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A Mixed-Methods Exploration to Develop and Test the Alberta Cardiac Surgery Patient Experiences Survey

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A Mixed-Methods Exploration to Develop and Test the
Alberta Cardiac Surgery Patient Experiences Survey

by

Kyle Alexander Robert Kemp

A THESIS

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ABSTRACT

With an increased focus on patient-centred care (PCC), many organizations conduct routine surveys as part of their core business. Many surveys that are used in the hospital setting have been designed to capture the experiences of a wide variety of patients. Thus, they do not ask condition-specific questions which may be important to patients. This mixed-methods thesis focused on examining and improving upon the measurement of patient experience among those who have undergone cardiac surgery.

The first part of this thesis used existing survey data linked with administrative records to examine the comprehensive experience of Albertans who underwent cardiac surgery over a four-year period. Part two was a qualitative project, where interviews were conducted to better understand the aspects of care deemed important to patients after cardiac surgery. In the final portion, learnings from our prior quantitative and qualitative work were integrated to develop and test a new condition-specific survey; the Alberta Cardiac Surgery Patient Experiences Survey (ACSPES).

In project one, patients reported very positive experiences. However, they did reveal potential areas for improvement. These included communication about potential side effects of new medications, night noisiness of the hospital environment, and cleanliness of their room/bathroom. In project two, participants highlighted five key themes important in their care - overall experience, communication, the physical hospital environment, care needs and ongoing management, and person-centred care. These findings aligned with those from project one, but also served to generate additional items which could be asked in a future survey. Project three demonstrated promising results pertaining to the content validity, test-retest reliability, and acceptability of the newly created ACSPES.

This thesis work has increased our understanding and learnings about the experiences of those who have undergone cardiac surgery across Alberta. It has also resulted in the creation of the ACSPEs; a tool which may be used to better capture the unique experiences of cardiac surgery patients. Data from the ACSPEs may be used to measure PCC in this cohort and may be integrated with administrative and other patient-reported data for future learnings. Additional psychometric testing of the ACSPEs is required.

PREFACE

As part of the program of study outlined in this thesis, the following three manuscripts have been published, or are in preparation for submission to peer reviewed journals (as described below). For each paper, Kyle Kemp led the study design, analyses, interpretation, manuscript writing, and journal submission. The thesis committee (Drs. Maria Santana, Hude Quan, Elizabeth Oddone Paolucci, and Merrill Knudtson) and other co-authors guided the work and contributed important intellectual content and feedback to each manuscript.

Chapter 2 has been published in the *Canadian Journal of Cardiology* as: Kemp KA, Quan H, Knudtson ML, Oddone Paolucci E, Santana MJ. Patient-reported experiences with coronary artery bypass grafting and valve replacement. *Canadian Journal of Cardiology*. 2019;35(10):1344-52.

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Chapter 4 is in preparation for submission to the *Journal of Patient Experience* as of December 2020: Kemp KA, Quan H, Knudtson ML, Oddone Paolucci E, Santana MJ. An assessment of the content validity, reliability and acceptability of the Alberta Cardiac Surgery Patient Experiences Survey.

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I am appreciative for the funding that I received to complete this work, through a Frederick Banting and Charles Best Canada Graduate Scholarship Doctoral Award from the Canadian Institutes for Health Research (CIHR). I am also fortunate to have received travel awards and prizes in recognition of my work from various groups including the CIHR Institute for Health Services and Policy Research (IHSPR), the Canadian Association for Health Services and Policy Research (CAHSPR), the International Society for Quality of Life (ISOQOL), the International Population Data Linkage Network (IPDLN), Statistics Canada, the Alberta Strategy for Patient-Oriented Research (SPOR), the Libin Cardiovascular Institute of Alberta, and the Department of Community Health Sciences at the University of Calgary.

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LIST OF ABBREVIATIONS

ABSPORu	Alberta Strategy for Patient Oriented Research Support Unit
ACSPES	Alberta Cardiac Surgery Patient Experiences Survey
AHRQ	Agency for Healthcare Research and Quality
AHS	Alberta Health Services
aOR	Adjusted Odds Ratio
APPROACH	Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease
CABG	Coronary Artery Bypass Graft
CAHSPR	Canadian Association for Health Services and Policy Research
CBC	Canadian Broadcasting Corporation
CCI	Canadian Classification of Interventions
CHD	Coronary Heart Disease
CHREB	University of Calgary Conjoint Health Research Ethics Board
CI	Confidence Interval
CIHI	Canadian Institute for Health Information
CIHR	Canadian Institutes for Health Research
CJC	Canadian Journal of Cardiology
CMS	Centers for Medicare and Medicaid Services
CPES-IC	Canadian Patient Experiences Survey – Inpatient Care
COSMIN	Consensus-based Standards for the selection of health Measurement INstruments
COVID-19	Coronavirus, SARS-CoV-2
DAD	Discharge Abstract Database
FOCUS	Fostering Open Conversations to Unleash Solutions
HCAHPS	Hospital Consumer Assessment of Healthcare Providers and Systems

HQCA	Health Quality Council of Alberta
ICC	Intraclass Correlation Coefficient
ICU	Intensive Care Unit
IHI	Institute for Healthcare Improvement
IOM	Institute of Medicine
IPDLN	International Population Data Linkage Network
I-PEQ (CHD)	Coronary Heart Disease In-Patient Experience Questionnaire
ISOQOL	International Society for Quality of Life
NSQIP	National Surgical Quality Improvement Program
PCC	Patient/Person-Centred Care
PCORI	Patient-Centered Outcomes Research Institute
PFAC	Patient and Family Advisory Committee
PHN	Personal Health Number
PPEQ	Picker Patient Experiences Questionnaire
PREM	Patient-Reported Experience Measure
PROM	Patient-Reported Outcome Measure
PSI	Patient Safety Indicator
QTAC-PREM	Quality of Trauma Care Patient-Reported Experience Measure
SAQ	Seattle Angina Questionnaire
SAS	Statistical Analysis System
SCN	Strategic Clinical Network
SF-12	12-Item Short-Form Health Survey
SPOR	Strategy for Patient-Oriented Research
SPSS	Statistical Product and Service Solutions
WOMAC	Western Ontario and McMaster Universities Arthritis Index

**CHAPTER ONE: PATIENT EXPERIENCE AND CONTRIBUTIONS TO PATIENT-
CENTERED CARE AND LEARNING HEALTH SYSTEMS**

1.1 Overview

1.1.1 Overview of the Topic

In 1998, Berwick and colleagues posited that the United States healthcare system should focus upon three fundamental aims in the pursuit of improvement. These were to: 1) improve the care experience, 2) improve the health of populations, and 3) reduce per capita healthcare costs.¹ This framework is known as the Triple Aim. Since its introduction, The Triple Aim has been adopted as a “guiding light” by many healthcare organizations, and in recent years, a fourth aim has emerged; to improve the staff experience. As such, many organizations now have evolved to refer to the updated framework as the Quadruple Aim.

Recognizing the importance of improving the patient experience, as outlined in the Triple Aim,¹ many healthcare organizations and government agencies conduct routine experience surveys as part of their core business. Surveys are widely used to capture what matters to patients, and to obtain feedback about the healthcare services that they receive. Surveying can take place across the multiple areas of the healthcare system or can be focused within a specific area. Insights from patient experience surveys can be used within the context of learning health systems (Figure 1.1).² A successful person-centred healthcare system is evidence-based, people-informed, and is responsive to issues that matter to the users of the healthcare system. These users are the patients, and surveys can be used to address the issues that matter to them.

In the inpatient setting, validated surveys such as the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS),^{3,4} the Canadian Patient Experiences Survey – Inpatient Care (CPES-IC),⁵ and the Picker Patient Experiences Questionnaire (PPEQ)⁶ have been used to highlight leading practices, as well as areas which may benefit from improvements. One of the limitations, however, is that most of the work conducted to date has tended to examine

experiences across many diverse clinical areas, at the region or hospital level. As such, opportunities to examine the experiences of specific clinical populations may be overlooked, or when examined, are subject to measurement using a generic list of questions designed for use across multiple populations. This can lead to questions about clinically relevant issues/processes of care not being asked, resulting in missed opportunities for learning and improvement.

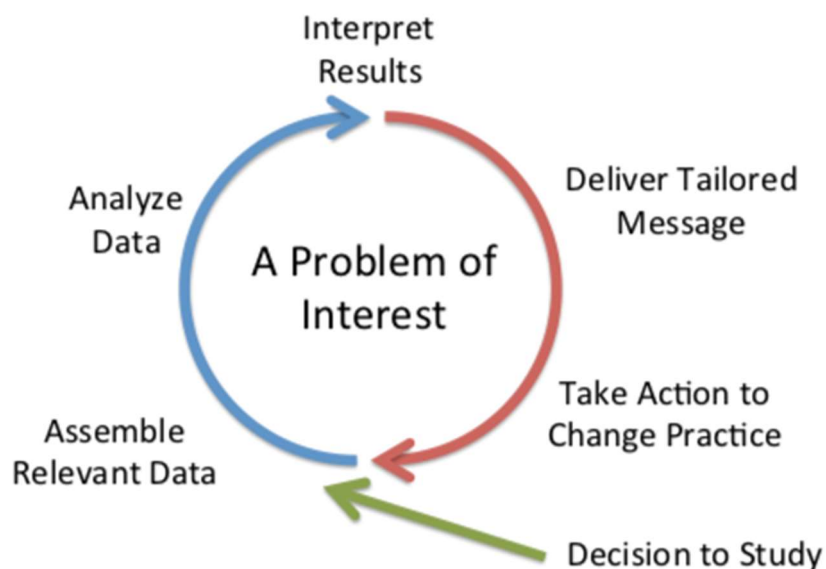


Figure 1.1 Learning health systems²

The thesis research presented here addressed this measurement issue in a defined clinical population – those who experienced cardiac surgery. Although many of the principles of this research may apply to other clinical areas, cardiac surgery was selected as the focus because procedures such as coronary artery bypass grafting (CABG), valve replacement, and angioplasty have a high impact to patients (e.g., mortality, morbidity, possible adverse events, need for lifestyle modification), as well as the healthcare system (e.g., high-volume, high-cost, potential for readmission/subsequent health services use). In short, improving the measurement and

assessment of experiences of patients in cardiac surgery may provide tangible benefits in the context of the Triple Aim.

1.1.2 Research Objectives

This mixed-methods program of research aimed to undertake a comprehensive examination of the experiences of patients who have undergone cardiac surgery across Alberta, Canada. Using existing tools and collaboration with patients, the final product of this work was the co-creation of an augmented, validated survey for use among this clinical group. The specific objectives of the research were to:

1. Examine the comprehensive experience of those undergoing cardiac surgery, using an existing generic survey and linkage with administrative data (Chapter 2);
2. Determine, through a qualitative investigation, the specific elements/processes of care that are important to those who have undergone cardiac surgery (Chapter 3);
3. Create a survey based on learnings from objectives 1 and 2, and to examine the content validity, reliability, and acceptability of the instrument in a cohort of cardiac surgery patients (Chapter 4).

In the remaining pages of this chapter, several foundational concepts will be introduced. The topics of patient-centred care (PCC), patient experience surveying, and learning health systems will be highlighted. An in-depth look at patient experience surveys in the inpatient setting and the main limitations of these will be provided. The chapter will then conclude with an overview of the three applied projects conducted as part of this manuscript-based thesis.

1.2 Background

1.2.1 Patient-Centred Care

The concept of “patient-centered care” (PCC) was introduced in the 1960s, as a recognition of the understanding of the patient as a unique human being.⁷ Since that time, PCC has evolved to take on many diverse meanings. These include a recognition of the need to treat patients based on their own terms, as well for providers to give patients the opportunity to ask questions about their care.⁸ In 1998, a tipping point in the evolution of PCC took place, with the appointment of the Committee on the Quality of Health Care in America. This committee was established with the mandate of identifying strategies to improve health care in the United States. It was comprised of a variety of stakeholders, including clinicians, policy makers, government, third-party payers, patients, and the public. One result of their efforts was the publication of a foundational report by Institute of Medicine (IOM), entitled “Crossing the Quality Chasm: A New Health System for the 21st Century”.⁹ In this work, six key aims were presented for improving care. These were that care should be safe, effective, timely, efficient, equitable, and *patient-centered*. Another notable outcome of this report was an operational definition of PCC: “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.”⁹ Although this definition places the patient at the forefront, it is widely acknowledged that the term “PCC” is an inclusive one, which recognizes the importance of family members and caregivers – individuals who may not be living with illness, but may be equally impacted, or who may provide supports to the patient.⁷ Many organizations have adopted the term “person-centred care” as it places the person first, by not reducing a person to the sum of their symptoms or given condition.⁷ This also recognizes that individuals may not always identify as patients.

PCC encourages active collaboration and shared decision-making between patients and providers to design and implement a comprehensive care plan.¹⁰ This is in contrast with the historical relationship between patients and providers, which has tended to be more of a paternalistic one, where providers may make treatment decisions in isolation of the patient. As such, PCC represents a paradigm shift in medicine. In addition, recognizing the patient's role at the centre of their care, there are many central elements to PCC. These are shown in Figure 1.2. Within the context of the Donabedian Model,¹¹ the recognition of the need to respect and value patient and family viewpoints extends beyond the process-level of care. At the structural level, patients and family members now play active roles in the planning and delivery of healthcare services, as well as improvement initiatives. Examples of this include Alberta Health Services (AHS),¹² the Ontario Hospital Association¹³ and Accreditation Canada.¹⁴ There is also heightened representation of PCC in health research. Since 2012, the Patient-Centered Outcomes Research Institute (PCORI) has funded more than \$2 Billion in patient-centred research and related projects.¹⁵ In Canada, the Strategy for Patient-Oriented Research (SPOR) was created in 2012 and is a coalition of federal, provincial, and territorial partners, under the responsibility of the Canadian Institutes for Health Research (CIHR).¹⁶ In promoting PCC and patient-oriented research, the broad mandate of SPOR is to ensure that the right patient receives the right intervention, at the right time.¹⁶



Figure 1.2 Conceptual representation of patient-centred care¹⁰

With respect to specific measures of PCC, these may be classified according to a framework developed by Santana et al (Figure 1.3).⁷ Although there are many frameworks pertaining to the measurement of PCC, this one is straightforward, as it contextualizes a list of proposed measures according to the Donabedian Model (structure, process, outcomes). In doing so, the framework by Santana et al. highlights that PCC, as well as its implementation, is a stepwise approach. The structure of a healthcare organization is key to establishing PCC processes. In turn, these processes may lead to better outcomes.

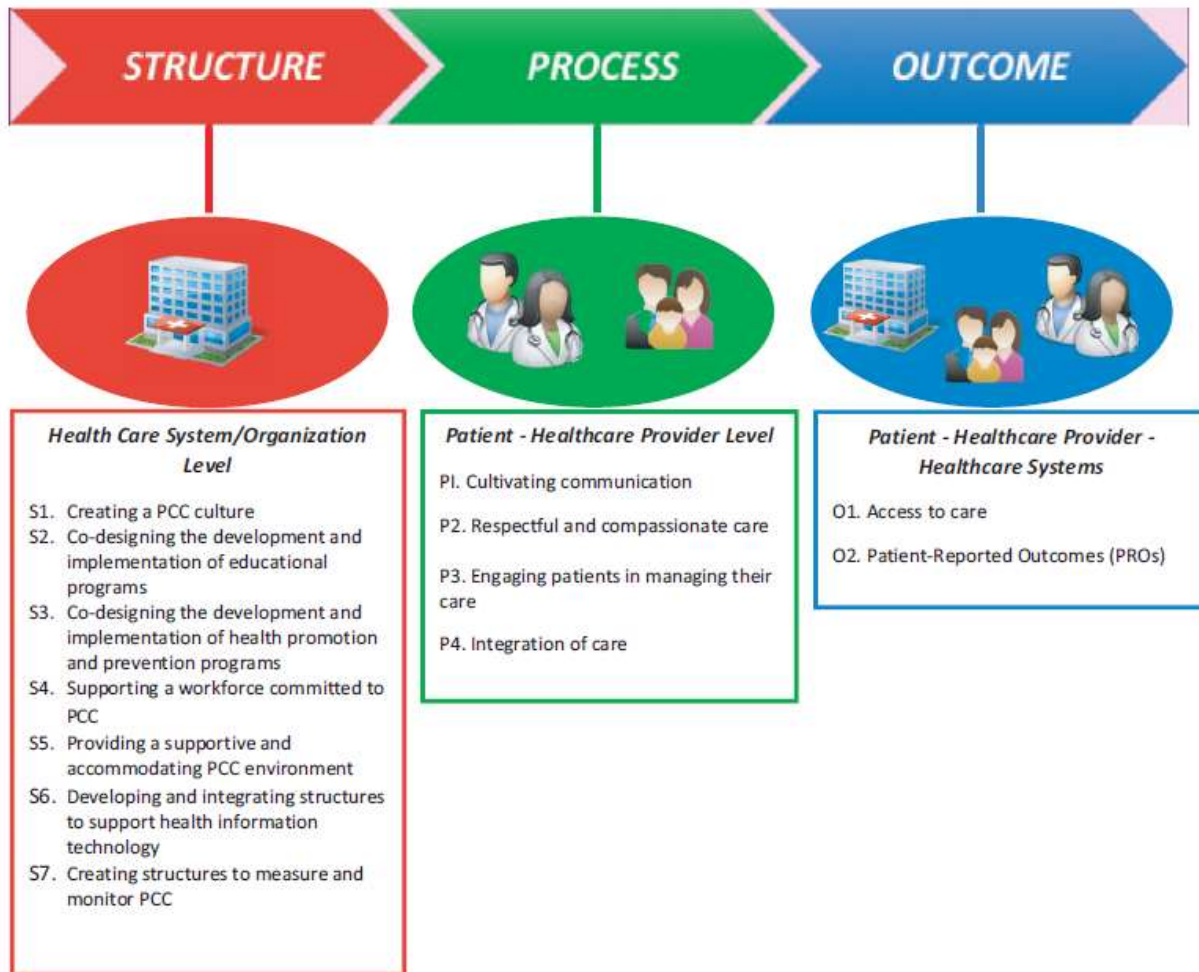


Figure 1.3 Framework for measuring patient-centred care⁷

At the structural level (health care system/organization level in Figure 1.3), there are many facilitators which can foster the successful measurement and practice of PCC. PCC must be a message that permeates an organization; one which must be reflected in its culture and executives. An example of creating this PCC culture entails embedding PCC within the core values of the organization and establishing an operational definition of PCC.⁷ As an example of this, AHS provides its mission statement; “to provide a patient-focused, quality health system that is accessible and sustainable for all Albertans” on their homepage.¹⁷ AHS has also adopted

the IOM definition of PCC⁹ and has ensured that this messaging is consistent across the organization. Measures of PCC at the process and structural levels will be discussed later.

1.2.2 Patient Experience – Origins, Importance, and Context

The Beryl Institute; a global community of practice committed to elevating the human experience in healthcare,¹⁸ defines patient experience as “the sum of all interactions, shaped by an organization’s culture, that influence perceptions across the continuum of care”.¹⁹ The concept of asking patients about their care experiences in a formalized manner dates back to the early 20th century, and has been attributed to Ernest Codman, a surgeon and “godfather” of the National Surgical Quality Improvement Program (NSQIP).²⁰ Figure 1.4 depicts the multitude of ways to document the patient experience.^{21,22} Each of these, whether quantitative or qualitative, has its own strengths and limitations in terms of their ease of use, descriptiveness, and generalizability.

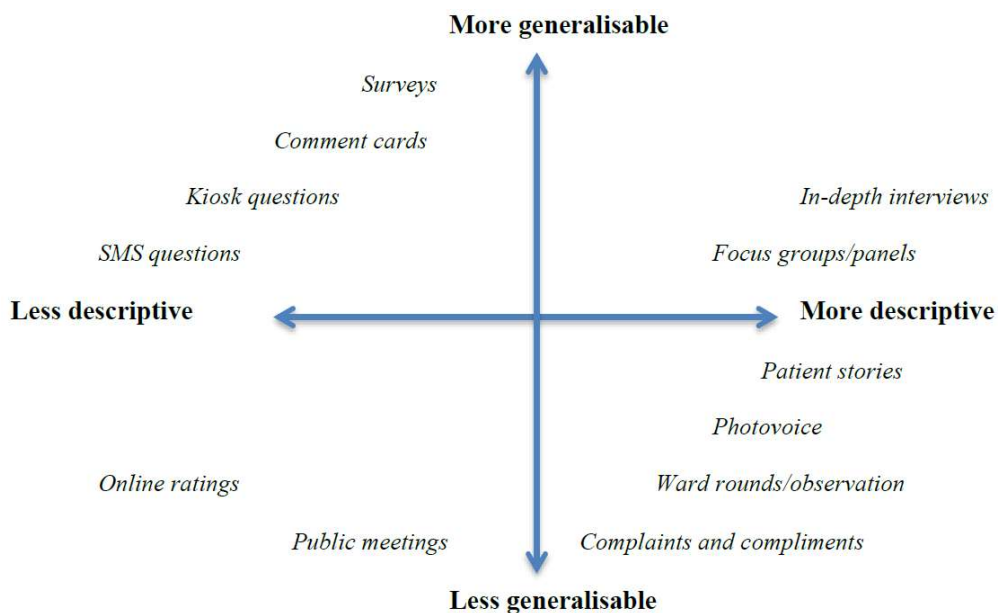


Figure 1.4 Methods used to measure patient experiences^{21,22}

The proliferation of patient experiences and associated measures coincides with the emergence of PCC. Since the time of Codman,²³ the idea of measuring patient experiences, predominantly using surveys, has experienced prolific growth. Due to their ability to capture feedback from large groups in a short amount of time, surveys are an attractive and widely used method.^{24,25} In addition to individual healthcare organizations/hospitals, many jurisdictions and public agencies have evolved to include surveying activities as part of their core business/mandate. A notable Canadian example is the Health Quality Council of Alberta (HQCA), which has conducted surveys to examine primary care, emergency departments, and continuing care for over a decade.²⁶ Another is the Ontario Ministry of Health and Long-Term Care, who implemented regular surveying and a parallel patient relations process as part of the Excellent Care for All Act of 2010.²⁷ Additionally, the British Columbia Office of Patient-Centred Measurement, in partnership with the Ministry of Health and local health authorities, has spearheaded survey development, data collection, and reporting of patient experiences in multiple care sectors for close to two decades.²⁸ These efforts to regularly capture the experience of health system users, have greatly contributed to learning health care systems across Canada.

1.2.3 Learning Health Systems

Learning health systems are ones in which “science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral by-product of the delivery experience”.²⁹ Successful learning health systems “learn” from a single incident or set of activities, from its own mistakes and sense-making, and from critical analyses of how systems give rise to actions.

To have a successful, patient-centred learning health system, it is essential to document the patient experience.³⁰ Providing this avenue for patient engagement allows organizations to use the feedback they receive to shine a light on leading practices, while determining processes of care that may need improvement, *in the eyes of patients*. In an investigation at four Veterans Affairs hospitals in the United States, Bokhour et al.³¹ sought to understand the key organizational factors for implementing PCC for care transformation. Through interviews with 108 senior leaders, middle managers, providers, and staff members, they highlighted actions in seven different domains, one which involved patient and family engagement.³¹ Historically, many healthcare service evaluations have failed to include the voice of patients and their family members. As such, there may have been missed opportunities to learn from patients and their loved ones. There may have been many reasons for this. First, despite the evolution of PCC as a measurable science, many may have felt that patient feedback is not a credible source of information, as patients lack the necessary expertise to properly evaluate the quality of their care.³² Second, in measuring PCC and patient experience as measures of quality of care, many may feel that they are confounded by factors not associated with processes of quality. For example, patients could rate their experience based upon their current health status, previous experiences, expectations of care, and their ability to acquire and pay for services. Third, some may believe that measures of PCC and patient experience are more reflective of patient wishes. For example, a clinician may opt to ignore evidence-based guidelines and order an unnecessary test or procedure. Although there may be legitimate instances where patient reports of their care may not be appropriate (e.g., cognitive impairment, patient unconscious due to injury or surgery, incapacitation due to drugs or alcohol), there is now greater recognition of the value of patient experience and its role in quality improvement activities.³⁰

1.2.4 Patient Experience Surveys in the Acute Hospital Setting

In North America, two validated surveys have emerged as the gold standard for measuring the patient experience in an acute, hospital setting. Beginning in 2002, the HCAHPS survey^{3,4} was jointly developed in the United States by the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Medicare and Medicaid Services (CMS). Following an initial research and testing phase, survey refinement work included a large three-state pilot, cognitive testing, cost-benefit analyses, and assessment of differences due to language and method of survey administration. In its current format, the HCAHPS is comprised of 29 questions for patients to evaluate the care received during their recent hospital stay. It assesses multiple aspects of care, including communication with nurses and doctors, communication about medicines, the physical hospital environment, discharge information, one's overall rating of the hospital, and one's willingness to recommend the hospital to family members or friends. Surveys are administered to a random sample of patients within 2 to 42 days of their discharge from hospital. The survey is available in seven languages (English, Spanish, Chinese, Russian, Vietnamese, Portuguese, and German) and can be administered in a variety of formats (mail, telephone, mail with telephone follow-up, and interactive voice recognition).

The HCAHPS survey and associated work has been defined by three broad goals, to: 1) produce data about patients' perspectives of care that allow objective and meaningful comparisons of hospitals on topics that are important to consumers, 2) create new incentives for hospitals to improve quality of care via public reporting, 3) enhance accountability in health care by increasing transparency of the quality of hospital care provided in return for the public investment.³³ In 2005, the National Quality Forum endorsed the HCAHPS survey, and the first public reporting of results followed in 2008. Since its initial implementation on a voluntary basis,

use of the HCAHPS has expanded to mandatory public reporting of results, under provisions of the Patient Protection and Affordable Care Act of 2010.³⁴ As of October 2019, over 8,000 HCAHPS surveys were completed each day, from over 4,400 American hospitals.³⁴ In addition to analyses performed by the CMS,³⁵ public results can be viewed on the Hospital Compare website.³⁶

Although not mandated outside of the United States, use of the HCAHPS survey has extended beyond its borders. In Alberta, Canada, the first HCAHPS pilot study was conducted in the former Calgary Health Region in 2004.³⁷ Following this, the survey was implemented on a continuous basis to evaluate patient experience in the region's hospitals. In 2010, five health regions (including the Calgary one) were amalgamated to form Alberta Health Services, the single health authority for the province of Alberta's 4.4 million residents.³⁸ Administration of the HCAHPS was expanded in 2011, to encompass 93 hospitals across the province. From 2011 to 2014, over 9,000 survey responses were captured each year.

Also, in 2011, recognizing the need for a standardized, pan-Canadian measure of patient experiences, a group of national and provincial stakeholders began collaborations with the Canadian Institute for Health Information (CIHI).⁵ Following initial engagement and consensus building, a preliminary version of the CPES-IC survey was developed, and pilot tested in 2013. As of today, the standard CPES-IC is comprised of 48 questions. This includes 22 questions from the HCAHPS survey, 19 questions which were developed to assess key areas relevant to the Canadian context (e.g., discharge from hospital, care transitions), and seven questions that collect demographic information (gender, year of birth, education level, cultural/racial background, self-reported physical health, self-reported mental health).³⁹ An open-ended question at the end of the survey asks respondents if there is anything else that they would like to

share about their hospital stay. Hospitals or organizations who use the CPES-IC may also add additional items deemed relevant to their patients and/or organization. The CPES-IC is administered in seven provinces (British Columbia, Alberta, Manitoba, Ontario, New Brunswick, Nova Scotia, and Prince Edward Island) on a voluntary basis.⁵ The survey can be administered by mail or telephone, in either English or French. In Alberta, the CPES-IC was adopted and implemented in April 2014, replacing the modified version of the HCAHPS which had been used until that date. Each year, AHS collects approximately 25,000 telephone surveys from patients discharged from 93 hospitals across the province. The question about overall rating of care is one of AHS' publicly-reported performance measures.⁴⁰ Since its inception, the CPES-IC has become recognized as the gold standard for measuring the inpatient hospital experiences of Canadians.

1.2.5 Limitations of Existing Surveys

Despite being widely adopted, validated measures, there are notable limitations of surveys such as the HCAHPS and CPES-IC. Although these were developed using direct patient input, the HCAHPS and CPES-IC were designed as generic, “one-size fits-all” tools for measuring the patient experience of many broad demographics and clinical conditions. As such, they do not take into account the potential unique care needs of specific clinical groups (e.g., cardiovascular disease, joint replacement, maternity). This represents a gap in the way that we document inpatient hospital experience and measure PCC in defined clinical groups. There are many parallels between the measurement of patient experience using patient-reported experience measures (PREMs), and quality of life using patient-reported outcome measures (PROMs). For example, a generic PROM such as the 12-Item Short Form Health Survey (SF-12)⁴¹ may contain questions relating to general health, but none relating to limitations due to symptoms specific to a

particular condition. Thus, generic PROMs may be supplemented by condition-specific measures such as the Seattle Angina Questionnaire (SAQ),⁴² or the Western Ontario and McMaster Universities Arthritis Index (WOMAC).⁴³

In similar fashion to the processes used to develop the HCAHPS, CPES-IC and the PROMs described above, there are examples of patient experience surveys being developed for certain clinical areas. Recognizing the uniqueness of the patient experiences of those who have sustained traumatic injuries, Bobrovitz et al.⁴⁴⁻⁴⁶ developed and validated the Quality of Trauma Care Patient-Reported Experience Measure (QTAC-PREM). Similarly, in conjunction with the PPEQ, Jenkinson et al.⁴⁷ reported upon the development and validation of the coronary heart disease in-patient experience questionnaire (I-PEQ (CHD)) in the United Kingdom.

1.3 Survey Development in the Context of PCC

1.3.1 Overview

As stated earlier, patient experience surveys are a popular method to measure and assess PCC. However, to be able to interpret the results and to act upon the findings from a survey, it is paramount that the instrument is valid and reliable. Therefore, one should follow a rigorous step-by-step process to develop an instrument, and to gather evidence to support its validity and reliability. In the case of the HCAHPS, this process took approximately a decade, involved extensive engagement with stakeholders, hundreds of focus groups with patients and providers, and multiple rounds of psychometric testing and refinements to arrive at the product currently in use. This section highlights key steps in the survey development process.

1.3.2 Step 1: Literature Review

A logical first step in the development of a patient experience survey is to conduct a thorough literature review. In doing so, one may determine if a similar measure already exists and/or if there are questions that have already been developed. The literature review should seek to include any validation studies using a comprehensive list of search terms. Multiple databases should be searched (e.g., PubMed, MEDLINE, Web of Science), and platforms such as Google Scholar may also reveal manuscripts published by key content/opinion experts. Grey literature and websites of key healthcare organizations/interest groups (e.g., Cleveland Clinic, The Beryl Institute, Kaiser Permanente) may uncover additional works such as whitepapers. Once all previous works have been gathered, each item should be read to determine relevance to the proposed survey to be developed. Multiple reviewers (i.e., at least two) should review all works to minimize bias, following which, the reviewers should gather to discuss and to gain consensus. Once the final list of relevant works has been agreed upon, a table may be created to compile the list of questions from the surveys which have been previously used.

At the conclusion of the literature review, one of three possible scenarios may occur. The first is that a previously validated instrument is ready for use. Prior to this, however, one must critically evaluate whether the instrument is appropriate for the intended use.⁴⁸ If the target population differs with respect of demographic, clinical, or other factors, then it would be prudent to perform additional tests of validity and reliability. This is extremely important in the areas of patient experience and PCC, as research has shown that responses to surveys may vary according to these factors.⁴⁹⁻⁵¹ One should also consider when the measure was originally developed. If a prolonged period has elapsed, it may not reflect advances in medical care which

took place since initial development. Simply said, the survey should reflect current treatment options, as well the context of the setting under study (e.g., Canadian healthcare system).

In scenario two, one or several questions (i.e., not a complete survey) may be revealed. Although not a complete survey, these items may provide a valuable starting point and guiding questions for interviews/focus groups with patients, to be completed as a next step of the survey development process. If the third scenario plays out, then no pre-existing surveys or pre-formed questions were revealed. In this case, one will rely upon patient feedback to generate items.

1.3.3 Step 2: Engage Patients

Following the literature search, the next step in the development process is to tap into the experiential knowledge of patients. From their feedback, a list of topics may be generated to form a preliminary (pilot) survey. To do so, one may elect to conduct individual (one-on-one) interviews – either in-person or over the telephone, or to conduct focus groups (group interviews) to be held in a convenient location. In deciding whether to conduct interviews or focus groups, there are a few key factors which should be considered. First, one must consider the nature of information that will be exchanged. If the topic will include items of a sensitive nature (e.g., illicit drug use, items relating to mental illness), then a one-on-one interview may provide additional means for privacy and confidentiality.⁵² An additional challenge with one-on-one interviews, however, may be a perceived power imbalance between the researcher and interviewee.⁵² Regardless of the method selected, one must ensure that participants feel that they are in safe place, and that they may freely share their experiences and opinions.

Second, one must consider the cost and resources needed for the selected method. One-on-one interviews can be very time-consuming, especially when considering the time needed to transcribe interviews. As such, one may opt for to conduct focus group interviews, where one

may extract qualitative data from many participants in a single session.⁵² Interviews and/or focus groups should continue until thematic saturation occurs. The themes and items which arise are subsequently derived from session transcripts to aid in the development of survey questions.

1.3.4 Step 3: Create a Pilot Survey

In this step, the results of a thematic analysis are used to create a version of the survey to be pilot tested. To do this, questions may be arranged according to the identified themes (e.g., communication with providers, medications, discharge information) from interviews/focus groups. Each question should be a Likert-type response (e.g., usually, always, sometimes, never; or: strongly agree, agree, disagree, strongly disagree). Each question should be clearly worded, and the use of double-barred questions (e.g., “how often was your hospital room clean and quiet?”), should be avoided. Any questions where respondents may provide an overall rating (e.g., overall care, care from doctors) may use a numeric scale, when 0 represents the worst possible rating, and 10 represents the best possible one. At the start of the survey, respondents should be provided with instructions on how to complete the survey (e.g., thinking about a specific hospital visit, completing the one answer that best describes their experience).

1.3.5 Step 4: Deploy the Pilot Survey

The next step in the survey development process is to deploy the instrument. To aid in this task, it may be beneficial to follow an established survey protocol methodology, such as the one presented by Dillman.⁵³ Once the pilot survey has been constructed, one or multiple modalities for survey administration/distribution may be selected. Each of these has their own strengths and weaknesses⁵⁴ and should be carefully considered in light of the population to be studied. Although not an exhaustive list, some of these considerations are shown in Table 1.1. Participants should be given a reasonable timeframe (e.g., two weeks) to complete the survey,

and once completed, there should be clear indication on how the survey may be returned to the research team (e.g., pre-addressed stamped envelope, clicking on a “submit button” for a web-based survey, etc.). After the reasonable timeframe has elapsed, if desired, a reminder may be sent to those who have yet to complete the survey.

In addition to the survey, participants should be asked to rate the survey in terms of its length, clarity, and content (e.g., questions which may be missing, misleading, redundant, or unclear). This can be done as part of the survey or by using cognitive interviews where each participant who completed the pilot survey may provide the research team with a deeper understanding as to how they responded to each question. An example of the use of cognitive interviews among Albertans is that of the QTAC-PREM, published by Bobrovitz et al.⁴⁵

Table 1.1 Strengths and weaknesses of common survey modalities

<u>Modality</u>	<u>Strengths</u>	<u>Weaknesses</u>
Mail (paper-based)	<ul style="list-style-type: none"> - Respondent can complete at their leisure - Respondent may reflect upon question(s) for prolonged time 	<ul style="list-style-type: none"> - Response rates tend to be lower than telephone - Potential for missing answers - Survey may be completed by someone other than patient
Telephone	<ul style="list-style-type: none"> - Higher response rate vs. mail - Much lower rate of missing responses (vs. mail) 	<ul style="list-style-type: none"> - May not be suitable for persons with hearing/speech impairments - Prone to social desirability bias
Interactive Voice Response	<ul style="list-style-type: none"> - Survey can be automated 	<ul style="list-style-type: none"> - Lacks the “human touch” – may be undesirable
Online	<ul style="list-style-type: none"> - May target groups who do not respond to phone/mail - Offers greater flexibility 	<ul style="list-style-type: none"> - Potential for missing data - Requires internet connection - May not be suitable for persons who lack computer literacy.

1.3.6 Step 5: Build Evidence of Validity and Reliability

In this final step, the primary goal is to evaluate aspects of validity and reliability of the survey using the data collected from respondents. Prior to doing this however, it is important to

understand that the concept of validity has evolved from its original representation as a static property from the early 20th century.⁵⁵ There are now many contemporary validity arguments which expand upon the original emphasis placed upon criterion, content, and construct validity. For example, Messick, a leading theorist, views validity as “an integrated evaluative judgement of the degree to which empirical evidence and theoretical rationales support the adequacy and appropriateness of inferences and actions based on test scores or other modes of assessment”.⁵⁶ Messick’s framework involves accumulating evidence from five sources (content, internal structure, relationships with other variables, response processes, and consequences)^{56,57} to provide a scientific basis for proposed score interpretations. As such, validity is a process, where interpretations of scores are then evaluated for validity, rather than the instrument itself.

Additionally, given the multitude of terms used to define specific measurement properties of an instrument, it is important to understand the meaning of each, and how they may be measured. For example, Mokkink et al.⁵⁸ have reported upon the consensus reached by an expert panel in the taxonomy, terminology, and definitions of measurement properties in the evaluation of health-related patient-reported outcome measures. These include properties such as content validity, construct validity, criterion validity, internal consistency, reliability, measurement error, and responsiveness of an instrument. These are presented in Table 1.2. Although not part of the list presented by Mokkink et al., others have highlighted the importance of evaluating elements of acceptability (e.g., the ease of use of an instrument).⁵⁹ Of note, it may not be possible to evaluate all the measurement properties outlined above in a single study. This reinforces the contemporary view of validity as a process, as opposed to a static, point-in-time concept.

Table 1.2 Definitions of measurement properties, as defined by Mokkink et al.⁵⁸

Domain	Measurement property	Aspect of measurement property	Definition	
Reliability			The degree to which the measurement is free from measurement error	
Reliability (extended definition)			The extent to which scores for patients who have not changed are the same for repeated measurement under several conditions: for example, using different sets of items from the same items (internal consistency), over time (test-retest) by different persons on the same occasion (interrater) or by the same persons (i.e., raters or responders) on different occasions (intra-rater)	
	Internal consistency		The degree of the interrelatedness among the items	
	Reliability		The proportion of the total variance in the measurements which is because of “true” differences among patients	
	Measurement error		The systematic and random error of a patient’s score that is not attributed to true changes in the construct to be measured	
Validity			The degree to which an HR-PRO instrument measures the construct(s) it purports to measure	
	Content validity		The degree to which the content of an HR-PRO instrument is an adequate reflection of the construct to be measured	
		Face validity		The degree to which (the items of) an HR-PRO instrument indeed looks as though they are an adequate reflection of the construct to be measured
	Construct validity			The degree to which the scores of an HR-PRO instrument are consistent with hypotheses (for instance with regard to internal relationships, relationships to scores of other instruments, or differences between relevant groups) based on the assumption that the HR-PRO instrument validly measures the construct to be measured
		Structural validity		The degree to which the scores of an HR-PRO instrument are an adequate reflection of the dimensionality of the construct to be measured
		Cross-cultural validity		The degree to which the performance of the items on a translated or culturally adapted HR-PRO instrument are an adequate reflection of the performance of the items of the original version of the HR-PRO instrument
Criterion validity			The degree to which the scores of an HR-PRO instrument are an adequate reflection of a “gold standard”	
Responsiveness			The ability of an HR-PRO instrument to detect change over time in the construct to be measured	

1.4 Thesis Outline

This manuscript-based thesis focuses on the examination and improvement of measurement of patient-reported experiences among those who undergo cardiac surgery. This work utilized a mixed-methods, sequential explanatory design.^{60,61} In this, quantitative and qualitative data are collected and analyzed in consecutive phases. Findings are then integrated, and results are interpreted in combination.

The three chapters that follow have been formatted for publication in various peer-reviewed journals. Chapter 2 provides a comprehensive look at the experiences of patients who underwent CABG and/or valve replacement over a four-year period, using the CPES-IC survey.⁶² This work demonstrates an applied example on how to collect and report patient experience survey data, and how learning more about the perspectives of patients can support patient-centred learning health systems. The work also provided a sense of the status quo of measurement, outlining potential areas for improvement. Chapter 3 reports upon the elements of care that are deemed important to those who have experienced cardiac surgery. The qualitative findings of this paper served to not only confirm the findings from the results of the previous quantitative study, but to highlight topics deemed important to patients which were not included in the CPES-IC.⁶³ Chapter 4 integrates the learnings from these two previous studies to create and examine the content validity, reliability, and acceptability of the Alberta Cardiac Surgery Patient Experiences Survey (ACSPES); a condition-specific instrument designed to provide utility beyond that of surveys such as the CPES-IC. This preliminary evaluation of the ACSPES was conducted among a cohort of patients who underwent surgery at the Foothills Medical Centre, in Calgary, Alberta. Finally, chapter 5 summarizes and discusses strengths and limitations, and presents future directions for this work.

CHAPTER TWO: PATIENT-REPORTED EXPERIENCES WITH CORONARY ARTERY BYPASS GRAFTING AND VALVE REPLACEMENT

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2.1 Abstract

Background: The Canadian Patient Experience Survey - Inpatient Care (CPES-IC) is a validated measure of adult inpatient experience. Linking surveys with administrative data can examine the experience of patients in specific demographic or clinical groups.

Methods: We examined survey responses obtained over a four-year period from patients who underwent coronary artery bypass graft (CABG) and/or valve replacement in Alberta. The 56-question telephone survey was administered within six weeks of discharge. Surveys were linked with administrative records to identify the Canadian Classification of Intervention (CCI) procedure codes which were in-scope. Responses to each question were reported as percent in “top-box”, where “top box” represents the most positive answer choice (e.g., “always”, “yes”).

Results: From April 2014 to March 2018, 1,082 surveys were completed by patients who underwent CABG and/or valve replacement. Respondents were predominantly male (73.8%), with a mean age of 64.7 ± 11.9 years. Overall, 73.3% of respondents rated their hospital care as 9 or 10 out of 10 (best), and 86.2% would “definitely recommend” the hospital to friends/family members. Top performing questions pertained to having a discussion about help needed after discharge (96.6% “yes”) and receiving written discharge information (93.2% responding “yes”). Lack of quietness of the hospital environment at night (34.8% “always”) and lack of staff sufficiently describing side effects of new medications (44.9% “always”) were identified as potential areas for improvement.

Conclusions: Our results provide patient-reported experiences about inpatient cardiac care in Alberta hospitals. The findings could inform quality improvement initiatives that are patient-centred.

2.2 Introduction

In 2001, the Institute of Medicine (IOM) report entitled “*Crossing the Quality Chasm: A New Health System for the 21st Century*” outlined how the health care delivery system could be designed to innovate and improve care.⁹ Six key aims were presented; that care should be safe, effective, timely, efficient, equitable, and patient-centered. Although there are many working definitions of patient-centered care (PCC), the most commonly used one was also presented. The IOM stated that PCC is “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.”⁹ Although this particular definition of PCC places the patient at the forefront, it is widely acknowledged that the term “PCC” may be expanded upon to include family members and informal caregivers.⁶⁴ Additionally, many jurisdictions and healthcare organizations have adopted the term “person-centred care” as it places the person first, by not reducing a person to the sum of their symptoms or given condition.⁶⁵

In medicine, PCC is often measured via surveys; specifically, ones which measure patient experience.^{21,22,25} Improving the patient experience is also one of the three aims of the Institute for Healthcare Improvement’s (IHI) Triple Aim Framework.¹ The idea of using patient feedback to improve care is not a new one. One of the earliest documented examples may be attributed to Ernest Codman at Boston General Hospital in 1910.⁶⁶ In the Canadian context, a 1994 article in the Journal of the Canadian Medical Association reported survey results from 4,599 patients discharged from 57 hospitals in 6 provinces.⁶⁷ Today, many Canadian organizations include patient surveys as part of their protocols/policies. Examples of these include the Canadian Institute for Health Information (CIHI),⁶⁸ Alberta Health Services,⁶⁹ the Health Quality Council

of Alberta,²⁶ Ontario Health (formerly Health Quality Ontario),⁷⁰ and the British Columbia Ministry of Health.⁷¹

Despite the proliferation of patient experience surveys and the potential for their use for clinical quality improvement activities, Canadian research in this area is scant. This is especially so when it comes to examining the experience of patients from specific demographic backgrounds, those living with specific clinical conditions, or who have undergone specific treatments. Examining the comprehensive experience of patients who have undergone cardiac procedures such as coronary artery bypass grafting (CABG) and valve replacement may provide tremendous value. Given the labour-intensive and costly nature⁷² of these procedures, as well as the additional impacts to patients and their families (e.g., prolonged hospital stay, lifestyle modification, associated recovery and morbidity),⁷³ it is critical to ensure that each cardiac procedure is a success. This is especially so within the context of the Canadian healthcare system – one with limited, publicly-funded resources.

Over the past decades, a great deal of quality improvement work has taken place to improve patient outcomes following cardiac surgery. Like in many medical specialties, however, the great majority of this work has tended to focus upon clinical outcomes (e.g., reducing mortality, increasing medication compliance, decreasing unplanned readmissions), without the inclusion of the “patient voice”. We propose that patient experience surveys, when linked with administrative data to specifically target specific clinical populations, can provide patient-reported information to make further improvements. As such, the goal of the present study was to examine the comprehensive experience of patients who have undergone CABG and/or valve replacement in hospitals in Alberta, Canada. To our knowledge, this study is the first of its kind in Canada; one which uses a validated survey and linkage with administrative records to do so.

2.3 Methods

2.3.1 Data Sources

Survey data for this study were obtained using a modified version of the Canadian Patient Experiences Survey – Inpatient Care (CPES-IC)⁷⁴ – encompassing hospital discharges from April 2014 to March 2018. The CPES-IC is a validated tool, which was developed by CIHI, in partnership with pan-Canadian stakeholders.⁷⁴ The survey is based upon the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), which is widely used in the United States, under mandate of the Patient Protection and Affordable Care Act of 2010.³⁴ As of December 2018, the CPES-IC was administered across seven Canadian provinces; British Columbia, Alberta, Manitoba, Ontario, New Brunswick, Nova Scotia, and Prince Edward Island.^{5,74} In Alberta, a modified version of the CPES-IC is administered via telephone by AHS. Adult patients (ages 18 years and older) are surveyed within 2 to 42 days following their discharge from hospital. The complete list of exclusion criteria for the survey are provided elsewhere.⁷⁵ Surveys are administered across 93 hospitals in the province, using a standard script and responses to frequently asked questions. A random sample of ten percent of eligible discharges is obtained from each hospital; resulting in approximately 25,000 completed surveys each year. The survey is comprised of 56 questions, requiring approximately 12 to 18 minutes to complete. Questions assess many aspects of care, including communication with doctors, communication with nurses, medications, patient/family involvement in care, pain control, the physical hospital environment, coordination of care, and discharge planning. Responses to each question are Likert-type scales (e.g., always, usually, sometimes, never), and in the case of questions which ask the respondent to provide an overall rating, this is done on a scale from 0 (worst) to 10 (best). For the purposes of this study, and to facilitate future inter-jurisdictional

comparisons, only the items on the standard CPES-IC survey were included for analysis. Items pertaining to hospital arrival and care received via the emergency department were also excluded. The complete list of survey questions which were examined, as well as their corresponding response options is provided in Table 2.1.

To obtain relevant clinical data, completed surveys were linked with corresponding inpatient records, from the Discharge Abstract Database (DAD).⁷⁶ In Alberta, the DAD captures all discharges from hospitals in the province, and is coded according to standards established by CIHI. By reviewing patient charts, health information professionals assign up to 25 diagnosis and 20 procedure codes to each inpatient record. Surveys were linked to inpatient records using the patient's personal health number (PHN), the hospital code (five-digit identifier), and the date of hospital discharge. To determine cardiac procedures which were in scope for this study, we selected patients based on the presence of appropriate Canadian Classification of Intervention (CCI) procedure codes in each record.⁷⁷ Patients with at least one CCI code for CABG (1.IJ.76^^) and/or valve replacement (1.HS.90^^, 1.HT.90^^, 1.HU.90^^, 1.HV.90^^) in any of the 20 procedure code fields were included. All eligible cases for the present study were treated at the two main cardiac surgery centres in Alberta: the Libin Cardiovascular Institute (Foothills Medical Centre; Calgary), and the Mazankowski Heart Institute (University of Alberta Hospital; Edmonton).

2.3.2 Statistical Analysis

Descriptive statistics were used to categorize the demographic and clinical characteristics of survey respondents. Demographic variables included sex, age group (18 to 59 years, 60 to 69, 70 years and older), education level (less than high school, high school or college, university), self-reported physical health, and self-reported mental health (both reported as excellent, very

good, good, fair, or poor). Clinical variables included admission type (urgent or elective), length of stay (less than 3 days, 3 to 7 days, more than 7 days), number of comorbid conditions (none, one, two or more), and discharge disposition (discharged home with/without support services vs. other). Number of comorbid conditions was calculated using the Elixhauser Comorbidity Index⁷⁸ according to a validated algorithm.⁷⁹ This list of demographic and clinical variables was selected, as these have been previously shown to be associated with a patient's overall rating of care on the survey.⁷⁵

Responses to each survey question were classified according to HCAHPS "top box" methodology.⁸⁰ "Top Box" survey responses represent the most positive response option to each question. For the "overall rating" questions, these are responses of 9 or 10, on the scale from 0 (worst) to 10 (best). For the "recommendation of hospital to family/friends" question, the "top box" response was "definitely yes". For most of the remaining questions, the "top box" response is "always" (e.g., nurses "always" treating the patient with courtesy and respect). The percent of respondents with a "top box" response was reported for each survey question.

Differences in percent of "top box" survey responses between clinical groups were assessed using Chi-square tests. Statistical significance was determined a priori as any p-value less than 0.05. Lastly, a multivariate logistic regression model was used to explore the potential relationship between odds of reporting a "top box" response for overall experience and the demographic/clinical variables listed above. All analyses were performed using SAS statistical software version 9.4 for Windows (SAS Institute Inc.) and IBM® SPSS® statistical software version 25 (IBM® Inc.). This study was approved by the University of Calgary Conjoint Health Research Ethics Board (CHREB, project number REB15-1838). Due to the retrospective nature of the data, a waiver of consent was granted by the ethics board. All study data were obtained via

a research agreement between the research team and AHS (agreement number 15539). This study was conducted at the University of Calgary, in Calgary, Alberta, Canada.

2.4 Results

Over the four-year study period, a total of 1,082 respondents who completed the CPES-IC in Alberta had undergone at least one of the included cardiac procedures. From this, 527 respondents (48.7%) underwent CABG only, 416 (38.5%) had an isolated valve replacement, and the remaining 139 respondents (12.9%) underwent a combination of CABG and valve replacement. The demographic and clinical profile of respondents is shown, both overall, and stratified by procedure type(s), in Table 2.2. Overall, respondents were primarily male (73.8%), 60 years of age or older (71.8%) and had an education level of high school diploma or greater (81.0%). Respondents had a more positive rating of their mental health than their physical one (69.6% vs. 44.2% responding “excellent” or “very good”). Clinically, most respondents were admitted to hospital on an elective basis (57.2%), remained in hospital for more than 7 days (53.4%), had at least one comorbid medical condition (81.6%), and were discharged home with/without support services (94.6%). Overall, patients had an average length of stay of 10.9 ± 8.3 days. The demographic and clinical profile of patients varied according to procedure type. For example, patients who underwent multiple procedures tended to be older, remain in hospital longer, and were less likely to be discharged home.

The percentage of respondents reporting “top box” responses to all survey questions is presented in Table 2.3, once again, for the entire study cohort, and stratified according to procedure type(s). Overall, 73.3% of respondents rated their overall care score as 9 or 10 out of 10 (highest). With respect to the other global rating questions, 86.2% said that they would

definitely recommend the hospital to family members or friends, 85.0% of respondents rated the degree that their hospital stay helped them as 9 or 10 out of 10, and 76.8% of respondents rated their overall hospital experience as 9 or 10 out of 10.

Beyond the global rating questions, on an overall basis, the top five performing questions pertained to patients having had a discussion about help needed after hospital discharge (96.6% responding “yes”), receiving written discharge information (93.2% responding “yes”), having been treated with courtesy and respect by nurses (88.3% responding “always”), having been treated with courtesy and respect by doctors (85.2% responding “always”), and staff having done everything they could to help with patients’ pain (81.1% responding “always”). Conversely, the five lowest performing questions pertained to quietness of the hospital environment at night (34.8% responding “always”), staff discussing possible side effects of new medications (44.9% responding “always”), cleanliness of the hospital room/bathroom (58.4% responding “always”), patients reporting receiving timely assistance after pressing the call button (63.5% responding “always”), and patients reporting being involved in decisions about their care (66.4% responding “always”).

The percent of respondents who reported a “top box” answer to each survey question was quite consistent across the surgical procedures studied. Statistically significant differences in percentage of “top box” responses were observed for only three questions. These questions pertained to quietness of the hospital environment at night (higher percentage reported by patients who underwent CABG and valve replacement) ($p=0.01$), patients receiving necessary information about their condition and treatment (higher percentage reported for isolated CABG) ($p=0.04$), and patients having a better understanding of their condition at hospital discharge

(higher percentage reported by patients who underwent a CABG alone, or in combination with valve replacement) ($p=0.01$).

Table 2.4 shows the results of the multivariate logistic regression. Odds of reporting a “top box” overall experience rating was associated with age, education level and self-reported mental health. When compared with respondents ages 70 years and older, those ages 18 to 59 years reported lower odds of having an overall experience rating of 9 or 10 (OR=0.53, 95%CI: 0.36-0.79). When compared with respondents with a university-level education, those who did not complete high school (aOR=2.09, 95%CI: 1.30-3.36), or with a high school or college education (aOR=1.51, 95% CI: 1.07-2.14) had higher odds of reporting a “top box” rating. When compared with respondents who reported having excellent mental health, those reporting very good or good (aOR=0.43, 95%CI: 0.29-0.63), and fair or poor (aOR=0.20, 95%CI: 0.10-0.38) had lower odds of reporting a “top box” rating. The c-statistic for the overall model was 0.680.

2.5 Discussion

Validated surveys are a valuable means for obtaining patient-reported experiences. In providing first-hand accounts of their interactions with the healthcare system and staff, patients can indicate high-performing areas, as well as areas of focus for quality improvement. The results in the present study were generally, quite positive. Approximately three quarters (73.3%) of the patients who completed the survey rated their overall care as 9 or 10 out of 10. Further, 86.2% of respondents stated “definitely, yes” when asked if they would recommend the hospital to family members or friends. With respect to questions pertaining to specific aspects of care, the top performing questions were about discharge planning (discussion of help needed when returning home, receiving written discharge instructions), being treated with courtesy and respect

by nurses and doctors, and hospital staff doing everything they could to help with patients' pain. On the other hand, patients identified several areas where improvements could be made. Respondents stated that they were often not told about the potential side effects of new medications, that their hospital environment was quite noisy at night, and that their room and bathroom were not always clean. These responses represent actionable items, which if improved, may also have positive impacts upon patient safety through reduced number of adverse medication events, better patient sleep (contributing to better recovery), and a possible reduction in the rate of hospital-acquired infection. Our results also identified opportunities for improvement through increasing patient involvement in their care decisions, as well as a need for greater discussion around patient worries, fears, and anxieties. This is especially important, as patients have fears and worries which extend far beyond the inpatient setting. Once returning home, patients who have undergone cardiac surgery are faced with the possibility of complications, modifications to their lifestyle/behaviours, and concerns about resuming their work or normal daily activities in a safe way.^{81,82} These are all areas which also fall under the umbrella of PCC. In addressing these, we can ensure that patient needs are met in a holistic fashion.⁹ With respect to overall experience, odds of reporting a "top box" rating was associated with respondent age, education level, and self-reported mental health. This suggests that not all groups of cardiac surgery patients may respond similarly to the survey. Further analyses among these groups may provide information to assist in the provision of PCC.

Although there is not a great deal of previous literature in this area, our results are similar to those published in 2004 from the National Framework for Coronary Heart Disease survey of patients in the United Kingdom.⁸³ In that survey, 51% of patients reported receiving only partial information, or no information at all concerning the side effects of medications. Further, 39% of

patients reported not being involved, or wanting to be more involved in decisions about their care and treatment. On a positive note, as in our study, most respondents reported positive interactions with healthcare staff, that they received information from staff in a way that they could understand, and that their pain was well-controlled.

There are notable strengths to our study. To measure patient experience, we used a validated survey (CPES-IC), which included standard scripts and prompts. This ensured that all survey content as well as their conduct had a high degree of rigour. All interviewers received ongoing training and 10% of all surveys were monitored for quality assurance purposes. To maximize the potential for respondents to participate, surveys were conducted on weekdays from 9AM to 9PM, and on Saturdays from 10AM to 4PM. When a potential respondent was not reached, interviewers continued to dial each number up to nine times, at different times on varying days. Contact information for each potential respondent was extracted from clinical information completed at the time of hospital admission/registration. Up to two phone numbers were available for each patient. These numbers did not discriminate between landline and mobile/cellular telephones. Another strength of our study was that we were able to capture the patient experience of cardiac patients in a very cost-effective manner. We were able to capitalize upon existing survey and administrative data infrastructure. By linking these two data assets, we were able to obtain feedback from a large sample of cardiac surgery patients at no additional cost. Given the structure of AHS, where the health authority is the sole provider of inpatient care in Alberta, the data sets used in the study included all hospitals in the province. This overcomes a significant data limitation in other Canadian jurisdictions, where systems may be fragmented; resulting in an inability to link data in a comprehensive fashion. Further, our data linkage methodology is easily adaptable to other clinical conditions and procedures. Lastly, as the CPES-

IC survey is conducted by AHS and other organizations on an ongoing basis, the data may be monitored to make insightful comparisons. This can include comparisons within a clinical area or facility over time (e.g., experience is improving/getting worse), between facilities, or between jurisdictions. All of these may facilitate mutual learnings and the spread of best practices in the spirit of the Triple Aim Framework.¹

There are some notable limitations of our study. A previous study of the HCAHPS in Alberta showed that when compared to all Alberta patients who were hospitalized (e.g., eligible patients who did not complete the survey), survey respondents tended to have shorter lengths of stay and fewer comorbidities.⁸⁴ Although this was not examined in the current study, this may have resulted in cardiac surgery patients with poorer outcomes (e.g., readmissions, adverse events) not being surveyed.⁸⁵ Secondly, as the survey was administered via telephone, our results may not be generalizable to a mail-out format, and may be prone to bias via social desirability on the part of respondents. In this regard, previous HCAHPS research has shown that phone respondents typically report higher scores, when compared with mail surveys.^{49,86} Surveys were administered up to 42 days (six weeks) following the patient's discharge from hospital. This may have resulted in some instances of recall bias. Additionally, the survey was conducted in English only among patients only, which may have precluded the participation of non-English speaking persons, as well as respondents who would otherwise be able to serve as a proxy. In our study, we used a conservative data matching protocol, where surveys were linked to corresponding inpatient records based on exact matches of PHN, hospital code, and discharge date. We then selected eligible cases based upon the inclusion of appropriate CCI codes. Therefore, it is possible that some surveys completed by cardiac surgery patients were excluded. We propose, however, since CABG and valve replacement represent major surgeries, that they would likely

be present in abstracted records. This, in combination with the high reliability of the DAD data from re-abstraction studies⁸⁷ leads us to believe that the impact of this potential limitation would be quite minimal. An additional limitation pertains to the generalizability of our results. We observed that patients had very positive ratings of their care. Given that our patients were treated exclusively at large academic centres, it is plausible that differing results may be observed in non-academic centres, or in smaller, community-based hospitals.

A final study limitation pertains to the generic nature of the CPES-IC instrument. As the same questions are asked of patients across a variety of medical specialties and conditions, the “one-size, fits-all” nature of the survey meant that no in-depth, cardiac surgery questions were asked. For example, we did not ask any questions pertaining to access to care (e.g., wait times), or about the immediate post-hospital period (e.g., referral and uptake of cardiac rehabilitation). Previous research has shown these to be among the key stressors for patients who undergo cardiac surgery.⁸⁸ Many of these topics were on the earlier-mentioned survey from the United Kingdom.⁸³ To address this gap, in collaboration with patient advocates, our research team is currently conducting a study to co-create a survey/additional questions specifically for cardiac surgery patients in the Canadian context. Additionally, despite the generic nature of the CPES-IC instrument, further research and data mining may reveal actionable findings. An example of this is the finding relative to night noise in hospitals. A good sleeping environment has been identified as a key aspect of senior-friendly hospital care; the presence of which having been shown to reduce the incidence of delirium in at-risk hospitalized seniors.⁸⁹ An examination of our own survey data revealed a link between night noise and unplanned readmissions, although that investigation included all survey respondents over a one-year period, as opposed to focusing on specific cohorts.⁹⁰ This also presents further opportunities to explore our cohort in further

research, within the context of “post-hospital syndrome” – a phenomenon presented by Krumholz et al. in 2013.⁹¹

2.6 Conclusions

Standardized collection and reporting of the patient experience are instrumental for improvements in patient-centered care. Patients from two surgical centres in Alberta provided their responses to a validated survey about their experiences with care. Their feedback has generated new patient-centered knowledge about areas where they believe care for CABG and valve replacement are performing well. Despite the positive feedback, they have also identified targeted areas for quality improvement, which, if improved upon, may result in improved outcomes as per the Triple Aim. Further research to compare patient-reported experience and outcomes is necessary in this clinical population. Our data linkage methods may be easily replicated to examine the comprehensive experience of other demographic and clinical cohorts as well. The integration of the “patient voice” via experience surveys within quality improvement work may result in further improvements in patient outcomes following cardiac surgery. By providing targeted, actionable, patient-reported data, we may see additional improvements in mortality, unplanned readmissions, and adverse events beyond what has been achieved to date.

Table 2.1 Questions on the standard CPES-IC instrument with corresponding response options

Question Wording	“Top” Box	“Middle” Box	“Bottom” Box
Using any number from 0 to 10, where 0 is the worst hospital possible and 10 is the best hospital possible, what number would you use to rate this hospital during your stay?	9 or 10	7 or 8	0 to 6
Would you recommend this hospital to your friends and family?	Definitely yes	Probably yes	Probably no Definitely no
Overall, do you feel you were helped by your hospital stay? Please answer on a scale where 0 is “not helped at all” and 10 is “helped completely.”	9 or 10	7 or 8	0 to 6
Overall, what is the rating of your hospital experience? Please answer on a scale where 0 is “I had a very poor experience” and 10 is “I had a very good experience.”	9 or 10	7 or 8	0 to 6
During this hospital stay, how often did nurses treat you with courtesy and respect?	Always	Usually	Sometimes Never
During this hospital stay, how often did nurses listen carefully to you?	Always	Usually	Sometimes Never
During this hospital stay, how often did nurses explain things in a way you could understand?	Always	Usually	Sometimes Never
During this hospital stay, after you pressed the call button, how often did you get help as soon as you wanted it?	Always	Usually	Sometimes Never
How often did you get help in getting to the bathroom or in using a bedpan as soon as you wanted?	Always	Usually	Sometimes Never
During this hospital stay, how often did doctors treat you with courtesy and respect?	Always	Usually	Sometimes Never
During this hospital stay, how often did doctors listen carefully to you?	Always	Usually	Sometimes Never
During this hospital stay, how often did doctors explain things in a way you could understand?	Always	Usually	Sometimes Never
During this hospital stay, how often were your room and bathroom kept clean?	Always	Usually	Sometimes Never
During this hospital stay, how often was the area around your room quiet at night?	Always	Usually	Sometimes Never

During this hospital stay, how often was your pain well controlled?	Always	Usually	Sometimes Never
During this hospital stay, how often did the hospital staff do everything they could to help you with your pain?	Always	Usually	Sometimes Never
Before giving you any new medicine, how often did hospital staff tell you what the medicine was for?	Always	Usually	Sometimes Never
Before giving you any new medicine, how often did hospital staff describe possible side effects in a way you could understand?	Always	Usually	Sometimes Never
Do you feel that there was good communication about your care between doctors, nurses and other hospital staff?	Always	Usually	Sometimes Never
How often did doctors, nurses and other hospital staff seem informed and up-to-date about your hospital care?	Always	Usually	Sometimes Never
How often were tests and procedures done when you were told they would be done?	Always	Usually	Sometimes Never
During this hospital stay, did you get all the information you needed about your condition and treatment?	Always	Usually	Sometimes Never
Did you get the support you needed to help you with any anxieties, fears or worries you had during this hospital stay?	Always	Usually	Sometimes Never
Were you involved as much as you wanted to be in decisions about your care and treatment?	Always	Usually	Sometimes Never
Were your family or friends involved as much as you wanted in decisions about your care and treatment?	Always	Usually	Sometimes Never
During this hospital stay, did doctors, nurses or other hospital staff talk with you about whether you would have the help you needed when you left the hospital?	Yes	n/a	No
During this hospital stay, did you get information in writing about what symptoms or health problems to look out for after you left the hospital?	Yes	n/a	No
Before you left the hospital, did you have a clear understanding about all of your prescribed medications, including those you were taking before your hospital stay?	Completely	Quite a bit	Partly Not at all
Did you receive enough information from hospital staff about what to do if you were worried about your condition or treatment after you left the hospital?	Completely	Quite a bit	Partly Not at all

When you left the hospital, did you have a better understanding of your condition than when you entered?	Completely	Quite a bit	Partly Not at all
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Table 2.2 Demographic and clinical profile of survey respondents (n=1,082 unless otherwise noted)

<i>Variable</i>	<i>All Patients</i>	<i>CABG only</i> <i>(n=527)</i>	<i>Valve only</i> <i>(n=416)</i>	<i>CABG+Valve</i> <i>(n=139)</i>
Sex				
Male	799 (73.8)	435 (82.5)	260 (62.5)	104 (74.8)
Female	283 (26.2)	92 (17.5)	156 (37.5)	35 (25.2)
Age group (years)				
18 to 59	305 (28.2)	140 (26.6)	154 (37.0)	11 (7.9)
60 to 69	388 (35.9)	225 (42.7)	116 (27.9)	47 (33.8)
70 and older	389 (35.9)	162 (30.7)	146 (35.1)	81 (58.3)
Education level (n=1,057)				
High School not completed	201 (19.0)	102 (19.8)	69 (16.9)	30 (22.6)
High School or College	568 (53.7)	271 (52.5)	228 (55.9)	69 (51.9)
University (any or completed)	288 (27.3)	143 (27.7)	111 (27.2)	34 (25.6)
Self-reported physical health (n=1,070)				
Excellent	122 (11.4)	63 (12.2)	48 (11.6)	11 (7.9)
Very Good	351 (32.8)	161 (31.2)	143 (34.5)	47 (33.8)
Good	426 (39.8)	214 (41.5)	155 (37.4)	57 (41.0)
Fair	147 (13.7)	68 (13.2)	58 (14.0)	21 (15.1)
Poor	24 (2.2)	10 (1.9)	11 (2.7)	3 (2.2)
Self-reported mental health (n=1,076)				
Excellent	323 (30.0)	152 (29.0)	126 (30.5)	45 (32.4)
Very Good	426 (39.6)	214 (40.8)	155 (37.5)	57 (41.0)
Good	253 (23.5)	119 (22.7)	105 (25.4)	29 (20.9)
Fair	66 (6.1)	35 (6.7)	23 (5.6)	8 (5.8)
Poor	8 (0.7)	4 (0.8)	4 (1.0)	0 (0.0)

Admission type				
Urgent	463 (42.8)	312 (59.2)	97 (23.3)	54 (38.9)
Elective	619 (57.2)	215 (40.8)	319 (76.7)	85 (61.2)
Length of stay (days)				
Less than 3	11 (1.0)	0 (0.0)	11 (2.6)	0 (0.0)
3 to 7	493 (45.6)	228 (43.3)	215 (51.7)	50 (36.0)
More than 7	578 (53.4)	299 (56.7)	190 (45.7)	89 (64.0)
Discharge disposition				
Home (with or without support)	1,023 (94.6)	503 (95.5)	403 (96.9)	117 (84.2)
All other locations	59 (5.5)	24 (4.6)	13 (3.1)	22 (15.8)

Table 2.3 Percent of respondents with top box responses, by survey question and procedure

<i>Item Description</i>	<i>Top Box Response</i>	<i>All Patients</i>	<i>CABG only</i>	<i>Valve Only</i>	<i>CABG & Valve</i>	<i>p</i>
Global ratings						
Overall rating of care	9 or 10	73.3	72.5	74.1	73.9	0.84
Recommendation of hospital	Definitely yes	86.2	86.5	85.4	87.5	0.81
Helped by hospital stay	9 or 10	85.0	85.3	84.0	87.0	0.68
Overall hospital experience	9 or 10	76.8	76.3	76.0	81.2	0.43
Care from nurses						
Nurse courtesy & respect	Always	88.3	89.9	85.5	90.7	0.08
Nurse listening	Always	74.9	76.9	71.9	76.3	0.20
Nurse explanations	Always	77.6	79.6	74.7	78.4	0.20
Call button assistance	Always	63.5	64.3	62.5	64.0	0.87
Timely bathroom assistance	Always	69.8	68.1	72.2	69.9	0.54
Care from doctors						
Doctor courtesy & respect	Always	85.2	85.4	85.4	84.0	0.92
Doctor listening	Always	79.6	79.4	80.2	79.0	0.94
Doctor explanations	Always	77.0	78.1	75.6	77.4	0.66
The hospital environment						
Room cleanliness	Always	58.4	58.8	56.2	63.5	0.31
Room quietness	Always	34.8	31.2	35.4	47.1	0.01
Pain control and medications						
Pain controlled	Always	68.4	68.1	68.4	69.6	0.95
Staff helped with pain	Always	81.1	80.1	81.2	84.8	0.52
Purpose of new medications	Always	74.3	76.5	73.3	69.0	0.22
Side effects of new medications	Always	44.9	46.2	45.4	38.7	0.37
Processes of care						

Communication between staff	Always	70.4	71.4	69.2	69.9	0.75
Staff informed/up to date	Always	69.4	69.0	68.3	74.5	0.38
Tests/procedures done on time	Always	77.8	78.5	76.9	77.9	0.87
Info about condition/treatment	Always	78.8	81.8	77.0	73.0	0.04
Support for anxieties/worries/fears	Always	67.5	67.8	66.6	68.6	0.91
Patient involvement in care	Always	66.4	65.4	67.1	68.2	0.77
Family/friend involvement in care	Always	78.7	78.3	79.1	79.3	0.95
Hospital discharge						
Help needed after discharge	Yes	96.6	96.6	97.5	94.1	0.21
Received written discharge info	Yes	93.2	92.2	95.1	90.7	0.12
Understanding of medications	Completely	80.7	80.5	81.9	77.9	0.59
Info about post-discharge worries	Completely	78.1	79.3	78.4	72.8	0.26
Better understanding of condition	Completely	72.6	76.6	66.4	76.3	0.01

Table 2.4 Logistic regression results (odds of having an overall hospital experience rating of 9 or 10 out of 10)

Variable	OR	95% CI
<u>Sex</u>		
Male	1.19	0.84-1.69
Female	1.00	---
<u>Age (in years)</u>		
18 to 59	0.53	0.35-0.78
60 to 69	1.04	0.70-1.53
70 and older	1.00	---
<u>Education level</u>		
High school not completed	2.10	1.31-3.38
High school or college	1.51	1.07-2.14
University (any or completed)	1.00	---
<u>Self-reported physical health</u>		
Excellent	1.00	---
Very Good/Good	0.71	0.39-1.29
Fair/Poor	0.77	0.38-1.56
<u>Self-reported mental health</u>		
Excellent	1.00	---
Very Good/Good	0.43	0.29-0.63
Fair/Poor	0.20	0.10-0.38
<u>Admission type</u>		
Urgent	1.23	0.86-1.75
Elective	1.00	---
<u>Surgery type</u>		
CABG only	0.70	0.41-1.19
Valve replacement only	0.80	0.46-1.39
CABG and valve replacement	1.00	---
<u>Number of comorbid conditions</u>		
None	1.06	0.68-1.66
One	1.02	0.73-1.43
Two or more	1.00	---
<u>Length of stay (days)</u>		
Less than 3	1.13	0.23-5.69
3 to 7	1.07	0.75-1.51

More than 7	1.00	---
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Discharge disposition

Home (with or without support)	2.32	1.24-4.37
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All other locations	1.00	---
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**CHAPTER THREE: ELICITING PATIENT EXPERIENCES ABOUT THEIR CARE
AFTER CARDIAC SURGERY**

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3.1 Abstract

Background: Experience surveys provide an opportunity for patients to give their feedback about healthcare processes and services. Unfortunately, the majority of current surveys have been designed as “one-size fits-all” tools, and thus, do not take into account items pertaining to specific clinical groups. The objective of this study was to gain a deeper understanding of the specific aspects of care deemed important to cardiac surgery patients.

Methods: Individual semi-structured telephone interviews were conducted with a cohort of patients who had previously underwent cardiac surgery. Interviews were recorded and transcribed. Using a phenomenological approach, a thematic analysis was used to generate a list of themes and subthemes deemed important by participants.

Results: Eight interviews were conducted in July and August 2019. Participants included seven males and one female, ranging from 55 to 84 years of age. Five key themes emerged from the data: (1) overall experience, (2) communication, (3) the physical hospital environment, (4) care needs and ongoing management, (5) person-centred care. Our interviews revealed that participants had many overwhelmingly positive experiences with care. Through reports of their own experiences, participants highlighted important areas that may be improved.

Conclusions: Our results confirm and expand upon those highlighted in quantitative research by our group. Findings and knowledge derived from this study may be used to inform quality improvement activities. These may also play a key role in the development of a patient experience survey, specifically for those who undergo cardiac surgery; thus addressing a potential limitation of surveys currently in use.

3.2 Introduction

Patient-centred care (PCC) is providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.⁹ In order to practice successful PCC, it is essential to offer opportunities for patients to provide feedback about the healthcare services that they receive. There is now wide recognition that these patient reports are not only complementary to healthcare provider's perspectives, but also provide unique information about what contributes to the quality and effectiveness of healthcare delivery.^{92,93}

Experience surveys are an attractive, cost-effective option to capture feedback from patients in a timely manner.⁹⁴ Since its launch in 2014, the Canadian Patient Experiences Survey – Inpatient Care (CPES-IC) has emerged as a gold standard for measuring the experiences of hospitalized Canadians.^{5,95,96} The CPES-IC was designed to capture the experiences of many broad groups of patients. This presents a potential limitation in that potentially relevant condition-specific questions are not asked.

Previously, our research group examined the experiences of patients who underwent cardiac surgery (coronary artery bypass grafting [CABG] and/or valve replacement) over a four-year period, using the CPES-IC.⁶² In addition to our main findings, we highlighted that the CPES-IC did not contain items which asked patients about their access to care, cardiovascular medications, lifestyle modification, and cardiac rehabilitation. Cardiac surgery has lasting impacts upon patients. A recent review demonstrated that those who experience a cardiac event have informational and care needs which extend far beyond the inpatient setting.⁹⁷ These can include navigating lifestyle changes, as well as the emotional reactions post-event. In continuing

to use the CPES-IC; a generic, “one-size fits-all” tool, to assess the experiences of cardiac surgery patients, we may only be capturing a portion of one’s experience.

Prior to developing new survey questions or an entirely new survey, however, it is important to know the aspects/topics of care which are important to patients. Therefore, this qualitative study was conducted to gain a deeper understanding of the elements of care which are important to cardiac surgery patients across our jurisdiction (Alberta, Canada).

3.3 Methods

3.3.1 Methodology

The methodology for this qualitative project was guided by the Canadian Institute of Health Research (CIHR) Strategy for Patient Oriented Research (SPOR) vision for patient engagement. This vision ensures that patients are active partners in health research that will lead to improved health outcomes and an enhanced healthcare system. We adopted all four guiding principles of this vision: inclusiveness, support, mutual respect, and co-building.⁹⁸ From the outset of the project, three patient partners from the Libin Cardiovascular Institute’s Person to Population (P2 Cardiovascular Health) Research Collaborative Group⁹⁹ collaborated with our research team. As individuals who had previously experienced cardiac surgery, their experiential expertise was invaluable to co-design the interview guide. They provided their advice on how to structure the interviews to ensure a logical flow of ideas, as well as which questions and prompts would be relevant to ask.

3.3.2 Participant Eligibility and Recruitment

Prospective participants were identified via collaboration with the Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease (APPROACH) team. APPROACH

is part of a national database which contains real-time data pertaining to cardiac patients and procedures.¹⁰⁰ Participants were eligible to participate if they were 18 years and older, and had been diagnosed with either stable angina or acute coronary syndromes resulting in surgical treatment with CABG and/or valve replacement within the previous six months at the Foothills Medical Centre (Calgary),¹⁰¹ or the University of Alberta Hospital (Edmonton).¹⁰² These two academic hospitals are the primary cardiac surgery centres for southern and northern Alberta, respectively.

Patients deemed eligible received a study invitation letter via e-mail, or regular mail, as per the contact information provided in the APPROACH database. Recruitment also took place via the assistance of social media (Facebook, Twitter) posts made by the Patient Engagement Platform of the Alberta SPOR Support Unit.¹⁰³ In all cases, persons expressing interest in the study were asked to contact the research team (primary author) via email or telephone. This also provided an opportunity for the research team to provide any additional details and to answer any questions prior to any agreement to participate. Efforts were made to obtain a purposive sample of participants according to sex, age, residence area (rural or urban), and clinical course (urgent or elective admission to hospital, cases with or without complications).

3.3.3 Data Collection

Individual, semi-structured interviews took place via telephone, as per participant convenience/availability. Following an introduction, each interview began with the collection of relevant demographics (e.g., age, city/town of residence, education level, employment status) and clinical (e.g., procedure(s) patient underwent, hospital, whether the patient experienced any complications/rehospitalizations) information. Participants were then asked to describe their clinical course, including their general impressions of care received. Questions then delved into

what each participant deemed important (i.e., stood out for them) in their journey leading up to, during, and following discharge from hospital. Initial questions were followed-up with key prompts to ensure respondents had an opportunity to provide deeper and more elaborate responses. The list of interview questions is provided as Table 3.1. All interviews were performed by one researcher (primary author), as part of his larger doctoral thesis work. He had received training on how to conduct research interviews and focus groups and had honed these skills during prior employment as a research coordinator. Interviews were conducted until thematic saturation (i.e., no new themes emerging)^{52,104} took place. Thematic saturation was determined and agreed upon by the two authors who completed the analysis of all data.

3.3.4 Data Analysis

As we were seeking to better understand the lived experience of cardiac surgery patients, the analysis was based on a phenomenological approach.⁵² To achieve this, interviews were audio-recorded and transcribed verbatim within two weeks of completion. Each interview transcript was then read by two authors, with key quotes highlighted. A thematic analysis was used to classify items according to care topic (e.g., care from nurses, medication, information exchange, etc.). The coding framework was developed inductively, by first examining the interview transcripts, then by coding the themes as they appeared within the data (as opposed to defining themes a priori). To increase the trustworthiness of our thematic analysis, we incorporated many of the criteria outlined by Nowell et al.¹⁰⁵ These included the two authors familiarizing themselves with the data, establishing themes (independently), and then reviewing these together. To limit potential biases due to reflexivity, one of the reviewing authors had no prior cardiovascular clinical or research experience. Following analysis, findings were reviewed

and discussed with the whole research team, which consisted of experts in qualitative and quantitative research, as well as one interventional cardiologist.

3.3.5 Ethics Approval

This study was approved by the University of Calgary Conjoint Health Research Ethics Board (CHREB, project number REB18-1180) and conducted at the University of Calgary, in Calgary, Alberta, Canada. All participants provided their written informed consent.

3.4 Results

Interviews took place with eight participants (seven males and one female) during July and August 2019 and concluded once thematic saturation was reached. Interviews ranged from 17 to 41 minutes in length. Participant age ranged from 55 to 74 years. A list of participant characteristics, which include age, gender, residence setting (urban/rural), employment status, and whether the participant experienced any complication(s) or readmission(s) to hospital are provided in Table 3.2.

After review of the transcripts, five key themes emerged: (1) overall experience, (2) communication, (3) the physical hospital environment, (4) care needs and ongoing management, (5) person-centred care. Where appropriate, sub-themes have been further classified and presented. Each of these themes and sub-themes are discussed briefly, with one to two supportive quotes as examples. The full list of participant quotes, arranged according to theme and sub-theme, is provided in Table 3.3.

3.4.1 Overall Experience

Our interviews revealed that participants had many overwhelmingly positive experiences with care. Despite this, participants were not shy to highlight important areas that may be

improved. The participants' overall experiences focused on their interactions with the clinical staff. This not only included doctors and nurses, but also allied health team members, such as physiotherapists. Participants expressed appreciation for the routine-like ability of the staff to perform their duties. In contrast, interactions with providers where empathy was lacking were described; for example, relating to anxieties around receiving the surgical intervention.

"I had excellent care overall. But there may be some small areas for improvement." (P8)

3.4.2 Communication

Throughout their surgical journey, participants experienced issues related to communication. This theme of communication included several sub-themes: 1) Informational needs through the surgical journey; 2) reporting concerns; 3) communication between staff.

3.4.2.1 Informational Needs Through the Surgical Journey

Participants had many comments/insights regarding informational needs. Most of the comments reflected the care received in-hospital, but also included the lead-up to hospitalization (in the case of pre-booked surgeries), during the discharge process, and after the patient returned home. Although some patients expressed receiving information, others highlighted this as a perceived gap. In one example, a participant perceived good communication by the time spent with the team, including explanations by the anesthesiologist and the involvement of his wife in this communication. For other participants, the information provided wasn't sufficient. Some highlighted the information ahead of the surgery, but that these gaps in information also extended to knowledge about recovery time and healing. Some participants highlighted good communication for post-hospital care, while recommending additional considerations. Good communication was regarded as paramount. Any absence could allow for potential distrust in the clinical staff, or the clinical plan.

“...oh yeah I had what you call pre-op visit which took up a better part of the day and then they really tell you or try to explain to you what’s going to happen I also met the anesthesiologist prior to my operation and just explained how you’re going to be numbed down and that kind of story and my wife was with me on that occasion as well so she knew what to expect.” (P4)

“...yeah there’s no problem with courtesy or respect. That was fine, but information...I don’t think I was given it very often.” (P1)

3.4.2.2 Reporting Concerns

Although participants tended to have overwhelmingly positive experiences, participants did express some concerns that the care they received. Many brought their concern(s) forward to the hospital staff, the health authority, or in one case, a politician in the patient’s electoral riding. Participants were adamant that they did not want their concern(s) to result in punishment to staff (e.g., disciplinary action, job loss), but rather, to serve as a lever for change to improve the care for future patients.

“I reported a nurse to the staff. He was always mad and slamming things. He was also bossing all of the other nurses around. I was afraid of him. I thought that this could be bad for other patients, so I reported him. The staff escalated my concern and I was contacted by Patient Relations. They also talked to my family to get statements from them.” (P5)

“The cardiologist and surgeon told me about the complaint process. It seems like a lot of work but I don’t want to get anyone fired. They told me that they did their job, and they were very transparent. I did report my issue because they (the local health authority)

need to know that for the benefit of others. I appreciated the chance to share my experiences. The system needs to be improved and fine-tuned along the way.” (P8)

3.4.2.3 Communication Between Staff

Participants indicated that one potential area for improvement in their care would be the communication and coordination between staff members. These perceived breakdowns occurred not only within teams, but between different areas of the healthcare system (e.g., between paramedics and hospital staff). This may also be related to comments regarding the “machine-like” processes of care which were highlighted earlier. Quotes in this sub-theme seem to imply that patients consider clear and united directives from their healthcare professionals as important. Further, there was indication of the need from patients for professionals to be on the same page for treatment and to be clear and transparent in communicating with each other.

“The staff disagreed about whether I should get a pacemaker and I was caught in the middle.” (P5)

3.4.3 The Physical Hospital Environment

Several participants expressed concerns with the physical environment of the hospital. For instance, one participant expressed his wife’s challenges with finding parking during his urgent admission to hospital. Other concerns included annoyances with roommates and difficulties sleeping, which also extended to complaints with furnishings such as the hospital bed and placement of the air conditioning system.

“When I got to the hospital, she (patient referring to his wife) followed the ambulance and it took her 45 mins to find parking, so that was stressful.” (P8)

3.4.4 Care Needs and Ongoing Management

Participants stressed the importance of having their care needs met. This encompassed not only immediate acute care needs but extended to once leaving the hospital and returning to normal life. The theme of care needs and ongoing management included two sub-themes: 1) Access to care and post-hospital needs; 2) medications and pain control.

3.4.4.1 Access to Care and Post-Hospital Needs

With respect to access to care, participants who were booked on an elective basis expressed that they were pleased, and perhaps even surprised at the speed with which they received care. Some stressed the importance of a cardiac rehabilitation program once discharged from hospital. This expanded to discussions of being referred to cardiac rehabilitation years ago, and not appreciating fully how the program may help them to prevent further cardiac events. Participants also provided feedback about perceived shortcomings of such programs, including barriers (e.g., living in a rural area, cost) and programming being designed for a broad spectrum of patients with differing needs. Further comments were made about one's return home and how their care continued after leaving the hospital. Many expressed ongoing physical and psychological concerns/limitations. There were also comments from participants about the desire to have routine testing following discharge from hospital; expressing the comfort that would bring in having an objective measure of their medical status.

"I understood and was fine with my place on the waiting list. I was given a 3 month window and I was done in 6 weeks. I was called on a Monday to tell me to come in on Friday. I was scared to do it." (P7)

"I went to cardiac rehabilitation 4 years ago after I had my heart attack. I didn't take it seriously. One thing that I would stress is that it is so vitally important. If I had realized

that that was to prevent what I was going to go through in a few years, I would have taken it more seriously.” (P5)

3.4.4.2 Medications and Pain Control

Participants highlighted the importance of adherence to their pain medication. This importance was perceived not only as the need to take medications as prescribed/suggested but also as a potential safety aspect of stopping pain medications like opioids when leaving the hospital.

“I wouldn’t wish that pain on my worst enemy....But, they gave me a lot of great drugs for the pain. I was taking an opioid in hospital, but I didn’t want to take it home.” (P7)

3.4.5 Person-Centred Care

Participants spoke of their desire for programs and services to be more tailored to them as individuals. They also discussed the desire for inclusion of themselves and family members in decisions about their care. This theme of person-centred care can be further classified into two sub-themes: 1) individualized care, and 2) patient/family involvement in care.

3.4.5.1 Individualized Care

Participants provided many salient quotes regarding the need for protocols, services, and program offerings to be tailored to their individual needs. Concerns were also expressed regarding the perceived limitations of the regimented protocols and staff attitudes towards these. There was a sense of protocols being rigidly designed for the whole rather than the individual patient at hand. In the comments, one can observe that this sentiment extended to medications and tests, as well as interactions between the patient and staff members.

“...the only thing that I experienced afterwards was they gave everybody the same set of drugs as a protocol and it’s the same thing for all heart patients and I never really had

high blood pressure, but they gave me pills for controlling blood pressure. They gave me pills for lowering blood pressure so I already had really low blood pressure, but they still gave me pills.” (P1)

3.4.5.2 Patient/Family Involvement in Care

Participants expressed the desire to be involved in their care. In some instances, this extended to the inclusion of family members. There were also comments that expressed the burdens that may be inadvertently placed upon family members.

“...(patient referring to his wife) she was with me all the way the operation was probably tougher on her than it was me.” (P4)

3.5 Discussion

This qualitative descriptive study showed that patients who underwent cardiac surgery were grateful for, and appreciative of the staff during their hospitalization. Overall, participants reported receiving good care, but also highlighted areas for potential improvements. These focused upon six aspects of care: 1) the perceived limitations of regimented protocols and staff attitudes towards these, 2) perceived breakdowns in communication/coordination of care – not only within teams, but between different areas of the system, 3) the physical environment of the hospital, 4) the need for information while in hospital, and in managing ongoing care concerns after leaving, 5) expressing/reporting concerns with care, and 6) perceived shortcomings of the “one-size fits-all” design of cardiac rehabilitation programs. Improvements in these areas can have positive impacts in the provision of patient-centred care. However, it should be noted that these recommendations can vary in terms of their actionability. As an example, providing more information to patients and families via handouts, or as one participant suggested, in a video,

may be easy to implement. Conversely, efforts to improve the physical environment may involve significant financial investments and may be limited by existing hospital infrastructure. Despite these challenges, participants in this study characterized the period following surgery as one of a lack of comfort, where one feels ill and is at heightened sensitivity to noise, distractions, and a lack of privacy. Efforts to improve the ability for patients to self-isolate in a comfortable environment following surgery may have great positive impact.

On a more global scale, the experiences of participants highlight the importance of harnessing patient feedback to inform and promote continuous improvement of healthcare services. Participants recognized the crucial role that they can play in quality improvement and were pleased that future patients could benefit from their own experiences. Through the methods used in this study, which were developed in collaboration with patient partners, and the resulting analyses, this study provides reports upon the aspects of care deemed most important to those who undergo cardiac surgery. In addition to the utility for quality improvement purposes, our findings can inform the development of additional survey questions to evaluate processes of care not addressed in existing surveys.

The results of this qualitative study align well and expand upon the results from our previous quantitative study of survey results using the CPES-IC instrument.⁶² In that previous study, over one thousand participants who underwent CABG and/or valve replacement highlighted their high regard of their nurses and doctors. Like in the present study, concerns pertaining to coordination of care amongst staff members, lack of information provision (e.g., medication side effects), night noise on the hospital unit, and cleanliness of the hospital room were also reported.⁶² Our findings pertaining to importance of informational needs, and the desire for more personalized programming in cardiac rehabilitation have been shown

elsewhere.¹⁰⁶ Further, the desire that participants expressed for ongoing information (i.e., after leaving hospital) about their condition, appropriate symptom management, and the safe return to normal activities has been echoed in prior work.⁸²

3.5.1 Limitations

There are notable limitations associated with this study. Although the age and sex distribution of participants mirrors that of cardiac surgery recipients in our jurisdiction,¹⁰⁷ it is possible that our findings may not be generalizable to younger patients or women. Younger cardiovascular patients have been shown to have additional/different needs when compared with older individuals who undergo cardiac surgery.¹⁰⁸ This was highlighted by one of our study participants with respect to the program offerings of cardiac rehabilitation. It is also plausible that our findings may not report upon the differing needs of women who undergo cardiac surgery. It has been shown that sex-related disparities exist in the diagnosis, treatment, and ongoing management of cardiovascular disease.¹⁰⁹ Additionally, our interviews were conducted in English only, amongst participants who identified as Caucasian. As such, it is possible that our results may not apply to non-English speakers, visible minorities, and those who identify as Indigenous. Apart from the one female participant who had completed high school, our study participants had a high level of education. Although we did not collect information about job role or income, this may result in our results not being applicable to those who are less affluent. Future research is necessary to determine if our findings apply to these aforementioned groups. Finally, given that interviews occurred following hospital discharge, one cannot discount the potential for recall bias.⁵² Although one may assume that cardiac surgery is a vivid, memorable experience in one's life, it is possible that participants may forget specific details of their care once they are discharged.

3.5.2 Strengths

There are also several methodological strengths of this study. One of which was in its qualitative design. Through in-depth interviews, we were able to better understand the experiences of patients who underwent cardiac surgery at two teaching hospitals in our province. Our organic approach to interviewing, where we asked participants what they felt was important during their experience, coupled with pertinent probing questions allowed for rich discussions. Participants were quite candid in their responses and were easily able to shine a light upon successes, while making constructive, actionable suggestions for improvement. Another study strength was the patient-oriented design. Three patient partners played a valuable role in shaping the interview guide. This resulted in focused, pertinent questions being asked, from the perspective of those who had themselves, previously experienced cardiac surgery.

3.6 Conclusions

The findings of this study highlight the aspects of care which are deemed important to those who have experienced cardiac surgery at the two major surgical centres in Alberta, Canada. These findings could inform quality improvement activities. Next steps include dissemination to the surgical cardiac teams and quality experts, as well as an exploration of routine collection of this data to inform quality improvement activities in cardiac surgery. It is important to note that to-date, the measure used to collect patient experiences is generic in nature. As such, it potentially misses out on assessing aspects of care that are important to cardiac surgery patients. Knowledge derived from this study may play a key role in the development of a patient experience survey, specifically for those who undergo cardiac surgery.

Table 3.1 Interview questions

1. Please tell us about your recent experience with heart surgery. (Probes: What went well, what would you improve?)
2. Thank you for sharing your experiences. Now knowing what you know, if you could go back in time, is there anything that you wish you knew ahead of time?
3. What kinds of things did you value about your experience? What matters to you? (Probes: how healthcare service providers interact with you, features of the hospital, begin able to access services, information sharing, having family/friends as part of your care team)
4. A product of this work will be to develop a survey to improve care, and to highlight areas where care is done well. Are there any other things that you think are important to include?
5. Do you have any questions for us? Or is there anything you would like to add about your experience?

Table 3.2 Characteristics of interview participants

Participant	Sex	Age	Setting	Education Level	Employment Status	Complication	Readmission
P1	Male	65	Rural	Master's	Retired	No	No
P2	Male	55	Urban	Bachelor's	Full-time	Yes	No
P3	Male	63	Rural	Master's	Part-time	No	No
P4	Male	68	Rural	College Diploma	Retired	Yes	No
P5	Female	74	Urban	High School	Retired	Yes	Yes
P6	Male	73	Urban	Bachelor's	Retired	No	No
P7	Male	58	Urban	College Diploma	Retired	Yes	No
P8	Male	65	Urban	Bachelor's	Part-time	Yes	No

Table 3.3 Quotes obtained from interview participants

Theme	Sub-Theme	Quote
Overall Experience		<p><i>“I had excellent care overall. But, there may be some small areas for improvement.” (P8)</i></p> <p><i>“...what made it positive is that I was exposed to everybody there and they were good people they were attentive, and you can tell that they weren’t just after the job and they were meant to be there to be helpful and that was nice.” (P2)</i></p> <p><i>“...the whole time was very positive it just seemed like it was an assembly line once I got into the system I felt it was just one after the other I guess people were having heart attacks nonstop end it seemed like they had it down to a science and getting into the operating room they put that wire up your arm to see all your vitals and everything and so that was really cool the whole flushing of the system putting that liquid in that was really cool and the doctors talking to me the whole time that was a very positive experience.” (P1)</i></p> <p><i>“(Regarding the insertion of the pacemaker)...This was the only time that I felt the staff was not nice to me. I was told that this would be a quick thing but it took over one hour. I was very stressed because I get claustrophobic. When I asked if they were almost done, the doctor replied “I’m done when I’m done”. After, the same doctor also snapped at my daughter when she asked about possible complications. The doctor was much nicer to me when I went to see her again about 3 months later.” (P5)</i></p>
Communication	<i>Informational needs through the surgical journey</i>	<p><i>“...oh yeah I had what you call pre-op visit which took up a better part of the day and then they really tell you or try to explain to you what’s going to happen I also met the anesthesiologist prior to my operation and just explained how you’re going to be numbed down and that kind of story and my wife was with me on that occasion as well so she knew what to expect.” (P4)</i></p> <p><i>“...yeah there’s no problem with courtesy or respect. That was fine, but information...I don’t think I was given it very often.” (P1)</i></p> <p><i>“I never received any information before my operation. I had no explanation on what to expect, nothing. I didn’t know that they would cut me down the sternum.” (P5)</i></p> <p><i>“...one thing is the heart surgeon is cracking your ribs open right? I did not know if I was going to die, and you don’t really know how long it takes to recover because your ribs have been split open right? So, they say 12 weeks and you can go back to work. I don’t know how long it takes for him to have that done. I thought that’s when I can go back to work but the effects on the cuts and the veins and stuff was the hardest part for me to understand like how long will it take. So yeah, if it’s six months then yeah it’s understandable.” (P4)</i></p>

		<p><i>“The nurses were great they went through all the points on the checklist and from being a non-medical person it made sense and you begin to understand what it is. So a video (referring to post-hospital care while at home) would actually help with more of what I don’t know.” (P2)</i></p>
	Reporting concerns	<p><i>“I reported a nurse to the staff. He was always mad and slamming things. He was also bossing all of the other nurses around. I was afraid of him. I thought that this could be bad for other patients, so I reported him. The staff escalated my concern and I was contacted by Patient Relations. They also talked to my family to get statements from them.” (P5)</i></p> <p><i>“The cardiologist and surgeon told me about the complaint process. It seems like a lot of work but I don’t want to get anyone fired. They told me that they did their job, and they were very transparent. I did report my issue because they (the local health authority) need to know that for the benefit of others. I appreciated the chance to share my experiences. The system needs to be improved and fine-tuned along the way.” (P8)</i></p> <p><i>“...and then I complained to my MLA (elected Member of the Legislative Assembly), but now he’s retired so that didn’t go anywhere but yeah that’s something that’s important.” (P1)</i></p> <p><i>“(referring to an incident where the patient hurt his neck while staff was administering medication)...yes it’s obviously unfortunate it leaves a bad taste in your mouth for sure.” (P2)</i></p>
	Communication between staff	<p><i>“The staff disagreed about whether I should get a pacemaker and I was caught in the middle.” (P5)</i></p> <p><i>“There was a lack of communication between the paramedics and the hospital. The paramedics gave me a blood conditioner which ended up delaying my surgery. I was immobilized for 72 hours with a heart pump to allow for the meds to clear. They didn’t want to operate on me because of the risk of me bleeding out. So, I had extra time in the ICU and I was immobile.” (P8)</i></p>
The physical hospital environment		<p><i>“When I got to the hospital, she (patient referring to his wife) followed the ambulance and it took her 45 mins to find parking, so that was stressful.” (P8)</i></p> <p><i>“...they put me in a ward of a whole bunch of other people and that was absolutely horrible because I’m a light sleeper and so snoring and grumbling from other people so that wasn’t fun. So, it would be nice to have a more private room when I just got out of surgery instead of being stuck in a ward with a bunch of other people.” (P1)</i></p> <p><i>“Once I got downstairs to the [floor number] floor, there’s a mishmash of patients and some people are just awful people...Nobody wants to be in the hospital for too long but some people complained way too much about the staff about one of the women in the private room and you know we were four in a room and it was a little tough.” (P4)</i></p> <p><i>“The only complaint I have was about my bed. I had a private room which was great, but I had an old bed. It was very uncomfortable and it would twist my body, and I would wake up in agony. They then transferred me to a general room that had a newer bed that was much better.” (P7)</i></p>

		<p><i>"I had one spot by the window and the air-conditioning. After major surgery you're very depleted and I got very cold." (P2)</i></p>
<p>Care needs and ongoing management</p>	<p><i>Access to care and post-hospital needs</i></p>	<p><i>"...so we're finally back with the surgeon on Friday and they put me on their shortlist and next Tuesday I get the phone call to come in so I didn't have to go through the proper process of about 3 months to get you booked in for surgery and about a month to get a call two or three sessions and tests and tell you about everything so I had a quick one." (P2)</i></p> <p><i>"I understood and was fine with my place on the waiting list. I was given a 3 month window and I was done in 6 weeks. I was called on a Monday to tell me to come in on Friday. I was scared to do it." (P7)</i></p> <p><i>"I went to cardiac rehabilitation 4 years ago after I had my heart attack. I didn't take it seriously. One thing that I would stress is that it is so vitally important. If I had realized that that was to prevent what I was going to go through in a few years, I would have taken it more seriously." (P5)</i></p> <p><i>"I was asked to attend a session twice a week or three times a week I'm not sure for 12 weeks. And having lived to tell, it was a charge for \$500, which I didn't feel was fair so I turned it down thinking that I would come up with my own exercise regimen and my cardio machine. He [patient's cardiologist] wasn't very happy that I turned it down. You know circumstances...I'm not driving into town three days a week. I don't have that resolve. As for my wife coming with me, she's still working so there's no way she could've done that." (P4)</i></p> <p><i>"I had a stent put in, but I still did not feel right. I had some weird freak-outs – panicking that I was having another heart attack. When I was in cardiac rehab, I had an anomaly on a stress test. An angiogram revealed blockages in my heart. So I ended up having a double bypass. The results of the stress test recognized my problem, so I was really happy that I had access to cardiac rehab." (P7)</i></p> <p><i>"I needed a lot of care when home. My daughter stayed with me the whole time when I was in the hospital and after I went home.... I was given antipsychotics over 2 months and I was asked if I wanted to see a psychologist – the psychologist was very helpful." (P5)</i></p> <p><i>"I just asked my family doctor and said I'm pretty sure my doctor said I should have another test in a few years and it turns out he never relayed any information from them about that. Should there be more tests a few years later?" (P1)</i></p> <p><i>"Feedback to the patient after (surgery) is important. The stress tests and discussions at 6 weeks, 3 months, and etcetera were key. The numbers are also objective. I was doing great, but then 4 years later I all of a sudden needed heart surgery. Could we test more? I know it's invasive and there's a cost to all</i></p>

		<p><i>that, but it would have been good to know if I had a gradual decline, or if one day it just fell off a cliff.” (P8)</i></p>
	<p><i>Medications and pain control</i></p>	<p><i>“I mean the type of recovery we were going through as long as you just took your meds listen to the nursing staff.” (P4)</i></p> <p><i>“There was a hunt for morphine in a panic. They couldn’t get it out of lock-up quick enough. I get that morphine is protected, but I needed it quickly to save my life. There needs to be a provision for protocol override. There was no guidance and it was a total scramble. They just kept giving me more and more medications – nitro and morphine. Then about 3 hours later, the pain just stopped. The spasm eased and blood flow was restored.” (P8)</i></p> <p><i>“I wouldn’t wish that pain on my worst enemy....But, they gave me a lot of great drugs for the pain. I was taking an opioid in hospital, but I didn’t want to take it home.” (P7)</i></p>
<p>Person-centred care</p>	<p><i>Individualized care</i></p>	<p><i>“I was referred to “heart university” and I attended. It was totally worthwhile. It serves a broad spectrum of people there, and I was one of the youngest. It’s one-size fits-all so it’s not tailored to a specific person. There are people there from over 80 years old to in their 50s so the program has be general to ensure relevance. But, there is a big difference between having 10 to 15 years of life left versus 10 to 15 years of work left.” (P8)</i></p> <p><i>“Just what I mentioned before, the nursing staff are really touchy about how you react. How you lie down in the bed, how do you get in the bed, how do you get out the bed, and if you follow those instructions you’ll be fine, but you know in some cases people find it really difficult but because they’re overweight and when you’re 60 to 68 it becomes quite tough. So, it’s really good advice that you get in the hospital.” (P4)</i></p> <p><i>“The discharge criteria checklist was great. I worked towards it, but I knew I was doing much more than most people in there. I was up and walking. I was doing the stairs – which maybe I shouldn’t have been, and the PT that they assigned to me was great. I was in better shape and I didn’t have any other health conditions like diabetes or high blood pressure. I could tell just by looking around at the heart rate monitors that I was doing better. I was at about 56, and others were at like, 138.” (P7)</i></p> <p><i>“...the only thing that I experienced afterwards was they gave everybody the same set of drugs as a protocol and it’s the same thing for all heart patients and I never really had high blood pressure, but they gave me pills for controlling blood pressure. They gave me pills for lowering blood pressure so I already had really low blood pressure, but they still gave me pills.” (P1)</i></p> <p><i>“You get a sense that everything is business as usual. My case was very unique and that plays into my comments. I had a bypass failure or spasm. After the surgery, I was blasted awake with pain at 3 in the morning. I felt like I was having a heart attack, but the staff didn’t believe me. They told me I was experiencing pericarditis but I knew it wasn’t that! I had a visual of my pain and I just felt that the patient</i></p>

		<p><i>isn't believed. This was a big concern for me. There was no communication provided to me, except to discount what I was saying, despite the feeling that I was fighting for my life." (P8)</i></p> <p><i>"I saw the physiotherapist for a neck issue and the lower back. I was asking about that, but she was just concerned about me being able to do my flights of stairs." (P2)</i></p>
	<p><i>Patient/family involvement in care</i></p>	<p><i>"It is important for those who think their health is important and want to be involved." (P1)</i></p> <p><i>"...(patient referring to his wife) she was with me all the way the operation was probably tougher on her than it was me." (P4)</i></p> <p><i>"My wife was only able to be there for one meeting with internal medicine. It would be nice to have someone else there if the timing works out." (P8)</i></p>

**CHAPTER FOUR: AN ASSESSMENT OF THE CONTENT VALIDITY, RELIABILITY,
AND ACCEPTABILITY OF THE ALBERTA CARDIAC SURGERY PATIENT
EXPERIENCES SURVEY**

4.1 Abstract

Surveys such as the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) and the Canadian Patient Experiences Survey – Inpatient Care (CPES-IC) were designed to capture the experiences patients who are hospitalized due to a variety of conditions and reasons. Given this “one-size, fits-all” approach, additional questions pertaining to relevant clinically important topics, or those pertinent to a particular condition or procedure will not be asked. This study assessed the content validity, test-retest reliability, and acceptability of the Alberta Cardiac Surgery Patient Experience Survey (ACSPES) – a newly-created survey specifically for patients who undergo cardiac surgery. Eligible participants from three cardiology units at a large teaching hospital received a study invitation letter following their discharge from hospital. Surveys consisted of 60 questions to assess multiple aspects of care, from intake/arrival at the hospital, to discharge and follow-up care. Participants could complete the survey via e-mail or by regular mail, as per their preference. For assessing test-retest reliability, those who agreed to complete the survey a second time were provided a follow-up survey two weeks later. Over a four-month period, 91 participants (64 males, 27 females), ranging from 34 to 89 years of age, completed the survey. Participants provided very positive feedback about the survey content as well as its acceptability. Suggestions for improvements were also provided. These included content-related suggestions, perceived difficulties in answering certain questions, a desire for more open-ended responses, and the opportunity to expand upon certain answers. Fifty participants completed the retest survey, where 16 of the 30 items assessed (53%) had an intra-class correlation/Kappa value of 0.70 or greater. These preliminary results are promising with respect to the content validity, test-retest reliability, and acceptability of the ACSPES. Further

study to evaluate additional measurement properties is warranted to inform the potential for use and adoption of the ACSPEs.

4.2 Introduction

Validated patient experience surveys are widely used to obtain feedback from large groups of health system users.^{21,22,24,25,30} In the acute care setting, data and results derived from surveys such as the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS),^{3,4} the Picker Patient Experience Questionnaire,⁶ and the Canadian Inpatient Experiences Survey – Inpatient Care (CPES-IC)⁵ are used to highlight leading practices, as well as care processes needing improvement in the eyes of patients.

Despite being widely adopted, validated measures, a limitation of the surveys currently in use stems from their “one-size, fits-all” approach. If a patient is hospitalized due to a hip fracture, cardiac surgery, medical management of a chronic illness, or to deliver a baby, the same questions will be asked of them. As such, additional questions pertaining to relevant clinically important topics, or those pertinent to a particular condition or procedure will not be asked. Previous research by our group has reported upon the experience of patients who underwent coronary artery bypass grafting and/or valve replacement.⁶² In this work, we highlighted that our use of the CPES-IC survey precluded any questions pertaining to access to care, cardiac rehabilitation, safe resumption of normal activities, and coordination with primary care. That study was followed up with a qualitative one to determine the aspects of care that are important to inquire about among cardiac surgery patients.⁶³ Interviews conducted during the latter study confirmed that there are aspects of care not on the CPES-IC that could be asked of future patients who experience cardiac surgery.

To address these gaps, our research team developed a draft survey; the Alberta Cardiac Surgery Patient Experiences Survey (ACSPES). In this article, we describe a cohort study to evaluate selected measurement properties of the ACSPES instrument. Specifically, our objective was to assess the content validity, test-retest reliability, and acceptability of the ACSPES. As the ACSPES is new, a secondary objective was to describe the instrument for readers.

4.3 Methods

4.3.1 Survey Creation and Content

Findings from the aforementioned qualitative study conducted by our group⁶³ were coupled with those from a literature review, which sourced two pertinent surveys of inpatient care. The first was the Alberta version of the Canadian Patient Experiences Survey – Inpatient Care (CPES-IC).^{5,95} This item was developed by the Canadian Institute for Health Information, in collaboration with provincial and territorial stakeholders. In addition to the core items on the survey, each organization that administers it may include additional questions for their own purposes. The second survey was the Coronary Heart Disease In-Patient Experience Questionnaire I-PEQ (CHD)⁴⁷ – an item developed in the United Kingdom. As a result, a 60-question draft survey was created, spanning the patient journey of cardiac surgery, from intake/access to returning home and the initiation of cardiac rehabilitation.

The survey was comprised of questions relating to aspects such as overall care, emergency or elective care (as applicable), nurses, doctors, physical attributes of the hospital (e.g., cleanliness, quietness), coordination of care, provision of information, discharge planning, cardiac rehabilitation, coordination with primary care, and patient concerns. The majority of questions were closed-ended, with a Likert-type response (e.g., always, usually, sometimes,

never). A question pertaining to one's overall rating of care was on a scale of 0 (worst) to 10 (best). At the conclusion of the survey, participants were asked to provide some additional demographic information. This included their age, sex, location of residence (urban vs. rural), highest level of education attained, and their self-reported physical and mental/emotional health (response options for each: excellent, very good, good, fair, poor).

The survey included three open-ended questions. The first asked participants who indicated that they had a concern about their care to provide more details as to the nature of this concern. The second one was included due to the timing of the survey, which coincided with the novel coronavirus (COVID-19) pandemic. Participants who indicated that their care was impacted by COVID-19 were asked to provide further detail as to how. In the final open-ended question, participants were given the opportunity to include any other comments that they deemed relevant to their care.

Within the survey, there were five opportunities for skip logic, as per the participant's reported course of care. At the beginning of the survey, there were questions pertaining to urgent and elective (e.g., pre-booked) surgery, as per the participant's course of care. In a second section, participants who indicated that they had experienced pain were asked how often their pain was well controlled, and how often hospital staff did everything they could to help with pain. In a third section, participants who responded that they had received new medication(s) during their hospital stay were asked how often hospital staff described: a) the purpose and b) possible side effects of new medication(s). In a fourth instance of skip logic, participants reporting that they had been referred to cardiac rehabilitation but did not attend were asked the reason(s) why. Towards the end of the survey, participants with a concern about their care were asked to describe it (in an open-ended comment box, as stated earlier). Those who indicated that

they reported their concern to the hospital, health authority, or staff members were asked about: a) whether they felt their concern was welcome, b) whether they felt their concern was taken seriously, and c) their degree of satisfaction as to how their concern was handled and addressed. At the end of the survey, participants were reminded that if they had any concerns about their health or ongoing management of their condition, they should contact their healthcare provider or HealthLink (i.e., a free telephone service staffed by Registered Nurses who provide health information across Alberta). The telephone number and e-mail address for the Alberta Health Services (AHS) Patient Relations department were also provided to participants, if they wished to provide a formal compliment or complaint about the care they received. The complete survey, as provided to participants is included as Appendix F.

4.3.2 Participant Recruitment and Eligibility

To adhere to all relevant sections of our jurisdictional Health Information Act,¹¹⁰ the study recruitment plan was developed in conjunction with AHS. As our provincial health authority, AHS is the sole provider of hospital care to Alberta's 4.4 million residents.³⁸ Each week, AHS generated a list of patients discharged from the three cardiology units at the Foothills Medical Centre (Calgary). To be eligible for the survey, patients were required to be 18 years or older at the time of hospital discharge, have remained in hospital for a minimum of 24 hours, be discharged home, and have not been diagnosed with COVID-19. Eligible patients were mailed a study invitation letter (Appendix E) that contained a brief description of the study and contact information for the research team. Those interested in participating were asked to contact the research team via telephone or e-mail. Once contact was made with the research team, consenting participants were provided with the survey by e-mail or regular mail, as per their preference. E-mail surveys and data were administered using the REDCap platform.¹¹¹

4.3.3 Assessment of Aspects of Validity, Reliability, and Acceptability

In our approach to assessing the validity of the ACSPEs, we took on a more contemporary definition, as outlined by Messick.⁵⁶ This views validity as “an integrated evaluative judgement of the degree to which empirical evidence and theoretical rationales support the adequacy and appropriateness of inferences and actions based on test scores or other modes of assessment”. Validation, in this framework, expands upon the traditional approach to validity assessment, which emphasizes upon content, construct, and criterion validity. In doing so, the framework involves accumulating evidence from five sources (content, internal structure, relationships with other variables, response processes, and consequences)⁵⁷ to provide a strong scientific basis for proposed score interpretations. As such, validity is seen as a process, where the interpretations of scores that are then evaluated for validity, rather than the instrument itself. Given the multitude of terms used to define specific measurement properties, we adopted those of the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) expert panel.⁵⁸ Although not included in this original publication, we also included elements of acceptability⁵⁹ in our evaluation.

To evaluate *content validity* (i.e., the degree to which the content of an instrument is an adequate reflection of the construct to be measured)⁵⁸ of the ACSPEs, we viewed respondents as the “experts” in their own experiences. In an open-ended question at the end of the survey, they were asked to reflect upon their experiences to determine if any questions were missing or not relevant to them. Respondents could also indicate whether all necessary response options were present.

To evaluate *test-retest reliability* (i.e., the extent to which scores for patients who have not changed are the same for repeated measurement over time),⁵⁸ those who completed the

survey were asked for their consent to complete it a second time. Participants who indicated their willingness to do so were sent the survey 14 days after completion of the first survey. The retest survey asked participants to provide their initials to match responses from both rounds. Further, to limit the potential for response shift,¹¹² participants were asked to confirm that they had not been readmitted to hospital, or had their health deteriorate since taking the first survey. Those who indicated that either of these scenarios took place were excluded from the retest survey. Percent agreement, as well as the intraclass correlation coefficient (ICC; two-way, mixed effects),¹¹³ or Cohen's kappa, were calculated for all questions, as appropriate.¹¹⁴

To evaluate *acceptability* (i.e., the ease of use of an instrument),⁵⁹ a survey question asked respondents about their impressions of the survey. Respondents could indicate whether the survey was easy to read and understand and was of suitable length. We also examined all completed surveys for missing responses.

4.3.4 Additional Analyses

Demographic and clinical characteristics of the sample were reported using descriptive statistics. The percent of respondents rating at the ceiling (i.e., most positive answer choice) for each question was also reported. The degree of association between individual survey questions and the overall rating of care item were reported using the Spearman's rho.¹¹⁵ Interpretation of the size of the correlation coefficient was as follows: 0.00 to 0.30 – negligible; 0.30 to 0.50 – low, 0.50 to 0.70 – moderate, 0.70 to 0.90 – high, 0.90 to 1.00 – very high.¹¹⁶ The percentage of missing responses to each question was also reported. Only completed surveys, as determined by the participant completing the final survey question, were included in analyses. All analyses were performed using SAS version 9.4 for Windows (SAS Institute Inc.) and IBM® SPSS® version 25 (IBM® Inc.). This study was approved by the University of Calgary Conjoint Health

Research Ethics Board (CHREB, project number REB19-1937), and was conducted at the University of Calgary, in Calgary, Alberta, Canada.

4.4 Results

4.4.1 Profile of Participants

From June 1 to September 30, 2020, a total of 1,004 patients were discharged from hospital, and were mailed a study invitation letter. Of these, 107 expressed interest in the survey by contacting the research team. Ninety-one participants went on to complete the baseline survey, with the majority (n=78, 86%) opting for the e-mail option. The final survey response rate was 9.1%. Participants completed the survey at an average of 27 days following discharge from hospital (range: 9 to 85 days). When compared with non-responders (n=913), those who completed the survey had a similar sex distribution (respondents: 70% males vs. 65% among non-respondents), average age (67.6 vs. 66.9 years), and average length of stay (4.5 vs. 5.0 days).

The demographic and clinical profile of participants is shown in Table 4.1. The sample was comprised of 64 males and 27 females, with an age range of 34 to 89 years. The majority of participants lived in an urban area (n=74, 81%), and had an education level of college or greater (n=68, 75%). During their hospital stay, which ranged from 1 to 19 days, participants reported having a variety of surgical procedures, including angioplasty, pacemaker insertion, coronary artery bypass grafting, valve replacement, cardiac ablation, and stent insertion. Participants reported having better mental/emotional than physical health (70% vs. 45% reporting “excellent” or “very good”).

4.4.2 Content Validity

Participants provided very positive feedback about the survey's content, its acceptability, and usability. The majority expressed that the survey adequately captured their experiences with care, that it was straightforward, had a logical flow (i.e., starting with intake/admission to hospital, and concluding with discharge and follow-up care), was easy to understand, and took a reasonable amount of time to complete. One participant provided a very salient comment about their importance of surveys such as the ACSPEs:

“These surveys are important so that patients can receive the right care.

Patients cannot be treated like a number.”

Several participants provided opportunities for improvements to the survey. A list of these, as classified according to content and acceptability of the instrument, is provided in Table 4.2. Examples of content-related suggestions included having a better definition of what was considered to be a cardiac surgery, having a better description of which hospital stay to consider (as some patients may have been hospitalized multiple times), perceived difficulties in answering certain questions (based upon one's course of care, the lack of a “not applicable” option to certain items, or being unconscious for a prolonged period), the desire for more open-ended responses, and the opportunity to expand upon certain answers being the current “yes/no” or numerical rating options.

4.4.3 Test-Retest Reliability

Seventy participants indicated their willingness to complete the retest survey. Of these, 16 failed to complete it, and another four indicated that they had been re-hospitalized or had their health worsen since the first survey. This resulted in 50 participants (56% of respondents; 41 males, 9 females) who completed the retest survey at a mean interval of 19.1 days (range: 14 to

46). Test-retest results are also shown as part of Table 4.3. Percent agreement ranged from 54% to 94%. Of the 30 items assessed, 16 (53%) had a percent agreement of 80% or greater, and 27 (90%) had agreement of 70% or better. ICC/Kappa values ranged from 0.17 to 0.92, and 16 items (53%) had a coefficient of 0.70 or greater. With respect to ceiling score, the percent of respondents with the most positive answer choice to each item ranged from 86% (doctor courtesy and respect, recommendation of hospital) to 26% (quietness of hospital room).

4.4.4 Acceptability

In addition to the comments shown in Table 4.2, a high degree of acceptability of the ACSPEs was shown via the small number of missing responses. The majority of questions (n=23, 74%) were answered by all respondents. Five questions (16%) had one missing response, two (6%) had two missing responses, and one question (3%) had three missing responses.

4.4.5 Correlation Between Individual Questions and Overall Rating of Care

Excluding the rating question regarding recommendation of the hospital, the five questions with the highest observed correlation with the overall rating of care pertained to patient involvement in care decisions ($r=.49$, $p<.001$), information about condition and treatment ($r=.46$, $p<.001$), patients gaining a better understanding of their condition ($r=.46$, $p<.001$), receiving information about post-discharge worries ($r=.45$, $p<.001$), and doctors listening carefully to patients ($r=.40$, $p<.001$). These correlations would all be classified as low. Complete results from the correlational analyses are shown as part of Table 4.3.

4.5 Discussion

This cohort study was conducted to assess the content validity, test-retest reliability, and acceptability of the newly created ACSPEs; a survey designed to measure the experiences of

those who have undergone cardiac surgery. The study demonstrated promising results in a preliminary cohort of 91 consenting participants who completed the survey, including over half (n=50, 56%) who completed the retest survey.

From the perspective of content validity, most participants expressed that the items comprising the survey made sense and were adequate for capturing their comprehensive experience with cardiac surgery. Participants highlighted the logical flow of the survey; beginning with access/admission to the hospital and concluding with elements of the hospital discharge process, coordination with follow-up care (i.e., cardiac rehabilitation, primary care), and an understanding of when normal activities could be safely resumed. Many items also demonstrated acceptable levels of test-retest reliability, with the majority of survey questions having agreement of 70% or better. Resultant ICC/Kappa values were also quite promising. Respondents had very high regard for their care, with the majority rating at the ceiling (i.e., most positive answer choice) for most questions.

In the context of acceptability, participants provided excellent suggestions for improvements to assist in the use and interpretation of the ACSPEs. Many of these are easily actionable (e.g., qualifying statements about surgeries in scope, defining which hospital discharge to consider, additional “not applicable” options to certain questions) and will be reflected in the future version of the survey. Although results relating to specific elements of care were not a declared focus of the present study, it is also important to note that approximately one in five (n=18, 20%) of participants stated that they had a concern with care. Providing opportunities for patients to bring concerns forward is paramount to improving care and patient safety.¹¹⁷ As such, we propose that the ACSPEs may play an important role within existing frameworks^{118,119} to respectfully manage and learn from concerns that are brought forward.

This project also serves to highlight the successful collaboration between our research team and our local authority. Our approach, which capitalized upon existing data infrastructure and analytic expertise, enabled all study recruitment and project activities to be completed with minimal disruption to the healthcare system and to patients. This success of this approach cannot be overstated, particularly considering the significant challenges imposed by the COVID-19 pandemic. Of note, the majority of study participants elected to complete the survey via e-mail. This highlights the feasibility of online questionnaires among older adults and supports the findings of a systematic review conducted by Remillard et al.¹²⁰ Use of e-mail experience surveys may be a viable option where other modalities (e.g., telephone) may not be feasible, or the clinical population may be precluded from participation (e.g., speech difficulties, those who may have hearing impairments). We propose that learnings from our approach to patient partnership and collaboration with our health authority may be leveraged by others looking to do similar research across a variety of clinical areas.

In contrast with these strengths, there are notable limitations of this study. A primary one lies within our small response rate of 9%. This is much lower than seen in routine surveying of adult patients¹²¹ and parents of hospitalized children¹²² within our health authority. We propose three reasons for the low response rate. First, there were significant restrictions in place for contacting patients due to the COVID-19 pandemic. This precluded us from engaging with, and contacting patients and provider stakeholders directly, as no doubt, there were bigger issues at play. Ideally, recruiting patients at the point-of-care (i.e., while in hospital), with the permission and guidance of the clinical team, may have bolstered our recruitment rate. Secondly, the clinical information system used (by our health authority) to compile the list of eligible patients did not contain any clinical details (e.g., treatments or procedures administered). As such, we were

unable to obtain the true number of surgical patients who were sent an invitation letter. To support this, approximately 30 patients contacted the research team to indicate that they had not undergone cardiac surgery, but were managed via non-surgical means (e.g., testing, medication, monitoring, education about their condition, etc.). Instances such as these would result in increasing our denominator, thus, decreasing our reported response rate. Third, due to additional costs and logistics involved, we did not send any reminders to participants. Providing these, as suggested in formal surveying protocols such as the one outlined by Dillman⁵³ may have increased the response rate. Despite the reasons behind our response rate, it is important to note that our sample was representative (i.e., similar age, sex distribution, length of hospital stay) of the greater patient population who received cardiac care during the study timeframe.

Other study limitations, however, may impact the generalizability of our findings. As our survey was conducted by e-mail and mail, our findings may not be generalizable to other modes of administration (e.g., telephone, interactive voice response). To this end, prior works have shown that HCAHPS^{49,86} and CPES-IC¹²³ survey results vary according to the mode of surveying used, with telephone respondents typically providing more positive ratings. Our survey was also conducted in English only. Finally, despite being administered at a mean interval of 27 days from hospital discharge; a much shorter recall period than used in comparable surveys, the possibility of recall bias cannot be discounted.

4.6 Conclusions

This study presents the ACSPEs – an instrument designed to capture the experiences of those who have undergone cardiac surgery. Our preliminary results are promising with respect to the content validity, test-retest reliability, and acceptability of the instrument. Further study to

evaluate additional measurement properties, such as construct validity and criterion validity may further inform the use and adoption of the ACSPEs. Inclusion of the ACSPEs as a measure of patient experiences within existing clinical and administrative datasets/registries may also provide further insights. Combining the ACSPEs with other patient questionnaires (e.g., patient-reported outcome measures) may result in reduced survey burdens. Future research is necessary to examine use of the ACSPEs among cardiac patients who are treated non-operatively.

Table 4.1 Profile of study participants (n (%), unless otherwise indicated)

Variable	Value
Sex	
Male	64 (70%)
Female	27 (30%)
Mean age in years (SD, range)	67.6 (11.9, 34-89)
Mean length of stay in days (SD, range)	4.5 (3.6, 1-19)
Location of residence	
Urban	74 (81%)
Rural	17 (19%)
Level of Education attained	
High School or less	21 (23%)
College or Diploma	26 (29%)
University	42 (46%)
Declined to respond	2 (2%)
Self-reported physical health	
Excellent	9 (10%)
Very good	32 (35%)
Good	29 (32%)
Fair	17 (19%)
Poor	4 (4%)
Self-reported mental/emotional health	
Excellent	24 (26%)
Very good	40 (44%)
Good	22 (24%)
Fair	5 (6%)
Poor	0 (0%)

Table 4.2 Suggestions to improve the survey content, acceptability and usability

<u>Content-related comments</u>
I did have to look up angioplasty to be sure that my stent implantation was covered under that title.
Please ask about lighting. Staff forgot to turn off lights in the middle of night - agony if you're trying to recover/rest. Also, you failed to ask about the hospital food, which should be a cornerstone of good health.
There should have been questions more specific to my condition and experiences. I've had several heart attacks, bypass surgery and many angioplasty plus stents.
I would suggest asking questions regarding mental health issues patients may experience both in the hospital and once released. An area I feel that is lacking is wrap-around services for the mental health of patients (e.g. sleeping issues, anxiety, etc.) after their cardiac procedure is finished at the hospital.
<u>Comments about acceptability and usability</u>
The question about whether the follow up with your family doctor was organized could have another optional answer, as they told me to set up an appointment with my family doctor, it wasn't organized for me.
I can see why the questions are asked but some could a verbatim response. For example, the question about the folks in the emergency room. I was given a small amount of sedative and can't remember too much.
The options for response seem at odds with many of the questions. The generic response options seem too vague. While this survey is entitled to be regarding cardiac surgery experience it seems to be entirely focussed on the hospital stay, not the procedure and cardiac care.
At some points I would like to add space to add my comments. For example why I answered Yes or No to a particular question.
My only concern is that there was no way, other than in the very last section, to identify the circumstances surrounding my hospital stay, I was unable to participate in the initial assessment of my condition as I was unconscious. Also, in terms of COVID-19 - we are all affected by it in most aspects of our lives, and the effects did not adversely affect my care.
The questions about emergency - it generally takes some time before you are seen by a doctor / specialist so there generally is a lot of waiting. The term 'too long' is very subjective.
Too long. Question re: involvement of family in care decisions is awkward - some decisions are inappropriate for family involvement, but you are asking about how often they were involved, not how often compared to my preferences/expectations. Also, which age do you want (age now or at event)?
Question regarding testing and procedure scheduling didn't allow for a not applicable response.
I required resuscitation ... was sedated and intubated. I was admitted on a Wednesday afternoon and woke up extubated on Friday ... I remember nothing of the procedure. Some questions need a not applicable response.
In my case, there was no need for my family to participate in my treatment. There is no answer stating family involvement unnecessary.
I would have liked being able to expand on a few answers instead of just yes or no, 1-10.

The initial question about the surgery wasn't clear to me whether you wanted historical procedures or the most recent procedure. Some of the questions weren't relevant to me as I didn't stay overnight (such as was the room quiet).

Table 4.3 Item correlations, percent at ceiling, percent agreement, and test-retest reliability statistics

Item Number and Description	Correlation with Overall Rating	Percent at Ceiling	Percent Agreement	Retest Reliability Coefficient
Care from nurses				
10. Nurse courtesy and respect	0.16	85%	92%	0.63
11. Nurse listening	0.26	73%	82%	0.69
12. Nurse explanations	0.18	66%	82%	0.68
13. Call button response	0.17	72%	76%	0.85
Care from doctors				
14. Doctor courtesy and respect	0.30	86%	94%	0.54
15. Doctor listening	0.40	75%	88%	0.69
16. Doctor explanations	0.31	77%	90%	0.89
Physical environment				
17. Room cleanliness	0.24	64%	80%	0.81
18. Room quietness	0.07	26%	63%	0.82
Pain control and medications				
21. Pain well controlled	0.25	63%	80%	0.35
22. Staff helped with pain	0.37	80%	73%	0.35
24. Purpose of new medications	0.27	64%	70%	0.69
25. Side effects of new medications	0.06	28%	70%	0.88
26. Met with pharmacist	0.18	38%	86%	0.87
Information and decision-making				
27. Communication between staff	0.30	54%	72%	0.71
28. Staff informed and up-to-date	0.38	64%	80%	0.83
29. Tests/procedures done on time	0.21	64%	82%	0.80
30. Information about condition and treatment	0.46	64%	82%	0.85
31. Involvement in care decisions	0.49	70%	82%	0.73
32. Family/friend involvement in care decisions	0.10	55%	72%	0.67

Returning home				
33. Discussed help needed at home	0.09	67%	54%	0.17
34. Information about symptoms/health problems	0.13	75%	90%	0.81
35. Clear understanding of medications	0.35	68%	76%	0.56
36. Information about post-discharge worries	0.45	57%	73%	0.70
37. Better understanding of condition	0.46	53%	69%	0.85
38. Resumption of usual activities	0.30	60%	72%	0.65
39. Follow-up with family doctor	0.21	53%	70%	0.28
40. Referral to cardiac rehabilitation	0.18	51%	88%	0.88
Overall impressions				
43. Overall rating of care	n/a	37%	72%	0.92
44. Recommendation of hospital	0.50	86%	90%	0.38
Concerns with care				
45. Concern about healthcare services	0.30	780%	n/a	n/a

CHAPTER FIVE: SUMMARY

5.1 Summary of Main Findings

Knowledge derived from the patient experience can be used to enhance healthcare services and can foster patient-centred learning health systems. Assessing one's experiences with care using surveys, is fundamental to understanding what is working well and what can be improved in the eyes of patients. In addition to improvements within the context of the Triple Aim framework,¹ patient-reported experiences may inform conversations pertaining to value-based healthcare, which is shown according to a framework by Teisberg et al.¹²⁴ in Figure 5.1. Prior to using results and drawing inferences from an experience survey, however, we must ensure that the instrument used is a) valid - that it measures the right things by asking questions that are relevant to patients, b) reliable - that it is consistent, and c) feasible - that it is amenable to completion by being easy to understand, and of acceptable length. In collaboration with patient partners and the provincial health authority, this mixed-methods thesis work provides an in-depth look into the experiences of patients who have undergone cardiac surgery in Alberta. It also addresses and improves upon gaps in measurement and knowledge that can be derived from this clinical and surgical group, through the development and testing of the ACSPEs instrument.



Figure 5.1 Framework for implementation of value-based healthcare¹²⁴

This thesis includes three phases that inform the development of the ACSPEs. The first phase includes a study⁶² in which we leveraged and linked routinely captured survey and administrative data to take a deeper dive into the comprehensive experience of Albertans who underwent cardiac surgery over a four-year period. This study⁶² revealed that respondents had a high overall rating of their care and were quite likely to recommend the hospital to family members and friends. Moving beyond global indicators of patient satisfaction, we examined 26 other survey questions to learn more about patient experiences with specific processes of care. Some examples of these included: how often nurses and doctors explained things in a way patients could understand, how often staff did everything they could to help with pain, how often patients were involved in decisions about their care, and whether patients received information in writing about discharge instructions. This approach was novel, and had not yet been done in this clinical and surgical population using the CPES-IC.^{5,39,95,123} Our results showed that the top performing questions (i.e., ones with the highest percentage of “top box” ratings, as identified by the most positive answer choice) pertained to discharge planning (e.g., discussion of help needed when returning home, receiving written discharge instructions), being treated with courtesy and respect by nurses and doctors, and hospital staff doing everything they could to help with the patient’s pain. Conversely, lowest performing questions (i.e., ones with the lowest percentage of “top box” ratings) pertained to staff informing patients about the potential side effects of new medications, night noise of the hospital environment, and cleanliness of the hospital room and bathroom. The results also highlighted further opportunities for improvements via increasing patient involvement in their care decisions, and a need for greater discussion around patient worries, fears and anxieties. These findings aligned with those from prior research among

adult¹²⁵ and pediatric inpatients¹²² in Alberta. Although not an a priori goal of the first study from this thesis,⁶² the work also served to highlight care topics/processes that may be relevant to cardiac surgery patients, but not asked as part of the existing CPES-IC instrument.

In a second phase, a qualitative project,⁶³ we interviewed Albertans who had previously had cardiac surgery to gain a deeper understanding about the aspects of care that were important to them. Participants emphasized the importance of the overall care experience, communication, the physical hospital environment, ongoing care needs and management, and person-centred care. Participants highlighted that their experiences with cardiac surgery began before admission to hospital and ended long after being sent home. Our findings echoed those of our previous qualitative studies,^{81,82,106} and revealed additional condition-specific topics that could be potentially addressed in a future survey specifically designed for this clinical group.

In the third and final phase of this doctoral study, we integrated content from the CPES-IC⁵ and IHD (CHD)⁴⁷ surveys with learnings from our qualitative work⁶³ to develop and test a new condition-specific survey, the ACSPES. Among a cohort of 91 patients who underwent surgery during a four-month period (June to September 2020), we revealed that the newly developed ACSPES had adequate content validity, and acceptability. In a subset of 50 patients, test-retest reliability was also shown to be good,¹¹³ with the majority of items having an ICC of 0.65 or greater. Somewhat surprising, given the average age of participants, was that most preferred to complete the survey via e-mail. Many participants provided positive comments about their experience with the survey instrument, and on a larger scale, some expressed their appreciation for being able to provide information about their own experiences to positively impact care for future patients. Study participants also provided several suggestions to improve the survey. The main

findings from the combined research, with emphasis upon the mixed-methods approach and mixing of the results, are summarized in Table 5.1.

Table 5.1 Summary of main results from this thesis

Study	Main Results
Phase 1 (Quantitative)	<ul style="list-style-type: none"> - 1,082 surveys completed over a four-year period - Experiences with care were quite positive - <u>Best-performing items</u>: <ul style="list-style-type: none"> - Discussion of help needed when returning home - Receiving written discharge instructions - Being treated with courtesy and respect by nurses and doctors - Hospital staff doing everything they could to help with pain. - <u>Opportunities for improvement</u>: <ul style="list-style-type: none"> - Being told about the potential side effects of new medications - Night noise of the hospital environment - Cleanliness of the hospital room and bathroom - Some potentially relevant questions not asked in the CPES-IC
Phase 2 (Qualitative)	<ul style="list-style-type: none"> - Eight individual, semi-structured interviews - <u>Emergence of five key themes</u>: <ul style="list-style-type: none"> - Overall experience - Communication - Physical hospital environment - Care needs and ongoing management - Person-centred care - Many aspects of care discussed, confirming findings from phase 1 - Additional aspects of care which could be asked on a future survey
Phase 3 (Preliminary use of the ACSPEs)	<ul style="list-style-type: none"> - Integration of results from phases 1 and 2 - 91 participants, with 50 re-test surveys - Participants indicated evidence of content validity - Majority of questions ICC/Kappa of 0.70 or greater - Very few missing items - Participants provided actionable ideas to improve the survey

5.2 Implications for Measuring Person-Centred Care

Patients have many diverse values, cultural norms, care needs, and communication styles; all of these affect person-centred care (PCC). Using the Donabedian model as a guide, the

framework by Santana et al.⁷ outlines PCC domains that measure structures that are important to provide PCC (e.g., health system policies), processes that are involved in the delivery of PCC (e.g., respectful and compassionate care, communication, engaging patients in managing their care, integration of care) and outcomes (e.g., overall ratings of patient experiences). These PCC domains are easily derived from existing patient experience surveys. Given the promising results with respect to the content validity, reliability, and acceptability of the ACSPEs, the instrument may be used to measure aspects of PCC.⁷ Most items included in the CPES-IC and ACSPEs are classified under the process area of the Santana's Framework.⁷ In analyzing and reporting the results of patient experience surveys, it is important to remember that survey respondents provide feedback based on their own perceptions, and there are no right or wrong answers. Each person's care experiences are equally valid and should be treated as such. An example to illustrate this pertains to communication with healthcare providers. As an individual with a graduate-level education, who has worked in healthcare for close to 20 years and has experienced the healthcare system numerous times as a patient, parent, and caregiver, my ability to understand medical information is quite high. In contrast, someone with no healthcare experience, or who has a lower level of education may have a different experience. Despite receiving the same explanation about our condition, the latter person may report not receiving information in a way they could understand and may require additional support.

5.3 Implications for Measuring Quality of Care

Like PCC, quality of care is a very broad term, and can be a difficult concept to quantify and define.^{11,25} In his discussion on how to assess quality of care, Donabedian stated that one should begin with the measurement of performance of physicians and other health

practitioners.¹¹ He also proposed that there were two elements of clinician performance which should be considered - technical and interpersonal. Technical performance is an assessment of the knowledge and judgements which are used to arrive at an appropriate care plan, as well as the comparison of these to best practices. Technical performance is more straightforward, and in the example of cardiac surgery, the surgeon has received many years of training, has received board certification, has had opportunities to hone and refine skills, and is up-to-date and knowledgeable on the latest evidence to support their practices. Interpersonal performance is judged by the exchange of information which occurs between patient and provider. The patient may communicate information to the clinician, and based on this, the clinician provides information about the illness and its management in a fashion which may encourage the patient to be an active participant in his or her care. Interpersonal performance encompasses things like delivering bad news, and providing care that is responsive, compassionate, and empathetic. Although Donabedian did not impose a hierarchy on technical and interpersonal performance, he proposed that interpersonal communication is the driver of technical care. This is important, as the nature of interpersonal communication can be complex. Further, the necessary interpersonal skills are ones which many clinicians may rarely, if ever, have the opportunity to practice and refine over their career. To this effect, in 2011, Atul Guwande, a renowned surgeon, writer, and public health leader, wrote about how his performance seemed to be plateauing. He proposed, like with athletes and professional singers, that medical professionals could benefit from a coach – one who observes and identifies opportunities for improvement.¹²⁶ Having regular reviews of patient experience results pertaining to interpersonal communication may afford clinicians with the necessary opportunities to reflect and refine their skills in a non-judgemental way. Quality

consultants, coupling the data with principles from implementation science and audit and feedback¹²⁷⁻¹²⁹ could serve as the “coaches” for high-performing clinicians and teams.

It is also important to highlight the role of patients and of managing appropriate care expectations in the delivery of high-quality PCC. PCC is not about simply caving to patient wishes or wants. It is about having an informed, two-way conversation to determine the best treatment options for a given patient within the context of evidence-based medicine. It takes time to practice effective PCC, and to build a rapport between provider and patient. In recent years, patients have increasingly sought out information about their condition and treatment via resources on the internet.¹³⁰ As a result, they may take on a stronger position when advocating for a given treatment or diagnostic test. This may cause tension, and place providers in a challenging position; one where they must inform the patient that a given treatment or test is not indicated, while respecting the patient as a person. A well-documented example of this is antimicrobial stewardship,¹³¹ where despite the wishes of patients, physicians must advise that prescribing antibiotics is not appropriate for managing the common cold.¹³² Although potentially difficult, these types of conversations also help ensure that our limited healthcare resources are used in a prudent fashion, while serving to educate and empower patients.

To make impactful and lasting improvements in PCC and quality of care, it is also essential to address factors beyond those in the process-level of Donabedian’s model. It is important to not only focus upon clinicians and patients, but to also include the administrators and executives who help shape structural elements, such as a healthcare organization’s mandate and underlying policies. Within the context of the framework of Santana et al.,⁷ and that of this research, AHS has a strong organizational commitment to PCC and to improving care for patients and families. Beyond its mission statement, which is “*to provide a patient-focused,*

quality health system that is accessible and sustainable for all Albertans”,¹⁷ the Patient First Strategy¹² is one of its four foundational strategies. In addition to having a Patient and Family Advisory Committee (PFAC),¹³³ patients and family members play active roles throughout the organization. Examples of this include AHS’ Strategic Clinical Networks (SCNs).¹³⁴⁻¹³⁶ Beyond this, AHS has recognized the importance of regularly capturing patients’ feedback about the care they receive. They have committed the necessary funds, infrastructure, and expertise to administer the CPES-IC across the province.

5.4 Use of Patient Experience Data to Improve Care

Although using patient experience data for quality improvement may seem intuitive, there are very few studies which outline systematic approaches to do so. This is highlighted by a 2016 review paper by Gleeson et al.,¹³⁷ in which over 5,000 abstracts were screened, and only 11 full texts retained. The authors highlighted that this is a relatively new area, and that many interventions may have not been published in peer-reviewed media or may not be publicly available. They also concluded that, at the time of their publication, there was no one single best way to collect or use patient reported experience data, and that more research is needed to understand how this data may be used for quality improvement.¹³⁷ In the broader sense of patient feedback, Berger et al.¹³⁸ conducted interviews with clinical staff, administrators, and quality consultants at three large hospitals in Sao Paulo, Brazil. They highlighted many practices that contributed to their success in using patient feedback to improve care. These included: 1) hospitals having clear objectives that value patients’ perspectives, 2) enabling a non-punitive culture to encourage patient feedback, 3) having multiple venues for patients to provide their feedback, including formal surveys, social media, and informal feedback (verbally) with care

teams, 4) examining specific aspects of patient experience surveys (as opposed to merely focusing on overall ratings of care), 5) incorporating quality improvement methodology such as Plan, Do, Check, and Action cycles, and 6) aligning organizational processes to support quality improvement activities. These practices address many of the structural and process elements of the Donabedian model, as described earlier.

In the United States, patient experience data may serve another purpose. As the collection and public reporting of hospital-level HCAHPS data is mandatory under the Patient Protection and Affordable Care Act,³⁴ it is routinely used for marketing and competition purposes. Online ratings provide hospitals with a data-driven way to attract clients (patients), and to drive brand loyalty. In this respect, there is a potential for patient experience to take on more features of simple customer service, in addition to those of evidence-based medicine. Examples of this include the HCAHPS Star Ratings,^{139,140} as well as the Net Promoter Score.¹⁴¹

5.5 Strengths

There are three primary strengths of this work. These centered around: a) our collaborative approach with patients, and their active involvement to co-design and test the ACSPEs, b) the mixed-methods research skills and approach to data validation and triangulation, and c) our novel collaboration with health system partners such as AHS, APPROACH, and the University of Calgary, to collect the data required to successfully complete this work during the challenging period of COVID-19. First, patients played many key roles in this thesis work. In study one, they provided in-depth feedback about their care, as captured via the CPES-IC instrument. In the second study, one with a truly patient-oriented design, patients played a more active role by helping to shape the interview guide and study protocol. By providing their own

experiential knowledge about cardiac surgery, they ensured that the interview questions were relevant. In study three, in addition to responding to the draft ACSPES, patients provided their feedback about the content of the instrument and made suggestions about how the survey could be improved for future patients. A second strength was our mixed-methods design. This allowed us to not only support our quantitative findings from study one, but to augment them with rich, qualitative accounts of care. The in-depth interviews conducted in our second study allowed us to better understand and appreciate the experiences of patients who have undergone cardiac surgery in Alberta. Feedback obtained during interviews about what mattered to patients throughout their course of care was necessary and instrumental in developing the ACSPES. Finally, a strength which cannot be underestimated, was our ability to collaborate with AHS and other partners. In study one, AHS provided all necessary data to perform the work under a research agreement with our team. In study two, our partners within APPROACH, AHS, and the Patient Engagement Platform of the Alberta SPOR SUPPORT Unit (ABSPORu) assisted with participant recruitment. In study three, AHS assisted with study recruitment by compiling weekly lists of eligible patients and initiating contact with prospective participants on our behalf. As study three took place during COVID-19, this ensured that the study could take place, while adhering to all necessary public health orders, hospital visitation restrictions, and relevant areas of Alberta's Health Information Act.¹¹⁰

5.6 Limitations

The main limitations of this work are associated with the potential impacts upon the generalizability of our results. First, given that all works featured in this thesis required participants to provide their experiences about their cardiac surgery, there is always the

possibility for recall bias.⁵² Second, all surveys or interviews (as required) were completed in English, and were only completed with patients. Given this, anyone unable to communicate in English (verbally, or in writing) may have been precluded from participating in aspects of the research. As such, our results may not be generalizable to a non-English speaking population, or to individuals who may have differing care needs. A third limitation was that all study participants were treated at Alberta's two large cardiac surgery centres. As such, it is plausible that our findings may not apply to those treated in non-academic centres, or in smaller, community-based hospitals. Future research is required to address these potential limitations.

The final limitations are associated with the low response rate observed in the phase three of the study (approximately 9%). Due to limitations in existing data infrastructure at the time of hospital discharge, we were unable to determine whether a patient received cardiac surgery during their hospital stay. As such, AHS mailed an invite letter to all patients discharged from the cardiac units which were in-scope. This resulted in phone calls and e-mails to the research team and/or AHS from patients who were not eligible for the study. An alternative strategy would have been to wait until the abstracted clinical record was generated in the DAD.⁷⁶ However, this would have been up to 45 days following the patient's discharge, a situation not acceptable in light of the limitations imposed by recall bias. It should be noted that patients who currently complete the HCAHPS or CPES-IC survey must do so within 6 weeks of discharge from hospital, for this reason.^{5,95,142} A potential remedy for this in a future version of the ACSPEs would be to include an appropriate screener question, where prospective participants could be asked to confirm their eligibility by checking off responses from a list of eligible procedures. All other participants could be classified as "non-surgical" and assessed/analyzed

separately. This can also help to determine if the ACSPES may be applicable for assessing the experience of non-surgical patients.

5.7 Outcomes and Dissemination of this Research

This thesis presents the most comprehensive look at the hospital experience of cardiac surgery patients done to date. It has also resulted in the creation of a survey to capture the experiences of said patients. The ACSPES can be used to identify care processes which are working well, as well as those that can stand to be improved in the eyes of patients. Integration of the ACSPES within existing clinical data may lead to improvements in PCC and outcomes for future patients. Findings from the three phases of this doctoral work were first shared with committee members, all of whom approved subsequent submissions to peer-reviewed journals (studies 1 and 2), and a variety of conferences. Results from project one were published in the *Canadian Journal of Cardiology*,⁶² and was the subject of an accompanying editorial¹⁴³ to highlight the work for readers. The manuscript also received attention from the Canadian Broadcasting Corporation (CBC) Radio Edmonton, who invited me as a guest to discuss the findings and implications for PCC. The second manuscript, describing the findings from the qualitative interviews, has been published in *CJC Open*.⁶³ The third manuscript, focusing on the development, content validity, test-retest reliability, and acceptability of the ACSPES, is under review by the authorship team. It will be submitted to the *Journal of Patient Experience*, following completion of my doctoral degree.

In addition to publishing my findings, I have had the privilege of presenting my doctoral work at a variety of academic conferences. These included the Canadian Association for Health Services and Policy Research (CAHSPR), International Society for Quality of Life (ISOQOL),

International Population Data Linkage Network (IPDLN), Alberta SPOR Summer Institute, APPROACH National conference, and Libin Cardiovascular Institute of Alberta Tine Haworth Research Day. I have also presented to key groups including the Libin Cardiovascular Institute's Person to Population (P2) patient stakeholders, the AHS Cardiovascular Health and Stroke SCN,¹⁴⁴ CIHI, and Health Quality Ontario. My doctoral work has also been featured in two videos^{145,146} and one podcast.¹⁴⁷ In addition to my formal thesis work, I have been fortunate to be able to work and collaborate with many great people over the course of my doctoral studies. This has enabled me to publish 14 manuscripts (11 as first author) and 47 conference abstracts during this time. These have all related to furthering the science of patient experience.

5.8 Future Directions

5.8.1 Work to Improve and Streamline the ACSPEs

In study three of the thesis, participants suggested improvements to the ACSPEs. These included the addition of qualifying statements about surgeries that are in-scope, defining which hospital discharge to consider (as patients may have had multiple hospital visits), and inclusion of a “not applicable” option to certain questions. These are easily actioned and will be incorporated in a future version of the survey. Although the survey demonstrated satisfactory levels of content validity and reliability, we have continued recruitment beyond the work of this thesis, in order to study the ACSPEs further in a larger sample, and to also include non-surgical patients. Future analyses will incorporate factor analysis, in order to further classify the study questions into potential domains. This can also serve to eliminate any questions that are statistically redundant. Following initial validation, these methods were used to streamline the

HCAHPS survey, and to further classify its items into seven domains (aspects of care), which are still reported to-date.¹⁴⁸

5.8.2 Quality Improvement and Performance Reporting

For PCC to be valued alongside other dimensions of care quality, measures of patient experience must be included among the broader set of measures used to assess performance and promote quality improvement. Given that the ACSPEs has shown adequate content validity, reliability and acceptability, the measure is appropriate for quality improvement and/or performance reporting purposes. Measures from the ACSPEs can be used in isolation, and in association with other measures of health system performance. In isolation, the ACSPEs can assess a variety of topics deemed important to patients. Given that it evaluates the complete patient journey, from accessing care, to during the hospital stay, to returning home following surgery, there are many potential learning opportunities. As demonstrated using the CPES-IC (project 1), the ACSPEs can be used in a similar fashion for patients to highlight leading practices, while suggesting areas for improvement. As mentioned earlier, AHS has created structures to measure the patient experience and to use it to monitor PCC performance. In recognizing the value in the systematic collection and evaluation of the patient experience, data currently collected via the CPES-IC is not seen as an “add-on”, but rather, as embedded as part of clinical care. After analysis, the data is reported across AHS in a variety of reports. Results can also be viewed by all AHS staff members, in a variety of clinical dashboards.^{149,150} Reporting is done at the province, zone, and hospital levels, and in the case of larger hospitals, by discharge unit. Users can examine data within a given period (i.e., quarter, year), over multiple time periods to examine trends in the results, and in comparison. Finally, results from the overall

rating of inpatient care are a publicly reported performance measure. These are all potential opportunities for reporting data from the ACSPEs.

A fundamental recognition of the Triple Aim framework is that each aim does not exist in isolation of the others. For example, a reduction in hospital readmissions (improved population health) may be associated with a better patient experience as well as a subsequent reduction in costs. Berwick and colleagues¹ were also quick to point out, however, that improving one aim may actually have a detrimental effect on the others. An example of this is in the adoption of new drugs and technologies – items which may result in improved outcomes, but also come with increased costs for patients and/or providers. In addition to presenting patient experience survey results in isolation, they may be presented alongside those of existing indicators as a means of enhancing conversations about health system performance within the context of the Triple Aim. Patient-reported experience measures can also be integrated within existing clinical databases and information systems such as APPROACH,¹⁰⁰ and Connect Care¹⁵¹ to better tell the story about system performance. This integration can serve to better understand how the patient experience relates to existing measures, which are primarily derived from administrative hospital data. An example of this is the HQCA's Fostering Open Conversations to Unleash Solutions (FOCUS) website,¹⁵² in which performance measures derived from administrative data are presented with measures from patient experience surveys in the settings of emergency departments, continuing care, and primary care across Alberta. In the cardiac realm, data acquired using the ACSPEs can be integrated within the existing Cardiac Care Quality Indicators Report – a joint venture of CIHI and the Canadian Cardiovascular Society.¹⁵³

5.8.3 Research

There remains a lack of published literature demonstrating how patient experience data can be used to improve care in the setting of cardiac surgery. As such, the ACSPEs can be leveraged to learn more. As with the discussion of quality improvement and performance reporting, future research can examine patient experience data in isolation, and in relation with other elements of the Triple/Quadruple aim. In addition to work formally presented in this thesis, I have led and conducted extensive research using the HCAHPS, CPES-IC, and Child HCAHPS surveys in Alberta using data from 2011 to 2019. Although not limited to a given clinical population, these previous studies offer insights for future research in cardiac surgery that can be explored using the ACSPEs.

First, it is important to assess whether survey respondents are representative of the greater population under study. This is paramount to discussions about the generalizability, and trustworthiness of the results. In study three, we showed that respondents to the ACSPEs had similar a similar sex distribution, average age, and average length of stay as those who were eligible but did not complete the survey. In a previous study, we compared the demographic and clinical characteristics of HCAHPS survey respondents with those of eligible non-respondents. We found no differences with respect to demographics but did observe that survey respondents had a shorter average length of hospital stay, required less intensive care unit (ICU) care, and tended to be discharged home more often than non-respondents.⁸⁴

Following this, we conducted three studies which examined the demographic and clinical drivers of overall experience, the correlation of individual questions and domains with the overall rating of care, and the relationship between qualitative complaints and the overall rating of care. These studies all used data from the HCAHPS. In the first of these papers, we observed

that males, younger patients, those who had higher levels of education, those born in Canada, and patients who were not discharged home were more likely to not report an overall experience of 10 (best) out of 10.⁷⁵ In the second paper, we reported that questions about coordination amongst providers and the domain of communication with nurses showed the highest correlation with the overall rating of care.¹²⁵ This is valuable information, as it suggests that targeted efforts to improve these aspects of care may result in the greatest impact upon patients' overall experience. In the third paper, we examined just under 9,000 surveys, in which approximately 20% of respondents provided an open-ended complaint about their care.¹⁵⁴ The most frequent complaints pertained to nursing care, medications, and food. In theming the complaints and looking at their relationship with the overall rating of care, we observed that complaints pertaining to mixed-gender rooms were most detrimental to the overall rating of care. Another important finding from this work was that those who reported that their complaint was raised with staff or the organization, and that they were satisfied with how the complaint was handled and addressed, showed no difference in their overall rating of care when compared with those without a complaint. This finding is extremely important in the context of PCC, as it demonstrates that effective complaint resolution can have a positive impact upon one's care experience.

In addition to the aforementioned studies, which looked at patient experience data in isolation, we explored patient experience in relation with other measures of quality and health system performance. In a first, we examined the association between patient safety indicators (PSIs) and ratings of overall care, nurses, and doctors. From this, patients who had one or more PSIs in their inpatient record had lower ratings of care on these three survey ratings of care.¹²¹ Future research that expands on this, to explore specific elements of communication versus PSIs

in cardiac care may highlight potential associations between elements of patient experience and patient safety. In a second publication, we examined the association between two survey questions pertaining to a) patient involvement in their care decisions, and b) whether patients received written discharge information/instructions, and unplanned readmissions in the year following the index hospital stay. We reported that those who reported being less involved in their care, or who did not receive written discharge information had higher odds of being readmitted to hospital.¹⁵⁵ Finally, in a subsequent paper, we examined the relationship between patient-reported night noise in hospital and unplanned readmissions using the CPES-IC. We demonstrated that those who reported that their hospital environment was not always quiet at night were more likely to be readmitted to hospital in the following 30 or 90 days.¹⁵⁶ Further works have also examined disparities in patient experience according to sex,¹⁵⁷ health condition,¹⁵⁸ and hospital type.^{75,122} All of the research outlined above can be explored in a cardiac cohort using the ACSPEs. This may also spur further qualitative work to better understand the underlying factors which contribute to the observed results.

5.9 Conclusion

Experience surveys are widely used to obtain feedback from patients about the healthcare services that they receive. In the context of patient-centred, learning health systems, they provide patient-reported data to inform the delivery of healthcare services. In its comprehensive, mixed-methods approach, this thesis has provided an in-depth look at the experiences of patients who have undergone cardiac surgery across Alberta. It has also integrated learnings from patients to develop the ACSPEs - a survey instrument which may better capture the unique experiences of cardiac surgery patients. Preliminary use of the ACSPEs revealed promising results pertaining to

the content validity, test-retest reliability, and acceptability of the instrument. Future research to conduct additional psychometric testing of the ACSPEs and to evaluate additional properties related to validity in a larger cohort of patients is required. Data from the ACSPEs may be used alone, or in combination with administrative and other patient-reported data to inform patient-centred learning health systems.

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**APPENDIX A: THE ALBERTA CARDIAC SURGERY PATIENT EXPERIENCES
SURVEY, MAIL VERSION**

The Alberta Cardiac Surgery Patient Experiences Survey

Instructions

- ✓ Please only fill out this survey if you recently had cardiac (heart) surgery.
- ✓ Please answer all the questions by checking the box to the left of your answer.
- ✓ Unless you are told otherwise, please only provide your one most appropriate answer to each question.
- ✓ Based on an answer choice, you may be told to skip over some questions in this survey. When this happens, you will be provided with instructions.
- ✓ Your response to this survey is voluntary, and will provide us with important information about what patients think about cardiac surgery care in Alberta.
- ✓ Please note that the survey is double-sided – there are questions on the front and back of each page.

SECTION 1: A brief introduction to your experience

1. Please tell us what surgery/surgeries you experienced:

Please select all that apply

- Coronary Artery Bypass Graft (CABG)
- Percutaneous Coronary Intervention (Angioplasty)
- Valve Replacement
- Pacemaker Insertion
- Other, please specify: _____

SECTION 2: Your entry to the hospital

2. Was your hospital stay for your heart surgery planned in advance, or was it an emergency?

- Planned in advance (***please go to Question 3***)
- Emergency (***please go to Question 6***)
- I was already in the hospital for something else (***please go to Question 9***)

3. How do you feel about the length of time you were on the waiting list before your admission to hospital?

- I was admitted as soon as I thought was necessary
- I should have been admitted a bit sooner
- I should have been admitted a lot sooner

4. Before coming to the hospital, did you have enough information about what was going to happen during the admission process?

- Not at all
- Partly
- Quite a bit
- Completely

5. Was your admission into the hospital organized?

- Not at all
- Partly
- Quite a bit
- Completely

Please only answer Questions 6 to 9 if you were admitted through the Emergency Department (you responded “Emergency” to Question 1)

6. When you were in the Emergency Department, did you get enough information about your condition and treatment?

- Not at all
- Partly
- Quite a bit
- Completely

7. Were you given enough information about what was going to happen during your admission to the hospital?

- Not at all
- Partly
- Quite a bit
- Completely

8. After you knew that you needed to be admitted to a hospital bed, did you have to wait too long before getting there?

- Yes
- No

9. Was your transfer from the Emergency Department into a hospital bed organized?

- Not at all
- Partly
- Quite a bit
- Completely

SECTION 3: Your care from NURSES

10. During this hospital stay, how often did nurses treat you with courtesy and respect?

- Never
- Sometimes
- Usually
- Always

11. During this hospital stay, how often did nurses listen carefully to you?

- Never
- Sometimes
- Usually
- Always

12. During this hospital stay, how often did nurses explain things in a way you could understand?

- Never
- Sometimes
- Usually
- Always

13. During the hospital stay, after you pressed the call button, how often did you get help as soon as you wanted it?

- Never
- Sometimes
- Usually
- Always

SECTION 4: Your care from DOCTORS

14. During this hospital stay, how often did doctors treat you with courtesy and respect?

- Never
- Sometimes
- Usually
- Always

15. During this hospital stay, how often did doctors listen carefully to you?

- Never
- Sometimes
- Usually
- Always

16. During this hospital stay, how often did doctors explain things in a way you could understand?

- Never
- Sometimes
- Usually
- Always

SECTION 5: The physical environment

17. During this hospital stay, how often were your room and bathroom kept clean?

- Never
- Sometimes
- Usually
- Always

18. During this hospital stay, how often was the area around your room quiet at night?

- Never
- Sometimes
- Usually
- Always

19. During this hospital stay, what type of room were you in?

- Private room (I was the only patient in my room)
- Room with one roommate (2 patients, including you)
- Room with more than one roommate (more than 2 patients, including you)

SECTION 6: Pain control and medications

20. During this hospital stay, did you need medicine for pain?

- Yes
- No (*please go to Question 23*)

21. During this hospital stay, how often was your pain well controlled?

- Never
- Sometimes
- Usually
- Always

22. During this hospital stay, how often did the hospital staff do everything they could to help you with your pain?

- Never
- Sometimes
- Usually
- Always

23. During this hospital stay, were you given any medicine that you had not taken before?

- Yes
- No (*please go to Question 26*)

24. Before giving you any new medicine, how often did hospital staff tell you what the medicine was for?

- Never
- Sometimes
- Usually
- Always

25. Before giving you any new medicine, how often did hospital staff describe possible side effects in a way you could understand?

- Never
- Sometimes
- Usually
- Always

26. During your hospital stay, did you meet a pharmacist?

- Yes
- No
- I don't know/can't remember

SECTION 7: Information exchange and decision-making

27. During your hospital stay, did you feel that there was good communication about your care between doctors, nurses and other hospital staff?

- Never
- Sometimes
- Usually
- Always

28. How often did doctors, nurses and other hospital staff seem informed and up-to-date about your hospital care?

- Never
- Sometimes
- Usually
- Always

29. How often were tests and procedures done when you were told they would be done?

- Never
- Sometimes
- Usually
- Always

30. During this hospital stay, how often did you get all the information you needed about your condition and treatment?

- Never
- Sometimes
- Usually
- Always

31. Were you involved as much as you wanted to be in decisions about your care and treatment during this hospital stay?

- Never
- Sometimes
- Usually
- Always

32. Were your family or friends involved as much as you wanted in decisions about your care and treatment?

- Never
- Sometimes
- Usually
- Always
- I did not want my family or friends to be involved
- I did not have family or friends to be involved

SECTION 8: Preparation for, and returning home

33. During this hospital stay, did doctors, nurses or other hospital staff talk with you about whether you would have the help you needed when you left the hospital?

- Yes
- No
- I did not require any help after I left hospital

34. During this hospital stay, did you get information in writing about what symptoms or health problems to look out for after you left the hospital?

- Yes
- No

35. Before you left the hospital, did you have a clear understanding about all your prescribed medication, including those you were taking before your hospital stay?

- Not at all
- Partly
- Quite a bit
- Completely

36. Did you receive enough information from hospital staff about what to do if you were worried about your condition or treatment after you left the hospital?

- Not at all
- Partly
- Quite a bit
- Completely

37. When you left the hospital, did you have a better understanding of your condition than when you entered?

- Not at all
- Partly
- Quite a bit
- Completely

38. When you left the hospital, did hospital staff tell you when you could resume your usual activities (such as work, driving a car and sexual activity)?

- Not at all
- Partly
- Quite a bit
- Completely

39. When you left the hospital, were arrangements made for you to see your family doctor after you returned home?

- Yes
- No
- I don't know
- I do not have a family doctor

40. Were you referred to a cardiac rehabilitation program?

- Yes
- No (*please go to Question 42*)
- I don't know (*please go to Question 42*)

41. Do you plan on attending/have you attended the cardiac rehabilitation program?

- Yes (*please go to Question 42*)
- No

42. If no, what are your reason(s) for not attending?

Please select all that apply

- Too difficult to travel to the sessions
- Too expensive (e.g. gas, parking)
- The timing of the sessions was inconvenient
- I am scared
- I have other health concerns which prevent me from attending
- Other, please specify: _____

SECTION 9: Your overall impressions

43. Using any number from 0 to 10 where 0 is the worst hospital possible and 10 is the best hospital possible, what would you use to rate this hospital during your stay?

- 0 (worst possible hospital)
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 (Best hospital possible)

44. Would you recommend this hospital to your family and friends?

- Definitely no
- Probably no
- Probably yes
- Definitely yes

SECTION 10: Concerns about your care

45. Do you have a concern about any health care services you received during this hospital stay?

- Yes
- No (*please go to Question 51*)

46. What is the nature of this concern?

47. Which of the following best describes what you have done about your concern?

- Talked directly with a health care professional while in hospital
- Phoned patient relations intake line
- Sent an e-mail to Alberta Health Services (AHS)
- Wrote a letter to AHS
- Completed on-line patient feedback form on the AHS web site
- Told family member or friend
- Other (please specify): _____

48. Did you feel your concern was welcome?

- Yes, definitely
- Yes, somewhat
- No

49. Did you feel your concern was taken seriously?

- Yes, definitely
- Yes, somewhat
- No

50. To what extent were you satisfied or dissatisfied with how your concern was handled and addressed?

- Very dissatisfied
- Dissatisfied
- Neutral
- Satisfied
- Very satisfied

SECTION 11: About you

51. Please tell us your age in years: _____

52. Are you male or female?

- Male
- Female
- Prefer not to respond

53. Do you live in an urban or rural area?

- Urban
- Rural

54. In general, how would you rate your overall physical health?

- Excellent
- Very good
- Good
- Fair
- Poor

55. In general, how would you rate your overall mental or emotional health?

- Excellent
- Very good
- Good
- Fair
- Poor

56. What is the highest grade or level of school that you have completed?

- 8th grade or less
- Some high school, but did not graduate
- High school, or high school equivalency certificate
- College, CEGEP or other non-university certificate or diploma
- Undergraduate degree or some university
- Post-graduate degree or professional designation

57. Was your care impacted by COVID-19?

- Yes
- No (*please go to question 59*)

58. Please describe how your care was impacted by COVID-19:

SECTION 12: Additional comments

59. Is there anything else you would like to share about your hospital stay?

SECTION 13: Your impressions of this survey

60. What were your impressions of this survey? For example, was it too long/too short, any missing/unnecessary questions? Was it easy to read and understand?

61. As this is a new survey, part of the testing that we are doing is to have a group of patients complete it twice (to make sure that the survey measures things consistently).

May we send you the survey a second time?

- Yes
- No

62. If you checked “yes”, please provide us with your name and mailing address:

Thank you for taking the time to complete this survey!

If you have any questions about your ongoing heart health, please contact your family doctor or cardiologist's office.

For any minor health questions, you can contact HealthLink at 811 (toll-free).

If you have any compliments or concerns about the care you received, or any feedback that you wish to provide, you may contact the Alberta Health Services Patient Relations department at 1-855-550-2555 (toll-free).