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Patients' experiences of illness, operation and outcome with reference to gastro-oesophageal reflux disease

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Patients' experiences of illness, operation and outcome with reference to gastro-oesophageal reflux disease

Background. Describing the illness-story from a patient perspective could increase understanding of living with a chronic disease for health professionals and others, facilitate decision-making about treatment and enhance information about the outcome from a patient perspective.

Aim. To illuminate patients' illness experiences of having a gastro-oesophageal reflux disease (GORD), going through surgery and the outcome.

Methods. Twelve patients were interviewed 5 years after having had the operation; six patients had had fundoplication via laparoscopy and six via open surgery. Each patient was asked to talk openly about their experiences, thoughts, feelings and consequences of living with the illness, going through surgery and the period from surgery to the day of interview. A qualitative content analysis was performed concerning the context of the data and its meaning.

Findings. Three central categories were identified and nine subcategories: *living with GORD* – symptoms of the disease affecting daily living, taking medicines, work, family and social life; *concerns related to surgery* – decision-making about the operation, influence by physicians; *life after the operation* – outcomes and consequences, side-effects and complications of the operation, sick leave, information and sharing experiences with future patients. All patients were free from symptoms of the illness after surgery independent of type of surgery, but side-effects from surgical treatment varied individually. Interviewees would have liked information concerning side-effects after surgery from previous patients.

Conclusions. This study contributes to knowledge about patients' long-term suffering, their control of symptoms and how they have tried to cure themselves, but also about their concerns about surgery and the importance of surgical treatment to their quality of life. They wanted information about treatment, outcome and

consequences, not only from a health care perspective but also from previous patients having had the same treatment.

Keywords: antireflux surgery, content analysis, illness experiences, information-communication technology, nursing, patients

Introduction

The ability to imagine the illness experience and to empathize with those who are ill is limited and by eliciting descriptions of patients' experiences with illness, an understanding of their needs can be developed and anticipated (Morse & Johnson 1991). Furthermore, there is a growing interest in providing information to support patients' participation in choosing treatments and other decision-making (Coulter 1998). Patients require access to quality, evidence-based information so that they can take an active part in decisions about their health care (Shepperd *et al.* 1999). Conversations with patients with gastro-oesophageal reflux disease (GORD) show that they request honest and clear information from health professionals but also from patients who have previously undergone antireflux surgery. These patients can report their experiences of illness before surgery as well as outcomes of the operation. No such information is to our knowledge available and describing the illness-story, life with the disease, with and after surgical treatment, and illuminated from a patient perspective, are important for improved quality of care. This could increase understanding of living with a chronic reflux disease for health professionals and others, facilitate decision-making about surgery for patients and enhance information about the outcome of the operation from a patient perspective. It is important for significant others and for health care workers to increase their understanding about the way people with illness experience the illness (Söderberg 1999) but also how they experience treatments and outcomes.

GORD is defined as chronic symptoms or mucosal damage produced by abnormal reflux of gastric contents into the oesophagus (DeVault *et al.* 1999). Classic symptoms like heartburn, acid regurgitation and chest pain have a negative impact on daily life before the operation (Nilsson *et al.* 2002). It is by nature a chronic disease and many patients can control the symptoms by changing their habits through diet, antacids and over-the-counter acid suppressants. When the symptoms get worse, patients need medical treatment. DiPalma (2001) gives a review of management of severe GORD. Lifelong medication, above all proton pump inhibitors (PPIs), that is acid suppression or surgical treatment, are the options. When medication is inadequate, the patient has

side-effects of medication, or is unwilling to take lifelong medication, the only alternative is surgery (Johnsson 1994).

Surgical treatment aims at constructing a mechanism capable of preventing the reflux of gastric contents into the oesophagus whilst retaining ability to swallow and belch (Johnsson *et al.* 1987). The disease affects millions of people and for patients with severe GORD surgical treatment is an effective way to control the gastro-oesophageal reflux (Rattner & Brooks 1995). Results of surgery have generally been good (DiPalma 2001). Since 1991 this has been performed either by laparoscopic or open surgery (Dallemagne *et al.* 1991, Watson & Jamieson 1998). However, surgical treatment can have side-effects. Half of the patients have increased flatulence after fundoplication and a quarter have difficulties in belching (Johnsson *et al.* 1987, Johansson *et al.* 1993). Although, many studies have examined quality of life using different questionnaires (Rattner & Brooks 1995, Nilsson *et al.* 2002), there are to our knowledge no qualitative studies using a narrative approach.

The study

Aim

The aim of our study was to illuminate patients' illness experiences of having GORD, going through surgery and the outcome.

Method

The study reported here is a part of a larger study in which the same respondents also took part (Nilsson *et al.* 2000, 2002, Wenner *et al.* 2001). Between April 1995 and December 1997, 94 patients underwent antireflux surgery due to GORD. Sixty patients agreed to participate in a randomized control study treated with fundoplication (wrapping the gastric fundus around the lower end of the oesophagus) either by laparoscopic ($n = 30$) or open surgery ($n = 30$). As the earlier studies used a quantitative approach with a more medical focus, it was important to put a naturalistic emphasis into this study (Lincoln & Guba 1985). By eliciting descriptions of patients' experiences with illness, an understanding of their needs can be developed and anticipated (Morse & Johnson 1991).

Respondents

From the 60 patients, a purposeful sampling strategy was used to identify 12 respondents according to type of operation and sex. Six respondents from each group (three male and three female) were interviewed and their ages ranged from 36 to 58 years (median 56 years) in the laparoscopy group and from 49 to 63 years (median 59 years) in the open surgery group. Different occupations were represented, from working alone (such as farmers and flooring-layers) to working with other people (such as preschool teachers and sales workers). Respondents were recruited consecutively and asked to participate when they had their 5-year follow-up check. Recruitment continued until the sample size of six from each group was reached.

Ethical issues

Respondents gave informed consent to participating in the study, which was approved by the Research Ethical Committee of the Medical Faculty, Lund University (§ LU 409-94).

Interviews

Interviews were conducted by the first author and lasted from 40 to 100 minutes. They were audio taped in the respondent's home ($n = 7$), at the first author's office ($n = 3$) or in a secluded room at the respondent's place of work ($n = 2$), according to their preference. Respondents were invited to talk openly about their experiences, thoughts, feelings and the consequences of living with their illness, going through surgery and the period until the day of interview. Follow-up questions were asked to deepen, develop further or clarify the narrative. The sample consisted of 12 patients and each was given a number (p1-p12) for data reporting purposes to provide evidence of a balance of reporting across the whole spectrum of responses.

Data analysis

The interviews were transcribed verbatim and the text was analysed by means of qualitative content analysis as inspired by Burnard (1991, 1995). The text was read, bearing in mind the aim of the study, in order to obtain a sense of the content. The process was interpretive, seeking to categorize data and looking for core meanings and to group those meanings together (Burnard 1991). By hearing the entire story from beginning to end from several participants, common patterns become evident to the investigator (Morse & Johnson 1991). According to Downe-Wamboldt (1992), the objective of content analysis is to provide knowledge and understanding of the phenomena under study, and 'The researcher analyses the content of the narrative to determine themes or patterns' (Polit & Hungler 1999, p. 251).

All transcripts were first read and reread to gain a sense of the whole. The central categories related to the aim were Living with GORD, Concerns related to surgery, and Life after the operation. Next, meaning units, that is various sentences, phrases and statements, were extracted. All text was used except that referring to issues unrelated to the topic. Each meaning unit was analysed using questions such as 'What is this?', 'What does it stand for?' (Polit & Hungler 1999, p. 576) and codes, categories and subcategories were generated and sorted according to how the data related to the three central categories above. Examples of the process of content analysis of small pieces of text are illustrated in Figure 1. To increase credibility, all authors, throughout the analysis, read the text, reflected on, interpreted, discussed and revised the coding to reach general agreement concerning the three categories and nine subcategories presented in Table 1.

Meaning unit	Code	Sub-category	Category
Yes, it was not so very good, it was not, and it is true. So it was always pain in the stomach, you see, always heartburn and acid regurgitations, it did not matter what I ate	Has always pain in the stomach, heartburn and acid regurgitations from any food	Symptoms of the disease affecting daily living	Living with GORD
My father had this operation 1970 and he was never quite satisfied, still had his symptoms left so I was a little bit scared and thought I will wait for development to move forward. And I was right!	Father had had the operation, still suffering – waiting for technology to develop	Decision-making about the operation	Concerns related to surgery
Not having a Linc©...no more, so it is – yes, you can't describe it!	No medication after surgery	Outcomes and consequences	Life after the operation

Figure 1 Examples of the analysis process, from meaning unit to category.

Table 1 GORD-patients' experiences of illness, operation and outcome; categories and subcategories

Categories	Subcategories
Living with GORD	Symptoms of the disease affecting daily living Taking medicines Work, family and social life
Concerns related to surgery	Decision-making about the operation Influence by physicians
Life after the operation	Outcomes and consequences Side-effects and complications of the operation Sick leave Information and sharing experiences to future patients

Findings

Living with GORD

Symptoms of the disease affecting daily living

Respondents described life with an always-present illness. The symptoms had started years before, often in their 20s or even earlier, and had successively become worse and finally too hard to live with. They adjusted themselves to restrictions of daily living and these restrictions increased over time. From their point of view, they tried to live a normal life and considered themselves as healthy. They accepted their symptoms as inevitable and increased the medication in order to control their symptoms and to cure them. Different strategies were used, like avoiding certain food and drinks, not carrying heavy things, sleeping with the head raised; instead of bending, they would go down on their knees when tying shoelaces, etc. They felt an inexpressible longing for food and drinks that they could not tolerate, e.g. fruit and vegetables. One respondent, however, refused to change diet and instead ate and drank what she liked and put up with the pain afterwards:

...because you had remedies; you ate it in large quantities, had a glass of water and then it was gone, then you had to take new ones and you continued like that all the time (p. 7).

When bending I always had acid regurgitations, the gullet was an open wound (p. 2).

Three days later after having had sausages for lunch, I could belch and have it back in my mouth and that was disgusting, you see (p. 1).

The symptoms escalated over the years from mild to unbearable, with corrosive damages in the throat. Many respondents said that stress added their troubles with acid regurgitation,

vomiting and pain. Daily difficulties were constantly burning pain, acid regurgitation and contents from the stomach that rushed into their mouth. This became worse at night because when asleep they woke up with a full mouth and often were woken by coughing caused by stomach contents pouring into the windpipe, leading to feelings of annoyance and fear: what would happen if they did not wake up? In spite of disturbed sleep and even sleeping sitting in a chair, most respondents managed to go on and endured living with the worsened symptoms:

I woke up more or less every night with my mouth full of stomach contents, you cough and then when you are asleep – it feels almost like you are suffocating (p. 6).

Taking medicines

All respondents had been taking medication for years and could not manage without it. They had started with mild drugs available without prescription and over the years passed on to the strongest ones after seeing a physician. Medication was a temporary help and made the disease manageable. All respondents took proton pump inhibitors or similar drugs, and mostly thought this medication was effective:

You ate packages of medicine every week – nothing helped but you still hoped. It was hard, very hard (p. 2).

Work, family and social life

Respondents were hardworking and very loyal to their places of work. They worked despite their symptoms, taking their medicine and were on sick leave only occasionally or never. Their work was affected and hard to endure when it involved physical work such as bending or lifting. Furthermore, the illness had no visible signs and symptoms and that made it difficult for them to go on sick leave. Stress and working too hard aggravated the illness:

You woke up at about 1 o'clock and then couldn't sleep any more and then you are supposed to start working at 8 o'clock and that was hard. Then you had to swallow and swallow (p. 12).

I personally felt it as a relief to have the operation; it was a document, evidence to all who had not believed me that this was true, that I had not been deluding myself (p. 8).

Respondents' descriptions varied with respect to how their illness had influenced their family life. Most reported that the illness did not influence members of the family but only themselves, while others felt it was hard for the whole family and their chances of engaging in social life because of not being able to eat and drink normally. Many respondents

described how family members had the same symptoms and respondents often compared themselves to them. They believed the problem might be hereditary:

My family hasn't suffered...the children were already born when I had this and I had this all the time (p. 11).

I am tough, I never complain. Sure, they saw you were not feeling good, but you got used to it. You do that with pain and stuff like this, it's a part of life (p. 2).

Concerns related to surgery

Decision-making about the operation

The illness escalated and most respondents described the nights as dreadful. When nights became unbearable, they were referred to a surgical department and the diagnosis of GORD was confirmed by different investigations. Some respondents suspected that they had a gastric ulcer because the symptoms got worse when they suffered from stress and because they took proton pump inhibitors.

Most respondents felt relief when given the diagnosis and deciding to have the operation. For some it was a hard decision to have an operation but at the same time it was a way to get rid of their troubles. Some had been waiting for surgical technology to develop and an operation was the last option. Many had never had an operation before and felt that they were unaware of what it could mean. They saw it as something positive and felt trust in the operation, and also saw it as important to try to get healthy. The operation to them was a means to get rid of the problem. However, two female respondents expressed fearfulness of anaesthesia. One of these women had later experienced awareness during the operation but said very definitely that this had not left any traumatic implications: 'If I should need another operation I wouldn't hesitate' (p. 1).

Influence by physicians

Respondents put their confidence in their physicians and they influenced the respondents a great deal by inspiring feelings of trust and security. Most respondents reported that the doctors encouraged and supported surgery, and they felt confident and secure when the doctor advised the operation. Some were urged by the doctor to have the operation because, as they were told, they were too young to be on medication for the rest of their lives:

It felt as if I could only lie down and put my life in their hands and then it was all ready, that's what it felt like (p. 1).

If the doctor was insecure or showed any doubt, then the respondent was influenced likewise by these opinions:

I was a little bit scared from the beginning because when we talked about operation, it was so complicated and I felt that the doctor did not want me to do the operation, I felt insecure... (p. 10).

Life after the operation

Respondents' experiences of the outcome of the operation were overall positive, independent of type of surgery, and were in accordance with the generated subcategories. However, when striking characteristics relating to the laparoscopic or open surgery groups were found, these are referred to.

Outcomes and consequences

All respondents described how their symptoms had disappeared after the operation. They had expected a good outcome but many regarded this as better than expected and they described a normal life, eating what they wanted, drinking coffee, sleeping the whole night through and no more medication. The feelings of being able to eat and drink what they wanted were tremendous. Many respondents described managing their work better after the operation and even saying that it had been a requirement for being able to continue working:

I have not yet to this day had any problems concerning digestion and acidity of the stomach, regurgitation, and heartburn. There is nothing of the kind, and no traces of the symptoms have come back. They have done it so well that I can even belch (p. 1).

You cannot describe it, because I thought I will be better, but being totally out of symptoms, I never believed that (p. 2).

The operation was a wonder. If I hadn't done it, I had been very bad today and I had probably not been working (p. 8).

One respondent discovered cancer in her stomach a couple of years later, because of the absence of the reflux symptoms.

For the first postoperative days, most interviewees described pain when eating and drinking. However, in the open surgery group three women and two men talked about pain related to the surgical technique and described the first days after operation as rather painful. Except for one of the men, they also felt great tiredness/weakness and had no energy. One respondent's incision ruptured because he started working too soon, which he considered his own fault. Another considered that the incision was an obstacle to returning to work faster. Most respondents did not like the scar for cosmetic reasons:

I bet myself to get well as soon as possible and only 1 week after the operation I was back at work helping a little bit (p. 10).

Hell of a pain. I had an incision all over my belly...when I came home from the hospital, I was enormously tired (p. 6).

When looking back, I think the big problem was the wound (p. 11).

Side-effects and complications of the operation

All respondents had some side-effects of the operation, particularly eating difficulties and flatulence, but were bothered in varying degrees. After the operation, all had difficulties in eating related to a rapid feeling of fullness, and described a new technique for eating. They could not eat as quickly as many had used to do or take large bites of food. They had to chew very carefully and wash down their food with water otherwise the food got stuck. After about 6 months most respondents described their eating habits as normal, but some said that they still did not take big bites of food and tried not to eat so fast:

I had a little trouble in the beginning but that was because I took too big bites and that I ate as I used to, then I learned to eat less and to wash it down. Before I never drank until after the meal (p. 2).

I am eating normally now, everything. Yes, if I am in a hurry, it can become like blocked. Then I have to lie down on the floor and it will disappear (p. 12).

All respondents described problems with flatus or wind. These problems had not, as the eating problems had, become normal after 5 years and problems with wind persisted. They described different ways of managing this related to their kind of work and social surroundings, and no problems if working outdoors or alone. The wind was socially embarrassing and if they had to suppress it they got an awful pain in the stomach and in chest. Several respondents even described confusion with heart disease when they felt severe bloating, causing terrible tensions in their chest. When they were at home or had a 'free' work situation they could neglect it but those who were surrounded by other people described the severe pain and even attacks of cramp as unbearable. Many described the smell as stinking and nauseous. They were satisfied that they could control passing flatus but wondered if this would become involuntarily when they got older. A few could belch, and one respondent described a new way of belching by moving his body in a certain way in order to force him to belch. Being able to belch relieved many of the problems with the wind. Most respondents were not able to vomit and some described fear of being sick with influenza. Many also described a rumbling and noisy stomach. They described different strategies to control these new side-effects, for example, trying to avoid rushing about:

My stomach feels bloated, I put on a pair of trousers in the morning and think the clothes are fitting and by noon, I have to unbutton (p. 6).

They said you could get troubles with flatulence but that it would be to this extent, I hadn't even dreamt about...I wish I could belch when I am feeling as I was ready to burst (p. 3).

Two complications of paralytic ileus were described, one with open surgery and one in the laparoscopy group. Both these patients had previously had their appendix removed. Another respondent from the open surgery group described going acutely to the hospital because of feeling of sickness, gastroenteritis. One respondent from the laparoscopy group had intestinal infection with heavy diarrhoea and described how this made him socially isolated since it was uncontrollable and made him hesitant about whether the operation had been worthwhile:

One month afterwards I got ileuses, then I was enormously ill..., so I couldn't vomit, and that is a disadvantage, not being able to vomit (p. 5).

The operation was very good but having these infected intestines, dependent on a lavatory all the time (p. 7).

Sick leave

Some respondents described alertness and fast recovery and going back to work almost immediately, but some needed a longer recovery owing to open surgery combined with a manual job. Others who did manual labour, independent of type of surgery, felt they needed a longer time to recover. Many respondents also felt overstretched and needed a long time for recovery since their illness had bothered them for such a long time:

My work demanded lifting and I couldn't do that and then it was psychological too, feeling bad for maybe 10 years before the operation and not taking care of yourself like you should have done. Then afterwards coming back and start taking care of yourself, psychological pain, like waking up to life again, and that taxed all my powers (p. 1).

Information and sharing experiences to future patients

Most respondents were satisfied with the preoperative information they had received. They knew all about having to eat slowly, chewing carefully, washing down food with water and to avoiding carbonated drinks. Furthermore, they knew about probably not being able to belch and vomit, and increased bloating:

They told me about the wind and that I would have problems vomiting and with the wind. So I was a little prepared for that...and

that there might be some side-effects afterwards. It didn't come as a surprise! (p. 6).

They said, however, that it would have been good to have had information from patients who had already had the operation, since it was hard to imagine the side-effects. Some told about how patients who were going to have an operation had phoned them and asked about their outcome. Some of those who had open surgery lacked information about how to treat the incision. One respondent described how she massaged and softened the incision with an ointment but she had been told about that by her daughter's physician when her daughter was treated for burns.

All respondents emphasized the importance of having an operation and recommended it to other patients with the same troubles as they had had. They had recovered from GORD and many described a better quality of life afterwards. Respondents who had suffered from severe side-effects were more hesitant but admitted that it was a relief having no more illness symptoms. They were well informed and knew that the outcome of an operation was very individual. One patient described before and after the operation as compared to hell and heaven. Another described the outcome as 98–99% health and 1–2% wind:

I advise everyone with these symptoms, go for it, is it like this, so have the operation! (p. 4).

The operation was great but this other trouble... (p. 7).

I ate a whole bottle of pills per week...no, I have not taken one pill since the operation. That's good – really you have to admit that (p. 9).

Discussion

The main findings in this study demonstrate human responses to illness, surgical treatment and the outcome as described by the experts, the GORD patients themselves. Respondents voluntarily shared their illness experiences and how they coped in everyday life. Novels describing patients' illness experiences have become invaluable sources for medical and health care professionals and students to get 'inside information'. However, novels usually describe the experiences of only one person and are often considered limited and therefore dismissed as biography, merely describing extraordinary personal experiences (Morse & Johnson 1991). Qualitative research methods, on the other hand, can allow for the development of rigorous information. The findings from such studies can be of use for consumer health information, patient education and for health professionals meeting GORD-patients. Further, socials trend are towards

evidence-based health care and growing awareness of the need to equalize relationships between health professionals and lay people (Coulter 1999). To see patients as experts in their illness experiences is common among qualitative health researchers. In these efforts information and communication technology (ICT) are used and will increase: 'Consumer health informatics is the branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems' (Eysenbach 2000, p. 1713). It is important, however, that the content of the information put into these systems is research-based, with patients seen as experts.

Our respondents emphasized that they were satisfied with the preoperative information they had received but also pointed out that it was hard to imagine the consequences of the operation. They expressed a wish to have this information from former GORD patients. As some of the respondents had had inquiries via telephone from prospective surgery patients, there seems to be an urgent requirement for anticipatory preoperative information. The most important pre- and postoperative information needs were considered to concern postoperative pain and symptoms after surgery (Lithner & Zilling 2000). One way to gain this knowledge is to gather illness narratives from people who have the experiences.

Most respondents in present study put their confidence in the physician concerning decision-making about the operation. They also reported that the physician/surgeon suggested the operation.

This phenomenon in decision-making is described as an Illness-Constellation Model by Morse and Johnson (1991), explaining that when the individuals no longer can manage their symptoms alone, a critical point is reached whereby the person transfers responsibility for decision-making to the physician. When the sick person enters the medical system, choices become a medical prerogative. One of the factors that contributes to relinquishing of control on the part of the patient and at the same time feeling trust in a new situation is that 'In the physician-patient relationship the physician is often viewed as expert and the patient as the follower of expert advice' (Morse & Johnson 1991, p. 325). To enable patients to join the decision-making process regarding their health, patient information must meet scientific standards (Coulter 1998). Patient partnership is on the agenda in England (Coulter 1999) and is based on patients being seen as experts as well as on doctors' skills. Patients know about the illness experiences, social circumstances, habits and behaviours, attitudes to risk, values and preferences and doctors are well informed about diagnostic techniques, the causes of

diseases, prognosis, treatment options and preventive strategies. Both types of knowledge are necessary to manage illness successfully and as partners they should be prepared to share information and take decisions jointly (Coulter 1999).

All patients reported that the operation took away their symptoms of the disease although they had some side-effects, depending on how they coped individually. There were no differences between men and women but their working conditions affected how they managed their side-effects. We found no differences in respondents' experiences according to type of operation, with the exception of the early postoperative period: respondents from the open surgery group felt more pain, to some extent felt more tired and had a scar.

Another finding from this study is the respondents' experiences of recovery. As their symptoms had bothered them for such a long time, many felt overstretched and needed a long time for recovery. Not only type of operation but length of illness probably have consequences for the period of sick leave needed. Because of the long period of illness experiences described, it might be reasonable to suggest patients have the operation done earlier, to limit both suffering and the costs of sick leave.

Health care and nursing are fields of intensive and frequent information needs. A well informed patient is not only a nursing responsibility but also a part of caring. It was surprising that two patients reported that they had not received any information about treating their wound after open surgery. To promote and prevent health is a nursing challenge and will probably in the future be based on ICT. The need for information starts when illness begins and illness does not begin when the individual meets health professionals (Morse & Johnson 1991). As the illness narratives revealed, it began insidiously and escalated over the years.

Study limitations

Some limitations of this study should be taken into account. The respondents were interviewed about their illness experiences 5 years after operation. This could make it difficult for them to remember how it was to live with the illness before surgery; on the other hand, they had suffered for a very long time. Respondents also took part in a larger study and they knew the interviewer. This could lead to them thinking that they had already described certain topics and therefore not elucidating fully their illness stories. The interviewer knew more about the context from previous studies (Nilsson *et al.* 2000, 2002, Wenner *et al.* 2001), but all authors were involved in analysing the text and agreement was reached after discussing and revising the categories. The interviews

were transcribed verbatim and quotations from the original text were presented to illustrate the categories. The respondents narrated both positive and negative statements and described similar events. Other GORD patients will probably recognize similar events and be able to refer to these findings. According to Lincoln and Guba (1985) these are methods contributing to credibility, transferability, dependability and confirmability and lend trustworthiness to the findings.

Conclusion

This study contributes to knowledge about patients' long suffering, their control of symptoms and how they tried to cure themselves, but also to their concerns before and about surgery and the importance of the surgical treatment for their quality of life. Patients want and need information about treatments, outcomes and consequences both from a patient perspective and from a health care perspective. Further research is needed to extend the use of illness narratives as expert stories. Another implication for research is to see the patient as an expert in a user-friendly ICT environment. Easily accessible information on the internet could help patients to participate in decision-making about different treatments.

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