Caring for a frail older person: The association between informal caregiver burden and being unsatisfied with support from family and friends.

Lopez Hartmann, Maja^{1 2}

De Almeida Mello, Johanna³

Anthierens, Sibyl²

Declercq, Anja³

Van Durme, Thérèse⁴

Cès, Sophie⁴

Verhoeven, Véronique²

Wens, Johan²

Macq, Jean⁴

Remmen, Roy²

¹Department of Nursing, Karel de Grote University College, Antwerp, Belgium

²Department of Primary and Interdisciplinary Care, University of Antwerp, Wilrijk (Antwerp), Belgium

³LUCAS - Centre for care research & consultancy, KULeuven, Leuven, Belgium

⁴Institute of Health and Society, Université catholique de Louvain, Louvain-la-Neuve, Belgium

Corresponding author:

Lopez Hartmann Maja

Karel de Grote University College, department of Nursing

Brusselstraat 45

B-2018 Antwerpen

Belgium

E-mail: maja.lopezhartmann@kdg.be

Caring for a frail older person: The association between informal caregiver burden and being unsatisfied with support from family and friends.

3-5 key words

Informal caregivers, frail older people, caregiver burden, social support

3-5 key points

- 58.6% of the primary informal caregivers of frail older people in this study experienced burden.
- The proportion of informal caregivers with burden increased with the impairment level of the frail older person cared for: 41.9% in the low impaired group, 55.2% in the mildly impaired group and 62.7% in the moderate to severely impaired group.
- Logistic regression analysis showed that being unsatisfied with social support from family and friends was associated with burden (OR 1.85; 95%CI 1.53–2.23).
- Our findings underline the importance of perceived social support in relation to caregiver burden reduction.
- Interventions to improve perceived social support that focus on the informal caregiver to feel more connected to others could be beneficial and therefore be promoted.

Abstract

Background/Objective: Although informal caregivers (ICG) find caring for a relative mainly satisfying, it can be difficult at times and it can lead to a state of subjective burden characterized by -among others- fatigue and stress. The objective of this study is to analyse the relationship between perceived social support and subjective burden in providing informal care to frail older people.

Methods: A descriptive cross-sectional study was conducted using data from a large nationwide longitudinal effectiveness study. Pearson correlations were calculated between the variables for support and burden. Logistic regression models were applied to determine the association between being unsatisfied with support and burden, taking into account multiple confounding variables.

Results: Of the 13229 frail older people included in this study, 85.9% (N=11363) had at least one informal caregiver. Almost 60% of the primary informal caregivers manifested subjective burden, measured with the 12-item Zarit-Burden-Interview (ZBI-12). The percentage of informal caregivers that were unsatisfied with support from family and friends was on average 11.5%. Logistic regression analysis showed that being unsatisfied with support is associated with burden (OR1.85; 95%CI1.53–2.23). These results were consistent for the three groups of impairment level of the frail older persons analysed.

Conclusions: The association between perceived social support and subjective caregiver burden was explored in the context of caring for frail older people. ICGs who were unsatisfied with support were more likely to experience burden. Our findings underline the importance of perceived social support in relation to caregiver burden reduction. Therefore efforts to improve perceived social support are worth evaluating.

Introduction

The increasing number of frail older people is a worldwide concern as it may threaten the sustainability of public health care systems[1]. Although healthy ageing and keeping elderly persons active has been proposed as a concept that may help to decrease this risk, measures are needed to cope with the increasing care demands of this frail older population[1]. When in need of care, many frail older people prefer to stay in their homes[2]. The proportion of non-institutionalised people over the age of 65 receiving informal care in Europe is on average 29% and increases with age; the average for people aged 80 years and older is 47.5%[3]. Informal care is mainly provided by relatives, especially spouses and adult children[4]. The majority of these caregivers are female, mostly daughters, daughters-in-law and wives[2].

While many informal caregivers (ICG) report positive attitudes towards caring, it can also be challenging and may cause the ICG to experience physical and mental health problems[5], financial problems and social isolation[6]. A negative appraisal of the caregiving situation by the ICG can lead to a state of subjective burden characterized by - among others- fatigue and stress[7]. Several contextual factors can contribute to perceived caregiver burden. These encompass the level of dependency on the frail older person, presence of cognitive or behavioural problems of the frail older person, the number of hours spent by the ICG providing care and living with the frail older person[8].

Studies on social support in the context of informal caregiving show positive effects of social support on psychological outcomes like subjective burden[7, 9-11]. In a recent comprehensive meta-analysis, del-Pino-Casado-et-al-(2018) studied the association between social support and burden in caregivers of adults and older adults. They highlight that especially perceived social support is more related to subjective burden than received social support. Perceived and received social support both look at the functional dimension of social support (emotional, instrumental and informational). The difference lies in the fact that perceived social support measures satisfaction, adequacy and availability of support, whereas received social support measures frequency of support[7]. Nevertheless, del-Pino-Casado-et-al-(2018) also acknowledge the mixed findings in the literature on the relationship between social support and caregiver

burden. Taken into account that in their meta-analysis all adults (18 years old and more) were included, the question remains if the findings can be transferred to the frail older population.

The large number of participants in this study and focus on solely the frail older population provides the opportunity to contribute to the evidence already established by among others del-Pino-Casado-et-al-(2018), but focused on informal caregivers of frail older people with low, mild and moderate to severe impairment levels.

Consequently, the objective of this study is to analyse the association between informal caregiver's subjective burden and perceived social support in providing informal care to frail older people. Additionally, potential differences in association between burden and social support according to level of impairment of the frail older people will be studied.

Methods

Context

This is a nested descriptive cross-sectional study in a larger nationwide longitudinal effectiveness study (Protocol 3) that evaluates innovative interventions to delay institutionalization of frail older persons, maintain or improve their functional status and their quality of life while assessing the cost of staying at home and the impact on the burden of their main ICG. The protocol of this effectiveness study was previously published[12].

Participants

People aged 65 years or older were eligible to be included in the study if they were frail. Frailty was measured either with a score of 6 or more on the Edmonton Frailty Scale[13], needing assistance on the Belgian version of the Katz dependency scale[14] or having a dementia diagnosis. A frail older person experiences losses in one or more domains of physical, psychological and social functioning and this may result in an increase of the risk of adverse outcomes[15]. Presence of an ICG was questioned in the InterRAI-HC as "Are there informal caregivers available and what is their relationship with the older person?". The primary informal caregiver was, according to the older person, the person who helps him/her the most or whom he/she can rely on most. It

could be a spouse, another family member, friend or neighbour but not a paid care provider[16].

Data collection

At inclusion in the study, described in de-Almeida-Mello-et-al(2012), a global assessment of the frail older person was made using the interRAI-HC instrument[12]. The interRAI-HC instrument is a comprehensive assessment to map the needs and the care context of the person being cared for. The outcomes from the instrument have been internationally validated in comparison with gold standard measures[17-21].

ICGs filled out the 12-item Zarit-Burden-Interview (ZBI-12) to assess the level of caregiver burden[22]. The cost of living at home, including time spent caring and use of formal care and support services was assessed by an ad-hoc economic questionnaire made for this study[23].

Variables used in the analysis

The variable 'feeling supported' was measured with an item from the interRAI-HC instrument, which assesses whether or not the primary ICG was unsatisfied with the support received from family and friends. The answer could be either 'yes' or 'no'. Caregiver burden was measured with the ZBI-12[22]. Caregivers rated their self-perceived burden on a 5-point Likert scale where 0=never and 4=nearly always, and scores ranged from 0 to 48 with a score of 10 indicating burden and a score of 17 or more indicating clinically significant (high) burden [24].

The level of impairment of the frail older person was defined as a composite score. Stratification was made between low, mild and moderate to severely impaired older persons using their scores on the Activities of Daily Living Scale(ADL) (range0-6), Instrumental Activities of Daily Living Performance Scale(IADLP) (range0-48) and the Cognitive Performance Scale(CPS) (range0-6) in the interRAI-HC instrument.

- Low impairment: low IADLP (IADLPscore<24), low ADL (ADLscore<3) and low cognitive impairment (CPSscore<3)
- Mild impairment: high IADLP (IADLPscore >=24), low ADL (ADLscore<3) and low cognitive impairment (CPSscore<3)
- Moderate to severe impairment: high IADLP impairment (IADLPscore >=24) and high ADL or cognitive impairment (ADLHscore>=3 or CPSscore>=3)

Statistical analysis

The Chi square test was used to determine the differences in characteristics among the ICG such as cohabitation and relationship with the frail older person. ANOVA tests were performed to analyse the differences between the subgroups of people for age and scores on the scales for ADL, IADLP, CPS and the Depression Rating Scale (DRS, range 0-14).

Pearson correlations were calculated to determine the pairwise correlation coefficients between the dichotomous variables for feeling supported and for burden. Univariate and multivariate logistic regression models were applied to calculate the association between unsatisfied with support and burden, taking into account the confounding variables; measured using items of interRAI-HC; age of the ICG (continuous), cohabitation (yes/no), presence of behaviour problems (6 items), ADLscore (4 items), IADLPscore (8 items), CPSscore (5 items) and DRSScore (7 items)[17]. The odds of burden was expressed in odds ratio (OR) with a 95% confidence interval (CI). All analyses were performed using Stata/IC11.1. A probability value of <0.05 was considered significant.

Ethics

This study was approved by the Belgian Privacy Commission and by the Ethics committee of the Belgian Universities involved (B40320108337).

Results

Description of the population

Out of the 13229 frail older people included in the study, 85.9% (N=11363) had at least one ICG, and 42.3% also had a secondary ICG. The primary ICG was mainly an adult child (56.5%) or a spouse (29.3%). Almost 60% of the primary ICG (58.6%) had a score of 10 or more on the ZBI-12scale, meaning that they experienced burden ($ZBI-12 \geq 10$). The percentage of ICG with high burden ($ZBI-12 \geq 17$) was 28.4%. The proportion of ICG with burden increased with impairment level: 41.9% in the low impaired group, 55.2% in the mildly impaired group and 62.7% in the moderate to severely impaired group. Almost one out of five ICGs (18.8%) expressed feelings of sadness, anger or depression. A third of all ICGs (33.2%) felt unable to maintain to function as an informal caregiver. The percentage of ICG that was unsatisfied with the support they received from family and

friends was on average 11.5%, and was the highest in the moderate to severely impaired group (12.9%).

Table 1 Description of the population; frail older people and primary informal caregivers. Stratification by impairment level of the frail older people.

Frail older people with at least one informal caregiver (ICG)	Total (N= 13229)	Low impaired (N=2142)	Mildly impaired (N=2770)	Moderately to severely impaired (N=8317)
Gender (female)	68.6%	70.2%	74.3%	65.9%
Age (median)	82	80	82	82
ADLscore (0-6) (median)	3	0	2	3
IADLPscore (0-48) (median)	34	15	32	38
CPSscore (0-6) (median)	1	0	0	2
DRSscore (0-14) (median)	1	1	0	1
% having behaviour problems	12.5%	5.2%	4.6%	17.4%
% having depression (DRSscore $\geq$ 3)	29.9%	29.7%	22.0%	32.5%
% having primary ICG	85.9%	61.8%	84.8%	87.6%
% having secondary ICG	42.3%	25.6%	46.0%	44.6%
Primary informal caregiver	N= 11363 (85.9%)	N=1323 (61.8%)	N=2350 (84.8%)	N=7288 (87.6%)
Age (median)	59	57	57	62
Relationship to frail older person				
Adult child	56.5%	62.2%	68.0%	51.5%
Spouse	29.3%	18.6%	17.2%	35.6%
Sibling	3.7%	4.9%	4.1%	3.3%
Other relative	5.1%	6.0%	5.1%	4.8%
Other	5.5%	8.3%	5.6%	4.8%
% living with frail older person	38.5%	22.4%	23.7%	46.8%
% with feelings of sadness, anger, depression	18.8%	12.8%	11.1%	22.5%
% unable to maintain as caregiver	33.2%	33.6%	27.3%	33.7%
% unsatisfied with support by family and friends	11.5%	8.4%	8.7%	12.9%
Primary informal caregiver filled out the ZBI-12	N=8619 (75.9%)	N=997 (75.4%)	N=1867 (79.4%)	N=5755 (79.0%)
% with burden on ZBI-12scale:				
ZBI-12score $\geq$ 10 (burden)	58.6%	41.9%	55.2%	62.7%
ZBI-12score $\geq$ 17 (high burden)	28.4%	16.9%	21.4%	33.0%
ADL: Activities of Daily Living IADLP: Instrumental Activities of Daily Living Performance CPS: Cognitive Performance Scale DRS: Depression Rating Scale Behaviour problems: Variable to indicate the presence of behaviour problems (daily or less than daily). ZBI-12: Zarit Burden Interview, 12-item version.				

Association between being unsatisfied with support by family and friends and perceived burden.

A weak but significantly positive correlation was found between perceived burden (ZBI-12>10) and feeling unsatisfied as an ICG with the support received from family and friends ($r=0.1373$, $p<0.001$). There was also a weak but significantly positive correlation between perceived high burden (ZBI-12>17) and feeling unsatisfied as an ICG with the support received from family and friends ($r=0.1907$, $p<0.001$).

Table 2 shows the multivariable logistic regression analysis to explain the association between being unsatisfied with support by family and friends and perceived burden/high burden. Analyses for the total group of ICG and the three subgroups per frail older persons' impairment levels were performed taking into account the confounding variables age of the ICG, cohabitation, presence of behaviour problems, ADLscore, IADLPscore, CPSscore and DRSscore. Out of a total of 11363 ICG, data of 6442 ICG could be included in the logistic regression analysis. ICG not included in the analysis either did not have a complete ZBI-12 ($N=2744$) or had at least 1 other necessary item missing ($N=2177$). Additional analysis of the characteristics of ICG with ($N=8619$) and without complete ZBI-12 ($N=2744$) showed no significant differences.

Table 2 Logistic regression analysis of the association between burden / high burden and being unsatisfied with support from family and friends: analysis on the total population and on subgroups.

ALL primary informal caregivers (N= 6442)									
ICG with burden (ZBI-12≥10)					ICG with <u>high</u> burden (ZBI-12≥17)				
	OR	95% CI		P-value		OR	95% CI		P-value
Unsatisfied with support	1.85*	1.53	2.23	<0.001	Unsatisfied with support	1.97*	1.67	2.33	<0.001
Living together	1.25*	1.10	1.43	0.001	Living together	1.48*	1.29	1.70	<0.001
CPS score	1.13*	1.09	1.17	<0.001	CPS score	1.18*	1.14	1.23	<0.001
ADL score	1.03*	1.00	1.07	0.049	ADL score	0.98	0.94	1.02	0.266
DRS score	1.12*	1.10	1.15	<0.001	DRS score	1.13*	1.10	1.16	<0.001
Age ICG	0.99*	0.98	0.99	<0.001	Age ICG	0.99*	0.98	0.99	<0.001
Behaviour	1.55*	1.37	1.75	<0.001	Behaviour	1.45*	1.33	1.63	<0.001
A probability value of <0.05 was considered significant and indicated with * next to the OR									
Informal caregivers of LOW IMPAIRED older people (N=706)									
ICG with burden (ZBI-12≥10)					ICG with <u>high</u> burden (ZBI-12≥17)				
	OR	95% CI		P-value		OR	95% CI		P-value

Unsatisfied with support	2.54*	1.42	4.54	0.002	Unsatisfied with support	2.66*	1.44	4.89	0.002
Living together	1.41	0.94	2.13	0.098	Living together	1.32	0.78	2.23	0.301
CPS score	1.12	0.89	1.41	0.343	CPS score	1.33	0.99	1.77	0.052
ADLH score	0.95	0.78	1.15	0.577	ADLH score	1.03	0.79	1.34	0.833
DRS score	1.16*	1.08	1.24	<0.001	DRS score	1.11*	1.03	1.20	0.009
Age ICG	0.98*	0.96	0.99	<0.001	Age ICG	0.97*	0.95	0.99	0.001
Behaviour	1.53	0.94	2.46	0.084	Behaviour	1.52	0.95	2.43	0.080
A probability value of <0.05 was considered significant and indicated with * next to the OR									
Informal caregivers of MILDLY IMPAIRED older people (N=1505)									
ICG with burden (ZBI-12≥10)					ICG with <u>high</u> burden (ZBI-12≥17)				
	OR	95% CI		P-value		OR	95% CI		P-value
Unsatisfied with support	1.61*	1.06	2.44	0.025	Unsatisfied with support	2.55*	1.70	3.82	<0.001
Living together	1.09	0.83	1.44	0.539	Living together	1.49*	1.08	2.06	0.016
CPS score	1.20*	1.04	1.37	0.010	CPS score	1.37*	1.16	1.60	<0.001
ADL score	1.18*	1.05	1.33	0.007	ADL score	0.94	0.81	1.09	0.404
DRS score	1.09*	1.03	1.15	0.004	DRS score	1.13*	1.07	1.20	<0.001
Age ICG	1.00	0.99	1.01	0.588	Age ICG	0.99	0.98	1.00	0.210
Behaviour	1.44	0.96	2.16	0.082	Behaviour	2.42*	1.64	3.57	<0.001
A probability value of <0.05 was considered significant and indicated with * next to the OR									
Informal caregivers of MODERATELY TO SEVERELY IMPAIRED older people (N=4231)									
ICG with burden (ZBI-12≥10)					ICG with <u>high</u> burden (ZBI-12≥17)				
	OR	95% CI		P-value		OR	95% CI		P-value
Unsatisfied with support	1.86*	1.48	2.33	<0.001	Unsatisfied with support	1.79*	1.48	2.17	<0.001
Living together	1.35*	1.15	1.58	<0.001	Living together	1.51*	1.28	1.77	<0.001
CPS score	1.11*	1.07	1.16	<0.001	CPS score	1.13*	1.09	1.18	<0.001
ADL score	0.96	0.91	1.02	0.161	ADL score	0.91*	0.86	0.96	<0.001
DRS score	1.14*	1.11	1.17	<0.001	DRS score	1.13*	1.10	1.16	<0.001
Age ICG	0.98*	0.98	0.99	<0.001	Age ICG	0.99*	0.98	0.99	<0.001
Behaviour	1.55*	1.36	1.78	<0.001	Behaviour	1.40*	1.26	1.57	<0.001
A probability value of <0.05 was considered significant and indicated with * next to the OR									

A logistic regression analysis showed that being unsatisfied with support from family and friends was the highest predictor for burden and high burden among the variables in Table 2 in the total population studied and in all subgroups.

Overall, ICGs who were unsatisfied with support from family and friends were more likely (OR1.85; 95%CI 1.53–2.23) to perceive burden compared to informal caregivers who were satisfied with support when all other measured confounders were held

constant. The association between being unsatisfied with support and high burden was slightly stronger with an odds ratio of 1.97 (95%CI 1.67–2.33).

In the subgroup of ICG caring for a low impaired older person, the odds of perceiving burden when being unsatisfied with support was higher (OR2.54; 95%CI 1.42–4.54) than when satisfied with support. The odds ratio of perceiving high burden was 2.66 (95%CI 1.44–4.89) when being unsatisfied with support in this subgroup.

When caring for a mildly impaired older person, being unsatisfied with support from family and friends was associated with burden and high burden with odds ratios of 1.61 (95%CI 1.06–2.44) for burden and 2.55 (95%CI 1.70–3.82) for high burden.

In the group of moderately to severely impaired older people, ICG who were unsatisfied with support had a higher chance of perceiving a burden (OR1.86; 95%CI 1.48–2.33), and were also more likely to perceive a high level of burden (OR1.79; 95%CI 1.48–2.17) compared with ICG who were satisfied with the support they receive from family and friends.

Discussion

Main results

This study showed a significant positive association between feeling unsatisfied with the support provided by friends and family and perceived burden among ICG of non-institutionalised frail older people. These results were consistent for the three groups of impairment level of the frail older person.

The results confirm the hypothesis of the recent qualitative study that feeling supported in providing informal care to frail older people is associated with developing caregiver burden[10]. In that study, adult daughters of community-dwelling frail older people who reported to feel sufficiently supported by friends and family tended to have a lower level of burden than women who were unsatisfied with the support they received.

Strengths and limitations

Although the importance of social support for ICG in general is not a new finding[7, 25, 26], our results add to the evidence that perceived social support and subjective caregiver burden are associated in the context of caring for frail older people.

Strengths of this study are the large number of frail older people and ICGs included in the study. This is important when drawing recommendations for policy makers to promote early needs assessment and prevention. Another strength is that thanks to the large number of participants and the focus on the specific frail older population, a stratification in different levels of impairment was possible to analyse the association between perceived social support and subjective caregiver burden according to impairment level of the frail older person.

A significant limitation of this study was that only one 'yes/no' item was available in the interRAI-HC on the perception of informal social support. This measure lacks sensitivity and context. 'Feeling supported' can be interpreted in many ways depending on the context and psychosocial status of the ICG. Future research on social support in the context of informal caregiving should define clearly the type of social support assessed and use measures and instruments that are more sensitive to personal and contextual factors of the ICG[7]. In this study we could only assess whether the ICG was satisfied or not. Qualitative research investigating why ICG are dissatisfied and what is effective social support according to the experience of the ICG could be helpful in developing social support interventions[27].

Another limitation is that 'time spent caring' could not be included in the final analysis. The variable had a strong correlation with 'cohabitation' and therefore the two could not be inserted in the model at the same time. The final selected model was the model with the best fit for all variables. A possible explanation for the large correlation between the two variables could be that many cohabiting ICG filled out that they spent 24 hours per day on caring. Time spent caring is an important factor in determining the role of the ICG, as well as distance for non-cohabiting ICG[23, 28].

Recommendations for primary care practice

Early detection of risk factors or signs of burden is important to prevent ICGs from getting overburdened, so that they will not experience negative health outcomes as a result of caring, and to help them cope with caring for their loved ones. It is often difficult for ICGs to admit to themselves (and even more difficult to others) that they are

in need of social support from family and friends. The care provided by the ICG is not always visible to others[10]. It is important that primary care providers can detect this often under reported need, and that they can help the ICG in finding support in their own social network. Del-Pino-Casado-et-al(2018) recommend the promotion of increasing perceived social support by interventions to make the ICG feel more connected rather than to build new connections[7]. This might be even more necessary for spouses than for adult children since they are less likely to seek informal support [28]. Support groups are a valuable intervention to increase social support and reduce psychological effects of informal care on the ICG[9, 29, 30]. Keeping in mind the recommendation of Del-Pino-Casado-et-al to focus on feeling connected instead of building connections, family group conferences are promising interventions to increase perceived social support for the informal caregiver. More research is needed on the effect of family group support interventions to increase perceived informal support for ICG caring for older people[29].

Conclusion

In this study the association between perceived social support and subjective caregiver burden was explored in the context of caring for frail older people. ICGs that were unsatisfied with support from family and friends were more likely (OR1.85; 95%CI1.53–2.23) to experience burden compared to informal caregivers that were satisfied with support. These results were consistent for the three groups of impairment level of the frail older person analysed. Although our cross-sectional study cannot infer a causal relationship, our findings underline the importance of perceived social support in relation to caregiver burden reduction. Interventions to improve perceived social support that focus on the informal caregiver to feel more connected to others are worth evaluating.

Reference list

1. Cesari, M., et al., *Frailty: An Emerging Public Health Priority*. Journal of the American Medical Directors Association, 2016. **17**(3): p. 188-192.
2. Pickard, L., *The supply of informal care in Europe*. 2011, European Network of Economic Policy Research Institutes.
3. Riedel, M.K., Markus, *Informal care provision in Europe: Regulation and profile of providers*, ed. E.N.o.E.P.R. Institutes. 2011.
4. Betini, R., *Caregivers in distress: Using interRAI assessments to target and evaluate community based interventions*. 2017, UWSpace.
5. Schulz, R.S., Paula R., *Physical and Mental Health Effects of Family Caregiving*. American Journal of Nursing, 2008. **108**(9 (supplement)): p. 23-27.
6. Ranmuthugala, G., et al., *Impact of home based long term care on informal carers*. Aust Fam Physician, 2009. **38**(8): p. 618-20.
7. del-Pino-Casado, R., et al., *Social support and subjective burden in caregivers of adults and older adults: A meta-analysis*. PLOS ONE, 2018. **13**(1): p. e0189874.
8. Mello, J.d.A., et al., *The determinants of informal caregivers' burden in the care of frail older persons: a dynamic and role-related perspective*. Aging & Mental Health, 2017. **21**(8): p. 838-843.
9. Lopez-Hartmann, M., et al., *The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: a systematic review*. Int J Integr Care, 2012. **12**: p. e133.
10. Lopez Hartmann, M., et al., *Understanding the experience of adult daughters caring for an ageing parent, a qualitative study*. Journal of Clinical Nursing, 2016. **25**(11-12): p. 1693-1702.
11. Shiba, K., N. Kondo, and K. Kondo, *Informal and Formal Social Support and Caregiver Burden: The AGES Caregiver Survey*. Journal of Epidemiology, 2016. **26**(12): p. 622-628.
12. De Almeida Mello, J., et al., *Interventions to delay institutionalization of frail older persons: design of a longitudinal study in the home care setting*. BMC Public Health, 2012. **12**: p. 615.
13. Rolfson, D.B., et al., *Validity and reliability of the Edmonton Frail Scale*. Age and Ageing, 2006. **35**(5): p. 526-529.
14. KATZ, S., *Assessing Self-maintenance: Activities of Daily Living, Mobility, and Instrumental Activities of Daily Living*. Journal of the American Geriatrics Society, 1983. **31**(12): p. 721-727.
15. Gobbens, R.J., et al., *Toward a conceptual definition of frail community dwelling older people*. Nursing Outlook, 2010. **58**(2): p. 76-86.
16. Van Durme, T., et al., *Tools for measuring the impact of informal caregiving of the elderly: A literature review*. International Journal of Nursing Studies, 2012. **49**(4): p. 490-504.
17. Carpenter, G. and J. Hirdes, *Using interRAI assessment systems to measure and maintain quality of long-term care*, in *OECD/European Commission A Good Life in Old Age? Monitoring and Improving Quality in Long-term Care*, O.H.P. Studies, Editor. 2013, OECD Publishing.
18. Burrows, A., et al., *Development of an MDS-based depression rating scale for use in nursing homes*. . Age Ageing, 2000. **29**: p. 165-72.
19. Morris, J., et al., *Scaling functional status within the interRAI suite of assessment instruments*. BMC geriatrics, 2013. **13**: p. 128.

20. Morris, J., et al., *Outcome Measures for Use with Home Care Clients*. Canadian Journal on Aging, 2000. **19**(2): p. 87–105.
21. Wellens, N., M. Deschodt, and S. Boonen, *Validity of the interRAI Acute Care based on test content: a multi-center study*. Aging Clin Exp Res. , 2011. **23**: p. 476–486.
22. Bédard, M., et al., *The Zarit Burden Interview A New Short Version and Screening Version*. The Gerontologist, 2001. **41**(5): p. 652-657.
23. Cès, S., et al., *A systematic review of questionnaires used to measure the time spent on family care for frail older people*. International Journal of Care and Caring, 2017. **1**(2): p. 227-245.
24. Zarit, S.H., C.R. Anthony, and M. Boutselis, *Interventions with care givers of dementia patients: comparison of two approaches*. Psychol Aging, 1987. **2**(3): p. 225-32.
25. Yurtsever, S., et al., *The relationship between care burden and social support in Turkish Alzheimer patients family caregivers: Cross-sectional study*. Journal of Nursing Education and Practice, 2013. **3**(9): p. 1.
26. Han, J.W., et al., *Effects of social supports on burden in caregivers of people with dementia*. International Psychogeriatrics, 2014. **26**(10): p. 1639-1648.
27. Winslow, B.W., *Family Caregivers' Experiences with Community Services: A Qualitative Analysis*. 2003. **20**(5): p. 341-348.
28. Cès, S., et al., *Les aidants proches des personnes âgées qui vivent à domicile en Belgique : un rôle essentiel et complexe*. 2017, Fondation Roi Baudouin.
29. Strozier, A.L., *The effectiveness of support groups in increasing social support for kinship caregivers*. Children and Youth Services Review, 2012. **34**(5): p. 876-881.
30. Ong, H.L., et al., *Resilience and burden in caregivers of older adults: moderating and mediating effects of perceived social support*. BMC Psychiatry, 2018. **18**(1): p. 27.