The experiences of patients who had major abdominal surgery regarding the active involvement of family caregivers at the surgery ward: An interpretative phenomenological analysis

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LIST OF ABBREVIATIONS AND RELEVANT DEFINITIONS

AE	Dr. Anne Eskes (senior researcher)
COREQ	Consolidated Criteria for Reporting Qualitative Research
FCC	Family Centered Care
FC	Family Caregiver
FI	Family Involvement
FIP	Family Involvement Program
IPA	Interpretive Phenomenological Analysis
MH	Mariken Horst (principal researcher)
NI	Nina van Ingen (member of the research team)
WMO	The Medical Research Involving Human Subjects ACT

Abstract

Background

Family Centered Care (FCC) contributes to a higher quality of care for the patient. However, family involvement (FI) in patients care may also influence the needs and autonomy of the patient. A university hospital in the Netherlands developed a family involvement program (FIP) to actively involve family caregivers (FCs) in patients care after major abdominal surgery. This project shows positive quantitative outcomes; however, it does not give insight into patients' experiences regarding FI. Understanding these experiences is essential for further development of FI within hospitals.

Aim:

To explore the experiences of patients who received the FIP regarding the active involvement of FCs after major abdominal surgery during admission at the surgery ward.

Method

An interpretative phenomenological (IPA) was performed. 13 face to face in-depth interviews were undertaken with participants who were recruited from the university hospital where the FIP was performed. Data was analyzed by two independent researchers and discussed with the research team.

Results

From the 13 patients, 12 underwent surgery because of cancer. All patients were cared for by their partners. Five main themes played a key role in the FIP: (1) sense of being home, (2) strengthening existing relationships (3) contribution to recovery, (4) feeling safe and confident and (5) expectations and obstacles within the relationship between patient, FC and the healthcare professionals.

Conclusion

FI is beneficial for patients during hospital admission. Patients feel more at home, safe, confident and relaxed. FIP strengthens the relationship with their FC. However, clear guidance about what is expected from the patient within the FIP is necessary.

Recommendations

The FIP need to be well coordinated and the healthcare team has to create clear guidance about what participating means for the patient, the FC and the healthcare professional.

Keywords

Family Caregiver · Hospital · Surgery · Interpretive Phenomenological Analysis · Experiences

Samenvatting

Achtergrond

Familiegerichte zorg (FGZ) voor volwassenen wordt steeds belangrijker tijdens opname in het ziekenhuis. Familieparticipatie (FP) heeft mogelijk ook nadelige effecten op de behoeften van de patiënt. Een universitair ziekenhuis in Nederland heeft een familie-participatie-programma (FPP) ontwikkeld om de kwaliteit van zorg te verbeteren. Tijdens het FPP helpt de familie mee in de zorg tijdens de opname in het ziekenhuis, nadat patiënten abdominale chirurgie hebben ondergaan. Om FGZ verder te ontwikkelen, is het belangrijk dat er beter begrip komt over wat FP betekent voor de patiënt.

Doel

Onderzoeken wat de ervaringen zijn van patiënten die meededen aan het FPP tijdens hun opname in het ziekenhuis, nadat ze abdominale chirurgie hebben ondergaan.

Methode

Een interpretatieve fenomenologische analyse (IPA) is uitgevoerd. Hiervoor zijn 13 diepte-interviews uitgevoerd. Participanten zijn geworven in het universitaire ziekenhuis waar FPP wordt uitgevoerd. De data is geanalyseerd door twee onafhankelijke onderzoekers en bediscussieerd binnen de onderzoeksgroep.

Resultaten

12 van de 13 patiënten werden geopereerd vanwege de diagnose kanker. Alle patiënten werden verzorgd door hun partners. Vijf hoofdthema's speelden een rol voor patiënten, namelijk: (1) gevoel van thuis, (2) versterken en uitdagen van de relatie met de mantelzorger, (3) bijdrage aan herstel, (4), je veilig en zeker voelen en (5) de relatie tussen patiënt, mantelzorger en de zorgprofessionals.

Conclusie

FP is gunstig voor patiënten tijdens hun ziekenhuisopname. Patiënten voelen zich meer thuis, ze voelen zich veiliger, zelfverzekerder en meer ontspannen. Het FPPP versterkt de relatie met hun mantelzorger. Er zijn echter wel duidelijke richtlijnen nodig over wat wordt verwacht van patiënten wanneer zij meedoen aan het FPPP.

Aanbevelingen

Het FPP dient goed gecoördineerd te worden en de zorgverleners dienen duidelijke richtlijnen te creëren over wat meedoen aan het FPPP betekent voor patiënt, familie en de zorgverlener.

Kernwoorden

Familie gerichte zorg · Ziekenhuis · Chirurgie· Interpretatieve fenomenologische analyse · Ervaringen

Introduction

Family Centered Care (FCC) is gaining importance during hospital admission in adult care. When FCC is offered during admission, the family caregiver (FC) has the opportunity to stay with the patient, care for the patient,[1,2] and negotiate with healthcare professionals about the treatment options.[3] These family caregivers (FCs) are defined as 'any person who, without being a healthcare professional, usually lives with the patient and, in some way, is directly implicated in the patient's care or is directly affected by the patient's health'.[4]

At adult hospital wards where FCC is offered, it has been shown that it can improve collaboration between the patient, family members and the healthcare team,[5] and that it contributes to a higher quality of care, self-management and quality of life for the patient.[6-8] FCC also has the potential to decrease patient's anxiety, to contribute to a sense of wellbeing[9] and to encourage patient's safety.[10] Furthermore, it can improve the quality of the transition from hospital to home, because the family involvement (FI) in care activities during hospitalization prepares patient and family to deliver adequate care in the home setting.[11]

As mentioned above, quantitative data regarding FCC show beneficial effects for patient care because it enhances support, communication, decision making and quality of care.[12] According to a recently published review, patients value uniqueness, autonomy, compassion, professionalism, responsiveness, partnership and empowerment in various contexts in healthcare.[13] FCC may contribute to these qualities.[12]

Besides positive results, FCC may also cause negative effects. As FCs can be overprotective, frightened and tense,[14,15] it may interfere with the needs and autonomy of the patient, values which are important to a patient.[13,16] Another study shows that family and nurses experience a lack of guidance within FCC. This leads to ambiguity regarding the distribution of roles and tasks, resulting in a grey area which directly affects patient's care and safety.[17] There is a question about how this grey area is experienced by the patient.

Based on the positive results of FCC, a university hospital in the Netherlands developed and implemented an evidence-based and theoretically grounded family involvement program (FIP) to enhance the active involvement of FCs in fundamental care for post-surgical patients through a multi-component intervention.[18,19] When the FIP is offered, a FC stays at least 8 hours per day with the patient throughout the complete admission at the surgery ward, and helps with fundamental care activities, including: support, mobilization, breathing exercises and oral care. [18] Furthermore, the hospital aimed to create a homely ambiance in the FIP rooms.[20] The support of FI might especially be auspicious during surgical admission because these patients are at high risk for feelings of stress and anxiety,[21] due to the physical trauma of the surgery and its unpredictable outcomes.[22]

As part of the evaluation of the FIP, the question arose of what the active involvement of FCs during surgical admission means to patients in detail. Gaining this understanding will provide a solid basis for further development of a FI approach within hospitals. Thus, this study aims to gain in-depth insight into the experiences of patients who received the FIP regarding the active involvement of FCs after major abdominal surgery during their stay at the surgery ward.

Aim

The objective is to explore the experiences of patients who received the FIP regarding the active involvement of family caregivers after major abdominal surgery during the admission period at the surgery ward.

Method

3.1 Design

To create understanding of the phenomenon ‘experiences of patients who had FCs actively involved during postsurgical care’, a qualitative study was carried out, following the principles and guidelines of Interpretive Phenomenological Analysis (IPA).[23,24] IPA fits the aim of this study as phenomenological research focuses on the way the participants make sense of their lived experiences and it seeks to understand a particular phenomenon.[24] The method and reporting followed the consolidated criteria for reporting qualitative research (COREQ). [25]

3.2 Population and domain

A purposeful sample[26] of patients were recruited. All patients participated in the FIP after major abdominal surgery during their stay at the surgery ward in a university hospital in the Netherlands with over 1000 beds.[27]

Eligibility criteria were:
1. Underwent major elective abdominal surgery,
2. Participated in the FIP,
3. Had a minimum age of 18
4. Spoke Dutch fluently.

3.3 Ethics

Ethical clearance for the study was attained through the Medical Ethics Review Committee at the University Hospital. The Medical Research Involving Human Subjects ACT (WMO) does not apply for this project. All participants signed informed consent and they were told that they were free to withdraw at any moment.

3. 4 Procedure

The study was conducted during the period January – June 2019. After discharge from the hospital, patients were approached by phone to ask if they were interested in participating in an interview. Interviews were conducted in a private room at the hospital prior to or after an outpatient appointment, or at the patient’s home. One patient was interviewed on the last day of her admission. The interviews were held between interviewer and participant in a private room, in order that the participants could talk freely, and did not need to take the FC’s feelings into consideration. The interviews were audiotaped with a smartphone. Afterwards the audiotapes were transcribed in verbatim.[28] All participants gave approval for the use of their transcripts.

3.5 Data collection

Data were collected through conduction of semi-structured, face to face, in-depth interviews, using an interview guide (appendix A).[24] The first interview was pilot tested. After the pilot interview, the guide was reconsidered, and some limited changes were made. To ensure reflexivity during the process, the interviewer wrote fieldnotes.[24] Using semi-structured interviews enabled the interviewer to create a conversation with the purpose to talk about FI, but without dictating a certain path.[24] In-depth conversations were created, so the participants felt the space to express themselves in their own words, and the interviewer had the opportunity to expand upon the participants' stories and lived experience.[24] To ensure confirmability, the researcher intended to bracket her own knowledge as much as possible, since she is a registered nurse with professional experience and scientific knowledge on major abdominal surgery and FI. By bracketing, the interviewer attempted to limit her own assumptions and preconceptions about FI.[24] Interviewing continued until meaningful and detailed data was generated and until it was clear that extra interviewing was not leading to new patterns and understanding about the participants' experiences.[24] This moment of data saturation was discussed with the research team (MH, NI, AE) after the 13th interview. To ensure credibility, participants were asked if they wanted to do a member check.[28]

3.6 Data analysis

The transcripts were imported into NVivo 12, a software program for analyzing qualitative data. After re-reading the transcripts, they were initial coded.[24] Paragraphs and sentences were ordered by highlighting the structure of the participants' experiences about FI. After the initial coding, emerging themes were searched for. In every following analysis of a transcript, new themes were search for. Therefore, data collection and analysis were an iterative process. Credibility and Internal reliability were ensured by applying researchers' triangulation.[24] The principal researcher (MH) and a second researcher (NI) individually coded the transcripts and discussed the themes. This process happened under the supervision of the coordinating researcher (AE). To create trustworthiness, the researchers discussed the outcomes with each other to create a dialogue about what FI means for the participant in the context of the hospital. This dialogue contributed to the interpretative account of the data and created a more rigorous and objective analysis.[24,28] During the entire period of interviewing, the researcher discussed the research process with neutral colleagues who were familiar with qualitative research and interviewing. This improved the quality of the interviews.[28]

Results

Of the 37 patients approached by phone, 13 were interested in participating in an interview and were included in the study. The period between surgery and interviewing varied from one to seven months. Interviews lasted between 43 min and 66 min; most were 55 minutes. Four participants wanted a member check.

Insert Table 1

The characteristics of the participants are showed in Table 1. Analysis of the interviews revealed that five main themes played a key role when participants participated in the FIP, namely: (1) sense of being home, (2) strengthening existing relationships (3) contribution to recovery, (4) feeling safe and confident and (5) Expectations and obstacles within the relationship between the patient, the FC and the healthcare professionals.

1. Sense of being home

The participants shared a room with FCs and were accompanied by them during the whole admission period. Participants emphasized that the fact they could be together with their loved one all the time, gave them a feeling of being at home. They felt safe and comfortable. As one participant explained this feeling:

> ‘*I almost experienced the admission as being sick at home. As if the family doctor stops by to check how you are… Well, it gave a sense of being at home… It gave me the feeling I could really be myself’. (P8)*

> *‘[when there were visitors] My husband almost took on the role of a host. ‘Do you guys want coffee? I’ll go and get some’. That created such a different ambience… it also means that I could talk with my visitors. It is so different than if you tell them: over there you can get coffee. It is just, the whole ambience is different. It felt homelier.’ (P4)*

Together with the FC it was possible for the participants to create a cozy and pleasant atmosphere in their room and talk about the small and big things in life. They experienced privacy because they were together all the time. So much so that, for eleven participants it felt as if they could create the same environment as at home.

> ‘*We had the news on all the time, and I loved how we discussed about the things we saw. Being able to talk about everyday problems and to argue about them’. (P11)*

> *‘Well, you are able to talk about pleasant things. About the children or everyday issues. When you have to wait until your visitors arrives at visiting hours, well yeah, that is very different. Then you need to wait the whole morning and afternoon.’ (P13)*

Participants considered the continuity of presence that the FC gave them as meaningful, since most participants experienced it as tiring to see so many different healthcare professionals every day. They emphasized that they could rely and trust on their FC during this period.

> *‘It gave me a familiar feeling. You see so many healthcare professionals every day and then my love is there, all the time…. It gave me a feeling of safety… She gave me the help I needed’ (P3)*

Many participants experienced feelings of peace and restfulness during their admission. The sense of being dependent on each other for a period of time in a nice room with the possibility to talk endlessly, make jokes, say nothing, or read a book, gave most participants a feeling of having a break.

> *‘It maybe sounds weird, but I described it once as ‘it was just as if you were on holiday and you needed to stay in because of the bad weather’. That sounds strange of course, but we had lots of fun together. The nurses were nice, the doctors were dedicated, so [the admission period] was also a moment of peace. Something you share and experience together. That is how I described it. An all-inclusive vacation with bad weather.’ (P4)*

2. Strengthening and challenging existing relationships

Almost all participants felt very grateful for the care and commitment they got from their FC. Participating in the FIP allowed them to create a deeper connection with their loved ones. They feel closer and more connected with their partners and it contributed to a strong relationship.

> ‘*Doing this together made us even stronger. We support each other more and we love to spend more time together. It brought us closer, I know that for sure. Well, it really brought me closer to her. I tell her every day, maybe 10 times a day, how much I love her. Wherever I am I tell her, even if I need to scream, I don’t care who hears it.’ (P3)*

> *‘My wife is so much stronger than she believes. I just didn’t find a way to convince her of her own strength.... She did so much for me in the hospital. I’m really grateful. She deserves a medal. I appreciate her more and more.’ (P11)*

All participants repeatedly mentioned the great value of being able to experience all the facets of the disease and the admission together and to this day, they still share this memory. They experienced it as a luxury to be together, support each other and being able to stay longer than the normal visiting hours.

> *‘It meant so much for me that we could just be together. That we could share things during the hospital stay. We have shared so much in life together, and being able to share this admission as well, is so meaningful to me... Just the idea of having him with me in the hospital and that I can hold him whenever I want. Those are the moments I cherish... The fact that he was there for me, gave me so much support.’ (P10)*

Despite the many benefits, patients also experienced downsides of the FIP. Five participants spoke of the difficulty knowing that your FC had seen you in all stages of the admission period, including when the patient was in a critical condition and in a lot of physical and mental pain. The participants saw that their FC was stressed or exhausted.

> *‘My wife has seen more of my pain than I did. I wasn’t always there [conscious]. I find that terrible. That’s the only thing I didn’t want. I wish she would not have seen those moments’ (P3)*

> *‘I could see that he was getting exhausted. He let a lot of tears. Just because he was so tired. … I did worry about him and that wasn’t nice. Because you are sick yourself and then you also start worrying about someone else... I liked it when he was with me in the hospital because it made me feel safe... But sometimes I thought, go home for the weekend... Because I saw him suffering. (P6)*

3. Contribution to recovery

Many participants indicated that the FC protected them, and that the FC was actively aware of the state of their physical deterioration and progress. They found it comforting that there was always care available when they needed it. In urgent situations, like vomiting of diarrhea, they did not have to wait for a nurse.

> *‘If he hadn’t screamed down the hallway that moment, I wouldn’t have been here anymore. I was so ill that moment, when he saw me passing out. And then he yelled that there had to come a doctor… I went to the ICU for emergency. If he wasn’t there, I would be dead now. That is also what the doctor said: you owe your life to your husband’. (P6)*

Almost all participants mentioned that being surrounded by their loved ones changed their attitude. For instance, it had more impact when their FC told them to eat, walk, brush their teeth or do breathing exercises, than if a nurse or doctor asked them to do those activities. This resulted in an increased level of fundamental care activities. Reasons from participants to not act included stubbornness, pride, laziness or feeling too tired or too sick.

> *When the nurse asked me to do breathing exercises, I find it was patronizing. When my husband said I needed to do my exercises he did it with some witticism, which made me do it.’ (P4)*

‘

> *‘Participating in the FIP meant that I recovered faster because my wife motivated me... When I just got rid of a nurse because I didn’t want to walk, my wife was there and pushed me. Well yeah, then I didn’t have any choice... My wife pushes me more. She knows which buttons to push to make me do something.’ (P11)*

When the participants talked about the company of their loved one, it was apparent that it released some of their stress and made them more relaxed. They mentioned that they felt less tense, both during the day and at night.

> *‘You behave differently to your husband then to the hospital staff. It feels different. It’s more familiar… The staff didn’t know me, my husband knows me very well. His presence released the stress I felt around strangers.’ (P12)*

4. Feeling safe and confident

At the date of discharge, almost all participants felt ready and confident to go home. Because their partners were there during the whole admission, they did not need to explain anything. Information about the surgery, complications and homecare was explained to them. Because the participants were often asleep or not alert, their FC acted as a fundamental support in recording and remembering everything that happened during the admission.

> *‘Going home was easier for several reasons... How the tube feeding worked was well explained to both of us. It is very helpful that this was explained to two people during the FIP. Then you both know... He helped me with questions we needed to ask the doctor before we went home. That was very useful. Being together helped us to communicate with doctors and nurses and to prepare for the admission.’ (P4)*

> *‘My wife learned everything about the tube feeding in the hospital. In the beginning she needed to get the hang of it, but after that it went well. When we got home, we could do it all by ourselves... The nurses in the hospital were very supportive in teaching my wife what she should or should not do.’ (P8)*

Undergoing surgery and recover in the hospital, was for all participants an intense and frightening period. They had to wait and see if complications developed. In addition, it takes some time before the doctors know if their patient’s tissues are free from cancer. Because the participants were accompanied by their loved ones, they were able to better cope with the stressors of the admission.

> ‘*The admission would have been much harder if he were not there with me... if I had concerns, I could talk to him about it. I mean, he was there all the time. When I would not participate in the FIP, I know I could also call him. But now he was physically there with me, he sat with me and held my hand.’ (P10)*

All participants spoke of the fact that their FCs helped them to put their thought and feelings in perspective. All participants had feelings varying from worrying, being frightened, feeling depressed, feeling sad or being in pain. Having their FC with them and listening to them, felt for them as if their worries decreased and it made them calm in periods of dark feelings.

> *That my wife could spend the night was great. She laid next to me. That made me feel safe. Nothing bad could happen.' (P11)*

> '*When you are alone, you start worrying. But when you can talk about things together, that doesn't happen. And my husband is very easy-going. He doesn't make things bigger…. At one moment I felt really miserable because the drain in my back hurt so much. And he said: 'It is what it is right now.' And when you are all alone, you start thinking 'why does this happen to me?' … The fact that someone is there with you all the time helps. (P4)*

5. Expectations and obstacles within the relationship between patient, family caregiver and the healthcare professionals

During the admissions, the patients and FCs had different expectations of the relationship with the healthcare professionals. This could create obstacles in the communication. For example, it was notable during the interviews that three participants found that they did not get the attention from the nurses that they desired. They felt as if the nurses did not give them as much attention as other patients. In contrast, the other participants had a good relationship with all the nurses and really felt they could rely on them. However, the participants who longed for more attention did not discuss this with the nurses but kept this point of frustration to themselves. The other participants were able to express their feelings to the nurses and ask attention whenever they needed it.

> '*At one moment I ate too much, so I started vomiting. So, then my wife asked a nurse to come and help her. It also puts the responsibility on yourself - if you want, you can get the attention of the nurses. If you stay together in the room all time, and don't ask for help if you need it, nothing will happen. We could always ask for help and then we got the help.' (P8)*

At the same time, almost all participants - including those who desired more attention - had a sense of unburdening the nurses because their FC was there. They felt reluctant in calling the nurses, and only did it in emergencies. Some participants figured that the FIP was developed because of the financial cuts in healthcare.

> *‘I can call a nurse and then they will come and respond to my questions about what I should do. But if it is possible to discuss these questions with my wife and she can tell me what I should to when I’m in pain. Then I also have my answer and I don’t have to call the nurses every time… I won’t want the nurses here, I’ve seen how busy they are, extremely busy… I know I can call them. But I won’t. Only if it is very critical. But if my wife could also do it, then it was also solved. (P7)*

Regarding the communication from the doctors and nurses; this was mostly focused on the patient, but there was always room for the FC to contribute to a conversation. Whenever the patient was asleep or away for medical examinations, the conversation was held with the FC.

> *They [healthcare professionals] stop by at your bed, you shake hands, they’ll introduce themselves. And then ask, ‘how are you today?’ And uh, that is how the conversation goes. If my wife felt the need to attend the conversation, then she certainly did. And then it was just uh... well a conversation between us three.’ (P9)*

A negative experience was the fact that half of the participants experienced a lack of guidance during the admission period. What they were expected to do was not communicated, for example it was unclear to them when the nurses should be called, and what to do if they saw their FC struggling. They missed a central point of contact of whom they could ask their questions. This grey area made them feel less safe.

> **‘***In the beginning, there was a grey area. It was completely unclear what we needed to do. It became clear because she was assertive. Especially her, because I was too sick. She asked [the nurses], ‘what do you expect from me? I want to help but I don’t even get the chance. You are [the nurses] doing everything.’ (P1)*

Discussion

Based on this study, we identified five major themes about patients experiences when their FCs are actively involved during the FIP. The participants in this study mentioned that they had a sense of being home and felt strengthened and challenged in their existing relationships. Furthermore, it contributed to their recovery, and it made them feel safe and confident. Within the relationship between patient, FC and the healthcare professionals there were different expectations and obstacles.

The findings in this study show that feeling safe and feeling at home are of great importance for patients during admission. Participants often felt confident and relaxed during the FIP. This well-rested feeling not only contributes to patients' physical and emotional health [29], but also may support wound healing[30] Furthermore, a feeling of being at home may also support the transition to home, as it is shown that there is an association between experiencing a smaller contrast between home and the hospital, and feelings of anxiety and satisfaction.[31] Creating a smaller contrast was also one of the purposes of the FIP, since the hospital created a homely ambiance in the FIP rooms. The fact that participants in our study experienced feelings as if they were being cared for at home and the thereby experienced feelings of safety, relaxation and confidence, may be explained by a study of Schuchman et al. [32] which shows that home care improves quality of life for patients and their caregivers, in comparison to hospital care.[32] What also may have contributed to this feeling is that all the FCs were partners of the participants. This enabled the participants to maintain their usual habits with their partners as much as possible. These results seem to be consistent with previous research about children and the elderly, which found that it is important for them to feel at home during admission and to be surrounded by family and familiar items. [33-36] Furthermore, the presence of the FC made the participants feel calm. They also felt more capable of coping with all the stressors they had to deal with during admission. A study that also showed the great importance of having a relative close to feel strong, understood and safe, is a systematic review of Wassenaar et al.[37] at the Intensive Care Unit (ICU). Considering these results, it is interesting to note that FCC is widely accepted in pediatrics, but not in adult care. A Cochrane Review from 2007 shows that FCC for children in the hospital is already usual care for decades.[38] Interestingly, a relevant finding in our study is that FCC can be as beneficial for adult people as it is for children and elderly. Which is also mentioned by Clay et al. by stating that 'FCC is no longer just for pediatrics'.[39] The results of the study also showed that the participants felt strengthened and challenged in their relationship with their FC. This is in line with research findings that showed that couples who experience a cancer diagnosis as being sick together and who battle the cancer together, become closer and stronger, and experience personal growth.[40-42] Similar to these previous research findings, the majority of the participants in our study participated in the FIP with their partners and underwent surgery because of the cancer diagnosis, and experienced and battled the diagnosis and operation together. However, our study also showed the possibility for participants to experience discomforting emotional and physical facets because of the presence of the FC. This is supported by research about cancer caregiving which shows that informal cancer caregiving can create a burden and mental and physical health problems to the caregiver.[43,44] Since our study shows that it can be hard to deal with the burden of the FC, it may be possible that the presence of the FC can negatively influence the quality of the admission period for the patient. This should be taken into account in the future in the development of the FIP. What is surprising in this study is that participating in care during hospitalization seemed obvious for both patient and FC. This approach to caregiving mirrors the current transformation in healthcare, in which informal caregiving is increasing and care is considered a shared responsibility. [45-47] Informal caregiving is growing especially for elderly and cancer patients. This can be a positive trend in healthcare; however, healthcare professionals need to be well-educated and competent in delivering family-centered care.[48-50] A study of Uysal et al[51], shows that patients can experience low quality of care when the FC is not around, because the nurses do not have enough time to take good care of the patients. This is confirmed by our study, since the participants felt reluctant in calling the nurses because they fear adding to the nurses' workload. Some participants also experienced a lack of guidance in the FIP; therefore, expectations and guidelines need to be clear and well communicated between patient, family and healthcare professionals.[52,53] In contrast with these findings, is the fact that the participants in our study do not always accept the care of the nurses. They told the researchers that it had more impact when their FC asked them to take good care of themselves instead of when a healthcare professional asked them. This is in line with a structured review[54] that examined the effect of programs that increase family support in disease management. This review shows that when family uses supportive communication techniques, health behavior is improved.[54] It can thus be suggested that delivering good quality FCC is complex. In order to deliver effective FCC, healthcare professionals need to be well-educated about communicating with all types of patients and family, and healthcare teams need to cooperate effectively.

This study had several strengths and limitations. Using IPA is a strength of the study because IPA enabled the researchers to create detailed knowledge about the patients lived experience.[24] To strengthen the validity of this study, the collected data was analyzed by two independent researchers and the themes were discussed by the research team.[28] The COREQ criteria were used to ensure all relevant elements of qualitative research were applied to this study.[25] A limitation of this study may be that the sample was relatively similar. There was little variation in age, surgery, or in the relationship to the FC. However, a homogenous sample is beneficial within IPA, because the divergence and convergence of the experiences can be examined in detail. The population of this type of surgery is also representative.[24] During the admission period, the FIP was still in the implementation phase. This could have been the cause of the lack of guidance and structure that the participants experienced. Implications for clinical practice are that the FIP needs to be well-coordinated and that the healthcare team should create clear guidance about what participation means for patient, FC and healthcare professionals.

Conclusion

During the admission period, it seems to be beneficial for patients to be accompanied and cared for by their FC. Patients feel more safe, confident and relaxed. It strengthens and challenges the relationship with their FC. To ensure a good relationship between patient, FC and healthcare professionals, it is necessary to create clear guidance about what is expected from the patient within the FIP.

Table 1

Participant	Participation in FIP	Age	Male/ Female	Relationship to FC	Married (years)	Diagose	Surgery
1	10 days	66	Male	Partner	40	Cancer	Oesphagus
2	14 days	56	Male	Partner	29	Cancer	Liver
3	18 weeks	70	Male	Partner	50	Cancer	Oesphagus
4	8 days	62	Male	Partner	42	Cancer	Oesphagus
5	14 days	74	Female	Partner	55	Cancer	Pancreas
6	12 weeks	70	Female	Partner	43	Cancer	Pancreas
7	10 days	62	Male	Partner	40	Cancer	Liver/bile ducts
8	14 days	67	Male	Partner Father	44	Cancer	Oesphagus
9	9 days	64	Male	Partner	42	Cancer	Oesphagus
10	20 weeks	61	Female	Partner	42	Cancer	Stomach
11	7 days	38	Female	Partner	9	Fistulae	Intestines
12	11 days	80	Female	Partner	43	Cancer	Pancreas
13	21 days	76	Male	Partner	48	Cancer	Pancreas

References

1. Cené CW, Johnson BH, Wells N, et al. A Narrative Review of Patient and Family Engagement: The "Foundation" of the Medical "Home". Med Care 2016. DOI: 10.1097/MLR.0000000000000548.

2. Shields L, Zhou H, Pratt J, et al. Family-centred care for hospitalised children aged 0-12 years. Cochrane Database Syst Rev 2012. DOI: 10.1002/14651858.CD004811.pub3.

3. Uniacke S, Browne TK and Shields L. How should we understand family-centred care?. J Child Health Care 2018. DOI: 10.1177/1367493517753083.

4. Martínez-Martín P, Forjaz MJ, Frades-Payo B, et al. Caregiver burden in Parkinson's disease. Mov Disord 2007. DOI: 10.1002/mds.21355.

5. Choi Y and Bosch SJ. Environmental affordances: designing for family presence and involvement in patient care. HERD 2013.

6. Christian BJ. Translational Research - The Value of Family-Centered Care for Improving the Quality of Care for Children and their Families. J Pediatr Nurs 2016. DOI: 10.1016/j.pedn.2016.03.001.

7. Mackie BR, Marshall A and Mitchell M. Acute care nurses' views on family participation and collaboration in fundamental care. J Clin Nurs 2018. DOI: 10.1111/jocn.14185.

8. Park M, Giap T, Lee M, et al. Patient- and family-centered care interventions for improving the quality of health care: A review of systematic reviews. International Journal of Nursing Studies 2018. DOI: 10.1016/j.ijnurstu.2018.07.006.

9. Mackie BR, Mitchell M and Marshall PA. The impact of interventions that promote family involvement in care on adult acute-care wards: An integrative review. Collegian 2018. DOI: 10.1016/j.colegn.2017.01.006.

10. Berger Z, Flickinger TE, Pfoh E, et al. Promoting engagement by patients and families to reduce adverse events in acute care settings: a systematic review. BMJ Qual Saf 2014. DOI: 10.1136/bmjqs-2012-001769.

11. Naylor MD, Brooten DA, Campbell RL, et al. Transitional care of older adults hospitalized with heart failure: a randomized, controlled trial. J Am Geriatr Soc 2004. DOI: 10.1111/j.1532-5415.2004.52202.x.

12. Olding M, McMillan SE, Reeves S, et al. Patient and family involvement in adult critical and intensive care settings: a scoping review. Health Expect 2016. DOI: 10.1111/hex.12402.

13. Bastemeijer CM, Voogt L, van Ewijk JP, et al. What do patient values and preferences mean? A taxonomy based on a systematic review of qualitative papers. Patient Educ Couns 2017. DOI: 10.1016/j.pec.2016.12.019.

14. Cioffi J. Culturaly diverse family members and their hospitalised relatives in acute care wards: a qualitative study. The Australian journal of advanced nursing : a quarterly publication of the Royal Australian Nursing Federation 2006.

15. Engström B, Uusitalo A and Engström A. Relatives' involvement in nursing care: a qualitative study describing critical care nurses' experiences. Intensive Crit Care Nurs 2011. DOI: 10.1016/j.iccn.2010.11.004.

16. Lindberg C, Fagerström C, Sivberg B, et al. Concept analysis: patient autonomy in a caring context. J Adv Nurs 2014. DOI: 10.1111/jan.12412.

17. Alshahrani S, Magarey J and Kitson A. Relatives' involvement in the care of patients in acute medical wards in two different countries-An ethnographic study. J Clin Nurs 2018. DOI: 10.1111/jocn.14337.

18. Eskes A, van Langen R and Nieveen van Dijkum E. Family Involvement in Hospital Care After Major Surgery: Is It Feasible?, https://www.nursingrepository.org/bitstream/handle/10755/624216/Eskes_91681_Info.pdf?sequence=2&isAllowed=y (2018).

19. Ball J, Ballinger C, De Iongh A, et al. Determining priorities for research to improve fundamental care on hospital wards. Research involvement and engagement 2016. DOI: 10.1186/s40900-016-0045-8.

20. Eskes A, Schreuder M, Smith R, et al. Programma betrekt mantelzorgers actief bij postoperatieve zorgverlening. TVZ 2018. DOI: 10.1007/s41184-018-0217-0.

21. Anna Rosiek, Tomasz Kornatowski, Aleksandra Rosiek-Kryszewska, et al. Evaluation of Stress Intensity and Anxiety Level in Preoperative Period of Cardiac Patients. BioMed Research International 2016. DOI: 10.1155/2016/1248396.

22. Lepage C, Drolet P, Girard M, et al. Music decreases sedative requirements during spinal anesthesia. Anesth Analg 2001.

23. Creswell JW and Poth CN. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. Los Angeles, CA: SAGE Publications, 2017, p.473.

24. Smith JA, Flowers P and Larkin M. *Interpretative phenomenological analysis*. 1. publ. ed. Los Angeles, Calif. [u.a.]: Sage, 2009.

25. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care 2007. DOI: 10.1093/intqhc/mzm042.

26. Palinkas L, Horwitz S, Green C, et al. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. Adm Policy Ment Health 2015. DOI: 10.1007/s10488-013-0528-y.

27. Federatie Medisch Specialisten. Het Academisch Medisch Centrum (AMC)- Stages Anesthesiologie, https://www.opleidingsetalage.nl/opleiding/academisch-medisch-centrum/anesthesiologie (n.d.).

28. Holloway I and Wheeler S. *Qualitative research in nursing and healthcare*. 3rd ed ed. Chichester, West Sussex, U.K: Wiley-Blackwell, 2010, p.297.

29. Örsal Ö, Alparslan G, Özkaraman A, et al. The Effect of Relaxation Exercises on Quality of Sleep Among the Elderly: Holistic Nursing Practice Review Copy. Holistic Nursing Practice 2014. DOI: 10.1097/HNP.0000000000000032.

30. House SL. Psychological distress and its impact on wound healing: an integrative review. Journal of wound, ostomy, and continence nursing : official publication of The Wound, Ostomy and Continence Nurses Society 2015. DOI: 10.1097/WON.0000000000000080.

31. González MG, Kelly KN, Dozier AM, et al. Patient Perspectives on Transitions of Surgical Care: Examining the Complexities and Interdependencies of Care. Qualitative Health Research 2017. DOI: 10.1177/1049732317704406.

32. Schuchman M, Fain M and Cornwell T. The Resurgence of Home-Based Primary Care Models in the United States. Geriatrics (Basel, Switzerland) 2018. DOI: 10.3390/geriatrics3030041.

33. Coyne I. Children's Experiences of Hospitalization. Journal of Child Health Care 2006. DOI: 10.1177/1367493506067884.

34. Coyne I and Kirwan L. Ascertaining children's wishes and feelings about hospital life. Journal of child health care : for professionals working with children in the hospital and community 2012.

35. Smit D, de Lange J, Willemse B, et al. The relationship between small-scale care and activity involvement of residents with dementia. International Psychogeriatrics 2012. DOI: 10.1017/S1041610211002377.

36. Hammer RM. The lived experience of being at home. A phenomenological investigation. Journal of gerontological nursing 1999.

37. Wassenaar A, Schouten J and Schoonhoven L. Factors promoting intensive care patients’ perception of feeling safe: A systematic review. International Journal of Nursing Studies 2014. DOI: 10.1016/j.ijnurstu.2013.07.003.

38. Shields L, Pratt J, Davis LM, et al. Family-centred care for children in hospital. The Cochrane database of systematic reviews 2007. DOI: 10.1002/14651858.CD004811.pub2.

39. Clay AM and Parsch B. Patient- and Family-Centered Care: It's Not Just for Pediatrics Anymore. AMA J Ethics 2016.

40. Ussher JM, Tim Wong WK and Perz J. A qualitative analysis of changes in relationship dynamics and roles between people with cancer and their primary informal carer. Health 2011. DOI: 10.1177/1363459310367440.

41. Kayser K, Watson LE and Andrade JT. Cancer as a "We-Disease". Families, Systems, & Health 2007. DOI: 10.1037/1091-7527.25.4.404.

42. Mosher CE, Adams RN, Helft PR, et al. Positive changes among patients with advanced colorectal cancer and their family caregivers: a qualitative analysis. Psychology & Health 2017. DOI: 10.1080/08870446.2016.1247839.

43. Teixeira RJ, Remondes-Costa S, Graça Pereira M, et al. The impact of informal cancer caregiving: A literature review on psychophysiological studies. European journal of cancer care 2019. DOI: 10.1111/ecc.13042.

44. Applebaum AJ and Breitbart W. Care for the cancer caregiver: A systematic review. Palliative & supportive care 2013. DOI: 10.1017/S1478951512000594.

45. Mosher C, Adams R, Helft P, et al. Family caregiving challenges in advanced colorectal cancer: patient and caregiver perspectives. Support Care Cancer 2016. DOI: 10.1007/s00520-015-2995-z.

46. Oliva-Moreno J, Peña-Longobardo LM, García-Mochón L, et al. The economic value of time of informal care and its determinants (The CUIDARSE Study). PLOS ONE 2019. DOI: 10.1371/journal.pone.0217016.

47. Saltman RB, Dubois HFW and Chawla M. The Impact of Aging on Long-Term Care in Europe and Some Potential Policy Responses. International Journal of Health Services 2006. DOI: 10.2190/AUL1-4LAM-4VNB-3YH0.

48. Caty S, Larocque S and Koren I. Family-Centered Care In Ontario General Hospitals: The Views of Pediatric Nurses. Canadian Journal of Nursing Leadership 2001. DOI: 10.12927/cjnl.2001.19119.

49. Harvey P and Ahmann E. Validation: A Family-Centered Communication Skill. Nephrology nursing journal : journal of the American Nephrology Nurses' Association 2016.

50. Salman A, McCabe D, Easter T, et al. Cultural Competence Among Staff Nurses Who Participated in a Family-Centered Geriatric Care Program. Journal for Nurses in Staff Development (JNSD) 2007. DOI: 10.1097/01.NND.0000277179.40206.be.

51. Uysal N, Gürol Arslan G and Mete S. The feelings and experiences of hospitalized patients regarding informal caregivers: a qualitative study. Social Work in Health Care 2019. DOI: 10.1080/00981389.2018.1531102.

52. Gerritsen R, Hartog C and Curtis J. New developments in the provision of family-centered care in the intensive care unit. Intensive Care Med 2017. DOI: 10.1007/s00134-017-4684-5.

53. Davidson JE, Aslakson RA, Long AC, et al. Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU. Critical care medicine 2017. DOI: 10.1097/CCM.0000000000002169.

54. Rosland A and Piette JD. Emerging models for mobilizing family support for chronic disease management: a structured review. Chronic Illness 2010. DOI: 10.1177/1742395309352254.

Appendix A

Interview schedule

1. How did you experience the admission period?
   Possible prompts: Quality of care, communication
2. How did you experience the FIP during admission?
   Possible prompts: Fundamental care activities, rooming-in, care delivery of FC, ambiance, satisfaction, guidelines, agreements
3. Can you tell me about how you experienced the presence of your FC?
   Possible prompts: Support, safety, stress, distribution of roles, autonomy
4. How would you describe yourself as a person?
   Possible prompts: Character, coping
5. Can you tell me about the nature/quality of the relationship with your FC?
   Possible prompts: Could you describe your relationship? (When married/living together: Why did you fell in love?) How do you see your FC? Why did you want to participate in the FIP?
6. How did the FIP influence the relationship with your FC?
   Possible prompts: Did it changes the way you look at your FC? Depth within relationship, collaboration, trust, communication, ambiance. (When married/living together: Do you see your partner as your loved one or as your caregiver?)
7. How did the FIP influence the relationship with the healthcare professionals?
   Possible prompts: Communication, collaboration
8. How did your FC contribute to understanding of what happened and what was explained in the hospital?
   Possible prompts: Family conferences, consultations and visits

Reflecting questions:

1. Why?
2. How?
3. Can you tell me more about that?
4. Can you tell me what you were thinking?
5. How did you feel?