

Being a fellow patient to a critically ill patient leads to feelings of anxiety – an interview study

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KEYWORDS

Qualitative study, fellow patients, anxiety, patient interaction and professional support

ABSTRACT

Objectives

To explore in-patients' experiences being a fellow patient to patients who become critically ill.

Design

The study was designed as a qualitative phenomenological study.

Setting

The study was conducted in a surgical ward of a hospital in Denmark.

Subjects

Fifteen fellow patients to patients, who became critically ill.

Results

Three key themes emerged from the analysis of the data: patients' interaction, anxiety, and professional support. These findings demonstrated the importance of understanding how patients experienced being a fellow patient to patients, who become critically ill, their views on interacting with such a patient, how the patients who become critically ill influenced them, and what kind of support they needed from the health professionals.

Conclusion

The findings highlighted the different emotions and feelings experienced by fellow patients. It showed how the impact of the situation can lead to anxiety, a feeling of being forced into patient inter-action and the lack of professional support. Health professionals should have a central role in supporting the fellow patients and communicating with them about their experiences and this does not seem to be fulfilled sufficiently in daily clinical practice.

INTRODUCTION

During the last decade hospital interactions have been studied in various settings (Birklund and Larsen 2013). Often the interaction has been between different support groups, patient schools, special surgical techniques or a specific illness (Birklund and Larsen 2013). Most studies investigated the patient/nurse interaction or the doctor/patient relationship (Birklund and Larsen 2013; Larsen et al 2013). The perspective has changed during the last years from a focus on the health professionals to a focus on the patients' view (Larsen et al 2013). Still today, little research has focused on the patient-to-patient interaction. A recent study on the relationship between fellow patients stated, that 90% of patient interaction in the ward was with fellow patients and only 10% was with health professionals (Larsen et al 2013). The study found, that interactions between patients were ambiguous, meaning the negative experiences were interconnected to the positive experiences, and the interaction was linked to the strength of the fellow patient (Larsen et al 2013). These numbers underline that more studies are needed to be able to understand the relationship between patients. A study on roommates' stress stated, that being with similar fellow patients reduced anxiety (Kulik et al 1993). Thus patients who were preoperatively assigned with a postoperative patient experienced less anxiety before an operation. The argument was the fellow patient could see that the other patients had a positive recovery (Kulik et al 1993).

The patients' perspectives of quality of care often differed from, how the hospitals structured their resources (Brooks 1999). Patients often had a more individual human perspective on quality of care and often the impression was that the quality of care was linked to personal and individual care (Armstrong et al 2003; Brooks 1999). Critically ill patients had an impact on the general ward staffing resources, and often the less dependent patients were affected. The critically ill patient demanded constant professional attention, which challenged the ward resources. The less dependent patient had to put their needs for care on hold, until the critically ill patient regained stability (Armstrong et al 2003; Steiner et al 2001).

Historically, hospitals were designed to focus on resources which lead to patients having to share rooms regardless of how sick they may be; a situation that could result in stress and insecurity for the fellow patients (Kulik et al 1993). Therefore, this study wanted to explore not only the patients' preferences, but focus on the feelings and the perspectives of fellow patients to patients, who become acutely ill (Rukstele and Gagnon 2013). The aim of this study was to investigate in-patients' experiences of being a fellow patient to patients, who become critically ill.

METHODOLOGY

Design

The approach in this study was to understand how in-patients' meanings and emotions were created through their experiences as fellow patients. The design was a qualitative study using individual interviews with a phenomenological approach to reach a deeper understanding of the fellow patients' experiences. When doing phenomenological research it obliges the researcher to hold back pre-understandings and assumptions to let new approaches and meanings emerge. To do so, two of the authors strove to set aside their pre-understandings of the phenomenon by letting the second author interview the first author about prior knowledge of the phenomenon. By doing so they were able to let new and deeper understandings become apparent (Finlay 2009 ; Fontanna 1994).

Participants

Patients were recruited from a Danish university hospital. Patients had to be gastroenterological surgical in-patients, be mentally and physically able to take part in an interview session and be willing to give informed

consent. The nurse-patient ratio for this gastroenterological ward was one nurse to four patients. The participants had to meet the criteria of being a fellow patient to a surgical in-patient, whose physical status deteriorated severely within the previous 24 hours with either a transfer to ICU or who was not expected to survive and therefore was transferred to a single-bed patient room. Patients that met these criteria were invited to participate in a semi-structured individual interview.

Data collection

Individual semi-structured interviews were used to explore their experiences, feelings and meanings by being a fellow patient to an acutely ill patient. The semi-structured interview guide was prepared and tested in a pilot test involving three participants. This was to confirm its suitability to the subsequent interviews (Shenton 2004). The semi-structured interview guide was developed through these three interviews. All interviews were performed while the fellow patients were still hospitalised. All interviews were recorded and transcribed into full text. Data saturation was reached when no new approaches or new meanings came up during the interviews.

Ethical considerations

The study was reported to the Danish Data Protection Agency and was, according to Danish law, exempt from ethical approval from The Ethical Committee of The Capital Region of Denmark (H-2-2013-FSP56). The fellow patients were informed they could withdraw from the study at any time and it would not influence their treatment or care. Before each interview the participants were reassured of the confidentiality of the interview data, both orally and in writing, and all gave both written and oral consent to participation.

Data analysis

The interviews were transcribed into full text and a qualitative content analysis was used for analysing the data (Graneheim and Lundman 2004) (table 1), which involves the following steps: dividing the data into condensed meaning units, codes and then into themes. The two researchers performed the analysis in parallel processes; disagreement was discussed and resolved within the research group. The analysis of the interviews was an ongoing process within the first and second author. The analysis began with repeated and thorough readings of all text, to understand each part of the data as a whole and in its parts. When a theme emerged, the analysis focused on rereading the text to focus on the meaning units. These meaning units were clustered into patterns of understanding the phenomenon (Armstrong et al 2003; Steiner et al 2001).

Table 1: Illustration/sample of the analytical process

Interview data	Meaning unit/ condensed meaning unit	Code	Sub-Theme	Theme
<p>Interviewer: How could the health professionals have helped you in this situation</p> <p>Fellow patient: Yes-they didn't move the critical ill patient and I don't know why. But maybe because they were low on staff members or because they were very busy. Because it all happened so fast...</p>	They were low on staff members or because they were very busy. It happened so fast	Low staff, busy, happened so fast	Understanding/ acceptance	Lack of support

RESULTS

Twenty six patients were screened and of these three were excluded due to mental illness, four due to linguistic difficulties, and four did not wish to participate. Thus, fifteen patients were interviewed. The median age of the fellow patients was 70.5 years ranging from 57 to 88 years, ten were male and five were female (table 2). All the participants were Danes. The interviews lasted up to 20 minutes. Three key themes emerged from the interviews: patients' interaction, anxiety and professional support. Table 3 shows statements taken from the interview data that were representative for the emerging themes.

Table 2: Baseline characteristic of the interviewed fellow patients

Informers	Sex	Age, years	Diagnose	Type of operation	ASA score
1	Female	78	Ileus	Explorative laparotomy	2
2	Female	78	Colon cancer	Hemicolectomy	2
3	Female	71	Lung cancer	Gastroscopy	2
4	Female	88	Diverticulosis	Colonoscopy	2
5	Female	78	Constipation	–	3
6	Male	81	Colon cancer	Colostomy	3
7	Male	66	Cholecystitis	–	2
8	Male	60	Pancreatic cancer	–	3
9	Male	57	Parastomal hernia	Laparoscopic herniotomy	2
10	Male	65	Cholecystitis	Laparoscopic cholecystectomy	3
11	Male	77	Peptic ulcer	Gastroscopy	3
12	Male	72	Hepatocellular carcinoma	–	3
13	Male	63	Pancreatic cancer	Gastroscopy	3
14	Male	67	Rectal cancer	–	3
15	Male	57	Strangulated inguinal hernia	Explorative laparotomy	1

Patients' interaction

Fellow patients described the emotional involvement they had in the critically ill patient. It was particularly difficult to handle the feelings of inability to help, and was often combined with a strong feeling of sympathy and wanting to care for the patient. The fellow patients felt a need and a responsibility to act as a substitute caregiver. However, they knew they could not offer much help, in spite of a strong desire to do so. A paradoxical feeling arose, as fellow patients felt they were forced into the interaction and at the same time were unable to leave the room and the situation.

Anxiety

Often fellow patients felt pacified in the interaction with the critically ill patient, they felt torn between a need to stay and a wish to leave the situation. The situation seemed forced on the fellow-patients and left them with an existential awareness of their own illness. These experiences were stressful and unpleasant for the fellow patients and left them with a feeling of anxiety. The anxiety was connected to their illness being reflected in the critically ill patients' severe and acute deterioration. The fellow patients often felt responsible for the critically ill patient. Many of the interviewed fellow patients felt a loss of control over the situation and they could not predict what was going to happen. Their loss of control in the situation often led to feeling paralyzed and unable to think rationally. A way to cope with the situation could be to ignore the severity of the critically ill patient or try to be in control of the situation by constantly trying to hold on to facts or seeking information.

Many experienced trouble sleeping and were more sensitive to noise, voices and technical equipment.

Professional support

A key issue for the fellow patients was the lack of information from the health professionals. They felt unsupported and left on their own. The situation with the critically ill patient left them with a need to talk about what had happened, they had many thoughts and their emotions were a balance between hope and despair. The experience left them with a feeling of anxiety over their own illness, and they described a wish to talk to the health professionals as an opportunity to manage their own feelings. Often the fellow patients were not asked to leave the room or there was not enough shielding from the critically ill patient and the fellow patient felt they were as much present in the situation as the critically ill patient and the health professionals were not helping the fellow patient out of the room or put shielding up.

Table 3: Study findings: Patient interaction, anxiety and professional support

Themes	Fellow patients' narratives across the interviews
Patient interaction	<ul style="list-style-type: none"> I wanted to ask, if there was anything I could do for him, but I was very tired myself, and I didn't feel it was my help he needed, what could I do, get him a glass of water! So I didn't do anything. Suddenly his breathing changed, it was different, I thought about calling for help, but fortunately there were two health professionals outside the room, and they came and helped. I haven't slept all night- Wanted to help, asked if there was anything I could do, if I could help out, I would have, we must help each other, but I couldn't. I was sorry that they put the shielding up, actually, because then I couldn't keep an eye on her.
Anxiety	<ul style="list-style-type: none"> No one dreamt that it would last for 4 hours and I was not offered any assistants. I just lay there. I was glad that I could watch TV- the thoughts could then wander, the TV made it possible for me to get different pictures and sounds in my head, it was like I could push negative thoughts away. I felt very bad that she was screaming. I didn't know if I should call for help. I didn't do anything, didn't know what I should do. It felt chaotic, and I was in it all, but couldn't offer any help I was not aware that I could leave the room, not on my own. Perhaps the health professionals could have assisted me. I was reminded that we all have to say goodbye and die - it made me nervous, it is not very pleasant to see a man fight for his life. The situation has put a pressure on me. It made me think about my situation, I want to function better. I was anxious, in the end I could hardly continue with anything. I tossed and turned, I have not been able to sleep.
Professional support	<ul style="list-style-type: none"> The health professionals were very busy so they asked me to leave the room, after a while they came back and talked to me, but they were only talking about breakfast and nothing about what had happened. Sooner or later the health professionals will come, but it can take up to 45 min. It was very hard to get in contact with them. It would have been nice if one of the nurses would have come up to me and said something about the incident, I have never experienced anything like this before. It would have been nice if they had moved me to the hall, I did not feel there was any opening for this. If I should have left the room, I didn't know?- There was no one who said anything, or put any shielding up. I would have appreciated some help. Who is worse than the other- Yes perhaps he was sick ill, but suddenly he was acutely ill - but possibly he was not more ill than me.

DISCUSSION

These findings demonstrated the importance of understanding how patients experience being a fellow patient to a patient who becomes critically ill, their perspectives on interacting with other patients, how the critically ill patient affected them, and their need for professional support.

Patient interaction

A Danish study argued that positive interaction between fellow patients was more common than negative (Larsen et al 2013), but the interaction was often ambiguous. The negative experiences of insecurity and devaluation in the Danish study were similar to the findings found in this study. Here the interactions between patients were ambiguous and the negative experiences were interconnected to the positive experiences and the interaction was linked to the strength of the fellow patient. The study argued that the strength was connected to patients' ability to withdraw themselves from the interaction (Larsen et al 2013). Fellow patients felt responsible for the critically ill patient and often did not feel they could leave the room, which often meant they began to reflect on their own illness and situation. This could be connected to a feeling of being forced into the acute situation and not have the possibility to withdraw themselves (Larsen et al 2013). This study pinpointed that patients felt a natural obligation to try to help the critically ill patient. The urge to care for others is fundamental to most humans, regardless of own illness, and is a basic condition (Birklund and Larsen 2013). Here the study presents an understanding of the emotional effect on the fellow patient; the stress and the anxiousness followed by attending an acute and critical situation with a very ill patient.

Anxiety

Fellow patients tried to cope with the situation by ignoring the severity of the critically ill patient. They felt stressed or left with a feeling of not being able to separate themselves from the incident. A previous study on fellow patients' anxiety stated that sharing a room with a surgical patient, well over his own operation, seemed calming and reassuring (Kulik and Mahler 1987). This study showed that almost all the fellow patients had a negative reaction towards the critically ill patient, regardless of the patients' prior status. These differences could be a result of patients sharing rooms not being equally ill or due to the fact that the situation changed so rapidly. At the same time it was important to remember that even if the fellow patients were less dependent in the situation, they were still ill and some in a critical state. Many were already balancing between emotions, and trying not to be overwhelmed by possible worst-case-scenarios. They needed hope and a feeling of control. A study on patients' coping strategies going through a gastric diagnosis found four coping patterns: 1) rational awaiting patterns where the focus was kept on facts; 2) denial, overlooking signs of danger; 3) painful control where they tried to avoid imagining; and 4) acceptance, where the patient openly seeks information (Giske and Gjengedal 2007). In this study there were similarities to these patients in their coping strategies. Often fellow patients tried to accept the situation or denied it if the outcome of the critically ill patient was severe. They were already balancing different emotions and being a fellow patient to a critically ill patient only made them more anxious. Regardless of which coping strategy they used many of them felt stressed or overwhelmed by the situation.

Professional support

A study on patients' experiences of self-care argued that patients need support to make sense and adapt to a new situation and they use health professionals, families and fellow patients to obtain this support (Kidd et al 2008). To prepare themselves for what was in store or needed to be faced, patients often used fellow patients to preserve their identity (Kidd et al 2008). The participants were fellow patients to critically ill patients who may have caused the participants to feel they could not use them for support, but instead the presence of the acutely ill patient had a negative effect on them. The room situation or atmosphere changed when the other

patient in the room became critically ill, and the fellow patient and the acutely ill patient were no longer equal in their path, which may be the reason why the fellow patient was left feeling more anxious (Kidd et al 2008).

This anxiety often left the fellow patients with a need to talk about the incident with the health professionals but often their request for help was not met. This support by talking about the incident had such an importance for the fellow patients, that health professionals should not ignore it.

Strengths and limitations

The method used was aiming to uncovering themes, patterns, concepts, insights, and understandings (Malterud 2001). Interviews were the only method and it could be argued, that if we also had included systematic observations of fellow patients, it would have provided a deeper understanding of their experiences. Furthermore, the study took place in only one setting, so it is likely that all possible angles of fellow patients' experiences were not covered. However, the study aimed for descriptions of patients' experiences of being a fellow patient to patients who become critically ill and by including 15 patients and making the analysis process as open and specific, the data found in this study were sufficient to hypothesize three different themes (Delmar 2010).

CONCLUSION

Understanding the experiences and feelings of a fellow patient to an acute and critically ill patient is clinically important for health professionals. The findings highlight the values of the different emotions and feelings a fellow patient goes through and the impact it has on their situation, often leading to anxiety, a feeling of being forced into a patient interaction, and the lack of professional support they felt was needed. Health professionals should play a central role in supporting the fellow patients. Health professionals can use these results, in forming their understanding of the fellow patients and tailoring their practice for more individual support in the care of the patients.

RECOMMENDATIONS

Fellow patients, who had experienced a patient become critically ill, needed support from health professionals. The fellow patients felt anxious and forced into the situation. Health professionals therefore most use these experiences in considering care models that address the needed support, so they can tailor their practice to a more individualised care resulting in an increase in patient satisfaction. Consideration needs to be given to models, that address these patient's needs, including exploring the potential to offer single rooms to all patients or the ability to separate the critically ill patients from the less dependent patients in the hospitals. The nurse-patient ratio was not discussed in this paper, but this angle is an important issue that should be explored in future studies.

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