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Hagedoorn, Ellen; Paans, Wolter; van der Schans, Cees P.; Jaarsma, Tiny; Luttkik, Maria-Louise; Keers, Joost

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Family caregivers' perceived level of collaboration with hospital nurses: A cross-sectional study

Ellen I. Hagedoorn RN, PhD, Senior lecturer/researcher^{1,2,3,4}  |
 Wolter Paans RN, PhD, Professor^{3,4} | Cees P. van der Schans CE, PT, PhD, Professor^{1,2,5} |
 Tiny Jaarsma RN, PhD, Professor⁶ | Marie Louise A. Luttk RN, PhD, Professor³ |
 Joost C. Keers PhD, Head research institute^{1,7}

¹Research Group Healthy Ageing, Allied Health Care and Nursing, Hanze University of Applied Sciences, Groningen, The Netherlands

²Department of Health Psychology, University Medical Center, University of Groningen, Groningen, The Netherlands

³Research Group Nursing Diagnostics, Hanze University of Applied Sciences, Groningen, The Netherlands

⁴Department of Critical Care, University Medical Center, University of Groningen, Groningen, The Netherlands

⁵Department of Rehabilitation, University Medical Center, University of Groningen, Groningen, The Netherlands

⁶Department of Social and Welfare Studies (ISV), Linköping University, Linköping, Sweden

⁷Martini Hospital, Groningen, The Netherlands

Correspondence

Ellen I. Hagedoorn, Hanze University of Applied Sciences, P.O. Box 3109, 9701 DC Groningen, The Netherlands.
 Email: e.i.hagedoorn@pl.hanze.nl

Abstract

Aim: To describe the extent of perceived collaboration between family caregivers of older persons and hospital nurses.

Background: Collaboration between hospital nurses and family caregivers is of increasing importance in older patient's care. Research lacks a specific focus on family caregiver's collaboration with nurses.

Method: Using a cross-sectional design, 302 caregivers of older patients (≥ 70 years) completed the 20-item Family Collaboration Scale with the subscales: trust in nursing care, accessible nurse and influence on decisions. Data were analysed with descriptive statistics and bivariate correlations.

Results: Family caregivers rated their level of trust in nurses and nurses' accessibility higher than the level of their influence on decisions. Family caregivers who had more contact with nurses perceived higher levels of influence on decisions ($p \leq .001$) and overall collaboration ($p \leq .001$).

Conclusion: Family caregivers' collaboration with nurses can be improved, especially in recognizing and exploiting family caregivers as partner in the care for older hospitalized persons and regarding their level of influence on decisions.

Implications for Nursing Management: Insight into family caregivers' collaboration with nurses will help nurse managers to jointly develop policy with nurses on how to organise more family caregivers' involvement in the standard care for older persons.

KEYWORDS

collaboration, family caregivers-nurses, hospitalization, partnership

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1 | INTRODUCTION

The care for older home-dwelling persons by family members is intensifying due to the ageing population, and, relatedly, a growing number of older persons experiencing chronic conditions (WHO, 2015). As a result, a growing number of family members are becoming informal partners of health care professionals, such as nurses (Broese van Groenou & De Boer, 2016). Older persons are often hospitalized as a result of chronic illness or for diagnosis, and hospital admissions are generally becoming shorter. Consequently, they may not achieve a stable health status before their discharge from the hospital, making the care provided by family caregivers more complex and burdensome (Reinhard et al., 2012). Patient and Family Centred Care (PFCC) acknowledges that families are crucial to the health and well-being of older persons and advocates for quality and safety within the health care system (Conway et al., 2006). PFCC as well as the World Health Organization recognizes that family members are essential partners of the caregiving team (WHO, 2013). Therefore, it is important that family caregivers can decide how to participate in decision making and how to collaborate with hospital nurses in the delivery of care (Wittenberg et al., 2018). The quality and continuity of care for older adults who are temporarily admitted to the hospital improves when hospital nurses involve family caregivers in caregiving and decision-making (Bridges et al., 2010; Neumann et al., 2018; Park et al., 2018). Involvement of older persons' caregivers during the hospitalization reduces potential complications (Li, 2005) and reduces the length of stay (Park et al., 2018) and the risk of hospital readmission (Park et al., 2018; Rodakowski et al., 2017). Also, the physical and psychological conditions of both the patient (Weinberg et al., 2007) and the caregivers themselves improve when family caregivers are involved (Hartmann et al., 2010; Neumann et al., 2018). Most encouraging interventions to advance involvement and constructive relationships between health care professionals and family caregivers entail clear communication, building and negotiating relationships with professionals, and effective collaboration strategies (Bélanger et al., 2016; Haesler et al., 2010; Park et al., 2018).

Previous studies primarily report on experiences of family caregivers' involvement in the care for hospitalized older persons based on qualitative studies. These studies indicated that family caregivers find their ability to influence decisions seriously reduced when an older person is admitted to the hospital (Lowson et al., 2013; Nyborg et al., 2017). These caregivers did not always feel acknowledged as competent care partner by professionals (Aasbø et al., 2017; Lindhardt et al., 2006) and experienced an insufficient exchange of information and knowledge about disease related aspects, care and support (Bove et al., 2016; Røthing et al., 2015). Although qualitative studies give in-depth insight into the content and experience of caregiving and collaboration, they do not provide insight into the extent to which collaboration between family caregivers and hospital nurses is present in nursing

practice. By quantitatively measuring family caregivers' perceived collaboration, more insight can be obtained into the various aspects of collaboration in order to formulate specific areas for improvement.

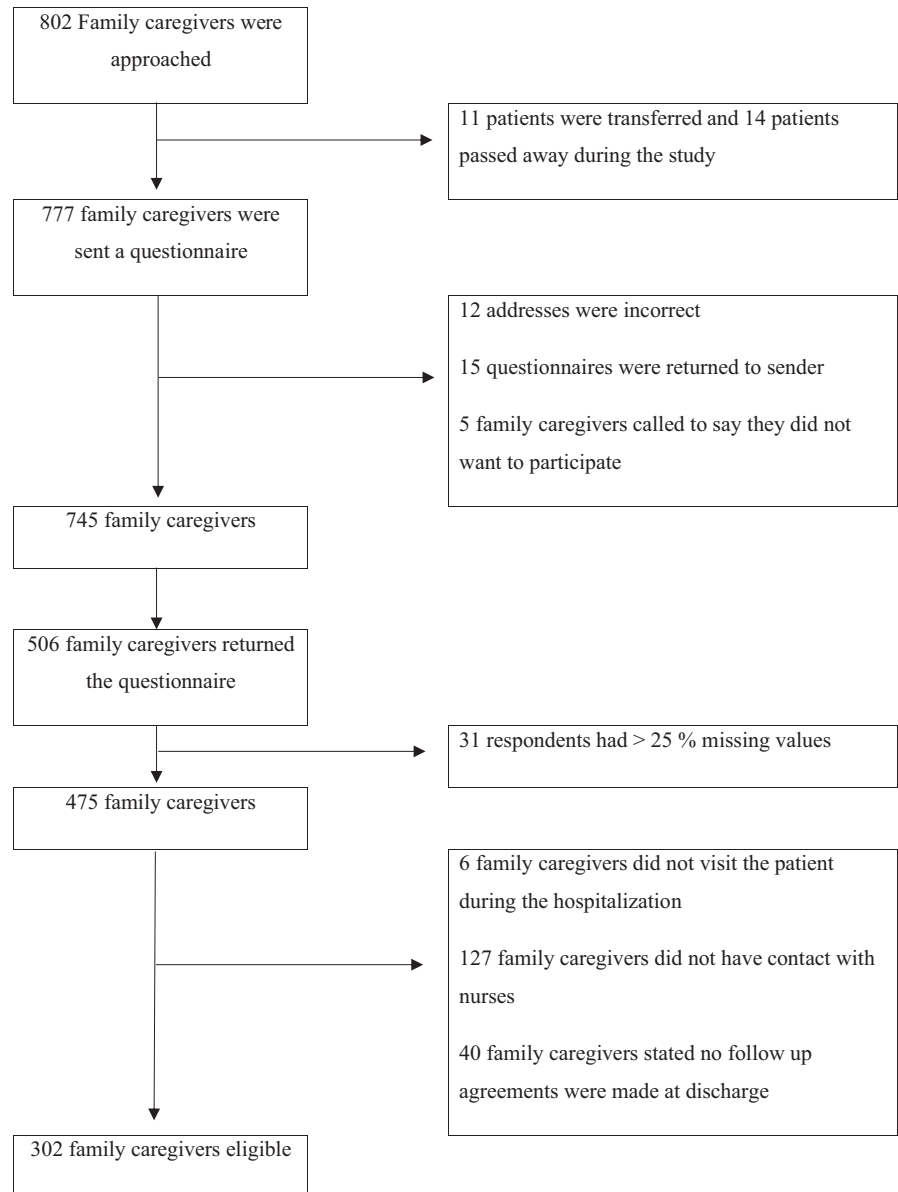
Collaboration can be defined as a caring partnership in which caregivers are regularly informed and involved in decision-making processes (Haesler et al., 2010). Such a collaborative relationship is characterized by trust and respect as well as open communication that subsequently enable a negotiation of the roles between nurses and family caregivers at any particular point in time (MacKean et al., 2005). Relationships between families and health care professionals (e.g. nurses) develop sequentially in three phases: involvement, collaboration and empowerment (Elizur, 1996). A collaborative relationship necessitates a more active role of nurses and requires a more mutual character than involvement and empowerment (Elizur, 1996). In this study, collaboration was defined as nurses responsible for the daily nursing care pro-actively initiate contact with family caregivers of older patients and actively involve these caregivers in a process of information exchange and shared decision-making as partners in care.

Lindhardt Nyberg and Rahm Hallberg (2008a) developed a theoretical framework of collaboration between family caregivers and hospital nurses. The framework consisted of five domains: 'contact and information', 'attributes for collaboration', 'promoters and barriers' and 'outcomes of collaboration' (Lindhardt Nyberg, & Rahm Hallberg, 2008a). A 56-item Family Collaboration Scale (FCS) was developed based on this framework, which has a broad scope and measures aspects other than only collaboration. To measure collaboration only, the FCS previously was revised to a 20-item scale using Lindhardt theoretical framework of collaboration and evaluated using face and content validity methods (Hagedoorn et al., 2019). In the current study, we aim to describe to what extent family caregivers of older persons perceive collaboration with hospital nurses.

2 | METHODS

2.1 | Design and participants

This study has a cross-sectional descriptive design. To identify family caregivers of older persons ≥ 70 years who were admitted to the hospital for at least 2 days, a convenience sample was employed. To measure collaboration, the family caregivers had to have been in contact with nurses during hospitalization and involved in discharge follow-up agreements. Excluded were family caregivers of patients who were admitted for a day, living in a care facility, had cognitive impairment or were too ill to be approached for the study. Patients themselves identified their family caregiver as a person who was important for their support at home. Assuming that five to ten respondents for each of the 20 items of the FCS are needed, a sample size >150 is desired (Streiner et al., 2015).

FIGURE 1 Flowchart of eligible respondents

2.2 | Measurements

The validated 20-item FCS was used to measure collaboration, consisting of three subscales: *Trust in nursing care*, *Accessible nurse* and *Influence on decisions* (Hagedoorn et al., 2019). A higher score on the self-report Likert (1–5) type statements represents a higher level of collaboration. Response alternatives were *totally disagree* – *totally agree* or *never-always*. Internal reliability was good, with ordinal alphas of 0.81, 0.87 and 0.88, respectively, on the subscales, and a Cronbach's alpha of 0.89 for the total FCS (Hagedoorn et al., 2019).

Data on family caregiver characteristics included age, gender, marital status, relationship to the patient, living together with the patient, professional background in health care, highest level of education, and type and frequency of support offered to the patient at home. These variables were part of the original FCS and, therefore, were included.

2.3 | Data collection

This study was ruled not to be under regulation of the Medical Research Involving Human Subjects Act (Reference METc2015/620). Ethical committees of the hospitals each granted permission for the study. Data were collected in October–December of 2016 and April–June of 2017 as part of an earlier study to psychometrically evaluate the FCS. Charge nurses received written and oral information about the aim of the study prior to the start.

Patients were screened by charge nurses and approached and informed by data collectors with written information. Patients were asked to provide names and addresses of their primary caregivers. Eligible family caregivers were sent a survey and a return envelope to their home address by post after discharge of the patient out of the hospital. One reminder was sent to non-responders 2 weeks later. Written consent was granted by patients as

TABLE 1 Characteristics of family caregivers

	Mean (SD)
Age (year)	64.8 (13)
Gender	%
Female	71
Male	29
Marital status	
Married/living together	90
Single/divorced/widowed	10
Relationship to patient	
Partner	50
Daughter/son	39
Other*	11
Living with patient	
Yes	50
No	50
Highest level of education	
Primary/lower vocational education	24
Secondary education: lower general/upper vocational/upper general	52
Bachelor/master education	24
Professional background in health care	
Yes	23
No	77
Frequency of support at home	
Every day	44
4–6 times a week	11
2–3 times a week	23
Once a week or less	22
Duration of support at home	
More than 1 year	62
4–6 months	9
3 months or shorter	7
Since discharge of relative out of hospital	22
Frequency of hospital visits	
Every day	83
A few times a week	15
Once a week	1
Less than once a week	1
Frequency of contact with nurses during hospitalization	
More than 10 times	10
5–10 times	23
1–4 times	67

* 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).

well as their family caregivers and both were informed that their participation was voluntarily, and that data would be processed anonymously.

2.4 | Data analysis

Descriptive statistics were used to report mean item scores and standard deviations. Correlations between family caregivers' characteristics and the total and subscales sum scores of the FCS were explored using a bivariate analysis with simple bootstrapping for the correlation coefficient since the data are not normally distributed. Correlations with a correlation coefficient of ≥ 0.30 are considered to be influential (Field, 2014). Ordinal and ratio variables were analysed with Spearman's correlation, and nominal variables were measured with Cramer's V. SPSS version 24.0 (IBM Corp., 2016) was used for data analyses.

3 | RESULTS

Of the 506 family caregivers who responded (63%), 302 were eligible based on the inclusion criteria, as outlined in Figure 1. Family caregivers' characteristics presented in Table 1 show that most of them were female (71%), and the majority was married or living together with their partner (90%). Nearly all of the caregivers were either a partner (50%) or a child (39%) of the patient; 50% were living with the patient; and 62% provided support for more than 1 year. Most caregivers (83%) visited the patient every day during hospitalization or a few times (15%) per week, and 67% had contact with nurses one to four times during the hospitalization.

The mean scores of the subscales and total FCS are presented in Table 2, with a higher score representing a higher level of collaboration. Overall, family caregivers perceived their influence on decisions at the lowest mean score of 59, and the score was highest on the items of the subscale of trust in nursing care and accessible nurse with a mean score of 75 and 74 out of 100, respectively.

In Table 3, response percentages and mean score of family caregivers' perceived level of collaboration are presented per item. Items of the subscale trust in nursing care demonstrate that most family caregivers (95%) perceived nurses to be respectful towards patients (4.5), 86% perceived nurses to be competent (4.4), and 88% had trust in the necessary nursing care (4.4). Almost three quarters (73%) of the caregivers felt that they were properly informed about the patients' illness with a mean score of 3.9 (Item 3). Items of the subscale *accessible nurse* also show mean scores of approximately 4, indicating that family caregivers perceived most nurses (89%) to be willing to help, and 76% stated that nurses had taken the time to talk with them. Items of the subscale *influence on decisions* show that almost one third of the family caregivers (72%) felt properly informed about plans for the patient's discharge, and most (81%) were satisfied with follow-up agreements with mean scores between 3.6 and 4.2. Items concerning nurses actually inquiring about family caregivers' knowledge of the patient and using that knowledge show lower mean scores (2.6) compared to other item mean scores of this subscale. In total, 19% of the family caregivers could influence decision made regarding patient care, which was rated with the lowest mean score of 2.2.

TABLE 2 Scale scores of the Family Collaboration Scale and subscales

Subscale	Mean (SD) 100-point range
Trust in nursing care	75.4 (15.7)
Accessible nurse	73.5 (17.4)
Influence on decisions	58.8 (21.5)
Total Family Collaboration Scale	67.4 (15.6)

Correlations between caregivers' characteristics and the total and subscales of the FCS are presented in Table 4. A positive correlation was ascertained between caregivers who live with the patient and their level of trust in nursing care and the level of influence on decisions. A positive relationship was also found between family caregivers' frequency of contact with

nurses and their level of influence on decisions as well as overall collaboration.

4 | DISCUSSION

The extent of perceived collaboration between family caregivers of older persons and hospital nurses was measured with the subscales trust in nursing care, accessible nurse and influence on decisions of the FCS. The results of this study show that overall family caregivers perceived nurses as trustworthy, competent and accessible, which was also found in other studies (Lindhardt et al., 2008b, 2018). These are necessary aspects in order to establish collaboration (Haesler et al., 2010; MacKean et al., 2005; Wittenberg et al., 2018). Family caregivers who live with the patient rate a higher level of trust in nursing care and influence on decisions than those who do not live with the patient, which was also found

TABLE 3 Percentages of responses and mean scores of family caregivers' collaboration

Item #/Subscales	Percentage of responses ^a			Mean (SD)
	1-2	3	4-5	
Subscale Trust in nursing care				
1. Nurses struck me as quite competent	4	10	86	4.4 (0.85)
2. I trusted that my family member received all the necessary care during their stay	5	7	88	4.4 (0.87)
3. I felt properly informed about my family member's illness	14	13	73	3.9 (1.2)
4. Nurses treated patients with respect	1	4	95	4.5 (0.63)
5. In any contact you had with the nursing staff, how often did you yourself initiate this? ^b	38	41	21	2.8 (1.2)
Subscale Perceived accessible nurse				
6. It was easy to contact a nurse that was familiar with my family member	7	24	69	3.9 (0.96)
7. The nursing staff were happy to help whenever I sought them out	3	8	89	4.3 (0.76)
8. The nursing staff had the time to speak to me	5	19	76	4.1 (0.89)
9. I felt comfortable in expressing my feelings	9	21	70	3.9 (1.0)
10. I felt comfortable in expressing any criticism	19	28	53	3.4 (1.1)
11. Nurses were understanding towards my situation as a family member of the patient	8	16	76	4.0 (0.98)
Subscale Perceived influence on decisions				
12. The nursing staff inquired about my knowledge of my family member's situation	47	31	22	2.6 (1.2)
13. The nursing staff used my knowledge of my family member to their advantage	44	36	20	2.6 (1.2)
14. I was able to influence decisions that were made with regard to the care provided to my family member (<i>eating, drinking, mobilizing, lifestyle</i>)	61	20	19	2.2 (1.3)
15. I was satisfied with the influence I was allowed to exercise	14	21	65	3.7 (1.2)
16. I was properly informed about the plans for my family member after he/she was discharged from the hospital	17	11	72	3.8 (1.4)
17. I was involved in making plans for my family member when he/she discharged from the hospital	28	18	54	3.4 (1.5)
18. I was happy with the follow-up agreements that were made once my family member was discharged from the hospital	10	9	81	4.2 (1.1)
19. I feel that my family member was discharged from the hospital at the proper time	13	10	77	4.1 (1.2)
20. I have received sufficient information with regards to how I can best help my family member	25	12	63	3.6 (1.5)

^a1-2: never /totally disagree; 4-5: always/totally agree.

^bItem was reversed.

TABLE 4 Correlations between family caregiver characteristics and total and subscales FCS

Scale and subscales	Total FCS	Trust in nursing care	Accessible nurse	Influence on decisions
Characteristics	Coefficient	Coefficient	Coefficient	Coefficient
Age ^a	0.065	0.229**	-0.019	0.030
Gender ^b (0 = female)	0.448	0.267	0.241	0.321
Marital status (0 = married)	0.404	0.162	0.256	0.432
Relationship to patient ^b (0 = partner)	0.443	0.369*	0.293	0.379
Living with patient ^b (0 = yes)	0.463	0.406**	0.292	0.399*
Highest level of education ^a	-0.087	-0.274**	0.032	-0.053
Professional background in health care ^b (0 = yes)	0.472	0.291	0.302	0.324
Frequency of support at home ^a	0.064	0.133*	0.020	0.023
Duration of support at home ^a	-0.054	-0.134*	-0.055	-0.001
Frequency of hospital visits ^a	-0.009	0.055	-0.026	-0.020
Frequency of contact with nurses during hospitalization ^a	0.366**	0.062	0.283**	0.398**
Duration of patient hospital admission ^a	0.001	-0.127*	0.054	0.017

^aOrdinal and ratio variables were analysed with Spearman's correlation.

^bNominal variables were analysed with Cramer's V.

* $p \leq .05$.

** $p \leq .001$.

in a study on family caregivers of intensive care patients (Epstein & Wolfe, 2016). Results also show that a majority of caregivers felt properly informed about the patients' illness during hospitalization, another core concept of PFCC (Conway et al., 2006). A review of literature shows that family caregivers of older persons experiencing chronic diseases are in need of basic disease information that is proactive, understandable and tailored to caregivers' individual needs (Washington et al., 2011).

In one fifth of the family caregivers, nurses inquired about the carer's knowledge of the patient's situation and in the same number nurses utilized the caregiver's knowledge to their advantage. This shows that nurses may not see family caregivers as competent partners in care (Aasbø et al., 2017; Bélanger et al., 2016). In addition, only one fifth of the family caregivers indicated that they had influence on decisions about the patient's care activities, such as eating, drinking, mobilizing and lifestyle. Family caregivers generally know best what the patient's habits and lifestyle preferences are in regard to eating, drinking and activities of daily life. Other studies also found that caregivers experienced limited influence on decisions regarding care activities after an older home-dwelling adult was admitted to the hospital (Bragstad et al., 2014; Bridges et al., 2010; Lindhardt et al., 2006; Lowson et al., 2013; Popejoy, 2011). Acknowledgment and a greater appreciation of family caregivers' role can facilitate collaboration (Wittenberg et al., 2018). It is remarkable that two thirds of the caregivers rate their actual level of influence on decisions as low, while the same number was satisfied with the overall influence they had. Family caregivers may be satisfied with their influence on decisions because they expect to have less influence when their relative is admitted to the hospital (Lindhardt et al., 2006; Lowson et al., 2013)

for they consider the hospital as a nurses' domain (Li, 2004), and, therefore, adapt themselves to the hospital system (Allen, 2000; Walker & Dewar, 2001).

In this study, only 21% of the nurses initiated contact with caregivers themselves during the hospitalization. It might be that nurses mostly consider patients as their main concern (Ekstedt et al., 2014; Mackie et al., 2018) or do not consider family caregivers as informal partners in the care of older persons (Bélanger et al., 2016; Lindhardt et al., 2008; MacKean et al., 2005). This could also explain why 23% of the family caregivers who responded to the survey were not eligible, and, primarily, because they had no contact with nurses during the hospitalization other than a greeting and a goodbye.

In Western societies, there is increasing emphasis on older persons' self-care in order to stay at home longer, and, consequently, an increasing dependency on their family caregivers. In line with the theory of PFCC, family caregivers need to participate in decision-making and collaborate with hospital nurses in the delivery of care for older persons (Coyne et al., 2011). A first step towards collaboration is that nurses pro-actively initiate contact with family caregivers and assess and negotiate their respective roles as partners in care (MacKean et al., 2005; Røthing et al., 2015). Since 83% of family caregivers in this study visited the patient every day, there appears to be ample opportunities for nurses to meet with them during the hospitalization. When nurses acknowledge and utilize these carers' expertise in negotiating patients' care plans care can be more tailored to the patients' preferences, and subsequently, the quality and continuity of care for the elderly can be better monitored. Other components of collaboration concern nurses who actively involve family caregivers in processes of information sharing and shared decision-making (Elizur, 1996; Haesler

et al., 2010). By involving family caregivers as part of the regular nursing process, collaboration with all family caregivers can be formalized from admission to discharge (Haesler et al., 2010; Ris et al., 2018).

To implement these practices, first there needs to be a clear strategy on how to include family caregivers in regular nursing care (Ris et al., 2018), because a lack of policy may also be a reason why nurses do not routinely involve caregivers in discussions (Moyle et al., 2011). For a successful implementation, it is important for nurse managers and policymakers to support nurses' own initiatives (Hansson et al., 2017), and to formulate policies together with them (Scerri et al., 2015). Finally, adequate resources as well as organisational and managerial support are required in more patient and family focused care (Coyne et al., 2011; MacKean et al., 2005; Walker & Dewar, 2001).

4.1 | Limitations of the study

A strength of this study is that the sample of family caregivers was obtained from five general hospitals, even though it concerned a single country study. Collaboration in this study was measured with the validated 20-item FCS showing good psychometric properties for this study population. Several study limitations can be identified. First, the cross-sectional design limits the ability to interpret causality between the different variables, which could be hypothesized in experimental research. Second, the convenience sample that was obtained may have resulted in a limited number of eligible patients and selection bias may have occurred because some patients and family caregivers did not want to participate in a study in general. A number of steps were taken to ensure that the most appropriate patients and their most significant family caregivers were included. As a result, 23% of family caregivers who responded to the survey were not eligible, and therefore, an important group of family caregivers may have been missed from whom no insight was gained in their collaboration needs with nurses. Next, family caregivers' prior experiences with hospital admissions can be a barrier of collaboration (Lindhardt Nyberg et al., 2008a) and, therefore, may have affected their responses and the validity of the study results. Because the survey was based on self-reporting statements, it may have provoked subjective and socially desirable responses.

5 | CONCLUSION

This study highlights specific areas of collaboration between family caregivers and nurses that can be improved. Although it is positive that most family caregivers perceive nurses as trustworthy and accessibility, and that most were satisfied with the influence they were able to exercise, involvement of caregivers in decisions regarding the patients' daily care needs to be improved. Family caregivers play an important role in managing older persons' chronic conditions and self-care abilities at home. Nurses need to utilize family caregivers'

knowledge when preparing care plans in order to maintain continuity of care when an older person is temporarily hospitalized. PFCC theories advocate to engage patient and their informal caregivers as partners in care to guarantee the quality and continuity of care. By doing so as part of the regular nursing care, all family caregivers get the opportunity to be involved as informal care partners. This is especially important in countries where nurses are also responsible for the coordination of care during the hospitalization of these older patients. Further research should focus on the effects of collaboration between family caregivers and nurses as part of the regular care in intervention studies.

6 | IMPLICATIONS FOR NURSING MANAGEMENT

This study contributes to the knowledge about collaboration between family caregivers of home-dwelling older persons and hospital nurses. The extent to which family caregivers perceive collaboration with hospital nurses suggests that family caregivers adhere to the hospital system and therefore seem to be satisfied with the influence they can exercise. It is therefore important that nurses pro-actively initiate contact with family caregivers of older persons to find out how they want to be involved in the patients' decision-making and care planning. Hospital policy and nursing position statements underline the importance of patient' and family caregiver' involvement in nursing care without addressing how such policy should be implemented. The results of this study can facilitate nurse managers to jointly develop policy with nurses on how to organise collaboration with family caregivers as part of the standard nursing care in order to improve the quality and continuity of care for older home-dwelling persons who are temporarily hospitalized.

CONFLICT OF INTEREST

The authors have no conflicts of interests to disclose.

ETHICAL APPROVAL

The Medical Ethics Review Committee of the University Medical Center Groningen approved this study (Reference METc 2015/620).

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Ellen I. Hagedoorn  <https://orcid.org/0000-0002-1887-7447>

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