Does patient engagement matter in surgery?

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THESIS FORMAT

This thesis is presented in a manuscript-based format and includes 3 distinct manuscripts which have either already been published or are being submitted for publication. The first manuscript is a retrospective observational cohort study that has been published in *Surgery*. The second manuscript is a prospective cohort study that has been published in *JAMA Surgery*. The third manuscript is a Rasch analysis that will be submitted to *JAMA Surgery*.

The thesis includes an Introduction (Chapter 1) and a Discussion (Chapter 5), as well as short preambles connecting one manuscript to the next. There will be some degree of repetition, as expected due to the format of the thesis, however this was minimized. Please note that each manuscript (Chapters 2.2, 3.2 and 4.2) was formatted to the specific journal requirements and has its own reference list and associated Tables, Figures and Appendices. The master reference list compiled at the end of the thesis in Chapter 7 pertains only to the Introduction and Discussion chapters.

CONTRIBUTIONS TO ORIGICAL KNOWLEDGE

The work presented in this thesis represents original contributions and adds to the body of knowledge on patient engagement in surgical patient populations. This work highlights the correlation between clinical and patient-reported outcomes in patients undergoing surgical interventions, and how patient engagement impacts those outcomes. It also assesses the validity of the tool currently available to measure patient engagement.

While I have received support from my supervisor and committee members, and input from co-authors for each study, the data presented in the following chapters represents my original work.

AUTHOR CONTRIBUTIONS

I have made a substantial contribution to all the individual manuscripts contained in this thesis. I developed the original research questions in collaboration with my thesis supervisor, Dr. Liane Feldman. I was responsible for defining the thesis objectives which were approved by my thesis committee. With the guidance of my supervisor, I developed the study design and methods, and performed the data acquisition, data analysis and drafting of the manuscripts in collaboration with the co-authors.

The contribution of individual authors of each manuscript in this thesis is described below:

1. **Dumitra T**, Trepanier M, Fiore Jr JF, Kaneva P, Carli F, Fried GM, Feldman LS, Lee L. The relationship of two postoperative complications grading schemas with postoperative quality of life after elective colorectal surgery. *Surgery*. 2019 Oct;166(4):663-669.

   Study conception: Dumitra T, Feldman LS, Lee L
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2. **Dumitra T**, Ganescu O, Hu R, Fiore Jr. JF, Kaneva P, Mayo N, Lee L, Liberman AS, Chaudhury P, Ferri L, Feldman LS. Association between patient activation and healthcare utilization after thoracic and abdominal surgery. *JAMA Surgery*. 2021 Jan 1;156(1): e205002.

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LIST OF TABLES AND FIGURES

LIST OF ABBREVIATIONS

ASA	American Society of Anesthesia
BMI	Body mass index
CABG	Coronary artery bypass graft
CCI	Complication Comprehensive Index
CI	Confidence Interval
CIHI	Canadian Institute for Health Information
CLSC	Local Community Service Center
DIF	Differential item functioning
DSQ	Dossier Santé Quebec
ED	Emergency Department
ERP	Enhanced recovery program
HRQoL	Health-related Quality of Life
IBD	Inflammatory Bowel Disease
IQR	Interquartile range
LOS	Length of stay
MCID	Minimal clinically important difference
MCS	Mental component score
MGH	Montreal General Hospital
MUHC	McGill University Health Center
PA	Patient activation
PAM	Patient Activation Measure

PCS	Physical component score
PF	Physical functioning
PRO	Patient-reported Outcome
PROM	Patient-reported Outcome Measure
PSI	Person separation index
QHR	Quebec Health Record
QOL	Quality of Life
QUAID	Question Understanding Aid
RCT	Randomized Clinical Trial
RVH	Royal Victoria Hospital
SD	Standard deviation
SDM	Shared decision making

ABSTRACT

Patient engagement has emerged as a fundamental component of patient-centered care. Multiple studies have demonstrated an association between higher levels of patient engagement and improved clinical outcomes, higher patient satisfaction, lower health system utilization and lower costs. Furthermore, it may be a modifiable risk factor. However, there are large knowledge gaps regarding the role of patient engagement in surgical patients and its association with postoperative clinical and patient-reported outcomes (PROs). Therefore, the main objective of this thesis was to estimate the impact of patient engagement on postoperative outcomes in patients undergoing major abdominal and thoracic procedures.

Prior to undertaking this, it was necessary to first understand the relationship between clinical outcomes and patient reported outcomes. Recent studies suggest that healthcare professionals, payers and patients may value clinical and patient-reported outcomes differently. While clinical outcomes are traditionally reported, there is interest in the use of PROs to provide additional targets for quality improvement. A retrospective study of the impact of postoperative complications on health related quality of life (HRQoL - SF-36 scores) was performed. The study included 402 patients undergoing elective colorectal surgery. Patients with complications had lower physical and mental component scores at 4-and 8-weeks postoperatively compared to patients without complications ($p<0.05$). The Comprehensive Complication Index was found to more accurately reflect the impact of complication severity on HRQoL when compared to the Clavien Dindo grading scheme.

The main study was a prospective cohort of adult patients undergoing major elective and emergency abdominal and thoracic surgery over a two-year period. A total of 653 patients were included. Patient engagement was measured in the immediate postoperative period using the

Patient Activation Measure (PAM) questionnaire. Postoperative outcomes were assessed up to 30-days after hospital discharge. Low patient engagement was an independent predictor of unplanned healthcare utilization (OR 3.15, 95% CI 2.05-4.86; $p<0.001$), emergency department visits (OR 1.64, 95% CI 1.02-2.64, $p=0.04$), complications (OR 1.63, 95% CI 1.11-2.41; $p=0.01$) and length of stay (adjusted mean difference 1.19 days, 95%CI 0.06-2.33; $p=0.04$). However, low patient engagement was not associated with a higher risk of readmission ($p=0.90$).

The PAM questionnaire is currently the only tool supported by high-level validity evidence available to measure patient engagement, but it was developed and validated in patients with chronic medical conditions. Therefore, the validity of PAM in surgical patients from the main study was tested using a Rasch model, a modern psychometric technique to analyze categorical data and guide development of more precise survey tools that measure latent traits. The original survey did not fit the Rasch model. Results were not affected by age, sex or education level. Targeting of items to people with lower ability was poor. Two response categories were combined due to low frequency of response. Two items were removed, one due to poor residual item fit and another due to potential local response-dependence. With these changes, PAM can be used in clinical practice to reliably measure patient activation in patients undergoing major abdominal and thoracic surgery.

In conclusion, evidence was provided to support the measurement of patient engagement in surgical patients and its association with important postoperative clinical and patient-reported outcomes. The currently available patient engagement measurement tool does not perfectly fit a Rasch model but may still be used in surgical patients in its current form to identify targets of intervention. Future research should focus on developing interventions to improve low engagement and how these interventions may impact postoperative outcomes and costs.

ABREGE

L'engagement des patients est devenu un élément fondamental des soins centrés sur le patient. Plusieurs études ont démontré une association entre des niveaux élevés d'engagement et de meilleurs résultats cliniques et utilisation du système de santé, une plus grande satisfaction et des coûts réduits, et peut être un facteur de risque modifiable. Il existe cependant de grandes lacunes dans les connaissances sue le rôle de l'engagement chez les patients chirurgicaux et son association avec les résultats cliniques postopératoires et rapportés par les patients (PRO). L'objectif principal de cette thèse est d'estimer l'impact de l'engagement sur les résultats postopératoires des patients subissant des procédures abdominales et thoraciques majeures.

Des études récentes suggèrent que les professionnels de la santé, les contributeurs financiers et les patients valorisent différemment les résultats cliniques et les PRO. L'utilisation des PRO pourrait fournir des cibles supplémentaires d'amélioration de la qualité des soins. Une étude rétrospective de l'impact des complications postopératoires sur la qualité de vie liée à la santé a été réalisée chez 402 patients subissant une chirurgie colorectale élective. Les patients avec complications ont eu des scores de composantes physique et mentale inférieurs à 4 et 8 semaines postopératoire comparés aux patients sans complications ($p<0,05$). L'Index Compréhensif de Complication reflète plus précisément l'impact de la gravité des complications sur la qualité de vie que le système de Clavien Dindo.

L'étude principale est une étude de cohorte prospective qui a recruté 653 patients adultes subissant une chirurgie abdominale et thoracique majeure sur deux ans. L'engagement des patients a été mesuré à l'aide du questionnaire de mesure d'activation du patient (PAM). Les résultats postopératoires ont été évalués jusqu'à 30jrs après la sortie de l'hôpital. Un faible engagement des patients est un prédicteur indépendant de l'utilisation non planifiée des soins de

santé (OR 3,15[2,05-4,86];p<0,001), des visites aux urgences (OR 1,64[1,02-2,64];p=0,04) et des complications (OR 1,63[1,11-2,41]; p=0,01). Cependant, un faible engagement des patients n'est pas associé à un risque plus élevé de réadmission (p=0,90).

Le questionnaire PAM est actuellement le seul outil disponible pour mesurer l'engagement des patients qui est soutenu par des preuves de validité de haute qualité. Cependant, il a été développé et validé chez des patients chroniques. La validité de PAM chez les patients chirurgicaux de l'étude principale a été testée à l'aide d'un modèle Rasch, une technique psychométrique moderne qui guider le développement d'outils d'enquête plus précis qui mesurent des traits latents. Le modèle original ne correspond pas au modèle de Rasch. Les résultats ne sont pas affectés par l'âge, le sexe ou le niveau d'éducation des patients. Le ciblage des items est mediocre chez les patients avec un engagement inférieur. Deux catégories de réponses ont été combinées en raison de la faible fréquence des réponses. Deux items ont été supprimés, l'un en raison d'un mauvais ajustement des items résiduels et l'autre en raison d'une dépendance potentielle à la réponse locale. Avec ces changements, le PAM peut être utilisé en pratique clinique pour mesurer de manière fiable l'activation des patients chirurgicaux.

En conclusion, nos évidences soutiennent l'importance de quantifier l'engagement des patients chez les patients chirurgicaux et son association avec d'importants résultats cliniques postopératoires et PRO. L'outil de mesure de l'engagement actuellement disponible ne correspond pas parfaitement à un modèle de Rasch, mais peut toujours être utilisé chez les patients chirurgicaux pour identifier les cibles d'intervention. Des recherches futures devraient se concentrer sur le développement d'interventions pour améliorer un faible engagement et sur l'impact de ces interventions sur les résultats et les coûts postopératoires.

CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

1.1 Patient-centered model of care

Since the 1990s, there has been a major transformation in healthcare to ensure patient involvement in decisions regarding their health care. The Chronic Care Model developed by Wagner et al. called for a change in the health care system to promote interactions of proactive clinicians with more informed and active patients. Effective self-management is essential to minimize the emotional impact of disease [1]. In 2016, the World Health Organization put forth its global strategy on integrated people-centered health services [2]. This called for a paradigm shift in the way health services are not only delivered but how they are funded and managed. The primary goal of this strategy is to empower and engage individuals in their care and includes participatory decision making between patients, their families, and clinicians.

Active patient engagement has emerged as a pillar of the patient-centered model of care[1]. Patient engagement includes a willingness to take an active role in one's own care, building confidence in one's ability to manage their own care, and acquiring the necessary knowledge and skills to make medical decisions [3]. Successful implementation of a patient-centered model is necessary to ensure high quality patient care at a systems level and to optimize patient outcomes. This development is reflected in changes in policy and laws across North America and Europe, emphasizing the growing role of patient engagement across all levels of decision making[4]. In the United States, The Affordable Care Act made patient engagement a central component of health policies and created Accountable Care Organizations to prompt patient engagement [5]. Despite a central role for patient engagement, there is a lack of clarity on its definition and several related terms are often used interchangeably. A recent systematic review by Harrington et al. revealed the 13 terms most commonly used[6]. Based on these results, a word map was created to better visualize and highlight the variability in definitions used in this area of research (Figure 1).

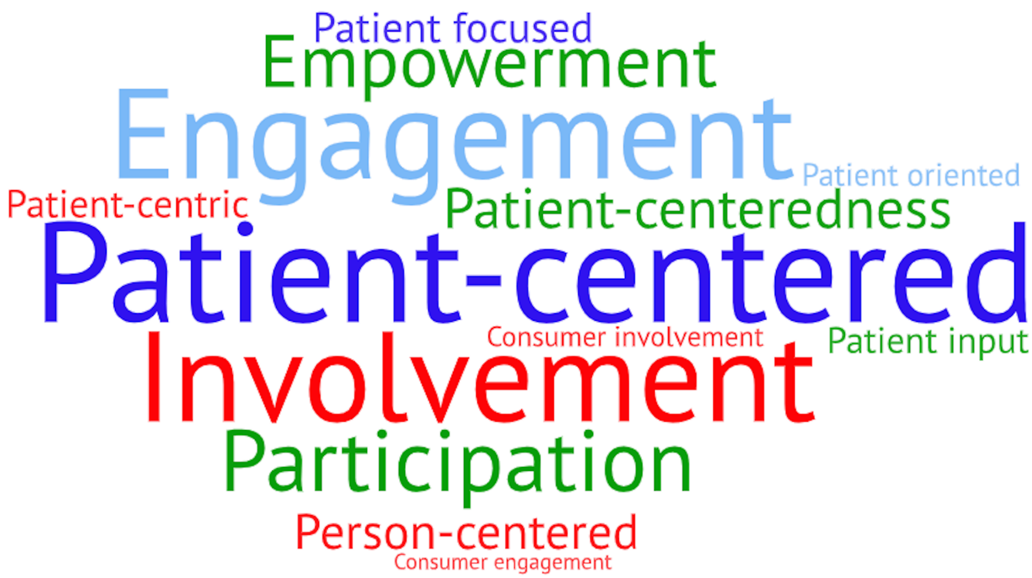

Figure 1 – Word map depicting frequency of use of terms referring to patient-centered care using results published by Harrington et al. in Value in Health, 2020.

1.2 Patient-centered care in surgery

A large body of work remains to be done to accurately measure patient engagement and understand its role across various patient populations. This may be of particular importance in patients having surgery, as these interventions result in significant physical and emotional stress, and are often described as overwhelming and life-changing events by patients[7]. Therefore, understanding the role of patient engagement and improving the patient-centered care approach in surgical patients is fundamental to promote high quality care and optimize outcomes.

The perioperative care trajectory includes the preoperative, intraoperative and postoperative periods, and different strategies may be required throughout this process in order to provide a patient-centered approach. In the preoperative setting, physicians, patients, and their families must discuss the interventions, complications, and the recovery process. The meaning of surgical recovery itself remains poorly understood and encompasses the time from the surgery to the time the patient returns to normal function with early, intermediate and late phases[8]. It is a complex process that incorporates multiple dimensions, including biological and physiological variables; symptoms; physical, emotional, social and economic function; as well as health perception and overall quality of life[9,10]. All these dimensions should be considered in a shared decision making (SDM) process involving the clinician and the patient, as well as family members and significant others [11]. In shared decision making, the clinician describes the risks and benefits of various options while the patient shares their values and preferences that may impact their choice. SDM has been referred to as the "pinnacle of patient-centred care" and is being adopted worldwide [12,13]. It must be considered in the context of discussions about the various treatment options, the value of surgical treatments and the expectations regarding the postoperative care process. Active participation in SDM requires patients not only to understand, but also to engage with healthcare providers and apply information[14]. A randomized controlled trial (RCT) demonstrated that SDM improved postoperative pain control in patients undergoing spine surgery[15]. Another recent RCT revealed that participation in SDM was associated with improved health outcomes and higher patient satisfaction in patients undergoing knee replacements[16]. To successfully implement SDM, options must be appropriately presented as well as to why patients are offered a role in the decision-making. Most importantly, they must be offered high quality information about the consequences of each option which requires a certain level of health literacy and patient education[17]. Despite the overall low level of evidence to date, guidelines for best practices strongly endorse patient education as a cornerstone of perioperative care [18,19].

Traditionally, the intermediate phase of recovery encompassing the time the patient spends in hospital after surgery has been most relevant to clinicians. The reorganization of perioperative care to a centered-patient model with enhanced recovery pathways (ERPs) has reduced the focus on in-patient care [20]. ERPs are multidisciplinary, coordinated and standardized care plans that integrate evidence-based interventions of 20 or more elements all along the perioperative trajectory[21]. They emphasize early oral nutrition, multimodal opioid-sparing analgesia, and early mobilization, all of which require some degree of active participation from patients in order to be effective. We now recognize that the patient holds a crucial role in the recovery process. A certain level of knowledge and understanding is required for patients to be able to follow care plans. This has been extensively studied in patient with chronic medical conditions such as diabetes and hypertension [22,23]. Similarly, medication compliance and early mobilization are important in patients undergoing surgical interventions to maintain appropriate pain control and ensure a prompt return to baseline function [8,10,18,24]. A recent RCT of 2084 patients undergoing elective colorectal surgery demonstrated that higher adherence to a patient-centered care plan was associated with fewer complications [25]. This suggests an important potential role for patient participation in improving surgical outcomes.

1.3 Outcome reporting in surgery

In the past three decades, outcomes for patients undergoing major surgery have been dramatically improved through the introduction of minimally invasive surgery and standardized ERPs [26-28]. There is no one optimal way to measure outcomes and quality in surgery as the definition may vary between the different stakeholders involved with the surgical procedure[8,9]. While short-term clinical outcomes are important, they are no longer sufficient to measure surgical success. Yet studies continue to identify gaps between outcomes of interest to patients and those most relevant to clinicians and payers [9,27,29]. Healthcare professionals, hospital administrators and policy makers most commonly report clinical and economic outcomes such as complication rates, length of stay (LOS), emergency department (ED) visits and costs[30,31]. However, patients prioritize quality of life and the return to normal functioning and regular activities [9,32]. It is in this context that patient-reported outcomes (PROs) are essential. PROs are quantified using patient-reported outcome measures (PROMS) which are assessments of health status directly reported by patients without being interpreted by others[33]. PROMs capture the multidimensionality of the surgical recovery process. As such, a patient-centered outcomes evaluation framework should include clinical outcome measures that also impact PROs in order to better reflect the patient perspective.

1.4 The impact of patient engagement on outcomes

Accurate measurement of patient engagement has been as challenging as defining it. However, the construct of "patient activation" has emerged to address this variability. This new behavioural concept encompasses the core components of patient involvement and self-efficacy [34]. Defined as the knowledge, skills, motivation and confidence required to impact one's own healthcare, patient activation emphasizes patients' readiness along with their capacity to manage their care, health and behaviours [35]. The Patient Activation Measure (PAM) questionnaire was created to quantify the construct of patient activation. The PAM survey consists of thirteen items in a hierarchical order on a unidimensional scale[34,36]. The score, ranging from 0 to 100, allows for the classification of patients into four increasing levels of activation. Patient with the lowest level of activation are passive recipients of care and do not understand that playing an active role in their own health is important. At the highest level of activation, patients are able to adopt new behaviours as well as maintain them in times of increased stress. Previous studies provide evidence supporting its validity in a variety of medical conditions[37-42].

Most of the evidence on the association between patient activation and health outcomes was derived from patients with chronic medical conditions. Patients with higher levels of engagement are more likely to use preventive screening measures and less likely to engage in unhealthy behaviours[35]. A randomized study of patients with end-stage renal disease found that patient empowerment and self-efficacy can be improved using a patient empowerment program designed to increase self-awareness, set goals and manage stress [43]. The PAM survey is also appropriate for use in the hospital setting in addition to the outpatient setting[38]. A study of older adults hospitalized for a minimum of 72 hours found that person-centered support from nurses was the strongest predictor of patient activation[44].

Multiple studies support that patient engagement is a modifiable risk factor [40,41,45,46]. Most interventions target patient participation or health literacy and aim to increase patient engagement either through direct coaching or mobile technology. An RCT in patients with cardiovascular risk factors found that the use of a telephone coaching intervention was associated with a significant improvement in PAM scores and a higher rate of enrollment and participation in prevention programs [47]. A systematic review of RCTs by Kinney et al. including patients with different chronic illnesses concluded that highly engaged patients were less likely to be hospitalized and to return to the ED [46]. This same study revealed that interventions focusing on improving patient engagement can positively impact medication adherence in certain chronic conditions [46]. Another systematic review of RCTs found that highly engaged type 2 diabetic patients had greater improvements in their glucose control and had a lower rate of diabetic-related complications compared to patients with lower engagement [45]. Higher levels of patient engagement are also associated with lower healthcare costs [48]. Studies of strategies to improve patient activation find the most significant changes to be in patients with lower levels of activation at baseline [49]. Efforts and interventions should therefore be focused on patients with the lowest activation to achieve the greatest impact.

A secondary analysis of an RCT to reduce cardiopulmonary rehospitalization estimated the association between patient activation and 30-days post-discharge healthcare utilization [50]. This study revealed that patients at the lowest level of activation have nearly twice the risk of post-discharge readmission (IRR 1.93, 95%CI 0.94-1.80) and a 68% higher risk of return to the ED (IRR 1.68, 95%CI 1.7-2.63)[50]. Surgical patients account for a fifth of all post-discharge returns to the ED in Canada and a quarter of all readmission, generating over $15 million and $4.5 billion, respectively in costs every year[51]. Elective surgical patients are different than those with chronic medical conditions in that there is a set date for the intervention that will impact their health acutely, and a preoperative period of variable duration. The preoperative period may be the best time to identify the most vulnerable patients and to deploy strategies to improve patient engagement.

However, there is very little available evidence estimating the association between patient engagement and outcomes in surgical patients. Patients who undergo surgery often have chronic conditions but additionaly experience physical and emotional stress due to the procedure itself [7]. A higher level of patient engagement was associated with higher patient participation and adherence to a physical therapy program after spine surgery [52]. Evidence from RCTs have demonstrated the benefit of perioperative education programs in improving pain control after hand surgery[53] and knee surgery[54]. Higher levels of patient engagement in patients undergoing knee or spine surgery are also associated with reduced hospital LOS and higher levels of patient satisfaction[52,54,55]. But there is little high-quality evidence estimating the impact of patient engagement on outcomes for patients undergoing major abdominal or thoracic surgical interventions. It is important to understand the impact of patient engagement at every step of the perioperative care process to improve the patient-centered care provided. This thesis will highten our understanding of patient engagement in a surgical population and potentially provide a novel avenue for quality improvement efforts focused on clinical and patient-reported outcomes.

1.5 Thesis objectives

The objectives of this thesis were threefold:

1. To estimate the extent to which clinical outcomes correlate with patient-reported outcomes in patients undergoing elective colorectal surgery;
2. To estimate the extent to which patient engagement is associated with unplanned healthcare utilization after hospital discharge from surgery;
3. To evaluate the validity of the Patient Activation Measure questionnaire in patients undergoing surgical interventions using a Rasch model.

The hypotheses of this thesis were that:

1. Postoperative complications negatively impact postoperative patient-reported health-related quality of life after colorectal surgery;
2. Low patient engagement is associated with higher unplanned healthcare use (including emergency department visits and readmissions) post-discharge after major surgery;

3. The Patient Activation Measure is a valid tool that can be used in patients undergoing a surgical intervention.

To accomplish the objectives of this thesis:

1. I performed a retrospective study of the impact of postoperative complications on health related quality of life using data from four prospective observational trials of patients undergoing elective colorectal surgery. I compared two approaches to grade complication severity in terms of their association with health-related quality of life in these patients;
2. I performed a prospective study of the association of patient activation levels at time of surgery on clinical and patient-reported outcomes in patients undergoing elective and emergency thoracic or abdominal surgery. This was the first study to assess the impact of patient engagement in a large cohort of patients undergoing a surgical intervention;
3. I performed a Rasch analysis of the Patient Activation Measure questionnaire used to measure patient engagement in the prospective study. With this study, we assessed the validity of this questionnaire in a surgical population. We also assessed the quality of the individual items included in the questionnaire.

CHAPTER 2: IMPACT OF CLINICAL OUTCOMES ON PATIENT REPORTED OUTCOMES

CHAPTER 2.1 – Preamble

In Chapter 1, I provided a definition of patient engagement and the importance of understanding its role in surgical patients. It has been identified as a potentially modifiable independent patient factor that is associated with a variety of relevant health outcomes. Previous studies support an association between higher levels of patient engagement and decreased hospital length of stay, decreased emergency department visits and readmissions, and lower overall costs[35,50,56,57]. This association has been well studied in patients with chronic medical conditions but remains poorly understood in surgical patients.

In the last decades, several innovations, including minimally invasive surgery and the implementation of standardized perioperative care pathways have improved postoperative outcomes[58]. However, complications remain relatively common and are costly. Studies have shown there is a gap in the outcomes that are considered important between patients and healthcare professionals[27]. Healthcare professionals more commonly report clinical and health systems outcomes such as length of stay, complications and costs, while patients value the return to normal functioning and their quality of life[31]. In order to effectively impact patients' engagement in their perioperative course, we must first understand the relationship between clinical outcomes and patient reported outcomes as the basis of a patient-centered framework. Tools selected to measure morbidity should consistently capture the impact on health-related quality of life when used for comparative effectiveness research aimed at improving patient care.

In this manuscript, we performed a retrospective study of data obtained from four completed prospective observational trials in patients undergoing colorectal surgery. We estimated the extent to which postoperative complications correlate with patient-reported outcomes. We focused on the impact of postoperative complications as it is the most cited clinical outcome of interest in surgical studies [59]. To achieve this goal, we performed multivariate linear, logistic and fractional polynomial regression analyses to determine the independent effect of postoperative complications severity on health-related quality of life. This manuscript was published in *Surgery*.

CHAPTER 2.2 – The relationship of two postoperative complications grading schemas with postoperative quality of life after elective colorectal surgery

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ABSTRACT

Introduction: There are several grading schemes for surgical complications, but their relationship on patient-reported outcomes is not well understood. Therefore, our objective was to examine the effect of two different complication grading schemas on health-related quality of life (HRQoL) in colorectal surgery patients.

Methods: An analysis of adult patients undergoing elective colorectal surgery from 2005-2013 was performed. HRQoL was measured using SF-36 preoperatively, at 4-and 8-weeks postoperatively. 30-day morbidity was classified using Clavien-Dindo grading (I-IV) and Comprehensive Complication Index (CCI, 0-100). The main outcomes were change in physical (PCS) and mental (MCS) summary scores postoperatively. Multivariate logistic and fractional polynomial regression analyses were used to determine the relationship between complication severity and HRQoL.

Results: A total of 402 patients were included in the study. Overall morbidity was 46%. Patients with complications had lower PCS and MCS scores at 4-and 8-weeks postoperatively compared to patients without complications ($p<0.05$). On multivariate regression, there was no dose-response relationship between Clavien-Dindo grade and postoperative PCS and MCS scores. Adjusted change in PCS and MCS had a more appropriate dose-response relationship with CCI scores.

Conclusion: In patients undergoing colorectal surgery, there is a more consistent relationship between the CCI and postoperative HRQoL compared to the Clavien-Dindo classification.

INTRODUCTION

Surgical morbidity is an important postoperative outcome, but it is inconsistently defined. The Clavien-Dindo classification is most commonly used, in which complications are graded on an ordinal scale (I-V) based on the treatment provided to manage the complication [1]. Studies have shown a clear relationship between higher grades of complication and hospital length of stay (LOS)[2] and costs[3]. As the Clavien-Dindo grade reports the single most severe postoperative complication, it does not account for multiple complications and their potential cumulative effect on patient outcomes.

To overcome some of these limitations, the Comprehensive Complication Index (CCI) was proposed as an alternative to the Clavien-Dindo classification. The CCI reflects the total complication burden by assigning a weight to each complication accounting for each Clavien-Dindo grade resulting in a cumulative score from 0 to 100 [4, 5]. Specific weights were assigned by incorporating both patients' perspectives of their experience of complications and physician perspectives. For instance a single Clavien-Dindo I complication gives a CCI score of 8.9, a Clavien-Dindo grade IIIa gives a CCI score of 26.2 which is lower than two Clavien-Dindo grade II complications in the same patient (CCI = 29.6). The CCI has a stronger correlation with postoperative LOS [6] and overall costs [7] than the single Clavien-Dindo grade for a variety of surgical interventions. The CCI may be a more sensitive measure of morbidity as it accounts for all postoperative complications and scores their severity on an additive linear rather than ordinal scale.

However, these audit measures such as LOS and costs may not be as meaningful to patients[8]. The recent focus on patient-centered care and patient-reported outcomes (PROs) emphasizes health-related quality of life (HRQoL) as an important outcome target for quality improvement. Grading schemes for complication severity should therefore reflect the impact on HRQoL during postoperative recovery, as well as correlate with clinical outcomes like length of stay and cost. However, the relationship between these complication grading schemes (Clavien-Dindo and CCI) on patient-reported outcomes has not been well described. Therefore, the main objective of this study was to examine the relationship between the two different grading systems (the Clavien-Dindo system and the CCI) and HRQoL in adult patients undergoing elective colon or rectal surgery. We hypothesized that there would be an incremental dose-response relationship between postoperative HRQoL and complication severity. That is, we expected that the 4- and 8-week changes in physical and mental HRQoL scores would be greater with increasing complication severity as measured by the Clavien-Dindo and CCI scores.

METHODS

Participants and Setting

A secondary analysis of data collected during four prospective trials at two university-affiliated tertiary care institutions from 2005 to 2013 was performed. These included two trials investigating preoperative exercise training[9, 10] one trial investigating thoracic epidural analgesia versus intravenous lidocaine for perioperative pain management[11], and one study investigating enhanced recovery versus conventional care[12]. The study population consisted of adult patients over the age of 18 years old who underwent scheduled resections of the colon and/or rectum. Patients were excluded if they did not speak or understand English or French, one of the official languages. Patients were also excluded if they had neurological or cognitive impairments that precluded them from answering questionnaires.

Measures

Demographic data, including age, sex, body mass index (BMI) and comorbidities were collected. Comorbidities were classified using the American Society of Anesthesiology (ASA) physical status score, as grade 1, 2 or 3 and more. Underlying diagnosis was classified as malignancy, inflammatory bowel disease (IBD) or other benign diseases. The type of surgical procedure, new stoma creation, surgical approach (laparoscopic or open) and administration of adjuvant chemotherapy were recorded. Hospital length of stay (LOS) was calculated from the date of the elective surgery to the date of hospital discharge. All postoperative complications were prospectively recorded within 30 days of the index surgery and each graded using the Clavien-Dindo classification of surgical complications[1]. Clavien-Dindo Grade III and IV complications were combined together due to event number restrictions. All charts were retrospectively reviewed to confirm no complications were missed. The total complication burden for each patient was scored using the publicly available CCI calculator [5] (© AssesSurgery GmbH 2019), incorporating the number and severity of all postoperative complications within 30-days of the index surgery. While the Clavien-Dindo is based on an ordinal scale selecting the single most severe postoperative complication, the CCI score summarizes the complete spectrum of complications in a single score ranging from 0 to 100 [4].

Outcomes

All participating patients completed a HRQoL questionnaire preoperatively (baseline), at 4 weeks and at 8 weeks postoperatively. HRQoL was assessed using the SF-36 questionnaire [13, 14], measuring eight different health dimensions: physical functioning (PF), role physical, bodily pain, general healthy, vitality, social functioning, role emotional and mental health. Two summary scores were calculated, the physical component summary (PCS) and mental component summary (MCS) scores and normalized using the 1998 US population normal to a mean of 50 and standard deviation of 10 [15]. The SF-36 has been previously used in clinical and research settings to measure quality of life after surgery [16, 17]. A recent study has demonstrated its validity in patients undergoing colorectal surgery [18], with scores on the physical functioning domain adequately correlating with other measures of exercise capacity. The main outcome was the change in PCS and MCS scores from baseline of the SF-36 at 4-weeks and 8-weeks postoperatively.

Statistical Analysis

Summary descriptive statistics using means with 95% confidence intervals (CI) or median Interquartile Range (IQR) when appropriate were used to characterize the study population. Mean (SD) PCS and MCS scores were calculated at baseline, at 4-weeks and 8-weeks postoperatively overall and by Clavien-Dindo grade and compared using ANOVA. Mean scores (95% CI) were compared for patients with and without complications using t-test. Missing data were handled using multiple imputations using chained equations (10 imputations). Using this method, missing items are estimated using a regression model from other observed data and repeated 10 times to generate 10 different imputated data sets. Uncertainty around the imputated point estimates incorporate the between (datasets) and within (variable) variances according to Rubin rules [15]. Multiple linear regression was used to determine the independent effect of Clavien-Dindo complication grade on the change in 4- and 8-week PCS and MCS, adjusted for age, sex, baseline PCS or MCS score, BMI, ASA, diagnosis, surgical approach, stoma creation, length of stay. Absolute PCS and MCS scores at 4- and 8- weeks were used as the dependent variable in multiple regression analyses while adjusting for baseline scores.[19] We also investigated the effect of complication timing by including an interaction term occurrence of the complication (<7 days or ≥7 days postoperatively). Subgroup analysis was performed using physical functioning (PF) subscale scores, as well as by diagnosis (malignancy and IBD, as we hypothesized that these patients may have had different baseline scores). Since the relationship between CCI and HRQoL scores was hypothesized *a priori* to be non-linear and in order to preserve the continuous nature of the covariates introduced, a multivariable fractional polynomial (MFP) plot was used to graph the adjusted change in PCS and MCS scores by CCI score. This model combines backward elimination with a systematic search for the most suitable transformation to represent the influence of each continuous covariate on the outcomes while accounting for missing data using multiple imputations. Goodness of fit of this model was compared to that of simple linear regression of CCI as well as the regression model using the Clavien-Dindo grading schema using adjusted-R2. A sensitivity analysis was also performed using complete cases in the multivariate linear regression. All statistical analysis was performed using STATA version 14.2 software (StataCorp, CollegeStation, TX, USA). Statistical significance was set at a p-value of 0.05.

RESULTS

A total of 402 patients were included in this study cohort. Patient and operative characteristics, and clinical outcomes are shown in Table 1. Overall, 46% of the study cohort had at least one postoperative complication within 30-days of the index surgery, a rate similar to previous studies [17]. The majority of these complications were minor complications (19% Clavien-Dindo grade I and 18% Clavien-Dindo grade II), whereas 9% of the study cohort had complications grade III and IV. There was no 30-day mortality. The median CCI score of the cohort was 8.8 [IQR 0 – 20.9].

Mean preoperative, 4- and 8-weeks postoperative PCS and MCS scores by Clavien-Dindo grade are shown in Figure 1 and Figure 2 and Table 2. Baseline scores were available in 98% of patients (n=392) and there were 21% and 35% missing data at 4- and 8-weeks respectively. Patients with any postoperative complications had significantly lower PCS and MCS scores at 4-weeks as well as 8-weeks postoperatively when compared to patients without complications (Table 3). Patients without malignancy or inflammatory bowel disorder had significantly higher PCS scores at baseline (IBD 47.3 (SD 9.70), malignancy 49.2 (SD 9.60), Other diagnoses 52.4 (SD 8.86), p<0.005). The mean PCS score at baseline significantly differed between non-complicated and the three Clavien-Dindo groups, with Clavien-Dindo grade II being the lowest (p=0.035) whereas the mean MCS scores did not significantly differ at baseline (Table 2).

On multiple regression, the changes in postoperative PCS and MCS scores were independently affected by baseline scores at both 4 and 8 weeks (Table 4). At 4 weeks postoperatively, PCS scores were significantly decreased by Clavien Grade III or more, whereas at 8 weeks, PCS were significantly decreased by Grade II complications. MCS scores were significantly decreased by complications of Grade II or more at 4 weeks and by complications Grade III or more at 8 weeks postoperatively. Similar results were noted when analyzing absolute physical functioning subscale scores and when analyzing patient subgroups by diagnosis (malignancy vs non-malignancy, Supplemental tables 1 and 2). The timing of complications after the index surgery (<7 days or ≥7 days) was not an independent predictor of change in PCS scores or MCS scores postoperatively. The sensitivity analysis revealed similar results using complete cases and multiple imputed data.

When using the CCI as the complication grading schema, MFP plots demonstrated a more linear decrease in MCS scores with increasing CCI scores after adjusting for confounders, both at 4-weeks (Adjusted R2=0.051 vs 0.022) and 8-weeks (Adjusted R2=0.037 vs 0.023) postoperatively compared to simple linear regression. Adjusted PCS scores at 4 weeks decreased with increasing CCI scores but this relationship was not as prominent at 8 weeks postoperatively (Figure 3). Furthermore, the relationship between HRQoL and CCI was not linear as model fit characteristics of the multiple fractional regression were better for both MCS scores compared to multiple linear regression models, adjusting for the same covariates. Moreover, MFP regression of CCI had a consistently better model fit compared to Clavien-Dindo grading for both PCS (adjusted R2=0.069 vs 0.033 at 4 weeks, 0.040 vs -0.011 at 8 weeks) and MCS scores (adjusted R2=0.051 vs 0.023 at 4 weeks, 0.037 vs -0.014 at 4 weeks). This suggests there would be a better prediction of postoperative PCS and MCS scores using CCI compared to Clavien-Dindo grading system.

DISCUSSION

With increasing attention being focused on patient-centered value-based care, there is a growing interest in PROs as a key component to guide quality improvement initiatives [20]. Studies have shown there is a gap in the outcomes that are considered important between patients and healthcare professionals.[8] Healthcare professionals are more interested in clinical outcomes such as length of stay, complications and healthcare costs, but patients value the return to normal functioning and quality of life [21]. It would therefore be of significant importance if the relationship between the commonly-used complication grading schema and patient-reported HRQoL could be established.

This study focused on the relationship between postoperative complications, which occurred in 46% of this study cohort, and HRQoL. Patients with complications had lower PCS scores and MCS scores at 4- and 8-weeks postoperatively. However, when assessing these complications by severity, the impact of the Clavien-Dindo grading system on PCS and MCS scores was inconsistent. That is, there were not consistently significant adjusted differences in PCS and MCS scores compared to baseline as the Clavien-Dindo grade increased. There are several potential reasons for this finding. The main issues with the Clavien-Dindo classification include the fact that it is reported on an ordinal scale, it only includes the most severe complication (i.e. it is not cumulative), and that the grade is based on the treatment received [5]. For example, a severe wound infection that requires a prolonged duration of dressing changes is classified as a grade I complication, whereas an anastomotic bleed that requires endoscopic control only is categorized as a grade IIIa complication. While this may be relevant from a length of stay or cost perspective, the impact on patients' HRQoL is not as intuitive, as is suggested by the results of this study. However, there were relatively few grade III-IV complications, which may bias the results.

Comparatively, we reported a stronger relationship between complication burden as measured by the CCI and 4- and 8-week HRQoL. This was evidenced in our analysis both graphically and through a better prediction of postoperative PCS and MCS scores using the CCI compared to Clavien-Dindo grading system. However, most patients had CCI scores between 0 and 30, thus increasing the uncertainty of this correlation with CCI scores above 50. The results of this present study suggest the CCI could be a better a more inclusive measure of morbidity as it accounts for the overall burden of complications weighted using both clinician and patient perspectives.

There may be several other explanations for the findings of this study. We used both SF-36 summary scores (PCS and MCS) for our analyses, but only the PCS followed the expected postoperative trajectory (decline at 4-weeks compared to baseline, followed by return to baseline at 8-weeks[22, 23]) whereas the MCS did not. This could partly explain why we did not identify an appropriate dose-relationship between Clavien-Dindo complication grade and 4-week HRQoL. However, subgroup analysis using the physical functioning subscale (which has been previously shown to follow this hypothesized trajectory after abdominal surgery[24]) also reported similar results. We also considered the indication for surgery as a potential confounder. Patients with IBD and diverticular disease are often symptomatic at the time of surgery and have lower HRQoL at baseline, whereas patients with malignancy are often asymptomatic.[25] Large improvements in HRQoL may be expected as a result of surgery[25], which may bias potential effects of complications in this specific group of patients. This was reflected in our subgroup analysis where we noted patients with malignancy to have a more significant change in PCS and PCS scores compared to non-malignancy patients.

The results of this study should be interpreted in view of other limitations. There were only two time points at which HRQoL was measured. It is unclear whether additional measurements prior to 4 weeks would have identified a more obvious dose-response relationship. Complications that occur earlier may have less of an impact at 4-weeks then those occurring later. However, in our results the interaction term for the timing of complications did not affect the results of the model. There was also some missing data 21% at 4-weeks and 35% at 8-weeks postoperatively. We attempted to minimize their impact using multiple imputations and this yielded similar results to the complete case analysis. There may have been other unmeasured confounders factors that could have affected HRQoL, especially at 8 weeks, such as delivery of adjuvant systemic therapy in patients with malignancy, although this would have affected only a small proportion of patients. Moreover, all patients in this study were enrolled in prospective trials which may impact their quality of life scores. Although they are an overall small percentage of patients at our center, the First Nations population from Northern Quebec could not be captured as most do not speak one of the province's official languages (English or French). Future prospective studies should also include First Nations patients to account for this unique population and provide QoL in all available languages. Patients with neurological or cognitive impairments are also an important demographic that could be represented using QoL reporting from the caregivers' perspective. The results of this study may also not be generalizable to other surgical populations, as the patient cohort in this study only included elective major colorectal resections performed in a high-volume specialist referral center.

CONCLUSION

The findings of this study suggest that postoperative complications negatively impact HRQoL after colorectal surgery. However, the impact of complications as graded by the Clavien-Dindo classification system on HRQoL does not follow a consistent pattern. Rather, this study reported that the relationship between HRQoL and CCI is more appropriate. This study adds to the growing body of literature demonstrating that the CCI is a better and more inclusive morbidity reporting tool given its more consistent relationship with quality of life.

This has important implications for outcome reporting as it could be used in comparative effectiveness research to improve patient care. However, these findings should be further reproduced in other surgical populations and with other PRO measures.

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Table 1. Characteristics of patients included in the study.

Data presented as n(%) unless specified

Variables	Total (n=402)
Age, mean (SD)	61.5 (13.9)
Sex, male	220 (55)
BMI*, mean (SD)	27 (5.0)
ASA†	
I	62 (15)
II	258 (64)
III+	82 (21)
Laparoscopic approach	231 (58)
New stoma	119 (30)
Indication for surgery	
Malignancy	268 (67)
IBD‡	48 (12)
Other benign	86 (21)
Adjuvant Chemotherapy	71 (18)
Overall Complication Rate	186 (46)
Clavien I	78 (19)
Clavien II	74 (18)
Clavien III/IV	34 (9)
CCI§, median (IQR)	8.8 [0 – 20.9]
Length of Stay, median (IQR)	7 (3 – 8)

*BMI: Body mass index (kg/m^2); †ASA: American Society of Anesthesiology physical status score; ‡IBD: Inflammatory bowel disease; §CCI: Comprehensive Complication Index

Table 2. SF-36 Physical and Mental Component means preoperatively, at 4 weeks and at 8 weeks postoperatively

Data presented as mean (SD)

Variables	PCS baseline	PCS 4 weeks	PCS 8 weeks	MCS baseline	MCS 4 weeks	MCS 8 weeks
Overall	48.4 (0.66)	41.6 (0.61)	47.1 (0.67)	48.4 (0.77)	47.9 (0.78)	50.3 (0.68)
No Complications	50.1 (0.66)	44.3 (0.66)	49.1 (0.77)	49.0 (0.71)	50.5 (0.76)	51.3 (49.7)
Clavien-Dindo I	52.4 (0.87)	43.2 (1.13)	48.6 (1.20)	47.4 (1.28)	47.2 (1.42)	51.2 (1.35)
Clavien-Dindo II	46.7 (1.12)	39.8 (1.35)	41.1 (1.48)	46.5 (1.46)	45.4 (1.79)	48.0 (1.51)
Clavien-Dindo III/IV	47.4 (1.94)	37.1 (1.83)	42.8 (2.92)	48.5 (1.86)	43.1 (2.70)	45.0 (3.11)

Table 3. Mean Physical and Mental Component Summary scores in patients with and without complications.

Data presented as means (SD)

Variables	Complications	No complications	P-value
Preoperative PCS*	49.2 (0.70)	50.1 (0.66)	0.320
Preoperative MCS†	47.2 (0.86)	49.0 (0.71)	0.055
4-week PCS*	40.8 (0.81)	44.3 (0.66)	**0.001***
4-week MCS†	45.8 (1.04)	50.5 (0.76)	**0.0002***
8-week PCS*	44.6 (0.96)	49.1 (0.77)	**0.0003***
8-week MCS†	48.9 (0.99)	51.2 (1.35)	**0.033***

*PCS: Physical Component Summary; †MCS: Mental Component Summary.

Table 4. Multivariate regression of predictors of change in PCS and MCS scores

Data presented as coefficients (95%CI)

Variables	Change in PCS at 4 weeks	Change in PCS at 8 weeks	Change in MCS at 4 weeks	Change in MCS at 8 weeks
Age	-0.01 (-0.09 – 0.07)	0.04 (-0.05 – 0.12)	0.08 (-0.03 – 0.18)	0.03 (-0.07 – 0.13)
Male	0.73 (-1.15 – 2.60)	**2.54 (0.38 – 4.70)**	0.30 (-1.90 – 2.50)	1.94 (-0.47 – 4.36)
BMI*	0.07 (-0.12 – 0.26)	0.10 (-0.11 – 0.31)	0.09 (-2.84 – 2.21)	0.07 (-0.14 – 2.85)
Diagnosis				
Benign (ref)	Ref	Ref	Ref	Ref
Malignancy	1.72 (-0.91 – 4.33)	-0.86 (-3.70 – 1.97)	-0.64 (-3.60 – 2.32)	-1.05 (-4.44 – 2.33)
IBD†	2.17 (-2.55 – 6.89)	0.40 (-4.19 – 4.98)	0.80 (-5.33 – 6.92)	0.63 (-3.89 – 5.15)
ASA‡				
≤ 2 (ref)	Ref	Ref	Ref	Ref
≥ 3	1.32 (-1.07 – 3.72)	-2.21 (-4.70 – 0.28)	-0.29 (-3.50 – 2.92)	-0.06 (-2.92 – 2.80)
Baseline score	**-0.62 (-0.73 - -0.52)**	**-0.66 (-0.78 – -0.54)**	**-0.56 (-0.68 – -0.45)**	**-0.62 (-0.73 – -0.50)**
Approach				
Open	Ref	Ref	Ref	Ref
Laparoscopic	**2.55 (0.51 – 4.58)**	1.62 (-0.78 – 4.02)	-0.32 (-2.84 – 2.21)	-1.27 (-4.34 – 1.80)
Stoma creation	-1.87 (-4.33 – 0.59)	-2.44 (-4.90 – 0.01)	-1.36 (-4.35 – 1.63)	0.35 (-2.31 – 3.01)
Complications				
None	Ref	Ref	Ref	Ref
Grade I	-0.58 (-2.98 – 1.83)	-0.77 (-3.37 – 1.83)	-2.54 (-6.18 – 1.08)	-0.44 (-3.42 – 2.53)
Grade II	-0.99 (-3.62 – 1.64)	**-3.84 (-7.00 – -0.73)**	**-3.93 (-7.66 – -0.20)**	-1.68 (-5.20 – 1.83)
Grade III+	**-5.20 (-8.88 – -1.53)**	-1.44 (-5.60 – 2.71)	**-6.88 (-11.47 – -2.30)**	**-5.20 (-10.06 – -0.34)**
Length of stay	**-1.32 (-0.26 – -0.01)**	**-0.12 (-0.26 – -0.01)**	0.01 (-0.15 – 0.15)	-0.03 (-0.18 – 0.11)

*BMI: Body mass index (kg/m^2); †IBD: Inflammatory bowel disease; ‡ASA: American Society of Anesthesiology physical status score.

FIGURE 1 – Mean Physical Component Summary score over time by Clavien-Dindo complication grade.

(Mean and 95% Confidence Interval)

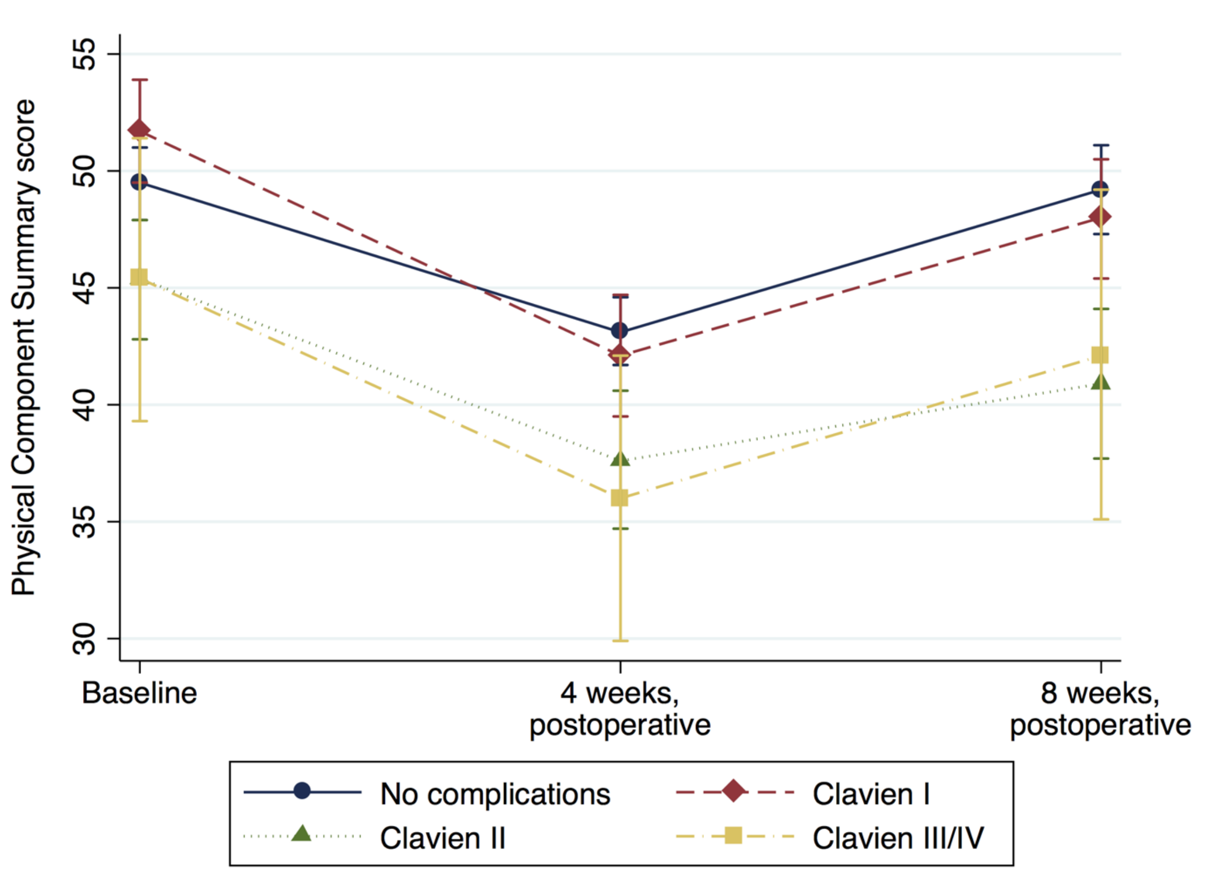


FIGURE 2 – Mean Mental Component Summary score over time by Clavien-Dindo complication grade

(Mean and 95% Confidence Interval)

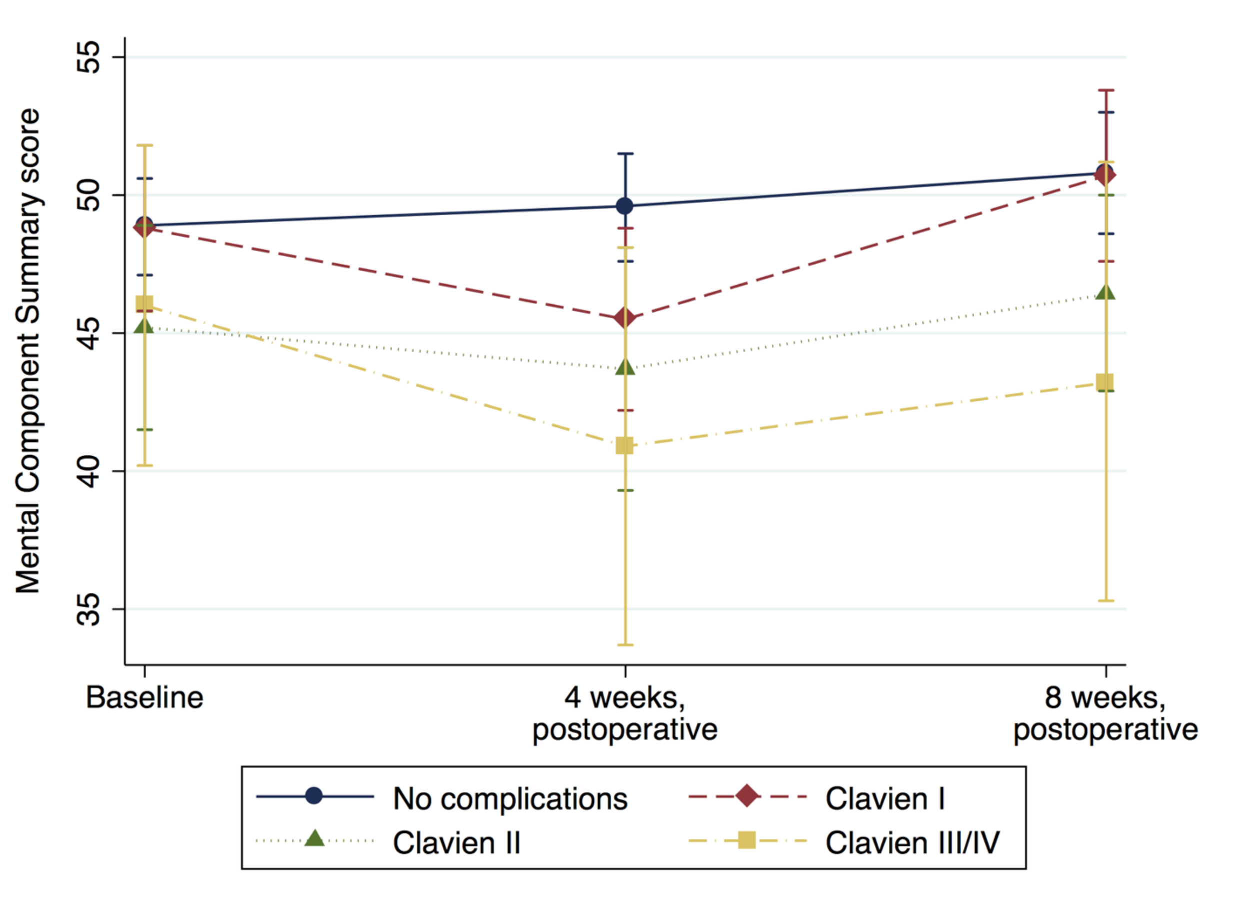
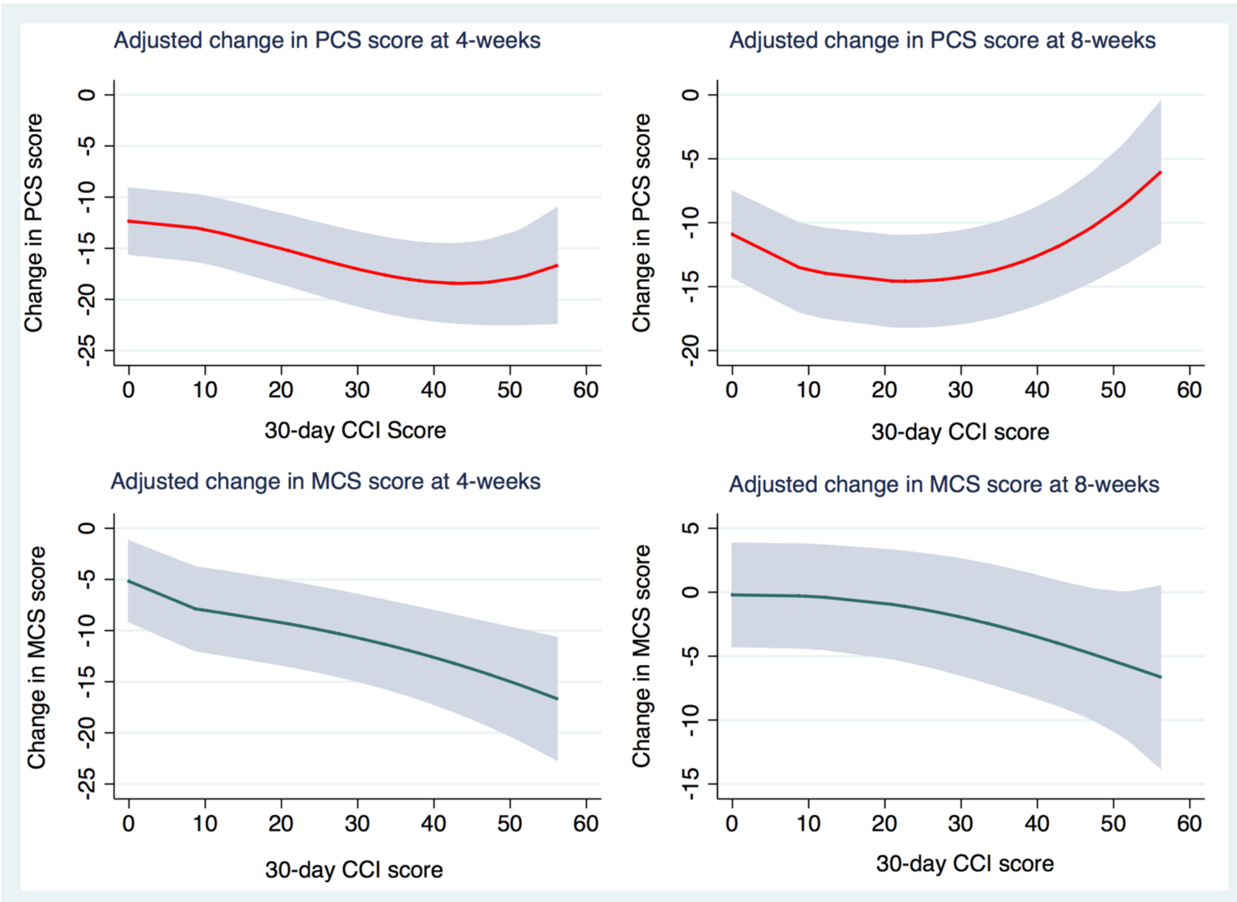


FIGURE 3 - Adjusted Change in physical and mental summary scores at 4 and 8 weeks postoperatively using multivariate fractional polynomial plots

Adjusted for age, sex, BMI, ASA, diagnosis, surgical approach, stoma creation and LOS



Supplemental Table 1. Multivariate regression of predictors of change in PCS scores in patients with benign disease and patients with malignancy

Data presented as coefficients (95%CI)

Primary Diagnosis	Non-malignancy		Malignancy	
Variables	**Change in PCS[‡] at 4 weeks**	**Change in PCS[‡] at 8 weeks**	**Change in PCS[‡] at 4 weeks**	**Change in PCS[‡] at 8 weeks**
Age	0.04 (-0.13 – 0.20)	0.01 (-0.19 – 0.22)	-0.02 (-0.12 – 0.08)	0.07 (-0.06 – 0.20)
Male	1.06 (-3.45 – 5.57)	1.13 (-5.05 – 7.31)	0.39 (-1.84 – 2.61)	**2.92 (0.63 – 5.22)**
BMI[*]	-0.01 (-3.45 – 5.57)	-0.09 (-0.66 – 0.49)	0.05 (-0.17 – 0.29)	**0.22 (0.01 – 0.44)**
ASA[c]				
≤ 2 (ref)	Ref	Ref	Ref	Ref
≥ 3	-1.45 (-8.03 – 5.14)	-1.83 (-8.30 – 4.64)	2.32 (-0.48 – 5.11)	-2.37 (-5.41 – 0.68)
Baseline score	**-0.77 (-1.01 - -0.53)**	**-0.60 (-0.87 – -0.34)**	**-0.56 (-0.69 – -0.44)**	**-0.67 (-0.79 – -0.54)**
Approach				
Open	Ref	Ref	Ref	Ref
Laparoscopic	2.17 (-0.34 – 7.68)	-0.87 (-2.65 – 9.87)	**-3.23 (0.92 – 5.55)**	1.58 (-1.57 – 4.75)
Stoma creation	0.04 (-5.05 – 5.12)	0.08 (-6.72 – 6.88)	-1.76 (-4.33 – 0.80)	-2.27 (-5.36 – 0.81)
Complications				
None	Ref	Ref	Ref	Ref
Grade I	-0.69 (-6.24 – 4.86)	-1.74 (-9.07 – 5.59)	-0.18 (-2.91 – 2.56)	-2.47 (-5.11 – 2.18)
Grade II	-2.79 (-9.24 – 3.65)	-4.58 (-12.79 – 3.63)	-0.06 (-3.28 – 3.15)	**-5.25 (-9.27 – -1.22)**
Grade III+	-3.48 (-11.06 – 4.10)	1.30 (-8.01 – 10.62)	**-6.36 (-11.11 – -2.62)**	-2.07 (-8.33 – 4.19)
Length of stay	-0.14 (-0.32 – 0.03)	-0.09 (-0.28 – 0.10)	-0.14 (-0.40 – 0.12)	-0.18 (-0.45 – 0.09)

[*]BMI: Body mass index (kg/m^2); [†]ASA: American Society of Anesthesiology physical status score; [‡]PCS: Physical Component Summary.

Supplemental Table 2. Multivariate regression of predictors of change in MCS scores in patients with benign disease and patients with malignancy

Data presented as coefficients (95%CI)

Primary Diagnosis	Non-malignancy		Malignancy	
Variables	**Change in MCS‡ at 4 weeks**	**Change in MCS‡ at 8 weeks**	**Change in MCS‡ at 4 weeks**	**Change in MCS‡ at 8 weeks**
Age	0.11 (-0.10– 0.32)	0.04 (-0.17 – 0.26)	0.08 (-0.04– 0.21)	0.07 (-0.09 – 2.95)
Male	-1.25 (-6.29 – 3.79)	-1.32 (-6.27 – 3.99)	0.64 (-2.20 – 3.48)	**3.47 (0.52 – 6.41)**
BMI*	0.08 (-0.40 – 0.56)	-0.15 (-0.43 – 0.74)	0.13 (-0.16 – 0.42)	0.14 (-0.10 – 0.39)
ASA†				
≤ 2 (ref)	Ref	Ref	Ref	Ref
≥ 3	0.47 (-6.01 – 6.96)	-1.50 (-8.76 – 5.76)	-0.58 (-4.96 – 2.85)	-0.01 (-4.08 – 4.08)
Baseline score	**-0.42 (-0.64 - -0.19)**	**-0.63 (-0.90 – -0.35)**	**-0.60 (-0.73 – -0.46)**	**-0.66 (-0.77 – -0.55)**
Approach				
Open	Ref	Ref	Ref	Ref
Laparoscopic	2.55 (-2.96 – 8.07)	2.58 (-4.69 – 9.85)	-1.67 (-4.67 – 1.34)	-2.51 (-5.54 – 0.52)
Stoma creation	1.91 (-3.46 – 9.28)	1.57 (-6.63 – 9.78)	-1.81 (-4.96 – 1.35)	-1.19 (-1.65 – 4.03)
Complications				
None	Ref	Ref	Ref	Ref
Grade I	-2.97 (-9.76 – 3.82)	-0.75 (-5.67 – 7.16)	-2.65 (-6.43 – 1.14)	-0.83 (-4.61 – 2.95)
Grade II	-3.04 (-11.8 – 5.75)	-1.32 (-10.5 – 7.81)	-4.17 (-8.43 – 0.09)	-4.00 (-8.16 – 0.15)
Grade III+	-7.71 (-16.2 – 0.78)	0.95 (-9.03 – 10.9)	-5.70 (-11.49 – 0.08)	**-9.85 (-16.5 – -3.16)**
Length of stay	0.05 (-0.17 – 0.26)	0.02 (-0.17 – 0.22)	-0.09 (-0.45 – 0.27)	-0.10 (-0.40 – 0.20)

*BMI: Body mass index (kg/m^2); †ASA: American Society of Anesthesiology physical status score. ‡MCS: Mental Component Summary.

CHAPTER 3: IMPACT OF PATIENT ENGAGEMENT ON POSTOPERATIVE OUTCOMES

CHAPTER 3.1 – Preamble

In the previous chapter, we demonstrated the association between postoperative complications and patient-reported outcomes in patients undergoing elective colorectal surgery. The findings of our study suggested that postoperative complications negatively impact health-related quality of life in these patients. Moreover, we used two grading systems to measure postoperative complications, Clavien-Dindo classification system and CCI. We concluded that the CCI should be favoured to measure postoperative complications as it was sensitive to both clinical and patient perspectives.

Recent studies have suggested that low levels of patient engagement may be a potential risk factor for postoperative complications in patients undergoing spinal surgery[52,60]. This may be related to patients' level of understanding and engagement in adhering to certain aspects of a perioperative care [61]. Effective patient education strategies may empower patients and better prepare them for their admission and recovery [62]. Our literature review did not identify any studies investigating the association between patient engagement and postoperative clinical and patient-reported outcomes in patients undergoing abdominal and thoracic surgery.

In Chapter 3, we estimated the extent to which patient engagement is associated with postoperative clinical outcomes and PROs. We performed a prospective cohort study of adult patients undergoing elective and emergency thoracic and abdominal surgery. The Patient Activation Measure (PAM) questionnaire was used to quantify patients' engagement, and clinical and patient-reported outcomes were assessed at two postoperative time points. The manuscript was published in *JAMA Surgery*.

CHAPTER 3.2 – Association between patient activation and healthcare utilization after thoracic and abdominal surgery

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KEY POINTS

Question: Does patient activation (ie knowledge, skills, motivation and confidence to participate in care) predict unplanned healthcare utilization post-discharge after major surgery?

Findings: In this prospective study of over 650 patients, patients with low levels of activation have a higher risk of 30-days post-discharge unplanned healthcare utilization and complications and a longer length of hospital stay compared to patients with high levels of activation.

Meaning: Patients at higher risk of costly unplanned healthcare use post-discharge can be identified prior to hospital discharge.

ABSTRACT

Importance: Increased patient activation (PA, i.e. knowledge, skills, motivation and confidence to participate in care) may result in improved outcomes, especially in surgical settings.

Objective: To estimate the extent to which PA predicts 30-day post-discharge unplanned healthcare utilization after major thoracic or abdominal surgery.

Design, Setting and Participants: This prospective cohort study was performed at two centers of a tertiary care hospital network between October 2017 and January 2019. Adult patients undergoing thoracic or abdominal surgery were included. Of 880 patients assessed for eligibility, 692 were deemed eligible, of whom 34 declined to participate, 1 withdrew consent and 4 were excluded after consent.

Exposure: PA was measured immediately after surgery during the initial admission using the Patient Activation Measure (score 0-100). Patients were dichotomized into low and high PA groups using previously described thresholds (≤55.1).

Main outcomes: The primary outcome was unplanned 30-day post-discharge healthcare utilization (composite including emergency department(ED) and outpatient clinic visits and/or hospital readmission). Secondary outcomes were length of stay, 30-days ED visits, 30-days readmissions and postoperative complications.

Results: A total of 653 patients admitted for thoracic, general, colorectal and gynecologic surgery were included in the study (mean age 58 years, 56% female, 56% minimally invasive, 8% emergency surgery), of which 23% had low level PA. Baseline characteristics were similar between patients with low and high level PA. Low PA was an independent predictor of unplanned healthcare utilization(OR 3.15, 95% CI 2.05-4.86; p<0.001), emergency department visits(OR 1.64, 95% CI 1.02-2.64, p=0.04), complications(OR 1.63, 95% CI 1.11-2.41; p=0.01) and length of stay (adjusted mean difference 1.19 days, 95%CI 0.06-2.33;p=0.04). Low PA was not associated with a higher risk of readmission (adjusted OR 1.04, 95%CI 0.56-1.93; p=0.90).

Conclusions: In this study, low level of PA was associated with post-discharge unplanned healthcare use, hospital stay and complications after major surgery. Identification of patients with low activation may allow the implementation of interventions to improve healthcare knowledge and support self-management post-discharge.

INTRODUCTION

Unplanned healthcare utilization after hospital discharge is common, costly and in certain cases, avoidable[1]. Surgical patients account for a fifth of all post-discharge emergency department (ED) visits and a quarter of readmissions[2]. Therefore, post-discharge hospital utilization is often used as a measure of healthcare quality[3]. Strategies to improve the quality of surgery and resource utilization have tended to focus on clinician behaviour and health care system organization[4]. However, new interventions such as Enhanced Recovery Pathways and prehabilitation require patient participation to address health behaviours such as tobacco use, physical activity and nutrition. Strategies to encourage patient and care-giver engagement are included in best practices guidelines for perioperative care, but the evidence supporting these interventions is limited[5].

Patient activation (PA) has emerged as an important pillar of a patient-centered model of care[6]. PA is a novel behavioural concept defined as the knowledge, skills, motivation and confidence to participate in one's own healthcare[7]. PA encompasses multiple key components of patient involvement, including self-efficacy and readiness to change health-related behaviours[7]. Evidence supports that in patients with chronic medical conditions, a higher level of activation is associated with improved self-management behaviours, patient satisfaction and health outcomes[8-12]. Highly activated patients tend to have better problem-solving skills as well as peer support [10]. Importantly, studies suggest that tailored interventions to increase PA may decrease unplanned healthcare use such as ED visits and readmissions[13,14] and reduce health care costs[15].

Despite evidence supporting the role of PA in improving the outcomes of chronic medical patients [14], the impact of PA on postoperative outcomes remains unclear. If PA was associated with surgical outcomes, this would suggest a novel potentially modifiable target for quality of care improvement. The primary purpose of this study is to estimate the extent to which patient activation predicts 30-day post-discharge unplanned healthcare visits (a composite including ED visits, outpatient clinic visits and/or hospital readmission) after major thoracic or abdominal surgery. Secondarily, we explored the association of PA with hospital length of stay, ED visits, readmissions and postoperative complications.

METHODS

The design and reporting of this study were in accordance with the STROBE statement for observational studies[16].

Study Design

We conducted a prospective cohort study in two hospital sites of the McGill University Health Care Center (MUHC), between October 2017 and January 2019. This study was approved by the institutional ethics review board (MUHC Authorization PAM/2018-3778); Study protocol in Appendix 1). Patients who met inclusion criteria were approached the day after surgery by a member of the research team and provided written consent. Consenting patients were informed at time of enrollment of the primary outcome of the study and evaluated twice in the postoperative period. The hospital evaluation included the Patient Activation Measure (PAM), a socioeconomic questionnaire, a health status questionnaire and review of the medical record for information about underlying diagnosis, co-morbidities and surgical procedure. Post-discharge at 30-days, patients were contacted by telephone by one researcher who was blinded to their baseline characteristics and activation level. Patients were asked to self-report any unplanned healthcare visits (ED, clinic or general practitioner visit, or hospital readmission) as well as complete the health status questionnaire. MUHC hospital records and the Dossier Santé Québec

(DSQ) were reviewed for unplanned clinic visits or calls, emergency department visits and readmissions to verify information given by patients. While the DSQ does not capture health care visits per se, it contains all blood tests and imaging performed within the province's public health network.

Study cohort

Adult patients over 18 years old undergoing elective or emergency General, Thoracic, Colorectal, Gynecologic, Vascular or Urologic surgery were considered for inclusion. Patients were recruited from October 31st 2017 to April 6th 2018 and from October 1st 2018 to January 18th 2019. Trauma and transplant patients were excluded, as were patients requiring an ICU stay of more than 3 days. Patients who did not speak or understand English or French or had neurological or cognitive impairments that precluded them from answering questionnaires were excluded from the study.

Study Measures

Demographic data, including age, sex, body mass index (BMI) and comorbidities were collected. Comorbidities were classified using the Charlson Comorbidity Index (CCI) adjusted for age [17]. The underlying diagnosis, type of surgical procedure and surgical approach were recorded, as well as whether the procedure was elective or an emergency. Socioeconomic questionnaires included education level, employment status, type of work, and average annual income. Patient activation was assessed using the Patient Activation Measure Questionnaire (PAM® Survey) supplied by ©Insignia Health, 2016, on a research license [18]. The survey includes 13 items evaluating knowledge, skills, beliefs and confidence. An overall score (0 to

100) categorizes patients into four levels: level 1 (scores ≤ 47), level 2 (scores ≥47.1 and ≤ 55.1), level 3 (scores ≥55.2 and ≤ 72.4), level 4 (scores ≥72.5). Consistent with other studies, patients were dichotomized into low PA (levels 1 and 2) and high PA (levels 3 and 4) groups [14]. At the lowest level, patients are considered passive recipients of care, and at the highest level, patients are able to adopt new behaviours and maintain them under stress. The EQ-5D questionnaire was used to measure perceived health status [19] including the EQ-5D-5L assessing 5 dimensions (mobility, self-care, usual activity, pain or discomfort, and anxiety or depression), and a visual analog scale (EQ VAS) assessing global health (range 0-100). The minimal clinically important difference (MCID) of the EQ-VAS is estimated at 10 in most studies[20] and a mean MCID of 0.074 has been reported for each of the 5 individual dimensions[21].

Study Outcomes

The primary outcome variable of this study was the occurrence of any unplanned post-discharge healthcare visit 30 days after hospital discharge. This included hospital readmission, ED visits and clinic visits (including general practitioner, surgical clinic and nursing clinic). Visits to outside hospitals were identified by patient self-report and confirmed if a record in the DSQ was found. Hospital readmissions and ED visits were also analyzed separately as secondary outcomes as they are the costliest unplanned visits. Other secondary outcomes included index hospital length of stay (LOS), 30-day postoperative complications, return to work and post-discharge health status. Postoperative complications were identified from the MUHC record and recorded up to 30 days after hospital discharge. Each complication was graded using the Clavien-Dindo classification[22] and quantified using the Comprehensive Complication Index (range 0 to 100)[23,24].

Sample Size Calculation

A previous study assessing the impact of PA on 30-day post-discharge hospital utilization in medical patients[14] with 10% Level 1 patients and 45% Level 4 patients reported a 1.75 incidence risk ratio (95% CI 1.06-1.80, $p<0.001$) of 30-day post-discharge hospitalization in level 1 compared to level 4 patients. Based on these data, accounting for 2-sided testing with an α of 0.05, power of 80%, and a 10% loss to follow-up, we estimated that a total of 650 patients would be required for this study.

Statistical Analysis

All patients enrolled in the study were included in the analysis. Summary descriptive statistics using frequency, proportion, mean (SD) or median (IQR) were used to characterize the patient population. Demographics, patient characteristics and rates of postoperative outcomes were compared between patients with high versus low level PA using Chi-square or Fisher's exact test (categorical variables), and t-test or 2-sided Wilcoxon-Mann-Whitney test (continuous variables). Missing data for clinical outcomes for patients that could not be reached at 30-days were handled using multiple imputations using chained equations (10 imputations). Using this method, missing items are estimated using a regression model from other observed data and repeated 10 times to generate 10 different imputed data sets. Uncertainty around the imputed point estimates incorporate the between (datasets) and within (variable) variances according to Rubin rules[25]. Multiple logistic regression was used to determine the independent association of PA level on unplanned post-discharge healthcare utilization, ED visits and readmissions adjusted for age, sex, education level, employment status, income, Charlson comorbidity index, surgical approach and emergency surgery. Multiple logistic or linear regression was also used to determine the independent association of PA level with postoperative complications and LOS adjusted for age, sex, Charlson comorbidity index, surgical approach and emergency surgery. For the analysis of LOS, we considered variables present at baseline, so did not include postoperative complications. All analyses were conducted using STATA 15 software (StataCorp. 2017. *Stata Statistical Software:Release 15*. College Station, TX:StataCorp LLC). Statistical significance was set at a p-value of 0.05.

RESULTS

A total of 1801 patients underwent elective (n=1261) and emergency (n=540) in-patient surgery in the specialities of interest during the study periods. Of these, 880 were assessed for eligibility, and 692 eligible patients were approached for recruitment, of whom 34 declined to participate (4.9%), 1 withdrew consent voluntarily and 4 patients were excluded as the surgical procedure did not meet inclusion criteria (Figure 1). Of the 653 patients included, the median PAM score was 65.5 (IQR 55.6-75); 23% had low level PA l (n=49 level 1 and n=103 level 2) and 77% had high level PA (n=261 level 3 and n=240 level 4). A total of 59 patients (9%) could not be reached for the phone interview and were excluded from the analysis of 30-days patient-reported health state only. Losses to follow up were similar between the two groups (10% low PA and 9% high PA).

Baseline demographic and clinical characteristics of patients are reported in Table 1. Patients with low activation were more likely to report being employed in a job requiring physical work. Other variables including comorbidity index, employment status, education and income level were similar between groups. Patients with low PA reported significantly lower overall health (mean VAS 52[95%CI 49-55] vs 59[95%CI 57-60)]; p<0.001) and significantly higher anxiety/depression (1.90[95%CI 1.74-2.06] vs 1.63[95%CI 1.56-1.71]; p=0.002) (Table 1). Overall, 8% of patients underwent emergency surgery.

Unplanned healthcare utilization at 30-days post-discharge was significantly higher in patients with low PA compared to patients with high PA (42% vs 20%; p<0.001). However, hospital readmissions were similar between the two groups (11% vs 11%) (Table 2). Of the ED visits, only 6(5.7%) occurred at a site other than the MUHC and all readmissions were at our center only. Reasons for ED visits are reported in supplemental Table 1.

Patients with low PA had longer initial hospital LOS compared to patients with high level PA (median 3.5 vs 3 days; p=0.04). A total of 223 patients (34%) developed postoperative complications (Table 2). When assessing the timing of the complication, there were 94 patients with complications diagnosed post-discharge, with a similar proportion in the two PA groups (48% vs 40%, p=0.29). Global health state was higher 30-days after discharge compared to immediately post-operatively, yet patients with low PA remained lower than patients with high PA (mean 70[95%CI 67-73] vs 77[95%CI 75-79]; p<0.001). For employed patients reached at 30-days (n=259), those with low PA were less likely to have returned to work at 30-days post-discharge (29% vs 45%; p=0.02).

On multivariate logistic regression, low level of PA was associated with a higher risk of unplanned healthcare visits compared to high level PA (adjusted OR 3.15, 95%CI 2.05-4.86; p<0.001 (Table 3). Low level PA was also associated with an increased risk of ED visits (adjusted OR 1.64, 95% CI 1.02-2.64; p=0.04) but was not associated with a higher risk of readmission(adjusted OR 1.04, 95%CI 0.56-1.93;p=0.90) (Table 3). Low activation was associated with an increased risk for complications (adjusted OR 1.63, 95%CI 1.11-2.41;

p=0.01), as was Charlson comorbidity index, while minimally invasive surgery was protective (Table 4). Low level PA was also an independent predictor of LOS (adjusted mean difference 1.19 days, 95%CI 0.06-2.33; p=0.04), along with comorbidity index and emergency surgery (supplemental Table 2). The unadjusted univariate regressions are included in Supplemental Tables 3 to 5.

DISCUSSION

Identifying modifiable risk factors for unplanned healthcare utilization is of significant importance not only from a healthcare system perspective, but also from patients' perspective, when considering the distress associated with a hospital visit[26,27]. In this study, a lower level of patient activation was associated with a higher risk of unplanned healthcare utilization 30 days after major thoracic and abdominal in-patient surgery. While low PA level increased the risk of ED visits, it did not affect hospital readmission. These results support that determining PA level preoperatively could help identify patients at higher risk of unplanned visits and prompt interventions to adequately prepare and support them after discharge.

These findings are similar to previous literature supporting PA as a predictor of adherence to healthy behaviors and screening testing, clinical outcomes, and hospital and emergency department visits, independent of sociodemographic characteristics[9,10,14,28-30]. However, most of this work was in the context of chronic medical conditions. To our knowledge, this is the first study of the role of patient activation in patients undergoing thoracic and abdominal surgery. A few previous studies assessed the role of PA in the functional recovery of patients undergoing orthopedic surgery[31-33]. Similar to previous studies, we found that PA was independent of age, sex, level of education, employment status and annual income and therefore may be a novel and potentially modifiable variable.

Patients with lower levels of activation were at higher risk for developing a complication. The Clavien complication severity grade distribution did not differ between the two groups, but low PA patients had a higher median comprehensive complication index, which is considered a more sensitive indicator of the total burden of complications[23]. PA has been shown to correlate with patient participation in rehabilitation programs after orthopedic surgery, which may explain the relationship to postoperative complications[31,34]. We considered whether the higher risk of complications was the reason for the unplanned visit or was rather a reporting bias in that patients with lower levels of PA were also more likely to seek medical attention post-discharge and be evaluated. However, the proportion of patients presenting with a post-discharge complication was similar between the PA levels, suggesting the occurrence of complications was not the sole driver of the unplanned visit.

While low PA was associated with a higher risk of ED visits, these did not result in a higher risk of readmissions, in contrast to patients with chronic medical conditions[14]. This suggests that the reason for the ED visit could have potentially been managed in a different setting[1,35-38]. Having the ability to identify patients at risk for potentially avoidable ED visits may help build a more tailored and patient-centered discharge plan[3,4,39,40]. The answers provided on the PAM questionnaire may suggest specific areas where patients need help, such as further education, skills development or nursing or social worker support. Importantly, PA level is changeable, and can be increased through tailored interventions focused on skills-training and encouragement of a sense of ownership of health[41]. Furthermore, in chronic diseases, activation-focused interventions including coaching, education and peer support can result in sustained improvements in self-management behaviours and clinical outcomes, as well as reduced use of health care services[11,12,37].

Surgical patients differ from chronic medical patients in the acute nature of their therapeutic management[42]. Major surgery results in a predicable decline in functional status and health-related quality of life which requires a period of recovery of weeks to months. In this study, patients with low level PA reported lower overall health state and lower scores in mobility, ability to perform usual activity, pain and anxiety/depression compared to patients with high level PA. Moreover, for employed patients, a higher proportion of patients with high PA levels returned to work within 30 days after discharge. This may be due to the fact that patients with low PA were more likely to have a physical job and reported lower scores for pain, activities, mobility and anxiety/depression.

This study has several strengths. It included a relatively large sample of patients undergoing a wide range of major surgical procedures, adding to its generalizability. The review of the provincial health record identified ED visit testing occurring at outside centres. Patient-reported unplanned healthcare use allowed for the capture of office and clinic visits that are not included in hospital and provincial records. Patients were informed of the primary outcome at time of enrollment which sensitized documentation of unplanned healthcare uses. Observer bias was also minimized as the researcher assessing outcome variables was unaware of the patient baseline characteristics and activation level.

The results of this study should be interpreted in light of several limitations. First, we could not reach 59 patients one month after surgery. However, the losses to follow up were similar between the two groups (10% low PA and 9% high PA). We relied on patients to report clinic and general practitioner visits that are not recorded in the provincial record and did not have access to clinical records from outside the MUHC. In addition, the main finding of the association between PA and unplanned visits was maintained when only considering ED visits, which were fully captured, with only 6% occurring at an outside institution. Second, although this is a relatively large study, we approached only half of the patients undergoing potentially relevant procedures during the study period. This may be due to delayed recording of surgical admissions in the operating room database we used to identify patients. In addition, while the study protocol specified inclusion of both emergency and elective patients, our patient identification strategy resulted in the unexpected underrepresentation of emergency surgery patients (8% of the study population vs 30% of procedures during the study periods). Although we adjusted for this variable in our regression models, this may limit the applicability of the results to elective procedures only and the impact of PA in emergency surgery warrants future investigation. Third, this study was performed at an academic medical center in Canada and results may only be generalizable to similar settings. However, the distribution of the PA levels was consistent with previous studies from other geographic locations and patient settings[13,14,43,44].

CONCLUSION

The results of this study suggest that patients with low levels of activation are at increased risk of early unplanned healthcare utilization post discharge after major surgery, including ED visits, without an increased risk in readmission. Lower level PA was also associated with increased risk of 30-days complications, longer hospital stay and lower health-related quality of life during the recovery period. As a more patient-centered approach to surgical care is increasingly advocated, the identification of patients with lower levels of activation could prompt the provision of additional support through targeted education or other resources to improve postoperative outcomes.

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Figure 1. Patient selection flow diagram.

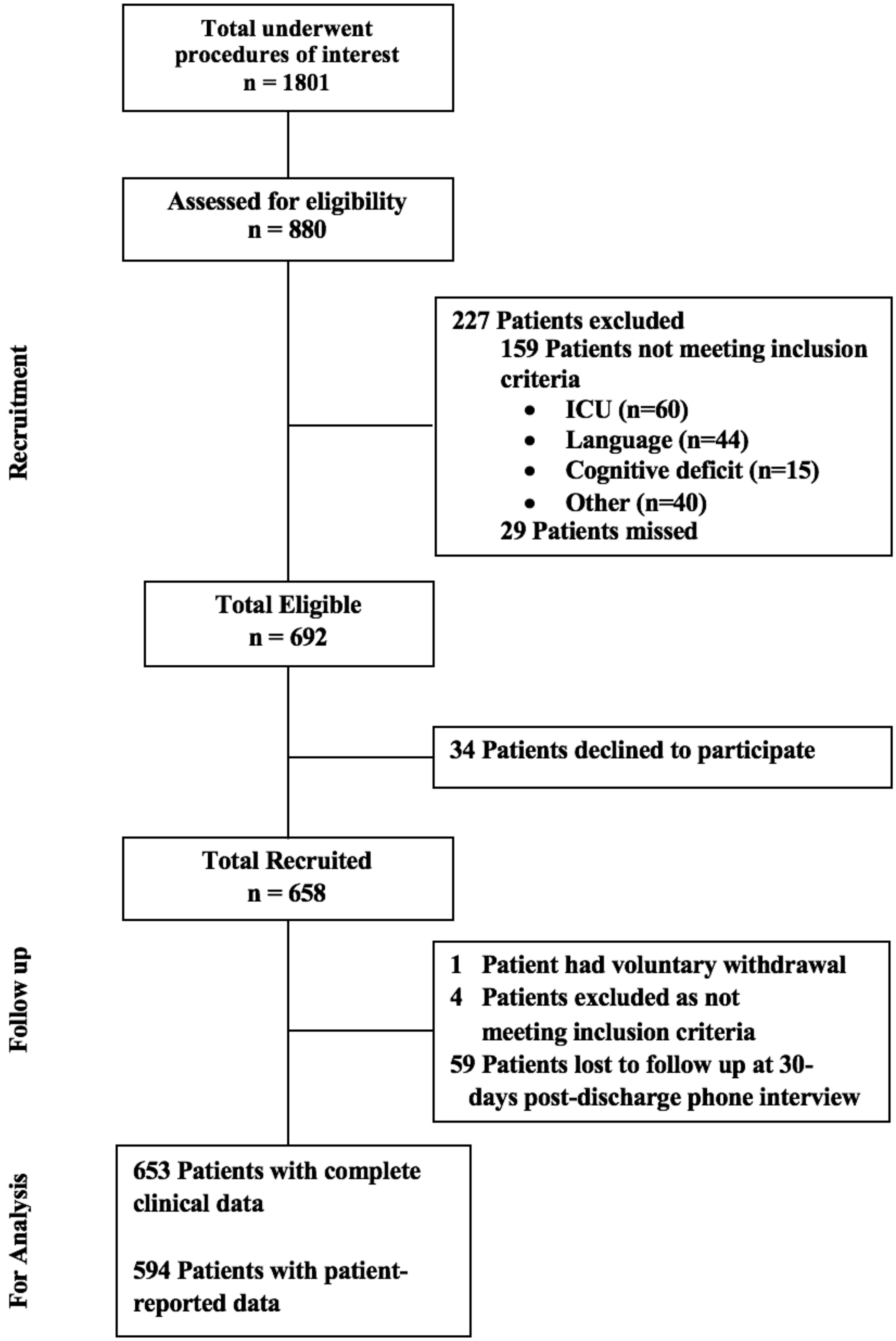

Table 1. Baseline demographic and clinical characteristics and in-hospital health state

Variables	Total (n=653)	Low PAM (n= 152)	High PAM (n=501)	p-value
Age, mean (SD)	58 (15)	56 (16)	58 (15)	0.16
Sex, male	284 (44)	70 (46)	214 (43)	0.44
BMI, mean (SD)	29 (9)	28 (9)	29 (9)	0.16
Charlson Comorbidity Index, mean (SD)	3.8 (2.6)	3.6 (2.7)	3.6 (2.7)	0.36
Language				
English	326 (50)	85 (56)	241 (48)	
French	307 (47)	65 (42)	242 (48)	0.14
Other	14 (2)	1 (1)	13 (32)	
Missing	6 (1)	1 (1)	5 (1)	
Education level				
Less than high school	52 (8)	13 (9)	39 (8)	
High school or equivalent	178 (27)	44 (29)	134 (27)	0.83
More than high school	419 (64)	95 (62)	324 (64)	
Missing	4 (1)	0 (0)	4 (1)	
Employment status				
Employed	289 (44)	69 (45)	220 (44)	
Homemaker/retired/student	261 (40)	57 (38)	204 (41)	0.84
Disabled	79 (12)	19 (12)	60 (12)	
Unemployed	24 (4)	7 (5)	17 (3)	
Type of work *(n=289)* [a]				
Office work	139 (48)	21 (30)	118 (54)	
Physical work	96 (33)	33 (48)	62 (28)	0.001*
Other	54 (19)	15 (22)	40 (18)	
Average income per year				
<30,000 $	43 (7)	12 (8)	31 (6)	
30,000-59,999 $	110 (17)	27 (18)	83 (17)	0.21
≥60,000 $	102 (16)	17 (11)	85 (17)	
Declined to disclose	34 (5)	12 (8)	22 (4)	
Not applicable	364 (55)	84 (55)	280 (56)	
Diagnosis of malignancy	367 (56)	86 (57)	281 (56)	0.92
Emergency surgery	52 (8)	14 (9)	38 (8)	0.50
Surgical approach:				
Minimally invasive	366 (56)	85 (56)	281 (56)	
Open	263 (40)	62 (41)	201 (40)	0.95
Converted	24 (4)	5 (3)	19 (4)	

Table 1. Baseline demographic and clinical characteristics and in-hospital health state (cont.)

Variables	Total (n=653)	Low PAM (n= 152)	High PAM (n=501)	p-value
Procedure Category:				
Thoracic	175 (27)	41 (27)	134 (27)	
General Surgery	132 (20)	38 (25)	94 (19)	
Colorectal	95 (15)	25 (16)	70 (14)	
Gynecology	96 (15)	21 (14)	75 (15)	
Bariatric	53 (8)	7 (5)	46 (9)	0.26
Hepatobiliary	46 (7)	10 (6)	36 (7)	
Urology	48 (7)	7 (5)	41 (8)	
Vascular	8 (1)	3 (2)	5 (1)	
EQ VAS score, median (IQR)	57 (50–70)	50 (40–65)	60 (50–75)	<0.001*
EQ-5D-5L, mean (SD)				
Mobility	2.73 (1.17)	2.88 (1.18)	2.68 (1.16)	0.06
Self-Care	2.96 (1.33)	3.07 (1.30)	2.92 (1.34)	0.24
Usual Activity	4.27 (1.19)	4.43 (1.10)	4.22 (1.21)	0.05
Pain or Discomfort	2.77 (0.83)	2.80 (0.85)	2.76 (0.82)	0.68
Anxiety or Depression	1.70 (0.91)	1.90 (1.00)	1.63 (0.88)	0.002*

Data are presented as no. (%) unless otherwise specified
Abbreviations: PAM=Patient Activation Measure (range of 0-100); BMI=body mass index; VAS=visual analogue scale.
[a] Among patients employed
*p-value statistically significant <0.05

Table 2. Post-operative clinical and self-reported outcomes 30 days after hospital discharge.

Variables	Total (n=653)	Low PAM (n=152)	High PAM (n=501)	p-value
Any unplanned healthcare utilization	164 (25)	64 (42)	100 (20)	<0.001*
Emergency Department visits	106 (16)	33 (22)	73 (15)	0.03*
Readmission	71 (11)	16 (11)	55 (11)	0.89
Outpatient clinic visit	77 (12)	41 (27)	36 (7)	<0.001*
Return to work within 30 days *(n=259)* [a]	108 (42)	18 (29)	90 (45)	0.02*
Lost days from work, median (IQR)	19 (15 – 22)	18 (15 – 21)	19 (15 – 22)	0.68
Hospital LOS, median (IQR)	3 (1 – 5)	3.5 (2 – 6)	3 (1 – 5)	0.04*
Postoperative complications	223 (34)	63 (41)	160 (32)	0.03*
Clavien-Dindo Grade				
None	430 (67)	89 (59)	341 (68)	0.14
I	107 (16)	28 (18)	79 (16)	
II	64 (10)	18 (12)	46 (9)	
III+	52 (8)	17 (11)	35 (7)	
Comprehensive complication index				
median (IQR)	0 (0 – 9)	0 (0 – 15)	0 (0 – 9)	0.02*
mean (SD)	7.7 (14.6)	9.6 (15.7)	7.1 (13.2)	0.06
Timing of complication *(n=223)* [b]				
In hospital (initial admission) alone	129 (58)	33 (52)	96 (60)	0.29
Post-discharge alone	67 (30)	17 (27)	50 (31)	0.54
Both	27 (12)	13 (21)	14 (9)	0.01*
Mortality	5 (1)	1 (1)	4 (1)	0.67
EQ VAS, mean (95%CI) *(n=576)* [c,d]	75 (74-77)	70 (67-73)	77 (75-79)	<0.001*
EQ-5D-5L, mean (95%CI) *(n=576)* [c,e]				
Mobility	1.68 (1.62-1.75)	1.87 (1.73-2.02)	1.63 (1.56-1.71)	0.003*
Self-care	1.61 (1.54-1.67)	1.73 (1.58-1.87)	1.57 (1.49-1.65)	0.05
Usual Activity	2.39 (2.33-2.47)	2.64 (2.51-2.77)	2.33 (2.25-2.40)	<0.001*
Pain or Discomfort	1.79 (1.74-1.86)	1.95 (1.82-2.07)	1.75 (1.69-1.81)	0.006*
Anxiety or Depression	1.43 (1.38-1.49)	1.64 (1.50-1.77)	1.37 (1.31-1.43)	<0.001*

Data are presented as No. (%) unless otherwise specified.
Abbreviations: PAM=Patient Activation Measure (range of 0-100); VAS=visual analogue scale.
[a] Among patients employed
[b] Among patients with postoperative complications
[c] Among patients with 30-days post-discharge phone follow-up
[d] Scores range from 0 to 100, with higher scores indicating higher quality of life
[e] Scores range from 1 to 5, with lower scores indicating higher quality of life
*p-value <0.05

Table 3. Multivariate logistic regression of predictors of overall unplanned healthcare visits and ED visits 30-days after discharge.

Variables	Unplanned healthcare visits		ED visits		Readmissions	
	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value
PAM level						
High level	1 [Ref]	Ref	1 [Ref]	Ref	1 [Ref]	Ref
Low level	**3.15 (2.05-4.86)**	**<0.001***	**1.64 (1.02-2.64)**	**0.04***	1.04 (0.56-1.93)	0.90
Age	0.99 (0.97-1.02)	0.63	0.99 (0.97-1.02)	0.74	1.01 (0.98-1.04)	0.53
Sex						
Male	1 [Ref]	Ref	1 [Ref]	Ref	1 [Ref]	Ref
Female	0.89 (0.59-1.36)	0.60	1.41 (0.90-2.21)	0.13	1.21 (0.70-2.10)	0.11
Education level						
Less than high school	1 [Ref]	Ref	1 [Ref]	Ref	1 [Ref]	Ref
High school or equivalent	0.82 (0.37-1.78)	0.61	0.71 (0.21-1.64)	0.43	0.46 (0.18-1.20)	0.11
More than high school	0.84 (0.40-1.73)	0.63	0.72 (0.33-1.59)	0.42	0.51 (0.21-1.22)	0.13
Employment status						
Employed	1 [Ref]	Ref	1 [Ref]	Ref	1 [Ref]	Ref
Unemployed	5.45 (0.60-49.9)	0.13	2.61 (0.25-27.5)	0.43	0.75 (0.03-16.9)	0.86
Homemaker/retired/ student	2.96 (0.37-23.6)	0.31	1.02 (0.10-10.3)	0.99	0.30 (0.01-6.45)	0.44
Disabled	3.99 (0.49-32.7)	0.20	1.41 (0.14-14.6)	0.77	0.43 (0.02-9.63)	0.59
Income						
≥60,000$	1 [Ref]	Ref	1 [Ref]	Ref	1 [Ref]	Ref
<30,000$	0.72 (0.27-1.91)	0.51	0.92 (0.32-2.65)	0.89	0.90 (0.26-3.13)	0.87
30,000-59,999$	1.68 (0.86-3.27)	0.12	1.65 (0.78-3.51)	0.19	0.96 (0.38-2.38)	0.92
Declined to disclose	1.02 (0.37-2.80)	0.97	1.40 (0.45-4.41)	0.56	0.86 (0.20-3.79)	0.85
Charlson Comorbidity Index	1.04 (0.93-1.17)	0.45	0.97 (0.85-1.11)	0.64	0.94 (0.80-1.09)	0.40
Surgical Approach						
Open	1 [Ref]	Ref	1 [Ref]	Ref	1 [Ref]	Ref
Minimally invasive	0.81 (0.55-1.21)	0.32	1.05 (0.67-1.67)	0.82	0.66 (0.38-1.14)	0.14
Converted to open	0.47 (0.15-1.52)	0.21	0.68 (0.18-2.55)	0.57	0.54 (0.12-2.49)	0.43
Emergency Surgery	1.28 (0.61-2.71)	0.51	1.43 (0.64-3.21)	0.39	1.54 (0.57-4.31)	0.40

Data presented as Adjusted Odds Ratio (95% confidence interval).
Abbreviations: PAM=Patient Activation Measure (range 0-100).
ED=Emergency Department. OR=odds ratio.
* p-value <0.05

Table 4. Multivariate logistic regression of predictors of 30-days overall complications

Variables	Adjusted OR (95% CI)	p-value
PAM level		
High level	1 [Ref]	Ref
Low level	**1.63 (1.11-2.41)**	**0.01***
Age	1.00 (0.99-1.02)	0.71
Sex		
Male	1 [Ref]	Ref
Female	1.18 (0.83-1.67)	0.35
Charlson Comorbidity Index	**1.11 (1.01-1.21)**	**0.03***
Surgical Approach		
Open	1 [Ref]	Ref
Minimally invasive	**0.58 (0.41-0.81)**	**0.002***
Converted to open	1.28 (0.55-3.00)	0.57
Emergency Surgery	1.07 (0.55-2.07)	0.84

Data presented as Adjusted Odds Ratio (95% confidence interval).
Abbreviations: PAM=Patient Activation Measure (range 0-100); OR=odds ratio
* p-value <0.05

Supplemental Table 1. Reasons for 30-days post-discharge ED visits

Reason for ED visit	Total number (n=106)	Low PAM (n=34)	High PAM (n=72)
Wound infection or collection	13	5	8
Pain	13	3	10
Abscess	9	5	4
Bleeding	6	2	4
Bowel obstruction	6	1	5
Anxiety	4	2	2
Recurrent pneumothorax	4	0	4
Urinary retention	4	3	1
Urinary tract infection	4	0	4
Wound concerns (without infection)	4	1	3
Dyspnea	3	2	1
GI discomfort (nausea, bloating, constipation)	3	2	1
Migraine or vertigo	3	2	1
Vascular thrombosis (portal, splenic, ovarian veins)	3	1	2
Anastomotic stenosis	2	1	1
Empyema or Pneumonia	2	1	1
Ileus	2	0	2
Incisional hernia	2	1	1
Internal hernia	2	0	2
Drain concerns (chest tube and Jackson-Pratt)	2	0	2
Acute kidney injury	1	0	1
Anastomotic leak	1	0	1
Bronchoesophageal fistula	1	0	1
Dysphagia	1	0	1
Fatigue	1	0	1
Fever	1	1	0
Gastroparesis	1	1	0
Hemorrhoids	1	0	1
Kidney stone	1	0	1
Pulmonary embolism	1	0	1
Prolapsed ileostomy	1	0	1
Renal artery pseudoaneurysm	1	0	1
Septic shock	1	0	1
Syncope	1	0	1
Upper respiratory tract infection	1	0	1

Data presented in No.

Abbreviations: ED=emergency department

Supplemental Table 2. Univariate logistic regression of predictors of overall unplanned healthcare visits and ED visits 30-days after discharge.

Variables	**Unplanned healthcare visits**		**ED visits**		**Readmissions**	
	OR (95% CI)	**p-value**	**OR (95% CI)**	**p-value**	**OR (95% CI)**	**p-value**
PAM level						
High level	1 [Ref]	**Ref**	1 [Ref]	**Ref**	1 [Ref]	Ref
Low level	**3.05 (2.03-4.58)**	**<0.001***	**1.63 (1.03-2.58)**	**0.04***	0.97 (0.54-1.77)	0.94
Age	0.99 (0.97-1.00)	0.06	**0.98 (0.97-0.99)**	**0.02***	0.99 (0.98-1.01)	0.46
Sex						
Male	1 [Ref]	Ref	1 [Ref]	Ref	1 [Ref]	Ref
Female	0.93 (0.64-1.35)	0.71	1.27 (0.85-1.91)	0.25	1.23 (0.75-2.01)	0.41
Education level						
Less than high school	1 [Ref]	Ref	1 [Ref]	Ref	1 [Ref]	Ref
High school or equivalent	0.90 (0.44-1.85)	0.78	0.77 (0.35-1.71)	0.53	0.45(0.18-1.12)	0.09
More than high school	0.89 (0.46-1.72)	0.74	0.84 (0.41-1.75)	0.65	0.58 (0.26-1.30)	0.19
Employment status						
Employed	1 [Ref]	Ref	1 [Ref]	Ref	1 [Ref]	Ref
Unemployed	1.39 (0.58-3.30)	0.13	1.94 (0.79-4.78)	0.15	1.93 (0.67-5.52)	0.22
Homemaker/retired/ student	0.69 (0.47-1.02)	0.06	**0.58 (0.36-0.95)**	**0.03***	0.81 (0.46-1.44)	0.47
Disabled	1.07 (0.61-1.87)	0.81	0.99 (0.52-1.90)	0.98	1.33 (0.63-2.79)	0.45
Income						
≥60,000$	1 [Ref]	Ref	1 [Ref]	Ref	1 [Ref]	Ref
<30,000$	0.99 (0.41-2.38)	0.99	1.07 (0.40-2.85)	0.90	1.01 (0.33-3.11)	0.99
30,000-59,999$	**1.98 (1.07-3.68)**	**0.03***	1.65 (0.80-3.40)	0.17	0.98 (0.42-0.23)	0.97
Declined to disclose	1.29 (0.50-3.28)	0.60	1.39 (0.46-4.24)	0.56	0.83 (0.20-3.42)	0.80
Charlson Comorbidity Index	0.98 (0.91-1.05)	0.56	0.93 (0.86-1.01)	0.10	0.97 (0.88-1.06)	0.40
Surgical Approach						
Open	1 [Ref]	Ref	1 [Ref]	Ref	1 [Ref]	Ref
Minimally invasive	0.74 (0.51-1.06)	0.10	0.94 (0.61-1.46)	0.78	**0.56 (0.34-0.94)**	**0.03***
Converted to open	0.47 (0.15-1.41)	0.18	0.69 (0.19-2.46)	0.56	0.51 (0.11-2.28)	0.38
Emergency Surgery	1.37 (0.73-2.60)	0.33	1.71 (0.83-3.52)	0.15	1.54 (0.62-3.81)	0.35

Data presented as Adjusted Odds Ratio (95% confidence interval).
Abbreviations: PAM=Patient Activation Measure (range 0-100). ED=Emergency Department. OR=odds ratio.
* p-value <0.05

Supplemental Table 3. Univariate logistic regression of predictors of 30-days overall complications

Variables	Unadjusted OR (95% CI)	p-value
PAM level		
High level	1 [Ref]	Ref
Low level	**1.51 (1.04-2.19)**	**0.03***
Age	1.01 (1.00-1.03)	0.71
Sex		
Male	1 [Ref]	Ref
Female	**1.42 (1.03-1.97)**	**0.04***
Charlson Comorbidity Index	**1.13 (1.05-1.20)**	**<0.001***
Surgical Approach		
Open	1 [Ref]	Ref
Minimally invasive	**0.52 (0.37-0.73)**	**<0.001***
Converted to open	1.16 (0.50-2.70)	0.73
Emergency Surgery	0.86 (0.46-1.58)	0.62

Data presented as unadjusted Odds Ratio (95% confidence interval).
Abbreviations: PAM=Patient Activation Measure (range 0-100); OR=odds ratio
* p-value <0.05

Supplemental Table 4. Univariate linear regression of predictors of length of stay

Variables	Unadjusted OR (95% CI)	p-value
PAM level		
High level	1 [Ref]	Ref
Low level	2.60 (0.73-9.27)	0.14
Age	**1.06 (1.02-1.09)**	**0.003***
Sex		
Male	1 [Ref]	Ref
Female	2.00 (0.67-5.94)	0.21
Education level		
Less than high school	1 [Ref]	Ref
High school or equivalent	1.34 (0.15-11.8)	0.79
More than high school	0.57 (0.08-4.34)	0.59
Employment status		
Employed	1 [Ref]	Ref
Unemployed	0.74 (0.04-13.7)	0.84
Retired/homemaker/student	**3.58 (1.11-11.5)**	**0.03***
Disabled	0.85 (0.15-4.88)	0.86
Income		
≥60,000$	1 [Ref]	Ref
<30,000$	0.45 (0.04-5.40)	0.53
30,000-59,999$	0.40 (0.06-2.65)	0.34
Declined to disclose	0.37 (0.02-5.62)	0.47
Charlson Comorbidity Index	**1.70 (1.39-2.08)**	**<0.001***
Surgical Approach		
Open	1 [Ref]	Ref
Minimally invasive	**0.01 (0.00-0.03)**	**<0.001***
Converted to open	0.19 (0.01-3.03)	0.24
Emergency Surgery	**10.5 (1.65-67.3)**	**0.01***

Data presented as Adjusted Odds Ratio (95% confidence interval).
Abbreviations: PAM=Patient Activation Measure (range 0-100); OR=odds ratio.
* p-value <0.05

CHAPTER 4: VALIDITY OF A PATIENT ENGAGEMENT MEASURE IN SURGICAL PATIENTS

CHAPTER 4.1 – Preamble

In Chapter 2, we explored the relationship between clinical outcomes of interest to healthcare professionals and patient-reported outcomes. We advocate that both be reported in high quality surgical research to adequately present results in a patient-centered framework. In Chapter 3, we further assessed the role of patient engagement in a prospective study of diverse surgical patients. We found evidence for an important association between patient engagement as measured by PAM and both clinical and patient-reported outcomes. In order to next determine whether patient engagement is modifiable in surgical patients, we must first provide evidence for the validity of tools used to measure this construct. Although the PAM questionnaire was developed over 2 decades ago, we did not identify other tools in the literature specifically designed to quantify patient engagement. Yet, the ability to measure is vital for the improvement of quality in health care. The prominent physicist Lord Kelvin best stated: “To measure is to know. If you cannot measure it, you cannot improve it.”

The purpose of Chapter 4 is to provide evidence for the validity of the PAM questionnaire to measure engagement in patients undergoing abdominal and thoracic surgery. We used data obtained in the prospective study of Chapter 3 and performed a secondary Rasch analysis, a psychometric technique developed to help researchers create more precise measuring instruments. This type of analysis compares individual responses of a PRO measure with a Rasch model. Chapter 4 will thus allow us to determine whether the PAM has properties of an interval scale in our patient population or whether each item stands on its own. In additions, we used a question understanding aid tool to assess the quality and identify problems in the wording of the items in PAM. This manuscript will be submitted to *JAMA Surgery*.

CHAPTER 4.2 – Evidence for the validity of the Patient Activation Measure Questionnaire in surgical patients: a Rasch analysis

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ABSTRACT

Objective: There is evidence supporting the validity of the Patient Activation Measure (PAM-13) to measure patients' knowledge, skills and confidence in managing their chronic medical conditions. However very few studies have used this measure in surgical patients. This study aims to provide evidence for the validity of the PAM-13 in patients undergoing major abdominal and thoracic surgery.

Methods: Adults undergoing major thoracic or abdominal surgery at two university-affiliated healthcare centers were enrolled from 2017 to 2019 in a prospective study relating patient activation to postoperative outcomes. PAM-13 was administered in the immediate postoperative period. Rasch analysis was used to evaluate the fit of PAM items to the Rasch model; item fit, unidimentionality, differential item functioning (DIF) and person-item targeting were assessed. Question Understanding Aid (QUAID) tool was used to assess the quality of PAM-13 items.

Results: PAM-13 survey was completed by 653 patients. There were no missing responses. Very few patients answered "Strongly Disagree". Overall, 2 items did not fit the Rasch model. All items fit the model appropriately, except for item 4. There was evidence of potential local response-dependence for one item. Unidimensionality was confirmed once it was removed and there was no DIF identified for age, sex and education level. Targeting of items to people with lower ability was poor. The person separation index (PSI) of the adjusted model was acceptable (0.77). QUAID evaluation identified some problematic terms in the survey questions and answer options.

Conclusion: Using Rasch analysis, we identified some issues with the PAM-13 questionnaire in its current form. However, with a few changes, it can reliably be used in clinical practice to measure patient activation in patients undergoing major abdominal and thoracic surgery. These results support further research in the role of patient activation in surgical patients.

INTRODUCTION

Patient engagement is now acknowledged to be a fundamental component of the current and evolving patient-centered healthcare model[1]. Successful implementation of such a model requires direct collaboration with patients and their support systems. Patient activation, defined as the knowledge, skills, motivation and confidence to participate in one's own healthcare, is a novel behavioural concept that encompasses several components of patient involvement [2, 3]. It includes self-efficacy, self-management and readiness to change health-related behaviours. Evidence supports patient activation as a factor related to improved self-management behaviours, patient satisfaction and health outcomes, and reduced health resource utilization and costs[4-7]. However, most of the evidence stems from studies in patients with chronic illnesses. The effect of patient activation in acute care settings has not been well established.

Measurement capability is necessary for improvement of health care quality. The lack of measures that are fit for the purpose of measuring patient activation in surgical patients is a limiting factor in the development of crucial aspects of a patient-centered model in this population. Very few patient-reported measures of patient engagement or activation have been validated or implemented in a real-time clinical setting[8]. The Patient Activation Measure (PAM) survey is a conceptually vigorous and psychometrically sound measure that includes 13 items in its most current version (PAM-13) [2, 9]. The items in PAM-13 measure 3 constructs. There are 10 items measuring beliefs, 1 item focused on an action and 1 item focused on knowledge. PAM-13 was developed using Rasch measurement theory, a modern psychometric method that keeps the conceptual underpinning of the instrument at the center of its model and provides diagnostic statistics that help identify anomalies in the scores. Using Rasch theory provides several advantages. It allows to calibrate all items on the same ruler and to generate a true interval score which permits to evaluate changes over time with accuracy and precision. It also allows the generation of scales that are not dependant on patients baseline characteristics.

Recent evidence supports an association between higher levels of activation and reduced length of stay and unplanned post-discharge healthcare resource use in a surgical cohort[10]. However, PAM was developed to assess engagement in patients with chronic medical conditions and did not originally include surgical patients. Therefore, the psychometric properties of PAM amongst patients undergoing abdominal or thoracic surgery remain to be determined. The primary objective of this study was to use Rasch analysis to test measurement properties of the PAM-13 questionnaire in patients undergoing abdominal and thoracic surgery and to identify whether the score is interpretable by age, sex and education. The secondary objective of this study was to assess the quality of PAM-13 using a novel evaluation tool, the Question Understanding Aid (QUAID) tool.

METHODS

Study design and Participants

A secondary analysis of data collected during a prospective cohort study at two university-affiliated tertiary care institutions was performed. The aim of this study was to estimate the extent to which patient activation predicted 30-day post-discharge unplanned healthcare visits after in-patient thoracic and abdominal surgery [10]. The study population consisted of adult patients over the age of 18 years old who underwent both major elective and emergency thoracic and/or abdominal surgeries requiring an overnight hospitalization at a minimum (including general, thoracic, colorectal, gynecologic, vascular and urologic surgery). Patients were excluded if they did not speak English or French, or if they had neurological or cognitive impairments preventing them from answering questionnaires. Patients were enrolled postoperatively during their initial hospital stay and completed the 13-item Patient Activation Measure, a socioeconomic questionnaire and a health status questionnaire. Patients were then contacted 30-days post hospital discharge and asked to self-report any unplanned healthcare visits.

Measures

Demographic data including age, sex, body mass index (BMI) and comorbidities (classified using the Charlson Comorbidity Index[11, 12] adjusted for age) were collected. The underlying diagnosis, surgical procedure and surgical approach, as well as whether the procedure was performed on a scheduled or emergency basis, were recorded. Patient's education level, employment status, type of work and average annual income was collected using a socioeconomic questionnaire. Patient activation was assessed using the PAM-13 as supplied by ©Insignia Health, 2016, on a research license [13]. The 13 items query knowledge, skills, beliefs and confidence in managing one's healthcare [2, 14] each rated on a 4-point Likert scale: Strongly Disagree, Disagree, Agree, Strongly Agree with an extra category for Not Applicable. A continuous score from 0 to 100 is derived which is categorized into four levels of activation: level 1 (scores ≤ 47), level 2 (scores ≥47.1 and ≤ 55.1), level 3 (scores ≥55.2 and ≤ 72.4), level 4 (scores ≥72.5). At level 1, patients are considered passive recipients of care, and at level 4, patients are considered able to adopt new behaviours and maintain them under stress.

Statistical Analysis

All patients enrolled in the study were included in the analysis. Summary descriptive statistics using frequencies, proportions, means (SD) or medians (IQR) were used to characterize the patient population for demographic variables, clinical variables and postoperative outcomes.

Rasch Analysis

The PAM questionnaire was originally developed using a Rasch analysis. The aim of a Rasch analysis is to identify items that do not fit a hierarchy of low to high ability. This theory is based on the underlying logic that participants will have a higher probability of correctly answering items that are easier and a lower probability of answering items that are harder. These items are all placed on the same measurement ruler, with easier items at the lower end of the measure and more difficult items at the top end of the scale. It compares individuals' responses to items on a measure to what would be expected from the Rasch model. This provides evidence as to whether scores obtained for individual items of the measure can be added together to obtain an overall score, allowing a determination of whether the outcome measure has properties of an interval scale which is a condition required for mathematical transformations.

The Rasch partial credit model was used through RUMM2030 version 5.8.1 l[15]. The steps taken to fit the data to the model followed guidelines recommended by Tennant and Conaghan[16, 17]. The explanation for the iterative steps in a Rasch analysis and the interpretation of the parameters from the Rasch model according to the work of Mayo and of Hum[18] are provided in Supplement 1.

Items that did not fit the Rasch model were investigated and removed one at a time until the best model was obtained. Item and person fit statistics were re-examined after each deletion to identify improvements to the model. A person-item threshold distribution plot, a plot of the distribution of people and items along with the ability metric of the latent trait of patient engagement, was used to assess whether the final set of items optimally targeted the population. The threshold map was used to illustrate the hierarchical nature of the final model. An ideally targeted measure should include a set of items that spans the full range of the theoretical latent construct. The appropriate sample size for Rasch analysis depends on the required degree of precision of the person and item estimates, and the targeting of the sample. A sample size of 64 participants is considered sufficient to provide a stable item calibration within ±0.5 logit when the sample is well targeted, rising to 144 participants when the sample is poorly targeted[19]. The sample size for this analysis was 653. This larger-than-needed sample size may result statistical misfit of items and so analyses on reduced sample sizes were also carried out to reduce the probability of false misfit due to the large sample size.

Qualitative assessment of PAM-13 Questionnaire

The quality of individual PAM-13 items in our patient population was assessed using the Question Understanding Aid (QUAID) tool (http://quaid.cohmetrix.com/). QUAID is a software developed by the University of Memphis to assist methodologists in identifying problems that respondents might have in comprehending the meaning of questions [20]. These problems include the wording, syntax and semantics of questions posed and may help enhance the reliability and validity of questions. The five main problems analyzed are: (1) unfamiliar technical terms, (2) vague, imprecise or relative terms, (3) vague or ambiguous noun phrases, (4) complex syntax, and (5) working memory overload. Each individual PAM-13 item was inserted as the "Question", surgery was selected as the "context" and the 5 answer choices (strongly disagree, disagree, agree, strongly agree, not applicable) were inserted in the "Answer" box.

RESULTS

A total sample of 653 patients were included in the study cohort, with no patients excluded from this analysis. Baseline demographic, clinical and operative characteristics of all participants are shown in Table 1. Using the existing measurement framework, the median PAM score was 65.5 (IQR 55.6-75), with 7% of patients at level 1 activation (n=49), 16% level 2 (n=103), 40% level 3 (n=261), and 37% level 4 (n=240) (Table 1). The frequency distribution of patients' responses to individual PAM-13 items is shown in Table 2 and Figure 1. The question most commonly responded to with Not Applicable was PAM-13 item-4 ("I know what each of my prescribed medication does") (n=13, 2%). Assessing item-responses, the most frequent response categories were Strongly Agree (n=3804/8489, 45% of all person-item-responses based on 653*13*5) followed by Agree (n=3566/8489, 42%). Patients answered Strongly Disagree and Disagree at a higher frequency on items 8 through 13 compared to lower hierarchical items (items 1 through 7). Very few people chose "Strongly disagree" for any of the item and so this answer category was combined with "Disagree", bringing category responses to three.

Rasch Analysis

The first analysis of the PAM-13 with three categories showed no disordered thresholds. However, Item 4, "I know what each of my prescribed medications do", showed misfit with a fit residual of +3.889, above the threshold of +2.5. As this item was less relevant to a surgical population and the research team felt that the item queried information that most non-medical people would not know, it was removed. After removing Item 4, Item 8, "I understand my health problems and what causes them" showed misfit (fit residual +2.672) which remained even after reducing the sample size to 300 (≈10 per threshold). Before deleting this item, the residual correlation matrix showed a response dependency between Item 10 (“I have been able to maintain the lifestyle changes for my health that I have made”) and Item 13 (“I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress”), with a high degree of residual correlation (>0.3). This suggests responses to Item 10 can determine responses to Item 13. As uniqueness of the information provided by the items is a requirement of the Rasch model, to remove the local dependency, Item 10 was removed as it reflects an action whereas all other items reflect beliefs. All remaining 11 items fit the Rasch model with good overall model fit ($\chi 2$ 117.4, df 99, p=0.1).

The independent t-test showed that 41 of the 653 (6.28%) of the person estimates derived from the two most different subsets of items differed from estimates derived from all items, however the 95% confidence interval (4.4% to 8.2%) included the 5% value indicating that unidimensionality was still supported. There was no differential item functioning (DIF) when considering patient factors (sex, age (≥ 70 and < 70), education level (less than high school, high school or equivalent, above high school).

The final analysis of 11 items (after removing items 4 and 10 for misfit and local dependency) resulted in a set of items with good fit to the Rasch model, with the item-trait interaction not significant ($\chi 2$ = 117.4, df = 99, p = 0.1). Figure 2 shows the distribution of the items (lower part of the graph) and participants (upper part of the graph) across the measure of self-reported patient activation (horizontal axis), from the lowest ability on the left to the highest ability on the right. The threshold map (Figure 3) demonstrates a different ordering of items with item 1 remaining the easiest and item 12 being the most difficult one for participants to answer. Figure 2 shows that targeting of the items to the sample was not optimal although the distribution was near normal. The items ranged from ≈-3 to +2 logits and the persons ranged from ≈-2 to more than +4 logits. Participants were mostly at the higher end of the activation latent construct with a mean logit score of 1.124 (SD: 1.36). The floor effect was 0% and the ceiling effect was 5.4% (n=35). Figure 2 also shows that participants at the highly activated end of the scale were not measured as reliably as there are no items that extent into that range. This means no items were difficult enough to properly test high functioning patients and accurately test self-reported patient activation across a wide range. The final analysis reliability was acceptable with a PSI of 0.777.

Qualitative assessment of PAM-13 Questionnaire

Using the QUAID tool, the context of the question which we selected to be "surgery" was considered appropriate for all the items (Table 5). Of the 13 items, 6 were determined to have some unfamiliar, vague or imprecise terms that may hinder the content (items 1, 2, 4, 5, 10 and 13). These were "each medication" in question 4 and "lifestyle" and "exercising" in questions 10 and 13. The word "care" was identified as being vague or ambiguous in items 1, 2 and 5. Moreover, the relative term "most" in question 5 was imprecise as it refers implicitly to an underlying continuum. Assessing the response options, the term "strongly" was determined to be imprecise.

DISCUSSION

The cornerstone of a successful patient-centered approach is providing care that considers patients' needs, beliefs, skills and confidence. Patient activation has been identified as a behavioural concept that may aid in improving the quality of healthcare provided[21, 22].

The goal of this study was to contribute evidence as to whether the PAM-13 questionnaire was fit-for-purpose for a patient population undergoing abdominal or thoracic surgery. The results showed that a three-point Likert scale suited the distribution of raw scores better than the original 4-point ordinal scale.

Two items did not fit the Rasch model. Prior to commencing the Rasch analysis, we had identified Item 4 ("I know what each of my prescribed medications do") as a possible problematic statement in the context of a surgical population based on its wording and patient's questions during survey administration. This item was removed in our final model as it did not fit the hierarchy. Compared to patients with chronic illnesses, medications prescribed specifically for surgical patients are predominantly on an as-needed basis such as anti-emetics and analgesics. Moreover, these medications are prescribed for a succinct period rather than long-term use for chronic conditions as is the case with anti-hypertensive or oral hypoglycemic agents. Item 4 had the highest rate of Not Applicable response, and the QUAID evaluation further identified concerns with the words used in this item (Table 5). Previous studies providing validity evidence for the PAM-13 in different patient populations have found similar results[8]. These results suggest this item may be difficult to understand and may not be applicable to patients undergoing surgical procedures.

The disordered threshold of Item 1 ("I am the person who is responsible for taking care of my health") could be due to patients' difficulty to differentiate between options Disagree and Strongly Disagree. QUAID evaluation also revealed this item may be ambiguous or vague as "taking care of" can have a broad spectrum of interpretations. A Swedish study[23] validating PAM-13 in medical and surgical patients found similar results, as have other studies testing the validity of a translated questionnaire. As previously demonstrated and supported by the probability curve (Figure 2), collapsing the answer categories solved this issue in the final model. The final set of 11 of the PAM-13 items fit the Rasch model with possible construct under-representation at the high activation end of the construct.

The original PAM survey, developed using Rasch analysis, consisted of 22 items which rendered its use in clinical practice more challenging[14]. The shorter 13-item survey was developed to enhance its use by healthcare professionals and decrease its burden and cost[2, 24]. Although within acceptable range, a loss of precision in the shorter version; this was also noted in our study[2]. The mean PAM-13 score was 66 (SD 0.55) which is similar to mean scores in previous surgical studies[25, 26], but ten points higher than mean scores in medical patients[2, 9]. The frequency distribution of the PAM-13 items (Table 2) showed a higher proportion of patients choosing Agree and Strongly Agree response categories. In the final model of 11 items, no participants were found in the low activation range when assessing person-item distribution (Figure 2) which reveals poor targeting. Poor targeting suggests a lower reliability which may affect the ability to differentiate between people along the trait continuum[27]. In this context, it implies imprecise measurement of patient activation for patients at the lower end of the scale. Poor targeting can lead to construct under-representation and limit the interpretation of the overall score. Targeting was also noted to be lower in other validation studies[23, 28].

Local independence assures that each item measures a relevant aspect of a construct and does not depend on the answer to another item[29]. Items 10 and 13 demonstrated dependency, more easily understood as redundancy. This result could stem from the fact that both questions refer to the same action of maintaining lifestyle changes or due to similar difficulty in answering the two questions. Presence of local dependence was resolved by removing item 10. Structural validity is determined by confirming unidimensionality of the construct in a Rasch analysis. Removal of item 10 also confirmed unidimensionality (% outside range 6.3%). The lack of differential item functioning demonstrated well-performing items across age, sex and level of education. These findings are similar to previous literature supporting patient activation as being independent of sociodemographic characteristics[30, 31].

In order to generate an overall PAM-13 score, a minimum of eleven out of the thirteen items must be answered[2]. Therefore, the modifications made in our study to fit the questionnaire to the Rasch model by removing items 4 and 10 would not hinder its continuous use in clinical practice. Interestingly, the two items that did not fit the scale tested knowledge (item 4) and an action (item 10), whereas all other items were centered on the construct of belief. Ideally, a patient-reported outcome measure should focus on measuring one construct. When considering the development of interventions to improve patient engagement, it is easier to modify knowledge or an action rather than a belief. In the short term, the few identified deficiencies of the PAM-13 can be addressed by prefilling the answer to items 4 and 10 as "Not Applicable" and allowing patients to answer the rest of the questionnaire. A more robust solution to address the identified deficiencies in the long term is to develop a revised psychometrically evaluated version of the questionnaire that directly applies to a surgical population. The QUAID evaluation also revealed terms that could be modified in order to improve understanding of the questions. Of note, the term "strongly" in the answer categories is deemed imprecise and can affect participants' responses[20, 32]. A survey with shorter questions may also improve precision of responses[33].

This study has several strengths. To our knowledge, this is the first study using a modern psychometric method such as Rasch analysis to determine the suitability of PAM-13 to measure patient activation in patients undergoing a major surgical intervention. This method offers a richer description of the performance of each survey item than the classical test theory[34]. There is growing interest in the utility of PAM-13 and improving our understanding of its measurement properties in different disease populations is crucial. The heterogenous patient sample included in this study is the first to include patients undergoing a variety of abdominal and thoracic surgeries. The large sample size (>250 patients) confirms a robust estimate of item parameters[19]. The high responsiveness to the items also strengthens our results. Furthermore, patients in our sample had different sociodemographic backgrounds and increased the diversity of our sample. A previous study of this patient sample confirms the association between higher patient activation and improved patient outcomes[10].

These results should be interpreted in light of several limitations. Firstly, one of the criteria to perform appropriate functioning of rating scale categories is for category frequencies to be similarly distributed across items[35]. Answers in this study were mostly skewed towards the higher response categories, which highlights difficulties in interpreting results. One explanation for these findings could be the smaller proportion of patients with lower levels of activation. Our study included 23% of patients with low levels of activation (level 1 and level 2). However, the overall PAM-13 score distribution in this sample is similar to that observed in previous studies. Future studies should assess larger groups of patients with low levels of activation to ensure that accurate measurement properties are obtained for surgical patients. Secondly, PAM-13 was only measured in the immediate postoperative period. We recommend a longitudinal analysis to assess the responsiveness of PAM-13 which would allow to identify time differences in psychometric evaluation. Finally, all of our analyses used a Bonferroni correction to adjust the p-values. This is a conservative approach that may under-estimate the number of irregularities in the survey.

CONCLUSION

A patient-centered approach to healthcare requires greater involvement from patients themselves. In order to improve and enhance patient engagement, targets must be identified to concentrate efforts in developing suitable resources for patients and their caregivers. The results of this study suggest that PAM-13 is not suitable in its current form to measure patient activation in patients undergoing major abdominal or thoracic surgery. Post hoc statistical changes permit its use in a valid and reliable way[36]. Although there is a great interest in measuring patient activation worldwide, very few tools exist to do so. A healthcare provider may still use PAM-13 responses to design a tailored treatment plan, however, survey results should be interpreted with caution due to its non-optimal targeting. These findings call for further research and development on this construct. Qualitative studies in surgical patients and the development of a modified PAM survey focusing on surgical patients' perioperative experience would allow for a more precise characterization of activation in these patients.

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Table 1. Baseline demographic and clinical characteristics and in-hospital health state

Variables	**Total (n=653)**
Age, median (IQR)	59.7 (47.8-69.3)
Gender, male	284 (44)
BMI, mean (SD)	29 (9)
Charlson Comorbidity Index, mean (SD)	3.8 (2.6)
Language	
English	326 (50)
French	307 (48)
Other	14 (2)
Education level	
Less than high school	52 (8)
High school or equivalent	178 (27)
More than high school	419 (65)
Employment status	
Employed	289 (44)
Homemaker/retired/student	261 (40)
Disabled	79 (12)
Unemployed	24 (4)
Type of work *(n=289)* [a]	
Office work	139 (48)
Physical work	96 (33)
Other	54 (19)
Average income per year	
<30,000 $	44 (7)
30,000-59,999 $	112 (17)
≥60,000 $	102 (16)
Declined to disclose	34 (5)
PAM raw score	
PAM score, mean (SD)	66.4 (0.6)
PAM level 1	49 (7)
PAM level 2	103 (16)
PAM level 3	261 (40)
PAM level 4	240 (37)
Diagnosis of malignancy	367 (56)
Emergency surgery	52 (8)
Surgical approach:	
Minimally invasive	366 (56)
Open	263 (40)
Converted	24 (4)

Table 1. Baseline demographic and clinical characteristics and in-hospital health state (cont.)

Variables	**Total (n=653)**
Procedure Category:	
Thoracic	175 (27)
General Surgery	132 (20)
Colorectal	95 (15)
Gynecology	96 (15)
Bariatric	53 (8)
Hepatobiliary	46 (7)
Urology	48 (7)
Vascular	8 (1)
EQ VAS score, median (IQR)	57 (50–70)
EQ-5D-5L, mean (SD)	
Mobility	2.73 (1.17)
Self-Care	2.96 (1.33)
Usual Activity	4.27 (1.19)
Pain or Discomfort	2.77 (0.83)
Anxiety or Depression	1.70 (0.91)

Data are presented as no. (%) unless otherwise specified
Abbreviations: PAM=Patient Activation Measure (range of 0-100); BMI=body mass index; VAS=visual analogue scale.
[a] Among patients employed
*p-value statistically significant <0.05

Table 2. Frequency distribution of answers on the individual PAM items

Items	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Applicable
1. When all is said and done, I am the person who is responsible for taking care of my health problem.	2 (0.3)	13 (2.0)	181 (27.7)	457 (70.0)	0
2. Taking an active role in my own health care is the most important thing that affects my health.	1 (0.2)	13 (2.0)	228 (34.9)	410 (62.8)	1 (0.2)
3. I am confident I can help prevent or reduce the problems associated with my health condition.	2 (0.3)	54 (8.3)	304 (46.6)	293 (44.9)	0
4. I know what each of my prescribed medications does.	17 (2.6)	120 (18.4)	241 (36.9)	262 (40.1)	13 (2.0)
5. I am confident I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	5 (0.8)	50 (7.7)	302 (46.3)	295 (45.2)	1 (0.2)
6. I am confident that I can tell a doctor my concerns I have even when he or she does not ask.	1 (0.2)	38 (5.8)	225 (34.5)	388 (59.4)	1 (0.2)
7. I am confident I can follow through.	0	29 (4.4)	250 (38.3)	374 (57.3)	0
8. I understand my health problems and what causes them.	21 (3.2)	126 (19.3)	251 (38.4)	255 (39.1)	0
9. I know what treatments are available for my health problems.	16 (2.5)	107 (16.4)	310 (47.5)	218 (33.4)	2 (0.3)
10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising.	5 (0.8)	97 (14.9)	283 (43.3)	266 (40.7)	2 (0.3)
11. I know how to prevent further problems with my health condition.	10 (1.5)	121 (18.5)	344 (52.7)	176 (27.0)	2 (0.3)
12. I am confident I can figure out solutions when new problems arise with my health condition.	9 (1.4)	122 (18.7)	351 (53.7)	171 (26.2)	0
13. I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress.	17 (2.6)	101 (15.5)	296 (45.3)	239 (36.6)	0

Data presented as No.(%)
Number of possible item-responses for each person is 13*5 or 65.
Number of possible person-item-responses is 65*653 or 42,445

Table 3. Results of the Rasch Analysis

Version	Data change	Overall model fit $\chi 2$ (df) [p]	Item Location (SD)	Item fit Mean (SD)	Person Location (SD)	Person fit Mean (SD)	PSI
Original model (13 items)	none	Disordered thresholds					
13 items	Rescored item #1	152.2 (104) [0.0015]	0	0.7967	1.934	1.262	0.805 [Good]
12 items	Removed item #4	159.1 (108) [0.0010]	0	0.8181	2.008	1.309	0.7797 [Good]
Final model (11 items)	Removed item #10	117.4 (99) [0.1153]	0	0.0547	2.075	-0.381	0.7777 [Good]

Abbreviations: PAM=Patient Activation Measure; PSI=Person separation index; X^2=Chi Square; df=degrees of freedom; SD=standard deviation.

Table 4. Individual item fit.

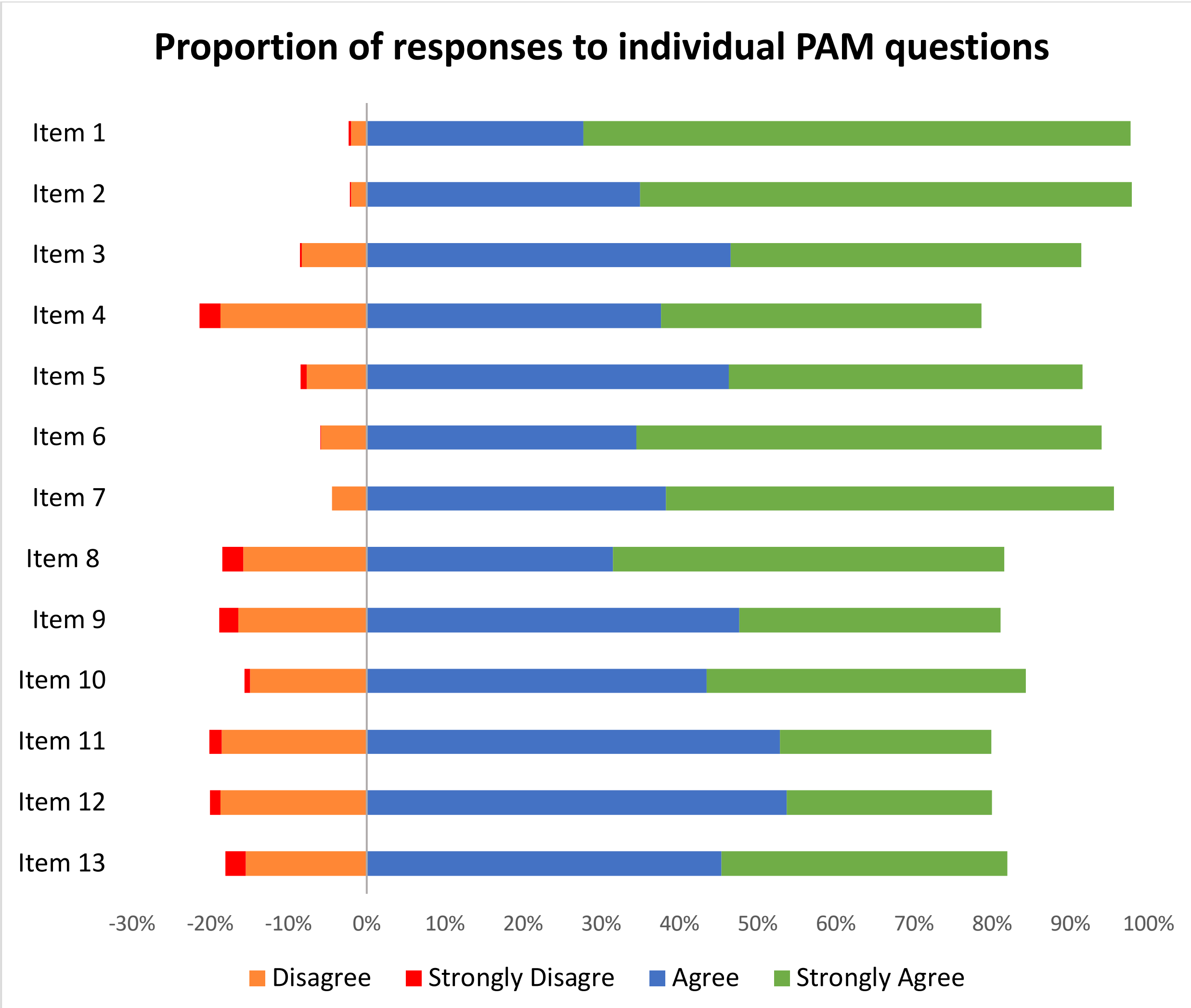
Item	Response categories	Item location (SE)	Item Fit Residual Mean	Item-trait Probability
1*	3	-0.31 (0.08)	-0.23	0.112
2	4	-0.81 (0.08)	0.16	0.427
3	4	-0.29 (0.07)	0.99	0.626
4	4	0.64 (0.06)	**3.94**	0.010
5	4	0.09 (0.07)	0.63	0.595
6	4	-0.77 (0.07)	-1.76	0.001
7	4	-2.03 (0.08)	-1.62	0.047
8	4	0.71 (0.06)	2.26	0.392
9	4	0.68 (0.06)	-1.42	0.219
10	4	0.14 (0.06)	1.03	0.587
11	4	0.67 (0.07)	-1.15	0.092
12	4	0.64 (0.07)	-0.03	0.325
13	4	0.64 (0.06)	-0.02	0.464

Abbreviations: SE=Standard Error
* Item response categories modified due to disordered thresholds.

Table 5. Question Aid (QUAID) evaluation of PAM survey items in the context of surgery

Item	Question problems	Problem words	Context	Answers evaluation
1. When all is said and done, I am the person who is responsible for taking care of my health	vague or ambiguous noun-phrases	"care"	good	"strongly": vague adverb "applicable": unfamiliar term
2. Taking an active role in my own health care is the most important thing that affects my health	vague or imprecise relative terms vague or ambiguous noun-phrases	"most": frequency ambiguity "care": vague noun	good	"strongly": vague adverb "applicable": unfamiliar term
3. I am confident that I can help prevent or reduce problems associated with my health	none	x	good	"strongly": vague adverb "applicable": unfamiliar term
4. I know what each of my prescribed medications do	unfamiliar technical terms	"each", "medication"	good	"strongly": vague adverb "applicable": unfamiliar term
5. I am confident that I can tell when I need to go to the doctor or whether I can take care a health problem myself	vague or ambiguous noun-phrases unfamiliar technical terms	"care", "problem": vague nouns	good	"strongly": vague adverb "applicable": unfamiliar term
6. I am confident I can tell a doctor concerns I have even when he or she does not ask	none	x	good	"strongly": vague adverb "applicable": unfamiliar term
7. I am confident that I can follow through on medical treatments I may need to do at home	none	x	good	"strongly": vague adverb "applicable": unfamiliar term
8. I understand my health problems and what causes them	none	x	good	"strongly": vague adverb "applicable": unfamiliar term
9. I know what treatments are available for my health problems	none	x	good	"strongly": vague adverb "applicable": unfamiliar term
10. I have been able to maintain (keep up with) lifestyle changes for my health like eating right or exercising	unfamiliar technical terms	"lifestyle", "exercising"	good	"strongly": vague adverb "applicable": unfamiliar term
11. I know how to prevent further problems with my health	none	x	good	"strongly": vague adverb "applicable": unfamiliar term
12. I am confident I can figure out solutions when new problems arise with my health	none	x	good	"strongly": vague adverb "applicable": unfamiliar term
13. I am confident I can maintain lifestyle changes, like eating right and exercising, even during times of stress	unfamiliar technical terms	"lifestyle", "exercising"	good	"strongly": vague adverb "applicable": unfamiliar term

Figure 1. Frequency distribution of answers to PAM-13 items



PAM = Patient Activation Measure

Figure 2. Person-Item Threshold Distribution.

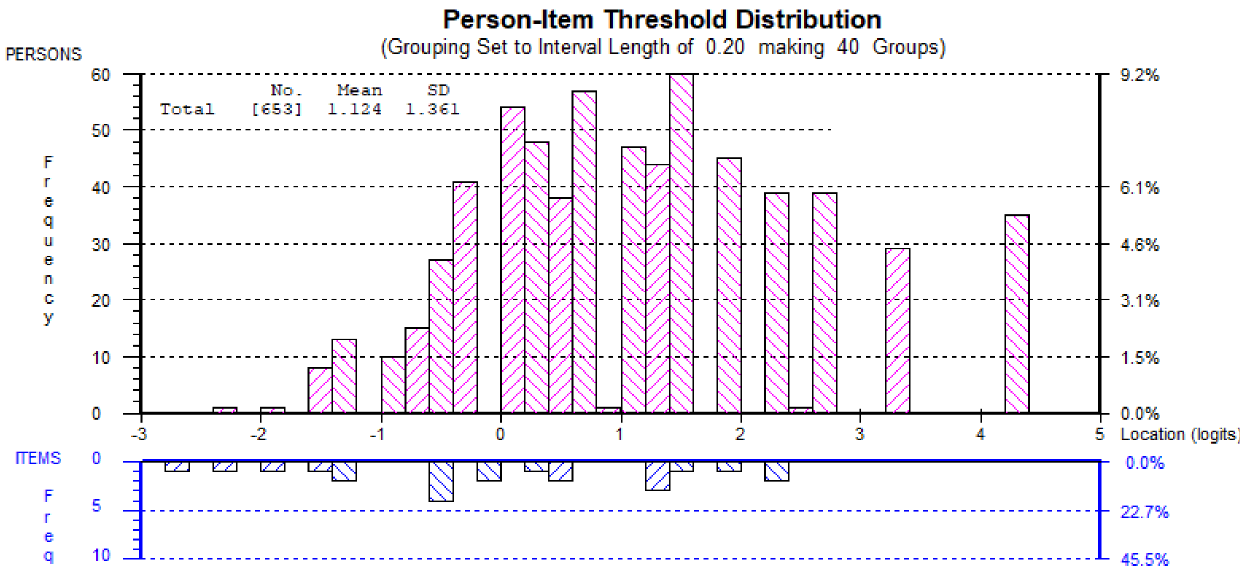
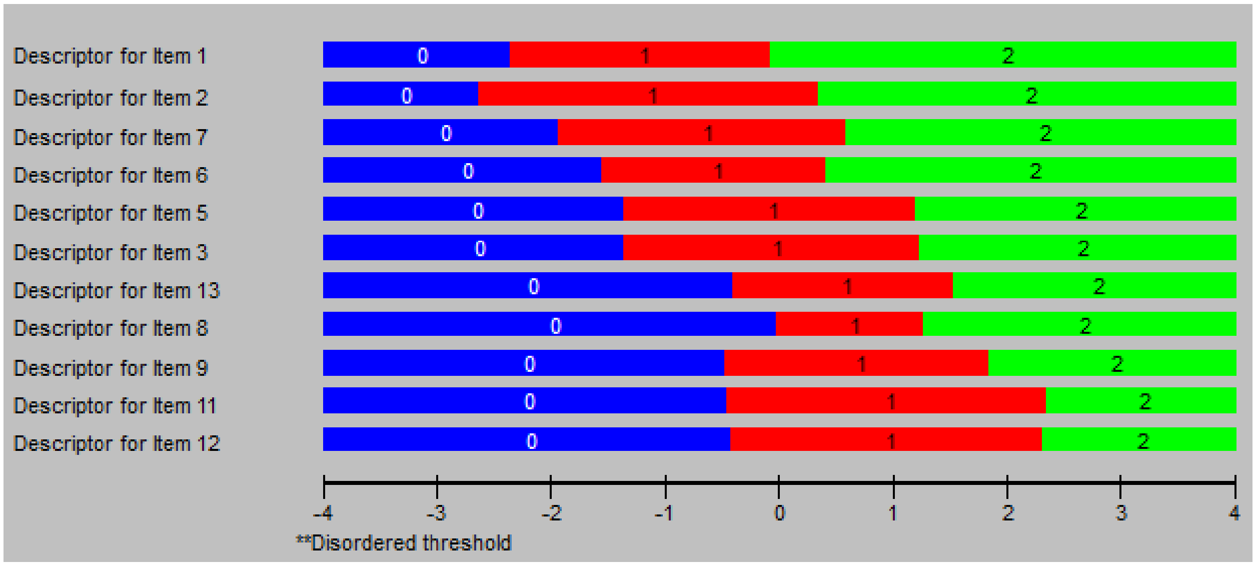


Figure 3. Threshold map



Supplementary Table 1. Explanation of steps taken to fit the data to the Rasch model

Threshold order	There should be a logical ordering to the response options such that endorsing a more optimal response option should situate the person at a higher level of the latent trait; more people should endorse a lower response level, and fewer people should endorse a higher response level. Disordered thresholds were resolved by rescoring and collapsing adjacent response options, sometimes reducing the responses to binary. The number of thresholds is equal to the number of response options - 1 and reflects the number of "jumps" the person has to make for each item.
Fit to the Rasch model	The items should line up hierarchically such that those items that need little ability to endorse at the most optimal response level are at the low end and those items requiring more ability to endorse are higher. Overall goodness of model fit is indicated by a non-significant Chi-square test (p>0.05) after a Bonferroni adjustment for the number of items. Fit of each item and each person is as important, or even more important, than overall fit. Item and person fit is indicated when fit residual (deviance from pure linearity) values are within ±2.5 and the Chi-square test for fit is non-significant (>0.05). Those items that fail this criterion need to be looked at carefully to ensure their importance in scoring the latent trait. A fit residual of >+2.5 indicates the item does not fit the latent trait; a fit residual of <-2.5 indicates the item overfits and may be redundant.
Unidimensionality	A requirement of the Rasch model is that a single latent trait is being measured. This is assessed using a principal component analysis (PCA) of the fit residuals. The person-ability estimates derived from all pair-wise comparisons of the two most disparate set of items (those with the highest positive and negative loadings on the first factor) are compared using independent t-tests. For a set of items to be considered unidimensional, less than 5% of *t* values should be outside ± 1.96. When this value is greater than 5%, a binomial test of proportions is used to calculate the 95% confidence interval (CI) around the *t*-test estimate. Evidence of unidimensionality is still supported if the 5% value falls within the 95%CI.
Response dependency	Uniqueness of the information provided by the items is a requirement of the Rasch model. Items with pair-wise residual (after controlling for the latent trait) correlations greater than 0.3 could indicate lack of independence of the responses which inflates the reliability. Solutions include creating a super-item which combines the response options across items or choosing the one item that best suits the testing context.

Supplementary Table 1. Explanation of steps taken to fit the data to the Rasch model (Cont.)

Differential item functioning (DIF)	The items should have the same ordering of difficulty across all people being measured defined by personal factors such as gender, age, and education level in this study. DIF is an indicator of item bias. Typically, DIF is indicated with a significant F-test from a two-way analysis of variance (ANOVA). A caution is that with large and sample sizes anything may be significant; with small sample sizes, nothing may be significant. A close visual inspection of the item characteristic curve plotted by the level of each factor will support or not the information from the statistical approach. Two options are available for items with DIF, deletion or split scoring.
Targeting	An ideally targeted measure should include a set of items that spans the full range of the theoretical latent construct (-4 to +4 logits), and have a mean location of 0 logits with a standard deviation (SD) of 1. Ideally, the person estimates from this measure should be centered on location 0 with a SD of 1. A positive mean value would indicate that the sample was located at a higher level than the average difficulty of the scale.
Discrimination or person-separation	This indicates how well people are differentiated by the spread of the item-difficulty. The person-separation index (PSI) is interpreted like a Cronbach's alpha. The larger the index, the better is the discrimination which facilitates the measurement of change. Values of >0.9 are suitable for measuring within-person change, values >0.7 are suitable for detecting group differences.

CHAPTER 5 – DISCUSSION

5.1 General Findings and Limitations

Patient engagement is now recognized as a fundamental component of patient-centered care. It involves patients' recognition of the role they play in their healthcare, their knowledge and skills to manage their care, and the motivation and confidence to be active participants in their care [34,36]. Patient engagement has been demonstrated to be independent of age, sex, education level or socioeconomic status [48]. It has been associated with emergency room visits, healthcare resource utilization, patient satisfaction and healthcare costs in patients with chronic medical conditions [48,55,57,63]. Most importantly, patient engagement appears to be a modifiable factor through various interventions such as coaching, education, and peer support [57]. Given the strong association between patient engagement and clinical and patient-reported outcomes in medical patients, it may also be a crucial risk factor in surgical patients. Nonetheless, little consideration has been given to the role of patient engagement in the perioperative course of surgical patients and how it may impact their postoperative outcomes. The overarching objectives of this thesis were to understand the correlation between clinical and patient-reported outcomes, to assess the association between patient engagement and these outcomes, as well as to evaluate our ability to measure patient engagement in surgical patients. The work presented in this thesis will ultimately serve to understand how to better equip patients prior to a surgical intervention in order to improve recovery and value.

I first began by performing a secondary analysis of data obtained in four prospective studies to assess the association between clinical outcomes and patient-reported outcomes (Chapter 2). While increasing attention has been focused on patient-centered care, studies have demonstrated a persistent gap in the outcomes that are considered important between healthcare professionals and patients. Complications are a major outcome that impact not only clinical measures such as length of stay and healthcare costs, but also patients' quality of life, recovery and return to normal life [64-66]. Therefore, it is important to select outcomes of relevance to multiple stakeholders when designing and measuring the impact of surgical interventions. At this point, the Clavien Dindo classification remains the most commonly used method to report and grade complications [67,68]. In this study, we measured the association of postoperative 30-day complications with PROs using the extensively validated SF-36 health-related quality of life questionnaire. We assessed both the physical and mental summary component scores of the SF-36 index as these are two separate dimensions of QOL [69]. We focused on the change in those scores at 4 and 8 weeks from baseline to have a more accurate representation of postoperative recovery compared to a single point in time.

The primary results of our study confirmed the direct impact of complications on postoperative quality of life. Patients experiencing any postoperative complications had significantly lower mental and physical component scores, both at 4 weeks and 8 weeks postoperatively compared to patients without complications. When assessing individual complication grading scores, the Comprehensive Complication Index (scored from 0-100) had a stronger correlation with SF-36 scores than the Clavien-Dindo grade (I-IV). By assigning a weight to each complication using both clinician and patient inputs, the CCI accounts for all complications rather than the most severe one alone[70-73]. Several studies have demonstrated a stronger association between the CCI compared to the Clavien-Dindo grade with other clinical outcomes such as LOS in patients undergoing various types of surgeries[73,74]. Our multivariate logistic regression and multivariable fractional polynomial regression models confirmed the superiority of the CCI compared with the Clavien-Dindo grade system for estimating the impact of complications postoperative HRQoL after adjusting for all confounding variables. As we adopt a more patient-centered framework of care, tools measuring morbidity should capture both clinical and patient-reported outcomes using multidimensional outcome measures. As the CCI to better reflects the impact of morbidity on HRQoL, this study provides further evidence to support its use to report complications in surgical outcomes studies.

Prior to developing interventions to potentially target patient engagement, the specific impact of patient engagement in perioperative care processes and outcomes must be better understood. In the next chapter, I investigated the association between patient engagement and both postoperative clinical and PROs (Chapter 3). We conducted a prospective observational study of patients undergoing elective and emergency thoracic and abdominal surgery. We chose to include patients undergoing a variety of major procedures such as urology, vascular and gynecology in addition to general surgery and its subspecialties to increase generalizability of our results. We measured patient engagement during the index admission and found a similar distribution of engagement level to what has been reported for patients with chronic medical conditions [50], with 23% of patients at low engagement level. This study included 653 patients undergoing both elective and emergency thoracic and abdominal surgery, which is the largest to date to measure and report patient engagement in surgical patients. Studies in patients with chronic medical conditions support the association between patient engagement and clinical outcomes, ED visits and adherence to healthy behaviours, independent of sociodemographic characteristics[35,37,75]. We confirmed that patient engagement was independent of sex, education level, income, and employment status in a surgical cohort.

We then turned our attention to the association of level of engagement with postoperative outcomes. We measured clinical outcomes 30 days after discharge and PROs using EQ-5D, a commonly used measure of HRQoL [9]. In addition to electronic medical records, patients were interviewed at 30-days post discharge to capture any potential healthcare professional visits outside our home institution. We minimized missing outcome data due to patient recall bias by collecting data using the provincial EMR (Dossier de Santé Québec). The proportion of patients with one or more unplanned healthcare system visit (the primary outcome) was significantly higher in patients with low engagement compared to patients with high engagement (42% vs 20%). Most importantly, the rate of ED visits was significantly higher in patients with low engagement (22% vs 15%). After correcting for all confounding factors, low patient engagement remained independently associated with a higher rate of ED visits (OR 1.64; 95%CI[1.11-2.41]). This type of unplanned visit takes a heavy toll in our healthcare system. Not only are ED visits very costly but they increase patient distress, and some may be preventable with appropriate patient communication and access to out-patient resources [19,76].

Patients with low engagement also had a higher rate of postoperative complications (41% vs 32%) and had a higher burden of complications as measured by the CCI. One way to explain these results could be that patients with low engagement have more complications which leads to a higher rate of appropriate ED visits. However, the rate of complications after discharge did not differ between the two groups and could therefore not be the only factor contributing to these visits. Moreover, we did not find any association between patient engagement and readmissions in both unadjusted and adjusted analysis. One theory is that patients with low levels of engagement may have a poorer understanding of their treatment plan, lack the skills to cope with unexpected events or are unable to access additional available resources such as nursing or outpatient clinics [77,78]. Finally, I assessed the impact of patient engagement on patients' quality of life using the EQ-VAS global score and individual EQ-5D-5L components. This score was measured at baseline during the index admission, with an even distribution between patients with low and high engagement. However, at 4 weeks after discharge, patients with lower levels of engagement also had lower overall HRQoL (70 vs 75, $p<0.001$) with lower scores across most individual domains. Therefore, patient engagement was associated with clinical outcomes as well as patient-reported outcomes. These results suggest that patient engagement may be a potential new target for preoperative intervention in order to improve surgical quality and value. Altogether, our novel results highlight the importance of measuring the engagement of surgical patients.

Further work will be required to better understand how to meet the individual needs of patients with low activation scores. Patient activation includes four components: knowledge, skills, confidence, and motivation to take charge of one’s healthcare. We do not yet know based on our results which elements can be modified and whether those changes will impact outcomes. The PAM survey does not directly point to one specific target for interventions but helps understand at which stage patients are on the activation scale. Future studies should focus on identifying how to modify and improve patient engagement. The results of our study suggest low patient engagement is an independent risk factor for poorer outcomes. Studies in patients with chronic medical conditions have demonstrated that engagement is modifiable [47,49,75,79]. A recent RCT of patients undergoing total knee replacement demonstrated the benefit of a multimedia platform in improving patients’ engagement and participation in their postoperative recovery program[54]. There is an opportunity to intervene when low levels of engagements are identified in patients in the preoperative period prior to scheduled surgery. In order to achieve this, we need an appropriate screening tool that is valid in patients undergoing surgical interventions.

With all these results in mind, I set out to evaluate the validity of the Patient Activation Measure questionnaire in patients undergoing surgical interventions (Chapter 4). PAM-13 is the most conceptually vigorous and psychometrically sound instrument to quantify patient engagement. Other measures such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) and the Patient Health Engagement (PHE) tools have been used in the literature [80], although neither encompasses all aspects of patient engagement including knowledge, skills, motivation and confidence. To our knowledge, PAM-13 is the only internationally accepted and widely validated tool. However, it was developed and calibrated at its inception in patients with chronic medical conditions. In the PAM-13 questionnaire, participants rate their level of agreement to each of the 13 items using a 4-point Likert scale form Strongly Disagree to Strongly Agree. It is a hierarchical model, meaning items appearing later on the questionnaire are more difficult to answer than earlier ones [56]. Determining the psychometric properties of this tool in surgical patients requires sufficient sample size. We thus used the patient population of Chapter 3 as our study population, providing a robust sample size of 653 patients [81]. I first calculated the response frequency and mean response score from 1 to 4 for each item. The mean response score decreased from 3.67 (SD 0.02) for item-1 down to 3.16 (SD 0.03) for item-13. This result corroborates previous findings of this being a hierarchical scale[39,82].

I then performed a Rasch analysis, a modern psychometric method that is recommended in the development of clinically meaningful measures[83-88]. Patient engagement is a latent trait that cannot be directly measured. Rasch models are used to create a measurement scale for latent traits on a continuous scale based on ordinal data (like a ruler). This theory stems from the logic that participants will have a higher probability of correctly answering items that are easier and a lower probability of answering items that are harder. The idea is to model the probability of a specific response to an item (e.g. right or wrong answer) as a function of the difference between a person's ability and the items' difficulty[83]. Rasch analysis maximizes homogeneity of the trait and reduces redundancy to yield a more valid and simple measure, independently of the sample used.

The Rasch analysis investigates why the data do not fit the Rasch model based on specific criteria and provide clear diagnostic statistics that can help identify inconsistencies in its scores[89]. It investigates the spread of item values, the precision of measurement, the fit of the items and persons to the model, the overall reliability of the measure and its simplicity (unidimensionality)[90,91]. We found that items performed well across age, sex and levels of education, consistent with previous publications suggesting that patient activation is independent of sociodemographic characteristics [37,56]. The model also showed poor targeting of PAM-13 in our study population. This implies that the tool provides an imprecise measurement in patients with lower levels of activation which may limit the interpretation of the overall score in surgical patients. We recognize this as a significant limitation that is likely caused by the small sample size of patients with low levels of activations. This limitation could not be mitigated in this study but is important to consider when designing future studies.

When assessing fit residuals of each item in the model (how well do the items fit in the standard model), item 4 was the only item with a high fit residual and was removed from the adjusted model. Finally, we assessed the independence of each item to measure a relevant aspect of the construct, i.e. if certain items are redundant. Indeed, we found items 10 and 13 to be dependent and removing item 13 resolved this issue in the adjusted model. After these modifications, the final analysis showed acceptable fit of the remaining items in the Rasch model. This is the first study using modern psychometric theory to validate the use of PAM in patients undergoing thoracic or abdominal surgery. Our results encourage the continued use of PAM-13 as a measure of engagement in patients undergoing surgical interventions. New patient engagement measures should focus on the challenges specific to surgical patients and the perioperative care pathway that may influence recovery.

5.2 Future Directions

Several questions have emerged from this dissertation and provide direction for future research. Since the initiation of this work, other research groups have similarly demonstrated the impact of postoperative complications on health-related quality of life. A group from Sweden reported significantly lower HRQOL in patients experiencing complications after esophageal cancer surgery and this effect persisted in the long-term, up to 10 years after surgery[92]. However, these results were not fully replicated in a study of patients undergoing coronary artery bypass grafting (CABG)[64] where HRQOL was measured 1 and 12 years postoperatively. Although patients with complications did not have lower overall HRQOL scores, they did score significantly lower in the physical and social functioning domains. These results underscore the importance of further research in understanding not only how complications impact patients' quality of life after surgery but how these vary at different time points in both the short and long term.

In this dissertation, I studied the role of patient engagement in patients undergoing surgical interventions and its importance as one of the pillars of patient-centered care. Future studies are required to confirm our results in other surgical populations. These may also allow to discern which components of patient engagement (knowledge, skills, beliefs, and motivation) are most important in the surgical patient population. This will be important to develop interventions to address specific needs for individual patients. Looking at knowledge specifically, the concept of health literacy has emerged as an important determinant of health outcomes in surgical patients [93,94]. A recent study of 552 patients undergoing colorectal surgery reported that low health literacy (present in 8.3% of patients) was independently associated with a significantly higher risk of postoperative complications (OR 2.03, p=0.046) [94]. We also recognize the lack of clarity in the definition of patient engagement which could lead to varied results. Terms are often used interchangeably in the literature, including patient-centredness, involvement, participation, activation or empowerment. Future research should address surgical patients' understanding of patient engagement.

The relative lack of validated tools to measure patient engagement may have posed a barrier to research in surgical patients. PAM-13 is easy to administer and is relatively short, making it readily accessible in clinical practice. We were able to demonstrate a strong relationship between PAM-13 scores and postoperative clinical and patient-reported outcomes. Integration of this survey into electronic medical records may increase its uptake in research initiatives and its overall implications. As patient engagement is associated with increased unplanned healthcare utilization, future work should estimate the costs associated with low activation. This will provide the argument to support development of interventions to improve patient activation. We identified 2 of 13 items on the PAM-13 that did not fit the Rasch model in our patients. Interestingly, a minimum of eleven items must be answered in order to generate an overall PAM-13 score [36]. The Rasch analysis does therefore not preclude its use for the time being. Our results suggest the importance of evaluating patients' response to individual items in addition to overall scores. This may allow healthcare professionals to identify patients' specific needs for targeted interventions. Future work could focus on developing a patient engagement tool specific to patients undergoing surgical interventions.

Our work has provided supporting evidence that patient engagement can be measured in surgical patients and that it is associated with clinical and patient-reported outcomes. The next step is to determine whether it is modifiable in the preoperative period. Studies of patients with chronic medical conditions suggest that patient engagement can be modified through coaching and peer-support groups [47,49,79,95,96]. Future studies could address whether prehabilitation, an individualized multimodal preoperative program to optimize patients' physical, nutritional and psychological status, impacts patient activation scores [97,98]. Ultimately, future research would provide evidence regarding which types of interventions are suitable to address patient-specific drivers of low patient engagement.

CHAPTER 6 – CONCLUSION

In this doctorate thesis, I focused on the construct of patient engagement and its role in surgical outcomes. Patient engagement is not a "one size fits all" concept and requires significantly deeper understanding before we can consider design effective interventions. I demonstrated the association between complications and patient-reported outcomes in patients undergoing surgical procedures. These results should encourage the use of multidimensional measures in defining surgical outcomes and quality. In a prospective cohort study, I then reported a significant association between low patient engagement level and longer LOS, higher rates of complications, lower HRQOL and higher rates of unplanned healthcare related visits. Finally, I demonstrated that the validated PAM-13 survey, with certain small modifications, can be used to accurately measure patient engagement in surgical patients. Finally, future research goals were proposed that builds on the current work to develop and study interventions that may improve patient engagement and ultimately improve surgical quality and value.

APPENDIX 1: IRB PROTOCOL

MUHC Authorization PAM/2018-3778

Title: Does patient activation matter in surgery? The relationship between patient activation and postoperative outcomes

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BACKGROUND:

The introduction of standardized perioperative care pathways has decreased complications after major surgery and reduced hospital length of stay. However, this approach has not reduced emergency department (ED) visits or readmissions after discharge, which remains around 20% and 10% respectively (1). In Canada, surgical patients account for 20% of all ED returns after discharge, averaging 320$ per visit, and 24% of all 30-day readmissions, averaging 10 000$ per readmission (2). Strategies to improve quality of surgery and resource utilization have traditionally focused on clinician behavior and on organization of the health care system, but there is increasing attention on the role of patient activation, defined as a patient's knowledge, skills, beliefs and confidence in managing their health and care (3).
A number of studies have demonstrated an association between higher levels of activation and improved healthcare outcomes, higher patient satisfaction, lower health system utilization and lower costs, over a wide range of health conditions and economic backgrounds (4). After discharge in medical patients, a low level of activation was associated with significantly increased rates of re-hospitalization and visits to the emergency department (ED) (4). Importantly, patient activation may be modifiable through coaching, education and peer support (5). A study in orthopedic surgery suggested that higher levels of activation are associated with better patient-reported outcomes after surgery (6). However, the relationship between patient activation and outcomes in other surgical populations is still unknown.

Research Question:

1. To what extent does patient activation impact on postoperative outcomes in patients undergoing thoraco-abdominal surgery?

Hypothesis:

We hypothesize that lower levels of activation will be associated with higher rates of postoperative emergency department visits and readmissions after discharge.

METHODS

Study design:
We will perform a prospective cohort study and enroll patients undergoing General or Thoracic Surgery at the McGill University Health Centre (MUHC) (Montreal General Hospital (MGH) or Royal Victoria Hospital (RVH)). There will be no interventions on patients.
Consenting patients will be interviewed twice:
(1) once during their hospital stay after their surgery: Patients will be visited in their hospital room.
(2) once at one month after discharge: Participants will be contacted for self-reported health care facility visits (emergency department, CLSC, family doctor) and readmissions to non-MUHC hospitals.

Study Participants:
Adult patients over 18 years old undergoing elective or emergency General or Thoracic surgery at the Montreal General Hospital and the Royal Victoria Hospital will be considered for inclusion. Criteria for exclusion will be medical conditions that preclude patients from responding the questionnaires (i.e. cognitive) and/or inability to understand or read English or French.

Recruitment process and interviews:

There will be two methods of recruitment:
(1) Before surgery: At the preoperative clinic
Patients who meet the inclusion criteria will be informed about the study by clinician (the physician or the nurse) at the preoperative clinic. If a patient is interested in the study, the clinician will inform the research assistant/coordinator who will approach the eligible patients to discuss the study in detail and sign the consent form.

(2) After the surgery: At hospital ward (RVH or MGH)
Patients who meet the inclusion criteria will be informed about the study by their treating clinician (the physician or the nurse) at the hospital (MGH or RVH). If a patient is interested in the study, the clinician will inform the study coordinator who will organize a visit to the patient hospital room. A research team member will visit the eligible patient in her/his hospital room after the surgery to explain the study in detail and sign the consent form.

Patients who agree to sign the consent form will be followed up according to the study protocol. The interviews will be conducted by trained personnel not involved in clinical treatment of the patients.

Hospital interview
It will be up to the participant to decide whether to answer the questions at the time of signing the consent form or choose another day or time. The patient will be asked to answer to the patient activation measure questionnaire, to complete a questionnaire on socioeconomic characteristics as well as a health-status questionnaire. The duration of the interview will be about 10 minutes.
One month interview
Patients will be contacted by phone at 30 days after discharge for self-reported ED visits, CLSC or family doctor visits, and readmissions to non-MUHC hospitals. The patients will be asked to answer the health-status questionnaire. The duration of this follow-up will be about 5 minutes.

Measurements and outcomes

Patient Activation
Patient activation will be assessed with the 13-item patient activation measure (PAM) questionnaire (Appendix A), a highly validated tool of patient engagement (3). This questionnaire is already being used in an ongoing trial involving colorectal surgery patients (ref: 15-638-MUHC). After the surgery, while in the hospital, patients who agree to participate will be asked to complete the patient activation questionnaire (PAM). Scoring of the questionnaire will be conducted according to standard methods to provide a level from 1 (score of 47 on 100 or lower) to 4 (score of 67 on 100 and above).

Socioeconomic characteristics and Health status
In addition to the PAM questionnaire, patients will be asked to complete a short questionnaire assessing socioeconomic characteristics (Appendix B). Patients will be asked to complete the 5-item EQ-5D, a standardized health-status instrument, to measure their perceived health status prior to the surgery and at 30 days after discharge (Appendix C).

Demographics and Clinical information
Demographic data (age, sex, diagnosis, American Society of Anesthesiologists (ASA) score),

medical history, and information relevant to the surgical procedure (e.g. surgery performed, technical details, transfusion requirements, intraoperative complications) will be obtained from medical records. The MUHC medical record will be reviewed 30 days after the surgery to record postoperative complications, duration of primary hospitalization, post-operative ED visits and readmissions. The Québec Health Record (QHR) (or Le Dossier Santé Québec (DSQ) may be accessed to collect essential health information that will not be available in the MUHC hospital charts. For example, we may collect information about an ultrasound performed at another clinic/hospital other than MUHC one if it is considered to be related to the surgery the patient had at our institution.

Outcomes

The primary outcome will be all unplanned post-discharge hospital re-utilization within 30 days of discharge, which includes visits to the emergency department, unplanned visits to other health care facilities (CLSC (Local Community Service Center), family doctor, etc.), and unplanned readmissions. Secondary outcomes will be: (1) ED visits and hospital readmissions analyzed as separate variables, (2) postoperative complications, (3) patient reported health status (using EQ-5D score) and (4) cost of unplanned hospital re-utilization services.

Data Collection and *Confidentiality*:

All data will be entered and stored in a password-protected system of electronic data capture (REDCap; Research Electronic Data Capture, hosted at Research Institute of MUHC), and subsequently transferred to the statistical program for analysis. A study ID number will be assigned to each participant. Information collected in paper-based forms will be kept in locked cabinets within a locked office (Steinberg-Bernstein Centre for Minimally Invasive Surgery Research Office, Room 19E 125). Participants will be identified by a code to protect their identity. A document linking the codes to the participants' identity will be kept separately in a password protected file, which can only be accessed by the study staff.

All data will be kept under safe storage for 7 years and then deleted, shredded or incinerated. Only investigators will have access to the data. Furthermore, the results and the project may be published, but patients' identity will not be revealed.

Facilities available:

The project will be coordinated by the Steinberg-Bernstein Centre for Minimally Invasive Surgery. Computer facilities for data management and locked storage space will be available through the Steinberg-Bernstein Centre for Minimally Invasive Surgery (Research Office located at the Montreal General Hospital, Room E19 125).

Sample size and Analysis

Around 20% of patients reutilize hospital services in our center postoperatively after bowel resections alone (7). We estimate that a sample of 650 patients will provide over 80% power to detect a difference of 10% in hospital reutilization rates between patients with low (Level I and II) and high levels of activation (Level III and IV), accounting for an alpha of 0.05 and unequal sample sizes (28% Level I and II, 72% Level III and IV, (3)). Multivariate logistic regression and Poisson regression models will be used to analyze the data. The cost of the services used will be estimated using the Canadian Institute for Health Information (CIHI) cost database.

Feasibility:
Over 800 patients undergo the procedures of interest annually at the McGill University Health C entre. In previous clinical studies enrolling patients in our preoperative center, we estimate that 75% of patients would be eligible and willing to participate. Hence, a minimal sample of 650 patients can be feasibly recruited within an 18-month study enrolment period.

Significance:
This will be the first study of patient activation in a thoracic and abdominal surgery population and its potential association with post-operative outcomes. Defining this relationship is the first step in investigating interventions designed to impact patient engagement and improve postoperative outcomes. We may be able to identify the patients at risk that could benefit from individualized patient education and coaching to increase knowledge and confidence, tailor discharge planning and guide post-discharge follow-up. This has the potential to improve postoperative care and reduce costly unplanned ED visits and readmissions after surgery.

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Patient Activation Measure (PAM) 13™

License Materials

Enclosed you will find the products associated with your copyright license of the Patient Activation Measure (PAM). Specifically, you will find:

- **The PAM 13 measurement instrument**. PAM assesses a consumer's knowledge, skills and confidence for self-management. PAM segments people into one of four progressively higher levels of activation.

- **High level coaching guidance**. This document provides general guidance on patient coaching using PAM level insights

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think others want you to say.

If the statement does not apply to you, circle N/A.

1. When all is said and done, I am the person who is responsible for taking care of my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2. Taking an active role in my own health care is the most important thing that affects my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3. I am confident I can help prevent or reduce problems associated with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4. I know what each of my prescribed medications do	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6. I am confident that I can tell a doctor concerns I have even when he or she does not ask	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7. I am confident that I can follow through on medical treatments I may need to do at home	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8. I understand my health problems and what causes them	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9. I know what treatments are available for my health problems	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
11. I know how to prevent problems with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
12. I am confident I can figure out solutions when new problems arise with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

Characterizing patients at each level of PAM

Level	Likely Patient Characteristics	Strategic goal	Action planning
1	Does not feel in charge of their own health and care. Managing health is overwhelming for them with all of life's other challenges. Lacks confidence in their ability to manage health. Has few problem solving skills and poor coping skills. They may not be very aware of own behaviors	Understand they hold the key to their future health and functioning. Understand through their own actions they can have a positive impact on their health. Create awareness between cause and effect. Work on problem solving and coping, using the small steps approach. To build ownership and motivation, focus on the issues the patient wants to focus on.	Monitor choices and outcomes: when you do X how do you feel? This could include some self-monitoring— they could note how they feel when they do the behavior. Consider learning more about your condition, finding one simple thing you could do to take a role (bring 3 questions to your next doctor visit). Patients need encouragement, they can be involved, they can make a difference, they can do this! They need to begin to build confidence.
2	May lack basic knowledge about their condition, treatment options, and/or self-care. Have little experience or success with behavior change. Look to their doctor to be the one in charge. Low confidence in their ability to manage health.	Gain an adequate knowledge base for making good choices. Build confidence by achieving success in very small behavioral modification steps. Start to build stress management and problem solving skills	Continue to increase awareness and build knowledge. Start taking small steps toward best-practice evidenced based behavior. Consider small steps like replacing a cookie for snack with a banana. Don't change the whole routine, just one small aspect where they can have success. Do they understand the reasons for their medications and what they are doing for them? Do they understand how to deal with side-effects and what they should be watching for? Have them make a list of things they do and do not understand about treatment options and medications.
3	Have the basic facts of their conditions and treatments. Some experience and success in making behavioral changes. Some confidence in handling limited aspects of their health.	Start to build on their past experience and successes to increase their confidence and ability in handling all aspects of their condition. Extend and maintain behavior change. Achieve best-practice self-care, still one step at a time, over time. Work on problem solving and stress management	Start building a sense of efficacy for specific behaviors—taking small steps that relate to their quality of life goals and clinical indicators. Continue to build the knowledge base as it relates to the widening issues that emerge with the new behavioral goals. Throughout level 3 develop best-practice self-care according to evidenced based guidelines.

4	Have made most of the necessary behavior changes, but may have difficulty maintaining behaviors over time or during times of stress.	Focus on increasing their confidence and skills for maintaining behaviors and coping with stress. Develop skills in coping and problem solving.	The focus is on maintaining behaviors. Start building a sense of efficacy for coping with problem situations that throw them off track. Identify situations where they still fall short. Develop skills to prevent these: planning ahead for known situations, stress management skills, etc. Continue to build the knowledge base as it relates to the widening issues that emerge with the maintaining behavioral goals. Reach toward new goals to continue to improve health to optimal health. Focus on any "lagging" behaviors

Examples of how to use patient responses to PAM questions and open a more in-depth dialog.

PAM Question	**Example of questions to follow up with after patient has filled out the PAM**
I know what each of my prescribed medications do	I see you aren't sure about your medications would it be okay if we took a few minutes to talk about that
When all is said and done, I am the person who is responsible for taking care of my health	You said you agree you are the person who is responsible for taking care of your health? Tell me more about how you feel.

NOTE: patients who are depressed or have sub-clinical depression are less likely to get activated until the depression is addressed. Screening for depression is recommended prior to any attempts to activate patients.

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APPENDIX B

ID #:
Date:

Socioeconomic Characteristics

1. Where do you currently live?
   - ☐ Personal home
   - ☐ Rehabilitation facility
   - ☐ Nursing home
   - ☐ Other

2. What is your current working status?
   - ☐ Employed (full-time or part-time)
   - ☐ Unemployed
   - ☐ Homemaker/retired/student
   - ☐ Disabled

3. If working, what type of work do you do?
   - ☐ Office work
   - ☐ Physical work
   - ☐ Other, specify:

4. If working, what is your annual salary, before taxes?
   - ☐ Less than $30,000
   - ☐ Between $30,000 and $60,000
   - ☐ Between $60,000 and $90,000
   - ☐ $90,000 or more

5. What is your highest level of education?
   - ☐ Less than high school
   - ☐ High school or equivalent
   - ☐ More than high school

6. Do you have someone to assist you at home?
   - ☐ Yes
   - ☐ No

7. If Yes, please indicate who is helping you?
   - ☐ Relative/friend
   - ☐ Housekeeper
   - ☐ Formal caregiver
   - ☐ Other, specify:

EQ-5D Health Questionnaire

Client ID ☐ New User ☐ Existing User ☐

Date ☐

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility
I have no problems in walking about ☐

I have some problems in walking about ☐

I am confined to bed ☐

Self-Care
I have no problems with self-care ☐
I have some problems with washing or dressing myself ☐
I am unable to wash or dress myself ☐

Usual Activities (*e.g. work, study, housework, family or leisure activities*)
I have no problems with performing my usual activities ☐
I have some problems with performing my usual activities ☐
I am unable to perform my usual activities ☐

Pain / Discomfort
I have no pain or discomfort ☐
I have moderate pain or discomfort ☐
I have extreme pain or discomfort ☐

Anxiety / Depression
I am not anxious or depressed ☐
I am moderately anxious or depressed ☐
I am extremely anxious or depressed ☐

Visual Analogue Scale

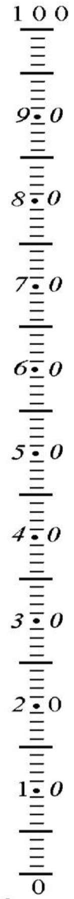
Please indicate on this scale how good or bad your own health state is today.

The best health state you can imagine is marked 100 and the worst health state you can imagine is marked 0.

Please draw a line from the box to the point on the scale that indicates how good or bad your health state is today.

Your own health state today

Best imaginable health state



Worst imaginable health state

Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

CHAPTER 8: REFERENCES

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