

Informal caregivers' personal needs – investigating the role of individual differences

Katharina Bidenko (✉ katharina.bidenko@uni-wh.de)

Witten/Herdecke University

Sabine Bohnet-Joschko

Witten/Herdecke University

Research Article

Keywords: Personal needs, Informal caregiver, Elderly, Home care, Quantitative Research

Posted Date: September 22nd, 2022

DOI: <https://doi.org/10.21203/rs.3.rs-2003576/v1>

License:   This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Abstract

Background: Although understanding informal caregivers' personal needs is crucial for providing appropriate support, prior research shows shortcomings in this area. The aim of the current study is to investigate individual differences in informal caregivers' perceived personal needs depending on sociodemographic factors and home care situation.

Methods: The study uses a cross-sectional sample of 1,429 informal caregivers in Germany. They were surveyed by a questionnaire. Multivariate analysis of variance and regression analysis was carried out to investigate determinants of caregivers' perceived personal needs.

Results: Significant differences in caregivers' personal needs could be found. Women caregivers have a higher need for support in almost all domains than men do. Young caregivers have higher needs for financial and work-related support. Further, unemployed caregivers need more financial security and social contacts, while employed seek help with combining work and care. The informal caregivers' network and the care recipients' health status are other significant determinants of caregivers' perceived personal needs.

Conclusions: Informal caregivers need different information and support depending on their individual situation. Understanding their specific needs in different situations is of primary importance to provide optimal support and help caregivers to maintain their own health. Policymakers and service providers could consider the current findings to develop services oriented toward caregivers' personal needs and communicate them to potential users.

1. Introduction

Increasing average life expectancy and decreasing average birth rates in many developed nations has resulted in a growing number of elderly people with chronic conditions and a reduced healthcare workforce to provide for their needs [1]. Due to the preferences of elderly people to stay as long as possible at home, a greater number of older adults in need of care rely on informal help from family and friends. Informal care at home is therefore at the heart of long-term care [2]. It is widely recognized that informal caregivers often experience health and financial burdens [3]. Support services aim to provide them with vital information, skills, relief, and support. However, informal caregivers rarely make use of them [4]. Some researchers suggest that the reason for the low use is that current support services rarely meet caregivers' needs [5–7].

Informal caregivers have various needs that are often complex [7, 8]. A more detailed understanding of their needs in different situations could help develop targeted support services and therefore increase their use. Although knowledge about caregivers' needs is crucial, prior research shows shortcomings in studies from this area [9, 10]. Most of the studies are indication-specific [6, 11, 12], or use explorative approaches [13, 14]. Quantitative research on personal and situational characteristics that determine caregivers' needs are rare [3, 11]. Such research, however, is required to identify caregivers with specific

needs and target them with suitable services. For example, full-time employed women who combine work and care are likely to have other needs for support than retired older adults providing care for their partner. Therefore, understanding different caregivers' needs is crucial and is the focus of current research.

Furthermore, previous research does not sufficiently account for caregivers' personal needs. Traditionally, caregivers' support services address the management of the care situation. So, for example, in Germany caregivers are offered care courses to learn techniques in providing personal care at home [15]. However, recent results show that caregivers' also need support to manage their own health and life. For example, they need to be able to combine work and care or maintain their own physical and mental health [7, 8, 16]. Focusing on caregivers' personal needs is particularly important since caregivers themselves tend to neglect their own needs [17]. They focus primarily on the needs of the person receiving care and could be therefore at high risk of harm to their own health and well-being.

The aim of the current research was, therefore, to explore the caregivers' personal needs in relation to their sociodemographic factors and the care situation. Caregivers' perceived personal needs (CPPN) are defined in the current study as needs articulated by caregivers themselves and related to their own health and life. Based on previous studies on caregivers' needs [4, 18] and expert reviews, our study defines five main domains of CPPN: (1) maintaining one's own physical and mental health, (2) social contacts and exchange of experiences, (3) work and care, (4) financial security, and (5) free-time opportunities and other activities. Our approach simultaneously investigates the effect of sociodemographic and care-related factors on the five domains of CPPN and allows a deeper understanding of the differences in needs.

First, we contribute to the previous research by focusing solely on caregivers' personal needs for support since up until now there is a gap in the literature on this issue. Second, we investigate the role of sociodemographic factors and the care situation to give a more detailed understanding of caregivers' personal needs. Third, we use a large-scale sample of informal caregivers with no limits on age, indication, or type of relationship so that our results are widely applicable and provide insights into needs of a broad population of informal caregivers. Our results provide the basis for developing personalized need-based support services oriented directly toward informal caregivers. Policymakers and practitioners could apply our findings to help informal caregivers in need of support and to stabilize home care.

2. Materials And Methods

2.1. Research design and sample

The current research used cross-sectional data derived from a written survey of 1,429 informal caregivers conducted between November 2018 and March 2019. Participation in the survey was voluntary and anonymous. The study received approval from the medical ethics committee of Witten/Herdecke University (registry number 241/2017). All individuals signed informed consent forms before participating.

The survey included relatives, friends, or neighbors aged 18 years and older who regularly take care of or look after a person in need of care or did so in the last 12 months. The questionnaire was available online. However, we also offered the paper form of the questionnaire so that people with less or no access to the internet were able to participate in the study. The questionnaire was pretested with seven representatives from the target group.

2.2. Recruitment

Informal caregivers were recruited via print and online media. Local newspapers and specialized magazines for informal caregivers reported about the study. Further, online communities in social networks and forums supported the recruitment by spreading information and inviting caregivers to participate. Institutions that operate in the field of professional care also granted access to informal caregivers. Cooperative partners acted as gatekeepers and invited informal caregivers to participate in the study.

2.3. Questionnaire and measures

The questionnaire begins by collecting data on the care situation. The following care-related information was collected:

- The severity of the care recipient's physical and mental limitations (as assessed by caregivers on the 7-point Likert scale, in which 1 signifies "no limitations at all" and 7 signifies "very severe limitations").
- The informal network of the caregiver (assessed as the total number of persons involved in caregiving including the respondent).

Further, we surveyed the caregivers' perceived personal needs (CPPN). As noted we defined the following five domains of CPPN:

- (1) Maintaining one's own physical and mental health,
- (2) Social contacts and exchange of experiences with other caregivers,
- (3) Possibilities to combine work and care,
- (4) Financial help and security, and
- (5) Free-time opportunities and other activities.

The items were based on prior literature [4, 18] and twelve expert reviews from the field of the caregiver support and consulting. The expert review technique [19] was used to ensure that the proposed set of five items found in the literature reflect well the main aspects of caregivers' personal needs. Caregivers were asked how important they rate each of the five domains on the 7-point Likert scale, in which 7 signifies "very important" and 1 signifies "not important at all".

Finally, caregivers were asked to provide demographic information, which included:

- Gender;
- Age in years;
- Employment status (employed full-time; employed part-time; unemployed; not working for other reasons) of the informal caregiver.

2.4. Statistical analysis

Descriptive analysis was performed with means, standard deviations, and percentages. Two-way Multivariate Analyses of Covariance (MANCOVA) was used to determine if and how the five CPPN domains mentioned in the previous section were affected by the following six personal and care-related factors:

- (1) Age of the caregiver in years
- (2) Gender of the caregiver
- (3) Employment status of the caregiver
- (4) Informal Network of the caregiver
- (5) Physical Limitations of the care recipient
- (6) Mental Limitations of the care recipient

The MANCOVA combines analysis of variance and regression analysis and allows investigating group differences in categorical variables and estimating the effects of metric variables simultaneously [20]. Since gender and employment status are categorical variables, they were included as fixed factors in the model. Metric variables (caregiver's age, informal network, and severity of the care recipients' limitations) were used as covariates.

We conducted the overall multivariate analysis to test for the effects of the independent variables. For categorical variables, if significant differences were found on the multivariate level a USD post-hoc test was used to identify what the specific differences were. We tested the effects of the metric variables by estimating the regression coefficients. For all measurements, a 5% significance level was used. The analysis was conducted using the Statistical Package for Social Sciences (SPSS) program.

We checked for the assumptions before conducting the analysis. First, missing data were identified in some of the CPPN domains with a proportion of 0.2%. Since the proportion of missing values was relatively low, we handled missing values by imputing item mean scores [21]. A further assumption of the multivariate normality of the outcome variables was checked by studying the distribution charts. We detected skewness of the data in all five domains of CPPN. To deal with the skewness, a logarithmic transformation of the data was performed. This method allows transforming skewed data so that it

approximately follows a normal distribution [22]. We decided to use Pillai's trace in the MANCOVA model since this statistical test is the most robust in dealing with departures from the assumptions [23].

3. Results

3.1. Descriptive statistics

The first step of our analysis involved calculating descriptive statistics. Of the total sample of 1,429 caregivers, 81% were women. The average age was 54 years. About a quarter of the caregivers (25.5%) were full-time and about one-third (31.5%) were employed part-time. About 10% were unemployed and about 34% were not working for other reasons (e.g., retired or in school). On the 7-point Likert scale, in which 7 signifies "very severe limitations" and 1 signifies "not limitations at all," the severity of the care recipients' physical limitations was on average about 5 points (4.99) and above the severity of mental limitations with 4.6 points. As to the CPPN domains, the highest score was for the need to have more free time (5.76), followed by the need to maintain one's own health (5.63). The next highest ranked item was that caregivers rated social contacts as 5.38 points average. Finally, the need for financial security and the need to combine work and care domains were rated 5.15 and 4.77 points, respectively. The descriptive statistics of the sample are detailed in Table 1.

Table 1: Sample Description (N=1,429)

Characteristics	Percentage/Mean (SD)
Gender	
Female	81%
Age	54 (12.21) years
Employment	
Employed full-time	25.5%
Employed part-time	31.5%
Unemployed	9.1%
Not working for other reasons	34.1%
Informal Network	1 (1.3) person
Limitations of person receiving care	
Physical (1-7)	4.9 (1.62) Points
Mental (1-7)	4.6 (1.85) Points
Need for Support (1-7)	
Maintaining one's own physical and mental health	5.63 (1.83) points
Social contacts and exchange of experiences	5.38 (1.94) points
Work and care	4.77 (2.48) points
Financial security	5.15 (2.25) points
Possibilities for free time	5.76 (1.85) points

SD – standard deviation;

3.2. The overall effect of personal and care-related factors on CPPN

First, an overall multivariate test for the significance was conducted to consider the effects of multiple factors. Table 2 displays how personal and care-related factors are associated with all five domains of CPPN. Pillai's Trace statistics showed significant effects of all variables ($P < 0.01$). We observed the largest size of the effect by the age of the caregiver accounting for about 12.4% of the variance in CPPN (part. $\text{Eta}^2 = 0.124$). Psychological limitations of the person receiving care also have a relatively large effect and account for 5.5% of the variance, followed by the employment status of the caregiver with 4.8%. Physical limitations have a lower effect of only 2.5%, as well as informal network and gender of the caregiver.

Table 2: Multivariate Tests

Effect	Pillai's Trace			Partial Eta Squared
	Value	F	Significance	
Gender	.015	4.283	.001	.015
Age	.142	40.008	.000	.124
Employment	.150	14.117	.000	.048
Informal network	.021	6.026	.000	.021
Limitations (physical)	.025	7.108	.000	.025
Limitations (mental)	.058	16.424	.000	.055

3.3. Significant determinants of CPPN domains

After obtaining a significant multivariate test for particular main effects, we examined the univariate F tests for each variable. Table 3 presents the specific CPPN domains that are affected by the independent variables.

TABLE 3 NEAR HERE

Table 3: Between-subject effects

Independent variables	Dependent variables	Type III sum of squares	df	F	Significance
Gender	Health	.500	1	11.693	.001
	Contacts	.463	1	9.139	.003
	Work	.445	1	5.605	.018
	Finances	.001	1	.018	.892
	Free time	.472	1	9.896	.002
Age	Health	.152	1	2.808	.094
	Contacts	.004	1	.210	.647
	Work	11.185	1	117.869	.000
	Finances	6.955	1	89.977	.000
	Free time	.154	1	2.375	.124
Employment	Health	.165	3	1.282	.279
	Contacts	.470	3	3.093	.026
	Work	10.133	3	42.573	.000
	Finances	2.134	3	10.008	.000
	Free time	.294	3	2.056	.104
Informal network	Health	.914	1	21.361	.000
	Contacts	.677	1	13.356	.000
	Work	.384	1	4.840	.028
	Finances	1.070	1	15.047	.000
	Free time	.959	1	20.089	.000
Limitations (physical)	Health	.378	1	8.843	.003
	Contacts	.209	1	4.116	.043
	Work	.779	1	9.824	.002
	Finances	2.106	1	29.630	.000
	Free time	.802	1	16.815	.000
Limitations (mental)	Health	2.820	1	65.935	.000
	Contacts	3.152	1	62.204	.000

Work	1.130	1	14.248	.000
Finances	1.480	1	20.815	.000
Free time	2.470	1	51.756	.000

df- degrees of freedom;

First, the results of the between-subject effects indicated that the CPPN domains health, free time, social contacts, as well as work and care differed significantly based on caregivers' gender. Figure 1 compares significant differences between gender groups. In all four domains, women have significantly higher needs than men ($P < 0.01$). The perceived need for free time is rated by women as on average 5.89 points, which is about 0.7 points higher than men rank it. The need to maintain their health is on average 5.76 for women, which is above the value of 5.06 for men. Social contacts are rated 5.48 by women and 4.95 by men. Women rate work issues 4.97 points, while men rate them 3.9 points.

FIGURE 1 NEAR HERE

Second and as shown in Table 3, the results also indicated that caregivers differed significantly based on their employment status in the social contacts, work and care, and finances domains ($P < 0.05$). We conducted the LSD post-hoc test to detect significant differences between the groups. The results of the post-hoc between-subject effects are shown in Table 4.

Table 4: Post-hoc between-subject effects

Need domain	Employment status	M (SD)	Post-hoc results
Social contacts	Full-time	4.92 (2.1)	Lower than in all other groups**
	Part-time	5.39 (1.9)	Lower than unemployed*, higher than full-time**
	Unemployed	5.85 (1.6)	Higher than full-time**, higher than part-time*
	Not-working	5.59 (1.9)	Higher than full-time**
Work and care	Full-time	5.43 (2.1)	Lower the part-time*, higher than not-working**
	Part-time	5.79 (1.8)	Higher than all other groups*
	Unemployed	5.26 (2.2)	Lower than part-time, higher than not-working
	Not-working	3.20 (2.6)	Lower than all other groups**
Financial security	Full-time	4.81 (4.8)	Lower than part-time and unemployed **
	Part-time	5.67 (5.6)	Higher than full-time and not working**, lower than unemployed**
	Unemployed	6.30 (6.3)	Higher than all other groups**
	Not-working	4.62 (4.6)	Lower than part-time and unemployed**

M – Mean; SD – standard deviation;

The results of the post-hoc tests show that full-time employed caregivers have a significantly lower need for social contacts compared to other groups (M = 4.92). The highest need for social contacts is among caregivers who are unemployed (M = 5.85) or not working for other reasons (M = 5.59). Work and care is more important for part-time employed caregivers (M = 5.79). Full-time employed and unemployed caregivers rate the importance of work and care at a moderate level (M = 5.43 and M = 5.26), and finally caregivers who are not working have a lower need in this domain (M = 3.2). Financial security is more important for unemployed caregivers (M = 6.3), followed by part-time employed (M = 5.67). Full-time employed and not-working caregivers evaluate it as less important (M = 4.81 and M = 4.62). Figure 1 demonstrates the average scores of each employment group.

Third, the age of the caregivers significantly affects the work and care domain as well as the domain financial security ($P < 0.01$). We observe that with increasing age the importance of work and care ($B = -0.06$) as well as financial security decreases ($B = -0.05$). The effect on the work and care domain is slightly higher than on financial security.

Fourth, the severity of physical and psychological limitation of the person receiving care significantly influenced all CPPN domains. With more severe physical and mental limitations of the person receiving care, caregivers have higher CPNN. The strongest effect of the severity of physical limitations is on the financial security domain ($B = 0.21$; $P < 0.01$). In contrast, the severity of mental limitations have the highest impact on the social contacts domain ($B = 0.23$; $P < 0.01$), followed by the health domain ($B = 0.22$; $P < 0.01$).

Finally and fifth, the informal network of the caregiver is a significant determinant of the level of CPPN in all five domains. The need for support in all domains is higher, when the informal network of the caregiver is smaller. These effects are especially high on the domains of financial security ($B = -0.17$; $P < 0.01$) and free time ($B = -0.17$; $P < 0.01$).

Table 5 provides an overview of the regression coefficients for the metric variables caregivers' age, informal network as well as the severity of physical and mental limitations of the care recipient.

Table 5: Regression coefficients

Dependent variable	Parameter	Regression Coeff.	SD	Sig.
Work and Care	Age	-.058	.005	.000
Finances	Age	-.049	.005	.000
Health	Informal network	-.164	.037	.000
Social contacts	Informal network	-.133	.039	.001
Work and Care	Informal network	-.103	.044	.019
Finances	Informal network	-.173	.043	.000
Time-out	Informal network	-.168	.037	.000
Health	Physical limitations	.094	.029	.001
Social contacts	Physical limitations	.084	.031	.007
Work and Care	Physical limitations	.128	.035	.000
Finances	Physical limitations	.213	.034	.000
Time-out	Physical limitations	.137	.029	.000
Health	Mental limitations	.221	.026	.000
Social contacts	Mental limitations	.230	.027	.000
Work and Care	Mental limitations	.131	.031	.000
Finances	Mental limitations	.151	.030	.000
Time-out	Mental limitations	.208	.026	.000

SD – standard deviation; Sig. – significance;

4. Discussion

The current study provides an important view of the needs of informal caregivers who take care of older and disabled people at home. We considered the socio-demographic factors and caregiving context to provide a deeper understanding of informal caregivers' personal needs. An issue that received less attention so far. We also used a large-scale sample, which allows us to draw conclusions on a broad group of informal caregivers. Previous studies focused only on specific groups of informal caregivers [11, 12].

Our contribution to the research on equity in health is that we show how supportive actions could not only focus on care-recipients needs but also consider informal caregivers by supporting their health as well as their professional, social and private life. Our results will help identify caregivers who are at higher risk of health problems and address them with appropriate support services.

All five central domains of caregivers' perceived personal needs differed significantly according to the six investigated factors: caregivers' age, gender, employment status, the severity of the care-recipients' limitations, and the size of the informal network. The effects of all these factors are discussed in detail below.

From prior research it is known that informal caregiving is predominantly performed by women, and they are more intensively involved in it than men [24]. Our first finding showed that women are not only the main group of caregivers but also the main target group for support services. Women caregivers feel highly concerned about their own physical and mental health, need more free time and social support. They also have a higher need of support to combine work and care. Support programs should give more attention to women caregivers and motivate them to use support services more intensively.

Second, our findings indicate that younger caregivers are more concerned about financial and work issues. A large proportion of caregivers are of employment age and take care of their elderly relatives at home [25]. A series of support programs address the work and care issues of these people. However, these programs should also account for the needs of young professionals, who are concerned about their long-term career path and financial security. Especially in a long-term perspective, informal caregivers can experience considerable wage penalties due to care provision [26].

Third, special attention is required to caregivers who are unemployed, since they are not only in a higher need for financial and work-related support but also have a greater need to socialize. Social isolation of informal caregivers in home care is one of the problems mentioned in the previous research [27]. Since unemployed caregivers cannot socialize with coworkers and neglect caregiving tasks at work, they need other opportunities for social interactions that could be addressed by support services.

Although caregivers' employment can be a resource for maintaining mental health [28], many caregivers experience difficulties combining work and care [29]. According to our results, this is true for both employed and unemployed caregivers. Obviously, caregivers have trouble not only in finding a job when they care for an older and/or disabled person but also in combining an existing job with care responsibilities. Support programs on combining work and care should address both issues.

Fourth, an informal network of the caregiver showed to be an important source of help. All five aspects of caregivers' personal needs are lower when the informal network is larger. According to our results, caregivers with poor informal networks especially need more free-time opportunities and support in combining work and care. Caring often requires permanent presence from the caregiver allowing less flexibility for work and other activities.

Finally and fifth, our results indicate that caregivers of people with severe limitations have higher perceived personal needs. This is consistent with prior findings showing that caregivers of patients with severe limitations experience a higher burden [3]. The more complex the caregiving situation is, the more often caregivers are overwhelmed and need additional help.

Less obvious and particularly important is that mental limitations of the care-recipient have a greater effect on personal needs than physical limitations. Our results show that caregivers in such situations need primarily to maintain their own health and have social contacts. Caring for a person with mental limitations often requires constant availability as well as the ability to manage behavioral and personality changes, which is often emotionally difficult for caregivers and leads to social isolation and mental health problems among caregivers [30]. For this reason, informal caregivers of people with severe mental limitations need intensive emotional and social support.

Our study also has some limitations. First, our survey was conducted in Germany. The relatively low need for financial support compared to other domains might be specific to this country. A further limitation of this study was the cross-sectional design, which did not allow for observing the effect controlling for all possible confounders. Finally, we could not consider cultural differences in the present study due to the low proportion of our study sample of caregivers (or parents of caregivers) who immigrated to Germany.

In sum, we observed that women and unemployed caregivers in complex care situations with a poor informal network are in higher need of relief and support. At the same time, young and employed caregivers could benefit from support in employment issues. Caregivers of people with mental limitations need to maintain their own health and social life.

The current study provides knowledge for the development of personalized services that support caregivers in managing their own needs. Since informal caregivers are often highly burdened and experience health problems due to caregiving [31], addressing their personal needs is an important political and social issue.

Abbreviations

CPPN – caregivers' perceived personal needs

Declarations

Ethics approval and consent to participate

All methods were carried out in accordance with relevant guidelines and regulations. Participation in the study was voluntary and anonymous. The study was approved by the medical ethics committee of Witten/Herdecke University (registration number: 241/217). Informed consent was obtained from all participants.

Consent for publication

Not applicable.

Data availability

The data that support the findings of this study are held by Witten/Herdecke University. Restrictions apply to their availability due to the privacy policy and therefore are not publicly available. Data are however available from corresponding author upon reasonable request.

Competing interests

The authors declare that they have no conflict of interest.

Funding

The work was supported by the Ministry of Labor, Health and Social Affairs of North Rhine-Westphalia (Germany) and long-term care funds (grant number: 34.04.01-62-4856). The funding bodies had no influence on the study design, the data collection, analysis, and interpretation of data, nor in writing the manuscript.

Authors' Contributions

KB: Conceptualization, Investigation, Data Curation, Methodology, Software, Formal analysis, Writing - Original Draft, Visualization.

SBJ: Conceptualization, Validation, Writing - Review & Editing, Supervision, Project administration, Funding acquisition.

Acknowledgements

We would like to thank all informal caregivers and gatekeepers for supporting our survey.

References

1. Rodríguez Mañas L, García-Sánchez I, Hendry A, Bernabei R, Roller-Wirnsberger R, Gabrovec B, Liew A, Carriazo AM, Redon J, Galluzzo L et al: Key Messages for a Frailty Prevention and Management Policy in Europe from the ADVANTAGE JOINT ACTION Consortium. *J Nutr Health Aging* 2018, 22(8):892–897.
2. Barczyk D, Kredler M: Long-Term Care Across Europe and the United States: The Role of Informal and Formal Care. *Fiscal Studies* 2019, 40(3):329–373.
3. Hughes TB, Black BS, Albert M, Gitlin LN, Johnson DM, Lyketsos CG, Samus QM: Correlates of objective and subjective measures of caregiver burden among dementia caregivers: influence of unmet patient and caregiver dementia-related care needs. *Int Psychogeriatr* 2014, 26(11):1875–1883.
4. Cascioli T, Al-Madfai H, Osborne P, Phelps S: An evaluation of the needs and service usage of family carers of people with dementia. *Quality in Ageing and Older Adults* 2008, 9(2):18–27.

5. Dam AEH, Boots LMM, van Boxtel MPJ, Verhey FRJ, de Vugt ME: A mismatch between supply and demand of social support in dementia care: a qualitative study on the perspectives of spousal caregivers and their social network members. *Int Psychogeriatr* 2017;1–12.
6. Rosa E, Lussignoli G, Sabbatini F, Chiappa A, Di Cesare S, Lamanna L, Zanetti O: Needs of caregivers of the patients with dementia. *Arch Gerontol Geriatr* 2010, 51(1):54–58.
7. Stirling C, Andrews S, Croft T, Vickers J, Turner P, Robinson A: Measuring dementia carers' unmet need for services—an exploratory mixed method study. *BMC Health Serv Res* 2010, 10:122.
8. De Cola MC, Lo Buono V, Mento A, Foti M, Marino S, Bramanti P, Manuli A, Calabro RS: Unmet Needs for Family Caregivers of Elderly People With Dementia Living in Italy: What Do We Know So Far and What Should We Do Next? *Inquiry* 2017, 54:46958017713708.
9. Caress A-L, Luker KA, Chalmers KI, Salmon MP: A review of the information and support needs of family carers of patients with chronic obstructive pulmonary disease. *Journal of Clinical Nursing* 2009, 18(4):479–491.
10. Silva AL, Teixeira HJ, Teixeira MJC, Freitas S: The needs of informal caregivers of elderly people living at home: an integrative review. *Scandinavian journal of caring sciences* 2013, 27(4):792–803.
11. Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM: Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. *J Am Geriatr Soc* 2013, 61(12):2087–2095.
12. McCabe M, You E, Tatangelo G: Hearing Their Voice: A Systematic Review of Dementia Family Caregivers' Needs. *Gerontologist* 2016, 56(5):e70-88.
13. Gusdal AK, Josefsson K, Adolfsson ET, Martin L: Informal Caregivers' Experiences and Needs When Caring for a Relative With Heart Failure: An Interview Study. *J Cardiovasc Nurs* 2016, 31(4):E1-8.
14. Hirakawa Y, Kuzuya M, Enoki H, Uemura K: Information needs and sources of family caregivers of home elderly patients. *Archives of Gerontology and Geriatrics* 2011, 52(2):202–205.
15. Lethin C, Leino-Kilpi H, Roe B, Soto MM, Saks K, Stephan A, Zwakhalen S, Zabalegui A, Karlsson S: Formal support for informal caregivers to older persons with dementia through the course of the disease: an exploratory, cross-sectional study. *BMC Geriatr* 2016, 16:32.
16. Vaingankar JA, Subramaniam M, Picco L, Eng GK, Shafie S, Sambasivam R, Zhang YJ, Sagayadevan V, Chong SA: Perceived unmet needs of informal caregivers of people with dementia in Singapore. *Int Psychogeriatr* 2013, 25(10):1605–1619.
17. Tatangelo G, McCabe M, Macleod A, You E: "I just don't focus on my needs." The unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study. *Int J Nurs Stud* 2018, 77:8–14.
18. van den Berg B, Spauwen P: Measurement of informal care: an empirical study into the valid measurement of time spent on informal caregiving. *Health Econ* 2006, 15(5):447–460.
19. Ikart E: Survey Questionnaire Survey Pretesting Method: An Evaluation of Survey Questionnaire via Expert Reviews Technique. *Asian Journal of Social Science Studies* 2019, 4:1.

20. Huberty CJ, Petoskey MD: Multivariate Analysis of Variance and Covariance. In: Business, Education 2000.
21. Carpita M, Manisera M: On the Imputation of Missing Data in Surveys with Likert-Type Scales. *Journal of Classification* 2011, 28(1):93–112.
22. Shu X: Knowledge Discovery in the Social Sciences: A Data Mining Approach, 1 edn: University of California Press; 2020.
23. Finch H: Comparison of the Performance of Nonparametric and Parametric MANOVA Test Statistics when Assumptions Are Violated. *Methodology: European Journal of Research Methods for the Behavioral and Social Sciences* 2005, 1:27–38.
24. Sharma N, Chakrabarti S, Grover S: Gender differences in caregiving among family - caregivers of people with mental illnesses. *World J Psychiatry* 2016, 6(1):7–17.
25. Geyer J, Schulz EJD-W: Who cares? Die Bedeutung der informellen Pflege durch Erwerbstätige in Deutschland. 2014, 81(14):294–301.
26. Conway K: The Experience of Adult Children Caregiving for Aging Parents. *Home Health Care Management & Practice* 2018, 31(2):92–98.
27. Faronbi JO, Faronbi GO, Ayamolowo SJ, Olaogun AA: Caring for the seniors with chronic illness: The lived experience of caregivers of older adults. *Arch Gerontol Geriatr* 2019, 82:8–14.
28. Bidenko K, Bohnet-Joschko S: Vereinbarkeit von Beruf und Pflege: Wie wirkt sich Erwerbstätigkeit auf die Gesundheit pflegender Angehöriger aus? *Gesundheitswesen* 2020, 83(02):122–127.
29. Hansen T, Slagsvold BJEjoa: Feeling the squeeze? The effects of combining work and informal caregiving on psychological well-being. 2015, 12(1):51–60.
30. Ainamani HE, Alele PE, Rukundo GZ, Maling S, Wakida EK, Obua C, Tsai AC: Caregiving burden and mental health problems among family caregivers of people with dementia in rural Uganda. *Glob Ment Health (Camb)* 2020, 7:e13.
31. Schmitz H, Westphal M: Short- and medium-term effects of informal care provision on female caregivers' health. *Journal of Health Economics* 2015, 42:174–185.

Figures

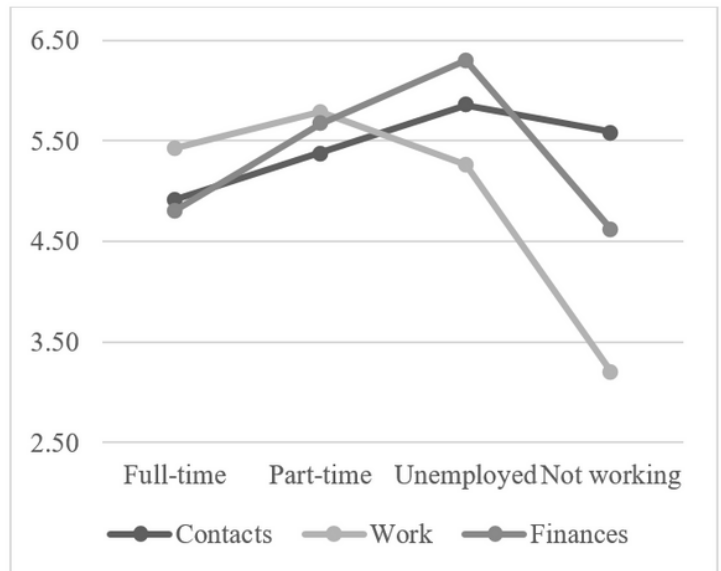
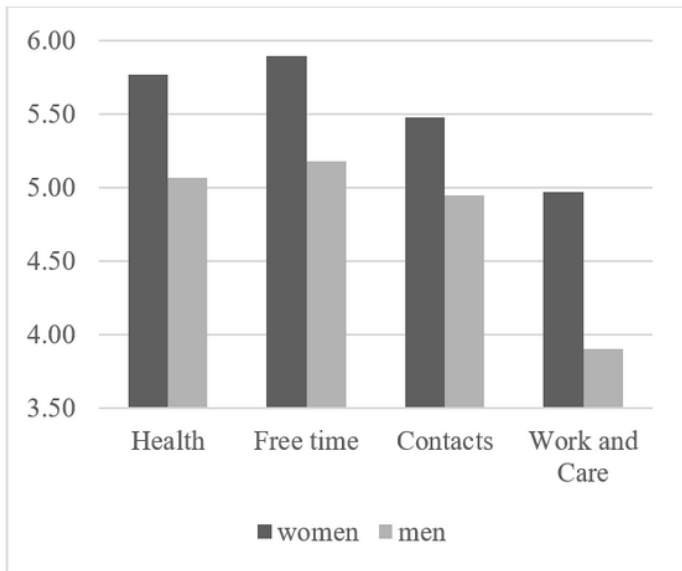


Figure 1

Differences in CPPN based on gender and employment status

CPPN – Caregivers’ perceived personal needs;