, i.e. 2.2 hours a week, whereas the amount of unpaid work forgone was higher (1.2 respectively 0.6 hours a week). In case of CVA we collected no information about the amount of leisure before the informal care episode started. A majority of RA caregivers indicated to spent time on leisure before the caregiving episode started. Assuming that all CVA caregivers enjoyed leisure before becoming a caregiver, CVA caregivers slightly more often indicated to have given up leisure in order to provide informal care (32.2 percent

versus 30.3 percent). Moreover, the average number of hours of leisure forgone was higher in the CVA group (8.8 versus 6.1 hours a week).

In total, CVA caregivers indicated higher opportunity costs than RA caregivers: 12.4 hours versus 9.5 hours per week respectively. It is worth noting that table 2 also indicates rapidly decreasing numbers of completed surveys when asking about numbers of hours forgone, which leads to average scores for RA for instance based on only 30 caregivers.

As mentioned above it is perhaps difficult for informal caregivers to indicate the amount and sources of time forgone if a clear starting point is lacking as in RA, because the caregiving episode started probably many years ago, for example before retirement. Moreover, the number of care tasks provided as well as the time spent on caregiving may slowly increase, without clear start points. Such increases may go unnoticed. This makes it expectedly difficult for the RA respondents to indicate time spent on other activities forgone. We tested for this hypothesis by means of a simple correlation coefficient between respondents indicating both their opportunity costs of time and the number of years they provide care yet. The relative strong correlation coefficient of 0.50 supports this hypothesis. Because we expected difficulties in indicating their opportunity costs of time, we also asked RA caregivers on what activities they would spend their time if they no longer had to fulfill care tasks. Table 5.2b shows the results.

**Table 5.2b:** Alternative question posed to RA informal caregivers (153)

	Percentage respondents indicating they would spend freed time on activity	Mean hours a week
Paid work	6.5 (10)	0.6 (100)
Unpaid work	9.2 (14)	1.0 (100)
Leisure	59.5 (91)	5.7 (100)
Total	65.4 (100)	7.3 (100)

*N between brackets*

Most informal caregivers preferred to spend freed time on leisure. The absolute numbers of caregivers indicating that they preferred to spend freed time on paid work or unpaid work resemble those in table 5.2a. For leisure however, there is a substantial difference compared to the results reported in table 5.2a. In terms of hours per week, both methods yield similar results for unpaid work as well as for leisure. However, the amount of paid work is in the alternative question (table 5.2b) lower compared to the amount of

the table 5.2a question. This might be related to the fact that some caregivers have retired within the long time interval of 11.4 years between the start of providing informal care and date of survey completion. Therefore, although the alternative method may be useful in a context of long term care and slowly progressive diseases, the validity of provided answers remains to be established.

### **Proxy good method – measuring time investment**

In applying the proxy good method, time investments on different caregiving tasks needs to be assessed. We distinguished HDL, ADL and IADL tasks and travel time. The time investments for the two populations are presented in table 5.3.

Table 5.3 presents both the percentages of caregivers performing specific activities as well as how many hours a week they spent on these activities. Most informal caregivers performed HDL tasks, and the time investment in these tasks was relatively large, i.e. 21.2 hours a week. A majority of caregivers were also involved in IADL tasks, yet the time involved in these tasks was substantially lower compared to HDL, i.e. 3.7 hours a week. About one third of the informal caregivers was involved in ADL tasks, which required around two hours per week. More CVA than RA caregivers had to travel which probably has to do with the fact that far more RA caregivers were partners to the care recipient. The overall percentage of caregivers performing tasks was similar in both groups, but the RA caregivers providing some 7 hours more care per week. This difference is related to the performance of HDL tasks, probably because more RA caregivers are men who indicate HDL perhaps more often as informal care compared to CVA caregivers.

The large amount of time invested in HDL tasks may reflect the fact that “normal” HDL tasks are not fully separated from additional HDL tasks. Therefore, we compared the time allocation of these caregivers to that of the general public, using the results from the TBO study described above. We predicted the time spent on different HDL tasks by OLS-regression (see appendix A). If these predictions would match reported values or if reported values would even be higher than predictions, this would be an indication that normal rather than additional time use would be reported. The results are shown in table 5.4.

**Table 5.3: Informal care time in mean hours a week**

	CVA <sup>1</sup>	Mean hours a week	RA <sup>1</sup>	Mean hours a week
Preparation of food and drinks	56.8	3.3	76.7	5.0
Time investments in shopping, groceries etc.	85.3	4.6	87.2	6.3
Housecleaning	62.5	2.3	86.0	2.0
Washing, ironing or sewing	62.9	0.2	43.0	0.9
Caring for and playing with own children	4.8	2.4	11.3	4.2
Chores, gardening, maintenance	43.8	1.3	74.2	2.9
<b>HDL (Total)</b>	<b>89.0</b>	<b>14.0</b>	<b>94.1</b>	<b>21.2</b>
Aiding patient with personal care	18.2	0.6	34.9	1.3
Aiding patient in visiting the toilet	8.5	0.1	6.7	0.1
Aiding patient moving around within the house	18.6	0.4	17.7	0.5
Aiding patient with eating and drinking	19.2	0.5	10.3	0.2
<b>ADL (Total)</b>	<b>32.9</b>	<b>1.6</b>	<b>37.3</b>	<b>2.1</b>
Aiding the patient in travelling outside the house	38.5	0.6	38.8	1.1
Aiding the patient with visiting and in excursions	45.5	0.9	51.4	1.2
Aiding the patient in contacting health care suppliers	59.7	0.6	60.5	0.9
Aiding patient in organising home adaptations, etc.	34.4	0.2	23.2	0.1
Aiding patient in financial matters (insurance, rent)	55.1	0.6	39.7	0.4
<b>IADL (Total)</b>	<b>76.9</b>	<b>2.9</b>	<b>68.6</b>	<b>3.7</b>
Travelling to and from patient	42.4	1.7	8.8	0.3
<b>Total</b>	<b>94.5</b>	<b>20.2 (218)</b>	<b>96.1</b>	<b>27.4 (147)</b>

<sup>1</sup> Percentage indicating that they spend time on the activity

<sup>2</sup> Mean hours a week spend on this activity given that they indicated to spend time on the activity

N between brackets

**Table 5.4:** Housework part of informal care

Variable	CVA		RA	
	Forecast Normal	Reported additional	Forecast Normal	Reported additional
Preparation of food and drinks	7.6	3.3	9.8	5.0
Time investments in shopping, groceries etc.	2.9	4.6	4.3	6.2
Housecleaning	1.6	2.3	2.5	1.8
Washing, ironing or sewing	1.0	0.2	1.6	1.0
Caring for and playing with own children	3.3	2.4	4.0	4.3
Chores, gardening, maintenance	4.1	1.0	3.7	3.0
<b>Total</b>	<b>20.6</b>	<b>13.9</b>	<b>26.0</b>	<b>21.3</b>
N	204		135	

Table 5.4 shows that total reported time investment in HDL tasks is less than predicted time investment: 6.7 hours less for CVA and 4.7 hours less for RA. Yet the differences are small compared to the total time investment especially in case of RA. We tested with a t-test if the difference between the predicted and reported HDL time was significant. This was the case in both populations (CVA:  $p < .0001$  and RA:  $p = 0.0086$ ). Still, given the relatively high numbers of reported additional hours, which implies that total time spent on HDL would be 34.5 and 47.3 hours per week for CVA and RA respectively, one may wonder whether the HDL results in table 3 are not an overestimation.

### Comparing the two methods - measurement

When we look at the measurement of time, the proxy good and the opportunity method yield different results. The average weekly time spent on caregiving is 20.2 hours in case of CVA and 27.4 hours in case of RA using the proxy good method (table 3). The opportunity cost method yields substantial lower estimates: 12.4 and 9.5 hours respectively (table 5.2a). The alternative opportunity cost used in the RA population leads to even lower

time estimates (7.3 hours). These substantial differences demand more research in terms of validation of the measurement methods.

Another important aspect of the comparison is the number of respondents that complete the questions. As can be derived from tables 5.2 and 5.3, the measurement questions related to the proxy good method appear to perform much better than those related to the opportunity cost method.

### Money value using the opportunity cost method

According to equation 1, in the opportunity cost method the hourly wage of informal caregivers is used to value the provided informal care. Table 5.5 shows these wage rates, while those for RA are somewhat overestimated, because they represent hourly household income.

**Table 5.5: Opportunity cost method and proxy good method compared**

	CVA per hour	CVA per week	RA per hour	RA per week
Opportunity cost method	17.34 (n=60)	204.64 (n=23)	10.64 (n=37)	49.18 (n=7)
Proxy good time with housework	17.34 (n=60)	336.20 (n=59)	10.64 (n=37)	178.84 (n=37)
Proxy good method Without housework	18.24 (n=218)	119.80 (n=218)	20.24 (n=147)	153.51 (n=147)
With housework	13.51 (n=218)	239.24 (n=218)	12.19 (n=147)	334.76 (n=147)

The subgroup with available information about income from paid work was relatively small. Combined with missing data of time investment according to the opportunity cost method, the numbers used in final calculations (without imputations and other missing variable interventions) becomes very low:  $n = 23$  for CVA and  $n = 7$  for RA. Using these cases only the average costs per week for CVA were 204.64 Euro and for RA 49.18 Euro. If we impute the available information for the total sample these numbers would change for CVA to 215.02 Euro (17.34 Euro times 12.4 hours per week) and for RA to 101.08 Euro (10.64 Euro times 9.5 hours per week).

The opportunity cost method is often applied by combining time input rather than activities forgone with an hourly wage rate. If we adopt that approach, e.g. if wage rates are combined with the time investment as indicated in table 3, costs per week would

amount to 336.20 Euro for CVA and 178.84 Euro for RA. These figures are based on the sub-sample of caregivers for which time and income information was available. Leaving out HDL activities (if one considers these to result in an overestimation of time investment) would change the results to 72.38 Euro for CVA and 27.66 Euro for RA. If one would apply the average wage rate to the whole group that indicated time investment, the weekly cost estimates would change into 350.27 Euro for CVA and 291.44 Euro for RA. These differences in results demonstrate that the operationalisation of the methods and the sub-samples used to calculate costs can cause large differences in results.

### **Money value using the proxy good method**

For applying the proxy good method to value informal care, one has to find a close market substitute as a proxy for the value of informal care. In The Netherlands professional home care seems to be a good proxy. The tariff of a professional caregiver for HDL tasks is approximately 8.53 Euro per hour, for ADL tasks 32.67 Euro per hour and for IADL tasks also 32.67 Euro per hour.

Using these figures, the cost estimates can be derived, as shown in table 5. The hourly wage rate differs between CVA and RA because the combination of different types of tasks is different for the two groups. Again, two estimates are shown, one with and one without HDL time investment. The costs for RA appeared to be higher compared to CVA.

### **Comparing the two methods - valuation**

When we compare both methods, it is clear that important differences arise, both between as well as within methods when using different operationalisations. Some of the differences relate back to the differences in measured time investment (measurement according to equation 1 or 2). Other differences relate to distinct hourly values of professional care (housework is cheaper compared to personal care) or even to the use of hourly instead of private household income in case of RA. It is also worth noting that we only value the informal caregivers' opportunity costs of time with the opportunity cost method. But in comparing the opportunity cost method with the proxy good method one should also take into account other caregiver opportunity costs like financial outlays. This because these costs are included in the tariffs of professional caregivers as used with the proxy good method. See (Netten, 1990) for an overview of other caregiver opportunity costs. In sum, weekly cost estimates range from 72.38 to 350.27 Euro for CVA caregivers and 49.18 to 334.76 Euro for RA caregivers.

## 5.4 Discussion

This chapter aims to discuss the usefulness and difficulties in applying two often recommended methods to value informal care in economic evaluations of health care: the opportunity cost method and the proxy good method. Valuing informal care is a two stage process. (1) Measurement of the amount and sources of time forgone in order to be able to provide informal care (opportunity cost method), or measurement of the amount of time invested in informal care (proxy good method). (2) Economic valuation: determining accurate shadow prices per hour of provided informal care.

Results show that the two methods do not differ very much with respect to the valuation step. Higher opportunity costs per hour in case of RA compared to CVA are related to the use of family income in case of RA and private income in case of CVA. Differences between the methods are quite small or explained by the relative low prices of housework in case of the proxy good method with housework. The measurement step however, seems to be more problematic and crucial, as the opportunity cost method and proxy good method yield quite different results. On average total weekly time spent on care giving is 20.2 hours in case of CVA and 27.4 hours in case of RA using the proxy good method, whereas the opportunity cost method yields much lower estimates (12.4 and 9.5 hours respectively). The measurement questions related to the proxy good method appear to perform better than those related to the opportunity cost method, at least from a response point of view. This does not necessarily imply that the answers are reliable. [Van den Berg, Submitted #128] for instance compared the results of a retrospective way of questioning like here proposed in the proxy good method with a diary (within subject comparison). They concluded that a retrospective way of questioning involves an overestimation of the provided informal care. A comparison of our results with national time allocation data revealed that the number of additional HDL hours for informal care as derived from the survey might be an overestimation (between subject comparison). Further research could focus on measurement of informal care using for instance diaries with a focus on informal care (between subject comparison). Diaries are however more costly for researchers and time consuming for respondents.

In general, clarification of terms used in the survey measuring time seems to be crucial. Our analysis seems to indicate that the terms 'unpaid work' and 'leisure' in the opportunity cost method were not entirely clear for all respondents. This because the 60

percent of RA caregivers indicating that they spent time on leisure before the caregiving episode started is strikingly low (table 5.2a). One would expect a percentage close to 100 percent, as almost everybody enjoys leisure now and then. The same holds for unpaid work because one would expect that almost everybody performs some unpaid work (in and around the house). For the measurement of time we recommend to add an additional open answer category in order to give respondents the possibility to indicate possible other opportunity costs. This holds also, but to a lower extent, for the proxy good method. Giving respondents the opportunity to indicate other informal care tasks could provide additional insights.

In applying the proxy good method, one could also use the market prices of house workers. On the one hand this would be a better proxy because the market for house workers is not as heavily regulated as the health care market. On the other hand the quality of home keepers could be less than the quality of the professional caregivers due to for instance education and training. So, using the salaries of house workers could underestimate the value of informal care. There is also an institutional argument in favor of the professional caregiver. If in The Netherlands no informal caregiver would be present, the care recipient would get professional care as a consequence of his insurance and he does not need to hire a house worker.

It is conspicuous if we compare our results with for instance (O'Shea and Blackwell, 1993) that in particular our informal caregivers reported lower opportunity costs of paid work forgone. They found that on average 24 percent of informal care provided was at the costs of paid work, 37 percent at the costs of unpaid work, 32 percent at the costs of leisure. O'Shea and Blackwell (1993) also added a category voluntary activity forgone and found that 7 percent was at the costs of voluntary activity. Moreover, their average amount of time spent on providing informal care was around twice as much compared to our estimates (50.5 hours a week versus 20.2 and 27.4 for CVA and RA respectively). Our chapter adds to this literature by estimating the opportunity costs of caring directly from informal caregivers involved in the caregiving episode instead of indirectly through for instance the general population as O'Shea and Blackwell (1993) did. They justified their approach by assuming that care recipients were not able to indicate informal caregivers' opportunity costs of care and they only interviewed care recipients. We interviewed both care recipients and their informal caregivers. Timmermans (2003) found that informal caregivers (a sample of the general population in The Netherlands) on average worked 9.9 hours a week less due to providing informal care. This is much higher

compared to our findings. However, Timmermans (2003) included also respondents who stated that they rejected additional paid work due to their caregiving responsibilities. Informal caregivers who indicated that they were stopped with paid work reported an average of 9.1 hours per week, while informal caregivers with a paid job reported 3.6 hours per week less paid work due to the provision of informal care.

In order to assure the incorporation of informal care in economic evaluations, it would be useful to develop more precise guidelines for the operationalisation of both methods instead of just the recommendation to apply one of them. A comparable operationalisation is necessary in order to ensure comparison in results between different studies that provide economic valuations of informal care and also between different economic evaluations.



# 6 Economic valuation of informal care: The contingent valuation method applied to informal caregiving<sup>1</sup>

## Summary

*This chapter reports the results of the application of the contingent valuation method (CVM) to determine a monetary value of informal care. We discuss the current practice in valuing informal care and a theoretical model of the costs and benefits related to the provision of informal care. In addition, we developed a survey in which informal caregivers' willingness to accept (WTA) to provide an additional hour of informal care was elicited. This method is better than normally recommended valuation methods able to capture the heterogeneity and dynamics of informal care.*

*Data were obtained from postal surveys. A total of 153 informal caregivers and 149 care recipients with rheumatoid arthritis returned a completed survey. Informal caregivers reported a mean WTA to provide a hypothetical additional hour of informal care of 9.52 Euro (n=124). Many hypotheses derived from the theoretical model and the literature were supported by the data.*

*CVM is a promising alternative for existing methods like the opportunity cost method and the proxy good method to determine a monetary value of informal care that can be incorporated in the numerator of any economic evaluation.*

## 6.1 Introduction

Informal care plays a substantial role in the total care provided, especially in case of care for people with chronic diseases and terminally ill people (Norton, 2000). It is care provided by someone from the social environment of the care recipient, for example a spouse, parent, sister or neighbour. Informal care is a heterogeneous commodity in the sense that important differences in time investments, duration of providing informal care and number of provided care tasks exist between informal caregivers. Moreover, providing informal care is often a dynamic process. The process is closely connected with the care demands of the care recipient that are in turn dependent on for instance the care recipient's health status. We define informal care therefore as:

---

<sup>1</sup> Based on Van den Berg, B., Brouwer, W.B.F., Van Exel, J.A.J., Koopmanschap, M.A., 2004. Economic valuation of informal care: The contingent valuation method applied to informal caregiving. Accepted for publication Health Economics.

*“A quasi or non-market composite commodity consisting of heterogeneous parts produced (paid or unpaid) by one or more members of the social environment of the care recipient as a result of the care demands of the care recipient”* (Van den Berg et al., 2004).

In this definition we have left open the possibility for informal caregivers to be paid. It is often debated whether or not informal caregivers may receive some form of payment and still be considered informal caregivers. This question is increasingly relevant now that *personal budgets* become a more popular instrument of financing health care, with which informal caregivers may be paid as well as formal caregivers (Tilly et al., 2000).

In economic evaluations that take the societal perspective everyone affected by an intervention should be considered and all significant outcomes and costs that flow directly or indirectly from the intervention should be counted regardless of who experiences the outcomes and costs (Russell et al., 1996) and (Drummond et al., 1997). This implies that informal care should be incorporated in economic evaluations of health care. In practice however, informal care is often neglected in economic evaluations (Stone et al., 2000). This may bias economic evaluations of interventions that depend on (substantial) use of informal care. Partly, this neglect of informal care may reflect the fact that the valuation of informal care is troublesome. The costs of informal care are to an important extent related to time inputs by relatives and friends of the care recipients and their time is difficult to measure and value (Van den Berg et al, 2004). See Netten (1990) for an overview of other costs related to informal care, such as home adaptations and the costs of assistance devices.

It is suggested to incorporate the changes in use of informal caregiver time as direct non-health care costs into the numerator of the cost-effectiveness ratio in economic evaluations (Luce et al., 1996, p.177). Two monetary valuation methods are often recommended to value the time investment in informal care: the opportunity cost method (valuing hours spent on informal care at a – would be – wage rate) and the proxy good method (valuing informal care hours at the wage rate of a professional caregiver) (Posnett and Jan, 1996), (Russell et al., 1996) and (Drummond et al., 1997). However, both methods are rather insensitive to the heterogeneity and dynamics of informal care. Still, the opportunity cost method only considers what is sacrificed in order to be able to perform informal care (e.g., paid work, unpaid work or leisure) but does not incorporate the preferences of informal caregivers in terms of their current use of time. Moreover, finding appropriate wage rates for the retired, the disabled, or for sacrificed leisure by for instance

eliciting (would be) wage-rates, seems difficult. The proxy good method uses the price of market alternatives to value informal care. Indeed, informal care can be seen as a quasi-market commodity as market alternatives like professional nurses or house workers are available and consequently market prices exist. However, it is debatable whether informal care and the market alternatives are full substitutes. Moreover, this method also neglects informal caregiver's preferences.

Both methods also do not incorporate the full effects of providing informal care for the informal caregivers and therefore do not capture the full impact of providing informal care. It is increasingly recognized that providing informal care has both positive and negative effects on the informal caregiver, (dis)benefits, like for example enjoying providing care for someone you love or decrements to informal caregivers' health as a result of straining care tasks (Orbell et al., 1993), (Kramer, 1997), (Hughes et al., 1999) and (Schulz and Beach, 1999). It is suggested to use health-related quality of life measurement in informal caregivers to measure the full impact of informal care, e.g., (Mohide et al., 1988) and (Brouwer et al., 1999). However, this implies that next to care recipient's outcomes, informal caregiver's outcomes should be used as an outcome measure in economic evaluations. Luce et al. (1996, p.177) therefore argue that the preferred solution would be a monetary valuation method, capable of capturing all relevant aspects of informal care. The results could then be incorporated into the numerator of any economic evaluation. This is especially preferable in situations in which informal care is not the main focus of an economic evaluation. When evaluating, for example, support programs for informal caregivers the costs and (health) effects related to informal care may of course be further distinguished, see e.g. Drummond et al. (1991).

A method capable of capturing all relevant aspects of informal care should ideally be sensitive to the different circumstances informal caregivers are faced with and reflect the true preferences of informal caregivers. The contingent valuation method (CVM) is such a method at least in theory. To date this method has not been used to value informal care to our best knowledge. In this chapter we report an application of CVM to value informal care using a sample of 153 caregivers providing care to care recipients with rheumatoid arthritis.

The main focus of the chapter is to attempt to value the full impact of providing informal care on the informal caregiver through asking informal caregivers how much monetary compensation they minimally require in order to provide an additional hour of informal care per week. CVM, in the form of willingness to accept (WTA) in this chapter,

has the advantage of being sensitive to the circumstances and preferences of informal caregivers in comparison to the opportunity cost method and proxy good method.

The outline of the chapter is as follows. First, we discuss a theoretical framework for the valuation of informal care. Second, we describe the methods used in this study. Then we present the data and the results after which the chapter concludes.

## 6.2 Theoretical background: welfare economics

A theoretical model of providing informal care has been developed by Smith and Wright (1994). The aim of their model was to consider the full impact of informal care. Their particular concern was "...to discuss how to evaluate the contribution of informal carers in economic appraisals of alternative forms of continuing care for chronically disabled people (Smith and Wright 1994, p.137)." Smith and Wright (1994) tried to combine the concepts of direct and indirect utility and exclude topics from other disciplines like family roles, obligations, rights, duties and responsibilities.

Figure 6.1: Informal caregiver’s marginal costs and marginal benefits of providing informal care

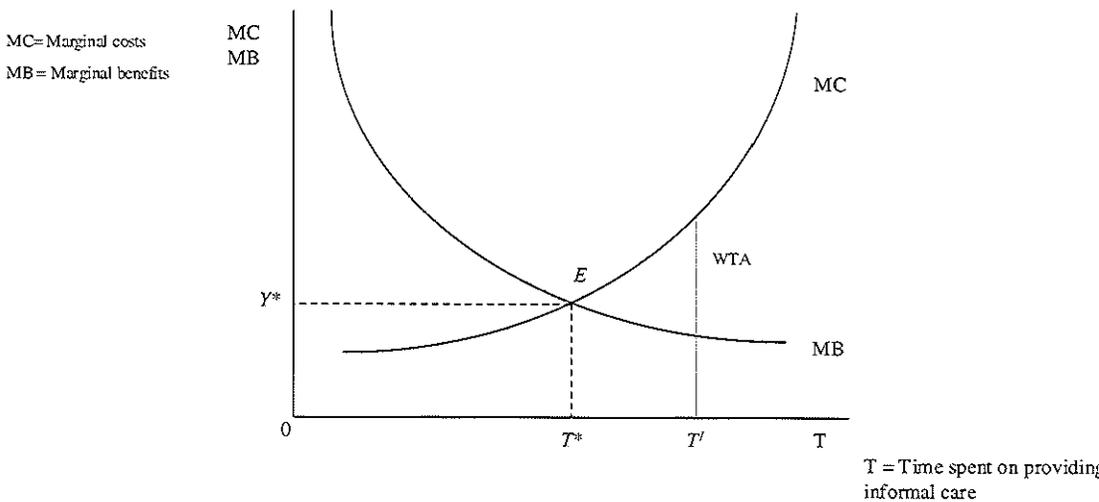


Figure 6.1 illustrates the informal caregiver’s marginal costs (MC) and marginal benefits (MB) of providing informal care based on (Smith and Wright, 1994). The MC include among other things the opportunity costs of time, financial outlays, forgone career opportunities, higher morbidity and mortality risks, and strain. The positive slope of the

MC curve indicates the higher MC of allocating an additional time unit to informal caregiving, for most of the informal caregivers. On the other hand, the MB among other things contain friendship, companionship, pleasure and the informal caregiver's perception of the utility of the care recipient from being informally cared for. The MB curve has a negative slope to show that for most informal caregivers an increase in the time spent in caregiving will decrease the MB of caring but they will remain positive, contrary to Smith and Wright's marginal valuation line (MVh), which has a constant downward slope down to zero.  $T^*$  denotes the optimal level of informal care provided from the viewpoint of the informal caregiver. From that point onward, providing informal care yields more costs than benefits. It is important to stress that this point of optimality does not necessarily coincide with the optimal  $T^*$  from the care recipient's (or even societal) perspective. Given utility interdependence between informal caregiver and care recipient, the informal caregiver will incorporate his perception of the preferences of the care recipient in his decision.

It is also worth noting that beyond  $T^*$  providing additional hours of informal care is not rational without adequate compensation. Of course, social and institutional restrictions or transaction costs may cause some temporary variation around point  $T^*$ . Yet beyond that point informal care leads to more costs than benefits. This interpretation of  $T^*$  is different from that of Smith and Wright (1994), who indicate that as long as the marginal benefits are positive, "positive utility is derived from caring" (Smith and Wright, 1994). We would rather suggest that this is only the case until  $T^*$ . Moreover, Smith and Wright (1994) indicate that beyond  $T^*$  "there is a perceived burden on the carer as the marginal valuation is substantially lower than the marginal costs" (Smith and Wright, 1994). We would use the term disutility here as opposed to Smith and Wright (1994) who talk about disutility beyond the point from where the MVh line crosses  $T$ .

The interpretation of  $T^*$  depends on what is included in the MC and MB curves. We suppose that all relative costs and benefits of alternatives are included in the MC and MB of informal care. Thus, when MC and MB intersect (at  $T^*$  in Figure 6.1), it may be more advantageous to hire professional care or to leave the care recipient without additional care from that point onward. The intersection therefore indicates that some alternative is better than informal care from the informal caregiver's viewpoint. Furthermore, it is worth noting that Figure 6.1 is static and does not describe the dynamics of informal care very well. In the short run the position of MC and MB may indeed be considered fixed as shown in Figure 6.1. However, in the long run the MC and MB curves can shift, for example, due to a change in health status and the resulting care demands of

the care recipient. Finally, the relative magnitudes of the slopes of the MC and MB curves can differ substantially between informal caregivers. CVM is capable to measure the informal caregiver's net difference between MC and MB. The next session discusses this method in more detail.

### **6.3 Contingent valuation method**

CVM is a monetary valuation method, capable of deriving the net value per hour informal caregiving from the perspective of the informal caregiver. It is an often used valuation method rooted in applied welfare economics. CVM is based on the work of Hicks (1939), who developed measures of losses and gains by holding utility constant. In comparison to other valuation methods like the opportunity cost method and proxy good method, CVM holds the advantage of being sensitive to real preferences of individuals, because utility is assumed to be held constant. See for general overviews of CVM Mitchell and Carson (1989), Johansson (1995), and for applications in health care, Diener et al. (1998), Klose (1999), and Olsen and Smith (2001).

Hicks (1939) developed different measures of (dis)benefit; compensating variation and surplus, and equivalent variation and surplus. On an applied level, one can use willingness to pay (WTP) or willingness to accept (WTA). Therefore, in applied work the central issue in measuring (dis)benefits is whether to use WTP or WTA questions. In many cases this is just a question of property rights. In other words, does the respondent have to buy or to sell the commodity under valuation? (Bromley, 1995) Therefore, in many applications in health care it is natural to use WTP because one values respondents' benefits from, for instance, new technologies or medicines. Indeed, Diener et al. (1998), Klose (1999), and Olsen and Smith (2001) report that over ninety percent of the CVM applications in health care use WTP. But, because conventional economic theory states that in most circumstances WTP and WTA yield roughly the same results (Willig, 1976), one could in principle apply both to all situations. However, empirical studies show that WTA often exceeds WTP (Brown and Gregory, 1999). Therefore, it is argued to apply WTP instead of WTA because it gives an under bound estimate of the valuation (Brown and Gregory, 1999). See Brown and Gregory (1999) for an extensive summary of reasons for the WTP-WTA disparity. In health care applications, just a few studies tested for the WTP-WTA disparity. Borisova and Goodman (2003), for instance, applied CVM to value travel time for methadone maintenance clients. They found somewhat higher WTA values compared to WTP values.

In the context of having to give up time, as is the case in our study, it is natural to use WTA. In terms of Figure 6.1, this means that providing an additional hour informal care ( $T^1-T^0$ ) involves both MC and MB. WTA measures informal caregivers' required compensation in cases where their MC exceeds their MB. That way, CVM should be capable of providing a preference based net valuation of informal care. In sum, we opt for a property right argument instead of an empirical argument in the decision between the application of WTP or WTA. Applying WTA yields an estimation of the value of the hour, which has to be sacrificed in order to be able to provide informal care. Therefore, the value of this time input is seen as a cost.

Although having the advantage of being sensitive to preferences of respondents and having a theoretical foundation in welfare economics, CVM has often been criticised. In principle, these criticisms hold both for WTP and WTA. Criticisms include the use of survey questions, strategic behaviour, scope validity as well as the relation between CVM answers and respondents' income. The use of hypothetical rather than actual choice situations is a major concern, especially for economists, reflecting their preference for revealed rather than stated preference methods. CVM holds the danger of strategic behaviour by respondents (Mitchell and Carson, 1989). However, when respondent's answers do not directly influence reimbursement or provision of the commodity, as is the case with public commodities, the risk of strategic behaviour by respondents is limited (Pauly, 1995). It has also been questioned whether respondents can answer meaningfully to the sometimes very hypothetical questions posed (Carson, 2001). The more concrete and conceivable the hypothetical situation under valuation is, the more likely it seems that the provided answers are reflecting some real preference (Fischhoff, 1991). Caution is warranted in applying CVM to situations where respondents find the questions posed contradictory or upsetting (Pauly, 1995). In fact, this has been put forward as an argument against the application of CVM to value informal care (Smith and Wright, 1994). We believe however (and will demonstrate so in the remainder of this chapter) that it is possible to formulate questions on informal care in such a way that respondents do not consider them to be upsetting. Another concern in the application of CVM is that answers should be but sometimes are not sensitive to the quantity of the commodity under valuation, for example, to save two whales one would have to be willing to pay more than to save only one whale. See for detailed discussions of 'scope validity' Kahnemann and Knetsch (1992), Milgrom (1993), Carson (1997), Kahneman et al. (1999b) and Carson (2001). CVM can also conflict with equity considerations, as it is not an income-neutral

valuation method (Johansson-Stenman, 2000) and (Donaldson et al., 2002). Therefore, it is sometimes argued that CVM should not be applied to value health care commodities. Recent applications of CVM have used the correlation between income and WTP as a measure of theoretical validity, while early day applications saw it as a point of concern in the equity debate (Olsen and Smith, 2001, p.46). The importance of the issue is clear and any economic evaluation of health care involving informal care should preferably highlight the distributional consequences of a certain intervention or method. It is worth noting that the opportunity cost method as an important alternative for CVM to value informal care also depends systematically on income. This does not hold for the proxy good method.

## **6.4 CVM applied to informal caregiving**

### **6.4.1 Developed survey**

Our central objective was to find a monetary value for informal caregiver's time. We applied CVM to value informal care by assessing an informal caregiver's willingness to accept (WTA) to provide an additional hour of informal care. Therefore, we used a specific study design, in order to be able to acknowledge the diversity of care situations in relation to CVM.

We asked the informal caregiver if other caregivers were involved in the caregiving process and if the care recipient was on a waiting list for professional or residential care. Moreover, we asked respondents how many hours they spent on informal caregiving during the last week according to a list of sixteen care items. We distinguished three types of care tasks: (1) housework (HDL) like cleaning, (2) activities of daily living (ADL) like personal care and, (3) instrumental activities of daily living (IADL) like organizing home adaptations or contacts with health care suppliers. Then we described a hypothetical situation with governmental support possibilities. This was a scenario to prevent 'out of the same pocket' expenditures and to make clear that informal caregivers got the compensation in terms of a net sum of cash money.

*“Suppose your partner needs one additional hour of care a week and that the government will pay you to provide this additional hour of care. Which one of the following tasks would you preferably provide during that hour?”*

*(1) House work, (2) personal care, (3) support, (4) organizational tasks, (5) social support, (6) I do not want to provide additional care, and (7) other tasks, like .....*”

Subsequently we asked them:

*“What is the minimum amount of money you would want to receive from the government to provide this additional hour of care? (1)  $fx$  Euro, (2) Less than  $fx$  Euro, that is....., (3) More than  $fx$  Euro, that is....”*

We choose a dichotomous choice format with open follow-up question. The respondents could accept or reject a certain bid  $fx$  ( $x \in \{4.54, 6.81, 9.08, 11.34, 13.61\}$ ) in Euros, initial  $fx$  ( $x \in \{10, 15, 20, 25, 30\}$ ) in Dutch guilders. We also gave them the opportunity to fill in a higher or a lower bid if  $fx$  was either too low or too high. The bids were chosen because they encompass the market prices and health sector tariffs for housework and they were randomly distributed over the respondents. This approach has been successfully applied before (Baarsma, 2000) and extensively discussed (Kartman et al., 1997). We choose this format because in the pilot phase of this study direct open-ended questions turned out to be too difficult for respondents. The pilot phase gave us the understanding that the respondents understood the task they were confronted with.

To get a broad picture of the informal caregiving situation and to be able to capture the heterogeneity of providing informal care, we asked informal caregivers as well as care recipients some additional questions in order to have context information, which may influence WTA. We measured health-related quality of life of both informal caregivers and care recipients with the EQ-5D (EuroQol Group, 1990), (Essink-Bot et al., 1993), and (Dolan, 1997). Many instruments are developed to measure informal caregiver's subjective burden of providing informal care (Kramer, 1997). We applied the Caregiver Reaction Assessment (CRA) (Given et al., 1992) and (Jacobi et al., 2003), because it, as opposed to most subjective burden instruments, contains both a positive (“self-esteem”) and negative dimensions (“disrupted schedule”, “financial problems”, lack of “family support”, and “loss of physical strength”). The CRA however, has no sum score. Therefore, we also used a visual analogue scale (VAS) ranging from 0 (“not hard at all”) to 100 (“much too hard”) to measure the overall subjective burden of informal caregiving. Finally, we asked both informal caregivers and care recipients some socio-demographic questions. We used postcode areas as a proxy for income. This has been shown to be a reliable method (Smits et al., 2002).

## 6.4.2 Hypotheses

In order to capture all relevant aspects of informal care, CVM should be sensitive to the different circumstances faced to informal caregivers. We formulated fifteen hypotheses based on the theoretical model, the literature on CVM and previous research on informal caregiving to get an impression of the validity of the WTA approach to value informal care. Most hypotheses concern the preferences, capabilities and responsibilities of the informal caregivers, institutional factors or address the scope validity of informal care. Our hypotheses are listed in Table 6.6.

As can be seen in Table 6.6, we hypothesised that WTA increases with:

- the informal caregiver's income;
- the fact that an informal caregiver is not willing to supply an additional hour of informal care (preference);
- the fact that the care recipient is on a waiting list for professional care (institutional);
- the number of hours of care already provided by the informal caregiver (scope);
- a higher subjective burden on the sub scales "disrupted schedule", "financial problems", "lack of family support" and "loss of physical strength" (capability);
- a higher overall subjective burden (capability) and;
- providing informal care to a care recipient who also receives other informal care (responsibility).

On the other hand we hypothesised that WTA decreases with:

- higher EQ-5D scores of the informal caregiver (capability) and the care recipient (scope);
- higher subjective burden on the sub scale "care-derived self-esteem" (preference);
- providing informal care to a care recipient who also receives professional care (responsibility) and;
- having flexible working hours in a paid job as informal caregiver (institutional).

To understand the reasoning behind the hypotheses, it is important to have some idea about the relative position of the caregiver to T\* in Figure 6.1. Two sources of collected information give an indication. First, if the care recipient is on a waiting list for professional or residential care and second if the informal caregiver is unwilling to provide an additional hour of informal care. We expect a relatively higher WTA in both of these

cases. Subjective burden may have some relation with the relative position of informal caregivers in Figure 6.1. It gives an indication of the informal caregiver's direct (dis)utility. However, the exact nature of this relationship is unclear. We do expect that higher subjective burden (meaning higher scores on the negative domains and lower scores on the positive domain) translates into higher WTA. In relation to health-related quality of life, we expect that a relatively low health-related quality of life of the informal caregiver and the care recipient lead to a higher WTA. For informal caregivers this is expected because a low health-related quality of life implies a relatively low capability to care, and for the care recipient this relationship is expected because a relative low health-related quality of life implies more care demands. Moreover, it would help to confirm the validity of CVM in this context if informal caregivers consider the quantity of their current amount of provided informal care. We name the latter two hypotheses scope effects. It is worth nothing that this reading of scope effects differs from the common interpretation in the CVM literature. Usually, tests for sensitivity to scope can be implemented either internally or externally (Carson et al., 2001). An internal test elicits the same respondents' WTP or WTA for different quantities of the commodity under valuation, while an external test elicits the WTP or WTA of different but statistically equivalent subgroups for different quantities of the commodity under valuation. Being the only person responsible for the provision of care may be relatively burdensome and therefore lead to a higher WTA. It is plausible that providing informal care for people with a paid job could involve for instance additional stress. Therefore, an informal caregiver with flexible working hours in a paid job would experience fewer problems in combining informal care with his paid job and is therefore expected to require less compensation, *ceteris paribus*. Finally, WTA answers, as opposed to WTP answers, are not as strictly influenced by budgetary constraints (income is often used as a proxy for the budget constraint). Yet in our application people with a higher income have higher opportunity costs of providing informal care in terms of forgone paid work time and leisure (the shadow price of leisure is forgone paid work) compared to people with a relative lower income. Therefore, we expect that people with a relative higher income require more compensation compared to people with a relative lower income.

### **6.4.3 Study sample**

The data for this study were collected as a supplement of the RA+ study, a panel study of health care utilisation among people with rheumatoid arthritis (RA) (Jacobi et al., 2001) and (Jacobi et al., 2003). In the 2001 wave of this panel, 365 of 683 care receivers indicated to

receive informal care. We approached all care receivers and asked the 365 receiving informal care to hand over our mail survey to their primary informal caregiver. Moreover, we asked all care receivers to complete a mail survey themselves. We included a question for the 318 care receivers without informal care if they perhaps currently received informal care. If so, we also asked them to hand a mail survey over to their primary informal caregiver.

A total of 153 informal caregivers returned the mail survey and we have data for 149 pairs of care receivers and informal caregivers. The care receivers of four informal caregivers did not return their survey. Moreover, 21 care receivers had deceased, 12 were irretrievably relocated and four respondents sent in their survey too late for analysis.

## **6.5 Results**

### **6.5.1 Background statistics**

Table 6.1 gives the descriptive statistics of the study sample. Just 24.7 percent of the informal caregivers are female. This is striking because normally the majority of informal caregivers is female. An obvious explanation is that 91.5 percent of the informal caregivers are partners of the care recipient and the incidence of RA is much higher in women as compared to men. Informal caregivers' and care recipients' age ranges between 26.0 - 87.1 and 28.3 - 85.2 respectively. The occupation percentages add up to over 100 percent because some respondents indicate two main occupations.

**Table 6.1: Characteristics informal caregivers and care recipients**

<i>Characteristic</i>	<i>Mean</i>
<i>Informal caregivers</i>	
Age <sup>1</sup>	62.1
Sex <sup>2</sup>	75.3
Partner <sup>3</sup>	91.5
Live together	87.6
<i>Education</i>	
Low	34.9
Middle	46.3
High	13.4
<i>Occupation</i>	
Paid job	35.3
Flexible job	51.6
House worker	17.7
Retired	49.7
Disability pension	7.2
<i>Income<sup>4</sup></i>	
Income 1	20.3
Income 2	40.5
Income 3	19.6
Income 4	0.8
Income unknown	13.8
<i>Care recipient</i>	
Age <sup>1</sup>	62.1
Sex <sup>2</sup>	16.1
<i>Education</i>	
Low	43.9
Middle	38.5
High	9.5
<i>Occupation</i>	
Paid job	15.4
House worker	38.9
Retired	32.2
Disability pension	19.5
No	10.1

<sup>1</sup> In years

<sup>2</sup> Percentage males

<sup>3</sup> Percentage partners

<sup>4</sup> Income 1 is the lowest category and income 4 the highest.

Table 6.2 gives some other background characteristics of the study sample, such as care duration, the amount of informal care provided, subjective burden and EQ-5D scores.

**Table 6.2:** Characteristics informal caregivers and care recipients

Characteristic	Mean	Min	Max
<i>Informal caregivers</i>			
Care duration <sup>1</sup>	11.4	0.2	50.3
Performing HDL tasks <sup>2</sup>	94.1		
HDL	21.7	0.5	115.5
Performing ADL tasks <sup>2</sup>	37.3		
ADL	5.4	0.6	31.5
Performing IADL tasks <sup>2</sup>	68.6		
IADL	5.2	0.3	26.0
Total informal care time	27.1	0.3	133.5
Opportunity costs paid work <sup>2</sup>	6.1		
Opportunity costs unpaid work <sup>2</sup>	8.0		
Opportunity costs leisure <sup>2</sup>	18.9		
CRA subscale 1	13.2	5	25
CRA subscale 2	7.3	3	15
CRA subscale 3	12.2	5	25
CRA subscale 4	9.0	4	18
CRA subscale 5	29.4	11	35
Subjective burden (VAS)	24.6	0	100
EQ-5D	0.78	-0.074	1
<i>Care recipients</i>			
EQ-5D	0.48	-0.43	1
Waiting list <sup>2</sup>	5.9		
Professional care <sup>2</sup>	26.1		
Other informal care <sup>2</sup>	68.0		

<sup>1</sup> In years

<sup>2</sup> In percentage

The mean care duration is 11.4 years, reflecting the fact that rheumatoid arthritis is a slowly progressive disease. Six percent of the care recipients is on a waiting list for professional or residential care. Almost 40 percent of the informal caregivers perform ADL tasks while 68.6 percent of them perform IADL tasks and more than 90 percent perform HDL tasks. The EQ-5D scores of the informal caregivers are much higher than those of

the care recipients (0.78 versus 0.48). In order to provide informal care, informal caregivers sacrifice leisure (18.9 percent), unpaid work (8.0 percent) and paid work (6.1 percent). Many informal caregivers (67 percent) did not indicate what time use was sacrificed in order to provide care. To some extent this may have to do with the fact that for most informal caregivers providing informal care has become part of their normal time use, given the average care duration of over 11 years. The mean CRA scores on the negative subscales 1 to 4 are relatively low compared to the maximum feasible scores (25, 15, 25, 20 respectively), indicating a moderate burden on average. Moreover, the mean score on the positive subscale 5 is relatively high compared to its maximum (35) indicating that the informal caregivers in our sample derive a lot of self-esteem from providing informal care.

**6.5.2 Informal care tasks**

We asked respondents to indicate their favourite informal care task. Table 6.3 presents the answers on these questions.

**Table 6.3:** Most favourite informal care task of informal caregiver in percentages and in mean WTA

<i>Preferred informal care task</i>	<i>Percentage</i>	<i>Mean WTA</i>	<i>N</i>	<i>Min</i>	<i>Max</i>
House work	64.1	9.72	91	0	31.76
Personal care	4.6	7.20	7	0.45	13.61
Support	9.8	8.10	13	0.91	18.15
Organisational tasks	0	0	0	0	0
Social support	4.6	8.70	6	4.54	11.34
I don't want to provide an additional hour	8.5	10.59	6	0	27.23
Other tasks, like.....	7.2	9.25	8	0	43.11

Over 64 percent of the informal caregivers indicate housework as their favourite informal care task. Nobody indicates organisational tasks as their favourite task, while 68.6 percent of the informal caregivers perform organisational tasks (Table 6.2). In addition, 8.5 percent of the informal caregivers is not willing to provide an additional hour of informal care, and 5.9 percent of the informal caregivers care for a care recipient on a waiting list for

formal care. This means that at least 14.4 percent of the respondents appears to be at or beyond point T\* in Figure 6.1.

### 6.5.3 WTA

We offered the informal caregivers a WTA start bid that they could either accept or reject. In the latter case, they could subsequently indicate a higher or a lower WTA. Table 6.4 shows the results of the WTA question.

**Table 6.4:** Part of the respondents that accept or reject the WTA start bid for an additional hour informal care a week

<i>Start bid<sup>1</sup></i>	<i>Accept<sup>2</sup></i>	<i>More<sup>2</sup></i>	<i>Less<sup>2</sup></i>	<i>Miss<sup>2</sup></i>	<i>N<sup>3</sup></i>	<i>Mean<sup>1</sup></i>	<i>S.D.<sup>1</sup></i>	<i>Min<sup>1</sup></i>	<i>Max<sup>1</sup></i>
4.54	34.3	31.4	2.7	31.4	35	6.19	3.03	0.00	13.61
6.81	48.4	12.0	19.4	19.4	31	5.81	2.63	0.00	11.34
9.08	52.3	18.2	13.6	15.9	44	9.67	5.34	0.00	27.23
11.34	44.0	24.0	16.0	16.0	25	14.57	7.31	6.81	31.76
13.61	50.0	22.2	22.2	5.6	18	14.32	9.79	0.00	43.11
Total	45.8	21.6	13.7	19.0	153	9.52	6.58	0.00	43.11

<sup>1</sup> *Euros*

<sup>2</sup> *Percentages*

<sup>3</sup> *Number of observations*

45.8 Percent of the informal caregivers accepted the start bid, 21.6 percent indicated a higher WTA than the offered start bid, and 13.7 percent indicated a lower WTA than the offered start bid. Finally, 19.0 percent did not answer the WTA question. The results in Table 4 indicate the existence of a starting point bias. We tested for starting-point bias by OLS-regression with WTA as dependent and the start bid as independent variable. Over 24 percent of the variance in WTA is explained by the start bid (t-value = 6.22 and p-value < .0001). If we correct for general background characteristics the start bid is still significant (t-value = 5.82 and p-value < .0001).

We corrected for starting point bias by running first an OLS-regression with the start bid as independent variable next to the other independent variables in Table 6.5 and WTA as dependent variable. Then we predicted the corrected WTA per informal caregiver. Finally, we run an OLS-regression with the corrected WTA as dependent variable and the

variables in Table 6.5 as independent variables. This corrected WTA was used to test our hypotheses.

### 6.5.4 Explaining WTA

Tables 6.3 and 6.5 explain informal caregivers' WTA. Informal caregivers indicate a different WTA for different informal care tasks (Table 6.3). WTA varies from 7.20 Euro (personal care) to 10.59 Euro (not willing to provide an additional hour). The latter informal caregivers indicate a higher mean WTA compared to the others. This may imply that they are at or beyond point T\* (Figure 6.1) and therefore require a higher amount of money to invest an additional hour in informal care.

**Table 6.5:** Corrected OLS regression of WTA<sup>a</sup>

<i>Independent variable</i>	<i>Parameter estimate</i>	<i>Standard error</i>	<i>t-Value</i>	<i>Prob &gt;  T </i>
Intercept*	21.81	9.18	2.38	0.0218
<i>Informal caregiver</i>				
Dummy income 1 (1=yes)	-0.49	1.55	-0.32	0.7526
Dummy income 2 (1=yes)*	7.39	1.29	5.72	<.0001
Dummy income 3 (1=yes)*	7.27	1.44	5.05	<.0001
Dummy income unknown (1=yes)*	-4.30	1.45	-2.97	0.0048
Age	-0.15	0.10	-1.50	0.1410
Dummy sex (1=male)*	5.87	2.67	2.19	0.0335
Dummy education 1 (1=yes)	0.74	1.05	0.71	0.4844
Dummy education 2 (1=yes)	0.58	0.98	0.59	0.5586
Dummy paid job (1=yes)	-1.79	1.45	-1.23	0.2236
Dummy house worker (1=yes)*	5.16	1.22	4.24	0.0001
Dummy retired (1=yes)	-1.39	1.38	-1.01	0.3173
Dummy flexible job (1=yes)*	-5.35	0.79	-6.75	<.0001
EQ-5D*	13.88	2.68	5.18	<.0001
Marginal hour IC	-0.15	0.89	-0.17	0.8667
Opportunity costs paid work (1=yes)*	-5.14	2.33	-2.21	0.0325
Opportunity costs unpaid work (1=yes)*	5.62	2.02	2.78	0.0080
Opportunity costs leisure (1=yes)	0.95	1.16	0.82	0.4185
CRA sub1	0.04	0.12	0.32	0.7504
CRA sub2	0.16	0.14	1.14	0.2591
CRA sub3*	-0.40	0.11	-3.66	0.0007
CRA sub4	0.10	0.18	0.53	0.5993
CRA sub5*	-0.38	0.11	-3.27	0.0020

*Continued on the next page*

<i>Independent variable</i>	<i>Parameter estimate</i>	<i>Standard error</i>	<i>t-Value</i>	<i>Prob &gt;  T </i>
Vas subjective burden*	-0.09	0.02	-3.90	0.0003
Dummy WTA housework (1=yes)	-1.64	1.21	-1.35	0.1825
Dummy WTA personal care (1=yes)*	-5.19	2.16	-2.41	0.0202
Dummy WTA mobility (1=yes)	-0.90	1.51	-0.60	0.5547
Dummy WTA support (1=yes)*	6.04	1.78	3.39	0.0015
Dummy WTA I don't want (1=yes)*	10.85	2.07	5.24	<.0001
Informal care years	-0.07	0.05	-1.48	0.1449
Dummy relationship (1 = partner)	-4.25	3.32	-1.28	0.2070
<i>Care recipient</i>				
EQ-5D*	-5.96	1.49	-3.99	0.0002
Age	-0.02	0.09	-0.22	0.8294
Dummy sex (1=male)*	7.10	2.80	2.54	0.0147
Dummy education 1 (1=yes)*	7.37	1.29	5.71	<.0001
Dummy education 2 (1=yes)	1.40	1.14	1.23	0.2243
Dummy care recipient on waiting list (1=yes)*	8.30	1.85	4.49	<.0001
Dummy care recipient receives professional care (1=yes)*	-5.10	1.09	-4.66	<.0001
Dummy other informal care (1=yes)	1.89	0.98	1.93	0.0597

\*  $R^2 = 0.8841$ ;  $Adj R^2 = 0.7863$   $F = 9.04$ ;  $N = 84$ .

\* Significant at the 95% confidence level.

Table 6.5 shows that informal caregivers' WTA can be explained by different characteristics of the caregivers: income, sex (men indicate a higher WTA compared to women), occupation (housewife or househusband compared to other), informal caregivers' and care recipients' EQ-5D, opportunity costs (compared to no opportunity costs), subjective burden ("lack of family support", "care-derived self-esteem", and VAS) and care tasks. Characteristics of the care recipients play also a role: sex (a higher WTA in case of male care recipients), care recipients' education (low education leads to higher WTA compared to high education). Being on a waiting list for professional or residential care raises the WTA and receiving professional care lowers WTA.

### 6.5.5 Hypotheses

Tables 6.5 and 6.6 show whether the results supported our hypotheses.

Table 6.6: Hypotheses

<i>Hypothesis</i>	<i>Independent variable</i>	<i>Effect dependent variable</i>	<i>Result</i>
1	Higher income	Higher WTA	Accepted
2	Not willing to supply an additional hour	Higher WTA	Accepted
3	Care recipient on waiting list	Higher WTA	Accepted
4	More hours of informal care	Higher WTA	Rejected
5	Higher EQ-5D informal caregiver	Lower WTA	Rejected
6	Higher EQ-5D care recipient	Lower WTA	Accepted
7	Higher subjective burden "disrupted schedule"	Higher WTA	Rejected
8	Higher subjective burden "financial problems"	Higher WTA	Rejected
9	Higher subjective burden "lack of family support"	Higher WTA	Rejected
10	Higher subjective burden "loss of physical strength"	Higher WTA	Rejected
11	Higher subjective burden "care-derived self-esteem"	Lower WTA	Accepted
12	Higher subjective burden (VAS)	Higher WTA	Rejected
13	Care recipient receives professional care	Lower WTA	Accepted
14	Care recipient receives other informal care	Higher WTA	Accepted
15	Flexibility of paid work	Lower WTA	Accepted

Many hypotheses are accepted. Especially the hypotheses concerning institutional factors (hypotheses 3 and 15), preferences (hypotheses 2 and 11), and responsibilities (hypotheses 13 and 14) are accepted. Moreover, the joint influence of the different income dummies on WTA is significant (F-value = 28.25, p-value < .0001) (hypothesis 1). One hypothesis about scope validity is accepted (hypothesis 6).

Seven hypotheses are rejected. We tested the influence of the informal caregivers' current amount of time spent on informal caregiving (hypothesis 4) in three different ways: (1) By considering the total amount of time spent on informal care by care task, (2) by considering only the total amount of time spent on informal care and (3) by considering the required additional hour of informal care relative to the total amount of time spent on informal care. In all cases no statistically significant influence of the time investment on WTA could be detected. This might imply that informal caregivers are insensitive for the current amount of time spent on caregiving when indicating their WTA for providing an

*Chapter 6: Economic valuation of informal care: The contingent valuation method applied in informal caregiving*

additional hour. There is a statistically significant influence of the caregiver's EQ-5D on WTA (hypothesis 5). The influence does, however, not have the expected negative sign. The different CRA sub scales and the VAS show a heterogeneous pattern. This may be partly the result of the fact that many of the subjective burden elements have a relationship with other variables. For instance, hypothesis 7 is rejected, but this may be related to the significant influence of opportunity costs. Similar relationships may exist between the variables in hypotheses 8 and 1, those in hypotheses 9 and 14, and those in hypotheses 10 and 5. Hypothesis 12 is also rejected. The influence of the self-rated burden on WTA is significant but negative where a positive influence was expected. This is perhaps because the impact of "care-derived self-esteem" on total subjective burden is large. Moreover, as we have seen in Table 3, the mean overall subjective burden is just 24.6, while the distribution is skew with a median of 16, a 25 percent quartile score of 0 and a 75 percent quartile score of 40. Finally, the different care task dummies (F-value = 16.14, p-value < .0001) and the different opportunity cost dummies (F-value = 6.95, p-value = .0006) have a significant influence on WTA. We did not formulate hypotheses to this effect.

### **6.5.6 Non-response**

We have seen in Table 6.3 that 19 percent of the informal caregivers are not willing to respond the WTA question. Non-response analysis indicates that respondents who are unwilling to indicate their WTA are older (p-value < .0001), more often partner of the care recipient (p-value = 0.0002), without a paid job (p-value = 0.0069), more often situated in a relatively low CRA sub scale "financial problems" (p-value = 0.0453) and indicate a relatively low overall subjective burden (p-value = 0.0004).

In addition, due to missing values of other independent variables, only 55 percent of all responses are used to test the hypotheses (Table 6.5). There are some statistically significant differences in the known informal caregiver characteristics used in and excluded from the OLS regression. Male informal caregivers are more likely to be excluded from the regression (p-value = 0.0030). This holds also for non-partners (p-value = 0.0053), informal caregivers without a paid job (p-value = 0.0122), informal caregivers with a relatively low CRA sub scale "self esteem" score (p-value = 0.0192), and informal caregivers with an unknown income (p-value = 0.0428).

## 6.6 Discussion and conclusions

If one takes a societal perspective in economic evaluations, informal care should be incorporated in the analysis. Therefore, it should be valued. If informal care is not the main focus of an economic evaluation, it should be valued in monetary terms to incorporate it on the cost-side of an economic evaluation. The valuation of informal care is however troublesome. Therefore, this chapter investigates the use of CVM in valuing informal care.

The recommended opportunity cost and proxy good methods both seem unable to capture the full impact of informal care. CVM may be better capable of fully valuing informal care, as it is more sensitive to the heterogeneity and dynamics of informal care. An important advantage of CVM compared to the other two methods is its ability to elicit informal caregivers' preferences and to provide a total valuation. That means that all informal caregiver's costs and benefits, as shown in Figure 6.1, in principle are taken into account and not just the informal caregivers' costs of caregiving or a societal proxy for those costs. The outcome of CVM is a monetary value, which facilitates the incorporation of results in economic evaluations in which care recipients' effects are the primary outcome measure. Therefore, one could incorporate the impact of providing informal care for the informal caregiver valued with CVM on the cost side of the cost-effectiveness ratio. The same kind of reasoning holds here as is, for instance, the case in incorporating both production losses and gains on the cost side of an economic evaluation (Torrance, 1986).

Using additional measures of the impact of informal care in combination with CVM may lead to a misrepresentation of the full impact of informal caregiving or to double counting of different costs or benefits. In principle, CVM could also be used for economic evaluations in the form of a cost-benefit analysis in which informal caregivers' effects are the primary outcome measure. Our results however, do not provide evidence about the sensitivity of CVM in the context of informal caregivers' effects as the primary outcome measure in economic evaluations. We recommend future research in this area.

We have presented the provision of informal care as an unrestricted and rational process. But if one wishes to apply CVM to incorporate informal in economic evaluations one has to recognise that there are in practice often combinations of informal and formal care. In addition, due to real life restrictions such as the rationing of professional care, the optimal amount of informal care from the viewpoint of the informal caregiver may not always be provided. Moreover, in economic evaluations, an incremental approach is central, calculating the additional costs and benefits in comparison to some alternative. This implies that we have to measure the amounts of time spent on informal care by informal caregivers

under the two different treatment regimes. The difference in time investment by informal caregivers between these alternatives should subsequently be valued in such a way that the results reflect the care situation under study. CVM is capable of providing such preference based net valuations.

We presented in this chapter the results of a first application of CVM to value informal care. The mean WTA for an additional hour of providing informal care was 9.52 Euro. Most (almost 65%) informal caregivers preferred to provide an additional hour of housework. We could therefore compare our result with the market wage rate of a housekeeper. The tariff on the black market is 7.94 Euro and the maximum tariff in the health care sector per hour housework is 22.83 Euro (Oostenbrink et al., 2000). So, compared to the tariff for professional trained housekeepers our results are quite low and more comparable with the wage rate of unskilled housekeepers.

We have seen that 67 percent of the informal caregivers revealed no opportunity costs of their time, while on the other hand 81 percent of the informal caregivers were willing to indicate their WTA. On first sight this may imply an overestimation of the full impact of informal care when using WTA compared to the opportunity cost method. However, probably many informal caregivers were not able to indicate their opportunity costs because they provided on average informal care for more than 11 years. Improved methods for assessing missed opportunities due to informal caregiving seem needed therefore.

We have to be careful in generalising our results because our sample consisted of informal caregivers for care recipients with rheumatoid arthritis solely. The sample was rather small and there seems to be a non-random non-response. Older caregivers, partners living together with the care recipient and caregivers without a paid job and with a relatively low overall subjective burden and subjective burden concerning financial problems due to providing care were statistically significant less willing to respond than their counterparts. Larger and more heterogeneous samples may provide stronger results and may enhance the generalisability of results. We also had to deal with starting point bias, probably a result of our dichotomous choice format with open follow-up questions. In future research, one could try to work with open-ended questions, despite of our negative experience with this format in a small pilot of this study. Moreover, it would be interesting to collect additional qualitative information in future research about respondents' reasons for the values they stated as is, for instance, recommended by the NOAA panel (Arrow et al., 1993). Our study was not developed to test for scope effects. Future research could develop tests for

scope effects to confirm the validity of CVM in the context of the valuation of informal care.

Our empirical results indicate that CVM is sensitive too much of the heterogeneity and dynamics of informal care. Many hypotheses derived from the theoretical model and literature could be accepted, in particular those concerning income, institutional factors, preferences and responsibilities. The two hypotheses under the name scope showed a mixed pattern, however. Informal caregivers providing care to care recipients with a relatively low health-related quality of life require *ceteris paribus* more compensation compared to their counterparts. However, the WTA of our respondents proved to be insensitive to the amount of informal care provided, in contrast to our expectations. This of course may also reflect that the total amount of care provided is less important than other characteristics and perhaps even to some extent determined by these other characteristics, like subjective burden. The hypotheses about informal caregivers capabilities especially measured by the negative dimensions and the overall subjective burden as well as informal caregiver's health-related quality of life were all rejected. Informal caregiver's health-related quality of life, subjective burden 'lack of family support' and overall subjective burden were statistically significant but had the 'wrong' sign, while the others were not statistically significant. An explanation for this could be that informal caregivers do not experience that much subjective burden (on average 24.6 on a scale of 0-100). The same holds for the negative domains and also for informal caregiver's health-related quality of life (mean 0.78 with a maximum of 1). Still, CVM seems able to capture much of the heterogeneity of informal care, as e.g. can be illustrated with its sensitivity to different care tasks provided. The different opportunity cost dummies had a significant effect on WTA indicating that informal caregivers who were able to indicate their opportunity costs seem to reflect their opportunity costs in their WTA.

In advance, we questioned the applicability of CVM in the case of informal caregiving because it is suggested that financial considerations are often low on the informal caregiver's agenda (Smith and Wright, 1994). This could be a major problem in the elicitation of an informal caregiver's WTA. As we have seen, 81 percent of the informal caregivers were willing to express their WTA for providing an additional hour of informal care. This supports the application of CVM to value informal care. Therefore, we encourage the application of our approach in different populations. We hope that this chapter has demonstrated that CVM is a promising alternative valuation method for the economic valuation of informal care.



# 7 The economic value of informal care: A study of informal caregivers' and patients' willingness to pay and willingness to accept for informal care<sup>1</sup>

## Summary

*We provide a new test of the feasibility of using contingent valuation to value informal care. We start with a theoretical model of informal caregiving and derive that willingness to pay depends positively on wealth and negatively on own health, whereas the effect of other's health is sign-ambiguous. These predictions are tested in two new datasets on patients' and caregivers' willingness to pay (WTP) and willingness to accept (WTA) for informal care. The data are generally consistent with the theoretical predictions: wealth generally has a positive impact and own health a negative impact. Other's health has a mixed effect. We find only small differences between WTP and WTA. Our findings suggest that contingent valuation may be a useful technique to value informal care in economic evaluations of health care.*

## 7.1 Introduction

It has been argued that economic evaluations should adopt the societal perspective (Russell et al., 1996) and (Drummond et al., 1997). This means that everyone affected by the intervention should be considered and that all significant outcomes and costs that flow from the intervention should be counted (Russell et al., 1996). Informal care is a significant part of the total care provided to care recipients with chronic or terminal diseases (Norton, 2000). In spite of this, the costs and effects of informal care, both for the informal caregiver and for the patient they care for, are often ignored in economic evaluations (Stone et al., 2000). This might be due to a lack of valuation methods that are both theoretically valid and empirically feasible.

The existing literature on the valuation of informal care focuses on the informal caregivers, in particular on the valuation of the time spent on providing informal care. The two methods that have been proposed to value the time spent on providing informal care

---

<sup>1</sup> Based on Van den Berg, B., Bleichrodt, H., Eeckhoudt, L., 2004. The economic value of informal care: A study of informal caregivers' and patients' willingness to pay and willingness to accept for informal care. Accepted for publication Health Economics.  
*Chapter 7: The economic value of informal care: A study of informal caregivers' and patients' willingness to pay and willingness to accept for informal care*

are the opportunity cost method and the replacement cost method. Neither of these methods accurately reflects the preferences of the informal caregiver and of the patient. The opportunity cost method values informal care by foregone wages and, therefore, ignores the (dis)utility that informal caregivers derive from providing informal care. For a cost analysis this is appropriate, for a full cost-benefit analysis the opportunity cost method is too narrow. The replacement cost method (also called proxy good method) values informal care at the price of the market substitute, professional care, and, therefore, assumes that informal care and professional care are perfect substitutes. This assumption is not realistic, however. The informal caregiver decided to provide informal care because he or the patient considered professional care too expensive or of too low quality (Gronau, 1986), or because professional care is not available, e.g. when the patient is on a waiting list for professional care or out of a feeling of obligation. Valuing informal care at the price of professional care, in consequence, does not reflect the preferences of the informal caregiver and the patient.

The valuation of the effects of informal care for the patient are rarely addressed, probably because it is believed that these will be picked up by quality of life estimates. This belief may not be justified, however, because the common methods for valuing health-related quality of life are unable to detect the interdependency between the preferences of patients and informal caregivers. For instance, the EQ-5D asks respondents to focus solely on their own health status. Such interdependencies can, however, be important in the provision of informal care.

The aforementioned problems can in theory, be avoided by using the concept of willingness to pay (WTP) or willingness to accept (WTA). The contingent valuation method (CV) is one way to measure WTP or WTA. CV is rooted in applied welfare economics and directly elicits informal caregivers' and patients' preferences. The feasibility of applying CV to value informal care has been shown in chapter 6. That chapter, however, was somewhat ad hoc in that it lacked a formal theoretical model of the valuation of informal care. Hypotheses were merely formulated on the basis of a graphical model and on intuitive grounds. Chapter 6, moreover, focused mainly on the preferences of the informal caregivers.

The aim of the present chapter is to extend the research initiated in chapter 6 into the feasibility of using CV to value informal care. We present an economic model of informal care that takes into account the perspectives of both the informal caregiver and the patient and that models the interdependencies in their preferences. We use this model

to derive hypotheses about the willingness to pay and the willingness to accept for informal care of the caregiver and the patient and about the effect of changes in certain key variables on the valuation of informal care. We then test these hypotheses in two new datasets.

In what follows, section 7.2 describes our theoretical model of informal caregiving and derives the hypotheses to be tested. Section 7.3 describes the two datasets, while section 7.4 results. Finally, section 7.5 concludes the chapter.

## 7.2 Theory

### 7.2.1 The Informal Caregiver

Consider first the informal caregiver. We assume that the informal caregiver derives utility from consumption ( $c_{ic}$ ), his own health ( $h_{ic}$ ), and the health of the patient ( $h_p$ ). The patient receives both formal care (FC) and informal care (IC). We assume that informal care has a positive effect on the patient's health,  $\frac{\partial h_p}{\partial IC} > 0$ . To justify this assumption suppose that a patient has problems with mobility. Providing informal care for this patient may mean helping him with moving around and, consequently, the mobility of the patient improves. Obviously, the more care is provided, the more opportunities the patient has to move around and the more his mobility improves. Our conclusions are, however, not affected in case informal care does not improve the health of the patient,  $\frac{\partial h_p}{\partial IC} = 0$ . No assumptions are imposed about the effect of formal care on the patient's health. The informal caregiver's utility becomes:

$$U^{ic} = U^{ic}(c_{ic}, h_{ic}(IC), h_p(IC, FC)), \quad (1)$$

where  $U^{ic}$  is the caregiver's utility function. Whether this is a von Neumann-Morgenstern utility function or any other type of multi-attribute utility function is immaterial for our analysis. The only restriction we impose on  $U^{ic}$  is that it is increasing and concave in consumption, the caregiver's health, and the patient's health.

As seems plausible, caregiving is more urgent the worse is the patient's health and we, therefore, assume that the effect of informal care on the patient's health is larger the

worse is the health of the patient:  $\frac{\partial^2 h_{ic}}{\partial h_p \partial IC} < 0$ . This latter assumption is not necessary; all conclusions derived below remain valid when  $\frac{\partial^2 h_{ic}}{\partial h_p \partial IC} = 0$ .

Several studies suggest that informal care may have a negative effect on the informal caregiver's health (Hughes et al., 1999), (Schulz and Beach, 1999) and we, therefore, let  $\frac{\partial h_{ic}}{\partial IC} \leq 0$ . Because caregiving is more burdensome the worse is the health of the patient, we assume that the negative effect on the caregiver's health is larger the worse is the health of the patient:  $\frac{\partial^2 h_{ic}}{\partial h_p \partial IC} < 0$ . Again, this latter assumption is not necessary; all conclusions derived below remain valid when  $\frac{\partial^2 h_{ic}}{\partial h_p \partial IC} = 0$ .

Reflecting the institutional setting in the Netherlands (we will use the data from two Dutch samples to test some predictions of the model), we take formal care as exogenously given. We also assume that the amount of informal care is exogenously given. We believe that this assumption most closely mirrors the practice of informal caregiving. Alternatively, we could take the amount of informal care as endogenous, i.e. as determined by the optimizing behavior of the caregiver. Modifying the analysis in this way does not change the predictions of the model as we show in Appendix 1.

The informal caregiver has initial wealth  $W_{ic}$  and can earn labor income at wage rate  $r$ . The amount of time the informal caregiver can work depends on the amount of informal care he provides, assuming that there is no joint production between paid work and providing informal care. The informal caregiver's budget constraint then becomes:

$$W_{ic} + r(1-IC) = c_{ic} \quad (2)$$

Substitution of (2) into (1) gives:

$$U^{ic} = U^{ic}(W_{ic} + r(1-IC), h_{ic}(IC), h_p(IC, FC)) \quad (3)$$

We can now determine the informal caregiver's willingness to pay for a decrease in the amount of informal care, defined as the maximum amount of wealth he is willing to give up for a decrease in the amount of informal care that he provides. That is, we seek to determine the amount  $\Delta$  that solves

$$U^{ic}(W_{ic}-\Delta + r(1-IC-\delta), h_{ic}(IC-\delta), h_p(IC-\delta, FC)) = U^{ic}(W_{ic} + r(1-IC), h_{ic}(IC), h_p(IC, FC)) \quad (4)$$

Totally differentiating (3) gives:

$$V^{ic} = \frac{dW_{ic}}{dIC} = r - \frac{\frac{\partial h_p}{\partial IC} \frac{\partial U^{ic}}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U^{ic}}{\partial h_{ic}}}{\frac{\partial U^{ic}}{\partial W_{ic}}} \quad (5)$$

The first term in (5) represents the monetary gain from reducing the amount of informal care, additional labor income. The second term denotes the monetary value of the change in utility that follows a decrease in informal care. The sign of the second term is ambiguous, because  $\frac{\partial h_p}{\partial IC} > 0$  and  $\frac{\partial h_{ic}}{\partial IC} \leq 0$ . However, we found that informal caregivers generally want to pay for a reduction in the amount of informal care they provide, even

when they have no paid job. This implies that  $\frac{\partial h_p}{\partial IC} \frac{\partial U^{ic}}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U^{ic}}{\partial h_{ic}}$  is negative. The intuition behind this negative sign is that the informal caregiver provides more informal care than he considers optimal (recall that the amount of informal care is exogenously determined). That is, in the case of no wage income, the benefits of giving informal care are less than the costs, or  $\frac{\partial h_p}{\partial IC} \frac{\partial U^{ic}}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U^{ic}}{\partial h_{ic}}$  is negative. To also take into account the

possibility of zero willingness to pay, we assume that  $\frac{\partial h_p}{\partial IC} \frac{\partial U^{ic}}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U^{ic}}{\partial h_{ic}} \leq 0$ .

Let us examine what happens if some key variables change. First we consider the effect of a change in the patient's health. From (5) we obtain:

$$\frac{\partial V^{ic}}{\partial h_p} = - \frac{\frac{\partial U^{ic}}{\partial W_{ic}} \left( \frac{\partial h_p}{\partial IC} \frac{\partial^2 U^{ic}}{\partial h_p^2} + \frac{\partial^2 h_p}{\partial IC \partial h_p} \frac{\partial U^{ic}}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial^2 U^{ic}}{\partial h_p \partial h_{ic}} + \frac{\partial^2 h_{ic}}{\partial IC \partial h_p} \frac{\partial U^{ic}}{\partial h_{ic}} \right) - \frac{\partial^2 U^{ic}}{\partial h_p \partial W_{ic}} \left( \frac{\partial h_p}{\partial IC} \frac{\partial U^{ic}}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U^{ic}}{\partial h_{ic}} \right)}{\left( \frac{\partial U^{ic}}{\partial W_{ic}} \right)^2}$$

(6)

The term  $\frac{\partial^2 U^{ic}}{\partial h_p \partial h_{ic}}$  indicates how the informal caregiver's marginal utility of health changes with the patient's health, and the term  $\frac{\partial^2 U^{ic}}{\partial h_p \partial W_{ic}}$  indicates how the informal caregiver's marginal utility of wealth depends on the health of the patient. It might be reasonable to assume that both terms are nonnegative. We can see no plausible reason why the caregiver would value additional health or wealth less when the patient is in better health. On the other hand, it is conceivable that he values extra health or wealth less if the patient is in worse health. In that case, the terms  $\frac{\partial^2 U^{ic}}{\partial h_p \partial h_{ic}}$  and  $\frac{\partial^2 U^{ic}}{\partial h_p \partial W_{ic}}$  are positive. If we

assume that  $\frac{\partial^2 U^{ic}}{\partial h_p \partial h_{ic}}$  and  $\frac{\partial^2 U^{ic}}{\partial h_p \partial W_{ic}}$  are both positive, then the first term in the numerator of

(5) is negative. If  $\frac{\partial h_p}{\partial IC} \frac{\partial U^{ic}}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U^{ic}}{\partial h_{ic}}$  is zero then an increase in the patient's health

increases the caregiver's willingness to pay. If  $\frac{\partial h_p}{\partial IC} \frac{\partial U^{ic}}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U^{ic}}{\partial h_{ic}}$  is negative, the effect of a change in the patient's health on the amount the informal caregiver's willingness to pay is sign-ambiguous.

The effect of the informal caregiver's health on his willingness to pay is equal to:

$$\frac{\partial V^{ic}}{\partial h_{ic}} = - \frac{\frac{\partial U^{ic}}{\partial W_{ic}} \left( \frac{\partial h_p}{\partial IC} \frac{\partial^2 U^{ic}}{\partial h_p \partial h_{ic}} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial^2 U^{ic}}{\partial h_{ic}^2} \right) - \frac{\partial^2 U^{ic}}{\partial h_{ic} \partial W_{ic}} \left( \frac{\partial h_p}{\partial IC} \frac{\partial U^{ic}}{\partial h_{ic}} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U^{ic}}{\partial h_{ic}} \right)}{\left( \frac{\partial U^{ic}}{\partial W_{ic}} \right)^2}$$

(7)

We assume that  $\frac{\partial^2 U^{ic}}{\partial h_{ic} \partial W_{ic}}$ , which indicates how the marginal utility of wealth depends on health, is nonnegative. This assumption is common in the literature on willingness to pay ((Jones-Lee, 1974), (Weinstein et al., 1980)) and there exists some empirical evidence to support it ((Viscusi and Evans, 1990), (Sloan et al., 1998)).

Hammerschmidt et al. (2004) found, however, that  $\frac{\partial^2 U^{ic}}{\partial h_{ic} \partial W_{ic}}$  is negative. If  $\frac{\partial^2 U^{ic}}{\partial h_{ic} \partial W_{ic}}$  is nonnegative then  $\frac{\partial V^{ic}}{\partial h_{ic}}$  is negative. Hence, the better the caregiver's health status, the less he is willing to pay to reduce the amount of informal care that he provides. In the derivation of (7) we assumed that the effect of informal care on the patient's health and on the informal caregiver's health do not depend on the health of the informal caregiver. It seems conceivable that the positive effect of informal care on the patient's health increases with the caregiver's health and that the negative effect of informal care on the caregiver's health is less the better is the caregiver's health. The conclusions are not affected if we make these assumptions.

The effect of the informal caregiver's wealth on his willingness to pay is equal to:

$$\frac{\partial V^{ic}}{\partial W_{ic}} = - \frac{\frac{\partial U^{ic}}{\partial W_{ic}} \left( \frac{\partial h_p}{\partial IC} \frac{\partial^2 U^{ic}}{\partial h_p \partial W_{ic}} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial^2 U^{ic}}{\partial h_{ic} \partial W_{ic}} \right) - \frac{\partial^2 U^{ic}}{\partial W_{ic}^2} \left( \frac{\partial h_p}{\partial IC} \frac{\partial U^{ic}}{\partial h_{ic}} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U^{ic}}{\partial h_{ic}} \right)}{\left( \frac{\partial U^{ic}}{\partial W_{ic}} \right)^2} \quad (8)$$

Under the assumptions made above, the first term in the numerator of (8) is sign-ambiguous, the second term is positive. It seems reasonable, however, that *ceteris paribus* the effect of the patient's health on the caregiver's marginal utility of wealth is small compared to the other terms in (8). If so, the effect of wealth on willingness to pay for a reduction in informal care is positive, i.e., the higher the caregiver's wealth, the more he is willing to pay for a reduction in the amount of informal care.

### 7.2.2 The Patient

Let us next consider the patient. We assume that the patient derives utility from his consumption ( $c_p$ ), the informal caregiver's health, and his own health. The patient's utility is increasing and concave in all its arguments. Due to his illness, the patient does not engage in labor market activities. Besides informal care, the patient may also receive formal care. The price of formal care is set, without loss of generality, equal to 1 per unit of formal care. As before, the amount of formal care and the amount of informal care are exogenously given. The patient's utility is equal to

$$U^P = U^P(c_p, h_{ic}(IC), h_p(IC, FC)), \quad (9)$$

where  $U^P$  is a general multiattribute utility function. The patient's budget constraint is:

$$W_p = c_p + FC \quad (10)$$

and thus

$$U^P = U^P(W_p - FC, h_{ic}(IC), h_p(IC, FC)) \quad (11)$$

The patient's willingness to pay for increases in informal care is defined as the amount  $\Delta$  that solves

$$U^P(W_p - \Delta - FC, h_{ic}(IC + \delta), h_p(IC + \delta, FC)) = U^P(W_p - FC, h_{ic}(IC), h_p(IC, FC)) \quad (12)$$

and is equal to:

$$V^P = - \frac{dW_p}{dIC} = \frac{\frac{\partial h_p}{\partial IC} \frac{\partial U^P}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U^P}{\partial h_{ic}}}{\frac{\partial U^P}{\partial W_p}} \quad (13)$$

Because  $\frac{\partial h_p}{\partial IC} > 0$  and  $\frac{\partial h_{ic}}{\partial IC} \leq 0$ , (13) is sign-ambiguous. We found, however, that patients are willing to pay for increases in the amount of informal care, and hence, it seems plausible to assume that  $\frac{\partial h_p}{\partial IC} \frac{\partial U^P}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U^P}{\partial h_{ic}}$  is positive. Given that the amount of informal care is exogenously given, this positive sign suggests that the amount of informal care the patient receives is less than he considers optimal.

We next consider the effect of changes in the key variables, starting with the effect of a change in the patient's health.

$$\frac{\partial V_P}{\partial h_p} = \frac{\frac{\partial U_P}{\partial W_p} \left( \frac{\partial h_p}{\partial IC} \frac{\partial^2 U_P}{\partial h_p^2} + \frac{\partial^2 h_p}{\partial IC} \frac{\partial U_P}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial^2 U_P}{\partial h_p \partial h_{ic}} + \frac{\partial^2 h_{ic}}{\partial IC} \frac{\partial U_P}{\partial h_{ic}} \right) - \frac{\partial^2 U_P}{\partial h_p \partial W_p} \left( \frac{\partial h_p}{\partial IC} \frac{\partial U_P}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U_P}{\partial h_{ic}} \right)}{\left( \frac{\partial U_P}{\partial W_p} \right)^2}$$

(14)

As noted, empirical evidence suggests that the marginal utility of wealth increases with own health and, therefore,  $\frac{\partial^2 U_P}{\partial h_p \partial W_p} \geq 0$ . It is further conceivable that the patient enjoys increases in his own health at least as much when the informal caregiver is in good health than when he is in bad health. This implies that  $\frac{\partial^2 U_P}{\partial h_p \partial h_{ic}} \geq 0$ . Under these assumptions,  $\frac{\partial V_P}{\partial h_p}$  is negative and willingness to pay for increases in informal care decreases with the patient's health. This seems plausible: the better the patient's health the less he needs additional informal care and the less he will, in consequence, be willing to pay for additional informal care.

Equation (15) shows the effect of the informal caregiver's health on the patient's willingness to pay.

$$\frac{\partial V_P}{\partial h_{ic}} = \frac{\frac{\partial U_P}{\partial W_p} \left( \frac{\partial h_p}{\partial IC} \frac{\partial^2 U_P}{\partial h_p \partial h_{ic}} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial^2 U_P}{\partial h_{ic}^2} \right) - \frac{\partial^2 U_P}{\partial h_{ic} \partial W_p} \left( \frac{\partial h_p}{\partial IC} \frac{\partial U_P}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U_P}{\partial h_{ic}} \right)}{\left( \frac{\partial U_P}{\partial W_p} \right)^2}$$

(15)

It seems reasonable to assume that  $\frac{\partial^2 U_P}{\partial h_{ic} \partial W_p}$  is nonnegative. That is, the patient enjoys extra wealth at least as much when the caregiver is in good health than when he is in bad health. If so, under the assumptions already made, (15) is sign-ambiguous. Adding assumptions about how the effect of informal care on the patient's health and on the informal caregiver's health depends on the health of the caregiver does not change this conclusion.

Finally, consider the effect of changes in wealth on the patient's willingness to pay for an increase in informal care:

$$\frac{\partial V_P}{\partial W_P} = \frac{\frac{\partial U^P}{\partial W_P} \left( \frac{\partial h_p}{\partial IC} \frac{\partial^2 U^P}{\partial h_p \partial W_P} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial^2 U^P}{\partial h_{ic} \partial W_P} \right) - \frac{\partial^2 U^P}{\partial W_P^2} \left( \frac{\partial h_p}{\partial IC} \frac{\partial U^P}{\partial h_p} + \frac{\partial h_{ic}}{\partial IC} \frac{\partial U^P}{\partial h_{ic}} \right)}{\left( \frac{\partial U^P}{\partial W_P} \right)^2} \quad (16)$$

The first term of (16) is sign-ambiguous, the second negative. It might be expected, however, that *ceteris paribus* the effect of the informal caregiver's health on the patient's marginal utility of wealth,  $\frac{\partial^2 U^P}{\partial h_{ic} \partial W_P}$ , is small compared to the other terms in (16). If so, (16) is positive and the patient's willingness to pay for an increase in informal care will increase with income.

The theoretical predictions derived in this section are summarized in Table 7.1. The table shows the effect on the informal caregiver's and the patient's willingness to pay of the three key variables wealth, patient's health, and informal caregiver's health. A plus-sign indicates a positive relationship, a minus-sign indicates a negative relationship, and a question mark means sign-ambiguous.

**Table 7.1:** Theoretical predictions

	V <sup>ic</sup>	V <sup>p</sup>
h <sub>p</sub>	?	-
h <sub>ic</sub>	-	?
W	+	+

## 7.3 Methods

We collected two sets of data to test the predictions of our theoretical model, summarized in Table 1. The first data set consisted of patients with rheumatoid arthritis (RA) and their informal caregivers. These data were collected as a supplement of the RA+ study, a panel study of health care utilisation among people with RA ((Jacobi et al., 2001), (Jacobi et al., 2003)). In the 2001 wave of this panel, 365 out of 683 care recipients indicated to receive informal care. We mailed them a postal survey. Moreover, we asked them to hand over an enclosed survey to their primary informal caregiver. Because we collected the data as a supplement to the RA+ study, patients were encouraged by their physicians to participate.

The second data set was collected six months after the RA sample with the aid of Dutch regional support centres for informal caregivers. We approached 59 regional centres,

40 of which were willing to participate in the research. Through these centres, we sent 3258 postal surveys to informal caregivers and asked them to hand over an enclosed survey to the patient they cared for. We refer to this data set as the heterogeneous (HET) sample.

In both samples we determined patients' willingness to pay (WTP) for an additional hour of informal care per week and their willingness to accept (WTA) for a reduction by one hour in the amount of informal care they currently received. For the informal caregivers we determined their WTA to provide an additional hour of informal care per week and their WTP to reduce the amount of informal care they provided by one hour per week. In the latter case we told them that another caregiver would provide that hour of care instead. We feared that if we did not tell the caregivers that their care would be replaced, some of them would be unwilling to answer because the care recipient needed the care. Note that the replacement of care does not affect our theoretical predictions. Assuming that the difference in quality of the care is negligible, it follows that  $\frac{\partial h_p}{\partial IC} > 0$ . It is easily verified that setting  $\frac{\partial h_p}{\partial IC} = 0$  in Eqs. (6) – (8) does not affect the entries of Table 7.1.

The full wording of the questions is given in Appendix 1. In case the patient was a child or the patient was not able to fill in the survey due to his health problems, the parents or the informal caregiver were asked to complete the 'objective' part of the survey, questions like gender and age. They were instructed not to fill in the 'subjective' questions like WTP or WTA.

There is a continuous debate about payment formats in CV studies. Open-ended questions might be the best way to elicit respondents' maximum or minimum prices because this question format does not involve any of the biases that have been identified in the literature. Mitchell and Carson (Mitchell and Carson, 1986) showed that open-ended questions work smoothly when respondents are familiar with the concept under valuation. We felt that this condition is fulfilled for the valuation of informal care. In the pilot study for RA we found, however, that respondents had difficulties with the open-ended question format. We therefore opted for dichotomous questions with open-ended follow up. The respondents could either accept or reject a bid of  $x$  Dutch guilders, where  $x$  was one of  $\{10, 15, 20, 25, 30\}$ . This corresponds to the following amounts in Euros:  $\{4.54, 6.81, 9.08, 11.34, 13.61\}$ . The bids were randomly allocated to the respondents. If a respondent rejected the bid, he was asked to state the bid that he would accept. This kind of approach

has been successfully applied before (Baarsma, 2000). In the HET sample we used open-ended questions, because these questions worked well in the pilot tests of this study.

In both samples, we measured health-related quality of life of the informal caregivers and the patients through the EQ-5D algorithm (Dolan, 1997). In the RA-population, we also measured the impact of providing informal care on the informal caregiver through the Caregiver Reaction Assessment (CRA) ((Jacobi et al., 2003), (Given et al., 1992)). In the RA sample, we used postal codes as a proxy for household wealth. It has been shown that this proxy method is reliable (Smits et al., 2002). In the HET sample, the patient and the caregiver were asked to state their net monthly family income. The time spent on providing informal care was measured by presenting a list of sixteen care tasks. Informal caregivers were asked to report the time they spent on these tasks during the week preceding the interview.

Patients were asked whether they received any other informal care and professional home care and whether they were on a waiting list for professional care. Informal caregivers were asked whether they had paid work, about their social relationship with the patient, whether they lived together with the patient, and how many years they already provided informal care. Finally, patients and informal caregivers were asked some socio-demographic questions.

## **7.4 Results**

One hundred forty nine pairs of patients and their informal caregivers completed the RA survey, a response rate of 40.8%. Four hundred forty-four pairs of patients and their informal caregivers completed the HET survey. There were also 65 patients in the HET survey who completed a survey without their informal caregiver returning the questionnaire and 421 informal caregivers who completed the questionnaire without their patient returning the questionnaire. Hence, the final HET sample consisted of 509 patients and 865 informal caregivers, which amounts to a response rate of 21.1%. An explanation for the difference in response rate between the RA and the HET sample may be that in the RA sample, physicians supported the research and stimulated participation, while in the HET sample there were no such incentives to participate.

### **7.4.1 Sample characteristics**

Table 7.2 gives background information about the patients and their informal caregivers.

**Table 7.2: Characteristics care recipients and informal caregivers**

Characteristic	Mean RA sample	Mean HET sample
<i>Care recipients</i>		
Age (in years)	62.1	66.6
Sex (percentage males)	16.1	48.8
<i>Education (percentages)</i>		
Low	43.9	52.1
Middle	38.5	31.0
High	9.5	12.1
EQ-5D	0.48	0.30
Waiting list (percentage)	5.9	11.5
Professional care (percentage)	26.1	58.3
Other informal care (percentage)	68.0	41.6
<i>Income (percentages)</i>		
Income low	22.8	N/A
Income middle	41.6	N/A
Income high	24.2	N/A
Income unknown	9.4	N/A
Net monthly family income (Euro)	N/A	1371.3
<i>Informal caregivers</i>		
Age (in years)	62.1	60.2
Sex (percentage males)	75.3	23.3
Partner (percentage)	91.5	48.9
Live together (percentage)	87.6	58.2
Paid job (percentage)	36.9	23.4
<i>Education (percentages)</i>		
Low	34.9	37.9
Middle	46.3	44.7
High	13.4	16.0
<i>Income (percentages)</i>		
Income low	22.8	N/A
Income middle	41.6	N/A
Income high	24.2	N/A
Income unknown	9.4	N/A
Net monthly family income (Euro)	N/A	1627.28
Care duration (in years)	11.4	8.7
Total informal care time (hours per week)	26.4	49.0
EQ-5D	0.82	0.75
CRA loss of physical strength	2.26	N/A
N	149	509 patients and 865 informal caregivers

The table shows that there are some differences between the two samples. In the case of RA, almost 90 percent of the caregivers live together with their patient, in the HET sample this is true in approximately 60 percent of the cases. Other differences are that the proportion of male patients is higher in the HET sample, that quality of life, both of the patient and of the caregiver, is lower in the HET sample, and that the amount of informal care provided (in mean hours per week) is substantially higher in the HET sample.

Table 7.3 gives the diseases of the patients and the informal caregivers.

**Table 7.3:** Percentage patients and informal caregivers with certain disease in HET

Diseases	Patient <sup>1</sup>	Informal caregiver
Respiratory diseases	0.07	0.29
Circulatory diseases	0.19	0.45
Digestive diseases	0.07	0.09
Endocrine, metabolic and nutritional diseases	0.08	0.13
Musculoskeletal diseases	0.27	0.67
Neurological diseases	0.28	0.56
Skin diseases	0.05	0.06
Psychological diseases	0.20	0.16
N	865	865

<sup>1</sup> Reported by the informal caregiver

### 7.4.2 WTP and WTA

The response rate for the WTP/WTA questions ranges from 75.2% to 82.6% in the RA sample and from 51.2% to 63.9% in the HET sample. Within samples, there is not much difference in response rates between the WTP and the WTA questions.

Table 7.4 shows the mean and median results of the WTP and WTA questions. In both samples, WTA is higher than WTP. In all but one case the difference is significant. The difference between WTA and WTP is relatively small compared to CV studies that valued other types of “goods”. These studies typically found that WTA was at least two times larger than WTP (Horowitz and McConnell, 2002). Despite the different payment formats in the two populations, both mean and median WTP and WTA are quite similar. It is worth noting, however, that WTP for the informal caregiver is slightly overestimated because we told subjects that the hour of care they would provide less would be replaced.

This means that  $\frac{\partial h_p}{\partial IC}$  will be approximately zero, instead of positive when there is no compensation, and (4) shows that WTP is higher than when there is no compensation.

**Table 7.4: Results CV questions in Euro**

	Mean WTP (n)	SD	Mean WTA (n)	SD	Difference WTP-WTA	Median WTP	Median WTA
<b>RA</b>							
Care recipients	7.84 (120)	4.43	8.22 (112)	4.13	P = 0.1789	6.81	6.81
Informal caregivers	7.80 (114)	4.58	9.52 (123)	6.61	P = 0.0077	9.08	9.08
<b>HET</b>							
Care recipients	6.72 (325)	5.30	8.62 (308)	6.41	P < 0.0001	6.81	6.81
Informal caregivers	8.61 (443)	5.73	10.52 (503)	6.80	P < 0.0001	6.81	9.08

WTP and WTA are lower than the formal market tariffs for professional home care in the Netherlands. In 2002, the maximum price for professional housework was 26.70 euro and the maximum price for professional personal care was 34.10 euro. This maximum price was set by an agency responsible for setting the maximum prices for health care services.

### 7.4.3 Estimations

We next present empirical results on the relation between WTP and WTA and income and both the patient's and the informal caregiver's health-related quality of life. We tried several functional forms for the relation, including logarithmic and quadratic specifications. The models that we present are those that fitted the data best. Conclusions are not affected by only presenting the models that best fitted the data: it was never true that a variable that was statistically insignificant in the models presented was statistically significant in any of the other models. We estimated all models by ordinary least squares with robust standard errors.

As discussed before, in case of RA there may be a starting-point bias and we, therefore, corrected for the provided start bids by means of an independent variable. We did not have income information for a substantial part of the RA sample. We, therefore, used dummy variables, including a dummy "income unknown", to test for the effect of income.

**Table 7.5:** Informal caregivers' and patients' log WTP and log WTA in the RA sample (P values in parentheses)

Independent variables	Dependent variable: Informal caregivers' log WTA	Dependent variable: Informal caregivers' log WTP	Dependent variable: Patients' log WTA	Dependent variable: Patients' log WTP
Start bid	0.10 (0.000)	0.04 (0.135)	0.06 (0.000)	0.03 (0.146)
Dummy income low (inc. middle = ref.)	-0.36 (0.070)	-0.48 (0.033)	0.23 (0.100)	0.11 (0.544)
Dummy income high (inc. middle = ref.)	-0.05 (0.810)	-0.22 (0.229)	0.28 (0.019)	0.29 (0.015)
Dummy income unknown (inc. middle = ref.)	0.13 (0.317)	-0.47 (0.020)	0.02 (0.905)	-0.08 (0.616)
Informal caregiver's health		-1.64 (0.118)	0.70 (0.342)	
Informal caregiver's health <sup>2</sup>		1.29 (0.138)	-0.74 (0.190)	
Patient's health	0.49 (0.241)		-0.64 (0.001)	
Patient's health <sup>2</sup>	-1.17 (0.118)		0.50 (0.129)	
Intercept	1.43 (0.000)	2.28 (0.000)	1.59 (0.000)	1.73 (0.000)
R <sup>2</sup>	0.19	0.11	0.26	0.08
F-test for income dummies	3.36 (0.038)	0.65 (0.525)	2.37 (0.098)	3.18 (0.045)
N	121	113	109	120

Table 7.5 summarizes the data for the RA sample. The start bid has a higher coefficient in the regression for WTA than in the regression for WTP both for informal caregivers and for patients. Moreover, the start bid is only statistically significant in the regression for WTA. This suggests that the start bid has led to an upward bias in WTA, but not in WTP. The influence of income on WTP and WTA is largely in line with our theoretical predictions. If statistically significant, the dummy for low income is negative and the

dummy for high income is positive. Income has no significant impact on informal caregivers' WTP: the F-test for the joint influence of the income dummies is insignificant.

Own health has the predicted negative effect on patients' WTA; in all other regressions the impact of own health (i.e. the impact of caregiver's health on caregivers' WTA and WTP and of patient's health on patients' WTP) is not statistically significant. No statistically significant evidence of other's health (i.e. patient's health on caregivers' WTA and WTP and caregiver's health on patients' WTA and WTP) is observed. Measuring informal caregiver's health with the CRA subscale 'loss of physical strength' instead of the EQ-5D did not affect the above conclusions.

Tables 7.6, 7.7, 7.8, and 7.9 report the results for the HET sample. Because the HET sample consisted of patients and informal caregivers with various diseases there is a danger of heteroskedasticity. We therefore divided HET into different subgroups.

**Table 7.6: Informal caregiver's log WTA in the HET sample (P values in parentheses)**

Independent variables	A	B	C	D	E
Log monthly income	-0.10 (0.422)	0.04 (0.765)	-0.01 (0.897)	-0.08 (0.325)	0.01 (0.960)
Informal caregiver's health	1.51 (0.086)	-0.45 (0.008)	-0.53 (0.005)	-0.27 (0.059)	
Informal caregiver's health <sup>2</sup>	-1.64 (0.032)				-0.41 (0.010)
Patient's health	0.08 (0.615)	0.18 (0.214)	0.22 (0.054)	0.10 (0.381)	0.11 (0.358)
Patient's health <sup>2</sup>	-0.68 (0.041)	-0.56 (0.069)	-0.44 (0.086)	-0.27 (0.141)	-0.43 (0.123)
Constant	3.03 (0.001)	2.40 (0.010)	2.82 (0.001)	3.07 (0.000)	2.51 (0.004)
R <sup>2</sup>	0.16	0.06	0.08	0.03	0.05
N	94	166	94	172	182

*Note: subgroup A = Respiratory diseases; subgroup B = Circulatory diseases; subgroup C = Digestive diseases; Endocrine, metabolic and nutritional diseases; Skin diseases; Psychological diseases; subgroup D = Musculoskeletal diseases; subgroup E = Neurological diseases*

**Table 7.7: Informal caregiver's log WTP in the HET sample (P values in parentheses)**

Variable	A	B	C	D	E
Log monthly income	0.12 (0.261)	0.21 (0.014)	0.21 (0.038)	0.22 (0.015)	0.31 (0.006)
Informal caregiver's health	-0.64 (0.026)	1.82 (0.077)	1.74 (0.129)	1.87 (0.055)	1.42 (0.173)
Informal caregiver's health <sup>2</sup>		-1.58 (0.046)	-1.42 (0.127)	-1.73 (0.028)	-1.30 (0.109)
Patient's health	0.30 (0.018)	0.28 (0.033)	0.38 (0.040)	0.27 (0.042)	0.25 (0.057)
Patient's health <sup>2</sup>					
Constant	1.67 (0.046)	0.06 (0.936)	0.01 (0.994)	0.03 (0.971)	-0.63 (0.480)
R <sup>2</sup>	0.08	0.11	0.15	0.11	0.10
N	88	148	86	153	164

*Note:: subgroup A = Respiratory diseases; subgroup B = Circulatory diseases; subgroup C = Digestive diseases; Endocrine, metabolic and nutritional diseases; Skin diseases; Psychological diseases; subgroup D = Musculoskeletal diseases; subgroup E = Neurological diseases*

**Table 7.8: Patient's log WTA in the HET sample (P values in parentheses)**

Variable	A	B	C	D
Log monthly income		0.03 (0.805)		-0.02 (0.896)
Informal caregiver's health	1.00 (0.324)	-0.81 (0.358)		-0.09 (0.906)
Informal caregiver's health <sup>2</sup>	-1.14 (0.261)	0.57 (0.440)		-0.02 (0.973)
Patient's health	0.93 (0.126)	0.38 (0.218)	0.54 (0.101)	0.11 (0.712)
Patient's health <sup>2</sup>	-1.82 (0.052)	-0.90 (0.086)	-0.85 (0.061)	-0.41 (0.306)
Constant	1.95 (0.000)	2.20 (0.009)	2.10 (0.000)	2.31 (0.010)
R <sup>2</sup>	0.08	0.03	0.02	0.01
N	74	124	165	133

*Note:: subgroup A = Respiratory diseases; Digestive diseases; Endocrine, metabolic and nutritional diseases; Skin diseases; Psychological diseases; subgroup B = Circulatory diseases; subgroup C = Musculoskeletal diseases; subgroup D = Neurological diseases*

**Table 7.9:** Patient's log WTP in the HET sample (P values in parentheses)

Variable	A	B	C	D
Log monthly income			0.24 (0.071)	0.21 (0.071)
Informal caregiver's health		1.39 (0.199)	0.06 (0.839)	
Informal caregiver's health <sup>2</sup>		-1.25 (0.158)		
Patient's health		0.60 (0.100)	1.05 (0.033)	
Patient's health <sup>2</sup>	-0.66 (0.038)	-0.87 (0.133)	-1.38 (0.048)	
Constant	1.91 (0.000)	1.57 (0.000)	-0.01 (0.995)	0.29 (0.721)
R <sup>2</sup>	0.05	0.05	0.08	0.02
N	105	126	128	183

*Notes: subgroup A = Respiratory diseases; Digestive diseases; Endocrine, metabolic and nutritional diseases; Skin diseases; Psychological diseases; subgroup B = Circulatory diseases; subgroup C = Musculoskeletal diseases; subgroup D = Neurological diseases*

The stratification was based on the informal caregivers' and patients' illnesses. When there were not enough respondents per illness, we clustered them. The criterion was that there should be at least 50 respondents per subgroup and that there should be no evidence of heteroskedasticity in the resulting subgroups. As the tables show, the goodness of fit of the various models, as measured by the adjusted R<sup>2</sup> is low in some subgroups, which means that we should interpret the results with caution.

The effect of income on WTP and WTA is mixed. Income has the predicted positive effect on informal caregivers' WTP and, in two out of four subgroups, on patients' WTP. In all other cases, the effect of income is not statistically significant.

Own health generally has the predicted negative effect: in general informal caregivers' WTA and WTP decrease with caregivers' health and patients' WTA and WTP decrease with patients' health. In some cases the effect of patients' health is inverse U-shaped; WTP and WTA rise first as own health improves, then they fall.

The impact of other's health is mixed. Patient's health has generally a negative impact on informal caregivers' WTA, but a positive impact on caregivers' WTP; there is no

statistically significant effect of caregiver's health on patients' WTA and the effect on patients' WTP is inverse U-shaped.

## 7.5 Discussion

The aim of this chapter was to test in further detail whether CV can be used to value informal care. To that end we specified a theoretical model of informal caregiving and tested whether WTP and WTA satisfied the predictions that we derived from that model. Of course, one could object that a violation of these hypotheses might indicate a misspecification of the model. The model was rather general, however, and based on findings from the empirical literature. We, therefore, expect that most caregivers and patients behave approximately in the way specified by the model. Hence, if people are able to come up with meaningful answers to CV questions, then we would expect that their responses are to a large extent in line with the specified model.

With respect to the impact of income, we generally find the predicted positive effect in the RA sample and, to a lesser extent, in the HET sample. Own health generally has the predicted negative effect in the HET sample, but in the RA sample we only observe it for patients' WTA. The effect of other's health (for instance patient's health on caregiver's WTP and WTA and vice versa) varies. Recall that our model made no predictions regarding this effect. We tentatively conclude that our findings are generally in the direction predicted by the theoretical model, even though the effects are not always statistically significant and some deviations exist.

An encouraging finding for the use of CV to value informal care is that we find only small differences between WTP and WTA. The mean WTP is in all cases lower than the mean WTA and the ratio of mean WTA over mean WTP ranges from 1.0 in case of RA care recipients to 1.3 in case of HET care recipients. These ratios are quite small compared to other studies that report WTA/WTP ratios ranging from 1.4 (Eisenberger and Weber, 1995) to 61.0 ((Brookshire and Coursey, 1987), (Brown and Gregory, 1999)). For the medians the ratios are even closer to 1, only for informal caregivers in the HET sample is the ratio different from 1 (1.3). The reason why we find small disparities between WTA and WTP might be that our subjects have relatively well-defined preferences over informal care. Most likely they have thought about how much they would be willing to spend on additional care. In the other studies that have been reported in the literature, people are often asked for their valuation of goods on which they have spent little thought.

In such cases, people's preferences are likely to be more affected by biases (Fischhoff, 1991). These biases can explain the often huge differences between WTP and WTA.

In most applications of CV to health only WTP was asked ((Diener et al., 1998), (Olsen and Smith, 2001)). An exception is a study of Borisova and Goodman (2003), whose findings about the disparity between WTP and WTA are in line with ours. They applied CV to value travel time and found a ratio between WTA and WTP of 1.3.

Let us finally discuss two limitations of our study that may be addressed in future research. A first problem may be that the observed explanatory power of our models, in particular in the HET sample, was rather low. It should be kept in mind though that low  $R^2$  values are not uncommon in explaining individuals' subjective valuations. Objective variables do not fully explain individual choices since the importance of personality on determining individual well-being cannot be ignored. A recent review suggests that objective socio-economic and demographic variables can explain up to 20% of individual well-being (Kahneman et al., 1999a). Explanatory values that are comparably low as ours have been observed in other CV studies in health (Johannesson et al., 1993). A second limitation is that we did not test for scope effects: the finding that valuations are insensitive to the size of the effect. In our study this might have meant that respondents had the same WTP for, say, a two hour increase in informal care as for a one hour increase in informal care. It is well known from previous studies that scope effects can be important (Yeung et al., 2003). Whether they also affect the valuation of informal care remains to be tested.

## Appendix 1.

We show that taking informal care endogenous does not change our conclusions. We determine the optimal amount of informal care that the informal caregiver will supply. His optimisation problem is:

$$\max_{c_{ic}, IC, \lambda} L = U^{ic}(c_{ic}, h_{ic}(IC), h_p(IC, FC)) + \lambda(c_{ic} - W_{ic} - r((1-IC))). \quad (A1)$$

The first order conditions are:

$$\frac{\partial L}{\partial c_{ic}} = \frac{\partial U^{ic}}{\partial c_{ic}} + \lambda = 0 \quad (A2)$$

$$\frac{\partial L}{\partial IC} = \frac{\partial U^{ic}}{\partial h_{ic}} \frac{\partial h_{ic}}{\partial IC} + \frac{\partial U^{ic}}{\partial h_p} \frac{\partial h_p}{\partial IC} + \lambda r = 0 \quad (A3)$$

$$\frac{\partial L}{\partial \lambda} = c_{ic} - W_{ic} - r(1-IC) = 0 \quad (A4)$$

Totally differentiating (A1) gives

$$dL = \frac{\partial U^{ic}}{\partial c_{ic}} dc_{ic} + \left( \frac{\partial U^{ic}}{\partial h_{ic}} \frac{\partial h_{ic}}{\partial IC} + \frac{\partial U^{ic}}{\partial h_p} \frac{\partial h_p}{\partial IC} \right) dIC + d\lambda(c_{ic} - W_{ic} - r((1-IC))) + \lambda(dc_{ic} - dW_{ic} + rdIC) = 0 \quad (A5)$$

By (A2),  $\left( \frac{\partial U^{ic}}{\partial c_{ic}} + \lambda \right) dc_{ic} = 0$  and by (A4)  $c_{ic} - W_{ic} - r(1-IC) = 0$ . Hence, we are left with

$$\left( \frac{\partial U^{ic}}{\partial h_{ic}} \frac{\partial h_{ic}}{\partial IC} + \frac{\partial U^{ic}}{\partial h_p} \frac{\partial h_p}{\partial IC} + \lambda r \right) dIC - \lambda dW_{ic} = 0. \quad (A6)$$

Or

$$\frac{dW}{dIC} = \frac{\lambda_r + \frac{\partial U^{ic}}{\partial h_{ic}} \frac{\partial h_{ic}}{\partial IC} + \frac{\partial U^{ic}}{\partial h_p} \frac{\partial h_p}{\partial IC}}{\lambda} \quad (A7)$$

By (A2),  $\lambda = -\frac{\partial U^{ic}}{\partial c_{ic}} = -\frac{\partial U^{ic}}{\partial W_{ic}}$ , and hence we arrive back at (5). Note that this does not mean that willingness to pay will be the same. In fact, from (A3) we know that willingness to pay at the optimum amount of informal care is zero, whereas in (5) it may well be different from zero (when informal care is not at its optimal level). The predictions of the effects of changes in wealth, the patient's health and the informal caregiver's health on willingness to pay are, however, similar and this is what we intended to show.

## Appendix 2

### *Informal caregiver WTA*

*Suppose your patient needs per week 1 hour extra care and the government compensates you for this. What is the minimum amount of money you would want to receive from the government net of taxes to provide this additional hour of care? (1) fxc Euro, (2) Less than fxc Euro, that is....., (3) More than fxc Euro, that is....*

### *Informal caregiver WTP*

*Suppose there is a possibility for you to provide per week 1 hour less informal care. Someone else will replace you, so the total amount of care for the patient remains the same. What is the maximum amount of money you would want to pay in order that someone else takes over this hour of care? (1) fxc Euro, (2) Less than fxc Euro, that is....., (3) More than fxc Euro, that is....*

### *Patient WTA*

*Suppose you per week 1 hour less informal care and the government compensates you for this. What is the minimum amount of money you would want to receive from the government net of taxes for this hour less informal care? (1) fxc Euro, (2) Less than fxc Euro, that is....., (3) More than fxc Euro, that is....*

### *Patient WTP*

*Suppose you need an additional hour of informal care per week and you have to pay for this hour yourself. What is the maximum amount of money you would want to pay for this extra hour informal care? (1) fxc Euro, (2) Less than fxc Euro, that is....., (3) More than fxc Euro, that is....*

# 8 Economic valuation of informal care: The conjoint measurement method applied to informal caregiving<sup>1</sup>

## Summary

*This chapter reports the results of the application of the conjoint measurement method (CM) to determine a monetary value of informal care. Compared to the normally recommended valuation methods, like the opportunity cost method and proxy good method, CM is probably better able to capture the heterogeneity of informal care.*

*We developed a survey in which informal caregivers were asked to rate four different hypothetical informal caregiving situations, which differed with respect to care hours, care tasks and monetary compensation. Data were obtained from postal surveys. A total of 135 pairs of informal caregivers and care recipients with rheumatoid arthritis (RA) returned a completed survey and were used in the analysis.*

*Informal caregivers require an extra compensation of 1.00 Euro per hour for providing one additional hour of the same informal care task (meaning that from the seventh to the eighth hour, they require 8 Euro). For providing two extra hours of care, they require 2.00 Euro compensation per hour. The relative valuation of informal care tasks is very diverse. Respondents require a compensation of 13.43 Euro per hour for switching from providing light housework to personal care and 0.56 Euro per hour for switching from providing personal care to heavy housework. Though CM is sometimes regarded cognitively complex, 70 percent of the respondents were able and willing to evaluate the hypothetical caregiving scenarios. Especially elderly respondents had more difficulty with the method.*

*CM is seen as a promising alternative for existing methods to determine a monetary value of informal care. The presented valuations of informal care can be incorporated in the numerator of a cost-effectiveness ratio in economic evaluations of health care.*

## 8.1 Introduction

It has been argued that economic evaluations should preferably take the societal perspective (Russell et al., 1996) and (Drummond et al., 1997). This means that everyone affected by the intervention should be considered and all significant outcomes and costs

---

<sup>1</sup> Based on Van den Berg, B., Al, M., Brouwer, W.B.F., Van Exel, J.A.J., Koopmanschap, M.A., 2004. Economic valuation of informal care: The conjoint measurement method applied to informal caregiving. Accepted for publication Social Science and Medicine.

that flow from the intervention should be counted regardless of who experiences the outcomes and costs.

Informal care is a significant part of the total care provided to care recipients with chronic or terminal diseases (Norton, 2000). Despite the recommended societal perspective, the costs and effects of informal caregiving to the informal caregiver are often ignored in economic evaluations (Stone et al, 2000). The costs of informal care are to an important extent related to time inputs by relatives and friends of the care recipients<sup>2</sup>. It has been recommended to value these time inputs in monetary terms (Russell et al., 1996) and (Drummond et al., 1997). Two monetary valuation methods are often recommended to value the time input in informal care: the opportunity cost method (valuing hours spent on informal care at a – would be – wage rate) and the proxy good method (valuing informal care hours at the wage rate of a professional caregiver) (Posnett and Jan, 1996), (Russell et al., 1996) and (Drummond et al., 1997). However, both methods have important limitations and seem unable to incorporate the full impact in terms of costs and consequences of informal care (Chapter 3). Using (would be) wage-rates or the costs of professional care, leads to valuations of informal care that do not fully reflect the preferences of informal caregivers. It is for example increasingly recognized that providing informal care has both negative and positive aspects (Orbell et al., 1993) and (Kramer, 1997). Therefore, the valuation of informal care should reflect the individual's trade-off between the (direct) utility and (direct) disutility associated with providing (additional) informal care. In addition, (direct) utility derived from informal care may depend for example on the duration of care, intensity of care (e.g. hours per week), care tasks (e.g. personal care), caregiver characteristics (e.g. engaged in paid work or retired), care recipient characteristics (e.g. health state and preferences) and so on. Ideally, such differences would be monetarised and combined with informal caregiver's opportunity costs. This makes it possible to incorporate the full impact of informal caregiving in the cost side of any economic evaluation. However, the often-recommended opportunity cost and proxy good methods neglect many of the mentioned differences.

Alternatively, individuals may be asked to elicit their valuation of the informal care they provide directly. Using a stated preference method has important advantages compared to the opportunity cost and proxy good methods, among others the ability to elicit informal caregivers' preferences for different informal caregiving situations in terms

---

<sup>2</sup> See for an overview of other costs related to informal care, such as home adaptations and the costs of assistance devices Netten (1990).

of informal care hours and informal care tasks. One of these stated preference methods is the contingent valuation method (CV), in which informal caregivers are, for example, asked to elicit their willingness to accept (WTA) to provide an additional hour of informal care. Chapters 6 and 7 applied CV to informal caregiving.

The method put forward in this chapter is CV's 'cousin' in the family of stated preference methods, the conjoint measurement method (CM). In CM respondents are asked to rank or rate different hypothetical scenarios or to make pair wise choices. CM has important advantages as compared to CV. They include: (1) respondents are not directly asked to express an amount of money for a certain scenario as in CV, but to make a trade-off between different aspects of the scenarios presented. This implies that the focus in CM is not on money but on all the aspects of the presented scenario. Therefore, the danger of strategic answers on the one hand and protest answers on the other hand is less likely for CM as compared to CV. (2) More information about respondent's preferences is collected, because (instead of a single one as in CV) respondents simultaneously evaluate different scenarios. Moreover, information about respondents' relative preferences between scenarios is collected. (3) A more specific issue in the case of informal caregiving is Smith and Wright's expectation that CV is not applicable to value informal care because money is at least very low on the caregiver's agenda (Smith and Wright, 1994). Therefore, a valuation method like CM that focuses less on money would be preferred in that context. (4) CM as opposed to CV is perhaps better able to capture the heterogeneity of a commodity because it has an explicit focus on the different components of the commodity under valuation. Because of the heterogeneous nature of the commodity informal care, for instance in terms of different care tasks and different amounts of provided care, CM would be a better method to value informal care than CV. Nevertheless, an important disadvantage of CM compared to CV is the relatively large (cognitive) burden it puts on respondents. Therefore we will also address CM's feasibility in this chapter.

If we compare CM with the normally recommended methods to value informal care, we expect that CM will produce smaller values of providing informal care compared to the opportunity cost method and proxy good method respectively. In comparing the opportunity cost method with a stated preference method like CM it is crucial to recognise that the latter in principle includes both the informal caregiver's opportunity costs of time and the derived (direct) utility and (direct) disutility of providing care. This implies that an informal caregiver deriving more (direct) utility than (direct) disutility from providing care states a lower value for this care compared to his opportunity costs. Only if one assumes

that most informal caregivers derive more (direct) disutility than (direct) utility from providing care, which is an empirical issue, the opportunity cost method would provide lower values of informal care compared to a stated preference method. Moreover, they could indicate lower values than their opportunity costs of time because they feel that they are less specialised in providing care compared to their market activities.

Formulating expectations about the comparison of the proxy good method and CM is less straightforward. This holds because it is questionable whether respondents will base their responses (partly) on what professional caregivers would have earned. If not the comparison becomes a bit problematic, as respondents then have two unrelated sources of valuation. If respondents do compare their values with the values of a close market substitute, one could defend a same line of reasoning as presented above in the comparison between the opportunity costs method and CM. For example lower valuations in case of CM again if (direct) utility is expected to outweigh (direct) disutility. This expectation can also be supported by some basic principles from labour economics. Specialisation and education create higher comparative advantages of professionals versus non-professionals and therefore more valuable production. Consequently one could expect that informal caregivers report lower values in a stated preference approach if they compare themselves with professional caregivers. We will compare our CM results with those of the opportunity cost and proxy good methods.

This chapter proposes and reports the results of the application of CM to determine a monetary value of informal care. The outline of the chapter is as follows. We introduce the CM method and we describe the CM questions as developed and used during this study. Subsequently, the data and results are presented. Then we derive a monetary value of informal care provided to people with rheumatoid arthritis (RA). Finally we discuss these results and the feasibility of the application of a relative simple form of CM.

## **8.2 Method**

### **8.2.1 The conjoint measurement method**

Conjoint measurement (CM), also called conjoint analysis (CA), is a method for the analysis of respondents' preferences over a set of multi-attribute alternatives. Green and Srinivasan (1978) define CM as: *“any decompositional method that estimates the structure of a consumer's preferences [...], given his or her overall evaluation of a set of alternatives that are pre specified in terms of levels of different attributes.”* The idea behind this method is straightforward. One asks respondents for instance to rate different situations or commodity descriptions, often

called vignettes, to reveal their preferences. The situations differ according to some dimensions, called attributes. If the price or cost is included as an attribute, it is possible to derive implicit prices or costs for each of the other dimensions. So a monetary value of the good in question can be derived.

CM has its economic foundation in Lancaster's attribute based utility theory (Lancaster, 1991). Lancaster's contribution was that he stressed that a good possesses more than one characteristic. For example, a meal will have both nutritional and aesthetic characteristics in different relative proportions.

Within economic evaluations CM is of growing importance for the measurement of care recipient's preferences, see for instance Slothuus et al. (2002). See for overviews of the application of CM in health care Ryan et al. (1998), Ryan and Farrar (2000) and (Ryan and Gerard, 2003). The latter show that CM studies in health care are mostly applied to elicit preferences of care recipients or the community. Moreover, the main focus of CM studies is to value benefits and to use these valuations in economic evaluations.

While different CM techniques are available, such as ranking, rating and discrete choice or choice experiments, in health care a majority of applications use the discrete choice technique (Ryan and Gerard, 2003).

Waiting time is an important attribute in CM studies in health care (Ryan and Gerard, 2003). Other types of time are travel time, time to return to normal activities, duration of illness and time preferences. One CM study focuses on an explicit valuation of time (McIntosh and Ryan, 2002). With one exception (Borisova and Goodman, 2003), CM's cousin CV has not been used to value time in health care applications.

CM has a much longer history in other disciplines, for instance, in the transport economics literature. The method has been applied in that area for different purposes, for example, to value travel time, statistical lives, new travel alternatives or technologies, and externalities such as noise and pollution. Classical applications include the problem of shopping travel mode and destination choice (McFadden, 1974) the demand for electric cars (Beggs et al., 1981), the prediction of travel demand (Ben-Akiva and Lerman, 1985), and automobile demand (Train, 1986). More recent applications include (Calfee and Winston, 1998), (Hensher, 2001), (Saelensminde, 1999) and (Saelensminde, 2001), and (Cherchi and De Dios Ortúzar, 2002).

An important lesson from this literature is the hypothesis of Independence of Irrelevant Alternatives (IIA). The property of IIA means that respondents' choices do not depend on the nature of any of the other alternatives. In other words, very close substitutes

should not influence the choice probabilities. McFadden (1974) illustrates this with an auto/bus example. Splitting the bus alternative in two different colour busses all other things equal involves a higher probability that a bus will be chosen compared to a car which is undesirable from a researchers point of view. The influence of possible violations of the IIA depends on the analysis method chosen. Especially the ordered logit model suffers from these violations, while the ordered probit model does not (Hausman and Wise, 1978) and (Beggs et al., 1981).

On an applied level, we could compare our findings with the main results in the transport economics literature, see e.g. Small (1992) for an overview. However, one has to be careful in making these kind of comparisons, because results often depend strongly on the operationalisation of the method and the context of the study. Calfee and Winston, (1998, p.84), for instance, state that “values of time estimates differ greatly depending on the travel mode (e.g., bus versus car) and the purpose of the trip (e.g., work versus pleasure)”. They (Calfee and Winston, 1998, pp.92-93) also argue that “value of time estimates derived from a mode choice model reflect the relative comfort, convenience, privacy, and so on of auto versus transit, which will generally increase the value of travel time because transit modes are less desirable than auto in these respects.” Therefore, values of time derived from mode choices are usually higher than those derived from varying aspects concerning a single mode (e.g., route, transfers, externalities), because in the former case the estimated (mode-specific) values also reflect the relative comfort and convenience of alternative modes. The values of time also differ importantly when expressed as a proportion of respondents’ hourly wages. Values with a range of 20 to 100 percent of the gross wage were found (Calfee and Winston, 1998). Because these findings have a wide range and are context specific, we will not compare our results with these studies.

### **8.2.2 Informal care**

Informal care is here defined as “a non-market composite commodity consisting of heterogeneous parts produced by one or more members of the social environment of the care recipient.” Non-market means that no market prices exist. Therefore our central objective is to derive a monetary value for informal caregiver’s time. A heterogeneous good means that informal care consists of different tasks like housework, personal care or surveillance. The amount of informal care can also differ substantially between different caregiving situations, for example, according to the care demands of the care recipient and

dependent on the available amount of professional care or other informal care. As will be discussed later in more detail, we included some of these variations in our vignettes.

### **8.2.3 Survey questions**

Our central objective was to derive a monetary value of informal care consistent with the heterogeneous nature of both the commodity informal care and the informal caregivers' real life situation. Therefore we first asked the informal caregivers some questions about their current real life caregiving situation. These questions include how many years the informal caregivers have already provided informal care. We also asked respondents how many hours they spent on informal caregiving during the last week according to a list of sixteen care tasks. We distinguished between three types of care tasks: (1) housework (HDL) like cleaning, (2) activities of daily living (ADL) like personal care and, (3) instrumental activities of daily living (IADL) like organising home adaptations. We then measured health-related quality of life of informal caregivers and care recipients using the EQ-5D (Essink-Bot et al, 1993) and (EuroQol Group, 1990). Furthermore, we measured subjective caregiving burden. Many instruments are developed to measure subjective burden of informal caregiving (Kramer, 1997). Because it contains both a positive ("derived self-esteem") and negative dimensions ("disrupted schedule", "financial problems", lack of "family support", and "loss of physical strength") as opposed to most subjective burden instruments, we applied the Caregiver Reaction Assessment (CRA) [Given, 1992 #23]. The CRA has however no sum-score. To measure informal caregivers' overall subjective burden of providing care, we used a visual analogue scale (VAS) ranging from 0 ("not hard at all") to 100 ("much too hard") (Van Exel et al., 2004). We also asked both informal caregivers and care recipients some general background questions like whether or not they and their care recipient live together and some socio-demographic questions.

### **8.2.4 The conjoint measurement method to value informal care**

To value informal care, we introduced a hypothetical caregiving situation with a set of four vignettes and we asked respondents to rate them. See for an example of the exact question figure 8.1.

**Figure 8.1:** Example of a choice question

---

*“People who need care are often in different situations. Below, we sketch four different situations that probably differ strongly from the situation of your care recipient. Please, imagine yourself in those situations.”*

---

**Situation A:**

- Your care recipient needs 21 hours per week support with personal care
  - You provide every day 3 hours informal care, totalling 21 hours per week, with personal care
  - You receive in return an amount of 13.65 Euro per hour from the government tax-free.
- 

**Situation B:**

- Your care recipient needs 14 hours per week support with heavy housework
  - You provide every day 2 hours informal care, totalling 14 hours per week, with heavy housework
  - You receive in return an amount of 9.10 Euro per hour from the government tax-free.
- 

**Situation C:**

- Your care recipient needs 7 hours per week support with personal care
  - You provide every day 1 hour informal care, totalling 7 hours per week, with personal care
  - You receive in return an amount of 9.10 Euro per hour from the government tax-free.
- 

**Situation D:**

- Your care recipient needs 7 hours per week support with light housework
  - You provide every day 1 hour informal care, totalling 7 hours per week, with light housework
  - You receive in return an amount of 0 Euro per hour from the government tax-free.
- 

Please give the four situations a rating between 1 and 10. 10 is the from your perspective best imaginable and 1 the worst imaginable situation.

---

I give situation A, B, C and D rate ..... (subsequently for all situations)

---

Table 8.1 gives an overview of the attributes chosen, and the levels distinguished within each attribute.

**Table 8.1:** Overview of attributes and their levels

Attribute	Level	Code
Informal care task	Light house work	Dummy: 1 = yes
	Heavy house work	Dummy: 1 = yes
	Personal care	Dummy: 1 = yes
Informal care hours per week and per day	7	7
	14	14
	21	21
Informal caregiver's monetary compensation <sup>1</sup>	0 EURO per hour	0
	4.55 EURO per hour	4.55
	9.10 EURO per hour	9.10
	13.65 EURO per hour	13.65

<sup>1</sup> Originally 0/10/20/30 Dutch guilders

We opted for the attribute levels for different reasons. The three care tasks were chosen because they include the most important informal care tasks for people with rheumatoid arthritis (RA). Riemsma et al. (1997) found that more than half of the people with RA demanded care with heavy housework, one third with light housework, and around 20 to 60 percent with personal care dependent on the care task. They also found that informal caregivers provided on average 33 hours per week care for people with RA. We felt that this amount would be an upper bound for our population for two reasons. First, Riemsma et al. (1997) included only care recipients that already had RA for five years, while we did not exclude care recipients that had had RA for less than five years. Therefore, we expected that the care demands of our population would be less than Riemsma et al's population. Second, it is well known that time measurement is complicated and that the measured amount of time depends on the questions asked; see e.g. Juster and Stafford (1991). Riemsma et al. (1997) distinguished 28 care tasks as opposed to the 16 tasks we choose. It could therefore be expected that our population would report a somewhat lower amount of informal care provided and we chose therefore to include 7, 14 and 21 hours informal care per week respectively as the values of the time attributes. We selected the monetary compensation because it encompasses the Dutch market prices and health care sector tariffs for unskilled housework of 8.53 Euro per hour.

The three attributes and their chosen levels result in 6561 ( $3^{3*} 3^{3*} 3^4$ ) possible caregiving situations. We reduced these to a manageable number of 16 vignettes<sup>3</sup> and we chose one reference vignette and divided the remaining 15 in 5 groups of 3 vignettes. Thus, we ended up with 5 sets of 4 vignettes (each including the same reference vignette) distributed over 5 random subsets in the population.

### **8.2.5 Study sample**

The data for this study were collected as a supplement of the RA+ study, a panel study of health care utilisation among people with rheumatoid arthritis (RA) (Jacobi et al. (2001). In the 2001 wave of this panel, 365 of 683 care receivers indicated to receive informal care. We approached all and asked the 365 receiving informal care to hand over our mail survey to their primary informal caregiver as well as to complete a mail survey themselves. The 318 care receivers without informal care were asked whether they now did receive informal care. If so, the same procedure as before was followed.

A total of 153 informal caregivers returned the mail survey and we have data for 149 pairs of care receivers and informal caregivers. The care receivers of four informal caregivers did not return their survey. Moreover, 21 care receivers had deceased, 12 were irretrievable relocated and four respondents sent in their survey too late for analysis. Finally, the returned surveys of 18 informal caregivers were of insufficient quality. Therefore, the surveys of 135 informal caregivers and care recipient combinations were suitable for further analysis.

### **8.2.6 The derivation of a monetary value of informal caregiving**

In order to derive a monetary value of informal care one wishes to keep utility constant while varying the level of the different components (attributes) of utility. It is worth noting that respondents' ratings are proxies for respondents' utilities derived from the four different hypothetical situations. In varying these attributes one can derive the marginal rate of substitution between the attributes. If one includes a monetary compensation<sup>4</sup> as one of

---

<sup>3</sup> This is called an orthogonal array. Such orthogonal array is still able to estimate main effects, but not interactions. In an orthogonal array, each level of one attribute occurs with each level of another attribute with equal or at least proportional frequencies. We used the ORTHOPLAN procedure in the software package SPSS to arrange an orthogonal design.

<sup>4</sup> One has to be careful with the interpretation if one includes prices or costs as an attribute. See Ratcliffe (2000) for a critical discussion.

the attributes, the marginal rate of substitution between the attributes and the monetary compensation can be derived.

We state it formally using a random effects ordered probit model:

$$y^*_i = \mu + x'_{it}\beta + z'_i\gamma + \alpha_i + \varepsilon_{it} \tag{1}$$

where  $y^*$  is an unobserved latent variable denoting the utility respondent  $i$  ( $i = 1, \dots, N$ ) derives from vignette  $t$  ( $t = 1, \dots, 4$ ),  $\mu$  is a fixed constant,  $x_{it}$  is a K-dimensional vector of vignette attributes presented to respondent  $i$  at vignette  $t$ . Furthermore,  $z_i$  is a M-dimensional vector of respondents' and informal care characteristics, while  $\alpha_i + \varepsilon_{it}$  is the error term consisting of two components:  $\varepsilon_{it}$  denoting an individual specific component that is treated as a random variable, and  $\alpha_i$  denoting an individual specific component assumed to be fixed over the vignettes. Because the vignettes were randomly distributed among the respondents, we assume that there is no correlation between  $x_{it}$  and  $\varepsilon_{it}$ . Therefore the random effects ordered probit model is appropriate for our problem. Greene (2000) and Scott Long (1997) discuss the ordered probit model in more detail, while Hsiao (1986) and Verbeek (2000) give detailed discussions of random effect models).

As stressed before, we observe respondents' ratings 1 to 10 (transformed here to the range of 0 to 9):

$$\begin{aligned} y &= 0 \text{ if } y^* \leq 0, \\ &= 1 \text{ if } 0 < y^* \leq \mu_1, \\ &\cdot \\ &\cdot \\ &\cdot \\ &= 9 \text{ if } 8 \leq y^*. \end{aligned} \tag{2}$$

Given the fact that respondents could only give a rating from 1 to 10, they are supposed to choose the cell that most closely represents their own feelings. These ratings are proxies for a respondent's utility.

Moreover, we choose the ordered probit model to analyse respondents' ratings for two main reasons. First, because this model does not suffer from possible violations of the IIA property like the ordered logit model as discussed before (Hausman and Wise, 1978)

and (Beggs et al., 1981). Second, because it does not assume a cardinal interpretation of the ratings like OLS regression (Boyle et al., 2001).

If we replace  $x'_{it}\beta$  in (1) with the vignette attributes and  $y'_{it}$  with  $y_{it}$  we get:

$$y_{it} = \mu + \alpha_i \gamma + H_{it}\lambda + LH_{it}\lambda + HH_{it}\lambda + C_{it}\lambda + \alpha_i + \varepsilon_{it} \quad (3)$$

where  $H_{it}$  is the amount of informal care hours at vignette  $t$  presented to individual  $i$ . Similarly, LH denotes light housework, HH denotes heavy housework, while C is the informal caregiver's monetary compensation.

In order to derive the marginal rate of substitution between for instance the amount of informal care and an informal caregiver's monetary compensation ( $MRS_{HC}$ ) one keeps utility ( $y$ ) constant (a marginal rate of substitution is by definition the point of indifference between two commodities (Deaton and Muellbauer, 1980) and (Mas-Colell et al., 1995)). To state it formally:

$$MRS_{HC} = H/C \quad (4)$$

## 8.3 Results

### 8.3.1 Background statistics

Table 8.2 shows some descriptive statistics of the study sample. Just 17.4 percent of the informal caregivers are female. This is striking because normally the majority of informal caregivers is female. An obvious explanation is that in our sample 100 percent of the informal caregivers are partners of the care recipient and the prevalence of RA is much higher in women compared to men. Informal caregivers' and care recipients' age ranges from 32.8 to 87.1 and from 28.3 to 83.9 respectively. The occupation percentages add up to over 100 percent because some respondents indicated two main occupations.

Table 8.3 provides some other background characteristics of the study sample, such as care duration, the amount of provided informal care, subjective burden and EQ-5D-scores. The average care duration is 11.6 year reflecting the fact that RA is a slowly progressive disease. Of the care recipients is 6.7 percent on a waiting list for professional or residential care. Almost 40 percent of the informal caregivers perform activities of daily living (ADL) while more than 90 percent of them perform instrumental activities of daily living (IADL) and almost 90 percent perform housework (HIDL).

**Table 8.2:** Characteristics informal caregivers and care recipients (n=135)

<i>Characteristic</i>	<i>Mean</i>	<i>S.D.</i>
<i>Informal caregivers</i>		
Age <sup>1</sup>	63.0	13.3
Gender <sup>2</sup>	82.6	38.1
Partner <sup>3</sup>	100	0
Live together	97.0	17.0
Education		
Low	32.6	47.0
Middle	47.7	50.1
High	14.4	35.2
Occupation		
Paid job	34.1	47.6
House worker	16.3	37.1
Retired	52.6	50.1
Disability pension	7.4	26.3
Income <sup>4</sup>		
Income 1	19.3	0.40
Income 2	38.5	0.49
Income 3	21.5	0.41
Income 4	4.4	0.21
Income unknown	10.4	0.31
Flexible job <sup>5</sup>	51.1	50.2
<i>Care recipient</i>		
Age <sup>1</sup>	62.1	13.1
Gender <sup>2</sup>	15.2	36.0
Education		
Low	44.3	49.7
Middle	38.9	48.9
High	9.2	29.0
Occupation		
Paid job	15.2	36.0
House worker	41.7	49.5
Retired	31.1	46.5
Disability pension	19.7	39.9
No	11.4	31.9

<sup>1</sup> In years

<sup>2</sup> Percentage males

<sup>3</sup> Percentage partners

<sup>4</sup> Income 1 is the lowest category and income 4 the highest. We used postcode areas as a proxy for income. See Smits et al. (2002) for a discussion of this approach.

<sup>5</sup> Flexibility of the paid job in terms of control about one's own time schedule conditional upon having a paid job

**Table 8.3: Characteristics of the caregiving situation (n=135)**

Characteristic	Mean	Min	Max	S.D.
<i>Informal caregivers</i>				
Care duration <sup>1</sup>	11.6	1.0	50.3	8.7
Performing HDL tasks <sup>2</sup>	88.9			
Hours HDL tasks <sup>3</sup>	14.1	0	101.5	14.0
Performing ADL tasks <sup>2</sup>	39.3			
Hours ADL tasks <sup>3</sup>	2.2	0	31.5	5.0
Performing IADL tasks <sup>2</sup>	91.9			
Hours IADL tasks <sup>3</sup>	11.3	0	107.0	14.6
Total informal care time <sup>3</sup>	27.5	0	133.5	24.0
Gave up paid work <sup>3</sup>	5.2	1	10	3.7
Gave up unpaid work <sup>3</sup>	4.9	1	15	4.9
Gave up leisure <sup>3</sup>	8.2	2	24	6.4
EQ-5D	0.82	-0.074	1	0.22
CRA disrupted schedule	13.3	4	25	5.7
CRA financial problems	7.2	3	15	3.6
CRA lack of family support	12.3	3	25	5.2
CRA loss of physical strength	9.0	4	18	4.5
CRA self-esteem	29.3	11	35	4.6
VAS	24.5	0	100	25.7
<i>Care recipients</i>				
EQ-5D	0.48	-0.43	1	0.30
Waiting list <sup>2</sup>	6.7			25.0
Professional care <sup>2</sup>	26.1			
Other informal care <sup>2</sup>	68.0			

<sup>1</sup> In years

<sup>2</sup> In percentage

<sup>3</sup> Mean hours per week

EQ-5D scores of the caregivers are much higher than those of the care recipients (0.82 versus 0.48). In order to provide care, caregivers sacrifice leisure (18.9 percent), unpaid work (8.0 percent) and paid work (6.1 percent). 67 percent of the caregivers did not indicate what time use was sacrificed in order to provide care. To some extent this may have to do with the fact that for most caregivers providing care has become their normal time use, given the average care duration of over 11 years. This hypothesis is supported by a relatively strong correlation between respondents indicating both their opportunity costs of time and the number of years they provide care yet (correlation coefficient = 0.50).

### 8.3.2 CM Ratings

Table 8.4 gives the mean scores per vignette, uncorrected for characteristics of informal caregivers, RA care recipients and the caregiving situation.

Table 8.4: Mean score per vignette (n=97)

Vignette	Attribute			N (N missing)	Mean score	Minimum	Maximum
	Hours <sup>1</sup>	Tasks <sup>2</sup>	Money compensation				
A1 (Ref.)	21	3	13.65	18 (8)	6.17	1	10
A2	14	2	9.10	17 (9)	6.59	4	10
A3	7	3	9.10	16 (10)	6.56	2	10
A4	7	1	0	19 (7)	5.95	1	10
B1 (Ref.)	21	3	13.65	20 (11)	6.20	1	10
B2	7	1	4.55	21 (10)	7.00	1	10
B3	21	1	0	20 (11)	5.90	1	10
B4	14	1	13.65	21 (10)	6.14	1	10
C1 (Ref.)	21	3	13.65	26 (10)	5.73	1	10
C2	7	2	0	27 (9)	6.04	1	10
C3	21	2	4.55	26 (10)	5.08	1	9
C4	14	1	4.55	26 (10)	6.46	3	10
D1 (Ref.)	21	3	13.65	21 (4)	5.00	1	10
D2	7	1	9.10	22 (3)	7.55	4	10
D3	7	2	13.65	21 (4)	5.86	2	10
D4	14	3	0	21 (4)	5.10	1	10
E1 (Ref.)	21	3	13.65	12 (6)	6.33	3	10
E2	7	3	4.55	12 (6)	5.83	3	8
E3	7	1	13.65	12 (6)	7.42	5	10
E4	21	1	9.10	12 (6)	6.50	3	10
Overall ref.	21	3	13.65	97 (37)	5.82	1	10

Ref. = reference vignette

<sup>1</sup> Per week

<sup>2</sup> 1 = light housework, 2 = heavy housework, and 3 = personal care.

The first column in table 8.4 gives the five (A to E) different combinations of vignettes that randomly were distributed among the respondents. Column two 'Attributes' gives the attribute description, while the number of respondents completing the rating of the vignette in question is in column three. Then the mean score of the vignette next to its minimum and maximum are in columns four to six successively. It is worth noting that vignettes A1, ..., E1 are all the same and therefore the reference vignette.

The mean rating of the vignettes ranges from 5.00 to 7.55. Half of the vignettes have the widest possible range varying from 1 to 10. The other half has a somewhat smaller range. Our reference vignette has an overall mean of 5.82, but varies according to the set of vignettes relative to which it was evaluated. It is for instance on average preferred to vignette A4 with fewer hours (7 a week instead of 21 a week), another care task (light housework instead of personal care), but less money compensation (0 Euro versus 13.65 Euro). Vignettes A2 and A3 are preferred to vignette A1 (the reference vignette) despite their lower money compensation (9.10 Euro versus 13.65 Euro), since A2 and A3 require less hours of care per week (respectively 14 and 7), while A2 also involves another care task.

Table 8.4 also shows that not all respondents rated all four vignettes. In set E the number of observations is twelve in all cases, indicating that twelve respondents rated all vignettes. In case of D however, there is one more missing in D1, D3 and D4 compared to D2.

For the interpretation of these results it is worth noting that we assume that the respondents gave an ordinal interpretation to their ratings. Therefore, we used a random effects ordered probit to analyse the results.

### **8.3.3 Results of the random effects ordered probit**

Table 8.5 gives the results of the random effects ordered probit. In the first column are the independent variables and their estimated coefficients are in the second column. The first four independent variables are the vignette attributes. A star denotes that an independent variable is statistically significant at the  $p = 0.05$  level. To investigate the possible influence of background characteristics, we performed the analysis again, adding three blocks of explanatory variables. A block of informal caregiver's background characteristics like gender, a block of care recipient's background characteristics like health-related quality of life and a block of characteristics of the informal care situation like the total amount of informal care provided.

**Table 8.5:** Results random effect ordered probit; dependent variable is vignette rating (n=174)

Independent variable <sup>1</sup>	Parameter estimate	Standard error	Wald Chi-Square	Pr > ChiSq
Informal care hours*	-0.02	0.01	-2.30	0.02
Light housework*	0.29	0.13	2.20	0.03
Heavy housework	-0.01	0.15	-0.08	0.94
Informal caregiver's compensation*	0.02	0.01	2.04	0.04
Intercept 1*	-1.65	0.22	-7.38	0.00
Intercept 2*	-1.43	0.22	-6.62	0.00
Intercept 3*	-1.11	0.21	-5.31	0.00
Intercept 4*	-0.72	0.20	-3.54	0.00
Intercept 5	-0.29	0.20	-1.47	0.14
Intercept 6	0.13	0.20	0.63	0.53
Intercept 7*	0.44	0.20	2.20	0.03
Intercept 8*	1.03	0.21	4.97	0.00
Intercept 9*	1.19	0.21	5.73	0.00

<sup>1</sup> The intercepts belong to the results for the report marks 1 to 9. They can be used to compute the probability that a particular vignette gets a certain report mark. The probability that a certain vignette gets report mark 10 is 1 minus the probability that a report gets a 1 to a 9. See also equation 2.

Correction of the results of the ordered probit with these blocks of background variables did not provide additional insights (none of these variables were significant at the  $p = 0.05$  level). This is presumably due to the relative small sample size and the relative large loss of respondents due to the non-response on the vignette rating.

### 8.3.4 A monetary value of informal care

Equation (4) shows how to derive the marginal rate of substitution between the different vignette attributes, including how to derive a monetary valuation of informal care with CM. We can use the calculated coefficients from table 8.5 to derive them. Table 8.6 presents the results.

**Table 8.6:** rates of substitution vignette attributes

	MRS
H/C	-1.00
LH/C	13.43
HH/C	-0.56
H/LH	-0.07
H/HH	1.79

From table 8.6 we can derive that when informal caregivers would provide one extra hour informal care, their required compensation would *ceteris paribus* increase by 1.00 Euro (90% CI: [0.06-4.10])<sup>5</sup>. For example providing 15 instead of 14 hours personal care a week and an initial compensation of 4.55 Euro per hour makes that the informal caregivers require 5.55 Euro per hour (for each of the 5 hours) instead of 4.55 Euro per hour to provide the 15 instead of the 14 hours informal care a week<sup>6</sup>. Of course, the marginal costs of providing an extra hour informal care are crucial if one wishes to use this result to value informal care in economic evaluations. In the above case, the marginal costs are 19.55 Euro (14 \* 4.55 versus 15 \* 5.55). Likewise providing 16 hours instead of 14 would require an hourly compensation of on average 6.55 Euro per hour while the marginal costs are 41.10 Euro. Furthermore, we can see that light housework is preferred to personal care and light housework is preferred to heavy housework, while personal care is preferred to heavy housework. In monetary terms, informal caregivers demand a compensation for switching from light housework to personal care of *ceteris paribus* 13.43 Euro<sup>7</sup> per hour (90% CI: [2.23-53.62]), and a compensation of 0.56 Euro per hour (90% CI: [-1.47-55.34]) for switching from personal care to heavy housework.

### 8.3.5 Feasibility of CM

As can be derived from table 4, around 70 percent of the informal caregivers were willing or able to rate the vignettes. This questions the feasibility of CM to elicit informal caregivers' preferences. Therefore, we analysed whether or not the non-response on the rating questions is random. We did this by testing for differences in the means of the variables in table 8.2 and 8.3 between the respondents who did and did not rate the vignettes.

<sup>5</sup> Confidence interval based on Monte Carlo simulation, using the standard errors in table 5.

<sup>6</sup> 15 instead of 14 hours a week makes  $\Delta H = 1$ , while personal care does not change, so  $\Delta LH = 0$  and  $\Delta HH = 0$ .

<sup>7</sup> T1 is a dummy variable:  $\Delta T1 = 1$  if the informal caregiver switches from personal care to light housework).

We found that older informal caregivers were less able or willing to rate the vignettes (mean age 67.5 versus 61.2;  $p = 0.0159$ ). Furthermore, the non-responders were often either lower or higher educated ( $p = 0.0242$ ). Finally, the group non-responders contained relatively more old care recipients than the group responders (mean age 67.4 versus 59.9;  $p = 0.0027$ ). This is not surprising as all pairs of informal caregivers and RA patients are partners and, consequently, informal caregivers' and care recipients' ages are highly correlated.

## 8.4 Discussion and conclusion

In this chapter we have applied the CM method to determine a monetary value of informal care for RA care recipients. An important advantage of CM compared to more conventional methods like the opportunity cost method and the proxy good method is CM's ability to capture more accurately the informal caregiver's preferences concerning this heterogeneous commodity.

Informal caregivers require an additional compensation of 1.00 Euro per hour (for all hours provided) for providing an additional hour of the same informal care task. For providing two hours extra, they require an additional compensation of on average 2.00 Euro per hour. For the incorporation of informal care in economic evaluations we used marginal instead of average costs. So the marginal costs of switching from providing for instance 7 hours informal care per week without a monetary compensation to 8 hours informal care a week are 8 Euro. The marginal costs of providing 9 hours a week instead of the 7 without compensation are 18 Euro. Informal caregivers also require extra compensation of 13.43 Euro per hour when they switch from providing light housework to personal care. Moreover, they demand additional compensation of 0.56 Euro per hour when switching from providing personal care to heavy housework.

How do these findings relate to the often recommended methods to value informal care; the opportunity cost method and the proxy good method? Chapter 5 found values of 23.44 Euro and 12.19 Euro per hour informal care applying the opportunity cost method and proxy good method respectively using the same sample. If one excludes housework from the proxy good method because of persistent measurement problems, the value rises to 20.24 Euro per hour (it rises because housework is relatively cheap). Comparing these values with our results is not straightforward because CM produces only relative values. For instance, informal caregivers require a monetary compensation of 10 Euro per hour in order to increase the amount of provided care with 10 hours compared to

an initial situation without a monetary compensation *ceteris paribus*. This is a lower value compared to the values generated with the opportunity and proxy good methods, which may indicate that respondents derive more utility than disutility from providing informal care. Jacobi et al. (2003) provide some empirical evidence for the latter idea using the same sample. They compare the CRA scores on the positive domain “derived self-esteem” with two other samples: caregiving for people with dementia and for people with colorectal cancer. Caregivers for people with RA report somewhat higher scores compared to the caregivers for people with dementia indicating that they may derive more (direct) utility relatively from providing informal care.

Another explanation for the relatively low monetary value informal caregivers expressed could be the choice of our attributes: Informal caregivers in our sample indicate to provide 27 hours informal care a week. This implies that our hypothetical situations provide a lower bound compared to the real amount of informal care provided. This could explain the relative low marginal rate of substitution between additional care and a monetary compensation.

One has to be careful with the interpretation of our results. This is also recognised in the context of costs attributes versus price attributes (Ratcliffe, 2000). We asked informal caregivers implicitly to state their WTA to provide additional care. It is not possible to derive from our findings informal caregivers’ willingness to pay (WTP) for a reduction of informal care, as one may tempt to do. Since the questions posed to the respondents explicitly focussed on a monetary compensation (WTA) and not on WTP.

Another point of attention in this context is the incorporation of the results in economic evaluations. We suggest the incorporation of the results in the costs side of an economic evaluation. This because CM gives a monetary valuation of both the opportunity costs and the (direct) disutility and the (direct) utility of providing informal care. This makes that it is impossible to disentangle the costs and effects. Moreover, because effects are monetarised, they could by definition not be incorporated in the effect side of a cost-effectiveness analysis or a cost-utility analysis. This holds as long as the care recipient’s outcomes are the main focus on the effect side of the economic evaluation. If the informal caregiver is the focus of an economic evaluation, for instance the analysis of the costs and effects of a support program for informal caregivers, then CM is only appropriate in a cost-benefit analysis or if one uses CM to derive a utility instead of a monetary value of informal care. However, one has to be careful if one compares economic evaluations that use CM to incorporate the costs and effects of informal care with economic evaluations that only

incorporate the costs of informal care valued with the opportunity or proxy good methods. As we have seen, CM yields lower results than the opportunity and proxy good methods. This biases the incremental cost-effectiveness ratio. Therefore, a necessary condition for the comparison of the results of different economic evaluations is uniformity in the way informal care is valued. If one wishes to capture both the costs and effects of informal care as is suggested if one adopts a societal perspective, CM seems a better method compared to the opportunity cost and proxy good methods.

We constructed vignettes that present a wide range of informal caregiving situations. This was done in order to capture the heterogeneity of informal care. However, we only used three attributes. Therefore, much of the heterogeneity in terms of more qualitative information like subjective burden, health-related quality of life of informal caregivers and care recipients could not be captured. We tried to capture this heterogeneity by adding them as additional independent variables in the model. However, none of these variables were significant. This may indicate that they are less important than one might expect them to be, or that respondents are very well capable of dealing with hypothetical situations and abstracting from their own real life situation. Another explanation is the relative small sample size. The latter problem becomes more persistent if one looks at the relatively high non-response on the vignette rating questions.

A point of concern in the application of CM by means of written surveys is the non-response to the CM questions. We learned from an informal pilot study that rating the vignettes puts a substantial burden on respondents. In this study we found that around 30 percent of the informal caregivers did not rate the vignettes. Especially relative older informal caregivers and both lower and higher educated compared to the medium educated informal caregivers were less willing to rate the vignettes. However, since there were no differences in non-response for the large majority of explanatory variables and 70 percent of the respondents completed the CM questions, there is not enough reason to advice against the application of CM in future studies to value informal care. However, it is something to keep in mind for specific populations and in generalising our results.

Our application of CM showed that it is an interesting method to derive a monetary compensation of informal care. However, considering the standard errors and the confidence intervals a larger sample size is necessary to get more reliable estimates. This problem is also encountered in other applications of CM (Johnson et al., 2000) and (McIntosh and Ryan, 2002), and seems to be related to the orthogonal design adopted here. Therefore, future research could aim at confirming the feasibility of CM and our results for

RA in a bigger sample and with other than orthogonal designs. See for a discussion of possible designs (Huber and Zwerina, 1996) and (Carlsson and Martinsson, 2003). New applications of CM could also focus on other more heterogeneous populations in terms of care recipients' disease characteristics.

It is challenging to add additional attributes and levels to the vignettes in future research regarding the economic valuation of informal care. However, this could put greater burden on the respondents, perhaps at the costs of higher non-response, especially when attributes contain elements respondents are not familiar with (Ryan and Gerard, 2003). Ryan and Gerard (2003) also emphasize that there is no empirical evidence on what constitutes this complexity. Moreover, there is no evidence about the question how many attributes an optimal CM design might contain in order to prevent non-response. So this has to be established through a process of trial and error. Yet, we know that choosing from 32 alternatives with 26 attributes might be too hard for respondents (Ryan and Gerard, 2003). Van Ophem et al. (1999) suggest that this holds even if respondents are familiar with the commodity under valuation, in their case, the demand for classical music by people who like classical music.

Nevertheless, it would be very interesting to deal with greater heterogeneity of informal care by adding, for example, more care tasks. One could think about socio-psychological care tasks, for instance emotional support or supervising a care recipient, because they are also important in informal caregiving, especially in some disease specific populations like caregiving for people with dementia.

Another interesting issue relates to the qualitative information towards the provision of informal care. One could, for instance, add more qualitative information on the caregiving situation or an attribute covering the trade-off between informal caregiver's own tasks and other informal caregivers. Another option is to add more detailed information instead of our more general care tasks. For instance, instead of personal care one could distinguish support with washing the care recipient and support with dressing to get more detailed information about informal caregivers' preferences. Qualitative information could also be interesting because it is connected to the subjective burden literature, see for instance Pearlin et al. (1990), Kramer (1997), and Schulz and Beach (1999) for overviews. Normal the subjective burden measures are not preference based. CM could therefore add to this literature because it focuses explicitly on caregivers' preferences instead of just their problems in terms of burden. Adding care tasks provided by other informal caregivers could also fill a gap in the literature, in which the focus is

often just on primary informal caregivers (like in this study). Many empirical applications in the subjective burden literature involve just one, often the primary, caregiver. There could however arise conflicts between different informal caregivers caring for the same care recipient. This is recognised in the economic literature that uses, for instance, game theory to model this problem (Hiedemann and Stern, 1999). CM could also add to this literature. Moreover, the trade-off between professional and informal care would probably provide interesting information.

As discussed before, non-response on the vignette rating question is an issue in this study. A relatively simple but expensive solution for this issue could be oral instead of written surveys using trained interviewers. This may help to overcome a part of the non-response problem, as well as improving the quality of the data.

It is worth noting that the results of this study can also give information about the trade-offs informal caregivers make in choosing between the amount and the nature of the provided informal care. This can be a first step to understand the different perceptions of burden of care further and may aid in developing support programs for informal caregivers.

In sum, we suggest CM is a promising method in the context of informal care in general, and especially may be regarded as a promising alternative for the existing methods to value informal care, like the opportunity cost method and proxy good method. The presented monetary value of informal care can be incorporated in the numerator of a cost-effectiveness ratio in economic evaluations.



# 9 Economic valuation of informal care: A choice experiment applied to a heterogeneous population of informal caregivers<sup>1</sup>

## Summary

*This chapter reports the results of the application of a choice experiment (CE) to determine a monetary value of informal care. Compared to the normally recommended valuation methods, like the opportunity cost method and proxy good method, a CE is probably better able to capture the heterogeneity of informal care.*

*We developed a survey in which informal caregivers were asked to rate four different hypothetical informal caregiving situations (care hours, care tasks and monetary compensation). They were also asked to rate their current informal care situation compared to the four hypothetical situations. Data were obtained from postal surveys. These surveys were sent through regional support centres for informal caregivers of care recipients with various health problems. A total of 865 informal caregivers and 513 care recipients from this heterogeneous population returned a completed survey.*

*Informal caregivers require an extra compensation of 0.54 euro per hour for providing one additional hour of the same informal care task. They also require a compensation of 4.32 euro per hour for switching from providing light housework to personal care and 18.15 euro per hour for switching from providing heavy housework to personal care. Moreover, informal caregiver's current overall real life situation and some other real life background characteristics influenced the ratings, viz. choices.*

*We conclude that CE's are a promising alternative for existing methods to determine a monetary value of informal care. The presented valuations of informal care can be incorporated in the numerator of a cost-effectiveness ratio in economic evaluations of health care.*

## 9.1 Introduction

This chapter explores the use of choice experiments (CE's), also called conjoint measurement or conjoint analysis, to incorporate informal care in economic evaluations of health care. Chapter 8 proposed and discussed this approach before. However, chapter 8 used a relatively small sample (n=135) for the application of a CE and applied the CE to a

---

<sup>1</sup> Based on Van den Berg, B., Al, M., Brouwer, W.B.F., Van Exel, J.A.J., Koopmanschap, M.A., 2004. Economic valuation of informal care: A choice experiment applied to a heterogeneous population of informal caregivers. *Chapter 9: Economic valuation of informal care: A choice experiment applied in a heterogeneous population of informal caregivers* 179

homogeneous sample of informal caregivers in terms of disease characteristics, namely care recipients with rheumatoid arthritis. This chapter applies the CE to a relatively large sample of 865 informal caregivers providing care for care recipients with different diseases. They include neurological diseases, musculoskeletal diseases, psychological diseases, and circulatory diseases.

It is suggested to incorporate the changes in use of informal caregiver time as direct non-health care costs into the numerator of the cost-effectiveness ratio in economic evaluations (Russell et al., 1996, p.177). Two monetary valuation methods are often recommended to value the time investment in informal care. First, the opportunity cost method, valuing hours spent on informal care at a – would be – wage rate, and second the proxy good method, valuing informal care hours at the wage rate of a professional caregiver (Posnett and Jan, 1996), (Russell et al., 1996), and (Drummond et al, 1997). Both methods however, are rather insensitive to the heterogeneity and dynamics of informal care. They also do not incorporate the full effects of providing informal care for the informal caregivers and therefore do not capture the full impact of providing informal care. Moreover, the proxy good method does not reflect the true preferences of informal caregivers (Van den Berg et al., 2004).

In theory, stated preference methods like contingent valuation (CV) and CE are sensitive to the heterogeneity and dynamics of informal care, capable to capture all relevant aspects of informal care, sensitive to the different circumstances informal caregivers are faced with and capable of reflecting the true preferences of informal caregivers. The method put forward in this chapter is CV's 'cousin' in the family of stated preference methods, CE (Roe et al., 1996). In CE's respondents are, for instance, asked to rate different hypothetical scenarios. Chapter 8 gives a detailed discussion of the advantages and disadvantages of CE compared to CV and to the opportunity cost and proxy good methods. Here, we only stress that it is natural to apply CE to value informal care in order to incorporate it in economic evaluations, because of the heterogeneous nature of the commodity informal care. CE is especially developed to deal with the different components of a commodity as opposed to classical utility theory which assumed that individuals only derived utility from a commodity instead of the different sub components of the commodity under valuation (Lancaster, 1971). Chapters 3 and 8 discussed the complications that arise from the application of a total valuation method like a CE instead of partial valuation methods like the opportunity cost method or proxy good method to value informal care to incorporate it in economic evaluations.

CE's stem from mathematical psychology (Green and Rao, 1971). They are often applied in, for instance, the marketing literature (Green and Srinivasan, 1978) and (Green and Srinivasan, 1990), and in the transport economics literature (Calfee and Winston, 1998). The method is in transport economics applied for different purposes but also to value time, in particular to value travel time. The application of CE in health care is of increasing popularity. Ryan and Gerard (2003) give an overview of the application of CE in health care. Also within economic evaluations is CE of growing importance for the measurement of care recipient's preferences, see, for instance, Slothuus et al. (2002)). Ryan and Gerard (2003) state that CE studies in health care are mostly applied to elicit preferences for health care and to incorporate them in economic evaluations. While we asked our respondents to rate four different hypothetical situation and their own real life situation, a majority of applications in health care use binary choices or paired comparisons instead of ratings (Ryan and Gerard, 2003). Waiting time is an important attribute in CE studies in health care. Other types of time are travel time, time to return to normal activities, duration of illness and time preferences (Ryan and Gerard, 2003). Finally, most applications in health care use payment at the point of consumption (Ryan and Gerard, 2003), but, for instance, Van der Pol and Cairns (1998) use willingness to accept (WTA).

This chapter proposes and reports the results of the application of CE to determine a monetary value of informal care. The main focus of the chapter is to attempt to value the full impact of providing informal care on the informal caregivers through asking informal caregivers in a heterogeneous population to rate four different hypothetical informal care situations. We included a hypothetical monetary compensation in the four situations in order to be able to derive a monetary compensation for providing different amounts of informal care and different care tasks. Moreover, we collected information about informal caregivers' and their care recipients' real life care situation in terms of, for example, the amount and nature of provided care, health-related quality of life and subjective burden due to providing care and analysed whether they influenced the monetary valuation. We also asked informal caregivers to rate their own real life caregiving situation compared to the four hypothetical situations. Asking informal caregivers to rate their own situation is a methodological attempt to deal with the informal caregivers' real life circumstances. Next to the application of CE to a larger and heterogeneous sample, asking caregivers to rate their own situation is a new contribution of this chapter compared to chapter 8.

We chose to elicit real informal caregivers' preferences to provide care instead of the preferences of the general population. We did so because informal caregivers have experience in making choices about providing informal care. Therefore, they may be considered the best informed people and from a traditional welfare economic point of view the right individuals to state their preferences regarding informal care decisions. This may lead however to an underestimation of the monetary value of informal care because of the selection of respondents. Indeed, we only include individuals who have already shown to be willing to provide informal care in the elicitation of preferences, while people who are unwilling to provide care are expected to require *ceteris paribus* a relatively higher compensation. See Dolan et al. (2003) for a more elaborate discussion of the different perspectives that could be used to elicit preferences.

Another interesting question in relation to the selection of respondents is whether current informal caregivers can abstract from their own caregiving situation in order to express their preferences about hypothetical caregiving situations described in the vignettes used in the CE. On the one hand, the caregivers are expected to use their life experience in stating their preferences. However, on the other hand they need to abstract from their own specific situation to express their preferences for the different hypothetical situations. Therefore, currently providing informal care may improve respondents' ability to elicit preferences for hypothetical caregiving situations, but the appraisal of different caregiving situations may also be influenced by their current caregiving situation.

The outline of this chapter is as follows. Section 9.2 introduces the application of the CE in informal caregiving and describes the specific application of the CE in this study. Then we present the econometric model. Subsequently, we present the data and results. We derive a monetary value of informal care provided to a heterogeneous sample of informal caregivers in section 9.6. Finally, we discuss the results and conclude the chapter.

## **9.2 Developed vignettes**

In this section, we give a definition of the commodity informal care. Then we describe the developed vignettes. The vignette attributes were derived from the definition and from empirical findings in other studies.

### **9.2.1 Definition**

We define informal care as *"a non-market composite commodity consisting of heterogeneous parts produced by one or more members of the social environment of the care recipient"* (Van den Berg et al.,

2004). With the term non-market commodity we indicate that there exists no formal market for informal care and subsequently there exist no market prices. Therefore, this study aims to derive a monetary value for informal caregiver's time. A heterogeneous commodity means that informal care consists of different care tasks like housework and personal care. The amount of informal care can also differ substantially between different caregiving situations, for example, according to the demand of the care recipient and the available amount of professional care or other informal care. Chapter 3 gives a detailed discussion of the heterogeneous nature and dynamics of the commodity informal care. We included some of these variations in our vignettes and tried to capture other parts in the other independent variables.

### 9.2.2 Vignette attributes

Our vignette attributes are informal care hours, informal care tasks, and a monetary compensation, as denoted in table 9.1.

**Table 9.1:** Overview of attributes and their levels

Attribute	Level	Code
Informal care task	Light house work	Dummy: 1 = yes
	Heavy house work	Dummy: 1 = yes
	Personal care	Dummy: 1 = yes
Informal care hours per week and per day	7	7
	14	14
	21	21
Informal caregiver's monetary compensation <sup>1</sup>	0 EURO per hour	0
	4.55 EURO per hour	4.55
	9.10 EURO per hour	9.10
	13.65 EURO per hour	13.65

<sup>1</sup> Originally 0/10/20/30 Dutch guilders

Table 9.1 gives an overview of the attributes chosen, and the levels distinguished within each attribute. It also gives the coding of the data. When we developed our vignettes there was no information about the amount and nature of care informal caregivers in a heterogeneous population normally provide. But there was some information on a disease specific level, viz. a population informal caregivers providing care for people with rheumatoid arthritis (RA) (Riemsma et al., 1997). Therefore, the three care tasks were chosen because they include the most important informal care tasks (Riemsma et al., 1997).

Reimsma et al. (1997) also found that informal caregivers provided on average 33 hours per week care for people with RA. We felt that this amount would be an upper bound for our population. This because it is well known that time measurement is complicated and that the measured amount of time depends on the questions posed (Juster and Stafford, 1991). Riemsma et al. (1997) distinguished 28 care tasks as opposed to the 16 tasks we choose. It could therefore be expected that our population would report a somewhat lower amount of informal care provided and we chose therefore to include 7, 14 and 21 hours informal care per week respectively as the values of the time attributes. We selected the monetary compensation because it encompasses the Dutch market prices and health care sector tariffs for unskilled housework of 8.53 Euro per hour.

The three attributes and their chosen levels result in 6561 ( $3^{3*} 3^{3*} 3^4$ ) possible vignettes. We reduced these to a manageable number of 16 vignettes.<sup>2</sup> Then we chose one reference vignette and distributed the remaining 15 among 5 groups of 3 vignettes. Thus, we ended up with 5 sets of 4 vignettes (each including the same reference vignette). The sets were randomly distributed over our respondents.

In our application, we focused on the trade-offs between a monetary compensation and providing additional hours of care on the one hand and other care tasks on the other hand, because our objective was to derive a monetary valuation of informal care. Of course, the trade-off between informal care time and care tasks could also provide valuable information. Besides the information gathered in the CE exercise, we collected extra information on, for instance, the informal caregivers' objective and subjective burden and the rating of their own real life situation compared to the hypothetical situations as described in the vignettes. This information will be used as additional independent variables to see how they influence ratings (and possibly indirect the marginal rates of substitution).

### 9.2.3 The survey and vignette questions

Our central objective was to derive a monetary value of informal care consistent with the heterogeneous nature of this commodity. We therefore first asked the informal caregivers some questions about their current caregiving situation. These included how many years the informal caregiver provides informal care already. Moreover, we asked respondents

---

<sup>2</sup> This is called an orthogonal array. Such orthogonal array is still able to estimate main effects, but not interactions. In an orthogonal array, each level of one attribute occurs with each level of another attribute with equal or at least proportional frequencies. We used the SPSS orthoplan procedure to arrange an orthogonal design.

how many hours they spent on informal caregiving during the last week according to a list of sixteen care tasks. We distinguished between three types of care tasks: (1) housework (HDL) like cleaning and cooking, (2) activities of daily living (ADL) like personal care and, (3) instrumental activities of daily living (IADL) like contacts with health care.

Subsequently we introduced a hypothetical caregiving situation with a set of four vignettes and we asked respondents to rate them. See for an example of the exact question figure 9.1.

**Figure 9.1:** Example of a choice question

---

*“People who need care are often in different situations. Below, we sketch four different situations that probably differ strongly from the situation of your care recipient. Please, imagine yourself in the situations.”*

---

**Situation A:**

- Your care recipient needs 21 hours per week support with personal care
- You provide every day 3 hours informal care, totalling 21 hours per week, with personal care
- You receive in return an amount of 13.65 Euro per hour from the government tax-free.

**Situation B:**

- Your care recipient needs 14 hours per week support with heavy housework
- You provide every day 2 hours informal care, totalling 14 hours per week, with heavy housework
- You receive in return an amount of 9.10 Euro per hour from the government tax-free.

**Situation C:**

- Your care recipient needs 7 hours per week support with personal care
- You provide every day 1 hour informal care, totalling 7 hours per week, with personal care
- You receive in return an amount of 9.10 Euro per hour from the government tax-free.

**Situation D:**

- Your care recipient needs 7 hours per week support with light housework
- You provide every day 1 hour informal care, totalling 7 hours per week, with light housework
- You receive in return an amount of 0 Euro per hour from the government tax-free.

Please give the four situations a rating between 1 and 10. 10 is the from your perspective best imaginable and 1 the worst imaginable situation.

I give situation A, B, C and D rate ..... *(subsequently for all situations)*

Please compare your own real life situation with the four hypothetical situations. How would you rate your own real life situation? 10 is the from your perspective best imaginable and 1 the worst imaginable situation.

---

Because chapter 8 found a relatively high non-response on the vignette ratings, we put extra attention on the design of the survey. The hypothetical situations were presented on the back of the survey, which had a different colour compared to the remainder of the survey. The respondents could fold this page in such a way that the vignettes could be

placed next to the rating questions, instead of them being on a separate page as in the previous chapter.

To get a better picture of the current informal care situation, we also measured health-related quality of life of informal caregivers and care recipients using the EQ-5D (Essink-Bot et al., 1993). We furthermore measured subjective caregiving burden. Many instruments are developed to measure subjective burden of informal caregiving (Kramer, 1997). We applied the Caregiver Strains Index (CSI) (Jacobi et al., 2003) because it contains a total sum score as opposed to other instruments that focus on different sub aspects of providing informal care, like financial problems and lack of family support. The CSI has a minimum score of 0 indicating no subjective burden in terms of strain and a maximum score of 13 indicating much strain. A score of 7 or higher means that the informal caregiver is at risk. Finally, we asked both informal caregivers and care recipients some socio-economic questions.

### 9.3 Econometric model

In asking informal caregivers to rate four hypothetical caregiving situations, we assume these ratings to be a proxy of informal caregivers' (direct and indirect) utility and (direct and indirect) disutility ( $U^c$ ) derived from the four situations. This makes that our dependent variable is latent. We only observe respondents' ratings 1 to 10 (which were transformed to the range of 0 to 9):

$$\begin{aligned}
 y &= 0 \text{ if } y^* \leq 0, & (1) \\
 &= 1 \text{ if } 0 < y^* \leq \mu_1, \\
 &\cdot \\
 &\cdot \\
 &\cdot \\
 &= 9 \text{ if } 8 \leq y^*.
 \end{aligned}$$

Given the fact that respondents could only give a rating from 1 to 10, they were supposed to choose the rate that most closely represents their own feelings. These ratings are proxies for an informal caregiver's utility (derived from the hypothetical situation. Because respondents rated four different hypothetical situations our data have a panel structure:

$$y_{it}^* = \mu + x'_{it}\beta + z'_{it}\gamma + \alpha_i + \varepsilon_{it} \quad (2)$$

where  $y^*$  is an unobserved latent variable denoting respondent  $i$ 's ( $i = 1, \dots, N$ ) utility derived from vignette  $t$  ( $t = 1, \dots, 4$ ),  $\mu$  is a fixed constant,  $x_{it}$  is a  $K$ -dimensional vector of vignette attributes presented to respondent  $i$  at vignette  $t$ . Furthermore,  $z_{it}$  is a  $M$ -dimensional vector of respondents' and informal care characteristics including the rating of informal caregivers' own real life situation, while  $\alpha_i + \varepsilon_{it}$  is the error term consisting of two components:  $\varepsilon_{it}$  denoting an individual specific component that is treated as a random variable, and  $\alpha_i$  denoting an individual specific component assumed to be fixed over the different vignettes. Because the vignettes were randomly distributed over the respondents, we assume that there is no correlation between  $x_{it}$  and  $\varepsilon_{it}$ . Therefore the random effects ordered probit model is appropriate for our problem. Greene (2000) and Scott Long (1997) discuss the ordered probit model in more detail, while Hsiao (1986) and Verbeek (2000) give detailed discussions of random effects models. An alternative for the random effects ordered probit is a random effects ordered logit model. The latter model suffers, however, from violations of the Independence of Irrelevant Alternatives (IIA) property (McFadden, 1974) and (Beggs et al., 1981). This property means that adding a similar vignette, which resembles an existing vignette except for one irrelevant detail, should not alter the subsequent ratings. Other alternative methods for the analysis are OLS-regression or interval regression (Van Doorslaer and Jones, 2003). Both, however, assume a cardinal interpretation of the ratings (Boyle et al., 2001), which is a strong assumption.

If we replace  $x'_{it}\beta$  in (3) with the vignette attributes and  $y_{it}^*$  with  $y_{it}$ , we get our empirical model:

$$y_{it} = \mu + z'_{it}\gamma + H_{it}\beta_1 + LH_{it}\beta_2 + HH_{it}\beta_3 + C_{it}\beta_4 + \alpha_i + \varepsilon_{it} \quad (3)$$

In order to derive a monetary value of informal care one wishes to keep informal caregivers' utility constant while varying the level of the different components (attributes) of utility. These components consist in our application of care tasks, hours of care provided, and an hourly monetary compensation. In varying these attributes one can derive the marginal rate of substitution (MRS) between the attributes. Including a monetary

compensation<sup>3</sup> as one of the attributes, in our application in the form of willingness to accept (WTA), enables us to derive the MRS between the other attributes and the monetary compensation. For instance, to derive informal caregiver's WTA for extra informal care provided ( $MRS_{HC}$ ), one wishes to keep  $U^{ic}$  constant. We state it formally:

$$MRS_{HC} = H/C \quad (4)$$

## 9.4 Data

### 9.4.1 Study sample

The informal caregivers in this study were reached via Dutch regional support centres for informal caregivers. We approached 59 regional centres. Out of these, 40 centres were willing to participate in the research. We spread 3258 postal surveys via the 40 centres. This approach ensures us that informal caregivers are reached directly. The regional support centres are the only Dutch organisations where informal caregivers are registered and therefore through which it is possible to reach directly a heterogeneous sample of informal caregivers providing a substantial amount of informal care during a longer period of time. Alternatives, for example, disease specific groups or a representative sample from the Dutch population would not have ensured to reach a large sample of informal caregivers.

We received completed surveys from 865 informal caregivers and 513 care recipients. Out of these, 413 informal caregivers returned their survey without their care recipient and 452 couples of informal caregivers and care recipients returned the survey. There were also 61 care recipients who returned their survey while their informal caregiver did not. Those surveys were not analysed, because they do not contain information about informal caregivers' ratings of the vignettes. The returned surveys of 81 informal caregivers and 143 care recipients were of too bad quality or not filled in. Therefore, they were not used in the analyses. Finally, 30 informal caregivers and care recipients were untraceable/relocated.

### 9.4.2 Background statistics

Table 9.2 shows some descriptive statistics of the study sample.

---

<sup>3</sup> One has to be careful with the interpretation if one includes prices or costs as an attribute (Ratcliffe, 2000).

**Table 9.2: Characteristics informal caregivers (n=865) and care recipients (n=452)**

Characteristic	Mean
<i>Informal caregivers</i>	
Age <sup>1</sup>	60.2
Gender <sup>2</sup>	23.4
<i>Relation to care recipient<sup>3</sup></i>	
Partner	48.9
Parent	28.8
Child	10.3
Other	11.2
Live together <sup>4</sup>	58.2
<i>Education<sup>1</sup></i>	
Education 1	13.3
Education 2	24.6
Education 3	27.9
Education 4	6.2
Education 5	10.6
Education 6	12.5
Education 7	6.9
<i>Occupation<sup>1</sup></i>	
Paid job	23.4
Jobless	3.9
House worker	40.7
Retired	21.4
Disability pension	6.5
Other	2.7
Income <sup>5</sup>	1,627.28
<i>Illness care recipients according to informal caregivers<sup>3</sup></i>	
Dummy respiratory diseases	12.6
Dummy circulatory diseases	30.3
Dummy digestive diseases	11.9
Dummy endocrine, metabolic and nutritional diseases	12.8
Dummy musculoskeletal diseases	40.5
Dummy neurological diseases	46.1
Dummy skin diseases	8.3
Dummy psychological diseases	48.2
<i>Care recipients</i>	
Age <sup>1</sup>	66.6

*Continued on the next page*

Characteristic	Mean
Gender <sup>2</sup>	48.8
<i>Illness<sup>3</sup></i>	
Dummy respiratory diseases	13.5
Dummy circulatory diseases	28.1
Dummy digestive diseases	12.8
Dummy endocrine, metabolic and nutritional diseases	15.0
Dummy musculoskeletal diseases	48.2
Dummy neurological diseases	50.4
Dummy skin diseases	10.2
Dummy psychological diseases	36.5

<sup>1</sup> In years

<sup>2</sup> Percentage males

<sup>3</sup> Percentages

<sup>4</sup> Percentage living together

<sup>5</sup> Net monthly family income in euro

Three out of four informal caregivers were female. Informal caregivers' and care recipients' age ranged from 16.5 to 89.5 and from 2.5 to 98.5 respectively. Category education 1 is the lowest and category education 7 the highest education.

Table 9.3 provides some other background characteristics of the study sample, such as care duration, the amount of provided informal care, subjective burden and EQ-5D-scores.

The average care duration was 8.7 year reflecting that our population consisted of many informal caregivers that cared for care recipients with a chronic disease. Of the care recipients, 11.5 percent was on a waiting list for professional home care or residential care. 60.9 percent of the informal caregivers performed activities of daily living (ADL) while 87.4 percent of them performed housework (HDL). The EQ-5D scores of the informal caregivers were unsurprisingly much higher compared to those of the care recipients (0.75 versus 0.30 respectively). Finally, informal caregivers indicated that providing informal care was straining as can be concluded from the average CSI score of 7.9.

**Table 9.3:** Characteristics of the informal caregivers (n=865) and care recipients (n=452) caregiving situations

Characteristic	Mean
<i>Informal caregivers</i>	
Care duration <sup>1</sup>	8.7
Performing HDL tasks <sup>2</sup>	87.4
Hours HDL tasks <sup>3</sup>	93.3
Performing ADL tasks <sup>2</sup>	60.9
Hours ADL tasks <sup>3</sup>	51.8
Performing IADL tasks <sup>2</sup>	90.5
Hours IADL tasks <sup>3</sup>	68.9
Total informal care time <sup>3</sup>	175.1
EQ-5D	0.75
CSI	7.9
Rating current real life situation	6.2
<i>Care recipients</i>	
EQ-5D	0.30
Waiting list <sup>2</sup>	11.5
Other informal care <sup>2</sup>	41.6

<sup>1</sup> In years

<sup>2</sup> In percentage

<sup>3</sup> In mean hours per week

## 9.5 Results

### 9.5.1 Results of the random effects ordered probit

We give an ordinal interpretation to respondents' ratings and correct for correlation within respondents' answers. Therefore, we used a random effects ordered probit to analyse informal caregivers' ratings. Table 9.4 gives the results.

**Table 9.4:** Results random effects ordered probit of equation (3); dependent variable: rating informal caregiver

	Model 1		Model 2		Model 3		Model 4	
	Coef.	z-value	Coef.	z-value	Coef.	z-value	Coef.	z-value
<i>Vignette attributes</i>								
Dummy light housework (1 = yes)	-0.10	-1.80	-0.09	-1.57	-0.09	-1.40	-0.08	-0.84
Dummy heavy housework (1 = yes)	-0.40	-6.37	-0.42	-6.42	-0.47	-6.42	-0.31	-2.79
Informal care hours	-0.01	-3.11	-0.01	-3.44	-0.02	-3.53	-0.02	-3.06
Informal care monetary compensation	0.02	10.84	0.02	10.31	0.02	9.27	0.02	6.58
<i>Informal caregivers</i>								
Rating own situation			0.06	4.88	0.07	4.82	0.08	3.52
Age					-0.00	-0.36	-0.01	-1.42
Gender					-0.08	-1.06	0.01	0.09
<i>Education: ref. = education 7</i>								
Dummy education 1 (1 = yes)					0.20	1.23	0.26	0.95
Dummy education 2 (1 = yes)					0.26	1.79	0.43	1.69
Dummy education 3 (1 = yes)					0.17	1.20	0.30	1.24
Dummy education 4 (1 = yes)					0.02	0.12	-0.03	-0.10
Dummy education 5 (1 = yes)					0.13	0.88	0.44	1.72
Dummy education 6 (1 = yes)					0.14	0.98	0.28	1.15
Net monthly income					-0.00	-1.72	-0.00	-0.27
<i>Occupation: ref. = house worker</i>								
Dummy paid job (1 = yes)					0.02	0.28	-0.01	-0.07
Dummy jobless (1 = yes)					0.25	1.44	0.16	0.51
Dummy retired (1 = yes)					0.07	0.78	0.12	0.84
Dummy disability pension (1 = yes)					-0.13	-1.11	0.10	0.50
Dummy other main activity (1 = yes)					-0.16	-0.93	-0.44	-1.84
<i>Relation to care recipient: ref. = partner</i>								
Dummy parent (1 = yes)					-0.03	-0.34	-0.07	-0.35
Dummy child (1 = yes)					0.05	0.50	0.16	0.79
Dummy other (1 = yes)					0.13	1.07	0.03	0.15
Dummy same household (1 = yes)					0.26	3.03	0.24	1.65
Informal care years					-0.00	-0.68	-0.00	-0.79
<i>Continued on next page</i>								

	Model 1		Model 2		Model 3		Model 4	
	Coef.	z-value	Coef.	z-value	Coef.	z-value	Coef.	z-value
Dummy other informal care (1 = yes)					-0.03	-0.50	-0.06	-0.63
Dummy waiting list (1 = yes)					-0.24	-2.46	-0.19	-1.35
Informal care time					-0.00	-0.47	-0.00	-0.15
Informal care tasks					-0.01	-0.57	-0.00	-0.17
Dummy ADL tasks (1 = yes)					0.09	1.30	0.10	0.95
Dummy IADL tasks (1 = yes)					0.18	1.02	0.14	0.52
EQ-5D					0.15	1.04	0.41	1.81
CSI					0.03	2.25	0.04	2.20
<i>Illness care recipients according to informal caregivers (1 = yes)</i>								
Dummy respiratory diseases					-0.07	-0.94		
Dummy circulatory diseases					-0.02	-0.25		
Dummy digestive diseases					-0.18	-2.11		
Dummy endocrine, metabolic and nutritional diseases					0.09	0.74		
Dummy musculoskeletal diseases					-0.15	-2.55		
Dummy neurological diseases					0.02	0.30		
Dummy skin diseases					0.12	1.36		
Dummy psychological diseases					0.08	1.42		
<i>Care recipients</i>								
Gender							0.05	0.54
Age							0.00	0.94
EQ-5D							0.23	1.82
<i>Illness(1 = yes)</i>								
Dummy respiratory diseases							-0.06	-0.51
Dummy circulatory diseases							-0.29	-3.14
Dummy digestive diseases							0.08	0.67
Dummy endocrine, metabolic and nutritional diseases							0.16	1.34
Dummy musculoskeletal diseases							0.05	0.56
Dummy neurological diseases							0.13	1.50
Dummy skin diseases							-0.01	-0.12
Dummy psychological diseases							0.11	1.14
Intercept 1	-1.39	-15.83	-1.04	-9.22	-0.53	-1.48	0.23	0.37
Intercept 2	-1.10	-13.02	-0.75	-6.77	-0.22	-0.60	0.54	0.87

*Continued on next page*

	Model 1		Model 2		Model 3		Model 4	
	Coef.	z-value	Coef.	z-value	Coef.	z-value	Coef.	z-value
Intercept 3	-0.86	-10.38	-0.51	-4.63	0.04	0.10	0.77	1.25
Intercept 4	-0.48	-5.97	-0.14	-1.30	0.43	1.21	1.15	1.84
Intercept 5	-0.10	-1.21	0.24	2.16	0.82	2.30	1.49	2.39
Intercept 6	0.38	4.70	0.72	6.56	1.32	3.69	1.96	3.14
Intercept 7	0.84	10.31	1.18	10.59	1.80	5.02	2.42	3.86
Intercept 8	1.53	17.77	1.85	16.09	2.46	6.84	3.06	4.88
Intercept 9	1.79	20.00	2.11	17.92	2.75	7.61	3.38	5.38
N	2260		2108		1624		755	

We distinguish four models in table 9.4. Model 1 just presents the results of respondents' ratings of the vignettes. All coefficients are statistically significant at the 5 percent level, except for the dummy 'light housework'. Informal caregivers also rated their current situation compared to the four hypothetical situations. Model 2 gives the results corrected for the informal caregiver's rating of their current situation. Informal caregiver's current situation has a positive and statistically significant influence on informal caregiver's ratings of the hypothetical situations. This seems straightforward: the more positive informal caregivers are about their own real life situation, the more positive they rate the hypothetical situations.

We collected information about the informal caregivers' background, for example, socio-economic variables (table 9.2), and we measured informal caregiving characteristics, for instance, informal caregiver time spent on providing informal care, health-related quality of life and subjective burden (table 9.3). Model 3 gives the results corrected for those independent variables. The dummies 'informal caregiver and care recipient share the same household' and 'care recipient is on a waiting list' are statistically significant. Sharing the same household yields, *ceteris paribus*, higher ratings of the hypothetical situations compared to not sharing the same household. Providing care for somebody on a waiting list for professional care leads to lower ratings, *ceteris paribus*. Also, informal caregiver's subjective burden measured with the CSI has a statistically significant influence on the ratings. The positive sign is, however, somewhat surprising. A higher subjective burden yields higher ratings.

Finally, model 4 gives the results also corrected for care recipient's characteristics as reported by care recipients. The number of observations in model 4 is, however, quite low compared to models 1, 2 and 3 because fewer care recipients than informal caregivers

returned a survey. Care recipients' health status has a statistically significant (at the 10 percent level) impact on informal caregivers' ratings. The positive sign indicates that the healthier the care recipient is the higher informal caregivers' ratings are which is plausible.

A comparison of the coefficients of the attributes of models 1, 2 and 3 shows that only informal caregiver's monetary compensation remains quite stable after correction for other independent variables. Moreover, the coefficient of informal caregivers' rating of their real life situation goes up after correction for other real life variables. If we compare model 3 with model 4, the coefficients of the vignette attributes change a lot after correction for care recipients' characteristics. This may be due to the loss of many observations. However, in terms of statistical significance, the results of the four models are very stable.

## 9.6 Informal caregivers' monetary compensation

In the methods section we discussed how to derive a monetary valuation of informal care with CE. From the estimated coefficients of the models in table 9.4 we derive the informal caregivers' marginal rates of substitution, using equation (4). We present them in table 9.5.

**Table 9.5:** Informal caregivers' marginal rates of substitution

	Model 1	Model 2	Model 3	Model 4
Light housework/Monetary compensation	-4,32	-3,96	-3,93	-3,36
Heavy housework/Monetary compensation	-18,15	-19,30	-21,54	-13,37
Care hours/Monetary compensation	-0,54	-0,63	-0,72	-0,91
Light housework/Care hours	7,98	6,27	5,41	3,68
Heavy housework/Care hours	33,53	30,55	29,72	14,67

There is some variation in the MRS of the different vignette attributes between the distinct models. Moreover, in absolute terms the MRS between heavy housework and monetary compensation and heavy housework and care hours are quite high. On the other hand, the MRS between care hours and the monetary compensation is low with values of less than 1 Euro. Switching between care tasks seems to be more important in informal caregivers' valuation than providing an hour extra care per week.

## 9.7 Discussion and conclusion

In this chapter we applied a CE to determine a monetary value of informal care in a heterogeneous population of care recipients. An important advantage of CE compared to more conventional methods, like the opportunity cost method and the proxy good method, is CE's ability to capture more accurately the informal caregiver's preferences concerning this heterogeneous commodity.

Informal caregivers require an extra compensation of 0.54 Euro per hour for providing one additional hour of the same informal care task. They also require a compensation of 4.32 Euro per hour for switching from providing light housework to personal care and 18.15 Euro per hour for switching from providing heavy housework to personal care.

Respondents' preferences are systematically related with informal caregiver's and care recipient's characteristics. First of all, informal caregivers' ratings of their own real life situation, has a positive effect on their ratings of the hypothetical caregiving situations. Also informal caregivers' subjective burden, care recipients health-related quality of life, caring for somebody on a waiting list for professional care and sharing the same household with the care recipient has a statistically significant influence on the ratings. This seems to indicate that the informal caregivers' rating of the hypothetical care situations reflects, at least partly, their own experiences.

Our application of CE shows that it is an interesting method to derive a monetary compensation of informal care. This is especially the case, because all kind of real life information influences the informal caregivers' ratings. Although, in the context of hypothetical caregiving situations, one may be ambivalent about the desirability of such influences, the results stress the heterogeneity of the commodity informal care. Therefore, it would be challenging to add additional attributes and levels to the vignettes. This could however put greater (cognitive) burden on the respondents, probably at the costs of higher non-response. On the other hand, it would be interesting to deal with greater heterogeneity of informal care by adding, for example, more care tasks, more qualitative information, for instance, on the nature of the illness or the relationship with the care recipient or by adding an attribute covering the trade-off between informal caregiver's own tasks and other informal caregivers. Moreover, an attribute dealing with the trade-off between professional and informal care would probably provide interesting information. Oral surveys with trained interviewers may help to overcome part of the non-response problem.

In sum, we suggest that CE's may be regarded as a promising alternative for the existing methods to value informal care, like the opportunity cost method and proxy good method. The presented monetary value of informal care can be incorporated in the numerator of a cost-effectiveness ratio in economic evaluations of health care.

# 10 The well-being of informal caregivers: A monetary valuation of informal care<sup>1</sup>

## Summary

*This chapter estimates the value of providing informal care by means of a well-being valuation method. The value of providing informal care is monetarily evaluated by assessing the (compensating) income necessary to maintain the same level of well-being after an informal caregiver provides an extra hour of informal care. In the econometric analysis a distinction is made between the care recipient who is and the care recipient who is not a family member of the informal caregiver. The informal caregiver's well-being is measured by means of two self-reported subjective questions that were posed in a questionnaire answered by 865 Dutch informal caregivers between the end of 2001 and the beginning of 2002. The results indicate that, at sample average, an extra hour of informal care is worth about 15 Euros. This equals 15 or 16 Euros if the care recipient is a family member and about 8 or 9 Euros if not. The results obtained in this study are comparable to the results found when using the contingent valuation method on the same data set.*

## 10.1 Introduction

Economic evaluations of interventions in health care should adopt a societal perspective (Russell et al., 1996) and (Drummond et al., 1997). This implies that everyone affected by the intervention under study should be considered and that all significant outcomes and costs should be counted, valued and included (Russell et al., 1996). Informal care is a significant part of the total of care provided, especially to care recipients with chronic and terminal diseases (Norton, 2000). Still, the costs of informal care are often ignored in economic evaluations (Stone et al., 2000). This might be due to the lack of valuation methods that are both theoretically valid and empirically feasible (Chapter 3).

The existing literature on the economic valuation of informal care has mainly focused on the costs experienced by the caregivers, which are usually valued in terms of time spent on providing informal care. Two valuation methods are usually recommended and applied: the opportunity cost method and the proxy good method (Luce et al., 1996), (Posnett and Jan, 1996) and (Drummond et al., 1997).<sup>2</sup> Chapters 3, 6, 7 and 8 present

---

<sup>1</sup> Based on Van den Berg, B. and Ferrer-i-Carbonell, A., 2004. The well-being of informal caregivers: A monetary valuation of informal care. Submitted for publication.

<sup>2</sup> See, Netten (1990) for an overview and discussion of the costs, other than time, related to informal care.

detailed discussions on the disadvantages of both methods. The main shortcoming of the opportunity cost method is that it is too narrow for a full economic evaluation, and of the proxy good method is that it is not preference based as welfare economics demands. Moreover, neither of the two methods captures the morbidity and mortality risks associated with providing informal care (Hughes et al., 1999) and (Schulz and Beach, 1999). Therefore, chapter 3 called for the development of new methods to value the costs associated with providing informal care. It suggested the use of stated preference methods, such as contingent valuation (CV) and conjoint analysis (CA) as more adequate to value informal care.

This chapter presents an alternative valuation method in which the cost of providing informal care is valued in terms of the loss of well-being suffered by the informal caregiver. This method was first applied by Ferrer-i-Carbonell and Van Praag (2002). Chapter 3 suggested to apply this method to value informal care. The method uses an individual's self-reported well-being (or happiness) to estimate the (compensating) income necessary to maintain the same level of informal caregivers' well-being after providing an additional hour of informal care. The compensating income is taken as the monetary value of informal care. By looking at individuals' well-being this method aims at incorporating all the costs that caregivers experience. Thus not only time costs are incorporated, but also financial outlays related to informal care, such as telephone calls or home adaptations, and non-financial aspects, such as physical and mental tiredness associated with providing informal care. These costs are incorporated to the extent that they affect an individual's subjective well-being.

Compared to CV and CA, the method presented here has one main advantage: the well-being question is relatively easy to answer for respondents. It has been shown that the percentage of individuals who do not respond to well-being questions is very low (Van Praag and Ferrer-i-Carbonell, 2004). In the present sample, only 2.5% to 3.4% (depending on the questions used) of the informal caregivers failed to answer the well-being questions (compared with, for example, 6.7% who refused to give their income). In contrast, CV questions are more difficult for respondents to complete, as it asks them to give an explicit monetary value of the commodity for which no market exists. In this sample, (depending on the questions used) 42.8% to 49.8% of the informal caregivers failed to answer the CV questions. It is worth noting that the non-response on CV questions depends heavily on the choice format used. This sample consisted of open-ended questions, which are the most difficult for respondents to answer (Green et al., 1998). In another sample, using a

dichotomous choice CV question with an open follow-up question to value informal care the non-response was 19% (chapter 6). Even if lower than open-ended questions, the non-response is still much higher than for the well-being questions used in this chapter. Similarly, the answering of CA questions requires a considerable effort from the respondent. This is especially the case when the vignettes include many attributes or when attributes contain elements that the respondent is not familiar with (Ryan and Gerard, 2003) and (Van Ophem et al., 1999).

The present study contributes to the health economics literature in at least three aspects. First, it uses a fairly new valuation method that has never been applied to informal caregiving. Second, its results can be easily compared to earlier work that used the same data set to value informal care by means of CV (Chapter 7). This gives a unique opportunity to compare the outcomes of the two methods. If the monetary values obtained with the two methods are within the same range, the two methods will be externally validated. This is what in the literature is called convergent validity (Bishop, 1995) and (Clarke, 2002). Third, the empirical analysis distinguishes between two types of caregivers, depending on whether the care recipient is or is not a family member of the caregiver. This translates into two sorts of (compensating) income and thus into two values of informal care. This exercise illustrates the flexibility of the present method.

In what follows, section 10.2 describes the method, that is the survey questions used, the well-being model, and the econometric method. Section 10.3 presents the data and descriptive statistics. Section 10.4 gives the results for the well-being equation. Section 10.5 assesses the monetary value of informal care and compares it with the findings in other studies. Finally, section 10.6 presents the discussion and conclusions.

## **10.2 The well-being method to value informal care**

### **10.2.1 Survey questions**

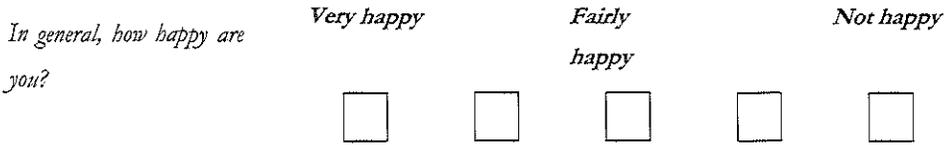
We give the three (groups of) questions that are most important for the present study: amount of informal care provided, two measures of well-being, and household income.

In the survey, informal caregivers are asked how much time they spent on providing informal care in the week preceding the interview. Additionally, the questionnaire includes a question on the social relationship between the informal caregivers and their care recipients. This allows us to distinguish between hours of informal care provided to a family member and to a non-family member. Family members are partners,

parents, children, sisters and brothers, and non-family members are friends, neighbours or in-laws of the informal caregiver.

The survey includes two questions in which informal caregivers are asked to indicate their own happiness by placing a cross in or on a visual analogue scale. The answer to these (or similar) questions give an indication of what is known as subjective well-being (see Section 10.2.2). The two happiness questions in the survey are phrased as follows:

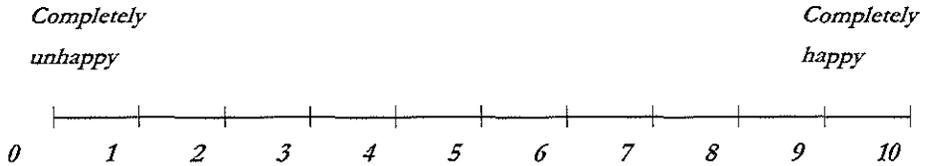
**Figure 10.1:** Satisfaction question, scale 1 to 5



and

*Please, indicate with a cross how happy you are at this moment on the scale below*

**Figure 10.2:** Satisfaction question, scale 0 to 10



Next to the verbal description, the scales (verbal labels versus 0 to 10), and starting points (very happy on the left side versus completely unhappy), the two questions also differ in respect to their place in the questionnaire. The first question (Figure 10.1) is included in a section with the socio-economic questions. The second question (Figure 10.2) is included in a section on the provision of informal care. The empirical analysis estimates the value of informal care by using both questions (see Section 10.5).

The third piece of information necessary to estimate the (compensating) income of providing an extra hour of informal care is the informal caregivers' income. The income question in the survey is:

Figure 10.3: Income question

*What is your net monthly family income, without holiday allowance?*

- Less than 1.200 Guilders per month*
- Between 1.200 and 1.600 Guilders per month*
- Between 1.600 and 2.000 Guilders per month*
- Between 2.000 and 2.500 Guilders per month*
- Between 2.500 and 3.500 Guilders per month*
- Between 3.500 and 5.000 Guilders per month*
- More than 5.000 Guilders per month*

The income question is thus asked in intervals. In order to value informal care in monetary terms, however, income is needed on a continuous scale (see Section 10.5). As a good approximation the mean of the interval is taken as the income of the respondent. Given that the intervals are fairly small (a Guilder is equivalent to about 0.45 Euros), this question provides a very good approximation of the *actual* income. For individuals in the lowest and highest category, household income was set at 800 and 7000 Guilders, respectively. Obviously, the imputed income for these two groups of individuals has the largest error. Nevertheless, only 19% of individuals indicated to have an income in one of these two categories.<sup>3</sup>

---

<sup>3</sup> An alternative method is to estimate an income equation. However, this option was discarded, as the data set does not contain sufficient information (explanatory variables) to explain income.

## 10.2.2 The well-being model

Subjective questions on life satisfaction have been used in economics to understand and explain individual well-being (Van Praag and Ferrer-i-Carbonell, 2004), (Clark and Oswald, 1994), (DiTella et al., 2001), (Easterlin, 2001), (Ferrer-i-Carbonell, 2004), (Ferrer-i-Carbonell and Frijters 2004), (Frey and Stutzer, 2002), (Frijters et al., 2004), (Oswald, 1997).

The first step of the present valuation method is to explain the well-being of the informal caregiver ( $W_{ic}$ ) by a set of objective variables. The following model is used to estimate  $W_{ic}$ :

$$W_{ic} = W(y, H_{ic}, x) \quad (1)$$

where  $y$  denotes the net monthly income,  $H_{ic}$  represents the hours of provided informal care per week, and  $x$  is a vector of individual socio-economic and demographic variables, such as age, working status, and whether or not having an illness.

Equation (1) postulates that informal caregivers' well-being depends, among other things, on income and on hours of provided informal care. The relationship between hours of provided informal care and well-being is expected to be negative, while the correlation between income and well-being is expected to be positive. From equation (1) one can derive the existing trade-off between income and hours of informal care provided. This trade-off is the monetary value of informal care. In micro-econometric terms, the monetary value of informal care is obtained by calculating the (compensating) income ( $\Delta y$ ) necessary to maintain informal caregivers' well-being ( $W_{ic}$ ) constant after increasing the amount of informal care provided ( $\Delta H_{ic}$ ). Formally, this is written as:

$$\frac{\delta y}{\delta H_{ic}} = - \frac{\delta W_{ic} / \delta H_{ic}}{\delta W_{ic} / \delta y} \quad (2)$$

For a theoretical discussion of this method, see Ferrer-i-Carbonell and Van Praag (2002).

Equation (1) is extended so as to allow the (negative) effect of providing informal care to depend on the (non-) family relationship between the caregiver and the care recipient. In the present sample, about 65% of the informal caregivers provide care to a family member (partner, parent, children, sister or brother). Previous research has shown

that providing informal care to close family members involves a relatively larger burden (both physically and emotionally) than providing care to non-family members (Hughes et al., 1999) and (Kramer, 1997). Therefore, we expect a stronger inverse relationship between hours of provided informal care and well-being for informal caregivers who are family of the care recipients than for informal caregivers who are not. If this is true, the monetary value of provided care will depend on whether the care recipient and the informal caregiver are family or not.

### 10.2.3 Econometric methods

The two measures of well-being provide different types of answers and thus will be regressed by a different method. In the subjective well-being literature, models of the type presented in equation (1) have been regressed with linear as well as with latent variable econometric techniques. The first ones assume that the answers to well-being questions are cardinal, while the second type of techniques only assumes ordinality. Ferrer-i-Carbonell and Frijters (2004) have shown that assuming cardinality or ordinality generates similar results. The first measure of well-being (see section 10.2.1) is regressed by means of an Ordered Probit (OP). This captures the fact that the answers can only take 5 discrete values and hence do not give the exact level of well-being but the range in which the caregiver well-being lies. Surprisingly, a significant number of caregivers answered the second well-being question (see Section 10.2.1) by placing a cross at any point of the 0 to 10 line (instead of only at the integer numbers, as expected). The coding of the answers took this into account by rounding the answer to one decimal number. Thus, the happiness question can take 101 values. Therefore, the OP is not a logical method to use. Instead, we use Ordinary Least Squares (OLS) regression.

The model to be econometrically estimated by OP is:

$$\begin{aligned}
 W_{ic}^* &= \alpha + \beta \text{Ln}(y) + \gamma \text{Ln}(H_{ic}) + \varphi (\text{Ln}(H_{ic}) * NF) + \delta x + \varepsilon \\
 W_{ic} = k &\leftrightarrow \mu_k \leq W^* < \mu_{k+1}
 \end{aligned}
 \tag{3}$$

where  $W_{ic}^*$  is the unobserved latent variable,  $W_{ic}$  is the observed well-being,  $NF$  is a dummy variable that equals 1 if the informal caregiver and the care recipient are not family related, and  $\varepsilon$  represents the unobservable error term. The specification for OLS is similar

to the one presented in equation (3). The only difference is that there is no latent variable involved.

Equation (3) shows that the household income and the provided number of hours of informal care are taken in logarithms. This specification is chosen so as to capture that the monetary value of informal care depends on the caregiver's income as well as on the current number of provided hours of informal care. The logarithmic relationship between income and well-being captures the usual assumption of diminishing marginal utility of income.

By rewriting equation (2) for the specification presented in equation (3), the monetary value of providing an extra hour of informal care to a family member can be written as:

$$\delta Lny = \left( \frac{\gamma}{\beta} \delta \ln H_{ic} \right) - 1 \quad (4)$$

and, if the care recipient is not a family member, as:

$$\delta Lny = \left( \frac{\gamma + \varphi}{\beta} \delta \ln H_{ic} \right) - 1 \quad (5)$$

Because both income and hours of informal care are expressed in logarithms, the absolute money value of each hour of informal care depends on both the current income and the number of hours already provided.

## 10.3 Data

The data used in the empirical analysis were collected with the help of the Dutch regional support centres for informal caregivers between the end of 2001 and the beginning of 2002. Fifty-nine regional centres were approached and 40 of which participated in the research. Through these centres, 3258 postal surveys were sent to informal caregivers. The final sample consisted of 865 informal caregivers, which amounts to a response rate of 26.6%. The main objective of this survey was to collect information that allows a valuation of informal care by using different methods, namely CV (Chapter 7), choice experiments (chapter 9) and the well-being method.

Table 10.1 presents descriptive statistics.

**Table 10.1:** Descriptive statistics (n=865)

	Mean	Std. Dev.
Well-being, 1 to 5	2.846	1.151
Well-being, 0 to 10	5.713	2.182
Hours informal care per week	49	52.49
Care recipient no family member	0.345	1.001
Net monthly household income*	1627.28	809.04
Informal caregiver is unemployed	0.015	0.122
Informal caregiver has children	0.812	0.391
Dummy sex: male	0.234	0.423
Informal caregiver is married	0.763	0.425
Age	60.2	12.1
Dummy education: low	38.5	48.7
Dummy education: middle	45.4	49.8
Dummy education: high	16.2	36.8
Dummy individual has an illness	74.7	0.44

\*In Dutch Guilders: 1 Euro = 2.20371 Guilders.

The mean reported well-being is quite similar for both well-being questions. The majority of the informal caregivers (65%) are family of the care recipient. On average, the informal caregivers in the sample provide many hours (49 a week) of care which is more than the average informal caregivers give in The Netherlands (Timmermans, 2003). The vast majority of informal caregivers are married women with children. Only 1.5% of the sample is unemployed, viz. they do not have a paid job nor are looking for it. The mean monthly household income is fairly low. It is just over 800 Euro net of taxes per month, while the

Dutch average is 917 Euro. An explanation is that the respondents in this sample are relatively old, with 35% being older than 65 years, the official retirement age. Moreover, the large amount of time spent on providing informal care may hamper having a (full-time) paid job. A large majority of the sample reports having one or more illnesses.

## **10.4 The well-being of informal caregivers: empirical findings**

In this section, we present and discuss the estimation results for the two well-being equations. Table 10.2 shows the results of the two questions and the two different specifications, i.e. with and without allowing the effect of hours of care provided to depend on the relationship between informal caregivers and care recipient.

Table 10.2 indicates that there is, as expected, a negative effect of the hours of care provided on the informal caregiver's well-being. This negative effect is smaller if the informal caregiver and the care recipient are no family. For instance, the estimated coefficient of the variable  $\ln(\text{hours of informal care})$  on the 1 to 5-question is  $-0.12$  ( $-0.222 + 0.100$ ) if the care recipient and informal caregiver are no family, and  $-0.222$  if they are family. Similar results are found when using the 0 to 10-happiness question instead.

Table 10.2 also shows that a fairly large number of coefficients are not statistically significant. As will be explained below, this could be due to the present sample specificities. Contrarily to the results presented here, the age coefficient is usually found to be statistically significant (Van Praag and Ferrer-i-Carbonell, 2004). A possible explanation is that our sample is fairly old. Therefore, there could be lack of heterogeneity to identify the age effect correctly. The non-statistically significant coefficient for male is not surprising. Being married, having children and level of education are, contrarily to the results presented in Table 10.2, usually found to have a strong coefficient on well-being (Van Praag and Ferrer-i-Carbonell, 2004). In 49% of the cases, informal caregivers in the sample are taking care of their own partner. Therefore, one tempting explanation for the not positive coefficient of "being married" is that the 49% married caregivers, even if happy to have a partner, perceive his or her presence as an emotional and physical burden. A possible explanation for the non-significant coefficient of having children is that, given the old age of the respondents, most of the children are not living at home and thus have less direct contact with them. Being unemployed, as expected, has a significant negative effect on well-being. Individual income has a significant positive coefficient, although for the 0 to

10-happiness question it is significant only at 10%. Caregivers who report to have an illness have a significant negative coefficient on well-being.

**Table 10.2:** Informal caregivers' well-being

	Happiness 1 to 5				Happiness 0 to 10			
	OP				OLS			
	<i>Specification 1</i>		<i>Specification 2</i>		<i>Specification 1</i>		<i>Specification 2</i>	
	Est.	z-value	Est.	z-value	Est.	t-value	Est.	t-value
Ln(Hours Informal Care)	-0.227	-5.730	-0.222	-5.590	-3.620	-4.780	-3.540	-4.680
Ln(Hrs. Inf. Care)*No Family	--	--	0.100	2.270	--	--	1.482	1.760
Dummy sex: male	0.029	0.290	0.047	0.470	2.488	1.270	2.762	1.410
Ln(age)	0.037	0.170	0.050	0.240	7.038	1.730	7.158	1.760
Informal caregiver is married	0.127	1.080	0.134	1.140	-1.281	-0.570	-1.143	-0.510
Informal caregiver has children	-0.084	-0.730	-0.073	-0.630	-2.374	-1.050	-2.219	-0.990
Dummy education: low*	0.013	0.100	0.000	0.000	4.176	1.650	3.977	1.570
Dummy education: middle*	-0.134	-1.180	-0.150	-1.310	2.051	0.920	1.779	0.800
Informal caregiver is unemployed	-0.752	-2.090	-0.736	-2.040	-10.660	-1.590	-10.334	-1.550
Ln(net income per month)	0.223	2.220	0.233	2.320	3.318	1.710	3.434	1.770
Individual has an illness	-0.462	-4.780	-0.452	-4.660	-4.822	-2.580	-4.635	-2.480
Intercept term 1	-0.366		-0.177		20.575	0.950	18.237	0.840
Intercept term 2	-0.006		0.184					
Intercept term 3	1.370		1.567					
Intercept term 4	2.103		2.304					
Number of observations	678		678		674		674	
Pseudo R <sup>2</sup>	0.042		0.045					
R <sup>2</sup>					0.061		0.066	

\*Reference group: informal caregivers with high education.

## 10.5 A monetary value of informal care

### 10.5.1 The well-being valuation method

Table 10.3 presents the results when the relationship between the care recipient and the caregiver is not taken into account. Table 10.4 shows the results when taking this relationship into account. As discussed in Section 10.3, the (compensating) income for an extra hour of informal care depends on the current income and the actual number of hours given (this because both variables enter the well-being equation in logarithms). To take this into account, Table 10.3 and 10.4 present the estimates of the value of informal care for various initial numbers of hours given. The income instead is taken at the sample average.

**Table 10.3:** Monetary value of informal care, *per hour*, first specification (in Euros)

Informal Care Hours	Happiness 1 to 5		Happiness 0 to 10	
	% of current income	Money value*	% of current income	Money value*
5 to 10	20.55%	151.967	22.61%	167.211
10 to 15	10.24%	75.731	11.13%	82.314
15 to 20	6.82%	50.423	7.37%	54.547
20 to 25	5.11%	37.791	5.51%	40.780
25 to 30	4.09%	30.220	4.40%	32.559
1 extra hour from average (Average hours= 49)	2.08%	15.393	2.23%	16.485

\* Income is set equal to the sample average

The sample average of hours of provided informal care is 49 per week. At this average, caregivers would need an income compensation of about 2% of their current income to maintain a constant well-being after providing one extra hour of informal care per week. Given the average caregiver income, this equals about 15 or 16 Euros per hour (depending on the well-being question used). In other words, at the average income and number of informal care hours given, the value of an extra hour is about 15 or 16 Euros. Thus, the money *value* of the 49 hours of informal care provided equals 734 or 784 Euros per week.

Table 10.3 also shows that, when the number of hours provided increases, the average value of *each* hour decreases. For example, the value of *each* hour of informal care for a caregiver who provides 27 hours of informal care per week is about 30 to 32 Euros. It is about 38-40 Euros if the caregiver provides 22 hours of informal care and 76-82 if she or he provides 12 hours a week.

**Table 10.4:** Monetary value of informal care, *per hour*, second specification (in Euros)

Informal Care Hours	Happiness 1 to 5		Happiness 0 to 10	
	% of current income	Money value*	% of current income	Money value*
<b>Caregiver is no family</b>				
5 to 10	8.82%	65.213	10.30%	76.159
10 to 15	4.76%	35.234	5.50%	40.679
15 to 20	3.27%	24.212	3.76%	27.828
20 to 25	2.50%	18.457	2.86%	21.161
25 to 30	2.02%	14.916	2.31%	17.076
1 extra hour from average (Average hours= 49)	1.07%	7.916	1.22%	9.008
<b>Caregiver is family</b>				
5 to 10	18.75%	138.658	20.86%	154.322
10 to 15	9.45%	69.871	10.38%	76.757
15 to 20	6.32%	46.721	6.90%	51.068
20 to 25	4.74%	35.097	5.17%	38.260
25 to 30	3.80%	28.106	4.14%	30.587
1 extra hour from average (Average hours= 49)	1.95%	14.395	2.10%	15.565

\* Income is set equal to the sample average

Table 10.4 shows the results when the effect of the hours of provided informal care on well-being is allowed to depend on the relationship between the caregiver and the care recipient. At the average number of provided hours of informal care (49), the monetary value of an extra hour is about 1% of the current caregiver income if the care recipient is not a family member, and almost 2% if the care recipient is a family member. At the average income, this is about 8 or 9 Euros and about 14 or 15 Euros, respectively (depending on the well-being question used). The difference between the two estimates is fairly large. This may capture the emotional involvement of the caregiver with a family related care recipient, which reduces caregiver's well-being considerably. Like in Table 10.3, the results presented here show a decreasing value of informal care, with an increasing number of hours of informal care provided.

### 10.5.2 A comparison with contingent valuation results

This section compares the above-described results with the ones found with a CV study. This comparison is especially interesting because both studies use the same data set. The

CV questions were posed in the form of informal caregivers' willingness to accept (WTA) in order to provide an additional hour of informal care per week (Chapter 7). Table 10.5 presents this comparison.

**Table 10.5:** Mean compensation with contingent valuation and well-being valuation (in Euros)

	Contingent valuation	Well-being valuation (Happiness 1 to 5)	Well-being valuation (Happiness 0 to 10)
All caregivers	10.52	15.39	16.49
Family related caregivers	10.64	14.40	15.57
Non-family related caregivers	9.44	7.92	9.01

The results of CV indicate that the difference in required compensation between family and non-family caregivers is small and not statistically significant. At the sample average of 49 hours a week, the monetary values found by means of the two methods diverge, with the monetary value found by means of the well-being method being larger. Nevertheless, both methods find monetary values that are within an acceptable range. It is worth noting that, although from the same survey, the two sub-samples are not identical: the CV question was answered by 503 informal caregivers, while more than 800 respondents answered the happiness questions. The well-being question has a much higher response than the CV-question.

## 10.6 Discussion and conclusion

This chapter presents a valuation study in which the well-being method has been used to monetarise the costs of providing informal care, so as to incorporate them in economic evaluations of health care. This method enables the valuation of finds the (compensating) income necessary to maintain a caregiver's well-being constant after providing one extra hour of informal care. In doing so, it aims at capturing all the "costs" incurred by the caregiver, including not only time spent but also, for example, physical tiredness and emotional involvement.

The contributions of this chapter to the literature can be summarized as: (1) it uses a fairly new method and proves its usefulness for the valuation of informal care; (2) it provides two monetary values, depending on whether the caregiver and the care recipient are family or not; and (3) it shows that the results found are, although not very close, in line with the ones found by CV, using the same data set. As the outcomes of the two methods

are comparable, the new method is externally validated. Moreover, the chapter also shows that different type of well-being questions have only a small effect on the results, which illustrates the internal validity of the method.

This chapter shows that the main advantages of the well-being valuation method compared to CV are that it is more flexible and the well-being questions are very easy to answer for respondents (as appeared by the relatively low non-response.) The method is also very flexible in the sense that it is easy to generate different results for different subgroups and different hypotheses.

In short, this chapter shows that the well-being valuation method is a promising alternative method to value informal care in economic evaluations of health care.

# 11 The economic effects of cash benefits in the long-term care sector<sup>1</sup>

## Summary

*This chapter examines empirically the consequences for quantity and price of long-term home health care when having a transition from a system based on supply regulation towards demand-side subsidy. In the Netherlands, demand-side subsidies were introduced in 1996. Clients receive a cash benefit to purchase the type of home care (housework, personal care, support with mobility, organisational tasks or social support) they need from the care supplier of their choice (private care provider, regular care agency, commercial care agency or paid informal care provider). Furthermore, they negotiate with the care supplier about price and quantity. Our main findings are the following. 1) There is hardly any change in the composition and the amount of care purchased between both systems. 2) In a system of demand-side subsidy, the component of the cash benefit a client has no residual claimant on, has a positive impact on the price of care, although it is not clear whether the positive impact is due to a lack of bargaining power or due to ex-post moral hazard. 3) In contrast, the components of the cash benefit a client has residual claimant on, have no or a negative impact on the price of care. Both results reject a lack of bargaining power of clients, but instead they point at the existence of ex-post moral hazard in a system of demand-side subsidy.*

## 11.1 Introduction

Although home care is a crucial element of long-term care, it has not received much attention in (health) economics (McKnight, 2004). This chapter analyses empirically the consequences of the structure of the finance system for quantity and price of home care. In many countries, long-term home health care is financed and organised through a system of supplier regulation, in which (social) insurers pay providers of care directly. Clients get their care in kind from regular agencies (regular care) without having to pay for it at the point of use (except for an income-related co-payment in some cases). Furthermore, they may purchase care on the private market from independent care suppliers either on a commercial or non-commercial basis (private care) or from commercial agencies (commercial care). On top of that, they may get informal care from relatives, friends and neighbours.

---

<sup>1</sup> Based on Van den Berg, B. and Hassink, W.H.J., 2004. The economic effects of cash benefits in the long-term care sector. Submitted for publication.

Some countries have developed alternative systems of demand-side subsidies in which clients get money (cash benefits also called consumer-directed services or direct payments) to purchase the care themselves instead of getting their care in kind (in which case they do not decide about the actual transaction of home care). There are no restrictions on the type of care nor on the care supplier the clients spend the cash benefit on. In this way, rather than providers of care, clients control their own health care in terms of quality, quantity and price.

Countries that have experimented with cash benefits include Austria, France, Germany, the Netherlands, the United Kingdom, and the United States (US). For a detailed description of the programs see Tilly et al. (2000) and Tilly and Wiener (2001). All of these countries are currently in transition from a system of supplier regulation towards demand-side subsidy, except for Austria, which has a system of demand-side subsidy only. Supplier-regulation dominates the long-term care sector in the Netherlands and the US<sup>2</sup>, while demand-side subsidy dominates in France and Germany (Tilly et al., 2000, p.2) and (Tilly and Wiener, 2001, p.2). Furthermore, the health care reform proposal of the Clinton administration dismissed in 1993 contained elements of demand-side subsidy. It proposed to require all states to offer the option of demand-side subsidies to people with a disability (Tilly and Wiener, 2001).

Basically, demand-side subsidies have evolved differently across countries and states (in case of the US). Thus, in some countries clients get a cash benefit, whereas in other countries they receive a voucher. Policy makers are concerned for an uncontrolled rise of demand for long-term health care services and the concomitant rise of health care costs, especially in the case of cash benefits. (Tilly et al., 2000, p.4) Therefore, in all countries eligibility for cash benefits is based on strict rules. Thus, only people with a severe disability are eligible and there is a maximum to the number of people with a cash benefit, to the cash benefit a person may get, and to the total cash benefit budget. Despite its increasing use and popularity in many countries, empirical knowledge about the effects of cash benefits in health care on price has been absent in economic literature so far. This chapter attempts to fill part of this gap, by getting some empirical evidence about the consequences of demand-side subsidies in the long-term home care market. In this respect, the Netherlands forms a unique setting to investigate a transition from supplier regulation to demand-side subsidies. Cash benefits were introduced in the long-

term home care sector in 1996. Between 1996 and 2001, the total annual budget was limited to a maximum of five percent of the total expenditures in the long-term home care sector.

We describe the main features of the Dutch system. An independent committee determines the amount of care a client can claim legally. Clients are compulsory insured both in the system of supplier regulation and demand-side subsidy. The client can opt to get either his care in kind (supply regulation) or to receive a cash benefit to purchase the care himself (demand-side subsidy). When the client opts for a cash benefit, he will receive a sum of money that is based on the amount and types of care needed. It can be used to purchase the type and quantity of care himself for the price the client negotiates with the care suppliers of his choice.

The first implication of a demand-side subsidy is that it may lead to a different amount and/or composition of health care consumed. In particular, the client could spend the money not only on regular care, but also on informal care, care from commercial agencies, or care from private care suppliers on a commercial or non-commercial basis. In this respect, care could be provided from an additional pool of labor. For example, the client may be less embarrassed to ask people for care than in a system of supplier regulation. The first specific question of this paper is whether the transition in the system of financing care leads to a change in the composition of purchased health care. Clients in the system of demand-side subsidy could, for instance, substitute more expensive for less expensive types of care.

The second implication of a demand-side subsidy is that it could lead to a higher price of care<sup>3</sup>, *ceteris paribus*. In the Dutch system of demand-side subsidy, the cash benefit consists of three components, for which the client has different rights about the unspent residual. The client has no residual rights on the first component, the personal budget, but he is the residual claimant of the lump sum, the second component, and the income-related co-payment, the third component. All three components together will be referred to as the cash benefit.

Two price-increasing mechanisms can be distinguished. The first mechanism is that clients can negotiate about the price, but they may be insufficiently informed on this

---

<sup>2</sup> In the US, many states have experimented with demand-side subsidy, especially Arkansas, California, Colorado, Florida, Kansas, Maine, Michigan, New Jersey, Oregon, Washington, and Wisconsin (Tilly and Wiener, 2001) and (Tilly et al., 2000).

<sup>3</sup> In this chapter, we distinguish hourly and monthly prices because some clients agree on hourly and some on monthly prices with their care suppliers. Table 11.5 will present regression results of hourly and monthly prices separately. For convenience we do not distinguish them in the text of the chapter.

matter or they have not enough market power, so that they may too easily accept an offered price, which could be too high. This mechanism is reflected by the outcome that all three components of the cash benefit have a positive impact on the hourly price. Because of the difference in residual claimancy right, clients may have different incentives to spend the cash benefit's components. The second price-increasing mechanism is ex post moral hazard<sup>4</sup> because the client is no residual claimant of the personal budget (the first component). Ex post moral hazard means that consumers purchase more expensive care than they would purchase if they were the residual claimants, *ceteris paribus*. The second specific question of this paper is whether the various components of the cash benefit have an upward effect on the price, either because of a lack of price information ("bargaining power") or because of ex post moral hazard.

In addition, in a system of demand-side subsidy, quality of care could be increased because of the larger potential of care suppliers and because of an increase in consumer's market power due to the cash benefit. However, problems of validity make it impossible to investigate empirically improvements in quality. For instance, from the client's perspective care provided by lower or unskilled care suppliers could be of a higher quality, although it may lead to care of a lower quality from a health care professional point of view, for example, measured in terms of education of the provider of care (Stiglitz, 2001). Quality of care is also experienced very subjectively among consumers of care. In this paper we abstract from a change in quality.

To answer the two research questions, we will use information from two unique surveys. The first survey asked 375 clients about the amount of care they got and whether or not they received a cash benefit. The second survey contains information on 301 clients with a cash benefit, for the sub-category nursing and caring. Next to the amount and types of care they purchase, the survey provides information on the price of care and the amount of the cash benefit (for each of the three components).

The outline of this chapter is as follows. Section 11.2 describes the Dutch institutional context in more detail as well as the rules concerning cash benefits. Section 11.3 gives the empirical models to test for implications of the quantity and composition of care between the systems (sub-section 11.3.1) and the implications for the price of care in a system of demand-side subsidies (sub-section 11.3.2). Section 11.4 describes the data sets and section 11.5 discusses the estimates. The data set described in sub-section 11.4.1 (sub-

---

<sup>4</sup> For an overview of different forms of moral hazard and of empirical studies in health care, see Zweifel and Manning (2000).

section 11.4.2) and the estimates of sub-section 11.5.1 (sub-section 11.5.2) are related to sub-section 11.3.1 (sub-section 11.3.2). Section 11.6 presents conclusions.

## **11.2 Institutional setting**

Long-term care, which is an important part of the Dutch health care sector, can be distinguished into home care and institutional care. In what follows we will focus on home care. Traditionally, the home care sector was based on supplier regulation. In this system, the client gets his care in kind through professional care suppliers from an agency, so-called regular care. The market of professional home care is regulated by means of entry barriers for new agencies and maximum prices determined by the government (CTG, in Dutch "College Tarieven Gezondheidszorg"). By means of entry barriers the government controls the quality of the care provided, for instance, by requiring educational standards for the employees of the care agencies.

Long-term home care is financed by means of compulsory social insurance, but there may be an additional income related co-payment. Consequently, a substantial part of regular care is free of charge to the client in the short run. Administration and payment are arranged among health care agencies and insurers. All insurers in a region handed voluntary over their implementation tasks (such as the purchase of care) to so-called regional care-offices (in Dutch "zorgkantoor"). In practice, the dominant player in the region executes the care office. Each region has an office, referred to as regional indication organ (RIO, in Dutch "Regionaal Indicatie Orgaan"), which determines independently the amount of regular home care an insured client may claim as a result of his health problems. Next to this regular care, clients are free to hire private care in the market from independent, private care providers on a commercial or non-commercial base, or from commercial agencies. Especially in case of housework there are many market alternatives for the regular care agencies. Often clients also get informal care from family or friends. About 750,000 informal care suppliers (the Netherlands has 16 million inhabitants) provide care for more than three months per year and for more than eight hours per week and 1.3 million informal care suppliers provide care for less than eight hours per week (Timmermans, 2003). About 1.7 million informal care suppliers provide care for less than three months per year.

For various reasons there has been a tendency in the long-term care sector from supplier regulation to demand-side subsidy. In the early 1990s, the main argument of interest groups was to achieve emancipation of clients with chronic diseases. Hence, they

would control their own health care services instead of being dependent on health care professionals and their agencies. In the late 1990s, there arose the additional motives that demand-side subsidy would increase the quality of home care and that it would reduce the scarcity in health care.

Since 1996, there has been a transition from supply control towards demand-side subsidy in the Dutch home-care sector. Between 1996 and 2001, the transition was partial. Most clients received regular care in kind (supply control), but they could opt for a cash benefit (demand-side subsidy). Cash benefits covered a maximum of five percent of the total Dutch expenditures in long-term home health care. Table 11.1 shows that the annual number of cash benefits increased rapidly after the introduction in 1996 from 5,401 to over 48,000 in 2002. To give an impression of the relative importance of cash benefits in the Dutch health care system, cash benefits accounted for 3.5 percent of the total expenditures in the sector nursing and caring in 1999. This sector accounts for about 20 percent of the long-term care sector. The long-term care sector accounts for 20 percent of the total annual health care expenditures of 36 billion euro.

**Table 11.1:** Annual number of cash benefits in the Netherlands 1996-2002

	1996	1997	1998	1999	2000	2001	2002
<b>Nursing and caring</b>	4,000	6,045	7,184	9,408	16,282	26,753	34,544
<b>Psychiatrically disabled</b>	1,400	1,500	3,101	3,641	6,195	9,164	11,197
<b>Mentally ill</b>	1	100	125	120	141	608	2,203
<b>Physically disabled</b>	0	0	0	0	0	57	95
<b>Total</b>	5,401	7,645	10,410	13,169	22,618	36,582	48,039

*Source: (Tweede Kamer der Staten Generaal, Meeting year 2002-2003).*

The cash benefit is the core of the system of demand-side subsidy. It consists of three components: (1) personal budget (In Dutch "trekkingsrecht"), (2) lump sum, and (3) co-payment. The personal budget is the part of the cash benefit that the client does not get directly. The Social Insurance Bank (SVB)<sup>5</sup> manages the personal budget. A client can instruct the SVB to pay his care provider, but he has to justify the expenditures of this part of the cash benefit.<sup>6</sup> The lump sum is used to compensate the client for transaction costs (overhead, unexpected costs, and cash payments) he makes in the very short run. Clients

<sup>5</sup> The Social Insurance Bank is a social security agency.

<sup>6</sup> This was the actual situation when we collected the data between December 2001 and February 2002. From April 2003, clients get the personal budget on their bank account and manage it themselves. They have to justify

get the lump sum on their banking account, and they do not have to justify their spending afterwards. In 2001, the lump sum had a maximum of 1,089 euro annually. Finally, there is an income-related co-payment. Appendix A contains a description of the scheme.

Clients may have different attitudes as to how they spend each of the three components of the cash benefit. They may be more inclined to spend carefully the lump sum and the co-payment, as they may keep the remaining amount of money that has not been spent. In contrast, clients may be indifferent in their way of spending the personal budget, since they cannot claim the unspent residual. It may lead to moral hazard.<sup>7</sup>

The RIO determines the size of the cash benefit, using the indicated amount of care needed. In an interview with the client, the RIO determines how many hours of different care types (parts or products) per week or per month a client needs. The different products are skilled and unskilled housework, personal care, specialised personal care, nursing, and specialised nursing. A main distinction between unskilled and skilled housework is that the client is either able or unable to give housework tasks to the care supplier. For instance, when a client cannot manage his own household, he needs skilled housework which means that the house worker not just follows the client's instructions but also determines that certain tasks need to be done.

Cash benefits are distinguished into four sub-categories: Nursing and caring, Psychiatrically disabled, Mentally ill, and Physically disabled. Each of these categories has a different type of cash benefit.<sup>8</sup> The categorization is made according to the client's health problems. For example, the sub-category nursing and caring is often used for elderly or people with a chronic disease who cannot care for themselves or for their household. The sub-category psychiatrically disabled differs also from the other three types with respect to the calculation of the amount of cash benefit. The largest sub-category is nursing and caring, which accounts for about 70 percent of the total number of cash benefits (see Table 11.1).

---

their spending afterwards. Control occurs by means of random checks, since there were many complaints from clients about the way the SVB managed the personal budgets.

<sup>7</sup> Clients cannot claim the unspent residual of the personal budget, except 10% if the client also gets a cash benefit in the next period. Possible other savings are returned to the insurance company.

<sup>8</sup> The four sub-categories were mainly distinguished for bureaucratic reasons. Since 1 April 2003, the different types of cash benefit are integrated into one type of cash benefit.

## 11.3 Empirical model

### 11.3.1 Quantity of care in supplier regulation and demand-side subsidy

We will investigate whether for different types of home care the quantity of care used differs between a system of supply regulation and a system of demand-side subsidy. A system of demand-side subsidy has a larger potential supply of care because clients with a cash benefit are free to hire the care supplier of their choice instead of only regular care suppliers in the system of supply regulation. This may lead to a change in the composition of health care provided, because paid informal care or private care are probably less expensive than regular care.

Below, we distinguish between informal care, regular care, and private care (an independent worker on a commercial or non-commercial basis), which will be abbreviated by IC, RC, and PC, respectively. Clients can get different types of care simultaneously. For each of the types of care we will specify a separate regression equation. The dependent variable  $Q_z$  is the quantity of care in hours per week of type  $z$  ( $z = IC, RC, PC$ , respectively). In particular, we are interested in the influence of the independent variable DCB, which is a dummy variable for cash benefit, on  $Q_z$ . DCB is a proxy variable for the system: Supplier regulation versus demand-side subsidy (DCB = 1 if in the system of demand-side subsidy (cash benefit) and 0 if in the system of supplier regulation (no cash benefit)). The regression equations are:

$$(1) \quad Q_{z,i} = \alpha_z * DCB_i + \beta_z' X_i + \varepsilon_i \quad z = IC, RC, PC; i = 1, \dots, n$$

where  $X$  is a vector that includes observed characteristics of the client. Subscripts  $i$  and  $z$  refer to the  $i$ -th individual client and the  $z$ -th type of care, respectively.  $\alpha_z$  is a parameter and  $\beta_z$  is a vector of parameters. Finally,  $\varepsilon$  is an i.i.d. stochastic error term.

We will estimate equations (1) as a Tobit model. The control variables in  $X$  are age, gender, (the logarithm of) net monthly household income, marital status, education, and type of care (distinguished by housework, personal care, support with mobility, organisational tasks, and social support).

With regression equations (1) we can test whether there are differences in terms of quantity of care used between the system of demand-side subsidy and the system of supplier regulation for the three different types of care, respectively. Therefore, we are

interested in the sign of  $\alpha_z$  in particular. A positive sign of  $\alpha_z$  indicates that clients use relatively more care of type  $z$  in the system of demand-side subsidy compared with clients in the system of supplier regulation, *ceteris paribus*.

### 11.3.2 Price of care in demand-side subsidy

Next, we will investigate the factors that influence price of care in a system of demand-side subsidy. In our period of investigation, there were shortages in the supply of home care. Hence, we would expect prices to rise in a situation of excess demand. Furthermore, the hourly and monthly price of care depends on the type of home care indicated. An empirical analysis has to control for both influences.

Then, we will focus on the effect of the three components of the cash benefit (personal budget, co-payment, and lump sum) on price. All clients receive a cash benefit in the system, for which they may decide how to spend it on what type and amount of care. For clients it may be difficult to negotiate about the price. Thus, we would expect a positive impact on the price for all three components of the cash benefit. In a system of supplier regulation this mechanism is absent as the clients do not need to negotiate about price (except for purchased care in the private market from independent workers).

Furthermore, the clients' incentives differ for different components of the cash benefit. Clients may keep both the unspent lump sum and the unspent income-related co-payment. For both components the incentive system may lead to lower prices, *ceteris paribus*. Clients are not allowed to keep the unspent part of the component of the cash benefit, *viz.* the personal budget. Consequently, a personal budget may lead to *ex post* moral hazard. With a higher personal budget, clients may consume care at higher prices, *ceteris paribus*. We test for moral hazard by measuring the impact of the size of the personal budget on price.

The second regression equation is a price equation. We specify the dependent variable as the logarithm of the mean price ( $P$ ), which is weighed for the different types of care received.

$$(2) \quad \text{Log}(P_i) = \gamma_1 * \text{Log}(PB_i) + \gamma_2 * \text{Log}(CP_i) + \gamma_3 * \text{Log}(For_i) + \lambda' X_i + \epsilon_i \quad i = 1, \dots, n$$

The three components of the cash benefit, the size of the personal budget, income-related co-payment and lump sum, are represented by the variables  $PB$ ,  $CP$  and  $For$  (all of them are in logarithms).  $\gamma_k$ ,  $k=1,2,3$ , are parameters and  $\lambda$  is a vector of parameters.

$X$  is a vector of control variables. In addition to the control variables in equation (1),  $X$

contains the indicated amount of care (distinguished by housework (skilled and unskilled), personal care, specialised personal care, and nursing per week) and the availability of care (regular and commercial).

With equation (2) we can test for two price-raising mechanisms of the cash benefit. First, a positive  $\gamma_k$  jointly for all components of the cash benefit ( $k = 1,2,3$ ) indicates that clients lack bargaining power. A higher budget will be used to purchase care at a higher price, *ceteris paribus*.

For the second mechanism, there will be an indication of moral hazard when  $\gamma_2$  and  $\gamma_3$  become negative, while  $\gamma_1$  remains positive. A positive sign of  $\gamma_1$  means that clients may pay a higher price when they are not the residual claimant of the unspent personal budget. In contrast,  $\gamma_2$  and  $\gamma_3$  are non positive, since clients are the residual claimant of the two remaining components of the cash benefit. Hence, there is an incentive to spend their money carefully.

## 11.4 Data

### 11.4.1 Data set 1: Supply regulation and demand-side subsidy

We will use data set 1 to estimate equation (1). It consists of both clients in the system of supplier regulation who get their care in kind and clients in the system of demand-side subsidy who receive a cash benefit. Clients in the latter system could get the four types of cash benefit as described in Table 1. We collected the data between October and December 2001. The sample was reached through the primary informal care suppliers of clients with long-term care demand. We reached the informal care suppliers via Dutch regional support centres for informal care providers and we approached 59 regional centres, of which 40 centres were willing to participate to our survey. The informal care providers handed over a survey to the people they care for, with the request to participate in the research. The questions posed to the care recipients had a broader scope than just the care provided by the informal caregiver who handed over the survey. This approach is the only way to obtain a heterogeneous sample of clients (in terms of disease characteristics) who use a substantial amount of long-term health care in the Netherlands. Alternatives like disease-specific groups or a sample from the Dutch population will not ensure to get such a sample. Our way of sampling implies that we selected from a population of clients with a higher demand of long-term home care. Presumably, informal

care suppliers that provide care for clients with intensive long-term home care register themselves by the regional support centres.

We distributed 3258 postal surveys via these centres. 875 informal care suppliers and 552 clients responded to the survey.<sup>9</sup> In the empirical analysis, we will use a net sample of 375 clients, for whom we have information on relevant variables. Data set 1 contains information on the type of long-term home health care clients use, distinguished by housework, personal care, support with mobility, organisational tasks, and social support. It contains also information on the amount of care clients get from different care suppliers, informal care suppliers (family and friends), regular care supplier providing professional care, and private care supplier, respectively. It is noteworthy that there are a few commercial agencies in the Netherlands that have a licence to provide regular care. However, clients in the system of supply regulation might have difficulties in making a distinction between regular care from regular agencies versus commercial agencies. Therefore, we did not distinguish between both agencies in data set 1. Other observable characteristics of the clients we will use in our analysis are the socio-demographic characteristics age, marital status, gender, and net monthly household income. Clients were not inquired about the price of care or about further details of the cash benefit. These issues were investigated in greater detail with our second sample that we will discuss in the next sub-section.

For the variables of data set 1 that we used in the empirical analysis we report the mean and standard deviation (of the mean), see Table 11.2. The mean age of the clients is 67 years, which is relatively high. This is not surprising, because elderly clients use long-term care relatively often. Women include 53 percent of the clients. A majority of clients is married (65 percent). 86 percent of the clients report that they use informal care for on average 25 hours per week. However, we reached the clients by way of their informal care suppliers. Therefore, one could argue that all clients use informal care. It could however be that since the informal care was temporary, some clients did not use informal care during the period of investigation. Many clients use regular care (40 percent) for on average 1 hour per week. It is striking that 23 percent of the clients use also private care (for 0.77 hours per week). Apparently, clients use relatively more informal care than regular and private care.

---

<sup>9</sup> In this paper we will not use the information of the informal care suppliers.

**Table 11.2:** Descriptive statistics of first data set (net sample) and clients distinguished by cash benefit

Variables	Net sample		Clients with cash benefit		Clients without cash benefit	
	Mean	Standard deviation of mean	Mean	Standard deviation of mean	Mean	Standard deviation of mean
Dummy cash benefit (no = 0; yes = 1)	0.14	0.02				
Age (in years)	66.80	0.86	59.17	2.48	68.03	0.89
Dummy gender (man = 0; woman = 1)	0.53	0.03	0.58	0.07	0.52	0.03
Net monthly household income (in euros)	1,351.4	33.45	1,507.5	96.12	1,326.	35.48
Dummy married (unmarried = 0; married = 1)	0.65	0.02	0.69	0.06	0.64	0.03
Education (in years)	11.93	0.17	12.87	0.46	11.78	0.18
Care supplier:						
Dummy informal care (informal care = 1; elsewhere = 0)	0.86	0.02	0.87	0.05	0.86	0.02
Dummy regular care (regular care = 1; elsewhere = 0)	0.40	0.03	0.37	0.07	0.41	0.03
Dummy private care (private care = 1; elsewhere = 0)	0.23	0.02	0.35	0.07	0.21	0.02
Hours of informal care per week	24.86	1.43	31.96	4.81	23.71	1.46
Hours of regular care per week	0.97	0.11	0.96	0.39	0.97	0.12
Hours of private care per week	0.77	0.18	1.13	0.38	0.72	0.20
Type of care:						
Dummy housework (housework = 1; elsewhere = 0)	0.77	0.02	0.79	0.06	0.77	0.02
Dummy personal care (personal care = 1; elsewhere = 0)	0.59	0.03	0.69	0.06	0.57	0.03
Dummy support with mobility (support = 1; elsewhere = 0)	0.57	0.03	0.60	0.07	0.56	0.03
Dummy organisational tasks (organisational tasks = 1; elsewhere = 0)	0.67	0.02	0.65	0.07	0.67	0.03
Dummy social support (social support = 1; elsewhere = 0)	0.70	0.02	0.67	0.07	0.71	0.03
Dummy client on waiting list (on waiting list = 1; not = 0)	0.04	0.01	0.02	0.02	0.04	0.01
Number of clients	375		52		323	

The incidence of various types of care ranges from 57 percent (support with mobility) to 77 percent (housework). Finally, just 4 percent of the clients are on a waiting list for regular care.

In our period of investigation, in the Netherlands the majority of clients received home care in kind and are consequently in the system of supply regulation. In the net sample, 52 respondents (14 percent of the clients) received a cash benefit.<sup>10</sup> From the 323 respondents without a cash benefit, 291 respondents answered a question about the reason for not applying for a cash benefit. The reasons why they did not apply for a cash benefit include: they were not aware of it (39.9 percent), they expected that they were not eligible to it (in terms of seriousness of the health problem) (21.2 percent), they could not give any reason (14.4 percent), they expected too much bureaucracy (13.1 percent), a cash benefit is not a good service (4.1 percent), and other reasons (7.4 percent).

Table 11.2 gives also the descriptive statistics for the sub-categories of clients with a cash benefit and without a cash benefit. The main statistically significant difference between the means of both groups is that clients with a cash benefit are almost ten years younger compared with the remaining clients.

### **11.4.2 Data set 2: Demand-side subsidy**

We used information from the second data set to estimate equation (2). In this data set, all clients are in the system of demand-side subsidy, since they all receive a cash benefit. Another important difference with the first data set is that the second data set contains information on the price of care, the three components of the cash benefit and the amount of care purchased from commercial agencies.<sup>11</sup>

We reached the respondents through Per Saldo, which is the Dutch association for people who receive a cash benefit. Between December 2001 and January 2002, we sent a postal survey to 3,000 people with a cash benefit. 609 respondents with a cash benefit returned a completed survey. There are no reasons to assume that the members of Per Saldo are not representative for the whole population of clients with a cash benefit in The Netherlands in the period of our investigation.

The second data set gives detailed information on clients' cash benefits. In order to have a more or less homogenous group of clients with the same type of cash benefit, we used

---

<sup>10</sup> This is irrespective of the four types of cash benefit (such as distinguished in Table 11.1).

<sup>11</sup> This differs from data set 1. The reason is that in contrast to clients in a supplier-regulated system, clients with a cash benefit are better able to distinguish between regular and commercial agencies since they purchase the care themselves.

clients from the category Nursing and caring. 404 out of 609 respondents were clients with a cash benefit Nursing and caring. The net sample of clients with a cash benefit Nursing and caring consists of 301 respondents<sup>12</sup>. We used the net sample in the empirical analysis.

Table 11.3 gives the descriptive statistics of the variables that was used as a control variable in the regression equation (2).

**Table 11.3:** Descriptives of data set 2: clients with a cash benefit for Nursing and caring

Variables	Hourly price		Monthly price	
	Mean	Standard deviation of mean	Mean	Standard deviation of mean
Hourly price of care (in euros)	18.91	1.05		
Monthly price of care (in euros)			1,401.24	227.99
Monthly personal budget (in euros)	1,254.10	108.10	1,226.93	123.21
Monthly co-payment (in euros)	119.42	9.99	118.66	11.14
Monthly lump sum (in euros)	157.29	17.79	143.27	19.39
Age (in years)	52.64	1.33	53.83	1.45
Dummy gender (woman = 1; man = 0)	0.24	0.03	0.22	0.04
Net monthly household income (in Euros)	1,603.01	58.00	1,693.76	66.36
Dummy married (married = 1; unmarried = 0)	0.68	0.04	0.69	0.04
Education (in years)	12.66	0.26	13.12	0.30
<u>Care supplier:</u>				
Proportion informal care	0.62	0.03	0.56	0.03
Proportion regular care	0.03	0.01	0.02	0.01
Proportion commercial care	0.13	0.02	0.15	0.03
Proportion private care	0.22	0.02	0.26	0.03
Hours of informal care (per week)	7.40	1.02	6.78	1.21
Hours of regular care (per week)	0.19	0.08	0.08	0.03
Hours of commercial care (per week)	1.56	0.59	1.35	0.31
Hours of private care (per week)	2.29	0.32	2.22	0.32
<u>Type of care:</u>				
Dummy housework (housework = 1; elsewhere = 0)	0.98	0.01	0.97	0.02
Dummy personal care (personal care = 1; elsewhere = 0)	0.69	0.04	0.67	0.04
Dummy support with mobility (support with mobility = 1; elsewhere = 0)	0.68	0.04	0.68	0.04

*Continued on the next page*

12 172 clients pay their care suppliers on an hourly basis and 129 on a monthly basis. Clients are free to agree on the payment with their care suppliers.

Variables	Hourly	Monthly		Standard deviation of mean
	price	price	Standard deviation of mean	
	Mean	Standard deviation of mean	Mean	Standard deviation of mean
Dummy organisational tasks (organisational tasks = 1; elsewhere = 0)	0.47	0.04	0.46	0.04
Dummy social support (social support = 1; elsewhere = 0)	0.57	0.04	0.60	0.04
<i>Indicated hours of care (per week):</i>				
Hours of skilled housework	5.47	0.43	4.87	0.48
Hours of unskilled housework	1.01	0.20	1.11	0.21
Hours of personal care	4.67	0.66	4.69	0.83
Hours of specialised personal care	0.23	0.14	0.11	0.11
Hours of nursing	2.25	0.45	1.66	0.37
Hours of specialised nursing			0.27	0.19
Non-availability regular care (no = 0; yes = 1)	0.17	0.03	0.16	0.03
Non-availability commercial care (no = 0; yes = 1)	0.35	0.04	0.43	0.04
Hours of purchased care (per week)	11.39	1.20	10.43	1.29
Number of clients	172		129	

There are no striking differences between the clients who pay their care recipients per hour or per month. We compare the descriptives of the variables in the net second sample with those of the clients in the first data set who received a cash benefit (see fourth column of Table 11.2). It is noteworthy that the amount of regular care in Table 11.2 can be compared with the sum of regular care and commercial care in Table 11.3, because we did not distinguish between both types of care in data set 1. For the sample of Table 11.2, informal care is given for on average 32 hours per week, whereas in the second data set informal care is given for on average about 7 hours per week. The reason for this difference is that the first data set was collected through informal caregivers connected to an interest group. It is likely that they, therefore, provide more informal care than the average informal caregiver in the Netherlands. Table 11.3 gives the proportions of purchased care. This is because we wish to correct for composition effects in equation (2). Moreover, the incidence of housework is somewhat higher in the second data set, while the incidence of support with mobility, organisational tasks and social support is somewhat lower.

Some variables of the second data set (Table 11.3) are not available in the first data set. The hourly price of care is on average 18.91 euro<sup>13</sup> and the mean monthly price is 1,401 euro. The monthly personal budget is about 1,240 euro, whereas the co-payment (about 118 euro) and the lump sum (about 150 euro) are substantially smaller. Clients paying their care suppliers on a monthly basis, spend on average 1,401.24 euro per month. This is 174.31 euro more than their monthly personal budget on which they do not have any residual claimant right. But the sum of their monthly personal budget, co-payment and lump sum is 1,488.86 euro. So, the clients spend on average 87.62 euro less on care than the care they need according to their indication.<sup>14</sup> On average, the clients purchase around 10 hours of care per week.

For the various types of care, the indicated numbers of hours are on average around 5 (housework, skilled), 1 (housework, unskilled), 4.5 (personal care), 0.15 (specialised personal care), 2 (nursing), and 0.27 (specialised nursing). Note that the sum of these components is almost 13 hours a week, which is higher than the average number of hours purchased. The dummies indicating scarcity are defined as that a client attempts to get care from an agency for regular or commercial care, but that this type of care is not available yet.

## 11.5 Estimates

### 11.5.1 Quantity of care in supply and demand-side subsidy

This sub-section gives the estimates of equations (1), using the data set discussed in Sub-section 11.4.1. Equations (1) are estimated for private care, regular care, and informal care separately. We will use a Tobit-model, in which we take the number of hours of care as dependent variable.<sup>15</sup> Table 11.4 presents the results.

In particular, we are interested in the effect of the cash benefit on the different types of care. For private care, the estimated coefficient on the dummy for cash benefit is positive and differs statistically from zero at the 10%-level only, whereas for the other types of care the estimated coefficients on the cash benefit are not significant.

---

<sup>13</sup> We constructed the mean hourly price of home care as follows: Hourly price =  $\sum_z p_z \cdot (q_z / (\sum_z q_z))$ , where  $p_z$  is hourly price of care type  $z$  and  $q_z$  is quantity of care of type  $z$ .

<sup>14</sup> It is not possible to do the same calculations for clients paying their care suppliers on an hourly base, because there could be a lot of variation in the amount of supplied care per week while questions were just asked regarding the last week and not regarding the last month.

<sup>15</sup> We also estimated a Tobit-model for the amounts of informal, regular and private care respectively, where the dependent variable was a log transformation of the hours of care. Our main conclusions are unaffected by this transformation.

**Table 11.4:** Tobit regressions of equation (1); dependent variable: number of hours of care per week<sup>a)</sup>

Dependent variable: Independent variables	Informal care		Regular care		Private care	
	Coef.	t-value	Coef.	t-value	Coef.	t-value
Dummy cash benefit (no = 0; yes = 1)	5.57	1.29	-0.55	-0.57	4.09	1.65
Age (in years)	-0.06	-0.66	0.03	1.41	0.04	0.76
Dummy gender (woman = 1; man = 0)	-4.88	-1.56	0.61	0.84	1.79	0.92
Log(net monthly household income)	5.74	1.45	-1.18	-1.27	8.53	3.29
Dummy married (unmarried = 0; married = 1)	6.12	1.61	-0.57	-0.66	-4.97	-2.13
Education (in years)	0.05	0.09	0.24	1.96	-0.12	-0.35
<u>Type of care:</u>						
Dummy housework (housework = 1; elsewhere = 0)	14.65	3.61	1.76	1.74	11.92	3.19
Dummy personal care (personal care = 1; elsewhere = 0)	10.46	3.27	4.74	5.59	-2.29	-1.13
Dummy support with mobility (support with mobility = 1; elsewhere = 0)	7.09	2.08	-1.28	-1.60	3.46	1.54
Dummy organisational tasks (organisational tasks = 1; elsewhere = 0)	12.65	3.39	-0.09	-0.10	2.14	0.88
Dummy social support (social support = 1; elsewhere = 0)	19.53	4.95	0.09	0.10	-2.61	-1.02
Standard error of regression	26.52		4.89		10.78	
Pseudo R <sup>2</sup>	0.05		0.06		0.07	
Number of clients	375		375		375	

<sup>a)</sup> Estimates are based on the first data set discussed in Sub-section 4.1.

Hence, there are hardly any differences in the composition of care between the system of supplier regulation and the system of demand-side subsidy. Furthermore, we found that additional education involves more use of regular care. An increase in household income leads to more private care purchased. Finally, unmarried people use more private care than married people.

### 11.5.2 Prices in demand-side subsidy

This sub-section presents the estimates of equation (2), using the second data set. We are especially interested in the effects of the (logarithm of the) three components of the cash benefit on the (logarithm of the) price. Table 11.5 gives the estimated coefficients for the hourly and monthly price separately.

**Table 11.5:** OLS regression of equation (2) with robust standard errors; dependent variables: log (hourly price) and log (monthly price)<sup>a)</sup>

Dependent variable Independent variables:	Log (hourly price)		Log (monthly price)	
	Coefficient	t-value	Coefficient	t-value
Log cash benefit	0.19	3.07	0.66	4.98
Log co-payment	-0.03	-0.94	0.02	0.21
Log lump sum	0.04	0.72	-0.46	-4.64
Age (in years)	0.00	-0.96	0.00	0.14
Dummy gender (woman = 1; man = 0)	-0.01	-0.06	0.45	1.50
Log household income	-0.03	-1.03	-0.13	-1.52
Dummy married (unmarried = 1; married = 0)	-0.15	-1.14	-0.06	-0.29
Education (in years)	-0.01	-0.65	0.03	1.00
<u>Care supplier:</u>				
Proportion informal care (ref. = proportion commercial care)	-0.94	-3.62	-0.55	-1.24
Proportion regular care (ref. = proportion commercial care)	-0.34	-0.96	-0.59	-0.31
Proportion private care (ref. = proportion commercial care)	-0.44	-2.04	-0.19	-0.51
<u>Type of care:</u>				
Dummy housework (housework = 1)	-0.40	-1.05	-0.64	-1.71
Dummy personal care (personal care = 1)	-0.05	-0.35	-0.39	-1.26
Dummy mobility outside (mobility outside = 1)	-0.22	-1.49	-0.20	-0.65
Dummy organisational tasks (organisational tasks = 1)	-0.20	-1.57	-0.32	-1.54
Dummy social care (social care = 1)	-0.33	-2.58	-0.29	-1.50

*Continued on the next page*

Dependent variable	Log (hourly price)		Log (monthly price)	
	Coefficient	t-value	Coefficient	t-value
<i>Indicated hours of care (per week):</i>				
Log indicated hours housework (skilled) per week	0.08	1.34	-0.17	-1.47
Log indicated hours housework (unskilled) per week	0.00	0.05	0.16	1.37
Log indicated hours personal care per week	0.02	0.43	0.11	0.97
Log indicated hours specialised personal care per week	0.29	2.14	0.40	2.34
Log indicated hours nursing per week	0.25	3.72	-0.07	-0.38
Log indicated specialised nursing			-0.61	-1.39
Availability regular care (yes = 1)	-0.01	-0.09	-0.35	-0.99
Availability commercial care (yes = 1)	-0.10	-0.70	-0.21	-1.01
Constant	3.36	4.64	6.59	5.18
Standard error of regression				
Number of clients	172		129	
R <sup>2</sup>	0.48		0.53	

<sup>a)</sup> Estimates are based on the second data set discussed in Sub-section 4.2.

The clients are no residual claimant for the component personal budget. Definitely, for this component the cash benefit has a positive impact on the price of care. For the equation estimated with hourly prices, the estimated coefficient on the logarithm of personal budget has a value of 0.19 and is significantly different from zero at the 1 percent level (for the estimate with monthly prices the coefficient becomes 0.66). Its value implies that a 1 percent increase in the personal budget leads to a 0.19 percent higher hourly price of care. Notice that the hourly price is 18.91 euro and the monthly personal budget is 1254.10 euro on average (Table 11.3).

For the two remaining components for which the client is a residual claimant we get the following estimation results. The estimated coefficients on the income-related co-payment are statistically insignificant, while the coefficient on the lump sum is statistically insignificant in the hourly price equation but statistically significant and negative in the monthly price equation.

Since we do not find positive coefficients for all three components jointly we can conclude that clients do not lack bargaining power. Instead the estimates point at the prevalence of ex-post moral hazard.

There is some evidence that for the hourly price equation the proportion of paid informal care and private care seems to have a downward effect on the hourly price, relative to the proportion of commercial care. For two types of care (specialised personal care and nursing in the hourly price equation) the number of indicated hours has an upward effect on the price. Two dummy variables indicating scarcity of care (regular and commercial care) seem to have no influence on the hourly prices paid.

## **11.6 Conclusion**

In this chapter we have investigated empirically the transition of a system of supplier regulation in long-term home care towards a system of demand side subsidy. Our main conclusions are twofold.

First, with respect to the quantity of care, our estimates show hardly any difference in the composition and quantity of care between both systems. This is remarkable, as one would expect there is more informal care in a system of demand-side subsidy.

Second, with respect to the price of home care, we find indication of an upward effect from the component of the cash benefit for which the client is no residual claimant. In contrast, for the two remaining components we find no indication of an upward effect on the price of home care. These outcomes reject the hypothesis that in a system of demand side subsidy clients have a lack of bargaining power. Instead, the estimates indicate that there is some ex-post moral hazard in a system of demand side subsidy.

## Appendix A

### Cash benefit co-payments

Income related co-payments cash benefits.

**Your age is 65 years or older. Below, you will find below your maximum weekly co-payment.**

The co-payment will be calculated over the gross family income. The maximum hourly co-payment is € 4.60.

Gross family income in 2001 in categories	Living together or being married Maximum per week	Single person household Maximum per week
To €12,526	€ 2.20	€ 2.20
From €12,526 to €16,182	€ 3.00	€ 7.00
From €16,182 to €18,270	€ 10.80	€ 25.80
From €18,270 to €20,880	€ 29.60	€ 40.00
From €20,880 to €25,056	€ 59.00	€ 61.20
From €25,056 to €40,718	€ 89.60	€ 103.80
From €40,718	€ 118.00	€ 129.80

**Your age is between 18 and 65 years. Below, you will find below your maximum weekly co-payment.**

The co-payment will be calculated over the gross family income. The maximum hourly co-payment is € 4.60.

Gross family income in 2001 in categories	Living together or being married Maximum per week	Single person household Maximum per week
To €15,138	€ 2.20	€ 2.20
From €15,138 to €19,316	€ 3.00	€ 7.00
From €19,316 to €22,970	€ 10.80	€ 25.80
From €22,970 to €26,624	€ 29.60	€ 40.00
From €26,624 to €31,844	€ 59.00	€ 61.20
From €31,844 to €48,550	€ 89.60	€ 103.80
From €48,550	€ 118.00	€ 129.80



# 12 The psychological effects of the monetarisation of informal care<sup>1</sup>

## Summary

*The increasing use of cash benefits in the long-term care sector enables clients to hire their informal caregivers. However information about the psychological effects of paying informal caregivers is lacking. This chapter examines empirically the psychological consequences of the monetarisation of informal care. We find that (1) paying informal caregivers involves no negative psychological effects, and (2) informal caregivers who are paid are more likely to state that caring is important to them. Results imply that paying informal caregivers with cash benefits involves no negative external effects in terms of psychological consequences.*

## 12.1 Introduction

Informal care is crucial for the long-term care sector (Van Houtven, 2000). In many countries, informal caregivers are responsible for the majority of home care provided to people with chronic diseases, or terminally ill people (Van den Berg, 2004), and many elderly. They get support from informal caregivers with, for example, housework, organisational and administrative tasks, or personal care. Providing informal care involves opportunity costs in terms of wages, and career opportunities forgone, and it may also increase morbidity and in some sub populations even mortality risks (Ettner, 1996), (Carmichael and Charles, 1998), (Carmichael and Charles, 2003), and (Schulz and Beach, 1999). There is an increasing volume of health and social policy literature on the position of informal caregivers (Timmermans, 2003). The main focus of this literature is on the effects of different ways to support informal caregivers. Partly based on the recommendations formulated in this literature, policy makers spend money from the health or social budget on the support given by informal caregivers.

In some countries it is possible to give informal caregivers a monetary compensation for their activities. This because long-term care is increasingly organised by means of cash benefits, also called consumer-directed services, direct payments or personal budgets. A cash benefit is a sum of money for a client to purchase care with instead of getting care in kind. Clients may use the cash benefit to purchase the amount and type of

---

<sup>1</sup> Based on Van den Berg, B., 2004. The psychological effects of the monetarisation of informal care. Submitted for publication.

care they want from the care provider of their choice for the price they negotiate. Care includes regular care from a professional agency, private care (both on a commercial or non-commercial basis) or informal care. In this way, clients rather than providers of care control their health care in terms of quality, quantity and price.

Countries that have experimented with cash benefits include Austria, France, Germany, the Netherlands, the United Kingdom, and the United States. See for detailed descriptions of their programs Tilly et al. (2000) and Tilly and Wiener (2001). Differences between the programs include policy makers' concern for an uncontrolled rise of demand for health care services and the concomitant rise of health care cost (Tilly et al., 2000). Therefore, in all countries eligibility for cash benefits is based on strict rules. Thus, only people with a severe disability are eligible and there is a maximum to the number of people with a cash benefit, to the cash benefit a person may get, and to the total cash benefit budget. Finally, not all programs allow clients to hire informal caregivers with cash benefits, because policy makers are afraid of a substitution effect of free informal care with paid informal care.

Paying informal caregivers for (part of) their care provided has as yet not been, as far as we are aware of, debated or analysed. This may be because informal care is often defined as unpaid care (Timmermans et al., 2004) and (Van den Berg et al., 2004). Chapter 3 argued that paid informal care is still informal care as long as an informal caregiver would not be willing to provide the same care to someone outside of his social environment for a similar compensation as he receives now.

It is argued that paying informal caregivers will cause their motivation to decline and involves crowding out effects (Timmermans, 2003). But there is no evidence to that effect; increasing the use of cash benefits in health care implies that informal caregivers more often get a monetary compensation for their efforts. Despite this increasing use and popularity of cash benefits in many countries and the importance of informal care in long-term care, empirical knowledge about the psychological effects of hiring informal caregivers with cash benefits in health care has been absent in the economic literature so far. The aim of this paper is to investigate empirically the psychological consequences of hiring informal caregivers with cash benefits.

The Netherlands is a unique setting to investigate the effects of paying informal caregivers. Cash benefits (in Dutch called 'personal budgets') were introduced in the long-term home care sector in 1996. Between 1996 and 2001, the total annual budget was limited to at maximum of 5 percent of the total expenditures in the long-term home care

sector. The main features of the Dutch system are as follows. An independent committee determines the amount of care a client is legally entitled to. The client can opt either to get his care in kind or to receive a cash benefit to purchase the care himself. A client who opts for a cash benefit will receive a sum of money that is based on the amount of care needed. It can be used to purchase the type and quantity of care himself from the care supplier of his choice, including informal caregivers. The client may negotiate about the price with the potential care supplier. Because the Dutch long-term care is in transition from a supplier regulated towards a demand-oriented system, clients can opt for care in kind or for a cash benefit they are free to spend as they like. This transition and freedom of choice constitute an ideal context to test for the psychological effects of paying informal caregivers.

We use information from a unique survey involving 522 informal caregivers. All of their care recipients get a cash benefit. Approximately half of the sample gets paid from the cash benefit. The survey also collected information on the psychological effects of informal caregiving, socio-demographic variables, and informal care characteristics.

The outline of this chapter is as follows. Section 12.2 describes the survey questions and the econometric model. The data collected are presented in section 12.3 and section 12.4 presents the estimates. Finally, section 12.5 discusses the estimations and policy implications.

## **12.2 Method**

### **12.2.1 Survey**

We conducted a survey among 522 informal caregivers. Questions that are central in the present study concern the payment of informal caregivers, psychological effects regarding the provision of informal care, and independent variables of informal caregivers and informal caregiving.

As to the payment of informal caregivers, the survey contains questions about whether or not informal caregivers get money for the informal care they provide, and, if so, how much money they get per month.

As to the psychological effects of informal caregiving, informal caregivers were asked about their attitude towards the provision of informal care. In psychology this subject comes under the heading of subjective burden (Kramer, 1997). We use questions from the Caregiver Strain Index (CSI) (Van Exel et al., 2004) and the Caregiver Reaction Assessment Scale (CRA) (Jacobi et al., 2003). Figure 12.1 gives the exact phrasing of the subjective burden questions in the survey.

**Figure 12.1:** Survey questions

Questions:

- 1) My care recipient appreciates my care efforts
- 2) Our emotional relationship has changed due to my care provision
- 3) I enjoy caring for my care recipient
- 4) Caring for my care recipient is important to me

Answer categories:

Yes/No

Other questions regarding the provision of informal care concern the amount of time informal caregivers spent on providing care in the week preceding the interview, the number of years they have already provided care, and the number of days a week they provide care, if they share the same household with the care recipient. They are also asked about their social relationship with the care recipient and socio-economic and demographic characteristics. Finally, caregivers are asked about the diseases of the care recipients and whether they suffer from a disease themselves. The latter is of importance because it is well-known that providing informal care may go at the costs of one's own health (Schulz and Beach, 1999) and, health problems of informal caregivers may cause psychological problems that need to be corrected for.

### **12.2.2 Econometric model**

It has been argued in the policy oriented literature that the payment of informal caregivers will crowd out their motivation and their self-esteem derived from the provision of informal care (Timmermans, 2003). We will investigate empirically whether and how the payment of informal caregivers influences their attitude towards the provision of informal care.

In our regression model, the dependent variable  $A_z$  is the informal caregiver's attitude towards the provision of informal care, where  $z$  ( $z = 1, \dots, 4$ ) represents to the four psychological attitude questions. The independent variable DPC is a dummy variable for the payment of informal caregivers (DPC = 1 if the informal caregivers get money and 0 if not). The regression equation is:

$$(1) \quad A_{z,i} = \alpha_z * DPC_i + \beta_z' X_i + \epsilon_i \quad z = 1, \dots, 4; i = 1, \dots, n$$

where  $X$  is a vector that includes observed characteristics of the client. Subscript  $i$  refers to the  $i$ -th individual client,  $\alpha_z$  is a parameter and  $\beta_z$  is a vector of parameters. Finally,  $\epsilon$  is an i.i.d. stochastic error term.

We will estimate the four equations (1) as a probit model. With regression equation (1) we can test whether there are differences in terms of psychological attitude towards the provision of informal care between caregivers who get money and caregivers who don't get money for the care they provide. Therefore, we are particularly interested in the sign of  $\alpha_z$ . A positive and statistically significant sign of  $\alpha_z$  ( $z = 1, \dots, 4$ ) indicates that informal caregivers who get paid have a relatively higher probability of giving a positive answer on the relevant psychological attitude question compared with informal caregivers who do not get paid.

We also estimate a similar equation with a continuous variable instead of the dummy variable  $DPC$  to test for the influence of the magnitude of the payment on the informal caregiver's psychological attitude towards the provision of informal care. This regression equation is:

$$(2) \quad A_{z,i} = \beta_z * \text{Log}(PC+1)_i + \beta_z' X_i + \epsilon_i \quad z = 1, \dots, 4; i = 1, \dots, n$$

where  $PC$  is the monthly amount of money the informal caregiver receives for his care tasks. A positive and statistically significant sign of  $PC$  indicates that  $A$  is positive, and a statistically significant sign of  $\beta_z$  ( $z = 1, \dots, 4$ ) indicates that informal caregivers who get paid more have a higher probability of having a positive attitude towards the psychological attitude question compared with informal caregivers who get paid less. In section 4 we will present estimates of equations (1) and equations (2).

## 12.3 Data

### 12.3.1 Data collection

We reached the respondents through Per Saldo, which is a Dutch association for people who receive a cash benefit. Between the end of 2001 and the beginning of 2002, we sent a postal survey to 3000 people with a cash benefit. This survey included a questionnaire for the informal caregiver and we asked them to give the questionnaire to their most important

informal caregiver, if available. 609 people with a cash benefit and 522 of their informal caregivers returned a completed survey<sup>2</sup>. There are no reasons to assume that the members of Per Saldo are not representative for the whole population of clients with a cash benefit in The Netherlands in the period of our investigation.

### 12.3.2 Descriptives

Table 12.1 gives the descriptives of the gross and net sample of informal caregivers.

**Table 12.1:** Gross and net sample

	Gross sample			Net sample	
	N	Mean	St. Dev.	Mean	St. Dev.
<b>Dependent variables</b>					
Question 1 (yes = 1)	503	0.84	0.36	0.84	0.37
Question 2 (yes = 1)	498	0.33	0.47	0.34	0.47
Question 3 (yes = 1)	501	0.90	0.30	0.91	0.29
Question 4 (yes = 1)	506	0.93	0.26	0.93	0.25
<b>Independent variables</b>					
<i>Payment of informal caregivers</i>					
Dummy payment (yes = 1)	499	0.56	0.50	0.52	0.50
Monthly amount of payment in euro	474	283.12	568.88	290.38	570.98
<i>Socio-economic and demographic variables</i>					
Dummy gender (male = 1)	522	0.36	0.48	0.39	0.49
Age	516	49.69	19.53	47.70	11.78
Dummy married (yes = 1)	522	0.82	0.38	0.86	0.35
Dummy children (yes = 1)	522	0.78	0.41	0.79	0.41
Net monthly income in euro	522	1634.30	778.77	1725.85	729.53
Education in years	522	13.45	3.30	13.79	3.12
Dummy paid work (yes = 1)	522	0.47	0.50	0.48	0.50
<i>Informal care variables</i>					
Weekly number of provided informal care in hours	522	29.17	59.78	34.21	67.72
Years of provided informal care	463	7.65	8.04	7.78	7.86
Weekly amount of days informal care provided	485	5.09	2.50	5.24	2.43
Dummy informal caregiver and care recipient share the same household (yes = 1)	517	0.62	0.49	0.65	0.48
<i>Continued on the next page</i>					

<sup>2</sup> We only use the data of the informal caregivers in this paper.

	Gross sample			Net sample	
	N	Mean	St. Dev.	Mean	St. Dev.
<i>Dummies social relation caregiver and care recipient</i>					
Partner (yes = 1)	522	0.37	0.48	0.40	0.49
Parent (yes = 1)	522	0.18	0.38	0.16	0.37
Child (yes = 1)	522	0.22	0.41	0.24	0.43
Else (yes = 1)	522	0.21	0.41	0.20	0.40
<i>Dummies diseases informal caregivers (yes = 1)</i>					
Respiratory diseases	522	0.10	0.30	0.09	0.29
Circulatory diseases	522	0.03	0.18	0.02	0.14
Digestive diseases	522	0.03	0.17	0.02	0.14
Endocrine, metabolic and nutritional diseases	522	0.03	0.17	0.02	0.15
Musculoskeletal diseases	522	0.39	0.49	0.38	0.49
Neurological diseases	522	0.17	0.38	0.17	0.38
Skin diseases	522	0.05	0.23	0.05	0.21
Cancer	522	0.03	0.17	0.03	0.17
Psychological diseases	522	0.09	0.28	0.09	0.28
<i>Dummy diseases care recipients (yes = 1)</i>					
Respiratory diseases	522	0.14	0.34	0.14	0.35
Circulatory diseases	522	0.16	0.37	0.15	0.36
Digestive diseases	522	0.10	0.30	0.12	0.33
Endocrine, metabolic and nutritional diseases	522	0.09	0.29	0.07	0.26
Musculoskeletal diseases	522	0.46	0.50	0.50	0.50
Neurological diseases	522	0.37	0.48	0.39	0.49
Skin diseases	522	0.09	0.28	0.09	0.28
Cancer	522	0.05	0.21	0.04	0.20
Psychological diseases	522	0.30	0.46	0.34	0.47
N				352	

The table shows that the probability of answering yes to the questions 1, 3, and 4 is very high, while only one third of the informal caregivers answered question 2 affirmatively. More than half of the informal caregivers get paid for their tasks and their mean monthly payment is around 290 euro. The caregivers provide more than 30 hours informal care per week. The majority of informal caregivers is female. This is consistent with other studies that find that providing informal care is still mainly a female activity (Carmichael and Charles, 1998). Almost half of the informal caregivers have a paid job, which is quite high in comparison with a male dominated Dutch caregiver sample (36.9% with a paid job) and a female dominated Dutch caregiver sample (23.4% with a paid job) (Van den Berg et al., In press-a). The high percentage might be explained by the relatively

low mean age of the caregivers in our sample. Most of the informal caregivers are partner of the care recipient.

## 12.4 Results

We present the estimates of equations (1) for the four psychological attitude questions, model 1 to 4 respectively. Table 12.2 gives the marginal effects of the probit model where DPC is the dummy variable for the payment of care (DPC = 1 if the informal caregivers get money and 0 if not).

**Table 12.2:** Probit regressions of equation (1); dependent variable: psychological attitudes<sup>a)</sup>

Independent variables	Model 1		Model 2		Model 3		Model 4	
	Marginal effect	T-value						
Dummy payment (yes = 1)	0.03	0.62	-0.07	-1.15	0.02	0.64	0.05	2.08
<i>Socio-economic and demographic variables</i>								
Dummy gender (male = 1)	0.05	1.14	-0.05	-0.75	0.01	0.23	0.03	1.08
Age	0.00	-0.03	-0.02	-0.86	0.03	2.03	0.00	0.49
Age <sup>2</sup>	0.01	0.10	0.13	1.04	-0.20	-2.10	-0.03	-0.60
Dummy married (yes = 1)	-0.03	-0.59	-0.02	-0.16	-0.03	-0.76	-0.03	-1.13
Dummy children (yes = 1)	-0.07	-1.25	0.07	1.30	0.02	0.39	0.02	0.64
Log net monthly income in euro	-0.01	-0.67	0.02	0.79	0.01	0.71	0.00	0.18
Education in years	-0.02	-3.22	0.00	0.31	-0.01	-1.13	0.00	-1.08
Dummy paid work (yes = 1)	0.07	1.57	0.09	1.51	0.01	0.40	0.00	-0.10
<i>Informal care variables</i>								
Log weekly amount of provided informal care in hours	-0.01	-0.76	0.02	1.11	0.01	0.88	0.01	0.86
Years of provided informal care	0.00	0.09	-0.01	-1.91	0.00	0.77	0.00	1.20
Weekly number of days informal care provided	-0.01	-0.46	-0.02	-1.17	0.00	-0.21	0.00	0.56

*Continued on the next page*

Independent variables	Model 1		Model 2		Model 3		Model 4	
	<i>Marginal effect</i>	<i>T-value</i>						
Dummy informal caregiver and care recipient share the same household (yes = 1)	0.08	1.07	0.17	1.64	0.09	1.53	0.03	0.73
<i>Dummy social relation informal caregiver and care recipient (ref. = partner)</i>								
Parent	-0.13	-1.36	-0.08	-0.76	0.03	0.66	0.03	0.79
Child	-0.18	-2.51	-0.01	-0.16	0.00	-0.02	-0.02	-0.60
Else	-0.01	-0.08	-0.19	-1.67	0.02	0.35	-0.01	-0.21
Informal caregiver has one of the illnesses (yes = 1)	-0.03	-0.76	0.04	0.71	0.02	0.77	0.01	0.40
<i>Dummy diseases care recipients (yes = 1)</i>								
Respiratory diseases	0.08	1.63	0.06	0.79	-0.01	-0.28	0.03	1.31
Circulatory diseases	0.02	0.41	-0.13	-1.71	0.00	0.12	0.03	1.11
Digestive diseases	0.04	0.61	0.08	0.94	0.05	1.37	0.00	0.06
Endocrine, metabolic and nutritional diseases	0.09	1.31	0.05	0.48	-0.04	-0.76	0.01	0.22
Musculoskeletal diseases	-0.03	-0.77	-0.07	-1.15	-0.01	-0.23	-0.01	-0.26
Neurological diseases	-0.01	-0.29	0.10	1.80	0.00	-0.02	0.03	1.34
Skin diseases	-0.02	-0.24	-0.01	-0.16	0.00	-0.01		
Cancer	-0.11	-1.09	0.18	1.24	-0.06	-0.88	0.00	0.09
Psychological diseases	-0.03	-0.70	-0.01	-0.10	0.02	0.73	0.01	0.49
N	352		352		352		352	
Pseudo R <sup>2</sup>	0.16		0.12		0.10		0.15	

<sup>a</sup> *Dependent variables:*

*Model 1: My care recipient appreciates my care efforts*

*Model 2: Our emotional relationship has changed due to my care provision*

*Model 3: I enjoy caring for my care recipient*

*Model 4: Caring for my care recipient is important to me*

The picture that emerges from the estimates is very clear. The coefficient on the dummy for payment of the informal caregiver is only statistically different from zero at the 5 percent level for model (question) 4. This implies that, more than unpaid informal caregivers, informal caregivers who get paid indicate that caring for their care recipient is important to them, *ceteris paribus*. More precisely, the probit-estimates indicate that

informal caregivers who get paid have a 5 percent points higher probability of stating that caring is important for them compared to those who do not get paid. As to the other three questions regarding appreciation, emotional relationship, and enjoy caring there seems to be no difference between paid and non-paid informal caregivers.

Table 12.3 gives the results of equations (2) in a way similar to the presentation of the results of equations (1). The only difference is that PC is a continuous variable.

**Table 12.3:** Probit regressions of equation (2); dependent variable: psychological attitudes<sup>3)</sup>

Independent variables	Model 1		Model 2		Model 3		Model 4	
	<i>Marginal effect</i>	<i>T-value</i>						
Log (amount of payment informal caregiver + 1)	0.01	0.90	-0.01	-1.41	0.00	0.93	0.01	1.98
<i>Socio-economic and demographic variables</i>								
Dummy gender (male = 1)	0.06	1.20	-0.06	-0.82	0.01	0.31	0.03	1.05
Age	0.00	-0.02	-0.02	-0.84	0.03	2.01	0.00	0.50
Age2	0.01	0.09	0.12	1.02	-0.19	-2.09	-0.03	-0.63
Dummy married (yes = 1)	-0.03	-0.58	-0.02	-0.16	-0.03	-0.75	-0.03	-1.14
Dummy children (yes = 1)	-0.06	-1.23	0.09	1.26	0.02	0.43	0.02	0.73
Log net monthly income in euro	-0.01	-0.70	0.02	0.80	0.01	0.69	0.00	0.16
Education in years	-0.02	-3.21	0.00	0.30	-0.01	-1.10	0.00	-1.12
Dummy paid work (yes = 1)	0.07	1.61	0.09	1.47	0.01	0.42	0.00	-0.13
<i>Informal care variables</i>								
Log weekly amount of provided informal care in hours	-0.01	-0.80	0.03	1.16	0.01	0.81	0.01	0.79
Years of provided informal care	0.00	0.07	-0.01	-1.86	0.00	0.74	0.00	1.22
Weekly number of days informal care provided	-0.01	-0.47	-0.02	-1.11	0.00	-0.25	0.00	0.41

*Continued on the next page*

Independent variables	Model 1		Model 2		Model 3		Model 4	
	<i>Marginal effect</i>	<i>T-value</i>						
Dummy informal caregiver and care recipient share the same household (yes = 1)	0.08	1.07	0.17	1.61	0.10	1.55	0.03	0.78
<i>Dummy social relation informal caregiver and care recipient (ref. = partner)</i>								
Parent	-0.13	-1.36	-0.08	-0.76	0.03	0.66	0.03	0.79
Child	-0.18	-2.52	-0.01	-0.15	0.00	-0.03	-0.02	-0.65
Else	-0.01	-0.09	-0.18	-1.66	0.02	0.35	-0.01	-0.22
Informal caregiver has one of the illnesses (yes = 1)	-0.03	-0.73	0.04	0.66	0.02	0.81	0.01	0.39
<i>Dummy diseases care recipients (yes = 1)</i>								
Respiratory diseases	0.08	1.66	0.06	0.77	-0.01	-0.28	0.03	1.35
Circulatory diseases	0.02	0.38	-0.13	-1.68	0.00	0.08	0.03	1.12
Digestive diseases	0.04	0.61	0.08	0.93	0.05	1.39	0.00	0.04
Endocrine, metabolic and nutritional diseases	0.09	1.32	0.05	0.47	-0.04	-0.76	0.01	0.24
Musculoskeletal diseases	-0.03	-0.79	-0.07	-1.12	-0.01	-0.26	-0.01	-0.26
Neurological diseases	-0.01	-0.30	0.11	1.82	0.00	-0.02	0.03	1.36
Skin diseases	-0.01	-0.22	-0.02	-0.19	0.00	-0.01		
Cancer	-0.11	-1.09	0.18	1.24	-0.06	-0.86	0.00	0.05
Psychological diseases	-0.03	-0.67	-0.01	-0.14	0.02	0.72	0.01	0.51
N	352		352		352		352	
Pseudo R2	0.16		0.12		0.10		0.15	

<sup>a</sup> *Dependent variables:*

*Model 1: My care recipient appreciates my care efforts*

*Model 2: Our emotional relationship has changed due to my care provision*

*Model 3: I enjoy caring for my care recipient*

*Model 4: Caring for my care recipient is important to me*

The results of table 12.3 are consistent with the results of table 12.2. There seems to be no relation between the amount of payment an informal caregiver receives and the psychological attitude questions regarding appreciation, emotional relationship, and enjoy caring. The relation between the amount of money an informal caregiver receives and the psychological attitude ‘caring being important for the caregiver’ is positive and statistically

significant at the 5 percent level. So, the larger the monetary compensation an informal caregiver receives for his care tasks, the more important caring seems to be for him.

In sum, our findings indicate that there seems to be no negative psychological effects of paying informal caregivers with a cash benefit.

## **12.5 Conclusion**

This chapter investigated empirically the impact of paying informal caregivers on some psychological aspects of their well-being; viz. (1) care recipients' appreciation of the informal caregivers' care efforts, (2) emotional relationships have changed due to the informal caregivers providing care, (3) caregivers enjoy caring, and (4) caring is important to caregivers.

The results showed that there is a difference in the statement 'caring is important to me' between caregivers who get and those who do not get paid, and between caregivers who get relatively more financial compensation versus caregivers who get relatively less compensation. On the other psychological statements, there seems to be no difference between both groups nor between caregivers receiving relatively more and less money. Our results imply that paying informal caregivers with cash benefits involves no negative external effects in terms of psychological consequences.

The policy implications of our findings could be that there is no problem with paying informal caregivers for their care provided in terms of negative external psychological effects. Support programs could therefore also focus on direct payment of informal caregivers in stead of only focussing on indirect payments like the provision of care leave facilities.

A drawback of this study might be that we just tested for four psychological attitude questions. Another drawback could be reverse causality. These issues warrant future research.

## 13 Conclusions and discussion

This chapter discusses the main conclusions of this thesis. All separate chapters ended with detailed conclusions and discussions of the results. We will not repeat these here. This final chapter brings together the various conclusions along the lines of the three research questions presented in the introduction. Moreover, this chapter will identify and discuss areas for future research.

### 13.1 Supply of informal care

The first research question was about the relation between providing informal care and other economic activities like paid work. Therefore, *chapter 2* provided a theoretical and empirical model of the informal caregiver's preferences regarding the supply of paid work and informal care simultaneously. It was shown that the supply of paid work was statistically significant in the informal care decision and that the supply of informal care was statistically significant in the decision regarding paid work.

These findings complement other studies on this topic. For instance, Carmichael and Charles (1998) modelled the provision of informal care as exogenous in analysing the opportunity costs of caregiving, just like Barmby and Charles (1992) and Carmichael and Charles (2003) did. Ettner (1995) investigated the effect of providing informal care on labour supply. Informal care was an endogenous variable in their models. Stern (1995) on the other hand, analysed the effect of labour supply on the decision to provide informal care, where labour supply was an endogenous variable. However, to the best of our knowledge, there were no studies that modelled informal caregiver's simultaneous supply of paid work and informal care, like we did. We found that the amount of provided informal care has a negative effect on the amount of provided paid work and that the amount of paid work has a negative effect on the amount of provided informal care. Large differences in caring and working exist between males and females and persons with and without young children.

We used a Tobit model to analyse the data, because it is an often applied model to analyse these kind of problems. Using a Tobit model implies that we considered respondents who did not provide informal care (respondents with zero hours) and respondents who provided informal care (respondents with positive hours) in one step. The same holds for respondents without a paid job (zero hours) and respondents with a

paid job (positive hours). This is sometimes seen as a disadvantage of the Tobit model, because the choice of becoming an informal caregiver could differ from making decisions about the amount of provided care (Verbeek, 2000). The second decision is conditional upon the first decision to provide care. It would therefore be better to analyse this problem with a two-step model, but it remains to be seen if this produces other results, see (Amemiya, 1981). The same reasoning applies to the decision to accept a paid job and the amount of paid work provided. Future research may apply this two-step approach.

## **13.2 Economic valuation of informal care**

Our second research question was about the incorporation of informal care in economic evaluations of health care. The *chapters 3 to 10* tried to provide guidance on how informal care should be incorporated in economic evaluations. *Chapter 3* discussed the current practice, *chapter 4* was an empirical investigation in the measurement of informal care, while the *chapters 5 to 10* were empirical contributions to the valuation of informal care. We discuss our main findings according to the following structure: (13.2.1) measurement, (13.2.2) valuation, (13.2.3) operationalisation, (13.2.4) hypotheses, (13.2.5) results, (13.2.6) non-response, and (13.2.7) recommendations for future research.

### **13.2.1 Measurement**

Measurement of informal care is for an important part measurement of time. The measurement of time allocation is troublesome (Juster and Stafford, 1991). This holds also for the measurement of time that informal caregivers spend on providing care. In the literature on the measurement of time, the diary is often seen as the gold standard (Juster and Stafford, 1991) and (Robinson, 1985). One could, however, put forward some minor qualifications. First, there is no standardised operationalisation of the diary. Second, there is no arranged way to correct for joint production in diaries. This is especially troublesome in the context of informal caregiving, where it is difficult to separate between the provision of household informal care tasks and normal housework. Third, a more practical problem is that a diary is time consuming to complete, leading to a high non-response.

In this thesis we used therefore a less time consuming, but presumably a less accurate, method to measure informal care time, namely the recall method. But this method has also a theoretical advantage compared to the diary. It is namely argued, but never empirically shown, that respondents take into account their joint production when completing the recall method.

To get an impression of the measurement bias due to the recall method, we compared the recall method with a diary by means of a within subject comparison. The diary was especially developed to account for joint production in the measurement of informal care. Respondents could separate between household informal care tasks and normal housework. Because of the lack of a standardised way to correct for joint production, we corrected for joint production in two different ways in order to examine whether or not this correction influenced the results.

*Chapter 4* showed that the recall method gives roughly the same results compared to the diary, if one assumes that respondents take into account joint production when completing the recall questionnaire. This assumption involves that time spent on different activities can add up to over 24 hours per day. If we however do not assume that respondents take into consideration joint production when completing the recall questionnaire, we also have to correct the diary for joint production. Under this second assumption, *chapter 4* showed that the recall method overestimated the time spent on providing informal care with more than two hours per day. Moreover, on the level of the individual care tasks, there was a lot of difference in results. For instance, the recall method gives an underestimation of eating and drinking of more than half an hour per day. This difference in results on a more detailed level makes it impossible to make a simple correction of the recall method with two hours per day.

We also compared the recall method at two moments in time in this chapter. It turned out that the recall method was unstable over time. This could be due to learning effects from completing a diary. In sum, we could not definitely conclude that the measurement of informal care with the recall method will yield reliable results. Measurement of informal care time with the recall method should therefore be interpreted carefully.

A more specific issue regarding the measurement of time compared to the above mentioned general issues, is how the measure informal caregiver's time forgone in order to provide informal care. This is crucial for the application of the opportunity cost method. Especially, when the provision of informal care started many years ago, as is the case in many chronic diseases. But, in most applications of the opportunity cost method, this issue is neglected by assuming that the time spent on providing informal care is exactly the same as the time forgone in order to be able to provide informal care. This seems straightforward, but implicitly assumes that there is no joint production and neglects income and substitution effects in the context of time measurement. In *chapter 5*, we

therefore developed and applied alternative questions to measure informal caregivers' opportunity costs of time and asked respondents to indicate how they would spend their time when they did not had to provide informal care anymore. Results showed that the measurement according to both operationalisations of the opportunity cost method is more problematic than its valuation.

*Chapter 5* tried also to separate between normal housework and informal care housework tasks in order to prevent double counting of housework in the application of the proxy good method. We did this by comparing the predicted housework time of the caregivers in our samples based on a representative sample of people in The Netherlands. This did not solve the problem of double counting, because many respondents spent less time on some housework tasks than predicted. An explanation could be that they substituted some housework tasks for other informal care tasks. We concluded that more precise guidelines are necessary regarding the measurement of time in the opportunity and proxy good methods, at least as long as it is still recommended to apply both methods to value informal care. Without these standardisation, results could substantially differ which hampers comparability of economic evaluations.

### **13.2.2 Valuation**

*Chapter 3* described and discussed the current practice of the incorporation of informal care in economic evaluations. We split up the valuation methods into three main categories: (1) revealed preference methods, (2) stated preference methods and (3) other methods. We observed that the standard handbooks about economic evaluations, viz. Gold et al. (1996) and Drummond et al. (1997) recommend two revealed preference methods to value informal care, namely the opportunity cost method and the proxy good method. The same holds for the other literature, see, for instance, Smith and Wright (1994) or Posnett and Jan (1996). The opportunity cost method is seen as the theoretically correct method, while the proxy good method is considered as a good alternative.

Despite the opportunity cost method is seen as the theoretically correct method to value informal care, *chapter 3* stated that the focus of opportunity cost method is too narrow to value the full impact of providing informal care. The same holds for the proxy good method. Informal care is namely not only about the cost of paid work, unpaid work or leisure, but it involves also morbidity and even mortality risks (Schulz and Beach, 1999). Moreover, providing informal care involves both direct disutility and direct utility for

informal caregivers. Another theoretical disadvantage of the proxy good method is that is not preference based, as welfare economics demands.

We proposed two stated preference methods as better alternatives for the opportunity and proxy good methods, at least in theory, in order to value the full impact of providing informal care, namely the contingent valuation (CV) method and choice experiments (CE). *Chapter 3* discussed also the use of other methods to value informal care. It suggested especially to apply the well-being valuation (WBV) method as an alternative method to value the full impact of providing informal care. To the best of our knowledge, CV, CE and WBV, were not applied to value informal care yet. We applied them in this thesis: CV (*chapters 6 and 7*), CE (*chapters 8 and 9*), and WBV (*chapter 10*). The three proposed alternatives are, in theory, capable to value the full impact of providing informal care.

### **13.2.3 Operationalisation**

Because CV, CE, and WBV were not yet applied to value informal care, it was not always straightforward how to frame the questions. We opted for asking real informal caregivers to answer the questions, because they are familiar with decisions regarding the provision of informal care.

*Chapter 6* showed how to frame CV questions, in the form of willingness to accept (WTA), an exception in the health economics literature (Klose, 1999), to elicit the preferences of informal caregivers. First, we asked caregivers to indicate their most favourite care task, in order to account for the heterogeneity of the commodity informal care, and second we asked them to indicate their minimum WTA in order to provide an extra hour informal care per week.

*Chapter 8* on CE showed how to develop relatively simple vignettes to elicit informal caregivers' preferences. We asked informal caregivers to abstract from their real caregiving situation and to imagine four different hypothetical caregiving situations, described in the vignettes. The vignettes consisted of only three attributes: care tasks, care time, and monetary compensation. Then we asked informal caregivers to compare the four situations, and to rate them according to their preferences. In *chapter 9*, we also asked informal caregivers to rate their own caregiving situation compared to the hypothetical situations, as a challenge to account for the individual heterogeneity.

*Chapter 10* described the necessary pieces of information in order to apply WBV to value informal care: informal caregivers' income, their time spent on providing care and their subjective happiness.

### 13.2.4 Hypotheses

In order to test the above mentioned statement that CV, CE, and WBV are capable to value the full impact of providing informal care, we derived some theoretical hypotheses from economic models and derived some hypotheses from the (empirical) literature.

First, in *chapter 6*, regarding CV, we derived some hypotheses from a graphical economic model and the literature. We tested whether or not there was a relation between informal caregivers' willingness to accept in order to provide an additional hour of informal care and some background characteristics. Especially, hypotheses about informal caregiver's and care recipient's health-related quality of life, informal caregiver's income, and institutions were accepted. Hypotheses about informal caregiver's subjective burden and CV's scope validity were not accepted.

Because the hypotheses as tested in *chapter 6* were not derived from a mathematical but a graphical economic model, there could be lack in precision. Presumably, the issue of interdependent utility functions of informal caregivers and their care recipients is important in the context of informal caregiving. *Chapter 7* tried to solve both issues. It presented a formal economic model of informal care that took into account the perspectives of both the informal caregivers and their care recipients and modelled the interdependencies in their preferences, assuming that informal caregivers take into account the health status of their care recipients and vice versa. We tested whether or not there was a relation between informal caregivers' and care recipients' willingness to accept and willingness to pay and own income, health and others health. The effect of income on WTP and WTA was mixed. Own health generally had the predicted negative effect. The impact of other's health varied, but the theoretical model made no predictions regarding this effect.

Regarding CE, we adopted an empirical approach, mainly from the informal caregivers' perspective. *Chapter 8* showed that there was no relation between the vignette ratings and informal caregivers' or caregiving characteristics. Especially, informal caregivers' rating of their own caregiving situation and their health-related quality of life were related to their vignette ratings, in *chapter 9*. *Chapter 10* showed that the time spent on providing informal care was negatively and informal caregivers' income was positively related to informal caregivers' happiness, as we had hypothesised. Moreover, we also compared our findings of the relation between other variables, like sex and income, and happiness with results of other studies in the literature on happiness. Again, the perspective

of this chapter was the informal caregivers'. The perspective of the care recipient in this method is only useful when we were able to disentangle the positive effect of receiving informal care on happiness on the one hand and the negative effect of being cared for by a loved one on happiness on the other hand.

In sum, *chapters 6 to 10* suggested that CV, CE, and WBV might be fruitfully applied to value the full impact of providing informal care.

### 13.2.5 Results

Despite the recommendations in the literature to apply the opportunity cost method or the proxy good method to value informal care, it is unknown how both methods relate to each other. Therefore, *chapter 5* applied and compared the two methods. A second reason for this comparison was to serve as a benchmark in this thesis to compare their results with the results of the proposed alternative methods to value informal care. *Chapters 6 and 7* applied CV to value informal care, *chapters 8 and 9* applied CE, and *chapter 10* applied WBV.

Table 13.1 summarises the main results of the different valuation methods. It is worth noting that not all the valuation methods were applied to the same population.

**Table 13.1:** Comparison of results of different valuation methods from the informal caregiver's perspective (in euro per hour)

Method	Population		
	CVA	RA	LOT
Opportunity cost (average)	17.34	10.64	
Proxy good (average)	13.51	12.19	
CV ( <i>WTA</i> ) (marginal from sample average)		7.80	10.52
CV ( <i>WTP</i> ) (marginal from sample average)		9.52	8.61
CE (marginal from 15 to 16 hours per week)		16.00	8.00
WBV ( <i>Happiness 1 to 5</i> ) (marginal from sample average)			15.39
WBV ( <i>Happiness 0 to 10</i> ) (marginal from sample average)			16.49

Moreover, even if they were applied to the same population, then due to item non-response it was not exactly the same group of respondents that answered each of the questions. Sometimes, the same method was operationalised in a different way (see the subsequent chapters for more details).

Table 13.1 gives an impression of the convert validity of the different methods to estimate a monetary value of informal care. It shows that hourly monetary values according to all valuation methods are within the same range: between 8 and 17.34 Euro. There are no outliers. However, the highest value (opportunity cost method in CVA) is twice the lowest value (CE in LOT), 17.34 versus 8.00. Applicants of the methods should therefore be aware that results strongly depend on the valuation method. It is argued in *chapter 3* that a total valuation method is required to value the full impact of providing informal care. As long as CE and WBV do not have the same theoretical basis in welfare economics, we would suggest using CV for the economic valuation of informal care in economic evaluations.

The interpretation of the values is not always the same. Sometimes the point of estimation is at the sample average: opportunity cost and proxy good methods. CV and WBV gives values at the margin from the sample average hours informal care provided. CE gives values dependent on the initial hypothetical compensation that could be varied.

Finally, it is striking that despite CV, CE, and WBV seem to value the full impact of providing informal care, as opposed to the opportunity and proxy good methods, their values do not systematically differ from the values derived with the latter two methods. An explanation could be that the derived direct utility and indirect utility from providing informal care are in balance.

### **13.2.6 Non-response**

Next to the proposed theoretical arguments regarding the choice of valuation methods and the discussed convert validity, there is also the empirical issue of the non-response. We first compare our findings with suggestions in the literature. The non-response gives at least also an impression of the respondents' understanding of the methods. Therefore, secondly we compare the non-response of the different methods in this thesis to value informal care.

In the literature there is some suspicion towards the application of CV to value informal care. It is argued that money is low on the informal caregivers' agenda (Smith and Wright, 1994). *Chapter 6* presented empirical evidence on this issue. It was shown that most

respondents were willing to answer questions about a hypothetical monetary compensation for the provision of additional informal care.

It is well known from the literature that completing questions regarding CE involves a relatively high burden for respondents. Especially, when respondents have to rank many vignettes or when vignettes consist of many attributes. A relatively high non-response, especially when it is not randomly, could bias the results of the method. *Chapter 8* showed that non-response is indeed a problem in CE. Even in a relatively simple CE, rating four vignettes with three attributes, the non-response was almost fifty percent.

Surprisingly, *chapter 5* showed that applying the opportunity cost method involves also a high non-response. Only, a quarter of the sample answered the questions regarding this method. This was surprising, because the current literature did not yet notice this disadvantage of the method. Perhaps, because the method is often operationalised in a different way, not asking respondents the time they had given up in order to provide informal care but just the time they spend on providing informal care assuming that both are equal.

This thesis showed that applying the proxy good method (*chapter 5*) and WBV (*chapter 10*) involved relatively the less non-response: respectively 4% and 2.5% to 3.4% (depending on the questions used). It is worth noting that applying WBV requires, for example, also income information (non-response of 6.7%). This result is an empirical argument in favour of both methods.

In contrast, 42.8% to 49.8% (depending on the questions used) of the informal caregivers failed to answer the CV questions in LOT (*chapter 7*). It is worth noting that the non-response on CV questions depends heavily on the choice format used. LOT consisted of open-ended questions, which are the most difficult for respondents to answer (Greenet al., 1998). RA used a dichotomous choice CV question with an open follow-up question and had a non-response of 19% (*chapter 6*). CE scored relatively bad with a non-response of 50% (*chapter 8*), while the opportunity cost method involved the highest non-response: 75% (*chapter 5*).

Finally, empirical results in this thesis showed also that on sample averages, the non-response seemed not to bias the results. This suggests that in terms of non-response all methods could equally been applied to value informal care.

### **13.2.7 Unresolved issues and recommendations for future research**

There are a few specific unresolved issues which could be solved in future research. Regarding the measurement of time in general and also regarding the measurement of informal care time, a crucial issue is joint production. Future research should therefore focus on this question. In the application of the diary we corrected for joint production in two different ways, but how to correct for joint production is still debatable. Moreover, the study design was based on a within sample comparison. It would be interesting to see whether between sample comparisons will lead to the same results. It could namely be that our design involved learning effects for respondents by completing first the diary and afterwards the recall method. Between sample comparison would not involve such learning effects, but it introduces probably other unobserved heterogeneity. A final issue in the measurement of informal care time is the number of care tasks distinguished. It is questionable whether adding extra informal care tasks to the recall method, will yield more reliable results. Research could try to solve the question what is the optimal number of care tasks in the recall method, in order to get the most reliable results compared to the diary.

A recurrent issue in the literature on CV, is the issue of scope validity, see for instance Mitchell and Carson (1989) and Brown and Gregory (1999). This means that, according to economic theory, the respondents' preferences for the commodity under valuation should be but are not always sensitive to the amount of the commodity. We did not test for scope validity in the usual way in the context of informal caregiving. A test could, for instance, be asking the same respondent how much he minimum was willing to accept in order to provide one extra hour of informal care per week versus four extra hours. This issue should be resolved in future research, in order to recommend with certainty for the application of CV to value informal care in economic evaluations.

Our applications of CE showed that it is an interesting method to derive a monetary compensation of informal care. Because the applications were relatively simple (we only considered care hours, care tasks and a monetary compensation), future research could and should focus on more complicated designs. It would, for instance, be challenging to add additional attributes to the vignettes (probably in an interview setting), like qualitative information on the caregiving situation, the trade-off between informal caregiver's own tasks and other informal caregivers, care tasks provided by other informal caregivers or professional caregivers.

CE are sometimes called CV's close cousins in the family of stated preference methods (Roe et al., 1996). They do not have the strong welfare economic theoretical foundation as CV, but they also do not suffer from some biases like strategic bias as CV does. Theoretical work is necessary regarding the foundations of CE. This in order to develop and test the internal validity of CE according to economic theory.

*Chapter 3* discussed the usefulness of other methods (non-monetary valuation methods next to WBV) that already were applied to value informal care. We concluded that the other methods (objective burden, health-related quality of life and subjective burden) were not, just like the revealed preference methods, able to value the full impact of informal care. They may therefore only be used in combination with other, complementary, methods in order to value the full impact of informal care. We also suggested that applying a combination of different methods involves the danger of double counting. It also does not naturally value the full impact of informal caregiving. For example, a combination of the opportunity cost or proxy good method with health-related quality of life is not able to detect the interdependencies in the informal caregiver's and care recipient's utility functions. A combination of the opportunity cost or proxy good method with health-related quality of life supplemented with process utility may involve double counting in relation to health-related quality of life and process utility. Obviously, future theoretical and empirical research could therefore contribute to the incorporation of other methods to value informal care.

### **13.3 Cash benefits**

The final research question of this thesis was about the (economic) consequences of the introduction of cash benefits in the long-term home health care sector in general and particularly for informal care. *Chapter 11* was an empirical examination of the economic consequences of the introduction of cash benefits for quantities and prices of different types of care.

We found a shift towards more private care and some evidence of ex post static moral hazard. Moreover, we observed no substitution of regular care for informal care due to the introduction of cash benefits, as is sometimes suggested by policy makers.

*Chapter 12* discussed the psychological consequences of the payment of informal caregivers with cash benefits. It was argued that this payment involved negative psychological effects in the motivation of informal caregivers. We did not find empirical support for this hypothesis regarding (1) care recipients' appreciation of the informal

caregivers' care efforts, (2) the changed emotional relationships due to the provision of care, (3) caregivers enjoy caring, and (4) caring is important to caregivers.

The policy implications of our findings are that there is no problem with paying informal caregivers for their care provided in terms of negative external psychological effects. Support programs could therefore also focus on direct payment of informal caregivers in stead of only focussing on indirect payments like the provision of care leave facilities.

### **13.4 Other areas for future research**

Thus far many areas and topics for future research were already suggested. But here finally a few general remarks about areas for future research that mainly deal with the applications and implications of our findings for policy making.

Regarding the supply of informal care it would be interesting to analyse how informal caregivers will respond to the introduction of new schemes regarding the combination of providing informal care and paid work in real life, such as paid leave or respite care. These kinds of natural experiments would obviously involve all kind of difficulties in the sense that they could lead to inequalities that are societal unacceptable. However, such analyses could provide crucial information about the costs and benefits of actual policy measures.

The same kind of reasoning holds within the framework of economic evaluations. It would be interesting to apply the valuation methods as discussed in this thesis in real economic evaluations. This thesis tested the valuation methods empirically in terms of, for instance, feasibility, construct validity and content validity. Though the data were collected from real informal caregivers and their care recipients, respondents were not exposed to an intervention, as is generally the case in an economic evaluation. It is therefore not possible to conclude whether or not the valuation methods are sensitive enough to discriminate between, for example, an experimental group and a control group.

A complementary issue in the context of informal care in economic evaluations is whether the care recipients or the informal caregiver is the main object of the intervention under study. The cited handbooks concerning economic evaluations Gold et al. (1996) and Drummond et al. (1997) focus on care recipients. Other studies, for instance Mohide et al. (1988) and Drummond et al. (1991) focus conversely on interventions to support informal caregivers. The main aim of this thesis was the incorporation of informal care in economic evaluations regarding care recipients instead of economic evaluations of support programs

of informal caregivers. Despite this aim, CV could also be used in a cost-benefit analysis of a support program for informal caregivers. The same holds for CE, but CE could also be applied to derive utility scores in a cost-utility analysis of support programs for informal caregivers.

It would be superfluous to stage the same kind of reasoning regarding natural experiments about the chapters on the effects of cash benefits. But future research in this area could focus on two partly different and partly interrelated issues. First, it would be interesting to analyse in more detail how prices and quantities of purchased care would be realised. Especially, when cash benefits are seen as crucial tools to increase efficiency and consumer choice in the long-term care, as is the case in The Netherlands. Symmetric market power between different market parties is crucial for the functioning of markets. Detailed information about the realisation of prices and quantities could help with possible adjustment of the rules regarding cash benefits. Second, cash benefits are perhaps not feasible for all consumers in the long-term care sector. Detailed information about possible sub groups that do not opt for cash benefits could protect them against a possibly rigorous implementation of this tool. But also cash benefits for consumers that are not very well able to express their preferences as a result of their illness could involve some problems. Guardians can manage their cash benefit, but this introduces a complicated principal agent problem. We ask some attention for this principal agent problem in future research. One could, for instance, test whether or not there are differences in the way cash benefits are spend between clients who manage their own cash benefits and clients with a guardian, *ceteris paribus*. This, to test if guardians act mainly according to their own preferences or according to the preferences of their clients.

## 13.5 Epilogue

This thesis tried to fill some gaps in the economic literature about informal care. It provided some theoretical and empirical innovations regarding the simultaneous supply of informal care and paid work. The same holds for the incorporation of informal care in economic evaluations, with a focus on three new valuation methods in this area, viz. CV, CE, and WBV. About the (economic) effects of the introduction of cash benefits in the long-term care sector was hitherto no information, while many countries experiment with cash benefits.

Unfortunately, we could not definitely, solve all the problems in the raised areas. Particularly, they include: (1) more work is necessary regarding the valid measurement of

time spend on informal caregiving. (2) The usefulness of applying stated preference methods to value informal care, for instance, respondents from the general population instead of real informal caregivers in case of CV and CE, scope validity in CV, more complicated vignettes in CE, and the care recipients' perspective in WBV. (3) Developing and applying non-monetary methods (in chapter 3 called other methods) to value informal care. (4) Applying the proposed methods to evaluate support programs for informal caregivers and comparing their results. (5) Trying to get a clearer picture about the role of interdependent utility functions in the valuation of informal care. This issue deserves also much more attention in other areas of health economics. (6) Cash benefits get presumably a more dominant position in regulating long-term care and perhaps also in other health care sectors. More theoretical and empirical work is necessary regarding their incentives. But we believe that this thesis has contributed to the clarification of at least some of these issues. Hopefully, the results of this thesis would stimulate and accelerate future theoretical and empirical research about informal care in general and in particular about the position of informal care in health care and in health care decision making.

It is almost impossible to work on this topic without getting any involvement with some of the experienced problems of informal caregivers. Especially, visiting informal caregivers to test a developed survey or getting phone calls from respondents completing the surveys, puts your attention on their, sometimes, painful life circumstances. Therefore, policy makers will hopefully also use the results of this thesis to develop health care and social care institutions without adverse incentives in the sense that the burden, in the broad sense of the word, of long-care in an ageing society is solely on the shoulders of informal caregivers.

## References

- Amemiya, T., 1981. Qualitative Response Models: A Survey. *Journal of Economic Literature* 19 1483-1536.
- Arrow, K.J., 1963. Uncertainty and the welfare economics of medical care. *American Economic Review* 53 (5), 941-973.
- Arrow, K.J., Solw, R., Portney, P.R., 1993. Report of the NOAA Panel on Contingent Valuation. *Federal Register* 58(1), 4601-4614.
- Baarsma, B., 2000. *Monetary Valuation of Environmental Goods: Alternatives to Contingent Valuation*. 302, University of Amsterdam,
- Barmby, T., Charles, S., 1992. Informal Care and Female Labour Supply. *The Scottish Journal of Political Economy* 39 (3), 228-301.
- Beggs, S., Cardell, S., Hausman, J., 1981. Assessing the potential demand for electric cars. *Journal of Econometrics* 16 1-19.
- Ben-Akiva, M., Lerman, S.R., 1985. *Discrete Choice Analysis: Theory and Application to Travel Demand*. The MIT Press: Cambridge, Massachusetts.
- Bergstrom, T.C., 1997, A survey of theories of the family. In: Rosenzweig, M.R., Stark, O. (Eds.) *Handbook of Population and Family Economics*. Elsevier: Amsterdam 21-79.
- Bishop, R.C., Champ, P.A., Mullarkey, D.J., 1995. Contingent valuation. In: Bromley, D.W. (Eds.), *The Handbook of Environmental Economics*. Basil Blackwell: Oxford.
- Blau, D.M., Hagy, A.P., 1998. The Demand for Quality in Child Care. *Journal of Political Economy* 106(1) 106 (1), 104-146.
- Boadway, R., Bruce, N., 1984. *Welfare Economics*. Basil Blackwell: Oxford.
- Borgermans, L., Nolan, M., Philp I., 2001. Europe. In: Philp, I. (Ed.), *Family Care of Older People in Europe*. IOS Press: Amsterdam 3-25.
- Borisova, N.N., Goodman, A.C., 2003. Measuring the value of time for methadone maintenance clients: willingness to pay, willingness to accept, and the wage rate. *Health Economics* 12 323-334.
- Boyle, K.J., Holmes, T.P., Teisl, M.F., Roe, B., 2001. A Comparison of Conjoint Analysis Response Formats. *American Journal Agricultural Economics* X3 (2), 443-454.
- Bromley, D.W., 1995. Property rights and natural resource damage assessments. *Ecological Economics* 14 129-135.

- Brookshire, D.S., Coursey, D.L., 1987. Measuring the value of a public good: an empirical comparison of elicitation procedures. *American Economic Review* 77 554-566.
- Brouwer, W.B., van Exel, N.J., Koopmanschap, M.A., Rutten, F.F., 1999. The valuation of informal care in economic appraisal. A consideration of individual choice and societal costs of time. *Int.J.Technol.Assess.Health Care* 15 (1), 147-160.
- Brown, T.C., Gregory, R., 1999. Why the WTA - WTP disparity matters. *Ecological Economics* 28 323-335.
- Calfee, J., Winston, C., 1998. The value of automobile travel time: implications for congestion policy. *Journal of Public Economics* 69 83-102.
- Carlsson, F., Martinsson, P., 2003. Design techniques for stated preference methods in health economics. *Health Economics* 12 (4), 281-294.
- Carmichael, F., Charles, S., 1998. The labour market costs of community care. *Journal of Health Economics* 17 (6), 747-765.
- Carmichael, F., Charles, S., 2003. The opportunity costs of informal care: does gender matter? *Journal of Health Economics* 22 781-803.
- Carson, R.T., 1997. Contingent Valuation Surveys and Tests of Insensitivity to Scope. In: Kopp, R.J., Pommerehne, W.W., Schwarz, N. (Eds.), *Determining The Value Of Non-Marketed Goods*. Kluwer: Boston/ Dordrecht/ London.
- Carson, R.T., Flores, N.E., Meade, N.F., 2001. Contingent Valuation: Controversies and Evidence. *Environmental and Resource Economics* 19 173-210.
- Checkovich, T.J., Stern, S., 2002. Shared Caregiving Responsibilities of Adult Siblings with Elderly Parents. *The Journal of Human Resources* 37 (3), 441-478.
- Cherchi, E., De Dios Ortúzar, J., 2002. Mixed RP/SP models incorporating interaction effects: Modelling new suburban services in Cagliari. *Transportation* 29 371-395.
- Clark, A.E., Oswald, A.J., 1994. Unhappiness and unemployment. *Economic Journal* 104 648-659.
- Clarke, P.M., 2002. Testing the convergent validity of the contingent valuation and travel cost methods in valuing the benefits of health care. *Health Economics* 11 117-127.
- Clipp, E.C., Moore, M.J., 1995. Caregiver time use: an outcome measure in clinical trial research on Alzheimer's disease. *Clin Pharmacol Ther* 58 (2), 228-236.
- Dautzenberg, M., 2000. Daughters caring for elderly parents. Maastricht University.
- Davis, K.L., Marin, D.B., Kane, R., Patrick, D., Peskind, E.R., Raskind, M.A., Puder, K.L., 1997. The Caregiver Activity Survey (CAS): development and validation of a new

- measure for caregivers of persons with Alzheimer's disease. *Int J Geriatr Psychiatry* 12 (10), 978-988.
- Deaton, A., Muellbauer, J., 1980. *Economics and consumer behavior*. Cambridge University Press: Cambridge.
- De Groot, A.W.M., Van Praag, B.M.S., Velthuisen, J.W., 2000. Wie dan zorgt ... In: Hazeu, C.A., Eggelte, J.J.A., Den Butter, F.A.G. (Eds.), *Naar een vrijwel volledige arbeidsparticipatie*. WRR: Den Haag 143-217.
- Diener, A., O'Brien, B., Gafni, A., 1998. Health care contingent valuation studies: a review and classification of the literature. *Health Econ.* 7 (4), 313-326.
- DiTella, R., MacCulloch, R.J., Oswald, A.J., 2001. Preferences over Inflation and Unemployment: Evidence from Surveys of Subjective Well-being. *American Economic Review* 91 335-341.
- Dolan, P., 1997. Modelling valuations for EuroQol health states. *Medical Care* 35 (11), 1095-1108.
- Dolan, P., Olsen, J.A., Menzel, P., Richardson, J., 2003. An inquiry into the different perspectives that can be used when eliciting preferences in health. *Health Economics* 12 545-551.
- Donaldson, C., Birch, S., Gafni, A., 2002. The distribution problem in economic evaluation: income and the valuation of costs and consequences of health care programmes. *Health Economics* 11 (1), 55-70.
- Drummond, M.F., Mohide, E.A., Tew, M., Streiner, D.L., Pringle, D.M., Gilbert, J.R., 1991. Economic evaluation of a support program for caregivers of demented elderly. *Int.J.Technol.Assess.Health Care* 7 (2), 209-219.
- Drummond, M.F., O'Brien, B.J., Stoddart, G.L., Torrance, G.W., 1997. *Methods for the Economic Evaluation of Health Care Programmes*. Oxford Medical Publications: Oxford.
- Easterlin, R.A., 2001. Income and happiness: Towards a unified theory. *The Economic Journal* 111 465-484.
- Eisenberger, R., Weber, M., 1995. Willingness-to-pay and willingness-to-accept for risky and ambiguous lotteries. *Journal of Risk and Uncertainty* 10 223-233.
- Essink-Bot, M.L., Stouthard, M.E., Bonsel, G.J., 1993. Generalizability of valuations on health states collected with the EuroQol-questionnaire. *Health Economics* 2 (3), 237-246.

- Ettner, S.L., 1995. The Impact of "Parent Care" on Female Labor Supply Decisions. *Demography* 32 (1), 63-80.
- Ettner, S.L., 1996. The Opportunity Costs of Elder Care. *Journal of Human Resources* 31 (1), 189-205.
- EuroQol Group, 1990. EuroQol--a new facility for the measurement of health-related quality of life. *Health Policy* 16 (3), 199-208.
- Ferrer-i-Carbonell, A., 2004 Accepted for publication. Income and Well-Being: An Empirical Analysis of the Comparison Income Effect. *Journal of Public Economics* 88 1359-1386.
- Ferrer-i-Carbonell, A., Frijters, P., Forthcoming. How important is methodology for the estimates of the determinants of happiness? *Economic Journal* 114 641-659.
- Ferrer-i-Carbonell, A., Van Praag, B.M.S., 2002. The subjective costs of health losses due to chronic diseases. An alternative model for monetary appraisal. *Health Economics* 11 709-722.
- Fischhoff, B., 1991. Value Elicitation: Is There Anything in There? *American Psychologist* 46 (8), 835-847.
- Frey, B., Stutzer, A., 2002. What Can Economists Learn from Happiness Research? *Journal of Economic Literature* 40 402-435.
- Frijters, P., 1999. Explorations of welfare and well-being. University of Amsterdam.
- Frijters, P., Haisken-DeNew, J.P. , Shields, M. A., 2004 Money Does matter! Evidence from increasing real incomes and life satisfaction in East Germany following reunification. *American Economic Review* 94(3), 730-740.
- Gallagher, S.K., Mechanic, D., 1996. Living with the mentally ill: Effects on the health and functioning of other household members. *Social Science and Medicine* 42 (12), 1691-1701.
- Garbacz, C., Thayer, M.A., 1983. An experiment in valuing senior companion program services. *The Journal of Human Resources* XVIII(1), 147-153.
- Gerard K., Mooney, G., 1993. QALY league tables: handle with care. *Health Economics* 2(1), 59-64.
- Given, C.W., Given, B., Stommel, M., Collins, C., King, S., Franklin, S., 1992. The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Res Nurs Health* 15 (4), 271-283.
- Gold, M.R., Siegel, J.E., Russell, L.B., Weinstein, M.C. (Eds.), 1996. *Cost-Effectiveness in Health and Medicine*. Oxford University Press: Oxford.

- Green, D., Jacowitz, K.E., Kahneman, D., McFadden, D., 1998. Referendum contingent valuation, anchoring, and willingness to pay for public goods. *Resource and Energy Economics* 20 85-116.
- Green, P.E., Rao, V.R., 1971. Conjoint Measurement for Quantifying Judgmental Data. *Journal of Marketing Research* VIII (August), 355-363.
- Green, P.E., Srinivasan, V., 1978. Conjoint Analysis in Consumer Research: Issues and Outlook. *Journal of Consumer Research* 5 103-123.
- Green, P.E., Srinivasan, V., 1990. Conjoint Analysis in Marketing: New Developments With Implications for Research and Practice. *Journal of Marketing* 3-19.
- Greene, W.H., 2000. *Econometric Analysis*. Prentice Hall: New Jersey.
- Gronau, R., 1986. Home production - a survey. In: Ashenfelter, O., Layard, R. (Eds.), *Handbook of Labor Economics*. Elsevier Science Publishers: Amsterdam.
- Hammerschmidt, T., Zeitler, H.P., Leidl, R., 2004. A utility-theoretic approach to the aggregation of willingness to pay measured in decomposed scenarios: development and empirical test. *Health Economics* 13 (4), 345-361.
- Hausman, J.A., 1981. Exact Consumer's Surplus and Deadweight Loss. *American Economic Review* 71 662-676.
- Hausman, J.A., Wise, D.A., 1978. A Conditional Probit Model for Qualitative Choice: Discrete Decisions Recognizing Interdependence and Heterogeneous Preferences. *Econometrica* 46 (2), 403-426.
- Hawrylyshyn, O., 1977. Towards a definition of non-market activities. *Review of Income and Wealth* 23 79-96.
- Heckman, J.J., 1976. The Common Structure of Statistical Models of Truncated, Sample Selection and Limited Dependent Variables, and a Simple Estimator for such Models. *Annals of Economic and Social Measurement* 5 475-492.
- Hensher, D.A., 2001. The valuation of commuter travel time savings for car drivers: evaluating alternative model specifications. *Transportation* 28 101-118.
- Hicks, J.R., 1939. The Foundations of Welfare Economics. *The Economic Journal* 49 (196), 696-712.
- Hiedemann, B., Stern, S., 1999. Strategic play among family members when making long-term care decisions. *Journal of Economic Behavior & Organization* 40 29-57.
- Homan, M.E., 1988. *The Allocation of Time and Money in One-Earner and Two Earner Families; An Economic Analysis*. Erasmus University Rotterdam, Rotterdam.

- Horowitz, J.K., McConnell, K.E., 2002. A Review of WTA / WTP Studies. *Journal of Environmental Economics and Management* 44 426-447.
- Humbert, M., Van den Dungen, A., 1994. Mantelzorg voor mensen met een chronische ziekte. In: Duijnste, M.S.H., Cuijpers, W.J.M.J., Humbert, M.J., Mantelzorg voor mensen met een chronische ziekte: Een literatuurstudie naar de rol van mantelzorg voor mensen met een chronische ziekte op basis van Nederlandse studies gepubliceerd in de periode 1980-1993. NCCZ: Zoetermeer 9-79.
- Hsiao, C., 1986. *Analysis of panel data*. Cambridge University Press: Cambridge.
- Huber, J., Zwerina, K., 1996. The Importance of Utility Balance in Efficient Choice Designs. *Journal of Marketing Research* 33 (3), 307-317.
- Hughes, S.L., Giobbie-Hurder, A., Weaver, F.M., Kubal, J.D., Henderson, W., 1999. Relationship between caregiver burden and health-related quality of life. *Gerontologist* 39 (5), 534-545.
- Huijsman, R., Klazinga, N.S., Scholte op Reimer, W.J.M., Van Wijngaarden, J.D.H., Van Exel, N.J.A., Van Putte-Boon, C., Prestholt, F.T., Koopmanschap, M.A., Niessen, L.W., 2001. Beroerte, beroering en borging in de keten: Resultaten van de Edisse-studie van drie regionale experimenten met stroke service. ZON-MW: Den Haag.
- Jacobi, C.E., Triemstra, M., Rupp, I., Dinant, H.J., Van den Bos, G.A., 2001. Health care utilization among rheumatoid arthritis patients referred to a rheumatology center: unequal needs, unequal care? *Arthritis Rheum* 45 324-330.
- Jacobi, C.E., Van den Berg, B., Boshuizen, H.C., Rupp, I., Dinant, H.J., Van den Bos, G.A.M., 2003. Dimension-specific burden of caregiving among partners of rheumatoid arthritis patients. *Rheumatology* 42 1-8.
- Johannesson, M., Johansson, P.O., Kriström, B., Borgquist, L., Jönsson, B., 1993. Willingness to pay for lipid lowering: a health production function approach. *Applied Economics* 25.
- Johansson, P.O., 1995. *Evaluating health risks: An economic approach*. Cambridge University Press: Cambridge.
- Johansson-Stenman, O., 2000. On the Value of Life in Rich and Poor Countries and Distributional Weights Beyond Utilitarianism. *Environmental and Resource Economics* 17 299-310.
- Johnson, F.R., Banzhaf, M.R., Desvousges, W.H., 2000. Willingness to pay for improved respiratory and cardiovascular health: a multiple-format, stated-preference approach. *Health Econ* 9 295-317.

- Jones-Lee, M.W., 1974. The Value of Changes in the Probability of Death or Injury. *Journal of Political Economy* 82 835-849.
- Juster, F.T., 1985. Conceptual and Methodological Issues Involved in the Measurement of Time Use. In: Juster, F.T., Stafford, F.P. (Eds.), *Time, Goods, and Well-Being*. Institute for Social Research The University of Michigan: Ann Arbor.
- Juster, F.T., Stafford, F.P., 1991. The allocation of time: empirical findings, behavioral models, and problems of measurement. *Journal of Economic Literature* XXIX 471-522.
- Kahneman, D., Diener, E., Schwarz, N., 1999a. *Foundations of Hedonic Psychology: Scientific Perspectives on Enjoyment and Suffering*. Russell Sage Foundation: New York.
- Kahneman, D., Ritov, I., Schkade, D., 1999b. Economic Preferences or Attitude Expressions?: An Analysis of Dollar Responses to Public Issues. *Journal of Risk and Uncertainty* 19 (1-3), 203-235.
- Kahnemann, D., Knetsch, J.L., 1992. Valuing Public Goods: The Purchase of Moral Satisfaction. *Journal of Environmental Economics and Management* 22 57-70.
- Kartman, B., Stalhammar, N.O., Johannesson, M., 1997. Contingent valuation with an open-ended follow-up question: a test of scope effects. *Health Economics* 6 (6), 637-639.
- Klose, T., 1999. The contingent valuation method in health care. *Health Policy* 47 (2), 97-123.
- Kooreman, P., Wunderink, S., 1996. *The Economics of Household Behaviour*. MacMillan Press: Houndmills.
- Kramer, B.J., 1997. Gain in the caregiving experience: where are we? What next? *Gerontologist* 37 (2), 218-232.
- Lancaster, K., 1971. *Consumer demand: a new approach*. Columbia University Press: New York.
- Lancaster, K., 1991. *Modern Consumer Theory*. Edward Elgar: Aldershot.
- Leblanc, A.J., London, A.S., Aneshensel, C.S., 1997. The physical costs of AIDS caregiving. *Social Science and Medicine* 45(6), 915-923.
- Linder, S.B., 1970. *The Harried Leisure Class*. Columbia University Press: New York.
- Low, J.T., Payne, S., Roderick, P., 1999. The impact of stroke on informal carers: a literature review. *Social Science and Medicine* 49(6), 711-725.

- Luce, B.R., Wanning, W.G., Siegel, J.E., Lipscomb, J., 1996. Estimating Costs in Cost-Effectiveness Analysis. In: Gold, M.R., Siegel, J.E., Russell, L.B., Weinstein, M.C. (Eds.), *Cost-Effectiveness in Health and Medicine*. Oxford University Press: New York.
- Mas-Colell, A., Whinston, M.D., Green, J.R., 1995. *Microeconomic Theory*. Oxford University Press: Oxford.
- McDaid, D., 2001. Estimating the costs of informal care for people with Alzheimers's disease: methodological and practical challenges. *Int J Geriatr Psychiatry* 16 400-405.
- McDaid, D., Cookson, R., 2003. Evaluating health care interventions in the European Union. *Health Policy* 63 133-139.
- McDaid, D., Cookson, R., Maynard, A., Sassi, F., 2003. Evaluating health interventions in the 21st century: old and new challenges. *Health Policy* 63 117-120.
- McFadden, D., 1974. Conditional Logit Analysis of Qualitative Choice behavior. In: Zarembka, P. (Eds.), *Frontiers in Econometrics*. Academic Press: New York.
- McIntosh, E., Ryan, M., 2002. Using discrete choice experiments to derive welfare estimates for the provision of elective surgery: Implications of discontinuous preferences. *Journal of Economic Psychology* 23 367-382.
- McKnight, R., 2004. Home care reimbursement, long-term care utilization, and health outcomes. no. Cambridge, MA.
- Michalopoulos, C.K., Robins, P.K., 2000. Employment and Child Care Choices in Canada and the United States. *Canadian Journal of Economics* 33 (2), 435-470.
- Milgrom, P., 1993. Is sympathy an economic value? Philosophy, economics, and the contingent valuation method. In: Hausman, J.A. (Eds.), *Contingent Valuation: A Critical Assessment*. Elsevier Science Publishers: Amsterdam.
- Mitchell, R.C., Carson, R.T., 1989. *Using Surveys to Value Public Goods: The Contingent Valuation Method*. Resources for the Future: New York.
- Mohide, E.A., Torrance, G.W., Streiner, D.L., Pringle, D.M., Gilbert, R., 1988. Measuring the wellbeing of family caregivers using the time trade-off technique. *J.Clin.Epidemiol.* 41 (5), 475-482.
- Muurinen, 1986. The Economics of Informal Care: Labor Market Effects in the National Hospice Study. *Medical Care* 24 (11), 1007-1017.
- Netten, A., 1990. *An Approach to Costing Informal Care*. no. DP 637, University of Kent, Canterbury.

- Ng, Y.-K., 1983. *Welfare Economics: Introduction and Development of Basic Concepts*. London: Macmillan Press.
- Norton, E.C., 2000. Long-Term Care. In: Culyer, A.J., Newhouse, J.P. (Eds.), *Handbook of Health Economics*. Elsevier: Amsterdam.
- OECD Health Data, 2004. <http://www.oecd.org>.
- Olsen, J.A., Smith, R.D., 2001. Theory versus practice: a review of 'willingness-to-pay' in health and health care. *Health Economics* 10 (1), 39-52.
- Oostenbrink, J.B., Koopmanschap, M.A., Rutten, F.F.H., 2000. Handleiding voor kostenonderzoek: Methoden en richtlijnprizen voor economische evaluaties in de gezondheidszorg. College voor zorgverzekeringen: Amstelveen.
- Orbell, S., Hopkins, N., Gillies, B., 1993. Measuring The Impact of Informal Caring. *Journal of Community & Applied Social Psychology* 3 149-163.
- O'Shea, E., Blackwell, J., 1993. The relationship between the cost of community care and the dependency of old people. *Social Science and Medicine* 37 (5), 583-590.
- Oswald, A.J., 1997. Happiness and economic performance. *The Economic Journal* 107 1815-1831.
- Pauly, M.V., 1995. Valuing health care benefits in monetary terms. In: Sloan, F.A. (Eds.), *Valuing health care: Costs, benefits and effectiveness of pharmaceuticals and other medical technologies*. Cambridge University Press: Cambridge.
- Pearlin, L.I., Mullan, J.T., Semple, S.J., Skaff, M.M., 1990. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 30 (5), 583-594.
- Phelps, C.E., 1997. *Health Economics*. Addison-Wesley: Reading, Massachusetts.
- Pollak, R.A., Wales, T., 1981. Demographic Variables in Demand Analysis. *Econometrica* 49 (6), 1533-1551.
- Posnett, J., Jan, S., 1996. Indirect cost in economic evaluation: the opportunity cost of unpaid inputs. *Health Economics* 5 (1), 13-23.
- Powell, L., 2002. Joint Labor Supply and Childcare Choice Decisions of Married Mothers. *The Journal of Human Resources* 37 (1), 106-128.
- Ratcliffe, J., 2000. The use of conjoint analysis to elicit willingness-to-pay values. Proceed with caution? *Int. J. Technol. Assess. Health Care* 16 (1), 270-275.
- Rice, J.A., 1995. *Mathematical Statistics of Data Analysis*. Duxbury Press: Belmont.
- Riemsma, R.P., Klein, G., Taal, E., Rasker, J.J., Wiegman, O., 1997. Mantelzorg bij mensen met Reumatoïde Artritis. no. *Aspekt* 56, Universiteit Twente, Enschede.

- Robinson, J.P., 1985. The Validity and Reliability of Diaries versus Alternative Time Use Measures. In: Juster, F.T., Stafford, F.P. (Eds.), *Time, Goods, and Well-Being*. Institute for Social Research The University of Michigan: Michigan.
- Roe, B., Boyle, K.J., Teisl, M.F., 1996. Using Conjoint Analysis to Derive Estimates of Compensating Variation. *Journal of Environmental Economics and Management* 31 145-159.
- Russell, L.B., Siegel, J.E., Daniels, N., Gold, M.R., Luce, B.R., Mandelblatt, J.S., 1996. Cost-Effectiveness Analysis as a Guide to Resource Allocation in Health: Roles and Limitations. In: Gold, M.R., Siegel, J.E., Russell, L.B., Weinstein, M.C. (Eds.), *Cost-Effectiveness in Health and Medicine*. Oxford University Press: New York.
- Rutten, F.F.H., 1996. Economic evaluation and health care decision-making. *Health Policy* 36 215-229.
- Rutten, F.F.H., 2000. Historische ontwikkeling. In: Rutten-van Mólken, M.P.M.H., Van Busschbach, J.J., Rutten, F.F.H. (Eds.), *Van kosten tot effecten*. Elsevier Gezondheidszorg: Maarssen.
- Ryan, M., Farrar, S., 2000. Using conjoint analysis to elicit preferences for health care. *British Medical Journal* 320 (7248), 1530-1533.
- Ryan, M., Gerard, K., 2003. Using choice experiments to value health care programs: current practice and future research reflections. *Applied Health Economics and Health Policy* 2 (1), 55-64.
- Ryan, M., McIntosh, E., Shackley, P., 1998. Methodological issues in the application of conjoint analysis in health care. *Health Economics* 7 (4), 373-378.
- Saelensminde, K., 1999. Stated choice valuation of urban traffic air pollution and noise. *Transportation Research Part D* 4 13-27.
- Saelensminde, K., 2001. Inconsistent choices in Stated Choice data: Use of the logit scaling approach to handle resulting variance increases. *Transportation* 28 269-296.
- Schulz, R., Beach, S.R., 1999. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *Jama* 282 (23), 2215-2219.
- Schut, F.T., 2003. *De zorg is toch geen markt? Laveren tussen marktfaalen en overheidsfaalen in de gezondheidszorg*. Inaugurale rede: Erasmus Universiteit Rotterdam.
- Schut, F.T., Hassink, W.H.J., 2002. Managed competition and consumer price sensitivity in social health insurance. *Journal of Health Economics* 21 1009-1029.

- SCP, 1995. Tijdsbestedingsonderzoek 1995 - TBO'95. Amsterdam: Steinmetz-archief (Steinmetz-archief studienummer P1383).
- SCP, 2001. Vrij om te helpen: Verkenning betaald langdurig zorgverlof. SCP: Den Haag.
- Sloan, F.A., Viscusi, W.K., Chesson, H.W., Conover, C.J., Whetten-Goldstein, K., 1998. Alternative approaches to valuing intangible health losses: the evidence of multiple sclerosis. *Journal of Health Economics* 17 475-482.
- Slothuus, U., Larsen, M.L., Junker, P., 2002. The contingent ranking method—a feasible and valid method when eliciting preferences for health care? *Social Science and Medicine* 54 (10), 1601-1609.
- Small, K.A., 1992. *Urban Transportation Economics*. Harwood Academic Publishers: Chur.
- Smith, K., Wright, K., 1994. Informal care and economic appraisal: a discussion of possible methodological approaches. *Health Economics* 3 (3), 137-148.
- Smits, J., Westert, G.P., Van den Bos, G.A.M., 2002. Socioeconomic status of very small areas and stroke incidence in the Netherlands. *J Epidemiol Community Health* 56 637-640.
- Spauwen, P., 2002. *Tijdsbesteding van Mantelzorgers*. Universiteit Utrecht.
- Stern, S., 1995. Estimating Family Long-term Care Decisions in the Presence of Endogenous Child Characteristics. *The Journal of Human Resources* 30 (3), 551-580.
- Stiglitz, J.E., 2001. The Contributions of the Economics of Information to Twentieth Century Economics. *The Quarterly Journal of Economics* 115 (4), 1441-1478.
- Stone, P.W., Chapman, R.H., Sandberg, E.A., Liljas, B., Neumann, P.J., 2000. Measuring costs in cost-utility analyses. Variations in the literature. *Int. J. Technol. Assess. Health Care* 16 (1), 111-124.
- Tilly, J., Wiener, J.M., 2001. *Consumer-Directed Home and Community Services: Policy Issues*. no. Occasional Paper Number 44, The Urban Institute: Washington, DC.
- Tilly, J., Wiener, J.M., Cuellar, A.E., 2000. *Consumer-Directed Home and Community Services Programs in Five Countries: Policy Issues for Older People and Government*. no. The Urban Institute: Washington, DC.
- Timmermans, J.M., Schellingerhout, R., Boer, A.H.d., 2004. Wat heet mantelzorg? Prevalentie van verschillende vormen van mantelzorg in Nederland. *Tijdschrift voor Gezondheidswetenschappen* 82 (4), 229-235.
- Timmermans, J.M. (ed.), 2003. *Over de hulp van en aan mantelzorgers*. SCP: Den Haag.

- Torrance, G.W., 1986. Measurement of health state utilities for economic appraisal. *Journal of Health Economics* 5 1-30.
- Train, K., 1986. *Qualitative Choice Analysis: Theory, Econometrics, and an Application to Automobile Demand*. The MIT Press: Cambridge, Massachusetts.
- Tweede Kamer der Staten Generaal, Meeting year 2002-2003. Cash benefits [in Dutch]. no. 25657 (26). The Hague.
- Van den Berg, B., 2004. Dragen de sterkste schouders de zwaarste lasten? Een discussie over de positie van mantelzorgers ten opzichte van de AWBZ-zorg. *Tijdschrift voor Politieke Economie* 26(2), 24-37.
- Van den Berg, B., Al, M.J., Brouwer, W.B.F., Van Exel, J.A.J., Koopmanschap, M.A., 2004. Economic valuation of informal care: The conjoint measurement method applied to informal caregiving. Accepted for publication *Social Science and Medicine*.
- Van den Berg, B., Bleichrodt, H., Eeckhoudt, L., 2004. The economic value of informal care: A study of informal caregivers' and patients' willingness to pay and willingness to accept for informal care. Accepted for publication *Health Economics*.
- Van den Berg, B., Brouwer, W.B.F., Koopmanschap, M.A., 2004. Economic valuation of informal care: An overview of methods and applications. *European Journal of Health Economics* 5 (1), 36-45.
- Van den Berg, B., Brouwer, W.B.F., Van Exel, J.A.J., Koopmanschap, M.A., 2004. Economic valuation of informal care: The contingent valuation method applied to informal caregiving. Accepted for publication *Health Economics*.
- Van den Berg, B., Rutten, F.F.H., 2002. Meten en evalueren in de zorg. *Economisch Statistische Berichten* 87 (4371), 581-583.
- Van den Berg, G., Van den Berg, B., 2000. *Individuele voorkeuren ten aanzien van huishoudelijke hulp*. NIZW: Utrecht.
- Van der Pol, M., Cairns, J., 1998. Establishing patient preferences for blood transfusion support: an application of conjoint analysis. *Journal Health Services Research Policy* 3 70-76.
- Van Doorslaer, E., Jones, A.M., 2003. Inequalities in self-reported health: validation of a new approach to measurement. *Journal of Health Economics* 22 61-87.
- Van Exel, N.J.A., Scholte op Reimer, W.J.M., Brouwer, W.B.F., Van den Berg, B., Koopmanschap, M.A., Van den Bos, G.A.M., 2004. Instruments for assessing the burden of informal care giving for stroke patients in clinical practice: a

- comparison of CSI, CRA, SCQ and self-rated burden. *Clinical Rehabilitation* 18 203-214.
- Van Houtven, C.H., 2000. Informal care and elderly health care use. Department of Health Policy and Administration, University of North Carolina, Chapel Hill.
- Van Houtven, C.H., Norton, E.C., 2004. Informal care and health care use of older adults. *Journal of Health Economics* 23 1159-1180.
- Van Ophem, H., Stam, P., Van Praag, B.M.S., 1999. Multichoice Logit: Modelling Incomplete Preference Rankings of Classical Concerts. *Journal of Business & Economic Statistics* 17 (1), 117-128.
- Van Praag, B.M.S., Ferrer-i-Carbonell, A., 2004. *Happiness Quantified. A satisfaction calculus approach.* Oxford University Press: Oxford.
- Verbeek, M., 2000. *A Guide to Modern Econometrics.* John Wiley & Sons: Chichester.
- Viscusi, W.K., Evans, W., 1990. Utility functions that depend on health status: estimates and economic implications. *American Economic Review* 80 353-374.
- Weinstein, M.C., Shepard, D.S., Pliskin, J.S., 1980. The Economic Value of Changing Mortality Probabilities. *Quarterly Journal of Economics* 94 373-396.
- Willig, R.D., 1976. Consumer's surplus without apology. *American Economic Review* 66(4), 589-597.
- Wimo, A., von Strauss, E., Nordberg, G., Sassi, F., Johansson, L., 2002. Time spent on informal and formal care giving for persons with dementia in Sweden. *Health Policy* 61 (3), 255-268.
- Yeung, R.Y.T., Smith, R.D., McGhee, S.M., 2003. Willingness to pay and size of health benefit: an integrated model to test for 'sensitivity to scale'. *Health Economics* 12 791-796.
- Zweifel, P., Breyer, F., 1997. *Health Economics.* Oxford University Press: New York.
- Zweifel, P., Manning, W.G., 2000. Moral hazard and consumer incentives in health care. In: Culyer, A.J., Newhouse, J.P. (Eds.), *Handbook of Health Economics.* Elsevier Science: Amsterdam.



# Samenvatting

## Mantelzorg: een economische benadering

### 1. Inleiding

Als gevolg van deze stijging van de kosten in de *care* sector is in beleidskringen discussie ontstaan over de vraag hoe de AWBZ vormgegeven moet worden om verdere kostenstijgingen te voorkomen en efficiencywinsten te behalen. Economische evaluaties zijn in de *care* sector een beproefd middel en zouden daarom een rol kunnen spelen in deze discussie. Een economische evaluatie is een analyse om bijvoorbeeld verschillende technologieën in de gezondheidszorg te vergelijken in termen van kosten en opbrengsten. Naast deze discussie is ondanks de stijging van de uitgaven in de *care* sector de tevredenheid van de zorgconsumenten niet evenredig toegenomen. Deze ontevredenheid van zorgconsumenten wordt deels veroorzaakt doordat ze weinig invloed kunnen uitoefenen op de zorg die ze ontvangen: gebrek aan keuzevrijheid.

De *care* sector heeft enkele specifieke kenmerken in vergelijking met de *cure* sector. Dit maakt het lastig om beleidsmaatregelen die in de *cure* sector worden of zijn geïmplementeerd om kostenstijgingen te voorkomen en om efficiëntie en keuzevrijheid te vergroten niet zomaar toegepast kunnen worden in de *care* sector. Zo is er in de *care* sector vaak sprake van een veelal langdurige relatie tussen zorgvragers en zorgaanbieders, omdat de zorgvraag vaak chronisch is. Het financieren van huishoudelijke hulp uit het collectief gefinancierde verstrekkingenpakket heeft een relatief groot risico op *moral hazard*. *Moral hazard* houdt in dat mensen meer of duurdere zorg vragen als gevolg van verzekeringsdekking vergeleken met een situatie waarin ze zelf voor de kosten moeten opdraaien. In ieder huishouden moet huishoudelijk werk verricht worden waardoor een beroep op middelen uit het collectief gefinancierde verstrekkingenpakket aantrekkelijk kan zijn. Bij de uitkomsten en kwaliteit van zorg gaat het vaak om het welzijn van de zorgvrager en diens sociale omgeving en niet zozeer om het verbeteren van de gezondheid van de zorgvrager zoals in de *cure* sector. Deze specifieke kenmerken van de *care* sector zijn methodologisch en beleidsmatig interessant. Ze staan centraal in dit proefschrift. Daarbij wordt de meeste aandacht besteedt aan mantelzorg.

Een belangrijk thema van dit proefschrift is hoe te voorkomen dat er een ongewenste verschuiving van de collectief gefinancierde zorglasten plaatsvindt vanuit het gezondheidszorgbudget naar de private sfeer van de zorgvragers en hun mantelzorgers. Als mantelzorg buiten beschouwing wordt gelaten, kan een interventie in de gezondheidszorg relatief kosteneffectief lijken te zijn. Maar deze relatief gunstige kosteneffectiviteit wordt dan alleen veroorzaakt doordat de kosten en effecten van mantelzorg onzichtbaar, lees niet meegenomen, zijn. Dit impliceert het gevaar van beleidsaanbevelingen waarbij gezondheidszorgkosten worden verplaatst naar de private sfeer van de mantelzorgers. Daarnaast staan het aanbod van en de vraag naar mantelzorg centraal in dit proefschrift. Evenals de (economische) effecten van de introducties van persoonsgebonden budgetten (pgb's) in de *care* sector. Een pgb is een som geld waarmee zorgvragers zelf hun zorg in kunnen kopen bij de zorgaanbieder van hun keuze. Deze pgb's worden gezien als een belangrijk instrument om consumentensoevereiniteit te waarborgen in de *care* sector.

## 2. Onderzoeksvragen

Dit proefschrift bestudeert mantelzorg vanuit een economisch perspectief. Het behandelt drie verschillende maar gerelateerde economische problemen ten aanzien van mantelzorg:

- 1) Wat is de relatie tussen het verlenen van mantelzorg en andere economische activiteiten zoals betaald werk?
- 2) Hoe moet mantelzorg worden meegenomen in economische evaluaties binnen de gezondheidszorg?
- 3) Wat zijn de (economische) gevolgen van de introductie van persoonsgebonden budgetten in de AWBZ sector en in het bijzonder voor mantelzorg?

We bespreken de drie onderzoeksvragen hieronder afzonderlijk. In paragraaf 3 de relatie tussen het verlenen van mantelzorg en andere economische activiteiten, in paragraaf 4 de economische waardering van mantelzorg waarbij we eerst het meten van mantelzorg (paragraaf 4.1) en vervolgens het waarderen van mantelzorg (paragraaf 4.2) behandelen en in paragraaf 5 de (economische) gevolgen van de introductie van pgb's in de AWBZ sector. Hierbij hanteren we steeds de volgende structuur: allereerst presenteren we de achtergrond en de aanleiding van de onderzoeksvraag. Wanneer het noodzakelijk is, bespreken we vervolgens de onderzoeksmethode. Daarna beschrijven we hoe de gebruikte data zijn verzameld en hoeveel mensen aan het onderzoek hebben deelgenomen. Dan presenteren we de belangrijkste onderzoeksresultaten. Tenslotte bediscussiëren we de onderzoeksresultaten en trekken we de belangrijkste conclusies.

### 3. Mantelzorg in relatie tot andere economische activiteiten

Het aanbod van mantelzorg hangt samen met andere economische activiteiten van de (potentiële) mantelzorger, zoals het verrichten van betaald of onbetaald werk. Er is veel literatuur over de karakteristieken van mantelzorgers. Mantelzorg wordt bijvoorbeeld vaak verleend door vrouwen aan hun partner of ouders. Economen benadrukken vaak de opportuniteitskosten van het verlenen van mantelzorg. Zij stellen dat mantelzorg ten koste gaat van bijvoorbeeld het verrichten van betaald werk.

In deze literatuur wordt echter nauwelijks rekening gehouden met het zogenaamde endogeniteitsprobleem van het verrichten van betaald werk en het verlenen van mantelzorg. Endogeniteit betekent dat het verrichten van betaald werk van invloed kan zijn op het verlenen van mantelzorg en dat het verlenen van mantelzorg van invloed kan zijn op het verrichten van betaald werk. Het negeren van dit endogeniteitsprobleem kan leiden tot een onderschatting of overschatting van deze invloeden. Een oplossing van dit endogeniteitsprobleem is belangrijk omdat het zorgt voor een completer inzicht in de keuzeprocessen van mantelzorgers.

Dit endogeniteitsprobleem is gemodelleerd en empirisch getoetst op een steekproef van 1106 respondenten. Iedereen had iemand met een zorgvraag in hun sociale omgeving en was daarom een potentiële mantelzorger. 67,7 procent van de potentiële mantelzorgers had betaald werk en 32,3 procent niet. Driekwart van de respondenten is mantelzorg gaan verlenen en een kwart niet.

We vinden dat het verlenen van mantelzorg een negatieve invloed heeft op de hoeveelheid verricht betaald werk. Het hebben van betaald werk heeft een negatieve invloed op de hoeveelheid verleende mantelzorg, maar de hoeveelheid betaald werk heeft hierop geen invloed. Dit lijkt erop te duiden dat mantelzorgers de gevraagde zorg leveren, ondanks hun arbeidsmarktverplichtingen. Wanneer beleidsmakers een groter deel van de zorg door mantelzorgers zouden willen laten verrichten, zijn er mogelijk effecten te behalen wanneer ze zich richten op het keuzeproces van potentiële mantelzorgers tussen het verrichten van betaald werk en het verlenen van mantelzorg. Zo zouden ze niet-mantelzorgers, indien wenselijk, kunnen stimuleren om mantelzorg te gaan verlenen. Doordat het verlenen van mantelzorg een negatief effect lijkt te hebben op de hoeveelheid verricht betaald werk zouden beleidsmakers zich ook kunnen richten op het ondersteunen van mantelzorgers bij het verlenen van hun zorg.

## 4. De economische waardering van mantelzorg

Mantelzorg wordt regelmatig genegeerd in economische evaluaties binnen de gezondheidszorg. Bijvoorbeeld doordat het perspectief van een verzekeraar in plaats van het maatschappelijk perspectief wordt gehanteerd of vanwege meet- en waarderingsproblemen van mantelzorg. Een gevolg zou kunnen zijn dat beleidsmakers besluiten om een interventie in de gezondheidszorg te implementeren op basis van de resultaten van een economische evaluatie omdat de interventie relatief kosteneffectief lijkt te zijn. Wanneer deze relatief gunstige kosteneffectiviteit slechts wordt veroorzaakt doordat de kosten en effecten van mantelzorg niet zijn meegenomen, zal het implementeren van de interventie ertoe kunnen leiden dat gezondheidszorgkosten worden verplaatst naar de private sfeer van de mantelzorgers.

### 4.1 Meten

Het betrouwbaar meten van mantelzorgtijd is een noodzakelijke voorwaarde voor het waarderen van mantelzorg. Tijdsmeting blijkt echter lastig te zijn. Eén van de problemen is dat mensen vaak verschillende activiteiten tegelijk combineren, zoals auto rijden en radio luisteren. Dit wordt joint productie genoemd. Bij mantelzorg kan deze joint productie extra lastig zijn doordat mantelzorgers bijvoorbeeld huishoudelijk werk, dat ze ook of juist niet deden wanneer ze geen mantelzorg zouden verlenen, combineren met mantelzorgactiviteiten.

In dit proefschrift is om praktische redenen de herinneringsmethode gebruikt om mantelzorgtijd te meten. Het dagboek is een andere methode om tijd te meten en wordt gezien als de gouden standaard. Daarom hebben we de twee methoden met elkaar vergeleken en hebben we getest in hoeverre de herinneringsmethode stabiele resultaten genereert.

Hiervoor hebben we 199 mantelzorgers benaderd via de regionale steunpunten mantelzorg die zijn verenigd in X-Zorg en worden vertegenwoordigd door de Landelijke Organisatie Thuisverzorgers (LOT) en via de belangenvereniging voor mensen met een pgb, Per Saldo. Deze mantelzorgers hebben gedurende twee dagen binnen dezelfde week een door ons ontwikkeld dagboek bijgehouden. Vervolgens hebben ze over dezelfde week een door ons ontwikkelde vragenlijst met de herinneringsmethode ingevuld. Bovendien hebben 150 mantelzorgers (waarvan 70 met een stabiele gezondheidstoestand) op twee

meetmomenten, december 2001 en april 2002, de herinneringsmethode ingevuld om de stabiliteit van de methode te testen.

Zonder correctie voor joint productie zijn er nauwelijks verschillen tussen dagboek en herinneringsmethode. Volgens beide methoden besteden mantelzorgers gemiddeld ongeveer acht uur per dag aan zorg. Met correctie voor joint productie overschat de herinneringsmethode de hoeveelheid verleende mantelzorg echter met ongeveer twee uur per dag ten opzichte van de dagboekmethode. Een ander probleem met de herinneringsmethode is dat deze instabiel blijkt te zijn wanneer resultaten van twee verschillende meetmomenten met elkaar worden vergeleken. Dit zou het gevolg kunnen zijn van leereffecten doordat de herinneringsmethode op het tweede meetmoment een week na het bijhouden van het dagboek is ingevuld. De herinneringsmethode lijkt de hoeveelheid verleende mantelzorg dus te overschatten. Deze informatie is van belang bij het interpreteren van de hoeveelheid tijd die mantelzorgers elders in dit proefschrift rapporteren te besteden.

Een specifiek probleem bij het meten van mantelzorgtijd hangt samen met één van de waarderingsmethoden voor mantelzorg, namelijk de opportuniteitskosten methode. Voor deze methode is het noodzakelijk om de tijd te meten die een mantelzorger heeft opgegeven om zorg te kunnen gaan verlenen. Vooral wanneer mantelzorgers al lang zorg verlenen, kan dit problematisch zijn. Daarom hebben we een alternatieve methode ontwikkeld waarbij we mantelzorgers vragen aan welke activiteiten (betaald en onbetaald werk en vrije tijd) voor hoeveel uur per week ze hun tijd zouden gaan besteden wanneer ze geen mantelzorg meer zouden hoeven te verlenen.

255 mantelzorgers voor mensen met een cerebrovasculaire aandoening (CVA) en 153 mantelzorgers voor mensen met reumatoïde artritis (RA) hebben geparticipeerd in dit onderzoek door middel van het invullen van een door ons ontwikkelde vragenlijst. Vergelijking van beide groepen is interessant omdat een CVA een duidelijk startpunt heeft en RA niet, waardoor het bij CVA relatief eenvoudig zou kunnen zijn om opgegeven tijd te meten en bij RA niet.

Vergelijking van de twee groepen leert dat het voor CVA-mantelzorgers iets eenvoudiger is om de gestelde vragen te beantwoorden. De alternatieve vragen zijn door RA-mantelzorgers veel beter ingevuld dan de normale vragen. Dit suggereert dat de door ons ontwikkelde methode een beter alternatief is dan de normale methode.

## 4.2 Waarderen

Wanneer er in de internationale literatuur aandacht is voor het opnemen van mantelzorg in economische evaluaties dan staat de economische waardering van mantelzorg meestal centraal. De opportuniteitskosten methode wordt gezien als de theoretisch correcte methode om mantelzorg te waarderen, terwijl de proxy goed methode wordt aanbevolen als een bruikbaar alternatief. In de opportuniteitskosten methode wordt mantelzorg gewaardeerd tegen de prijs van het opgegeven alternatief, meestal het netto uurloon van de mantelzorger. De proxy goed methode waardeert mantelzorg tegen de prijs van een alternatieve dienst, bijvoorbeeld professionele thuiszorg.

Dit proefschrift betoogt dat de focus van zowel de opportuniteitskosten methode als van de proxy goed methode te beperkt is om een complete economische waardering van mantelzorg te geven. Het verlenen van mantelzorg leidt namelijk tot verhoogde morbiditeitrisico's en in sommige subgroepen mantelzorgers zelfs tot verhoogde mortaliteitrisico's die niet meegenomen worden in beide methoden. Bovendien brengt het verlenen van mantelzorg zowel positief als negatief direct nut voor de mantelzorger met zich mee dat beide methoden negeren. Een specifiek aanvullend probleem met de proxy goed methode is dat deze niet is gebaseerd op de preferenties van zorgvragers noch van mantelzorgers, zoals de welvaarteconomische theorie vereist.

Daarom beveelt dit proefschrift drie andere methoden aan die theoretisch wel een complete economische waarde van mantelzorg genereren. Het gaat om de contingente waarderingsmethode, de vignettenmethode en de welzijnswaarderingmethode. Voor zover we hebben kunnen nagaan zijn deze drie methoden niet eerder toegepast om mantelzorg te waarderen. In dit proefschrift worden ze toegepast en wordt getest of ze aan de theoretische verwachtingen voldoen. Bovendien worden de opportuniteitskosten methode en de proxy goed methode in dit proefschrift toegepast om mantelzorg in Nederland te waarderen en de uitkomsten van deze twee methoden te vergelijken met de resultaten van de drie eerder genoemde methoden.

We hebben de methoden toegepast op verschillende populaties mantelzorgers, zogenaamde ervaringsdeskundigen. Voor de operationalisatie van de contingente waarderingsmethode betekent dit dat bijvoorbeeld aan mantelzorgers is gevraagd hoeveel compensatie in geld ze van de overheid zouden willen ontvangen om per week een hypothetisch uur extra mantelzorg te gaan verlenen. Bij de vignettenmethode hebben we aan mantelzorgers gevraagd om zich te verplaatsen in vier hypothetische situaties die kunnen afwijken van hun eigen situatie. De situaties variëren in zorgtaken, in uren

mantelzorg per week en in financiële compensatie van de overheid. Mantelzorgers hebben hun voorkeuren voor deze situaties aangegeven door middel van rapportcijfers. Daarnaast hebben ze aangegeven of ze deze hypothetische situaties hoger of lager waarderen dan hun eigen situatie. De welzijnswaarderingmethode vereist dat mantelzorgers aangeven hoe gelukkig ze zijn op bijvoorbeeld een verbale of numerieke schaal. Beide schalen zijn in dit proefschrift toegepast en vergeleken.

De opportuniteitskosten methode en de proxy goed methode zijn toegepast op twee populaties: 255 CVA-mantelzorgers en 153 RA-mantelzorgers. De contingente waarderingmethode en de vignettenmethode zijn ook toegepast op de 153 RA-mantelzorgers alsmede, evenals de welzijnswaarderingmethode, op een populatie van 865 mantelzorgers die zorg verlenen aan mensen met diverse aandoeningen, benaderd via X-zorg.

Het blijkt dat de contingente waarderingmethode vooral samenhangt met hypothesen over de gezondheidsgerelateerde kwaliteit van leven van mantelzorgers en zorgvragers, met hun inkomen en met instituties zoals flexibiliteit van betaald werk. Hypothesen over de subjectieve belasting en tijdsbesteding zijn verworpen. Nutinterdependenties, zoals het meewegen van aspecten van het leven van een naaste, zijn cruciaal in de context van de waardering van mantelzorg. Ontwikkelde hypothesen ten aanzien van deze problematiek zijn over het algemeen niet verworpen. De waardering van mantelzorg via de vignettenmethode lijkt vooral samen te hangen met de waardering van de eigen situatie door de mantelzorgers en met hun eigen gezondheidsgerelateerde kwaliteit van leven. Zoals verwacht, hangt de tijd die mantelzorgers besteden aan zorgverlening negatief samen met hun geluk, terwijl hun inkomen positief met hun geluk samenhangt. Eén en ander suggereert dat de drie alternatieve waarderingmethoden in staat zijn om een complete waardering van mantelzorg te genereren.

Tabel 1 geeft een samenvatting van de belangrijkste resultaten van de vijf verschillende waarderingmethoden.

**Tabel 1:** Vergelijking van de resultaten van de verschillende toegepaste waarderingsmethoden vanuit het perspectief van de mantelzorger (in euro per uur)

Methode	Populatie		
	CVA <sup>1</sup>	RA <sup>2</sup>	LOT <sup>3</sup>
Opportunitetskosten methode (gemiddelde)	17.34	10.64	
Proxy goed methode (gemiddelde)	13.51	12.19	
Contingente waarderingsmethode (willingness to accept) (marginaal ten opzichte van het gemiddelde)		7.80	10.52
Contingente waarderingsmethode (willingness to pay) (marginaal ten opzichte van het gemiddelde)		9.52	8.61
Vignettenmethode (marginaal van 15 naar 16 uur per week)		16.00	8.00
WBV (Geluk verbaal: 1 tot 5) (marginaal ten opzichte van het gemiddelde)			15.39
WBV (Geluk numeriek: 0 tot 10) (marginaal ten opzichte van het gemiddelde)			16.49

<sup>1</sup> CVA: 225 mantelzorgers voor mensen met cerebrovasculaire aandoeningen

<sup>2</sup> RA: 153 mantelzorgers voor mensen met reumatoïde artritis

<sup>3</sup> LOT: 865 mantelzorgers voor mensen met allerlei verschillende aandoeningen

De tabel geeft inzicht in de externe validiteit van de verschillende methoden. Uitkomsten variëren tussen de 8 en 17 euro per uur. Interpretatie van de resultaten is niet altijd identiek. Soms gaat het om een gemiddelde waarde per uur zoals in de opportunitetskosten methode en in de proxy goed methode. De contingente waarderingsmethode en de welzijnswaarderingmethode geven een marginale waarde ten opzichte van het steekproefgemiddelde, terwijl de waardering op basis van de vignettenmethode afhangt van het startpunt. In tabel 1 bijvoorbeeld een verandering van 15 naar 16 uur mantelzorg per week. Het is opvallend dat de resultaten van de opportunitetskosten methode en de proxy goed methode niet systematisch af lijken te wijken van respectievelijk de contingente waarderingsmethode, de vignettenmethode en de welzijnswaarderingmethode. Deze laatste drie methoden genereren in tegenstelling tot de eerste twee methoden een complete

waardering van mantelzorg. Een mogelijke verklaring is dat het directe nut en disnut van mantelzorgverlening in balans zijn.

Op het vlak van de non-respons scoren de proxy goed methode en de welzijnswaarderingmethode relatief goed. De opportuniteitskosten methode en de vignettenmethode komen er relatief slecht vanaf en de contingente waarderingmethode is een middenmoter.

## **5. De (economische) effecten van het persoonsgebonden budget**

In veel landen wordt langdurige zorg georganiseerd en gefinancierd door middel van zorg in natura. Dit houdt in dat zorgfinanciers de zorgaanbieders direct, zonder tussenkomst van de zorgvragers, betalen voor hun diensten. Sinds de jaren negentig van de vorige eeuw is er in een aantal landen een alternatief systeem ontwikkeld waarbij zorgvragers van zorgfinanciers een budget (in Nederland een pgb) ontvangen. Hiermee kunnen ze zelf zorg in kopen bij wie ze willen voor de prijs die ze met aanbieders overeenkomen, inclusief hun mantelzorgers. Tot op heden is er weinig bekend over de economische effecten van pgb's.

De economische effecten van pgb's zijn geanalyseerd aan de hand van een zelf ontwikkelde vragenlijst over onder andere zorggebruikgegevens, ingevuld door 609 mensen met een pgb, bereikt via Per Saldo. Resultaten laten zien dat mensen met een pgb meer private zorg, meestal verleend door freelancers, inkopen vergeleken met mensen die zorg in natura ontvangen. Voor reguliere thuiszorg en mantelzorg vinden we geen verschillen tussen mensen met een pgb en mensen met zorg in natura. De prijzen die mensen met een pgb betalen voor hun zorg liggen gemiddeld iets lager dan de prijzen die in het naturasysteem worden betaald: 18,91 versus 25,40 euro per uur. Een mogelijke verklaring voor de ongeveer 25 procent lagere prijzen die mensen met een pgb betalen, zijn de transactiekosten voor bijvoorbeeld gebouwen van de thuiszorg die in het naturasysteem wel en in het pgb-systeem niet vergoed worden.

Een pgb is opgebouwd uit drie componenten: een inkomensafhankelijke eigen bijdrage, een vrij te besteden bedrag (voorheen een forfaitair bedrag) en een niet vrij te besteden bedrag dat teruggeven moet worden wanneer het niet wordt opgemaakt. Binnen de groep mensen met een pgb lijken de eigen bijdrage en het vrij te besteden bedrag geen invloed te hebben op de hoogte van de betaalde prijzen (bij maandprijzen lijkt de hoogte van het vrij te besteden bedrag een negatieve invloed te hebben op de prijs). Een relatief hoger niet vrij te besteden bedrag lijkt echter te leiden tot relatief hogere betaalde prijzen

ceteris paribus. Een 1 procent hoger niet vrij te besteden deel van het pgb ten opzichte van een maandgemiddelde van 1.254,10 euro lijkt te leiden tot een 0,19 procent hogere uurprijs voor zorg. Voor cliënten die een maandprijs betalen, geldt dat een 1 procent hoger niet vrij te besteden deel van het pgb ten opzichte van een maandgemiddelde van 1.226,93 euro lijkt te leiden tot een 0,66 procent hogere maandprijs. Wanneer mensen met pgb zorg inkopen zonder dat ze hiervoor uiteindelijk financiële consequenties ondervinden, lijken ze minder geneigd te zijn om een zo laag mogelijke prijs te bedingen: *moral hazard*.

Om efficiëntere zorginkoop door mensen met een pgb te stimuleren, zou de inkomensgerelateerde eigen bijdrage of het vrij te besteden bedrag omhoog moeten. Verhogen van de eigen bijdrage heeft als belangrijk nadeel dat het kan leiden tot toegankelijkheidsproblemen in de zorg. Dit kan leiden tot gebruik van relatief duurdere zorg op lange termijn. Het verhogen van het vrij besteedbare bedrag is daarom een beter alternatief. Dit zou kunnen stuiten op maatschappelijke weerstand omdat mensen middelen uit het collectief gefinancierde verstrekkingenpakket voor private doelen kunnen gaan gebruiken. Hetzelfde gebeurt echter in de *care* sector, maar dan op het niveau van de zorgverzekeraars.

Er is weinig bekend over de effecten die het betalen van mantelzorgers, bijvoorbeeld uit een pgb, heeft voor de mantelzorgers. Het is wel gesuggereerd dat het geven van een financiële compensatie aan mantelzorgers negatieve psychologische effecten heeft voor bijvoorbeeld hun intrinsieke motivatie of voor de relatie tussen mantelzorg en zorgvrager.

Deze hypothesen hebben we getest door middel van een ontwikkelde vragenlijst die is ingevuld door 522 mantelzorgers bereikt via Per Saldo. Ongeveer de helft van deze mantelzorgers geeft aan dat ze uit het pgb betaald worden voor (een deel van) hun zorgverlening, gemiddeld bijna 300 euro per maand. De resultaten lijken erop te duiden dat het betalen van mantelzorg niet leidt tot negatieve psychologische effecten voor de mantelzorg in termen van zelfwaardering, emotionele relatie tussen mantelzorg en zorgvrager en plezier in het verlenen van zorg. Er lijkt wel een positief verband te zijn tussen het betalen van mantelzorg en de kans dat een mantelzorg aangeeft dat het verlenen van zorg belangrijk is. De resultaten impliceren dat het betalen van mantelzorgers geen negatieve externe effecten in de vorm van psychologische attitude lijken te hebben. Voor beleidsmakers lijkt er dus vanuit dit oogpunt geen belemmering te zijn om mantelzorgers financieel te compenseren of om het betalen van mantelzorgers vanuit een pgb te verbieden.

## 6. Epiloog

Dit proefschrift heeft geprobeerd enkele problemen in de economische literatuur ten aanzien van mantelzorg op te sporen en op te lossen. Er blijft echter een bijna onuitputtelijke onderzoeksagenda open staan. Hopelijk stimuleert dit proefschrift toekomstig economisch onderzoek naar mantelzorg en naar de positie van mantelzorgers binnen de gezondheidszorg.

Het is vrijwel onmogelijk om aan het thema mantelzorg te werken zonder oog te krijgen voor sommige problemen die mantelzorgers ervaren. Vooral het bezoeken van mantelzorgers om een ontwikkelde vragenlijst te testen of het beantwoorden van telefonische vragen over een uitgezette enquête geeft af en toe een blik achter de schermen van hun soms zware levensomstandigheden. Hopelijk zullen beleidsmakers de resultaten van dit onderzoek dan ook gebruiken om instituties te ontwikkelen, zowel in de gezondheidszorg als in het welzijnswerk en op de arbeidsmarkt, die ervoor zorgen dat de lasten, in de breedste zin van het woord, van zorg in een vergrijzende samenleving niet volledig op de schouders van de mantelzorgers worden gelegd.



# Dankwoord

Tijdens mijn afstudeerstage voor de studie Sociale en Institutionele Economie aan de Universiteit Utrecht bij de Stichting voor Economisch Onderzoek groeide mijn interesse om AIO te worden. Mijn belangstelling voor gezondheidseconomie werd gestimuleerd door enkele personen die mijn weg kruisten. Ik noem met name Werner Brouwer en Esther Mot. Deze contacten leidden tot mijn aanstelling als AIO bij de instituten Beleid en Management Gezondheidszorg en Medische Technologie Assessment van de Erasmus Universiteit Rotterdam en bij het Centrum voor Zorg Onderzoek van het Rijksinstituut voor Volksgezondheid en Milieu in Bilthoven.

De wetenschappelijke resultaten die leidden tot het schrijven van mijn dissertatie waren niet tot stand gekomen zonder de hulp en medewerking van veel mensen die ik daarvoor hartelijk dank.

Allereerst de mantelzorgers en hun zorgvragers voor het invullen van de verschillende vragenlijsten. Ik heb hen kunnen bereiken via het Edisse project, het Jan van Breemen Instituut, de regionale steunpunten mantelzorg met als koepelorganisatie X-zorg, de Landelijke Organisatie Thuisverzorgers en Per Saldo.

In de eerste fase van het onderzoek brainstormde ik veel met mijn copromotor Marc Koopmanschap, waardoor nieuwe ideeën ontstonden. Marc, ik waardeer het dat je mij altijd scherp en kritisch hield. De projectleider van het door ZonMw gefinancierde project 'Valuing informal care in health technology assessment', Werner Brouwer, alsmede Trudi van den Bos, Job van Exel en Marc Koopmanschap voor het ontwikkelen van de vragenlijsten en de dataverzameling. Dit vormde de basis voor het succesvol afronden van een aantal wetenschappelijke artikelen, waarvan er vijf onderdeel uitmaken van dit proefschrift. Veel heb ik te danken aan mijn promotor Frans Rutten die vooral in de eindfase een belangrijke rol heeft vervuld. Frans, ik heb met name waardering voor je zakelijke manier van begeleiden en je duidelijke aanwezigheid op de achtergrond.

Naast bovengenoemden is tevens een eervolle vermelding voor de andere co-auteurs op zijn plaats. In alfabetische volgorde dank ik hen hartelijk. Maiwenn Al, jouw statistische kennis was van groot belang om het onderzoek met de vignettenmethode tot een goed einde te brengen. Han Bleichrodt, mijn theoretische kennis van de micro-economie is dankzij jou verdiept. Ada Ferrer-i-Carbonell, your sharp analysis and efficient way of working helped to produce a high quality paper. Louis Eeckhoudt, the way you are able to grasp complex ideas in a few minutes is unique. Wolter Hassink, de lange sessies

vond ik leerzaam en boeiend. Pol Spauwen, jouw creativiteit bij ontwikkelen van het dagboek en het uitvoeren van het tijdsbestedingsonderzoek waardeer ik zeer. Isolde Woittiez, de wijze waarop je complexe econometrische concepten voor mij verduidelijkte, is ook voor mijn toekomst waardevol.

Zonder jouw grote kennis van de Engelse taal, Wien Limburg, waren mijn papers een stuk minder leesbaar geweest. Jouw suggesties gingen vaak verder dan alleen taalcorrectie. Hartelijk dank voor je ondersteuning.

Als twee instituten bij een onderzoek betrokken zijn, zorgt dit soms voor extra complicaties. Voor hun steun hierbij bedank ik Dirk Ruwaard, Hans Jager en Caroline Baan.

Mijn dank gaat ook uit naar de leden van de beoordelingscommissie, prof. dr. B.M.S. van Praag, prof. dr. F.T. Schut en prof. dr. C.N. Teulings. Ook dank ik prof. dr. H. Bleichrodt, dr. M. Mootz, prof. dr. R. Veenhoven en dr. I. Woittiez voor het feit dat ze opponeren bij de verdediging van mijn proefschrift.

Dennis en Pol, tijdens de studie en activiteiten voor ECU'92 is onze vriendschap gegroeid. Bedankt dat jullie paranimf willen zijn.

Laila, bedankt voor de vormgeving van de omslag, Herman voor de prettige samenwerking tijdens het drukken van het proefschrift en Ilir voor de hulp bij de opmaak van het binnenwerk.

In de afgelopen jaren is er intensief met me meegedacht en meegeleefd. Daarom veel dank aan kamergenoten (Martijn, Janneke en Jeroen), collega's en vrienden.

Tenslotte wil ik mijn familie hartelijk bedanken voor hun steun. Mijn broer Jan en mijn schoonzus Anja en hun kinderen, Jessica, Theresia, Joris en Nikita, mijn zus Rita en mijn zwager Benny en hun kinderen, Heiny, Arne, Joanne, Gertjan, Niek en Femke, jullie hebben altijd belangstelling getoond voor mij en mijn onderzoek. Dat waardeer ik bijzonder. Ma en pa, zonder jullie onvoorwaardelijke steun had ik het niet gered!