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

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

Psychometric evaluation of a revised Family Collaboration Scale

E.I. Hagedoorn

W. Paans

T. Jaarsma

J.C. Keers

C.P. van der Schans

ML.A. Luttik

W.P. Krijnen

Abstract

Measuring family caregivers' experiences of collaboration with nurses is important in the context of health care reforms that advocate an increased role of families in care. The Family Collaboration Scale (FCS) measures collaboration between nurses and family caregivers. However, the scale has a broad scope. Thus, the study aim was to construct a measure that is focused on collaboration only. After revision, a 25-item version of the FCS was sent to 777 family caregivers of hospitalized patients ($\geq$ 70 years). Psychometric evaluation was employed by the Non-Parametric Item Response Theory to evaluate how items of the revised FCS behave. In total, 302 (39%) family caregivers were found eligible, mean (SD) age 65 (13) and 71% female. A 20-item FCS is proposed showing good psychometric properties. This study contributes to the limited knowledge of measuring collaboration between family caregivers and nurses.

Introduction

Family caregivers play an important role in the self-management of older people living at home.[1-3] They are often intermediaries between their ill family member and healthcare professionals and can be important in communicating with care professionals and being influential when making decisions on behalf of their family member.[4] The support and care of family caregivers for older patients who live at home is intensifying in the context of healthcare reform in western societies. Older people are more frequently hospitalized for diagnostics or due to the consequences of chronic illnesses.[5] In general, the length of hospital stay is becoming shorter and, as a result, these people may not achieve a secure health status before being discharged. The care and support that family caregivers offer their ill family member post-discharge becomes more complex, resulting in greater demands on the caregivers.[6,7]

The quality and continuity of care for older adults improves when nurses view family caregivers as care partners8 and collaborate with them.[9,10] Nurses play an important role in utilizing the expertise of family caregivers who care for a relative.[11-13] Although it seems evident that nurses need to collaborate with family caregivers of older patients, there is still limited knowledge on how family caregivers experience this collaboration. 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 outcome.[14] This definition is in accordance with a study of Boyle and Kochinda[15] 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 owned jointly, and collective responsibility exists for the results.[15] Studies show that it is important for family caregivers of older patients to be treated as partners in decision-making rather than as passive recipients of information.[16,17] Also, involvement of family caregivers during the admission and discharge-planning phase achieves an effective exchange of information and calibration of expectations regarding possible transition outcomes.[18] Collaboration in this study, therefore, 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.

Considering the importance of collaboration, there is a need for a psychometrically sound and feasible instrument to measure collaboration between nurses and family caregivers

from the perspective of the caregivers. Thus far, most instruments measure interprofessional collaboration between health care professionals[19] or concern instruments which were adjusted on base of theory of interprofessional collaboration to measure collaboration between formal providers and family caregivers.[20] The Family Collaboration Scale (FCS) measures collaboration between nurses and family caregivers of older hospitalized patients from the perspective of the caregivers as well as prerequisites for and outcomes of collaboration.[21] Even though the FCS showed good psychometric properties, Lindhardt and colleagues suggested that the feasibility of the instrument is to be improved by a reduction of items.[18,21,22]

The FCS is based on a tentative theoretical framework of collaboration covering four areas, specifically, (1) promoters and barriers of collaboration, (2) contact and communication (3) attributes for collaboration, and (4) outcome of collaboration.[21] This theoretical framework is described in more detail by Lindhardt and colleagues[17,21,23] and the tentative model of collaboration was added in Appendix 5.1. In order to specifically measure collaboration and not, for example, the promotors and barriers, this theoretical framework was used to select only those items of the FCS that specifically measure collaboration. This is further explained in the method section. The use of a valid scale in Dutch is needed to measure family caregivers' experiences of collaboration and to identity differences between and within groups. The broad scope of the original FCS was a reason for a modification of the scale. Thus, the aim of this study was to construct a more concise FCS based on the theoretical framework of Lindhardt and colleagues[21] that is valid and reliable.

Method

A cross sectional design was used to collect quantitative data. A postal survey was sent, and a convenience sample of family caregivers was identified who met the following inclusion criteria: they were a family caregiver of a home-dwelling patient ≥ 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 one day. 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 were defined as individuals who are important in the patients' support at home, are not paid for their support, and were identified as such by the patients themselves. These individuals could be partners, family members, friends, neighbors,

etc. Patients could identify more than one family caregiver to be included in the study. Family caregivers that cared for older patients were recruited from five general hospitals in the Netherlands and 22 hospital wards, namely six internal medicine wards, five cardiology wards; five pulmonology wards, five neurology wards, and one geriatric ward.

Revision of the FCS

Instrument

The FCS consisted of 72 self-report Likert-type statements and five subscales, namely, 'trust and its prerequisites', 'quality of contact with nurses', 'influence on decisions', 'influence on discharge' and 'achieved level of information'.[21] Reported internal reliability was good, with Cronbach's alpha values of .84 -.94 for the subscales.[21] Response alternatives were: to a large degree, some degree, lesser degree and not at all (rated 1–4, 1 being the highest level of collaboration), Totally agree, Agree, Disagree, Totally Disagree and frequently a 'don't know' option, and in other cases Always, very often, often, sometimes, seldom and never (rated 1–6). Since its first publication in 2008, the FCS was modified by the original first author as part of a European study into an instrument of 56 items. Results of this study were recently published, suggesting that the 56 item FCS would benefit from adjustment and reduction in order to create a more feasible and valid measure for monitoring and development of collaboration in a hospital.[22]

Translation of the FCS

The FCS was first translated from Danish into Dutch using the first six steps of the bidirectional translation method of linguistic-cultural adaptation suggested by Wild and colleagues,[24] consisting of a set of principles of good practice in the area of translation and cultural adaptation. First, permission was obtained from the original author of the FCS. Next, two independent professional translators provided the forward and back translation of the original scale from Danish into Dutch and from Dutch into Danish. Reconciliation of the first translation into Dutch was discussed by the first author and one co-author (EH and MLL). The original author of the FCS screened the back translation of the scale into Danish. Some minor changes to some of the sentences were suggested during the back translation. All of the modifications were discussed by the professional translators and two authors (EH and MLL) in order to reach consensus. The final step of cognitive debriefing was performed as part of the face validity of the modified FSC (See Face Validity).

Reduction of items of the FCS

In order to specifically measure collaboration, the theoretical framework of collaboration of Lindhardt and colleagues[21] was then used to select only those items of the FCS that specifically measure collaboration. Therefore, all of the items of the FCS were linked to the theoretical framework underlying the original scale.[25] This theoretical framework consisted of four areas: (1) promoters and barriers of collaboration, (2) contact & communication (3) attributes for collaboration and (4) outcome of collaboration.[21] Next, the items that did not contribute to the research aim were identified by two authors (EH an MLL) and removed from the scale. This concerned a total of 12 items, mostly concerning items of the area of 'promotors and barriers' or items of contact & communication.

If questionnaires are long, they require considerable cognitive effort to answer them decreasing the validity of the measurement.[25] In addition, a total of seven items of the FCS consisted of multiple questions that made the scale longer and the item more difficult to understand. These multiple question items were transformed by two authors into single question items with a consistent 5-point Likert scale. Finally, the two authors screened the remaining items for redundancy of content based on a consensus discussion.[25] Two items showed considerable overlap with four other items and were, therefore, removed from the scale.

Change of scoring format

No clear indication was found for using 4 and 6-point Likert scale categories in one scale. Therefore, all response alternatives were expressed in a 5-point Likert scale in order to achieve concise and uniform scaling to make completion of the scale easier for respondents.[25] Response alternatives were 'Never- Always or 'Strongly disagree' to 'Strongly agree' with the response categories 2, 3 and 4, respectively, in the middle with a higher score representing a better experience of collaboration. A Dutch and English translation of the 25-item FCS is found in Appendix 5.2 as it was translated from Dutch by a professional academic translator for specific use in this publication.

Face Validity

Face validity facilitates the judgement of appropriateness that the items of the scale assess the concept to be measured and are comprehensible (cognitively) to the study population.[24,25] Thus, the modified FCS was tested by three family caregivers of an older person who had been admitted to the hospital in the last six months. These family caregivers were acquaintances of the first author. They found all of the items to be comprehensible and

relevant for measuring collaboration with nurses in the hospital. One family caregiver suggested adding the option Living Apart Together (LAT) to the living situation since this is a well-accepted way for older people to have a relationship in the Netherlands without living together. This suggestion was incorporated into the questionnaire.

Content validity

To assess the degree to which the items of the FCS measured the construct of collaboration between family members and nurses, a panel of 23 experts was consulted.[26] These experts were hospital nurses currently working with older patients and their family members. Each member of the panel was sent an online list of the 25-item FCS by email. These members were asked to rate each item as 1=very irrelevant, 2=irrelevant, 3=relevant, and 4=very relevant. Scores 1 and 2 were considered "not relevant", and scores 3 and 4 were considered "relevant".[27] Next, the Item Content Validity Index (I-CVI)[27] was determined. This is a proportional score that is calculated by dividing the number of respondents who considered the item to be relevant by the total number of respondents. When items were assessed with a I-CVI score of .78 or higher, these were considered to have good content validity.[26] Items with a I-CVI score < .78 were removed from the scale.

Data collection

Nurses in charge screened newly 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 nursing students. Next, the name(s) and addresses of primary caregivers were obtained from the patient. Approximately four to seven days following the discharge of the patient from the hospital, a survey and a return envelope were sent to family caregivers' home addresses. By filling out and returning the questionnaire, family caregivers provided their consent for participation in the study. After two weeks, a reminder was sent once to non-responders. Patients gave written permission for obtaining patient characteristics from their patient chart concerning age, gender, marital and living status, and length of hospital stay. Data were collected in 2016 and 2017.

Ethics

The Medical Ethics Review Committee of the University Medical Center Groningen ruled that this study was not under regulation of the Medical Research Involving Human Subjects Act (Reference METc 2015/620). Permission to perform the study was granted by the directors of 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. Family caregivers voluntarily participated in the study and gave their consent for participation and publication of the results before completing the survey. Patients received written and oral information about the study and gave their informed consent for obtaining patient demographics and for publication of the results. The patients and their caregivers were allowed to refuse to participate. Results were processed anonymously.

Data analyses

Four 'negatively' formulated items, i.e., 4, 7, 8, and 16 were reversed in category in order to facilitate data analysis. Questionnaires with more than 25% of missing values (>5 missing items) in the total FCS were removed. Missing values of questionnaires with < 25% missing were replaced by the series mean of the total scale in SPSS that is rounded to the nearest integer.[29] An explorative factor analysis was performed to assess the dimensionality of the scale using the Expectancy Moments (EM) method.[30] A scree plot was produced, and confidence intervals of the eigenvalues were computed. The number of eigenvalues significantly >1 can be an indication of the dimensionality of subscales.[31]

Factor analysis on Polychoric correlations[32] using Oblimin rotation was used to rotate to simple structure. Factor loadings of ≥ 0.32 were considered for interpretation with > 0.71 (*excellent*); .71 - .63 (*very good*); < .63 - .55 (*good*); < .55 - .45 (*fair*); < .45 - .32 (*poor*).[33] Point Polyserial correlations were employed to determine the correlation between the directly ordinal observable variable and the unobservable latent trait variable representing the concept to be measured. These correlations are comparable to factor loadings, however, provide a better estimate of the loadings because they are corrected for the fact that the items are ordinal.[34] Score distributions in percentages of responses were analyzed using SPSS.[35] Internal consistencies were measured by ordinal alpha[35] as well as Cronbach's alpha[37] for comparative purposes with other studies with values >.7 being considered as acceptable.[38]

To evaluate how the selected items of the revised FCS behave in a population of Dutch family caregivers, the Non-Parametric Item Response Theory (NIRT)[39] was used as it provides a flexible method to investigate item properties.[40] It predicts the individual response patterns on the ordinal scale by specifying how the underlying latent traits (a set of factors) interact with the item's characteristics.[30] This method was selected because its Item Characteristic Curves (ICC), Option Characteristic Curves (OCC), and Expected Item Scores (EIS) provide a detailed insight into how each item performs in relation to the underlying concepts of the FCS.[41] In addition, the correlation between the subscales were explored to

evaluate their overlap. For these analyses, the R package KernSmoothIRT was used.[39] The ICC's and OCC's were employed analogously by TESTGRAF.[42] The ICC estimates the expected score on a particular item as a function of the overall perception of collaboration and, therefore, shows the relationship between the preferences on any item and the underlying trait.[25] An OCC is a graphical representation of the relationship between the position on the latent trait (degree of collaboration) and probability of endorsing a particular choice option of an item.[42] It assumes that the probability of obtaining higher responses on an item increases as the family caregiver's perception of collaboration increases.[30]

Results

Initially, 802 family caregivers were approached to participate in the study of which 506 responded, and 302 were eligible to participate (see flowchart in Figure 1). The sample consisted of family caregivers with a mean (SD) age 65 years old (13); 71% was female. Half of the family caregivers were partners (50%) or the patient's child (40%). Most were married or living together with their partner (90%). Over half of the family caregivers (52%) indicated secondary education as their level of education, 24% indicated primary/ lower vocational, and 24% a higher educational level. Although the main focus of the study is on family caregivers, some characteristics of patients of whom the family caregiver participated were given here to offer a patient related context to the family caregivers included in the study. The mean (SD) age of the patients who were admitted to the hospital was 79 (6.1), 159 (54%) were men, 191 (65%) patients were married, 75 (25%) widowed, and 22 (8%) were single. Their mean (SD) length of stay in the hospital was nine (SD 6.4) days.

The content analysis of the 25-item FCS was performed by ten (43%) of the expert nurses by rating all 25 items of the FCS. All items scored an I-CVI of .78 or higher, except items E4 and E8 with scores .60 and .50, respectively. These two items were removed from the item set. Most items had a percentage of 1-4% missing values; moreover, items 12, 22, and 28 had 4-6%, and items 14 and 21 had 10% and 11% missing values, respectively.

A total of 238 and 237 (50%) of the family caregivers answered 'not applicable' on items 11 (*I was able to influence decisions that were made with regards to the treatment of my family member*) and 13 (*Nurses and I were in agreement with regards to what should happen to my family member (for example, which tests, treatment, nursing care, instructions he/she needed)*), respectively. Since this applies to half of the respondents, these two items were not considered for further analysis.

802 Family caregivers were

approached

11 patients were transferred and 14 patients
passed away during the study

777 family caregivers were

sent a questionnaire

12 addresses were incorrect

15 questionnaires were returned to sender

5 family caregivers called to say they did not
want to participate

745 family caregivers

506 family caregivers returned

the questionnaire

31 respondents had > 25 % missing values

475 family caregivers

6 family caregivers did not visit patient in
hospital during the hospitalization

127 family caregivers did not have contact with
nurses

40 family caregivers stated no follow up
agreements were made at discharge
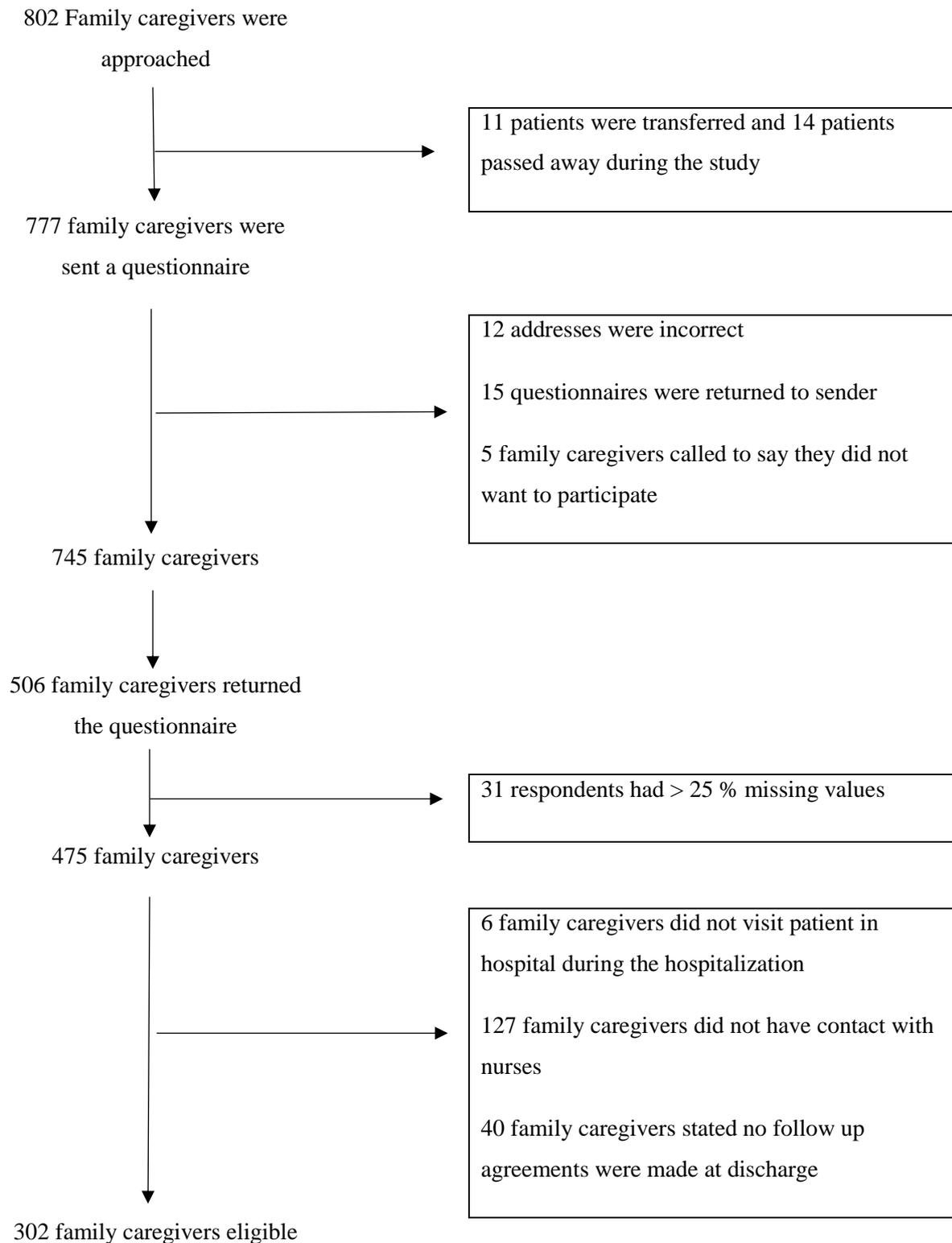
302 family caregivers eligible

Figure 1. Flowchart of eligible respondents

Psychometric evaluation of the revised FCS

Dimensionality

The eigenvalues and their 95% confidence intervals of the 21-item FCS were (1) 8.30 (95% CI: 7.50-9.15); (2) 2.56 (95% CI: 2.29-2.97); (3) 1.84 (95% CI: 1.59-2.19); (4) 1.16 (95% CI: 1.07-1.43); (5) .99 (95% CI: .91-1.18), respectively, providing some evidence for a four-factor structure. The Scree Plot in Figure 2 supports a three-factor structure since the third eigenvalue from Factor Analysis (FA) is greater and its fourth eigenvalue is smaller than 1.
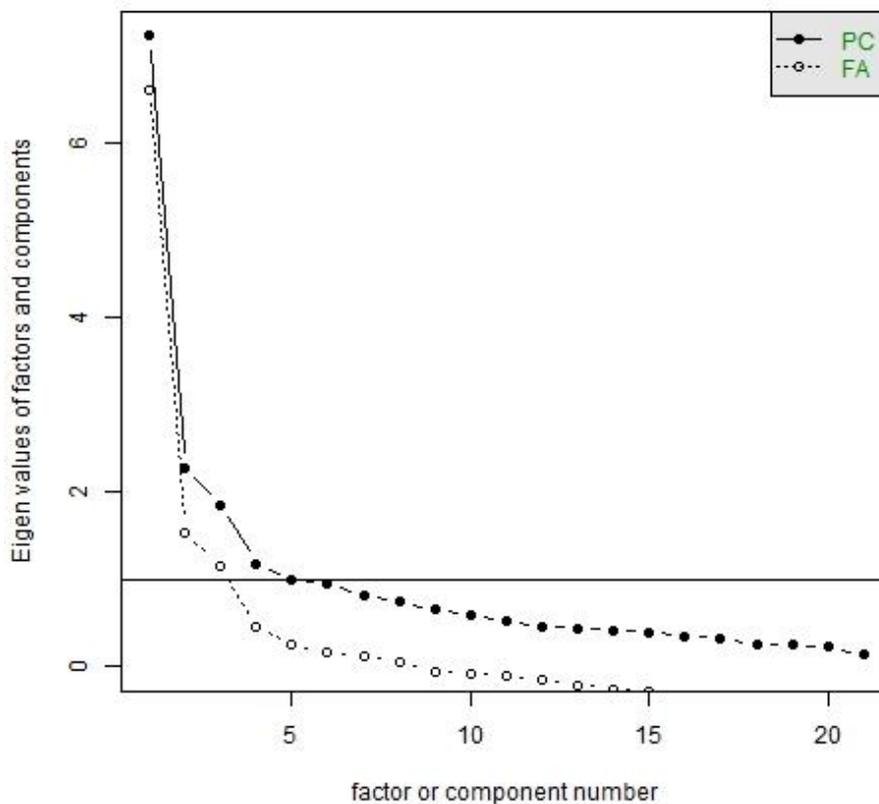
PC: Principal Component factor; FA: Factor analysis (Principal axis factor)

Figure 2. Scree plot

Next, an Exploratory Factor Analysis was employed to further explore the dimensionality of the scale (See Table 1). Items with factor loadings of >.32 were considered for further analysis, resulting in the exclusion of item 7 (*I experienced nurses being too busy*) with factor scores of .0216, .1316 and -.1053 on factors 1, 2 and 3, respectively. This resulted in a 20-item version of the FCS being suitable for further analysis.

Table 1. Explorative factor analysis of the revised Family Collaboration Scale*

Items/Subscales		Factor structure		
		1	**2**	**3**
	Subscale Trust in nursing care			
2	Nurses struck me as quite competent	0.94	0.05	-0.02
3	I trusted that my family member received all the necessary care during their stay	0.94	0.06	-0.04
5	I felt properly informed about my family member's illness	0.52	0.01	0.47
6	Nurses treated patients with respect	0.43	0.32	0.03
16	In any contact you had with nurses, how often did you yourself initiate this?	0.36	-0.06	0.14
	Subscale Accessible nurse			
18	Nurses were happy to help whenever I sought them out	0.07	0.93	-0.09
19	Nurses had the time to speak to me	0.03	0.84	-0.02
20	I felt comfortable in expressing my feelings	-0.09	0.77	0.09
17	It was easy to contact a nurse that was familiar with my family member	0.09	0.74	0.00
22	Nurses were understanding towards my situation as a family member of the patient	0.06	0.66	0.24
21	I felt comfortable in expressing any criticism	-0.22	0.65	-0.01
	Subscale Influence on decisions			
25	I was involved in making plans for my family member when he/she was discharged from the hospital	-0.00	-0.00	0.88
24	I was properly informed about the plans for my family member after he/she was discharged from the hospital	0.08	0.08	0.78
9	Nurses inquired about my knowledge of my family member's situation	-0.05	-0.08	0.76
10	Nurses used my knowledge of my family member to their advantage	-0.23	0.07	0.68

Table 1. Continued

Items/Subscales	Factor structure		
	1	**2**	**3**
28 I have received sufficient information with regards to how I can best help my family member	0.26	0.10	0.65
12 I was able to influence decisions that were made with regards to the care provided to my family member	-0.35	0.04	0.61
14 I was satisfied with the influence I was allowed to exercise	0.15	0.29	0.48
26 I was happy with the follow-up agreements that were made once my family member was discharged from the hospital	0.39	0.12	0.42
27 I feel that my family member was discharged from the hospital at the proper time	0.43	0.11	0.37

The three identified subscales were labelled with names that best represented the overall meaning of items that constitute the factors,[26] using a consensus discussion of four authors. This resulted in a three-factor structure that was interpretable as 'Trust in nursing care', 'Accessible nurse,' and 'Influence on decisions'. Although item 27 showed a higher but comparable factor loading on factor 1, its conceptual meaning fits better to factor 3. As shown in Table 1, the subscale 'Trust in nursing care' consisted of five items that represent family caregivers' feelings of trust in nurses' care. The subscale 'Accessible nurse' consisted of six items that represent family caregivers' personal perceptions of their actual contact with the nursing staff. The subscale 'Influence on decisions' consisted of nine items that reflect the actual family caregivers' experiences of being consulted and involved in decisions. In Table 1, items are arranged according to the factor structure that suited best with the factor loadings. For reasons of clarity and consistency of reference, the original numbering of the 25-item FCS was maintained in Table 1 and 2.

Score distribution

As seen in Table 2, score distributions show responses on all categories (choice options) of the Likert scales (1-5). Most of the items are somewhat asymmetrically distributed with small percentages on response categories 1 and relatively large percentages on response categories 4. Items in subscale 'Perceived influence on decisions' also show asymmetric distributions but in various ways.

Internal consistency

The ordinal and Cronbach's alpha coefficients for the subscales of the modified FCS of .81 - .88 and .74 - .85, respectively, are moderate to large with a large Cronbach's alpha of .89 for the total FCS (See Table 2).

Point polyserial correlations

The size of the Point Polyserial Correlations of the items and latent trait concept of family caregivers' trust in nursing care and their perceptions of accessible nurses are good to excellent with somewhat lower correlations on items 6 and 16 compared to the first three items. Point Polyserial Correlations of the items with the latent trait of influence on decisions are somewhat lower compared to the other subscales but their size is sufficient to good.

Table 2. Psychometric properties of the revised Family Collaboration Scale

Item # / Subscales	Percentages per category of response*					α if deleted	Point polyserial correlations
	1	**2**	**3**	**4**	**5**		
Subscale Trust in nursing care							
2. It was my impression that nurses were competent	1	3	10	28	58	.63	.80
3. I felt confident that my family member received all the necessary care during their stay	1	4	7	31	57	.63	.80
5. I felt well informed about my family member's illness	5	9	13	34	39	.67	.77
6. Nurses treated patients with respect	.5	.5	4	36	59	.71	.61
16. In any contact you had with nurses, how often did you yourself initiate this?	15	22	41	11	11	.79	.58
Ordinal alpha total subscale						.81	
Cronbach's alpha total subscale						.74	
Subscale Perceived accessible nurse							
17. It was easy to contact a nurse that was familiar with my family member	2	5	23	41	29	.81	.74
18. Nurses were willing to help whenever I sought them out	1	2	8	44	45	.80	.79
19. Nurses had the time to speak to me	1	4	19	39	37	.80	.76
20. I felt comfortable in expressing my feelings	3	6	21	37	33	.80	.80
21. I felt comfortable in expressing any criticism	10	6	39	28	17	.85	.64
22. Nurses were understanding towards my situation as a family member	3	4	15	41	37	.80	.78
Ordinal alpha total subscale						.87	
Cronbach's alpha total subscale						.84	

Table 2. Continued

Item # / Subscales	Percentages per category of response*					α if deleted	Point polyserial correlations
	1	**2**	**3**	**4**	**5**		
Subscale Perceived influence on decisions							
9. Nurses inquired about my knowledge of my family member's situation	27	20	31	15	7	.83	.70
10. Nurses used my knowledge of my family member to their advantage	26	18	36	14	6	.84	.65
12. I was able to influence decisions that were made with regards to the care of my family member	43	18	20	14	5	.85	.52
14. I was satisfied with the influence I was allowed to exercise	7	6	21	41	25	.83	.69
24. I was kept informed about planning care regarding my family member's discharge out of the hospital	14	4	11	32	39	.83	.75
25. I was involved in making plans concerning my family member's discharge out of the hospital	20	9	18	20	33	.82	.79
26. I was in agreement with follow-up agreements that were made when my family member was discharged from the hospital	5	4	10	26	55	.84	.61
27. I feel that my family member was discharged from the hospital at the proper time	7	7	9	25	52	.85	.57

Table 2. Continued

	Percentages per category of response*					α if deleted	Point polyserial correlations
Item # / Subscales	**1**	**2**	**3**	**4**	**5**		
28. I have received sufficient information with regards to how I can best help my family member	16	9	12	25	38	.82	.78
Ordinal alpha total subscale						.88	
Cronbach's alpha total subscale						.85	
Cronbach's alpha total scale						.89	

*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 better experience of collaboration.

Item- and option characteristic curves

Item Characteristic Curves (ICC) and Option Characteristic Curves were employed for each item of the FCS and were plotted as a function of expected total scores. For illustrative purposes, the ICC and OCC of two FCS items are provided here. The vertical dashed lines in the figures below represent the 5th, 25th, 50th, and 95th quantiles of the expected scale score.

In Figure 3a, the ICC of item 5 shows a relatively steep increasing curve as desirable and indicating that, the more informed family caregivers feel about the disease of the patient, the higher their perceived trust in nursing care. The OCC in Figure 3b shows that the higher choice options of item 5 are being utilized with a higher probability with increasing expected total trust in nursing care score which was also seen in Table 2.
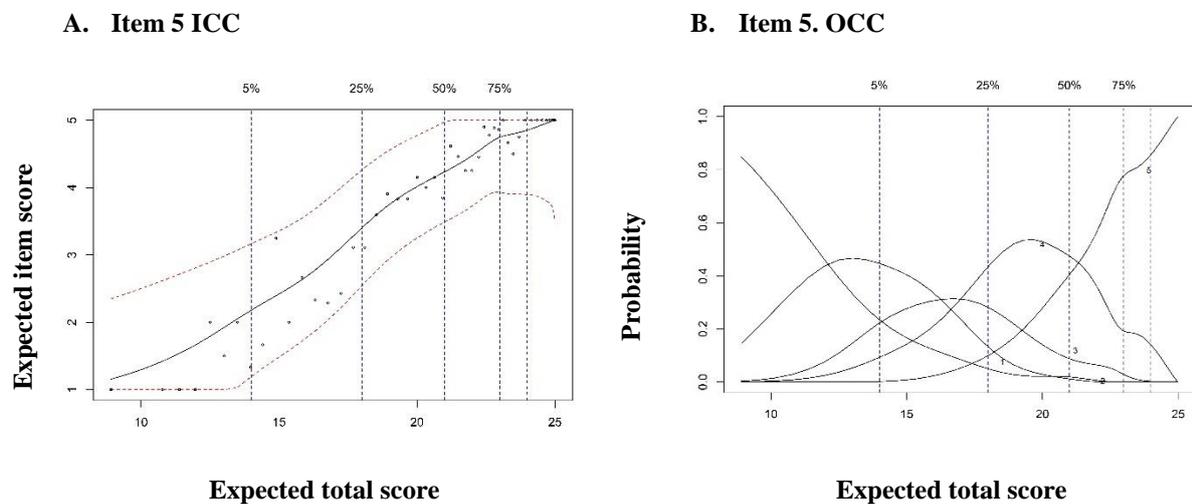
A. Item 5 ICC   **B. Item 5. OCC**

Figure 3. ICC, OCC and, EIS of item 5 (I felt well informed about my family member's illness)

An item with a flatter ICC curve is, for example, item 12 in Figure 4a. It shows that options 3 through 5 of item 12 were chosen only by nurses with a largest quantile of expected score on the latent trait representing perceived influence on decisions. This is in line with the OCC of this item in Figure 4b demonstrating that there is a high probability that choice option 1 is selected and that this item discriminates less between the choice options 2, 3, and 4.
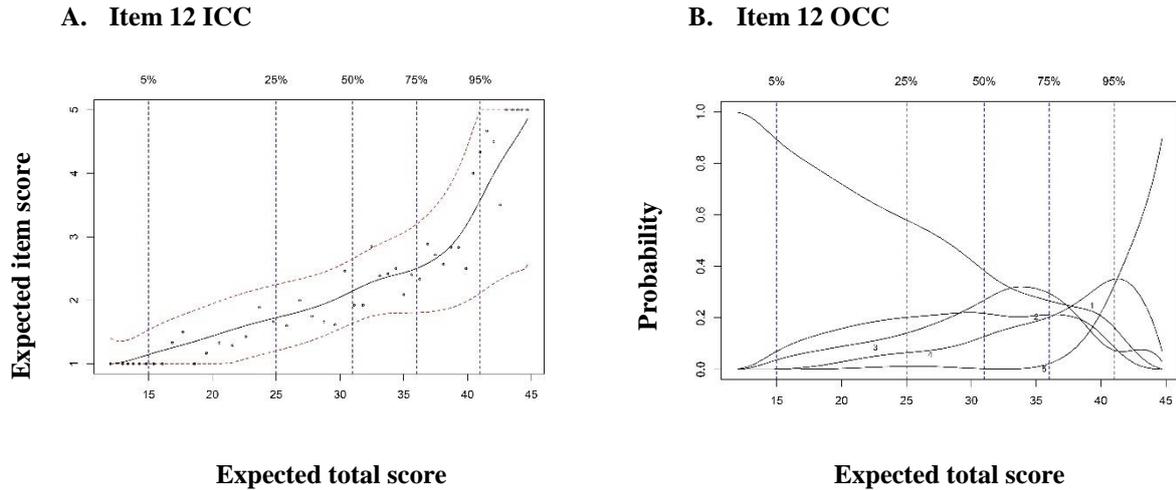
A. Item 12 ICC

B. Item 12 OCC

Expected total score

Expected total score

Figure 4. ICC and OCC of item 12 (*I was able to influence decisions that were made with regards to the care of my family member*).

Exploration of subscale construct

To explore the construct validity of the subscales, correlations between latent variables and sumscores of each subscale are given in Table 3. The subscales show relatively small positive correlations with each other meaning that the subscales each explain a separate portion of collaboration variance.

Table 3. Correlations between the three subscales of the FCS

	Trust	**Accessible**	**Influence**
Trust	1.00	.38	.40
Accessible		1.00	.50
Influence			1.00

Trust: Subscale Trust in nursing care; Accessible: Subscale Accessible nurse; Influence: Subscale Influence on decisions.

Discussion

The aim of this study was to create a scale that is concise, valid and reliable and measures collaboration between family caregivers of older patients and hospital nurses. In this study we modified an existing scale in order to specifically measure the concept of collaboration from the perspective of family caregivers. A thorough process was followed to modify the FCS using the theoretical framework of Lindhardt and colleagues[21] underlying the original scale. A 20-item, Family Collaboration Scale Dutch language version was found consisting of three-subscales showing good psychometric properties. Point Polyserial Correlations show that most items correlate well with the underlying continuous latent variable of the three subscales of collaboration, implying a good item fit within the three subscales.

We believe that an important aspect of the modification is the shortening of the scale in order to only measure collaboration. For the general population, it is preferable to use smaller scales because the items require less cognitive effort to answer them[25] while maintaining a valid and reliable scale. The 20-item FCS shows good reliability expressed in internal consistencies with ordinal alpha values of .81-.88 and Cronbach alpha values of .74-.85 on the three subscales and a total Cronbach alpha value of .89, comparable but somewhat lower than the 77-item[21] and 56-item FCS.[22] The three subscales of the 20-item FCS exhibit a high degree of similarity with the subscales of the original FCS and the theoretical framework of collaboration. The subscale 'Trust in nursing care' appears to be a more specific aspect of the original subscale 'Trust and its prerequisites'[21] and seemingly a logical consequence of the fact that prerequisites of collaboration were not included in the 20-item FCS. The subscale 'Accessible nurse' is similar but more specific than the original subscale 'Quality of contact with nurses'. The subscale 'Influence on decisions' can be considered as a combination of the original subscales 'influence on decisions', 'influence on discharge' and 'achieved level of information'.

A number of items show ceiling effects that were also found by Lindhardt and colleagues.[21] Items that elaborate more on family caregivers' feelings seem to have more responses in the higher response categories, for example, see item 3 (*I felt confident, that my family member received all the necessary care during his/her stay*) in Table 2. Positively skewed responses are mostly given towards the favourable end, and this is most acute when a rating scale is used to evaluate staff.[25] Some of these items measure satisfaction with nurses'

care and, therefore, it is likely to assume that family caregivers might have given socially desirable responses to the statements of these subscales.

In addition, items that measure actual contact or involvement appear to provoke more responses in the lower response categories, for example, item 12 (*I was able to influence decisions that were made with regards to the care of my family.* It is likely to assume that family caregivers experienced that they were not able to influence decisions made as was also found by Walker and Dewar[43] in a qualitative study on facilitating carers' involvement in decision-making. This pattern can also be influenced because family caregivers did not seem to recognize themselves in the role of a collaborative partner in shared decision making, because 61% of the family caregivers scored 'not applicable' on items 11 (*I was able to influence decisions that were made with regards to the treatment of my family member)* and 13 (*Nurses and I were in agreement with regards to what should happen to my family member (for example, which tests, treatment, nursing care, instructions he/she needed))*. An item is most commonly omitted because it does not apply to the person, or the person does not recognize her/himself in the item.[25(p135)] A major role of family caregivers is to be a collaborating partner of the health care professionals.[8] It is possible that family caregivers might not recongnize themselves sufficiently in the role of collaborating partner of nurses. Collaborative relationships develop sequentially in three phases: Involvement- establishing basic bonding and communication channels; Collaboration – forming partnership based on the recognition of common goals; and Empowerment – sharing of power and responsibility.[44] Collaboration requires a more active role and has a more reciprocal character than involvement. When nurses and family caregivers collaborate, they are actively involved in a process of information exchange and joint decision-making as partners in care. We believe that collaboration should be part of the regular daily nursing care on a hospital ward, where negotiating of care aspects with older hospitalized patients and their family caregivers, if applicable, are a structural part of the admission process and at least one structural family meeting is organized for each patient a few days before discharge. It can be expected that when nurses collaborate with patients and their family caregivers as part of the professional profile, continuity of care before and after hospitalization can be maintained, subsequently promoting the patient's self-care.[45,46]

In this study multiple steps were performed in order to develop a valid and reliable revision of the FCS. At first, items were selected based on the theoretical framework of collaboration that was developed based on thorough research aimed at specifically measuring collaboration between nurses and family caregivers.[17,21,22] Content validity performed on the

25 items of the first version of the revised FCS by 10 expert nurses validated the selected items and has resulted in a more validated scale.

Next, factor analysis was performed on Polychoric correlations[32] since the measurement concerned ordinal data and factors were considered to be correlated. Researchers are encouraged to use ordinary least squares estimations with Polychoric correlations in the factor analyses when analyzing ordinal data.[47] All items loaded good to excellent to three subscales of the FCS, and therefore can be considered relevant for the concept to be measured. Exploration of the construct validity shows that the correlations between the subscales of the FCS ranged from .38 to .50, indicating that they were low to moderately correlated, with the highest correlation between the subscales 'accessible nurse' and 'influence on decisions'. This might suggest that family caregivers can experience a higher level of collaboration, when nurses are more accessible.

Reliability was measured by internal consistency of the items with Cronbach's alpha as well as the ordinal alpha for comparative purposes. The ordinal reliability alpha provides consistently suitable estimate of the theoretical reliability regardless of the theoretical reliability, the number of scale points and the skewness of the scale point distributions.[37] Eliminating any item did not improve the alpha coefficients, suggesting that all items correlate well with the domains of collaboration. The internal consistency of the total score of .89 showed a strong reliability of the total FCS and supports it use in further studies.

Two items were removed from the analyses because 50% of the family caregivers checked these items as 'not applicable', which might suggest that family caregivers did not recognize themselves as informal care partners who need to be involved in decision making processes. Since expert nurses found these items to be relevant in measuring the construct of collaboration between family members and nurses, we recommend (or it could be a consideration) to include these two items in the revised version of the FCS in future research without a 'not applicable' option.

With this study, we were able to construct a scale that measures how family caregivers of older patients perceive their collaboration with nurses in the hospital. The 20-item FCS Dutch language version demonstrated good psychometric properties and can be used to measure family caregivers' collaboration with nurses. By employing the Non-Parametric Item Response Theory, the model interpretations fit more flexibly to the actual family caregiver perceptions of collaboration. This method of analysis generates specific information on item characteristics that can be employed to further improve the FCS into a more international context. The FCS was validated in a hospital setting measuring collaboration between family

caregivers of older hospitalized persons and nurses. Family caregivers 'perceived collaboration in, for instance, long term care in nursing homes or home health care can be seen from another perspective with more long-term goals and other desired collaboration related outcomes. Therefore, the instrument might need to be psychometrically tested in other care settings such as elderly care and home care.

With this scale, insight can be provided in a reliable and valid manner into the degree to which collaboration between family caregivers and nurses takes place in care settings. This insight can stimulate awareness among nurses about their role with regard to working with family caregivers as partners in care. In addition, specific improvements can be formulated with regard to those aspects where collaboration with family caregivers can be improved, for example organizing planned communication between nurses and family caregivers and involve family caregivers in decision making with regard to care activities.

Strengths and Limitations

A convenience sample of family caregivers from 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 appropriate 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 appropriate 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 family caregivers who were sent a survey but did not meet the inclusion criteria for this study. Their 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.[21] Family caregivers' experiences of collaboration entail subjective responses and might provoke socially desirable behaviour which could possibly influence the reliability of study results. The content validity of the modified FCS as was performed by expert nurses, was performed after data collection was completed. It would have been better to do that before as was first intended. Since the modified FCS is a different scale than other versions of the FCS, a limitation of this study is the impossibility of comparing the results with other studies. An additional limitation of this study was that no comparison with other instruments measuring collaboration between family caregivers and nurses has been undertaken to measure construct validity.

Conclusion

This study shows that the revised Family Collaboration Scale is a valid and reliable scale that can be used to measure how family caregivers experience their collaboration with nurses. The constructed smaller scale could be considered to be more feasible while maintaining good psychometric properties. As collaboration with family caregivers as partners in care is considered an important principle of good nursing care quality, this study provides a contribution to the limited knowledge of the concept of collaboration between family caregivers and nurses and to the measurement of this concept in a valid and reliable way.

Supporting information

Appendix 5.1. Tentative model of collaboration.

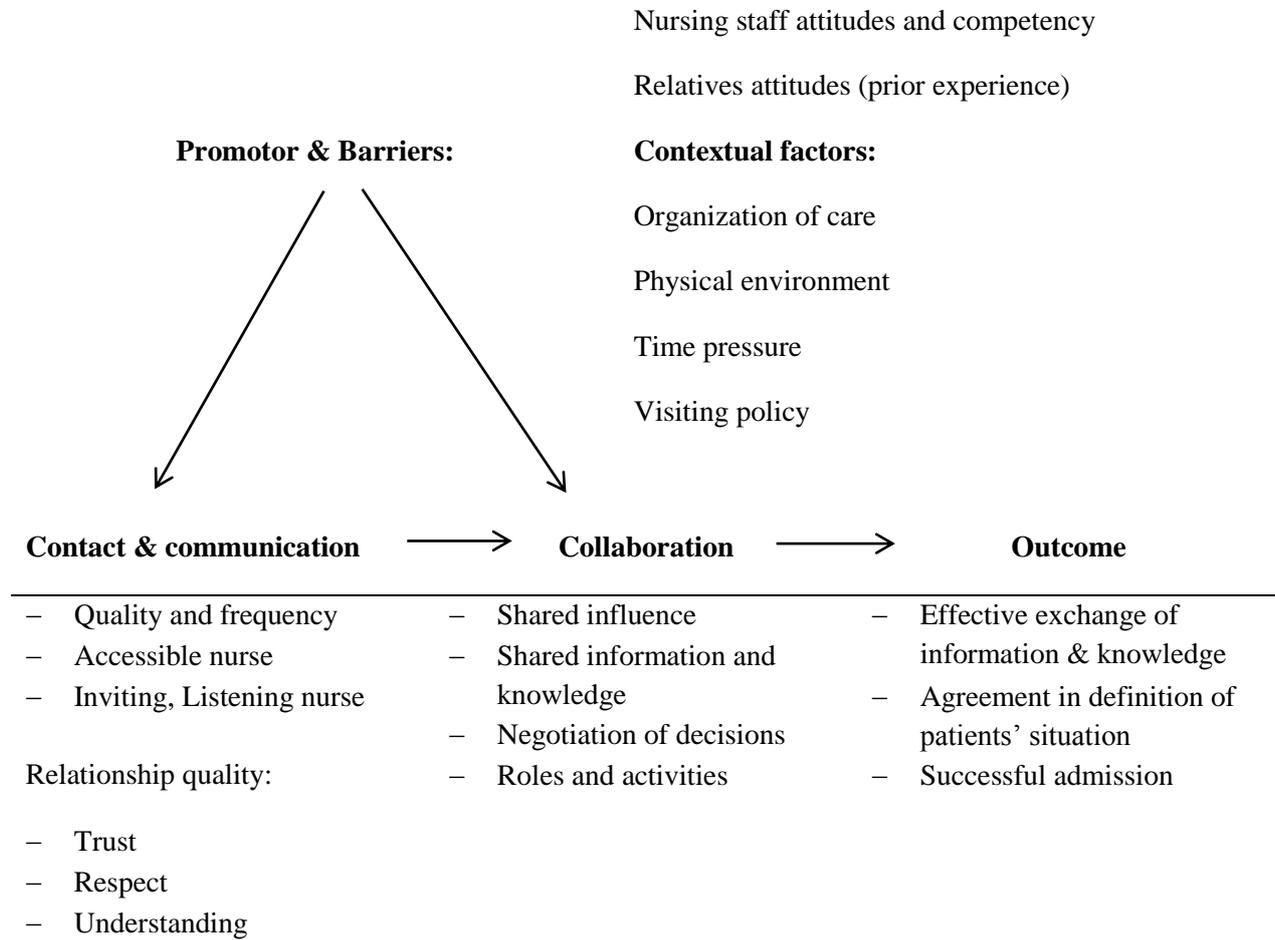Appendix 5.2. 20-item Family Collaboration Scale in Dutch and English

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. Vassilev I, Rogers A, Sanders C, et al. Social networks, social capital and chronic illness self-management: a realist review. *Chronic Illn.* 2011;7:60-86. https://doi.org/10.1177/1742395310383338

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. World Health Oranization. World Report on Ageing and Health. http://www.who.int/ageing/publications/world-report-2015/en/ Published 2015. Accessed February 2, 2016.

6. 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.

7. 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.

8. 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.

9. 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

10. 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. Nur.* 2008;17:482–490. https://doi.org/10.1111/j.1365-2702.2007.01955.x

11. 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.

12. Bragstad L, Kirkevold M, Hofoss D, Foss C. Informal caregivers' participation when older adults in Norway are discharged from the hospital. *Health Soc.Care Community*. 2014b; 155-168. https://doi.org/10.1111/hsc.12071

13. 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.

14. Cambridge University Press. Cambridge Dictonaries online. Definition collaboration. http://dictionary.cambridge.org/us/dictionary/business-english/collaboration Accessed March 14 2015.

15. 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

16. Åstedt-Kurki P, Paavilainen E, Tammentie T, Paunonen-Ilmonen M. Interaction between adult patients' family members and nursing staff on a hospital ward. *Scand. J. Nurs. Sci.* 2001;15:142-150. https://doi.org/10.1046/j.1471-6712.2001.00012.x.

17. Lindhardt T, Bolmsjo I, Hallberg I. Standing guard-being a relative to a hospitalised, elderly person. *J Aging Stud.* 2006;20:133–149. https://doi.org/10.1016/j.jaging.2005.06.001

18. 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. *Scand. J. Caring Sci.* 2008a;22:507–519. https://doi.org/10.1111/j.1471-6712.2007.00558.x.

19. Walters SJ, Stern C, Robertson-Malt S. The measurement of collaboration within healthcare settings: a systematic review of measurement properties of instruments. *JBI Database Syst. Rev. Implement. Rep.* 2016;14:138-97. https://doi.org/11124/JBISRIR-2016-2159

20. 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

21. 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.* 2008b;45:1329-1343. https://doi.org/10.1016/j.ijnurstu.2007.10.006

22. 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 of Nurs.Meas.* 2018;26: 311-340. https://doi.org/10.1891/1061-3749.26.2.311

23. Lindhardt T, Rahm Hallberg I, Poulsen I. Nurses' experience of collaboration with relatives of frail elderly patients in acute hospital wards: A qualitative study. *Int. J Nurs. Stud.* 2008;5:668-681. https://doi.org/10.1016/j.ijnurstu.2007.01.010

24. Wild D, Grove A, Martin M, Eremenco S, McElroy S, Verjee-Lorenz A, Erikson P. Priciples of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: report of the ISPOR task force for translation and cultural adaptation. *Value Health*. 2005;8:94-104. https://doi.org/10.1111/j.1524-4733.2005.04054.x.

25. Streiner DL, Norman GR, Cairney J. *Health Measurment Scales a practical guide to their development and use.* 6th ed. Oxford, UK: Oxford University Press; 2015.

26. Polit DF, Tatano Beck C. *Nursing Research: Appraising Evidence for Nursing Practice*. 7th ed. Philidelphia, PA: Wolters Kluwer Lippincott Williams & Wilkins; 2010.

27. Polit D, Beck C, Owen S. Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Res Nurs. Health*. 2007;30:459-467. http://dx.doi.org/10.1002/nur.20199

28. Lawshe CH. A quantitative approach to content validity. *Pers. Psychol.* 1975;28:563-575. https://doi.org/10.1111/j.1744-6570.1975.tbo01393.x

29. 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.

30. Chalmers PR. mirt: A Multidimensional item response theory package for the R environment. *J Stat. Softw.* 2012;1-29. https://doi.org/10.18637/jss.v048.i06.

31. Kaiser HF. The application of electronic computers to factor analysis. *Educ. Psychol Meas.* 1960;20:141-151. https://doi.org/10.1177/001316446002000116

32. Basto M, Pereira JM. An SPSS R-Menu for Ordinal Factor Analysis. *J Stat. Softw.* 2012;46:1-29. https://doi.org/10.18637/jss.v046.i04

33. Tabachnick BG, Fidell LS. *Principal components and factor analysis. In using multivariate statistics.* 4th ed. Needham Height, MA: Allyn & Bacon; 2007.

34. Bedrick EJ, Breslin FC. Estimating the ployserial Correlation Coefficient. *Psychom.* 1996;61:427-443. https://doi.org/10.1007/BF02294548

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

36. Zumbo BD, Gadermann AM, Zeisser C. Ordinal Versions of Coefficients Alpha and Theta for Likert Rating Scales. *J Mod. Appl. Stat. Methods.* 2007;6:21-29. https://doi.org/10.22237/jmasm/1177992180

37. Cronbach LJ. Coefficient alpha and the internal structures of tests. *Psychom.* 1951;16:297-334. https://doi.org/10.1007/BF02310555

38. Nunnally JC, Bernstein IH. *Psychometric theory.* 3rd ed. New York,NY: McGraw-Hill; 1994.

39. Mazza A, Punzo A, McGuire B. KernSmoothIRT: An R Package for Kernel Smoothing in Item Response Theory. *J Stat. Softw.* 2014; 058(i06). https://www.jstatsoft.org/index.php/jss/article/view/v058i06/v58i06.pdf

40. Junker BW, Sijtsma K. Nonparametric Item Response Theory in Action: An Overview of the Special Issue. *Appl. Psychol. Meas.* 2001;25:211-220. https://doi.org/10.1177%2F01466210122032028.

41. Orlando Edelen M, Reeve BB. Applying item response theory (IRT) modeling to questionnaire development, evaluation, and refinement. *Qual. Life Res.* 2007;16:5-18. https://doi.org/10.1007/s11136-007-9198-0.

42. Ramsey J. Kernel Smoothing Approaches to Nonparametric Item Characteristic Curve Estimation. *Psychom.* 1991;56:611-630. https://doi.org/10.1007/BF02294494

43. 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.

44. 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

45. 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.

46. Wright LM, Leahey M. *Nurses and Families - a guide to family assessment and intervention.* 6th ed. Philidelphia, PA: F.A. Davis Company; 2013.

47. Gaskin CJ, Happell B. On exploratory factor analysis: A review of recent evidence assessment of current practice, and recommendations for future use. *Int. J Nurs. Stud.* 2014; 51: 511-521. http://dx.doi.org/10.1016/j.ijnurstu.2013.10.005

Appendix 5.1. Tentative model for collaboration

Nursing staff attitudes and competency

Relatives attitudes (prior experience)

Promotor & Barriers: **Contextual factors:**

Organization of care

Physical environment

Time pressure

Visiting policy

Contact & communication → **Collaboration** → **Outcome**

Contact & communication	Collaboration	Outcome
– Quality and frequency	– Shared influence	– Effective exchange of information & knowledge
– Accessible nurse	– Shared information and knowledge	
– Inviting, Listening nurse	– Negotiation of decisions	– Agreement in definition of patients' situation
Relationship quality:	– Roles and activities	– Successful admission
– Trust		
– Respect		
– Understanding		

From: 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.* 2008b;45:1329-1343. https://doi.org/10.1016/j.ijnurstu.2007.10.006

Appendix 5.2. 25-item Family Collaboration Scale in Dutch and English

(Including three extra questions; 1, 15 and 23, to identify the target population).

No.	Question in Dutch	Question in English	Response options
1.	Hoe vaak heeft u uw familielid/naaste bezocht tijdens de ziekenhuis opname?	How often did you visit your family member/loved one during the hospital admission? **(Conditional question 1)**	Every day A few times a week Once a week Less than once a week I did not visit my relative in the hospital (continue to question 23)
2.	Ik had de indruk dat de verpleegkundigen bekwaam waren	The nursing staff struck me as quite competent	Totally disagree – Totally agree
3.	Ik had het vertrouwen dat mijn familielid/naaste tijdens de opname de noodzakelijke zorg kreeg.	I trusted that my family member/loved one received all the necessary care during their stay	Totally disagree – Totally agree
4.	Er waren te veel verschillende mensen bij de verpleging van mijn familielid/naaste betrokken	There were too many people involved in the nursing care of my family member/loved one	*Question was dropped*
5.	Ik voelde mij goed geïnformeerd over de ziekte van mijn familielid/naaste	I felt properly informed about my family member's/loved one's illness	Totally disagree – Totally agree
6.	Verpleegkundigen behandelden de patiënten met respect (*de toon, de aanspreekvorm, andere zaken van betekenis voor behoud van de patiënt zijn waardigheid*)	Nursing staff treated the patients with respect (*tone of voice, form of addressing, other matters concerning keeping the patients' dignity*)	Never - always
7.	Ik maakte mee dat verpleegkundigen het erg druk hadden	I experienced nursing staff being extremely busy	*Question was dropped*
8.	Ik moest erop letten dat mijn familielid/naaste de zorg kreeg die hij nodig had (*erom vragen dat hij voldoende eten en drinken kreeg, hulp met uit bed komen, ed.*)	I had to make sure that my family member/loved one received the care she/he needed (*e.g. requests for sufficient food/drinks, assistance to get out of bed, etc.*)	*Question was dropped*

No.	Question in Dutch	Question in English	Response options
9.	De verpleegkundigen vroegen naar mijn kennis over de situatie van mijn familielid/naaste (*gezondheid, hoe hij zich redt, ed.*)	The nursing staff inquired about my knowledge of my family member/loved one's situation (*general health, how he/she managed etc.*)	Never - always
10.	Verpleegkundigen maakten gebruik van mijn kennis over mijn familielid/naaste	The nursing staff used my knowledge of my family member/loved one to their advantage	Never - always
11.	Ik had invloed op beslissingen die werden genomen over de behandeling van mijn familielid/naaste	I was able to influence decisions that were made with regards to my family member/loved one's treatment	Never – always/ Not applicable
12.	Ik had invloed op beslissingen die werden genomen over de zorg van mijn familielid/naaste (*eten, drinken, mobiliseren, leefstijl*)	I was able to influence decisions that were made with regards to the care provided to my family member/loved one (*eating, drinking, mobilizing, life-style*)	Never - always
13.	De verpleegkundigen en ik waren het eens over wat er met mijn familielid/naaste moest gebeuren (*bijv. welke onderzoeken, behandeling, verpleging en instructies hij/zij moest hebben*)	The nursing staff and I were in agreement with regards to what should happen to my family member/loved one (*for example which tests, treatment, nursing care, instructions he/she needed*)	Never – always/ Not applicable
14.	Ik was tevreden over de invloed die ik kreeg	I was satisfied with the influence I was allowed to exercise	Never - always
15.	Ongeveer hoe vaak had u tijdens de gehele opname contact met de verpleegkundigen van de afdeling (*meer dan goedendag en tot ziens*)	Approximately how often were you in contact with nurses during the entire process (*more than hello and goodbye*) **(Conditional question 2)**	Not at all (continue on to question 23) 1-4 times 5-10 times More than 10 times
16.	Als u contact had met de verpleegkundigen, hoe vaak had u dan zelf het initiatief voor het contact genomen?	In any contact you had with the nursing staff, how often did you yourself initiate this?	Never - always
17.	Het was gemakkelijk contact te krijgen met een verpleegkundigen die mijn familielid/naaste kende	It was easy to contact a nurse that was familiar with my family member/loved one	Never - always
18.	De verpleegkundigen waren welwillend als ik contact met ze opnam	The nursing staff were happy to help whenever I sought them out.	Never - always

No.	Question in Dutch	Question in English	Response options
19.	De verpleegkundigen hadden tijd om met mij te praten	The nursing staff had the time to speak to me	Never - always
20.	Ik had het gevoel dat het prima was dat ik uiting gaf aan mijn gevoelens	I felt comfortable in expressing my feelings	Totally disagree – Totally agree
21.	Ik had het gevoel dat het prima was dat ik uiting gaf aan mijn kritiek	I felt comfortable in expressing any criticism	Totally disagree – Totally agree
22.	Verpleegkundigen begrepen mijn situatie als familielid/naaste	Nurses were understanding towards my situation as a family member/loved of the patient	Totally disagree – Totally agree
23.	Zijn er bij het ontslag van uw familielid/naaste nog vervolgafspraken gemaakt?	Have follow-up appointments been made at discharge of your family member/loved one? **(Conditional question 3)**	Yes No (continue on to question 27)
24.	Ik werd geïnformeerd over de plannen voor mijn familielid/naaste na ontslag uit het ziekenhuis	I was properly informed about the plans for my family member/loved one after he/she was discharged from the hospital	Never - always
25.	Ik werd betrokken bij het maken van plannen voor mijn familielid/naaste na ontslag uit het ziekenhuis	I was involved in making plans for my family member/loved one when he/she discharged from the hospital	Never - always
26.	Ik kon mij vinden in de vervolgafspraken, zoals ze zijn gemaakt voor mijn familielid/naaste bij het ontslag uit het ziekenhuis.	I was happy with the follow-up agreements that were made once my family member was discharged from the hospital	Totally disagree – Totally agree
27.	Mijn familielid/naaste werd naar mijn mening op het juiste moment ontslagen	I feel that my family member/loved one was discharged from the hospital at the proper time	Totally disagree – Totally agree
28.	Ik heb voldoende informatie ontvangen over hoe ik mijn familielid/naaste het beste kan helpen (*waaronder ook instructies en begeleiding*)	I have received sufficient information with regards to how I can best help my family member/ loved one (*including instructions and assistance*)	Totally disagree – Totally agree

Permission to use, translate and revise the instrument was granted by Dr. Tove Lindhardt.