

The experiences of family caregivers who participated in the family involvement program during hospital admission of a patient undergoing major abdominal surgery.

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Course	Master Thesis (Final)
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Organization of internship	The Amsterdam University Medical Center (location AMC)
Date of submission	25 th June 2019
Words abstract	296
Words Dutch abstract	290
Words total	3797
References	Vancouver reference style
Guideline	Consolidated criteria for Reporting Qualitative research (COREQ)
Journal	Journal of Family Nursing

LIST OF ABBREVIATIONS AND RELEVANT DEFINITIONS

AE	Anne Eskes (senior researcher)
COREQ	Consolidated Criteria for Reporting Qualitative Research
IPA	Interpretive Phenomenological Analysis
MH	Mariken Horst (member of the research team)
NvI	Nina van Ingen (principal researcher)
FC	Family Caregiver
FCs	Family Caregivers
FIP	Family Involvement Program
QIP	Quality Improvement Program

SUMMARY

ARTICLE INFO	Summary
<i>Keywords:</i>	<i>Background:</i> Attention to the delivery of family-centred care in hospital has increased
<ul style="list-style-type: none">• Family caregiver• Surgical care• Interpretive Phenomenological Analysis• Hospital	because of the beneficial role family can play. However, there can be downsides of family involvement, as is shown in chronic care. A university hospital in the Netherlands started a project of the family involvement program (FIP) in post-surgical patient care. The project shows positive quantitative outcomes. Nevertheless, it does not give in-depth insight in experiences of Family caregivers (FCs) who participated in the FIP. <i>Objective:</i> To explore experiences of family caregivers who participated in the family involvement program during hospital admission at the surgical department of patients undergoing major abdominal surgery. <i>Method:</i> This study utilized a qualitative research design, situated within an interpretative phenomenological analysis (IPA) approach. Data were collected from purposively sampled FCs by using semi-structured interviews, 1 to 6 months after hospital admission. Interviews were digitally recorded, transcribed and analyzed using the IPA method. The study adhered to the COREQ guidelines. <i>Results:</i> Interviews were conducted with 12 participants (5 males). The length of hospital stays varies between 7 till 135 days. Seven main themes were identified: “being closely involved”, “being meaningful”, “Adopting the role of FC”, “Cooperate with healthcare professionals”, “Losing touch with yourself”, “Strengthen the bond of the relationship”, “Different experiences in previous admissions without FIP”. FCs performed various care activities and experienced the admission as a precious time. There were some hard moments and negative feelings. Above all, the FIP had a positive impact on their relationship and brought them closer together. <i>Conclusion:</i> Active participation of FCs during hospital admission is valuable. Even though FCs experienced sometimes hard moments they would not have missed it. FCs became a partner in hospital care and performed a variety of basic care activities. However, clear instructions and meeting FCs’ expectations is essential.

SAMENVATTING

De aandacht voor patiënt- en familie gecentreerde zorg neemt toe, ook in Nederland. Een groot universitair ziekenhuis startte in 2018 met een project om mantelzorgers al tijdens de ziekenhuisopname actief te betrekken bij de zorg voor hun naaste.

Het project bood mantelzorgers de mogelijkheid om 24/7 aanwezig te zijn. Daarnaast werden zij gecoacht om verzorgende taken uit te voeren. Het project liet positieve uitkomsten zien. Uit literatuur blijkt echter dat mantelzorgers meer kans hebben op overbelasting en vermoeidheid. De vraag is hoe mantelzorgers het hebben ervaren om actief ingezet te worden in de zorg voor hun naaste gedurende de ziekenhuisopname. Om daarachter te komen zijn 12 interviews gehouden met deze mantelzorgers. Deze interviews werden uitgevoerd 1 tot 6 maanden na ontslag.

Uit de interviews blijkt dat het voor mantelzorgers ontzettend waardevol was om aanwezig te mogen zijn gedurende de hele ziekenhuisopname. In deze periode hebben de mantelzorgers verschillende zorgtaken uitgevoerd zoals: het bieden van ondersteuning tijdens wassen en aankleden, het verlenen van wondzorg en het verschonen van het bed. Opvallend was dat mantelzorgers ondanks de zorgtaken zich vooral partner voelde. Het was voor hen dan ook vanzelfsprekend om deel te nemen aan het project. De ziekenhuisopnames kende ook moeilijke momenten en gingen gepaard met heftige emoties, maar het heeft vooral de relatie met hun partner versterkt. Doordat de mantelzorgers continu aanwezig konden zijn waren zij overal van op de hoogte. Dit betekende dat ze elkaar niks hoefde uit te leggen en alle emoties met elkaar hebben kunnen delen. Dit zorgde voor een soepelere overgang naar huis.

Bovenal blijkt vooral dat ondanks de zware momenten en de heftige emoties het gevoel van dankbaarheid overheerst. Dankbaarheid dat ze aanwezig mochten zijn tijdens een intense periode wat ze niet hadden willen missen.

INTRODUCTION AND RATIONALE

Reasons for being admitted to hospitals are various,^{1, 2} and transition from hospital to home can be complex. Family Caregivers (FCs) can play an important role in a patient's discharge from hospital and during the time after discharge.³ These FCs can be defined as "any person who, without being a professional or belonging to a social support network, usually lives with the patient and, in some way, is directly implicated in patients' care or is directly affected by the patient's health problem".⁴

Attention to delivery of patient and family centred care in hospitals has increased in recent years.⁵ In pediatric wards, involvement of family members is almost standard; however, for hospitalized adults, care is slowly shifting to a more family-centered approach.^{6, 7} Family-centred care is more than presence of family or close friends during hospitalisation, it includes family involvement in all aspects of care delivery.^{5, 8} Family involvement can be divided in five main components namely, (1) presence and visitation, (2) having needs met or being supported, (3) communication/receiving information, (4) decision making and (5) contribution to care.⁹

Previous published studies shows the beneficial role that FCs may play in hospital care of adults.^{5, 7, 10-16} The presence of FCs tends to reassure and soothe the patient.^{5, 10} This can be supported by creating family-centered rooms which could lead to an increase of family presence and support in patient care.¹¹ Presence of family members during medical rounds has been shown to facilitate patient-physician communication and self-management behaviors in older patients.^{13, 14} Family involvement may also increase patients sense of wellbeing and decrease the level of anxiety.^{7, 12} Moreover, it can have a positive effect on mobility.⁷ It can also shorten the length of stay¹⁵ and it encourages patients' safety and quality of care.¹⁶

Besides the above-mentioned advantages, previous research in different healthcare settings, especially in chronic and long-term care (e.g. oncology and geriatric care) pointed out that there is also a downside of involving family members in care. A key aspect is the role change which means adopting the caring role. It can result to a dynamic change in the relationship between family caregiver and patient.¹⁷⁻¹⁹ Family caregiving can cause caregiver burden which can lead to adverse effects on emotional, social, financial, physical and/or spiritual functioning.²⁰⁻²² FCs have a higher prevalence of anxiety and depressive disorders.^{23, 24} Furthermore, the likelihood of fatigue and sleep difficulties are higher for FCs.^{25, 26} In contrast to studies on FCs in chronic care, less information is available about experiences and perceptions of FCs who are actively involved on general nursing wards during hospital admission.

To enhance a more patient- and family approach, a university hospital in the Netherlands started a quality improvement project (QIP) and implemented a family involvement program intervention (FIP) in post-surgical patient care. This program aimed to motivate FCs to be actively involved in basic care activities, and consists out of five main components, namely (1) information about basic care activities; (2) task-oriented training; (3) hands-on participation in basic care; (4) presence of FCs during medical ward rounds; (5) rooming-in (at least 8 hours a day)²⁷ Based on quantitative results of a feasibility study, it was shown that 90% of the FCs who participated in the FIP felt better prepared for discharge. (Schreuder – submitted work) Furthermore, they valued the program as not too burdensome and their scores on CarerQol-7d did not decrease over time.²⁷ However, the quantitative approach used does not give in-depth insight in what the FIP in hospital means to FCs in detail. Hence, a qualitative study focusing on the experiences of these is essential.²⁸ Therefore, the following objective guided this qualitative research: Explore the experiences of family caregivers who participated in the family involvement program during hospital admission at the surgery department of patients undergoing major abdominal surgery?

METHOD

Design

To elucidate FCs' experiences who participated in the FIP, a qualitative interpretative phenomenological study was conducted. The IPA approach was the strongest feasible design for this study because the common lived experiences of FCs were examined.²⁹ The study had used the interpretative paradigm to ensure that experiences of family were addressed in relation to a broader context. The method and reporting had followed the consolidated criteria for reporting qualitative research (COREQ).³⁰

Participants and sampling

The study was conducted between January 2019 and June 2019 at two nursing wards at a university hospital in the Netherlands. The study population consisted of FCs who participated in the FIP during hospital admission. Purposive sampling was used to recruit participants. As there are no strict guidelines regarding sample size of IPA research we aimed to interview at least 12 FCs.²⁹

Participants were included when they met the following inclusion criteria: 1) age equal or above 18 years; 2) able to communicate in Dutch; 3) participated in the FIP 4) presented during admission (minimum of 8 hours per day) at least the first 5 days on nursing ward and (5) the patient had undergone a major abdominal surgery. To capture a wide range of perspectives and facilitate a broad understanding and validation of findings, variation in gender, age and relationship between FC and patient was sought.^{31, 32}

Data collection

Individual semi-structured interviews were conducted between January and April 2019. The interviews, which lasted from 35 to 70 minutes (mean 50 minutes), were recorded and transcribed verbatim. The primary researcher was also the interviewer. She is a registered nurse who has no knowledge of the study population and no professional relation with the participants. An interview schedule based on literature^{9, 17-19} and knowledge of the research team was used and contained some topics and questions. (See figure 1) The interview schedule was discussed with the research team to ensure quality. The first interview was a pilot-interview to test the complete procedure of interviewing and the interview schedule. The credibility was established by generating a non-judge- mental atmosphere during interviews ensuring to learn from the FCs.³³

The interviews took place one to six months after hospital admission. Most of the interviews were scheduled directly after an appointment at the outpatient clinic, four interviews

were held in the FCs own house. All interviews took place without presence of other persons, so participants were encouraged to speak freely.

Descriptive background variables concerning age, gender, relation to patient, work experience, length of stay, performed care activities and received home-care were obtained during the interview. Transferability was facilitated through this description of participant characteristics and study setting.³³ During the study the researcher made written field notes that helped in the interpretation of data and validation of results.³² To ensure credibility all participants had the opportunity to review and edit their interview. The aim of this member check was that participants can check if recorded information is correctly or not.³³

Data analysis

IPA described by Jonathan smith²⁹ was used to analyse data. Data analysis was conducted independently by two researchers (Nvl; MH) and supported by NVivo 11 software³⁴. The data analysis process equates the six steps of IPA.²⁹ First, all transcripts were (re)read to become familiar with the data. During second step, two independent researchers (NVI; MH) analysed and open-coded the transcripts. These codes where the first step in labelling, compiling and organising data in meaningful groups. Thirdly, initial codes were turned into emergent themes. During fourth step, the two researchers independently searched for connection across emergent themes and grouped them together. When themes fits the data, the researchers moved to the next case and repeated the above described process. Lastly, during six step, the same researchers looked for patterns across cases. The researchers used joint meetings to reach agreement on interpretation of the data and work towards consensus. All steps were done under supervision of a senior researcher (AE). This investigator triangulation deep the researchers understanding of FCs' experiences and it increased the credibility of results.³⁵ Data collection and analysis were an iterative process.

Procedures

Between June 2018 and March 2019 FCs of patients who were admitted to surgical ward and provided FIP have been face to face informed about the study by nurses. When FCs were suitable for this study they were asked to participate. An initial list of 37 FCs who probably met the inclusion criteria was identified and contact details were registered. The researcher (Nvl) approached all of them by phone and asked again to participate, gave comprehensive information about the study and checked if they met the inclusion criteria. When they gave verbal consent, the appointment for the interview was made. In 26 cases, FCs refused participation. Reasons for refusal were as follows: no time, too burdensome or health related problems to the patient. In a few cases, FCs did not fit the inclusion criteria. Recruitment

continued until data saturation was reached and this was after the 12th interview. FCs were verbally and written informed prior to each interview. They were asked verbally and in writing to participate in the study and provided written confirmation of willingness to participate.

Ethical issues

The study was approved by the Medical Ethics Review Committee at the University Hospital (ref no: W18_048 # 18.066). The Medical Research Involving Human Subjects ACT (WMO) does not apply for this project. Participants were assured anonymity, and all data material was treated confidentially.

RESULTS

Between January 2019 and June 2019, 12 FCs (5 male) were interviewed. All interviewees were in intimate relationship with the patient. Most participants had a professional background in (nursing) care. Three participants participated in FIP during several admissions. Table 1 shows main characteristics and performed care activities of FCs. The analysis identified seven main themes:

Being closely involved

FCs experienced the hospital admission as a precious time. To them it was extremely valuable to be with their partner during this emotional time and witness their progress. Someone explained that just being there for your partner is an important component of the FIP:

“We didn’t have intense conversations, absolutely not. Being there is the essence, that was precious for me” (P8)

Being present during hospital admission gave FCs a general feeling of a better understanding of the healthcare process. Being closely involved also meant they were present during impressive situations, such as the side effects of the operation when their partner had pain or experienced severe nausea and vomiting:

“It was really hard, she had a lot of back pain, caused by her stomach which was not functioning. I fondled her back to relieve the pain, I did that for 14 days.” (P5)

A few FCs told about the moment when their partner was mentally confused or had some depressive feelings which were hard to see. Other hard moments were when their partner had an emergency admission to the Intensive Care Unit (ICU) because of a life-threatening situation. These situations were emotional and painful. However, they were grateful to be part of these situations to support their partner. Despite the intensity of these situations, they persisted that they would not have missed it:

“He went to the ICU...The situation was critical. That was really hard, it was one week after the surgery. It was painful seeing him like that ... It was just like a movie, he did not look like my partner... A lot of doctors around his bed, it took so long” ... Imagine I was home and the hospital called me and told me about his situation. I would be extremely shocked, I think I would hit a tree on my way to the hospital... I am happy that I was there the whole time” (P4)

Being meaningful

Being a crucial part of their partner's hospital admission gave FCs a general feeling of being meaningful during this emotional time:

"It affects the feeling of what you mean and how important you are... and what you mean for each other. It is precious to see, it just happened even when you don't talk about it. It is nice to being valuable for someone. That is a great feeling and it gave me a feeling of fulfillment." (P3)

They were able to provide comfort and a sense of relief for their partners. It felt valuable to be a constant in the lives of their partners. According to FCs it all comes down to trust, closeness and actually being there for their loved ones. They felt they had unique knowledge of their partners health needs. That was helpful to recognize gaps in care or intervene in care that may have a negative impact:

"I saw everything, I would even see things which were unaware for my partner. I could even tell the doctors some information like "yes but he didn't sleep for the whole night". While my partner maybe denies that.." (P3)

In two cases the partner was chronically ill, therefore the FC was familiar with the role. They felt knowledgeable in care practices:

"At some point, she wasn't doing well. If I wasn't there with her, and she laid there alone with the nurses and doctors. I think they did not recognize that she wasn't doing well. Because they don't know her. (P11)

Adopting the role of family caregiver

Besides being there for their loved ones FCs also performed various care activities, such as; supporting basic ADLs and toilet hygiene, changing of bed sheets, injection of Fraxiparine, taking care of abdominal drains and feeding tubes, taking care of wound dressing and administration of oral medication:

"I did everything, except the reserved procedures. I helped her out of bed and with showering. When she need help in the night I was there for her. She had a stoma, so I helped her with the stoma care. I think 99% of the care was done by our self. (P10)"

Furthermore, they stimulated their partners mobilization and supported their oral intake. This meant pushing through even when their partners weren't motivated to be active:

"Mobilization, she refused to mobilize... When the nurse asked her to mobilize she said, "no I will do that with my partner" Then I said, "come on, we go walk" She said, "No I don't do that". But I'm in the position to be angry on her and I said, "Yeah right, you came out of your bed now" It worked because she dared not saying no to me." (P11)

Most important thing remains that these FCs felt themselves not caregivers but, loving spouse and for them it is natural to care for their loved ones. Many assumed that caregiving was a natural consequence of their intimate relationship and that is just "what you do".

"It is natural to do that. Everyone said to me "that you can do that, for 4.5 month". For me it is not a problem. Of course, there were moments that I want to go out of the hospital but that is normal. However, it is natural to do, I don't mind. (P10)"

Cooperate with healthcare professionals

FCs were trained in performed basic care activities when they needed. They felt that they could rely on nurses:

"Taking care of wound dressing, etcetera. So, I was sufficiently informed and there was the opportunity to ask questions. The nurses involved during the entire process like 'you can look over my shoulder while I'm doing this' or 'If you don't want to do this, you don't have to'" (P9)

Participating in care was not always an easy task. A pitfall for some of the FCs however, was absence of clarity and guidelines provided by the hospital. They needed clear instructions about their tasks. Some of them also missed feedback from nurses on their performed care activities. Some of the interviewees also stressed the importance of setting boundaries, knowing your limits and communicating these to medical staff.

"For me it was not clear what they expected from me. It is comfortable when instructions will be given by nurses. Like "you can do this or this" After a while it becomes clearer "Oh there I can find the bedsheets". However, during the start of the admission it felt like "What do you exactly expect from me? (P8)

During medical rounds some FCs felt included and had the opportunity to ask questions. Yet, others had the feeling these medical rounds were more patient centered. In their opinion, they

were capable of noticing important signs of illness in their partner. These observations were being reported to medical staff:

“The doctors communicated most of the time with my partner but if I had a question they also listened to me.” (P5)

Losing touch with yourself

The downside of being there is that it can be hard which can lead to; anxiety about losing your partner, exhaustion as a symptom of sleepiness or concerns, helplessness because of loose of control, boredom because of not knowing what to do.

“It was pretty exhausting. When I was home I felt like a young father. We don’t have children but during the hospital admission I had 6/7 wake-up calls each night” (P12)

“What was hard for me? I think the hardest moments were the moments when I didn’t know what to do, just sitting there on my bed with my legs tucked under me.” (P3)

Furthermore, neglecting yourself was mentioned as a potential. But none of the interviewed FCs felt like this program was a burden. Half of FCs experienced that it was beneficial for their own state of mind to take a step back from the situation and focus on their own needs:

“I went to the city to go shopping with my daughters, it was only for a few hours... That gave me the strength to go on with that program” (P7)

This does not apply for all FCs, for some of them it was difficult to leave their partners. One FC did not go to an important event because he had the feeling that he could not leave his partner alone.

Strengthen the bond of the relationship

Being involved during admission process made FCs realize how important their relationship is to them. During this time, they shared their emotions with their partners which brought them closer together and strengthened the bond. Moreover, there was time to have deep conversations with each other.

“In our marriage we had some kind of routine... this admission brought us closer together” (P5)

Because of their involvement there was no need to explain each other anything related to the admission, because the FC was constantly informed about the whole process. Being involved

also meant that they could see each other in a different light. They were able to witness vulnerability of their loved one. However, this close involvement can also lead to irritation or arguments caused by for example: having different views on care, frustration the FC experienced when they felt that their partner was not motivated enough to recover or being too closely together in a relatively small room.

“It happened like “No I don’t want that” or “No I can’t do that” or “Will you stop whining about what I have to do”. Sometimes I was a little bit compelling like “come on I know you can” Than he said “No I can’t” ... I want him to recover while he felt miserable which resulted in a clash. (P1)

Different experiences in previous admissions without FIP

The upside to this program is that FCs do not have to leave their partners behind in hospital. This is a reassurance for them, knowing and seeing that their partner is well taken care of. Also, general visiting hours does not apply to them. A few FCs valued they did not have to come home to an empty house. Additionally, being constantly in the loop means avoiding stress of not knowing what is going on with their partner:

“During a regular admission they separate us when she needed me the most. That gave me a lot of stress, more stress than when I would sit next to her hospital bed for the whole night... She was admitted in another hospital before, I could visit here until 09.00 p.m. For me it was hard to leave her alone. The next morning, I was there immediately at 08.00 a.m. at the start of the visiting hour”. This resulted in the fact that I got not enough sleep and I ate unhealthy because the hospital didn’t offer me a meal. So, I did not take care of myself.” (P11)

Moreover, one FC said the admission felt like a holiday, two other FCs said it felt like home. Being closely involved during hospital admission meant that FCs are more confident when their partners are discharged in comparison to earlier ‘regular’ admissions before. Furthermore, it positively affects the transition home, it runs smoother due the involvement during the entire process. Half of the interviewed FCs said their partners did not need any kind of home-care. However, they did not relate this to the program but to the state their partners were in.

“It gave a feeling of confidence because I was there for the whole time. I knew exactly what was happened” (P10)

DISCUSSION

This study explored experiences of FCs who participated in the FIP. This study makes explicit how meaningful it was for FCs to be actively involved during hospital admission of their partner. FCs experienced the FIP as precious time and had a general feeling of understanding the process better. Besides the fact that FCs performed various care activities, the essence for them was being there for their loved ones. However, there were some hard moments and some negative feelings. Above all, the FIP had a positive impact on their relationship and brought them closer together. Seven main themes were identified related to the FCs experiences: being closely involved, being meaningful, adopting the role of family caregiver, cooperate with healthcare professionals, losing touch with yourself, strengthen the bond of the relationship, different experiences in previous admission without FIP.

Being closely involved also meant that FCs were present during impressive situations. Even though these situations could be emotional, FCs were grateful that they were part of these situations. These results reflect those of previous studies who established that families who witnessed resuscitations (including intubations, and central line insertions) experienced no increase in immediate distress and a trend toward less post-traumatic stress. Moreover, they experienced a lower family psychological distress compared to those who were not witnessed.³⁶⁻³⁸ Healthcare professionals are not always receptive to family presence during invasive procedures because they think that it could be emotionally or psychologically traumatic.³⁹ Nevertheless, it seems that being present during invasive procedures helps to understand the seriousness of their partners illness, and acceptance that everything possible was done for their loved ones.³⁹

Another component of being involved is decision making,⁹ which is fundamental to the concepts of participation.⁴⁰ FCs are often an essential part of health-related decision making.⁹ However, in this study decision making is not mentioned by FCs. This can be explained by the fact that it was not covered in the interview schedule. Either way, most of FCs in our study felt included during the medical rounds and felt the opportunity to ask questions. In a meta-analytical review of Wolff et al.¹³ it was shown that family involvement during medical rounds provide some emotional support, encouragement, reassurance and company. FCs could also help to remember or recall information, providing information to healthcare professionals and to help patient understand.¹³

There are similarities between experiences expressed in this study and those described by Mackie et al.⁴¹ That study found out that it was important for FCs to be present and to offer support. Those FCs also felt that they had unique knowledge of their relatives, which made them critical on delivered care. They pointed out that FCs were often knowledgeable and acted

as a patient advocate or assisted in direct care which enhances patient care.⁴¹ FCs in our study did not explicitly mention (improved) quality of care. What they valued was the feeling of being there for their loved ones. This finding was also reported by Cypress and Frederickson⁴² who described that being present offers FCs the opportunity to being close. It helped them to protecting and supporting their loved ones. Besides, it offers FCs the opportunity to see conditions change over time and it strengthen the bond of the relationship.⁴²

FCs did not experience the FIP as too burdensome. This finding is contrary to previous studies which have suggested that being a FC can cause burden which can lead to adverse effects.²⁰⁻²² This result may be explained by the fact that it was not chronically informal caregiving. For most of participants it was a relatively short period. Besides, they had a feeling that they could rely on nurses. There were some feeling of anxiety, exhausting and sleepiness which are in line with those of previous studies.²³⁻²⁶ Although, exhausting and sleepiness in our study could be related to the demand of care from their loved ones during night.

In our study FCs performed a variety of basic care activities and were trained by nurses. The involvement of FCs was described in a program with a clear policy. Though, FCs which were interviewed participated in the FIP during a transitional stage. The QIP was ended and the FIP became part of usual care. That transitional stage made that the FIP not always being performed correctly according to policy and guidelines. This probably explain that some FCs experienced an absence of clarity and guidelines provided by hospital. For them it was not always clear what the hospital expected. This may affect our study results

Nurses play a significant role in collaborating with FCs as care partner.⁴³ They had to support FCs.⁴⁴ A recent study shows that FCs who perceived collaboration with nurses is significantly associated with preparedness for caregiving at home. Being better prepared leads to less experiences strain by FCs and it contributes to a better quality of life for both their relative and themselves.⁴⁵ Consistent with the study of Hagedoorn et al.⁴⁵ our research found that FCs had more confidence after discharge compared to earlier 'regular' admissions. Being involved positively affects transition home. FCs did not relate their involvement to receiving of homecare. A possible explanation for this might be that FCs are modest and did not realize that taking care of wound dressing and Fraxiparine at home is not taken for granted.

This study has some strengths and limitations. Rich descriptions of setting and sample have been provided which strengthens our study. To strengthen credibility of the study, data were independently analyzed by two researchers and supported by a senior researcher during the entire process. Furthermore, field notes were made, member checks were held and COREQ was used to enhance the quality of the outcomes. A limitation of this study was failing of purposive maximum variation sampling. It is acknowledged that all participants were in intimate relationship with the patient. This may affect the generalizability of the results, so

future research into other caregiver relationships could be interesting. Most participants had a professional background in nursing care, which could be related to a desire to care. Moreover, the sample mainly constituted of native Dutch FCs. Differing cultural and ethnic backgrounds were not captured. A recent study shows that a reason of providing informal care could be related to ethnic background.⁴⁶ Our study is a one-center study, which limiting generalizability of the results. The FIP consist of a detailed policy for healthcare professionals and information for patient and FCs. Nevertheless, the healthcare professionals affect the way how it will be implemented and plays a crucial role. It is important that nurses and doctors make visible what they expect from the FCs. Nurses and doctors had to create a warm environment, so that FCs felt they could rely on them. Because most of the FCs need clear instructions and feedback and need the opportunity to ask questions.

Conclusion

Based on this study, we showed that active participation of FCs during hospital admission is valuable. Even though FCs experienced sometimes hard moments they would not have missed it. FCs became a partner in hospital care and performed a variety of basic care activities. However, clear instructions and meeting FCs' expectations is essential. The FIP gave the hospital admission another dimension.

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APPENDIX A

Interview schedule	
<p><i>Introduction:</i> Thank you for agreeing to speak with me today about your experiences with the family involvement program. The interview will take approximately 60 – 90 minutes to complete. Please remember that everything you share with me will be kept strict confidential. (Refer to the informed consent). There are no right or wrong answers to those questions, I am only interested in your experiences. If you feel not comfortable with questions, let me know. If you wish to decline to answer, you may do so. You do not have to explain that. If you need to take a break, please let me know. Do you have any other questions? Before I begin, do I have your permission to audio-record this interview? (start audio) – This is an interview about the experiences of the family involvement program, this interview is on (date) and he/she understands that this interview is being recorded. Is this correct?</p>	
Openings question	How did you experience the hospital admission of (name patient)?
Family involvement program	Can you tell me something about your experiences with the family involvement program? Can you tell me about the things you took care for during the hospital admission of (name patient)?
Receiving information	Can you describe the kind of information you got before the start of family involvement program?
Interaction with healthcare professionals	Can you describe how you experienced the communication with the healthcare professionals? With nurses? During the medical round?
(Caring) role	What did the change of role mean to you? What did contribute to care mean to you? What does it mean for your relationship?
Presence	What did it mean for you that you could be present 24 hours?
Contribution to care	What helped you to contribute in care? What hindered you to contribute in care?
Feeling and thoughts	Can you give me some insight in the meaningful moments during the hospital admission? Can you give me some insight in the hard moments during hospital admission?

Figure 1. – Interview schedule

Table 1. – Baseline characteristics

N. FC	Gender	Age (years)	Relation to the patient	Working in the healthcare sector	Length of stay (days)	Performed care activities	Receiving of home-care
1	F	60-69	Married	Yes	10	* Supporting basic ADLs (Showering, dressing, oral care) * Mobilization * Encouraging and supporting of oral intake * Injection of Fraxiparine	No
2	F	50-59	Married	Yes	2 admissions (7, 5)	* Supporting basic ADLs (Showering, dressing, oral care) * Changing of bed sheets * Mobilization * Injection of Fraxiparine * Supporting wound dressing * Taking care of the stoma	Yes
3	M	50-59	Married	Yes	8	* Changing of bed sheets * Mobilization * Injection of Fraxiparine * Taking care of abdominal drains * Taking care of the feeding tube	No
4	F	60-69	Married	Yes	2 admissions (98, 28)	* Supporting basic ADLs (Showering, dressing, oral care shaving) * Changing of bed sheets * Mobilization * Administration of oral medication	Yes
5	M	70-79	Married	No	14	* Supporting basic ADLs (Showering, dressing, oral care) * Supporting toilet hygiene * Changing of bed sheets * Mobilization * Injection of Fraxiparine * Taking care of abdominal drains * Taking care of the feeding tube * Administration of rectal medication	No
6	M	70-79	Married	No	3 admissions (21, 56, 5)	* Supporting basic ADLs (Showering, dressing) * Supporting toilet hygiene * Changing of bed sheets * Mobilization * Injection of Fraxiparine * Taking care of abdominal drains	No
7	F	60-69	Married	Yes	10	* Supporting basic ADLs (Showering, dressing) * Changing of bed sheets * Cleaning of the room * Mobilization * Encouraging and supporting of oral intake * Encouraging the revalidation process	Yes
8	F	60-69	Married	No	14	* Supporting basic ADLs (Showering, dressing)	No

						<ul style="list-style-type: none"> * Supporting toilet hygiene * Changing of bed sheets * Mobilization 	
9	F	60-69	Married	Yes	10	<ul style="list-style-type: none"> * Supporting basic ADLs (Showering, dressing, oral care) * Supporting toilet hygiene * Changing of bed sheets * Mobilization * Encouraging and supporting of oral intake * Supporting wound dressing 	No
10	M	60-69	Married	No	135	<ul style="list-style-type: none"> * Supporting basic ADLs (Showering, dressing, oral care) * Supporting toilet hygiene * Changing of bed sheets * Mobilization * Taking care of the stoma 	Yes
11	F	30-39	Married	Yes	7	<ul style="list-style-type: none"> * Supporting basic ADLs (Showering, dressing) * Mobilization * Supporting wound dressing * Taking care of the stoma 	No
12	M	70-79	Married	No	11	<ul style="list-style-type: none"> * Supporting basic ADLs (Showering, dressing, oral care) * Supporting toilet hygiene * Changing of bed sheets * Mobilization * Encouraging and supporting of oral intake 	No

Abbreviations: ADL = Activities of Daily Living;