

INFORMATION NEEDS OF DIGESTIVE TRACT SURGERY PATIENTS BEFORE AND AFTER THE SURGERY: AN EXPLORATORY STUDY OF WESTERN LITHUANIA

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Abstract. *The aim of this study was to describe the information needs of patients undergoing gastrointestinal surgery in Western Lithuania. Methods. This data were collected from patients of three Klaipeda city hospitals performing digestive tract surgeries in January – March 2015. The interview responses (n = 86) were analyzed inductively with thematic content analysis. Results. The interview revealed lack of information about disease, treatment and nursing care. The participants expressed fear and worries about their forthcoming surgery, anesthesia, pain, the ways of pain management, possible complications and their prevention as well as the future concerning their disease in general. Conclusions. The results show that the participants had not got enough information about treatment, nursing, anesthesia, rehabilitation, wound care or about post-surgery period. Instead they felt fear and anxiety. The participants were not included into treatment and nursing processes. According to the participants' responses, the information needs were different before and after the surgery. Lack of information prevents patients from acting self-dependently in their care. Practice implications. Patient oriented approach to patient education and innovative ways of information delivery are needed in Lithuanian nursing care of patient's having a gastrointestinal surgery.*

Keywords: *digestive tract surgery, information needs, patients' education.*

Introduction

Information has a distinct value to operative care from the perspective of both the patient and the professional. The communication between professionals and patients has been changing and now the trend is to give increasing responsibility to the patient (Weiner, 2012). Understanding the information helps

the patient to make treatment decisions, supplement information or advice provided by a health professional, self-manage his health or health conditions, troubleshoot symptoms, provide a second opinion, modify health and lifestyle behaviors, enhance interactions with healthcare providers, decide if a visit to the doctor is necessary, choose a health care provider, prepare for consultation, clarify or validate information received from another source, increase knowledge of the disease or medical condition, identify underlying causes of a condition, seek alternative treatment options, take charge of one's life, or seek emotional support (Ramsey, Corsini, Peters, & Eckert, 2017).

For patients it is crucial both before and after an operation to have the relevant information, so that they can act in their own care and feel empowered (Poland et al., 2017). Individuals with different diseases seek information about their specific situation, illness, treatment plan, alternative treatment, and prognosis (Ramsey, Corsini, Peters, & Eckert, 2017).

Information provided for patients is important for patients' empowerment and enablement because it helps to create supportive environment, to develop personal skills (Schmidt et al., 2015) and to strengthen patient's sense of control and self-efficacy (Lavery, Dixon, & Millett, 2015). It is important to notice that patients' needs are specific to their individual clinical situation and patients with different diseases have different desires for information about their disease and their treatment which may influence the way they manage their long-term disease (Ramsey et al., 2017). A lot of studies (Salz et al., 2014; Papadacos et al., 2015; Søndergaard et al., 2013) have been carried out to learn about information needs of patients with cancer.

Digestive tract diseases and digestive tract surgeries are increasing due to food quality, eating disorders and unhealthy eating habits (Conceição, Utzinger, & Pissetsky, 2015). Fast way of life, eating in haste, unsuitable choice of products, and constant stress and tension are some of the reasons why the number of people having digestive troubles has been increasing (Yau & Potenza, 2013).

There are no current guidelines to support the information delivery of digestive tract surgery patients in Lithuania. Hence, there is a need to explore the information needs for these patients in order to provide better communication and enable individuals to manage their illness.

The aim of this study was to find out what the informational needs of patients undergoing digestive tract surgery in Western Lithuania are.

Methods

In 2013 a pilot research was performed in three hospitals of Klaipėda city the purpose of which was to find out if the patients who were to undergo digestive tract surgery lack information about treatment and nursing. Participants over 18

years old (n = 52) participated in the interview during their hospitalization.

The results of the pilot study were that the patients lack knowledge about care and treatment; and that they would like to be included in the processes of care and treatment. The participants felt that they were not included in their care plan process. They wanted to have the opportunity to take part in nursing planning and treatment. The participants needed more information about their disease, symptoms management and self-care at home after surgery. A great part of participants wanted to be included in the processes of nursing and treatment, and they also wanted to receive the information in writing. According to the pilot study data, the participants had not received enough information after digestive tract surgery: the research was carried out to ascertain what type of information the patients need before and after the surgery (Šakienė, Istomina, & Salantera, 2014). A topic list was created based on this pilot study.

The data for the main study were collected in 3 hospitals of Klaipeda city in the period between January and March, 2015. The inclusion criteria for the participants were as follows: age 18 or above, the time before or after digestive tract surgery, able to understand, speak, read and write in Lithuanian or English. All together 86 patients participated in the interview during their hospitalization. The topic list (formed in the pilot study) covered information needs about treatment, the surgery itself, nursing, anesthesia, nutrition, rehabilitation, wound care, physical activity, fear and anxiety. Participants responded to a structured interview based on the topic list.

In the data analysis, the answers were divided into the following categories: information concerning oneself, concerning fear and anxiety, and information concerning the surgery and care. The interview responses were analyzed inductively with thematic content analysis. The main issue was to describe the logic in how categories, subcategories and themes were abstracted, understood and connected to the aim and each other. Respondent answers were grouped into subcategories of “time” in which the following questions were attributed: how long the surgery will take, when the surgery will finish and other questions connected with time. In the subcategory “technique” the questions connected with surgery technique was attributed, i.e. in which way the surgery will be performed, if there will be a wide surgery cut, how many sutures there will be, if it is a complicated surgery, etc. In the subcategory “being, feeling” there were the questions connected with fear, anxiety, i.e. if it is a dangerous surgery for one’s age, if the patient will feel pain after the operation, if the patient can die during the surgery, etc. The questions of the subcategory about “time”, “technique” were attributed to the information concerning the surgery and care, the questions of subcategories “being, feeling” were attributed to the category of fear and anxiety, while the questions which emphasized oneself, i.e. what medicine the patient will have to take, how to prepare oneself for the surgery and others were attributed to

the category concerning oneself.

The used coding unit was either a word or a phrase. The coded responses were divided into meaning units after thorough reading of the codes. The meaning units were then divided to sub themes and further gathered under themes (Creswell, 2013).

The approval of Ethical Committee of Klaipeda University and the permission of Heads of Klaipeda City hospitals to perform the study about “Patients information needs before and after digestive tract surgery” were obtained in 2013.

The participants were informed about the research and assured that their refusal to participate in the research would not affect their nursing, care or treatment in any way. They were also informed that they could withdraw from the study at any time if they wished. The information accumulated was processed confidentially so that the data was not disclosed at any stage of the research to anyone outside the research group.

Results

In total 86 patients participated in the main study. Their age ranged from 18 to 89 and 57 per cent of them were female and 43 per cent were male. Three quarters of the respondents lived in urban areas and the rest lived in rural areas. Three main themes were formed from the participants’ answers: information concerning oneself, concerning fear and anxiety and information concerning the surgery and care. The results are highlighted in Table 1.

Table 1 Patients’ information needs concerning digestive tract surgery

| DURING THE SURGERY | | |
|---|--|--|
| Information concerning oneself (subcategory feeling, being) | Fear and anxiety of the future (subcategory being , feeling) | Information concerning the surgery and care (subcategory time, “technique”) |
| Pain <ul style="list-style-type: none"> • what the pain is like • if I get pain medication • what kind of medication I get for pain • if I will feel pain during the surgery • how long the pain will last | <ul style="list-style-type: none"> • if I will wake up • if I will experience pain • if I can tell when I am in pain during the surgery • what the odds of dying are • if I am too old for safe surgery • if I will get information • if my life is in danger • who will inform me | Surgery technique <ul style="list-style-type: none"> • how long it takes • who will operate me • what the risks and complications are • will there be sutures • what type the sutures are • what will be operated • if I get a stoma • how big the stoma |

| | | |
|---|---|--|
| | | <ul style="list-style-type: none"> • what part of my digestive tract will be removed • what the surgery technique is • will I get anesthesia • will there be drains • why the stoma is needed • if surgery is safe • if the anesthesia is safe |
| RECOVERY AFTER THE SURGEY | | |
| Information concerning oneself | Fear and anxiety of the future | Information concerning the surgery and care |
| Pain <ul style="list-style-type: none"> • how much pain is normal • if the pain medication is effective • how to take the medication | <ul style="list-style-type: none"> • how much the recovery will cost • if I have to buy anything • if I will get a pain medication prescription • if it is possible to learn self-care • how my life changes • what factors cause death after surgery • what complications are dangerous | <ul style="list-style-type: none"> • how long the recovery period is • what the possible complications are • if my condition renews after the surgery • how likely it is for the cancer to spread • if the stoma will last forever • what the size of the wound is • if the drains are going to stay • where the dressings for the wound will be changed |
| | Own actions <ul style="list-style-type: none"> • what I can do to prepare myself for the surgery • when I can get up after the surgery • how I should prepare myself for the recovery • if I should buy any equipment • if I can prevent the possible complications • what my nutrition should be like • how I can take care of my wound • when I can take a shower • what is forbidden for me | |

Participants were mostly anxious to get general information about the surgery itself, i.e. how long it will take, how the doctor will performed it, what the surgery technique is, and what complications may occur. Pain was a matter of great concern for the individuals before the surgery as well as after. The participants wanted to know what the pain would be like, if they would experience pain at all, if they will get pain medication, what type of medication it would be,

etc. These issues may cause stress before the surgery. The participants felt fear and anxiety about experiencing pain, about odds of dying, if the operation would be complicated, if their life was danger, if the anesthesia was safe or if they would wake up, etc. Many of these questions were repeated by the participants. At the same time the participants were interested only in a very narrow scope of their own actions. They expressed only two main concerns: what they could do to prepare themselves for the surgery and when they would get up after the surgery.

The participants' needs were oriented to get information about the surgery procedures and nursing care related to anesthesia. The participants did not have enough knowledge about anesthesia. They were afraid of not waking up, of feeling pain, they were afraid of the influence of anesthesia on their health in the future, and that it could shorten their lifetime. The participants were afraid to speak and/or behave strangely under anesthesia. The results showed that the information needs about anesthesia were different before and after the surgery. Before the surgery the participants wanted to know what kind of anesthesia would have applied to them, if they would feel pain during the surgery, how they would know that they were feeling pain, if they would not wake up while under the surgery, if anesthesia was harmful for health, what type of anesthesia would be used, what complications might occur, if there was a possibility to choose the type of anesthesia.

After the surgery the participants' information needs were: how anesthesia affected their health, if they spoke during the surgery, what was their behavior like while under the anesthesia, if anesthesia really shortens one's lifetime, and what type of anesthesia was used.

After the operation the participants had both short-term and long-term concerns. Individuals were worried about the wounds, the length of the recovery period, possible complications, the possibilities of the illness to renew, and the possibilities of getting cancer.

The pain issue was also a matter of concern after the surgery. The participants were worried about how much pain is normal, if they will get pain medication prescription, and if the pain medication is effective. All these questions caused fear and anxiety about possible complications, factors that can cause death after the surgery, about changes in life, about the learning the self-care, and the costs of the recovery.

The scope about one's own actions was much wider in the post-operative period. The participants of the research shared their concern about the ways they could prepare themselves for the recovery, the equipment they should purchase, the nutrition, and taking care of the wound.

Discussion

This study revealed that the participants had a wide variety of information needs both before and after the surgery. Before the surgery the needs concentrated on the operation, pain and issues that caused fear and anxiety, but very little on one's own actions. After the operation the information needs shifted to cover one's own actions, but still there were information needs about pain management, issues that caused fear and anxiety and issues concerning the operation and care. It might be that having more information would be helpful to diminish patients' fear and anxiety.

The unmet information needs during the discharge can contribute to poor patient outcomes and readmission, it is critical that clinical staff and nurses accurately identify patients' information needs and find ways to meet these needs. Awareness of the patient's met and unmet expectations should enable staff to understand the patient's perspective and improve communication.

Rogers (2011) notes the provision of additional written information on surgery might lead to a better understanding of the problem and might thus improve patient satisfaction with the care provided. The danger is that satisfaction about information received is improved but with no evidence of improved recall of knowledge. Therefore, responding to patients' needs for information should include certain mediators. The concept of information behavior is helpful to understand patients' information needs in relation to patients' characteristics that enable to foresee the added value (i.e. patient's enablement) in delivering information.

Patient information must be personalised and made understandable. This can improve self-preparation and participation in the own recovery. Special needs must be addressed early and followed up (Samuelsson, Klarin, Lökk, Gunnarsson, & Iwarzon, 2018).

The participants of this study were able to verbalize their concerns about going home with a wound. Concerns about discharge may help to direct patient teaching in preparation for discharge. Educational material for patients could include the most common concerns, as well as ways to avoid misinformation about wound care. Discharge teaching needs to begin early so that patients feel they have adequate time to learn and ask questions.

Ramsey et al. (2017) found that information related to a specific illness or disease was the most common type of information sought by patients. Our research was oriented to evaluate the needs for information of patients dealing with digestive tract surgery. We found it important to aim our study to a narrow field of participants' with digestive tract surgery. This way we received targeted information about the issues that are relevant to this exact group of patients.

Strengths and limitations of the study

This descriptive study has some limitations and strengths. They can be viewed from the perspectives of credibility, dependability, conformability and consistency as well as transferability (Bernard, 2012). The credibility was established by using a research team that has knowledge about the care of digestive tract patients and patient education. The established topic scheme that was used might have guided the respondents to choose the topics that were on the list and hence to diminish the credibility. However, based on the responses the topics were not limited only to the topics of the interview. Dependability was supported by describing the analysis process and giving an example of it in the methods section. However, the translation of responses into English might be mistaken and some information might have been lost during the translation process. Conformability and consistency were strengthened by using a second opinion in forming the analysis themes. Transferability of the results is limited. Patient education practices differ from country to country, and it is obvious that the patients' knowledge needs also differ. The results of this study might apply to Lithuania but even in that case the transferability can be questionable. Even so, this study gives important information about the information needs of the studied group of patients and can guide future research.

Conclusions

The participants lacked information about treatment, nursing, anesthesia, rehabilitation, wound care and about post-surgery period because of which it is possible to assume they feel anxiety. The participants did not receive enough information and they were not included into treatment and nursing processes. The information needs of the participants were different before and after surgery. The benefits of additional information might comprise increased patients' involvement in decision-making and their ability to cope with stressful circumstances during the diagnosis, operation, and post-operative phases, adaptation to a diet and a stoma, It might contribute to patients' anxiety, relief, reduction in mood disturbances, and better communication with family members.

Practice implications

The participants lacked information about their treatment. Knowing what questions are important to the patients the medical staff could prepare information leaflets, educational plans or something else where the patients will get answers to the most frequent questions they are anxious about.

References

- Bernard, H.R. (2012). *Social Research Methods: Qualitative and Quantitative Approaches*. SAGE Publications
- Conceição, E.M., Utzinger, L.M., & Pisetsky, E.M. (2015). Eating Disorders and Problematic Eating Behaviours before and after Bariatric Surgery: Characterization, Assessment and Association with Treatment Outcomes. *European Eating Disorders Review*, 23(6), 417-425.
- Creswell, J.W. (2013). *Qualitative inquiry & research design: Choosing among five approaches*. Los Angeles: SAGE Publications.
- Laverty, A.A., Dixon, A., & Millett, Ch. (2015). Do Patients' Information Requirements for Choice in Health Care Vary with Their Socio-Demographic Characteristics? *Health Expectations*, 18(5), 1127–1138.
- Papadakos, J. et al. (2015). Informational Needs of Gastrointestinal Oncology Patients. *Health Expectations*, 18(6), 3088–3098.
- Poland, F. et al. (2017). Developing Patient Education to Enhance Recovery after Colorectal Surgery through Action Research: A Qualitative Study. *BMJ Open* 7(6).
- Ramsey, I., Corsini, N., Peters, M.D., & Eckert, M. (2017). A rapid review of consumer health information needs and preferences. *Patient education and counseling*, 100(9), 1634-1642.
- Rogers, P.N. (2011). Does an Information Leaflet About Surgical Site Infection (SSI) Improve Recollection of Information and Satisfaction of Patients? A Randomized Trial in Patients Scheduled for Digestive Surgery. *World Journal of Surgery*, 35, 1212–1213.
- Šakienė, L., Istomina, N., & Salantera, S. (2014). Attitude of the Patients With Digestive Tract Surgery Towards Information Needs During the Perioperative Care. *Sveikatos mokslai*, 24(5), 26–30. Retvited from <http://sm-hs.eu/index.php/smhs/article/view/sm-hs.2014.088>.
- Salz, T. et al. (2014). Colorectal Cancer Survivors' Needs and Preferences for Survivorship Information. *Journal of Oncology Practice*, 10(4), e277–82. DOI: <http://ascopubs.org/doi/10.1200/JOP.2013.001312>.
- Samuelsson, M.E., Klarin, I., Lökk, J., Gunnarsson, U., & Iwarzon, M. (2018). The older patient's experience of the healthcare chain and information when undergoing colorectal cancer surgery according to the enhanced recovery after surgery concept. *Journal of Clinical Nursing*, 27, e1580–e1588. DOI:10.1111/jocn.14328.
- Schmidt, M. et al. (2015). Patient Empowerment Improved Perioperative Quality of Care in Cancer Patients Aged > 65 Years - a Randomized Controlled Trial. *PLoS ONE*, 10(9), 1-21.
- Søndergaard, E.G. et al. (2013). A Survey of Cancer Patients' Unmet Information and Coordination Needs in Handovers - A Cross-Sectional Study. *BMC Research Notes* 6(1).
- Weiner, J.P. (2012). Doctor-Patient Communication in the e-Health Era. *Israel Journal of Health Policy Research*, 1(1), 1–7.
- Yau, Y.H.C., & Potenza, M.N. (2013). Stress and Eating Behaviors. *Minerva Endocrinologica*, 38(3), 255–267.