

AN EXPLORATION OF THE ROLE OF FAMILY MEMBERS IN PRE-SURGICAL
VISITS

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Abstract

Objective

There is little academic literature describing the nature of pre-surgical visits. To address this dearth and informed by a patient-centered approach, this dissertation examined the dynamics of the pre-surgical encounter.

Methods

Based on secondary analysis of presurgical recordings with 61 patients and eight surgeons. Patients were recruited at nine surgical oncology clinics at an academic hospital from July 2015-September 2016. First, I described the human-centered design (HCD) process used to develop an advance care planning decision support video aimed to enhance the patient-centeredness of the pre-surgical encounter. Second, I quantitatively explored how companions modify surgeons' and patients' contributions. Poisson and logistic regression models were used to assess differences in accompanied vs. unaccompanied visits regarding communication, as captured by the Roter Interaction Analysis System, and satisfaction. Models were fit using generalized estimating equations. Finally, I qualitatively examined case studies of how shared decision making manifests in the context of an unexpected decision in this encounter.

Results

First, over 450 stakeholders contributed to setting objectives, applying for funding, and providing feedback on the storyboard and the video. Opinions were compiled and conflicting approaches negotiated resulting in a tool that satisfied stakeholders. Second, companion presence was associated with a 29% increase in surgeon talk in the visit overall (IRR 1.29, $p=0.006$), and a 41% increase in the amount of

medical information provided (IRR 1.41, $p=0.001$). Companion presence was associated with 45% less patient disclosure related to lifestyle/psychosocial topics (IRR 0.55, $p=0.037$). In adjusted analyses, companions' presence was associated with 23% lower levels of patient-centeredness (IRR 0.77, $p=0.004$). Finally, four presurgical visits were identified as having a disruption. Each case study explores the disruption, participants' reactions to and resolution of the disruption. Cross-cutting themes include companions' patient autonomy-enhancing and detracting behaviors, and surgeons' collaborative, facilitative, and informative behaviors.

Conclusions

By improving our understanding of these visits, we can better prepare patients, their companions, and surgeons for these encounters, and ideally make these encounters more patient-centered. As this is the first study to explore in-depth the nature of these pre-surgical conversations, further analyses are required with a more diverse population.

Key Words:

Patient- and family-centered care; human-centered design; advance care planning; Surgery/surgical care; cancer, decision support tools; companion/caregiver; patient-provider communication; decision-making

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Table of Contents

Acknowledgements	iv
List of Tables	viii
List of Figures.....	viii
Introduction.....	1
Overview of Papers.....	3
Conceptual Framework.....	4
Literature Review	6
Paper One: A Human-Centered Design Approach for Developing an Advance Care Planning Video for Patients Preparing for Major Surgery	13
Paper Two: Companions’ Involvement During Pre-Surgical Consent Visits and its Relationship to Visit Communication and Satisfaction.....	33
Paper Three: A Qualitative Exploration of Disruption in the Presurgical Consent Visit for Patients Undergoing Major Surgery for Advanced Cancer	57
Discussion.....	89
Research Implications	89
Strengths.....	94
Limitations	95
Programmatic and Policy Implications	97
References	99
Sarina Isenberg’s CV.....	108

List of Tables

Tables	Page Number
Table 1. Stakeholder Feedback on Decision Support Tools	30
Table 2. Stakeholder Feedback on from the Johns Hopkins Patient and Family Advisory Council and How the Team Addressed Said Feedback	31
Table 3: Examples of Key RIAS Composite Codes	53
Table 4: Demographics of Patients with and without Companions (n=61)	54
Table 5: Bivariate Models Depicting How Companions' Presence Affected Session Communication	56
Table 6: Unadjusted and Adjusted Models Depicting How Companions' Presence Affected Patient-Centeredness of the Pre-Surgical Session	58
Table 7: Demographics of patients, companions, and surgeons	88
Table 8: Summary of case study results	89
Table 9: Illustrative examples of physician role categories	90

List of Figures

Tables	Page Number
Figure 0. Conceptual Framework	6
Figure 1. Human-Centered Design Process to Develop the Video	32
Figure 2. Examples of the storyboard panels (“prototypes”)	33
Figure 3. Screenshots from the Video	34
Figure 4: Visualization of Clayman et al’s companion autonomy-related companion behaviors	87

Introduction

Patients with advanced cancer undergoing major surgery often experience conditions such as functional decline, frailty, comorbidities, and polypharmacy, which may increase their risk for complications during surgery, as well as increase risk for post-operative morbidity and mortality.^{1,2} Major cancer surgery involves a significant risk of death or disability.³ In this subset of non-emergent high risk major surgery, patients require postoperative life-sustaining treatments in an intensive care unit.⁴ For example, upper gastrointestinal cancers typically require extensive and aggressive surgery that may lead to persistent pain, decreased quality of life, diminished appetite, and decreased emotional and social functioning for months to years following surgery.^{5,6} These surgeries may be palliative, rather than curative.

A pre-surgical visit is frequently held close to the planned surgery to obtain patient consent and review surgical risks and benefits, potential postoperative morbidities, pain management and quality of life considerations.⁵⁻⁷ The decision to undergo non-emergent cancer surgery occurs before the pre-surgical visit and is commonly planned following extensive discussion of surgical risks and benefits between a patient and surgeon, and frequently, one or more family members.

These pre-surgical visits for patients with cancer frequently include an accompanying family (“companion”) and this is especially common in patients with cancer wherein approximately 66% of them are accompanied to their visits.⁸ In visits for patients with cancer where “bad news” was expected, the rate of accompaniment was 86%.⁹

There is little academic literature describing the nature of pre-surgical visits. While there has been research on patient-provider-companion communication in other contexts,

and especially in primary care,^{10,11} pre-surgical communication has been little studied.

In light of this dearth of research and informed by an overarching patient- and family-centered approach, this dissertation seeks to examine the dynamics of the pre-surgical visit using a variety of methods. First, I describe the human-centered design process used to develop an advance care planning (ACP) decision support video aimed to enhance the patient-centeredness of this pre-surgical encounter. Second, I quantitatively examine the role companions serve in pre-surgical encounter and how they modify the nature of the visit and the contributions of surgeons and patients. Finally, I qualitatively examine how shared decision making manifests in the context of an unexpected decision in this encounter and how companions contribute to decision making.

By enhancing understanding of the nature and contents of these visits, I hope that in the long-term we can better prepare patients, their companions, and surgeons for these encounters, and ideally, help to make these encounters more patient-centered.

In terms of the organization of this document, I begin my dissertation with an overview of the study aims, conceptual framework and literature review, followed by each of my three manuscripts. I conclude the dissertation with a discussion section that focuses on the research implications, strengths, limitations, and programmatic and policy implications of this research. I discuss themes across the three manuscripts, as well as key conclusions pertaining to each manuscript. After my references, and in accordance with guidelines, I include my most recently updated CV detailing my publications and research activities.

Overview of Papers

Paper One

Our team developed an ACP video decision support tool for patients preparing for major surgery. Since most existing decision support tools were developed with minimal patient and family member engagement, we engaged patients and other key stakeholders throughout all stages of the support tool project¹²⁻¹⁴ This paper (1) explored how the study team leveraged a human-centered design (HCD) approach¹⁵ to facilitate deep engagement with stakeholders, and (2) illustrated some of the challenges encountered in incorporating an HCD method when developing a patient-centered tool.

Paper Two

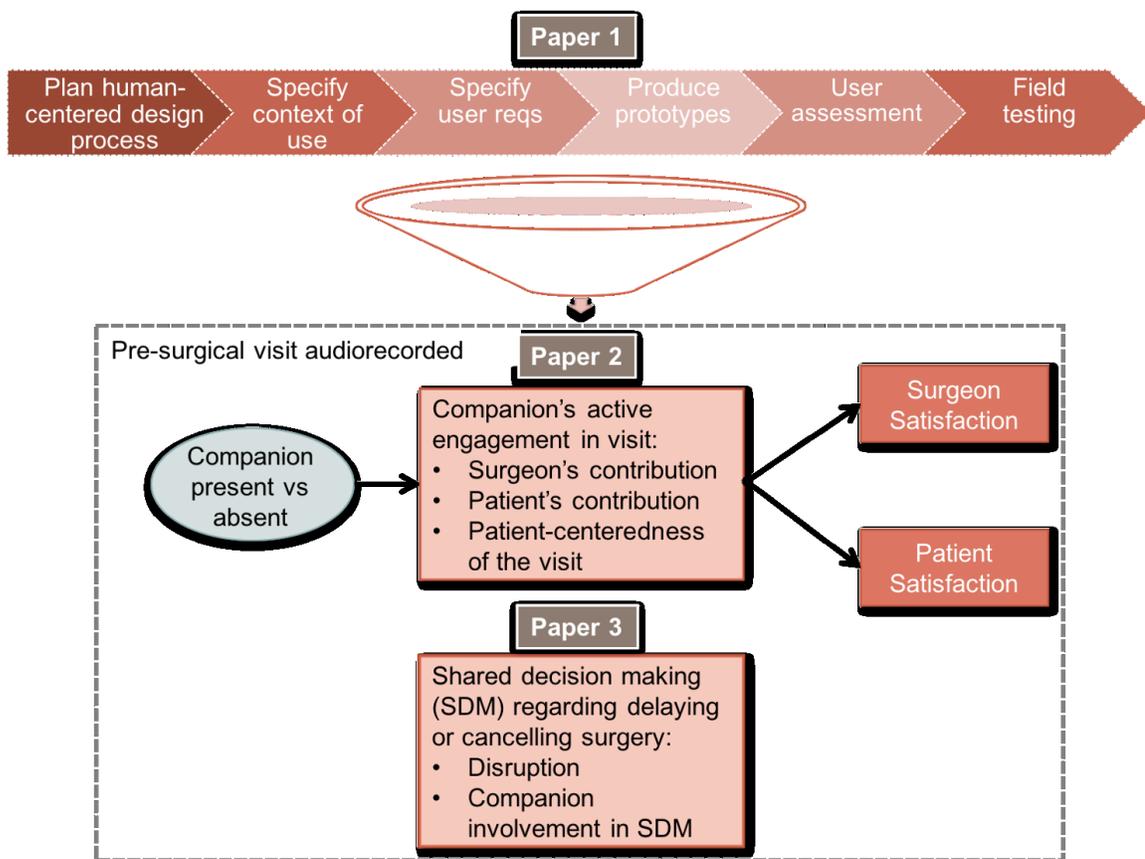
To our knowledge, there has been little exploration of the role of companions in non-routine medical appointments, specifically in the high-stakes context of conversations regarding major cancer surgery. Addressing this gap, this study was designed to assess the impact of family companion presence on patient-provider communication during pre-surgical clinic visits with surgical oncologists. The primary aim was to assess differences in provider-patient interactions when companions were and were not present in the pre-surgical visit. Secondly, we also explored associations between a companion's presence and both 1) the patient-centeredness of the pre-surgical visit; and, 2) patient and surgical oncologist satisfaction with the pre-surgical visit.

Paper Three

While most pre-surgical visits proceed as expected, some involve a re-evaluation of whether to proceed with the surgery, effectively disrupting the anticipated surgical plan, herein referred to as a disruption. Disruptions may result in a decision to proceed as

planned, postpone the surgery for weeks or months, or cancel the surgery. These deliberations often include weighing surgical implications for meeting the patient’s medical goals and subsequent quality of life. This paper explored four case studies of a surgical plan disruption to illustrate how a patient, an accompanying family member, and surgeon negotiate an unanticipated reevaluation of a presumed surgical plan and the role each participant plays in contributing to the subsequent surgical decision.

Conceptual Framework



The overarching structure of the model is based on Wolff and Roter’s (2011) “Family Involvement in Interpersonal Care Processes” framework that depicts how external factors influence the interaction between patients, families, and companions,

which then influences patient outcomes.¹¹ Paper One describes the process used to design the intervention video for the parent study, which targets the nature of the pre-surgical exchange, and thus the contents of that process are funneled into the pre-surgical visit. Paper One did not specifically aim to address companions' impact on the visit or the nature of disruptions and decision-making, thus the three aims cannot be said to work in complete concert with each other. Consequently, Paper One is depicted as outside of and yet encompassing the pre-surgical visit.

Papers Two and Three are embedded within the pre-surgical visits that are audiorecorded. The visual rendering of Paper Two depicts its analysis of the impact that companion's presence has on: surgeon's contribution, patient's contribution, and the patient-centeredness of the exchange. This paper also investigates how the companion's presence and active engagement might impact patient and surgeon satisfaction. The rectangle containing Paper Three illustrates that it explores four case studies of shared decision making in the audiorecorded visits. The use of the same rectangular shape as Paper Two and the placement of these two aims within the same dotted box indicates that Paper Three focuses on a subset of the data included in Paper Two.

Literature Review

Role of Advance Care Planning in the Pre-Surgical Visit and the Development of a Decision Support Tool

The Case for Integrating Advance Care Planning into the Pre-Surgical Visit

While patients undergoing major surgery may be stratified for which perioperative complications they will likely experience, it is difficult to impossible to predict which patients will die or suffer a major perioperative complication.¹⁶⁻¹⁸ Patients with advanced cancer undergoing major surgery often experience conditions such as functional decline, frailty, comorbidities, and polypharmacy, which may increase their risk for complications during surgery, as well as increase risk for post-operative morbidity and mortality.^{1,2} Upper gastrointestinal cancers typically require extensive and aggressive surgery that may lead to persistent pain, decreased quality of life, diminished appetite, and decreased emotional and social functioning for months to years following surgery.^{5,6} Moreover, while patients with upper gastrointestinal cancers receive surgery for Stage I or early Stage II disease, these rapidly progressive cancers typically reach Stage III or IV disease within months to one or two years after surgery.¹⁹ For example, patients with pancreatic adenocarcinoma who undergo pancreaticoduodenectomy often have stage 1 or 2 disease²⁰ and, although they do have a chance of being cured, they also have a greater than 85% of five-year mortality rates.¹⁹ The potential consequences of these surgeries coupled with the likelihood of disease progression and mortality²¹⁻²⁴ suggest that the pre-surgical environment might be the appropriate place to engage in advance care planning.

Advance care planning (ACP) offers individuals the opportunity to clarify their health care goals, concerns, and wishes in preparation for situations where they may be

unable to make their own decisions.²⁵ As aforementioned, patients undergoing major cancer surgery are at risk for perioperative morbidity and mortality; as such, it would be appropriate for them to engage in pre-surgical ACP.^{5,6,26} However, evidence suggest ACP conversations rarely occur between patients and surgeons.^{27,28} Surgeons do not often discuss the potential for post-operative prolonged life support as they feel it shifts the conversation towards comfort care²⁸ and away from their goal of defeating death.²⁷ This lack of ACP communication highlights a shortcoming in patient-centeredness in this domain.

ACP discussions may decrease health care utilization, while increasing patient satisfaction, use of hospice and palliative care, and compliance with a patient's end-of-life wishes.²⁹⁻³³ For family members, ACP may also decrease anxiety, depression, and stress, while increasing satisfaction with the quality of care.^{29,34,35} ACP is appropriate for individuals at any age or stage of illness³⁶ and has not been associated with harm in previous studies.³⁷ Finally, the 2014 Institute of Medicine report *Dying in America* advocates for increased ACP to explore patient wishes before they become acutely ill.³⁸

There are multiple barriers to optimal verbal communication regarding ACP in the patient-doctor relationship. Verbal communication about ACP is inherently inconsistent and subjective, and thus challenging to standardize.³⁹⁻⁴³ Conversations may also inaccurately convey the burden and outcomes of medical interventions, particularly when the patient has no previous knowledge or experience of aggressive medical treatments (i.e., intubation, artificial ventilation) and/or settings (i.e., an intensive care unit).⁴⁴

ACP Interventions in the Pre-Surgical Population

A recent systematic review of palliative care interventions for surgical populations⁴⁵ highlighted five studies that explored ACP interventions in pre-surgical populations.⁴⁶⁻⁵⁰ These interventions involved further training or activation of surgical providers (i.e., surgeons, anesthesiologists, and/or nurses) to have an ACP conversation with the patient and family prior to surgery and/or involvement of a palliative care specialist to preoperatively discuss ACP with the patient. These interventions found improved concordance and decreased decisional conflict between patients and surrogates about goals of care,^{46,47,49} improved documentation regarding power of attorney,⁴⁸ and were deemed helpful by study participants;⁴⁷ none of these trials documented harms to patients or family members.

To help facilitate ACP conversations, recent research has emphasized potential benefit from using decision aids and/or support tools. Decision aids facilitate individuals in making particular medical choices;⁵¹ whereas, decision support tools educate individuals to think about a particular decision but neither provide a comprehensive list of options nor proscriptively advise the viewer which option to choose.⁵² Video-based ACP decision support tools are efficacious in empowering patients and families to have ACP discussions, create an advance care plan, and/or choose between varying treatment goals and options.⁵¹⁻⁵⁶ Video ACP tools have inherently stable content and thus may be a more objective, simple to understand, and realistic modality through which to educate and activate patients about ACP.^{52,57} While thirteen randomized controlled trials in varying populations support that video-based ACP tools can empower patients and families to have ACP-related discussions,^{53,55,56,58-67} none have been developed for, or tested in, a surgical population.⁶⁸

According to the National Quality Forum, patient- and family-centered care is: "an approach to the planning and delivery of care across settings and time that is centered around collaborative partnerships among individuals, their defined family, and providers of care. It supports health and well-being by being consistent with, respectful of, and responsive to an individual's priorities, goals, needs, and values."⁶⁹ Patient-centeredness is increasingly recognized as a facet of quality medical care,⁷⁰ and there has been an international push to incorporate patient-participation into the full continuum of care.⁷¹⁻⁷⁷ Health care and regulatory agencies have consequently altered processes to better recognize and incorporate patient's preferences, needs, and perspectives.^{70,78} Patients and their medical care teams also often have different ideal outcomes;^{79,80} as such, it is important that patients are involved in the development of research agendas and goals.

A potential approach to integrated patient-centered care is human-centered design (HCD), which aims to mitigate competing view points by engaging all potential stakeholders in the design of tools targeted to meet the needs of users. Developed in computer science, HCD approaches incorporate the user's perspective into the software development process to achieve an optimal system that is informed by the users.¹⁵ HCD approaches have recently been applied to medical contexts as a way to redesign medical care coordination and health education tools.⁸¹⁻⁸³

Considering the Role of Companions during the Pre-Surgical Visit

Major surgery involves a significant risk of death or disability.³ Although most surgeries will be performed successfully, patient morbidity and mortality persist,^{16,17,84,85} and some surgeries require postoperative life-sustaining treatments in an intensive care unit.⁴ A pre-surgical visit is frequently held close to the planned surgery to obtain patient

consent and review surgical risks and benefits, potential postoperative morbidities, pain management and quality of life considerations.⁵⁻⁷ The decision to undergo non-emergent cancer surgery occurs before the pre-surgical visit and is commonly planned following extensive discussion of surgical risks and benefits between a patient and surgeon, and frequently, one or more family members.

Surgical intervention is a first-line treatment for many cancers and represents a major, potentially stressful treatment event for patients and their family companions (e.g. spouses, children, siblings, close friends who accompany patients to visits).⁸⁶ To enhance the patient-centeredness of the the perioperative journey, we need to better understand and consider the role that companions serve in that journey. Most research focused on medical decision making in the surgical context focuses on the doctor-patient relationship.¹⁰ The relative lack of consideration of companions in past studies is a gap in the literature as treatment decision-making often involves the triadic exchange between a patient, a companion, and a physician.¹¹ The gravity of the treatment decisions made during these conversations between patients, their companions, and surgeons is considerable and can form impressionable experiences that influence patient and family quality of life before, during, and after surgery.⁸⁷

Companion's Participation's Impact on Patients

In routine medical care, there is evidence that when companions are present in the visit, patient ratings of visit satisfaction are higher in interpersonal rapport, informativeness, and care quality.^{11,88-90} When family members prompt patients to discuss concerns, state their opinion or ask questions, patients ask significantly more questions of their doctor and are less likely to passively accept physician information.⁸⁹ Occasionally

when together, patients and their companions may proactively direct the course of the visit by orienting the doctor to their agenda, introducing new topics, and disclosing more information.⁸⁹ Therefore, it is perhaps unsurprising that many patients report preferring to be accompanied by and involve their family companions when making treatment decisions.⁹¹

While many patients may prefer being accompanied, there appear to be some differences in communication outcomes between accompanied and unaccompanied visits. Patients accompanied in consultations were less involved than unaccompanied patients in routine medical visits for older patients,⁹² and in the geriatric setting.⁹³ However, no differences were found in patient participation comparing accompanied and unaccompanied patients in the oncology setting.⁹⁴ A qualitative study of 28 conversations between patients, oncologists, and companions (wherein patients had life limiting cancer) found companions frequently spoke on behalf of patients during discussions of prognosis and treatment choices, despite the patient being capable of speaking for him/herself.⁹⁵

This act of companion's speaking on behalf of patients has been conceptualized as a duality of autonomy-enhancing and autonomy-detracting behaviors. From a theoretical standpoint, Clayman et al.'s framework conceptualized companion roles into two categories characterized by five subcategories. Companion behaviors can enhance patient autonomy through facilitating one of three functions: patient understanding, patient involvement, or doctor understanding. Conversely, companion behaviors can detract from patient autonomy through either controlling the patient or building alliances with the physician against the patient.⁹⁶ According to this theory, in a single encounter, the same companion can exhibit autonomy-enhancing and autonomy-detracting behaviors.

Importantly, companions' engagement does not always have a positive influence on patients. Companions do occasionally disagree with patients on treatment decisions and care; among lung cancer patients, rates of conflict range from 11-33%.⁹⁷ Further, the family history and dynamic may impact patient's medical treatment adherence and consequently his/her engagement during the visit; for example families that are less cohesive and higher conflict have patients with lower treatment adherence.⁹⁸

Companion's Participation's Impact on Surgeons

Research also suggests that the companion's participation will impact the surgeon's assessment. Physicians give more information when family members are present than when patients are unaccompanied^{99,100} and report that the presence of a companion increases patient information recall,¹⁰¹ engagement in medical decision-making,⁹⁶ adherence to medical treatments,⁹⁸ and physician understanding.¹⁰²

As evinced through this literature review, further research is needed in two areas. First, the development of a patient-centered ACP decision support tool for patients undergoing major surgery. Second, an exploration of the role that companions serve in the pre-surgical visit. This dissertation aimed to contribute to those two research gaps.

Paper One: A Human-Centered Design Approach for Developing an Advance Care Planning Video for Patients Preparing for Major Surgery

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Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

Abstract

Background: Video-based advanced care planning (ACP) tools have been studied in a variety of medical contexts; however, none have been developed for patients undergoing major surgery. Moreover, none have used a human-centered design (HCD) approach to optimize engagement and input of end users and key stakeholders into tool development.

Objective: Implement human-centered design (HCD) to develop an advance care planning (ACP) decision support video for patients and their family members when preparing for major surgery.

Methods: The study investigators partnered with surgical patients and patient family members, surgeons, and other health professionals to design an ACP decision support video using key HCD principles.

Results: Over 450 stakeholders were engaged in the development process contributing to the setting of objectives, applying for funding, providing feedback on the storyboard and several iterations of the decision tool video. Following the HCD process, stakeholders' opinions were compiled and conflicting approaches negotiated resulting in a tool that satisfied all stakeholders.

Conclusion

The HCD approach facilitated open discussion and the ability to elicit and balance diverse and sometimes competing viewpoints.

Practice Implications

The early engagement of user and stakeholders throughout the development process may help to ensure tools address the stated needs of these individuals.

Word count: 199

Introduction

Advance care planning (ACP) offers individuals the opportunity to clarify their health care goals, concerns, and wishes in preparation for future situations where they may be unable to make their own decisions. Patients undergoing major surgery are at risk for perioperative morbidity and mortality, and candidates for preoperative ACP;^{5,6,26} however, ACP conversations rarely occur between surgeons and their patients before major surgery.^{27,28} Some have argued that surgeons avoid discussions of post-operative prolonged life support as they feel it shifts the conversation towards comfort care²⁸ and away from their goal of defeating death.²⁷

To help facilitate ACP conversations, recent research finds potential benefit from decision aids and/or support tools. Decision aids facilitate the making of particular medical choices;⁵¹ whereas, decision support tools educate individuals to think about a particular decision but neither provides a comprehensive list of options nor proscriptively advises on an option to choose.⁵² ACP decision support videos are efficacious in empowering patients and families to have ACP discussions, create an advance care plan, and/or choose between varying treatment goals and options.⁵¹⁻⁵⁶ While decision support tools have been studied, none have been developed for a surgical population.⁶⁸ Moreover, most decision support tools have been developed with minimal patient and family member engagement in their design.¹²⁻¹⁴ According to the National Quality Forum, patient- and family-centered care is: "an approach to the planning and delivery of care across settings and time that is centered around collaborative partnerships among individuals, their defined family, and providers of care. It supports health and well-being by being consistent with, respectful of, and responsive to an individual's priorities, goals,

needs, and values."⁶⁹ Human-centered design (HCD) is an approach that uses patient- and family-centered engagement to optimize the input of diverse end users and key stakeholders into the tool design.

Human-centered design (HCD) approaches help to mitigate competing viewpoints by engaging all potential stakeholders in the design of tools targeted to meet the needs of users. Developed in computer science, HCD approaches incorporate the user's perspective into software development to achieve an optimal system that is informed by the users.¹⁵ HCD approaches have only recently been applied to medical contexts as a way to redesign medical care coordination and health education tools.⁸¹⁻⁸³ Given the challenges inherent in ACP discussions prior to major surgery, we hypothesized that a HCD approach could facilitate patient-centeredness in research and care.

As most existing decision support tools were developed with minimal patient and family member engagement,¹²⁻¹⁴ our project aimed to (1) explore how the study team implemented a HCD approach¹⁵ to facilitate engagement with stakeholders, and (2) illustrate the challenges encountered in use of the HCD approach when conflicting stakeholder opinions arise. The video was developed to facilitate patient-centered in the pre-surgical visit, as well as motivate discussions surround advance care planning.

Methods

From July 2013 to June 2015, the team engaged patients, families, health services researchers, surgeons, nurse practitioners, and other health care professionals to help design the ACP design support tool video. We used a six stage HCD process to develop the tool (Figure 1): (1) Plan HCD process; (2) Specify where video will be used; (3) Specify user and organizational requirements; (4) Produce and test prototypes (i.e.,

storyboards of the video); (5) Carry out user-based assessment; (6) Field test with end users. This approach adapts Maguire's high-level stages specific to the computer science field to the surgical context,¹⁵ while also incorporating Elwyn et al.'s specifications for patient-oriented decision support tool development.¹² Specifically, Elwyn et al suggest using qualitative methods to assess patient needs early in tool development, synthesizing evidence through systematic reviews, using visual storyboards, and testing the prototype video with patients and health professionals.¹²

The Johns Hopkins School of Public Health Institutional Review Board approved all related study protocols.

Results (i.e., the HCD Process)

Stage One: Plan HCD process

The research team planned the HCD process, which involved creating an initial, smaller stakeholder panel—comprised of research team members, patient advocates, and healthcare providers—to discuss and agree upon project objectives and to apply for research grant funding. This process culminated in submission of a grant to the Patient-Centered Outcomes Research Institute. The grant was approved in May 2013 thereby funding the development and effectiveness testing of a decision support video for patients and families preparing for major cancer surgery.

Stage Two: Specify Where the Tool Will Be Used

Over the next 11 months, the team sought input from the stakeholder panel to determine the best context and location for the use of the tool. Refinements were completed through a series of (1) research team in-person meetings; (2) key informant interviews with 22 surgeons, palliative care clinicians, and decision support tool content

experts¹⁰³, and; (3) a culminating stakeholder summit. This summit involved a diverse group of 14 stakeholders including two patient/family members, three surgeons, two palliative care physicians, one decision-support tool developer, one palliative care nurse, one surgical nurse, one patient-centered outcomes research expert, and three public health researchers. Clinician participants were individuals who had content expertise in palliative care in the surgical world and/or patient-centered research for surgical trials. Patient and family member partners were patients and/or family members of study-related clinicians who had expressed an interest in participating in these stakeholder groups. Stakeholders indicated they thought that tool should be developed for patients preparing for major cancer surgery and that the video should be presented to patients after a decision to pursue surgery but prior to the surgery itself.

Stage Three: Specify User and Organizational Requirements

The team further explored and clarified the stakeholder and organizational needs through a stakeholder summit, wherein the research team presented participant stakeholders with 16 decision support tools. These tools were selected for the following criteria: they were either widely used in clinical practice and/or thought to be valuable or influential as indicated through interviews with key informants;¹⁰³ tools were widely studied as found in our systematic review;⁶⁸ or tools were widely viewed as indicated by the number of “hits” on videos found in our YouTube review.^{104,105} The research team solicited stakeholder feedback on the specific content and style of existing decision support tools that each stakeholder felt to be meaningful and/or relevant. Representing both user and organizational perspectives, the stakeholders discussed both what they perceived should be the goals and content for the project decision support tool as well as

what were likely to be cultural barriers and/or constraints for operationalizing those goals and content with the decision support tool (Table 1).

Stage Four: Produce and test prototypes

In Stage Four, the research team produced design examples, otherwise known as “prototypes,”¹⁵ through storyboarding¹⁵ different scenarios (Figure 2). To implement the HCD approaches and test the prototype with a variety of users, we rented a booth at the Maryland State Fair. State Fairs, which typically have agricultural and livestock exhibitions as well as carnival and amusement activities, are gaining traction as research recruitment sites due to high attendance and attendee diversity.^{106,107} The State Fair is an 11-day event held annually in Timonium, Maryland and attended by approximately 400,000 people. Individuals who indicated that they or a loved one had undergone major surgery were eligible to participate and were invited to review the storyboard. Participants (n=359) reviewed the storyboards and completed a de-identified 10-item Likert scale survey regarding their perception of the storyline. 87% noted that they would be “very comfortable” or “comfortable” seeing the storyboard prior to major surgery, 89% considered the storyboards “very helpful” or “helpful”, and 89% would “definitely recommend” or “recommend” this story to others preparing for major surgery. More detailed results from this engagement at the State Fair have been described elsewhere.¹⁰⁸

In response to data collected in Stages 2-4 and through interaction with participants at the State Fair, the team worked with a medical videographer to film content in medical settings – hospital, operative room, surgical intensive care unit– as well as in home settings with patients and family members. Another stakeholder summit brought together patients, family members, and other key stakeholders to view the

different video-recorded interviews, select the final eight interviews to be used in the video, and to continue to discuss the specific interview content and framing that should be selected for inclusion in the final video. We attempted to keep the stakeholders constant across the different summits; however, there were some differences as not all stakeholders from the previous summit were able to attend this one. Of note, the patient and family member partners were the same across the two summits.

Informed by this input, the research team edited the video through fourteen different versions. Each version was reviewed through one-on-one engagement with key stakeholders, such as surgeons, palliative care clinicians, patients, and family members. This engagement involved the participant viewing the video and then providing informal feedback either through a direct written email, a phone call, or an in-person meeting with the study PI (RAA). Over this ten-month period and through one-on-one review with 20 diverse stakeholders, a final prototype version of the video was developed for Stage Five of the design process.

Stage Five: Carry Out User-Based Assessment

Stage Five in the HCD approach involved a stakeholder-based assessment,¹⁵ which entailed presenting the 7.5 minute refined prototype of the decision support video to the Johns Hopkins Patient and Family Advisory Council in June 2015. The Council is an established group who meet monthly to identify patient and family needs and concerns, and act as advocates to integrate patient-centered care across the hospital. Of the 28 Council members present at this meeting, 15 were patients/family members, and 13 were faculty/hospital employees. None of these Council members had been involved in our previous engagements related to this project.

Overall, council members were pleased with the video, expressing they liked the pacing, visuals, and messaging. Council members discussed three overarching concerns regarding the video, which the team incorporated into the finalized video (Table 2).

Stage Six: Field testing with end users

Screenshots from the video appear in Figure 3. The final evaluation phase is also referred to as “field testing” and involves testing the tool with actual end-users,¹² or patients facing decisions and health professionals who are interacting with these patients.¹² This phase was a randomized control trial to test the effectiveness of the video, compared to a control video.¹⁰⁹ Effectiveness was gauged using the patient-centeredness ratio calculated in the Roter Interaction Analysis System (RIAS), a quantitative coding system for medical dialogue.¹¹⁰ The patient-centeredness summary score is ratio of the psychosocial and socio-emotional elements of exchange about the lived illness experience of patients relative to statements that reflect a more biomedical and disease focused perspective.¹¹¹⁻¹¹⁷ A value greater than 1 indicates a more patient-centered encounter; whereas, a value less than 1 indicates a less patient-centered encounter. We hypothesized that patients who viewed the intervention video would have a more patient-centered encounter, as compared to patients who viewed the control video. Trial results are still under analysis.

Discussion

This paper describes the process used to develop the first ACP decision support video for a surgical population, and one of the first studies to use a HCD approach to design a decision support video to facilitate patient-surgeon communication. By using an HCD process, the research team was able to incorporate insights from a diverse array of

stakeholders, which allowed for a final product that considered competing values, beliefs, and experiences. For example, while research suggests that surgeons are typically resistant to engaging in ACP,^{27,28,118-120} the HCD process seemed to change surgeon's minds regarding ACP as demonstrated by their approval of the video and willingness to allow recruitment from their outpatient clinics for our randomized control trial testing the effectiveness of the video.

Throughout the design process of the video, the research team was challenged in how to balance the competing stakeholder beliefs that the video should have a positive tone while also presenting realistic needs for preoperative ACP; these competing beliefs were further emphasized in the feedback from the Patient and Family Advisory Council. At the end of the process not all conflicting opinions were perfectly resolved. The diversity of opinions expressed underscore the importance of engaging multiple stakeholders at different points to adequately obtain all possible concerns about the prototype and design (i.e., thematic saturation). These challenges exist in this field^{27,28,118-120} and it is important to consider them, engage with them, and also acknowledge that they may not be resolved unequivocally.

The most challenging aspect of designing the video content involved whether to be explicit regarding why patients should engage in ACP prior to major surgery. While some patient stakeholders expressed a desire for graphic and explicit ACP messaging, multiple surgeon stakeholders were concerned that such messaging would scare some patients who they considered to be already emotionally overwhelmed in preparation for their upcoming surgery. Complicating this further was that the team knew that surgeons would be gatekeepers for both recruitment for the clinical trial testing the video (Stage 6), as

well as final dissemination of the final video. The added voiceover language to address this difficult balance was deemed appropriate, and not too inflammatory, by surgeon stakeholders, and, compared to the video viewed by the Advisory Council, it was more explicit about why patients should engage in ACP prior to surgery. Notably, this voiceover was not vetted with our patient stakeholders prior to starting our randomized control trial. In retrospect, that additional seeking of input might have been beneficial. This conflict regarding how to discuss ACP in this context is emblematic of the power imbalance that exists between surgeons' and patients' opinions.

This conundrum raises the question: who is the audience in a human-centered approach? While the end-users are patients and caregivers, surgeons and other health professionals play an integral role in assisting patients with developing advance care plans, comprehending the medical gravitas of decisions, and acting as gatekeepers for any patient tools. Notably the final video was less directive and graphic than the previous ACP videos,⁵³⁻⁵⁶ on which this video was partially based. The different preferences between patients and health professionals—albeit regarding other healthcare decisions—has been a noted consideration in the development of other patient decision support tools.¹² This challenge emphasizes the importance and usefulness of HCD for developing these ACP tools in the preoperative setting.

The juxtaposition between patient and caregiver's desire for more explicit images and messaging with surgeons' desire to avoid distressing patients also aligns with the aforementioned distinction between decision aids and decision support tools. Where decision aids are proscriptive and provide a great deal of information regarding choices,⁵¹ decision support tools help patients to think about decisions, but are more a prompt than

an aid.⁵² Some key patient stakeholders, particularly those on the Advisory Council, were advocating more for a decision aid, while the surgeons, and ultimately the study investigators, preferred that the video instead be a decision support tool.

The hesitation among surgeons in this study to provide explicit messaging regarding ACP reflects past studies that have examined surgeon's attitudes and behaviors towards ACP. A qualitative study of audio-recorded preoperative visits between patients and surgeons found that surgeons often did not discuss the potential for post-operative prolonged life support.¹²⁰ In exploring the rationale behind this behavior, some surgeons perceive ACP discussions also as shifting the conversation from cure to comfort care.²⁸ Other surgeons' have expressed that their goal for patients is to defeat death as compared to ACP discussions which focus more on understanding patient goals regarding quality of life.²⁷ Yet, amidst this surgical culture generally opposed to ACP, this study created an ACP video for surgical patients that surgeons were overwhelmingly amenable to sharing with their patients. That the team achieved this speaks to both the strength of the HCD methods as well as the benefits in engagement with surgeons, patients, and their companions throughout the process. It may take participation in this process of tool development to change surgeon's perspectives towards advance care planning; therefore, further dissemination of this tool may be hindered by a lack of readiness due to a lack of other surgeons' engagement in the development process.

To the authors' knowledge, there are no known interventions examining how to change surgeon behavior in the context of ACP. That said, there have been physician education and workshops with demonstrated improvements in ACP and goals of care readiness and knowledge, and communication outcomes with oncologists,^{121,122} medical

oncology fellows,^{123,124} palliative care physicians,¹²¹ junior-doctors (i.e., medical interns in Australia),¹²⁵ geriatric and palliative medicine fellows,¹²⁶ and pulmonary and critical care fellows.¹²⁷ Future research might consider adapting the aforementioned interventions to the surgical oncology context to better facilitate these advance care planning discussions.

Limitations

HCD approaches are traditionally reserved for consumer product development and only recently have been used in the healthcare setting.⁸¹⁻⁸³ In the design of the ACP decision support video, necessary deviations to these traditional design approaches were made towards the goal of creating a stakeholder-engaged video that addressed sensitive needs. For example, Step One was done with a select group of stakeholders as a result of resource restraints; whereas, traditional approaches would have used all stakeholders. Furthermore, though we interacted with a large and diverse group of over 450 stakeholders, their viewpoints may not necessarily be generalizable. However, the engagement at the State Fair involved a diverse sampling of the population whose input was likely more generalizable than the sample at the Patient and Family Advisory Council.

Conclusions

For a video-based ACP decision support tool to achieve acceptance in the clinical setting, key stakeholders—patients and their family members, and surgeons—must be supportive of the tool and its creation. By applying HCD approaches, we used input from a variety of stakeholders throughout the process to create a final product that appeared acceptable to all.

Practice Implications

Future studies could consider leveraging an HCD approach to develop decision support tools. This approach can assist others with engaging a diversity of key decision makers and balancing differing opinions and worldviews. Future research should continue to investigate how to best balance stakeholder perspectives in creating patient-centered interventions that improve quality of care.

Tables and Figures for Paper One

Table 1. Stakeholder Feedback on Decision Support Tools

Style Concepts Identified by Stakeholders as Preferable
<ul style="list-style-type: none">• Use vignettes/ “real stories from patients and family members”
<ul style="list-style-type: none">• Framed in “how you want to live” rather than in a “death/dying” and “what do you want to die like?” context
<ul style="list-style-type: none">• Specific to surgical populations
Content Identified by Stakeholders as Preferable
<ul style="list-style-type: none">• Upbeat in tone
<ul style="list-style-type: none">• Involve both younger and older patients
<ul style="list-style-type: none">• Involve patients of multiple races and ethnicities.

Table 2. Stakeholder Feedback on from the Johns Hopkins Patient and Family Advisory Council and How the Team Addressed Said Feedback

Stakeholder Concerns Regarding the Video	How Concerns were Addressed in the Final Video
<p>The video involved an interview with a surgeon who noted that the hospital is “safe” and that, “You [the patient] will get through this.” Council members perceived these comments to be potentially falsely reassuring as they highlighted unavoidable risks inherent to major surgery.</p>	<p>The team removed the mention of the surgery as “safe”. After much discussion with the key surgeon stakeholders, the team maintained the quotation “You will get through this.” Surgeon stakeholders emphasized the importance of balancing reassurance to patients during this distressing time while also setting realistic patient expectations. Retaining this phrase in the video was contrary to patient suggestions.</p>
<p>Some council members felt that the video’s discussion of goals of care was too vague and stated a preference for the video to more explicitly discuss advanced directives, do not resuscitate orders, and other ACP-related goals.</p>	<p>In reviewing this feedback with several surgeons involved with the project, they felt that explicitly referring to advanced directives might cause patients and their family members distress. Surgeons were also opposed to showing images of feeding tubes and resuscitation. However, in balance of these surgeon and patient concerns, a voiceover was added to a section of the video that explicitly mentioned for patients to ask about the “risks for your surgery...this could include rare things like stroke, or a long hospital or intensive care unit stay with you even depending for a while on machines for things like breathing or feeding. Your loved one needs to be ready to speak for you in those rare circumstances.”</p>
<p>The video ended with a non-spoken, written text reinforcing the salient messages of the video. Council members felt that this text was too complicated, and that there was a need for a voiceover to accompany the visual text, particularly for those with low literacy.</p>	<p>The team simplified this messaging through the use of the Flesch-Kincaid test, which is a readability grade-level scale ranging from grades 0-12 that determines readability based on sentence length and number of syllables per word.¹²⁸ The scale is now automated software in Microsoft Word and has demonstrated reliability and validity.¹²⁹ The final phrasing in the video had a Flesch-Kincaid score of a grade 5.3 reading level: “Before surgery, identify the person who will speak for you. Talk with that person. If issues should arise, that person needs to be ready to speak for you. Tell your surgeon and surgical team who will speak for you.” Based on this feedback, the team also added a voiceover with these revised words.</p>

Figure 1. Human-Centered Design Process to Develop the Video

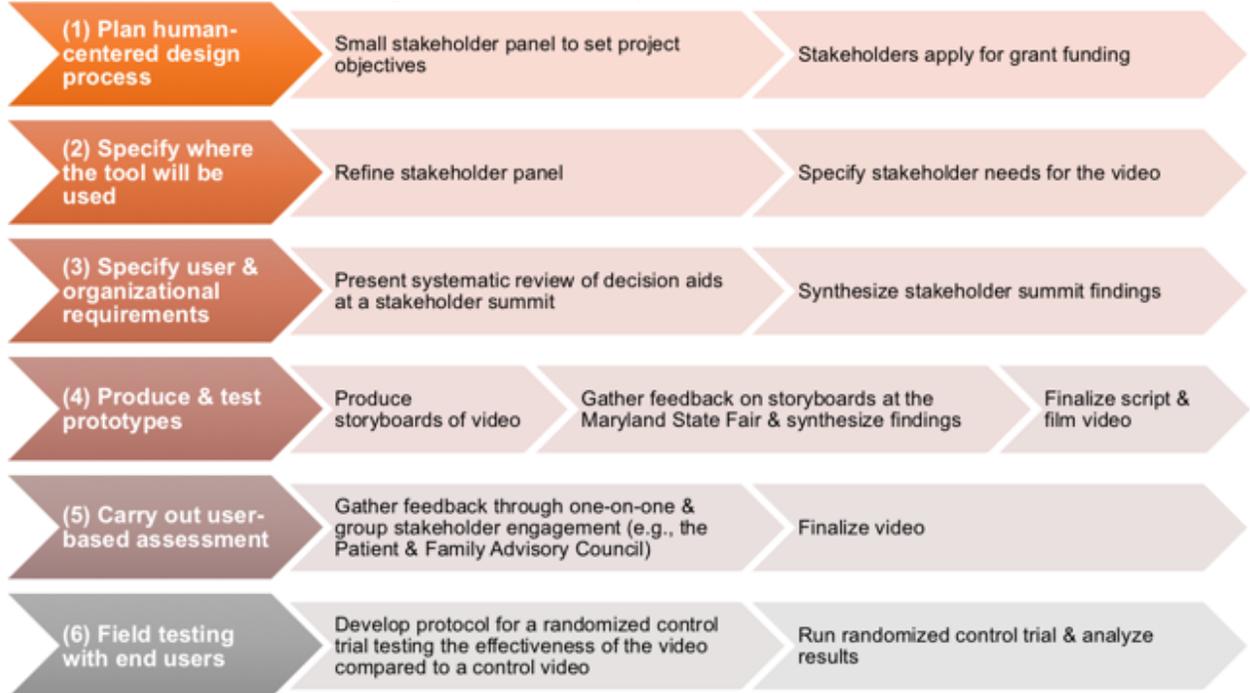


Figure 2. Examples of the storyboard panels (“prototypes”)

Scene 1: Your First Appointments



Scene 3: The Pre-Operative Waiting Area



Scene 4: The Operating Room



Scene 5: The Waiting Room



Figure 3. Screenshots from the Video

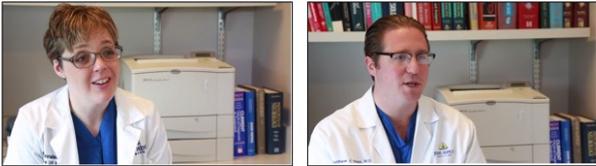
Patients and Companions Discussing Their Experiences



Images of the Perioperative Journey



Physicians Discussing Surgery



Final Messages at the End of the Video

Before surgery...
Identify the person who speaks for you.

Before surgery...
Talk with that person.
If issues should arise, that person
needs to be ready to speak for you.

Before surgery...
Tell your surgeon and surgical team
who will speak for you.

Paper Two: Companions' Involvement During Pre-Surgical Consent Visits and its Relationship to Visit Communication and Satisfaction

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Word count: 3,546

Abstract

Objective: To examine the nature and consequences of family member presence in pre-surgical visits to discuss major cancer surgery on visit communication and post visit satisfaction.

Methods: Secondary analysis of 61 pre-surgical visit recordings with eight surgical oncologists at an academic tertiary care hospital. Recordings were analyzed using the Roter Interaction Analysis System (RIAS) and surgeons, patients, and family companions completed a short post-visit satisfaction questionnaire. Poisson and logistic regression models were used to assess differences in communication and satisfaction when companions were present and not present. The models were fit using generalized estimating equations (GEE) to account for nesting of patients within surgeons.

Results: There were 46 visits (75%) in which companions were present, and 15 (25%) in which companions were not present. Companion communication was largely emotional and facilitative, as demonstrated by RIAS. In unadjusted analyses, companion presence was associated with a 29% increase in surgeon talk in the visit overall (IRR 1.29, $p=0.006$), and a 41% increase in the amount of medical information provided (IRR 1.41, $p=0.001$). Companion presence was associated with 45% less patient disclosure related to lifestyle/psychosocial topics (IRR 0.55, $p=0.037$). In adjusted analyses, companions' presence was associated with 23% lower levels of patient-centeredness (IRR 0.77, $p=0.004$). There was no difference between visits with and without companions in patient or surgeon satisfaction.

Conclusion: Presence of companions alters patient-surgeon communication during presurgical visits for major cancer surgery by increasing the medical focus of the

discussion; surgeons conveyed more medical information, and patients disclosed less lifestyle and psychosocial information in these visits.

Keywords: companion; family caregiver; patient-provider communication; decision-making; cancer; surgery

Abstract word count: 237

1. Introduction

Major surgery involves a significant risk of death or disability.³ A pre-surgical visit is frequently held immediately before planned surgery to obtain patient consent and review surgical risks and benefits, potential postoperative morbidities, pain management and quality of life considerations.⁵⁻⁷

Patients are often accompanied by a family member (i.e., companion) to medical visits and while the study of patient accompaniment is growing,^{10,11} most studies have focused on the consequences of having a companion present in ambulatory care medical visits. These studies have found that when companions are present in visits, patient ratings are higher across visit satisfaction dimensions of interpersonal rapport, informativeness, and care quality.^{11,88-90} Companions have been reported to help patients become more active participants in their conversational exchanges by asking more questions and discussing more of their concerns with providers as opposed to being passive recipients of information.⁸⁹ When together, patients and their companions proactively direct the course of the visit by orienting the provider to their agenda, introducing new topics, and disclosing more information.⁸⁹ Therefore, it is perhaps unsurprising that the great majority of patients value the involvement of family when making treatment decisions.⁹¹

Importantly, companions' engagement does not always have a positive influence on patients. Companions do occasionally disagree with patients on treatment decisions and care; among lung cancer patients, rates of conflict range from 11-33%.⁹⁷ Further, the family history and dynamic may impact patient's medical treatment adherence and

consequently his/her engagement during the visit; for example families that are less cohesive and higher conflict have patients with lower treatment adherence.⁹⁸

While the findings noted have relevance for family involvement in surgical decisions, there has been little exploration of the family role within high stakes, pre-surgical visits in which decisions about major elective cancer surgery is discussed. The purpose of this study was to examine the impact of family companion presence on communication during pre-surgical visits, particularly in regard to the impact of companion presence on the overall patient-centeredness of the session and patient and surgical oncologist satisfaction with the visit.

Methods

1.1. Study Design

This study is based on secondary analysis of 61 digitally-recorded pre-surgical visits with oncological surgeons that occurred between July 2015 and September 2016. The parent study was a randomized clinical trial designed to evaluate how pre-surgical visit communication might be affected by a video designed to prepare patients and family members for major surgery.¹⁰⁹ Nine surgical oncologists at an academic tertiary care hospital agreed to participate in the study as they had sufficient cancer patient populations, the nature of the surgeries they performed were likely to result in a short term intensive care unit stay for their patients, and they were willing to be in the trial. If surgeons were willing to have their patients recruited into the study, he/she had to schedule a dedicated pre-surgical consent visit—separate from the initial visit for surgical evaluation—with the patient approximately one week prior to surgery, and consent to audio recording of the visit. While not all participating surgeons' standard practices

involved a separate pre-surgical visit, for the purposes of this study, they agreed to have two visits prior to surgery with study participants.

Adult patients scheduled to undergo elective major cancer surgery were recruited from these nine surgical oncologists' outpatient clinics. Patients were only eligible if, for a variety of medical reasons, the surgeon planned to postoperatively admit the patient to the surgical intensive care unit (SICU). Patients had to be scheduled for non-emergent surgery such that they had at least a day to review the video prior to consenting to surgery. Other inclusion criteria were: plan to undergo surgery with one of the study surgeons, age 18 or above, able to give informed consent, and able to speak English. Patients were excluded if they had visual or hearing impairments rendering them unable to view and/or hear the study videos.

Study staff set up two tape recorders in the examination room to record the visit interaction. After the visit, the surgeon, patient, and companion each completed a short satisfaction questionnaire about the visit. Demographic information was collected via self-report from patients at an earlier visit, and from companions at the time of the audiorecorded visit. Further details about the parent trial have been described elsewhere.¹⁰⁹ The Johns Hopkins School of Medicine Institutional Review Board approved this study.

2.2 Dialogue Coding using the Roter Interaction Analysis System (RIAS)

The pre-surgical recordings were analyzed with the Roter Interaction Analysis System (RIAS), a systematic, quantitative coding system for medical dialogue that has demonstrated reliability and predictive validity.^{110,130-134} The coding system assigns one of 37 mutually exclusive and exhaustive categories to each complete thought expressed by every speaker; in this study including the surgeon, patient, and his/her companion.

Often individual RIAS codes are combined to create composite categories, as reflected in Table 3, including medical questions (related to medical history, symptoms and treatment), psychosocial/lifestyle questions, patient education and counseling – medical, patient education and counseling - psychosocial, emotional responsiveness, facilitation and patient activation, positive talk, negative talk, social talk, and procedural talk. These 10 composites summarize the individual codes available in the RIAS system. The results from these composites are the number of times these themes were mentioned in the exchange. In addition to the content codes, the RIAS coder also rates each speaker on global affect using a 6-point Likert scale reflecting positive (i.e., warmth, engagement, interest, respectfulness) and negative (i.e., irritation, anxiety, dominance, hurried) affective dimensions.

RIAS variables were combined to calculate a patient-centeredness summary score, which has shown predictive and concurrent validity for a variety of patient and physician outcomes in prior studies.¹¹¹⁻¹¹⁷ The patient-centered summary score includes provider, patient, and companion communication codes combined as a ratio to reflect the visit balance of psychosocial and emotional communication to biomedically-focused exchanges. The numerator of the ratio reflects elicitation and discussion of patients' experiences, beliefs, preferences, emotional responses and engagement in treatment decision making while the denominator includes other core elements of medical interaction in the biomedical realm critical to diagnosis and treatment like symptom and treatment history, information and counseling related to patient adherence and prescribing of medications, tests and referrals, and the weighing of risks and benefits or proposed treatments and alternatives. The ratio summarizes the cumulative relative balance of visit interaction across these two

critically important facets of medical interaction consistent with conceptual discussions of patient-centeredness in the literature and discussed in more detail elsewhere.¹³⁵

2.3 Visit Satisfaction Measures

The study team adapted measures developed and used by Roter and colleagues in previous studies to address patient satisfaction with interpersonal and informational aspects of medical visits.¹³⁶⁻¹³⁹ This measure is a six-item Likert scale with five response options: strongly disagree, disagree, neutral, agree, and strongly agree. Examples of questions from the patient satisfaction scale include: “My time was well spent in this visit,” “I trust the surgeon,” and “I understand the most important information discussed by the surgeon.” Of note, the version of the scale used for companions featured eight items, with the two additional: “My presence was meaningful for me in this visit” and “My presence was meaningful for the patient in this visit.” The internal reliability of these questionnaires was tested with Cronbach’s alpha: surgeon satisfaction: 0.93; patient satisfaction: 0.97; companion satisfaction: 0.99.

2.4 Analysis

Comparisons of demographics between patients with and without companions were performed using the Mann-Whitney test (for continuous variables) and Fisher’s exact test (for categorical and dichotomous variables). Poisson models for the 10 composite RIAS variables were fit that included a main term, fixed effect for the presence/absence of a companion; the relative mean number of times the theme was discussed comparing the companion to non-companion interactions are reported. The models were fit using generalized estimating equations¹⁴⁰ to account for the nesting of patient/family within surgeon. The models assumed the patients/families were

exchangeable within surgeon and standard errors were computed using robust variance estimates to account for potential over/under dispersion in the data.

The models described above were extended to determine the effect of companion presence on the patient-centeredness summary score which combines the number of psychosocial and emotional communication themes and number of biomedically-focused content within a given patient/surgeon exchange, both of which are random variables. Poisson models using GEE was fit to the outcome, the number of themes, which included main terms for the type of communication (psychosocial vs. biomedical) and the presence/absence of a companion and the interaction of these two main terms. The coefficient for the interaction provides an estimate of the relative size of the patient-centeredness score comparing patient/surgeon exchanges with and without a companion present. The models were nested by surgeon and assumed the patients/families were exchangeable within surgeon and standard errors were computed using robust variance estimates to account for potential over/under dispersion in the data. Covariates were selected based on bivariate analyses if p-values were <0.05 (i.e., race, surgeon's medical information and counselling, surgeon's procedural talk, surgeon's lifestyle/psychosocial questions, patient's lifestyle/psychosocial information sharing), and on other similar studies^{10,11} (i.e., patient and surgeon satisfaction, patient age, gender, and education level, length of visit).

Satisfaction scores were dichotomized as perfect satisfaction (1) or any score less than perfect (0). Logistic regression models based on GEE were used to compare the odds of perfect satisfaction across exchanges with and without a companion present. Patients/families were assumed to be exchangeable within a surgeon and robust standard

errors were used to account for any over/under binomial dispersion. All analyses were conducted using Stata 13.¹⁴¹

3 Results

Of the 61 audio-recorded visits, 46 (75.41%) included one or more companions, and 15 (24.59%) did not include a companion. Of these 46 visits, there were 55 companions present in total—38 visits were with one companion, seven with two, and one visit with three. Eight surgeons contributed patients who were eligible for the study and each were recorded with an average 7.63 patients (standard deviation 6.93), range 1-23. While the study recruited patients from the nine participating surgeons, only eight surgeons had patients that were eligible for the trial and enrolled.

Of the 55 companions present in the 46 visits, 36 (65.45%) were female (Table 2). The majority of companions were spouses (n=29; 52.73%) followed by children (n=11, 20.00%), with the remainder being mostly other family members. Fewer than 7.27% of companions were not family members (Table 4). There were no significant differences in patient demographics comparing patients with and without companions in the visit (Table 4).

3.3 Description of Family Companions' Communication

Of the 46 visits in which companions were present, companions contributed 11% of the the conversation, surgeons contributed 62%, and patients 27%. Conversely, in the 15 visits in which companions were not present, surgeons contributed 63% and patients 37% of the visit dialogue. The two most frequent ways companions contributed to the dialogue, as analyzed with RIAS, were with positive talk (mean 15.17 (standard deviation

21.82)) and by facilitating patient communication (mean 10.33 (standard deviation 12.85)) (Table 5).

3.2. Companions' Impact on Surgeons' and Patients' Communication

3.2.1. Companions' Impact on Surgeons' Communication

Companion presence was associated in unadjusted analysis with surgeons contributing 29% more talk to the visit dialogue (p 0.006), a 41% increase in the amount of medical information the surgeon provided (p 0.001) and a 30% increase in procedural talk (p=0.028) (Table 5). Companion's medical questioning was associated with an increase in the surgeon's medical information sharing (IRR 1.02, CI 1.01, 1.04, p=0.004).

3.2.2. Companions' Impact on Patients' Communication

Companion's presence was not associated with the how much the patient talked overall in the visit; however, companions' presence was associated with a 45% decrease in patients' disclosures about lifestyle and psychosocial topics (p 0.037) (Table 5). A post hoc sensitivity analysis found that the relationship between companion presence and fewer patient statements about lifestyle/psychosocial information remained significant after controlling for the surgeon's lifestyle/psychosocial questions and the length of the visit (IRR 0.51, CI 0.35, 0.76, p=0.001).

3.2.3. Companions presence and overall patient-centeredness of the visit

Table 6 presents the multivariate analysis of overall patient-centeredness of the pre-surgical visit. Significant predictors in the model included the presence of a companion, showing a 23% reduction in the overall patient-centeredness of the visit (p 0.001), accounting for key patient and surgical communication codes patient and surgeon

satisfaction with the visit, and covariates (length of visit, patient's age, race, education level, and gender) (Table 6).

There was no difference between visits with and without companions in patient (OR 0.68; CI 0.34, 1.34; 0.264) or surgeon satisfaction (OR 1.03; CI 0.63, 1.68; 0.911).

4. Discussion and Conclusion

4.1 Discussion

These results contribute to a small literature describing high-stakes discussions about major cancer surgery and are the first to describe how the presence of family companions affects communication in this setting. Three-in-four patients in this study were accompanied by at least one family member or friend. Most companions were female (65%) and spouses (53%) or children (20%). Sessions averaged 18.55 minutes, and the presence of companions did not affect visit length.

The key communication features distinguishing accompanied visits, compared to unaccompanied visits, were the surgeon talking more overall, the surgeon providing more medical information and procedural talk, and the patients providing less lifestyle/psychosocial information. We also found that the presence of a companion significantly diminished the overall level of visit patient-centeredness. Finally, despite these differences in encounters when companions were and were not present, there were no differences in patient nor surgeon visit satisfaction.

Similarly high proportions of patient accompaniment was found in a study of oncology consultations where "bad news" was disclosed wherein 86% of patients were accompanied by companions.⁹ These high proportions may reflect in part the high-stakes nature of these encounters where patients are often strongly encouraged to bring family

companions to assist in navigating and coping with these discussions. The finding that most companions were female (65%) and spouses (53%) is in line with Wolff and Roter's meta-analysis of studies of family presence in routine medical visits for older patients, that showed 79.4% of companions were female and 54.7% were spouses.¹¹ Of note, we compare to Wolff and Roter's meta-analysis as it is the most comprehensive analysis of the role of companions in medical visits to date; however, we draw this comparison with the caveat that there are clear differences in the pre-surgical visit and routine medical visit.

Our finding of no significant difference in the length of the pre-surgical visits for accompanied vs unaccompanied patients may have been the result of participating surgeons changing their usual practice by holding dedicated consent visits for the study; surgeons may have been very attentive to patients regardless of accompaniment.

The distribution of talk observed in our study among accompanied patients (27%), surgeon providers (62%), and companions (11%) is similar to the proportion of talk observed in Wolff and Roter's meta-analysis of routine medical visits, where the distribution breakdown was 32.4% patients, 53.3% physicians, and 14.9 % companions.¹¹ While companions in our study only contributed 11% of the talk in these interactions, they had a significant impact on patient-surgical provider communication during the visit.

Companion presence was associated with the surgeon talking more overall, providing more medical information, and procedural talk. Since companions asked on average 5.26 medical questions per visit (Table 5), the surgeons' increase in medical and procedural talk may have been in response to these questions; indeed, a post hoc sensitivity analysis showed that companion's medical questioning was associated with an

increase in the surgeon's medical information sharing. As patients' medical question asking did not differ when companions were present, companions' questions were in addition to what patients were already asking. These findings are consistent with prior research reporting that oncologists were more informative when patients were accompanied by a companion.^{99,100}

In their meta-analysis, Wolff and Roter found that when companions were present, patients engaged in less psychosocial information giving.¹¹ Our results were similar: patients accompanied by companions shared less lifestyle/psychosocial information even though companion presence did not impact the frequency of patient communication overall. Our observed decrease in lifestyle/psychosocial information sharing when companions were accompanied vs unaccompanied was not sufficiently explained by our finding that surgeons asked fewer lifestyle/psychosocial questions when companions were present; the post hoc sensitivity analysis found that the relationship between companion presence and fewer patient statements about lifestyle/psychosocial information remained significant even after controlling for the surgeon's lifestyle/psychosocial questions and the length of the visit.

Several reasons might explain why there was less psychosocial exchange between patients and surgeons when companions were present. First, companion communication most frequently centered on rapport building, and, furthermore, included lifestyle/psychosocial information (Table 5), thereby preemptively communicating the information that would have been communicated by patients if they were unaccompanied. Future research should explore whether companion psychosocial

communication is an enhancer or suppressor of addressing patient psychosocial and lifestyle concerns.¹⁴²

Second, the visits analyzed in this study were follow-up consent visits that followed a prior visit with the surgeon where an initial assessment was performed. Hence, discussion of lifestyle and psychosocial concerns may have been addressed in prior interactions between the patient and surgeon.

Companion's presence decreased the patient-centeredness scores of the visit. These differences in patient-centeredness scores between patient accompanied and unaccompanied visits was driven by a marked increase in components of the denominator of the ratio. Specifically, surgeons gave more medical information and engaged in more procedural talk when companions were present, and companions contributed medical information (Table 5).

To explain the patient-centeredness finding, companions might perceive patients as anxious prior to major cancer surgery and too affectively overwhelmed to give focused attention to the encounter. Consequently, companions may feel compelled to "step up" and advocate for the patient by asking technical questions about the surgery to help him/her better understand and visualize the patient's journey. Indeed, the second most frequent companion communication behavior was facilitation and patient activation, at a mean of 10.33 statements per recording. A qualitative study of 28 conversations between patients, oncologists, and companions (wherein patients had life limiting cancer) found companions frequently spoke on behalf of patients during discussions of prognosis and treatment choices, despite the patient being capable of speaking for him/herself.⁹⁵ Companions, especially those for highly independent patients (such as those in our

sample—most companions did not indicate they assisted patients with activities of daily living), might see their role in these pre-surgical encounters as informational social support. The companion's presence might be beneficial to the patient; however, the extent of that benefit might not be captured by the patient-centeredness ratio.

It is also important to highlight that the perioperative experience is stressful for companions, as well as patients.¹⁴³⁻¹⁴⁵ Many of these companions undertake the many tasks of family caregiving before, during, and after surgery. Family members often deliver the majority of medical care to patients in the home, including wound management, medication administration, and symptom monitoring and management. Considering these responsibilities, companions may have many information needs of their own during pre-surgical visits to help them prepare for supporting the patient, which may explain the increase in surgeon communication about medical information and procedures. The perioperative experience of cancer family caregivers has been noted to be understudied in general,⁸⁷ representing a potentially fruitful direction for triadic perioperative communication.

Despite differences in accompanied vs unaccompanied encounters, there were no differences in patient nor surgeon visit satisfaction. This finding counters past studies of patient and surgeon satisfaction. When companions are present in routine medical care, patient ratings of visit satisfaction are higher in interpersonal rapport, informativeness, and care quality, compared to when companions are not present.^{11,88-90} Although some studies have found companions occasionally conflict with patients on treatment decisions and care,⁹⁷ which may negatively impact patients' perceptions of companions' presence in visits, the majority of studies suggests companions' presence has a positive benefit.

Regarding physicians, a study of primary visits found physicians report that the presence of a companion increases their understanding and subsequent satisfaction with the visit.¹⁰² In this pre-surgical setting, companions may be acting as extensions of the patient, not changing the feel of the conversation but rather furthering patient's goals and expectations. In presurgical visits, patient and surgeon satisfaction may not be predicated upon patient-centeredness, but rather upon the conveyance of timely, surgery-related information.

4.2 Limitations

This study has several limitations. The companion survey featuring information regarding their relationship and role to the patient was only added two months into the study; therefore, there are 11 companions that did not complete this information. Second, there may be unmeasured characteristics that affected communication (e.g., relationship history between patient and companion, companion education level). Third, given that these are elective surgeries that require private insurance or personal means to afford such procedures, the population is limited in this way. These characteristics, coupled with our smaller sample size, may limit the generalizability of this study. Fourth, we cannot draw conclusions between the varied behavior of companions and their different genders, relationships, and roles as the RIAS coder did not distinguish between companions in visits when there was more than one companion present. Fifth, due to a need to protect the identity of the surgeons involved in our trial, we are unable to analyze how particular surgeon characteristics may impact triadic communication outcomes. For example, some participating surgeons routinely had two pre-surgical visits with patients, while others did not, which may have altered their approach to this additional visit. Finally, the lack of

significant difference in satisfaction comparing accompanied and unaccompanied visits may be a result of lack of variability in the satisfaction scores as a result of the positive skewness of the satisfaction data. In addition, the smaller sample size may have been unable to detect differences.

4.3 Practice Implications

The presence of companions alters provider-patient communication during high-stakes medical encounters about major cancer surgery. Future work is needed regarding how companion presence during patient-provider interactions might be optimized to facilitate positive outcomes during and after these clinic visits. Companions are likely to be decision makers if the patient becomes too ill to voice his/her preferences; therefore, their early engagement is integral to informed decision making.

4.4 Conclusions

This is the first study to begin to parse out the nuanced details of the nature of the patient-companion-surgeon exchange in the pre-surgical visit. This is an area ripe for further exploration. Future studies should continue to explore the role that companions serve in the pre-surgical visit.

Aim 1 Tables

Table 3: Examples of Key RIAS Composite Codes

RIAS Composite Code	RIAS Codes	Examples from Recordings
Questions - medical	Medical or therapeutic questions—either open or closed Bid for repetition	<ul style="list-style-type: none"> • Patient: Now could you explain that to me because I never did understand the difference between the colon and the small intestine?
Information and counseling - medical	Gives medical or therapeutic information Counsels medical or therapeutic	<ul style="list-style-type: none"> • Surgeon: You have that really big stent in there. • Surgeon: Being a little bit generous in weight around the middle, weight and obesity do increase your risk of surgical complication.
Questions - lifestyle/ psychosocial	Lifestyle or psychosocial questions—either open or closed	<ul style="list-style-type: none"> • Patient: How soon after the surgery can I go back to work? • Companion: What changes will occur in my dad's day-to-day life, if any, as a result of losing 20-30% of his pancreas and his spleen?
Information and counseling: lifestyle/psychosocial	Gives lifestyle or psychosocial information Counsels lifestyle or psychosocial	<ul style="list-style-type: none"> • Patient: I'm prepared to do it [surgery].
Activation	Asks for opinion Asks for permission Asks for reassurance Asks for understanding Back channels Paraphrase, checks for understanding	<ul style="list-style-type: none"> • Surgeon: Here is your liver—does that make sense? • Companion: Her prognosis is good, right?
Positive talk	Laughs, tells jokes Expresses approval Compliments Shows agreement, understanding	<ul style="list-style-type: none"> • Surgeon: You are just doing your best. • Companion: Your analogies are very good. • Patient: I have faith in you as a surgeon.
Emotional talk	Empathy statements Legitimizing statements Concern, worry Reassurance, optimism Partnership statements Self-disclosure	<ul style="list-style-type: none"> • Surgeon (to companion): It's very difficult to watch a family member go through this. • Patient: I'll take those odds any day! • Patient: I'm looking forward to relaxing and not going to work for two months. • Surgeon: I promise you it's no worse than getting a little IV in your arm. • Surgeon: This is a very normal feeling to have. You are not alone. A lot of women have these feelings.
Negative talk	Disagreement Criticism	<ul style="list-style-type: none"> • Companion: It looks easy • [In response to the above statement] Surgeon: It's not that easy.
Social talk	Personal remarks	<ul style="list-style-type: none"> • Surgeon: I forgot to ask: how was the cruise?
Procedural talk (orientations and instructions)	Transitions Gives orientation, instructions	<ul style="list-style-type: none"> • Surgeon: I will just mention one more thing (orient). • Surgeon: I'm going to sit down right now and talk about what the proposed surgery is.

Table 4: Demographics of Patients with and without Companions (n=61)

Variable	Total (n=61)	Visits with Companions (n=46)	Visits without Companions (n=15)	P-value ⁱ
Age Mean (SD)	61.68 (11.72)	61.87 (12.48)	61.13 (9.42)	0.86
Sex; n(%) Female Male	36 (60.00) 24 (40.00)	26 (57.78) 19 (42.22)	10 (66.67) 5 (33.33)	0.76
Race; n(%) White/Caucasian Black/African American Asian or Multi-Race	50 (83.33) 8 (13.33) 2 (3.33)	40 (88.89) 4 (8.89) 1 (2.22)	10 (66.67) 4 (26.67) 1 (6.67)	0.10
Education; n(%) Less than/equal to high school Greater than high school	30 (50.00) 30 (50.00)	22 (48.89) 23 (51.11)	8 (53.33) 7 (46.67)	1.00
Primary Diagnosis; n(%) Pancreatic Cancer Hepatobiliary & GI Cancers Gynecological Cancers Colon Cancer Sarcomas Other	22 (36.67) 18 (30.00) 9 (15.00) 4 (6.67) 6 (10.00) 1 (1.67)	17 (37.78) 16 (35.56) 5 (11.11) 3 (6.67) 4 (8.89) 0 (0.00)	5 (33.33) 2 (13.33) 4 (26.67) 1 (6.67) 2 (13.33) 1 (6.67)	0.19
Existence & Severity of Complication with Surgery (n=57) ⁱⁱ ; n(%) No Complication Grade I Grade II Grade III Grade IV	24 (42.11) 13 (22.81) 11 (19.30) 3 (5.26) 6 (10.53)	18 (42.86) 10 (23.81) 7 (16.67) 3 (7.14) 4 (9.52)	6 (40.00) 3 (20.00) 4 (26.67) 0 (0.00) 2 (13.33)	0.83
Sex of Companion (n=59) ⁱⁱⁱ ; n(%) Female Male	-	36 (65.45) 19 (34.55)	-	-

ⁱ Comparisons of demographics between patients with and without companions were done with the Mann-Whitney test (for continuous variables) and Fisher's exact test (for categorical and dichotomous variables).

ⁱⁱ While there were 61 audiorecordings or pre-surgical visits, not all patients went for surgical, which is why there are only 57 patients with data regarding complications.

ⁱⁱⁱ While there were 46 audiorecorded visits with companions present, 28 has one companions, seven had two companions, and one had three companions; therefore, there is demographic data on 55 companions in total.

Companion Relationship to Patient (n=59); n(%)				
Spouse (Married/Common Law)		29 (52.73)		
Boyfriend/Girlfriend/Fiancé		2 (3.64)		
Parent	-	2 (3.64)	-	-
Child		11 (20.00)		
Sibling		6 (10.91)		
Aunt/Uncle		1 (1.82)		
Friend		4 (7.27)		
Companions Roles (n=54) ^{iv} ; n(%)				
Physical Activities (e.g., feeding)		13 (25.00)		
Specific Tasks (e.g., driving)		31 (59.62)		
Emotional Support		50 (96.15)		
Religious/Spiritual Support		22 (42.31)		
Accompany to Medical Appointments	-	44 (84.62)	-	-
Participate in Treatment Discussions				
During Medical Appts		46 (88.46)		
Monitor Symptoms and Health		34 (65.38)		
Medical Decision Maker		20 (38.46)		
Surgeon; n(%)				
1	23 (37.70)	18 (39.13)	5 (33.33)	0.75
2	9 (14.75)	7 (15.22)	2 (13.33)	
3	8 (13.11)	7 (15.22)	1 (6.67)	
4	8 (13.11)	4 (8.70)	4 (26.67)	
5	3 (4.92)	2 (4.35)	1 (6.67)	
6	2 (3.28)	2 (4.35)	0 (0.00)	
7	1 (1.64)	1 (2.17)	0 (0.00)	
8	7 (11.48)	5 (10.87)	2 (13.33)	
Sex of Surgeon; n(%)				
Female	17 (27.87)	12 (26.09)	5 (33.33)	0.74
Male	44 (72.13)	34 (73.91)	10 (66.67)	

^{iv} The question regarding the role that companions serve in relation to the patients was introduced after data collection began; therefore, we are missing data on five companions.

Table 5: Bivariate Models Depicting How Companions' Presence Affected Session Communication

RIAS Composite Code	Visits with Companions (n=46) Mean (SD)	Visits without Companions (n=15) Mean (SD)	IRR (CI) ^v	P-value
Overall visit				
Length of the visit (minutes)	19.06 (13.67)	16.98 (10.74)	1.25 (0.90, 1.76)	0.186
Companion Behaviors				
Total contribution to the dialogue	48.48 (47.96)	-	-	-
Questions - medical	5.26 (6.70)	-	-	-
Information & counseling - medical	4.0 (5.2)	-	-	-
Questions - lifestyle/ psychosocial	0.70 (1.52)	-	-	-
Information & counseling: lifestyle/psychosocial	3.33 (4.71)	-	-	-
Activation	10.33 (12.85)	-	-	-
Positive talk	15.17 (21.82)	-	-	-
Emotional talk	3.15 (4.16)	-	-	-
Negative talk	0.15 (0.36)	-	-	-
Social talk	4.63 (9.98)	-	-	-
Procedural talk	1.22 (2.17)	-	-	-
Positive affect	4.47 (0.82)	-	-	-
Surgeon Behaviors				
Total contribution to the dialogue	257.35 (147.65)	212.20 (134.69)	1.29 (1.08, 1.56)	0.006
Questions - medical	5.87 (7.28)	4.67 (4.69)	1.16 (0.86, 1.56)	0.327
Information & counseling - medical	148.50 (99.38)	110.40 (76.79)	1.41 (1.16, 1.72)	0.001

^v Poisson model using generalized estimating equations, assuming exchangeable correlation structure and robust standard errors.

RIAS Composite Code	Visits with Companions (n=46) Mean (SD)	Visits without Companions (n=15) Mean (SD)	IRR (CI) ^v	P-value
Questions - lifestyle/ psychosocial	1.26 (2.64)	2.33 (2.64)	0.55 (0.30, 1.01)	0.054
Information & counseling: lifestyle/psychosocial	7.04 (8.51)	6.27 (5.74)	1.16 (0.90, 1.50)	0.251
Activation	22.98 (14.45)	25.67 (15.99)	0.97 (0.84, 1.12)	0.682
Positive talk	21.87 (13.72)	19.33 (13.10)	1.24 (0.96, 1.61)	0.100
Emotional talk	31.09 (20.17)	29.53 (24.86)	1.16 (0.88, 1.52)	0.294
Negative talk	0.78 (1.11)	0.33 (0.82)	2.35 (0.69, 7.96)	0.171
Social talk	8.28 (9.33)	5.27 (3.31)	1.57 (0.99, 2.49)	0.053
Procedural talk	9.33 (10.43)	8.00 (8.32)	1.30 (1.03, 1.64)	0.028
Positive affect	5.47 (0.59)	5.51 (0.48)	1.00 (0.98, 1.04)	0.490
Patient behaviors				
Total contribution to the dialogue	114.37 (78.85)	123.73 (83.17)	1.01 (0.74, 1.38)	0.950
Questions - medical	8.96 (7.38)	8.52 (7.10)	1.08 (0.72, 1.63)	0.707
Information and counseling - medical	14.24 (11.59)	13.93 (13.39)	1.10 (0.81, 1.50)	0.540
Questions - lifestyle/ psychosocial	0.83 (1.52)	0.60 (0.99)	1.57 (0.67, 3.67)	0.296
Information & counseling: lifestyle/psychosocial	7.17 (6.74)	14.40 (12.75)	0.55 (0.32, 0.96)	0.037
Activation	32.15 (33.57)	32.67 (29.51)	1.12 (0.87, 1.44)	0.379
Positive talk	33.61 (26.26)	32.27 (19.56)	1.07 (0.74, 1.56)	0.714
Emotional talk	8.65 (6.42)	13.80 (17.60)	0.66 (0.40, 1.08)	0.095
Negative talk	0.52 (1.03)	0.27 (0.46)	1.58 (0.94, 2.65)	0.082
Social talk	4.26 (3.86)	4.00 (2.83)	1.06 (0.73, 1.55)	0.744
Procedural talk	3.35 (3.25)	2.47 (1.92)	1.40 (0.98, 1.99)	0.061
Positive affect	4.64 (0.76)	4.67 (0.78)	0.99 (0.94, 1.05)	0.841

Table 6: Unadjusted and Adjusted Models Depicting How Companions' Presence Affected Patient-Centeredness of the Pre-Surgical Session

Variable	Unadjusted Analysis		Adjusted Analyses	
	IRR (CI) ^{vi}	P-value	IRR (CI) ^{vii}	P-value
Companion Present	0.77 (0.67, 0.90)	0.001	0.77 (0.64, 0.92)	0.004
Length of the visit (minutes)	0.99 (0.99, 1.00)	0.112	1.00 (1.00, 1.01)	0.256
Surgeon information and counseling - medical	1.00 (1.00, 1.00)	<0.001	1.00 (1.00, 1.00)	<0.001
Surgeon procedural talk	1.00 (1.00, 1.02)	0.593	1.01 (1.01, 1.01)	<0.001
Patient information and counseling - lifestyle/psychosocial	1.01 (1.00, 1.02)	0.020	1.02 (1.00, 1.03)	0.014
Surgeon satisfaction	1.09 (0.71, 1.69)	0.688	1.10 (1.00, 1.21)	0.042
Patient satisfaction	0.97 (0.83, 1.13)	0.668	1.01 (0.94, 1.10)	0.745
Age	1.00 (0.99, 1.01)	0.585	1.00 (1.00, 1.01)	0.982
Sex (female)	1.14 (0.90, 1.45)	0.283	0.93 (0.85, 1.01)	0.103
Race				
White/Caucasian	Reference		Reference	
Black/African American	1.12 (0.92, 1.38)	0.242	1.06 (0.76, 1.47)	0.743
Asian or Multi-Race	1.22 (0.73, 2.06)	0.446	1.01 (0.88, 1.15)	0.936
Education: greater than high school	0.77 (0.59, 1.01)	0.061	1.11 (0.98, 1.25)	0.090

^{vi} Poisson model using generalized estimating equations, assuming exchangeable correlation structure and robust standard errors.

^{vii} Poisson model using generalized estimating equations, assuming exchangeable correlation structure and robust standard errors. This model adjusts for surgeon's medical information and counseling, surgeon's procedural talk, patient's lifestyle/psychosocial information, patient satisfaction with visit, surgeon satisfaction with visit, length of visit, patient's age, race, education level, and gender.

Paper Three: A Qualitative Exploration of Disruption in the Presurgical Consent Visit for Patients Undergoing Major Surgery for Advanced Cancer

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ABSTRACT

Background

The decision to undergo non-emergent surgery for cancer typically occurs after risks and benefits have been discussed between surgeons, patient, and accompanying family members. Sometimes, unanticipated clinical information or quality of life considerations (“disruptions”) arise during these pre-surgical visits, which raise doubts regarding the surgical plan and lead to a discussion of whether to proceed as planned, postpone or cancel the surgery. Little is known about how often unanticipated changes to the surgical plan occur. This paper explores case studies of how a patient, companion, and surgeon negotiate surgical plan disruptions.

Methods

This study is based on secondary analysis of pre-surgical recordings with 61 patients and nine surgeons, collected as part of a randomized control trial designed to evaluate the impact of an advance care planning video on pre-surgical visit communication. Patients were recruited at nine surgical oncology clinics at an academic tertiary care hospital from July 2015-September 2016.

Qualitative analysis incorporated existing theory and inductively developed codes to enrich the development of case studies in which a disruption in the surgical plan was identified.

Results

Four of the 61 pre-surgical visits were identified as having a disruption. Each case study explores the presentation of the disruption, patient reaction to the disruption, companion involvement and role in the encounter, and resolution of the disruption. While each disruption involves a nuanced approach to decision making, there are cross cutting themes across the cases. Specifically, analysis of these visits explored companion roles, including: patient autonomy-enhancing behaviors and patient autonomy-detracting behaviors. This analysis also addressed variation and similarities in surgeons' behaviors, including examples of collaborative, facilitative, and informative behaviors.

Conclusions/Implications

As more high risk surgeries are performed on sicker and older patients, decision making regarding whether to pursue surgery may become increasingly complex, and lend itself more frequently to disruptions. Disruption reflects the engagement and mutual influence of multi-party participants in treatment decision making. By enhancing our understanding of disruptions, we hope to assist in the delicate communication and shared decision making needed for a patient and family centered resolution.

Word Count: 338

KEYWORDS: Surgical care, companion/caregiver, patient-provider communication

INTRODUCTION

Major surgery involves a significant risk of death or disability.³ A pre-surgical visit is frequently held close to the planned surgery to obtain patient consent and review surgical risks and benefits as well as potential postoperative morbidities, pain management and quality of life.⁵⁻⁷ The decision to undergo non-emergent cancer surgery occurs before the pre-surgical visit and is commonly planned following extensive discussion of surgical risks and benefits between a patient and surgeon, and frequently, one or more family members.

While most surgeries proceed as planned, some involve a pre-operative re-evaluation of whether to proceed with the surgery, effectively disrupting the anticipated surgical plan, herein referred to as a disruption. Disruptions may result in a decision to proceed as planned, postpone the surgery for weeks or months, or to cancel the surgery. These deliberations often include weighing surgical implications for meeting the patient's medical goals and subsequent quality of life. Treatment deliberations frequently include an accompanying family and this is especially common in the oncology where almost two-thirds of patients are routinely accompanied to their visits.⁸ Accompaniment is even higher when new clinical information is anticipated; Eggly and colleagues found that 86% of cancer patients are routinely accompanied when "bad news" is expected.⁹

Objectives

This paper explores four case studies of a surgical plan disruption to illustrate how a patient, an accompanying family member, and surgeon negotiate an unanticipated reevaluation of a presumed surgical plan and the role each participant plays in contributing to the subsequent surgical decision. Qualitative case study research provides

an opportunity to explore how each person involved in the exchange impacts the final decision.

METHODS

The proposed study is secondary analysis of 61 pre-surgical visit recordings attended by 61 patients, 9 oncological surgeons, with at least one accompanying family member present in 49 (73%) of recorded visits, collected as part of a randomized clinical trial to evaluate the impact of an advance care planning (ACP) video designed to prepare patients and family members for major surgery on pre-surgical visit communication. Patients scheduled to undergo elective major cancer surgery and their surgeons were recruited from the clinics of single large academic tertiary care hospital. Patients provided written consent to participate in the study, and study staff obtained oral consent from accompanying family members and all medical professionals present for the audio-recorded visit.

The Johns Hopkins School of Medicine Institutional Review Board approved the parent study and the secondary analysis.

Analytic Approach

All 61 pre-surgical recordings were reviewed for an unanticipated re-evaluation of the surgical plan that led to a reevaluation of a presumed surgical plan. The selected recordings were de-identified, transcribed, and analyzed in MaxQDA software.¹⁴⁶ The coding framework was informed by a deductive framework of interpersonal power dynamics reflecting patient and family communication in medical visit interaction⁹⁶ and surgeon and patient communication.^{147,148} After indexing these codes, an inductive constant comparison method was used to identify and refine emergent themes into a

finalized coding structure¹⁴⁹ that achieved theoretical saturation.¹⁵⁰ The final codebook evolved from the transcripts, as well as those that reflected the theories outlined below. Various MaxQDA analytical tools¹⁴⁶ were used to visualize the data and examine the intersection of key themes across case studies.

Theoretical frameworks

Each case study was examined in light of Clayman et al.'s framework that distinguishes companion roles as autonomy enhancing or detracting.⁹⁶ As reflected in Figure 4, companion behaviors that enhance patient autonomy facilitates patient understanding of the physician, encourages patient engagement in the medical dialogue, and assists physicians in understanding patient disclosures; autonomy detracting behaviors include those in which the companion acts to control patient communication or ally with the surgeon against the patient. Observational studies of accompanied medical visits found that autonomy-enhancing behaviors are more frequent than detracting behaviors but both types may be enacted during the course of a visit.^{96,151} Five codes reflecting companions' autonomy-enhancing and detracting behaviors were included in the study codebook (Figure 4).

Power dynamics were also coded as suggested by Uy et al.'s conceptualization of four patient-physician prototypical relationships under conditions of critical illness¹⁴⁷ including: the informative physician who provides medical information and treatment options; the facilitative physician who provides medical information while also linking treatment options to patients' treatment preferences; the collaborative physician who elicits and links patient preferences with treatment options and provides treatment recommendations; and, the directive physician who makes treatment plans and decisions

without elicitation of patient input. Examples of surgeon behaviors reflective of these relations coded in the current study are also included in Table 3.

Each case study follows the same presentation format beginning with visit quotes that present the disruption to the surgical plan, the patient reaction to the disruption, the companion response or contribution, attempts to resolve the disruption by discussing alternative plans, and the final decision when known. While this format often follows the temporal order in which these events unfold in the visit, it is not always the case. To make it easier for a reader to follow the sequence of quotes, visit statement numbers identified by MaxQDA¹⁴⁶ are included with each quote.

RESULTS

Four instances of surgical plan disruption were identified in the 61 pre-surgical visit recordings. The patients in three of these visits were accompanied by a single companion and one patient was accompanied by two companions. Of the 9 surgeons participating in the study, only 2 were recorded in visits with plan disruptions; three patients saw the same surgeon and one patient was seen by a second surgeon. Table 7 provides a demographic summary of the four patients.

Each of case studies is described below. To facilitate comparisons across the case studies, Table 8 provides a brief summary of key characteristics.

PATIENT 1

Disruption

Patient 1 is an 80-year-old man with a large abdominal tumor that was scheduled for removal the following week. The patient, accompanied by his wife, came to the surgical visit with the expectation of having cancer surgery. From the beginning of the

visit, the surgeon expressed concern about the going forward with the plan as the patient's worsening heart condition and consequent kidney failure would likely contribute to postoperative complications.

Surgeon A: Hi, how are you folks?

Patient 1: I am OK doctor, if you tell me I will be OK.

Surgeon A: I am not sure. So a few things. I think the [hospital] admission is a worrisome sign with sort of the heart going with the stress. The second thing is your ... kidneys are very damaged. Um this kidney is completely occupied by tumor. The other kidney also looks pretty dead...I would say [you have a] 70% risk of dialysis...The risks are piling up. Yes, there is a benefit, but if we cannot get you safely through surgery and back home, then the equation changes...The best scenario is to remove the tumor, but [at] what costs...and does it get us to a good quality of life? Not only does it mean can we get you through the operation, but can we get you home living a meaningful life? Being in a nursing home for the rest of your life is not what anybody wants. (S129-135)^{viii}

This exchange is the first indication of a need to reassess the surgical plan. In the above statement, the surgeon wavers between outlining the risks and benefits of the procedure and implicitly recommending that the patient not pursue surgery raising the possibility of a long-term nursing home care stay.

Patient reaction to disruption

The patient appears surprised by the news and after the surgeon reiterates that the patient may be confined to a nursing home after the surgery, the patient asks: "What is the point of putting me in [a] nursing home?" (S151). A dialogue about the consequences of the surgery unfolds and the patient seems to recognize that the surgeon is making an implicit recommendation and confronts him/her to be explicit: "You don't recommend surgery" (S179). This statement is said in a grave tone suggesting that the patient is trying to come to terms with the implications of the recommendation. The surgeon replies, "I

^{viii} S129-135 represents the MaxQDA statement number, which corresponds with each time a person in the interaction speaks. We use these statement numbers to make the sequence of statements in the discussion clear the reader.

am very seriously concerned. I am almost debating not doing the surgery” (S180). The use of the word “almost” suggests the surgeon has not yet made a decision regarding the plan or is holding back from changing the plan unilaterally.

Companion involvement and role in the encounter

Directly following this exchange, the patient’s wife voices a concern that the patient has debilitating pain that is negatively impacting his quality of life. The topic of pain was introduced with no explicit reference to the disruption.

The thing is, he is ok, but he has pain [in his abdomen]. If we can do something about the pain, then I am sure he is going to feel better... Because me I watch every minute... If you could do something... Because he...wants to do everything, he is a very strong personality. (S183-191)

It is unclear if the patient’s wife is suggesting that if surgery is too risky, she would like her husband to receive a treatment to mitigate his pain or if she thinks that if he is relieved from pain his strong personality would enable him to do more. The surgeon replies that he/she will refer the patient to a pain management clinic and get him a consultation with a palliative care physician to discuss how to “get [the patient] to a good quality of life” (S206).

Following the discussion regarding symptoms, the patient asks for a third time, “so no operation?” (S210). The surgeon replies, “I don’t think so,” but that they could “do some radiation to help along with the palliation” (S211). The patient’s wife becomes distraught and leaves the room:

Companion 1: I am getting out.

Patient 1: Sit down.

Companion 1: No! You can stay.

Patient 1: Sit down!

Surgeon A (to Companion 1): You ok, sweetie? You ok?

[Door opens and closes and Companion 1 leaves the room] (S214-218)

The surgeon's affectionate use of "sweetie" seems to be an attempt to calm down the distraught wife. The exchange between the patient and his wife highlights tension; the wife leaves the room despite the patient asking her to sit down twice. The patient does not appear to be upset with his wife for leaving, but rather is concerned, explaining that his wife lost her first husband to cancer.

Patient 1: She has problems...She lost a husband like that before.

Surgeon A: It's bringing back---

Patient 1: It's coming back.

Surgeon A: I'm sorry, I really am. (S221-226)

This sharing of past loss seems to acknowledge that the patient and his wife have come to realize that he may face a similar fate. The surgeon asks, "How are you feeling about all this? What are your goals in life now?" (S230-234). The patient's response indicates he has decided not to pursue surgery because of its long-term implications.

Patient 1: I have a good time. Look I am 80 years old, my father lived to 82, my mother lived to 86...So, I can't have it all in my life...I have grandchildren and I enjoy to be with them. I enjoy to be with them. Goal? I don't have a goal. I have seen, I have seen everything. From the top to the bottom, I have seen everything.

Surgeon A: You have led an interesting life. I have to say I really enjoy talking to you. I wish I could sit here and talk to you a long time. But I think my concern, and I am trying to put myself in what I would recommend to my family. If you told me you wanted to try everything, and there are some people who don't understand how miserable life can be sitting in the hospital with tubes sticking out of you. And then dialysis—

Patient 1: Dialysis, I could take. But I would not be able to take the nursing home for the rest of my life. I don't know how long I will live. (S235-251)

The surgeon takes a reassuring and personal tone and going so far as to suggest that this is "what I would recommend to my family".

Later in the visit, the wife's behavior upsets and frustrates the patient. The nurse practitioner who had followed the wife out of the room, returned to relay the wife's primary concern: "She tells me that she just doesn't want you to have pain anymore.

That's all she worries about" (S316). The wife voices her concern indirectly through the nurse practitioner, to seemingly ensure that the surgeon will address this issue. However, upon hearing this concern again, the patient becomes frustrated.

Patient 1: I don't have pain.

Surgeon A: Is it just uncomfortable?

Patient 1: She doesn't understand. I don't have pain.

Surgeon A: What do you have? Pressure?

Patient 1: Pressure! That is all. And if I am sitting, nothing.

Surgeon A: You are fine?

Patient 1: Yes!

Surgeon A: Then maybe that is all.

Patient 1: I can't walk from here to the door.

Surgeon A: But maybe a wheelchair would help? (S317-326)

Though the patient indicates that his pain is not the problem, and he is irritated by his wife's insistence, he discloses difficulty with walking.

Resolution of the disruption

The disruption of the surgical plan was partially resolved. The surgeon does not explicitly advise the patient not to get surgery, but rather cautions him strongly:

I am really reluctant to push ahead with the surgery. I don't want to hurt you. I want you to enjoy what you got rather than push us over the edge and then regret this and say now we are in trouble. There is a real risk of dying, there is a real risk of some bad complications. Living on dialysis is, some people never want to do it. (S172)

There are times earlier in the encounter where the patient asks the surgeon for clarification.

Patient 1: Are you suggesting doctor not an operation?

Surgeon A: I want you all to think about it over the weekend with the new pieces of information we didn't have the last time. This information is not so good. (S193-4)

The surgeon never gives the patient a clear directive regarding the surgery, but rather provides a cautionary opinion with the ultimate decision deferred to a later time.

Decision

The patient's planned surgery was cancelled; however, the possibility of palliative surgery to debulk a portion of the tumor was still under consideration. The surgeon concluded the visit advising the patient "to see those two people [the medical oncologist and palliative care specialist]" (S281). He/she also assured the patient that he/she will "sit in a room with the medical oncologist and radiation oncologist" to "make a decision" regarding "debulking [part of the tumor] just to get comfort" (S256-8).

The patient did not undergo surgery—neither the original planned surgery nor the debulking—and continued to have bi-monthly check ups with his oncologist.

The case summary

In line with Uy et al.'s delineation of the physician roles, the surgeon is largely collaborative, illustrated by provision of medical information, elicitation of treatment preferences, engagement in deliberative behaviors, and delivery of treatment recommendations. However, during the discussion in which the disruption is resolved, a change in role occurred. The proposed meeting between three physicians to decide whether the patient would undergo palliative surgery did not include the patient. In contrast to the collaborative approach to resolving the original surgical disruption, the decision to conduct palliative surgery reflected a more directive approach. Illustrative quotations of these behaviors appear in Table 9.

The patient's wife engages in predominantly autonomy-enhancing behavior⁹⁶ by facilitating patient understanding through asking the doctor questions and facilitating doctor understanding by mentioning the patient's pain. Though, towards the end of the visit, her reiteration of her concerns regarding the patient's pain frustrates the patient and

detracts from his ability to voice his concerns, it also empowers him to have a conversation with the surgeon about functional limitation and his potential need for a wheelchair.

PATIENT 2:

Disruption

Patient 2 is a 25-year-old woman diagnosed with a bowel tumor. She was accompanied to her visit by her mother and father two weeks before her scheduled cancer resection surgery. The planned surgery would impair the patient's future fertility and she has already decided to delay surgery by at least a month so that she may undergo fertility treatments to have her eggs harvested. Moreover, the patient's radiologist advised that the the risk of local metastases would fall from 100% to 20-30% with pre-surgical radiation that would also delay the surgery by a few months. The surgeon seems tentative regarding radiation because of the patient's age.

Why am I hesitating in you? I am usually a big believer in radiation. It is because you are very young and younger people are more sensitive to radiation than older people...I worry about kids getting radiation over adults because your bodies are still dividing so they are more exposed to the radiation's side effect. (S101)

During this presurgical visit, the patient must decide whether to delay surgery for only one to two months to allow for egg harvesting, or to delay surgery for several months to allow for both egg harvesting and presurgical radiation.

Patient reaction to disruption

The patient often responds to the surgeon's comments and questions with "yes" and "mmhmm" and she appears to defer to her parents to ask most questions. The patient does not react to the disruption directly but rather she asks the surgeon questions about the procedure.

Patient 2: And the colon, like what, what will those side effects be?

Surgeon A: I may need to take the colon out because [the tumor is] stuck to it. (S157-158)

Companion involvement and role in the encounter

The companions become more engaged in the dialogue after the surgeon asks for their input about whether or not to further delay surgery for the radiation.

Surgeon A: So, mom and dad.

Companion 2a (mother): Ugh

Surgeon A: It's hard, I know especially with your kid, its really hard. I feel for you guys.

Companion 2b (father): Yeah

Surgeon A: [to patient] Because you are their little baby. We think of you as a kid.

Patient 2: [Laughs]

Surgeon A: Sorry. I know you don't think of yourself as a kid. (S120-6)

The surgeon's comments acknowledge the complicated power dynamics between parents and a young adult who are all now having to weigh risks and benefits to make a complicated medical decision. The mother then asks several questions about the surgery and often refers to her own experience as a two-time cancer survivor who had undergone cancer treatments.

Surgeon A: I may need to [remove] the right side [of the colon], just the low piece, just this much of her colon.

Companion 2a (mother): So she will be kind of like me, a little bowel incontinent.

Surgeon A: [To Companion 2a] Not incontinent, just a looseness. Usually losing your right colon in the beginning makes you a little looser and then it settles in in the next three months... [To the patient] Yeah you won't be as bad as mom. (S158-167)

The mother repeats the surgeon's explanations, which may act to both reassure her daughter and facilitate her understanding:

Companion 2a (mother): [The rate of malignancies is] less than 1% with the radiation?

Surgeon A: Mmmhmm. Second malignancy in the future.

Companion 2a (mother): Less than 1%, that sounds really low.

Surgeon A: Well you want it to be really, really low.

Companion 2a (mother): Yeah, it is actually really good. (S170-4)

Once during the visit, the mother aligns with the surgeon rather than the patient.

The patient found a radiologist close to her home that she prefers to see, but the surgeon advises the patient to receive care at the academic cancer center, which is a two-hour drive for the patient. The mother seems to support the surgeon's position.

Surgeon A: I will talk to [our radiation oncologist] this afternoon. I will see if she likes [the radiologist who is closer to the patient's home] and then get the scoop.

Patient 2: Because that would just be a half hour drive.

Surgeon A: It's a half hour drive, it's not the end of the world.

Companion 2a (mother): But if it's her life, then we will come here. I mean, if it's that.

Surgeon A: People have stayed in [temporary patient housing] for five weeks. (S195-9)

The patient's comment regarding the convenience of the alternative radiation services is partially countered by the mother's characterization of the choice between radiation facilities as a potential decision of life or death. The mother's declaration that "we" will do as the surgeon recommends, seemingly places the mother at the helm of the decision making process.

The patient's father participates less actively in the visit than her mother. After the patient indicates the radiologist advised that radiation would reduce the rate of recurrence from 100% to 20-30%, the father replies:

Companion 2b (father): But there may be no guarantee.

Surgeon A: It's never a guarantee. Unfortunately, the only person who gives guarantees are people, not doctors. If [a doctor] has given you a guarantee, be worried. (S113-4)

The father's comment reinforces that even though radiation has a high likelihood of reducing risk of local recurrence, it cannot guarantee the cancer will not recur. The surgeon's response to the father's comment reiterates its salience that there is uncertainty

surrounding treatment outcomes.

Resolution of the disruption

The surgeon provides information regarding the patient's options, but ultimately empowers the patient to make a decision about treatment.

Where are you feeling about all this? Because at the end of the day, this is your body, not mine. And you are going to have to make a decision. Because this is debatable. Do we do radiation or not? And the way I think of it, is that if you say, "I want to do everything in my power." Then I will be there. But if you say "I would rather take my chances, and if it comes back here, we will tackle it as it goes." That's another viewpoint, you see what I'm saying? (S103)

Later in the visit, the surgeon reiterates that the "big question is radiation" (S142) thereby implying that the decision rests with the patient. The patient seems dissatisfied with this response and asks the surgeon for an opinion on what the patient should do regarding radiation.

Patient 2: And so, you aren't recommending radiation, or--?

Surgeon A: No, I think, my sense is that as long as you have heard the side effects. I think [the radiation oncologist] and I are leaning towards it.

Companion 2a (mother): You were? OK.

Surgeon A: Yeah, as long as you know some of the things we talked about. (S151-6)

The patient may have been confused by the surgeon's previous statements as they were not explicit recommendations. The patient requests a clear recommendation from the surgeon and the surgeon indicates a preference for radiation.

Decision

In the visit, patient never explicitly indicates her decision, nor does the surgeon solicit the patient's decision. In the above quotation, the patient's acknowledgement of side effects seems to subtly signify that she will move forward with the procedure. Much later in the visit, the patient's father seeks to confirm this decision.

Companion 2b: So have we decided on a radiation, or?

Surgeon A: Yeah, the only thing to debate is where to do it. (S319-320)

The patient decides to delay the surgery until after egg harvesting and subsequent radiation. The surgeon concludes the visit with “I will cancel surgery for next week” and instructs the patient to “find out your last date [for radiation], and let the scheduler know and then we will arrange a date for surgery” (S328).

The case summary

In line with Uy et al.’s physician roles, the surgeon is collaborative, as exhibited by the surgeon’s display of behaviors aligned with this role: he/she provides medical information, elicits treatment preferences, engages in deliberative behaviors, and gives treatment recommendations. Illustrative quotations of these behaviors appear in Table 9.

The patient’s mother mostly engages autonomy-enhancing behaviors that facilitate patient understanding through asking the doctor questions about the post-operative period, and repeating the surgeon’s explanations of postoperative risks. However, when the patient indicates she would like to receive radiation close to home and the surgeon suggests the patient instead travel two hours to receive radiation at the same facility as her upcoming surgery, the mother sides with the surgeon, which would be characterized as alliance building behavior. The patient’s father rarely participates in the visit, but his few contributions can be characterized as autonomy enhancing as they involve questions about the treatment trajectory.

PATIENT 3

Disruption

Patient 3 is a 67-year-old man scheduled to have surgery in a week to remove a large intra-abdominal tumor. The patient's wife accompanies him to this visit. Prior to this visit, the surgeon had ordered a CT-scan and presents the results early in the visit.

Surgeon A: Now I am going to try to pull up the scans. It seems to be shrinking.

Companion 3: Wow.

Surgeon A: And in fact, I can't find it on this page. But I think I see it. I still think we should go in and take a look and take whatever it is out...It's been confounding me. Like I've been sitting here the last 15 minutes trying to pull it up. So you did not do radiation this summer, right? You have just been waiting to see me? And I delayed the surgery, which rightly or wrongly, but whatever it is good news for the most part.

Patient 3: Yeah, yeah.

Surgeon A: But I just don't know what to do with this.

Patient 3: Yeah, wow. (S18-25)

The shrinking was unexplained; the patient had undergone neither radiation, chemotherapy, nor immunotherapy. The option to move forward with the surgery is no longer clear, and a decision must be made about whether to pursue surgery.

Patient reaction to disruption

The surgeon reiterates uncertainty regarding how and when to treat the tumor, and the patient responds with his preference:

Surgeon A: I am still inclined to say that we should just operate and take a look.

Patient 3: Right, I would probably go crazy if you didn't. (S26-7)

While the surgeon's recommendation is not delivered with assurance, the patient seems committed to proceeding with surgery.

Companion involvement and role in the encounter

The patient's wife is fairly vocal and provides the surgeon with information that the patient has not. For example, while discussing the logistics of the upcoming surgery, she indicates that the patient's hernia causes him pain, which leads the surgeon to propose an additional surgical plan for repair.

Companion 3: The other thing I noted, which is bothering me a lot, is the area around the hernia. He has a lot of pain around the stoma.

Patient 3: Lots of pain.

Companion 3: Is there any way to—Is it possible to—

Surgeon A: We will try to revise the hernia a little bit. I mean, you know, fix it. We will need a plastic surgeon to fix your belly wall. Ok so resection of [the tumor] [and] repair of [the] hernia. (S86-89)

In the next segment, the surgeon jokes about the patient's eagerness for surgery and the wife supports the patient by noting how much it is on his mind and how hard it is. The surgeon responds by acknowledging the patient and his wife's concern and noting that all surgeries contain risks and should not be decided upon lightly.

Surgeon A [to Nurse Practitioner A]: He is eager for the surgery! I am trying to talk him out of it. He's not buying that!

Companion 3: Well I have to say it is so in his mind. He has been really like—you know, it's hard. He feels—

Surgeon A: I've seen family members through surgery. Surgery is surgery, we never dismiss it. (S149-152)

Resolution of the disruption

The surgeon's caution regarding surgery may be interpreted as opposition to the patient and his wife's wishes to move forward with the procedure. Surgery is presented as an option and reiterates that the patient can change his mind. However, the surgeon empowers the patient in a protective, supportive way.

Surgeon A: So you can sign the consent. And if you change our mind and say 'Doctor, I don't want surgery Monday.' That is fine...Never feel the pressure.

Companion 3: Mmmhmm.

Surgeon A: And if ...you wanted to watch it another 2-3 months, I would be on board.

Patient 3: I don't want to.

Surgeon A: Surgery is surgery.

Patient 3: I don't want to. I don't want to.

Surgeon A: You sure?

Patient 3: I...I want to go now. I... Yes. I would like to have...would like to know what I have. [*Note: here ellipses connote pauses in the patient's speech, compared to omissions of text*]

Surgeon A: Well the good thing is that it is probably benign. It thinks

it's...Cancer does not get smaller without treatment.
(S65-73)

The patient reiterates three times that he wants to proceed with the surgery, and his last declarative statement, replete with pauses and repeated words, suggests he is struggling to communicate his wishes. The surgeon may feel less compelled to be directive, particularly with the “good news” that the patient’s tumor has shrunk to the point where surgery may be unnecessary.

During the visit, neither the patient nor the companion solicit the surgeon’s advice on what to do; however, the surgeon reiterates that “this is no small operation” and that the risks of the surgery might not be quite worthwhile if “the tumor is benign” (S95). The patient does not respond to this statement, which may indicate the patient is not open to cancelling the surgery even if the tumor is benign.

Towards the end of the encounter, the surgeon reluctantly advises the patient to proceed with surgery.

Surgeon A: I will talk to [our medical oncologist]. I guess we should still explore you since we already have the date for surgery.

Patient 3: Yeah and the date was so hard to get.

Surgeon A: Is it hard?

Nurse Practitioner A: It was so hard to get!

[Nurse Practitioner A and Surgeon A laugh].

Surgeon A: It is hard to live with nothing because it is a real option to sit. It’s shrinking away in front of us. (S130-5)

The surgeon is reticent to recommend surgery and the patient presents a pragmatic argument about the need to keep the date due to scheduling difficulties. Some of the tension in the exchange was ameliorated by the patient’s facetious tone, coupled with the NP’s exclamation and subsequent laughter. The surgeon reiterates that cancelling surgery is a viable option given the most recent scan results.

Decision

The patient decides to proceed with the surgery. The above quoted section regarding scheduling is the last time in the recording that the deliberation is mentioned.

The case summary

In line with Uy et al.'s physician roles, the surgeon is facilitative, as displayed by his/her provision of medical information, and elicitation for the patient's treatment preferences. Illustrative quotations of these behaviors appear in Table 9.

All of the patient's wife's behaviors in the visit can be considered autonomy-enhancing for the patient, as she facilitates doctor understanding through expanding upon the patient's history of a hernia, as well as facilitated patient understanding through asking the doctor questions about the procedure.

PATIENT 4

Patient 4 is a 66-year-old man who, accompanied by his wife, meets with Surgeon B one week before surgery to discuss surgical removal of a tumor within an intra-abdominal organ. The patient previously had part of the organ surgically resected and the upcoming surgery is to remove the entire organ along with the recurrent tumor. Shortly after the surgeon enters the room, the patient introduces a concern that could disrupt the surgical plan.

Patient 4: OK I have one question. I've had too much time to think about all this. And I know we have to fix that, we have to take the tumor out, but in your mind is there any relatively safe alternative to taking [the entire organ] out? (S19)

The patient does not express the reason why he wants to keep the organ, nor does the surgeon inquire. The surgeon listens to the patient's concern and then proposes three options to address it. First, the patient could choose not to have surgery: "One alternative

is to do nothing.” (S20). The surgeon however cautions that since the patient had cancer in his lymph nodes when his original tumor was removed, “your biology [of your tumor] is one that will go elsewhere” (S24). The second option is a partial organ resection which would involve surgically resecting the portions of the organ where there is recurrent tumor while attempting to leave unaffected areas. The third option involves the removal of the entire organ. The surgeon notes that the third option - this complete resection – may also have the benefit of possibly producing less of an inflammatory response, and thus an easier recovery, than a partial resection.

Patient reaction to disruption

After the surgeon presents the three options, the patient continues to pursue partial organ resection as an option; this later exchange with the surgeon is discussed in the “Resolution of the Disruption” section of this case study. Otherwise the patient rarely initiates dialogue, but speaks in response to his wife and the surgeon.

Companion involvement and role in the encounter

The wife’s involvement is predominantly characterized by asking medical questions about the procedure. For example, her inquiry about the patient’s hernia reminds the surgeon he will need to consider that during the procedure:

Companion 4: Several years after the [first] surgery, he developed a massive hernia...which I understand is fairly common...Are we at risk for this?

Surgeon B: Now you had the hernia fixed?

Patient 4: I have mesh.

Surgeon B: Yeah. Hopefully what I can do is, that mesh is well incorporated into the abdominal wall, hopefully I can just close that mesh right to mesh, and then we will be fine. I can’t guarantee he’s not going to get a hernia, but he has the mesh, so it’s already reinforced. (S59-66)

The wife occasionally dominates the conversation and interrupts the patient:

Patient 4: The other thing that surprised me is that I am still losing weight. I

lost—

Surgeon B: [interrupting] Are you taking the [medicines] already?

Patient 4: Yeah—

Companion 4: [interrupting] I think my observation over the last week, ten days, is that he has eaten better. He is eating three meals a day, he's snacking. Not big meals, but I was surprised that he was losing weight. It looked to me like he was eating better than he had in a long time.

Surgeon B: I mean for nutrition, there are really two options; there is IV nutrition, which has risks, and there is a feeding tube, and I don't think he looks unwell enough to consider doing something like that before surgery. (S77-85)

When the patient shares with the surgeon his concerns about his weight loss, the surgeon interrupts him to ask a question, and then the wife interrupts the patient to respond with her perception of the patient's weight loss. The wife seems to assume ownership over the patient's medical information when the patient is attempting to share it himself. While the information the wife provides contains helpful insights to the surgeon and ensures the accuracy of information, the wife appears to prevent the patient from articulating his own concerns. The surgeon responds to the wife, referring to the patient in the third person implying the conversation is between him and the wife.

Towards the end of the visit, the wife returns to the patient's desire to have the surgeon leave behind a part of the organ.

Companion 4: Alright, but just to entertain [his] wonderful fantasy about this [organ] that he wants to hold onto. If you go in and take just the tumor, how much more from a recovery standpoint can he expect if you take the whole thing or not?

Surgeon B: It's going to be no different. It can be a harder recovery to leave in [part of the organ] because you can leak from the surface of it...Another reason to not leave a piece of it. (S136-7)

The wife seems to mock the patient's wishes with the phrase "wonderful fantasy." In this way, she appears to be allying herself with surgeon and communicating that she is not in agreement with her husband.

Resolution of the disruption

Conflict between the patient and Surgeon B becomes evident towards the end of the visit. The patient appears unhappy with the information the surgeon provided and expresses his continued desire to maintain a part of his organ.

Companion 4: Did you get answers that you wanted?

Patient 4: No. I don't want my [organ] to go.

Surgeon B: The option is there.... I just—

Patient 4: [interrupting] No, I'm not saying that—

Surgeon B: [interrupting] I just can't tell you what is going to happen though.

Patient 4: I am not saying that. I, I, I, the given to me is...removing the tumor [in part of the organ]. It's the next step and trying to figure a way around [removing the entire organ].

Surgeon B: I know. I told I hate that operation. I wouldn't—

Patient 4: [interrupting] I can tell ya that I hate it more.

Surgeon B: I know. I don't like it...I don't take it lightly, but I don't have a good alternative. (S105-117)

The patient stutters in his delivery, a trait not previously exhibited in his statements, and which may indicate further agitation. The patient pushes back against the surgeon's suggestions and the surgeon reiterates that the patient has a choice while subtly suggesting that complete removal of the organ is his/her preferred option.

Decision

The patient's unhappiness about the upcoming procedure continues until the end of the visit.

Patient 4: I don't like it [having the entire organ removed].

Surgeon B: I know you don't.

Patient 4: But I don't see how I have any choice.

Surgeon B: My job is to give you the information. I can't change it.

Patient 4: Right. (S138-142)

The surgeon reiterates that he/she is a messenger of the information, and that the decision rests with the patient. The patient emphasizes he feels powerless and without a decision to make. The patient's scheduled surgery occurred and his entire organ was removed.

The case summary

In line with Uy et al.'s physician roles, the surgeon is informative in providing various surgery options to the patient; however, the surgeon does not elicit treatment preferences—possibly because the patient indicated early in the encounter that his preference is to maintain a part of his pancreas. Illustrative quotations of these behaviors appear Table 9.

While the patient's wife displays some autonomy-enhancing behaviors through facilitating patient understanding to ask the surgeon questions, many of her statements in the visit can be characterized as autonomy-detracting. Her autonomy-detracting behaviors includes aligning with the surgeon's preferences to do a full organ removal and against the patient's preference for a partial removal. She also occasionally interrupts the patient and dismisses his concerns.

DISCUSSION

Nature of Disruptions

Out of the 61 presurgical consent visits recorded in this study, only four met our definition of disruption as an unanticipated re-evaluation of the surgical plan. As a whole, the four case studies present the textured experience of patients, accompanying family members, and surgeons when things do not go as planned. Given the apparent rarity of disruptions and the case study approach we have taken to describe them, we cannot gauge whether the behaviors observed are representative of anything beyond the particular clinical circumstances described and individuals who are present. Nevertheless, these four cases illuminate a phenomenon – disruption – that has not been well described and that has relevance for the delivery of patient and family-centered care.

The behaviors exhibited by patients, their companions, and surgeons can be described using the frameworks that informed the codebook^{96,147} with a result that reinforces the complexity and multidimensionality of behavior. The subsequent paragraphs explore how our findings both diverge and converge with the existing theories and research.

In each case, the companion played an active and important role in the conversation, sometimes more active than the patient, and contributed to decision making. Past studies' examination of the prominence of a companion's involvement in medical visits have diverging results. One study of oncology interactions found that companions tend to ask more questions than patients when the physician communicates "bad news".⁹ Further, a study of patients with life limiting cancer found that companions frequently speak on behalf of patients during discussions with physicians regarding prognosis and treatment choices, despite the patient being capable of speaking for him/herself.⁹⁵ Conversely, a study of lung cancer patients found patients were more active and assertive than their companions.⁸ Given that the patients in this study are a mix of ages from young adult to geriatric, and in the surgical oncology setting, there is not a direct comparison to existing studies.

Despite differences in the clinical circumstances and the visit participants, in our study patient's companions helped facilitate communication during the visit and assist the patient in navigating the disruption. The facilitative communication role of patient companions is well established in regard to routine medical visits. A meta-analysis of adult medical visits found that the most frequent engagement of companions in visit communication was via giving information or explaining the medical condition or needs (41.6%), and asking questions (41.1%).⁸⁸ Similarly Laidsaar-Powell et al.'s systematic

review of physician–patient–companion communication within medical encounters found that companions of patients with chronic illnesses (including cancer) often provided emotional and informational support.¹⁰ Specifically, companions of patients with cancer have been shown to act as conduits for information between patient and provider, facilitate deliberations over treatment options, and assist the patient with considering options.¹⁵²

This qualitative study’s nuanced examination of the role of patients and companions suggests the complexity of exchanges and relationships expressed during these visits. Although an autonomy detracting behavior may mitigate patient control over an exchange, it may also act to improve communication with the surgeon and benefit the patient. For example, when Patient 1’s wife mentions that his pain is decreasing his quality of life, the patient disagrees and expresses frustration with his wife’s comments; however, her comment leads to a discussion of the patient’s difficulty walking and the surgeon’s proposal of a wheelchair.

Limitations

While nine surgeons contributed pre-surgical visit recordings, disruptions were identified in the visits of only two. Furthermore, three out of the four disruptions occurred with single surgeon. While it is possible that this surgeon’s communication style, approach towards shared decision making, and/or the nature of the surgeries performed contributed to disruptions, we cannot draw such conclusions and it may very well be a matter of chance. In addition, all four patients were individuals that identified as non-Hispanic Caucasians who travelled from a distance to seek care at this hospital, thus these findings may not be generalizable to other patients and companions.

Implications

Building on past studies that demonstrate the importance of the companion's involvement in medical visits,^{10,96,153} these case studies embed patients in a social network that includes family members who are often present during high stakes medical visits. The early engagement of companions is integral to informed decision making because they are also likely to be decision makers if the patient becomes too ill to voice his/her preferences, as well as caregivers regardless of which surgical decision is chosen as these patients are at high risk of recurrence and death.

As more high risk surgeries are performed on sicker and older patients,¹⁵⁴ decision making regarding whether to pursue surgery may become increasingly complex,²¹⁻²⁴ and lend itself more frequently to disruptions as exhibited in this study. The intricate environment in which patients, their companions, and surgeons decide whether to proceed with surgery is layered with considerations regarding the risks and benefits of surgery,^{5,6} the way in which existing comorbidities may increase these risks,^{1,2} and the tradeoffs regarding proceeding with surgery when an underlying disease is likely to progress with high mortality rates.¹⁹ By enhancing our understanding of how patients, their companions, and surgeons negotiate disruptions in a surgical plan, we hope to assist in the delicate communication and shared decision making needed for a patient- and family-centered resolution.

Aim Two Figures and Tables

Figure 4: Visualization of Clayman et al's companion autonomy-related companion behaviors

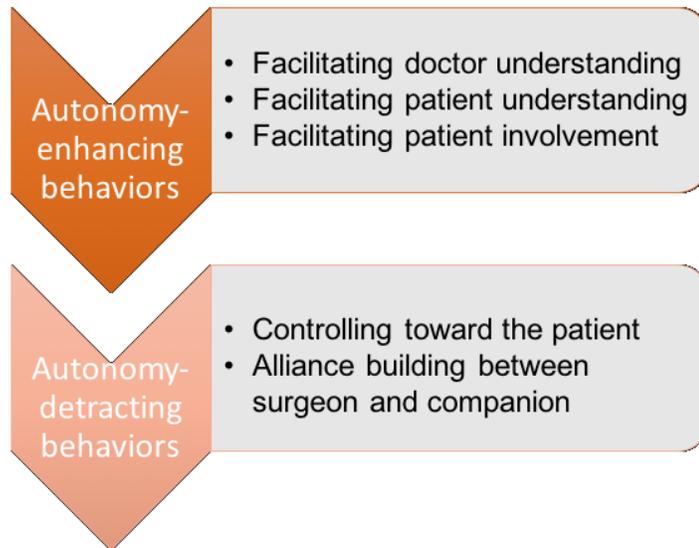


Table 7: Demographics of patients, companions, and surgeons

	PATIENT 1	PATIENT 2		PATIENT 3	PATIENT 4
Age	80	25		57	66
Gender	Male	Female		Male	Male
Race	Caucasian	Caucasian		Caucasian	Caucasian
Education	High school	Graduate degree		College	College
Surgery	Intraabdominal tumor resection	Interabdominal tumor resection		Intraabdominal tumor resection	Hepatopancreatobiliary cancer resection
Companion gender	Female	Female	Male	Female	Female
Companion relationship	Wife	Mother	Father	Wife	Wife

Table 8: Summary of case study results

Examples of these categories from the transcripts are contained in the body of the results.

Category	PATIENT 1	PATIENT 2	PATIENT 3	PATIENT 4
Disruption	<ul style="list-style-type: none"> Surgeon wants to cancel surgery because of patient's health concerns (cardiac, kidney), which render surgery higher risk. 	<ul style="list-style-type: none"> Patient's radiation oncologist suggested delaying surgery for egg harvesting and radiation. 	<ul style="list-style-type: none"> Surgeon suggests that the patient cancels surgery because the tumor shrank. 	<ul style="list-style-type: none"> Patient does not want his entire organ removed, and surgeon presents options.
Patient reaction to disruption	<ul style="list-style-type: none"> The patient asks very few questions of the surgeon. 	<ul style="list-style-type: none"> The patient rarely initiates dialogue. 	<ul style="list-style-type: none"> Patient appears agitated that the surgeon is reticent to perform surgery. 	<ul style="list-style-type: none"> Patient appears resistant to surgeon's arguments.
Companion involvement	<ul style="list-style-type: none"> Wife leaves the exam room halfway through the visit due to distress. 	<ul style="list-style-type: none"> Mother is largely facilitative, though occasionally detracts autonomy from patient. Father does not participate often. 	<ul style="list-style-type: none"> Wife helps the patient make a decision. 	<ul style="list-style-type: none"> Wife distances herself from patient and appears to align with the surgeon.
Resolution to the disruption	<ul style="list-style-type: none"> The surgeon never gives the patient a directive regarding the surgery, but rather provides a cautionary opinion. 	<ul style="list-style-type: none"> The surgeon provides information regarding the patient's options, but ultimately empowers the patient to make a decision about treatment. 	<ul style="list-style-type: none"> Conflict between surgeon and patient because surgeon is not directive and leaves the decision to the patient. 	<ul style="list-style-type: none"> Patient is dissatisfied with surgeon discouraging his desire to maintain a part of his organ.
Decision	<ul style="list-style-type: none"> Likely cancel surgery and sees palliative care specialist and pain management 	<ul style="list-style-type: none"> Delay surgery to have eggs harvested and radiation. 	<ul style="list-style-type: none"> Patient decides to move forward with surgery as scheduled. 	<ul style="list-style-type: none"> Patient decides to move forward with surgery as scheduled and have entire organ removed.

Table 9: Illustrative examples of physician role categories

Domain of communication	Illustrative Example
PATIENT 1: Collaborative surgeon	
Provides medical information	Surgeon A: Um this kidney is completely occupied by tumor. The other kidney also looks pretty dead...I would say [you have a] 70% risk of dialysis... The risks are piling up. Yes, there is a benefit, but if we cannot get you safely through surgery and back home, then the equation changes. ...The best scenario is to remove the tumor, but [at] what costs ...and does it get us to a good quality of life? (S133-135)
Elicits treatment preferences	Surgeon A: How are you feeling about all this? What are your goals in life now? (S230-234).
Engages in deliberative behaviors	Surgeon A: I am really reluctant to push ahead with the surgery...I want you to enjoy what you got rather than push us over the edge and then regret this...There is a real risk of dying, there is a real risk of some bad complications. Living on dialysis is, some people never want to do it. (S172)
Gives treatment recommendations	Surgeon A: See those two people [the medical oncologist and palliative care specialist]. (S281)
PATIENT 2: Collaborative surgeon	
Provides medical information	Patient 2: And the colon, like what, what will those side effects be? Surgeon A: I may need to take the colon out because [the tumor is] stuck to it... Patient 2: OK and what did you say the rate for other malignancies? Surgeon A: It's less than 1%. (S157-169)
Elicits treatment preferences	Surgeon A: Where are you feeling about all this? Because at the end of the day, this is your body, not mine. And you are going to have to make a decision. Because this is debatable. Do we do radiation or not? (S103)
Engages in deliberative behaviors	Surgeon A: And the way I think of it, is that if you say "I want to do everything in my power." Then I will be there. But if you say "I would rather take my chances, we will tackle it as it goes." That's another viewpoint, you see what I'm saying? (S103)
Gives treatment recommendations	Patient 2: And so, you aren't recommending radiation, or--? Surgeon A: No, I think. My sense is that as long as you have heard the side effects. I think [the radiation oncologist] and I are leaning towards it. (S151-4)
PATIENT 3: Facilitative surgeon	
Provides medical information	Surgeon A: Now I am going to try to pull up the scans. It seems to be shrinking. Companion 3: Wow. Surgeon A: And in fact, I can't find it on this page. But I think I see it. (S18-20)
Elicits treatment preferences	Surgeon A: So you can sign the consent. And if you change our mind and say 'Doctor, I don't want surgery Monday.' That is fine...Never feel the pressure. Companion 3: Mmmhmm. Surgeon A: And if this is truly the size it is and we will be calling results soon, and you wanted to watch it another 2-3 months, I would be on board. Patient 3: I don't want to. (S65-68)
PATIENT 4: Informative surgeon	
Provides medical information	Surgeon B: Usually people, believe it or not, when they have their entire [organ] removed, recover a little bit better than when they have a [part of it removed]. The reason being that I think, I can't prove this, when [part of the organ] is still in place, people have a big inflammatory response. When you take out the whole [organ], actually you don't. (S48)

Discussion

Research Implications

Through three different methods, this dissertation applied a patient- and family-centered approach to enhance understanding of the pre-surgical visit for major cancer surgery with a particular focus on the role of companions in these exchanges.

I quantitatively demonstrated that while surgeons talk more and provide more biomedical information when companions are present in the pre-surgical visit, patients also disclose less psychosocial information, and the overall patient-centeredness of the visit is diminished. Despite these changes, there was no difference in both patient and surgeon satisfaction comparing visits with and without companions. This decrease in patient-centeredness but no difference in satisfaction suggests that patients and companions might expect biomedical information about their upcoming procedure in the pre-surgical visit, while seeking psychosocial and patient-centered support either at other visits with the surgeon, or potentially with other practitioners—be it nurse practitioners, oncologists, primary care physicians, et cetera.

The qualitative care studies seem to support the general themes of the quantitative study. In visits featuring a disruption, companions became the patient advocate, often speaking on the patient's behalf and helping to facilitate decision-making, despite the patient being capable of speaking for him/herself. In a sensitivity analysis, all four of the case study visits had patient-centeredness scores less than one, indicating that they focused more on biomedical information than psychosocial information. Even visits that seemingly cater to patients and companions needs through shared decision making are predominantly biomedical, potentially as a result of the pre-surgical context.

Both the quantitative and qualitative analysis of study visits suggest that the pre-surgical visit is complex, which may have contributed to stakeholders' diverging opinions during the human-centered design process regarding what would be most helpful to motivate patient-centered pre-surgical and advance care planning discussions. The quantitative and qualitative findings provided information about the pre-surgical visit that was previously unknown to this research group and our stakeholders. As the human-centered design process preceded the quantitative and qualitative studies, in some ways the video was developed without full knowledge regarding the context that the intervention was targeting. That is not to say that this dissertation provides the complete picture and we are now able to design an effective video, but that the video was targeting a multi-layered encounter that requires further study.

In the subsequent paragraphs, I highlight some of the major findings from each manuscript and outline areas wherein further research is needed. As I assert in the limitations sections, due to several demographic factors and a smaller sample size, this study has limited generalizability. Further research into the pre-surgical context among diverse populations is needed to begin to better understand this context and consequently develop ways to effectively enhance its patient-centeredness.

Paper One

Throughout the design process of the video, the research team was challenged in how to balance competing stakeholder beliefs: while some patient stakeholders expressed a desire for graphic and explicit ACP messaging, multiple surgeon stakeholders were concerned that such messaging would distress patients who they considered to be already emotionally overwhelmed in preparation for their upcoming surgery. Complicating this

further was that surgeons were gatekeepers for recruitment for the randomized control trial and dissemination of the final video. At the end of the human-centered design process, not all conflicting opinions were resolved.

This conundrum raises the question: who is the audience in a human-centered approach? While the end-users are patients and caregivers, surgeons and other health professionals play an integral role in assisting patients with developing advance care plans and comprehending the medical gravitas of decisions. Notably the final video was less directive and graphic than the previous ACP videos,⁵³⁻⁵⁶ on which this video was partially based. The different preferences between patients and health professionals—albeit regarding other healthcare decisions—has been a noted consideration in the development of other patient decision support tools.¹² This challenge emphasizes the importance and usefulness of HCD for developing ACP tools in the pre-surgical setting.

The hesitation among surgeons in this study to provide explicit messaging regarding ACP reflects past studies that have examined surgeon's oppositional attitudes towards ACP.^{27,28,120} Yet, amidst this surgical culture generally opposed to ACP, this study created an ACP video that surgeons were amenable to sharing with their patients.

Paper Two

Companion presence was associated with the surgeon talking more, providing more biomedical patient education and counselling, and procedural talk. These findings are consistent with prior research reporting that oncologists give more information when patients are accompanied by a companion.^{99,100} Other studies have also shown that physicians use more biomedical communication with patients who are older and sicker,¹⁵⁵⁻¹⁵⁸ which reflects our patient sample.

Accompanied patients shared less lifestyle/psychosocial information than unaccompanied patients, even though companion presence did not impact the frequency of patient communication overall. Woolf and Roter's meta-analysis similarly found that when companions were present, patients engaged in less psychosocial information giving.¹¹ This finding might be explained by a variety of reasons. First, companion communication most frequently centered on rapport building, which may have preemptively communicated the information that would have been elicited by the surgeon's asking of lifestyle/psychosocial questions and that would have been communicated by unaccompanied patients. Future research should explore whether companion psychosocial communication is an enhancer or suppressor of addressing patient psychosocial and lifestyle concerns.¹⁴² Second, the visits analyzed in this study followed a prior visit where assessment of lifestyle and psychosocial concerns may have been addressed.

Companion's presence decreased the patient-centeredness of the visit. Post hoc analysis showed that differences in patient-centeredness scores between accompanied and unaccompanied visits was driven by a marked increase in components of the denominator of the ratio: surgeons' biomedical information giving and procedural talk, and companions' contribution of biomedical information.

To explain the patient-centeredness finding, companions might perceive patients as too overwhelmed before surgery to give focused attention to the encounter; therefore, they might feel compelled to advocate for the patient. Companions, especially those for highly independent patients (such as those in our sample), might see their role in pre-surgical encounters as informational social support driven to better visualize the patient's

journey. The companion's presence might be beneficial to the patient; however, the extent of that benefit might not be captured by the RIAS patient-centeredness ratio.

Moreover, the perioperative experience is stressful for companions.¹⁴³⁻¹⁴⁵ When the patient transitions home after surgery, companions often deliver the majority of medical care to patients. Companions may therefore have information needs regarding how to better support the patient, which could increase surgeon communication about biomedical information. As the perioperative experience of companions for patients with cancer has been noted as understudied,⁸⁷ this study represents a potentially fruitful foundation for future research on patient-companion-provider pre-surgical communication.

Despite differences in accompanied vs. unaccompanied encounters, companion presence did not impact surgeon nor patient visit satisfaction. In this pre-surgical setting, companions may be acting as extensions of the patient, furthering both patients' and surgeons' goals and expectations. In the presurgical visit, patient and surgeon satisfaction may not be centered upon the nuances of the communication, but rather upon the conveyance of necessary information at that time.

Future studies should continue to explore companions' role in the pre-surgical visit, as well as collect data on patients', their companions' and surgeons' expectations of what information should be discussed during this visit.

Paper Three

In each case study, the companion played an active and important role in the conversation, and contributed to decision making. This finding has been noted in other oncology studies. One study of patients with life limiting cancer found that companions

frequently speak on behalf of patients during discussions with physicians regarding prognosis and treatment choices, despite the patient being capable of speaking for him/herself.⁹⁵

Notwithstanding differences in the clinical circumstances and the visit participants, patient's companions helped facilitate communication during the visit and assist the patient in navigating the disruption. The facilitative communication role of companions is well established in routine medical visits. A meta-analysis of adult medical visits found that the most frequent engagement of companions in visit communication was via giving information or explaining the medical condition or needs (41.6%), and asking questions (41.1%).⁸⁸ Specifically, companions of patients with cancer have been shown to act as conduits for information between patient and provider, and facilitate deliberations over treatment options.¹⁵²

This qualitative study's examination of the role of patients and companions suggests the complexity expressed during these visits. Although an autonomy detracting behavior may mitigate patient control over an exchange, it may also act to improve communication with the surgeon and benefit the patient. For example, when Patient 1's wife mentions that his pain is decreasing his quality of life, the patient expresses frustration with his wife's comments; however, her comment leads to a discussion of the patient's difficulty walking.

Strengths

This dissertation has provided me with valuable training. I used diverse methods from multi-level models with generalized linear estimating equations and poisson and dichotomous outcomes to qualitative case studies analyzed inductively and deductively,

to human-centered design processes. I also gained helpful experiences as Project Manager of the trial supervising data collection, analysis, and manuscript writing.

In terms of the strengths of this dissertation as it relates to its contribution to the literature, to our knowledge, these results are some of the first to describe how the presence of family companions significantly alters communication in the setting of high-stakes discussions about major cancer surgery.

Further, this is the first study to begin to parse out the nuanced details of the nature of the patient-companion-surgeon exchange in the context of disruption regarding the surgical plan. To our knowledge, this disruption phenomenon has not been previously described in the literature. This disruption analysis evolved organically from my data collection and interactions with participants, and captures a phenomenon that would have been difficult to capture a priori.

Finally, this study innovatively used an HCD approach to design a decision support video to facilitate patient-surgeon communication. While research suggests that surgeons are typically resistant to engaging in ACP,^{27,28,118-120} the HCD process seemed to change surgeon's minds regarding ACP as demonstrated by their approval of the video and willingness to allow recruitment from their outpatient clinics for our randomized control trial.

Limitations

Across all three aims, there are limitations relating to generalizability. Paper One engaged over 450 stakeholders recruited from a variety of sources; however, there is still a possibility that the resulting findings had limited generalizability. The overall parent study recruited 92 patients, we obtained 61 audiorecordings for Paper Two, and the case

studies in Paper Three featured four audiorecordings. The patient population consisted of individuals undergoing elective surgeries that require private insurance or personal means to afford such procedures. With regards to Paper Three, all four patients were individuals that identified as non-Hispanic Caucasians who travelled from a distance to seek care at this hospital. I have highlighted below further limitations pertaining to each specific aim.

Paper One

HCD approaches are traditionally reserved for consumer product development and only recently have been used in the healthcare setting.⁸¹⁻⁸³ In the design of the ACP decision support video, necessary deviations to these traditional design approaches were made towards the goal of creating a stakeholder-engaged video that addressed sensitive needs.

Paper Two

First, the companion survey featuring information regarding their relationship and role to the patient was only added two months into the study; therefore, there are 11 companions that did not complete this information. Second, there may be unmeasured characteristics that affected communication (e.g., companion education level). Third, given that these are elective surgeries that require private insurance or personal means to afford such procedures, the population is limited in this way. These characteristics, coupled with our smaller sample size, may limit the generalizability of this study. Fourth, we cannot draw conclusions between the varied behavior of companions and their different genders, relationships, and roles as the RIAS coder did not distinguish between companions in visits when there was more than one companion present. Fifth, due to a need to protect the identity of the surgeons involved in our trial, we are unable to analyze how particular surgeon characteristics may impact triadic communication outcomes. For

example, some participating surgeons routinely had two pre-surgical visits with patients, while others did not, which may have altered their approach to this additional visit.

Paper Three

While nine surgeons contributed pre-surgical visit recordings, disruptions were identified in the visits of only two, and three out of the four disruptions occurred with a single surgeon. While it is possible that this surgeon's communication style, approach towards shared decision making, and/or the nature of the surgeries performed contributed to disruptions, we cannot draw such conclusions and it may be a matter of chance.

Programmatic and Policy Implications

By improving our understanding of the nature and content of these visits, we can better prepare patients, their companions, and surgeons for these encounters, and ideally make these encounters more patient-centered and helpful. While the longer term implications would involve the development of education-oriented interventions (i.e., establishing trainings to help surgeons tailor their communication approaches to the unique needs of both patients and their companions, establishing trainings to help patients and their companions prepare for these exchanges), further information is needed about these encounters to develop these interventions. As this is the first study of its kind to do a deep dive into the nature of these pre-surgical conversations, we must first engage in further exploratory and descriptive analyses with a more diverse population—as outlined in my research implications—before trying to modify these encounters.

The application of an HCD approach to developing an ACP decision support video, allowed for the incorporation of input from a variety of stakeholders, who were supportive of the tool's use in the clinical setting. Subsequent studies could consider

leveraging an HCD approach to develop ACP decision support tools. Moreover, future research should continue to investigate how to best balance stakeholder perspectives in creating patient-centered interventions regarding communication and ACP.

Building on studies that demonstrate the importance of the companion's involvement in medical visits,^{10,96,153} my quantitative and qualitative manuscripts embed patients in a social network that includes family members who are often present during high stakes surgical visits. My quantitative analysis showed that the presence of companions alters patient-provider communication during pre-surgical encounters about major cancer surgery. I also qualitatively demonstrated how companions empower and facilitate shared decision making regarding treatment. Companions' importance goes beyond these encounters as they are also likely to be decision makers if the patient becomes too ill to voice his/her preferences, as well as caregivers regardless of which surgical decision is chosen as these patients are at high risk of recurrence and death. Future work is needed regarding how companion presence during patient-provider interactions might be optimized to facilitate positive outcomes during and after these pre-surgical visits.

Finally, as more high risk surgeries are performed on sicker and older patients,¹⁵⁴ decision making regarding whether to pursue surgery may become increasingly complex,²¹⁻²⁴ and lend itself more frequently to disruptions, as exhibited in the case studies. By enhancing our understanding of how patients, their companions, and surgeons negotiate disruptions in a surgical plan, we hope to assist in the shared decision making needed for a patient and family centered resolution.

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Sarina Isenberg's CV

Sarina R. Isenberg

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EDUCATION

PhD in Social & Behavioral Sciences: Bloomberg School of Public Health, Johns Hopkins University

2014-Present

- GPA of 3.95 (out of 4.00)
- Certificate in Public Health Economics

Master's of Arts in English Literature: Queen's University

2011-2012

- GPA of 4.15 (out of 4.30)

Bachelor of Arts: McGill University

2007-2011

- Honours in English Literature, Minor in Psychology, and Minor in World Religions
- Graduated First Class Honours, with Distinction; GPA of 3.74 (out of 4.00)

SCHOLARSHIPS AND AWARDS

Funding received upon entry into Johns Hopkins University

2014-2018

- Full tuition scholarship from the Department of Health, Behaviour, and Society, worth USD\$200,000
- Canadian Institutes of Health Research Doctoral Research Award (CIHR-DRA), worth CDN\$35,000/year for three years
- Organization of American States (OAS) Scholarship Award, worth USD\$20,000 over two years. Selected as the only Canadian recipient for this award for 2015 and 2016.
- Doctoral Distinguished Research Award, worth USD\$4,000
- Doctoral Special Project Funding Award, worth USD\$2,000

Funding received upon entry into Queen's University

2011-2012

- Social Sciences and Humanities Research Council Joseph-Armand Bombardier Canada Graduate Scholarship (SSHRC-CGS), worth CAD\$17,500
- Ontario Graduate Scholarship, worth CAD\$15,000
- Tri-Council Recipient Recognition Award, worth CAD\$5,000
- Entrance Award, worth CAD\$2,000

Funding Received at McGill University

2008-2010

- Two-time recipient of the Jane B. Hood Bursary in Honours English Literature, worth CAD\$6,000
- Member of the Golden Key International Honour Society, granted to students in the top 15% of their program

Funding received upon entry into McGill University

2007

- Canadian Millennium Scholarship Foundation Provincial Excellence Award, worth CAD\$20,000
- Other: Canadian Association of Principal's Award, York Region Student Success Award, D. Foley Activism Award

NON-RESEARCH WORK EXPERIENCE

Consultant, Deloitte Consulting, Strategy and Operations, National Health Services

Team January 2013-July 2014

- Promoted from Business Analyst to Consultant
- Engaged in management consulting advisory work for public sector health services clients in Ontario (e.g., hospitals, Local Health Integration Networks, Community Care Access Centres, research institutes, the Ministry of Health and Long-Term Care, and other health agencies)
- Involved in strategic planning, including conducting numerous stakeholder consultations, and developing an external scan, current state analysis, and strategic options and directions
- Conducted a program evaluation of an Ontario-wide public health prevention program, which included a value for money assessment, a gap analysis comparing the program to leading practices and other jurisdictions, and the provision of recommendations and an implementation plan
- Facilitated project management, including the development of project management tools, the creation of communications materials, and project workplans
- Supported change management and project management initiatives for a clinical information system implementation at a large Toronto teaching hospital
- Organized a national Lunch and Learn series surrounding trends and topics of interest in health services consulting

RESEARCH EXPERIENCE

Journal Peer Reviewer

- Ad hoc reviewer, *Patient Education and Counselling*
- Ad hoc reviewer, *Healthcare*
- Ad hoc reviewer, *Journal of Medical Ethics*

Project Manager, Patient-Centered Outcomes Research Institute Trial: Utilizing advance care planning videos to empower patients and family members preparing for major surgery, Bloomberg School of Public Health, Johns Hopkins University (PI: Dr. Rebecca Aslakson)

July 2015-Present

- Developed and implemented project management tools to ensure the data quality and scientific soundness of the study, including study protocol, a participant tracking tools, research assistant task lists
- Led the quantitative and qualitative analysis of the findings
- Supervised the Research Coordinator, Research Assistants, and Biostatistician
- Developed and wrote various manuscripts stemming from the study's findings
- Created and maintained the randomized control trial's REDCAP site for data collection
- Assisted with recruitment from the study site

Research Assistant, Center for Health Services and Outcome Research, Implementing quality measurement into improved quality of palliative care (PI: Dr. Sydney Dy)

May 2016-Present

- Assisted with writing the study protocol and preparatory material for qualitative interviews

- Conducted qualitative interviews and focus groups, and contributed to coding and analysis
- Trained students in qualitative interviews and analysis
- Helped develop a survey tools to assess providers' perception of quality palliative care at their institutions

Research Assistant, The Evolution of Palliative Care in Canada: Trends and Veterans' Specific Needs (PI: Dr. Sandy Buchman)

January 2017-March 2017

- Reviewed over 130 peer-reviewed, grey literature, and policy documents related to palliative care in Canada and internationally
- Co-wrote a report documenting the evolution of palliative care in Canada, emerging trends and promising practices
- Conducted stakeholder consultations with key providers of palliative care for veterans in Canada and the United States
- Co-developed a PowerPoint presentation based on the report

Co-Investigator, Agency for Healthcare Research and Quality: Assessment Tools for Palliative Care

Technical Brief (Co-PIs: Dr. Rebecca Aslakson and Dr. Sydney Dy)

January 2016-October 2017

- Assisted with writing the study protocol and preparatory material for key informant calls
- Screened articles for the technical brief
- Contributed writing to the final report, as well as manuscripts

Research Assistant, The Lighthouse Studies at Peer Point, Bloomberg School of Public Health, Johns Hopkins University (PI: Dr. Amy Knowlton)

October 2014-December 2015

- Developed patient and caregiver surveys for a 5-year National Institutes of Health-funded longitudinal study of advanced care planning and palliative symptom management among a population of racial/ethnic minorities living with HIV/AIDS
- Led the qualitative component of the aforementioned study, including conducting the one-on-one interviews, coding the transcripts in Atlas TI, and writing a manuscript
- Contributed extensively to existing manuscripts based on a longitudinal study and past studies of the research team
- Assisted in the writing of various federal and university research grant applications

Qualitative Consultant, Inner City Health Associates (St. Michael's Hospital)

October 2014-Present

- Initiated and collaborating on the design of a comparative effectiveness study testing the impact of a palliative care program for the homeless in Toronto, Palliative Education And Care for the Homeless (PEACH)
- Lead qualitative study design

Research Assistant, Institute for Global Tobacco Control

October 2014

- Collected data for the study: Tobacco Smoke Pollution on Outdoor Patios: Documenting Sources of PM_{2.5} Using Wearable Imaging
- Helped to revise and refine the study protocol
- Contributed to a manuscript on the testing of the validity of the technology for data collection

Advisory Member, Canadian Treatment Action Council Working Group

September 2012-June 2013

- Provided advisory oversight for the development, delivery, evaluation, and dissemination of the Tools for Access workshops for people who use(d) drugs
- Participated in outcome evaluations and supported research, policy analysis, and knowledge exchange opportunities

Assistant, Human Rights and Health Equity Office, Mount Sinai Hospital

September 2012-December 2012

- Wrote grant proposals for an upcoming Canada-wide conference on health equity
- Supported logistical organization for a symposium on health equity for the Toronto Central Local Health Integration Network
- Contributed writing and editing for a forthcoming manual and book chapter on health equity
- Updated website and assisted with the processing, filing, and resolution of human rights complaints within the hospital

Research Assistant, Dr. Ann Jolly, University of Ottawa Epidemiology Department

May 2012-December 2012

- Conducted interviews with people who inject drugs and street people in Ottawa, many of whom were HIV and/or Hepatitis C positive
- Engaged in qualitative narrative analysis of interview data
- Produced two papers for publication: one focuses on methods to improve harm reduction programs and introduce safer drug practices; another on evaluating key turning points and social determinants of health that lead to drug use

Research Assistant, Dr. Rosemary Jolly, Queen' University English Department

September 2011-February 2012

- Organized workshops for planning sessions regarding research on HIV/AIDS in rural South Africa

Research Assistant, Dr. John Lydon's Psychology lab, McGill Psychology

January 2011-June 2011

- Organized two speed dating studies and assisted with quantitative data entry and analysis
- Digitized lab materials, as well as updated computer software

Research Assistant, Dr. Debbie Moskowitz' Psychology lab, McGill Psychology

May 2009-August 2009

- Conducted the induction sessions and second sessions for the Couples Social Interaction Study

Research Assistant, Dr. Peter Gibian, McGill English Department

May 2009-September 2010

- Assisted with research for book projects on nineteenth-century cosmopolitanism, and the culture of conversation
- Performed extensive literature searches and reviews
- Edited forthcoming book reviews and articles and prepared course materials

Research Assistant, Dr. Amanda Grenier, McGill School of Social Work

May 2009-January 2011

- Assisted with the writing and editing of various qualitative papers for peer-reviewed journals
- Conducted qualitative analysis of interviews and performed literature searches on black demographics in Montreal
- Researched for and edited a book on critical gerontology: Grenier, A. *Transitions and the lifecourse: contested models of 'growing old'*. Policy Press: Ageing and the Lifecourse Series (Ed Judith Phillips).

Research Coordinator, Dr. David Zuroff's Psychology lab, McGill Psychology

January 2009-December 2010

- Posted advertisements for the Daily Diary Study of Mood, Personality, and Social Behaviour
- Scheduled participants, managed payment of monetary compensation, and assisted with quantitative data analysis
- Supervised three research assistants in their data collection
- Liaised between key stakeholders involved in the project

Research Assistant, Stress Trauma Anxiety Rehabilitation Treatment Clinic

May 2008-August 2008

- Conducted phone screenings for various clinical research trials
- Contributed to psychology manuscripts
- Performed literature searches

PUBLICATIONS

Published/In Press Refereed Journal Articles

Isenberg, S.R., Aslakson, R.A., Smith, T.J., Implementing evidence-based palliative care programs and policy for cancer patients: Epidemiologic and policy implications of the 2016 American Society of Clinical Oncology Clinical Practice Guideline Update. *Journal of Epidemiologic Reviews*. 2017. Doi: 10.1093/epirev/mxw002. Epub ahead of print.

Isenberg, S.R., Smith, T.J., Lu, C., McQuade, J., Razzak, R. Impact of a New Palliative Care Program on Health System Finances: An Analysis of the Palliative Care Program Inpatient Unit and Consultations at Johns Hopkins Medical Institutions. *Journal of Oncology Practice*. 2017. Doi: 10.1200/JOP.2016.014860. Epub ahead of print.

Isenberg, S.R., Holtgrave, D., Smith, T.J., Lu, C., McQuade, J., Razzak, R. Economic Evaluation of a Hospital-Based Palliative Care Program. *Journal of Oncology Practice*. 2017. Doi: 10.1200/JOP.2016.018036. Epub ahead of print.

Isenberg, S.R., Maragh-Bass, A.C., Ridgeway, K., Knowlton, A.R. A Qualitative Exploration of Chronic Pain and Opioid Treatment among HIV Patients with Drug Use Disorders. *Journal of Opioid Management*. 2017;13(1):5-16.

Aslakson, R.A., **Isenberg, S.R.**, Crossnohere, N.L., Conca-Chang, A.M., Yang, T., Weiss, M., Volandes, A.E., Bridges, J., Roter, D. Utilizing Advance Care Planning Videos to Empower Perioperative Cancer Patients and Families: The Protocol for a Patient-Centered Outcomes Research Institute-funded Study. *British Medical Journal (BMJ) Open*. 2017. In press.

Aslakson, R. Dy, S., Wilson, R.F., Waldfogel, J.M., Zhang, A., **Isenberg, S.R.**, Blair, A., Sixon, J., Robinson, K.A. Assessment Tools of Palliative Care. *Journal of Pain and Symptom Management*. In Press.

Aslakson R., Dy S.M., Wilson R.F., Waldfogel J.M., Zhang A., **Isenberg S.R.**, Blair A., Sixon J., Robinson KA. Assessment Tools for Palliative Care. Technical Brief No. 30 (Prepared by Johns Hopkins University under Contract No. 290-2015-00006-I.) *AHRQ Publication No. 14-17-EHC007-EF*. Rockville, MD: Agency for Healthcare Research and Quality; May 2017. www.effectivehealthcare.ahrq.gov/reports/final.cfm. doi: <https://doi.org/10.23970/AHRQEPCTB30>.

Dy, S., Abu Al Hamayel, N., Hannum, S.M., Sharma, R., **Isenberg, S.R.**, Kuchinad, K., Zhu, J., Smith, K., Lorenz, K., Kamal, A., Walling, A., Weaver, S.J. P Evaluating barriers and facilitators to quality measurement and improvement: Adapting surveys for implementation research in palliative care programs. *Journal of Pain and Symptom Management*. In press.

Mitchell, M.M., **Isenberg, S.R.**, Maragh-Bass, A.C., Knowlton, A.R. Chronic Pain Predicting Reciprocity of Support among Vulnerable, Predominantly African-American Persons Living with HIV/AIDS. *AIDS & Behavior*. 2017. In press.

Maragh-Bass, A.C., Zhao, Y., **Isenberg, S.R.**, Mitchell, M.M., & Knowlton, A.R. Have you talked about it: Advanced care planning among African Americans living with HIV in Baltimore. *Journal of Urban Health*. 2017. doi: 10.1007/s11524-017-0157-y. In press.

Mitchell, M.M., Nguyen, T.Q., **Isenberg, S.R.**, Maragh-Bass, A.C., Keruly, J., Knowlton, A.R., Psychosocial and Service Use Correlates of Health-Related Quality of Life Among a Vulnerable Population Living with HIV/AIDS. *AIDS Behavior*. 2016. Epub ahead of print.

Mitchell, M.M., Nguyen, T.Q, Robinson, A.C., **Isenberg, S.**, Beach, M.C., Knowlton, A.R., Patient-provider engagement and chronic pain in drug-using, primarily African-American persons living with HIV/AIDS. *AIDS Behavior*. 2016. Epub ahead of print.

Isenberg S, Holtgrave DR, Lu C, McQuade, J., Razzak, R. Weir, B., Gill, N., Smith, T.J. Evaluating the cost-effectiveness of the hospital-based palliative care program at The Johns Hopkins Hospital. *Journal of Clinical Oncology*. 2016;34(suppl 7); 23.

Isenberg S, Lu C, McQuade JP, Smith TJ, Razzak AR The estimated hospital-wide financial impact of a comprehensive inpatient palliative care (PC) program. *Journal of Clinical Oncology*. 2016;34(suppl 26); 173.

Mitchell, M.M., Maragh-Bass, A.C., Nguyen, T.Q., **Isenberg, S.**, & Knowlton, A.R. The Role of Chronic Pain and Current Substance Use in Predicting Negative Social Support Among Disadvantaged Persons Living with HIV/AIDS. *AIDS Care*. 2016; 28(10);1280-6.

Knowlton, A.R., Mitchell, M.M., Robinson, A.C., Nguyen, T.Q, **Isenberg, S.**, Denison, J. Informal HIV caregiver proxy reports of care recipients' treatment adherence: Relationship factors associated with concordance with recipients' viral suppression. *AIDS & Behavior*. 2015;19(11);2123-2129.

Colaiani, A, **Isenberg, S.**, Smith, T.J. How and why oncologists should do palliative care—or get some assistance doing it. *American Journal of Managed Care: Evidence-Based Oncology*. 2015;21(6);SP191-4. (Co-first authorship)

Isenberg, S. “Translating World Religions: Ralph Waldo Emerson’s and Henry David Thoreau’s “Ethical Scriptures” Column in *The Dial*.” *Comparative American Studies*. 2013;11(1).

Isenberg, S. “Deconstructing the Literary Paradoxes of the ‘Japji’: A Contradictory Morning Prayer and its Implications for the Sikh Religion.” *Canons: Undergraduate Journal of Religious Studies*. 2011;7; 9-19.

Journal Articles Under Refereed Review/Submitted

Isenberg, S.R., Roter, D., Smith, T.J., Aslakson, R.A. A Qualitative Exploration of Companion Involvement in the Preoperative Consent Visit for Patients Undergoing Major Surgery for Advanced Cancer.

Abu Al Hamayel, N., **Isenberg, S.R.**, Sixon, J., Hannum, S.M., Smith, K., Dy, S., Patients’ Perspectives on Palliative Care Quality: Prioritizing and Improving Palliative Care Quality Efforts in Elderly Patients.

Aslakson, R.A., Schuster, A.L.R., Lynch, T.J., Weiss, M.J., Gregg, L., Miller, J., **Isenberg, S.R.**, Crossnohere, N.L., Conca-Cheng, A.M., Volandes, A.E., Smith, T.J., Bridges, J.F.P. Developing the storyline for an advance care planning video for surgery patients: Patient-centered outcomes research engagement from stakeholder summit to State Fair.

Book Chapters

Isenberg, S.R. and Smith, T.J. “Financial Aspects of Outpatient Palliative Care.” *Textbook of Palliative Care*. Eds. Roderick MacLeod and Lieve Van den Block. Springer; 2018. Forthcoming.

Roter, D.L., **Isenberg, S.R.**, Czaplicki, L.M. (Forthcoming). "Chapter 62: The Roter Interaction Analysis System (RIAS): applicability within the context of cancer and palliative care." *Handbook of Communication in Oncology and Palliative Care*. 2nd ed. Eds. David Kissane, Barry Bultz, Phyllis Butow, and Ilora Finlay. Oxford University Press; 2017. In press.

Reports

Buchman, S and **Isenberg S.R.** The Evolution of Palliative Care in Canada: Trends and Veterans' Specific Needs. Report prepared for Veterans Affairs Canada. Toronto, Ontario; 2017.

Grenier, A., Airton, E., **Isenberg, S.** "Older People in the Black Community: The Black Demographics Project." Research Report prepared for Heritage Canada. Montreal: Heritage Canada Press; 2009; 24pp.

Working Papers

Isenberg, S.R., Crossnohere, N.L., Conca-Chang, A.M., Yang, T., Weiss, M., Bridges, J., Roter, Volandes, A.E., Aslakson, R.A., D. A Human-Centered Design Approach for Developing an Advance Care Planning Video for Patients Preparing for Major Surgery.

Isenberg, S.R., Roter, D., Smith, T.J., Aslakson, R.A. Companions' involvement during preoperative consent visits and its relationship to visit communication and satisfaction.

Isenberg, S.R., Smith, T.J., Lu, C., McQuade, J., Razzak, R. Estimating the Projected Five Year Cost-Savings of a Comprehensive Hospital-Based Palliative Care Program.

Isenberg, S.R., Piggott, D.A., Dy, S., Mehta, S.H., Kirk, G.D. Pain, Health Service Utilization and Mortality among Persons Aging with HIV Infection and Substance Use.

PRESENTATIONS

Invited Presentations

Isenberg, S.R. A Human-Centered Design Approach for Developing an Advance Care Planning Video for Patients Preparing for Major Surgery. *Armstrong Institute Internal Research in Progress Meeting*. Johns Hopkins Medicine Armstrong Institute for Patient Safety and Quality. Baltimore, MD. 4 April 2017. Oral Presentation.

Isenberg, S.R. Punctuated Equilibrium Theory in Health Policy Agenda Setting. *Policy Interventions for Health Behaviour Change*. Johns Hopkins Bloomberg School of Public Health. Baltimore, MD. 4 November 2016. Class Lecture.

Dy, S., Abu Al Hamayel, N., **Isenberg, S.R.**, Hannum, S.M. Implementation of palliative care quality initiatives: Patient, caregiver, and provider perspectives. *Grand Rounds*. Welch

Center for Prevention, Epidemiology and Clinical Research. 1 November 2016. Oral Presentation.

Isenberg, S.R. Improving Access to Palliative Care: Innovations in Research and Clinical Applications. Cambridge Women's Liberal Association. Cambridge, Ontario. 29 September 2016. Oral Presentation.

Isenberg, S.R. Creating culture change around palliative care at the interpersonal and hospital-levels. *Behavioral Sciences and Health and Supportive Care Research Seminar at the Princess Margaret Cancer Centre*. Toronto, Ontario. 19 September 2016. Oral Presentation.

Isenberg, S.R. Johns Hopkins and the American Health Care System: Insights from my research in palliative care and advance care planning. *Deloitte Canada's National Health Services Monthly Meeting*. Toronto, Ontario. 21 July 2016. Oral Presentation.

Conference Presentations and Chairing Roles

Isenberg, S.R., Roter, D., Smith, T.J., Aslakson, R.A. A Qualitative Exploration of Companion Involvement in the Preoperative Consent Visit for Patients Undergoing Major Surgery for Advanced Cancer. *Patient-Provider Collaboration Conference: Making Patient-Centered Care a Reality*. Baltimore, MD. 23 June 2017. Oral Presentation.

Isenberg, S.R., Aslakson, R. Dy, S., Wilson, R.F., Waldfogel, J.M., Zhang, A., Blair, A., Robinson, K.A. Patient and Caregiver-Reported Assessment Tools for Palliative Care: Summary of the 2017 Agency For Health Research and Quality (AHRQ) Technical Brief. *Multinational Association of Supportive Care in Cancer (MASCC)*. Washington, DC. 22 June 2017. Oral Presentation.

Isenberg, S.R., Aslakson, R. Dy, S., Wilson, R.F., Waldfogel, J.M., Zhang, A., Blair, A., Robinson, K.A. Assessment Tools of Palliative Care. *Palliative Care in Oncology Symposium*. San Francisco, California. 9 September 2016. Poster Presentation.

Isenberg, S.R., Lu, C., McQuade, J., Razzak, R., Gill, N., Cardamone, M., Torto, D., Langbaum, T., Holtgrave, D., Smith, T.J. The estimated hospital-wide financial impact of a comprehensive inpatient palliative care (PC) program. *Palliative Care in Oncology Symposium*. San Francisco, California. 9 September 2016. Poster Presentation.

Isenberg, S., Holtgrave, D., Lu, C., McQuade, J., Weir, B., Gill, N., Razzak, R., Smith, T.J. Calculating Quality-Adjusted Life Years to Determine the Cost Effectiveness of the Palliative Care Unit at the Johns Hopkins Hospital. *Academy Health Conference*. Boston, Massachusetts. 26 June 2016. Poster Presentation.

Isenberg, S., Holtgrave, D., Lu, C., McQuade, J., Weir, B., Gill, N., Razzak, R., Smith, T.J. Evaluating the cost-effectiveness of the hospital-based palliative care program at The Johns Hopkins Hospital. *American Society of Clinical Oncology (ASCO) Quality Care Conference*. Phoenix, Arizona. 27 February 2016. Poster Presentation.

Isenberg, S., Lu, C., McQuade, J., Smith, T.J., Razzak, R. Estimating the cost-savings of a comprehensive hospital-based palliative care program. *American Society of Clinical Oncology (ASCO) Quality Care Conference*. Phoenix, Arizona. 26 February 2016. Oral Presentation.

Isenberg, S., Lu, C., McQuade, J., Razzak, R., Smith, T.J. "Impact of a new palliative care program on health system finances." *Johns Hopkins High Value Research Symposium*. Baltimore, MD. 1 February 2016. Oral Presentation.

- Recipient of the Second Highest Abstract Score

Isenberg, S.R., Moore, M., Swoboda, S., Bridges, J., Smith, T.J., Pawlik, T., Weiss, M., Roter, D., Aslakson, R. "Developing and Implementing a Randomized Control Trial Testing the Effectiveness of a Video Decision Aid for in Engaging Patients and Family Members in Advanced Care Planning During Preoperative Visits." *Anesthesiology/Critical Care Medicine Research Day*. Baltimore, MD. 30 November 2015. Oral Presentation.

- Recipient of the Award for the Best Poster Presentation

Isenberg, S.R., Piggott, D.A., Dy, S., Mehta, S.H., Kirk, G.D. "Pain, Health Service Utilization and Mortality among Persons Aging with HIV Infection and Substance Use." *6th International Workshop on HIV & Aging*. Washington, DC. 6 October 2015. Poster Presentation.

Isenberg, S., Mitchell, M., Nguyen, T., Robinson, A., Knowlton, A. "Unstable housing is mediated by social support leading to reductions in health-related quality of life among former or current IDUs on ART in Baltimore, Maryland" *North American Housing and HIV/AIDS Research Summit VIII*. Washington, DC. 14 September 2015. Oral Presentation.

"Marginalization and Access." Chair. *Come Together: Digital Collaboration in the Academy and Beyond*. Queen's University. Kingston, Ontario. 13 May 2012.

Isenberg, S. "Coercion by a Sweeter Name: A Reevaluation of Henry David Thoreau's Orientalist Cosmopolitan Stance towards Hinduism in Walden and 'Ethnical Scriptures.'" *The Society for the Study of the Multi-Ethnic Literature of the United States/ United States Association for Commonwealth Literature and Language Studies Conference*. Fairmont Hotel. San Jose, California. 19 April 2012. Oral Presentation.

Isenberg, S. "A Jew is a Jew; is a Jew...?: Jew-ish Representations as Christian Self-Projections in the *Croxtton Play of the Sacrament*." *English Graduate Student Conference*. McGill University. Montreal, Quebec. 29 January 2012. Oral Presentation.

"Haunted Translations." Chair. *English Graduate Student Conference*. McGill University. Montreal, Quebec. 29 January 2012.

Isenberg, S. "A Very Yankee Sort of Oriental': Cosmopolitanism and Orientalism in Henry David Thoreau's Engagements with Eastern Religions." *New England American Studies Association Annual Conference*. Plymouth Plantation. Plymouth, MA. 5 November 2011. Oral Presentation.

Isenberg, S. “An Anti-Colonial Uprising or an Essentializing Black Spectacle: Orson Welles’s Problematic Portrayal of Race in ‘Voodoo’ *Macbeth*.” *Quebec Undergraduate English Conference*. Bishop’s University. Sherbrooke, Quebec. 19 March 2011. Oral Presentation.

“African-American Culture and Expression of Racial Identity.” Chair. *Quebec Undergraduate English Conference*. Bishop’s University. Sherbrooke, Quebec. 19 March 2011.

Isenberg, S. “The Difficulties of Integrative, Nonviolent Living: An Ecocritical Reading of Zakes Mda’s *The Whale Caller*.” *English Graduate Student Conference*. McGill University. Montreal, Quebec. 4 March 2011. Oral Presentation.

“Wealth & Privilege, Narrative & Rhetoric.” Chair. *English Graduate Student Conference*. McGill University. Montreal, Quebec. 4 March 2011.

Isenberg, S. “The Fabrication and Performance of Class in Charlotte Bronte’s *Jane Eyre* and George Eliot’s *Adam Bede*.” *Quebec Undergraduate English Conference*. Bishop’s University. Sherbrooke, Quebec. 13 March 2010. Oral Presentation.

Conference Proceedings

Isenberg, S. “An Anti-Colonial Uprising or an Essentializing Black Spectacle: Orson Welles’s Problematic Portrayal of Race in ‘Voodoo’ *Macbeth*.” *Narrativizing Identity: QUEUC 2011 Conference Proceedings*. Eds. Jessica Riddell and Melshean Boardman. Sherbrooke: Bishop’s UP, 2011. 103-110. Print.

PRESS COVERAGE

Doyle, Chase. “Palliative Care Program Eases Patient Symptoms and Hospital Costs. Value-Based Cancer Care. November 2016. Article can be viewed at:

<http://www.valuebasedcancer.com/issue-archive/2016/november-2016-vol-7-no-10/palliative-care-program-eases-patient-symptoms-and-hospital-costs>

- Article focusing upon Sarina’s research presented at the Palliative Care in Oncology Symposium (September 2016)

Nelson, Roxanne. “Who Knew? Inpatient Palliative Care Also Saves Money.” *Medscape Medical News*. 12 September 2016. Article can be viewed at:

<http://www.medscape.com/viewarticle/868672>

- Article focusing upon Sarina’s research presented at the Palliative Care in Oncology Symposium (September 2016)

Dangi-Garimella, Surabhi. “Hospital-Based Palliative Care Program Saves Costs and Improves QOL.” *American Journal of Managed Care*. 2 March 2016. Article can be viewed at: <http://www.ajmc.com/newsroom/hospital-based-palliative-care-program-saves-costs-and-improves-qol#sthash.YxowMhBR.dpuf>

- Article focusing upon Sarina’s research presented at the American Society of Clinical Oncology Quality Care Symposium (February 2016)

Harrison, Pam. "Cost of Advanced Cancer Reduced by Earlier Palliative Care." *Medscape Medical News*. 2 March 2016. Article can be viewed at:
<http://www.medscape.com/viewarticle/859696?src=sttwit>

- Article focusing upon Sarina's research presented at the American Society of Clinical Oncology Quality Care Symposium (February 2016)

"Sarina Isenberg, PhD Candidate, on Better Care at a Better Cost." *The ASCO Post*. 4 March 2016. Video can be viewed at:

<http://www.ascopost.com/videos/2016-quality-care-symposium/sarina-isenberg-phd-candidate-on-better-care-at-a-better-cost/>

- Four-minute video clip of Sarina discussing the research that she presented at the American Society of Clinical Oncology Quality Care Symposium

TEACHING EXPERIENCE

Teaching Assistant, Policy Interventions for Health Behaviour Change
2015-2017

Teaching Assistant, Modern British Fiction,
2011-2012

Teaching Assistant, Contemporary African Women's Writing
2011-2012

LEADERSHIP EXPERIENCE

Co-Chair, The Health, Behavior and Society Student Organization

May 2015-May 2016

- Collaborated with Department Chair to organize events and initiatives improving student engagement and community
- Worked with Department Chair and senior faculty to address students' concerns regarding PhD and Masters programs
- Organized orientation activities for incoming students
- Organized an awards ceremony for faculty and staff
- Organized a research symposium for second year doctoral students

Curriculum Committee Student Representative, Department of HBS

August 2015-August 2016

- Attended monthly meetings and shared student perspectives on curriculum and recommended changes

Editor-in-Chief, The English Students' Association Academic Journal The Channel

May 2010-May 2011

- Selected Senior and Assistant Editors for the department-wide, peer-reviewed undergraduate journal
- Decided which essays would be included and edited all published essays
- Secured funding for the publication of the journal

Editor-in-Chief, Speak! Magazine, Journalists for Human Rights, McGill Chapter

May 2010-January 2011

- Oversaw the publication of a quarterly magazine and trained other students in human rights journalism and editing

Vice President Academic, The Department of English Students' Association

May 2010-May 2011

- Organized academic conferences and opportunities for undergraduate students in the English Department
- Served as the student representative to the Department's Curriculum Committee
- Provided information sessions on various aspects of the department and its degree requirements

Director, McGill Global AIDS Coalition

May 2009-May 2010

- Oversaw all club activities, including World AIDS Week, a high school outreach program, International Women's Week, World Tuberculosis Day, an equitable licensing advocacy campaign, fundraiser concerts, and panel discussions with Canadian HIV/AIDS Legal Network, and politicians including Thomas Mulcair and Marc Garneau
- Acted as a liaison between the club, the Student Society of McGill University, and community advocacy organizations