Patient-reported participation in hepatopancreatobiliary surgery cancer care: A pilot intervention study with patient-owned fast-track protocols

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Abstract

Objective: Fast-track concepts have been implemented in hepatopancreatobiliary surgery cancer care to improve postoperative recovery. For optimal postoperative care, patient participation is also required. The aim was to investigate and analyse whether an intervention with patient-owned fast-track protocols (PFTPs) may lead to increased patient participation and improve information for patients who underwent surgery for hepatopancreatobiliary cancer.

Methods: A quantitative comparative design with a control and intervention group was used. The participants in the intervention group followed a PFTP during their admission. After discharge, the patients answered a questionnaire regarding patient participation. Data analyses were performed with descriptive statistics and ANCOVA.

Results: The results are based on a total of 222 completed questionnaires: 116 in the control group and 106 in the intervention group. It is uncertain whether the PFTP increased patient participation and information, but its use may indicate an improvement for the patient group.

Conclusion: A successful implementation strategy for the use of PFTP, with daily reconciliations, could be part of the work required to improve overall satisfaction with patient participation.

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KEYWORDS
fast-track surgery, hepatopancreatobiliary cancer surgery, information, patient participation, recovery, surgical care

1 | INTRODUCTION

In 1994, the World Health Organization highlighted the importance of solidarity, respect and justice, human rights, participation and dignity as important values in health care (World Health Organization Regional Committee for Europe, 1994). Patient participation is a broad concept, and no uniform definition exists (Cahill, 1996; Longtin et al., 2010; Sahlsten et al., 2008). Patient participation is
closely related to concepts such as person centeredness, self-care and empowerment (Lin et al., 2019; Longtin et al., 2010). To provide optimal care and treatment to patients with complex diseases, information must be shared between health care professionals and patients. Care should be provided safely and based on clinical attention, medical experience and education. Treatment should be planned to use a shared decision-making process between the caregiver and patient (Spatz et al., 2017). A presurgery session to provide personalized information and dialogue to patients improves understanding and knowledge and can provide increased patient participation (Ibrahim et al., 2019). Previous studies on participation among patients who have had surgery for upper abdominal cancer identify the need for both oral and written information as important for improving patient participation (Ibrahim et al., 2019; Larnebratt et al., 2019). Ibrahim et al. (2019) found that patients felt that they were receiving information preoperatively but that the information provided during the meeting that occurred could be too overwhelming and that oral information was easily forgotten when written information was not provided.

The goal of the fast-track multimodal concept for optimization and efficiency in perioperative care is to maintain the body's vital functions and optimize the possibilities for postoperative recovery. This means that the patient should be able to return to his or her normal work or daily life activities early (Kehlet & Wilmore, 2008; Pawa et al., 2012; Senturk et al., 2017). These concepts are based on high-quality patient information, high-quality pain relief, early postoperative nutrition and the restriction and early removal of drainage (Kehlet & Wilmore, 2008; Senturk et al., 2017; Siotos et al., 2018). Currently, there is limited knowledge and evidence on patients undergoing upper abdominal cancer surgeries and following a fast-track concept. Research conducted to investigate fast-track approaches in liver and pancreatic surgery has shown a reduction in postoperative complications and shorter hospital stays without an increased risk of readmission (Lei et al., 2015; Wu et al., 2015).

Currently, limited attention is given to patient participation among patients undergoing hepatopancreatobiliary (HPB) surgery and following a fast-track concept. The results from previous studies show that patients request additional information and for improved visibility of care goals and planning during the care period (Ibrahim et al., 2019; Larnebratt et al., 2019). Considering these findings, this study aims to investigate and analyze whether an intervention with patient-owned fast-track protocols (PFTPs) may lead to increased patient participation and improve information for patients who have hepatopancreatobiliary cancer. The research questions investigated are the following: Was there a significant difference in patient participation between the control and intervention groups? Can intervention with a PFTP lead to an increased level of information? The hypothesis of the study is that PFTP may increase satisfaction with patient participation.

2 | METHODS

2.1 | Design

This study employed a quantitative comparative design, and a control and intervention group were established to compare the differences between self-reported patient participation and information.

2.2 | Setting and sample

The patients were recruited from a surgical clinic at a University Hospital in southern Sweden. A consecutive selection procedure in both the control and intervention groups was used for the inclusion of patients who had surgery for liver, bile and pancreatic cancer and received care according to a fast-track protocol (see Figure 1). The inclusion criteria were patients over 18 years of age with malignant tumours in the liver, bile ducts, stomach or pancreas who underwent elective surgery and received care according to a fast-track concept. The exclusion criteria were patients with cognitive impairment or who had not mastered the Swedish language well enough to be able to complete the questionnaire. Due to COVID-19 and the pandemic situation in the hospital during the planned study period, inclusion in the intervention group was stopped earlier than planned.

Informed consent to participate in the study was obtained. A consent form stated that the study was voluntary and that the patient could withdraw consent and discontinue participation at any time, without giving a reason and without concern that such a decision would influence the care or treatment given. Confidentiality was guaranteed throughout the study. The study was performed in accordance with the ethical principles of the Declaration of Helsinki (World Medical Association, 2013), and the study was approved by the Regional Ethics Review Board (No. 2018/413–32).

2.3 | Control group/standard care

Most of the patients in the specific clinic receive fast-track care (HPB surgery).

However, the care process and care goals of the fast-track protocol were only known to the health care professionals in the control group, and the patients received standard care. The control group did not undergo an optimal fast-track concept in the standard care. The fast-track protocol adapted for medical professionals contained medical language and was not designed for patients. The patients included in the control group were not informed about the specific detailed goals preoperatively or goals for each day postoperatively due to the fast-track protocol and the care goals. The patients in the control group were only verbally informed about the fast-track care in the presurgery meeting with the surgeon and nurses but did not receive written specific detailed care goals for each day. A total of 116 consecutively sampled patients (control group) completed a questionnaire.
two to 3 weeks after discharge between December 2016 and December 2017. The patients received the questionnaire and a prepaid envelope.

2.4 | Intervention

The intervention group underwent an optimised and efficient fast-track protocol during perioperative care to optimise the possibilities for postoperative recovery and were provided high-quality patient information. The authors created the intervention to provide patients with written information as requested in a previous qualitative study (Ibrahim et al., 2019) and a better fast-track protocol in the clinical setting.

The specific care goals were discussed with the patients during the preoperative phase in the intervention group, and they received written information. The written PFTP first included general patient-friendly information emphasising the important components for optimal postoperative recovery, such as early mobilisation, early intake of fluids (oral) and nutritional supplements and explanations of the important part of the activities to be performed during the time of care (description under Section 2.5).

The group received a PFTP that was customised according to the specific diagnosis and surgical technique performed for the patient and a visual of the specific detailed care goals for each day. Patients who met the inclusion criteria were repeatedly asked face to face to participate in the presurgery meeting with the surgeons and the nurses. Patients were informed both verbally and in writing and received the PFTP in the preoperative phase to determine all the expected care goals. The patient-owned protocols contained written patient-adapted information and written visual postoperative care objectives. Both preoperatively and every day during the surgical care period, all care goals remained available to the patient and were discussed with the professionals. A total of 106 patients responded to the questionnaire 2 to 3 weeks after discharge between May 2019 and March 2020. No patients were recruited during the summer vacation period of July 2019. The patients received the questionnaire and a prepaid envelope. The intervention group’s questionnaire responses were compared with those of the control group (Larnebratt et al., 2019).

2.5 | Data collection and procedure

2.5.1 | PFTP

The PFTP was developed according to the existing fast-track protocols adapted for professionals. The fast-track protocols adapted for professionals were not written in patient-friendly language and were never designed to be disclosed or distributed to patients. The fast-track protocols adapted for professionals were designed to ensure that the staff are aware of the goals to be achieved every day, as well as to be able to detect abnormalities in patient postoperative health from the expected care. Ten patients, two physicians/surgeons and six registered nurses were involved in the design and the content of the PFTP. Small linguistic adjustments were made during the process. Four versions of the PFTP were constructed based on various diagnoses and surgical techniques.

Example from PFTP:

It is important that the body starts to move as soon as possible after surgery. You should therefore feel free to move in bed, take deep breaths and use breathing
exercises. It reduces the risk of blood clots and pneumonia. We recommend that you stay up and moving, alternating with rest in bed. The goal is for you to get up and stand/walk with the help of staff early after the surgery.

In connection with your surgery, you will receive anticoagulants to prevent blood clots. It is helpful when administered early during care for those receiving injections, so that you feel secure about the use of anticoagulant therapy when discharged from the hospital.

You are able to begin a liquid diet early after surgery, and after a few days you are allowed to eat solid food.

Since you had surgery on the pancreas, your blood sugar is monitored daily. The pancreas is the organ that produces insulin, and insulin regulates blood sugar in the blood. Because of this, your blood sugar is checked regularly after surgery. This is to determine whether you have high or low blood sugar, so that it can be fixed effectively.

The PFTP was designed to make written daily care goals available to patients postoperatively (already in the preoperative phase) to increase participation and improve information on the upcoming surgery. The written PFTP was constructed in an easy-to-understand manner with clear language. Several evidence-based interventions of the PFTP aim to optimise patient involvement and postoperative recovery. The PFTP contains written daily goals for physical activity, nutrition intake, respiratory exercises and thrombosis prophylaxis (see example). The protocol is adapted to be used postoperatively and completed daily by the patient. Patients would mark the specified boxes that correspond with the goals they achieved each day.

This also enables health care professionals and the patient to monitor the patient’s postoperative recovery every day with the purpose of using the information for clinical discussions and to improve patient participation and information.

2.6 | Questionnaire

Questionnaires were sent to patients who met the inclusion criteria. The questionnaire that was developed and validated by Arnetz et al. (2008) was used (Arnetz et al., 2008). The original questionnaire was written in Swedish and underwent several phases of review during development, such as combining information provided by patient focus groups, expert judgement and a literature review, to ensure high validity and reliability (Arnetz et al., 2008). The questionnaire was developed for patients with myocardial infarction, but items were applicable for other patient groups. The questionnaire consists of 45 forced-choice Likert-type scale questions divided into five domains: ‘patient participation’ (six items), ‘acute phase’ (seven items), ‘time in the hospital’ (12 items), ‘discharge’ (12 items) and ‘time at home’ (eight items). The authors of the questionnaire created six subscales that summarise the participants’ behaviour, their experiences of their care and their definition of patient participation. These six scales are patient participation, illness experience, information, patient needs, activity and treatment planning. All scale items ask the patient to rate a specific statement on a 4-point Likert scale ranging from 1 (no, not at all) to 4 (yes, to a great degree). Higher scores indicate more positive ratings. Scale values calculated the total score for each participant and converted the sum to a percentage. The maximum possible score is 100%. Scores for all scales are reported as the mean percentage scores. The validity and internal homogeneity of these scales were assessed in the study by Arnetz et al. (2008), from which the questionnaire was developed, and showed low correlation between the scales, indicating good scale independence. The questionnaire takes approximately 15 min for the patient to complete.

2.7 | Statistical methods

The demographic variables are presented as descriptive statistics with counts and proportions separated by the control and intervention groups. To examine the differences in the demographic variables between the groups, Z tests for proportions were carried out. The covariates used were age, sex and diagnosis. The sample size calculation for ANCOVA with a significance level of 0.05 and a power of 0.80 was sufficient. One-way ANCOVA was used to analyse the potential differences in the mean of each scale and the overall satisfaction with patient participation between the groups and was adjusted for the covariates age, sex and type of tumour (Field, 2018). To obtain proportions adjusted for the aforementioned covariates, the same method was applied when responses to the questions regarding participation and information were compared separately between the groups. To carry out those analyses, each answer option was recoded into a dummy variable, the average of which was the same as the proportion of responses to each answer option. The results from the ANCOVA are presented with their respective confidence intervals. The hypothesis of this study is that the PFTP may increase satisfaction with patient participation. The differences between the groups were considered statistically significant if they reached a significance level of 5% (P < 0.05). All analyses were carried out using IBM SPSS Statistics 25 (SPSS Inc., Chicago, IL, USA).

3 | RESULTS

The results are based on a total of 222 completed questionnaires, 116 in the control group and 106 in the intervention group. The response rate was 72% in the control group and 80% in the intervention group. Table 1 presents the patient characteristics. The mean care period and time in the University Hospital ward were 7.5 (control group) and 7.3 days (intervention group), respectively. No statistically
significant differences were found between the groups regarding response rate, time in ward or in the covariates for age, sex, tumour/diagnosis and postoperative complications (Clavien–Dindo classification).

### 3.1 Was there a difference in the importance of patient participation between the control and intervention groups?

The item that received clear information was most often rated by respondents from both groups as ‘true altogether’ and was considered essential for participation. Figure 2 presents what the different groups considered important for patient participation.

### 3.2 Can intervention with the PFTP lead to an increased level of information?

On the information scale, respondents had to assess their experiences with obtaining information during the care period (Table 3). In the intervention group, more respondents answered ‘yes, to a large extent’ regarding the attainment of information than in the control group. The intervention group responded positively to a greater extent than the control group, but none of the responses showed a statistically significant difference.

### 3.3 Can PFTP lead to increased patient-reported patient participation?

On all scales, respondents in the control and intervention groups rated themselves in a similar manner; no statistically significant differences were identified. Regarding the control and intervention groups’ estimates of overall satisfaction with participation, there was a positive increase that did not reach statistical significance ($P = 0.063$).

Figure 3 shows the scales and an estimate of the overall satisfaction with participation during the care period. Fewer patients responded to the activity subscale than to the other subscales.

### 4 DISCUSSION

After an intervention with the PFTP, a trend towards improvement in the grading of overall patient participation and information can be seen. Even if the intervention itself is relatively simple, the interaction with the context is still highly complex. Although no statistically significant differences were found between the groups, we plan to incorporate the PFTP into daily care based on this indication of improved results. The lack of statistically significant differences may be a reason for the sample size. Due to the pandemic situation in the hospital during the study period, inclusion in the intervention group was stopped earlier than planned.

Perhaps the intervention with the PFTP, which was completed daily postoperatively, may have contributed to this result. Offering patients the opportunity to be involved in their care requires time and a good working environment. The staff’s experience in involving the patient in their care can be limited by organisational structures. Nurses express a willingness to involve patients more, but workloads and administration time limit them from offering and motivating patients to participate in their care (Tobiano et al., 2015).

A study by Andersson et al. (2020) revealed that health care professionals regarded time constraints as an obstacle and that other
tasks were prioritised over involving patients in their own care. The PFTP was developed to increase the likelihood that the patient can contribute to achieving and discussing the goals of their care. Patients with a PFTP have an opportunity to take initiatives themselves to achieve their goals, such as requesting nutritional drinks or instructions on breathing exercises without the request being mediated by health care professionals.

Studies show that patients prefer to have an active role in their care but often experience limits that are beyond their control. This applies, for example, to the elderly and to oncology patients who are

**FIGURE 2** Control and intervention group responses on the patient participation scale. The data are presented according to adjusted proportions, and only positive alternatives were offered.

**TABLE 2** Control and intervention group regarding components in importance for patient participation

| What does patient participation mean to you? | Control group | Intervention group | P value<sup>b</sup> |
|--------------------------------------------|---------------|--------------------|-------------------|
|                                            | Per cent<sup>a</sup> (95% CI) | n | Per cent<sup>a</sup> (95% CI) | n |
| Clear information                          |               |                   |                   |
| Yes, to a great degree                     | 79.9% (72.5–87.2) | 115 | 81.9% (74.3–89.5) | 105 | 0.708 |
| To some degree                             | 20.1% (12.8–27.4) | 117 | 17.2% (09.6–24.8) | 108 | 0.588 |
| Ask questions                              |               |                   |                   |
| Yes, to a great degree                     | 75.9% (67.2–84.5) | 113 | 62.9% (54.0–71.9) | 104 | 0.042 |
| To some degree                             | 20.5% (12.1–28.9) | 110 | 37.1% (28.4–45.9) | 101 | 0.008 |
| Express personal views                     |               |                   |                   |
| Yes, to a great degree                     | 62.7% (53.5–71.9) | 114 | 56.7% (47.1–66.3) | 105 | 0.378 |
| To some degree                             | 31.3% (22.4–40.1) | 102 | 39.1% (29.9–48.3) | 97 | 0.229 |
| Involved in discussions about care and treatments | | | |
| Yes, to a great degree                     | 60.7% (51.4–69.9) | 114 | 49.2% (39.6–58.8) | 104 | 0.092 |
| To some degree                             | 31.2% (22.3–40.2) | 102 | 41.1% (31.8–50.4) | 97 | 0.136 |
| Involved in decision making about care and treatment | | | |
| Yes, to a great degree                     | 45.5% (36.2–54.8) | 113 | 46.1% (36.5–55.8) | 104 | 0.920 |
| To some degree                             | 39.5% (30.4–48.6) | 101 | 39.0% (29.5–48.5) | 96 | 0.939 |
| Main responsibility for future health      |               |                   |                   |
| Yes, to a great degree                     | 51.1% (41.7–60.5) | 114 | 58.5% (48.8–68.3) | 103 | 0.282 |
| To some degree                             | 38.3% (29.1–47.4) | 103 | 37.4% (27.9–46.9) | 95 | 0.896 |

<sup>a</sup>Estimated proportion with ANCOVA, adjusted for covariates (sex, age and tumour).

<sup>b</sup>F test.
unable to express their information needs and preferences. They do not ask questions or participate actively to the same extent as younger patients (Jansen et al., 2010; Posma et al., 2009). Many of the patients in this study were aged >70 which, based on previous evidence, may have contributed to their ability to achieve and discuss the goals of their care. These factors may affect the motivation of health care professionals to include the patient in his or her care. This may have affected the results of the study, as a prerequisite for the intervention is that the health care professional actively includes the patient in the daily care goals and the follow-up. Good communication and cooperation can contribute to a safe and empathetic experience. Previous studies describe security and empathy as important components for supporting the patient to achieve their set goals (Larsson et al., 2011), and patient involvement in complex cancer surgery can be facilitated by patient-centred care and providing support when the patient asks questions, providing an overview of the treatment pathway and articulating the transitions between treatment stages (Thaysen et al., 2019).

By introducing PFTP, the intention was that information should be clear and adapted according to the surgical intervention and patient group. The PFTP was developed preoperatively, which allowed the patient to prepare for what was expected in the postoperative phase. Obtaining preoperative information has been shown to be important preoperatively and an important factor in patient satisfaction (AMIN ET AL., 2017).
participation (Aasa et al., 2013). Health literacy is a term used to describe the extent to which the individual can understand basic information about health care to make conscious choices regarding care and treatment to achieve better health (Speros, 2005). The degree of health knowledge is influenced by the individual's previous knowledge and experiences, personality, culture, language and cognitive conditions (Parnell et al., 2019).

Studies have shown that patients are worried about early discharge due to uncertainty in alleviating postoperative symptoms (Jonsson et al., 2011). In the PFTP, the patients' daily goals are available with the intention of providing a high-quality-based intervention to prevent the occurrence of postoperative complications. The purpose of the fast-track protocol is to improve physical recovery postoperatively, which has been shown to lead to a shorter hospital stay and earlier discharge (Boulding et al., 2011; Lei et al., 2015). However, it has been shown that emotional and psychological aspects of recovery are not always considered when discharging patients, which may contribute to increased anxiety (Mako et al., 2016). By meeting the patient's need for information, the effectiveness of treatment can be improved and can contribute to an increased ability of the patient to cope with challenges and an altered quality of life (Abu Sharour et al., 2020).

By involving the patient in daily goals, the risk of communication deficiencies, such as misunderstandings, reduces the risk of errors. Setting daily goals with the patient can accelerate postoperative physical recovery and reduce the incidence of pain (Lee et al., 2018). It seems to be important to encourage patients and give them control in their situation, taking ownership of aspects of their care that they can influence. Activities in the care process should not come as a ‘surprise’ for the patient, for example, short time in hospital. Perceived patient participation and level of activity have shown strong associations with limited possibility for participation among those with lower activity levels (Westman et al., 2022).

The PFTP can be used to influence discussions regarding setting and evaluating daily goals. The goals are not individual but should be discussed according to the patient’s status and the possibility of achieving those goals. This can be an important intervention in surgical care due to its ability to reduce the risk of postoperative complications, reduce anxiety and help the patient feel optimistic about returning home.

The present study has strengths and limitations. There was a high response rate in the present study, which was a strength due to the vulnerability of this patient group. More patients with pancreatic and liver malignancies and fewer patients with bile duct or gastric cancer were included. However, this study provides a representative selection of those patient groups who had surgery during the study period as well as of the incidence of the different cancer diagnoses.

The study was performed during two time periods instead of using an RCT design, which may be a limitation. However, it can be challenging to integrate the control and intervention groups in clinical practice. A limit of the study may be that there is a concern that the contextual factors have changed over the two time periods when the data were collected.

The questionnaire used in this study aimed to encompass a broad perspective of the time in hospital and discharge and the time at home and was therefore chosen by the research team. No other questionnaire with this broad perspective in Swedish has been found. Fewer patients responded to the activity subscale than to the other subscales, perhaps because the patient group did not view the activity items (sexual activity, housework and driving) as relevant. A low response rate on the activity scale was found in both the control and intervention groups. This is interpreted as a systematic internal missing or non-random missing result.

A less positive perspective with the standardised programmes has been shown in previous studies, especially for older patients with comorbidities, reduced nutritional status and anaemia (Pawa et al., 2012; Sibbern et al., 2017). A fast-track protocol during hospital care contributes to a rapid physical recovery after surgery and involves shorter periods of care, but mental and emotional recovery is not so much in focus. Rapid physical recovery after surgery also needs to be improved along with the care that supports the patient’s emotional recovery post discharge (Mako et al., 2016).

Increased patient participation can lead to more effective treatment, better rehabilitation and recovery, higher quality of care, reduced frequency of readmissions, increased motivation and satisfaction with overall care (Arnetz et al., 2008, 2010; Boulding et al., 2011; Lee et al., 2018). By increasing the dialogue and exchange of information between health care professionals and patients, participation can occur, which in turn can reduce the incidence of postoperative complications and prolong the length of care (Boulding et al., 2011; Lee et al., 2018). It is also valuable to include the next of kin of this group of patients, as a study has shown that the next of kin are hidden by the patient but should support the patient in different ways after discharge (Ibrahim et al., 2020). Compliance with standardised postoperative care is lower than that with preoperative and intraoperative care. This may be due to factors that require the patient to actively participate in, for example, early enteral nutrition and responding to mobilisation deficiencies (Thorn et al., 2016). The intervention with the PFTP involved a daily follow-up with patients who set goals together with the responsible health care professionals in surgical cancer care. The interactions in this context are highly complex, and previous studies describe that contextual/external factor, such as a lack of time, heavy workload and high staff turnover, can negatively affect patient participation, patient information, implementation of interventions and new strategies in the workplace (Andersson et al., 2020; Fischer et al., 2016; Nilsen & Bernhardsson, 2019). These are also interpreted as possible challenges and barriers to interpreting these study results and integrating these changes into clinical care practice.

4.1 | Clinical implications

Surgical care professionals should work to achieve optimal person-centred care with high levels of information and encourage patient participation. The PFTP was a vision to motivate patients and improve information, and patient participation with joint dialogue and
continuous follow-up of daily goals can be used to involve the patient in their postoperative care and to promote self-care. This could lead to increased overall satisfaction and patient safety both in the short- and long-term outcomes of surgical cancer care. The clinical implications of PFTPs can facilitate the achievement of daily fast-track care goals and, when combined with different strategies suggested by the team, show positive effects.

5 | CONCLUSION

The intervention with PFTPs was more likely to improve the overall patient participation and information. The interaction with the care context is still highly complex and may be influenced by many factors, such as team collaboration and organisational structures. There also must be time to meet the patient and discuss their care goals regularly to improve self-care and coping, which we had a vision to achieve and will continue address both in clinical practice and in future research.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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