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# Caring Sciences EMPIRICAL STUDIES

# Informal caregivers' judgements on sharing care with home care professionals from an intersectional perspective: the influence of personal and situational characteristics

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# Informal caregivers' judgements on sharing care with home care professionals from an intersectional perspective: the influence of personal and situational characteristics

The European policy emphasis on providing informal care at home causes caregivers and home care professionals having more contact with each other, which makes it important for them to find satisfying ways to share care. Findings from the literature show that sharing care between caregivers and professionals can be improved. This study therefore examines to what degree and why caregivers' judgements on sharing care with home care professionals vary. To improve our understanding of social inequities in caregiving experiences, the study adopts an intersectional perspective. We investigate how personal and situational characteristics attached to care judgements are interwoven. Using data of the Netherlands Institute for Social Research, we conducted bivariate and multivariate linear regression analysis (N = 292). We combined four survey questions into a 1-4 scale on 'caregiver judgement' ( $\alpha = 0.69$ ) and used caregivers' personal (such as gender and health status) and situational characteristics

#### Introduction

It is expected that collaboration between caregivers1 and professionals who provide care to care recipients at home will be intensified. Recent European welfare policies

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(such as the care recipient's impairment and type of care) as determinants to discern whether these are related to the caregivers' judgement. Using a multiplicative approach, we also examined the relationship between mutually constituting factors of the caregivers' judgement. Adjusted for all characteristics, caregivers who provide care to a parent or child with a mental impairment and those aged between 45 and 64 years or with a paid job providing care to someone with a mental impairment are likely to judge sharing care more negatively. Also, men providing care with help from other caregivers and caregivers providing care because they like to do so who provide social support seem more likely to be less satisfied about sharing care. This knowledge is vital for professionals providing home care, because it clarifies differences in caregivers' experiences and hence induce knowledge how to pay special attention to those who may experience less satisfaction while sharing care.

Keywords: care at home, caregivers' judgements, caregiving, collaboration, diversity, home care professionals, informal care, intersectionality, sharing care.

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encourage care recipients to continue to live at home as long as possible, arrange their own care and to mobilise caregivers (1). Due to this emphasis on providing informal care at home, the amount of contact between caregivers and home care professionals will increase, which makes it important to find satisfying ways to share care (2-4). However, it becomes more and more clear that satisfying partnerships between caregivers and professionals have not yet been reached (5). More insight is needed into how caregivers look upon sharing care with home care professionals and which factors influence their

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Scandinavian Journal of Caring Sciences published by John Wiley & Sons Ltd on behalf of Nordic College of Caring Science. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made. judgements. Some studies explored collaboration or sharing care between caregivers and home care professionals (1, 6–11). These show that conflicts may arise when professionals fail to recognise caregivers' experience (10) and that it can be difficult for caregivers themselves to share responsibilities (11). It is unclear what specific conditions foster a negative judgement among caregivers on professional support. Insights into how caregivers' (combinations of) backgrounds influence their view on the professionals' role in care networks is needed in order to create fruitful combinations of informal and formal care (5), which can prevent caregiver burden (12, 13) and increase quality of care (14). This approach is known as the intersectional perspective. Here, we use this, by means of an in-depth analysis of differential judgements on sharing care.

This study will present a cross-sectional analysis of judgements of Dutch caregivers. The Netherlands is an interesting context because relatively many older adults receive home care, whether or not in combination with informal care (15, 16). Moreover, the chance of moving into institutional care has been relatively large for a long time but is decreasing nowadays (17). Dutch policy increasingly focuses on the collaboration between caregivers and publicly funded care provisions (17), so caregivers in the Netherlands are ideally seen as essential team members in providing care (5), a frame of reference Twigg (1989) labels 'carers as co-workers' (18). Therefore, the Netherlands is the proverbial example where improving collaboration between informal and formal care should be a relatively attractive option to professionals who face problems in this.

#### Sharing care

To work as a team, collaboration between caregivers and professionals is necessary. In definitions of collaboration, the concept of *sharing* is mentioned repeatedly (19). This may have meanings as having shared responsibilities, shared decision-making, having a shared care philosophy or shared values, shared planning and intervention or focussing on how different perspectives are shared (19). However, it comes to light that it can be difficult for caregivers to share responsibilities (11). There are studies that show conflicts in collaboration that arise when professional expectations of caregivers are contradictory or when a shared perspective on care is absent (10). Other studies report on professionals' tendency to overlook the possible role of caregivers in decision-making; their role is often not discussed (20), while acknowledging the role of caregivers facilitates collaboration (21). Relatives of care recipients who are more involved in collaboration with professionals are more satisfied about provided care than those who are not (14).

#### Personal and situational characteristics

Sharing care takes place in care networks where care recipients, caregivers and professionals meet. Satisfaction with support in care networks is assumed to be influenced by both personal and situational characteristics (22). Personal characteristics refer to individuals' social, demographic and health characteristics; situational characteristics, such as the care recipient's health status and the number of other available helpers, are external to the individual (22, 23). In this paper, we follow this line of reasoning: we will investigate whether and how personal and situational characteristics are related to the care-givers' judgement on sharing care with professionals.

There are few studies on caregivers' judgements which report the influence of personal and situational characteristics. Lindhardt, Nyberg and Hallberg (14), for example, investigated the influence of caregiver characteristics (e.g. age, gender, employment status), the caregiving situation (e.g. interrelationship between caregiver and care recipient) and caregiving motives on satisfaction with hospital care trajectories. Results showed that respondents who reported low satisfaction significantly more often were women, held a degree in health education and provided psychosocial or practical help (14). Durand, Kruger, Chambers, Grek and Charles (24) found that besides care recipients' impairment and the caregiver not living with the care recipient, the caregivers' cultural background and gender were predictors of dissatisfaction with community long-term care. A number of other characteristics were investigated as well, such as the caregivers' health and the availability of alternative caregivers, but results showed no significant influence. According to Lin, Fee and Wu (25), gender induces significant differences in caregivers' experiences, with female caregivers having more negative experiences than male caregivers. These differences seem to be associated with the caregivers' relationship with care recipients. These study outcomes underline the importance of looking at both personal and situational characteristics. Other studies report on the interaction of characteristics influencing the caregiving situation, for example, while examining differences in caregiver burden (26, 27) or the likelihood of being a caregiver (28, 29). Applying such an intersectional perspective can provide insights how personal and situational characteristics mutually strengthen or weaken each other in relation to caregiver judgements on professional care (30). This offers a way to understand the intersecting categories on the caregivers' judgement and thus to understand social inequities in individual caregivers' experiences (31).

This paper has three objectives. First, to describe caregivers' judgements regarding sharing care with home care professionals when taking into account their various backgrounds. Second, to find out whether personal and situational characteristics are related to caregivers' judgements on sharing care and third, to consider the interaction between these characteristics. Because there is little evidence that provides us with tools to choose which personal or situational characteristics might be related, we broadly examine interaction between these characteristics. Our study investigates various aspects of sharing care: sharing concerns about care recipients, agreement about needed care, awareness of the caregivers' needs and caregivers' general satisfaction in their contact with home care professionals. We expect the judgement of groups of caregivers with various backgrounds to be different and that personal and situational characteristics will explain a significant part of the caregivers' judgement on sharing care.

## Methods

#### Sample

To investigate the caregivers' judgement on sharing care, we used an existing dataset of the Netherlands Institute for Social Research about the extent, nature and consequences of providing informal care. Between September and December 2016, a quantitative study was carried out by Statistics Netherlands using online and telephone questionnaires among a representative sample of the Dutch population aged 16 and older (N = 18 882) to find out who provided informal care. Citizens within this sample received a letter asking them to fill in an online questionnaire. Two of the authors of our current study were involved in the development of this questionnaire. After receiving two reminders, those who did not respond yet were asked by trained researchers to respond to the questions by telephone. It resulted in a sample of 7462 respondents (32) (response rate 40% (33)). Because we used existing data, the measurement of the determinants we included in our analysis was not considered prior data collection. However, these measurements turned out to be suitable to apply an intersectional perspective to our study.

One-third of the respondents provided help to partners, family, friends or neighbours who needed help because of physical-, mental-, intellectual- or age-related impairments, but not doing this as a volunteer or a professional were considered informal caregivers (32). Of those, we selected caregivers who took care of care recipients who also received professional home care (N = 292). With 'home care', we mean both home help and district nursing care, two forms of home care that in the Netherlands have different legislation. The responsibility for home help lies at the municipalities, under the Social Support Act ('Wmo') (34) and comprises nonmedical services such as domestic help and social support.

District nursing care is provided under the Health Insurance Act ('Zvw') and consists of nursing and personal care. It is provided by district nurses, who assess the needs of care recipients and are expected to coordinate care (34).

#### Measurements

Caregiver judgement. Because sharing care is a concept that is mentioned repeatedly in definitions of collaboration (19), we used the variables available in our dataset that measured the concept of sharing care in order to better understand collaboration between caregivers and home care professionals. We combined four survey questions into a 1-4 scale we labelled 'caregiver judgement' (Cronbach's alpha 0.69) to investigate the caregivers' judgement on sharing care. The score of 1 reflected the least positive and the score of 4 the most positive judgement on sharing care with home care professionals. The four variables we used contained information about (1) how often caregivers could share worries about care recipients with professionals, (2) how often caregivers and professionals agreed about needed care for the care recipient, (3) how often caregivers thought professionals showed awareness of the caregivers' needs and (4) to what extent caregivers were satisfied with the contact they had with professionals.

Personal characteristics. We used gender (male or female), age (16-44, 45-64, 65+ years old), the caregiver's household situation (having a partner or not), employment status (no paid job/working less than 12 hours a week, or working more than 12 hours a week), level of education (lower, intermediate or tertiary education) and the caregivers' self-reported health status (not, slightly or heavily obstructed) as the caregivers personal characteristics, because it is known that these characteristics are related to caregiving (32). Unfortunately, the group of respondents with other ethnic backgrounds was too small; therefore, we were not able to examine ethnic backgrounds in our analysis. We also added personal motives of caregivers to our analysis: 'I like to take care of someone' and 'I think I should provide the care'. Respondents were asked whether they considered these statements as a motive to provide care.

*Situational characteristics.* We included the relationship between caregivers and care recipients (spouses, adult– child relationships, other family members or friends/ neighbours), the care recipient's impairment ('physical', meaning a temporary or permanent physical impairment, a terminal disease or age-related problems; or 'mental', meaning psychiatric problems, an intellectual disability or suffering from dementia), the type of provided informal care (home nursing care, domestic help or social support) and the question whether caregivers received help from other caregivers as situational characteristics. Next to that, we added two situational motives for providing care: 'I like to do it for this person' and 'There is no one else available'.

#### Analytic strategy

Quantitative methods to examine intersectionality allow specifically documenting inequalities within groups (35). About a decade ago, intersectionality was still an open-ended concept and methodological guidelines had not been fully developed yet (36, 37). Scott and Siltanen (38) now state that multiple regression analysis is a technique that is commonly used and widely identified as an appropriate approach when applying an intersectional perspective. Intersectionality-informed analysis incorporates both additive and multiplicative approaches, emphasising the need to apply the multiplicative approach in later stages of analysis (31). We therefore conducted both approaches. In order to adjust for selective nonresponse, the sample was weighted for a number of characteristics, such as marital status, gender and age (39).

We first explored differences in the judgements of caregivers with various personal and situational characteristics on sharing care using bivariate analysis. The caregivers' judgement scales' means were computed in order to investigate differences in caregivers' satisfaction about sharing care with home care professionals (Table 1).

Our second step was to incorporate an additive approach as our initial model. Multivariate linear regression analysis was used to investigate the individual effects of personal and situational characteristics on caregivers' judgements on sharing care with home care professionals when controlling for other variables in the model. Table 2 presents two different regression models. In the first model, we included caregivers' personal characteristics as independent variables because these are the most common used characteristics in intersectional research (40). In the second model, we also added the situational characteristics. By presenting two models, we are able to show the difference in judgements on sharing care while including only personal characteristics or by including situational characteristics as well.

Upon our second regression model, further analyses were then applied using multiplicativity to account for the conditional effects of intersecting categories (31). For this, interaction terms were used to examine the relationship between mutually constituting factors of the caregivers' judgement (Table 3). This way we investigated the association between the caregivers' personal and situational characteristics that were included in our analysis. Among the 90 interactions we tested, five interactions appeared to be significant. We tested for multicollinearity using variance inflation factors (VIFs) to find out whether multicollinearity was problematic for these five models. With all VIFs lower than 2.5, collinearity diagnosis was unproblematic (41). Data were analysed using STATA (version 15.1; StataCorp LLC. Texas, USA).

### Results

#### Differences in caregivers' judgements

Table 1 shows descriptive statistics regarding the respondents and different groups of caregivers' satisfaction about sharing care with home care professionals. 58% of the respondents is female and the majority is aged between 45 and 64 years, what also applies for having a partner. About half of the respondents is unemployed or works less than 12 hours a week. The level of education among respondents varies: a third of the respondents is lower educated, another third got intermediate education and the last third tertiary education. 72% of the respondents reported no physical or other limitations that hinder their daily activities, 16% and 12% stated having to cope with light or severe limitations, respectively. Most caregiving interrelationships are adult-child relationships, the caregiving being the adult or the child (59%). In most cases, the care recipient has a physical impairment, meaning he or she has a temporary or permanent physical ailment, a terminal disease or age-related problems.

Looking at the sharing care satisfactory scale, we see some significant differences between groups. Overall, caregivers are quite satisfied about collaboration with no scores lower than 2.80 on a scale from 1 to 4. When comparing groups based on the caregivers' personal characteristics, it turns out that younger caregivers ( $p \le 0.01$ ), caregivers who have a paid job and work 12 or more hours a week ( $p \le 0.01$ ), higher educated caregivers ( $p \le 0.01$ ) and caregivers who reported severe physical or other limitations that hinder their daily activities ( $p \le 0.01$ ) are less satisfied about sharing care than others. No significant differences were found comparing caregivers based on gender and household situation.

Motives for providing care have consequences as well: respondents who did not consider providing care 'because they like to take care of someone' as a motive are less satisfied about sharing care than caregivers who did consider this as a motive to provide care ( $p \le 0.01$ ). This also applies to respondents who did not consider providing care 'because they like to do it for a specific person' as a motive ( $p \le 0.05$ ). Finally, caregivers who state they provide care 'because there was no one else available' are less satisfied about sharing care than caregivers who did not consider this as a motive to provide care ( $p \le 0.01$ ).

Comparing groups based on other situational characteristics yields significant differences between caregivers

 Table 1
 Differences in caregivers' judgements

	Ν	%	Mean	Coef.	p > [t]
Gender	292				
Male	123	42	3.11		
Female	169	58	3.11	-0.01	0.894
Age	292				
65+	82	28	3.33		
45–64	168	58	3.10	-0.22	0.011
16–44	42	14	2.88	-0.42	0.001
Employment status	292				
Not working/	145	50	3.23		
working $<$ 12 hours					
Working > 12 hours	147	50	3.00	-0.20	0.008
Level of education	292				
Lower education	93	32	3.23		
Intermediate education	97	33	3.13	-0.10	0.270
Tertiary education	102	35	2.97	-0.27	0.003
Household situation	292				
With a partner	202	69	3.13		
Alone	90	31	3.08	-0.05	0.507
Self-reported health status	292				
Not obstructed	210	72	3.17		
Slightly obstructed	47	16	3.08	-0.09	0.401
Heavily obstructed	35	12	2.85	-0.34	0.004
Motives for providing care	292				
I like to take care of	231	79	3.05		
someone – does					
not play a role					
I like to take care of	61	21	3.35	0.28	0.002
someone – does play a role					
I think I should provide	94	32	3.15		
care – does not play a role					
I think I should provide	198	68	3.09	-0.04	0.655
care – does play a role					
I like to do it for this	66	23	2.96		
person – does not play a role					
I like to do it for this	226	77	3.15	0.18	0.043
person – does play a role					
There is no one else	241	83	3.18		
available – does					
not play a role					
There is no one else	51	17	2.80	-0.39	0.000
available – does					
play a role					
Interrelationship caregiver	292				
and care recipient					
Partner	50	17	3.50		
Adult–child	173	59	3.04	-0.43	0.000
Other family members	33	11	2.98	-0.54	0.000
Friends/neighbours	36	12	3.00	-0.48	0.000
Care recipient's	292				
impairment					
Physical impairment	188	64	3.18		
Mental impairment	104	36	2.98	-0.19	0.014

Table 1 (Continued)

	Ν	%	Mean	Coef.	p > [t]
Receiving help from	292				
other caregivers					
No	60	21	3.26		
Yes	232	79	3.07	-0.17	0.060
Type of provided informal care	292				
Home nursing care	84	29	3.31		
Domestic help	94	32	2.98	-0.34	0.000
Social support	114	39	3.06	-0.24	0.008

in conjunction with their interrelationships with care recipients. Those who care for a parent or child, to another family member or a friend or neighbour are less satisfied about sharing care than partners ( $p \le 0.01$ ). Next to that, caregivers who care for someone with a mental impairment, meaning someone who has psychiatric problems, an intellectual disability or is suffering from dementia, are less satisfied about sharing care than those who care for someone with a physical impairment ( $p \le 0.05$ ). Finally, caregivers who provide domestic help or social support are less satisfied than those who provide informal home nursing care ( $p \le 0.01$ ). No significant differences were found comparing caregivers based on the question whether caregivers received help from other informal caregivers.

# Influence of personal and situational characteristics on the caregivers' judgement

Table 2 shows two regression models. In model 1, personal characteristics of the caregivers are included  $(R^2 = 0.19)$ . Model 2 shows the influence of both personal and situational characteristics on the judgement of caregivers about sharing care with home care professionals  $(R^2 = 0.29)$ . The second model is thus an improvement compared to the first model.

In the first regression model, three of the caregivers' personal characteristics are significantly related to their judgement on sharing care. First, the younger caregivers are the less satisfied they are about sharing care ( $p \le 0.01$ ). Second, the higher the level of education of the caregiver, the less the satisfaction about sharing care ( $p \le 0.01$ ). Third, the caregivers' self-reported health status matters: a worse health status influences the caregivers' judgement on sharing care in a negative way ( $p \le 0.01$ ). It turns out that providing care because the caregiver likes to take care of someone influences his or her judgement in a positive way ( $p \le 0.01$ ). No significant relations were found between the caregivers' judge-

Table 2 Influence of personal and situational characteristics on the caregivers' judgement

	Model 1		Model 2		
	$R^2 = 0,19$ $N = 292$		$R^2 = 0.29$	N = 292	
	Coef.	P >  t	Coef.	p >  t	
Gender					
Male	0 (base)		0 (base)		
Female	-0.08	0.319	-0.07	0.354	
Age					
65+	0 (base)		0 (base)		
45–64	-0.14	0.174	-0.07	0.534	
16–44	-0.42	0.001	-0.25	0.034	
Employment status					
Not working/working < 12 hours	0 (base)		0 (base)		
Working > 12 hours	-0.13	0.174	-0.16	0.069	
Level of education					
Lower education	0 (base)		0 (base)		
Intermediate education	-0.04	0.665	-0.04	0.676	
Tertiary education	-0.26	0.007	-0.24	0.007	
Household situation					
With a partner	0 (base)		0 (base)		
Alone	0.06	0.426	0.05	0.567	
Self-reported health status					
Not obstructed	0 (base)		0 (base)		
Slightly obstructed	-0.24	0.015	-0.24	0.010	
Heavily obstructed	-0.51	0.000	-0.44	0.001	
Motives for providing care					
I like to take care of someone	0.26	0.003	0.22	0.013	
I think I should provide care	-0.08	0.302	-0.11	0.127	
I like to do it for this person			0.00	0.966	
There is no one else available			-0.31	0.000	
Interrelationship caregiver and care recipient					
Partner			0 (base)		
Adult-child			-0.21	0.061	
Other family members			-0.38	0.003	
Friends/neighbours			-0.41	0.001	
Care recipient's impairment			<b>2</b> (1 )		
Physical impairment			0 (base)	0.000	
Mental impairment			-0.02	0.828	
Receiving help from other caregivers			<b>2</b> (1 )		
No			0 (base)	0.400	
Yes			-0.06	0.486	
Type of provided informal care			0 (heas)		
Home nursing care			0 (base)	0.005	
Domestic help			-0.22	0.035	
Social support			-0.08	0.421	

ment on sharing care and gender, employment status, household situation and the care motive 'I think I should provide care'.

The second regression model includes both personal and situational characteristics. After adding the additional variables, the personal characteristics that showed a significant relation with the caregivers' judgement on sharing care in model 1 remain significant. Of the two situational motives for providing care in the second model, one turns out to be significantly related to the caregivers' judgement. Caregivers who stated they provide care 'because there was no one else available' are less satisfied about sharing care than caregivers who did not consider this as a motive ( $p \le 0.01$ ). Next to that, two of the other situational characteristics are significantly related to the caregivers' judgement. The interrelationship between caregivers and care recipients influences their judgement: people who provide care to other family members than a partner are less satisfied ( $p \le 0.05$ ). Finally, the kind of care the caregiver

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0.008	
	0 (base)
	0.12
	0 (base)
	-0.19
	0 (base)
	0.37
	0 (base)
	0.10
0.034	
	0 (base)
	0.07
	0 (base)
	-0.16
0.048	
	0 (base)
	0.21
	0 (base)
	-0.17
	0 (base)
	0.02
0.022	
	0 (base)
	-0.27
	0 (base)
	0.12
0.020	
	0 (base)
	-0.26
	-0.05
	0 (base)
	0.21
	-0.34
	0.048

provides affects the caregivers' satisfaction. Those who provide domestic help are less satisfied about sharing care than those who provide social support or home nursing care ( $p \le 0.05$ ). In the second model, no significant

relations were found between the caregivers' judgement on sharing care and the care recipient's impairment and the question whether caregivers received help from other caregivers.

As a last step in our analysis, we investigated the association between the characteristics in our second regression model while investigating the influence of characteristics on the caregivers' judgement on sharing care (Table 3). Five significant interactions were found. The care recipient's impairment interacts with three other characteristics while testing the relation of characteristics with the caregivers' judgement on sharing care: the interrelationship between caregiver and care recipient  $(p \le 0.01)$ , the caregiver's employment status  $(p \le 0.05)$ and the caregiver's age ( $p \le 0.05$ ). Caregivers who provide care to a parent or child with a mental impairment are likely to be less satisfied about sharing care (-0.19), as are employed caregivers (-0.16) and caregivers aged between 45 and 64 (-0.17) taking care of someone with a mental impairment. On the other hand, caregivers aged 65 or older who care for someone suffering a mental impairment are likely to be more satisfied about sharing care with professionals (0.21). Fourth, there is an interaction between gender and caregivers receiving help from other informal caregivers or not ( $p \le 0.05$ ). Female caregivers who receive help from others are likely to be more positive about sharing care with home care professionals (0.12), while men receiving help from other caregivers are less satisfied about sharing care (-0.27). The fifth and last interaction found is between one of the motives for providing care and the type of informal care provided  $(p \le 0.05)$ . In case the caregiver stated 'I like to take care of someone' was not a motive to provide care and the caregiver provided domestic help, he or she is likely to be less satisfied (-0.26). This also counts for those who did state this was a motive to provide care and who provide social support (-0.34).

#### Discussion

Overall, caregivers are quite satisfied about sharing care with home care professionals. However, results also show significant differences in the judgement of caregivers in relation to personal and situational characteristics. Younger caregivers, caregivers who work, higher educated caregivers and those who are confronted with severe care situations (as caregivers who reported limitations that hinder their own daily activities, those who care for someone with a mental impairment and those providing domestic help) are less satisfied about sharing care than others. Two motives for providing care influence the level of satisfaction: 'I like to take care of someone' in a positive way and 'There is no one else available' in a negative way. People who care for someone at more distance are less satisfied.

Because of the intersectional perspective of our study, we added interaction variables to our model to account for the conditional effects of intersecting categories (31). This resulted in significant associations between personal characteristics and situational circumstances, which means that some combinations of personal and situational characteristics mutually constitute the caregivers' judgement (31) and consequently amplify the chance of caregivers being negative about sharing care with home care professionals. The care recipient's impairment proved to interact with the interrelationship between caregiver and care recipient, the caregiver's employment status and the caregiver's age. Thus, those who provide care to a parent or child with a mental impairment and those with a paid job or aged between 45 and 64 providing care to someone with a mental impairment are likely to judge sharing care more negatively. Next to that, male caregivers who receive help from other informal caregivers and those who state they provide care because they like to do so and providing social support have a higher chance for a more negative judgement on sharing care with home care professionals.

There are two observations that we want to elaborate upon. First, other research focussing on caregivers' satisfaction with community long-term care showed being a female caregiver was a predictor of dissatisfaction (24). In that light, it is surprising that our findings did not show more significant gender differences in the caregivers' judgement. An explanation may be found in the age of caregivers in our sample: whereas other studies included predominantly older caregivers (aged 65 or older) (24, 25, 40), our study includes a proportion of caregivers aged younger than 65 as well. Second, we want to focus on the influence of the care recipient's impairment on the caregivers' judgement on sharing care. Other research showed that caregivers who provide help to people with a mental impairment experience more burden than other caregivers (26, 42). Our study also shows this group of caregivers is at risk of being less satisfied about sharing care compared to other caregivers, especially when they are aged between 45 and 64, when they have a paid job or when they provide care to a parent or child. This underlines the importance for professionals to pay extra attention to these groups of caregivers.

The data we used were collected using Dutch questionnaires only. This could explain the low level of respondents with other ethnic backgrounds. Because this group was too small to be able to draw valid conclusions upon, we did not include this variable in our analysis. However, we must point out that ethnic differences are observed across a wide variety of caregiving research. This suggests that a cultural lens is indispensable in coming to a better understanding of the caregiving experience (40). Also, using a larger sample size would allow us to use an even more intersectionality-informed way of classifying social groups, which would enable us to probe beneath the data to discover other interacting factors that may be present (31).

We used four questions to measure the caregivers' judgement on sharing care with home care professionals. This concept is a repeatedly mentioned concept in definitions of collaboration (19). The scale was useful to investigate the caregivers' judgement on sharing care. It might therefore be interesting to further investigate the usefulness of this scale, for example, in larger or other populations, in order to optimise it.

Our study only focussed on one side of care networks in which both professionals and care recipients are also involved. It is plausible that social identities of professionals and care recipients influence caregiving situations as well. For example, professionals' gender and age may differ and they can be motivated to provide care too by all sorts of reasons. Relationships and collaboration in care networks may thus be assessed differently based on the social identities of all those involved. As Richardson and Asthana (43) described, differences in demographic characteristics of professionals have also been proposed as a partial explanation of particular professional cultures. Differences in these cultures may also affect relationships in care networks, because these differences have consequences for the way in which professionals address issues.

Although we only focussed on caregivers in care networks, the intersectional perspective turned out to be a valuable approach to do so. Our study revealed several differences between groups of caregivers and showed that some of the explored personal and situational characteristics influence the caregivers' judgement. This affirms the assumption that satisfaction with support is influenced by both types of characteristics (22, 23). Investigating the interaction between characteristics uncovered that negative judgements on sharing care with home care professional correlate with both caregivers' personal and situational characteristics, as for example, age, the care recipients' impairment and the interrelationship between caregivers and care recipients. This knowledge is important for professionals providing home care, because it clarifies differences in caregivers' experiences and offers the opportunity to pay special attention to those who have a bigger chance of being less satisfied. Supporting interventions that work for one group may be ineffective for other groups (40). For example, working caregivers may need special leave arrangements at work, whereas caregivers who care for someone with a mental impairment may feel supported by contact with other caregivers (44). In our planned follow-up research, we will further discuss the meaning of our findings with stakeholders in order to get a better understanding of its consequences for caregiving practices. Because social identities of professionals and care recipients may influence caregiving situations

as well, it is important to involve both caregivers and other members of care networks in this discussion.

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# **Conflict of interest**

We do not have any conflicts of interest to declare.

# Author contribution

This manuscript is part of Yvette Wittenberg's PhD study. All authors have contributed significantly and are in agreement with the content of the manuscript. Yvette Wittenberg, Alice de Boer and Inger Plaisier conducted the quantitative analyses we used in our manuscript. All five authors thought along during the whole process and contributed to the writing of the manuscript.

# **Ethical approval**

In this study, data of the Netherlands Institute for Social Research were used. An ethical statement for this study

# References

- 1 Jacobs MT. Connecting to care. The interrelationships between informal and formal caregivers in care networks of community-dwelling older adults. Amsterdam: VU; 2016. Available from: http://dare.ubvu.vu.nl/ha ndle/1871/53879 [Accessed 6th June 2018].
- 2 Broese van Groenou MI, de Boer A. Providing informal care in a changing society. *Eur J Ageing* 2016; 13: 271–9.
- 3 Jacobs M, van Tilburg T, Groenewegen P, Broese van Groenou M. Linkages between informal and formal caregivers in home care networks of frail older adults. *Age Soc* 2015; 36: 1604–24.
- 4 Verver D, Merten H, Robben P, Wagner C. Care and support for older adults in The Netherlands living independently. *Health Soc Care Community* 2018; 26: e404–14.
- 5 Hengelaar AH, van Hartingsveldt M, Wittenberg Y, van Etten-Jamaludin FS, Kwekkeboom R, Satink T.

Exploring the collaboration between formal and informal care from the professional perspective – A thematic synthesis. *Health Soc Care Community* 2018; 26: 474–85.

- 6 Büscher A, Astedt-Kurki P, Paavilainen E, Schnepp W. Negotiations about helpfulness – the relationship between formal and informal care in home care arrangements. *Scand J Caring Sci* 2011; 25: 706–15.
- 7 de Koker B (ed). Beyond the support paradox. How the adult children and spouses of frail older persons in Flanders perceive formal home care. *Variaties op mantelzorg. De inzet en beleving van mantelzorgers in de context van de vermaatschappelijking van de zorg* [Variations on informal care. The commitment and experience of informal caregivers in the context of community care]. Antwerpen: Universiteit Antwerpen; 2018. p. 148–75.
- 8 Forbes DA, Markle-Reid M, Hawranik P, Peacock S, Kingston D, Morgan D, Henderson S, Leipert B, Jansen L. Availability and

was not necessary because the threshold criteria requiring an ethical statement were not met (i.e. risk for the respondents, lack of information about the aims of the study, examination of patients). The study was conducted taking into account the confidentiality and anonymity of respondents. All respondents participated in the study voluntarily after being informed about the aims of the study (informed consent).

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# **Data Accessibility Statement**

The used dataset (SCP – IZG 2016) is archived in the DANS repository. Access requires granted permission request. https://doi.org/10.17026/dans-xfy-4en6.

#### Note

1. In this paper, we label family members, friends, neighbours or other close ones who provide informal care to someone with health problems they know as "caregivers".

acceptability of Canadian home and community-based services: perspectives of family caregivers of persons with dementia. *Home Health Care Serv Q* 2008; 27: 75–99.

- 9 Triantafillou J, Naiditch M, Repkova K, Stiehr K, Carretero S, Emilsson T, Di P, Di P, Rastislav S, Brichtova BL, Ceruzzi F, Cordero L, Mastroyiannakis T, Ferr M, Vlantoni D. Informal care in the long-term care system. European Overview Paper. Athens/Vienna, Greece/Austria: Interlinks; 2010. Available from: http://interlinks.euro.centre.org/sites/ default/files/WP5\_Overview\_FINAL\_ 04\_11.pdf [Accessed 17th August 2018].
- 10 Ward-Griffin C, McKeever P. Relationships between nurses and family caregivers: partners in care? *Adv Nurs Sci* 2000; 22: 89–103. Available from: https://www.ncbi.nlm.nih.gov/pubmed/ 10711807 [Accessed 11th September 2018].
- 11 Aasbø G, Rugkåsa J, Solbrække K, Werner A. Negotiating the care-giving role: family members' experience

during critical exacerbation of COPD in Norway. *Health Soc Care Community* 2017; 25: 612–20.

- 12 Williams AM, Wang L, Kitchen P. Differential impacts of care-giving across three caregiver groups in Canada: end-of-life care, long-term care and short-term care. *Health Soc Care Community* 2013; 22: 187– 96.
- 13 Lethin C. Informal caregivers of older persons with dementia in eight European countries. Experiences, support, wellbeing and burden. Lund: Lund University, Faculty of Medicine; 2016. Available from: http://portal.research. lu.se/portal/files/11626472/Connie\_ Lethin\_webb\_papers\_3.pdf [Accessed 11th September 2018].
- 14 Lindhardt T, Nyberg P, Hallberg IR. Collaboration between relatives of elderly patients and nurses and its relation to satisfaction with the hospital care trajectory. *Scand J Caring Sci* 2008; 22: 507–19.
- 15 Suanet B, Broese van Groenou M, Van Tilburg T. Informal and formal home-care use among older adults in Europe: can cross-national differences be explained by societal context and composition? *Age Soc* 2012; 32: 491–515.
- 16 Statistics Netherlands. *Health and health care; personal characteristics*. Available from: http://statline.cbs.nl/ Statweb/publication/?DM=SLEN&PA= 83005eng&D1=86-89&D2=0-13&D3= 0&D4=1&LA=EN&VW=T [Accessed 15th August, 2018].
- 17 Verbeek-Oudijk D, Woittiez I, Eggink E, Putman L. Who cares in Europe? A comparison of long-term care for the over-50s in sixteen European countries. The Hague: The Netherlands Institute for Social Research; 2014. Available from: https://www.scp.nl/english/Publication ns/Publications\_by\_year/Publications\_ 2014/Who\_cares\_in\_Europe [Accessed 17th August, 2018].
- 18 Twigg J. Models of carers: how do social care agencies conceptualise their relationship with informal carers? J Soc Policy 1989; 18: 53–66.
- 19 D'Amour D, Ferrada-Videla M, San Martin Rodriquez L, Beaulieu MD. The conceptual basis for interprofessional collaboration: core concepts and theoretical frameworks. J Interprof Care 2005; 19: 116–31.

- 20 Groen van de Ven L, Smits C, Elwyn E, Span M, Jukema J, Eefsting J, Vernooij-Dassen M. Recognizing decision needs: first step for collaborative deliberation in dementia care networks. *Patient Educ Couns* 2017; 100: 1329–37.
- 21 Wittenberg Y, Kwekkeboom R, Staaks J, Verhoeff A, de Boer A. Informal caregivers' views on the division of responsibilities between themselves and professionals: a scoping review. *Health Soc Care Community* 2018; 26: e460–73.
- 22 Antonucci TC, Birditt KS, Sherman CW, Trinth S. Stability and change in the intergenerational family: a convoy approach. *Age Soc* 2011; 31: 1084–106.
- 23 Kemp CL, Ball MM, Perkins MM. Convoys of care: theorizing intersections of formal and informal care. J Aging Stud 2013; 27: 15–29.
- 24 Durand PJ, Kruger PD, Chambers LW, Grek A, Charles C. Predictors of caregivers' dissatisfaction with community long-term care services for seniors: results from the Canadian Study of Health and Aging. *Can J Public Health* 1995; 86: 325– 32.
- 25 Lin IF, Fee HR, Wu HS. Negative and positive caregiving experiences: a closer look at the intersection of gender and relationship. *Fam Relat* 2012; 61: 343–58.
- 26 Hastrup LH, van den Berg B, Gyrd-Hansen D. Do informal caregivers in mental illness feel more burdened? A comparative study of mental versus somatic illnesses *Scand J Public Health* 2011; 39: 598–607.
- 27 Skarupski KA, McCann JJ, Bienias JL, Evans DA. Race differences in emotional adaption of family care-givers. *Aging Ment Health* 2009; 12: 715–25.
- 28 Schulz R, Beach SR, Cook TB, Martire LM, Tomlinson JM, Monin JK. Predictors and consequences of perceived lack of choice in becoming an informal caregiver. *Aging Ment Health* 2012; 16: 712–21.
- 29 Tokunaga M, Hashimoto H. The socioeconomic within-gender gap in informal caregiving among middleaged women: Evidence from a Japanese nationwide survey. *Soc Sci Med* 2017; 173: 48–53.

- 30 Winker G, Degele N. Intersectionality as multi-level analysis: dealing with social inequality. *Eur J Womens Stud* 2011; 18: 51–66.
- 31 Rouhani S. *Intersectionality-informed Quantitative Research: a Primer*. Canada: Institute for Intersectionality Research and Policy, 2014. Available from: https://studylib.net/doc/10714284/ intersectionality-informed-quantita tive-research–a-prime [Accessed 20th September 2018].
- 32 de Klerk M, de Boer A, Plaisier I, Schyns P. Voor elkaar? Stand van de informele hulp in 2016 [There for each other? Unpaid help in 2016: a review]. Netherlands: The Netherlands Institute for Social Research; 2017. Available from: https://www.scp.nl/Publica ties/Alle\_publicaties/Publicaties\_2017/ Voor\_elkaar [Accessed 5th April 2019].
- 33 Janssen B. Onderzoeksverantwoording Dataverzameling Informele Zorg 2016 [Justification Datacollection Informal Care 2016]. Netherlands: Statistics Netherlands; 2017. Available from: https://www.scp.nl/Onderzoek/Bron nen/Beknopte\_onderzoeksbeschrijvin gen/Informele\_zorg\_IZG [Accessed 4th September 2018].
- 34 Kroneman M, Boerma W, van den Berg M, Groenewegen P, de Jong J, van Ginneken E. The Netherlands: health system review. *Health Syst Transit* 2016; 18: 1–239. Available from: http://www.euro.who.int/\_\_da ta/assets/pdf\_file/0016/314404/HIT\_ Netherlands.pdf [Accessed 11th September 2018].
- 35 Bauer GR. Incorporating intersectionality theory into population health research methodology: challenges and the potential to advance health equity. *Soc Sci Med* 2014; 110: 10–17.
- 36 Choo HY, Ferree MM. Practicing intersectionality in sociological research: a critical analysis of inclusions, interactions, and institutions in the study of inequalities. *Soc Theory* 2012; 28: 129–49.
- 37 Davis K. Intersectionality as buzzword. A sociology of science perspective on what makes a feminist theory successful. *Feminist Theory* 2008; 9: 67–85.
- 38 Scott NA, Siltanen J. Intersectionality and quantitative methods: assessing regression from a feminist perspective. *Int J Soc Res Methodol* 2017; 20: 373–85.

- 39 Roels J. Onderzoeksverantwoording Dataverwerking Informele Zorg 2016 [Justification Datacollection Informal Care 2016]. Netherlands: Statistics Netherlands; 2017.
- 40 (Blieszner R, Bedford VH eds). Handbook of Families and Aging, 2nd edn. 2012, Praeger, Santa Barbara.
- 41 Allison P. When can you safely ignore multicollinearity?September 10, 2012 [cited October 10, 2018]. United States:

Statistical Horizons. Available from: https://statisticalhorizons.com/multic ollinearity.

- 42 Gharavi Y, Stringer B, Hoogendoorn A, Boogaarts J, van Raaij B, van Meijel B. Evaluation of an interactionskills training for reducing the burden of family caregivers of patients with severe mental illness: a preposttest design. *BMC Psychiatry* 2018; 18: 1–8.
- 43 Richardson S, Asthana S. Inter-agency information sharing in health and social care services: the role of professional culture. *Br J Soc Work* 2006; 36: 657–69.
- 44 Movisie. Groepen mantelzorgers
   [Groups of caregivers]. [Cited November 20, 2018]. Available from: https://gemeenten.movisie.nl/doel/mantelzorgversterken/beleid/groepen-mantelzorgers.