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# *Valuing Informal Care in Europe*

## **Analytical Review of Existing Valuation Methods**

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# Executive summary

Informal care is generally defined as unpaid care provided to older and dependent people by a person with whom they have a social relationship, such as a spouse, parent, child, other relative, neighbour, friend or other non-kin (Triantafillou et al., 2010). This care is too often overlooked by researchers and policymakers and is frequently not systematically recorded or monitored given its ‘informal’ nature. The challenges posed by population ageing nevertheless call for efforts to assess the value of these invisible and growing care responsibilities, which put greater pressure on carers across Europe. While studying informal care, it is important to adopt a broad perspective so as to provide a comprehensive description of the social and economic costs of informal carers’ involvement in care toward a family member, friend or neighbour. Researchers and policymakers therefore need to acknowledge and evaluate both the contribution of informal care to the overall production of care as well as its impact on carers’ social and professional life in order to comprehensively appreciate the share contributed by carers within the total costs of care.

The main economic costs borne by informal care cover three different domains: “Employment consequences, Out-of-pocket expenses and Caregiving labour” (Keating, Lero, Fast, Lucas & Eales, 2013). In this report, we focus chiefly on the economic value of “caregiving labour” (i.e. the in-kind contribution made by carers) which is an important part of the total costs of care as a whole and of informal care.

In economic literature, valuation methods are primarily used to compare the cost-effectiveness of various healthcare interventions in order to inform the decision-making process. Yet, by failing to consider the costs borne by informal carers, these economic evaluations may favour interventions that involve the transfer of costs from the public health payer to the private sphere (e.g. early hospital discharges at home). Including the informal care dimensions in economic evaluations of healthcare interventions is therefore crucial to prevent placing additional pressure on informal

carers. In recent years, various attempts to evaluate the costs of informal care have been made. However, to date, there is no unified and widely-accepted method available to evaluate this form of non-market production.

Two core groups of economic valuation methods exist to assess the value of “caregiving labour” (i.e. the in-kind contribution of carers). ‘**Revealed Preferences**’ methods build on the value of the effort input or value of a corresponding good available on the market<sup>1</sup>, without considering the carer’s preferences. Other methods seek to include the negative and positive aspects of providing care from the informal carer’s perspective. These are the ‘**Stated Preferences**’ methods (the Contingent valuation method and the Conjoint measurement method<sup>2</sup>) and the ‘**Well-being**’ method. Table 1 below provides an overview of the existing methods, their valuation principle, strengths and shortcomings.

While valuation methods that aim to capture the carer’s preferences (‘Stated Preferences’ methods) seem appealing at first, they raise a series of complex scientific and political questions. The ‘Contingent valuation’ method is particularly appealing because it alludes to the burden of care, a dimension not addressed by any other method. Nevertheless, it may not be sensitive enough to assess the entire impact of informal caregiving on carers themselves. Moreover, our research underlines that valuation methods that consider both the positive and negative aspects (utility/disutility) of care from the carer’s perspective may ultimately yield lower results than methods that disregard these aspects. This holds consequences from a policy perspective since initiatives building on some of these methods may effectively underestimate the objective impact of care on carers and have detrimental effects for carers.

On the other hand, methods that do not consider the carer’s preferences seem to primarily consider informal care as a burden. The ‘proxy good’ method may be interpreted as the valuation of the plausible costs of care to support care recipients at home<sup>12</sup> should informal carers defect (as a result

Table 1. **Overview of monetary valuation methods in use**

	'Revealed Preferences'		'Stated Preferences'		Other methods
	Opportunity costs (input approach)	Proxy good <sup>3</sup> (output approach) <sup>4</sup>	Contingent valuation	Conjoint analysis	'Well-being' method
Main principle	Estimation of the benefit forgone due to spending time on providing informal care <sup>5</sup>	Estimation of the cost that would be paid if informal carers were replaced by professionals	Estimation of the monetary value carers would accept to provide 1 additional hour of care (or would accept to pay to reduce their caring time by 1 hour)	Similar as for the Contingent valuation, but with more details about the caring situation (i.e. 'attributes')	Econometric model to estimate the amount needed to compensate 1 additional hour of care while maintaining the same level of well-being
Type of indicator	Costs of informal care according to the wage rates of carers	Costs of informal care according to the market prices of close professional substitutes	Monetary valuation of the carer's preferences		Monetary value including the carer's preferences (satisfaction, discontent and other costs potentially affecting the carer's well-being like out-of-pocket expenses)
Strengths of the method	<ul style="list-style-type: none"> <li>➤ Based on carers' current engagement</li> </ul>	<ul style="list-style-type: none"> <li>➤ Relatively easy to use and interpret</li> <li>➤ Based on carers' current engagement</li> </ul>			
Shortcomings of the method	<ul style="list-style-type: none"> <li>➤ Difficulty to determine the time forgone per activity</li> <li>➤ Carers' preferences not captured</li> <li>➤ Difficulty determining opportunity costs for out-of-workforce carers</li> <li>➤ Value potentially influenced by negative impact of caring responsibilities on carer's wages</li> </ul>	<ul style="list-style-type: none"> <li>➤ Need a high level of accuracy in measurement of time per specific task</li> <li>➤ Carers' preferences not captured</li> </ul>	<ul style="list-style-type: none"> <li>➤ Based on a hypothetical scenario</li> <li>➤ Difficulty representing the marginal variation of 1 hour of caring</li> <li>➤ Risk of the scenario being misinterpreted</li> <li>➤ Other considerations than carer's preferences to determine the value</li> <li>➤ Format of answers likely to influence the distribution of values</li> <li>➤ Acceptable sensitivity (but to be further investigated)</li> </ul>	<ul style="list-style-type: none"> <li>➤ Based on a hypothetical scenario</li> <li>➤ Requires advanced econometric models</li> </ul>	<ul style="list-style-type: none"> <li>➤ Extensive data collection required</li> <li>➤ Value potentially influenced by the negative impact of being a carer on wages</li> <li>➤ Exclusion of non-carers' perceptions</li> </ul>
Assessed value per 1 hour of care*	<ul style="list-style-type: none"> <li>➤ Depends on the wage rates of carers</li> </ul>	<ul style="list-style-type: none"> <li>➤ €14.3 (2008, Spain)<sup>6</sup></li> </ul>	<ul style="list-style-type: none"> <li>➤ WTA: €13.9 (2001, Netherlands)<sup>7</sup></li> <li>➤ WTP: €13.3 (2008, France)<sup>8</sup></li> </ul>	<ul style="list-style-type: none"> <li>➤ €16.1 (2011, Netherlands)<sup>9</sup></li> <li>➤ €16.3 (2001, Netherlands)<sup>10</sup></li> </ul>	<ul style="list-style-type: none"> <li>➤ €11.9 (2001, Netherlands)<sup>11</sup></li> </ul>

\*Adjusted for 2018

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of an anticipated choice to stop providing care, or an unexpected halt due to health problems, hospitalisation or death, for example) (Paraponaris, Davin & Verger, 2012).

The 'opportunity cost' method assesses the value of informal care by considering the wage rate of working carers to value the activities they forgo due to the time they spend providing care. This method provides a complementary insight into the economic value of what individuals have renounced to provide care. Yet, use of this method is problematic when it comes to non-working carers. For people of working age, the value of a potential or minimum wage could be used as a suitable proxy. For retirees, 'Stated Preferences' methods may be useful for overcoming the absence of labour market participation.

As such, the 'proxy good' method offers a good perspective on the costs of informal care and, unlike the 'opportunity cost' method, allows various types of carers to be considered – whether active in or outside of the labour market. This again holds important political implications since the method gives a much more comprehensive and realistic view of the value of informal care.

Given the multiple societal questions informal care raises, we argue that each method studied in this report provides a specific take on the economic value of informal care. The ideal valuation method of informal care should thus build on a mixed approach that considers the typology of situations in which carers may find themselves.

# Chapter 1

# Introduction

## Scope of the report

Informal care is generally defined as unpaid care provided to older and dependent people by a person with whom they have a social relationship, such as a spouse, parent, child, other relative, neighbour, friend or other non-kin (Triantafyllou et al., 2010). This care is too often overlooked by researchers and policymakers and is frequently not systematically recorded or monitored given its 'informal' nature and the fact it takes place in the private sphere. The challenges posed by population ageing nevertheless call for efforts to assess the value of these invisible and growing care responsibilities, which are putting greater pressure on carers across Europe. Similarly, both researchers and policymakers need to acknowledge and evaluate the contribution made by informal care to the overall production of care in order to appreciate carers' share in the total costs of care.

The main economic costs of informal care borne by informal carers cover three different domains: "*Employment consequences, Out-of-pocket expenses and Caregiving labour*" (Keating et al., 2013). In this report, we focus on the economic value of "caregiving labour" (i.e. the in-kind contribution of carers), which is an important part of both the total costs of care and the total economic costs of informal care.

Different methods seek to assess the value of non-market commodities and have been applied to informal care. This report aims to review them and identify their strengths and weaknesses. We first describe the key principles underpinning the existing valuation methods of informal care and then present the theoretical and practical issues identified in the literature and by the authors. The report also makes some recommendations concerning the use of these methods. Beyond the consequences felt by informal carers themselves, informal care may affect the whole of society to various degrees, from the micro (families, employers) to the macro level (social security, public healthcare insurance, social care budgets). Still, it is important to note

this report does NOT capture all of the social and economic effects of informal care on the stakeholders involved. The report's scope is limited to a valuation method for informal care.

The research questions explored in this report include:

- Which are the existing methods for valuing informal care?
- What are the theoretical and practical issues each method raises?
- In which context are these methods considered (economic evaluation or not)?
- What are the estimated values of informal care according to each method?
- Which recommendations can be made based on this analytical overview?

## Informal care

### What is informal care and who are informal carers?

The EUROCARERS network defines informal carers as people of all ages who provide (usually unpaid) care to someone with a chronic disease, a disability or any other long-lasting-care needs outside of a professional or formal context (Eurocarers, 2018). So, a trained nurse may well qualify as both a formal carer in the workplace and an informal carer at home while providing care to a dependent parent. Recent research shows informal carers across the EU provide over 80% of all care (Hoffmann & Rodrigues, 2010). Care usually takes place within social relationships – the majority of carers are parents, partners, children, grandchildren, siblings, friends or neighbours. Because caring activities depend on the needs of the person requiring care, there is often no limit on the amount of care

provided or the time spent caring. The role played by informal carers in the provision of care is significant and carers are likely to face more and more pressure as the consequences of demographic ageing on the prevalence of chronic diseases and the sustainability of care systems unfold. Informal carers are involved in non-market production of care and their actual contribution to the total costs of care needs to be assessed in a valid and reliable way. In recent years, various attempts have been made to evaluate the costs of informal care. However, to date, there is no unified and widely-accepted method available to evaluate this form of non-market production.

### The contributions of carers

Various methods have been developed to assess the value of non-market commodities and have been applied to informal care. When it comes to measuring the economic value of “caregiving labour” (i.e. the in-kind contribution of carers), one finds two main categories of economic valuation methods.

The first category does not consider the actual preferences of carers. It consists of ‘**Revealed Preferences**’ methods which aim to assess the value of the effort input or of the corresponding

good available on the market<sup>13</sup>. ‘**Revealed Preferences**’ methods can be sub-divided into the ‘opportunity cost’ method and ‘replacement cost’ method (also known as the ‘proxy good’ method).

The second category of methods seeks to include the negative and positive aspects of providing care from the perspective of the informal carer – it incorporates ‘**Stated Preferences**’ methods and the ‘**Well-being**’ method. ‘**Stated Preferences**’ methods can be broken down into the ‘Contingent valuation’ method and the ‘Conjoint measurement’ method<sup>14</sup>.

### Overview of effects of informal care

#### Consequences for informal carers

While studying informal care it is important to adopt a broad perspective so as to be able to comprehensively describe the social and economic costs of informal carers’ involvement in care given to a family member, friend or neighbour. The multi-faceted impacts and consequences of informal care on carers must themselves be considered. For example, the extent and intensity of the informal care given may intersect with other social roles the informal carer may be playing; carers may face

Figure 1. **Economic costs of informal care for informal carers**

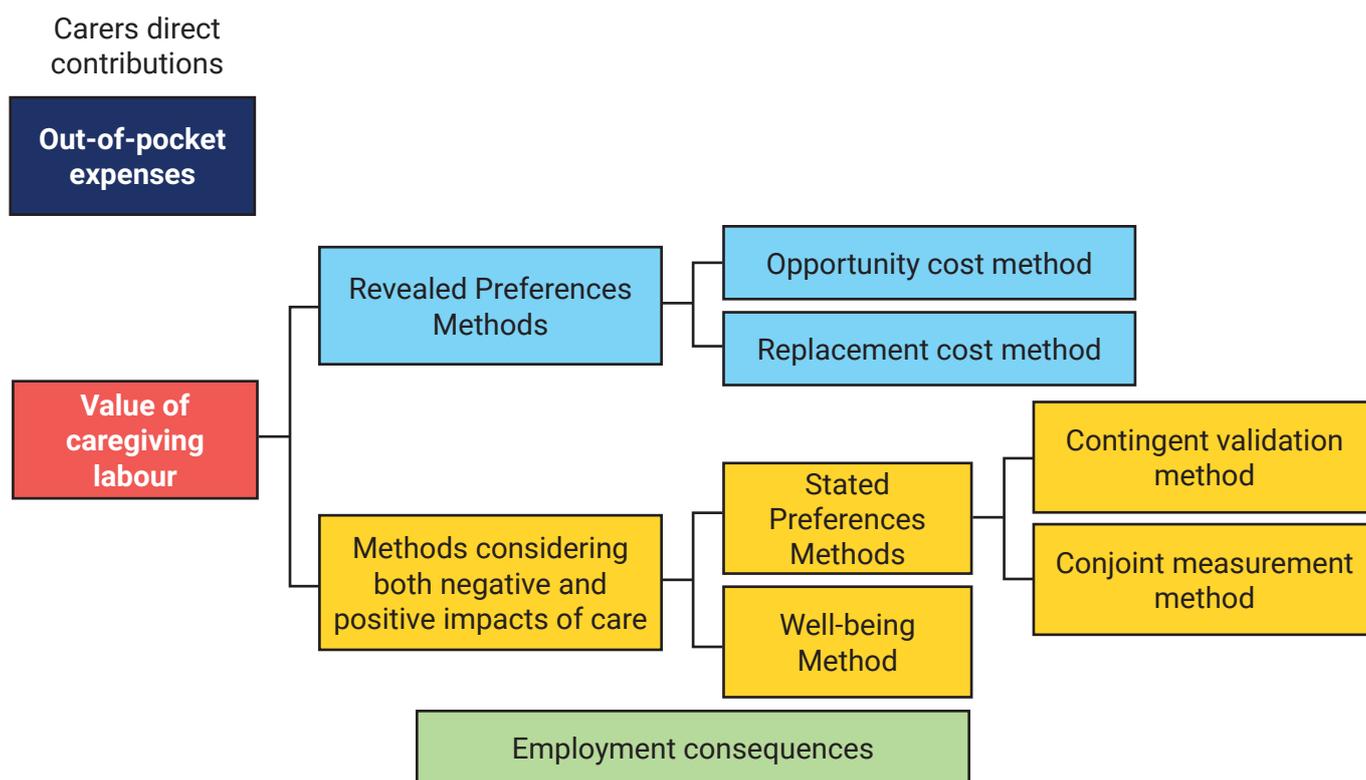


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exhaustion due to lack of respite; they may experience negative health and well-being outcomes or have trouble combining a demanding professional career with challenging caregiving responsibilities; they may reduce paid working hours or leave formal employment altogether in order to provide more informal care; they may also suffer financial issues due to out-of-pocket financial contributions made to the costs of formal care; they may experience family tensions as a result of their caregiving responsibilities; they may face discrimination at work, etc. On the bright side, informal carers may also derive positive feelings from their involvement in the non-market production of care. All of these aspects and the significant contribution given by informal carers to the total costs of care are nevertheless very often ignored, and rarely systematically monitored and assessed.

### Consequences for other stakeholders

A commitment such as that made by carers may also affect stakeholders outside of the care relationship on different levels: meso level, issues related to work–life balance, productivity, absenteeism, presenteeism, turnover or tensions between employees as a result of a staff member's informal caregiving responsibilities can entail both organisational and financial costs for employers. On the macro level, the prevalence of informal care may influence the level of healthcare expenditure, increase the cost and impact of sick leave and the labour market as a whole (for working carers and carers of working age). The gender dimension here is very strong since women are more likely than men to be required to assume care responsibilities for elderly family members with long-term care needs and are thus far more likely to reduce their working hours in the formal economy. As a result, mothers and women with caregiving responsibilities experience the highest employment gap and, according to the latest report on equality between women and men in the EU<sup>15</sup>, more than 19% of women who do not work left the workforce due to caregiving responsibilities. These aspects perfectly illustrate the invisible costs of informal care.

### Importance of the informal carer's perspective in economic evaluations

In economic literature, valuation methods are primarily discussed in view of their relevance to economically evaluating healthcare interventions. The aim of such evaluations is to compare both the costs and effects of various interventions in order to inform the decision-making process on the best option for financing. When healthcare

interventions are expected to impact informal carers, the impact assessment of the said interventions should also seek to capture the (positive and negative) effects on informal carers. "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" (van den Berg, Brouwer, van Exel & Koopmanschap, 2005).

It is crucial to include the dimensions of informal care in the economic evaluation of healthcare interventions considering the risks of shifting the related costs from public budgets on to families (Drummond, Sculpher, Claxton, Stoddart & Torrance, 2015). Indeed, by failing to consider the costs borne by informal carers, economic evaluations may favour interventions that entail the transfer of costs from the public health payer to the private sphere (e.g. early hospital discharges at home). Hence, it is recommended that economic evaluations of health interventions comprehensively assess all of the effects and costs on all of the relevant stakeholders. This process should include the perspective of informal carers, if relevant.

## Methodology

While this research remains exploratory, the objective is to describe the main methods that have been developed to value informal care, as well as their biggest strengths and shortcomings.

The literature research was largely conducted through use of the snowball method (i.e. from a list of references of relevant articles) and was iteratively updated according to relevant topics identified.

The qualitative analysis of the content of articles was performed in NVivo 10. Coding through NVivo allowed the various topics to be structured and discussed, including a link to the original sources. This enabled the consistency of the interpretation to be checked with the original texts.

**Table 2. Overview of the different types of costs and effects of informal care for relevant stakeholders**

		Micro level		
Perspective	Informal carers	Care recipient	Other relatives	
Contributions	<ul style="list-style-type: none"> <li>➤ Informal care</li> <li>➤ Out-of-pocket expenditure related to services or goods aimed at the care recipient (healthcare consumption, home care services, housing expenses, etc.)</li> </ul>	Assistance for Daily Life Activities and other health needs (e.g. chronic diseases or palliative care) / Reduced or non-existent unmet needs		
Negative impact	Negative effects on professional activity	<ul style="list-style-type: none"> <li>➤ Labour force participation: exit or preclusion</li> <li>➤ Lower wages due to discrimination</li> <li>➤ Working fewer hours</li> <li>➤ Less career progression</li> <li>➤ Reduced opportunity of positions</li> <li>➤ Risk of poverty</li> <li>➤ Negative impact on retirement income</li> </ul>		
	Loss in health and well-being		Risk of abuse	Impact on well-being of relatives (spouses, children, ...)
	Loss in social life and leisure			Family tensions
Positive impact	New skills acquired	May be used in search for employment		
	Well-being (e.g. Self-esteem, etc.)	Feeling of self-worth, seeing oneself as a valued member of family or informal network		
	Affective relationship	Care provision may enforce emotional attachment and understanding between family members		Emotional well-being, social life
	Consequences budgets	Possible substantial financial help		

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Meso level	Macro level	
<b>Employers</b>	<b>Social security</b>	<b>Others</b>

	<ul style="list-style-type: none"> <li>➤ Loss of productivity (due to absences or psychological burden)</li> <li>➤ Recruiting and training costs</li> <li>➤ Organisational issues to ensure temporary replacement of carers at work</li> <li>➤ Tensions between colleagues, greater strain (turnover)</li> <li>➤ Negative impact on users/clients</li> </ul>	<ul style="list-style-type: none"> <li>➤ Loss of fiscal incomes / threats to social security in old age due to smaller labour market participation</li> </ul>
➤ Sick leave	<ul style="list-style-type: none"> <li>➤ Health care expenditure</li> <li>➤ Sick leave</li> </ul>	
➤ May be valued by employers		
	Savings in formal long-term care: <ul style="list-style-type: none"> <li>➤ residential care facilities</li> <li>➤ healthcare and social care services in the community</li> </ul>	

## Chapter 2

# 'Revealed Preferences' methods

'Revealed preferences' methods build on the value of the effort input or corresponding good available on the market, without considering the carer's preferences. Two methods are presented in this section: the 'opportunity cost' method, which is based on the input approach, and the 'replacement cost' (also called 'proxy good') method, which is based on the output approach. These are the most commonly used methods.

### 'Opportunity cost' method

#### Valuation principle

**This method values informal care according to the benefit informal carers forego due to the time they spend caring.** *"The value of unpaid work is commonly set equal to the value of a competing use of time spent on paid labour"* (Krol, Brouwer & Rutten, 2013). Forgone benefits are therefore approximated by the wage rate of individuals, with the assumption being made that the opportunity cost is below the cost of equivalent care services available on the market (informal carers would otherwise choose those services).

#### Distinction between activities

Time is a specific resource that cannot be saved and is not extensible (Midy & Grignon, 2002). The time available to someone can only be distributed between working time, unpaid housework, and leisure. By providing informal care, informal carers give up on spending time on any of these three activities.

**The time spent caring is valued according to the current wages of informal carers.** This means the value of leisure time and unpaid work are seen as equivalent. From a theoretical viewpoint, the estimated value of the time spent for unpaid work (in this case unpaid care) and for leisure should be different if carers experience harmful effects from work activity. The 'opportunity cost' would then vary among between the three possible

uses of time and, ideally, the estimated value of each option should be further explored. However, in practice, valuation attempts do not differentiate the three possible uses of time. Moreover, in order to correctly estimate the opportunity cost, the time forgone per type of time allocation would be required, which of course would be extremely complex. Against this backdrop, van den Berg suggest a potential solution is to ask how carers' time allocation has changed since they became engaged in care. The valuation method would then build on assessments of the pre- and post-care time allocation.

#### Distinction between employed and unemployed

Posnett distinguishes working and leisure time (Posnett & Jan, 1996). For leisure time, ("*leisure' being all uses of time except paid employment*"), two types of activities are considered: "*pure leisure activity*" or "*household production*".

- *if the studied individuals are employed, the appropriate proxy to value pure leisure time would be the net wage rate.* For working time, the gross wage rate would be used when no replacement is available and the net wage rate when a replacement is available (i.e. in case carers are replaced at work).
- As for carers who are otherwise unemployed, the minimum wage rate at which a person would accept employment should ideally be known (unemployed carers usually value informal care above this acceptable minimum wage rate)(van den Berg et al., 2006). Posnett proposed using the potential wage rate as an appropriate substitute. However, for unemployed people, this wage rate is the absolute minimum rate at which they would accept employment since they do not work. The potential wage rate depends on skills and experience and requires individual data. Thus, to generalise results the wage rate of the individuals studied may be insufficient if the sample group is

unrepresentative of the carer population (and may only be useful for collecting data on time forgone). A pragmatic solution Posnett proposes is to use the wage of professionals who provide comparable services (i.e. the 'proxy good'/'replacement cost' method). Since informal care is mostly a quasi-market activity<sup>16</sup> (Posnett & Jan, 1996) the wage for equivalent services provides an idea of the minimum value of "the opportunities available for individual".

## Shortcomings of the 'opportunity cost' method

### Determining the types of activity forgone

Such a method would ideally require the types of activity forgone to be distinguished between pure leisure time, unpaid housework, and working time. This could be done by retrospectively assessing the activity forgone (although for long-standing informal care such a distinction might prove extremely complex) or by identifying the activities that would otherwise be performed in the absence of informal care (van den Berg et al., 2004).

Data collection on the different allocations of the time forgone may be difficult for the various reasons described below. First, the meaning of the terms 'Leisure' or 'Unpaid work' is often unclear for the surveyed individuals. On the other hand, the alternative question: "what type of time allocation would you prefer (between leisure, unpaid work, paid work) if you were not involved in informal care?" seems to work better with respondents. This question should therefore be preferred over the retrospective one (which type of activities did you give up as a result of your caregiving responsibilities?), particularly when an informal carer has made a long-standing commitment. Indeed, their circumstances may have changed over time, e.g. some may have retired and no longer work.

### Potential biases

With the 'opportunity cost' method, some issues remain with respect to assessing the cost of informal care (as described below). These include the correlation between labour market participation and informal care, the seemingly higher prevalence of informal care among low-paid workers or the wage rate differences that exist between working carers and non-carers due to lost career opportunities.

- Regarding the correlation between labour market participation and informal care, from a theoretical point of view, individuals may very well choose to provide care while engaging in

paid work. As a result, carers' participation in the labour force might be influenced by their level of engagement in caring. Likewise, carers determine their caring engagement according to their labour force participation. These two aspects are thus interdependent and individuals who do not work are actually more likely to provide intensive care.

- Individuals with a lower wage rate seem more prone to become a carer than others due to lower opportunity costs. This partly explains the gender dimension of informal care and the high proportion of women involved in caring.
- Some of the differences in the wage rates between working carers and workers without any caregiving responsibilities could be linked to the professional disadvantages generated by informal care (e.g. career advancement/job opportunities, salary rate) (Carmichael & Charles, 2003; Heitmueller & Inglis, 2007).

### Opportunity costs of leisure

Leisure is more often relinquished (Le Bihan-Youinou & Martin, 2006) than formal work engagement. Indeed, most informal carers are willing and determined to continue with their professional activities for several reasons (financial, respite moments, preserving their social identity). A reduction of working time is usually seen as a last-resort solution by working carers. The wage rate of individuals is therefore relevant for valuing leisure time unless individuals experience detrimental effects of working time. Different rates for working time vs leisure time should be considered, even though that is rarely the case.

### Valuation for people in retirement

The value of informal care provided by carers who are no longer active in the labour market is not determined. Some solutions exist with respect to the unemployed, but for people who are already retired the problem remains unsolved. For them, the opportunity cost cannot be considered as null. The wage given to formal carers could be used as an indicator and would represent a minimum value of the benefit (because of the possible satisfaction derived from caring). Their retirement income could also be used as a value of the benefit of informal care from the carer perspective.

Finally, it is important to note the negative consequences of informal care on informal carers' own health status (morbidity and mortality risk) are not captured by this method.

# The 'proxy good' method (or 'replacement cost' method)

## Valuation principle

The 'proxy good' method (or 'replacement cost' method) builds on the assumption that formal care is a substitute for informal care and that, consequently, the value of informal care can be evaluated via the cost of formal care. **The time spent caring is valued based on the market price of a professional who would theoretically replace the carer.** This method relies on the hypothesis that the informal care is equivalent to professional care as regards quality and efficiency from both the carer and care recipient's perspectives. The valuation may differ according to the types of tasks carried out (e.g. home care worker or nursing care). Here, it is assumed that informal care, as a non-market activity, has a professional equivalent.

## Shortcomings of the 'replacement cost' method

### Absence of standardised time measurement

This method mostly relies on the measurement of time per task. Yet, informal care is a complex social phenomenon and constructing a quantitative indicator of time raises several issues. Most surveys currently in use are lacking in comprehensiveness (important tasks, such as continence management, and relevance are overlooked while 'ordinary' tasks like visiting friends or relatives are included (Cès et al., 2017). For cohabitant carers, domestic tasks are public commodities<sup>17</sup> – in other words, they have shared benefits – and should therefore not be considered: *"housework is not needed because of the presence of the care recipient as, in fact, carers would have to perform these tasks anyway, even if the care recipient did not live there anymore"* (Cès et al., 2017). However, such a consideration is rarely taken into account.

### Choice of the valuation rate

In an ideal world, the time spent on each task should be estimated and valued considering the different wage rates of various professionals who would be hypothetically called to replace informal carers. Activities of Daily Living (ADL) – i.e. walking, feeding, dressing and grooming, toileting, bathing, and transferring – should be valued at a higher rate than Instrumental Activities of Daily Living (IADL)

– managing finances, transportation, shopping and meal preparation, housecleaning and home maintenance, communication, and medication – since they would likely involve nursing care (e.g. trained care professional or home worker, nurses...). This may also vary according to the profile of the care recipient (e.g. in the case of dementia care, trained home care workers may intervene more often). When it comes to the organisational aspects of the support and when the situation is particularly complex (e.g. with neurodegenerative diseases), specific types of professionals may be theoretically required to replace carers (e.g. case managers).

### Other responsibilities excluded from the time measurement

The 'replacement cost' method does not capture some of the carer's responsibilities which cannot be properly reflected in terms of time spent caring (e.g. being on call or decision-making) (Cès et al., 2017). For such tasks, a valuation method should be further developed to more realistically reflect the cost of care relatives provide through the 'proxy good' method (e.g. 24/7 services, legal advisers, etc.). The extended role of carers may be assumed by one or a combination of professional substitutes, although this is likely to remain fragmented and imperfect.<sup>18</sup>

## Comparison of the 'proxy good' and 'opportunity cost' methods

When considering the type of information required to assess the time spent on informal care and its estimated value, it is fair to say the two methods are comparable:

- First, a valid assessment of the amount of time is required:
  - type of time forgone (leisure, unpaid work, paid work); or
  - amount of time spent caring, per task.
- Second, the value of informal care is assessed using estimated prices.

For van den Berg (2006), time measurement seemed more valid based on the time spent per task than on the time forgone to provide informal care. An important issue van den Berg raises is the way of assessing the time spent per task: retrospectively or by use of a diary. The latter may prove to be more efficient but may also be too time consuming for large-scale data collection.

## Chapter 3

# Methods considering both the negative and positive aspects of informal care from the carer's perspective

### 'Stated Preferences' methods

These methods seek to include the negative and positive aspects of giving care from the perspective of the informal carer. They can be broken down into the 'Contingent valuation' method and the 'Conjoint measurement' method.

#### 'Contingent valuation' method

This method was originally developed to value environmental goods<sup>19</sup> and has since been applied in the area of health to value the benefits of new products and measures for consumers (such as a new technical device). The objective is to assess both the costs and benefits of non-market goods to optimise the decision. **The value is determined by consumers' preferences for different hypothetical choices ('Stated Preferences')**. Applied to informal care, this method allows a better approximation of the value informal carers attribute to their commitment. The Contingent valuation method's biggest advantage is that it integrates informal carers' actual preferences.

#### Valuation principle

Few studies have tested the Contingent valuation method as applied to informal care (de Meijer, Brouwer, Koopmanschap, van den Berg & van Exel, 2010; van den Berg, Brouwer, et al., 2005).

Two different forms of evaluation are possible, Willingness to Accept (WTA) and Willingness to Pay (WTP). **Willingness to Accept concerns "the valuation of the full impact of providing informal care on the informal caregivers by asking what minimum monetary compensation they require to provide an additional hour of informal care per week"** (van den Berg, Brouwer, et al., 2005). **Willingness to Pay (WTP) concerns the amount people are prepared to pay to reduce the total amount of caring time by 1 hour per week.** It is important to note the funding source is different for each of these options. Willingness to Accept (WTA) refers to public funding while Willingness to Pay (WTP) refers to out-of-pocket expenditure. Both forms were tested by De Meijer (de Meijer et al., 2010).

The Willingness to Accept (WTA) method assumes that an additional 1 hour of care would require financial compensation that would represent the net difference between the additional benefit and the costs of care. This method has been tested on two

samples. The first included spouse (mostly male) informal carers for rheumatoid arthritis (van den Berg, Brouwer, et al., 2005), while the second concerned a pooled dataset collected from carers and their care recipients<sup>20</sup> (de Meijer et al., 2010).

Different types of data were collected in the two studies:

- first, the type of care carers would prefer to provide – *housework, personal care, support, organisational tasks, social support or other*; and
- second, *the minimum amount of money that should be received from the government to provide an additional 1 hour of care.*

## Shortcomings of the Contingent valuation method

### Sensitivity confirmed...

The Contingent valuation method applied to informal care should vary according to the different drivers of the carer's circumstances: "*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*" (van den Berg, Brouwer, et al., 2005).

The valuation method's sensitivity is documented as follows (van den Berg, Brouwer, et al., 2005):

- The monetary compensation is higher:
  - when the person does not want to provide any additional hour,
  - when they have asked for more professional support,
  - when residential care has been opted for (care recipient on a waiting list),
  - for higher income levels.<sup>21</sup>
- The monetary compensation is lower when:
  - carers have flexible paid work,
  - the care recipient receives professional care,
  - care-derived self-esteem is present, and
  - the care recipient has a higher quality of life (as perceived by informal carers).

In the De Meijer study (2010):

- WTP is higher:
  - for organisational tasks, so too is mobility, personal care, social (lower WTP for domestic help),
  - for health (positively associated up to a score of 85, for persons feeling with deteriorated health status and in the 12 months before), and
  - among people with a higher income (own child care recipient), or the holder of funding (personal care budget).
- 'Willingness to Accept' is positively associated with "a subjective burden, a high education level, an above-average income, having domestic help, paid work, as an alternative use of time, taking care of a person with either physical or mental health problems, taking care of a personal care budget-holder, and a preference for organizational tasks", a long-lasting caring engagement (positively up to 13 years).
- Some differences are observed with regard to the age of the carer. This result is consistent and reflects two different situations for carers aged between 18–64 years old and above 64 years old.

### ...but not for all dimensions of the carer's circumstances

- Higher financial compensation is required when other carers are involved or when other carers have a better quality of life.
- No higher WTA is associated with the time spent caring or some of the tested dimensions of the burden such as financial problems, disrupted schedule, lack of family support, loss of physical strength, total subjective burden.<sup>22</sup>

Research shows the valuation method is not sensitive to the amount of time spent on caring (van den Berg, Brouwer, et al., 2005). Some hypothetical associations of the WTA in relation to specific dimensions of informal care were not corroborated. In particular, the overall subjective burden, health-related quality of life, and lack of family support were negatively associated with the WTA while a positive association had been expected.

The de Meijer study (2010) shows that older carers who have experienced health issues in the previous year and those with a higher education level are more disposed to pay for professional care or to receive a higher financial contribution to compensate their caregiving responsibilities. When the self-rated burden of care is high, informal carers indicate a higher *Willingness to Accept (WTA)* to provide an extra 1 hour of care. As for the duration of care, the WTA is higher for people who have been engaged in caregiving activities for less than 13 years and decreases after that.

### Methodological issues arising from the questions

- Research shows that in practice carers encounter difficulties in representing a marginal variation of 1 hour of care (Paraponaris, d’Alessandro, Davin, Protière & Tache, 2012). In their day-to-day activities, such a difference does not mean a tangible change in their time schedule<sup>23</sup> (particularly with high-intensity care or for non-regular care provisions or when only moral support is provided). The practical advantages of change as a result of the lack of support or a significant workload seem to be the main drivers of carers’ WTP. The attributed value is therefore more closely related to specific scenarios that respondents may imagine than to the broad value of informal care.
- In the van den Berg study (2005), informal carers first had to choose between the different activities they wished to spend more time on and then estimate the money compensation they would be willing to accept to provide an extra 1 hour of it. This proposition brings an intrinsic limitation since carers tend to choose the care activity they prefer/consider the least difficult to perform. The obtained value of informal care thus may be seen as more of an indication of the minimum compensation amount carers expect.
- Other limits relate to the activities they can choose from. First, the list is quite limited (“(1) Housework, (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...”), and not well defined (“support” or “housework”). The latter activity is questionable since for cohabitant carers, housework is a household public commodity – i.e. *all members of the same household jointly benefit from it. The causal link between the loss of ability of the care*

*recipient and these tasks is therefore not obvious for co-resident carers”* (Cès et al., 2017). Indeed, informal carers would in any case have to carry out these tasks were they to live on their own. Therefore, for cohabitant carers, housework should be considered an ‘ordinary task’ rather than an informal care task. The van den Berg study described above gives some interesting results in that regard: the majority of carers, especially when they cohabit with the care recipient, tend to select housework as the activity they would like to spend more time on (64% of the surveyed carers identified it as their favourite task).

### Considerations other than the carer’s preferences

The Contingent valuation method is based on hypothetical choices that are independent of contextual elements in order to reveal the carer’s preferences. However, responses may also be influenced by other considerations (such as the care recipient or family’s preferences, moral/ethical considerations) which might influence the results. Moreover, the proposed scenarios are only based on variations of the informal care situation.

In reality, variations in formal care provisions should also be addressed, particularly when the level of care needs is high (a combination of both formal care and informal care is then common) which may also be considered by informal carers.

When it comes to the Willingness to Pay (WTP), respondents provide a value which corresponds to the tariff of home care services (Paraponaris 2012), the co-payment of these services, the opportunity cost (carer wage), or budget constraints. Carers mentioned the dual costs of leisure: the costs of providing for the replacement of care by a professional and the costs of the leisure activity itself.

### The non-response issue or ‘protest answers’

The question is based on a hypothetical choice which likely fails to reflect the true preferences of carers. This issue is also prominent when there are implications regarding future funding or financial measures or when a misinterpretation of the questions might exist (respondents may fear they have to pay). This method does not allow for the training of carers and misinterpretations may be possible (unstable **‘Stated Preferences’**).

Therefore, use of this method should be cautiously assessed and applied in order to avoid biased answers and, ultimately, biased results (such as the context<sup>24</sup> and the way the questions are formulated).

In the setting of informal care, research shows that carers were reluctant to provide an estimation of monetary compensation (van den Berg, Brouwer, et al., 2005). They may also find it difficult to set a price for the support they provide, for ethical reasons. In the de Meijer study (2010), carers who were *“satisfied with the amount of care they provided were thus less likely to respond to CV questions”*. There might thus be bias since non-satisfied carers may provide a higher value of informal care than satisfied carers. Moreover, carers with a high objective and subjective burden (and with a professional activity, a co-resident) were less likely to respond to questions about their WTP compared to WTA. In the van den Berg study (2005), it was noted that non-respondents were often older, the partner of the care recipient, without any paid work and with limited risk of financial problems.

#### Endogeneity of the estimated value

The results show the answers given by informal carers are influenced by their income level<sup>25</sup> (van den Berg, Brouwer, et al., 2005). The value is influenced by the professional disadvantages encountered by informal carers. There are some equity considerations when applying this method in economic evaluations since the cost for informal carers may be underestimated.

#### Use in economic evaluations

According to van den Berg (2005), this method provides an estimation of the cost from the carer's perspective that can be added to the cost part of the cost-effectiveness ratio. Since the contingent valuation method aims to capture the net difference between the costs and benefits of caring, there is a risk of double accounting when incorporating other non-monetary outcomes (in the effectiveness part of the ratio). In a cost-benefit analysis, the results showed the monetary value is not sensitive enough to capture all of the effects for informal carers, particularly when the impact on informal carers is the primary outcome (such as psychological well-being). However, in the Meijer study (2010), the sensitivity was better for the WTA than in the van den Berg study, particularly for psychological burden. For this reason, WTA should be preferred over WTP.

#### Anchor bias

The way a question is formulated – as an open-ended question or with predefined values – may influence the value estimated by respondents. Yet, such bias is difficult to suppress.

In the case of informal care, two different answer

formats were tested in surveys (van Exel, Brouwer, van den Berg & Koopmanschap, 2006): the open-ended format, and the discrete-choice format with an open-ended follow-up question. It seems the open-ended format generated slightly higher values (although the difference was not significant) whereas the response rate was higher in the format of discrete choice with open-ended follow-up. Another experiment using an open-ended format showed that with the open-ended question format the value is higher in WTP and lower in WTA than with the bid format.

Other possible endogenous anchor bias may exist in the value elicitation: the tariff of home care services and the opportunity cost of informal carers (e.g. the hourly wage rate). Van Exel showed that the WTP is influenced by the tariff for professional care while the WTA is by the opportunity cost of carers.

The first drawback of the open-ended answer format is the frequency of non-responses, which is higher than with the discrete-choice format. The second drawback concerns the fact that other considerations (endogenous anchor) may apply, such as the proxy-good cost for the WTP or the opportunity cost for the WTA. The issue is therefore to choose the most preferable of the two possible anchor biases.

## Conjoint measurement method (or conjoint analysis or choice experiment)

### Valuation principle

*“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”<sup>26</sup> (van den Berg, Al, et al., 2005).*

This method relies on the “Independence of Irrelevant Alternatives” hypothesis.<sup>27</sup> The objective is to estimate the marginal rate of substitution (Carlsson & Martinsson, 2003) and, for the attributes, the marginal Willingness to Pay (or to Accept) (derived from the cost attribute). Van den berg used an orthogonal design: *“...where the levels of each attribute vary independently...”* (Carlsson & Martinsson, 2003).

## Data collection

Van den Berg (van den Berg, Al, et al., 2005) proposed four situations (not aimed to reflect the current situations of the carers) and asked to rate them between 1 (worst imaginable) and 10 (best imaginable) (see the appendix). The resulting rate is supposed to be a proxy for the carer's satisfaction.

Van den Berg used a regression model to statistically model the proxy for carer's utility which depends on:

- The scenario attributes
  - the number of informal care hours;
  - light or heavy housework or personal care (dummy variable: "1" housework, "0" personal care);
  - the monetary compensation.
- And the characteristics of the informal carers and the care recipients: Attributes of situations vary and "the monetary compensation can be derived" (as a specific attribute) from the statistical model.

The four situations vary according to:

- The informal care tasks:
  - "Light house work"
  - "Heavy house work"
  - "Personal care"
- Informal care hours per day:
  - from 1 to 3 (or 7 to 21 per week)

The implicit question in the four scenarios is about the Willingness to Accept to provide more care (not the WTP).

## Additional data collected

Van den Berg (van den Berg, Al, et al., 2005) collected the following data:

- the duration of providing informal care (in years),
- the time spent caring for: housework; activities of daily living and instrumental activities of daily living,

- health-related quality of life of both the carers and care recipients (EQ-5D),
- for the subjective burden, the Caregiver Reaction Assessment (without any sum score),
- for the overall subjective burden, a visual analogue scale ("0" not hard to "100" much too hard),
- cohabitant or not, and socio-demographic questions.

## Use in economic evaluation

Van den Berg recommended integration on the cost side of the cost-effectiveness or cost-utility of interventions that mainly target care recipients. For informal carers, the method can be used as part of cost-benefit analysis.

## Shortcomings of the Conjoint measurement method

This method requires advanced econometric models and has similarities with the 'Well-being' method: the monetary compensation required to keep the carer's satisfaction constant for hypothetical changes in informal care hours (with different contents of care).

The results obtained are not expressed in absolute but in relative values. Therefore, making a comparison with results of the 'Revealed Preferences' methods is not straightforward. Van den Berg found that an increase by 1 hour would require compensation of €1 "compared to an initial situation without a monetary compensation ceteris paribus" (for 10 additional hours, €10 per hour). To explain the low value, van den Berg considered that informal carers derive utility from providing care. Moreover, Van den Berg (van den Berg, Al, et al., 2005) tested 4 scenarios among carers who were already engaged in high-intensity care (on average 27 hours per week) while the different intensity of care in the scenario remained lower (7, 14, 21 hours).

Other studies found higher values: €16.3 (Van Den Berg, Al, Van Exel, Koopmanschap & Brouwer, 2008) or €16.1 (2011, Netherlands) (Hoefman et al., 2018).

In the van den Berg study (2005), 30% of carers did not respond. This issue should be carefully considered since rating the vignettes may be difficult. Adding more scenarios may come at the expense of a higher non-response rate. Professional interviews of carers instead of self-administrated questionnaires may improve the response rate.

# 'Well-being' valuation method

## Valuation principle

This method aims to assess the negative and positive effects of caring on the informal carer's well-being<sup>28</sup> from her/his own perspective (carer satisfaction).

## Hypothesis on the concept of well-being

Since all possible costs borne by informal carers are likely to impact their well-being, those related to their caring role – such as their financial contribution, the negative impact on their health and well-being, the time spent on care, etc. – are included in any valuation attempt.

Van den Berg explains the '**Well-being**' method<sup>29</sup> as follows: "**the monetary value of informal care is estimated by looking at the necessary income (compensating variation) to maintain the same level of informal caregiver's well-being after providing an additional hour of informal care**". In economics, this method is used to value non-market commodities. Van den Berg proposed use of this method for valuing informal care and tested it. The well-being assessment is proxied by the "*self-reported subjective well-being*".

## Two-step process

The valuation of the effects of informal care on carers' well-being is based on an econometric model:

- First, the effects of carers' caregiving activities and income on their well-being are estimated through self-reported perceived well-being, while controlling other possible factors that may also influence well-being – i.e. the demographic and socio-economic circumstances as well as the mental and physical health problems of the care recipient, if any.<sup>30</sup>
- Second, the variation in income required to compensate the adverse impact of care and maintain the same level of well-being after providing an additional 1 hour of informal care is estimated. This represents the estimated value of informal care.

Regression modelling of well-being uses three types of explanatory variables: the household's net income, the total number of hours of care provided per week, other individual characteristics

likely to influence well-being (i.e. socio-economic and demographic circumstances) as well as the presence/absence of mental and physical health issues of the care recipient.<sup>31</sup> The level of well-being is expected to rise along with the household's income while it is supposed to fall in line with the time spent caring. Carers may also derive benefits from caring called "direct utility" (satisfaction, self-esteem, etc.). In this modelling, the two opposite effects are not assessed separately. Nevertheless, overall, the global effect of caring is assumed to be negative.

The econometric model<sup>32</sup> is built as following: the compensating variation of income is lower for individuals spending more time on care than for individuals with fewer care hours. The negative impact on the carer's well-being is more notable when intensity of the care is low than when it is high – the marginal loss of well-being indeed shrinks as the number of care hours rises. The value would be €11.9 per hour (in the Netherlands, adjusted for 2018, van den Berg 2007).

## Data required

The data required for this method include:

- detailed information on the amount of informal care provided (i.e. amount of time spent caring),
- the carer's self-perceived well-being, which touches on the happiness question<sup>33, 34</sup> (van den Berg & Ferrer, 2007),
- the household's net income (ideally in an absolute value, not in intervals), and
- demographic and socio-economic characteristics.<sup>35</sup>

This method has the advantage of assessing the current subjective well-being (not hypothetical scenarios as occurs in the Contingent valuation method).

## Shortcomings of the 'Well-being' method

### Theoretical criticism

This method is often criticised because it uses subjective perceptions of well-being that may neglect the objective difficulties individuals encounter (for instance, self-perceived well-being may vary over time after an adverse event, the loss of well-being may be more important right after its occurrence than long after) (Ferrer-i-Carbonell,

2013). Moreover, individuals' perception of their own circumstances may also be influenced by how well they perform compared to others.

The '**Well-being**' method has already been used to provide a monetary value for the loss of well-being in other contexts such as airport-noise issues (Van Praag & Baarsma, 2004) or chronic diseases (Ferrer-i-Carbonell & Van Praag, 2002). This valuation method would nevertheless also be useful to apply to informal carers. However, the method requires that only individuals who are negatively impacted by the issued under study be surveyed. In the case of informal care, we therefore wonder whether studying only the perception of informal carers would be reliable given that any individual may become engaged in caring responsibilities. Consequently, it is fair to assume the absence of respondents who are not yet involved or have chosen not to become involved in caregiving activities in any survey on informal care may lead to an underestimation of the lost well-being and, therefore, of its monetary value.<sup>36</sup>

### Econometric modelling

Econometric modelling raises some important considerations for discussion:

- The income compensation required for well-off individuals is likely to be more substantial since the well-being gain generated by additional income would be lower for them than for low-income individuals (Ferrer-i-Carbonell, 2013). Since informal carers face restrictions in career opportunities and lower salary rates<sup>37</sup> (Carmichael & Charles, 2003), the value of informal care obtained through this modelling would also emphasise this issue.
- Providing care to someone with behavioural issues due to a cognitive condition has significant negative impacts on carers (Gaugler, Davey, Pearlin & Zarit, 2000; van der Lee, Bakker, Duivenvoorden & Dröes, 2014). An extra 1 hour of care may have a different impact on the well-being of a carer according to both the intensity of the care provided and the presence/absence of cognitive issues or mental health problems.<sup>38</sup>
- The empirical relationship between well-being and the intensity of care may nevertheless be more complex than an overall loss, some thresholds may exist: i.e. first, low-intensity care may not lead to a loss of well-being and, second, the threshold for when well-being starts to deteriorate may differ greatly

depending on the type of carer involved (e.g. cohabitant or not).

### Data collection

Extensive data must be collected to control for other potential confounding variables of well-being. The concept indeed relates to various domains of life: "*health, financial situation, job, leisure, housing, and environment*" (Van Praag, Frijters & Ferrer-i-Carbonell, 2003). All things being equal, the econometric model aims to assess the monetary value of compensating mechanisms with regard to the loss of well-being due to an extra 1 hour of informal care. All domains with a potential bearing on well-being should thus be investigated.

## Chapter 4

# Discussion and conclusions

While research on the matter is still a work in progress, this report seeks to provide a brief overview of the methods so far applied to assess the value of informal care. In doing so, we delineate the extent to which these methods provide valuable insights into the topic and we underline the (practical or theoretical) issues each generates.

**These methods can be grouped into two main categories which take account of the negative and positive impacts of care on the carers themselves from their perspective; in other words, the preferences of the carers.** Our work builds on the idea that addressing the current and growing care needs of the European population in a universal and equitable way will require a combination of substantial investment in formal care services and the development of support and empowering measures targeting informal carers. Carers will continue to play a significant role in the provision of care in Europe in the foreseeable future and we therefore believe their know-how and needs are worth listening to.

Against this backdrop, the valuation methods that aim to assess the carer's preferences, i.e. the negative *AND* positive aspects of caregiving from the carer's viewpoint ('Stated Preferences' methods) naturally piqued our interest. Our report is clear in showing these methods raise particularly complex questions, both academically and politically. Some 'Stated Preferences' methods offer interesting perspectives not captured by the 'Revealed Preferences' methods and which may be of interest for policy purposes. The 'Contingent valuation' method is especially appealing as it alludes to the burden of care, a dimension not addressed by any other method. Yet, the method partly fails to assess carers' preferences since other considerations (like ethical concerns or the carer's income level) may

come into play and influence the results. The 'Contingent valuation' method may hence not be sensitive enough to assess the entire impact of informal caregiving on carers themselves. Besides, more research should be carried out on the different profiles of care recipients (e.g. mental health conditions, levels of cognitive impairment, functional limitations, behavioural problems, chronic diseases, etc.).

In economic literature, the different valuation methods have mostly been discussed in the context of economic evaluations of healthcare interventions.<sup>39</sup> Researchers distinguish interventions that principally target the informal carer and their care recipient. In the case of interventions that focus on the care recipient, the challenge is to build one single monetary indicator<sup>40</sup> which would allow both the negative and positive impacts on informal carers to be captured in a comprehensive manner (van den Berg, Al, et al., 2005; van den Berg, Brouwer, et al., 2005) and would be incorporated on the cost side of the cost-effectiveness ratio.<sup>41</sup> The 'Stated Preferences' methods could be used to this end, but they lack sensitivity. Moreover, when appropriate circumstances are in place, informal carers may derive utility (i.e. satisfaction, self-esteem) from their caregiving role. Our research underlines that **valuation methods which consider both the positive and negative aspects (utility/disutility) of care from the carer's perspective may yield lower results than methods where these aspects are disregarded**, i.e. the '**Revealed Preferences**' methods (van den Berg, Al, et al., 2005; van den Berg, Brouwer, et al., 2005). **This holds deep implications from a policy perspective since initiatives building on some of the '**Stated Preferences**' methods may effectively underestimate the objective impact of care on carers and ultimately have detrimental effects**

**for carers. Generally speaking, the idea that the positive effects of informal care should be considered in the context of economic evaluations is also debatable since this aspect is not considered for market activities. Finally, it could be argued that valuation methods building on the preferences of carers assume that carers form an integral part of the long-term care workforce and are here to stay.**

Beyond the requirements of economic evaluations, the selection of the best methods should be approached in the setting of the broader discussion on how to value non-market activities in the economy. In reality, the question to be raised indeed concerns the status held by informal care compared to other market activities.

As highlighted in the report and above, the '**Revealed Preferences**' methods ('opportunity cost' and 'proxy good/replacement cost' methods) do not seek to capture the actual preferences of informal carers. **Politically speaking, we argue these methods seem to chiefly view informal care as a burden that should ultimately be minimised or only be addressed if/when carers become unable to remain involved in caring.** Among them, the 'opportunity cost' method seeks to assess the value of informal care by using the wage rate of working carers and the time of activities forgone due to the caregiving activities. This method gives a complementary insight into the economic value of what individuals have renounced as part of their provision of care. Yet, use of this method is problematic for non-working carers (young and older carers). For people of working age not active in the labour market, the value of a potential or minimum wage could be used as a satisfactory proxy. For retirees, '**Stated Preferences**' methods could be useful for overcoming the absence of labour market participation (making the 'Contingent valuation' method therefore interesting as the most-commonly studied one).

In the 'proxy good' method, both professional and informal care are assumed to be perfect substitutes for each other from the perspective of both informal carers and care recipients – which is, of course, often far from the case. Still, the 'proxy good' method can be interpreted as an approximation of the plausible costs of care needed to support care recipients at home<sup>42</sup> should informal carers stop providing care (as a result of an anticipated choice or, unexpectedly, due to health issues, hospitalisation or death, for example) (Paraponaris, Davin, et al., 2012).

Since carers are likely to derive some satisfaction (utility) from their caregiving activities and their time schedule may be less constrained (especially for cohabitant carers), informal carers are likely to spend more time on caring than trained professionals do. Thus, the administrative and transport costs (time and means) should also be added to the salary costs of formal/professional carers. It is consequently difficult to conclude whether the estimated value of informal care is on the upper or lower end of the actual replacement cost by formal care.

Another difference between the actual replacement cost and the cost estimate relates to the type of professional selected.<sup>43</sup> In an ideal world, in order to realistically assess the costs of substitution between informal and professional care, different salary rates should be used in studies that build on the 'Replacement cost' method since certain tasks may require the involvement of trained professionals (e.g. nursing care). That would entail a substantial data collection process in which the information would be broken down by task. This explains why most studies do not differentiate salary rates per task and, as a result, the wage rate of a low-skilled professional is generally used. Here again, the approach builds on the premise of perfect substitution existing between what the market provides and non-market work, which is questionable. For instance, the estimated price of a meal prepared by a relative may be much higher than one prepared by a home care worker. **Some researchers therefore tend to consider the market price as a minimal value of informal care** ("*what would it cost society to provide an acceptable substitute*") (Folbre, 2006).

Finally, it is important to note that many care recipients would have no choice but to turn to residential care should informal carers be unavailable. For highly-disabled care recipients (e.g. people with dementia), the intensive level of informal support provided at home can only be substituted by residential care, particularly for co-resident carers. If at all possible, the 'replacement cost' method should therefore seek to more accurately capture the actual replacement costs associated with both home and residential care. However, this type of assessment is rarely performed.

**As such, the 'proxy good' method offers a good view of the costs of informal care and, unlike the 'opportunity cost' method, allows various types of carers – be they active in or outside the labour market – to be considered. This again brings important political implications since**

**the method offers a much more comprehensive and realistic perspective on the value of informal care.** On the downside though, given the data currently available, the 'proxy good' method does not yet allow a comparable overview across EU member states. The method indeed depends on market prices which – along with quality – tend to vary differ from one country to the other. However, **this method also builds on measurement of the amount of time spent caring, which could constitute a good primary indicator for assessing and comparing the magnitude of carers' commitment across countries** (as recommended for non-market activities in the Report on the Measurement of Economic Performance and Social Progress, commission Stiglitz-Sen-Fitoussi, 2009).

Of all methods explored in this report, the 'Well-being' method seems the least appealing. It indeed builds on self-perceived well-being (which is difficult to measure) and the assumption that the level of the carer's well-being is correlated with the household's income. As a result, the income compensation required for more affluent carers is likely to be higher than for underprivileged ones for the same type and intensity of tasks since the well-being gain generated by additional income would be more limited for the former than for the latter. In addition, with this method, the marginal loss of well-being is inversely related to the increase in the number of care hours.

Given the multiple questions informal care raises for society, **we argue that each method studied in this report provides a specific take on the economic value of informal care. The ideal method for valuing informal care should thus build on a mixed approach that considers the typology of situations in which carers may find themselves.** The 'proxy good' method could ultimately be used to study all types of carers while both the 'opportunity cost' and 'contingent valuation' methods may prove useful for including the different circumstances of carers (working age or not). Yet it should still be noted these two methods remain insufficient for capturing the situation of young carers.

Although there is no unified methodology to assess

the value of informal care, various empirical studies have relied on some of the above-mentioned methods and give a good overview of the immense contribution carers make to care systems and society as a whole. In Spain, Oliva-Moreno (Oliva-Moreno, Peña-Longobardo & Vilaplana-Prieto, 2015) estimated the value of informal care given by the main informal carers to disabled people living within a household at between 1.7% to 4.9% of gross domestic product in 2008<sup>44</sup> (by using three different approaches: the 'proxy good' method, the 'opportunity cost' method, and the contingent valuation method) for a monetary value ranging from €23,064 to €50,158 million depending on the method. In Ireland, the value of informal care was estimated at 3.8% of the gross national product in 2011 (through the 'opportunity cost' method) (Hanly & Sheerin, 2017), making for a value ranging from €2.1 to €5.5 billion. In the USA, the value of informal elder care represented more than twice the total expenditure on formal long-term care services in 2011 (US\$ 522 billion by using the 'opportunity cost' method versus US\$ 211 billion for formal long-term care services) (Chari, Engberg, Ray & Mehrotra, 2015). In France, informal elder care is estimated at €6.6 billion (using the 'replacement cost' method) for 1999 which, at the time, represented 62% of the total costs of care (Paraponaris, Davin, et al., 2012). In Australia, the estimated value of informal care represented 3.8% of the gross domestic product (Deloitte Access Economics, 2015), making for a total of AUD 60.3 billion in 2015.

**To conclude this report, we advocate a broad perspective that separately includes all the costs and effects of care in order to be able to comprehensively describe the social and economic consequences of informal carers' involvement in care given to a family member, friend or neighbour (where the economic value of informal care is one of the most significant parts of the total cost of care). At the level of society, in view of the importance of the demographic changes that are expected it is crucial to routinely develop and implement tools that enable all the consequences of informal care for carers themselves and for all stakeholders involved to be assessed. This would also allow for the more accurate evaluation of the impact of innovative health/social care interventions or of any new social policies.**

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# Endnotes

1. *"The idea behind the output approach is to equate the value of the output produced by unpaid labour with the value of a corresponding good produced in the market"* (Sousa-Poza, Widmer & Schmid, 1999).
2. Also known as conjoint analysis or choice experiment
3. Folbre (Folbre, 2006) considers the 'proxy good' method as an output approach and emphasises the need to value the comparable market service (quality and even better by the price of similar goods, for instance *"the value of time devoted to cooking a meal can be determined by asking what it could cost to purchase a similar meal (or output) in the market then subtracting the cost of the capital goods, utilities and raw materials devoted to that meal"*).
4. *"The idea behind the output approach is to equate the value of the output produced by unpaid labour with the value of a corresponding good produced in the market"* (Sousa-Poza et al., 1999).
5. van den Berg, Brouwer & Koopmanschap, 2004
6. Oliva-Moreno 2015
7. de Meijer 2010
8. Alzheimer's Disease, Gerves, 2014
9. Hoefman, van Exel & Brouwer, 2018
10. van den Berg, Al, Brouwer, van Exel & Koopmanschap, 2005
11. van den Berg 2007
12. To note that a certain proportion of care recipients would go to residential care in the event of the absence of informal carers since informal care is a substitute for residential care, particularly when informal care is provided by a co-resident carer. Indeed, intensive supervision provided by a cohabitant carer allows care recipients to remain at home (e.g. dementia). The 'replacement cost' method should ideally also better reflect the real cost of replacement by considering the two types of support, at home or residential care. However, this type of estimation is rarely performed.
13. *"The idea behind the output approach is to equate the value of the output produced by unpaid labour with the value of a corresponding good produced in the market"* (Sousa-Poza et al., 1999).
14. Also known as conjoint analysis or choice experiment
15. 2018 Report on equality between women and men in the EU
16. Except for the time of carers with the care recipient *"in travel, waiting, consultation, treatment and rehabilitation"* (Posnett & Jan, 1996).
17. *"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."* (van den Berg et al., 2004)
18. This is not a normative judgement of professional care. This only means that, according to the perspective of the informal carer and the care recipient, professional care is not equivalent in terms of preferences.
19. In the USA, two Nobel Prize winners (Kenneth Arrow and Robert Solow) were mandated to determine recommendations to assess the value of environmental damages (following the Exxon-Valdez oil spill in 1989).
20. *"Registered at informal care support centres and the association of personal care budget-holders"*.
21. Persons with a higher income have greater opportunity costs of providing informal care in terms of forgone paid working time and leisure (the estimated price of leisure is forgone paid work) compared to people with a relatively lower income. Therefore, people with a relatively higher income are expected to require more compensation than people with a relatively smaller income.
22. Note that the instrument to measure the burden contains the positive item "care self-esteem" that positively influences the total score of the burden.
23. *"One (additional or less) hour of care to do what?"* (translated from Paraponaris, 2012)
24. Such as a study on the reimbursement level of the cost of healthcare interventions
25. Which is the main principle of the opportunity cost method
26. Based on Lancaster's utility theory: a good is characterised by different dimensions.

27. *"McFadden illustrates with an auto/bus example that very close substitutes influence the choice probabilities. Splitting the bus alternative into 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"* (van den Berg, Al, et al., 2005).
28. Note that it is also assumed there is interdependence between the well-being of the informal carer and the care recipient.
29. The theoretical basis is explained by (Ferrer-i-Carbonell & Van Praag, 2002).
30. Through regression modelling
31. A set of dummy variables in the regression model of van den Berg
32. The relationship between well-being and the two explaining variables (income and hours of care) is not linear but logarithmic. For income, it is consistent with the hypothesis that the benefit of income decreases for high levels of income (decreasing marginal utility). For informal care, the additional loss of well-being is less important with an extra 1 hour of care at a high intensity of support than at a low intensity of support.
33. The question about happiness may not be the only or ideal question for assessing subjective well-being. Other questions such as satisfaction with life in general or satisfaction with various domains of life may yield quite different estimates.
34. Two different questions on happiness were asked: at two different places in the questionnaire (to check whether after answering the questions on informal care the perception of happiness had changed) and to check consistency of the different presentations of the question on happiness (two scales of values, numerical versus verbal, two different orders of values starting with very happy versus very unhappy)
35. *"Gender; age; marital status; having children; level of education; whether the individual is unemployed; whether the caregiver has an illness"*.
36. Note that the theoretical modelling of the well-being method does not allow the preferences of non-carers to be included.
37. Carmichael showed that for females a low level of commitment if associated with lower earnings. For males, the association is identified for a higher intensity of caring ( $\geq 10$  hours) and the wage reduction is more important than for females.
38. This should be considered through an interaction variable in the regression model (intensity of care and presence of mental health problems).
39. The aim of economic evaluations is to compare both the costs and effects of different healthcare interventions in order inform the decision on the best alternative to fund: *"the comparative analysis of alternative course of actions in term of both their costs and consequences. Therefore the basic tasks of any economic evaluation are to identify, measure, value and compare the costs and consequences of alternatives being considered"*(Drummond et al., 2015).
40. With two different outcome measures (for care recipients and the informal carers), the calculation of a synthetic ratio between the variation of the total cost and the outcome would be impossible.
41. With two different outcome measures (for care recipients and the informal carers), the calculation of a synthetic ratio between the variation of the total cost and the outcome would be impossible.
42. Note that a certain proportion of care recipients would go to residential care in case of the absence of informal carers since informal care is a substitute for residential care, particularly when informal care is provided by a co-resident carer. Indeed, intensive supervision provided by a cohabitant carer allows care recipients to remain at home (e.g. dementia). The 'replacement cost' method should ideally also better reflect the real cost of replacement by considering the two types of support, at home or in residential care. However, this type of estimation is rarely performed.
43. Generalist method: one professional chosen (e.g. home worker) versus a specialist method ("various occupations such as a cook, gardener, accountant, etc. can be applied") (Sousa-Poza et al., 1999).
44. These figures are presented for comparative purposes (non-market activities are not considered in the accounting of GDP or GNP).



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