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## Family Nursing Conversations in Home Health Care

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# Chapter 7

General discussion

The studies in this thesis were conducted in the context of the health care problem faced by countries with aging populations: namely, increasing health care needs and decreasing availability of professional caregivers to fulfill these needs (World Health Organization, 2015b). In many countries, including the Netherlands, family members are called upon to fill this gap (Spasova et al., 2018). Intensive informal caregiving, however, puts family caregivers at risk of caregiver burden (Bom et al., 2019), which can contribute to further increases in health care needs (Bremer et al., 2015; Stall et al., 2018). To assess the feasibility of family nursing conversations to protect families' wellbeing in this context, the knowledge-to-action framework (Graham et al., 2006) was used to implement these conversations into nursing practice in the Netherlands. In family nursing conversations, nurses, patients, and their families work together to develop a care plan that aligns with the needs and preferences of all involved. The thesis focused on monitoring the use and assessing the effects of family nursing conversations in Dutch home health care nursing practice.

### **Summary of main findings**

#### ***Monitoring knowledge-use***

The goal of the mixed-methods study in Chapter 2 was to explore nurses' perspectives on the effects on their competency (attitudes, knowledge, and skills) of a 6-day educational intervention in family nursing conversations. A group of ten home health care nurses and eight hospital nurses participated in the educational program and the study. The participating nurses completed the "families' importance in nursing care – nurses attitudes" questionnaire before and after the educational program. The results indicated that the nurses' attitudes toward families were more positive after completing the educational program. Subsequent interviews with the nurses revealed that the educational program had increased their awareness of the importance of families in nursing care. The nurses explained that their focus had broadened to include patients' families, and their attitudes toward family nursing conversations had become more positive, especially in the context of home health care. In addition, the nurses reported that their theoretical and practical knowledge of Family Systems Nursing and family nursing conversations had increased. They also described improvements in their ability to organize, structure, and conduct family nursing conversations. As a result, they felt sufficiently competent to conduct family nursing conversations after the educational program. The program thus contributed to conceptual knowledge-use and successfully lowered the barrier to knowledge-use that a lack of education in Family Systems Nursing had previously presented.

The qualitative study in Chapter 3 aimed to monitor instrumental knowledge-use by describing how nurses applied the twelve components of family nursing conversations in conversations in their home health care practice. Ten home

health care nurses that participated in the educational program delivered a total of seventeen audio-recorded family nursing conversations and their written reflections on these conversations for analysis. All components were used in the conversations, with some being more frequently or easily applied than others. Additional experience in conducting family nursing conversations was deemed necessary to further improve the nurses' confidence and skill. Using their clinical judgment, the nurses adjusted or omitted components based on the needs of the family in the specific care situation. The components were thus used as a guideline, rather than a strict protocol. Overall, the nurses' application of the components in their practice demonstrated sufficient instrumental knowledge-use.

### ***Assessing the outcomes of knowledge-use***

The grounded theory study in Chapter 4 was designed to propose a model of the benefits and working mechanisms of family nursing conversations in home health care, as seen from the perspective of participating patients and their family members. Family members and patients from eleven families participated in a family nursing conversation and were each interviewed four to six weeks later. The resulting model consisted of four components. During and immediately after the family nursing conversation, patients and family members gained a sense of overview of the care situation, and the contact between the people involved improved. In the longer-term, these changes resulted in reduced caregiver burden and improved quality of care.

Chapter 5 described a cross-sectional study that quantitatively evaluated the model developed in the preceding chapter. In the study, 111 dyads (each consisting of a patient and a family member) completed a set of questionnaires regarding their overview of the care situation, the quality of contact among the people involved, caregiver burden, and quality of care. The results provide support for the qualitative model: Associations were found between "overview of the care situation" and "contact among the people involved" on one hand and "reduced caregiver burden" and "improved quality of care" on the other.

Chapter 6 presented a quantitative before-and-after study with a control group in which the effects of family nursing conversations on caregiver burden, family functioning, patient's quality of life, and amount of professional home health care were assessed. Intervention group families (21 patients, 34 family members) participated in two family nursing conversations, which were integrated into the usual home health care. The control-group families (30 patients, 27 family members) received home health care as usual. Both groups completed questionnaires before and three months after the intervention to assess family functioning, caregiver burden, and patient quality of life. The hours of home health care that a family

received per week were extracted from patient records. The results indicated that, after two family nursing conversations, family caregiver burden had remained stable over time in the intervention group, but had increased in the control group, and family functioning had improved. The family nursing conversations did not affect patients' quality of life. Finally, in the intervention group, there was a decrease in the number of hours of home health care provided per week, which was not found in the control group. Thus, the family nursing conversations had the intended effects on family caregiver burden and family functioning, without increasing the amount of professional home health care required.

### **Strengths and limitations**

A strength of this thesis is that it combined qualitative, quantitative, and mixed-method approaches. Combining research methods enables more effective research into complex health interventions such as family nursing conversations (Borglin, 2015). In addition, in the evaluation of a complex health intervention, it is important to focus not only on whether the intervention produced the intended effects, but also on evaluating the implementation processes, clarifying the working mechanisms, and identifying the contextual factors (Moore et al., 2015). In this thesis, the combination of research methods enabled a more complete understanding of the implementation processes (Chapters 2 and 3), working mechanisms (Chapters 4 and 5), and outcomes (Chapters 4 and 6) of family nursing conversations in home health care. Contextual factors were incorporated into the design and discussion of the results in each study. Nonetheless, contextual factors – such as societal developments, formal regulations, and organizational policy and support – could have been more explicitly integrated into the core of the thesis, for example in a study of promoting factors and barriers.

The real-life context of this thesis – namely, families facing the risk of caregiver burden and challenged family functioning and home health care nurses with heavy workloads – was both a strength and a limitation of the project. It was a strength because the creation of evidence in the real world, with the involvement of practitioners, increases the likelihood that the evidence will subsequently be used in practice (Green, 2008). The results described in this thesis can be expected to be seen when skilled nurses incorporate family nursing conversations with adults into their home health care practice. Home health care nursing patients in the Netherlands are primarily older adults – 75% are over the age of 67 years, with a median age of 84 years (Vektis, 2020). This is comparable to the average of 80 years in the study presented in Chapter 6 of this thesis. Underaged children were excluded from the family nursing conversations and thus from the studies in this thesis, both as patients and as family members. Therefore, the results of this thesis cannot be

generalized to children under the age of 18. The studies were conducted in the north of the Netherlands. There are some marked differences between the north (and other more rural areas) and the “Randstad,” the conurbation in the central-west. In more rural areas, such as the north, the demand for home health care is almost twice as high due to more pronounced ageing of the population (Vektis, 2020). In addition, the Randstad area is home to more people of a non-Western migration background: while this demographic comprises around 3% in most parts of the north and 8–12% in the largest cities there, figures reach 24–39% in the cities in the Randstad (CBS, 2021). Therefore, the results of the thesis should only be generalized to areas with populations similar to those found in the northern part of the Netherlands.

The real-life context of this thesis was a challenge for the study design and methods. It is likely that nurses with the heaviest workloads and family members with the most severe caregiver burdens are less represented in the results. This is due to a bias in both the selection of the nurses by their organizations and the selection of the families by their nurses. Reducing the time investment for study participation and selecting participants at random could reduce this selection bias in future studies. In addition, in Chapter 6, the sample size was smaller than intended due to the nurses and family members’ limited availability of time and energy to invest in study participation. These smaller sample sizes made it difficult to distinguish between the outcomes of the different target groups (e.g., patient diagnoses and family relationships). The results were found in the overall adult home health care population. However, it is unknown whether the results would apply equally to all subgroups within this population, or whether some or all of the effects of the family nursing conversations would be more pronounced in some subgroups than in others. Again, reducing the time and energy required for study participation could improve sample sizes and thereby provide further insights into what works for whom.

### **Contribution to the field of Family Systems Nursing**

The results of this thesis are promising with respect to the value of family nursing conversations in home health care. As such, they are well-aligned with the few other studies that have focused on Family Systems Nursing-based conversations in home health care. In palliative home health care, these conversations were considered to be valuable by couples (Benzein & Saveman, 2013) and nurses (Petursdóttir et al., 2019). Caregiver burden and anxiety and stress among informal caregivers of palliative patients decreased after participating in two conversations, while perceived support from the nurse increased, although results were somewhat mixed (Petursdottir et al., 2020, 2021; Petursdottir & Svavarsdottir, 2019). In families with a family member under the age of 65 years who had suffered a stroke,

participants considered the conversations to be useful (Östlund et al., 2016). One mixed-methods study revealed that, in these families, family health improved and family communication was enhanced (Sundin et al., 2016). In addition, after the conversations, the family assumed shared responsibility for the problems that they encountered. A feasibility study conducted with this population found that a series of three conversations was cost-effective compared to ordinary care (Lämås et al., 2016). Finally, in Sweden, efforts have been made recently to implement Family Systems Nursing conversations in home health care (Pusa et al., 2021). Nurses considered the conversations to be valuable for both themselves and the families. The co-creation of goals and plans was facilitated, and problems could be solved and prevented.

The study described in Chapter 4 is among the first to focus explicitly on the working mechanisms of Family Systems Nursing interventions (such as family nursing conversations) from the perspective of the families. Previous qualitative studies evaluating families' experiences of participating in these conversations have identified some potential working mechanisms. For example, families considered the structure of the conversation and the experience of talking with someone who is not a part of the family to contribute to their wellbeing (Benzein et al., 2015). Becoming visible to each other has also been highlighted as important (Dorell & Sundin, 2016). A recent study concludes that family health conversations support family functioning by increasing understanding and concern for one another and working through experiences (Ahlberg et al., 2020). In this light, the coherent model of the benefits and working mechanisms of family nursing conversations in home health care (Chapter 4) and the subsequent testing of the model in a quantitative study (Chapter 5) are valuable additions to the field. Insights into the working mechanisms of an intervention are essential for effective implementation and application in health care practice (Campbell et al., 2007).

The pretest-post-test study with control group described in Chapter 6 also contributes to the body of knowledge of Family Systems Nursing. At the start of this project in 2016, conversations based on Family Systems Nursing had primarily been studied using qualitative research designs (Östlund & Persson, 2014). Since then, the number of quantitative studies has increased. Nonetheless, the vast majority of these studies used a one-group design, and only a small number employed a control-group design. The studies with control group were conducted with a variety of patient populations, such as patients with schizophrenia (Hsiao et al., 2021); oncology patients (Faarup et al., 2019; Zimansky et al., 2020); and patients at a heart failure clinic (Østergaard et al., 2021). The exact contents and structures of the Family Systems Nursing conversations also varied, from one brief conversation

(Halldórsdóttir & Svavarsdóttir, 2012) to three structured one-hour conversations (Sundin et al., 2016). There were also differences in study design, specifically in the number of study participants and the number and timing of data collection. Finally, a wide variety of outcome measures was used, including illness symptoms (Hsiao et al., 2021); patients and family members' health status (Sundin et al., 2016); family caregiver anxiety (Petursdóttir et al., 2020); family functioning (Ågren et al., 2019); and perceived support from the nursing staff (Sveinbjarnardóttir et al., 2013). The mixed results found for nearly all outcome measures should thus be attributed to these differences. With a complex health intervention, the selection of outcome measures is complex and closely related to the development of the intervention (Buhse & Muhlhauser, 2015). Together, these studies gradually provide insights into what works for whom with regards to conversations based on Family Systems Nursing. The study in Chapter 6 was the first pretest-posttest study with control group to be conducted in home health care, and as such, it adds to this growing body of evidence.

### **Implications for Policy and Clinical Practice**

The evidence for the value of family nursing conversations in long-term home health care is promising but not yet substantial. Nevertheless, family nursing conversations meet the call from the World Health Organization for a paradigm shift in long-term health care toward people-centered care at home, which involves integrating the perspectives and needs of families (World Health Organization, 2015a). This shift to a person-and-family-centered approach is necessary to meet the challenges that health care systems are currently facing. Likewise, the Netherlands Institute for Social Research (SCP), a Dutch governmental agency, recommends that home health care organizations extend their range to include patients' families, as family members are both co-caregivers and co-care-recipients (De Klerk et al., 2017). Providing care to families is also part of the International Council of Nurses' definition of nursing (ICN, 2019). This thesis shows that family nursing conversations could be a means by which home health care nurses could meet this recommendation and extend their care to include patients' families.

### ***Access to care at home: advantages of family nursing conversations over current practice***

Family nursing conversations are a potential alternative to the conversations currently required in the Netherlands for home-dwelling adults and their informal caregivers to access care. Dutch care regulations grant home health care nurses and municipalities the task of making decisions about home health care access and support for informal caregivers. Since 2015, both home health care nurses and municipalities have been obliged to have conversations with patients and their

informal care networks to assess the needs of the situation and the capabilities and limitations of the people involved and to discuss their needs for professional care (Zorginstituut Nederland, 2019). These regulations correspond well with the contents of a family nursing conversation. In practice, however, the current conversations are quite different from family nursing conversations, and the latter have two advantages over current practice.

The first advantage of a family nursing conversation over current practice is that, in consultation with the care recipient, all important members of the social network are invited to the conversation. This offers opportunities to develop a customized approach in which the care load is spread more evenly and professional care fits the needs of the specific situation (Chapter 4; Pusa et al., 2021). In current practice, however, typically only the care recipient and sometimes the primary family caregiver are invited to the conversation. Sixty percent of primary informal caregivers were present at the most recent formal conversation with the home health care nurse about the amount and type of care (Francke et al., 2017). In four out of ten conversations with the municipality, only the care recipient was present (Social Planbureau Groningen, 2018). The current approach has two risks. First, it is less likely that the professional will obtain a complete picture of the care situation and the needs, capabilities, and limitations of all the people involved. Therefore, the outcomes of the conversation may be suboptimal for the specific care situation. Second, it is less likely that other members of the network will become involved in the care situation, which will maintain or even increase the care load for the primary caregiver. Intensive caregiving is a major risk factor for caregiver burden (Alice de Boer et al., 2020).

The other advantage of a family nursing conversation over current conversations regarding access to care is the focus on the wellbeing of the family and shared goals. In a family nursing conversation, the professional and the family mutually develop a care plan that is optimal for the specific care situation, taking any obstacles into account (Chapter 3 and 4; Pusa et al., 2021). The intention is not to increase family caregiving and decrease professional care, but to come to a division of tasks that works best for everyone involved – patient, family members, and professional caregivers. According to care recipients, the care-related wellbeing of informal caregivers was discussed in only 19% of the conversations in current home health care practice (Francke et al., 2017). Additionally, although family members are protected from being forced to provide care, many experience pressure to do so nonetheless (Hees et al., 2018). This is understandable in the broader context of growing health care needs and shortages of professional caregivers. Persuading family members to provide care, however, is likely to have the opposite effect to what is intended

(Oudijk et al., 2011). It also seems to be unnecessary: the vast majority of Dutch citizens consider it important that family members help each other in the event of health issues (de Boer et al., 2020). In addition, Dutch people tend to provide informal care because it is needed and because they enjoy it or want to make a contribution (Oudijk et al., 2011). People who do not participate in caregiving frequently face obstacles such as occupational and personal responsibilities, disturbed family relationships, and a lack of self-confidence in caregiving tasks (De Klerk et al., 2017). Moreover, informal caregivers are not always available. In aging societies, it is not only the availability of professional caregivers that decreases: the availability of informal caregivers – volunteers and family members – is also reduced (Kooiker et al., 2019). One in five Dutch citizens over the age of 65 years indicates that there is no one who could provide informal care for them (de Boer et al., 2020). In a family nursing conversation, any of these obstacles can be explored and taken into account in the care plan that is developed. Goals of the care plan could include extending or strengthening the care recipient's or the family's social network.

### ***Implementation of family nursing conversations in home health care***

Home health care organizations could consider the implementation of family nursing conversations for the benefit of not only patients and families but also home health care professionals. Nurses' workloads could be reduced by improving communication with and within families, as this would enable problems to be solved or prevented altogether (Chapter 6; Pusa et al., 2021). In addition, health care professionals are more likely to be informal caregivers themselves (De Klerk et al., 2021), so preventing or reducing caregiver burden is also important to home health care organizations as employers. Home health care organizations that are considering the implementation of family nursing conversations must address several conditions.

### ***Involvement of stakeholders***

When implementing a complex health intervention, such as family nursing conversations, it is important to involve key stakeholders in all phases (Richards & Hallberg, 2015). In this thesis, home health care nurses and managers, patients and families, nursing students and educators, and a health care insurance company each delivered the input for the design and methodology of the studies, offered practical support, or participated in the studies. The family nursing conversations provided an answer to a problem that concerned all of these stakeholders: how to organize care situations in home health care so that the needs, opportunities, and limits of patients, family members, and professional caregivers are integrated. It is important to reach agreement on the definition of the problem and the knowledge required to solve the problem. This agreement among key stakeholders would increase the

likelihood of successful implementation of Family Nursing Conversations in a home health care organization.

### *Education*

An important step toward implementation of family nursing conversations is education for practicing home health care nurses. This is a challenge, as large workloads will reduce the opportunities for nurses to participate in professional education (Coventry et al., 2015). A partially web-based educational program could be easier to integrate into nurses' schedules (Pusa et al., 2019). Train-the-trainer and peer-coaching could also be of use. The studies in Chapters 2, 4, and 6 found that organizational investment in education is likely to have long-term positive impacts on the quality of patient care and on nurses and families' wellbeing. Education for nursing students was not part of this thesis. Nonetheless, with the challenges that long-term care systems are facing, educational institutions could consider integrating family nursing conversations into undergraduate nursing curricula. As a family nursing conversation is a complex intervention that requires nurses to have a combination of attitudes, knowledge, and skills that take time to master (Chapters 2 and 3); has several interacting goals on the levels of the individual, the family, the professional, and the interactions between them; and requires the nurse to tailor the conversation's components to fit the needs of each unique care situation (Chapter 3), a step-by-step approach to educating nursing students in this intervention is advisable.

### *Management support*

The support of management staff is important for preventing a heavy workload from becoming a barrier to the use of family nursing conversations. Reducing nurses' workloads is important to protect both nurses' health and the quality of patient care (Pérez-Francisco et al., 2020). Unfortunately, heavy workloads are considered a major obstacle to the translation of evidence to practice (Williams et al., 2015). Indeed, a large workload has been found to reduce the likelihood of nurses engaging in family nursing conversations (Pusa et al., 2021). This is unsurprising because, under stressful conditions, people tend to value short-term rewards (e.g., solving an acute problem) above long-term punishments (e.g., spending time in the future resolving acute problems that could have been prevented earlier; Starcke & Brand, 2012). To facilitate the stress-reducing effects of family nursing conversations for both nurses and families, home health care organizations must incorporate the conversations into the care processes of all families at risk for caregiver burden. In that way, nurses under stress will not have to decide on a case-by-case basis whether to organize a family nursing conversation.

### *Sustained knowledge-use*

To sustain the use of family nursing conversations in a home health care organization, the intervention should be institutionalized, thus visibly integrated into organizational policy and practice (Duhamel, 2017). A useful approach could be to transform into an family nursing conversations all intake and evaluation conversations with patients whose family members are at risk for caregiver burden. This includes family members who provide intensive care or who provide care to their partner or to a patient with dementia, a terminal illness, or mental health problems (de Boer et al., 2019). The content of the intake and evaluation conversations would thus be broadened to include the experiences, needs, and ideas of the family, and any implicit or explicit pressure on family members to participate in caregiving would be removed. Organizational procedures would have to ensure that family members were actively invited to the intake and evaluation conversations. Nurses could use the twelve components of the family nursing conversation as a guideline to provide a clear overview of the care situation and improve the contact between the patient, family members, and professional caregivers (Chapters 3 and 4). The goals and plans agreed in the FNC must then have the support of all members of the home health care team (Pusa et al., 2021). In addition, reporting systems must allow reporting of the outcomes of the conversation so that these are available to all members of the family and of the home health care team.

### **Recommendations for future research**

Several recommendations for future research can be derived from this thesis. The first recommendation concerns the question of what works for whom. With a complex health intervention, it is quite likely that effects will differ based on the personal characteristics of the participants (Richards & Hallberg, 2015). Personal characteristics may also influence which components of the family nursing conversation contribute most to the effects. The illness of the patient and their gender, age, and social and cultural background may all influence the experiences and outcomes of the family nursing conversation. Likewise, the influences of family members' relationship with the patient and the quality and amount of their contact may be of interest in future research, as well as their gender, age, and social and cultural background. In patients with dementia and their families, for example, the participation of the patient in the conversation is more complex and not always advisable (Busted et al., 2019). Another subgroup of interest is families with a non-Western migration background. The use of home health care by people from this demographic is expected to increase in the coming years, both due to an aging population and the decline of the traditional view that family members should provide all care at home (Verstappen & Van Den Broeke, 2018). The specific needs of this population should be explored and perhaps incorporated into the components

of family nursing conversations.

A second recommendation, arising from the first, is to focus future research on variables associated with the nurses themselves that may influence the family nursing conversations and their outcomes. These variables might include nurses' attitudes, knowledge, skills, and professional and personal experiences. Previous research has for example shown that work experience and work setting influence attitudes toward the importance of families in nursing care (Hagedoorn et al., 2021), and that beliefs about the value of Family Systems Nursing affect implementation (Duhamel, Dupuis, Turcotte, Martinez, & Goudreau, 2015). Future research could focus on the influence of these nurse-related variables on the process during the family nursing conversation, and on the effects that the conversations have on families.

A final recommendation for future research concerns the research and implementation of family nursing conversations in settings other than home health nursing care with adult patients and family members. In the Netherlands, hospital nurses have participated in education in family nursing conversations (Chapter 2). Previous studies from Iceland, where Family Systems Nursing was implemented in all departments of a hospital, including the children's and psychiatric departments, have shown Family Systems Nursing to be promising in these settings as well (Svavarsdottir et al., 2012, 2015; Sveinbjarnardottir et al., 2013). Future studies could examine family nursing conversations by other professionals, such as social workers. To effectively study and implement family nursing conversations in other settings (such as hospitals and mental health care) in the Netherlands, it is recommended to apply the knowledge-to-action framework and begin by defining the problem that family nursing conversations should solve in that setting (Graham et al., 2006). In the following step, knowledge should be adapted to the local context; and the goal, structure, and organization of the family nursing conversation – including the components – must be reassessed and adapted to the specific setting. In the hospital setting, for example, the problems identified may be focused on reducing the length of hospital stays and preventing readmissions (OECD, 2021). Contact with the patient and family is generally more limited in time in this setting than it is in the home health care setting. In addition, inviting all those involved in the care situation to the family nursing conversation could be more difficult due to this limited timeframe. Nonetheless, conversations in which the patient, a family member, and a professional are present do occur (Hagedoorn et al., 2017); therefore, there are opportunities for a family nursing conversation. Dutch hospitals typically have transfer nurses who guide patients through the transfer from hospital to home or other care facility. An family nursing conversation could fit well with this specific role.

**Conclusion**

This thesis was intended to examine the feasibility of family nursing conversations in home health care nursing, with the goal of protecting families' wellbeing in a context that emphasizes informal care by family members. Nurses were able to apply Family Systems Nursing knowledge and conduct family nursing conversations in their home health care practice with adult care recipients and their families. As a result, families' wellbeing was protected and additional pressure on the care system was prevented. The results are promising with respect to the value of family nursing conversations for the wellbeing of families in long-term care situations.

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