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Family Nursing Conversations in Home Health Care

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Chapter 6

Effects of family nursing conversations on families in home health care:
A controlled before-and-after study

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ABSTRACT

Introduction

This study aimed to assess the effects of family nursing conversations on family caregiver burden, patients' quality of life, family functioning, and the amount of professional home health care.

Method

The study employed a controlled before-and-after design. Intervention group families participated in two family nursing conversations incorporated in home health care; control group families received usual home health care. Patients and family members completed a set of questionnaires upon entering the study and six months later to assess family caregiver burden, family functioning, and patients' quality of life. The amount of home health care was extracted from patient files. Data were collected between January 2018 and June 2019.

Results

Data of 51 patients (mean age 80; 47% male) and 61 family members (mean age 67; 38% male) were included in the results. Family caregiver burden remained stable in the intervention group whereas it increased in the control group. Family functioning improved significantly compared to the control group for patients and family members in the intervention group. No significant effects on patients' quality of life emerged. The amount of professional home health care decreased significantly within the intervention group whereas it remained equal in the control group.

Conclusion

Family nursing conversations prevented family caregiver burden, improved family functioning, but did not affect patients quality of life. In addition, the amount of home health care decreased following the family nursing conversations. Countries with ageing populations seek to reduce professional and residential care and therefore encourage family caregiving. Intensive family caregiving, however, places families at risk for caregiver burden which may lead to increased professional care and admission into residential care. This study demonstrates that family nursing conversations help nurses to prevent family caregiver burden and improve family functioning while decreasing the amount of home health care.

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INTRODUCTION

The need for long-term care at home increases as populations age and health care costs rise. Care at home is generally preferred by patients and since the costs for residential care exceed home health care costs also by governments (Colombo et al., 2011). As the availability of professional home health care is insufficient for the increasing needs, the importance of informal care intensifies (OECD, 2019). In most countries, 70 to 90 percent of caregivers are informal caregivers, primarily family members. Illness and caregiving within a family can be a major source of stress to which the family must adapt (Walsh, 2012, 2016a). Family members who provide intensive care are especially at risk for caregiver burden (Colombo et al., 2011). Therefore, family caregivers require adequate support to ensure that they can fulfill their caregiving tasks without compromising their own health.

Nurses are in a key position to support family caregivers of home dwelling patients. To do so, nurses must extend the focus of their care by including patients' families. Family responses to health problems are part of nurses' main focus (ICN, 2019). Nonetheless, nursing care that extends beyond the individual patient is not yet standard care. The Family Systems Nursing framework has been developed to focus on the family system rather than solely on the patient. In practice, it typically takes the form of conversations with families to improve families' health in illness situations (Wright & Leahey, 2013). For nurses to conduct these conversations and for home health care organizations and society to finance them, insight into their effects is crucial. To date, there is substantial support for conversations based on Family Systems Nursing from qualitative studies (Östlund & Persson, 2014). However, limited evidence is available from quantitative and experimental studies, especially for home health care. The purpose of this study, therefore, was to evaluate the effects of a specific Family System Nursing conversation, i. e., the family nursing conversation, in home health care.

Background

Family nursing conversations are based on the Family Systems Nursing framework. The underlying premise is that relationships between people, on the one hand, and health and illness, on the other hand, influence one another. To stimulate family and individual health, therefore, Family Systems Nursing, approaches the family as the unit of nursing care with a focus on both the patient and the family as well as both individuals and relationships and the interactions between them (Wright & Leahey, 2013).

A family nursing conversation is a preplanned conversation in which the patient,

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one or more family members, and the nurse discuss the care situation. The family and the nurse together decide who should participate in the conversation. Family nursing conversations consist of twelve core components that are constructed to foster family resilience processes (Broekema et al., 2020; Walsh, 2003, 2016b). The components include an exploration of the family's structure and network; sharing of experiences, emotions, and needs regarding the care situation; and formulating a shared goal and establishing agreements regarding the care situation. Other components are that nurses encourage open communication, acknowledge painful experiences, commend families for their strengths, and discuss, strengthen, and challenge family members' beliefs about health and illness. A family nursing conversation is indicated when one or more of the following NANDA-I nursing diagnoses (Herdman & Kamitsuru, 2014) apply to the family: 'risk of caregiver role strain', 'caregiver role strain', or 'interrupted family processes'.

The family nursing conversation components are intended to optimize family functioning, improve coordination between professional and family care, and ultimately prevent or decrease family caregiver burden. Poor family functioning is associated with caregiver burden (Liu & Huang, 2018). Optimal family functioning in the context of illness of an adult family member can be defined using five attributes: maintaining cohesive relationships, fulfilling family roles, coping with family problems, adjusting family routines, and communicating effectively (Zhang, 2018). These aspects are targeted in family nursing conversations. A grounded theory study indicated that these conversations improved contact within the family as well as between the family and professional caregivers and, thereby, reduced caregiver burden (Broekema et al., 2021). Coordination between professional and family care is important as both professional and family caregivers consider a partnership as crucial rather than working alongside one another (Hengelaar et al., 2018). In care situations, effective communication with professional caregivers is an essential need for family caregivers (Silva et al., 2013). However, the division of care responsibilities between professional and family caregivers is not always discussed (Wittenberg et al., 2019). This topic is explicitly addressed in family nursing conversations. Family members perceived these conversations to help them maintain a balanced division of tasks, establish and keep clear boundaries and identify and solve problems timely thus reducing caregiver burden (Broekema et al., 2021).

Qualitative studies have shown that families consider conversations based on Family Systems Nursing important and valuable (e.g. Benzein, Olin, & Persson, 2015; Dorell & Sundin, 2016; Robinson & Wright, 1992). The conversations were also found to support family functioning (Östlund & Persson, 2014). An integrative review of evidence for conversations based on Family Systems Nursing was

conducted in 2011 and highlighted the need for research with experimental and quasi-experimental designs (Östlund & Persson, 2014). Since then, the majority of experiments and quasi-experiments on Family Systems Nursing conversations have been conducted in Iceland in families with children. In sum, these studies revealed Family Systems Nursing conversations to increase parents' perceived support from nurses (e.g. Sigurdardottir et al., 2013; Svavarsdottir & Gisladottir, 2018; Svavarsdottir, Sigurdardottir, & Tryggvadottir, 2014) and, in some studies, to improve family functioning (Svavarsdottir et al., 2012, 2014; Svavarsdottir & Sigurdardottir, 2013).

In adults, a limited number of experimental or quasi-experimental studies have been conducted since 2011. Studies with control group design, however, are still scarce. The existing evidence suggests that conversations based on Family Systems Nursing can improve families' perceptions of the support they receive from professional caregivers (Petursdottir & Svavarsdottir, 2019; Sveinbjarnardottir et al., 2013) and may also improve family functioning (Lee et al., 2018; Sundin et al., 2016) and possibly health-related quality of life (Lämås et al., 2016) and caregiver burden (Petursdottir & Svavarsdottir, 2019). Results are, however, somewhat inconsistent with respect to these outcomes (Dorell et al., 2017; Faarup et al., 2019; Østergaard et al., 2018). In addition, the effects of these conversations in home health care have not yet been studied in an experimental design, with the exception of palliative home care (Petursdottir & Svavarsdottir, 2019). The effects on the amount of professional health care have not been explored to date either.

The research question of the current study is:

What are the effects of family nursing conversations incorporated into home health care when compared to the usual home health care on:

- a. family caregiver burden;
- b. perceived family functioning;
- c. patients' health-related quality of life;
- d. the amount of professional home health care?

THE STUDY

Aims

To assess the effects of family nursing conversations in home health care on family caregiver burden, family functioning, patients' quality of life, and the amount of professional home health care.

Design

This study employed a controlled before-and-after design, illustrated in figure 1. The intervention for the intervention group consisted of two family nursing conversations with a maximum of three months in between, embedded in home health care. The control group only received the usual home health care, of which family nursing conversations were not a part. The outcomes in both groups were assessed with questionnaires twice: at baseline (To), which was before the first family nursing conversation for the intervention group and six months after To (T1), which was three months after the second family nursing conversation for the intervention group. At this point, the lasting effects of the conversations and the arrangements that were made were expected to be evident.

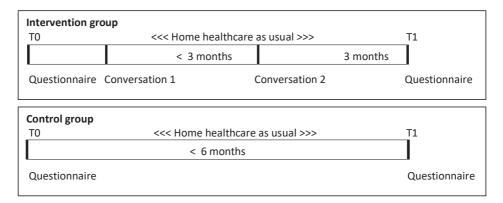


Figure 1. Study design

Participants

The sample consisted of home health care receiving patients and their family members. Three criteria for patients' and family members' eligibility for the study were established: 1) the patient should receive long-term home health care due to frailty (Gobbens et al., 2010) or chronic illness; 2) the nurse should consider one of the NANDA-I nursing diagnoses (Herdman & Kamitsuru, 2014) of 'risk of caregiver role strain', 'caregiver role strain', or 'interrupted family processes' as fitting with the family's situation; 3) the patient and one family member should be able and willing to complete a questionnaire.

In the Netherlands, home health care teams consisting of nurses, nursing aids and one or two coordinating nurses provide home health care to patients in a specific geographical area. Patients and family members in the intervention group were part

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of five home health care teams that the local management of the home health care organization selected. For the control group, the management selected five other teams that were comparable to the intervention group teams in terms of patient population and geographical area. Random allocation of teams to the intervention or control group would have induced a high risk of major differences between the groups, as the teams were selected to cover all available patient populations and geographical areas. All teams were selected based on their availability and willingness to participate in the study.

A power analysis that was based on the primary outcome, family caregiver burden (assessed with the CarerQoL-7D) (with a pre-planned power of o.8, an expected between-group difference of 8 points, and an estimated standard deviation of 16.5 (Lutomski et al., 2015)) resulted in a target sample size of 63 family members in each group. Considering expected dropout, the authors strived for 100 family members in each group. Expected dropout was based on nurses' estimations of patients moving to nursing homes, patient deaths, and lack of follow-up. An estimated 144 eligible patients and family members were approached to participate in the intervention group and 145 for control group participation; an estimated 18 and 29 respectively declined to participate. A total of 111 patients and 131 family members were allocated to the intervention or the control group. The data of 51 patients (54.05% dropout) and 61 family members (53.44% dropout) were included in the analyses and in the results. The reasons for dropout are listed in the flowchart in Figure 2; the main reasons in both groups were that the patient went to a nursing home or died and that the study, filling in questionnaires, was experienced as too burdensome. The intended number of participating family members was not achieved. As a result, the observed power was 0.64 for the primary outcome; family caregiver burden.

Intervention

Usual home health care is attuned to each patient's needs and may include assistance with personal care, specialized nursing care, and patient and family education. Usual home health care begins with an intake by the coordinating home health care nurse who devises a care plan that is subsequently executed by the team. Coordinating nurses evaluate the care plan at least every six months with the patient and sometimes a family member.

The intervention consisted of two family nursing conversations that were based on the twelve core components (Broekema et al., 2020). The conversations occurred in the patients' homes at a time that suited all participants. Nurses were granted 1.5 hours for planning, conducting, and reporting on each conversation. Nurses had the conversations with families for whom they already coordinated the usual home

health care. Thus, results of the conversations could be implemented in the care plan. The nurse and the family collectively decided upon the duration of the time in between the two conversations. This period was set at a maximum of three months in order to ensure continuity and follow-up on goals and agreements that were established in the first conversation.

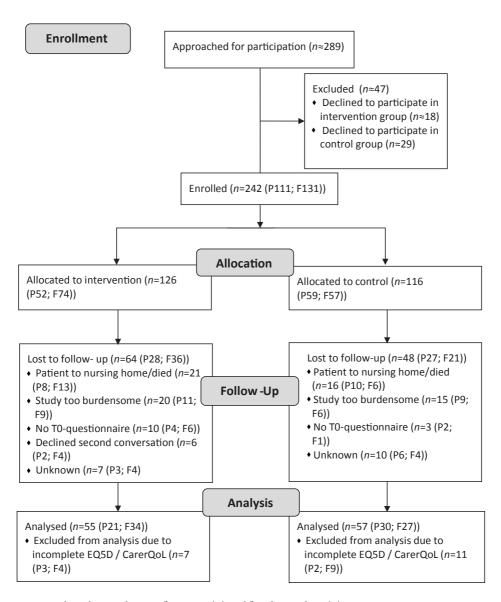


Figure 2. Flow chart inclusion of patients (P) and family members (F)

Prior to the study, the nine coordinating nurses from the five intervention group home health care teams received a six-day educational program in family nursing conversations focusing on their attitude, knowledge, and skills regarding family nursing conversations (Broekema et al., 2018) and the twelve conversation components. In a previous study, it was found that nurses apply the components as intended following this educational program, but use their professional judgment to adapt components to the specific needs of each family and care situation (Broekema et al., 2020). The components are not intended as a strict protocol but rather as a guideline. Intervention implementation was monitored in two-monthly meetings with the nurses, their managers, and the research team during the study period. In these meetings, intervention integrity was emphasized. Any problems that nurses encountered were discussed; primarily nurses' high workload and its impact on participant inclusion. Nurses described the conversations they had conducted. No major problems related to intervention fidelity emerged. During and in between meetings, nurses provided information regarding the dates and participants of each family nursing conversation to ensure that each participant was involved in two conversations that were no more than three months apart. Actual time in between the two conversations varied between six weeks and three months with an average of ten weeks and three days.

Data Collection

First, the coordinating nurses assessed families in their team for eligibility according to the three inclusion criteria. Subsequently, they approached patients and family members who were eligible to inform them about the study and invite them to participate, during a home visit or via telephone. Nurses informed patients and family members that the home health care organization considered support for patients' families important and that a study was being conducted to assess the effect of the organization's care on patients and family members. The family nursing conversation itself was not mentioned as part of the study information in order to minimize expectation effects. Next, participants received the To-questionnaire from the nurse and completed the questionnaire at their own time at home and returned it using the return envelope. Finally, after a maximum of six months, participants received the T1-questionnaire via mail, completed it and returned it using the return envelope. If the T1-questionnaire was not returned within a month, the nurse or a member of the research team contacted participants to inform about the status, and registered the reason for dropout if participants did not complete the questionnaire. The home health care teams were instructed not to help participants with completing the questionnaires. Participants were included in the study from January to December 2018; post-intervention data collection ended in June 2019.

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The regional medical ethical committee ruled that this study does not fall under the Dutch Medical Research Involving Human Subjects Act and, therefore, waived approval (METc2015.463). All participants signed an informed consent form before entering the study and were informed that they could retract their permission at any time. Patients and family members were informed that the decision on their participation would not in any way influence the care they received. In the intervention group teams, therefore, the nurse offered a family nursing conversation, regardless of whether or not families had decided to participate in the study. To protect participant anonymity, each participant was assigned a unique code in order to match the To to the T1 questionnaires. The link between the participant code and any identifiable information was kept in a password-protected file.

Outcome Measures and Validity, Reliability and Rigour

Demographic information on gender, age, education, and living situation was obtained from each participant. In addition, the nursing diagnosis (Herdman & Kamitsuru, 2014) that was the indication for the family nursing conversation and the reason the patient received home health care were registered.

Family caregiver burden was assessed with the Care-related Quality of Life (CarerQol). This instrument was developed to provide a comprehensive picture of the impact of informal caregiving. Its feasibility, test-retest reliability, and construct validity were determined to be sufficient in the Dutch population (Hoefman et al., 2011, 2013). The first part of the CarerQol consists of seven items with burden dimensions of informal caregiving; five negative aspects and two positive aspects. An example of a negative item is "I have relational problems with the care receiver (e.g., he/she is very demanding or behaves differently; we have communication problems)." Participants score each item on a three-point scale indicating the degree to which the respondent considers the description as according with the care situation: no, some, or a lot. The answers are transformed into a weighted sum score between o (worst caregiving situation) and 100 (best caregiving situation) that is based on tariffs for the Dutch population (Hoefman et al., 2014). Higher scores thus indicate lower caregiver burden or better care-related quality of life. The second part of the CarerQol is a Visual Analogue Scale (VAS) on which participants indicate how happy they currently feel, ranging from o ('completely unhappy') to 10 ('completely happy').

Patients' and family members' perceived family functioning was assessed with the Dutch version of the general functioning scale of the McMaster Family Assessment Device (FAD-N-GF). This instrument has demonstrated sufficient test–retest reliability, construct, and criterion validity (Hamilton & Carr, 2016). The scale has

twelve items that provide an overall picture of family functioning based on systemic and transactional characteristics, closely resembling Zhang's (2018) attributes of family functioning. Six items describe effective family functioning, and six items describe problematic family functioning. The items are scored on a four-point scale from totally disagree to totally agree. The total score is presented as the average item score with the scores on the negative items reversed.

To measure patients' health-related quality of life, the five-level EQ-5D was used. The EQ-5D consists of five health dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression that participants rate on a five-point scale ranging from no problems to slight problems, moderate problems, and severe problems to extreme problems. Convergent validity and test-retest reliability were sufficient in the Dutch population (Janssen et al., 2008). The instrument has been found to be easy to use in a previous evaluation of a Family Systems Nursing intervention (Lämås et al., 2016). Dutch tariffs were employed to transform each participant's answers into a score between 1 (no problems on all dimensions) and -0.329 (extreme problems on all dimensions) (Versteegh et al., 2016). In addition, participants rated their current health on a vertical VAS ranging from 0 ('the worst health you can imagine') to 100 ('the best health you can imagine'). Permission was obtained from the EuroQoL-group to use the instrument.

The amount of home health care that each family received was operationalized as the hours of usual home health care in the week prior to To and in the week of T1. This information was extracted from the organization's patient records.

In the T₁ questionnaires, patients and family members in the intervention group additionally indicated their agreement with five statements about the usefulness of the family nursing conversations on a scale of one ('totally disagree') to four ('totally agree').

Data Analysis

Data were analyzed in SPSS version 25. Participants were included in the analyses when the EQ-5D for patients or the CarerQol for family members was completed at both To and T1. Patient data were analyzed separately from family member data for all variables. The generalized estimating equations procedure was used to assess within- and between-group differences from To to T1 on all variables. This procedure was selected because it takes into account the correlations between repeated measures (Liu, Dixon, Qiu, Tian, & McCorkle, 2009). The main effect for Time (To and T1) within each group and the interaction effect of Time x Group (intervention and control) were assessed. The level of significance was established at <.050.

RESULTS

Study Participants

Background information on the 51 patients (21 in the intervention group) and 61 family members (34 in the intervention group) that were included in the analyses is presented in Table 1. The majority of the families that were included had a nursing diagnosis of risk of caregiver role strain. Patients were typically older adults with a mean age of approximately 80 years old. Family members were somewhat younger and were mostly partners and children of the patient. Overall, slightly more females than males participated. No significant differences between the groups emerged in background characteristics.

Table 1. Participants' demographics and differences between intervention and control group

	Patients			Family members			
Variable	Intervention (n=21)	Control (n=30)	p	Intervention (n=34)	Control (n=27)	р	
Age (mean (sd))	80.33 (6.67)	79.21 (8.51)	.616¹	68.27 (12.35)	65.78 (11.54)	.426¹	
Gender (number of males)	12 (57.14%)	12 (40.00%)	.2272	11 (32.35%)	13 (48.15%)	.295²	
Highest completed education (number)			.216²			.165²	
≤ Primary school	3 (14.29%)	6 (20.00%)		4 (11.76%)	1 (3.70%)		
High school	8 (38.10%)	4 (13.33%)		8 (23.53%)	2 (7.41%)		
Vocational education	6 (28.57%)	13 (43.33%)		15 (40.54%)	13 (48.15%)		
Higher education	3 (14.29%)	6 (20.00%)		7 (20.59%)	10 (37.04%)		
Other/unknown	1 (4.67%)	1 (3.33%)		0 (0.00%)	1 (3.70%)		
Living alone (number)	3 (14.29%)	9 (42.86%)	.193²	-	-	-	
Relationship to patient			-			.372²	
(number)							
Partner	-	-		20 (58.82%)	13 (48.15%)		
Child	-	-		12 (35.29%)	9 (33.33%)		
Other	-	-		2 (5.88%)	4 (14.18%)		
Paid job (number of yes)	-	-		10 (29.41%)	6 (22.22%)	.571²	
Living with patient (number of yes)	-	-		22 (64.71%)	15 (55.56%)	·599²	
Nursing diagnosis family (number)			.2182			.2232	
Risk of caregiver role strain	19 (90.48%)	28 (93.33%)		27 (79.41%)	25 (92.59%)		
Caregiver role strain	2 (9.52%)	2 (6.67%)		8 (23.53%)	2 (7.41%)		
Interrupted family processes	2 (9.52%)	0 (0.00%)		4 (11.76%)	0 (0.00%)		
Main reason for home health care (number)			·559²			.2932	
Dementia	8 (38.10%)	5 (16.67%)		14 (41.18%)	8 (29.63%)		
Parkinson's disease	2 (9.52%)	4 (13.33%)		5 (14.71%)	2 (7.41%)		
CVA/ABI	2 (9.52%)	2 (6.67%)		4 (11.76%)	2 (7.41%)		

Table 1. Continued

	Patients		Family members			
Variable	Intervention	Control	р	Intervention	Control	р
	(n=21)	(n=30)	_	(n=34)	(n=27)	
Diabetes/wound care	2 (9.52%)	4 (13.33%)		3 (8.82%)	3 (11.11%)	
Heart/lung disease	3 (14.29%)	6 (20.00%)		5 (14.71%)	4 (14.81%)	
MS/rheumatic disorder	2 (9.52%)	3 (10.00%)		2 (5.88%)	3 (11.11%)	
Palliative care	0 (0.00%)	1 (3.33%)		0 (0.00%)	1 (3.70%)	
Other somatic	6 (28.57%)	15 (50%)		7 (20.59%)	13 (48.15%)	
Other psychogeriatric	0 (0.00%)	1 (3.33%)		0 (0,00%)	1 (3.70%)	

¹Independent samples t test

All participating patients and all but one family members indicated that the family nursing conversations were useful to them (Table 2). With the exception of one or two participants, patients and family members agreed that the conversations had contributed to improved insight into the care situation; clear agreements about roles and tasks of the people involved in the care situation and insight in their needs and desires; and improved mutual understanding among family members.

Table 2. Family members' (FM) and patients' (P) evaluation of the family nursing conversations

		3 3	, .	,	
		Totally disagree n (%)	Disagree n (%)	Agree n (%)	Totally agree n (%)
I experienced the family nursing conversations	Р	0 (0.0)	0 (0.0)	8 (42.1)	11 (57.9)
as useful	FM	0 (0.0)	1 (3.0)	9 (27.3)	23 (69.7)
For me, the family nursing conversations have contributed to:					
improved insight in the care situation	P	0 (0.0)	0(0.0)	13 (68.4)	6 (31.6)
	FM	0 (0.0)	2 (5.9)	14 (41.2)	18 (52.9)
clear agreements about the roles and tasks of	P	0(0.0)	1 (5.6)	9 (50.0)	8 (44.6)
all people who are involved in the care situation	FM	0(0.0)	1 (2.9)	16 (47.1)	17 (50.0)
insights in the needs and desires of all people	P	0(0.0)	1 (5.6)	10 (55.6)	7 (38.9)
who are involved in the care situation	FM	0(0.0)	1 (2.9)	20 (58.8)	13 (38.2)
increased mutual understanding for each	P	1 (2.9)	1 (5.6)	11 (61.1)	6 (33.3)
other in our family	FM	0(0.0)	1 (2.9)	16 (47.1)	16 (47.1)

Below, the main results will be presented per research question; all scores and test results are presented in Table 3.

² Pearson Chi-Square test

Table 3. Family member, patient and home health care variables – Main and interaction effects of Time (To = pre-intervention; $T_1 = post-intervention$) and Group (group 1 = intervention; group 2 = control)

Variable (range)	Main ef	fect Time	within gr	oup 1	Main effect Time within group 2			Interaction effect Time x Group**		
	Mean (sd) To	Mean (sd) T1	ß (SE)	p	Mean (sd) To	Mean (sd) T1	ß (SE)	р	ß (SE)	р
Family member	rs' caregi	ver burde	n (CarerC	QoL) and	family func	tioning (I	FAD-N-GF)		
CarerQol 7D ^a (0–100)	83.05 (11.94)	84.49 (12.27)	1.44 (2.02)	.413	85.88 (11.24)	81.58 (11.65)	-4.30 (1.67)	.010*	5.74 (2.43)	.018*
CarerQol VAS ^a (0–10)	7.12 (1.23)	7.28 (1.18)	0.16 (0.18)	.378	7.13 (1.12)	6.84 (1.07)	-0.29 (0.18)	.092	0.45 (0.25)	.073
FAD-N-GF ^b (1-4)	2.61 (0.29)	3.46 (0.44)	o.85 (o.o9)	<.001*	2.80 (0.50)	3.18 (0.57)	0.38 (0.11)	<.001*	0.47 (0.14)	.001*
Patients' healtl	n-related	quality of	life (EQ5I	O) and fa	mily functio	oning (FA	D-N-GF)			
EQ5D 5D ^c (-0.33–1)	o.66 (o.18)	0.60 (0.22)	-o.o6 (o.o3)	.077	0.56 (0.21)	0.51 (0.26)	-0.05 (0.04)	.168	-0.01 (0.05)	.914
EQ5D VAS ^c (0–100)	60.71 (17.61)	63.90 (21.13)	3.19 (3.99)	.424	57.68 (21.58)	58.43 (17.43)	0.75 (3.18)	.813	2.44 (5.10)	.632
FAD-N-GF ^d	3.35 (0.50)	3.58 (0.47)	0.23 (0.10)	.023*	3.21 (0.42)	3.04 (0.38)	-0.18 (0.10)	.071	0.40 (0.14)	.004*
Home health care in hours per week in the week prior to To and the week of T1										
Hours	4.95 (3.62)	3.87 (3.42)	-1.07 (0.46)	.020*	5.71 (5.23)	5.87 (6.24)	0.16 (0.41)	.703	-1.23 (0.62)	.047*

^a n group 1 = 34; n group 2 = 27

Family Caregiver Burden (CarerQoL)

There was a significant interaction between Time and Group for the CarerQoL-7D (β (SE) = 5.74 (2.43), p = .018). Family members' care-related quality of life on the seven dimensions did not change significantly between To and T1 in the intervention group $(\beta (SE) = 1.44 (2.02), p = .413)$ whereas it decreased significantly in the control group $(\beta(SE) = -4.30 (1.67), p = .010)$, indicating increased burden in the control group. No significant interaction between Time and Group was found for the CarerQoL-VAS (\$\beta\$ (SE) = 0.45 (0.25), p = .073).

Family Functioning (FAD-N-GF)

For family members, there was a significant interaction between Time and Group for family functioning (β (SE) = 0.47 (0.14), p = .001). Family functioning improved significantly more from To to T₁ in the intervention group (β (SE) = 0.85 (0.09), p = <.001) than in the control group (β (SE) = 0.38 (0.11), p = <.001).

For patients, a significant interaction between Time and Group for family

^{*} Difference significant at p<.050

 $^{^{}b}$ n group 1 = 29; n group 2 = 20 ^c n group 1 = 21; n group 2 = 30

^{**} Model = intercept, time, group, time x group

^d n group 1 = 14; n group 2 = 21

functioning was found as well (β (SE) = 0.40 (0.14), p = .004). Family functioning significantly improved from To to T1 in the intervention group (β (SE) = 0.23 (0.10), p = .023) whereas no significant change emerged in the control group (β (SE) = -0.18 (0.10), p = .071).

Patients' Health-Related Quality of Life (EQ-5D-5L).

There were no significant interactions between Time and Group for patients' EQ-5D $(\beta(SE) = 0.01(0.05), p = .914)$ and EQ-5D-VAS $(\beta(SE) = 2.44(5.10), p = .632)$.

Amount of Professional Home Health Care per Week

A significant interaction between Time and Group was found for the number of hours of usual home health care per week (β (SE) = 1.23 (0.62), p = .047). In the intervention group, the number of hours significantly decreased from To to T1 (β (SE) = -1.07 (0.46), p = .020) whereas no significant change was found in the control group (β (SE) = 0.16 (0.41), p = .703).

DISCUSSION

The purpose of this study was to evaluate the effects of family nursing conversations in home health care. The results indicate that family nursing conversations improved family functioning and protected family caregivers' wellbeing by preventing increased caregiver burden whereas patients' quality of life was unaffected. The amount of usual home health care decreased following the family nursing conversations.

The results of this study demonstrate that family nursing conversations embedded in home health care can contribute to preventing family caregiver burden over time. Although the intended 8-point difference on the CarerQoL was not achieved, a substantial difference between the groups nonetheless emerged. The increase in family caregiver burden in the control group is to be expected in a population with frail older patients with gradually decreasing self-care abilities and increasing support needs (Dauphinot et al., 2016; Ransmayr et al., 2018; Van der Lee, Bakker, Duivenvoorden, & Dröes, 2014). A reason that family nursing conversations prevented this increase in caregiver burden can be found in previous qualitative studies. These indicate that conversations based on the Family Systems Nursing framework leave family members feeling strengthened and relieved and encouraged them to regard their own needs (Dorell et al., 2016) and made the illness situation more manageable through the support of other family members (Benzein et al., 2015).

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Results further demonstrate that perceived family functioning in both patients and family members improved significantly following the family nursing conversations. Other studies also found that poor family functioning is associated with caregiver burden (Francis et al., 2010; Heru et al., 2004; Tremont et al., 2006). However, in the control group, caregiver burden increased, but family functioning improved, although significantly less compared to the intervention group. The improvements in family functioning in the control group, therefore, were unexpected and could be a consequence of nurses' and families' study participation. Nurses may have become more aware of the nursing diagnoses related to caregiver burden and adjusted their practice. Family members' may have been stimulated to think about their family functioning by filling in the questionnaires.

Patients' quality of life did not improve following the family nursing conversation. A previous study, however, found improvements in middle aged stroke patients' quality of life as measured with the EQ5D (Lämås et al., 2016). The older and more heterogeneous patient sample in the current study might explain the lack of effect. In addition, the power in the relatively small patient sample may have been insufficient. Finally, it could be that effects on patients' quality of life only emerge after longer periods of time. Effects of family nursing conversations on patients' wellbeing must be further explored in future studies.

To our knowledge, the effects of conversations based on Family Systems Nursing on the required amount of professional care have not been previously studied. This study found a reduction in the amount of professional home health care after two family nursing conversations. Nurses explained this decrease by a more efficient distribution of professional care over patients and an increase in family caregiving. The effects of the conversations on the use of other types of health care and on personal and societal costs associated with caregiver burden (Colombo et al., 2011) must be assessed from a broader societal perspective in future research. It is possible that care in the intervention group has shifted from home health care to other health care services such as day care or nursing home care. However, this seems unlikely as the use of day care services and nursing home placement is usually related to increasing caregiver burden (Chenier, 1997; Kuzuya et al., 2011; Mittelman et al., 2006) and caregiver burden was prevented through the conversations.

This study was designed to test the effects of family nursing conversations as they are applied in a real life context as part of home health care with a high workload. Nurses fulfilled a dual role with organizing and conducting the conversations as part of usual nursing care as well as approaching potential participants and monitoring dropout. Nurses were also requested to register who they approached; who declined

and why; and to record which of the components they had applied. This seemed feasible to nurses beforehand, however, it was soon realized that it took too much time. According to the nurses, the inability to achieve the intended sample size was primarily due to the amount of time associated with the study for themselves and the families and not to the feasibility of the intervention. Nurses' comments during group meetings and participants' evaluations of the conversations suggest that the family nursing conversations were valuable to both nurses and families.

Implications

The positive impact of family nursing conversations on family functioning and caregiver burden are important findings in the context of policy changes that emphasize family caregiving (Broese Van Groenou & De Boer, 2016). Often, family relationships are not optimally suited for a situation of caregiving (Hogerbrugge & Silverstein, 2015). Home health care nurses are increasingly expected to provide care that is supplementary to the care offered by families (Broese Van Groenou & De Boer, 2016; Funk, 2013). To protect family members' wellbeing, nurses must provide support and collaborate with families (Calvó-Perxas et al., 2018; Wittenberg et al., 2019). It seems important, therefore, that these conversations become part of regular nursing education in order to optimally prepare nurses for their responsibilities to families in society. The International Family Nursing Association has established position statements on pre-licensure and graduate education that can be used to develop education (IFNA, 2013, 2018).

In future studies, the effects of family nursing conversations in subgroups such as specific patient diagnoses can be assessed. Additionally, the effects of the intervention on nurses' work satisfaction and nurse staffing ratios could be assessed as well as effects on nurse-family relationships. Finally, exploring the patterns of change as they occur over time following a family nursing conversation could assist in finding the optimal dose of the intervention and determining longer-term effects.

Limitations

Several study limitations were related to the pressure that the study put on participating nurses' workload. A first limitation is that the approach of eligible participants was not registered systematically. It could be that families that were heavily burdened are underrepresented in the results, especially since participants that were lost to follow-up frequently indicated that they experienced filling in the questionnaire as too burdensome. Nurses might have hesitated to approach families experiencing severe burden because they did not want to add further burden. On the other hand, families that are more heavily burdened have been found to be more likely to consent to participate in a survey study (Oldenkamp et al., 2016). Another

limitation was the smaller than intended sample sizes suggesting that the results must be interpreted with caution. A final limitation related to nurses' workload was that intervention fidelity was not assessed systematically in the current study.

In addition to these limitations, random allocation of participants to groups was not feasible as intervention group nurses participated in an educational program that would have changed their approach towards both intervention and control group participants (Broekema et al., 2018). Finally, as teams were not randomly selected, selected nurses may be more motivated for family-focused care than the average nurse.

Conclusion

An intervention consisting of two family nursing conversations integrated into home health care reduced the required amount of professional home health care while preventing an increase in caregiver burden and positively affecting family functioning. As such, this intervention helps nurses to extend their nursing care to include patients' families and could be a valuable response to the expected insufficient availability of professional care in ageing societies.

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