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A qualitative study

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The experiences of family caregivers who participated in a family involvement program after cancer surgery: A qualitative study

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ABSTRACT

Purpose: As recovery time after oncological surgery can be long, family caregivers often play an important role in the delivery of care after patients' discharge. To prepare carers for this role, we developed a family involvement program (FIP) to enhance their active involvement in post-surgical oncology care during hospitalization. The purpose of this qualitative study was to explore family caregivers experience of participating in a FIP.

Methods: We conducted semi-structured interviews with 12 family caregivers who participated in the family involvement program. The program is comprised of two main components (1) training and coaching of physicians and nurses; (2) active involvement of family caregivers in fundamental care activities. This active involvement included six activities. Data were analyzed using interpretative phenomenological analysis.

Results: Family caregivers positively valued the program. Active participation in post-surgical care was experienced as an acceptable burden. The program gave participants the ability to simply be present ('being there') which was considered as essential and improved their understanding of care, although family caregivers sometimes experienced emotional moments. Active involvement strengthened existent relationship between the family caregiver and the patient. Participants thought clinical supervision.
by nurses is important.

Conclusions: Physical proximity appeared as an essential part of the family involvement program. It helped carers to feel they made a meaningful contribution to their loved ones' wellbeing. Asking families to participate in fundamental care activities in post-surgical oncology care was acceptable, and not over-demanding for caregivers.

1. Introduction

Worldwide, esophageal and pancreatic cancer are the sixth and seventh leading cause of cancer-related mortality, respectively (Torre et al., 2015). In the upcoming years, the number of patients diagnosed with these two types of cancer is expected to increase significantly (Napier et al., 2014; Rahib et al., 2014). Most patients with esophageal and pancreatic cancer undergo some type of surgery. Recovery after major surgery may take weeks or even months (Lawrence et al., 2004).

As recovery time after surgery may be long, family caregivers often play an important role in the delivery of fundamental care to cancer patients after discharge. This fundamental care, sometimes referred to as essential or basic care, reflects a diverse range of care processes that combine the physical, psychosocial and relational dimensions of care (Feo and Kitson, 2016; Jackson and Kozlowska, 2018). Although these fundamental care activities seem to be simple, family caregivers often feel unprepared for this role and experience a lack of knowledge on how to deliver proper care (Reinhard, 2008). This could pose risk to patients as some surgical complications are believed to be potentially preventable (e.g. pneumonia, urinary tract infections, and delirium) (Bail et al., 2013; Baldwin et al., 2016; Cassidy et al., 2013; van der Maarel-Wierink et al., 2013), but are sensitive to adequate fundamental care. Therefore,

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educating family caregivers could improve the execution of fundamental care, and thereby reducing the risk of complications.

1.1. Our previous work

To prepare families for an active carer role after patients' discharge and to try to reduce the number of postoperative complications, and the number of unplanned hospital readmissions related to these complications, we developed an evidence-based intervention to enhance the active involvement of family caregivers in fundamental care for post-surgical oncology patients during hospitalization (Eskes et al., 2019). It was underpinned by a patient and family centered care (PFCC) approach. The family involvement program (FIP) was comprised of two main components (1) training and coaching of physicians and nurses in PFCC; (2) active involvement of family caregivers in fundamental care activities. This second component of the intervention is in addition to usual postoperative care. In a pilot study, we showed the program was feasible, and led to improved adherence to fundamental care activities, without increasing caregiver burden, (Schreuder et al., 2019). However, the quantitative approach chosen in the pilot study was unable to give in-depth insight in the experiences of family caregivers who actively participated in the FIP. Knowledge remains limited about the experiences of family caregivers in surgical oncology care, the impact of the FIP on family caregivers and their relationship with the patient. A deeper understanding of their experiences may help to enhance the implementation of a more patient- and family centered environment in post-surgical oncology care. Therefore, the aim of this qualitative study was to explore family caregivers experience of participating in a FIP.

2. Methods

This study is reported according to the Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014). Ethical approval was gained by the Medical Ethics Review Committee at the University Hospital (ref no: W18_048 # 18.066). Participants received no compensation for participating in this study.

2.1. Study design and setting

A qualitative study, using interpretative phenomenological analysis was conducted in two surgical wards in one 1000-bed university hospital that provided care to patients after oncological and gastrointestinal surgery. There were about 64 full-time equivalent nursing staff working on these two wards.

During hospital admission, the FIP was offered to all adult patients who underwent elective pancreatic or esophageal resection with an expected hospital stay of at least five postoperative days and who have a family caregiver who agreed to participate in care delivery (Eskes et al., 2019). We choose this 5-days cut-off point as it offers nurses the opportunity to train and coach family caregivers adequately under their supervision. Additionally, pancreatic and esophageal resection surgeries are complex major surgical procedures with a long recovery time. Therefore, it is likely these patients may require support from family caregivers after discharge. All nurses and physicians working on these two wards were trained to deliver the FIP. The training and coaching of physicians and nurses was mainly focused on the four core concepts of PFCC: (1) dignity and respect; (2) information sharing; (3) participation; and (4) collaboration (Johnson and Abraham, 2012).

To improve family caregivers' knowledge, skills, attitude, confidence and competence six main activities were carried out: (1) carers received information about fundamental care activities (2) family caregivers were trained to deliver fundamental care activities during hospitalization; (3) carers were invited to participate in fundamental care activities (i.e. oral hygiene, early mobilization, breathing exercises and cognitive activities); (4) shared goals were set with the patient, carers and nurse; (5) carers were invited to participate in medical ward rounds; (6) caregivers were asked to room-in for at least 8 h a day (i.e. physical proximity).

2.2. Participants and recruitment

All family caregivers who participated in the FIP were eligible to participate in this study. Purposive sampling was used in an attempt to maximize variability in terms of variation in gender, age and relationship between carer and patient, and therefore, capture a wide range of perspectives (Smith et al., 2009). We aimed to recruit 10–12 participants. This relatively small sample fits the interpretative phenomenological analysis approach as described by Smith et al. (2009) and is desirable to explore in detail the common lived experiences of carers. To participate as family caregiver in the FIP, carers met the following criteria:

- Aged 18 years or older;
- Present during the patient's first five postoperative days in hospital;
- Nominated by the patient as a family caregiver;
- Able to undertake care activities independently without support from healthcare professionals.

3. Methods

Between June 2018 and March 2019, all family caregivers who were involved in the FIP were informed about the study by three ward nurses, and were asked for permission to be contacted by the researcher. This resulted in a list of 37 carers who were contacted by one of the researchers (second author). Carers were called after patients' discharge and asked if they agreed to participate. If so, they received both orally and written information, and signed a consent form.

3.1. Data collection

A semi-structured interview schedule (Table 1) was developed based on previous research (Hughes et al., 2013; Olding et al., 2016; Seal et al., 2015) and local knowledge of the interdisciplinary research team (i.e. three nurse scientists, one surgeon, and one surgical resident). The first interview was a pilot-interview to test the interview procedure and interview schedule. No major changes were made, therefore it was included in the data. All individual interviews were conducted face-to-face by the same researcher (NvI), and all participants were interviewed. All interviews took place after patients' hospital discharge

Table 1
Interview schedule.

Opening 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 h?
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?

in a quiet place (i.e. after an appointment at the outpatient clinic; or in the home setting) at a time of mutual convenience. All participants were interviewed without the presence of other persons to put the participant at ease and to speak freely. The interviews were audio-recorded, and field notes were made during and after interviews to act as triggers for recalling the interview. These notes were used to help the interpretation of data and credibility of the findings. The trustworthiness was established by the sampling approach (i.e. variation) and by generating a non-judgemental atmosphere during the interview (Lincoln, 1985). Furthermore, iterative questions and probes were used to gain insights to inner feelings and thoughts. The interviewer attempted to achieve a mutual relationship with the participant and empowered the participants to speak up freely.

Additionally, baseline data were collected from all family caregivers (e.g. age, gender, relation to patient, and work experience).

3.2. Data processing and role of the interviewer

All interviews were transcribed verbatim. To ensure credibility, all interviewees received the transcripts and were asked for comments or corrections if necessary. No changes were requested.

The interviewer (NvI) had a master degree in nursing science, and she had no experience in surgery and/or oncology. NvI did not had a relationship with the participants prior to or outside of the research situation.

3.3. Data analysis

All data were analyses using the interpretative phenomenological analysis approach described by Smith et al. (2009). This approach is similar to thematic analysis, as both methods seek patterns in the data. However, the interpretative phenomenological analysis approach focuses on the understanding of the lived experiences of family caregivers in great detail (Braun and Clarke, 2006).

The interpretative phenomenological analysis approach was undertaken by the research team and guided by six steps: (1) (re)reading all transcripts to become familiar with the data; (2) initial coding; (3) developing emergent themes; (4) searching connection across emergent themes; (5) moving to next case, and repeating step 1 to 4; and (6) searching for patterns across cases. Step two, four and six were carried out by two researchers independently (NvI and MH). 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). Field notes were re-read to contextualise and check the coding. This investigator triangulation deepened the researchers understanding of the experiences of the family caregivers and it increased the credibility of results (Carter et al., 2014). Data management was carried out using NVivo© software (QSR International version 11.0, Australia).

4. Results

4.1. Participants

The interviews took place between January and June 2019 and lasted an average of 50 min (ranging from 35 to 70 min). The difference between patients' discharge and the interview date varied between the day of discharge to 228 days (median 81.5 days; interquartile range 126). Twelve family caregivers were interviewed (Table 2). Just over half of the carers ($n = 7$; 58%) had a professional background in (nursing) care, and some ($n = 3$; 25%) had already participated actively during previous hospital admissions. Twenty-five carers declined participation. Several reasons were mentioned: no time, too burdensome or (new) health-related problems of the patient. Five themes emerged from the analysis.

4.2. Being there is the essence and improves understanding of care

Family caregivers experienced the hospital admission as a precious time. Physical proximity during hospitalization, one of the elements of the FIP, was thought to be extremely valuable to as hospitalization was experienced as a stressful and emotional time. Physical proximity gave them the opportunity to witness patients' recovery progress. Carers explained that the main benefit of the program was the ability to just be there:

> "We didn't have intense conversations, absolutely not. Being there is the essence. That was precious for me"
>
> *(P8)*

Being closely involved during hospitalization which was part of the FIP also gave carers a better understanding of the healthcare process. They said that they had unique knowledge of their partners healthcare needs, and that this knowledge was helpful to recognize gaps in care or to intervene in care that may have a negative impact:

> "I saw everything. I would even see things that 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)*

On the other hand, physical proximity in post-surgical oncology care, which was embedded in the FIP, also meant that carers were confronted with ill patients (i.e. their loved ones) who suffered physically and/or mentally from the adverse effects of surgery (e.g. severe pain nausea and vomiting) and depressive emotions:

> "It was really difficult. She had a lot of back pain, caused by her stomach was not functioning. I fondled her back to relieve the pain. I did that for 14 days."
>
> *(P5)*

Being closely involved sometimes led to irritations and arguments between patient and carers for various reasons, e.g. having different views on care, frustration of the carer when they felt that their partner was not motivated enough to recover, or being too closely together in a relatively small patient room. As one mentioned:

> "It happened like "No I don't t want that" or "No, I can't do that" … Sometimes I was a little bit compelling … I want him to recover while he felt miserable which resulted in a clash."
>
> (P1)

4.3. Embracing carers role by nature

Family caregivers took their active participation in patient care activities, one part of the FIP, seriously. They were motivated and felt responsible for a proper execution of fundamental care activities (i.e. encouraging patient mobilization and supporting patients' nutritional intake). For example, they persisted, even if a partner was not motivated:

> "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)*

Reflecting their own role in the FIP, interviewees did not identify themselves as carer in the family program. They just felt that they were a

Table 2
Participant and patient characteristics.

FC	Gender	Age (years)	Working in the healthcare sector	Length of stay (days)	Receiving home-care	Performed care activities during hospitalization	Relationship to patient	Patient gender	Patient age (years)
1	F	60–69	Yes	10	No	* Supporting basic ADLs (Showering, dressing, oral care) * Mobilization * Encouraging and supporting oral intake * Injection of Fraxiparine	Partner	M	66
2	F	50–59	Yes	2 admissions (7, 5)	Yes	* Supporting basic ADLs (Showering, dressing, oral care) * Changing of bed sheets * Mobilization * Injection of Fraxiparine * Supporting wound dressing * Taking care of the stoma	Partner	M	56
3	M	50–59	Yes	8	No	* Changing of bed sheets * Mobilization * Injection of Fraxiparine * Taking care of abdominal drains * Taking care of the feeding tube	Partner	M	62
4	F	60–69		2 admissions (98, 28)	Yes	* Supporting basic ADLs (Showering, dressing, oral care shaving) * Changing of bed sheets * Mobilization * Administration of oral medication	Partner	M	70
5	M	70–79	No	14	No	* 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	Partner	F	74
6	M	70–79	No	3 admissions (21, 56, 5)	No	* Supporting basic ADLs (Showering, dressing) * Supporting toilet hygiene * Changing of bed sheets * Mobilization * Injection of Fraxiparine * Taking care of abdominal drains	Partner	F	70
7	F	60–69	Yes	10	Yes	* Supporting basic ADLs (Showering, dressing) * Changing of bed sheets * Cleaning of the room * Mobilization * Encouraging and supporting oral intake * Encouraging the revalidation process	Partner	M	62
8	F	60–69	No	14	No	* Supporting basic ADLs (Showering, dressing) * Supporting toilet hygiene * Changing of bed sheets * Mobilization	Partner	M	67
9	F	60–69	Yes	10	No	* Supporting basic ADLs (Showering, dressing, oral care) * Supporting toilet hygiene * Changing of bed sheets * Mobilization * Encouraging and supporting oral intake * Supporting wound dressing	Partner	M	64
10	M	60–69	No	135	Yes	* Supporting basic ADLs (Showering, dressing, oral care) * Supporting toilet hygiene * Changing of bed sheets * Mobilization * Taking care of the stoma	Partner	F	61
11	F	30–39	Yes	7	No	* Supporting basic ADLs (Showering, dressing) * Mobilization * Supporting wound dressing	Partner	F	38

(*continued on next page*)

Table 2 (*continued*)

FC	Gender	Age (years)	Working in the healthcare sector	Length of stay (days)	Receiving home-care	Performed care activities during hospitalization	Relationship to patient	Patient gender	Patient age (years)
12	M	70–79	No	11	No	* Taking care of the stoma * Supporting basic ADLs (Showering, dressing, oral care) * Supporting toilet hygiene * Changing of bed sheets * Mobilization * Encouraging and supporting oral intake	Partner	M	80

FC = family caregiver, respondent number; F = female; M = male; ADL = Activities of Daily Living.

loving partner, and that taking care of their loved one in a critical situation was common sense. They assumed 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)*

In the FIP, family caregivers were invited to be present during the medical rounds. During these rounds, some carers had the feeling that they were part of the team, and felt free to ask questions, and to discuss important signs of illness of their partner. Yet, others had the feeling that the focus was entirely on the patient without direct attention to them. As one mentioned:

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

4.4. *Clinical supervision needed by nurses*

Although all family caregivers participated in the FIP, they mentioned that participating in care was not always an easy task. They lacked clarity about tasks and wanted more guidance from the nurses:

> *"For me it was not clear what they expected from me. It is comfortable when instructions will be given by nurses … During the start of the admission it felt like "What do you exactly expect from me?"*
>
> *(P8)*

Although some of them wanted more feedback on their performance from nurses, other said that they could rely on nurses:

> "I was sufficiently informed and there was the opportunity to ask questions. The nurses involved during the entire process said things 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)

4.5. *Losing touch with yourself*

Family caregivers mentioned that they could lose touch with themselves due to their participation in the program as they were completely focused on their loved one. This could be a negative side effect, and some gave examples of their own experiences. Some experienced difficult times during hospitalization. They sometimes felt anxious, bored and helplessness because of a loss of control. Others mentioned that they felt exhausted as a result of sleeplessness or concerns:

> "It was pretty exhausting. When I was back 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)*

However, no carers experienced that they lost touch with themselves because of involvement in the FIP. In order to prevent this, about half of the carers mentioned that it was sometimes beneficial for their own state of mind to take a step back from the situation and focus on their own needs. One explained:

> "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).*

4.6. *Strengthening the relationship*

Participating in the FIP make family caregivers realize how important their relationship with their partner was to them. They shared emotions with their partners which brought them closer together and strengthened the relationship. Moreover, it led to more in-depth conversations:

> "In our marriage we had some kind of routine … This admission brought us closer together"
>
> *(P5)*

Because of the active involvement and the presence during hospitalization, carers appreciated that they had the same information as their loved one with the additional advantage that they did not need to demand a full explanation to them. Being involved also meant that carers and patients saw each other from a different perspective.

5. Discussion

Overall, the family caregivers had positive experiences regarding their active involvement in the FIP during post-surgical oncology care. Specifically, they emphasized the importance of physical proximity for oncological patients which was embedded in the FIP, but also for themselves. They experienced their involvement in the FIP as precious time, and had a better sense and knowledge of the recovery process of their loved one. Notably, we developed this FIP to try to reduce the number of postoperative complications, and the number of unplanned hospital readmissions related to these complications. Carers were fully informed about the aim of the program before hospital admission, however, the potential benefits of this program on clinical patient outcomes did not emerged as theme (e.g. reduction of readmissions).

The increased involvement in care as a result of the FIP, including the opportunity of physical proximity, seems to outweigh the potential negative aspects of the program (i.e. its burden). Being involved may also improve the quality of care, as carers are often knowledgeable and act as a patient advocate or assisted in direct care (Mackie et al., 2019).

Furthermore, others have shown that just being there, and supporting and protecting loved ones give carers the ability to be closed and to strengthen the relationship (Olding et al., 2016).

Our findings that family caregivers did not experienced the program as too burdensome may be explained by the fact that the in-hospital caregiving role did not last an extended period and that over half of the carers had a professional background in nursing. However, some mentioned that they had the feeling that the focus was entirely on the patient without direct attention to them. Therefore, it may be advised to provide psychosocial support to family caregivers in programs like FIP, as being a family caregiver can be taxing or lower quality of life (Haley, 2003; Hsu et al., 2019; Jadalla et al., 2020; Majestic and Eddington, 2019). Despite the mainly positive experiences of the FIP by family caregivers, some experienced anxiety, exhausting and sleepiness. Anxiety may be due to the FIP, as family caregivers are confronted with patients (i.e. loved ones) who suffer physically and/or mentally from the adverse effects of surgery. However, it is also known that family caregivers of patients with pancreatic cancer experience elevated anxiety levels (Janda et al., 2017). Anxiety appear even twice as likely as the patients they cared for (Janda et al., 2017). Furthermore, the experienced sleepiness and exhaustion may also be related to the hospital environment itself instead of the FIP, as it is known that the duration and quality of sleep in hospitalized patients are significantly affected by many hospital-related factors (Wesselius et al., 2018).

Several recommendations for those wanting to integrate active family involvement in post-surgical oncology care arise from this research. First, while family caregivers may be willing to participate in care, in addition to initial training, nurses and physicians have to be prepared to see family caregivers as partners, and act in a manner that promotes this involvement. Second, family caregivers require ongoing supervision by nurses. Thus, nurses are not abdicating their responsibility for these important tasks, but are delegating them to families, under their supervisor. Finally, nurses need to encourage family carers to take breaks as they need some respite themselves.

This study has both strengths and limitations. A strength is that it provides in-depth insights in the experiences of family caregivers who were actively involved in post-surgical oncology care on two nursing wards. A rigorous analysis was done, and rich descriptions exemplified by fundamental quotes were used to underpin the themes. As with other qualitative designs, the generalizability of the results is limited, but the results may be applicable to other care settings and sheds light on important considerations when planning a FIP. Furthermore, despite aiming for purposive maximum variation sampling the group of participants in the FIP was rather homogenous. For example, they were all of Dutch heritage, and half of them had a professional background in nursing. Therefore, different cultural and ethnic backgrounds were not captured, and the family caregivers included were likely more experienced in providing care than the general population. In addition to this, all family caregivers were in an intimate relationship and they said caregiving was a natural consequence of this relationship. However, this natural consequence may differ in other types of relationships (e.g. father, mother, friend, neighbor etc.).

In conclusion, physical proximity appeared as an essential part of the FIP. It let family caregivers feel meaningful. Asking families to participate in fundamental care activities in post-surgical oncology care seems to be acceptable, and not over-demanding. However, monitoring and clear instructions given by nurses are considered as important. The focus towards a more patient- and family centered environment may has consequences to hospital policies regarding family involvement in care, ward cultures, the capacity to learn and coach family caregivers, and family dynamics. Nurses have a unique position to encourage family caregivers to get actively involved in care, and to prepare them for the transition from in-hospital professional care to family care at home. It is important for nurses to realize that involving families during a stressful period can still be experienced as meaningful and acceptable, and not as an added burden.

CRediT roles

AM Eskes: conceptualization, methodology, quality control of data, data analysis and interpretation, writing - Original Draft.

CHNM van Ingen: conceptualization, methodology, investigation, quality control of data, data analysis and interpretation, writing - Original Draft.

MEE Horst: conceptualization, methodology, investigation, quality control of data, data analysis and interpretation, Writing - Review & Editing.

AM Schreuder: conceptualization, methodology, data analysis and interpretation, Writing - Review & Editing.

W Chaboyer: methodology, data analysis and interpretation, Writing - Review & Editing, supervision.

EJM Nieveen van Dijkum: conceptualization, methodology, data analysis and interpretation, Writing - Review & Editing, supervision.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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