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

Hagedoorn, Ellen Ingrid

DOI:
10.33612/diss.97727618

CHAPTER **6**

Family caregivers' perceived level of collaboration with hospital nurses

E.I. Hagedoorn

W. Paans

C. P. van der Schans

T. Jaarsma

ML. A. Luttik

J. C. Keers

Submitted

Abstract

Background: Collaboration between family caregivers of older patients and nurses in the hospital may improve quality and continuity of care during the hospitalization and after discharge. However, research regarding this issue is limited and lacks a specific focus on how family caregivers perceive their collaboration with nurses. The aim of this study is to describe to what extent family caregivers perceive this collaboration.

Method: Using a cross-sectional design, 203 family caregivers of hospitalized patients (≥ 70 years) completed the 20-item Family Collaboration Scale Dutch language version consisting of three subscales: trust in nursing care, accessible nurse, and influence on decisions. Data were analyzed using descriptive statistics and bivariate correlations.

Results: Family caregivers rated their level of trust in nurses and nurses' accessibility with mean scores of 75 and 74 (out of 100), respectively, and the level of their influence on decisions with a mean score of 59 (out of 100). Family caregivers who live with patients had higher levels of trust in nursing care (r =.41; $p \leq .001$) and influence on decisions (r =.40; $p \leq .05$) than those who do not. Family caregivers who had more contact with nurses perceived higher levels of influence on decisions (r =.40; $p \leq .001$) and overall collaboration (r =.37; $p \leq .001$).

Conclusion: In their collaboration with nurses, family caregivers rate their level of influence on decisions lower than their trust in nursing care and accessibility of nurses. This implies that the supporting role of caregivers and their structural involvement in decision making with regards to patients' care activities need to be acknowledged by nurses in order to improve their collaboration with family caregivers.

Introduction

Family caregivers have considerable influence on the health and selfcare abilities of older home-dwelling persons.[1-3] These caregivers can be considered as experts of the older persons as they plan an active role as an advocate and intermediate between the patient and health care professionals.[4-7] When older persons are admitted to the hospital, therefore, it is essential that nurses involve family caregivers as informal partners in care in order to accommodate the caregiver's roles.[8,9]

In health care, in general, the length of the hospital stay is becoming briefer and, as a consequence, there is a risk that older persons may not achieve a secure health status before being discharged. As a consequence, care and support provided by family caregivers after the patient's discharge have become more complex and demanding,[10] often resulting in family caregivers who feel unprepared for new or expanded caregiving tasks.[11,12] When family caregivers feel prepared for caregiving at home, the health and self-care abilities of older persons who have chronic conditions can improve.[1,2] Those who perceive a higher level of collaboration with hospital nurses feel better prepared for caregiving demands at home after the patient's discharge from the hospital.[13] The interventions that are most encouraging for promoting constructive staff–family relationships involve clear communication and active collaboration.[14,15] When health care professionals appreciate the contribution and role of family caregivers of older patients and collaborate with them as partners in nursing care, the quality and continuity of care for the older patient can be improved.[8,16,17]

Collaboration between nurses and family caregivers can be defined as a caring partnership through which family caregivers receive regular updates and are involved in decision making.[15] 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.[18] Relationships between families and health care professionals (e.g., nurses) develop sequentially in three phases: involvement, collaboration, and empowerment for which collaboration requires a more active role of nurses and has a more reciprocal character than involvement and empowerment.[19] For this study, we were interested in collaboration in such a way that nurses who are responsible for the daily nursing care proactively initiate contact with family caregivers of older patients and actively involve these caregivers in a process of information exchange and joint decision-making as partners in care.

Previous studies primarily reported on family caregivers' experiences of interactions with nurses in the hospital based on qualitative studies that indicate that family caregivers experience a lack of information and knowledge about disease related aspects, care, and support[20,21] and that their experiences of influence were limited.[22] When their role as an expert of the patient was acknowledged and valued, family caregivers perceived better interaction and collaboration with health professionals.[23,24]

Three studies specifically measured collaboration between family caregivers and healthcare professionals, such as nurses in the hospital, from the perspective of the caregiver. In one study, coordination between health care providers and informal caregivers on caregivers' preparedness for caregiving was explored using a survey that was based on a model of interprofessional collaboration.[25] In two other studies, collaboration between relatives of older patients and nurses was measured with the 56-item Family Collaboration Scale (FCS) that has a broad scope and measures aspects other than only collaboration.[26,27] In order to specifically measure how family caregivers perceive their collaboration with nurses, we aim to describe to what extent this collaboration occurs.

Method

This was a cross-sectional survey study.

Sample and setting

A convenience sample was used to identify one or more family caregivers of home-dwelling patients ≥ 70 years who were admitted to the hospital for at least two days. In order to measure collaboration between nurses and family caregivers, the following inclusion criteria for caregivers were formulated: the family caregiver 1) visited the patient in the hospital, 2) had contact with nurses during the hospitalization, and 3) was involved in making follow-up agreements at discharge. Family caregivers of those patients who were living in a care facility or had been admitted for day treatment were excluded. Family caregivers were defined as persons who are important for patients' support at home as identified by the patients themselves; the caregivers could be partners, family members, friends, neighbors, etc. who were not paid for their support. Family caregivers were recruited from five general hospitals in the Netherlands, i.e., 22 hospital wards, six internal medicine wards, five cardiology wards, five pulmonology wards, five neurology wards, and one geriatric ward.

Measurements

Family Collaboration Scale

Collaboration was measured with the '20-item Family Collaboration Scale' (FCS) Dutch language version which was found to be a valid and reliable instrument for measuring family caregivers' perceptions of collaboration with nurses in the hospital.[28] The 20-item FCS consists of three subscales: *Trust in nursing care*, *Accessible nurse*, and *Influence on decisions*. Psychometric properties showed sufficient ordinal alphas of .81, .87, and .88, respectively, and a Cronbach's alpha of .89 for the total scale.[28] Response alternatives are 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' characteristics

Data on family caregiver characteristics included age, gender, marital status, relationship to the patient, living together with the patient, professional background in healthcare, 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.

Procedure

Charge nurses screened admitted patients to determine whether they satisfied the inclusion criteria. When eligible, patients were approached and informed of the study purpose by data collectors who were fourth year bachelor nursing students. Next, the patient was asked to provide names and addresses of primary caregivers. Approximately four to seven days following the discharge of the patient from the hospital, a survey including a return envelope was forwarded 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' charts 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.

The Medical Ethics Review Committee of the University Medical Center Groningen approved this study (Reference METc 2015/620). Permission for the study was granted by the directors of the participating hospitals. Prior to its initiation, charge nurses were informed

about its purpose by their managers and through a newsletter. Data were collected in 2016 and 2017.

Data analyses

Questionnaires with more than 25% of missing values (>5 missing items) in the total FCS were excluded from analyses. Questionnaires with less than 25% missing values were replaced by the series mean of the total scale in SPSS that is rounded to the nearest integer.[29] For comparative purposes, the mean sum scores of the FCS and subscales were transferred to a 100-point scale. 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 ≥ .30 are considered to be influential. Ordinal and ratio variables were analyzed with Spearman's correlation, nominal variables were measured with Cramer's V. SPSS version 24.0[30] was used for data analyses.

Results

Initially, 802 family caregivers were approached to participate in the study of which 506 responded; 302 were eligible to participate (see flowchart in Figure 1).

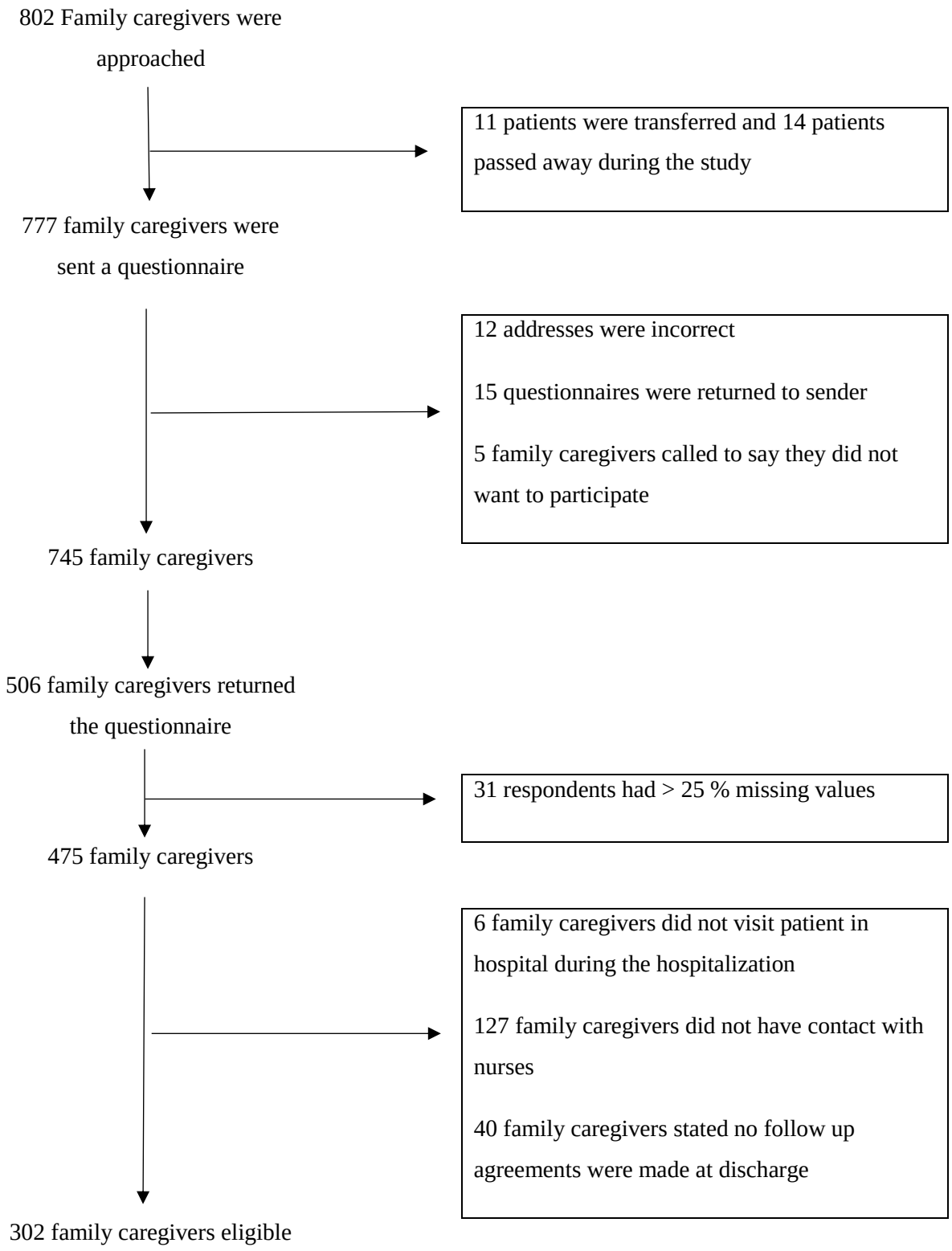

Figure 1. Flowchart of eligible respondents

Family caregivers' characteristics

In Table 1, the characteristics of family caregivers are presented. Most of them were female, and the majority was married. Most family caregivers were either a partner (50%) or a child (39%) of the patient; 50% were living with the patient; and 62% had supported the patient for more than one year. The majority of family 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.

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 healthcare	Yes	23
	No	77
Frequency of support at home	Every day	44
	4-6 times a week	11

Table 1. Continued

		%
	2-3 times a week	23
	Once a week or less	22
Duration of support at home	More than one 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	More than 10 times	10
nurses during hospitalization	5-10 times	23
	1-4 times	67

Even though the main focus of the study is on family caregivers, a number of characteristics of patients are also provided in order to offer a patient related context to the family caregivers included in the study. The average age (SD) of patients was 79.2 (6.2) years old with 163 (55%) men and 131 (45%) female. Of these patients, 174 (60%) were married or living together, 75 (26%) were widowed, and 39 were single (14%). The mean (SD) length of a hospital stay was nine (6.4) days.

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)

The higher the score, the higher the level of collaboration.

Collaboration

The mean scores of the subscales and total FCS are presented in Table 2. Overall, family caregivers perceive 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.

Table 3. Percentages of responses and mean scores of family caregivers' collaboration

Item #/ Subscales	**Percentage of responses***			**Mean (SD)**
	1-2	**3**	**4-5**	
Subscale Trust in nursing care				
1. Nurses struck me as quite competent	4	10	86	4.4 (.85)
2. I trusted that my family member received all the necessary care during their stay	5	7	88	4.4 (.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 (.63)
5. In any contact you had with the nursing staff, how often did you yourself initiate this? **	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 (.96)
7. The nursing staff were happy to help whenever I sought them out	3	8	89	4.3 (.76)
8. The nursing staff had the time to speak to me	5	19	76	4.1 (.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 (.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 regards to the care provided to my family member (*eating, drinking, mobilizing, life-style*)	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)

Table 3. Continued

Item #/ Subscales	Percentage of responses*			Mean (SD)
	1-2	**3**	**4-5**	
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)

* 1-2: never /totally disagree; 4-5: always/ totally agree; **item was reversed

In Table 3, the percentage of responses 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). A third (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 (8l %) were satisfied with follow-up agreements with mean scores between 3.6 – 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. Just over half of the family caregivers (61%) were able to influence the decisions that were made with regards to the care provided to the patient, which was rated with the lowest mean score of 2.2.

In Table 4, correlations between family caregivers' characteristics and the total and subscales of the FCS are presented. A positive relationship was ascertained between family caregivers who live with the patient and their level of trust in nursing care (V = .406; p = .000) and the level of influence on decisions (V= .399; p =.049). A positive relationship was also found between family caregivers' frequency of contact with nurses and their level of influence on decisions (r =.398; p=.000) as well as overall collaboration (r =.366; p=.000).

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]		.065	.229**	-.019	.030
Gender[b]	(0 =female)	.448	.267	.241	.321
Marital status	(0=married)	.404	.162	.256	.432
Relationship to patient[b]	(0= partner)	.443	.369*	.293	.379
Living with patient[b]	(0= yes)	.463	.406**	.292	.399*
Highest level of education[a]		-.087	-.274**	.032	-.053
Professional background in Healthcare[b]	(0= yes)	.472	.291	.302	.324
Frequency of support at home[a]		.064	.133*	.020	.023
Duration of support at home[a]		-.054	-.134*	-.055	-.001
Frequency of hospital visits[a]		-.009	.055	-.026	-.020
Frequency of contact with nurses during hospitalization[a]		.366**	.062	.283**	.398**
Duration of patient hospital admission[a]		.001	-.127*	.054	.017

[a] Ordinal and ratio variables were analysed with Spearman's correlation; [b]nominal variables were analysed with Cramer's V.

*P≤0.05; **P≤0.001

Discussion

In this study, we explored the extent to which family caregivers of older hospitalized patients perceive collaboration with hospital nurses as measured with the FCS consisting of the subscales *trust in nursing care*, *accessible nurse,* and *influence on decisions*. The results of this study show that, overall, family caregivers perceive nurses as trustworthy and accessible and also perceive the level of information they receive from nurses regarding the patients' illness, patients' discharge information, and discharge time as relatively high. Two thirds of the family caregivers rate their actual level of influence on decision regarding care activities as low (2.2 on item 14), although the same number was satisfied with the influence they had (3.7 on item 15). Only one fifth of the family caregivers stated that nurses inquired about their knowledge of the patient or used their knowledge to the nurses' advantage. In our study, no specific caregiver characteristics such as age, gender, level of education, and having a background in health care could be identified regarding their overall level of collaboration with nurses. Finally, a positive correlation was determined between family caregivers' frequency of contact with nurses and their level of influence on decisions and overall collaboration.

Family caregivers in this study seem to have trust in nursing care and perceive nurses as accessible and taking the time to talk to them which are the aspects of collaboration that are necessary to co-create a collaborative relationship.[18,19] 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 in a study on family caregivers of intensive care patients.[31] Collaboration between nurses and family caregivers involves not only a caring partnership that is characterized by trust, respect, and open communication but also concerns those caregivers who are actively involved in decision making processes.[15]

In this study, caregivers rated their satisfaction with the overall influence they had with a mean score of 3.7 (out of 5) and the ability to influence decisions that were made with regards to the care provided to the patient with a mean score of 2.2. This suggests that family caregivers are moderately satisfied but, at the same time, they felt that they were not sufficiently involved in decision making. In a qualitative study on opportunities to influence decisions regarding the care and treatment of an older hospitalized person, Nyborg, Danbolt, and Kirkevold[22] also found that caregivers experienced limited influence, and their opportunities to influence decisions ranged from feeling invisible and reactively waiting for

an invitation (especially older carers) to feeling visible and proactive in order to secure influence. These findings may suggest that health professionals, such as nurses, do not expect to involve family caregivers as partners in care. A reason might be that nurses mostly consider the patients as their main concern[14,32,33] and family caregivers as recipients of information about the decisions already made by health professionals.[6,34] In addition, nurses express theoretical support for collaboration with family caregivers which often does not translate to their clinical practise.[15,26,35]

Family caregivers also perceive the hospital as the domain of health professionals and, therefore, tend to adapt to the system.[34,35] or are unsure about what opportunities for involvement might exist.[36] 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.[18] 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. In an earlier study, we also found that family caregivers were largely present during planned discussions between nurses and patients and were pro-actively involved as a communication partner[37] which afforded opportunities to interact structurally with family caregivers. On the other hand, 127 family caregivers stated that they did not have any contact with nurses other than being greeted and saying goodbye during the hospitalization of the patient (Figure 1). To promote a constructive nurse-family relationship, nurses should take the initiative to communicate with family caregivers.[15,38]

We found that only 20% of caregivers stated that nurses asked them about their knowledge of the patient or used the caregivers' knowledge to their advantage. In a society such as the Dutch, there is increasing emphasis on older persons' self-care so that they can live at home longer. Therefore, nurses should involve family caregivers during the initial admission intake in decision making processes on a structural basis, especially in planning care activities. The family caregiver knows what the patient habits and lifestyle preferences are at home in regards to eating, drinking, and activities of daily life. Therefore, it is important that nurses acknowledge and utilize carers' expertise when negotiating the patients' care plan.[8] Discontinuity can arise between the care that is provided prior to and after a hospitalization when caregivers are insufficiently acknowledged and involved, often resulting in them feeling unprepared for caregiving at home.[11] When applicable, collaboration with family caregivers needs to be pro-actively organized by nurses in order to prepare these caregivers for caregiving after the patient's discharge[13] and for maintaining the quality and continuity of patient care.[9,14]

This is one of the first studies that specifically explores how family caregivers perceive their level of collaboration with nurses. This study highlights areas of improvement in the nurses' collaboration with caregivers. Professional nursing standards and family nursing theories claim that it is part of nurses' professional responsibility to support patients and their family to strengthen the self-management of older people when possible.[39,40] Contact between nurses and family caregivers, therefore, should be part of the regular nursing care, especially in countries where nurses are also responsible for the coordination of care during the hospitalization of these older patients and have the most contact with family caregivers.

When family caregivers are involved in the organization of care on a structural basis from admission to discharge, they contribute to the optimization of care that is offered to the patient in the hospital and at home following discharge by simultaneously monitoring the continuity of care.[8,16] Therefore, is it advised to pro-actively plan a meeting with patients, their caregivers, and other health professionals a few days after admission to the hospital. By collaborating with family caregivers on a structural basis, the quality as well as the continuity of care will be improved and, subsequently, the self-care abilities of a patient at home. In order to implement these practices, adequate resources as well as organizational and managerial support is required.[15,41] In addition, collaboration with patients and their family caregivers should be sufficiently anchored in hospital policies and health care professionals' curricula.

Strengths and limitations of the study

A convenience sample of family caregivers of five general hospitals in the Netherlands was obtained, and a number of steps were taken to ensure that the most appropriate patients and their most significant family caregivers were included. 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 23% of the family caregivers who were sent a survey but did not satisfy the inclusion criteria for this study; it primarily concerned those who had no contact with nurses during the hospitalization other than a greeting and a goodbye.

Prior experiences of family caregivers with a hospital admission of their relative were not taken into account and may have affected their responses as it was identified as a barrier of collaboration.[26] Family caregivers' perceptions of collaboration with nurses entail subjective responses and might provoke socially desirable responses which could influence the validity of our study results.

Conclusion

This study shows that family caregivers rate the collaboration domains 'trust in nursing care' and 'accessible nurse' as highest in that nurses showed respect for patients, were perceived as competent, and had taken the time to help family caregivers whenever they sought the nurses out. Family caregivers rated the domain 'influence on decisions' the lowest, especially their influence on decisions with regards to the care provided to the patient. This study contributes to the knowledge regarding collaboration between family caregivers of older patients and hospital nurses. The caregivers are important for older persons in managing their chronic conditions and their self-management abilities at home. Therefore, it is important that nurses approach family caregivers as partners in care and negotiate appropriate patient care in order to maintain continuity when an older person is temporarily hospitalized.

References

1. 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

2. 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

3. 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 Dial Transplant*.2018;33(7):1235–1244. https://doi.org/10.1093/ndt/gfx361

4. 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.

5. Hubbard G, Illingworth N, Rowa-Dewar N, Forbat L, Kearney N. Treatment decision-making in cancer care: the role of the carer. *J Clin Nurs*. 2010;19:2023–2031. https://doi.org/10.1111/j.1365-2702.2009.03062.x

6. Lindhardt T, Bolmsjo I, Hallberg I. Standing guard-being a relative to a hospitalised, elderly person. *J Aging Stud*. 2006;133–149. https://doi.org/10.1016/j.jaging.2005.06.001

7. Popejoy LL. Complexity of Family Caregiving and Discharge Planning. *J Fam Nurs.* 2011;61-81. https://doi.org/10.1177/1074840710394855.

8. 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

9. 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.

10. 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. Published August 2017. Accessed May 11 2018.

11. 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.

12. Silver HJ, Wellman NS, Galindo-Ciocon D, Johson 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

13. Hagedoorn EI, Paans W, Luttik MLA, Schans van der CP, Jaarsma T, Keers JC. The association of collaboration between family caregivers and nurses in the hospital and their preparedness for caregiving at home. *Geriatr Nurs*. 2019; Accepted for publication.

14. Bélanger L, Bourbonnais A, Bernier R, Benoit M. Communication between nurses and family caregivers of hospitalised older persons: a literature review. *J Clin Nurs*. 2016;26:609-619. https://doi.org/10.1111/jocn.13516

15. 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

16. 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. *Inter J Nurs Stud.* 2013;50(9):1197-1205. https://doi.org/10.1016/j.ijnurstu.2012.02.005.

17. Wassenaar A, Schouten J, Schoonhoven L. Factors promoting intensive care patients' perception of feeling safe: a systematic review. *Int J Nurs Stud*. 2014;51(2):261-273. https://doi.org/10.1016/j.ijnurstu.2013.07.003.

18. MacKean GL, Thurston WE, Scott CM. Bridging the divide between families and health professionals' perspectives on family-centred care. *Health Expect*. 2005;8:74-85. https://doi.org/10.1111/j.1369-7625.2005.00319.x

19. 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

20. Bove DG, Zakrisson A-B, Midtgaard J, Lomborg K, Overgaard D. Undefined and unpredictable responsibility: a focus groep study of the experiences of informal caregiver spouses of patients with severe COPD. *J Clin Nurs*. 2016;24:483-493. https://doi.org/10.1111/jocn.13076

21. Røthing M, Malterud K, Frich JC. Family caregivers' views on coordination of care in Huntington's disease: a qualitative study. *Scand J Caring Sci.* 2015;29:803-809. https://doi.org/10.1111/scs.12212

22. Nyborg I, Danbolt LJ, Kirkevold M. Few opportunities to influence decisions regarding the care and treatment of an older hospitalized family member: a qualitative study among family members. *BMC Health Serv Res*. 2017;17:619. https://doi.org/10.1186/s12913-017-2563-y

23. McPherson KM, Kayes NM, Moloczij N, Cummins C. Improving the interface between informal carers and formal health and social services: a qualitative study. *Inter J Nurs Stud*. 2014;51:418-429. https://doi.org/10.1016/j.ijnurstu.2013.07.006

24. Wittenberg, Y., Kwekkeboom, R., Staaks, J., Verhoeff, A., & Boer, de, A. (2018). Informal caregivers' views on the division of responsibilities between themselves and professionals: A scoping review. *Health Soc Care Community*. 2018;26:460–473. https://doi.org/10.1111/hsc.12529.

25. Weinberg DB, Lusenhop WR, Hoffer Gittell 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

26. 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;1329-1343. https://doi.org/10.1016/j.ijnurstu.2007.10.006.

27. Lindhardt T, Sivertsen D, Smith L, Klausen T, Andersen O. Collaboration Between Relatives of Older Patients and Nurses in Acute Medical Wards: Confirmatory Factor Analysis of the Revised Family Collaboration Scale. *J Nurs Meas.* 2018;26(2):311-340. https://doi.org/10.1891/1061-3749.26.2.311

28. Hagedoorn EI, Paans W, Jaarsma T, Keers JC, Schans van der CP, Luttik MA, Krijnen WP. Psychometric evaluation of a revised Family Collaboration Scale. *Geriatr Nurs*. 2019; Accepted for publication.

29. Downey RG, King C. Missing data in Likert ratings: A comparison of replacement methods. J Gen Psychol. 1998;125(2):175-191. https://doi.org/10.1080/00221309809595542.

30. IBM Corp. IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY, USA. 22 May 2016

31. Epstein EG, Wolfe K. A preliminary evaluation of trust and shared decision making among intensive care patients' family members. Appl Nurs Res.2016;32:286-288. https://doi.org/10.1016/j.apnr.2016.08.011

32. Ekstedt M, Stenberg U, Olsson M, Ruland CM. Health Care Professionals Perspectives of the Experiences of Family Caregivers during In-Patient Cancer Care. *J Fam Nurs.* 2014;20(4):462-486. https://doi.org/10.1177/1074840714556179.

33. Mackie BR, Marshall A, Mitchell M. Acute care nurses' views on family participation and collaboration in fundamental care. *J Clin Nurs.* 2018;27:2346-2359. https://doi.org/10.1111/jocn.14185.

34. Walker E, Dewar B. How do we facilitate carers' involvement in decision making? *J Adv. Nurs*. 2001;34:329–337. https://doi.org/10.1046/j.1365-2648.2001.01762.x.

35. Allen D.Negotiating the role of expert carers on an adult hospital ward. *Sociol health illn.* 2000;22:149-171. https://doi.org/10.1111/1467-9566.00197.

36. Laitinen P, Isola A. Participation of caregivers in elderly-patient hospital care: Informal caregiver approach. *J Adv Nurs.* 1993;18:1480-1487.

37. 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. https://doi.org/10.1186/s12912-017-0231-5

38. Ris I, Schnepp W, Mahrer Imhof R. An integrative review on family caregivers' involvement in care of home-dwelling elderly. *Health Soc Care Community*.2019;27: e95-e111. https://doi.org/10.1111/hsc.12663.

39. International Council of Nurses. Position statement: Scope of Nursing Practice. Retrieved from International Council of Nurses: https://www.icn.ch/sites/default/files/inline-files/B07_Scope_Nsg_Practice.pdf. Published 2018. Accessed May 26th, 2019.

40. Wright LM, Leahey M. *Nurses and Families - a guide to family assessment and intervention*. Philidelphia: F.A. Davis Company; 2013.

41. Coyne I, O'Neill C, Murphy M, Costello T, O'Shea R. What does family-centred care mean to nurses and how do they think it could be enhanced in practice. *J Adv Nurs*. 2011;67(12):2561–2573. https://doi.org/10.1111/j.1365-2648.2011.05768.x.