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Feature Article

Becoming visible – Experiences from families participating in Family Health Conversations at residential homes for older people

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Abstract

Having a sick family member living at a residential home for older people can be quite difficult for families, who as a result often suffer from feelings of forsakenness and powerlessness. In response, the purpose of this study was to illuminate family members’ experiences with participating in Family Health Conversations at residential homes for older persons 6 months after concluding the conversation series. Twenty-two family members who participated in the conversations later took part in group interviews, the texts of which were analyzed according to qualitative content analysis. Findings showed that participating in Family Health Conversations mediated consolation, since within such a liberating communicative interaction, family members for the first time felt visible as persons with individual significance. Family members reported a positive experience involving both being open to each other and speaking and listening to each other in a new, structured way. As a result, families were able to discover their family members’ problems and suffering, as well as to identify their family’s resources and strengths.

Introduction

A considerable amount of research on illness and ill health shows a significant impact on the quality of life for the person living with illness and for their significant others. When a family member is ill, it affects the whole family. Most studies focus on the individual family member’s experience of illness. When an old and sick family member’s condition worsens, the family often reaches a point where they no longer can provide care at home and they must consider to move to a residential home for older people. This move often involves feelings of failure and guilt on the part of the family. It might give the family a sense of relief, but also creates feelings of a guilt and remorse. Guilt is a powerful feeling caused by multiple factors. Although the families might have struggled for a long time with having the sick family member at home, they might still feel that they could have done more. They often feel a sense of failure regarding their inability to care for their sick family member. During the time of transition, families might also be affected by their sick family member’s emotional changes and feelings of becoming a burden to their family, and this might lead the family to question the placement decision, thus exacerbating the feelings of guilt.

Furthermore, when the older person is living in a residential home, the family members often do not dare to interfere by questioning the nurses’ activities, because they are afraid they will be perceived as demanding, and this will have a negative effect on their family member’s care. Some studies have also indicated feelings of powerlessness on the part of the family members because they feel a lack of control over the situation and an inability to influence the care that their loved one receives. Evidence from several studies points to the importance of involving families in health care, and families have been found to be important in care of patient with acute and chronic illness. In order for nurses to provide sufficient care, it is necessary for them to understand the needs of the families who have an older family member living in a residential home. This can be done by sharing the families’ experiences through dialogue. Families with an ill family member will be helped by nursing care that takes a Family Systems Nursing (FSN) approach. The concept of FSN includes the important role of family interaction in the older person’s life and also on all the other family members’ lives. FSN is an approach that focuses simultaneously on the ill person as well as the other family members. The aim of FSN is to preserve well-being, decrease suffering and support family health. According to the study by Östlund and Persson, FSN

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is a means to facilitate families’ communication, increase connectedness and well-being, and enhance confidence and capability in dealing with a sick family member. An examination of FSN interventions showed that family support is effective in improving well-being and health and in improving families’ abilities to manage their situations in relation to the problems described by the families.22–29

One example of an FSN intervention program is Family Health Conversations (FamHC). FamHC includes a person-centered approach,30 i.e., all family members are regarded as important, valid persons with their own experienced life world31 being made visible to the other family members. In FamHC all the people, in the family are regarded according to system theories. That is to say that all family members are considered as a system in which they are influenced by each other and influencing each other. System theories thus suggest that illness has an impact on the family as a system and a unit.32

The FamHC is a Swedish version of the Calgary models; Calgary Family Assessment Model (CFAM), which is a clinical model used to help families solve problem or issues based on the foundations of systems, cybernetics, communication, and change theory. The Calgary Family Intervention Model (CFIM) is a strengths–resilience-based family intervention model33; and the Illness Beliefs model (IBM)3 focuses on the family as a unit of care, and believes that our views determine the way we interpret the world and thus cope with problems. The FamHC has been shown to be a way to increase well-being for families in relation to their situation,34,25 and it has also been found to be cost-effective.35 FamHC comprises a number of core components.34 It focuses on the interplay and the relationship within the family and the non-hierarchical interplay between the family and the nurses. A central function of the FamHC is to identify the family’s internal and external resources, and seek to identify and strengthen what is healthy about the family’s situation instead of focusing on what does not function well.3,34–36 Narratives and reflections constitute the basis of the FamHC,23–34 and these reflections thus become a tool for understanding one’s own and others’ experiences, beliefs, and perspectives; and when needed, these reflections can encourage a change in beliefs and foster new insights.3,37 According to Wright and Bell,3 beliefs can be both facilitating and constraining. They determine how we respond to feelings, view the world, and handle situations. Family members, as well as nurses, have beliefs that facilitate and beliefs that constrain, and these beliefs are brought up and discussed during FamHC.

Having a family member living in a residential home is a family affair, and it can be difficult for the entire family. Experiences of being abandoned and unappreciated by the sick family member can cause ill health for other members of the family.37 In addition, being separated from one’s loved ones and not being involved in care can be challenging. Having adequate communication and support from the nurse is important in feeling involved, and good communication can lead to a trusting relationship with the nurse.38 The result of the above reported studies point to a need to expand the focus for care in order to support families that have a sick family member living in a residential home for older people. In addition the studies indicate a need for interventions to support both individuals and the family as a unit to minimize ill health, experiences of distress and broaden the concept of health to include the family as a whole. There is limited knowledge about this kind of family conversations in the context of residential homes for older persons. Thus the purpose of the study was to illuminate family members’ experiences of participating in Family Health Conversation at residential homes for older persons six months after concluding the conversation series.

Method

Design

This study has a qualitative design with semi-structured group interviews, analyzed using qualitative content analysis. Qualitative content analysis was chosen as a method that involves both manifest and latent interpretation of participating in Family Health Conversations.

Setting and participants

In this study, a total of 12 families consisting of 24 family members of residents staying in three residential homes for older persons in a municipality in the north of Sweden participated in Family Health Conversations. Recruitment of the family members was conducted by the heads of the residential homes for older persons, together with the nurse working at the residential home. Evaluative group interviews were conducted six months after completion of the Family Health Conversations. Two families declined to participate, and indicated that their reasons were health-related or due to lack of time. The participating family members were between 39 and 84 years old (Md = 55); 20 were women (5 wives and 15 daughters) and two were men (sons). The exclusion criteria were that they could not speak and read Swedish.

The procedure using Family Health Conversations

Each family participated in three Family Health Conversations (FamHC), lasting 45–60 min. Two nurses, trained in the FamHC concept were conversation leaders at each meeting. One had the overall responsibility for leading the conversation process, and the other observed, asked additional questions and reflected on the responses. The structure of the FamHC is three conversations held at two-week intervals, with each conversation having a different focus. The first conversation focused on the family’s experienced life situation. All family members were invited to offer their experiences and listen to each other’s viewpoints. The conversations focused on what was important for the family to talk about, and the dialogue was intended to identify strengths and resources that the families had, both within and outside the family, with the purpose of creating alternative ways to think about and best deal with their situations. The second conversation started with an opportunity to reflect on the first conversation, and focused on suffering, problems, and beliefs identified in the first session. The third conversation was similar to the first two, but focused on the future, family strengths, and resources inside and outside the family, to address the changes undergone to facilitate healing. At the end of each conversation, the nurses provide a summarized reflection on what had been highlighted during the conversations. Two weeks after the third conversation, a closing letter39 was sent to the home of all participating family members, and in it the nurses reflected on the content disclosed in the conversations.

Data collection

Six months after the FamHCS series was completed, semi-structured group interviews were performed with eight families,30,40 and individual interviews were performed with the two families in which only one family member had participated in the FamHC intervention. A researcher who had not participated in the conversations performed the evaluating interviews. The families were encouraged to speak freely, although an interview guide was used to add structure to the interviews. The interviews started with an open question: “Can you tell me about your experiences...
participating in the Family Health Conversations?” Clarifying questions were asked when necessary to illuminate their experiences, such as who, when, and what do you mean? The interviews took place in a meeting room in each residential home. Each interview lasted about 45–60 min and was digitally recorded and transcribed verbatim.

Data analysis

The interview texts were analyzed using qualitative content analysis. In the first step, the first author read each interview text several times in order to obtain a sense of the material as a whole. The second step was to divide the text into meaning units, which consisted of words that contained elements that were related to each other through their content. The meaning units were condensed and labeled with codes and then grouped and abstracted by content into sub-categories and into further categories. In an attempt to identify underlying meanings, there was a continuous process of moving back and forth and constantly comparing parts of the data with the whole material. Lastly, an overall and underlying meaning emerged from the categories, i.e., the theme.

Ethical considerations

Permission to conduct the study was given by the head of the units. Written and verbal information concerning the study aims, voluntary participation, and confidentiality were given to the participants in accordance with research ethics. The families agreed to participate in the Family Health Conversations. Furthermore, they also agreed to participate in evaluative interviews about how they had experienced the conversations. Consent to carry out and record the interviews was sought from the families before they were included. The regional Ethical Review Board of the university approved the study.

Findings

Theme

Being consoled

The analysis of the interview data showed that the families’ experience of participating in the FamHC could be described by the theme “Being consoled,” which consists of two categories: liberating communicative interactions and feeling visible. In addition, six sub-categories were identified. The experience of being consoled was created in the trustful relationship with the other family members and the nurse. As the nurse managed to create a trusting relationship, the families became strengthened and felt visible. This gave the families strength and they started to communicate and put words to feelings they did not know existed. This improved their understanding of each other and subsequently provided confirmation and consolation to family members.

Categories

Liberating communicative interactions

The families experience that it was the nurse who enabled good interactions within the families and between the family members and the nurses. The special interaction that occurred made it possible for the communication to be liberating for the families.

Communicating differently. The families experience that the FamHC was a different way of having a conversation and that it fulfilled a need for the families that had not been met earlier. The families experience amazement that the conversations were about them and that the conversations were so personal. The families experienced it as liberating to have the opportunity to talk about all the hard and difficult feelings that emerged from having a sick family member living in a residential home.

“I feel that it was really important to talk about the difficult emotions I experience as a family member.”

They experience that this approach to conversation stimulated the narrations and reflections that made new facilitating beliefs possible. The nurses asked questions and highlighted the problems in a different way, which was experienced as essential for the families to be able to see the problems from a different angle. The families experienced an unusually permissive climate in the conversations, with a good structure and framework. Furthermore, they also indicated that they wished they had had this type of family conversation earlier, before their family member moved to a residential home.

“I was astonished by how the nurse asked the questions; it was a new experience for me.”

Interacting sufficiently with the nurse. The families experienced it as valuable to have the opportunity to communicate with someone outside the family.

“I thought it was positive and valuable to discuss and talk about the tough situation with people outside the family. Yes, it was very, very good.”

In their experience, it was the nurses that enabled the conversations to yield such good interactions. The families experienced a great well-meaning from the nurses. They experienced that the nurses opened up, listened attentively, and showed a genuine

<table>
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<th>Meaning units</th>
<th>Condensation</th>
<th>Code</th>
<th>Subcategory</th>
<th>Category</th>
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<td>And I thought it was positive and valuable to discuss and talk about the tough situation with people outside the family. Yes, it was very, very good. At first it was hard to talk about all the hard feelings, but at the same time it was good that it could come out, everything that you feel. Not having to apologize for what you feel. I do not need to apologize for that I’m sorry.</td>
<td>It was a positive experience to talk with someone outside the family. It was good to put word to feelings, to be sad without having to apologize for that.</td>
<td>Positive to talk with someone outside the family. It was allowed to be sad.</td>
<td>Interacting sufficiently with the nurse. Putting words on little-known feelings.</td>
<td>Liberating communicative interactions. Feeling visible.</td>
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interest in the suffering and the problems expressed by the families. The families were amazed to receive this personal support in the conversations, and they felt that they, both as individuals and as a whole family, became visible and were allowed to be in focus.

“I experienced that I got to be myself, I got to say what I felt, and so they (nurses) are genuine too.”

The families experienced that the nurse understood what they wanted to say. The nurses added structure to the conversations, but the families felt that they themselves formed the content of the conversations in collaboration with the nurse.

“I felt consoled and strengthened by the conversations; it felt great.”

Feeling visible

To be seen and confirmed within these conversations made the families feel visible as a whole family for the first time.

Putting words on little-known feelings. Within the conversations, the families had the opportunity to put words to their feelings and to create new perspectives for viewing their situation, and these became visible to themselves and to the other participating family members. The families experienced feelings during the conversations that they did not know existed, and they described how the FamHC intervention contributed to being able to talk about their confused feelings. The families said that they felt permitted to be sad and cry during the conversations and that they were allowed to grieve.

“At first, it was hard to talk about all the hard feelings, but at the same time it was good that it could come out, everything that you feel. Not having to apologize for what you feel. I do not need to apologize for that I’m sorry.”

Furthermore, the families experienced the conversations as evolving. They could bring out their own stresses and strains, which alleviated some of the pressure and feelings of guilt that they suffered from. Family members experienced that they had a chance to be open-minded during the conversations, and this was valuable for enriching their stories about how they perceived the situation. Through this experience, much rose to the surface which was previously hidden, and the conversations provided an opportunity to talk about issues they had previously hesitated to discuss.

“I got a chance say what was in my heart. Things I never talked about before.”

Receiving understanding. The families experienced that the conversations offered an opportunity for family members to reflect on their situation and that this reflection increased their personal insight into their situation. They also reflected on other family members’ situations, which allowed them to re-evaluate and understand these situations from a different perspective. They gained a better understanding of each other due to these conversations.

“I became aware of my own and my sisters’ feelings.”

Feeling a sense of community. The conversations provided an opportunity for all participating family members to narrate their perspectives on their situation, and within the conversations the families experienced that they came closer to each other. They found it valuable that more than one family member simultaneously participated in the conversations because this made it possible to listen to each other and share their experiences and feelings. They could express all their concerns, suffering, anger, and disappointment, and it was liberating to share this with the other family members. The families expressed that many issues had been unspoken between them before these structured conversations. Within these conversations, they became closer as families by hearing each other’s thoughts (Table 2).

“To share feelings with each other was relieving.”

Discussion

The purpose of the study was to illuminate family members’ experiences of participating in Family Health Conversation at residential homes for older persons six months after concluding the conversation series. The main findings of the study were that participating in the FamHC made the families feel consoled. That someone captured them as a whole family was valuable and allowed them to experience confirmation, understanding, relief, and consolation. The FamHC highlighted problems experienced by the families in a new and improved way by allowing for conversations where the whole family would have the chance to talk about how they experienced their situation. They experienced being taken seriously as family members, and their suffering was confirmed. The FamHC made the family members feel liberated and relieved. They also gained an extended understanding about themselves and the other family members and reached an increased sense of togetherness, familiar community, and felt consoled.

The findings of this study can be understood in the context of a model of consolation by Norberg et al.45 that highlights becoming ready for consolation, being in communion, dialoguing, and shifting perspective. Each of these components is each a presupposition for the other components. Becoming ready for consolation means that both the person mediating the consolation and the person receiving consolation must be open, present, and available as a prerequisite for consolation. This is likewise found in our findings. Within the FamHC, the family members experienced a trusting relationship and permissive atmosphere and felt that the nurses had a genuine interest in the families. This made both the families and the nurses present, open and available in the conversations. The families experienced that through the nurses’ attentive listening, their suffering was uncovered and made visible. Further, the model of consolation states the importance of dialoguing and sharing the suffering that goes even beyond words.45 The family members in our study experienced that the FamHC made room for dialogue with the nurses. When the relationship is trustful, it makes it possible to share suffering, and the family members can then be open for moments of communion and sharing that can even occur in silence.45 As with the findings in our study, the model of consolation demonstrates that the consolation dialogue provides a new understanding of the situation and that this might lead to a shift in perspective. Indeed, the family members experienced a shift in their perspective by participating in the FamHC. They re-evaluated their situation and could see the problems and the suffering within a pattern of meaning, and this made their situation manageable despite all of the difficulties.

Table 2

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<tr>
<th>Theme</th>
<th>Categories</th>
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<tr>
<td>Being consoled</td>
<td>Liberating communicative interactions</td>
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<td></td>
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<td>Receiving understanding</td>
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<td>Feeling a sense of community</td>
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The families experienced that the favorable interaction with the nurses was essential to creating a communicative interaction. The genuine meeting with the nurse and within the family during the FamHC intervention was essential for the experience of a communicative interaction as it thus may include more than just the spoken word. Being in community with the other persons and feeling togetherness constitutes the basis for understanding each other, and understanding and fellowship mediate consolation. The family members experienced that the nurse provided the opportunity to share the other persons’ experiences and that the nurses made room for expressing hardship, which could then be understood as being available for the other person and as making room for the other person’s suffering.

Feeling visible was a new experience for the family members. To share their problems and suffering and, at the same time, to shed light upon their own strains alleviated some of the pressure the family experienced. The families in this study discussed how unspoken suffering is unbearable suffering. When you can talk about it together, the suffering is uncovered and consoling.47

The family members’ narratives made it possible to uncover suffering and to share beliefs with the nurses and within the family and to see the situation from a different angle. This is also in line with the metaphor of Roxberg et al49 of “to open the door,” which means that whoever provides consolation must be present and listening, otherwise the other person will not uncover their suffering. Within the FamHC, the families experienced that the “door was opened” by the nurses, and thus they felt confirmed and consoled. This made it easier for the families to develop a common family strategy for approaching future management of the situation in a good way together.

Methodological considerations

The methods for data collection and analysis can be assumed to be relevant, as the aim was to illuminate family members’ experiences of participating in Family Health Conversation at residential homes for older persons six months after concluding the conversation series. To strengthen the credibility of the study, both authors discussed each step together in the analysis process until a consensus about the findings emerged. Both authors also reflected independently upon the findings in relation to the interview texts to ensure that nothing was overlooked. The analysis of the text involved a process of moving between the whole and the parts of the data. Krippendorff50 asserts that a text never contains only one single meaning. Our interpretation of these findings is only one of many interpretations, but this interpretation seems to be the most trustworthy to us. The findings in this study may be transferred to similar contexts.

Conclusion and implication for practice

The families experienced the FamHC as a way of healing because the sharing and reflections within the FamHC intervention mediated a change in how they perceived their situation. After previously having had a long period of caring for their sick family member and neglecting their own needs, the families in this study reported that these conversations that focused on the whole family were a liberating experience. The family conversations offered an arena for listening to each other’s narrations with room for tears and grieving over the situation of having a sick family member. The family members were consoled when participating in the FamHC because their problems, suffering, strengths, and resources were uncovered and confirmed. The findings of this study show that there is a need to implement Family Health Conversations as a natural part in the context of residential care to enhance the caring relationship between family members and nurses.

Acknowledgment

KS and ÅD made the study design and the interviews; both authors have contributed to the data interpretation and ÅD did the manuscript in preparation. The manuscript has been approved by both authors.

References


