

Problems experienced by informal caregivers with older care recipients with and without cognitive impairment

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ABSTRACT

The care of older persons can have negative impact on the caregiver. The objective of this population-based observational study is to identify problems experienced by informal caregivers, and the extent of related difficulties, in their care of older care-dependent recipients with and without cognitive impairment. Caregivers ($n = 2,704$) caring for a home-dwelling person aged ≥ 75 years responded to a questionnaire with 23 questions on problems and related difficulties by mail. Prevalence of self-reported problems and related difficulties was calculated. The impact of the problem was estimated by weighing the percentage of problems reported as being difficult against the prevalence of problems. The median number of problems was 12 (range 0–23), with 5 (range 0–23) reported as difficult. Informal caregivers experience a variety of problems, with the impossibility to engage in joint social activities having the highest impact. The impact of problems increased when the care recipient had a cognitive problem.

KEYWORDS

Care issues of persons with dementia; cognition; community and home care; family geriatrics

Introduction

As in all aging societies, in The Netherlands the number of older and care-dependent adults is growing. Because recent Dutch policy is directed at keeping people in need of care, at home as long as possible, older adults in need of care become increasingly dependent on informal caregivers. In most cases informal caregivers stem from family (Oudijk, De Boer, Woittiez, Timmermans, & De Klerk, 2010). For example, in the USA 13% of adults aged ≥ 40 years provide care to their parents and another 73% is likely to do this in the future (Taylor, Parker, Patten, & Motel, 2013).

Care giving can be a source of satisfaction but also a source of stress and emotional strain. When informal caregivers feel that the care is not sufficient, this may lead to feelings of burn out, depression, and guilt. (Almberg, Grafström, & Winblad, 1997, Collins & Jones, 1997; Donaldson, Tarrier, & Burns, 1998;

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Edwards & Scheetz, 2002; Ekwall & Hallberg, 2007; Gonyea, Paris, & De Saxe Zerden, 2008; Madsen & Birkelund, 2013; Roach, Laidlaw, Gillanders & Quinn, 2013; Springate & Tremont, 2014) In particular, cognitive problems of the care recipient are related to an increased complexity of the care and increased burden of the informal caregiver (Fowler, Fisher, & Pitts, 2014; Nordtug & Hølen, 2011; Sequeira, 2013; Wenzel & Poynter, 2014). Apart from stress, problems in the social and relational domain occur, (Feinberg & Whitlatch, 2002), especially when the care recipient has cognitive problems (Harris, 2013; Luchetti et al., 2009). Although positive feelings, such as satisfaction and reciprocity play a role in care giving, care givers with a care recipient with cognitive problems experience these feelings to a lesser degree (Sequeira, 2013).

To provide appropriate support to informal caregivers, the associated problems need to be identified. Therefore, this study explores the prevalence and self-reported extent of difficulty of the problems faced by informal caregivers and evaluates to what extent these problems depend on the presence of cognitive impairment of the care recipient.

Methods

Study design

This population-based cross-sectional survey was conducted between March and May 2012.

The study was approved by the Institutional Review Board of the Leiden University Medical Center, The Netherlands.

Study population

The participants were informal caregivers registered at the Social Insurance Bank (SIB), an organization that implements national insurance schemes in The Netherlands. Eligible for the study were adults who provided informal care (in the last 12 months) to a home-dwelling adult aged ≥ 75 years who was also receiving professional care (e.g., home care, or assistance with practical activities in daily life; professional domestic assistance not included).

In The Netherlands, care-dependent people who are entitled to professional care can endorse their primary informal caregiver with an annual gift of €250 (via the government). Accordingly, 97,057 care-dependent eligible adults aged ≥ 75 years, living at home and entitled to professional care, provided the SIB with the names and addresses of their primary informal caregiver. As we aimed to have a balanced mix on gender, the SIB sent the questionnaire by mail to a random sample of (otherwise anonymous) 3,000 male and 3,000 female informal caregivers. We were unable to balance on relationship to care recipient as the SIB does not register this information.

The questionnaire

To develop a questionnaire addressing the daily problems of caregiving, we employed qualitative research methods based on grounded theory (Corbin & Strauss, 1990), conducting interviews with a sample of informal caregivers. Informal caregivers of care recipients with and without cognitive problems, participating in a research project on integrated systematic care for older people living at home (van Houwelingen, den Elzen, le Cessie, Blom, & Gussekloo, 2015), were invited to participate in an interview. Cognitive problems were measured by the Minimal Mental State Examination (Folstein, Folstein, & McHugh, 1975). We interviewed 15 males and 24 females; 21 were children, 10 were spouses, and 8 other. Thematic saturation was reached after 24 interviews for caregivers with care recipients without cognitive problems, and after 15 interviews in case of care recipients with cognitive problems. In these interviews participants were invited to speak freely about the following topics: (a) tensions and burdens in the process of caregiving, (b) changes in the relationship with the care recipient, (c) medical decision-making, and (d) cooperation with professional home care services. Items emerging from these interviews were transformed (by authors SvB and DPT using thematic topic analysis) into statements for use in the study questionnaire.

Subsequently, for the questionnaire, these items were thematically categorized into three domains: *demand* on the caregiver (6 items), *safety* of the care recipient (6 items), and *social-relational* issues (11 items).

To estimate prevalences, the respondents could express to what extent they recognized a particular problem on a 4-point Likert scale (1 = *never*; 4 = *always*) and to what extent they experienced this particular problem as being difficult (1 = *not difficult at all*, 4 = *really difficult*). To ensure that we would measure the degree of difficulty in this specific care situation, rather than merely hypothetical attitudes, for each item we included only those respondents who indicated that this problem did occur (sometimes, often, or always). For each item, the “self-reported difficulty” was dichotomized by recoding score 1 (not difficult at all) and score 2 (not really difficult) to “not difficult,” and recoding score 3 (a bit difficult) and score 4 (very difficult) to “difficult.”

In the questionnaire, several characteristics of the caregiver and care recipient were examined: including gender, age, type of relationship, and characteristics of the support, as well as care needs and assistance provided by professional home care. To assess the cognitive functioning of the care recipient, the first item of the Clinical Dementia Rating Scale (Hughes, Berg, Danziger, Coben, & Martin, 1982), which aims to detect memory impairment, was used. This question provided us information about the perception of the care giver about the memory of the care recipient.

To synchronize the answer scale of this latter item with the answer scale of most other items, this answer was transformed from a “yes/no” answer to an

answer on a 4-point Likert scale. Participants were also asked if the care recipient was suffering from forgetfulness: answers could be “most of the time,” “often,” “sometimes,” or “seldom.” We considered cognitive impairment to be present when respondents filled out “most of the time” or “often.”

Analyses

For each domain we performed the following psychometric analyses before performing principal component analyses. We calculated common variance and eigenvalue per domain. The constructs were tested toward sampling adequacy by the Kaiser-Meyer-Olkin (KMO) index, with values above .70 being considering adequate. Bartlett’s test of sphericity was used to verify whether the correlation matrix differed from an identity matrix. Results are shown in Appendix A. To test the reliability of our domain classification, the respondents who completed all items with respect to experienced difficulty were selected ($n = 1,863$; only respondents who experienced a certain problem, answered the question about difficulty). The dimensional structure of the items was tested with a principal component factor analysis (PCA) with Varimax rotation. Second, the internal consistency of the domain classification was tested with Cronbach’s alpha. Factor analysis showed that each domain consisted of one single factor. In addition, the internal consistency of the domains was confirmed by Cronbach’s alpha, which was high on all domains (demand: $\alpha = .90$, safety: $\alpha = .71$, social-relational: $\alpha = .80$).

We calculated the prevalence of problems and the experienced difficulty, in total, per domain and per problem. To compare prevalence of problems and the experienced difficulty, in total and per domain between informal caregivers with a care recipient *with* cognitive impairment (according to the questionnaire) with informal caregivers with a care recipient *without* cognitive impairment, we calculated the odds ratios for increase in risk of having a higher prevalence or higher experienced difficulty than the median value. We chose medians because in some groups the mean number of problems was different from the mean—i.e., a slightly skewed distribution. Medians were compared with Mann-Whitney U test.

To make a comparison per problem, the calculated impact for each problem was compared in both groups by weighing the percentage of problems reported as being difficult with the prevalence of the problems. Comparisons were tested using chi-square tests.

When a participant indicated that an item was experienced but the perception of difficulty was missing, this record was omitted from the “difficulty-analysis” of this item. When the item was not filled in for prevalence, this record was omitted from the analysis of prevalence of problems and the “difficulty-analysis” of this item.

Participants were also asked if the care recipient had a formal diagnosis of dementia. As a sensitivity analysis, within the group caring for recipients with

cognitive impairment, we compared those caring for individuals *with* a diagnosis of dementia to those caring for individuals *without* a diagnosis of dementia, regarding the number of experienced problems in total and per domain.

Results

Participants

The questionnaire was returned by 3,341 respondents (56%). However, as 627 of this latter group had missing values on the care recipient's age or housing condition, or had exclusion criteria (i.e., the care recipient was aged ≤ 75 years and/or living in a care center), and 10 participants had not filled in any answer at the 23 problem-statements, 2,704 respondents were left for further analysis. Of these remaining caregivers: 54% were children of the care recipient and 23% spouses. For the remaining 23% the care recipient was: mother-in-law ($n = 136$), father-in-law ($n = 28$), brother ($n = 20$), sister ($n = 38$), uncle ($n = 19$), aunt ($n = 65$), another male ($n = 92$), another female ($n = 211$). For 10 respondents this was unknown. Their median age was 61 (interquartile range 54–73) years and 53% was female (Table 1). All 2,704 participants filled in the 23 items, with a small number of missing values per item. On average 95% (range 90–97%) of each item was filled in for prevalence, and out of the positive answers on prevalence, 97% (range 95–98%) of each item was filled in for difficulty.

Prevalence of problems

Overall, the median number of self-recognized problems was 12 of 23 (range 0–23). Of these recognized problems, a median number of 5 (range 0–23) was reported as being difficult.

Table 1. Characteristics of the Informal Caregivers and Care Recipients.

	Study sample ($n = 2,704$)
Female	1,439 (53)
Age in years, median (IQR)	61 (54–73)
Relationship*	
Child	1,473 (54)
Partner	612 (23)
Other	619 (23)
Provided care in hours/week, median (IQR)	8 (4–16)
Type of delivered care*	
Personal care	891 (33)
Domestic assistance	2,320 (86)
Financial or administration	2,239 (83)
Assistance with transport outdoors	2,420 (89)
Emotional support	2,632 (97)
Cognitive impairment of their care recipient	773 (29)

Note. Figures are numbers (%) unless stated otherwise.

*Sum of percentages is > 100 because ≥ 1 answering option was possible.

The median number of problems on (a) the demand domain was 4 (range 0–6) with 1 problem (range 0–6) reported as being difficult, (b) on the safety domain 2 (range 0–6) with 1 problem (range 0–6) reported as being difficult, and (c) on the social-relational domain 6 (range 0–11) with 3 problems (range 0–11) reported as being difficult.

Risk of problems in care recipients with cognitive impairment

Figure 1 shows the increase in the median number of problems in case of a care recipient with cognitive impairment. Irrespective of the domain, compared to informal caregivers with a care recipient *without* cognitive impairment, those caring for someone *with* cognitive impairment had a 5-times higher risk to report more problems than the median total number of problems, odds ratio (OR) 5.0, 95% confidence interval (CI) [4.1, 6.0]; and a 4-times higher risk, OR 3.9, 95% CI [3.2, 4.7], to perceive more problems as being difficult than the median total number of problems reported as being difficult (Figure 2).

Within each domain, informal caregivers with a care recipient *with* cognitive impairment had a higher risk of having more problems than the median (Figure 1)—“demand domain” OR 2.2, CI [1.8, 2.6]; “safety domain” OR 6.0, CI [5.0, 7.2]; “social-relational domain” OR 4.8, CI [4.0, 5.8]—and more than the median number of problems perceived as being difficult —“demand domain” OR 1.8, CI [1.6, 2.2]; “safety domain” OR 2.9, CI [2.4, 3.4]; “social-relational domain” OR 2.9, CI [2.4, 3.4]—compared to those caring for someone *without* cognitive impairment (Figure 2).

In subgroup analyses for type of relationship we found that children experience more problems and perceive these as more difficult (see Appendix B).

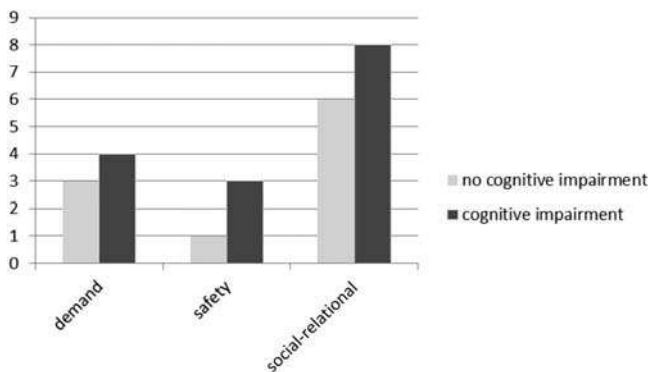


Figure 1. Median number of problems experienced on the three domains by caregivers with a care recipient without and with cognitive impairment. All p values < .001 (Mann-Whitney U test).

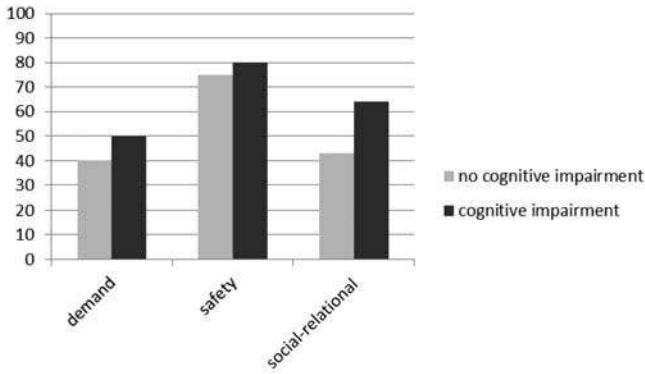


Figure 2. The median percentage of items per domain experienced as being difficult, by caregivers with a care recipient without and with cognitive impairment. All p values < .001 (Mann-Whitney U test).

Contribution of cognitive impairment to the impact of problems

Table 2 shows the risk for experiencing a problem, and for experiencing a problem as being difficult, for informal caregivers with a care recipient *with* cognitive impairment compared to caregivers with a care recipient *without* cognitive impairment. In the group caring for recipients with cognitive impairment, all problems have a higher impact. For both groups, the impossibility to engage in social activities with the care recipient had the highest impact. In the presence of cognitive impairment, problems on the social-relational domain had the highest impact, whereas in the absence of cognitive impairment problems on the demand domain had the highest impact.

Risk of problems with care recipients formally diagnosed with dementia

The risk of problems for informal caregivers with a care recipient with cognitive impairment according to the questionnaire, plus a formal diagnosis of dementia, compared to caregivers with a care recipient with cognitive impairment but without a formal diagnosis, was similar (ORs for the domains with problems and for self-reported difficulty on the domains were around unity; data not shown).

Discussion

The present study reveals that informal caregivers of care-dependent persons aged ≥ 75 years often experience problems on all three examined domains: *demand* on the caregiver, *safety* of the care recipient, and *social-relational* issues. In this total population of informal caregivers, the impossibility to engage in social activities together had the highest impact. Safety issues were



Table 2. Prevalence, Self-Reported Difficulty, and Impact of Problems of Caregivers, Depending on Cognitive Impairment of Care Recipients.

	% with problems		% with difficulty		% impact				
	Without ^a	With ^a	Without ^a	With ^a	Without ^a	With ^a			
<i>Demand on informal caregiver</i>									
This person doesn't seem to realize how much time and energy it takes to provide the care.	66	84	< .001	48	57	< .001	32	48	< .001
Since I can't let this person alone very often, I hardly have any personal time.	47	69	< .001	55	63	.005	26	43	< .001
Sometimes I need to say "no" to this person, otherwise providing support becomes too much for me.	47	59	< .001	60	71	< .001	28	42	< .001
I consider the intimacy of physical assistance as complex.	43	51	< .001	73	74	.808	31	38	.063
I provide much more care than other beloved persons.	84	88	.002	31	40	< 0.001	26	35	< .001
I provide much more care than I would actually prefer.	50	63	< .001	50	56	0.048	25	35	< 0.001
<i>Safety of care recipient</i>									
The older adult refuses to use support instruments (e.g., walker or alarm button).	38	60	< .001	64	80	< .001	24	48	< .001
The older adult forgets to take his medication.	31	75	< .001	55	62	.015	17	47	.017
Sometimes I use deceit to get the older adult to take the right medication.	5	23	< .001	35	42	.348	2	10	< .001
The older adult forgets the gas or pots/pans on the fire.	20	45	< .001	72	82	.002	14	37	.007
The older adult uses a car or bicycle although, in my opinion, this is irresponsible.	11	15	.006	76	92	.001	8	14	< .001
Actually, it's irresponsible to leave the care recipient alone at home.	43	74	< .001	73	80	.001	31	59	< .001
<i>Social-relational problems</i>									
Due to the need dependence of the older adult, nice trips together become difficult to realize.	80	87	< .001	65	74	< .001	52	64	< .001
Sometimes I feel ashamed of the behavior of the older adult.	30	44	< .001	69	75	.038	21	33	< .001
The older adult doesn't show much appreciation for the care that I provide.	35	51	< .001	50	56	.058	18	29	< .001
The older adult is becoming increasingly unkind to me.	33	55	< .001	65	67	.685	21	37	< .001
The older adult often asks the same questions, and forgets them again every time.	65	98	< .001	34	64	< .001	22	63	< .001
The older adult can become extremely sad or angry, caused by nothing in particular.	59	79	< .001	51	68	< 0.001	30	54	< .001
The roles between the older adult and myself are, so to speak, reversed.	60	89	< .001	37	54	< .001	22	48	< .001
The older adult is no longer able to pay attention to the things that happen in our life.	56	88	< .001	45	62	< .001	25	55	< .001
Sometimes I need to say "no" to the older adult, otherwise an irresponsible situation is created.	44	77	< .001	41	55	< .001	18	42	.093
The care recipient hides his/her inabilities and handicaps from others.	59	82	< .001	50	60	< .001	30	49	< .001
The person who I take care of "claims" me completely.	49	67	< .001	53	61	.004	26	41	< .001

Note. ^aWithout and with cognitive impairment.

often reported as being difficult, but were not frequently mentioned. When the care recipient was cognitively impaired, informal caregivers had a considerably higher risk of indicating problems (on all three domains) as being difficult. Although we hypothesized that having a formal diagnosis of dementia would make problems easier to deal with, no difference was found in the prevalence or impact of the examined problems.

Participants indicated that most problems occur on the social-relational domain with the care recipient; this confirms a study on caregivers of veterans with dementia showing relational strain as a common phenomenon (Bass et al., 2012). Social-relational issues concern the preexisting relationship, shifts in responsibilities within the relationship, and social interaction with others.

Informal care is characterized by the preexisting relationship between the care-receiving older person and his/her informal caregiver: In the present study the majority of informal caregivers was related to the elderly person in some way. This relationship may strengthen the significance of giving care, but may also complicate how to deal with the experienced problems. Many informal caregivers struggle with the changing role and relationship between themselves and the care-receiving older person. Especially in case of a care recipient with cognitive impairment, the roles and relationships are likely to change. In this study, caregivers found it burdensome that the care recipient is often unaware of the burden that the provision of care entails. Although incongruence in the mutual appraisal of caregiving difficulties has been reported (Lyons, Zarit, Sayer & Whitlatch, 2002), interventions seldom focus on this item (Carretero, Garcés, Ródenas, & Sanjosé, 2009).

The problems faced by caregivers in the care for an older person often arise due to a shift in responsibilities (Walker, 2007). The frequency and difficulty of such discomfort increases in the case of diminishing decisional capacity of the older person—e.g., in case of cognitive impairment. Caregivers then have to find a balance between respect for the autonomy of the older person and performing their caring duties.

Furthermore, caregivers may face a negative impact on their own social life, as the older person may no longer want to go out and/or cannot be left at home alone. An interesting result of the present study is that the impossibility to engage in social activities together was perceived as the most important problem among our caregivers.

Psycho-educational programs might alleviate the emotional discomfort of informal caregivers associated with social-relational issues, and provide them with skills and strategies to face the challenge of caregiving (Lyons et al., 2002). Such programs may also acknowledge and support informal caregivers in the knowledge that the (former) relationship has changed, and that meaningful joint activities have become impossible; this might stimulate informal caregivers to find new ways to achieve joint activities. Providing insight into the dilemmas inherent to the caregiver/care-recipient relationship and the

shift in responsibility might be helpful. However, compared with psycho-educational interventions, interventions offering respite care are reported to be the most effective in reducing caregivers' burden (Garcés, Carretero, Ródenas, & Alemán, 2010). Perhaps interventions aimed at organizing social events for caregiver and recipient together (focusing on their relationship) might be successful, such as the special "memory cafes" available in The Netherlands and other countries (Hope & Pope, 2014; Ryan, 2014).

Strengths and limitations

We only had information of the respondent and not of the nonrespondents, which makes it difficult to make a judgement about the representativeness of the sample. Therefore we compared our sample to other population-based studies with informal care givers. Another population-based study with informal caregivers caring for frail older people in The Netherlands had a similar response to the questionnaire as in this study (Looman, Fabbriotti, & Huijsman, 2014). The age of the caregivers was comparable. However, our study has a relatively small percentage of female care givers (53 vs. 75%). A comparable sample in the United States showed 26% of care givers were partners which is comparable to our study. The percentage of children was 38 whereas our study had 54% (Allen, Lima, Goldscheider & Roy, 2012).

Secondly, although we did not use a validated instrument to assess cognitive functioning/impairment of the care recipients, family/close others are reported to adequately estimate cognitive impairment (Teresi & Holmes, 1997). Therefore, the Clinical Dementia Rating Scale can be seen as a valid classification tool for use in this study.

Conclusion

Informal caregivers experience a variety of problems in the process of caregiving, many of which have a considerable negative impact.

Cognitive impairment of the care recipient increases the risk of informal caregivers having problems on the domains of demand, safety, and social-relational issues. Addressing and enhancing awareness of these problems may enable informal caregivers to better anticipate these problems and, together with the care recipient, alleviate the complexity of the dilemmas.

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Author contributions

Guarantor: D. P. Touwen had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: D. P. Touwen, J. Gussekloo, D. P. Engberts

Acquisition of data: D. P. Touwen, S. van Bruggen.

Analysis and interpretation of data: S. van Bruggen, J. W. Blom, D. P. Touwen, J. Gussekloo, C. Bode

Drafting of the manuscript: S. van Bruggen, J. W. Blom, D. P. Touwen, J. Gussekloo

Critical revision of the manuscript for important intellectual content: S. van Bruggen, J. W. Blom, D. P. Touwen, J. Gussekloo, D. P. Engberts, C. Bode

Obtained funding: D. P. Touwen, J. Gussekloo, D. P. Engberts

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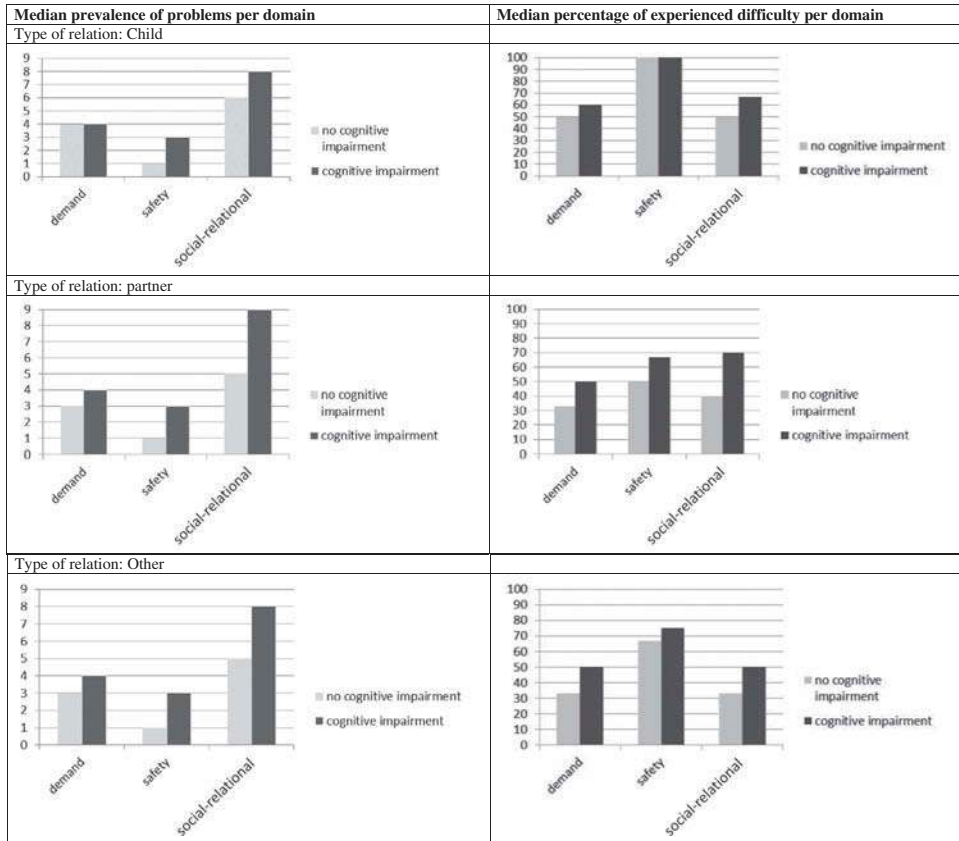
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Appendix A. Psychometric characteristics of the questionnaire.

Domain	Common variance	Eigenvalue	Kaiser-Meyer-Olkin measure of sampling adequacy	Bartlett's test of sphericity significance
Demand on caregiver	52.740	3.164	.862	$\chi^2 = 3532,798 (p = .000)$
Safety of care recipient	42.030	2.522	.802	$\chi^2 = 1769,69 (p = .000)$
Social-relational problems	49.953	5.495	.937	$\chi^2 = 8727,16 (p = .000)$



Appendix B. Table subgroup analyses by type of relation *Note.* Differences between care recipient with and without cognitive impairment were all significant. *Type of relation:* (a) Care recipient without cognitive impairment—prevalence in demand and social domain significantly different, with children experiencing more problems; experienced difficulty significantly different in all domains, with children experiencing more difficulty. (b) Care recipient with cognitive impairment—prevalence in social domain significantly different, with partners experiencing more problems; experienced difficulty significantly different in safety and social domains, with children experiencing most difficulty.