

University of Groningen

## Collaborative partnership between family caregivers and nurses in the care of older hospitalized persons

Hagedoorn, Ellen Ingrid

DOI:  
[10.33612/diss.97727618](https://doi.org/10.33612/diss.97727618)

**IMPORTANT NOTE:** You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

*Document Version*  
Publisher's PDF, also known as Version of record

*Publication date:*  
2019

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*

Hagedoorn, E. I. (2019). *Collaborative partnership between family caregivers and nurses in the care of older hospitalized persons*. Rijksuniversiteit Groningen. <https://doi.org/10.33612/diss.97727618>

### Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

### Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

*Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.*

**The association of collaboration between family caregivers and nurses in the hospital and their preparedness for caregiving at home**

E.I. Hagedoorn

J.C. Keers

T. Jaarsma

C.P. van der Schans

ML.A. Luttik

W. Paans

## **Abstract**

Family caregivers of an older person who was recently hospitalized often feel unprepared for their new or expanded tasks. Quality and continuity of care for older people is expected to improve when nurses collaborate with family caregivers as partners in care. The aim of this study was to explore the unique contribution of collaboration between family caregivers of older patients and hospital nurses as a possible predictor for preparedness of caregiving after hospital discharge. With a cross sectional design, a postal survey was sent to 777 family caregivers of home-dwelling hospitalized patients ( $\geq 70$  years). Regression analyses were used to test the association between collaboration and preparedness for caregiving. In total, 506 (68%) family caregivers responded of whom 281 (38%) were eligible. Their mean (SD) age was 65 (13) and 71% were female. Family caregivers' level of collaboration with nurses was significantly associated with their preparedness for caregiving.

## Introduction

Family caregivers play a crucial role in supporting their relative at home and, therefore, it is important that they feel prepared for caregiving when their older relative is discharged from the hospital.<sup>1-3</sup> Preparedness for caregiving can be defined as how well prepared the family caregiver believes him or herself to be for the tasks and stress of the caregiving role.<sup>4</sup> Feeling prepared for caregiving after a hospital discharge has been found to have a positive effect on both the patient and family caregiver.<sup>5</sup> Family caregivers' preparedness for caregiving is positively associated with patient outcomes such as reduced pain levels as well as improved functional and mental health status.<sup>6</sup> In addition, it is associated with better quality of life of the family caregiver<sup>7,8</sup> and with lower levels of caregiver strain and burden.<sup>4,9</sup>

Since older persons are more frequently hospitalized due to the consequences of chronic illnesses<sup>10</sup> and the length of hospital stay is shortening, the care that family caregivers offer their ill relatives at home has become more complex.<sup>11</sup> This often results in greater demands on these caregivers<sup>12</sup> who frequently feel unprepared for their new or expanded caregiving tasks.<sup>13,14</sup> Family caregivers feel better prepared for caregiving when they are offered more involvement in the coordination of care of their relative.<sup>6,13,15</sup> When nurses view family caregivers as care partners<sup>16</sup> and collaborate with them,<sup>2</sup> the quality and continuity of care for older adults improves.

Collaboration between nurses and family caregivers can be defined as the situation of two or more people working together to create or achieve the same thing.<sup>17</sup> This definition is in accordance with a study of Boyle and Kochinda<sup>18</sup> on enhancing collaborative communication between nurses and physicians in intensive care units. The authors defined collaboration as the process of joint decision-making between different parties where decisions are joint ownership and collective responsibility exists for the results.<sup>18</sup> Family caregivers perceive collaboration with nurses as a caring partnership through which they would receive regular updates and, most importantly, be involved in decision making.<sup>19</sup> Collaboration in this study means that nurses who are responsible for the daily nursing care of older people who are admitted to the hospital have contact with family caregivers and actively involve them in a process of information exchange and joint decision-making as partners in care. Nurses play an important role in collaborating with family caregivers as care partners<sup>2,20</sup> and in utilizing the expertise of those who care for a relative.<sup>1,21,22</sup> A part of nurses'

professional responsibility is to support patients and their family in order to strengthen the self-management of older people when possible.<sup>23,24</sup>

Based on these studies, it can be hypothesized that when family caregivers of older patients experience collaboration with nurses in the hospital, they are expected to feel prepared for caregiving at home. Therefore, the aim of this study was to explore the unique contribution of collaboration between family caregivers of older patients and hospital nurses as a possible predictor for preparedness of caregiving after hospital discharge.

## **Method**

A cross sectional design using a postal questionnaire was used to examine family caregivers' perceived level of collaboration with hospital nurses and their degree of preparedness for caregiving at home.

### **Sample and setting**

Since the focus of the study is on family caregivers, a convenience sample of family caregivers was identified who met the following inclusion criteria: they were a family caregiver of a home-dwelling patient of  $\geq 70$  years of age who was admitted to the hospital for at least two days. Excluded were family caregivers of patients who were living in a care facility or had been admitted for day treatment. To measure collaboration between family caregivers and nurses in the hospital, family caregivers also had to meet the following criteria: the family caregiver 1) visited the patient during the hospitalization, 2) had actual contact with nurses, and 3) were involved in making follow up agreements at discharge. In this study, family caregivers are defined as persons who are important for patients' support at home as identified by the patients themselves. Therefore, they could be partners, family members, friends, neighbors, etc. These individuals were not being paid for their support. Patients could also identify more than one family caregiver to be included in the study. Family caregivers of elderly patients were recruited from five general hospitals in the Netherlands with a total of 22 hospital wards, namely six internal medicine wards, five cardiology wards, five pulmonology wards, five neurology wards, and one geriatric ward.

### **Data collection**

The Medical Ethics Review Committee of the University Medical Center Groningen ruled that this study was not under the regulation of the Medical Research Involving Human Subjects Act (Reference METc 2015/620). Permission to perform the study was granted by

the directors of the participating organizations. Prior to the beginning of the study, charge nurses were informed about the purpose of the study by their managers and through a newsletter.

Charge nurses screened admitted patients to determine whether they met the inclusion criteria. When eligible, patients were approached and informed of the study purpose by data collectors who were fourth year bachelor nursing students. The name and addresses of primary caregivers were then obtained from the patient. Approximately four to seven days following the discharge of the patient from the hospital, a questionnaire and a return envelope was sent to family caregivers' home addresses. After two weeks, a reminder was sent to non-responders. Patients received written and oral information about the study and gave their informed consent for obtaining patient demographics from the patients' chart and for publication of the results. Family caregivers voluntarily participated in the study and gave their consent for participation and publication of the results before completing the survey. Patients and family caregivers were assured they could discontinue participation. Data were collected in 2016 and 2017.

## **Measures**

### *Preparedness for Caregiving*

Preparedness for caregiving was measured with the widely used 'Preparedness for Caregiving Scale' (PCS) of the Family Care Inventory.<sup>4,7,25-28</sup> The PCS consists of eight self-reported items that measure the degree of preparedness of family caregivers to take care of a relative at home. All of the response alternatives were expressed in Likert scales ranging between 1–5 with 1 being 'not at all prepared' and 5 'very well prepared'. Cronbach alphas of 0.88 – 0.93 have been reported for this scale.<sup>25,26</sup> The PCS was translated from English into Dutch by two independent professional translators providing forward and back translation of the instrument. Reconciliation of the first translation into Dutch was discussed by the first author and two co-authors. The Dutch and English versions of the PCS are found in Appendix 7.1. The reliability of the PCS in our population is excellent with a Cronbach's alpha of 0.945, compared to earlier reported studies.

### *Family Collaboration Scale*

Collaboration was measured with the '20-item Family Collaboration Scale' (FCS) Dutch language version that was found to be a valid and reliable instrument that measures family caregivers' experiences of collaboration with nurses in the hospital.<sup>29</sup> The 20-item FCS consists of three subscales, 'Trust in nursing care', 'Accessible nurse,' and 'Influence on

decisions' with ordinal alphas of .81, .87 and .88, respectively, and a Cronbach's alpha of .89 for the total scale<sup>29</sup>. Response alternatives were expressed in Likert scales from 1– 5, with a higher score representing a higher level of collaboration. Response alternatives are Never-Always or Totally disagree – Totally Agree. One 'negatively' formulated item of the scale (item 16) was subsequently reversed in order to facilitate data analysis.

#### *Family caregivers' demographics and caregiving history*

Family caregiver characteristics included age, gender, marital status, their relationship and whether they were living with the patient, highest level of education, work status, if they had children at home, if they had a professional background in healthcare, and the frequency and duration of offered support to the patient at home.

#### **Data analyses**

Data analyses were performed using IBM SPSS Statistics version 24.0.<sup>30</sup> Respondents who had > 25% (two items of the PCS or five items of the FCS) missing data were removed from the data analysis. Missing values of questionnaires with  $\leq 25\%$  missing were replaced by the series mean rounded to the nearest integer.<sup>31</sup> Family caregivers' and patients' demographic data were reported using descriptive statistics which were also used to analyse the mean scores (SD) of the two scales applied in this study. For comparative purposes, the mean sum scores of the PCS and the FCS were transferred to a 100-point scale. To determine the internal consistency of the PCS, Cronbach's alpha was calculated with a value of  $>.7$  considered acceptable.<sup>32</sup>

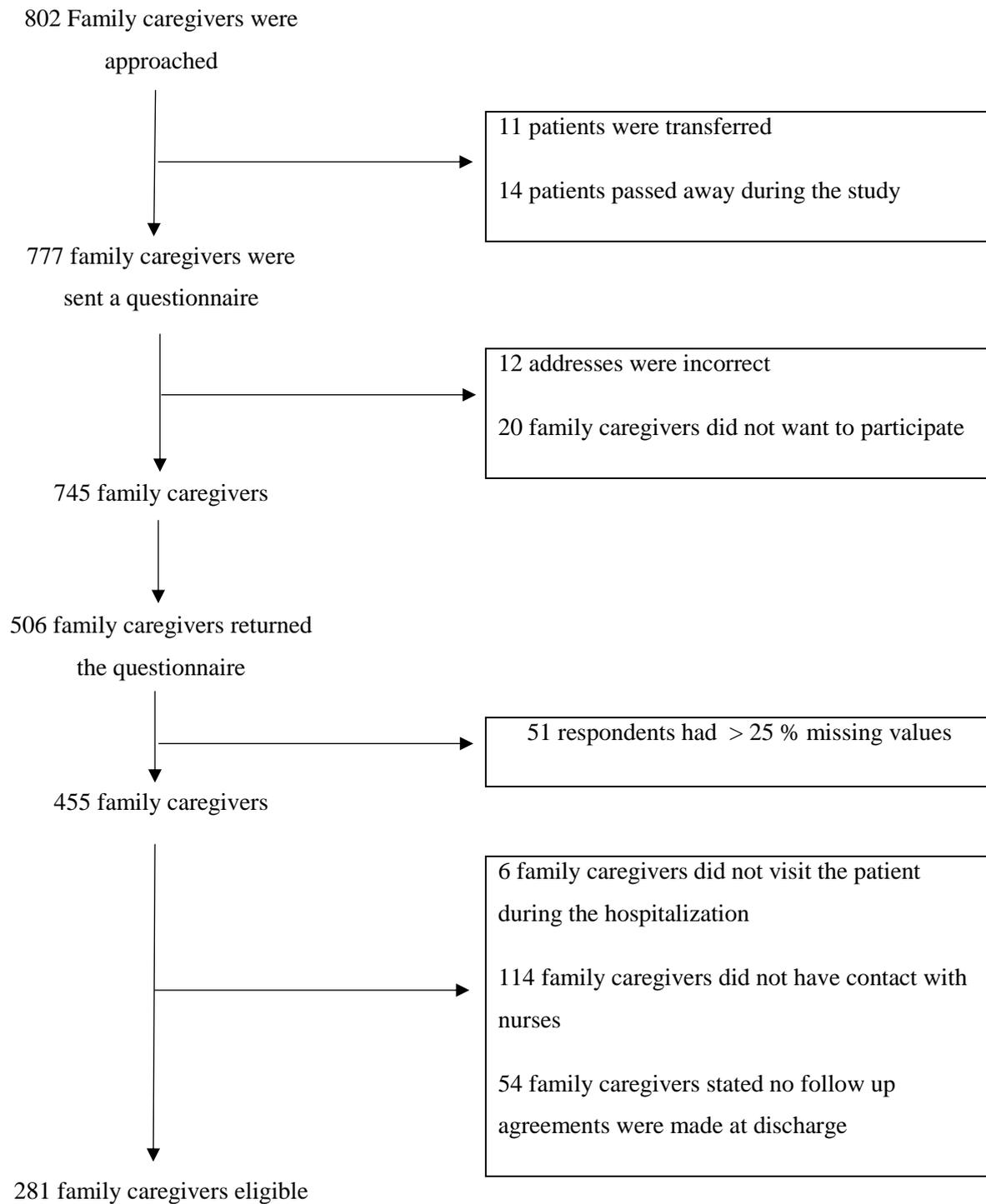
A univariate analysis was used to explore the influence of covariates and the independent variable of collaboration to family caregivers' degree of preparedness (see Figure 1). Next, multiple linear regression analyses were used to test the association between preparedness and collaboration as well as the covariates (see Figure 1). The covariates family caregiver's characteristics and the frequency and duration of their support were entered in Step 1 and Step 2, respectively, in order to statistically control for these. The independent variable collaboration was entered in Step 3 in order to explore its unique predictive value on preparedness. A regression analysis was performed using the Enter method, and outcome parameters were expressed in Beta, the standardized version of *b*-values. These values are easier to compare because they are not dependent on the units of measurement of the different parameters but measured in standard deviation units.<sup>33</sup> The significance level of .05 was used throughout based on T-tests.

<b>Steps</b>	<b>Covariates</b>	<b>Dependent variable</b>
1.	Family caregiver's characteristics	Degree of Preparedness
2.	Family caregiver's frequency and duration of support at home	
<b>Independent variable</b>		
3.	Family caregiver's level of collaboration	

**Fig. 1.** Study model

## Results

Initially, 802 family caregivers were approached to participate in the study of which 25 dropped out resulting in sending out 777 questionnaires (see Flowchart in Figure 2). A total of 506 (68%) family caregivers returned the questionnaire whereby 51 (10%) family caregivers were omitted from further analysis because more than 25% of the items were missing per subscale scale, resulting in 455 (59%) completed questionnaires. In addition, data from 174 (22%) family caregivers had to be excluded because of not meeting the inclusion criteria (See the flowchart in Figure 1). The PCS scale had a total of five missing values, and the FCS had 17 items with 1-3% missing values, one with 6% (item 14), and one item with 15% (item 21) missing values. These missing values were replaced by the series means.



**Fig. 2.** Flowchart of eligible respondents.

In Table 1, the family caregivers’ characteristics are provided. Most family caregivers were either the partner of the patient or a child. Most were women and married. Approximately half of the family caregivers live with the patient, and the majority have supported the patient for more than one year.

**Table 1.** Family caregivers' characteristics (N = 281)

<b>Variable</b>		<b>Mean (SD)</b>
Age		64.1 (13.1)
		<b>%</b>
Gender	Female	71
	Male	29
Marital status	Married/living together	89
	Single/divorced/widowed	11
Highest level of education	Primary/ lower vocational education	21
	Secondary education: lower general/ upper vocational/ upper general	53
	Bachelor/master education	26
Current health status	Average/poor	18
	Good	56
	Excellent / Very good	26
Past health status (1 year ago)	Somewhat worse / much worse	17
	About the same	76
	Much better / Somewhat better	7
Professional background in healthcare	Yes	24
	No	76
Children living at home	Yes	24
	No	76
Paid employment	Yes	39
	No	61

**Table 1.** Continued

Variable		%
Relationship to patient	Partner	48
	Daughter/son	41
	Other*	11
Living with patient	Yes	48
	No	52
Frequency of support	One a week or less	22
	2-3 times a week	24
	4-6 times a week	11
	Every day	43
Duration of support	Just now, since hospital discharge	22
	Less than 3 months	7
	4-12 months	9
	More than one year	62

\*niece/nephew (9), daughter/son in law (8), Brother/sister (3), Friend (3), Grandchild (2), Neighbour (2), family caregiver (2), sister in law (1) and stepdaughter (1).

Although the main focus of the study is on family caregivers, some characteristics of patients are provided to offer a patient related context to the family caregivers included in the study. The average age (SD) of patients was 79.4 (6.2) years old and 148 (54%) men and 126 (46%) female. Of these patients, 173 (64%) were married or living together, 74 (28%) were widowed, and 21 were single (8%). The average (SD) length of hospital stay was nine (6.2) days.

**Table 2.** Percentages of responses and mean scores of family caregivers' preparedness for caregiving

Item	Percentages of responses*					Mean	SD
	1	2	3	4	5		
1. How well prepared do you think you are to take care of your relative's physical needs?	16	21	32	23	8	2.87	1.17
2. How well prepared do you think you are to take care of your relative emotional needs?	8	20	32	30	10	3.15	1.09
3. How well prepared do you think you are to find out about and set up services for your relative?	7	18	33	31	11	3.22	1.08
4. How well prepared do you think you are for the stress of caregiving?	11	22	33	29	5	2.97	1.07
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your relative?	9	20	31	34	6	3.10	1.06
6. How well prepared do you think you are to respond to and handle emergencies that involve your relative?	8	15	28	37	12	3.32	1.11
7. How well prepared do you think you are to get the help and information you need from the health care system?	6	19	33	32	10	3.21	1.06
8. Overall, how well prepared do you think you are to care for your relative?	6	20	34	31	9	3.16	1.04
<b>Total score</b>						3.12	.092

\*Response alternatives were 1. Never- 5. Always or 1. Strongly disagree – 5. Strongly agree with the response categories 2, 3 and 4 in the middle; a higher score representing a higher degree of preparedness for caregiving.

In Table 2, descriptive statistics summarize the distribution of each PCS item. Percentages of responses show normal distributions. The mean items scores show a moderate degree of preparedness with scores ranging from 2.87 (possible range 1-5) for item 1 on how well-prepared family caregivers feel for taking care of the patient’s physical needs to 3.32 for item 6 on how well-prepared they are to respond to and handle emergencies.

The mean scale score on the PCS in Table 3 shows an average degree of family caregivers’ preparedness for caregiving with a mean score of 53.1 (100-point score) and a mean score of 67.5 on their experienced level of collaboration with nurses.

**Table 3.** Scale scores of PCS and FCS

Scale	Range	Mean (SD)	Mean (SD)	Cronbach’s alpha
		Raw score	100-points score	
Preparedness	8 - 40	24.99 (7.37)	53.1 (23.0)	.945
Collaboration	20 - 100	73.97 (12.48)	67.5 (15.6)	.892

In Table 4, the univariate analyses of preparedness for caregiving are first given together with the covariates family caregivers’ characteristics, frequency and duration of support and the independent variable collaboration. Most predictor variables are significantly associated with preparedness. A strong association with preparedness for caregiving was found for the independent variable of collaboration between family caregivers and nurses. Caregivers who are partner of the patient or live with them or those who have a higher level of education feel more prepared for caregiving. Also, family caregivers’ health status is positively associated with a higher degree of preparedness. Family caregivers who are older, who do not have paid work, and those who do not have a professional background in health care feel less prepared for caregiving.

**Table 4.** Univariate and multiple regression analysis of preparedness for caregiving

	Univariate analysis		Multiple regression analysis					
	Beta	<i>p</i>	Step 1		Step 2		Step 3	
			Beta	<i>p</i>	Beta	<i>p</i>	Beta	<i>p</i>
Age	-.144	.015						
Gender	-.025	.673						
Marital status	.068	.253						
Highest level of education	.191	.001	.158	.029	.150	.034	.180	.009
Children living at home	-.070	.246						
Paid employment	-.119	.046						
Relationship to patient	.143	.017						
Living with patient	.128	.032						
Background in Healthcare	-.235	<.001	-.212	.001	-.219	.001	-.233	<.001
Current health status	.161	.007						
Health status one year ago	.196	.001	.159	.021	.168	.013	.140	.032
Duration of support	.146	.025						
Collaboration	.223	<.001					.250	<.001
<b>R square</b>		.136*	.177**	.234**				

\*Significance level < .01; \*\*Significance level <.001. *P*: P-value < .05. Beta: Beta coefficient

Next, the model for each step of the multiple regression analyses is given in Table 4 with the family caregivers' characteristics in Step 1, the frequency and duration of support in Step 2, and the perceived level of collaboration in Step 3.

Table 4 shows that the family caregivers' perceived level of collaboration is significantly associated with their degree of preparedness even after correcting for covariates. Of the family caregivers' characteristics, highest level of education, background in health care, and health status one year ago are significantly associated with preparedness for caregiving. When correcting for frequency and duration of support in Step 2, these covariates are still significantly associated with preparedness as is also the frequency of support. In Step 3 of Table 4, these covariates remain significantly associated with preparedness when collaboration is added to the model. Based on the Beta coefficients in Step 3, the independent variable of collaboration has the highest Beta value and, therefore, the most important predictor value in the model.

As seen in Table 4, the R squares of the three steps show that family caregivers' characteristics, their frequency of support at home, and their level of collaboration explain 23.4% of their degree of preparedness for caregiving. Each step adds to the percentages of variances explained and are significant with  $p$ -values  $<.01$ . After correcting for covariates, family caregivers' perceived level of collaboration explains an additional 5.7% of the preparedness variance.

## Discussion

The results of this study show that family caregivers who perceive a higher level of collaboration with nurses also show a higher degree of preparedness for caregiving at home after discharge of the patient from the hospital. This study adds to the limited body of evidence of exploring the relationship between family caregivers' collaboration with nurses in the hospital and the caregiver's feeling of preparedness for taking care of an older person at home. Findings are supported by a study of Weinberg and colleagues<sup>6</sup> who found that relational coordination between informal caregivers of knee replacement patients and formal providers improved caregiver preparation to provide care, measured after six weeks surgery.

This is one of the few studies that specifically takes into account the concept of collaboration between hospital nurses and family caregivers who care for older persons. This study indicates that collaboration with family caregivers is significantly associated with their degree of preparedness. Therefore, collaboration between them and nurses improves family

caregivers' preparedness, which may in turn lead to experiencing less role strain when they are prepared for caregiving.<sup>5,9</sup> Findings are also in accordance with studies that found that, when nurses involve family caregivers of older patients during the admission and discharge phase, more effective exchange of information and calibration of expectations can be achieved<sup>33</sup> and, as a result, improved their feelings of preparedness for caregiving.<sup>15</sup> This may suggest that family caregivers who perceived a higher level of collaboration with nurses may have experienced a more effective exchange of information and, therefore, may know better what to expect at home and may have also felt more involved in decision-making. These findings underline the crucial role that nurses play in the collaboration with family caregivers in order to ensure optimal care for patients after hospital discharge. Earlier studies have shown that, when family caregivers feel prepared for caregiving at home, the health and self-care ability of older persons experiencing chronic conditions can also increase.<sup>34,35</sup>

Findings also show that family caregivers who have a background as a professional in health care experience a higher degree of preparedness for caregiving at home compared to those who did not have a background in healthcare. When family caregivers have prior experiences as a professional in healthcare, they may have a better idea on what to expect after discharge and, therefore, feel prepared for caregiving at home. No other studies addressing preparedness for caregiving were found to include this covariate as a characteristic of the caregiver. Family caregivers who support the patient more frequently and consequently have more experience also report a higher degree of preparedness for caregiving.

A higher level of education was also independently associated with a higher degree of preparedness in caregiving. This may imply that nurses need to keep family caregivers' level of understanding into account while communicating with them. Finally, family caregivers' self-reported previous health status (one year ago) was also positively related to a higher degree of preparedness for caregiving. This finding was supported by Bull, Maruyama, and Luo<sup>36</sup> who found family members' health status to be an indicator of potential health risk in the caregiving situation. In contrast, Hendriksson and Årestedt<sup>37</sup> ascertained no association between health and preparedness in a population of caregivers for relatives with a life-threatening illness. Still, it seems to be important for nurses to be attentive to or specifically ask about family caregivers' health status.

The overall mean score of 3.12 for preparedness for caregiving in this study was also found in a study on oncology patients<sup>5</sup> but was overall higher than what was found in other studies on heart failure patients<sup>27</sup> (2.1) and stroke survivors<sup>28</sup> (1.9) and in intervention studies that measured the effect changes of preparedness for caregiving with mean scores of 2.9, 2.9,

2.1 and 2.4, respectively.<sup>38-41</sup> In contrast, Scherbring<sup>9</sup> found a higher overall mean score of 3.5 on preparedness for caregiving in a population with caregivers of oncology patients. This could suggest that the family caregivers' degree of preparedness for caregiving could be further improved.

Referring to the overall mean score of collaboration of 67, findings of this study also imply that the involvement in the matter of collaboration with family caregivers could be further extended. On the one hand, this may be a cultural aspect in that nurses need to be aware of the role that family caregivers have in supporting the health and self-care ability of older patients in the hospital. Family caregivers should be considered as part of the healthcare team that needs to be prepared for caregiving tasks at home instead of relatives who primarily require information or who have practical problems that need to be solved.<sup>42</sup> This was also found in studies that have shown that, when nurses have a positive attitude towards families and believe family presence in the hospital is important, they are more likely to include families in nursing care.<sup>43,44</sup>

On the other hand, structural collaboration between nurses and family caregivers needs more attention because findings of this study show the importance that collaboration can have on family caregivers' preparedness for caregiving. Results emphasize the importance of patient and family focused care in order to maintain continuity of care as part of the professional nurses standard and subsequently promote patients' selfcare.<sup>23,24</sup> In order to do so, nurses must assume more of a coaching role supporting the patient's own resources while hospitalized instead of taking over patient and family caregivers' responsibilities. Lowson and colleagues<sup>2</sup> also found that family caregivers felt their role of 'conductors' of the patients' wellbeing and the person who coordinates the care as a liaison and advocate with formal caregivers vastly reduced to 'second fiddler' when their relative was admitted to the hospital. Overall, nurses can start collaboration with family caregivers by a three-phase sequence: 1) involvement through establishing basic bonding and communication channels, 2) collaboration by forming partnership based on the recognition of common goals and 3) empowerment by sharing of power and responsibility.<sup>45</sup> These steps are not unique to the nursing discipline but the awareness of the importance of collaboration can also apply to other health care professionals.

This study focused specifically on the association between family caregivers' experiences of collaboration with nurses in the hospital and their preparedness for caregiving and was measured with a valid scale on collaboration with nurses in the hospital. The study population was a general group of older persons who still live at home and were hospitalized.

This specific population of older hospitalized patients is critical because they have different, more vulnerable social networks than younger patients. Half of the family caregivers in this study were the patients' partners who are old themselves; the other half were children who have work and families of their own.

Previous studies have shown that there is a positive relationship between family caregivers' support and optimization of self-care abilities of elderly individuals experiencing chronic diseases.<sup>34,46,47,48,49</sup> As a consequence of a shift from professional care to informal care, family caregivers are increasingly expected to support their chronically ill family member at home.<sup>11</sup> Their role as informal partners in the care for older individuals is therefore of increasing importance for the health care system. This not only applies for family caregivers' contact with nurses in the hospital, but also other health care professionals. Our findings support the need for nurses to assess the role that family caregivers play in the care for older persons at home when they are admitted to the hospital. Family caregivers are largely present during planned discussions such as the admission interview and family meetings between nurses and older patient admitted to the hospital, creating many opportunities for nurses to assess their role at home.<sup>50</sup>

Family caregivers support their relatives in Activities of Daily Living (ADL), medication adherence, life style instructions and increasingly with nursing care activities. Therefore, it is important to ensure that family caregivers are prepared to cope with the increased demand of support at home. When family caregivers are involved in the organization of care from admission to discharge, they can contribute to the optimization of care offered to the patient in the hospital and at home when discharged and simultaneously monitor the continuity of care.<sup>2,51</sup> Secondly, family caregivers also need to be involved in order to tailor care and treatment options to patients' capabilities and preferences, as well as those of the family caregiver. When nurses involve family caregivers in the planning of care and actively collaborate with them in the decision-making process, the quality and continuity of care for older adults is likely to improve and might also result in a significant decrease in hospital admissions and days spent in the hospital.<sup>52</sup> Future research could focus on the effect that family caregivers' preparedness for caregiving might have on patient outcomes like quality of life and better self-care and fewer readmissions.

In most western societies, it is a trend that family caregivers must take on more responsibilities in caring for their older persons at home after they are discharged from the hospital. Therefore, the results of this study might be predominantly relevant for nurses in western societies. Nevertheless, it is likely that similar results might be applicable in other

countries; therefore, reproduction of this study in other countries could be relevant using this study as a reference.

### **Strengths and Limitations**

A convenience sample of family caregivers of five general hospitals in the Netherlands was obtained; therefore, the generalizability of the results might be limited. However, a number of steps have been taken to include the right patients and their most significant family caregiver. This resulted in a representative sample from which the right target group of family caregivers has been identified. In order to include the right target group, family caregivers' inclusion criteria could only be assessed after the patient was discharged from the hospital. This resulted in a reduction of 22% of the family caregivers who were sent a survey but did not meet the inclusion criteria for this study. The covariates and the independent variable of collaboration in this study predicted almost a quarter of the degree of family caregivers' preparedness for caregiving, suggesting that other variables may improve their preparedness for caregiving as well. Although this study shows a significant predictive value of collaboration, it is a cross sectional study and, no causal effects can be assumed.

Family caregivers' prior experiences with a hospital admission of their relative were not part of this study and may have affected their responses as this was identified as a barrier of collaboration.<sup>53</sup> Their feelings of preparedness and their experiences of collaboration entail subjective responses and might provoke socially desirable behaviour which could influence the reliability of study results. This is the first time that the 20-item FCS has been applied; therefore, it was not possible to compare the results with other studies.

### **Conclusion**

This study shows that family caregivers' perceived collaboration with nurses in the hospital is significantly associated with family caregivers' feelings of preparedness for caregiving. Collaboration between nurses and family caregivers of older patients in the hospital is a relatively new concept that becomes more important now that the role of these informal partners in care becomes more demanding. A prepared family caregiver experiences less role strain and, therefore, contributes to a better quality of life for both their relative and themselves. Prepared family caregivers need nurses who support patients' own social networks while being hospitalized by actively assessing the role of family caregivers and acknowledging them and collaborating with them as an informal partner in care.

**Supporting information**

Appendix 7.1. Caregiver Preparedness Scale in Dutch and English

## References

1. Bragstad L, Kirkevold M, Foss C. The indispensable intermediaries: a qualitative study of informal caregivers' struggle to achieve influence at and after hospital discharge. *BMC Health Serv Res.* 2014a;14:331. <https://doi.org/10.1186/1472-6963-14-331>.
2. Lowson E, Hanratty B, Holmes L, Addington-Hall J, Grande G, Payne S, Seymour J. From 'conductor' to 'second fiddle': Older adult care recipients' perspectives on transitions in family caring at hospital admission. *Int J Nurs Stud.* 2013;50:1197-1205. <https://doi.org/10.1016/j.ijnurstu.2012.02.005>
3. Martín J, Olano-Lizarraga M, Saracíbar-Razquin M. The experience of family caregivers caring for a terminal patient at home: A research review. *Int J Nurs Stud.* 2016;64:1-12. <http://dx.doi.org/10.1016/j.ijnurstu.2016.09.010>.
4. Archbold PG, Stewart BJ, Greenlick MR, Harvath T. Mutuality and Preparedness as Predictors of Caregiver Role Strain. *Res Nurs Health.* 1990;13:375-384. <https://doi.org/10.1002/nur.4770130605>.
5. Schumacher KL, Stewart BJ, Archbold PG. Mutuality and Preparedness moderate the effects of caregiving demand on cancer family caregiver outcomes. *Nurs Res.* 2007;56:425-433. <http://dx.doi.org/10.1097/01.NNR.0000299852.75300.03>.
6. Weinberg DB, Lusenhop WR, Hoffer Gittel J, Kautz CM. Coordination between formal providers and informal caregivers. *Health Care Manage Rev.* 2007;32:140-149. <https://doi.org/10.1097/01.HMR.0000267790.24933.4c>.
7. Shyu Y, Chen M, Chen S, Wang H, Shao J. A family caregiver-oriented discharge planning program for older stroke patients and their family caregivers. *J Clin Nurs.* 2008;17:2497-2508. <https://doi.org/10.1111/j.1365-2702.2008.02450.x>.
8. Zale EL, Heinhuis TJ, Tehan T, Salqueiro D, Rosand J, Vranceanu AM. Resiliency is independently associated with greater quality of life among informal caregivers to neuroscience intensive care unit patients. *Gen Hosp Psychiatry.* 2018;52: 27-33. <https://doi.org/10.1016/j.genhosppsy.2018.02.012>
9. Scherbring M. Effect of caregiver perception of preparedness on burden in an oncology population. *Oncol Nurs Forum.* 2002;29:70-76. <https://doi.org/10.1188/02.ONF.E70-E76>.
10. World Health Organization. World Report on Ageing and Health. <http://www.who.int/ageing/publications/world-report-2015/en/> Published 2015. Accessed February 2, 2016.
11. Reinhard SC, Levine C, Samis S. Home Alone: Family Caregivers Providing Complex Chronic Care. [https://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf](https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf). Published August 2017. Accessed May 11 2018.
12. Jacelon, CS. Directive and Supportive Behaviors Used by Families of Hospitalized Older Adults to Affect the Process of Hospitalization. *J Fam Nurs.* 2006;12: 234-250. <https://doi.org/10.1177/1074840706290264>.
13. Grimmer K, Moss J, Falco J. Becoming a carer for an elderly person after discharge from an acute hospital admission. *Internet J Allied Health Sci Pract.* 2004;2(4). <https://doi.org/doi:10.1186/s13643-016-0222-8>
14. Silver HJ, Wellman NS, Galindo-Ciocon D, Johnson P. Family caregivers of older adults on home enteral nutrition have multiple unmet task-related training needs and low overall preparedness for caregiving. *J Am Diet Assoc.* 2004;104:43-50. <https://doi.org/10.1016/j.jada.2003.10.010>

## The association of collaboration and preparedness for caregiving

15. Bull M, Hansen H, Gross C. Differences in Family Caregiver Outcomes by Their Level of Involvement in Discharge Planning. *Appl Nurs Res.* 2000; 76-82. [https://doi.org/10.1016/S0897-1897\(00\)80004-X](https://doi.org/10.1016/S0897-1897(00)80004-X)
16. Li H, Stewart BJ, Imle MA, Archbold PG, Felver L. Families and Hospitalized Elders: A Typology of Family Care Actions. *Res Nurs Health.* 2000;23:3-16. <https://doi.org/10.1177/0733464813483211>.
17. Cambridge University Press. Cambridge Dictionaries online. Definition collaboration. <http://dictionary.cambridge.org/us/dictionary/business-english/collaboration> Accessed March 14 2015.
18. Boyle DK, Kochinda C. Enhancing collaborative communication of nurse and physician leadership in two intensive care units. *J Nurs Adm.* 2004;34:60-70. <https://doi.org/10.1097/00005110-200402000-00003>
19. Haesler E, Bauer M, Nay R. Recent evidence on the development and maintenance of constructive staff–family relationships in the care of older people – a report on a systematic review update. *Int J Evid Based Healthc.* 2010;8:45-74. <https://doi.org/10.1111/j.1744-1609.2010.00165.x>
20. Wai-Yin AL, Yea-Ing L, Li-Chan L, Pei-Shan Y. Institutionalized elders with dementia: collaboration between family caregivers and nursing home staff in Taiwan. *J Clin Nurs.* 2008;17:482–490. <https://doi.org/10.1111/j.1365-2702.2007.01955.x>
21. Aasbø G, Rugkåsa J, Solbrække KN, Werner A. Negotiating the care-giving role: family members' experience during critical exacerbation of COPD in Norway. *Health Soc Care Community.* 2017;25: 612–620. <https://doi.org/10.1111/hsc.12350>.
22. Norlyk A, Martinsen B. The extended arm of health professionals? Relatives' experiences of patient's recovery in a fast-track programme. *J Adv Nurs.* 2013;69:1737–1746. <https://doi.org/10.1111/jan.12034>.
23. Leahey M, Harper-Jacques S. Family nurse relationships: core assumptions and clinical implications. *J Fam Nurs.* 1996;1:133-157. <https://doi.org/10.1177%2F107484079600200203>.
24. Wright LM, Leahey M. *Nurses and Families - a guide to family assessment and intervention.* 6<sup>th</sup> ed. Philadelphia, PA: F.A. Davis Company; 2013
25. Hudson PL, Hayman-White K. Measuring the Psychosocial Characteristics of Family Caregivers of Palliative Care Patients: Psychometric Properties of Nine Self-Report Instruments. *J Pain Sympt. Manage.* 2008;31:215-228. <https://doi.org/10.1016/j.jpainsymman.2005.07.010>
26. Henriksson A, Andershed B, Benzein E, Arestedt K. Adaptation and psychometric evaluation of the Preparedness for Caregiving Scale, Caregiver Competence Scale and Rewards of Caregiving Scale in a sample of Swedish family members of patients with life-threatening illness. *Palliat Medicine.* 2012;26:930-938. <http://dx.doi.org/10.1177/0269216311419987>
27. Petruzzo A, Paturzo M, Buck HG, Barbaranelli C, D'Agostino F, Ausili D., . . . Vellone E. Psychometric evaluation of the Caregiver Preparedness Scale in caregivers of adults with heart failure. *Res Nurs Health.* 2017;40:470–478. <https://doi.org/10.1002/nur.21811>.
28. Pucciarelli G, Savini S, Byun E, Simeone S, Barbaranelli C, Juárez Vela R, . . . Vellone E. Psychometric properties of the Caregiver Preparedness Scale in caregivers of stroke survivors. *Heart & Lung.* 2014;43:555-560. <http://dx.doi.org/10.1016/j.hrtlng.2014.08.004>
29. Hagedoorn E I, Paans W, Jaarsma T, Keers JC, Schans van der CP Luttik M.A, Krijnen WP. Psychometric evaluation of a revised Family Collaboration Scale in Dutch family caregivers based on the Item Response Theory. *Geriatric Nursing.* 2019 Accepted for publication.
30. IBM Corp. IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY, USA. 22 May 2016

## The association of collaboration and preparedness for caregiving

31. Downey RG, King CV. Missing data in Likert ratings: a comparison of replacement methods. *J Gen Psychol.* 1998;125:175-191. <https://doi.org/10.1080/00221309809595542>
32. Nunnally JC, Bernstein IH. *Psychometric theory.* 3rd ed. New York, NY: McGraw-Hill; 1994.
33. Field A. *Discovering Statistics using IBM SPSS Statistics* 4th ed. London, UK: Sage; 2014.
34. Lindhardt T, Nyberg P, Rahm Hallberg I. Collaboration between relatives of elderly patients and nurses and its relation to satisfaction with the hospital care trajectory. *Scandinavian J Caring Sci.* 2008;22:507–519. <https://doi.org/10.1111/j.1471-6712.2007.00558.x>.
35. Chen Y.-C, Chang L.-C, Liu C.-Y, Ho Y.-F, Weng S.-C, Tsai T.-I. The roles of social support and health literacy in self- management among patients with chronic kidney disease. *J Nurs Scholars.* 2018;50(3):265–275. <https://doi.org/10.1111/jnu.12377>
36. McCabe N, Dunbar SB, Butler J, Higgins M, Book W, Reilly C. Antecedents of self-care in adults with congenital heart defects. *Int. J Cardiol.* 2015;201:610-615. <http://dx.doi.org/10.1016/j.ijcard.2015.08.125>
37. Bull MJ, Maruyama G, Luo D. Testing a model for posthospital transition of family caregivers of elderly persons. *Nurs Res.* 1995;44:132-138.
38. Henriksson A, Årestedt K. Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: A correlational, cross-sectional study. *Palliat Medicine.* 2013;27:639–646. <http://dx.doi.org/10.1177/0269216313486954>
39. Boltz M, Resnick B, Chippendale T, Galvin J. Testing a Family-Centered Intervention to Promote Functional and Cognitive Recovery in Hospitalized Older Adults. *J American Geriatr Soc.* 2014;62:2398–2407. <https://doi.org/10.1111/jgs.13139>
40. Hendrix CC, Bailey DE, Steinhauser KE, Olsen MK, Stechuchak KM, Lowman SG., . . . Tulsy JA. Effects of enhanced caregiver training program on cancer caregiver’s self-efficacy, preparedness, and psychological well-being. *Support Care Cancer.* 2016;24:327-336. <https://doi.org/10.1007/s00520-015-2797-3>
41. Leutz W, Capitman J, Ruwe M, Nuneza Ching V, Flaherty-Robb M, McKenzie M, . . . Lee W. Caregiver Education and Support: Results of a Multi-site Pilot in an HMO. *Home Health Care Serv. Q.* 2002;21:49-72 [https://doi.org/10.1300/J027v21n02\\_04](https://doi.org/10.1300/J027v21n02_04)
42. Stone K. Enhancing preparedness and satisfaction of caregivers of patients discharged from an inpatient rehabilitation facility using an interactive website. *Rehab Nurs.* 2014; 39:76-85. <https://doi.org/10.1002/rnj.123>
43. Silva A, Teixeira H, Cardoso Teixeira M., Freitas S. The needs of informal caregivers of elderly people living at home: an integrative review. *Scand J Caring Sci.* 2013;27:792–803. <http://dx.doi.org/10.1111/scs.12019>
44. Hsiao C-Y, Tsai Y-F. Factors associated with the perception of family nursing practice among mental health nurses in Taiwan. *J Fam Nurs.* 2015;21:508–528. <https://doi.org/10.1177/1074840715606543>
45. Linnarsson JR, Benzein E, Arestedt K. Nurses' views of forensic care in emergency departments and their attitudes, and involvement of family members. *J Clin Nurs.* 2015;24:266-274. <https://doi.org/10.1111/jocn.12638>
46. Elizur Y. Involvement, Collaboration, and Empowerment: A Model for Consultation with Human-Service Agencies and the Development of Family-Oriented Care. *Fam. Process J.* 1996;35:191-210. <https://doi.org/10.1111/j.1545-5300.1996.00191.x>

47. Gallagher R, Luttik MLA, Jaarsma T. Social support and self-care in heartfailure. *J. Cardiovasc. Nurs.* 2011;26: 439-445. <https://doi.org/10.1097/JCN.0b013e31820984e1>
48. Neumann D, Lamprecht J, Robinski M, Mau W, Girndt M. Social relationships and their impact on health-related outcomes in peritoneal versus haemodialysis patients: a prospective cohort study. *Nephrol Dialysis Transplantation.* 2018;33:1235–1244. <https://doi.org/10.1093/ndt/gfx361>
49. Vassilev I, Rogers A, Sanders C, Kennedy A, Blickem C, Protheroe J, . . . Morris, R. Social networks, social capital and chronic illness self-management: a realist review. *Chron Illness.* 2011;7:60-86. <https://doi.org/10.1177/1742395310383338>
50. Wu J, Lennie T, Chung M, Frazier S, Dekker R, Biddle M, Moser D. Medication adherence mediates the relationship between marital status and cardiac event-free survival in patients with heart failure. *Heart Lung.* 2012;41:107-114. <https://doi.org/10.1016/j.hrtlng.2011.09.009>
51. Hagedoorn, E. I., Paans, W., Jaarsma, T., Keers, J. C., van der Schans, C. P., & Luttik, M. A. Aspects of family caregiving as addressed in planned discussions between nurses, elderly patients with chronic diseases and family caregivers: A qualitative content analysis. *BMC Nurs.* 2017; 1-10. doi:<https://doi.org/10.1186/s12912-017-0231-5>
52. Bridges J, Flatley M, Meyer J. Older people's and relatives' experiences in acute care settings: Systematic review and synthesis of qualitative studies. *Inter J Nurs Stud.* 2010;47:89-107. <https://doi.org/10.1016/j.ijnurstu.2009.09.009>
53. Ingadottir T, Jonsdottir H. Partnership-based nursing practice for people with chronic pulmonary disease and their families: influences on health-related quality of life and hospital admissions. *J Clin Nurs.* 2010;19: 2795-2805. <https://doi.org/10.1111/j.1365-2702.2010.03303.x>
54. Lindhardt T, Nyberg P, Rahm Hallberg I. Relatives' view on collaboration with nurses in acute wards: Development and testing of a new measure. *Inter J Nurs Stud.* 2008;45:1329-1343. <https://doi.org/10.1016/j.ijnurstu.2007.10.006>

**Appendix 7.1.** Caregiver Preparedness Scale in Dutch and English

No.	Question in Dutch	Question in English
1	Hoe goed denkt u voorbereid te zijn op het zorgen voor de lichamelijke behoeften van uw familielid /naaste?	How well prepared do you think you are to take care of your relative/friend's physical needs?
2	Hoe goed denkt u voorbereid te zijn op het zorgen voor de emotionele behoeften van uw familielid/naaste?	How well prepared do you think you are to take care of your relative emotional needs?
3	Hoe goed denkt u voorbereid te zijn op het uitzoeken en regelen van voorzieningen of zorg voor uw familielid/naaste?	How well prepared do you think you are to find out about and set up services for your relative?
4	Hoe goed denkt u voorbereid te zijn op de stress die het zorg verlenen met zich meebrengt?	How well prepared do you think you are for the stress of caregiving?
5	Hoe goed denkt u voorbereid te zijn op het aangenaam maken van zorgactiviteiten, voor zowel u als uw familielid/naaste?	How well prepared do you think you are to make caregiving activities pleasant for both you and your relative?
6	Hoe goed denkt u voorbereid te zijn op het ingrijpen en handelen in noodsituaties ten aanzien van uw familielid/naaste?	How well prepared do you think you are to respond to and handle emergencies that involve your relative?
7	Hoe goed denkt u voorbereid te zijn op het verkrijgen van hulp en informatie die u nodig heeft vanuit de gezondheidszorg?	How well prepared do you think you are to get the help and information you need from the health care system?
8	Hoe goed denkt u, over het algemeen genomen, voorbereid te zijn op het bieden van zorg aan uw familielid/naaste?	Overall, how well prepared do you think you are to care for your relative?