A systematic review of questionnaires used to measure the time spent on family care for frail older people

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Introduction

The commitment of the family carers to support frail older persons at home is an important issue for policymakers in the context of an ageing population. Being able to more accurately measure the time spent on family caring is therefore crucial for several reasons.

Caring has an impact on labour force participation (Bolin et al., 2008). Moreover, health care programmes may have an impact on the distribution of costs between the public budget and the private sphere (Weatherly et al., 2009, Drummond et al., 2005). Therefore, family care has to be integrated into economic evaluations, despite a lack of consensus on the best method to do this (Goodrich et al., 2012, Midy and Grignon, 2002, van den Berg et al., 2004). Measurement of the time spent on caring is an essential component used in various methods of evaluation of family care (van den Berg and Spauwen, 2006, Gerves et al., 2014, van den Berg et al., 2004, van den Berg and Ferrer, 2007). This indicator is also an interesting direct measure of the “*objective burden*” of carers.

However, there are problems with identifying the care activities that should be included to adequately measure the time spent on caring (van den Berg et al., 2004, Casey, 2011). Indeed, since family care is a partially “invisible” complex social process (Saillant, 1999, Membrado, 2005, Jansson et al., 2001) with multiple dimensions such as “*practice*”, “*knowledge*”, “*presence*” [...] (Saillant, 2000), or the accountability for the care recipient assumed by the family carers (Saillant and Gagnon, 2001), there is a considerable risk that a “reductionist” approach is adopted focusing only on the instrumental tasks (Membrado, 2005, Rigaux, 2009, Membrado, Lavoie, 2000). Hence, our first hypothesis is that the list of tasks mentioned in questionnaires used to measure time spent on family caring may not be exhaustive enough, i.e., important time-consuming tasks are omitted. Our second hypothesis is that explicit and well-defined choice of tasks is required since the frontier with ‘normal’ activities may sometimes be blurred, i.e., some activities listed in questionnaires may not be specific to caring. Hence, we aim to propose a comprehensive list of tasks that can be used to adequately measure the time spent on caring.

Methods

To evaluate the validity of the content of questionnaires, we categorized the domain of action of family carers into two types: activities of daily living defined as “*frequent common activities, including self-care, home maintenance and communication*” (Tornquist and Sonn, 2014); and intangible activities, i.e., those difficult to observe. The distinction between activities and actions proposed by Tornquist is also useful to analyse the content of questionnaires (Tornquist and Sonn, 2014): “*the activity consists of a*

group or a cluster or a sequence of actions, which are parts of components of the activity , and the activity is always something more than its action.”

To test the comprehensiveness of the activities mentioned in the questionnaires measuring time spent on caring, we used a list of activities performed on a daily basis described in validated scales measuring the functional limitations in performing these activities: the Activities of Daily Living (ADLs), “*activities oriented toward taking care of one’s own body*” (AOTA, 2014) and the Instrumental Activities of Daily Living (IADLs), “*activities to support daily life within the home and community that often require more complex interactions than those used in ADLs*” (AOTA, 2014). The rationale for comparing the content of the validated scales with the questionnaires is that family care is directly linked to functional disability.

For ADLs, we chose two scales because they have a good level of validity (Law and Letts, 1989) and have been widely used: the Katz Index of Independence in Activities of Daily Living (Katz et al., 1963, Robert et al., 2010) and the Barthel Index (Granger et al., 1979, DeLisa et al., 2005, Barthel, 1965) . These two scales assess the overall physical functioning of older adults using a list of daily activities. The Katz scale was elaborated according to the observation of reduced ability over time in the chronically illness and is used in different settings (Shelkey, 2012, Larson, 1991, McDowell, 2006). It is one of the few scales elaborated using theoretical conceptualisation of “*primary biological functions*” (McDowell, 2006). The Barthel index assesses more mobility items than does the Katz scale (*mobility on level surfaces and stair use*) and includes slightly more detail of personal care with *grooming*.

Finally, we assessed the completeness of the selected questionnaires by comparing the content with the Lawton IADL scale (Graf, 2007) measuring the level of disability for these activities. This scale has been tested on elderly people living at home and has been frequently used for this population (Vittengl et al., 2006, McDowell, 2006). We also considered the living arrangement of the carer (co-resident or not) with the care recipient. Indeed, for co-resident carers, household chores, home maintenance, outdoor work, finance management and shopping are public commodities (van den Berg et al., 2004), i.e., all cohabitants jointly benefit from these commodities, irrespective of whether or not they have disabilities. Therefore, the causal link between the loss of ability of the care recipient and these tasks is not obvious for co-resident carers. The solution proposed by van den Berg (Dumont et al., 2010, van den Berg and Spauwen, 2006) is to assess the increase in the time spent on doing these tasks as a result of a change in health status of frail older people. However, a longstanding caring relationship may hinder the assessment of the increase in workload. This solution may also be sex-biased, because these tasks are more routinely assumed by women than by men (Lee and Waite, 2008, Bianchi et al., 2000, Aassve et al., 2014). Men would declare more time spent on housework directly linked to the disability of their partners, whereas women may indicate a smaller increase in the time spent since they more often routinely performed these tasks before the occurrence of the functional limitations of their partner. According to this assumption, statistics about the carer’s commitment and workload would not correctly

reflect the reality for cohabitants. Indeed, the conclusion would pretend that men spent more time to help than women whereas the latter may actually have performed more IADLs and thus spent more time. At last, we also assert that housework is not necessary because of the presence of the care recipient as in fact carers would have to perform these tasks anyway after the care recipient has left the place. We, therefore, exclude these activities (including meal preparation) from time measurement for co-resident carers considering the weak correlation between the presence of the care recipient and the workload of these activities.

Intangible activities were identified in a qualitative study describing the role of family carers (Lavoie, 2000). Different types of activity were described: supervision, monitoring and psychological support. Firstly, supervision can be subdivided into the following categories: supervision of the care recipient and supervision of the formal care provided. We propose to restrict the supervision of the care recipient to the need for the presence of a family carer on a weekly-basis, i.e., the care recipient cannot stay alone to perform specific tasks or to prevent recurrent inappropriate behaviour, or the care recipient needs to be regularly advised on what to do at least on a weekly basis. Secondly, family carers may also perform some monitoring of the care recipient. This activity differs from supervision in that there is no systematic assistance on a regular basis. The aim of monitoring is to ensure a presence when there is a particular health risk because of acute health episodes. Finally, we consider psychological support as inherent to any affective relationship that cannot be univocally circumscribed (Rigaux, 2009). It should thus be excluded from the time measurement, except for cognitively impaired persons for whom the reciprocity of such support likely disappears as cognitive impairment worsens. In this case, psychological support is provided alongside other help as soon as there is contact between the carer and the care recipient. Therefore, we consider that the time spent on such support is already included by assessment of the duration of other forms of help and should thus be excluded from the time estimation.

Help with leisure activities or with maintaining social relationships is also difficult to delineate from “normal” activity in the setting of affective boundaries. We propose that the inclusion of such activity should be limited to the care recipients with significant loss of cognitive abilities as help with stimulating the frail older people can be considered part of the medical treatment in this case.

Literature search and selection

To identify the questionnaires used for measuring time spent on caring, we performed a systematic review of relevant studies. We searched the following databases for studies mentioning time spent on caring: MEDLINE (OVID), Embase (Embase.com), EconLit (EBSCO), PsycInfo (ProQuest), Sociological Abstract (ProQuest), Scopus and Cairn. Different terms and keywords were used to target family care: carers (Mesh term) or care, caring, carer, caregiver, caregiving and family or unpaid or informal.

A total of 2944 articles were identified, to which 6 were added by the snowball method. Two researchers (Sophie Cès and Johanna de Almeida Mello) selected the papers in two steps: firstly, from the title and scanning of the abstract (471 articles selected) and secondly, by full-text reading (59 articles selected). Criteria for selection were: studies validating time-use instruments of family care or assessing the time spent on family care or mentioning a time estimation of family care for frail older persons (either exclusively or not). Studies on specific diseases were excluded in order to avoid questionnaires focusing on a specific type of impairment, with the exception of dementia because of the high degree of disability at the end-of-life stage (the “population” criteria in the flow chart). Indeed, questionnaires designed for carers of persons with particular diseases may exclude some activities since the types of impairment may be limited (e.g. only functional limitations). The review was limited to the questionnaires used to broadly assess informal care for frail older people since the ultimate goal is to propose a list of activities to consider regardless the cause of disability. Additionally, only studies in high income countries, i.e., Europe, USA, Canada, Asia, Australia, and studies for which the questionnaires were in English, Spanish, Dutch or French were selected because of the languages mastered by the two researchers.

All types of questionnaire were included (national or international surveys, validated time-use instruments, and ad-hoc questionnaires) except for those with only one question on the time measurement without any list of activities.

Figure 1 Flow chart of the selection of articles

Data analysis

The activities mentioned in the selected questionnaires were analysed by two researchers using a software for qualitative data analysis (Nvivo version 10). This first synthesis of the activities listed in the questionnaires was subsequently validated by a second researcher. In a second stage, a critical review of the content of the questionnaires was performed.

Results

Nineteen questionnaires reported in 59 studies were selected for the review. We differentiated three types of questionnaire: instruments focusing on the time measurement of caring validated using

psychometric properties; ad-hoc questionnaires elaborated for a specific study; and national or international surveys that may have had a broader focus than time measurement and had recurrent data collection.

Table 1 Overview of the validated instruments

Name	Target population	References on the validation of the questionnaire	References of studies using time measurement
Resource Utilization in Dementia (RUD lite)	Family carers of people with dementia	(Wimo et al., 2010, Wimo and Nordberg, 2007, Neubauer et al., 2009a)	(Bakker et al., 2013, Chong et al., 2013, Ersek et al., 2010, Gerves et al., 2014, Gustavsson et al., 2011, Gustavsson et al., 2010, Haro et al., 2014, Nordberg et al., 2005, Wang et al., 2010, Wimo et al., 2013, Jönsson et al., 2006, Neubauer et al., 2008, Neubauer et al., 2009c)
van den Berg 2006	Family carers	(Van Den Berg and Spauwen, 2006)	(Van Den Berg and Spauwen, 2006)
Carer Activity Survey (CAS) 1997	Family carers of individuals with Alzheimer disease	(Marin et al., 2000, Davis et al., 1997)	(Jackson et al., 2013, Schneider et al., 2002, Gage et al., 2015)
Carer Activity Time Survey (CATS) 1996	Family carers of individuals with Alzheimer disease	(Clipp et al., 1996)	(Shikar et al., 2000)

Table 2 Overview of the ad-hoc questionnaires

	Target population	Country	References of studies using time measurement
Dumont 2010	Family carers of palliative care patients	Canada	(Dumont et al., 2010)
Harrow 2004	Family carers of individuals with Alzheimer disease	United States	(Harrow et al., 2004)
Jakobsen 2011	Family carers of people with dementia	Denmark	(Jakobsen et al., 2011)
Hassink 2011	Family carers	Netherlands	(Hassink and Van Den Berg, 2011)

Table 3 Overview of the national or international surveys

	Target population	Countries	Main goal of the questionnaire	References of studies using measurement time
Handicap-Santé 2008 questionnaires for resident and non-resident carers	Family carers of disabled persons or dependent older people	France	Family care	(Davin and Paraponaris, 2012, Paraponaris and Davin, 2015, Soullier, 2011)
National Carers Questionnaire 1996	Family carers of adults over the age of 50 years	United States	Family care	(Ory, Hoffman, Lee, Tennstedt, & Schulz, 1999)
National Carers Questionnaire 2009	Family carers of adults over the age of 18 years	United States	Family care	(Barrett, 2009)
Disability, Independence and Dependency Situations Survey (EDAD -2008)	Family carers of disabled persons	Spain	Multi-purpose	(Marcenaro-Gutierrez et al., 2012, Oliva et al., 2011, Oliva-Moreno et al., 2013, Peña-Longobardo and Oliva-Moreno, 2014b, Peña-Longobardo and Oliva-Moreno, 2014a, Jimenez-Martin and Prieto, 2012)
Common Assessment Tool (CAT) 2004	Family carers of persons aged 65 or more	Germany Greece, Italy, Poland, Sweden UK	Family care	(Balducci et al., 2008, Perrig-Chiello and Hutchison, 2010, Alwin et al., 2010)
Survey of Health, Ageing and Retirement in Europe (SHARE) Waves 1 (2004/05)	Aged 50 or over	European countries and Israel	Multi-purpose	(Albertini et al., 2007, Bolin et al., 2008a, Bolin et al., 2008c, Bonsang, 2009)
Survey of Health, Ageing and Retirement in Europe (SHARE) Waves-2 (2006/07)	Aged 50 or over	European countries and Israel	Multi-purpose	(Gannon and Davin, 2010, Alessie et al., 2014, Balia and Brau, 2014)
General Social Survey 2007 (GSS)	Aged 45 and over living in private households	Canada	Multi-purpose	(Jacobs et al., 2013)
General Social Survey 1996 (GSS)	All persons 15 years of age and older	Canada	Multi-purpose	(Latif, 2006, Lapierre and Keating, 2013)
National Long-Term Care Survey (NLTCs) 1999	All persons 65 and older	United States	Multi-purpose	(Wolff et al., 2007, Moore et al., 2001, Hong, 2006, Taylor et al., 2008)
National Long-Term Care Survey (NLTCs) 2004	All persons 65 and older	United States	Multi-purpose	(Hong, 2010, Casado et al., 2011)

Activities of Daily Living

For the ADL, the measurement of the time spent on caring is straightforward, because tasks are observable and less likely to be influenced by cultural context than Instrumental Activities of Daily Living. However, two shortcomings in time measurement were identified. Firstly, most of the

questionnaires were broad and general without describing the actions related to the activities. All questionnaires mentioned personal care but most of them did not provide the full list of actions related to this activity: three questionnaires did not list any action; two questionnaires mentioned only *bathing*; six questionnaires listed *bathing* and *showering* only; five questionnaires listed two other actions; one listed three actions; and only one mentioned six different actions. Secondly, even general tasks were sometimes omitted. Mobility inside the house and dressing were the most frequently cited activities (17/19). Sixteen questionnaires included help with eating, thirteen with using the toilet and nine with bed chair transferring. Finally, help when a person suffers from incontinence was the most rarely mentioned activity (4/19). Overall, only three questionnaires mentioned the six activities considered in the Katz scale and the Barthel index: personal care (bathing, grooming), dressing, eating, mobility inside the house (stair use, mobility on level surfaces, transfers), toilet use and incontinence (bowel, bladder).

Instrumental Activities of Daily Living

Similarly to the ADL, there are limitations in the completeness of questionnaires for IADL support. Only three questionnaires mentioned the seven types of activity considered in the Lawton IADL scale. The most frequent tasks listed were help with shopping, finances, housekeeping and transportation (16/19), laundry (10/19) and food preparation (13/19). However, some questionnaires provided no detail regarding the actions and simply mentioned “*housework*”, “*house chores*”. Medication taking was cited in 12 questionnaires and telephone use in only four questionnaires.

The particular status of IADLs for resident family carers

In the 19 questionnaires reviewed, three questionnaires had different questions based on the living arrangements of the family carer (co-resident or not). However, the Handicap-Santé 2008 survey is the only questionnaire that really distinguished between IADL tasks based on the living arrangements of the family carer. The version for extra-resident family carers included help with meal preparation, laundry, cleaning the home, home maintenance, dishwashing, financial management, shopping and outdoor work, whereas the version for co-resident family carers did not include these tasks if carers were already used to do it before the occurrence of disability. The SHARE survey also mentioned the living arrangements of the family carer (waves 1 and 2), but the estimation of time spent on caring was entirely limited to the extra-resident family carers.

Other activities cited but not listed in the Lawton scale

The following tasks not included in the Lawton scale were also mentioned in the selected questionnaires:

- Help with health care treatment (e.g. “*physiotherapy, massages, medical care such as dialysis, injections, bandages, heart monitor, blood sugar tests*”) was cited in six questionnaires. This type of task is worth mentioning since the amount of time needed may be considerable in persons with severe illness, multi-morbidity or end-stage disease. Technical tasks may also require considerable time to be spent acquiring the necessary skills, especially in the case of medical care,

such as dialysis, where the family carer is also supposed to act competently in cases of problems with the treatment or with a monitoring device.

- Mobility outside the house such as help with walking or with mobility with aids (in 5 questionnaires) is a task which can be easily assessed.
- The inclusion of “*Finding the person if they get lost*” (in 1 questionnaire) and “*find things that are lost*” (in 1 questionnaire) draws attention to potentially important tasks in looking after a care recipient with cognitive impairment.
- Making appointments and arrangements for the provision of care was included in five questionnaires and should be, because organization of formal services delivery can be time-consuming at specific moments, such as crisis situations or acute episodes of ill health (Saillant and Dandurand, 2002).
- The time taken to get to the care recipient’s home is seldom included in questionnaires (3 questionnaires over 19). This type of activity is not a direct form of help, but is a prerequisite for being able to provide help. Moreover, this activity is sometimes an important factor influencing the involvement of family carers (Joseph and Hallman, 1998).
- House adaptations (in one questionnaire), home maintenance and outdoor work (in seven questionnaires) are not activities that are regularly performed. Moreover, some of them may not be an absolute necessity to supporting the care recipient (e.g., decorating).
- Visiting family or friends and leisure participation are mentioned in five questionnaires without any condition on the care recipient’s profile.

Intangible activities

Supervision was not included in the majority of the questionnaires reviewed (13/19). Three questionnaires mentioned supervision without giving any further detail, and three questionnaires mentioned precise examples of supervision: communication with the care recipient to remind them how and when to do things or to answer repeated questions, or preventing the person from getting lost (the Carer Activity Survey 1997). Night disturbances were mentioned in the questionnaire by Jakobsen (Jakobsen et al., 2011) and night supervision in the Handicap-Santé 2008 survey (both non-resident and resident questionnaires). Both are interesting to mention because help during the night may be less associated with specific tasks.

Two questionnaires included monitoring of the condition of the care recipient (e.g., “*visiting or calling to make sure...* ”).

Psychological support (emotional, psychological, social support, presence) was mentioned in four questionnaires.

Table 4 Overview of the activities mentioned in the 19 questionnaire reviewed

		Number of questionnaire with mention of the activity
ADLs in the Katz scale and the Barthel Index	Personal hygiene care	19
	Dressing	17
	Feeding	16
	Mobility	17
	Toilet use	13
	Continence	4
IADLs in the Lawton scale	Meal preparation	13
	Housekeeping	16
	Laundry	10
	Finance management	16
	Medication	12
	Phone use	4
	Shopping	16
	Transportation	16
Other activities not mentioned in the Lawton scale	Participation to health treatment	6
	Finding the care recipient when lost	1
	Finding things lost	1
	Organization of formal care	5
	Mobility outside the house (except transportation)	5
	Time to get to the care recipient's dwelling	3
	Visiting family or friends and leisure participation	5
Intangible activities	Supervision of formal care	0
	Supervision of the care recipient	6
	Monitoring of the care recipient	2
	Psychological support	4

Synthesis

The comparison of the content of questionnaires with the scales measuring functional limitations and with the intangible tasks described in the qualitative study shows important risks of misestimating the time spent on family caring. The majority of the questionnaires reviewed risk underestimating the time, because important time-consuming tasks are often left out, such as the management of incontinence or supervision. We also found considerable heterogeneity in the list of activities mentioned in the questionnaires and many of them did not provide enough details about actions regarding the activities. Moreover, the potential help provided to care recipients suffering from cognitive impairment is not often addressed (e.g., finding a person who is lost, lost objects...). There are also different sources of potential

overestimation because of the inclusion of activities that are anyway often performed in the absence of a caring function (e.g., psychological support or visiting friends). Finally, there is no mention of the need for supervision in the questionnaires with a clear link to the degree of impairment of the care recipient. This omission may yield to an overestimation of the time spent on supervision because family carers may subjectively evaluate whether they provide such help or not.

From the content of the questionnaires and the two other data sources (validated scales and qualitative study), we developed a list of activities to consider in assessment of time spent on family caring. An important difficulty to consider is the risk of overlap between different moments in time. The first type of overlap is confusion in the time estimation: e.g., the time spent on helping with dressing can be counted several times, e.g., when helping with bathing or with toilet use. Therefore, each activity should be delineated as much as possible in terms of moments during the day. For instance, time spent in the bathroom is easily assessed, whereas moments of dressing are less identifiable because there are several occasions for dressing (in the morning, to go out, to get into bed...). Hence, to ease the time measurement, each activity for which the moment during the day is well circumscribed and identifiable should be assessed first. Other complementary activities can then be assessed outside the specific moments already evaluated: e.g., once the evaluation of time spent helping with personal hygiene care has already been performed, a complementary question is needed to assess the other moments used to help with dressing. This provides a kind of funnel structure for measuring time.

For intangible activities, the risk of overlap is real because family carers can perform these tasks at the same time as others. To avoid counting time twice, supervision and monitoring should thus be measured when no other help with ADLs or IADLs is provided (Wimo et al., 2000, Gerves et al., 2014). And monitoring should also be measured when no supervision is already provided.

Finally, it is also important to distinguish different levels of involvement in the personal intimacy of the care recipient when defining personal hygiene care. This differentiation is particularly useful to analyse specific behaviours according to the sex and family relationship of the family carer (e.g., differences between spouses and children). Therefore, we distinguished three types of activities with an increasing level of involvement in personal intimacy: grooming, bathing or showering, and urine and stool elimination, the latter demanding the highest level of intimate involvement.

Table 5 Activities of Daily Living to consider in the time measurement

Personal hygiene care (including help with mobility)	Grooming (particular parts of the body)	Shaving, combing, brushing teeth, washing hands, face and nail care	
	Bathing or showering	Getting in/out of the bathtub or the shower, washing, rinsing, drying off and dressing/undressing	
	Urine and stool elimination	Toilet use	undressing/dressing, mobility, cleaning after elimination, washing hands, or putting on and taking off diapers
		Bed pan use	
		Management of incontinence	

Other	Dressing/undressing	Getting dressed or undressed (upper and lower trunk), including tying shoelaces or fastening buttons for any other occasions than personal hygiene care
	Eating	Help with mobility to get to the room/ to sit down, cutting, spreading food, serving and/or helping with getting food or liquid into the person's mouth
	Mobility inside the house	At any other moment not previously mentioned, transfers in bed, bed to chair transferring (or between chairs), walking around in the house on the same level, moving from one floor to another (with or without any specific aid equipment)

Table 6 Instrumental Activities of Daily Living to consider in the time measurement

For extra-resident carers only	Meal preparation: food for the care recipient only	Washing, peeling, cutting vegetables or fruit, using and washing equipment, heating food or liquids and laying table
	Shopping: groceries for the care recipient only	Getting to shops, paying and bringing home
	Finances	Bills, banking, legal matters, insurance,...
	Housekeeping: only tasks performed on a regular basis	Dishwashing, dusting, cleaning up, washing floors, windows, straightening up, putting things away or finding things that are lost.
For all family carers	Laundry of the clothes/sheets of the care recipient	Washing clothes/sheets, ironing, tidying up, sewing
	Transportation to and/or participation at medical or administrative appointments	Use of any transportation means or help with mobility outside home (with walking or with aids) for medical or administrative purposes (excluding leisure)
	Transportation to visit friends or family or participation in leisure activity	Use of any transportation means or help with mobility outside home, only for care recipients with significant cognitive impairment
	Health treatment at home	Medication: pills, injections, infusions,
		Other participation for treatments: wound care, use of health technical device, physiotherapy or massages, emotional, behavioural therapies...
	Organisation of formal support	Making appointments, arrangements for the provision of care or social/health services (e.g., participation at coordination meetings)

Table 7 Intangible activities to consider in the time measurement

Supervision of formal care	When there is a particular need for the presence of the family carer, such as professional turnover or the care plan being changed, (communication needed, control of the quality of care, respect for the integrity of the care recipient...)
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Supervision of the care recipient (only moments when no other help with activities previously mentioned is provided)	In case of a potential risks of harming him- or herself and/or others or preventing the person from having inappropriate behaviour: communication with the care recipient to remind about/explain things to do, night supervision, at least on a weekly basis
Monitoring of the care recipient (only moments when no other help with activities previously mentioned is provided)	Presence of family carer required in case of a high risk of health status worsening

Finally, two other important tasks, which are not direct help activities, also need to be considered in the time measurement. Indeed, they involve the family carers, are potentially time-consuming and are directly related to the support of frail older people: commuting to the care recipient's dwelling and finding the care recipient when he/she gets lost.

Conclusion

Building a quantitative indicator to measure a complex social phenomenon requires clarification of the approach in order to be able to interpret the results, particularly regarding activities excluded from the measurement and the risks of bias. We critically analysed the content of several questionnaires using an analytical framework based on a combination of intangible activities, ADLs, and IADLs. Comparing the questionnaires with the activities listed in validated scales and a qualitative study enabled identification of important drawbacks of the questionnaires. From the synthesis of the three data sources, we were able to build a comprehensive list of contextualized activities, which is not only useful for measuring the time spent on caring, but also provides the possibility of an in-depth analysis of family care supply. However, determining which activities to measure represents a compromise between the specificity of the measurement, which requires ruling out activities not directly linked to the disability of the care recipients, and a definition of family care that is too narrow, potentially excluding relevant and time-consuming activities. Indeed, the frontier between 'normal' and 'family' care is sometimes tenuous and dependent on the profile of the care recipient.

The list proposed constitutes a first step in the design of a questionnaire enabling the time measurement of family care of frail older people. A qualitative study among carers would be necessary both to validate the list of activities on comprehensiveness and understanding and to identify potential practical issues.

Finally, to better grasp the importance of the family carer's commitment, we advocate examination of other important dimensions that cannot be included in the time measurement, such as for example, being constantly on call. Hence, further research using qualitative methods would be useful to develop

qualitative questions that can more comprehensively reveal the different degrees of accountability borne by family carers (Membrado, 2005, Saillant and Gagnon, 2001).

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