PaCER REPORT

ERAS FROM THE PATIENT PERSPECTIVE

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Executive Summary

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Introduction

This qualitative Patient and Community Engagement (PaCER) study is the patient experience component of *Enhancing Patient's Recovery After Surgery (ERAS): Strategy to Transform Patient Care and Maximize Expected Value* project. This study includes patients' experiences of ERAS protocols pre-surgery, in-hospital and post surgery.

PaCER Methods

PaCER enables specially trained patient researchers to engage in peer-to-peer qualitative research. There were two phases in this research, a Set or co-design focus group and a Collect phase consisting of narrative interviews. The research was iterative, following the pathways indicated by the patient participants. The data were analyzed using participatory grounded theory (Taram , Schacter & Stalker, 2005), a variation of Glazer & Strauss' (1967) grounded theory especially appropriate for patient to patient qualitative research.

Results

Our results indicated that patients perceived that, to be a programme focused on enhanced recovery, ERAS should include the process or journey from diagnosis to recovery. They believed pre-surgery attention to their physical and psychological wellbeing, being as fit as possible for surgery, was important and that post hospital care and connection could be improved to relieve the stress they encountered once they were home.

We identified four main themes or categories:

1) Pre-operative Experiences with eight sub categories: a) Knowledge of ERAS, b) Pre-operative information from surgeons and nurses, c) Pre-operative information from a group class, d) Stress. e) Fears about surgery, f) Worry about finances, work and family, g) Bowel preparation and travel related stressors, g) General lack of information.

2) In-hospital Experiences with Providers with five sub categories: a) Pain control, b) Journal, c) Following ERAS protocols, d) Medical care / post operative health, e) Rapport with providers.
3) Non Provider Related In-hospital Experience with two sub categories: a) Noise level, b) Nutrition.
4) Discharge and Post Discharge Experiences with four sub categories: a) Discharge information, b) Biopsy, test results, c) Medical concerns / home help, d) Need for a designated contact.

Discussion

Our findings that patients desired more pre and post surgical help to ensure an accelerated recovery are supported in the literature. There is also support for their request to understand all of the ERAS protocols, to know why they are being encouraged to walk, chew gum, and eat. There was unanimous agreement that if patients fully understood the benefits, the physiological reasons, they would pursue the protocols much more vigorously. The thread throughout our findings was a patient plea for inclusion in knowledge. They wanted to be part of a team focused on their recovery, to be done with not to. This is congruent with the shift toward patient centred care where patients and families are directly involved in the recovery process.

Recommendations

1. Fully explain every protocol and the purpose of the protocol to the patients both before surgery and while in-hospital so that they can become knowledgeable partners in their recovery
2. Extend ERAS programme to the pre- surgery phase (between diagnosis and surgery) so that patients can be ready emotionally, psychologically and physically for surgery.
3. Extend the ERAS programme to the post surgery recovery at home phase to avoid stressful situations for patients and families
4. Consider activating a volunteer programme where experienced patients can be available for conversations with new patients.

ERAS FROM THE PATIENT PERSPECTIVE.

INTRODUCTION

This qualitative Patient and Community Engagement (PaCER) study, is a patient experience component of *Enhancing Patient's Recovery After Surgery (ERAS): Strategy to Transform Patient Care and Maximize Expected Value* project. Enhanced Recovery After Surgery (ERAS) guidelines provide information on patient nutrition, pain management and mobilization. ERAS guidelines include a number of interventions supported by evidence. When ERAS guidelines are applied as part of a multi-disciplinary peri-operative care process, patients recover faster, have less perioperative stress, pain and gastrointestinal dysfunction, and reduced severity of complications . Not only does this benefit the patient directly, but enables Alberta Health Services to maximize both care and efficiency and ensure sustainable health care across the province.

The study explores the patient experience of the ERAS guidelines while in hospital as well as their knowledge and understanding of the ERAS protocols. In keeping with PaCER research philosophy, at the direction of the patient participants, we extended the study to include pre-surgery and post surgery experiences of ERAS. Patient and Community Engagement researchers (PaCERS) are patients trained in qualitative research and patient engagement at the Cumming School of Medicine, University of Calgary. All of the researchers in this study had previously undergone extensive surgery and two had experience of accelerated discharge. Using trained patients as researchers may reduce any perceived power imbalance between researcher and interviewee (Gillard, Simons et al., 2012; Berger, 2015) as participants view the focus groups and interviews as peer-to-peer interaction. The direction of the research is driven by the patient participants and they are an integral part of the iterative analysis process (Marlett, Shklarov et al., 2014).

Background and Context

Over the past few years, approximately ten years after the ERAS Study Group developed and published their first evidence-based consensus protocol (Fearon et al., 2005), a number of qualitative studies have surfaced to investigate patient experiences and satisfaction with the protocol. Overall, a consistently high level of satisfaction with ERAS has been reported (Blazeby et al., 2010), excluding the need to improve some of the specific services provided, such as preoperative preparation (Aasa et al., 2013; Sibbern et al., 2016) and postoperative support (Blazeby et al., 2010; Bernard & Foss, 2014).

Recently a systematic review of eleven qualitative studies pertaining to patient's experiences with Enhanced Recovery Programs (ERP) identified four main themes: 'information transfer', 'individualized treatment vs standardized care', 'balancing burdensome symptoms and expectations for rapid recovery', and 'sense of security at discharge' (Sibbern et al, 2016).

Provision of information is considered an essential component of the ERAS protocol because patients perceive that it facilitates the regaining of some measure of control, while lacking information leads to anxiety and feelings of insecurity (Lithner et al., 2012). Most patients rated the information they received during their preoperative preparation for surgery as being favourable and felt that the preparation permitted a sense of preparedness and purpose (Galli et al, 2015; Vandrevala et al., 2016). Patients were pleased to be active participants in their own care and recovery (Sibbern et al, 2016; Aasa et al. 2013) and stated that the understanding of their role as an active participant in their recovery was influenced by the expectations and rationales provided by their health care providers (Sibbern et al., 2016; Norlyk & Harder, 2009; Aasa et al. 2013). Many patients perceived a need for additional time to grasp the preoperative information and adequately prepare for their impending surgery (Sibbern et al, 2016; Aasa et al. 2013).

Nearly all published studies identified a theme that the process of convalescence truly begins in the home setting (Galli et al., 2015; Vandrevala et al, 2016): a place where access to usual food and typical sleep patterns can resume (Blazeby et al, 2010). However, a clear need to adopt standardized procedures to provide postoperative assistance and reassurance was apparent (Blazeby et al, 2010) as most patients wanted instructions to continue the process of active recovery at home (Lithner et al., 2012).

Some patients found it difficult to meet healthcare professionals' expectations regarding the structured, fixed ERAS regimen (Sibbern et al., 2016). Although most patients praised the structured regimen as a means of monitoring their progress and achievement of recovery goals (Bernard & Foss, 2014), patients that did not meet these milestone (as a result of unanticipated postoperative symptoms, such as pain, or functional limitations) perceived themselves as being 'outside' the program (Galli et al., 2015) and, particularly if discharge was delayed, a failure (Vandrevala et al., 2016). Patients stated that feeling individually supported was essential to their success in the ERAS program (Sibbern et al., 2016, Norlyk & Harder, 2009). They indicated that they required *personalized* support and contact by their healthcare providers to permit adherence to the standardized regimen (Aasa et al., 2013).

Methods

PaCER uses several qualitative research methods set within the patient engagement research framework outlined in *Grey Matters* (Marlett & Emes, 2010) For this study we chose grounded theory (Glaser & Strauss, 1967) as we as we wanted to understand the patient experiences with, and beliefs about the ERAS protocol in the hope of developing some theory around how patients could embrace and diligently follow ERAS protocols.

Recruitment and Inclusion Criteria

We used purposive sampling to recruit patients who had undergone colorectal surgery in the last 12 months and who had been identified by their surgeons as participants in the ERAS protocol programme. They were over 18 years and spoke English well enough to participate in a focus group or interview.

There were two phases of recruitment. Phase one included patients who were informed about the study prior to their surgery and had agreed to be contacted three months post surgery and phase two included patients who were in hospital and were one to three days post surgery. The phase one participants were all contacted by telephone to ensure that they fitted the criteria and understood the parameters of the study. The phase two participants were informed about the study by the ERAS project coordinator in the hospital chosen for the in hospital interviews. Phase two participants were also invited to take part in an interview three weeks after discharge from hospital

Participants

We recruited 27 patients, 15 in phase one and 12 in phase two. There were ten females and 17 males aged between 29 and 89 years. Patients were recruited from all five hospitals in Alberta that were using the ERAS protocols for colorectal surgery patients. We facilitated one focus group (seven participants) and interviewed eight patients in phase one and interviewed 12 participants in phase two (in hospital) with seven at home follow up interviews.

Data collection and Analysis

Following the PaCER methodology (Marlett & Eames, 2010) we held a five hour SET or Co-design group, and followed up with the COLLECT phase consisting of individual narrative interviews lasting 45 – 60 minutes.
Our patient engagement research process is iterative and amenable to changes in direction depending on the information received from any group or interview (Marlett, Shklarov et al., 2014). The SET or Co-design group is used to indicate what topics are of the highest importance to the patient participants and directs the initial guiding questions for the COLLECT interviews. This means that the patient participants and the patient researchers collaborate in the co-design group to determine the direction of the study. Each group or interview participant was asked the same initial question: *Please tell us about your post surgery experience while you were/are in hospital.* This opened the door for participants to describe their varied knowledge of ERAS and recount their experiences coping with the protocols. In the co-design group we encouraged discussion among the participants and only used short prompt questions to deepen the information being given. Narrative interviews encouraged participants to "tell their story" once more using prompts sparingly to elicit greater depth. PaCER audio records and transcribes all groups and interviews. We use a flip chart to take notes of participant conversation and take process recording notes in each group. All three are used in the analysis process and using

flip chart notes allows participants to review the information gathered ensuring our understanding of the data is accurate.

SET or Co-design Group

Our co-design group had seven participants representing four of the five hospital settings within the ERAS protocol programme in Alberta. The group lasted for five hours with two participants having to leave after three hours. In keeping with PaCER protocol we used the flip chart notes to develop the guiding questions for the COLLECT interviews. The flip chart notes were posted on the walls and the three participants were asked to check the veracity of the notes and were invited to give additional comments on all of the noted topics as well as identifying any omissions. PaCER does transcribe the co-design group when the COLLECT phase is completed and the quotes are used to enrich the data.

Topics of major importance to our participants used to formulate guiding questions for the COLLECT interviews were:

- *How nurses introduced and encouraged following ERAS protocols*
- *Pre surgery stress*
- *Surprise at the high level of gas pain*
- *Stress around biopsy results*
- *Nutrition*
- *Level of knowledge of ERAS*
- *Journals*

COLLECT Interviews.

We held eight narrative interviews, each lasting between 45 – 60 minutes, using the information gained iteratively as we progressed. The interviews were audiotaped and transcribed. All five hospitals were represented. When we had interviewed all of our available participants we found that most of our participants had varied memory gaps around some topics that had emerged as being important in the co-design phase. Since our previous method of recruiting involved a lengthy wait between recruitment and interviewing, we decided that the best method of recruiting participants was to access patients while they were in hospital with an in hospital interview and a follow up interview three weeks after discharge. This required an ethics amendment, which was submitted and approved. With time constraints in mind, one hospital was chosen and we interviewed 12 patient participants audiotaping and transcribing each interview. We reached saturation after ten interviews but completed the interviews we had scheduled. We also completed seven follow up at home interviews as we were unsure if participants might have different perceptions once they were home. None of the participants altered their views and saturation was reached.

The data were analyzed iteratively using grounded theory (Glaser & Strauss, 1967) and participatory grounded theory (Taram, Schacter & Stalker, 2007) until saturation was reached.

Research Credibility and Trustworthiness

We used several strategies to raise the credibility and trustworthiness of the research: (1) The patient researchers facilitating the groups, interviewing patients and analyzing the data had to understand, reflect on, and state his/her biases (Bogdan & Taylor, 1975; Kirk & Muller, 1975; Patton, 1990) (2) As surgical patients we had a familiarity with the experiences of the participants (Shenton, 2004). (3) We used research colleagues, academic supervisors from PaCER, and peers to review and discuss the emerging data, coding, and themes (Lincoln & Guba, 1986, Shenton, 2004). (4) We employed iterative questioning, triangulation (e.g., grounded theory and participatory grounded theory (Taram, Schacter & Stalker, 2007 and two different data collection techniques), and thick description of patient experiences (Lincoln & Guba, 1986, Patton, 1990). (6) We completed a literature review to assess the congruence of our findings with previous research (Berg, 1989; Lincoln & Guba, 1986; Morse et al., 2002; Shenton, 2004). (7) Patient to patient research lessens the reflexivity present when traditional healthcare providers are used (Berger, 2015).

Results

Introduction

It would appear from our results that the patient participants perceived that any enhanced recovery after surgery programme should start at diagnosis and continue through the in home recovery period. In their minds, confirmation of diagnosis and surgery was the start of their process toward recovery with every effort being taken by themselves and professionals to prepare them for surgery both mentally and physically and to ensure their continued recovery at home. They perceived that any enhanced recovery programme should not be confined to the in hospital post surgery recovery period.

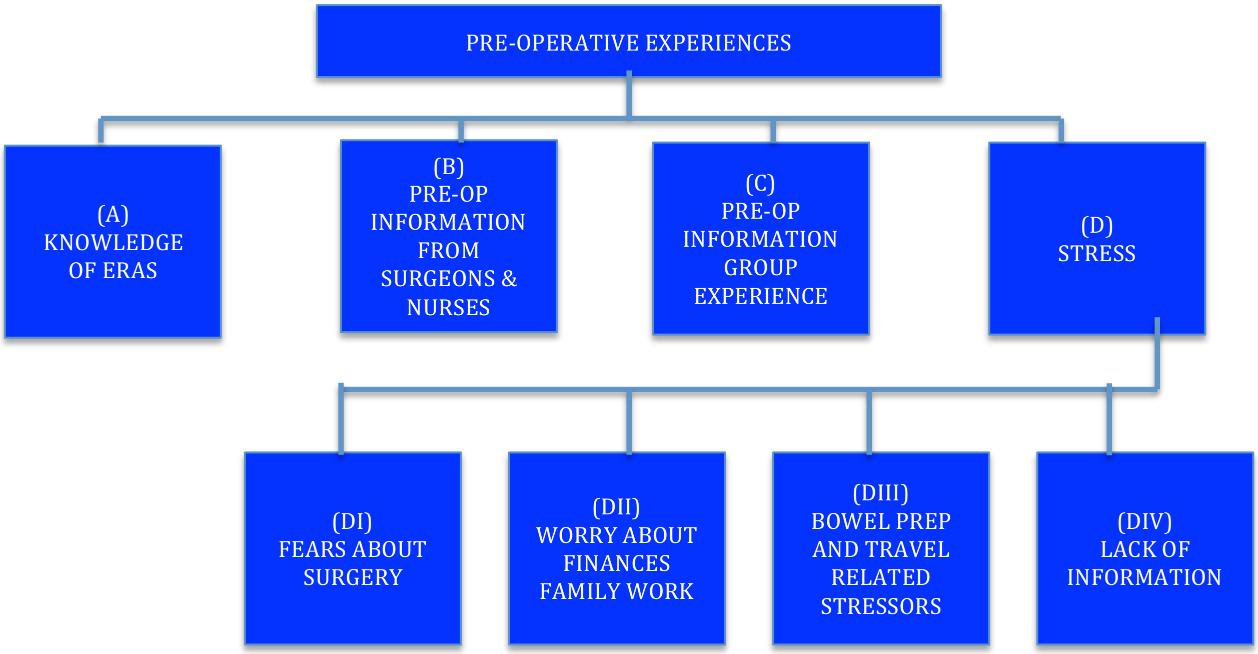
Figure 1

In keeping with their vision of surgery as a process or journey, the results section is divided into four categories: (1) Patient pre-operative experiences with eight sub categories; (2) In hospital experiences with providers with five sub categories; (3)

Non provider related in hospital experiences with 2 sub categories; (4) Post hospital discharge experiences with four sub categories.

1. Pre-operative experience (from diagnosis to surgery)

Figure 1



A. Knowledge of ERAS

Knowledge of the ERAS protocols was varied among all 27 participants ranging from no knowledge, even during post surgery recovery in hospital, to a complete understanding of the protocols, usually gained from their own research. Many of the patients who had been given an outline of the protocols, either in a formal group or by their surgeon and / or nurses chose to become more informed prior to surgery and two participants chose to "get themselves fit" for surgery.

Table 1

SUB CATEGORY	EXEMPLAR QUOTES
Knowledge of ERAS	**12)** I had no pre surgical awareness of the ERAS programme. **23)** I didn't get any information pre op about getting up drinking etc. **M14)** I didn't know anything about ERAS. It was mentioned

	but we didn't know what it was. **CI7-95**) if somebody comes up to you and says 'well, you should've went for walk for the first 3 weeks before your surgery but you can't tell them that the day of the surgery you have to tell them that way beforehand. Any information you're going to get that's going to improve or speed up your recovery 99% of the people in the world are going to do it unless you physically can't **M49)** I hadn't met the surgeon before I came in for surgery so we knew nothing. **9)** The ERAS program was clearly explained about the specialized diet, high carbohydrate diet, the physical exercises. (at class) **10**) As I've mentioned I've been boosting up my physical exercise pre-surgery with walking 6-10kms my dog Sammy. That was no problem as I've always been extremely active. Changing my diet to a high carbohydrate diet was no problem either. **S19** No, I had no knowledge of ERAS **S20 (Spouse)** No, I noticed it in the book that we got about the bowel surgery. It was mentioned. **S21** I'm not sure it is even in this book. It might have been in the papers that we were given.

B. Pre-operative information from surgeon and/or nurses

Few patients appeared to have been told about the ERAS protocols by their surgeons prior to surgery, while some noted that nurses had given them some information. It appeared that the surgeons were focused on having patients understand the surgical procedures and knowing what to expect when waking up post surgery than discuss or explain the ERAS protocols that would be in place during their in hospital recovery. One participant told us her surgeon had advised she need not to attend a special pre-operative information group. This participant stated that she wished she had chosen to attend as she did not believe she had enough information before her surgery and this had caused some stress during her recovery time.

Table 2

SUB-CATEGORY	EXEMPLAR QUOTES
Pre-operative information from surgeon and/or	**EN 388)** I met with the specialist and he explained everything to me and about the team he was putting together. They were concerned that I might not make it

nurses	through the operation. **CN7 -5)** I was diagnosed with cancer on April 13, 2015 so they booked me for surgery and had me meet with the surgeon and had me on I believe May 5 was my surgery, so they had me in very quickly. During my appointment with her before the surgery she explained everything quite well, exactly what they were going to be doing **M 1**) I just had what the doctors told me, nothing about ERAS **S14** No, we didn't have any of that (group or ERAS information) **S402** Yeah, they (doctors) told me what to expect (from surgery) **S403** They (doctors) didn't know what the extent of it was but did show me a picture of what was to be done. It needed to be done right away. **CI17)** At that time, I came back and I met with my surgeon who introduced me to the ERAS program. It was mainly through literature that introduced me to what ERAS is, just some light reading, here is what we'd like to do to prepare for surgery, here is what ERAS is **8)** My real exposure to ERAS came two weeks before my surgery at the pre-admission clinic. At the pre-admission clinic I met with three groups of nurses, the anesthesiologist, the entero -stomal nurses to help me. Where the main thrust of learning about ERAS came was meeting the nurses who were just godsends. I really look back fondly on that day. **S498** I think that would help. (doctor's office providing pre-surgery tips) **S805** No. My surgeon told me not to go to class, that there was no point. **S810** Yeah, even when I had my pre-op phone call with the nurses, I asked them about it (pre op class) and they said he didn't write a requisition for it and said not to worry about it. **S808** I think it (attending pre op class) would have helped my anxiety a bit. I've never seen an ostomy bag or dealt with anything like that before.

C. Pre-operative information group experience (PLC patients only)

The Peter Lougheed Centre is the only hospital in the ERAS programme that provides a pre-operative information class for patients having bowel surgery. Participants were very positive about their experiences and believed that they had many questions answered and some fears laid to rest. Some patients who attended would have preferred to have attended earlier during their wait for surgery period as they believed they might have been fitter for surgery had they had information about diet and fitness sooner. Some patients, those who apparently did not see a stoma nurse after the group, and were to have an ileostomy or colonostomy would have like more information in this area. However, all agreed that it was a worthwhile programme of great benefit to patients and families.

Table 3

SUB-CATEGORY	EXEMPLAR QUOTES
Pre-operative information group experience	**S261** I realized things going in that I didn't know. (pre-op educational class) the information was stuff that I needed to know. The dietician and the anesthesiologist, those things were nice to know and they had my interests in mind. **S269** The bottom line is that I didn't come here (hospital) uninformed. **347)** The classes were pretty informative but they were compressed. The nutrition should be a class within itself separate from the surgery. You are overwhelmed by what is going to happen with the surgery… **S557** There was probably 20 people in the room at least I'm guessing…patients and their significant others. We had the lovely little booklet that we went through. They explained as we were going along. It wasn't a read along which I thought was very nice. They explained it very well and she (nurse) was very open to questions which was great. **S1010** We went to a class and it was very good but there wasn't a lot in it on people that were going to have a bag. They said because not everyone was going to be getting one they weren't going to spend a lot of time on it **S576** It was very worthwhile…(pre-op class) **S565** We got the booklet to take home which I definitely looked at. (My spouse) did as well. It explained what would happen before going to the hospital, when you went to the hospital, Day 2,3,4 etc.. the different things…that you would get up, sit, walk etc. **S308** Yeah my partner was there. It was a good thing that both of us were there (pre-op class) because she remembered some of the stuff that I didn't. **S476** I went to class four days before surgery. The nurse we have today is the one that taught us. Earlier might have been better. **326)** With that preparation with the program you know what to do and to expect…they prepared you very well…when you woke up there was no anxiety…I really recommend that they keep up that program…

D. Stress

Many patients talked about various stressors they encountered while waiting for surgery. They believed that some help resolving the stressors would have allowed them to go into surgery much calmer and less worried and tired. Patients understood that the better their pre-surgery physical and mental health was the faster they might recover.

DI. Fears about surgery

Many patients experienced fears around their diagnosis and the upcoming surgery. There was consensus that some guidance around accessing services that would ameliorate the fear would be very useful in preparing for surgery. Few patients appeared able to reach out for this kind of help and those who did were given advice by friends or family who had been in similar situations. The services that some patients accessed on their own included various Wellspring programmes , a group for men with GI cancer, an AHS mindfulness for cancer patient's workshop, tai chi, yoga and visualization exercises. Almost all patients expressed some level of fear and believed they would have benefited from access to an appropriate service to help them through the time waiting for surgery. Guidance about appropriate services from health providers would have been welcomed.

Table 4

SUB-CATEGORY	EXEMPLAR QUOTES
Fears about surgery	**18)** There is a lot of stress and fear and those things can stop you getting well and healing fast. Should some thought be given to helping patients with stress and fears. Maybe there should be someone who can have a conversation with you so you can talk about all these things and make sure that you are in the best mind to be healed **CI1 5)** What I also found extremely helpful was that my friend recommended the Wellspring group here in Calgary. What I found working through them was not just working on the physical aspect but the mental aspect preparing for treatments and my upcoming surgery. I was going through visualization, relaxation, meditation, Tai Chi classes, yoga classes, keeping my spirits up, my good thoughts, positiveness. In addition to that through the psycho-social oncology department I joined the men's group for GI cancer patients and also prior to surgery I started a nine week workshop put on by AHS called Mindfulness Based Cancer Recovery. ... **94)** I think there is really nothing stressed about the mental, psychological aspects of it. For colorectal patients, you are

	going through a tumultuous time in your life. .. you are going wow!... faced with your own mortality… I went out searching for programs…I wasn't searching for ERAS but it found me and I embraced it. **115)** AHS doesn't have a lot of psycho-social programs whereas Wellspring does. They're two symbiotic relationships that can grow together. It does help the mental aspect preparing for surgery combined with the ERAS program is a win-win. **EN 57)** I think what could improve is the relationship between Tom Baker, Wellspring and AHS knowing what services they offer. **S335)** I'm afraid I'll get addicted to painkillers **S301** Anyway, I would like to see an organization PAA – Patients Against Anxiety. People like you that have gone through it (surgery) and can share their experience so that it will make it less frightening would be good. **CI8-68)** I was very nervous going in and getting up onto a cold operating table. Just literally I nearly freaked out. It would've been good to get some form of sedation, some form of something to help me in that situation…I was beginning to, to get to the stage that I literally started crying…I was terrified, I didn't know whether I was going to wake up, ever again

DII. Worry about finances, family and work

Patients worried that illness would negatively affect their jobs and financial situation. Not all participants were employed in jobs providing sick leave insurance coverage, some worried that they might not either be able to return, or even have a position when they had recovered from surgery. They worried about how the family was coping both with the illness and possible constrained finances. While patients recognized that such worries were not helpful as they prepared for surgery, they saw little that could be done apart from perhaps discussing it with a former patient or counselor, and trying to concentrate on being as well as possible. Most acknowledged that information about the length of the recovery period to give employers was variable and possibly inaccurate.

Table 5

SUB-CATEGORY	EXEMPLAR QUOTES
Worry about finances, family and work	**47**) One of the most difficult things was telling my boss I wouldn't be able to work I'm a college instructor. Telling family was really difficult too. I think talking to someone

	who has had this kind of experience would be really good- it would be helpful. Perhaps they could have a pre-op session telling you about what to expect so you know what's coming it would give us information and be less stressful. **61)** I had stress because of the finances. There should be some help about the mental problems that are caused by stress **CI7-179)** Plus, you need to be able to tell your work right, when I went in for my surgery I had only worked with this company for about a month and then all of a sudden I got diagnosed with this **CI7-179)** I made lots of phone calls back to work saying oh it's going to be longer, it's going to be longer. Whatever they can do to make it so that there is less surprises and then better off it is for most people **S455** I'm in the financial situation that I can retire anytime so I'm not going back to work for a while… **S606** People were saying why are you worrying about going back to work, that is the least of your worries, when you get back, you get back. That was the one thing I've learned in the last few months… **S607** I'm still concerned that they will lay me off when I go back. (to work). They can't while you're off, but once you go back they can lay you off without cause is what they call it. They can lay you off and don't have to give you a reason.

DIII. Bowel preparation and travel related stressors.

The patients who discussed the above issues were those who had mobility problems and/or patients who had a considerable distance to travel for surgery. The practice of admitting elective surgical patients on the day of surgery, usually early in the morning, put undue stress on these patients the night before surgery. Some patients believed that spending the night before surgery in hospital would have relieved this last minute stressor.

Table 6

SUB-CATEGORY	EXEMPLAR QUOTES
Bowel preparation and travel related stressors	M16) I want to tell you something, that prep it should, especially t his age (89) he should have been admitted the night before to the hospital. He had a very bad night and he

	was up all night where everything had let go and it was a real mess and he felt really bad. They should have had him in the night before to do stuff like that. It was very humiliating for him and he felt so bad. He had the oral enema and it was bad… He can't go very fast – he has bad legs. **S32** He has bad legs. He couldn't even get from here to the bathroom and that's why he messed and stuff… That's why they should have admitted him the night before (pre-op enema) . I am very adamant about that. **S127** That's my number one beef. (live in Medicine hat) We had to phone at 1:30 in the afternoon and they told me my surgery was at 6AM so we had to come in overnight here. **S128** We came in Monday afternoon and had to wait to call at 1:30. She said to call back at 2. If we were to phone at 1:30PM and the surgery was at 6AM we would have had to get up at 3AM to get down there. That's why we did that. (came into Calgary overnight) we didn't want to get stuck on the highway doing that.(bowel prep). They said to take it (bowel prep) at 10AM but we couldn't take it at 10 in the morning and you're driving still and you have to go. **S693** That's right. You go in for surgery in the morning…they take you in at 7AM. We had to drive in from Strathmore and have to get up at 5. Then the operation starts at about 10 or 11 o'clock. I lay there waiting. PLC2-1 and my stepson waited for me to come out of the recovery room. It was 6 o'clock at night before I got out of there. It just takes you down. (the long wait and surgery)

DIV Lack of information

Perceived lack of information about the results of scans, what the surgeon had planned to do and how long it would take to recover from the surgery were all pre surgery stressors discussed by some participants. They believed that uncertainty and not knowing had caused them undue anxiety, which negatively affected their pre-operative health. Those who had attended a pre-surgery class or had been able to discuss in depth their surgery with their surgeon or nurses believed that were able to go into surgery with more confidence knowing what to expect. Lack of information was more prevalent in patients who lived at a distance from the city. Most affected were two patients from southern Alberta had not met their surgeons prior to surgery and had little knowledge of their health status or surgical procedures; they simply knew they "needed bowel surgery".

Table 7

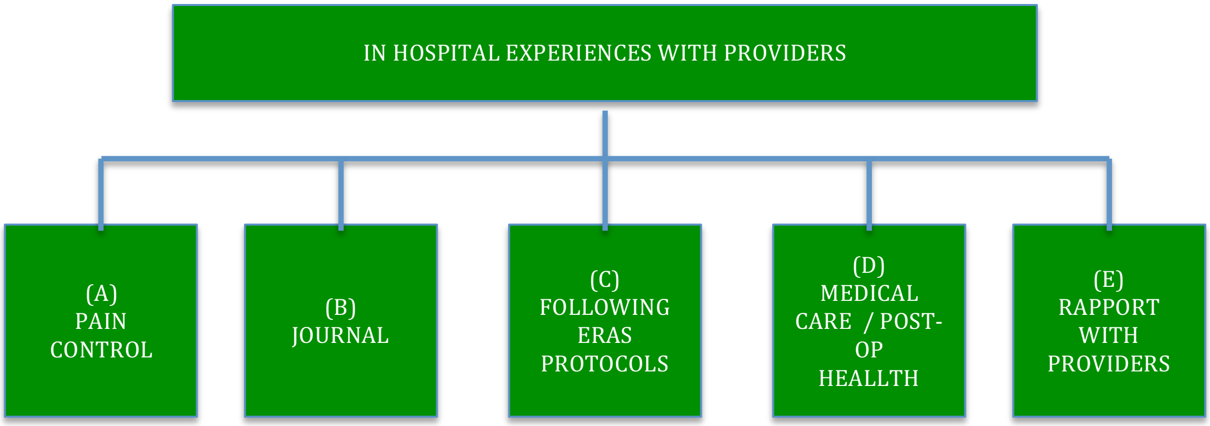
SUB-CATEGORY	EXEMPLAR QUOTES
Lack of information	**S142** They never told us what was going on. All they told us that there was a thing in there and it had to come out. There was a chance I'd need a (colostomy) bag. **S370** Pre-surgery I had lots of questions. Results from the scans, and all that, nobody would give me the answers. That was kind of stressful. **S373** I found out in the operating room in the morning…My wife and I had questions. What stage the cancer was and what they were going to do and no one would answer our questions because of the summer schedule. **S374** You should be able to get information**. (about diagnosis)** **S375** We were pretty anxious because we didn't have anything… (no information on diagnosis) **S485** Of course they did inform us about being fit but it was only 4 days before (surgery). **S487** If they wanted you to lose some weight they should be telling you. **CI7-190**) I race cars and stuff too, well how long do I have to wait until I can race my car. Well, you know the answer was very vague and I talk to one person and oh yeah you can't do that for a longtime and then I talk to another guy and they're like well, we're not going to be following you or something but wouldn't tell me if I'm allowed to do it or not allowed to do it. **M49)** I hadn't met the surgeon before I came in for surgery, but my daughter in law works in the OR at Brooks and she said he was a really good doctor. **EN 388)** I met with the specialist and he explained everything to me and about the team he was putting together (explaining why he went into surgery confident)

2. In hospital experiences with providers

A. Pain control

Most participants experienced some level of pain, especially during the first two days post surgery, but believed that providers did a really good job in trying to minimize the level to a three or a four on a pain scale. They perceived that there was a huge effort, including an increase in the pain medication dosage, to keep pain to a manageable level.

Figure 2



Many patients cited the nurses telling them they couldn't heal as well if they were in pain. One participant had a pain problem in the recovery room when her epidural did not work as expected and the nurse appeared to be surprised and a little disbelieving of her pain level on regaining consciousness. She did however receive medication to get this under better control.

The pain that surprised many participants was the high level of gas pain they experienced. These patients believed they should have been alerted to this possibility pre-surgery. A few patients had concerns about becoming addicted to the pain medication, but all except one patient eventually took the medication after providers explained that this was highly unlikely in their case. Those patients who had self administered pain medication appeared to feel good about having some sense of control over their pain medication and were less anxious than patients who were relying on providers to administer the drugs. A few patients feared falling asleep in case their nurse forgot to bring the medication at the appropriate time.

While there were isolated incidents when patients perceived their pain was not being managed, these were short lived and there was a general consensus that providers were highly invested in keeping pain to a level that all patients could manage.

Table 8

SUB-CATEGORY	EXEMPLAR QUOTE
Pain Control	**2**) I think there should be some pre surgical teaching about the air (gas) **3)** I had to hiccups for six days and I to think that they should have teaching pre surgery teaching about that air (gas) **23)** Everything seemed to go well and I had very little pain.

	I lifted up my shirt and saw my stoma and ostomy bag and knew that I was stitched up in my old back end but I had very little pain. **133)** when they decided to take my PCA pump off they should have given me my oral medication before they took it off. The pain hit me like a ton of bricks. I was gasping for air I was in so much pain. **EN 420)** When they put me into a regular room they took the epidural out and I was fed pain relief constantly by an IV. I never had any pain of any kind. **CI8-308)** I very rarely used the pump (for pain meds) and the morphine pump and I took very very little, I don't think that after day 2 I took any pain relief at all, I don't think that I needed it. **S7** Oh yeah. I've got this…(click, click)It's self-control. They don't want pain to go over a four. **S168** Yes. They told me about the importance of pain control **S329 (partner)** She doesn't want to take the oxycontin or pain medication as she has been told by someone she can get addicted. This is why I want her to take the medication that they are giving her here because they know what they can do and it is controlled healing. **S336** My pain is awful, not stabilized. It's 8-10. (pain level) (Nurses and spouse encouraging her to increase pain medication) **S364** They've been keeping me within their set goal of 3 or lower which is good. I've had a couple times and got uncomfortable. I spiked yesterday but it has improved every day. **S622** I remember coming out of surgery. I had had an epidural and they said what is your pain level?…my eyes were closed and I had no idea who the nurse was and I said eight. I could feel that she (nurse) didn't believe me, I could feel it (nurse not believing me) even with my eyes still closed…she says what's your pain level and I said it (eight) again.

B. Journal

Patients' use of a journal to track mobility, nutrition, breathing exercises, gum chewing and urinary output varied from no knowledge of a journal to very strict adherence to providers' requests to record everything. Hospitals had different versions of the journal and had different levels of encouraging patients to use the journal. Many patients who were given a journal to complete daily did not see the point of the journal and explained that they were too tired or too busy fulfilling the ERAS expectations to fill out all their activities. A few patients said it was helpful, but most felt it was not useful for them. Those who did faithfully complete the journal tended to believe it was useful for providers rather that patients.

Table 9

SUB-CATEGORY	EXEMPLAR QUOTES
Journal	**24)** Nurses insisted that I start writing my journal up. **78)** The nurses were motivating but I didn't want to write in the book the journal I got my mom or girlfriend to do it. Writing in the book was not my priority walking around helps the bowels more. **81**) The nurses kept coming to make sure I have filled it out. This (filling out journal) could be a key to getting out I thought, so my mum and girlfriend filled it out **EN 200)** Maybe it (journal) was in that package that I was given…and I didn't even notice… **EN 310)** Yeah, I kind of used it. **434)** No I don't think so I was given a journal **CI7-36** For me I think it was for just to keep a record I think it was more for them than it was for me **CI8-121)** I think certainly likely post-surgery I was quite weak and was quite worried about the outcome and filling out the logbook was probably very very low on the list of my priorities **EN 97)** Yes..I was given a booklet. I have to be brutally honest with you, I didn't fill it out. **EN 201)** Nobody even asked me about it. (the journal)

C. Following Eras protocols

The patients who were most assiduous in following the ERAS protocols were those who were told that they were in an ERAS programme, had been told what to expect and why they were being asked to follow the protocols. It appeared that fully understanding the reason for what they were being asked to do helped patients try harder to follow the protocols.

Some patients who did have some understanding of the protocols, but believed they were too unwell or unable to follow them, told us that their providers were sticking to the protocol without taking into account their physical health. They believed that their providers did not have enough knowledge of the protocols to make informed medical choices. Patients in all hospital sites apart from one in Calgary said provider knowledge appeared to be provider dependent rather than an overall culture within their unit. The uneven nature of providers' ability to be flexible and helpful around the ERAS protocols appeared to engender some anxiety around the protocols.

Most patients found the nutrition protocol the most difficult to follow as they were often nauseous or became anxious if they did not have a bowel movement and were encouraged to keep eating. The only vegan in the study found to ERAS post surgery diet did not provide food that she could eat. Only one patient in the study who was 89 years old and had mobility problems found walking a problem.

Patients liked the concept of being part of team that was invested in their speedy recovery rather than being told what they should be doing. The patients appeared to be more trusting of the providers who engaged with patients around their recovery. Being treated as an individual who was doing his/her best and perceiving that providers were not simply following rules allowed patients to invest more effort into following the protocols.

Table 10.

SUB-CATEGORY	EXEMPLAR QUOTES
Following ERAS protocols	**EN 430)** I think it probably would help to let them (patients) know that the biggest part is what you do, not what everyone else can do. **87)** The nurses and doctors were pushing me to eat. I did not understand how important it was to eat as soon as possible. I thought the body needs healing. I pushed through it but was very weak. I was trying to get my strength back. I was scared - it was nothing coming out, there were no bowel movements. They gave me Senakot but didn't listen when I told them that I usually take Metamucil three times a day. **115**) Some nurses just seem to follow the protocol and are not interested in what you are telling them about feeling not well or not having had a bowel movement **EN 38)** Every day after that I knew what was recommended up to four times a day, walk around my ward. I had a number of family and friends in to visit me…to heck with this let's do some laps. I did quite a bit of walking, some days were easier than others but I knew this is what you have to do.. **EN 202)** They have this program but to be honest with you I'm wondering how many of the staff in the unit even understand the program. **103)** Well, I think it would have helped from a mental standpoint if the nurses had talked more about ERAS. People (Patients) want to help and they want to have a sense of belonging especially in the hospital where you're recovering and going through a tumultuous amount of thoughts and again

	that feeling of belonging, hey we're on this ERAS program, this is what we found helps other patients… and it would help if you did this…that partnership, that team. **66)** By Thursday I was drinking, walking but nothing was coming through I had no bowel movement Friday afternoon four days after surgery I threw up. I was not in a colorectal ward (for my ileostomy) I was in a ward where everyone had jaw surgery – their jaws were wired shut, and I'm not sure the nurses knew as much as they could have. **S386** I ate the next morning. The doctor told me not to eat too much. it's (chewing gum) part of the (ERAS) **S388** I do deep breathing and coughing. Every hour I sit up…I'm up to 2000 right now. I do it ten times, wait the 3 seconds and then do it. It is useful. It (deep breathing and coughing) keeps the chest clear. I got off the oxygen a bit faster. **S237** I'm also very gluten intolerant. I'm vegan. It's a specific diet. This morning they (hospital kitchen) got the dairy and gluten thing but they sent me eggs. (vegan, can't eat). I did tell the nurse so hopefully lunch will be better. With my last surgery, my first meal had a big cup of milk and instant mashed potatoes which I'm sure had milk in it. I couldn't eat any of it. (hospital dinner post-op) It hasn't been a very good experience. **S406** They gave me some gum. I've been chewing it. I've gotten up and walked last night. This morning I was up and did a lap. I got up and ate breakfast in the chair. Then I actually did another two laps. Yeah, to get rid of the gas and lessen the risk of blood clots. (reason for getting up and moving asap.) **S679** I did it (used breathing machine) but didn't know why. I think people would be more diligent if they knew why the walking was so important, why the protein was so important… **S698** (age 89) They want to get you up and get you walking. Well, I had bad knees that when the doctors had time, I needed knee surgery. It just didn't work out for me…all the walking. I tried to walk as much as I could but I don't think it was enough to satisfy them. **S704** I had a catheter on and I had a little bubble on and they still want you to move with that. I don't know but it seems to me that there could be a better way to handle that than the way they were doing but that's just my view. (getting up post op) **S212** I sat in the bed and I had the thinnest sheet I'd ever seen.

	But I've been in hospital enough to know that they have a room with warm blankets so I sent him (partner) and he got me about 4 by the time I went into the OR. Yeah, the nurses weren't really around at all. (pre-op wait) **EN 374)** they came in and knew what they were doing, they told you what they were doing… you were a team working together…you had a lot of confidence in them… **13)** I don't know if it was part of the ERAS program. One thing I was just thrilled about, after I was admitted they gave me a gown. When I hopped up onto the gurney there was what looked like a vacuum cleaner hose. I wasn't quite sure what it was. This hose was attached to my gown and all of a sudden inflated my gown with really warm air. This is great! It was super comfortable. **EN 41)** That's what we did anyways but nobody gave me any direction that way… It would have been beneficial to be told that I could eat whatever I want. I wasn't told that, they just never said anything. I took that as okay. **EN 297)** I wasn't clear on the instructions…(re foods to eat). I think that could have been handled better on the instruction part… (in hospital)

D. Medical post-operative care

Although most patients reported an uneventful recovery in hospital, several patients discussed concerns they had with their post-operative care. These included lack of information around biopsies or post surgery status, inconsistency in information sharing between providers at shift changes, perceived mismanagement of nasogastric tubes and an inability to have a conversation with the surgeon. They stated that these issues caused undue anxiety and may have impeded their recovery time. Most of the patients concerned about biopsy results were not told that it could take some time to get the results. Those who were aware of this were less worried.

In addition three families told of their anxious waits to get information regarding their relative many hours after their expected arrival in a unit. Others related how well they had been kept informed and some were allowed into the recovery room when the patients were taking a longer time than normal to recover from the anesthetic .

Table 11

SUB-CATEGORIES	EXEMPLAR QUOTES
Medical post-operative care	**EN 397)** the next morning one of the specialists came down to my room to see me and met me in the hallway and he said "Oh my God! What the hell are you made out

	of?" I said "Something good!" He says "I expected to see this 3 or 4 days from now, not this morning!" So they couldn't believe how well I came out of that surgery… **EN 411)** I was only supposed to be in for 2 weeks but my bowel didn't want to work. That's why I was in there for so much longer. It's got to do its thing on its own. It's just a matter of time. They just kept monitoring it. They gave me laxatives and stuff so hopefully it would start up. **CI8-86)** There was one other post-operative issue I did have, a small amount of bleeding which concerned me greatly, I was wondering was I going to have to go down to surgery again .That was, I found, very worrying. It was difficult in that you know that I found the communications aren't as good on turnover of the nursing staff . (I found this) to be poor. One nurse would be monitoring that very closely and then making notes for the doctors and that, and then maybe the next (nurse)you'd have to start explaining all over again Try to get your concerns and your fears, communicated to them, I found that a little bit frustrating **CI8-276)** the fact that I was kind of bleeding the one nurse was quite concerned an she said well let me have a look every time you go and I'd press the bell and she might or might not come. And then another would have no interest whatsoever in looking at **M30)** Dr __ said when he came out of surgery that he had got all of the tumour. I want to know more. **S60** I want to find out how bad this cancer was and if it has travelled around. We haven't heard any of that. (test results) **S314** So, I didn't know what was happening to ______(partner) in recovery **S377** I don't know about the oncologist from the Tom Baker. We have to go see one even though they said that they removed it all so whether it is for follow up, I don't know. Just to question why. That was the only thing that was really creating anxiety was the not knowing. That's exactly what it is. Lack of power…It's got to be more transparent. I just want to know. I'm a grown adult. I have the right to know what's happening even if it is terminal. I need to know. **S527** I went down to recovery and couldn't get in and nobody would tell me where my husband was. **100**) The space between surgery and bowel movement was four days and all the time I was filling up my stomach

	and it was not good. I eventually vomited really badly. I think they should put a tube down your nose during surgery. I think this would be helpful **CI8-21**) The only negative part of my stay is that the NG tube wasn't monitored properly. After one day it had blocked I started vomiting quite badly with the NG tube in place which was not good. That was when, really my only complaint about the care that there was post-surgery **M22)** We haven't seen a doctor. The only time I've seen a doctor was when we were in the waiting room and he told us Dell had made it through. **S46** I haven't seen a doctor except for when we were in the waiting room and PLC4 was in surgery and they told us he had made it through the surgery. PLC4 saw him yesterday.

E. Rapport with providers (nurses).

Apart from one hospital, patients reported that good rapport or relationship with the nursing staff was provider dependent. Some nurses were really good at informing and supporting patients as individuals, others were less attentive or interested. Some patients perceived that, as discussed above some nurses were more focused on patients following the ERAS protocols that what was happening for the patient.

The exception to these experiences was the site for the in hospital interviews. As well as the patient accolades for the nursing staff we recorded, the researcher (an experienced surgical patient) observed and noted many supportive patient – nurse interactions where staff took time to listen and respond to patient concerns. The overall atmosphere was markedly friendly with staff encouraging patients who were walking the halls no matter whose patient they were. Those patients who were re-interviewed three weeks after they left hospital reiterated their positive experiences.

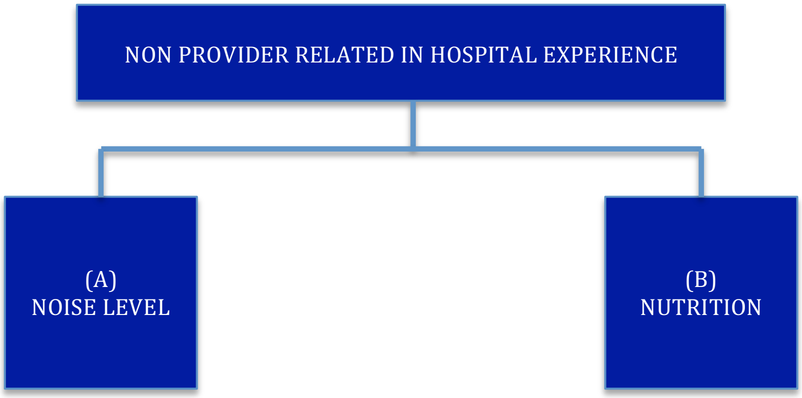
Table 12

SUB-CATEGORIES	EXEMPLAR QUOTES
Rapport with providers (nurses)	**24)** Nurses insisted that I start writing my journal up and pushed me to get up eat and drink **112)** The shift changes were difficult. You did not know if you would get the good nurse or one that was bad **115)** Some nurses just seem to follow the protocol and are not interested in what you are telling them about feeling not well or not having had a bowel movement

	EN 277) They were helping me, encouraging me, providing (for) me… It was a partnership. **M20)** The nurses have been very cooperative, they listen to what you have say. They ask a lot of questions, "are you sore?" They are probably the best nurses I've had around me. I know they are listening because when they come back in a little while the say so how is it now and they keep checking M45) The nurse was very good because he was in recovery for about five hours because he couldn't stay awake. We waited and waited and no-one told us anything so we went and asked they said he was okay but couldn't stay awake and we were allowed to go in to see him, **S125** They (nurses) are very congenial. They (nurses) have your best interests at heart for the most part. **S126** Everybody has a day or a moment. They (nurses) are human beings not human doings. **S264** The person there wasn't my anesthesiologist… but they care and that they are interested in my health and as professionals they don't just treat me as a little chart or a little number. **S265** They (medical staff) care about me as a human being, which was nice. **S344** Everybody has been just wonderful. I haven't had a complaint. **S392** Just beautiful. Very nice. (care and help from hospital staff) **S520** The nurses have been absolutely excellent. As a spouse…the nurses have been exceptional.

3. Non provider related in-hospital experiences

Figure 3



A. Noise level

Most of the participants complained that the noise level in hospital made it difficult for them to sleep even at night. They questioned whether this negatively impacted their recovery. They also wondered about the necessity to have blood samples taken in the middle of the night or very early in the morning. All said they were happy to be home and able to sleep without interruption.

Table 13

SUB-CATEGORY	EXEMPLAR QUOTES
Noise level	**40)** There is a terrible noise level in hospital I could not sleep. The noise echoed everywhere **82)** I couldn't sleep it was so noisy I think they let me out early because I was so exhausted **103)** The noise level from the other patients was not good. The beds were too close together. I had an IV pump constantly going off in my ear **104)** There was too much noise from the other patients in other rooms **105)** The noise is like being in an anthill **106)** People were going to the bathroom nonstop I don't know if it's better to be furthest away or closest to the washroom **107)** The noise was horrible **CI1-66)** One thing I did have a hard time sleeping…my roommates were loud and up all night, complaining…I put on my headphones…did meditation…block it out. **67)** You're getting your vitals taken every four hours. Calgary Lab Services in at 3:30 in the morning to take your blood. Your breakfast delivered at 7:30. So it's incredibly hard to sleep **EN 294)** I didn't like them waking me up at 5AM to take my blood pressure…Can't it wait until 7 but knowing nursing… **S972** Yes, I was ready to go home because I needed sleep. You don't get a lot of sleep in the hospital.

B. Nutrition

Most patients found the hospital food unpalatable and some would have preferred some guidance about appropriate food for relatives to bring from home. Patients who had been warned about the low fibre diet appeared more forgiving, but as noted above, options for gluten intolerant, vegetarian or vegan patients would have been appreciated. A few patients noted, that while they could and felt like eating nothing was available as they had recovered from surgery after the last mealtime .

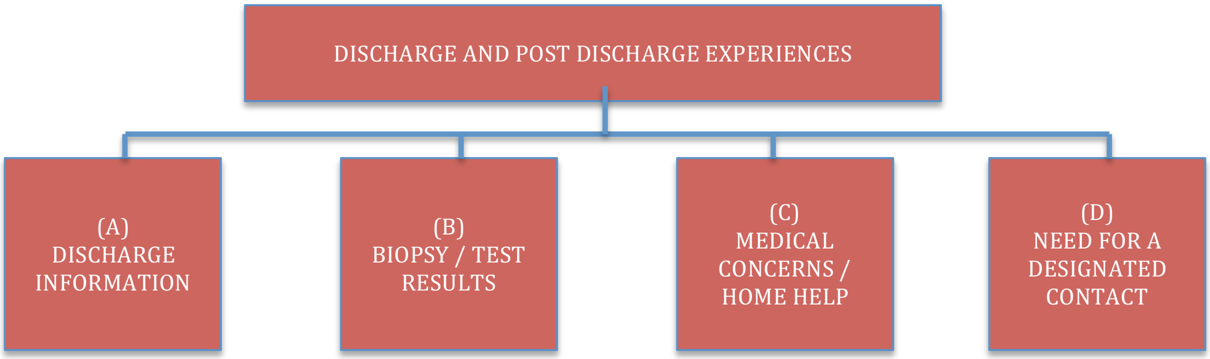
Table 14

SUB-CATEGORY	EXEMPLAR QUOTE
Nutrition	**91)** I lost 19 pounds. Since I'm underweight anyway, the weight loss was very significant for me. I'm now on a diet to gain weight **94)** You want to eat, but the food is really bad. The options are not huge, I'm not used to eating white bread. The sandwich meat in hospital was a bummer. You are used to eating healthy and they're feeding you unhealthy foods. But they did explain this to me pre-op. I managed to eat everything except the white bread. I ate because it was medicine and it would help me get better faster **25)** What I found helpful was to drink a lot of water. I went through a lot of water. **EN 40)** My daughter started to bring in some food which was so enjoyable. **EN 282)** They brought me white bread after the surgery… with a hunk of hard cheese in and no butter…can you think of a better way to get constipated without the surgery? **EN 28)** I was given it before I ate I think. (Ensure).It is really beneficial… mainly to compliment the meals.. The hospital gave me Ensure 5 times a day. The first couple was okay but when you are given it 5 times a day it becomes a drain on you.

4. Discharge and post discharge experiences

As participants associated their at home post surgery experiences with the level and quality of information they received at discharge we have coded the information under one category with four sub-categories

Figure 5



A. Discharge information

While a majority of patients believed they had adequate discharge information, some participants raised three major concerns which had not been fully explained; bleeding from the rectum, variation in bowel movements and diet. Mixed messages and differing provider advice also caused confusion for some patients. All of these issues caused varying level of anxiety for patients' management when home.

Table 15

SUB-CATEGORY	EXEMPLAR QUOTE
Discharge Information	**CI7-142)** that's the biggest thing that I noticed afterwards is that the bowel movements are different to compared to what they were and that was obviously still a bit of a shock that, we weren't expecting and things like that, it took a like time to get even close to a normal one and even now which I do find weird is that when you do pass gas or something like that is that the smell is terrible compared to what it used to be and none of that was explained, no nothing **CI2-126)** The surgery itself was actually a huge success but they didn't warn me about the number of accidents that I might have or things like that. From what I hear it is fairly common with a lot of people and that wasn't discussed at all… The fact is when you have a bowel surgery you don't go back to square one again. **S780** Dr. ____'s office mentioned that they (hospital) should have told us about that (post op rectal bleeding) in this case when they discharged you. **S781** When she came out of the bathroom and said that she was bleeding and I asked where and she said from the rectum. I told her that shouldn't be as everything is coming out through the stoma. We did go into a bit of panic that night. **S768** They should mention that (post op rectal bleeding) to patients when they leave the hospital so if you find that you

	are bleeding from your rectum it is quite normal to begin with. That is something that is not being told. **S957** Actually she (dietician) did come and said you can eat what you want. I thought no, this isn't right. (Then the stoma nurse) said yes, you can start adding stuff (diet post-op) but you have to be careful because you don't want a bunch of fibre yet. It was interesting because I asked the dietician about Metamucil because I had read about it, and she said that you're not going to need that. So, I asked one of the doctors, and he said Metamucil is your friend. **S965** The take home sheet that I had, it did say eat more small meals and make sure you drink a lot of water. Things like that. Helpful hints. I wanted more detail than that. **S978** The one thing that they should be telling people, I read this after I got home on a UK website, a paper written about reversals (I bent down to get something off the floor, and oh my Gosh! that hurt!) that said that you shouldn't been bending for 6 weeks. And I thought "Really?" Nobody tells you that. **S1013** Yes, I think we need to go home with more information. With me, the bag kept leaking but I had stoma nurses to go and see. **S802** I don't feel that they gave me much information about what to expect. (post op). What is normal or not normal…I experienced a little bit of bleeding. I was kind of concerned about that. It took the nurse (surgeon's office) quite a while to get back to me on that too. **S994** So when somebody said that it (controllability) should only be a couple of days because your sphincter wasn't affected. Then another doctor said it would be a couple of weeks and one of the stoma nurses said you should be fine, a couple of days…one doctor said a couple of weeks and another doctor said a couple of months. Well, this didn't help.

B. Biopsy and test results

Most patients did not have biopsy or other test results before leaving hospital, many not understanding the time necessary to review and report the results. Those most unhappy with not knowing had to wait six to eight weeks for their surgical follow up appointment to receive the results. This was a major anxiety that might have been avoided if the results had been available to the patients when they were sent to the surgeons or physicians. One participant learned his biopsy results when the Cross Cancer Clinic called to make an appointment with him. Participants believed that this worry negatively impacted the speed of their recovery.

Table 16

SUB- CATEGORY	EXEMPLAR QUOTE
Biopsy and test results	**42)** Huge shock when a call came from the Cross Cancer Center for me to start chemo. My surgeon had not given me the biopsy results I did not hear this from my surgeon **108**) I did not get my pathology results in hospital. I called the surgeon eight times but I did not get my pathology results until I had an appointment that was the follow-up six weeks later **109)** I was told I would be given the results as soon as possible **110)** I had the same experience waiting for six weeks. It's stressful **S709** You know, I still don't know everything yet and I'm home (full post op info about tumour)

C. Medical concerns and home help

Several participants had medical concerns such as problems with the incision, which caused anxiety as there was uncertainty about the best service to contact. Even the few participants who had needed and received home help believed that their home help had not received enough information from the hospital to be able to adequately support them.

Table 17

SUB-CATEGORY	EXEMPLAR QUOTES
Medical help and home help	**CI 179)** After I got home my incision broke apart in several spots so I had that to contend with for several weeks afterwards. I didn't get an infection because I know how to take care of that. My family doctor kept an eye on things for me…I thought they should have left my staples in a full 10 days and gave me a staple removal kit which they do at post- partum …and they go to their own doctors and have them taken out. They should do the same thing post- surgical or you come back as an outpatient into one of the clinics. **CI 181)** Part of mine was that my skin integrity wasn't very good so it separated within a couple of days…that

	is something that should have been thought about a bit more. **CI8-227**) (the wounds caused anxiety) yes, it did because I had a neatly stapled incision and then they popped a couple out and opened up the wound again and ohhh, this is not going in the right direction and I was quite anxious because at one stage I had transitioned from the nurse support coming into my home everyday to dress it to then coming in every second day and I was worried about infection and all of that. **S79** I had to call my surgeon. I wasn't sure that things were okay. I was in a lot of pain and different issues with the complication and everything. It took a lot of time for my surgeon's office to get back to me. It took a couple of days to get back to me. That was a bit frustrating. There was a little bit of anxiety. (waiting for surgeon to call back) **C18-245** Because you see when the public health nurse comes in she is just looking at an incision and that's it. What happened inside is of no concern or how you're getting on post-surgery is of no concern It's really only 'I'm here to dress your wound'. **S738** The home care knew that I'd had an operation and that I had a bag on and that had to be looked after but they didn't tell them that I'd had rectal cancer and that I still have some stuff coming from my rear yet and they don't know how to deal with that at all. I don't think they (home care staff) got the information that they needed to know what to do.

D. Need for a designated contact when patients go home

In light of the participant experience outlined above, many patients believed that it is necessary to provide them with some alternate contact than surgeons, physicians or Health Link to have their concerns addressed. Many hesitated to call their doctors' offices, especially about diet and what to expect around bowel movement and those who called around incision and bleeding concerns usually waited up to two days to have their questions answered. There was consensus that either a professional or experienced patient volunteer who either knew the answer or where to direct their concern would be an ideal resource for patients managing their recovery at home.

Table 18

SUB-CATEGORY	EXEMPLAR QUOTES
Need for a designated contact	**74)** It seems to end.(referring to no ERAS connection after going home) **EN 85**) but I think we could do a better job of assisting the patient not just before but afterwards and just say aren't you glad that you went on this ERAS program?…I call it a no-brainer. **EN 184)** I do think that there should be a follow-up phone call about a week from that enhanced program itself not just your doctor…how are things going, do you have any concerns, do you have any questions…you have someone to talk to… **EN 185)** I didn't really know what to do with this incision splitting apart…I went on the internet to find out what to do…I was doing everything right but it still concerned me, I was scared…I thought the whole thing would split open… **EN 252)** For me on a personal note, I would say no. (ERAS follow up) I think I was okay with it…but I do see the value of it…it can be scary. **EN 255)** I kind of wanted…when you were talking about checkups…I don't have anyone to call to see how I'm doing, if I'm okay… Yeah, I would have like that. **EN 358)** Yes it would have been helpful…(post discharge follow up) just to check and see how you were doing. **EN 359)** I did phone (the dietician from the ERAS group about certain things I could eat. I wanted to check with her and find out how you can do that. **EN 360)** Yes, when she had the seminar, I got her contact number and kept it. I phoned her to ask about eating skin and when I could go back on my regular diet. She asked about my bowel function and if I had any pain. That was great. I saw my surgeon in the meantime and that was okay. I felt more comfortable talking to her than the surgeon.

	CI8-212) Once you're discharged from hospital you are on your own… "You could spring a leak from your head and not have anyone to call!!" That's what I found that once you were discharged from hospital you were pretty much on your own! **CI8- 219)** I found that waiting for my follow up and that appointment with the surgeon that I had tons of questions **CI8-245)** The only thing is that once you leave hospital I think that some form of connection there. You know, you do feel a bit vulnerable and I was kind if terrified. You know when you look in the toilet and there's blood there. I was very very afraid of a rupture really or something like that The prospect of having to go back to the theatre again was just horrendous… When you do leave hospital you're literally cut off, and even for 3 days if you were to get a phone call Or something like that from the hospital to say 'How are you doing today?' It would give you more confidence **S796** It would be nice if they would continue care for a little while afterwards or if there was a different person that you had access to. **EN 186)** What they said was if you have any issues, call and go to Emerg but that's not helpful because you don't want to sit there for hours and hours. **S1009** I think having an ex-patient as contact post-op would be great.

Discussion

Participants in this study agreed that an ERAS programme should not be confined to the in hospital experience and believed such a programme should begin at diagnosis and be in place throughout the "waiting for surgery" period, the in hospital stay and continue post discharge until complete recovery has been attained. They believed that the most critical period for continued postoperative support (in the form of a designated contact) was between post discharge and their first surgical follow up visit (usually six weeks post surgery). These views are supported by Aasa et al. (2013) and Sibbern et al (2016) who cite the need for preoperative preparation and Blazeby et al. (2010) and Bernard and Foss (2014), who recommend post operative "at home support". The preoperatively well informed patients in our study, whether informed by surgeons, nurses or a preoperative class, experienced less anxiety, had less fears about surgery and some took the time to extend their knowledge through research and "get fit" for surgery. Patients, with the exception of two participants who chose to do their own ERAS research, after being introduced by their surgeons to the concept, believed that their emotional and psychological wellbeing was ignored between diagnosis and surgery. They described fears, anxiety, depression, worry about their families and work, that they experienced during the waiting period. They believe these had adversely affected their pre-surgery health. Almost all of the patients in the study believed that discharge information was less than what they would have liked and that they needed a contact phone number to discuss any concerns that had arisen.

The findings in the Sibbern et al. (2016) systematic review of eleven qualitative studies of patient experience with ERAS are reflected in this study. Most patients believed that they did not have enough information about ERAS. The wanted to understand why they were being asked to follow certain protocols and confirmed that they would "try much harder" if they knew the benefits that accrued from following the protocols diligently. Our findings about provider/nursing bedside care indicated that the participants who did experience "individualized care vs standardized care" were more likely to conscientiously follow the protocols, even though they may have lacked complete information. They told us that being listened to and treated like an individual not a chart made a huge difference in their journey to recovery. Some patients who were very sick post operatively felt that they were pushed too quickly into a rapid recovery mode and that the expectations were too high. These patients did not appear to experience any individualized care and perceived that they were somehow failing. "Security at discharge" varied among our participants. Most wanted to go home as sleeping was difficult as a result of the noise level (Vandrevala, 2016) and they found hospital food unpalatable. Feelings of security at home quickly disappeared if any symptoms such as rectal bleeding, which were fairly common, had not been identified as normal in the discharge information. Patients who had not received their biopsy results before leaving hospital showed more anxiety at discharge and this continued often until their six week follow up surgical visit. One patient learned his result when the Cancer Clinic phoned to make his chemotherapy appointment.

The participants in this study perceived they were going through a process or journey from diagnosis to recovery. The findings in the study indicate that there are four main areas in the current Alberta ERAS programme that patients believe could be strengthened to support them along this pathway: (1) preoperative support and information about ERAS (2) in hospital information about ERAS (3) Patient perception of empathetic, individualized nursing care (4) post discharge support and information.

(1) Preoperative support and information.

Few of our participants believed that they had been given adequate information and/or support during their preoperative phase (diagnosis to surgery). They perceived it was not enough to describe the ERAS protocols such as walking, chewing gum, protein diet etc., they believed that they would follow the protocols more assiduously if they understood the underlying medical reason for each protocol. We were repeatedly told "well if they had explained why they wanted me to walk, eat etc. I would have tried a bit harder". Knowing why ahead of time would have made acceptance easier. Patients also told us that they wished they had been warned at this stage that they would have excessive gas pain. Most of the patients encountered this and they had not been told about it.

Only two of our participants tried to "get ready for surgery". These participants exercised, altered their diet, and accessed psychological support such as cancer groups at a hospital, Wellspring, or individual therapists. They had followed up their surgical consult where ERAS had been talked about with their own research and had accessed available resources. Both stated that it would have been easier if they had been supported in finding these resources. The majority of the participants explained how stressed with fear and anxiety they had been during the wait for surgery. Many believed psychological help, help in dealing with family and work concerns and knowledge of calming aids such as meditation, yoga or Tai Chi would have improved their readiness for surgery. It should be noted that attendance at a pre-surgery class or pre-surgery interview with a nurse, while helpful, did not eliminate all the stress patients experienced.

Our participants noted a high level of gas pain for the first two days post surgery, which had not been mentioned in any pre-surgery education. As noted above they identified emotional and psychological stressors both per and post surgery. They would have preferred referral by their physicians to agencies or programmes that would alleviate these stressors and allow then to be fit for surgery and their recovery to progress.

Our findings correlate well with the systematic review of Sibbern at al., (2016), which uncovered that patients require time and support to practically and emotionally prepare for their surgery (Sibbern et al). Information provision is consistently cited (Lithner et al., 2012; Bernard & Foss 2014; Aasa et al., 2013) as an important means to prepare patients for surgery. Lithner et al., (2012) identified that patients require information to increase participation in their own care, facilitate the regaining of some measure of control, manage worries, and make their disease more comprehensible. A new field of research, known as prehabilitation, has begun to address these gaps. Prehabilitated patients are provided with personalized nutrition, exercise, and anxiety-reduction strategies four weeks before and eight weeks after their surgery. Prehabilitation investigations have reported a greater improvement in the functional recovery of colorectal surgery patients compared to the patients following standard ERAS care or even traditional rehabilitation (Gillis et al., 2014 & Li et al., 2013).

(2) In hospital information about ERAS

Almost a third of our participants, especially long distance or emergency patients, had no knowledge of the ERAS protocols. Some patients had heard the term but had no idea what was entailed, while others admitted that they had forgotten what they had been told. All patients agreed that an explanation of why they were being asked to follow the protocols was necessary as they struggled to try to follow such protocols as walking or eating. They were happy to hear a repetition of the reasons as they believed knowing and being reminded of the reason for attempting challenging activities would boost their enthusiasm to participate. They saw the explanation as an invitation to be part of a team or collaborative endeavour rather than a "being done to" chore. These findings concur with Sibbern et al. (2016), and Aasa et al., (2013) who found that patients are motivated by the idea of being an "active participant" in their recovery, and that an understanding of their role as participants in their own health recovery was influenced by the expectations and rationales provided by their bedside care providers.

(3) Patient perception of empathetic, individualized nursing care

Patients from most of the hospitals told us that one of the major stressors in hospital was the nursing shift change as they never knew if they would "get the bad nurse or the good nurse". In their eyes "bad nurses" did not listen to them, pushed too hard no matter how ill they were feeling, appeared to care only about fulfilling the protocol demands and seemed inflexible, while "good nurses" listened, encouraged and helped them through the ERAS protocols. We had patient stories of being pushed to eat fairly large amounts for several days when they had no bowel movement and ending up vomiting profusely, in one case with a gastro nasal tube inserted. Some patients perceived that the most inflexible nurses had not received adequate training in the ERAS protocols as they seemed to enforce them without reference to patient health and any complications that might be present. Comparably, a study by Norlyk & Harder (2009) identified that the absence of personalized support was viewed by some patients as a "top-down" approach, which was perceived as impeding their recovery.

While patients encountered both "good nurses and bad nurses" in four sites, our data showed that one hospital unit had no reports of "bad nurses" and there appeared to be no fear of the shift change. The patients from this unit consistently told us that the nurses listened to them, always came back in a timely manner to check up if there had been a concern, encouraged them to follow the protocols but were not overly insistent. This meant the patients tried to follow the protocols and most told us they actually challenged themselves to do their best. We heard these nurses care; "they will sit down and listen and talk to you rather than hovering as if they wanted to leave and if you are feeling awful or vomiting they will stay with you." One patient who had a lot of surgical experience summed it up: "these are the best nurses I have ever had". It appeared that this unit had somehow developed a culture or community of caring which positively impacted the patients and their recovery. It might be useful to discover how this was developed and what keeps it in place.

One important aspect of patient care that was uniform throughout all five sites was the ability of providers to manage and control the patient's post surgical pain level.

We were consistently told that the nurses “try to keep the pain level at a three or a four” which was bearable. We had only one patient who complained of enduring a pain crisis and this patient was not in a colorectal ward.

Not mentioned in the available qualitative literature was the high level of gas pain most of our participants encountered in the first two days post surgery.

(4) Post discharge Information and support

Most of the patients in the study believed that better discharge information was necessary. Many encountered situations where they needed helpful information about such things as nutrition, rectal bleeding, stoma care, stitches, and wounds. There was no detailed information given, and patients often saw their only recourse was to call their surgeons offices where response could take two or more days. All patients, whether satisfied with their discharge information or not, believed that they would like to have a contact they could call who would be able to answer questions and offer support. They saw the six-week follow up consult with their surgeons as failing to meet their needs as most of their concerns emerged during this period (before the consult). The need for greater postoperative discharge information and support has been well documented in the ERAS qualitative literature (Lithener et al., 2015; Blazeby et al., 2010; Bernard & Foss, 2015; Aasa et al., 2013).

Conclusion

The constant theme which appears to run throughout this study is: if you tell us why, help us understand what you want us to do we will be happy to do all we can. Patients’ perception that they are part of a team from *diagnosis to recovery* and have a major role to play will boost involvement in the already existing ERAS in- hospital protocols. Extending the precepts of enhanced recovery to the pre and post surgery phases in some of the ways suggested by our participants may pave the way for even better results.

Strengths and Limitations

This study was conducted through all phases of the research by patients (two with familiarity with accelerated discharge) who had experienced major surgery. Recognition by participants that the researchers shared their experiences of having to wait for elective surgery, undergo extensive surgical procedures and follow accelerated discharge protocols may have allowed participants to openly share their lived experience at a deeper level than would have been possible with “traditional” health care researchers. There was no perceived power imbalance and both researchers and participants were focused solely on patient concerns and perspectives (Gillard, Simons et al., 2012; Berger, 2015). The direction of the research was driven by the patient participants as co-design partners and they were an integral part of the analysis process (Marlett, Shklarov et al., 2014). We engaged with 27 ERAS patients form 5 hospitals in Alberta, a large sample for a qualitative research project and the data is authentic, thick and rich. Saturation was reached after the sixth in-hospital interview, but we decided to continue with our remaining six scheduled interviews to enrich the data.

Transferability of the findings may be limited as the participants were all from the same large healthcare system (Alberta Health Services), so there may be differences of experience and ERAS service delivery within other systems. While we attained diversity in age, gender, and home community, all of our participants apart from one were Caucasian. Participants from different cultural, ethnic and socioeconomic groups may have different lived experiences and further research is recommended.

Recommendations

1. Fully explain every protocol and the purpose of the protocol to the patients both before surgery and while in-hospital so that they can become knowledgeable partners in their recovery
2. Extend ERAS programme to the pre- surgery phase (between diagnosis and surgery) so that patients can be ready emotionally, psychologically and physically for surgery.
3. Extend the ERAS programme to the post surgery recovery at home phase to avoid stressful situations for patients and families
4. Consider activating a volunteer programme where experienced patients can be available for conversations with new patients.

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