

# Measurement of the time spent on informal caregiving to frail older people living in community

## Identification and delimitation of tasks

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- **Why measuring time ?**
- **How to identify a list of tasks to consider for measuring the time?**
- **The list of tasks proposed**
- **Conclusion**

# Why measuring time ?

- Informal care is « invisible »: measure of the importance of the informal caregiver's commitment
- To study the informal caregiver behaviours (labour force participation, articulation between formal and informal care...)
- To integrate the perspective of the informal caregiver in economic evaluation: the valuation of the cost of informal care

- Few papers in economics tackle the problem of defining the components of informal care and the measurement of time

Membrado 2005, Lavoie: Time measurement is criticized because of its narrow definition of informal care, too limited to observable tasks, close to the care professional field

- In qualitative analysis: papers tackle the problem of complexity without any full description of what informal care is, lack of concrete tasks

# The complex nature of caregiving

Saillant, 2000 : multiple dimensions as « *practice* », « *knowledge* », « *presence [...]* »

Saillant & Gagnon, 2001: the accountability for the care recipient assumed by the informal caregivers

Caron & Bowers, 2003: in terms of purposes

**How to identify a list of tasks to consider for measuring the time?**

- 1 The questionnaires used to measure the time spent on caregiving in published studies**
- 2 Qualitative analysis describing informal care for the « less tangible tasks »**
- 3 The validated scales measuring the functional limitations of the frail older people**

**Iterative process**

# Results



59 articles were selected from 2944 found, using 20 questionnaires measuring the time spent on care

### Validated instruments

Resource Utilization in Dementia (RUD)
van den Berg 2006
Caregiver Activity Survey (CAS) 1997
Caregiver Activity Time Survey (CATS) 1996

### Ad-hoc questionnaires

Dumont 2010
Harrow 2004
Jakobsen 2011
Hassink 2011

### National or international surveys

Handicap-Santé 2008 questionnaire for cohabitants and for non-cohabitants*
National Caregivers Questionnaire 1996
National Caregivers Questionnaire 2009
Disability, Independence and Dependency Situations Survey (EDAD - 2008)
Common Assessment Tool (CAT) 2004
Survey of Health, Ageing and Retirement in Europe (SHARE) Waves 1 (2004/05) -2 (2006/07)*
General Social Survey 2007 (GSS)
General Social Survey 1996 (GSS)
National Long-Term Care Survey (NLTC) 1999
National Long-Term Care Survey (NLTC) 2004

*MEDLINE (OVID), Embase (Embase.com) EconLit (EBSCO), PsycInfo (ProQuest), Sociological Abstract (ProQuest), Scopus and Cairn*

- **Activities of Daily Living (ADL):** basic self-care activities (basic needs)  
*The tasks described in the Barthel Index and the Katz scale*
- **Instrumental Activities of Daily Living (IADL):** more complex activities required in the environment, *the Lawton scale*
- **« Intangible » tasks:** tasks that cannot be easily observed

The tasks **to exclude** from the time measurement

# The Instrumental Activities of Daily Living for cohabitants

**Public commodities** (van den Berg et al., 2004), i.e. all cohabitants jointly benefit from this commodity, irrespective of whether they have disabilities: the informal caregiver does not only perform these tasks because of the presence of the care recipient

## A solution ?

Assess only the **increase of time due to the change of the health status of the frail older people** (*Dumont et al. 2010; van den Berg & Spauwen 2006*) ?

- **practical problem** since the longstanding caring relationship may hinder identifying an increase of the workload
- **gender biased** : women routinely more assume these tasks than men (Arnstein Aassve, 2014; Suzanne M. Bianchi, 2000; Yun-Suk Lee, 2008)



**Weak correlation between the presence of the care recipient and the workload of the household chores, except laundry**

# The Instrumental Activities of Daily Living

- **Food preparation**

- **Housekeeping** **To exclude for cohabitant informal caregivers,**

- **Finances**

- **Shopping**

- **The home maintenance**

- **Outdoor work**

## Other tasks to exclude

- **Inherent support to any affective relationship:** psychological support (4 questionnaires) **socializing and visiting friends** (5 questionnaires)

The tasks **to include in** the time measurement

# Activities of Daily Living

This list is a synthesis of all data from the questionnaires, the qualitative studies and the validated instruments on functional limitations.

Personal hygiene care

<b>Grooming</b>	face care, shaving, combing, brushing teeth and nails care
<b>Bathing/showering</b>	any help required such as getting in/out the bathtub or the shower, washing, rinsing drying the person and dressing/undressing
<b>Excrement elimination</b>	Toilet use: undressing/dressing, cleaning, washing hands
	Bed pan: material cleaning
	Incontinence management: putting on/off diapers
<b>Dressing</b>	Dressing or undressing, including tying shoelaces or buttons for any other occasions than personal hygiene care
<b>Eating</b>	cutting food, spreading butter, serving, helping with the use of cutlery
<b>Mobility inside the house</b>	Bed to chair transferring, use of stairs, walking around in the house at a same level with or without any specific aid equipment



# Instrumental Activities of Daily Living

Only for non cohabitants

the work is done  
only for the care  
recipient

<b>Meal preparation</b>	washing, peeling, cutting vegetables or fruits, using and washing equipment, heating food
<b>Shopping</b>	
<b>Housekeeping</b>	dishwashing, dusting, cleaning up, washing floors, windows, straightening up, putting things away or finding things are lost
<b>Finances</b>	bills, banking, legal matters, insurance

# Instrumental Activities of Daily Living

## For all informal caregivers

<b>Laundry of the care recipient clothes or sheets</b>	washing clothes (with or without machine), ironing clothes, tidying up, sewing clothes of the care recipient
<b>Health treatment at home</b>	medication: pills, injections, infusions,... physiotherapy, massages emotional, behavioral therapies prevention care (if not already included in the other tasks: e.g. bed sore prevention may already be included in the measurement of time spent on helping with mobility inside the house)
<b>Transportation and/or attendance to appointments</b>	only for the care recipient obligations and including mobility outside the house: medical appointments, legal matters,...
<b>Making appointments, arrangements for the provision of care</b>	

## Other tasks to include in the time measurement

**For all informal caregivers**

**Finding the person when he/her gets lost**

**Time to get to the care receiver's dwelling**

## « Intangible » tasks

### For all informal caregivers

<b>Supervision of formal care</b>	Because of a particular change in the provision of formal services such as the turnover or the care plan changed...
<b>Supervision of the care recipient</b>	<b>Risks of harming to him- or herself and/or to others:</b> communication with the care recipient to remind things to do, preventing the person from having inappropriate behavior and night supervision.
<b>Monitoring of the care recipient</b>	<b>in case of a health risk identified &amp; no supervision</b>

## There is no adequate questionnaire

- **Important risk of understatement** of the time measurement because time-consuming tasks miss (4/20 questionnaires mention the incontinence management cited in the scales , 7/20 mention the supervision)
- Lack of precision : 17/20 questionnaires only mention 1 or two tasks for personal care
- **Confusion of activities** which are usually performed in absence of a caregiving function (e.g. visiting friends, psychological support)

# Conclusion

**Original approach with  
the triangulation of  
the 3 types of data  
sources**



**Need for multidisciplinary research on this  
complex topic to avoid oversimplification**

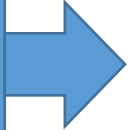
Quantitative indicator always pertains a way of defining, circumscribing, simplifying reality

A list of tasks with explicit arguments for choosing or excluding tasks



## The list of tasks proposed , a good starting point to:

Better grasp the importance of the informal caregiver's commitment



Quantitative indicator + qualitative questions

Better describe the informal caregiver's commitment



Accurately identify and study the tasks performed by the informal caregivers according to gender and family relationship: **the dyad informal caregiver/care recipient**

# References

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## According to the scales measuring the functional limitations and qualitative studies...

...there is no adequate questionnaire

- **IADL** : only 3/20 questionnaires consider all the different tasks mentioned in the Lawton scale: *finances, laundry, meal preparation, medication, shopping, telephone use, transportation*
- **ADL**: only 3/20 questionnaires list the 6 types of tasks included in the Barthel Index and the Katz scale  
*Dressing, eating, personal care, mobility inside the house, incontinence and using the toilets*
- « **Intangible tasks** » : **supervision** in only 7/20 questionnaires, **monitoring** in 2 questionnaires

2/20  
questionnaires  
with all types  
of tasks

## There is no adequate questionnaire

- the informal caregiver not being the respondent,
- time measurement limited to the non-cohabitants
- total time asked before describing the tasks to consider



**Questionnaires should be designed in a way that avoids as much as possible subjective interpretation**

# Selection of the questionnaires

MEDLINE (OVID), Embase (Embase.com) EconLit (EBSCO), PsycInfo (ProQuest), Sociological Abstract (ProQuest), Scopus and Cairn.

## Inclusion criteria

- Articles focusing on time measurement of informal care, validation of time-use instruments or studies assessing or using a time estimation
- Only studies including caregiving to a frail older person, either exclusively or not, were selected
- Any type of questionnaire: national or international surveys, validated time-use instruments, and ad-hoc questionnaires
- Developed countries: Europe, USA, Canada, Asia, Australia
- Questionnaires available in English, Spanish or French

## Exclusion criteria

- The questionnaires with only one question on the time measurement without any list of tasks
- Studies on specific diseases except dementia