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3 **Patient and physician perspectives on shared decision-making for coronary procedures in**  
4 **people with chronic kidney disease: patient-oriented qualitative study**  
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45 shared decision-making  
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## ABSTRACT

**Background:** Patients with chronic kidney disease (CKD) and heart disease face highly challenging treatment decisions. We sought to explore the perceptions of patients and physicians about shared decision-making for heart procedures for patients with CKD, as well as opinions about strategies and tools to improve these decisions.

**Methods:** This patient-oriented research initiative was supported by a patient advisory group, which included 4 patients with CKD or caregivers who partnered to inform the design and conduct of a qualitative descriptive semi-structured interview study, analyzed thematically. Twenty patient participants with CKD were recruited from a provincial cardiac registry and cardiology wards from a tertiary referral hospital in Calgary, Alberta. Ten cardiologists submitting referrals to the regional cardiac catheterization laboratory also participated.

**Results:** We identified several complexities related to bidirectional information exchange needed for shared decision-making about coronary procedures between patients with CKD and their physicians. Themes included challenges synthesizing best-evidence, variable patient knowledge seeking, timeliness in the acute care setting, and influence of roles on decision-making.

Important themes related to processes and tools to help support shared decision-making in this setting included personalization to reflect the variability of risks and heterogeneity of patient preferences as well as allowing room for physicians to share their clinical judgement.

**Interpretation:** Patients with CKD as well as physicians describe complexities in the bidirectional information exchange needed for shared decision making in cardiac care. Processes and tools to facilitate shared decision-making in this setting should be personalized and allow for incorporation of clinician judgement.

## PLAIN LANGUAGE SUMMARY

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People with chronic kidney disease (CKD) often develop heart disease. Although heart procedures can improve outcomes of high-risk patients and reduce symptoms, patients and physicians must accept potential risks and weigh whether benefits are anticipated to exceed these risks. Shared-decision making is an approach where clinicians and patients share best available evidence and work together to come to a decision informed by the clinician's expertise and the patient's values, goals, needs and preferences. In this study we explored the perceptions about challenges to shared decision-making in in this setting, as well as opinions about strategies and tools to improve these decisions. We partnered with 4 patients / caregivers with CKD to design and conduct a qualitative descriptive study, analyzed thematically. Twenty patient participants with CKD and 10 cardiologists were recruited to participate. Patients and cardiologists both highlighted the impact of variability in knowledge seeking and understanding by patients when discussing risks and benefits of procedures. Patients identified trust in the physician as key to their confidence in the decision-making process, while cardiologists identified an importance to their role in guiding patients towards invasive versus conservative treatment decisions based on their clinical assessment of several potential benefits versus risks. Barriers and potential usefulness of decision aids were identified by both patients with CKD and cardiologists. Our findings suggest that processes and tools to support shared decision-making in this setting should be personalized to reflect variability of risks and patient preferences and allow room for physicians to contribute their clinical judgement.

## INTRODUCTION

Invasive management of coronary artery disease, including coronary angiography with percutaneous or surgical revascularization, can improve long-term outcomes of high-risk patients and reduce angina symptoms, but patients and physicians must accept potential procedural risks and weigh whether benefits are anticipated to exceed these risks. The decision whether to pursue an invasive or medical approach to treatment for coronary disease may be particularly challenging for patients with chronic kidney disease (CKD) because these procedures may lead to worsening kidney function or precipitate a need for dialysis, and there is less certainty about the potential for treatment benefits (1-3). As a result, treatment selection appears to be significantly different for patients with CKD when compared to other groups of high-risk patients, with a 20 to 50% lower likelihood for patients with CKD to receive invasive management for non-ST elevation acute coronary syndrome (ACS)(4, 5) when compared to similar patients without CKD.

Ideally, both patients and clinicians make important contributions to treatment decisions for ACS. Recent research on the decision-making preferences of patients hospitalized with myocardial infarction (6) reported that over two thirds of patients wanted to play an active role in decision making, with the majority believing both patients and physicians share a role in arriving at treatment decisions. Despite this information, patients have reported that they often experience challenges participating in acute care decision-making and perceive that treatment decisions for ACS are often made for them rather than with them (7). Shared-decision making is an approach where clinicians and patients share best available evidence and work together to come to a decision informed by the physician's expertise and the patient's values and goals, needs and preferences, and risk tolerance (8, 9). It remains uncertain whether shared-decision making could be used to improve the decision quality and experiences of cardiac care for patients with CKD.

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3 This qualitative study explored the perceptions of both patients and physicians about  
4 challenges to shared-decision making in ACS care for patients with CKD, as well as opinions  
5 about strategies and tools to improve these decisions.  
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## 10 11 **METHODS**

12  
13 We used qualitative descriptive methods (10) to conduct and analyze individual, semi-  
14 structured interviews with patients with CKD who had recently experienced a non-ST elevation  
15 ACS, as well as individual semi-structured interviews with cardiologists experienced in ACS  
16 care.  
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### 23 *Setting*

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25 Patients were recruited from across Southern Alberta using the cardiac registry of the  
26 Alberta Provincial Project for Outcomes Assessment in Coronary Heart disease (APPROACH),  
27 and from a tertiary referral hospital (Foothills Medical Centre) and nephrology clinic (Sheldon  
28 Chumir Health Centre) in Calgary, Alberta. Patients were included if they had been diagnosed  
29 with CKD, had an eGFR  $< 45$  mL/min/1.73m<sup>2</sup> prior to hospitalization, and had been hospitalized  
30 with an ACS or underwent cardiac catheterization within the preceding year. Purposive sampling  
31 was used for the recruitment from CKD clinics to ensure patients who had experienced acute  
32 kidney failure requiring dialysis following invasive coronary procedures were included in the  
33 study.  
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46 Patients who were 18 years of age or older and able to communicate in English were  
47 initially introduced to the study by members of their clinical care team and provided with an  
48 information letter. Interested participants were asked to complete a consent to contact form, then  
49 contacted by the research associate who arranged an in-person or telephone interview with the  
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3 patient and any family member or caregiver that they also wished to include. Participating  
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5 patients and family members/caregivers were reimbursed \$50 (CAD).  
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8         Cardiologists from Alberta with expertise in the management of ACS were identified  
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10 through their referrals to the Cardiac Catheterization Lab booking office at Foothills Medical  
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12 Centre, Calgary, and invited via email to participate in an individual, semi-structured interview.  
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14 Physicians received no compensation for participating.  
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### 17 18 ***Sources of Data*** 19

20         The interview guide was developed based on the Ottawa Hospital Research Institute  
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22 (OHRI) needs assessment guidelines(11). Questions for patients explored reactions and decisions  
23  
24 surrounding their cardiac care, including their perceptions regarding information provided to  
25  
26 them at the time of the event, and their role in decision-making. Cardiologists answered  
27  
28 questions about their approach to decision-making for ACS care of patients with CKD, and their  
29  
30 own perceptions regarding practices, processes, and tools for shared decision-making. Interview  
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32 guides are provided in Appendix A and B.  
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36         Interviews with patients/caregivers and cardiologists were 30 to 40 minutes in duration  
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38 and conducted via telephone or in-person at a location convenient for the participant. One  
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40 research associate conducted all interviews to maintain consistency. All interviews were audio-  
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42 recorded, transcribed verbatim, and de-identified (except for patient/caregiver or cardiologist  
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44 designation) prior to analysis. Patient and cardiologist interviews ceased when no new  
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46 information was elicited in subsequent interviews for each group (i.e. data saturation).  
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### 51 52 ***Patient Engagement*** 53

54         The study was supported by a patient advisory group, which included 4 patients with  
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56 CKD or caregivers who met on a recurring basis for the duration of the study and provided input  
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3 to the programme of research. Patients partnered with us to inform the design of the study, the  
4 study information material for patients, as well as the interview questions for patients. During the  
5 analysis, 2 members of the patient advisory group (WP, CC) commented on the findings and  
6 themes and contributed to the dissemination plan including coauthoring the manuscript.  
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### 13 ***Data Analysis***

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15 Three research associates (JLF, PJ, TW) inductively analyzed each of the  
16 patient/caregiver and cardiologist transcripts using conventional content analysis (12). Each  
17 research associate independently reviewed and coded the transcripts using NVivo software(13).  
18 The research associates then met with the principal investigator (MJ) to discuss and reach  
19 consensus on emerging codes and themes. Research associates met after coding the first five  
20 transcripts to finalize the coding scheme, and the agreed upon codes and themes were  
21 systematically applied to all subsequent transcripts(14, 15). Themes, their descriptors, and  
22 representative quotes were presented to patient partners (WP, CC) for review and to ensure that  
23 their own experiences were reflected in the data.  
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### 37 ***Ethics Approval***

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39 The University of Calgary Conjoint Health Research Ethics Board approved the research  
40 project (CHREB #150476).  
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## 47 **RESULTS**

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49 We conducted interviews with 20 patients and 10 cardiologists between March and  
50 September 2018. The demographic characteristics of patient and physician participants are  
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3 provided in Tables 1 and 2, respectively. The patients were 42 to 83 years old and included 5  
4 (25%) women and 1 caregiver. Cardiologists had been practicing from 3 to 37 years.  
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8 We categorized themes according to current practices and perceptions of shared decision-  
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10 making in an acute setting, and recommendations and challenges to be addressed for future  
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12 decision aid tool development (Figure 1). Exemplar quotes from patients and physicians are  
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14 provided in Table 3.  
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## 17 18 **Complexity of Bidirectional Information Exchange in Practice**

### 19 20 ***Communicating Best Available Evidence***

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22 Cardiologists identified the complexity of the information provided in the discussion  
23  
24 about invasive versus medical management as a challenge to practicing shared-decision making.  
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26 In an attempt to reduce the density of information provided to patients, cardiologists described  
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28 simplification of their presentation of risks as “high, medium, or low risk” of requiring dialysis  
29  
30 “acutely” and “long-term”. According to cardiologists it was often quite difficult” for patients to  
31  
32 understand the risks, particularly the elderly. Patients, too, said their understanding of the risks  
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34 and benefits was limited. For patients what was important was the problem be fixed; that the  
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36 cardiologist “do what you need to do”.  
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### 40 41 ***Variable Patient Knowledge-Seeking and Desire for Information***

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43 While the cardiologists emphasized the volume of information they felt they needed to  
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45 provide patients for shared decision-making, patients varied in their levels of knowledge-seeking  
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47 and desire for this information. Many patients stated they had been given all the information they  
48  
49 needed to make an informed decision about invasive versus conservative management and were  
50  
51 satisfied with the explanations the cardiologists provided. For those patients who wanted more  
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53 information before making a treatment decision, some cardiologists identified additional steps  
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3 they would take to meet their patient’s information needs, such as obtaining a consult from  
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5 nephrology to discuss risk to renal health.  
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8 Some patients who reported worsening kidney function after angiography said they  
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10 would have wanted more information on these possibilities and risks and to be made aware of the  
11  
12 impact being on dialysis would have on their lives.  
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### 14 ***Feasibility of SDM in the Acute Care Setting***

15  
16 Both patients and cardiologists spoke about the difficulty of practicing shared-decision  
17  
18 making in the face of a stressful, life-threatening acute condition. Cardiologists acknowledged  
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20 the impact of patients needing more information and discussion time. They spoke of the  
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22 possibility for delayed decision-making to increase the potential risk of adverse effects while  
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24 trying to decide.  
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28 Patients, too, spoke about limitations in their own ability to process information, of being  
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30 “pretty sure” they knew what was happening, but not “100%”. Some described difficulty  
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32 recalling how decisions had happened, and of the discussions they assume they had with the  
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34 cardiologist. Patients were also aware time was a factor.  
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### 37 ***Influence of Roles on Shared Decision-Making***

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39 Patients perceived making limited contributions to the decision to pursue an invasive  
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41 versus medical treatment approach for their care, stating that they “didn’t really make the  
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43 decision” or they “went along with” the cardiologist’s recommendation. This deferral was due to  
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45 patient perceptions of the cardiologist as the expert and the comfort patients expressed in  
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47 thinking “the doctor should decide”. Patients spoke about trust in the expertise of the  
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49 cardiologist, and confidence that any actions taken by the cardiologist would result in the best  
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51 care.  
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3           Cardiologists acknowledged they provided nudges in one direction or another, providing  
4 the patient with recommendations as to which option they felt would be medically the most  
5 appropriate. Physician influence in the decision-making process was seen by cardiologists to  
6 come in the form of a recommendation, opinion, or selectively weighted presentation of options.  
7 These nudges, however, did not eliminate the importance of a discussion, from the cardiologists'  
8 perspectives. Cardiologists were particularly open to patient input in situations of equipoise in  
9 the decision when “the patient’s voice becomes much louder” and cardiologists endorsed a  
10 greater dependence on their patient’s values and preferences.  
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## 22 **Processes and Tools to Support Shared Decision-Making**

### 23 *Importance of Personalization to Individual Patients*

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25           Cardiologists emphasized the need for processes and tools for shared decision-making to  
26 address patient uniqueness, both based on different risk factors for relevant outcomes, and to  
27 help support a shared understanding of patient values and preferences.  
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34           Cardiologists spoke about each patient as a “complete individual”, and of the many  
35 considerations that factor into a recommendation to a patient when considering invasive versus  
36 conservative management. Cardiologists considered a wide range of individual factors, including  
37 the patient’s age, comorbidities, current level of kidney function, potential to benefit from  
38 revascularization, and the patient's treatment preferences. Cardiologists reported they placed  
39 particular importance on the patient’s kidney disease”, and whether the patient would entertain  
40 dialysis as an outcome. This respect for a patient’s goals of care created the importance to have  
41 this dialogue with the patient.  
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### 52 *Need to Maintain Physician Agency to Apply Clinical Judgement*

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3           Cardiologists were concerned that implementing processes and tools to support shared  
4 decision-making could threaten their agency in using their clinical judgement when  
5 recommending a course of action with patients. This perspective was influenced by their  
6 experiences using other risk tools available to them in cardiology. They expressed preference to  
7 evaluate the situation with each patient and determine clinically how high is their risk.  
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10           Cardiologists expressed caution against over reliance on tools. Cardiologists did not want  
11 the decision completely taken out of their hands, and were concerned about the potential to  
12 depend on risk estimates and then not use their clinical judgement or looking at the patient as a  
13 whole”.

## 24 **INTERPRETATION**

25  
26           In this qualitative study, patients with kidney disease and cardiologists with experiences  
27 caring for them recognized the desirability of the shared decision-making process when deciding  
28 upon whether or not to select invasive management for ACS (4, 5). However, cardiologists and  
29 patients identified several challenges with shared decision-making in practice, particularly with  
30 respect to complexities of bidirectional information exchange in this acute context in which both  
31 patients and cardiologists are aware that timeliness is crucial to optimizing treatment and  
32 outcomes. This setting posed challenges for cardiologists in how they presented complex  
33 information and for patients both in their ability to process information under duress of illness,  
34 and to understand complexities surrounding the potential risks and benefits. Some patients  
35 required additional information strategies, which were identified by cardiologists as an  
36 opportunity for decision-aid tools that could facilitate the information exchange needed to  
37 support such decisions. Patients who developed kidney failure after selecting invasive  
38 management indicated they would have preferred to know more about the impact of dialysis on  
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3 their quality of life, their perception being they had not been adequately prepared for this.  
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5 Despite feeling that they had limited influence on the decision, patients identified trust in the  
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7 physician, and respect for the cardiologist's expertise and guidance as key to their confidence in  
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9 the decision-making process. Cardiologists indicated that processes developed to support shared  
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11 decision-making in this setting need to allow for physician agency and clinical judgement, and  
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13 that decision-aid tools need to address the individualization of patients in assessment of risks and  
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15 consideration of patient values and preferences.  
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19 Our findings add to evolving knowledge on the practice of shared decision-making in  
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21 acute cardiac care. Probst *et al.* (16) recently described three factors that determine the  
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23 appropriateness of shared decision making in these settings, including clinical equipoise, the  
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25 patient being capable of making a decision, and that sufficient time is available. We found that  
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27 cardiologists valued their patient's voice when they were less certain about whether net benefits  
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29 exceeded risk for their patients with CKD. This finding may reflect the challenges physicians  
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31 face due to a lack of high-quality evidence to confidently guide treatment decisions and to be  
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33 able to individualize the risks and benefits to individuals with CKD in this setting. Better  
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35 information strategies may be needed in order to apply knowledge in this setting(1-3, 5), as it has  
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37 been argued that shared decision-making can be most valuable when the information needed to  
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39 understand risks and benefits is available (17). However, patients and physicians also  
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41 emphasized the patient's ability to synthesize relevant information within the short period of  
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43 time for decision making in acute care as a potential challenge to shared decision-making.  
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45 Additional tools such as decision aids were perceived as a potentially useful strategy to address  
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47 these barriers by reducing the time it takes for cardiologists to determine and communicate risks  
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3 and benefits, while increasing patient understanding, provided they support physician and patient  
4 agency over the final clinical decision.  
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8         Similar to our findings, other studies exploring shared decision-making in emergency  
9 care settings have found that while patients place high value on the opinion and expertise of the  
10 physician, they either wanted some degree of involvement in decision-making, or would have  
11 benefited from involvement(18, 19). Our findings highlight similar needs to develop processes  
12 and tools that address individual patient values, ensure timeliness of decision-making, and  
13 respect cardiologist expertise and judgement within the shared decision-making framework.  
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22         Strengths of this study are the inclusion of the perspectives of both patients and  
23 physicians, with purposive sampling that ensured we heard from patients without adverse events,  
24 as well as some who experienced kidney complications, including kidney failure requiring  
25 dialysis following invasive coronary procedures. There are also limitations to the study. First,  
26 our findings reflect only those of general decision-making experiences in the acute care context,  
27 so may not be similarly applicable to those who had unique decisional conflicts arise in their  
28 care. Second, our study was conducted at a single tertiary referral centre in Canada, which may  
29 have limited transferability to care in other regions and in other cultures. However, we included  
30 patients from rural and urban residences in order to address these groups' perspectives and  
31 participant demographics and care models from our study are similar to those elsewhere in  
32 Canada other high-income countries. Third, we recognize that patient experiences were likely  
33 influenced by how their own care providers presented the risks and benefits to them, and this  
34 study cannot answer how patient experiences, decisional conflict, and their preferences would be  
35 influenced by a different clinical decision-making approaches. Alternative study designs, such as  
36 discrete choice experiments or prospective clinical studies are required to understand how  
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3 patients' preferences may vary, and the impact that processes and tools to support shared  
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5 decision-making may have on their experiences with care.  
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8 Our patient-oriented research approach was based on the Canadian Institutes for Health  
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10 Research Patient Engagement framework and benefited from the lived experience of our patient  
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12 partners with CKD and heart disease. Involving them from the start of the design of the study  
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14 helped us to tailor our study questions and materials to our patient study population, and  
15  
16 reviewing the analysis of interviews with them strengthened our confidence in the relevance of  
17  
18 the themes that emerged from the research. Although working with our patient partners required  
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20 additional time and planning of face-to-face and telephone to work through the research process,  
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22 our team members with research and clinical experience were better able to synthesize findings  
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24 and identify their implications for improved future care from both the patient and physician  
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26 perspective, which is fundamental to the practice of shared decision-making.  
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31 The findings of our study have implications for clinical practice of shared decision-  
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33 making for ACS, and for future research on developing processes and tools to support shared  
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35 decision-making in this context. Our findings suggest that strategies and tools for shared  
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37 decision-making in this setting should address patient uniqueness and variability in values and  
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39 preferences, and incorporate physician agency and clinical judgement, which were perceived as  
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41 important by both patients and physicians. Future strategies in this area could focus on  
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43 developing decision-aid tools that provide individualized information about the risks of kidney  
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45 and heart disease outcomes, and include information on the impact of these outcomes, such as  
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47 need for temporary or permanent dialysis on quality of life. Given the important role that  
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49 cardiologists play in guiding these decisions, physicians should be a key target for training on  
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51 how to practice shared-decision making and for using decision-aids with their patients.  
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3 In conclusion, we identified several complexities related to bidirectional information  
4 exchange needed for shared decision-making about coronary procedures between patients with  
5 CKD and their physicians, including challenges synthesizing best evidence, variable patient  
6 knowledge seeking, timeliness in the acute care setting, and influence of roles on shared  
7 decision-making. Processes and tools to support shared decision-making in this setting should be  
8 personalized to reflect variability of risks and patient preferences and allow room for physicians  
9 to maintain their agency and contribute clinical judgement.  
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Confidential

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## AUTHORS CONTRIBUTIONS

All authors in this study have contributed to this manuscript and approve of this submission. JLF, PJ, TW, CC, WP and MTJ contributed to the study design, collected and analyzed the data, and drafted the article. All authors contributed to the design and provided critical important intellectual content to revisions to this manuscript.

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## TRANSPARENCY DECLARATION

MTJ has received investigator-initiated research grant funding for unrelated work from Amgen Canada. The other authors declare that they have no relevant conflict of interests. The results presented in this paper have not been published in whole or part elsewhere.

## CONFLICT OF INTEREST STATEMENT

None declared



## TABLES

Table 1. Characteristics of Patients (n=20)

<b>Characteristic</b>		
<b>Age, years</b>		
	Mean (SD)	65.2 (11.4)
	Range	42 to 83
<b>Gender, n (%)</b>		
	Male	15(75)
	Female	5(25)
<b>Previous consults with a cardiologist, n (%)</b>		
	Yes	16(80)
	No	4(20)
<b>Frequency of previous cardiology visits, n (%)</b>		
	Not at all	4(20)
	Less than once per year	5(25)
	Once per year	7(35)
	More than once per year	4(20)
<b>Previous consult with a nephrologist, n (%)</b>		
	Yes	14(70)
	No	6(30)
<b>Frequency of previous nephrology visits, n (%)</b>		
	Not at all	6(30)
	Once per year	5(25)
	More than once per year	9(45)
<b>Years with kidney disease, n (%)</b>		
	Less than 5 years	6(30)
	5-10 years	5(25)
	More than 10 years	4(20)
	Not aware of kidney disease	5(25)
<b>Acute kidney injury requiring dialysis, n (%)</b>		
	Yes	4 (20)
	No	16 (80)

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**Table 2.** Characteristics of physicians (n=10)

<b>Characteristic</b>		
<b>Gender, n (%)</b>		
	Male	5(50)
	Female	5(50)
<b>Years in clinical practice</b>		
	Mean	14.4
	Range	3 to 37
<b>Percent of time in clinical practice, n (%)</b>		
	25-50%	4(40)
	More than 50%	6(60)

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**Table 3.** Selected exemplar quotes from patients and physicians

Theme	Illustrative Quotes
<b>Complexities of Bidirectional Information Exchange</b>	
<b>Communicating Best Available Evidence</b>	
<i>Challenges with information complexity</i>	<p>The discussion about invasive versus medical management is a difficult discussion, and it's often quite difficult for the patients to understand why you would proceed with medical management as opposed to why would you just open up if there is a narrowing there? That is often hard to communicate to the patient. (physician 1)</p> <p>I think it's important to involve the patient but I think it may become overwhelming for the majority of my elderly patients in particular. (physician 5)</p> <p>It's a really complex question because patients present in such a wide variety of situations, so a lot depends on the acuity with which they come in. (physician 6)</p> <p>I was told at some point earlier, either I read it or I was told... that an angiogram would be destructive to my kidneys. ... and I had a choice: fix my heart, kill my kidneys, and live; not fix my heart and not live. (patient 4)</p>
<i>Presenting risks and benefits to patients</i>	<p>I don't usually give the patient numbers ... you have an x percent chance of ending up on dialysis. I usually will quote them a high, medium, or low risk of both needing dialysis acutely, as well as acute or permanent injury to their kidney, and then another risk for their need for long-term dialysis. (physician 5)</p> <p>In terms of patients with kidney disease, then the way I present it depends on what your GFR is before you go, but there is a risk. (physician 8)</p> <p>I don't remember being told there would be any risks. It was just, my thought was just do what you need to do. I don't look at that as a risk or anything like that. Like you've got to know what's wrong with it in order to fix it. (patient 2)</p> <p>It would have been more appropriate to have had that information from the cardiologist. I went through a bunch of tests and if at some point along that continuum, I had received a you may need an angiogram and you have chronic kidney disease and here are the implications, be ready. (patient 9)</p>
<b>Variable patient knowledge-seeking</b>	

<p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21</p> <p><i>Some patients require additional information strategies</i></p>	<p>There would absolutely be people who would benefit from that, no question, and there will absolutely be people who won't benefit from that. It's not just about the information, right, it's about getting the desired information to the right frame. (physician 7)</p> <p>The issue for me is I wasn't psychologically prepared for dialysis, so it came on, even though I intellectually knew it was going to happen someday, I wasn't anticipating it right away. (patient 1)</p> <p>Because the psychological effect of going in there with all the follow up appointments and all the issues that came up because of my kidney, I think it just makes sense to have all the information available before. You know, I was a tough case because you don't think it will happen to you, but it does and you have to live with it and, you know, I think I made the right decision. But being provided with more information is always better for everyone who's going through this issue. (patient 18)</p>
<p>22 23 24 25 26</p> <p><i>Some patients satisfied with information provided</i></p>	<p>I mean, I got all the information I needed and that pretty much ruled out everything ... and then just went from there. (patient 7)</p> <p>I can't think of anything that would have, I can't really think of anything that I needed to know that I didn't know. I was very satisfied with the explanations that were given to me. (patient 15)</p>
<p>27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47</p> <p><i>Some patients value more information on impact of complications</i></p>	<p>The only thing more information on possibilities, the risks. (patient 18)</p> <p>I would have loved to know if there was going to be any effects, specifically because it is such a serious procedure. I would have liked to know if there was going to be an impact. But no, I was not provided that information. (patient 19)</p> <p>Maybe a pre-op meeting to discuss other instances of things that could go wrong in the procedure, and other things that could happen like kidney disease. I think it's really important to inform people on specifically what every possible situation that could come out from you having it. ...Because the psychological effect of going in there with all the follow-up appointments and all the issues that came up because of my kidney, I think it just makes sense to have all that information available. You know, I was a tough case because you don't think it will happen to you, but it does and you have to live with it. And I think I made the right decision. But being provided with more information is always better for everyone who's going through this issue. (patient 16)</p>
<p><b>Feasibility of shared decision-making in the acute care setting</b></p>	
<p>48 49 50 51 52 53 54 55 56 57 58 59 60</p> <p><i>Challenges for patients to process information</i></p>	<p>Inability to process the information. When you are presenting information in that setting, they may completely forget that it was ever offered to them or it may appear as a kind of barrier or a wall. ... It has to be scaled right. (physician 2)</p>

	I mean it partly comes down to peoples' personalities. Some people need more time to digest stuff than other people. So you have to give the patients the opportunity to ask questions, and time to digest the information. (physician 9)
	I guess I was sick, I don't remember. I assume they asked me about it and I told them to go ahead because if I needed a stent or something then they would do it at that time I guess - angioplasty or something. I don't know. I was so sick, I don't remember. (patient 6)
<i>Challenges with timeliness</i>	I can see that sometimes things are delayed....And, if the patient needs more information and needs more discussion time ... then that takes a lot more of your time.... But, it could also lead to them perceiving that things took a lot longer.....And then there is always the risk of an adverse event occurring while you are trying to decide whether or not you want to do something or not. (physician 4)
	That decision was likely made by the Emergency Room attendants at the time. It wasn't made by me. ... but I do recall him informing me of the situation, what was happening, and what their plan of attack was. It wasn't as though they just did it without any kind of consultation with me. (patient 10)
	The situation was an emergency. There wasn't a lot of time to make decisions you know. You don't have the option or the luxury or the benefit of having a lot of time to make different decisions. (patient 14)
<b>Influence of roles on decision making</b>	
<i>Cardiologist recognition of appropriateness of SDM process</i>	I will always come with what my preference is and sometimes it is a true 50/50, but ultimately the decision is the patient's to make. (physician 4)
	I think information is power for the patients. (physician 8)
<i>Patient comfort deferring to physician recommendations</i>	I didn't really make the decision, but the big thing is, wouldn't you do it if you knew you could live longer? Even though I was worried that my kidneys could get damaged. The possibility of extending my own life was a bigger priority. (patient 8)
	So they more or less did what was necessary and I just went along with it. (patient 12)
	All of a sudden I'm flying out to Calgary to take a look at my heart and going through the same thing I saw my dad go through....I guess I'm relying on the doctors 100% and the nurses and all the medical staff. (patient 16)
	Actually my doctor told me it is the best way to know and I just wanted the best care. (patient 12)

<p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20</p> <p><i>Patient trust in physician expertise</i></p>	<p>In going through all of this process, and explaining these aspects, what it does is that it creates a situation of trust, I think, between the patient and the physician. So as you get to those grey areas that are really harder for the patient to understand, they are more willing to trust your interpretation. ...And they are always judging your perception versus theirs and back and forth of testing that. And when you get to those grey areas .. you want to first know that you can trust the guy who is giving you advice. (physician 2)</p> <p>When you are having a heart attack or when you've had a heart attack and you are in the hospital, you trust the doctors and whatever the procedure they feel would be the way to go to help you, you know you go along with it because you don't know any better.... when they decide that an angiogram was a good idea, well I just thought ok, let's do it. (patient 16)</p> <p>Doctor's suggestion. I believe he's the expert and he knows better than me. (patient 20)</p>
<p>21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60</p> <p><i>Cardiologist recommendations and nudges</i></p>	<p>I think if there is a clearcut benefit one side or the other then I would often try to talk to the patient about risk-benefits, and why we would think that one is of greater benefit than another approach. (physician 2)</p> <p>After going through with the patient the situation and looking at all the various risks, I would have a conversation with them about the pros and cons of both strategies. I would generally have a recommendation as to which one I feel would be medically the most appropriate, but we would have a conversation about it. (physician 4)</p> <p>I believe the situation is such that there will be a strong benefit from proceeding, I'm going to present it in that way... If I think the risk is very high, I'm going to present it that way. If there is some equipoise in the decision, well then the patient's voice becomes much louder. So when you are at clear ends of the spectrum you tend to encourage. When you are in the middle, you say ok, what do you think about this? Then their feelings about it become much more important because my understanding of the benefit is less clear. (physician 9)</p> <p>I always tell the patients, I'm going to give you the information, I'm also going to tell you what I think you should do... If I don't offer an opinion I'm not sure how useful I am to them. So I give them the information, I tell them what I think they should do based on the relative risks of the two options. (physician 10)</p> <p>Well he just explained that this was probably the best route to go or to at least to rule out some other things, whatever he thought and that was it. (patient 5)</p> <p>Yeah at that time from what I can recall, the doctor just basically said this is what the best procedure is to get the most accurate information from your heart and what it's doing and that was it. (patient 13)</p>

<b>Processes and tools for shared decision-making</b>	
<b>Importance of personalization</b>	
<i>Patient uniqueness and variability in risks of relevant outcomes</i>	Everybody comes in very uniquely and everyone's a complete individual. Like there's not a cookbook recipe for everyone in general. (physician 3)
	It's kind of multifactorial things that go into my head when I speak to these patients... it's not just one thing. (physician 4)
	The things that factor into what I would recommend to a patient are the age of the patient ... the comorbidities that patient has. (physician 9)
	Having a sort of patient information material is often very helpful. Some patient educational materials that might help you frame the conversation might be very helpful. (physician 6)
	It also changes depending how bad their renal function is, so obviously if their GFR is 50 I don't worry about it too much. Whereas if their GFR is near the line of requiring dialysis, I think about it more carefully and I also base that on what their wishes are from their goal of care, would their life be done if they ended up on dialysis and they would never do that. (physician 8)
<i>Variability of patient's values and preferences</i>	For patients who are willing to accept dialysis, should it ever become an issue, we talk a little bit about the lifestyle changes that are going to happen if that becomes necessary. But really the issue for most people is what is their priority? Ultimately they have to decide what they are comfortable with. (physician 5)
	I think you have to take into consideration the context. If you have somebody who says - in no way, shape or form I am ever going to agree to dialysis - and you know that you can be speeding that up. Each is unique, and it's important to have the dialogue with the patient. (physician 8)
<b>Maintaining physician agency and clinical judgement</b>	
<i>Perceived threat to clinical judgement</i>	A lot of physicians, myself included, also don't want the decision completely taken out of our hands. (physician 1)
	I personally don't use a risk score per se. I evaluate the situation with each patient and determine clinically whether, how high is their risk, basically. (physician 4)
<i>Influence of experiences with other risk scores</i>	We use a lot of different risk predictors. So fear would be that people would depend on that and then not use their clinical judgement or look at the patient as a whole anymore.... So could it be helpful? Yes, I think it could be helpful but also think there is room for error and abuse. (physician 2)
<i>Danger in relying too heavily on tools</i>	I just wouldn't want it to become a tool where we stop thinking because the tool says so. Like relying on the tool and stopping to examine the situation ourselves, that would be one of the dangers I would see in that. ...Well the only drawback.. I wouldn't want people to rely only on that tool. (physician 7)

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**LIST OF FIGURES**

**Figure 1.** Major themes and subthemes identified from analysis of interviews with patients and physicians

Abbreviations: SDM = Shared decision making, CKD = Chronic kidney disease

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# Patient and physician perspectives on SDM for coronary procedures in people with CKD

## Complexity of bidirectional information exchange in practice

### Communicating best available evidence

- Challenges with information complexity
- Presenting risks and benefits to patients

### Variable patient knowledge-seeking

- Some patients require additional information strategies
- Some patients satisfied with information received
- Some patients value more information on impact of complications

### Feasibility of SDM in the acute care setting

- Challenges for patients to process information
- Challenges with timeliness

### Influence of roles on shared decision-making

- Cardiologist recognition of appropriateness of SDM process
- Patient comfort deferring to physician recommendations
- Patient trust in physician Expertise
- Cardiologist recommendations and nudges

## Processes and tools for shared decision-making

### Importance of personalization

- Patient uniqueness and variability in risks of relevant outcomes
- Variability of patient's values and preferences

### Maintain physician agency to apply clinical judgment

- Perceived threat to clinical judgment
- Influence of experiences with other risk scores
- Danger in relaying too heavily on tools

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4 **SUPPLEMENTARY MATERIAL**  
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6 *Appendix 1: Interview guide for patients*  
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9 Thanks for agreeing to participate in this interview.

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11 Today I'm going to be asking you about your experiences making decisions about having an angiogram  
12 procedure.  
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15 The information that you share today will contribute to modifications to the decision-making process  
16 that we're hoping will result in improved communication between patients and doctors around  
17 angiograms for people with kidney disease.  
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21 The interview should take about half an hour.  
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23 [Review the consent form, and ensure the questionnaire is complete before continuing.]  
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26 Not everyone with heart issues needs an angiogram, so you may not have had the procedure done. But  
27 it may have come up when you were in the hospital as a possible test, although it may have been ruled  
28 out for you. We still want to hear from you even if you didn't have the procedure because you will have  
29 an important perspective.  
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32  
33 Ultimately, the goal of this session is to better understand what would have helped you, and could help  
34 others in the future, who have chronic kidney disease, and who need to decide whether to have an  
35 angiogram. We'll also be talking to doctors to find out about what they think. What kinds of tools would  
36 help them work with patients to come to a shared decision?  
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40 I want to emphasize that your participation is voluntary. This means you are free to stop the interview at  
41 any point.  
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44 I will be audio recording the interview. All your responses will be kept confidential. In the reports we  
45 may use individual quotes but we will not identify you by name.  
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48 What you say here will not impact your access to clinical care or the services you receive.  
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51 Do you have any questions?  
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53 Interview Questions  
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55 Topic 1 – Decision-Making  
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1. Before we get into this any further, do you know what an angiogram is? [if not, explain it briefly in lay terms]
2. Did you have one, or did your heart doctor talk about it with you?
3. How did you decide whether to have an angiogram?
4. Who made the decision – you, your doctor, or both together?
5. What information did you have?
6. Who gave you the information?
7. Did you understand the risks and benefits of the angiogram?
8. What did you understand they (risks and benefits) were?
9. Did you get information from someone other than your doctor or nurse?

#### Topic 2- Aids to Decision-Making

In this next set of questions we're going to talk about what information helped you make the decision, and what might have helped that you didn't have.

1. What information helped you the most in making a decision?
2. [If they were stuck between doing it or not] What convinced you make the decision you made?
3. What would you have liked to know, but didn't?
4. Who would you have wanted to talk to, but didn't?
5. Is there anything else you can think of that would have made the decision easier? [Probes: A pamphlet with some of the basic information? A list of questions most people ask (FAQ)? More time with the heart doctor?]
6. Would learning [more] about risks and benefits have helped?

We've reached the end of the questions. Is there anything I didn't ask that I should have, or anything else you wanted to mention?

Do you have any questions?

Thank you so much for sharing your experiences and ideas with me today.

We'll be summarizing the information from these interviews later in the project and sending out a report to people who participated and want to receive it. Would you be interested in receiving a brief summary of the results? What would be the best way to contact you when the report is ready?

## Appendix 2: Interview guide for physicians

First, thanks very much for agreeing to participate in this interview; we know that your time is valuable and appreciate you giving us some of it to help us understand your experiences managing acute coronary syndrome in patients with chronic kidney disease.

We are hoping that the discussions that we have today will take about 20 minutes.

Your participation is completely voluntary, which means you are free to leave the interview at any point. We will be using a tape recorder to make sure we don't miss anything that you tell us. In addition, we will be taking notes during our discussion. Please know that all your responses will be kept completely confidential.

Notes from this interview and the recordings and transcripts will be kept in a locked cabinet and in a password-protected folder on the computer. In the reports we will be using individual quotes but we will not identify anyone by name.

Any questions?

Great.... Let's begin

- 1) Can you tell me about the typical patient with chronic kidney disease who has an acute coronary syndrome and some of the most important decisions that you and these patients face?
- 2) I'd like to get more information on the choice of an invasive versus conservative management approach (i.e. decision to have an angiogram) in patients with chronic kidney disease. How do you introduce the topic of the angiogram to patients?
- 3) What options do you give?
- 4) What did you see as the main risks and benefits of these options? (Possible probes: risks: need for dialysis, worsening kidney function, acute kidney event, benefits: reduced risk of repeat heart attack, reduced risk of prehospitalization for coronary event, quality of life, mobility, mortality?)
- 5) Do you approach patients with CKD differently?
- 6) Can you describe how most patients make the decision to have the angiogram or not?
- 7) How long does this decision take?
- 8) Who is most involved in making the decision?
- 9) How did you think patients feel when they have to make this decision?  
(Probe:
 

a. Unsure about what to do?	f. Delaying decision-making?
b. Worried about what could go wrong?	g. Questioning what was important to you?
c. Distressed or upset?	h. Feeling physically stressed?
d. Constantly thinking about it?	Heart racing? Trouble sleeping?)
e. Wavering between choices?	
- 10) How would you describe the angiogram decision-making process: a) you make the decision for the patient, b) you share the decision with your patient, c) you provide support or advice for the patient to make the decision on his or her own?
- 11) Is it a difficult decision? What makes this decision difficult to make?  
(Probe: Do patients:

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- a. Lack information about the options?
  - b. Lack information about the risks and benefits?
  - c. Lack information on what others have chosen?
  - d. Feel pressure to choose one option over another?
  - e. Lack support from others?
  - f. Not feel ready to make a decision?
  - g. Lack the ability to make this decision?)
- 12) Is there anything else needed to help patients make this decision?
- 13) I will list some possible ways to help people make decisions, which do you think would be helpful from your perspective?
- a. Counselling from a healthcare provider
  - b. Discussion groups with others facing the same decision
  - c. Individualized health information
  - d. Information material → books, videos, website, decision-aid, etc.
- 14) Is there anything else you would like to add about ways to help others decide about receiving an angiogram?
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#### Closing

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We've reached the end of my questions. I'd like to thank you all again for your participation here today.