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Expressed emotions and experiences from relatives regarding having a family member living in a nursing home for older people

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Abstract

Objectives: The purpose of this study was to describe the topics relatives with a family member in a nursing home for older persons choose to talk about and focus on when participating in a nurse-led "Family Health Conversations" intervention. Family Health Conversations consisted of a series of three nurse-led conversations with each family, with a 2-week interval between meetings.

Methods: The Family Health Conversations meetings were tape-recorded and analyzed using qualitative content methods. The participants were relatives of family members living in a nursing home for older persons in a municipality in Sweden.

Results: The findings showed how the relatives talked about their suffering and difficulties concerning the new situation. The relatives talked about frustration and sadness together in a new way, with a focus on how to manage the future. They also wished that they had been offered an opportunity to talk about this with nurses earlier in the illness trajectory.

Conclusion: The relatives had a significant need to talk about their experiences together within the family and together with the nurses. Nurses have an especially important task in supporting relatives having a family member living in a nursing home.

Keywords

Family Health Conversations, relatives, nursing home, family systems nursing, family health

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Introduction

Many relatives experience hardship when a family member moves into a nursing home for older persons.[1,2] This is often because they lose day-to-day contact with that family member and also have to change their daily routines. They also often experience feelings of loneliness.[3] In this changed situation, relatives generally experience feelings of powerlessness, and feelings of frustration, failure, loss, and guilt have also been commonly reported.[1–5] Some relatives wish to remain involved in the lives of their family member following placement in a nursing home.[6] Knowing that their family member will receive good care brings a sense of belonging for relatives.[7] Research also shows that sharing the burden with family members and with nurses can decrease the burden on families and can increase health and well-being.[8]

The relationship between relatives and nurses is often shallow and difficult, and such strained relationships result in poor communication between nurses and relatives.[9] Many relatives do not feel comfortable expressing that something is wrong because they are afraid that it might lead to negative consequences for their sick family member.[10] In addition, nurses have their own personal and professional beliefs about families and diseases, and these beliefs have a significant impact on how a nurse sees, assesses, and cares for a patient.[11] Nurses might pay attention to both a patient and his or her relatives when a situation is a crisis not only for the patient but also for the whole family. Nurses should also pay more attention to a significant other's point of view, experiences, and desires.[12,13] Family systems nursing (FSN) is a theory which considers the family as a unit. FSN is a way for nurses to work with families in a systemic manner. It can be conceptualized as focusing on the whole family as a unit of care, on both an individual and the family simultaneously, and on interaction and reciprocity within the family. The

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goal of FSN is to sustain health and well-being in families. FSN takes place through relationships and communication between families and nurses.[13–18]

It is important for nurses to understand that family health and well-being are influenced by situations in which family systems change. If a family member is affected by disease and illness, it can affect all family members in terms of family function, family roles, and beliefs.[13] When family members living in nursing homes and their relatives are seen from a family systems perspective, the understanding of family life is enhanced. Therefore, it is important for nurses to see the family as a unit. Åstedt-Kurki et al.[9] showed that it is necessary to realize that family members are experts on their own lives and their own experiences with the patient's illness. Nurses, on the other hand, are experts in understanding disease diagnoses and nursing.

An FSN intervention called Family Health Conversations (FamHCs) has been implemented in Sweden. It is a series of three conversations that is considered to have a healing effect on families.[8,19–26] FamHC interventions are influenced by the Calgary Family Assessment Model (CFAM), the Calgary Family Intervention Model (CFIM),[13] and the Illness Beliefs Model (IBM),[11] but have been further developed to fit the Swedish context.[27] These conversations focus on the interplay and relationships among family members and their beliefs. FamHCs use a salutogenic approach[28] and emphasize the significance of narration and reflection.[29] The purpose of these conversations is to identify a family's problems and find the family's internal and external resources to strengthen their health.[14,25]

The findings from FamHCs show that family members gain insight and improve communication with each other and with nurses because the conversations make room for understanding each other better.[22] This gives nurses a tool for interacting and communicating with both individual family members and the family as a whole in a more supportive way.[15]

Purpose

The purpose of this study was to describe the topics relatives with a family member in a nursing home for older persons choose to talk about and focus on when participating in a nurse-led FamHC intervention.

Method

Design

A qualitative content analysis was used for this study, where both the manifest and latent meanings of the text were sought.[30]

Intervention and procedure

This study is part of a larger intervention of nurse-led FamHCs with families who have a family member living at a nursing home for older people. The larger study includes three nursing homes in a municipality in Sweden. This study includes data from one of these nursing homes, to comprise relevant amount data. The FamHC consists of a series of three 1-h conversations. The conversations were held at 2-week intervals and took place at nursing homes where the sick family member lived. Two nurses—one from the nursing home and one from the research group—trained in FamHC concepts served as conversation leaders at each meeting. One nurse had the overall responsibility for leading the conversations, and the other was a co-participant reflecting on the content of the narratives. The series of FamHC meetings focused on three different topics. The first conversation focused on how the family experienced the situation before and after their family member moved to the nursing home. The second conversation was a reflection on the first conversation and further highlighted the suffering and difficulties associated with the situation. The third conversation focused on the future and the resources and opportunities available to the family to solve the problems they were facing. The second and third conversations also reflected on the previous meetings so that the family members could reflect and see the situation from different points of view.

Relationships during these conversations were non-hierarchical, which means that the nurses and the families created the conversations together. The nurses were not the exclusive holders of the truth nor of solutions to the families' problems.[25] The goal of the conversations was to create a context for a change of beliefs and to support the building of new ideas, new meanings, and new possibilities in relation to each family's problems. In the FamHC model, nurses bring up questions designed to stimulate reflection, focusing on the resources and strengths the family has and on alternative ways to cope in the present as well as in the future.[14,25]

Setting and participants

Conversation leaders. A letter asking for study participants was sent to all nurses at the nursing home who had worked in nursing homes for more than 2 years. One nurse replied and was recruited to be the conversation leader (together with a nurse from the research group). The two nurses conducted the conversations together. One nurse was responsible for leading the conversation process, and the other nurse observed, asked additional questions, and reflected on the responses. The nurse from the nursing home only participated in the conversations and not in the analysis nor otherwise in the study.

During the conversations, the nurse invited all of the relatives to share how they experienced their current situation. The conversations were focused on the family members' own stories, and the nurse's role as conversation leader was to ask reflective questions so that family members had the opportunity to reflect on each other's stories. An example of these sorts of questions is: *When you hear your mother's*

Table 1. Details of the patients (n = 4).

Age	
Median (range)	80 (74–89)
Gender	
Men	4
Diagnosis	
Hypertension	4
Cerebral infarction	3
Alzheimer	1
Angina	1
Aortic insufficiency	1
Atrial fibrillation	1
Cerebrovascular dementia	1
Cholecystitis	1
Deep vein thrombosis	1
Diabetes	1
Glaucoma	1
Heart failure	1
Hip osteoarthritis	1
Limb prosthesis	1
Myocardial infarction	1
Operated hip fracture	1
Operated intestinal tumor	1
Pancreatitis	1
Transient ischemic attack	1
Months living at the nursing home	
Median (range)	16.5 (8–26)

story, what do you think? Based on the stories, each family identified what they wanted to talk about during the conversations. The nurses and the family together identified good and bad beliefs, which they then reflected upon. Throughout the three conversations, the researcher followed up with questions like: *Can you tell me more about it? What do you think about that? What do you do in such a situation?* Through all of the conversations, it was important to have silent moments to allow time for reflection so that new thoughts and ideas could arise.

All of the nurses were educated and trained in FamHCs before the study began.[31] The training included theories that formed the basis of FSN such as systems theory, communication theory, and reflection.

Families. This study included relatives from four families. The criteria for the relatives who were included in the study were that (1) they had a family member who was living at the nursing home and (2) the family consisted of at least two people. A family is a self-defined group of two or more individuals who are or are not bound by blood strain or by law, but work in a way that they experience their group as a family.[32] The families were selected by the head of the nursing home from the families who were considered to have substantial needs or a great deal of suffering. All of the families in the study were given both written and verbal information and were asked to provide written permission to participate in the study. The letter stated that participation in the study was voluntary and that all materials would be kept confidential.

Across all four families, the husband/father was the one who lived in the nursing home (Table 1). The study participants included wives from three of the four families and children from all four families (Table 2). The residents were also offered the opportunity to participate in the study, but none of them were present for the conversations because of their medical conditions.

Ethics

Permission to conduct the study was given by the head of the municipality, the head of administration, the head of the department, the heads of the units, and the participating nurses, and the study was approved by the regional Ethical Review Board (2011-335-31M). Consent to carry out and record the conversations was also sought and received from the families. The families and the nurses were assured that all information would be kept confidential in accordance with the principles of research ethics.

Data collection and analysis

The FamHCs were recorded and transcribed verbatim, and the conversations formed the unit of analysis. An inductive qualitative content analysis was used for analyzing the topics the relatives chose to focus on during the conversations.[30] The analyses were performed in several steps. The conversations from the first, second, and third meetings were analyzed separately throughout the analytical procedure. The transcripts from the conversations were carefully read by both authors to find meaning and to gain deeper understanding from those conversations, as well as to create an overall picture and a better understanding of the subject.

Then, meaning units were identified in accordance with the study aim from the transcribed conversations. The meaning units were then condensed in order to shorten the material while retaining meaningful content. The condensed meaning units were coded and sorted by subject. The codes were sorted into subcategories based on similarities and differences and then further abstracted into categories (Table 3).[30]

Findings

The findings show what experiences the relatives chose to focus on during a series of three nurse-led FamHC meetings, comprising a total of 12 conversations, and they contribute to improved understanding of families' situations with having a family member living at a nursing home for older persons. The results are presented by differentiating the three conversations in the series (Table 3). The headings are modeled after the categories to clarify the contents of the subcategories that are presented and taken together.

Table 2. Relatives who participated in the study (n = 11).

Relation to the patient	
Wife	n = 3
Son	n = 1
Daughter	n = 7
Age—median (range)	
Wife	75 (67–84)
Son	45 (45)
Daughter	49.3 (39–60)

Table 3. Overview of categories from the first, second, and third family conversations.

Conversation	Categories
The first conversation	Range of emotions before the move to the nursing home
	Reversal of roles
	Searching for strength
The second conversation	Demands of relatives
	Frustration and sadness
	Resource management
The third conversation	Change of perspective
	Agency for handling the future

The first conversation

The findings in the first round of conversations were about how the relatives talked about feelings and reactions before and after the sick family member moved to the nursing home for older persons.

Range of emotions before the move to the nursing home. The relatives talked about how they felt a great deal of worry, anxiety, and despair before the move of the sick family member to the nursing home for older persons because of the unsustainable home situation. They felt remorse because they could not manage to take care of the sick person at home, and they felt guilty of betraying their sick relative. The situation with a sick family member includes reduced health, lost prospects, and a lack of a healthy personality, which leaves the relative with feelings of frustration and sadness. They stated that it was difficult for them to watch their family member get sick and have their personality change and that this produced feelings of hopelessness because they could not influence the situation. They also talked about how they had difficulties with not being able to be truthful about the new situation and the future prospects for the sick family member, which led to them feeling sad and anxious. The relatives mentioned experiencing a lack of energy, a lack of personal time, and increasing pressure to keep the situation under control, which brought about feelings of guilt, anxiety, and inadequacy as well as symptoms of fatigue.

Reversal of roles. The relatives talked about how the children in the families took over the family responsibilities when the older family member got sick. They became more focused on solving problems, and they tried to maintain balance and stability within the family. The adult children in the families also talked about the importance of support and getting the healthy parent who remained at home to take care of themselves. They reported that they had to determine the healthy parents' own limitations in order to prevent exhaustion and to maintain the healthy parents' well-being.

Searching for strength. The relatives talked about how they reconciled themselves with the new situation of the family member moving to a nursing home for older persons, and this led to increased well-being for the relatives. They also highlighted the importance of caring for each other and for having their own free time to engage in important activities and how this helped heal and strengthen the family. This brought feelings of joy, happiness, and peace for the relatives. The families identified resources like acceptance and strong family relationships that helped strengthen their ability to cope with the new situation. The relatives reported feelings of safety and peace when the sick family member moved to the nursing home for older persons because they felt secure that the family member would receive good care 24 h a day, and this knowledge led to reduced guilt over the sick family member's situation. To have support outside the family, such as friends or support groups, was identified as being of major importance to the relatives. The feeling of not being alone and the opportunity to vent and talk about the situation within the family provided a sense of solidarity and strength.

The second conversation

In the second conversation, the findings showed how the families talked about their suffering and difficulties concerning the new situation.

Demands of relatives. The relatives talked about how they felt concerning the sick family member and how they had a need to have total control over the situation, which was on top of the sadness, suffering, and guilt they felt over the lost personality of the family member. They also talked about what they felt was required to visit the sick family member and the lack of time to do that and how that lead to further feelings of remorse, anxiety, and guilt. In the conversation, the healthy parent who remained at home told how they wanted to manage on their own and did not want the situation to be a burden for the rest of the family. With the increased demands, they felt that they wanted to manage everything by themselves, which was something the children in the families were not always aware of. However, not asking for help from the other family members when it was necessary led to further anxiety and fatigue in the healthy spouse who remained at home.

Frustrations and sadness. During the conversations, it was revealed that the grief processes surrounding the disease and

the loss of the sick family member's personality had left the relatives feeling frustrated and sad. The relatives talked about the knowledge that the sick family member would never recover and how this was emotionally draining. It also came up that losing the sick family member when they die was a scary proposition for the relatives. Even though their husbands were living at a nursing home and they were, in practice, living alone, the wives still felt fear about losing their life partner and being alone in the future.

Resource management. The relatives talked about searching for factual information about the disease their sick relative suffered from, as well as about what the future might hold and the likelihood of the sick relative dying, and such knowledge strengthened and soothed them. Increased knowledge gave the relatives a tool for handling the situation in a better way. Many of the relatives said that they wished they had had family conversations at the beginning of the disease process because the supportive conversations regarding advice and reflections had given the families the opportunities to vent and to process the situation. The relatives talked about other kinds of important resources like family, friends, and acquaintances that gave the family comfort and strength and improved their well-being. The relatives talked about how earlier life experiences, such as working in health care, had given them tools to solve problems in a satisfactory manner and how such experiences gave them a sense of calm and confidence in the situation. The relatives highlighted how when a family member gets sick, the disease affects the whole family and their relationships and might lead to deeper and closer relationships in the family.

The third conversation

In the third conversation, the findings show how the families talked about the future and how they were trying to manage to solve their problems.

Change of perspective. The relatives talked about how they had become reconciled and had come to terms with the situation of having a sick family member, and this had helped them to handle the future in a better way and allowed them to live their own lives. They felt an inner peace and a less guilty conscience. The relatives' ability to reflect on their own health also reduced the risk of suffering from fatigue. The relatives' progress in accepting the situation led them to realize their own limitations and thus coming to understand that they were already doing all they could do and thus felt less guilt and inadequacy. The relatives stated that FamHC had given them the opportunity to get a wider view through which to reflect on and process the whole situation.

Agency for handling the future. The relatives talked about their wish to be more involved in planning the sick family member's daily living. They wanted to bring strength and joy to the situation, for example, through jokes and humor, because this made it easier to deal with the situation. It was reported that the family members' ability to find solutions together for helping the sick person and the family gave them feelings of safety and satisfaction and that this had strengthened their family relationships.

Discussion

The purpose of this study was to describe the topics that the relatives of a family member living at a nursing home for older persons chose to focus on when participating in a nurse-led FamHC intervention. Through the FamHC meetings, it became clear that all of the family members were affected by having a sick family member living in a nursing home. The family members talked about how they were affected in different ways, such as having feelings of powerlessness and guilt, and that talking together in a structured format together with other family members within the FamHC intervention helped the family to develop coping strategies and to manage resources so as to more easily deal with situations that might arise in the future.

The relatives experienced a guilty conscience and feelings of frustration and sadness along with the demands involved in visiting the sick family member. This is in line with a study by Bauer[32] showing that there is a strong link between experiencing difficulties and having a family member living at a nursing home for older persons.

The relatives in our study also talked about feelings of powerlessness when they could not control the situation or stop the progression of the disease. The spouses experienced it as painful to lose their life partner and this led to feelings of suffering and fatigue. Previous studies have shown that spouses often have feelings of powerlessness associated with the loss of their lifelong partner.[5,33] The separation and emptiness became real when the partner moved to a nursing home, and they also suffered feelings of guilt an inadequacy for not having done enough for their partner. The children in our study talked about how they were ashamed of not being able to take care of their sick parent. However, when they came to accept having a family member living at the nursing home, this led to an inner peace and a less guilty conscience. This gave the relatives the strength to find solutions and new ways of looking at their lives and futures.

During the FamHC intervention, it became evident that the relatives in our study felt there was a lack of control and a lack of information about the situation and about the care that was being provided. A study by Nelms and Eggenberger[34] showed that it is important for relatives to get information so that they can better understanding the sick family member's condition because this can lead to acceptance and calm, which might also promote a better relationship between the relatives and the nurses. Other studies[35,36] have shown that when relatives have knowledge regarding the care of the sick and are active in the care planning and/or caregiving, they

cope better and gain the tools needed to support each other. The relatives then experience emotions like hope and strength and have a more positive outlook on the future.[36] In line with this, the relatives in our study talked about how they wanted to be more involved in the planning of the care for their sick family member. A study by Irving[37] showed that the most important desire among relatives was to be involved in decision-making in questions regarding their sick family member. When they are involved in this way, they feel more engaged and this improves their well-being. A study by Benzein et al.[35] showed the importance of involving families in the care of the sick family member. It is important, therefore, to invite and engage the relatives in providing the health care personnel with useful information about the patient. A good relationship between relatives and health care providers increases the supportive attitude of the relatives, and having good mutual communication, good information, and a proper approach can lead to a collective and nurturing form of collaboration.[10]

Regarding guilty feelings about the sick family member, the findings in our study showed a clear pattern during all of the conversations. The relatives were not always aware of why they had such feelings and whether they were related to their own needs or were due to the situation with the sick family member. A study by Tilse[38] showed that visiting the sick family member could help to reduce feelings of guilt among relatives, and Kellett[36] highlighted that such visits can maintain a sense of meaning and continuity in the relatives' lives. The adult children in our study also tried to get their healthy parent to realize their own limitations and to make them realize that they have their own life to take care of as well, and this reduced the guilty feelings they experienced.

The relatives had a significant need to talk about their experiences, probably because they had not been offered the chance to do so before. Nurses have an especially important role to play in supporting relatives when they have a family member living in a nursing home,[39] but it has been shown in a study by Benzein et al.[19] that despite nurses seeing the family as a single unit with its own set of resources, they seldom invite the whole family into conversations regarding the sick family member. This might be due to the nurses having both facilitating and constraining beliefs about families, and in that study, the nurses saw the families both as a resource and as a burden.

In our study, the relatives felt that the FamHC intervention should have come at an earlier stage in the sick family member's illness. In the family conversations, it came up that the relatives found strength and resources when talking together as a family and that this had helped them to become more aware of their own and the other family members' beliefs. It was meaningful for the relatives to be aware of the different family members' beliefs, and the FamHC intervention allowed these beliefs to be assessed by the individual, the family as a whole, and by the nurse who was leading the intervention. Beliefs are often an unconscious system of values and assumptions that have evolved through one's experiences. Beliefs form the basis of what we notice and how we interpret the world around us and how we think, feel, and act in different situations.[11] It has been considered in previous studies[13,20–24,26] how nurses, in conversations together with the family, can take advantage of existing family resources to successfully support the family's process of dealing with their everyday lives and promoting their own health and well-being.

Methodological considerations

This study provides a better understanding and deeper knowledge of the relatives' perceived experience of having a family member living in a nursing home for older persons through how they talk about their situation. The method of qualitative analysis was chosen because the families participating in the FamHC intervention were asked to share their experiences.[30] The qualitative content analysis used in this study is well-suited for studying what relatives of family members living at a nursing home for older persons choose to focus on when participating in nurse-led FamHCs. However, the nurse who participated in the intervention worked at the same nursing home the sick relative lived in so they already had a relationship with the families before the intervention started. This could have influenced the result of the study because they were already well acquainted with each other. Another limitation of the study was the fact that the conversations were conducted by newly trained nurses rather than nurses who were more experienced in FSN.

The idea behind the FamHC intervention was to let the relatives talk about their situation and to let them decide what the conversations would be about and in that way give them the power over the conversations' contents. This means that the results were shaped by the relatives' own stories and could not be formed in advance because the researchers did not know what the relatives would choose to talk about.

To strengthen the credibility of this study, the authors discussed each step, and because the authors would likely interpret the data according their preexisting understanding, a dialogue between the authors was used to validate the content and minimize the risk of misinterpretation.[40] Thus, for any discrepancies in interpretation, the authors discussed the issue until a consensus about the findings emerged. The analysis of the text involved a process of moving between the whole and the parts of the data. Our interpretation of these findings is only one of many possible interpretations, but this interpretation seems to be the most trustworthy to us. The findings in this study might be transferable to similar contexts.

Nursing implications

It is nurses' task to find opportunities to reduce suffering and to find relationships, space, and language that work in

synergy with families, that support them in identifying their own strengths and resources, and that allow them to find new strategies for managing their daily lives. This can prevent family illness, promote family well-being, and allow nurses to gain an understanding of the family members' experiences of the situation. Family conversations might reveal valuable information about the families' experiences and life situations, and this kind of knowledge is valuable for nurses to have in their daily care work. Studies by Benzein et al.[14] and Leahey and Harper-Jaques[41] point out that nurses should engage in family conversations to help families discover the strengths and resources they possess in order to find solutions to their problems. When relatives can share their experiences with each other, this has a strong and positive effect on their individual health. Through this kind of conversation, new questions will arise and new answers will be found, and through this approach, nurses can gain a better understanding of the unique characteristics of each family. It is thus valuable for the nurse to focus on the interactions and relationships between family members' beliefs and experiences rather than on individual family members.

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K.S. and Å.D. made the study design and the conversations; both authors have contributed to the data interpretation and Å.D. prepared the manuscript. The manuscript has been approved by both authors.

Declaration of conflicting interests

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Ethical approval

The Regional Ethical Review Board at Umeå University approved the study (DNr: 2011-335-31M).

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Informed consent

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Supplemental material

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