



Bachelor of Science in Medicine Degree Program
End of Term Final Report

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Project Title: Identifying Barriers for Successful Discharge Following Cardiac Surgery

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Summary (250 words max single spaced):

Introduction: Cardiac surgical procedures are being performed on older and more frail patients with numerous comorbidities. Despite successful hospital discharge, many of these patients experience inadequately controlled persistent pain, decreased functional status, depression, fatigue, sleep disturbances, and PTSD following surgery. Worse, patients with prolonged ICU stays have higher rates of rehospitalization, long-term morbidity and worse non-institutional survival. The rate of prolonged ICU stays is increasing in Manitoba, therefore, highlighting the need for a process to meet the needs of these complex patients.

Methods: A single centre, prospective, mixed methods cohort study employing a Lean transformation process and an interdisciplinary team in Manitoba, Canada, utilized patient and caregiver focus groups as well as cardiac surgeon surveys to identify barriers for successful transition of cardiac surgery patients from hospital to the community.

Results: The results show patients and caregivers are exposed to inadequacies surrounding information exchange, challenges regarding communication with healthcare providers and a significant financial burden when accessing healthcare. Furthermore, caregivers experience significant fear and isolation and need additional resources for support in the community. Lastly there appears to be a discordance in perception of "successful" discharge between the surgical team and the patient-caregiver unit.

Conclusion: This study shows that barriers to successful discharge largely involves how information is exchanged. An incongruent perception of discharge experiences between healthcare provides and patients suggests the need for modification of current discharge communication processes. Future study will seek to implement improvements in the themes identified to determine efficacy in reducing rehospitalization and improved HRQoL.

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1. Introduction

In the last 20 years, the aging Canadian population has resulted in cardiac surgery procedures being performed on older and more frail patients with numerous comorbidities.^{1,2} Despite several favourable reports using traditional outcome metrics such as in-hospital mortality following cardiac surgery, up to 20% of patients experience minimal to no improvement in their health related quality of life (HRQoL) following hospital discharge.³ Inadequately controlled persistent pain, decreased functional status, depression, fatigue, and sleep disturbances following surgery are some of the reasons “successfully” discharged patients continue to experience difficulties once discharged to the community.⁴⁻¹⁰

Patients who may have a more complicated perioperative course may often experience a prolonged intensive care unit length of stay (prICULOS). A prICULOS is defined as staying in the ICU for ≥ 5 days, which is 2.5-fold longer than the normal 2 day ICU length of stay represent a particularly vulnerable group of patients.¹¹⁻¹⁷ Specifically, Manitoban cardiac surgery patients who experience prICULOS have higher rates of rehospitalization, long-term morbidity and worse non-institutional survival (i.e. either deceased or admitted to a long-term care facility) than those patients without a prICULOS following cardiac surgery.¹⁴ Worse, some patients experience post-traumatic stress disorder (PTSD) and other mental health illnesses following traumatic life-threatening complications following a prolonged stay in the intensive care unit.³ Additionally, rehospitalization and a lack of physician visits within 30 days from hospital discharge pose a significant risk factor for poor 1-year non-institutional survival for these patients.¹⁸ Rehospitalization within 30 days of hospital discharge is associated with 2.29-fold risk in poor 1-year non-institutional survival for these patients.¹⁹ Therefore, both aging cardiac surgery patients who experience a prICULOS and a non-prICULOS require a process to meet their complex needs following hospital discharge.

To address this potential in gap in care for the older adult patient, an interdisciplinary team of care providers at St. Boniface Hospital were assembled to develop a process to decrease rehospitalization and improve 1-year functional survival (defined as alive and non-institutionalized) for cardiac surgery patients¹⁹. However, through preliminary face-to-face meetings, it became clear that there was insufficient knowledge about the current discharge process, and thus our team were attempting to develop a solution to a problem that was incompletely understood. The investigative team therefore endeavoured to undertake a more detailed evaluation of the current discharge experience for cardiac surgery patients and identify patient-specific values and modifiable insufficiencies that could be targeted for improvement. To be able address the potentially complex issues that were being investigated, our investigative team partnered with the Lean Transformation Office as a new initiative to determine opportunities for improvements in the current patient transition process from hospital to the community for cardiac surgery patients. Specifically, we sought to determine: 1. patient-centered values and difficulties following discharge from hospital after cardiac surgery; 2. potential barriers to successful discharge from hospital; 3. caregiver-centered values and difficulties during hospital discharge and in the community; 4. cardiac surgeon’s perspectives on patient-centered and caregiver-centered values and difficulties following discharge from hospital after cardiac surgery.

2. Methods

This is a single centre, prospective, mixed methods cohort study that was undertaken at the St. Boniface Hospital, Winnipeg, Canada. The University of Manitoba Research Ethics Board (REB) and the St Boniface Hospital Research Review Committee (RRC) approved the study.

Use of Lean Transformation

Lean thinking, a production improvement strategy initially developed by Toyota Motors, designed to determine value and waste in the workplace,²⁰ was chosen as a novel strategy to determine barriers to successful discharge for the cardiac surgical patient transitioning to the community. Using lean methods such as A3 problem solving and SIPOC (suppliers, inputs, process, outputs, and customers), the investigative team undertook a series of patient and caregivers focus groups as well as cardiac surgeon surveys to gain insight on the discharge experiences of these increasingly vulnerable patients. A3, a lean problem solving strategy, is used to efficiently organize strategies to improve upon a given problem.²¹ A3 focuses on the *initial state*, the *target state*, and acts to identify gap in knowledge with a *gap analysis*. Utilizing a gap analysis addresses inefficiencies surrounding a given issue which can be addressed using experimentation with the goal of reaching the proposed target state.²¹ The current state of cardiac surgery patients following discharge has been recently investigated by our Centre and has identified that Manitoban patients are becoming older and sicker that is associated with ICU and hospital length of stay as well as experience higher rates of rehospitalization following cardiac surgery, particularly after a prICULOS.^{18,19,22,23}

SIPOC (suppliers, inputs, process, outputs, and customers), a tool which summarizes the inputs and outputs of a given process, was then utilized to explore patient discharge. This allowed our investigative team to determine the granular steps in the current process of cardiac surgical patient discharge and identify the care providers involved in the process. From this process, it was determined that our A3 gap analysis would focus on patient-centered focus groups and surgeon surveys to gain an understanding of the barriers preventing successful transition to the community. Therefore, lean thinking assisted our team in organizing an approach to identify insufficiencies in the current healthcare model before proposing ideas for improvement. The initial overarching goal of this endeavour was to achieve an agreed upon target state of reduction rehospitalization by 25% within 24 months of initiating this process, and with the information gained using lean thinking, it was anticipated that the investigative team would have the data needed to accurately develop improvement strategies to begin to achieve the desired target state.

Determining Value for the Patient and Caregiver

Through the SIPOC process, it was identified that additional information was needed to understand patient and caregiver value in the transition process from the hospital back to the community. A mixed methods approach utilizing qualitative patient and caregiver focus groups and cardiac surgeon surveys was determined as the approach to be utilized to address the gap in knowledge of patient's values and barriers following their discharge from hospital. Focus groups (versus individual interviews) affords the opportunity for patients to discuss topics amongst individuals with a similar frame of reference, while also creating opportunity to make comments on other's point of view²⁴ to achieve a more organic patient-centered understanding of the issues.²⁴ A survey, in addition, was used to gain insights in the cardiac surgeons'

perspective of patient values and quality of life following discharge from hospital and compare the themes generated from the focus groups.

Sample and Setting

The patient population for this study was recruited from a previous study performed at this center, The Long tErM SuCcess Of Prolonged intEnsive care patients after Cardiac Surgery (TELESCOPE-CS; MS#JTCVS-17-987 under review). The TELESCOPE-CS cohort included patients greater than eighteen years of age who had undergone cardiac surgery at St Boniface Hospital. From this cohort, our study selected for prICULOS and non-prICULOS patients where were either 6 months or 12 months post cardiac surgery. The patient's primary caregivers in the community were invited to attend the focus groups alongside the patients.

Focus groups were divided by the patient's ICU length of stay following their cardiac procedure and the duration of time since hospital discharge. ICU length of stay was divided into prolonged ICU length of stay (prICULOS) and non-prolonged ICU length of stay (non-prICULOS), while duration of time since hospital discharge was divided into 6 months or 12 months post-discharge. This created four focus groups: 1. 6 months post-discharge with a prICULOS; 2. 6 months post-discharge with a non-prICULOS; 3. 12 months post-discharge with a prICULOS; 4. 12 months post-discharge with a non-prICULOS. Focus groups were conducted in a private room at St. Boniface Hospital and lasted between 90 and 120 minutes.

Study Procedure

Focus Groups: Focus group discussions began with both patients and caregivers in the same room and were lead by a primary moderator while three researchers were present to take notes on group dynamics. The focus groups were then segregated into separate patient and caregiver groups to provide an environment where patients and caregivers could engage in potentially sensitive discussions while the other were not present. Both groups were brought back together to conclude the focus groups and allow for the opportunity to discuss any topics not previously mentioned.

Surgeon Survey: Surgeon's surveys were developed using an online survey platform (Survey Monkey) designed to gain an understanding on how surgeons perceive their patient's quality of life, values, and needs following hospital discharge. Survey questions were developed and then discussed within the interdisciplinary research team to assess for completeness. Surveys were conducted and data was collected anonymously.

Data Analysis

Data analysis was carried out using qualitative content analysis. This process utilized both the manifest content to extract obvious and visible data and the latent content to identify relationships and apply interpretation.²⁵ Meaningful text was extracted from transcripts, defined as a meaning unit, and labelled with a word or phrase to summarize it the idea of the text, defined as a code.²⁵ After codes were applied for all meaning units, similar codes were grouped together into themes and sub-themes themes to capture the main ideas.²⁵ Surgeon surveys, due to the low number of potential respondents, were summarized in descriptive tables.

Quality of Research Process

Following both coding and theme generation, data were compared between two researchers to assess for likeness. This peer-review process was considered important because it allowed individual and outlying perceptions of content to be discussed to ensure a consistent and shared interpretation of content to maintain integrity.

3. Results

Focus Groups

Four themes and accompanying sub-themes were identified. These themes describe, first, issues surrounding the information provided to participants at the time of discharge from hospital, second, the impact of the discharge process on patients, third, the challenges of being a caregiver, and finally, participant's experiences with the health care system (*see table 1 for overview and specific participant quotes*)

Information Exchange

A key theme pertained to the difficulties and problems surrounding the information that is shared between the patient and members of the care team. This theme 'information exchange' includes the sub-themes '*information content*', '*ability to retain information*', '*planning for after discharge*', and '*information type*'.

Information content. Across all four focus groups, participants stressed that they exposed to an overwhelming amount of written and verbal content in a short period of time while some participants stated that the volume of information was so great that they felt they were unable to adequately consume and understand all of what was provided. The need for detailed and expansive content was not undervalued, however. Participants discussed the importance of having complete information when being discharged, but highlighted that the way it is delivered and the timeliness of the information is currently inadequate.

Ability to retain information. An additional sub-theme was participant's ability to retain and understand the information provided to them at discharge. Participants described having difficulty retaining the information received upon discharge, most notably due to poor memory and confusion during discharged. This, compounded with the overwhelming volume of information during the discharge process, appeared to be very stressing for many participants:

"...you are very confused, your memory is shot, and if you don't have someone like your significant other looking after you, I mean, I don't know how."

Participants also describe experiencing amnesia, stating that they have complete loss of memory surrounding their discharge process. Memory loss significantly impacted the ability to retain information for these participants as they were unable to recall their experiences with discharge in ICU, suggesting that the information provided to them during this time was not comprehended.

Planning for after discharge. Another sub-theme was having a plan in place for situations that may arise following hospital discharge, which largely centered around a lack of a protocol for medical emergencies. Participants in all focused groups described uncertainty and feeling

unprepared to handle emergency situations and lacked knowledge about who to call or where to go in an emergency. Additionally, immediacy of information was highly valued as participants described wanting quick and easy access to information during emergencies. Participants also emphasized a need for a call line to contact care providers quickly if needed:

“When you are in a situation you don’t want a number to call, you want someone you can speak to right away, not someone who will call you back in a bit. Because you need to know what to do right away.”

Information Type. Finally, participants expressed their thoughts about the different information types they given, namely regarding diet, exercise and recovery expectations. Discussion around diet highlighted the challenges faced with adapting to cardiac-patient-specific diets. Many participants expressed frustrations with inconsistent dietary recommendations, resulting in uncertainty of which recommendations to follow.

“I have had one doctor say here take this pamphlet, and I had one doctor tell me it was a bunch of crap. So, you have a message from one cardiologist and another one says that. I don’t know how to eat, because who do you believe?”

Adjusting diets to meet requirements for drugs, namely warfarin, was another challenge for some participants. These participants showed knowledge about drug-diet interactions, but lacked knowledge of how to make appropriate choices.

Exercise was another important topic as participants expressed not knowing how to exercise safely and were fearful of something bad happening to them. Similarly, experiences with physical recovery were discussed, highlighting aspect of recovery participants were unprepared for such as loss of hand dexterity and decreased memory. This suggests that patients are lacking information about what to expect during their recovery, highlighting a need for improved information exchange from care providers.

Experience of Discharge

Another main theme was the impact of the discharge process on participant’s emotions. This theme ‘*experience of discharge*’ includes the subthemes ‘*a desire to go but need to stay*’ and ‘*lack of understanding of process*’.

A desire to go but need to stay. Across all focus groups, participants experienced conflicting values at the time of hospital discharge. Participants described feeling a desire to leave hospital after their surgery, while also noting factors that lead them to believe they should have remained in hospital longer. Participants described being happy to go home and glad they could sleep in their own bed again as home was comforting to most participants due to many experiencing a prICULOS. However, while participants described wanting to get out of hospital, they also described feelings of insecurity and worry about what was to follow which resulted in participants feeling as though they should have stayed in hospital longer. Some participants explained that they needed to stay in hospital longer because they felt they had not recovered enough to go home. This resulted in some participants feeling as though their concerns about their physical state were invalidated. While participants may have expressed their desire to leave hospital, many had unmet needs that caused internal conflict and undue distress, highlighting a need for strengthened communication between patients and their care providers.

Lack of understanding of process. While participants described discomfort with the discharge process, their apprehensions appeared to be influenced by their lack of understanding behind the rationale to why they were discharged. As previously mentioned, discharge is a significant stressor for participants and communication can be complicated by the overwhelming volume of information being consumed by participants. This perceived lack of procedural understanding caused misconceptions about why participants were being discharge, resulting in further stressors for participants.

The Caregiver Experience

Another major theme across all focus groups which highlighted the unique challenges and emotional burden of being a caregiver for cardiac surgical patients. The theme 'the caregiver experience' consists of the following subthemes: '*fear of night time*', '*feelings of isolation*', and '*overreliance on caregivers*'.

Fear of night time. The responsibility of being a caregiver throughout the night was a significant theme for caregivers across all sessions. Most caregivers were solely responsible for caring for their loved ones during the night and expressed a distress about falling asleep as they were fearful of something happening to their loved ones. This resulted in loss of sleep which become taxing on these caregivers:

"You feel those first few days, you really feel abandoned, I swear if I slept two hours a night that week I was getting a whole lot of sleep. You are afraid. My wife got a mechanical valve and you listen for that tick because you are afraid to go to sleep. You don't want to wake up to something you don't want to wake up to."

The anxiety caregivers experienced at night was complicated by homecare only being available during the day. This meant that caregivers were expected to provide care at night without assistance. Caregivers depend on the expertise of homecare workers being present during the day and are comforted by the idea of someone to provide help if something were to happen to their loved ones. Caregivers expressed a desire to have homecare available at night as well as having access to a call line should they need assistance.

Feelings of isolation. An additional subtheme was the caregiver's feelings of isolation. Caregivers described feeling alone and scared because they were often the only ones responsible for their loved ones. Caregivers attributed this fear to a lack of direct caregiver support at home, suggesting these individuals need support in the community.

"I had no one. The first week scared me to death."

Caregivers also expressed feelings that the responsibility of caring for their loved ones was forced upon them. Many caregivers also felt unprepared to provide care as they believed they were unqualified to provide the care needed.

Overreliance on caregivers. Finally, caregivers discussed challenges with the degree of responsibility expected of them by the healthcare system. Caregivers described being denied homecare because they were assumed to be able to fulfill this role instead. This was a challenge for caregivers as many were often older and described themselves as physically incapable of providing adequate care for their loved ones. These caregivers felt they required additional support to care for their loved ones as the responsibility was too great for them to

handle, resulting in feelings of helplessness and abandonment. Conversely, several caregivers were also employed, which challenged their role as caregiver because of the need to balance work and their loved ones:

“I quit my job because I knew with my mom I had to do this, I couldn’t work and try to juggle everything.”

Perceptions of and Experiences with the Healthcare System

An additional main theme was challenges and frustrations associated with the healthcare system. The aspects of care discussed will explore the communication challenges with physicians and surgeons and the financial burden associated with surgery. This theme includes the following subthemes: ‘*communication*’ and ‘*financial burden*’.

Communication. In the subtheme of communication, participants described the issues surrounding interactions with physicians, surgeons, and homecare workers. Many participants explained that they felt the complexity of their care needs limited the role of their family physician. Participants also noted that their family physicians were overwhelmed with their care, suggesting that they were inexperienced with cardiac surgical patients. Participants did not appear to be troubled by this disconnect, rather, they conveyed a feeling of frustration and hopelessness with their situation. Participants also discussed their frustrations about the degree of communication with their cardiac surgeons. These participants described having to wait several months to regain contact with their surgeons, or a complete loss of contact all together, which was distressing for many as contact with the surgeon was seeing as a necessary part of recovery.

Financial Burden. Additionally, participants described the financial burden associated with their illness and treatment. Participants expressed that this financial burden stemmed from a multitude of sources, most notably emergency medical services, medications, and transportation. The cost associated with calling an ambulance was a large concern for participants, especially those relying on pension income, and was large enough to act as a deterrent from some seeking emergency services.

“I think the biggest problem is, because of the cost people who are having a major problem like heart attack or stroke, or whatever don’t want to phone because they know there is going to be dollars, and this puts a big blinder in front of you and you don’t want to be doing that.”

Medications were also a source of financial concern for many participants as some were required to pay significant amounts of money to obtain their necessary medications. Similarly, transportation and parking fees were financially difficult to manage as some participants were often required to attend several different appointments after discharge. For those who were unable to drive, the use of taxis was often necessary to attend these appointments. Transportation from one family’s rural community was enough of a deterrent for one participant to stop going to his cardiac rehabilitation program.

Surgeon Survey

Data generated from surgeon surveys are shown in *Figs. 1 & 2*, with an overall response rate of 88%. When asked about patient’s experiences with discharge, all questions were completed with most respondents answering in agreement (*Fig. 1*). Notably, surgeons believed that

patients are given clear information regarding nutrition and what to expect following discharge, while also agreeing that patients are discharged with adequate community support.

Questions targeting the time of the initial postoperative follow-up appointment showed that surgeons held, generally, a highly optimistic perception of patient outcomes (*Fig. 1*). The surgical team perceived that patients were satisfied with their mental and physical health, their decision to undergo surgery, and communication about recovery expectations. Most surgeons felt that patients are knowledgeable about when to seek emergency care. During the one-year post discharge timeline, however, a greater variation in surgeon perceptions of patients were observed. Here, most surgeons believed that their patients were not being seen for an annual post-discharge follow-up. Additionally, questions probing surgeon's perceptions on patient satisfaction with mental and physical health, recovery expectations, and decision to initially undergo surgery, showed that while the majority believed patients are satisfied with these aspects, some surgeons selected *I don't know*.

Finally, when asked to rank what they believed patients and caregivers valued most during discharge (*figure 2*) surgeons believed that information on what to do in case of an emergency was most valued for both groups, whereas information about diet and communication with surgeon post discharge was of least importance, respectively.

4. Discussion

This, prospective, mixed methods cohort study captured the perspectives of patients and caregivers with prolonged and non-prolonged stays in the ICU following cardiac surgery. Following a Lean value stream analysis process, focus groups and caregiver surveys were generated to gain insights in the identified gaps of knowledge of patient-caregiver centre value and barriers in successful transition from the hospital to the community. Four themes emerged from the focus groups, highlighting the challenges associated with information exchange, accessing health care, and the burden of discharge from for both the patient and caregiver perspective. This study's strengths include the comparative use of cardiac surgeon surveys, as well as the inclusion of caregiver's perspectives. These findings contribute to a broader understanding of the cardiac surgical patient experience after discharge as it addresses perspectives from the surgeons, patients, and caregivers to provide a complete understand of the issues surrounding discharge.

In consideration of information exchange during discharge from hospital, participants emphasized a lack of information regarding discharge procedure, including information on emergency protocols, diet, exercise, and recovery expectations. These discussions were similar to previous studies that showed when conversations are verified to have occurred, only 60% of respondents could not recall receiving information about at-home emergency protocol.²⁶ Similarly, a study by Calkins and colleagues reported that despite the physicians perception that 95% of patients understood when to return to regular at-home activity, only 58% of patients reported that they understood,²⁷ thus indicating not a lack of information sharing, but rather, an inadequacy in information delivery. Similarly, participant's knowledge may have been impacted by the amount of information received at discharged, as many participants discussed feeling overwhelmed by the volume of information they received. Participants who described feeling overwhelmed may have been unable to adequately comprehend discharge instructions as the volume of information at discharge may have been too large to sufficiently consume at once.

Memory loss and delirium further complicated information exchange and uncovered a potential inadequacy in the timing of information delivery. This is consistent with previous investigation of poor recall if information is shared at a time of stress and anxiety.²⁸ These findings have important implications for cardiac surgery patients as information received at discharge in the postoperative period may be inherently stressful for some patients, and thus hinder patient's ability to retain and comprehend information. This may result in patients feeling as though they lack necessary information, while instead, the lack of knowledge is a product of their impaired recall. Furthermore, these findings may also be attributable to an inadequacy in the methods used for information exchange. Prior research have shown that most medical advice is shared verbally and has proven to be a relatively ineffective method of information exchange, whereas written information results in better retention and recall, but has inherent challenges for low educated and non-native speaking patients.^{29,30} Therefore, further research is required to identify if the timing and method of information delivery impacts information exchange at discharge for the cardiac surgical patient.

Impaired cognition and complicated information delivery may also influence experiences discussed in the *experience of discharge* theme. Patients who are unable to retain or recall appropriate information may miss pertinent details about their discharge, resulting in patient misunderstanding. Similarly, patients who feel overwhelmed by discharge information may not be able to adequately comprehend the rationale, further leading to a lack of understanding. Consequently, patients who lack the appropriate understanding about discharge, may believe they needed to stay in hospital longer – an idea which was stressed by participants across all focus groups. Here, participants discussed their desire to be discharged from hospital, while also discussing conflicting aspects that lead them to want to remain in hospital longer. The distress associated with patients feeling the need to stay in hospital may have been impacted by their lack of understanding about discharge. If patients could sufficiently comprehend the discharge process, then perhaps they would feel more prepared for transition back into the community while reducing their perceived need to stay in hospital. This also highlights a potential need for the surgical team to determine individual patient values regarding hospital discharge to allow for a discussion to help relieve the apprehensions patients experience.

Exploration of participant's experiences with accessing the healthcare system outlined further challenges. Interesting discussion emerged in respect to the care of family physicians, where participants stated they felt their primary care physicians were overwhelmed with their care, while others discussed losing contact with their primary care physician all together. Previous research shows that postsurgical follow-up with primary care physicians following high risk surgical procedure decreases hospital readmission rates, however, patients are less likely to adhere to primary care follow-up if the visits seem unlikely to add value.³¹ Therefore, these findings suggest a need for improved primary care physician-patient relationships to ensure these patients stay within the system and receive the care they need while also highlighting a potential need for improved communication between the surgical team and primary care physicians. Similarly, participants discussed a desire for increased communication with their cardiac surgeon, while others discussed losing all contact with their cardiac surgeon after discharge. This has important implications for patient recovery and further highlights a potential need for protocols to be established to ensure that patients follow-up with their surgeon.

Further discussion regarding the healthcare system exposed the financial burden of ambulances, medication, and transportation. As cardiac surgical patients are members of an increasingly aging population with fixed incomes, the cost of accessing health care has significant implications. If families are unable to access emergency medical services and

rehabilitation programs out of fear of financial loss, these patients will not have access necessary health resources in the community. This may have further negative implications on patient recovery and outcomes.

In addition to the challenges associated with cardiac surgery patients, important and somewhat unanticipated hardships were also uncovered with respect to caregivers. An area of distress for these caregivers was providing care for loved ones at night, where caregivers often lost sleep because they felt the need to constantly check if their loved ones were alright. This was also observed in another study where men in particular were described as constantly vigilant when checking the well-being of their patient at night, resulting in the loss of sleep.^{32,33} Caregivers also discussed feeling isolated when caring for their loved ones and mentioned they felt unprepared and unqualified to provide care. Additionally, caregivers felt that the healthcare system relied too heavily on families for providing care and instead needed to focus more on the needs of the patient. These findings are congruent with other research which observed that caregivers received little guidance about their role and what to expect after discharge, had feelings of stress, vulnerability, and isolation, and unpreparedness to meet the role.³³⁻³⁵ Caregivers are an important component of the cardiac surgery patient as many patients are dependent on their care. Congruent with the findings of similar research, caregivers of critically ill patients may experience parallel traumatic events and report high levels of depressive symptoms persisting up to one year post-surgery^{36,37}, signifying that if we ignore the needs families, we may be jeopardizing their mental and physical health as well. Thus, it is imperative for care providers to not only focus on the needs of the patient, but to also uncover and address the needs of their caregivers as they too are responsible for patient care.

These focus groups allowed for the identification of patient-centered needs and values surrounding discharge from hospital. Now, data generated from surgeon surveys act as important insight into patient discharge from the perspective of healthcare providers it is importance for congruence between the surgical team and the patient experience to provide appropriate care for patients following discharge. Therefore, contrasting ideas between these groups will highlight potential areas for improvement regarding information exchange and patient interaction with physicians following patient discharge.

Several important observations can be made when comparing patient-centered themes with surgeon perspectives. It is noteworthy that the surgical team, generally, appeared to be optimistic about all aspects of the patient discharge as all questions pertaining to patient's value and experiences are viewed in agreement. This would suggest that, regarding the aspects of discharge addressed in the surveys, the surgical team, typically, views the hospital discharge process as a smooth and positive process. Contrary to these perceptions, focus group participants painted a much more problematic picture highlighting many issues about the discharge process.

Additionally, the surgical team ranked nutrition as the lowest patient value at discharge, while also being of the belief that the patients receiving adequate information on nutrition and diet adjustments for post discharge. Focus group participants emphasized being given inconsistent and incomplete information regarding diet and nutrition which caused a great deal of distress. Thus, an incongruence exists regarding patient's value of nutritional information and diet. Similarly, surgeons ranked emergency protocol information as the highest priority for patients and caregivers, which was also highly emphasized by focus group participants, showing an agreement among both groups. Interestingly however, focus group participants stated uncertainty and worry about potential at-home emergencies due to a lack of appropriate

information supplied at discharge, while survey data shows the surgical team generally perceived that patients understood how contact emergency services while also being in a majority agreement for patients received clear expectations about after discharge. Therefore, while surgeons show a similar appreciation for emergency protocol, they appear to overestimate the quality of information received by patients at discharge. The incongruence of perception that patients are receiving clear and complete information about emergencies risks further perpetuating families fear and uncertainty regarding potential emergency situations, and it is therefore paramount that the surgical team address these issues with their patients to ensure a shared understanding about patient knowledge. Also, surgeons ranked communication with the surgical team low in terms of patient value, where as previously discussed, patients and the caregivers identified that patient-surgeon communication was described to be currently lacking and was necessary for patient recovery.

While these data highly suggest a knowledge gap in the communication of patient values, it is critical to note that these findings do not serve to question the quality of care provided by cardiac surgeons but rather highlight new areas from improvement (i.e. identification the “unknown unknowns”) with respect to communication between the patient and the surgical team. At present only the patient’s surgeons as a preliminary trial for gathering perceptions of healthcare providers has been gathered. It is important, however, that all members of the patient care team become cognisant of the issues addressed in this study as cardiac surgery patient care is an interdisciplinary process and planned for a future analysis.

Strengths and Limitations

This study has several limitations. This study was conducted with a small patient population specific to one Canadian center, with unique geographic and socioeconomic context, which may affect the generalization of the findings to other centers within and outside of Manitoba, Canada. Through our focus groups, however, the investigative team believe that we have achieved “saturation” of the patient themes as identified in this analysis. Additionally, this study did not specifically evaluate this center’s discharge protocol and therefore could not verify the information participants received upon discharge. Specific participant demographics (i.e. procedure type, age etc.) were also not selected for inclusion and as such may provide a source of heterogeneity of elicited responses.

Conclusion

In this study, we sought to better understand the “known unknowns” and learn about the “unknown unknowns” in the transition process of the patient-caregiver unit from the hospital to the community. Specifically, with the use of a Lean process we identified possible barriers for successful discharge and highlight the patient-centered values for the cardiac surgery patient. We conclude that patients and caregivers are exposed to inadequacies surrounding information exchange, challenges regarding communication with healthcare providers and a significant financial burden that exists when accessing healthcare. Furthermore, caregivers experience significant fear and isolation and need additional resources for support in the community. Lastly there appears to be a discordance in perception of “successful” discharge between the surgical team and the patient-caregiver unit thus highlighting opportunities for knowledge translation and modification of the patient care clinical transition pathways. Future study will seek to implement improvements in the themes identified to determine efficacy in reducing rehospitalization and improved HRQoL in vulnerable older adult cardiac surgery patients.

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Figures and Tables:

Table 1. Summary of focus group themes including participant quotes as supportive evidence.

Theme	Subtheme	Participant Comments
Information exchange	Information content	<p>“There is so much information in the last day that you are in hospital, it’s so overwhelming.”</p> <p>“The day we were finally getting out, or we were getting out, I was getting a lineup at the door of physiotherapists, physiologists, pharmacy, homecare, social services, on and on and on, and my head wasn’t that great coming out of there. It was too much, it was way too much at the end.”</p>
	Ability to retain information	<p>“I have no memory of my four days in ICU.”</p>
	Planning for after discharge	<p>“...what do I do? Do I go back to the hospital? Do I go to emergency?”</p> <p>“I didn’t know where to go if I had questions, or who to call.”</p>
	Information Type	<p>“We used to eat vegetables all the time, but when I eat too much my INR goes out to lunch. So, I’m eating carbs, which isn’t good either.”</p> <p>“I’m scared stiff to exercise. I went to [the] Wellness [Centre], and I was on the [nitroglycerine] patch and it seemed to be helping, but if I do a little too much I feel it and I’m scared.”</p> <p>“I guess I wasn’t prepared for the length of time it took to get better, we aren’t talking months, were talking years here.”</p> <p>“Ever since I’ve had my surgery I’m so forgetful, is that natural?”</p>
Experience of Discharge	A desire to go but need to stay	<p>“I was eager to get out of that hospital and go home because there’s no place like home.”</p> <p>“I wasn’t ready to go”</p> <p>“I just thought that I was cut loose a little too soon”</p> <p>“They just kind of rolled their eyes and brushed it all off.”</p> <p>“Well after seven weeks, you want out [of the hospital]. But still I couldn’t walk very far.”</p>
	Lack of understanding of process	<p>“I was getting ready for discharge and I was a mess. I wasn’t ready to go, and I don’t think they wanted me to go, but they let me go.”</p>

		<p>“...they weren’t sure when I was going to go, and there were a couple days where I didn’t really understand what was going on.”</p>
The Caregiver Experience	Fear of night time	<p>“You just worry you know? Homecare doesn’t do any night shifts so its just on me and my brother and we do what we can, but we aren’t doctors or nurses so its scary.”</p> <p>“Just having someone so you can get a night sleep, and someone to reassure you things are going along fine. Even if it is a call line, someone that maybe knows your situation, and that can say okay well this is how you will go through this, this is how it will happen, so you don’t feel like you are alone.”</p>
	Feelings of isolation	<p>“I would feel more confident knowing there is someone else in the house at night in case you have to call an ambulance, or if they fall down you have an extra hand, or whatever the need is at that time. There may not even be any need.”</p> <p>“It seems crazy that they have this big surgery and they are all hooked up, and then they unplug things and its like okay they are coming home and its your turn.”</p>
	Overreliance on caregivers	<p>“The healthcare system is focusing too much on family and not the patient. He [The patient] had all these appointments, and it puts lots of responsibility on the family.”</p>
Perceptions of and Experiences with the Healthcare System	Communication	<p>“I mean, really, her role is pretty limited. There isn’t much she can do with my heart. I haven’t seen her for a while.”</p> <p>“...she’s a young doc, this is probably her first shot, I think she was a bit overwhelmed with things that happened to me.”</p> <p>“Well he felt he gave his life [to the cardiac surgeon], basically his heart to someone, and he’s never seen him [the cardiac surgeon] again.”</p> <p>“I would only say, sometimes the communication between the doctors could be improved on, I know they are busy, I know they deal with multiple patients, but I would just like to talk to them more.”</p>
	Financial Burden	<p>“...they are getting just Canada pension and with rent costs and all the rest of it, and medication they can’t afford it.”</p> <p>“...it was in the winter time and we just weren’t up to driving in from Lac du Bonnet [rural Manitoba].”</p>

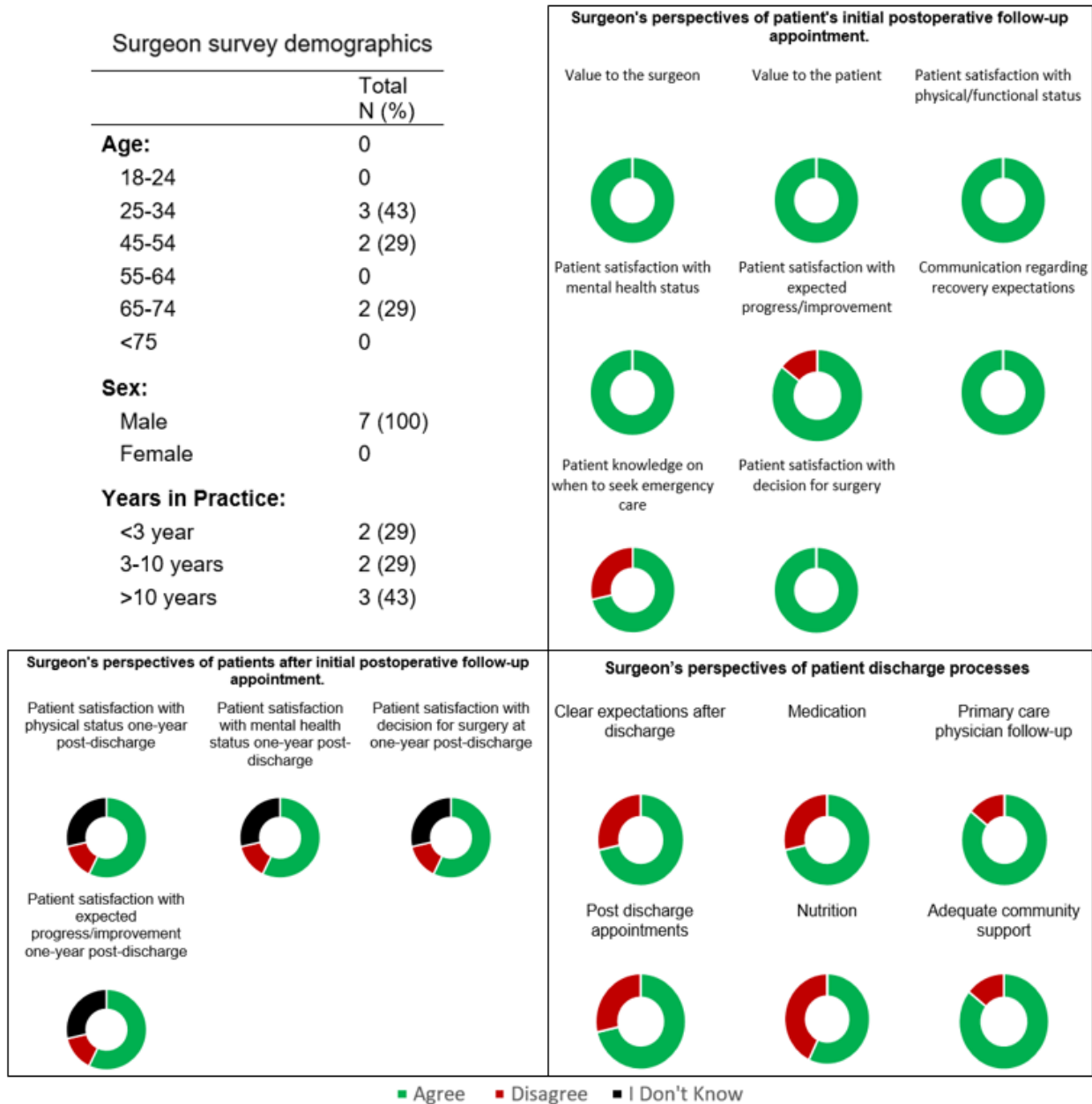


Figure 1. Summary of surgeon survey data addressing aspects of patient discharge from hospital.

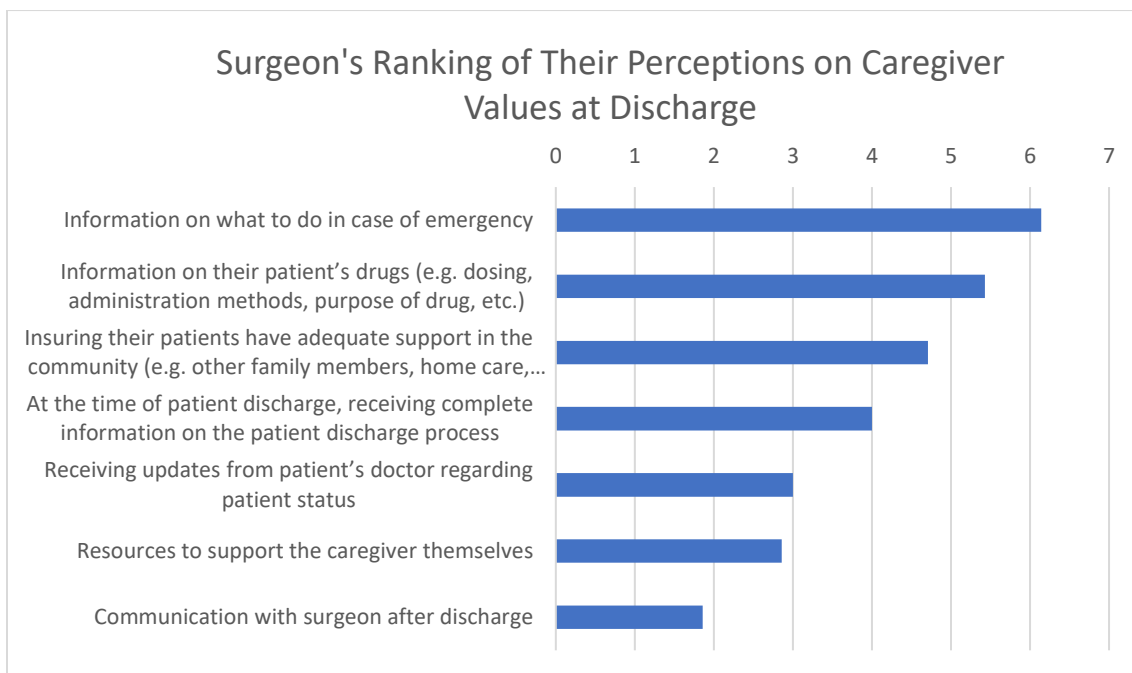
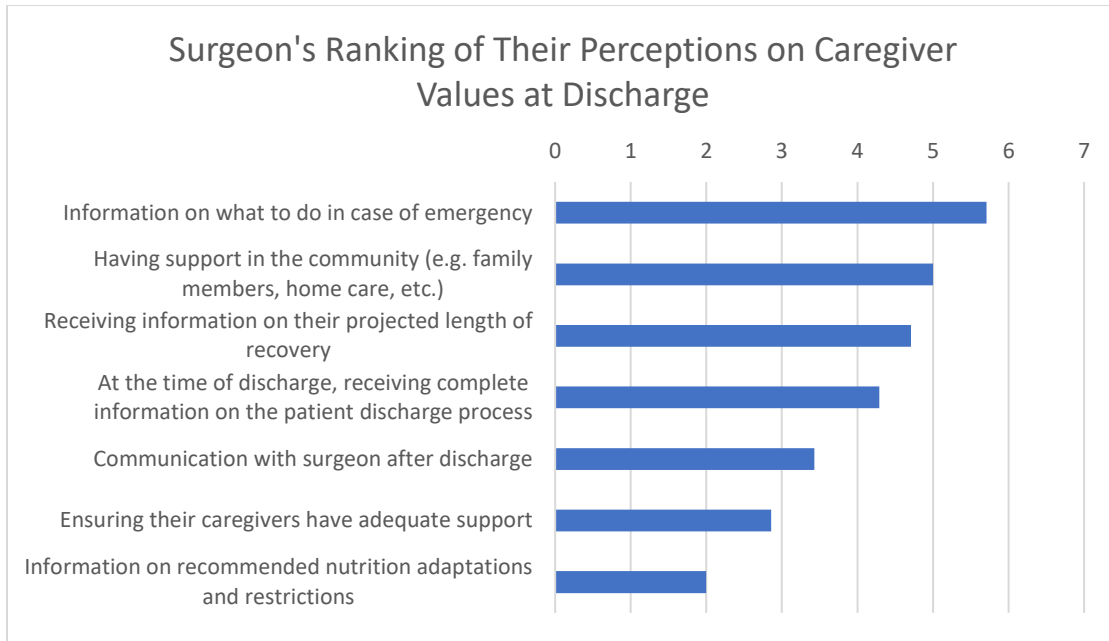


Figure 2. Perceived patient and caregiver values at the time of discharge. Surgeon's were asked to rank values from 1-7, where a value of one would suggest the most value. Ranks were attributed a numerical value and averages were calculated. Patient and caregiver values with higher scores depict higher perceived value.