PaCER REPORT

Patient Engagement to Identify Priorities for Shared Decision-making Tools in Cardiac Care: A PaCER Study

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Executive Summary

As part of their initiative to develop risk prediction tools that promote shared decision-making between patients and cardiologists the Alberta Provincial Project for Outcomes Assessment in Coronary Heart disease (APPROACH) research team partnered with the Patient and Community Engagement Research (PaCER) program at The University of Calgary to carry out patient-to-patient research with patients with acute coronary syndrome (ACS). The APPROACH team wanted patient input before embarking on a project that would lead to an electronic tool to address the issue of the appropriate use of early invasive coronary angiography versus non-invasive testing in this setting. The purpose of this study was to describe patient experiences with acute coronary syndrome (ACS) care and decision-making when admitted to acute care with an ACS event. The study was sponsored by Alberta Health Service's Cardiovascular Health and Stroke Strategic Clinical Network and APPROACH.

The study used the PaCER research method developed by Marlett and Emes and further refined in an innovative collaborative project between Alberta Health Services and the University of Calgary funded by the Canadian Foundation for Healthcare Improvement. The method has three phases: *Set* (setting the direction of the study) *Collect* (collecting data), and *Reflect* (confirming and expanding the data, and proposing actions) with participants from *Set* and *Collect*. These studies use a peer-to-peer process where patients with the same or similar chronic condition lead the study. As there were no experienced PaCER lead researchers with a history of ACS, two lead PaCER researchers were joined by two other PaCERs with cardiac health conditions.

The 20 study participants were recruited from the APPROACH registry. The inclusion criteria were: hospitalized in Calgary with a confirmed non-ST elevation acute coronary syndrome within the last year, and English fluency. In the *Set* phase seven patients took part in a focus group where they discussed how their treatment unfolded and what would have made it a better experience. In the *collect* phase thirteen patients participated in either a focus group or individual interview. The PaCER researchers used a collaborative process to analyse the *collect* data, and following a meeting with the research team, five categories of data were brought to a *reflect* focus group. The nine patients in this last focus group reflected on the fit of the data with their experiences, exploring some information in more detail and developing recommendations for the APPROACH team.

The key findings from this study are: (i) Most participants had not been actively involved in acute phase decision-making: cardiologists made decisions and then recommended treatments. (ii) In general, participants were satisfied to take a more passive role in acute decision-making, as many did not feel capable of thinking clearly due to the life-threatening nature of the situation. (iii) Consequently, study participants did not think that an electronic shared decision-making tool would be helpful on admission to hospital. (iv) However, they suggested that tools for use after the emergency phase of hospitalization would address their specific information needs and promote collaborative decision-making would have value.

The findings support patients' desire to be involved in other treatment decisions and to do that they need information specific to their individual circumstances and their prescribed medications. Participants thought that an individualized electronic tool for use once they were past the emergency phase of their hospitalization would begin to address their specific information needs and would promote collaborative decision-making. Based on these findings the PaCER researchers recommend that the APPROACH team: 1) refocus design of an individualized electronic decision-support tool for the acute phase of ACS to facilitate clinician decision-making 2) consider developing an electronic tool to facilitate shared decision-making in the non-emergency hospitalization phase; 3) consider replicating this study in other Alberta cardiovascular centers.

Introduction and Background

This is the report of a PaCER study sponsored by Alberta Health Service's Cardiovascular Health and Stroke Strategic Clinical Network: *Patient Engagement to Identify Priorities for Shared Decision-making Tools in Cardiac Care*. The principal investigator is Dr. Stephen Wilton and the Co-investigators are Drs Matthew James, Merril Knudtson, and Colleen Norris. The purpose of this study was to describe patient experiences with acute coronary syndrome (ACS) care and decision-making that would inform the design, implementation and testing of a tool that facilitates shared decision-making between patient and clinician. The research was carried out by two experienced patient-researchers from the Patient and Community Engagement Research (PaCER) program: Jean Miller and Sylvia Teare. As neither had a history of heart conditions they were assisted by two other PaCERs (Winnie Pearson and Colin Penman) who have a cardiac history.

This study is part of an initiative to develop tools that address the issue of patient involvement in decision-making during and after an ACS. Clinicians and patients are often faced with decisions about whether to proceed to early invasive coronary angiography and re-vascularization or persist with medical therapy and selective referral for angiography based on non-invasive testing. This decision point, one of the most contentious in cardiovascular medicine, has profound implications for patient outcomes such as mortality, bleeding and kidney injury events, as well as for system costs. While clinical practice guidelines exist, the APPROACH research team is developing risk prediction tools that facilitate shared decision-making between patient and clinician by clarifying options and allowing patients to identify their personal values related to potential benefits and harms associated with available choices. In order to ensure these shared decision-making tools address the needs of patients, the first stage of this work required critical input from patients and patient representatives. To that end, the research team partnered with the Patient and Community Engagement Research Program (PaCER) in the Institute for Public Health, Faculty of Medicine, University of Calgary who carried out the study. This would be followed by engaging patients in designing, implementing, and testing a computerized decision support system to facilitate shared decision-making in ACS management.

The PaCER program prepares patients, informal caregivers, and family members to carry out patient-to-patient research using a method designed to create a robust collective patient voice while maximizing patient engagement throughout the research process. Patient and community engagement researchers (PaCERs) are people with various health conditions who are trained to design and conduct health research using an established protocol of qualitative inquiry. The protocol was originally developed by Dr Marlett and Dr Emes (Marlett & Emes, 2010) from the University of Calgary for a seniors' resiliency project and further refined in an innovative collaborative project between Alberta Health Services and the University of Calgary, supported by Vecova Centre for Disability Services and Research and the Arthritis Society, and funded by the Canadian Foundation for Healthcare Improvement. The purpose of this collaborative project was to bring a stronger patient voice to health care transformation: two years later this has been shown to be the case (Marlett, Shklarov, Marshall, Santana, & Wasylak, 2014). The program provides support in designing research projects, supervision and mentorship to the PaCER researchers, and oversees the activities to assure methodological quality and the consistency of PaCER methods in the context of a particular study. (For more information on PaCER: http://www.pacerinnovates.ca/)

The PaCER research method has 3 phases: *Set, Collect*, and *Reflect*. (See Figure 1) The *Set* phase clarifies the scope and direction of the study. Data is then collected (*Collect* phase) from patients using a combination of further focus groups, semi-structured interviews, observation, or questionnaires. In the *Reflect* phase patients participate in another focus group where they review, discuss and attempt to come to a common understanding of the *Collect* findings and make suggestions on future research directions and knowledge dissemination. This iterative approach, driven by patients working with patients, brings a clearly patient voice to health system change. It results in a shared collective understanding of the issue, one that is solidly grounded in patient experience.

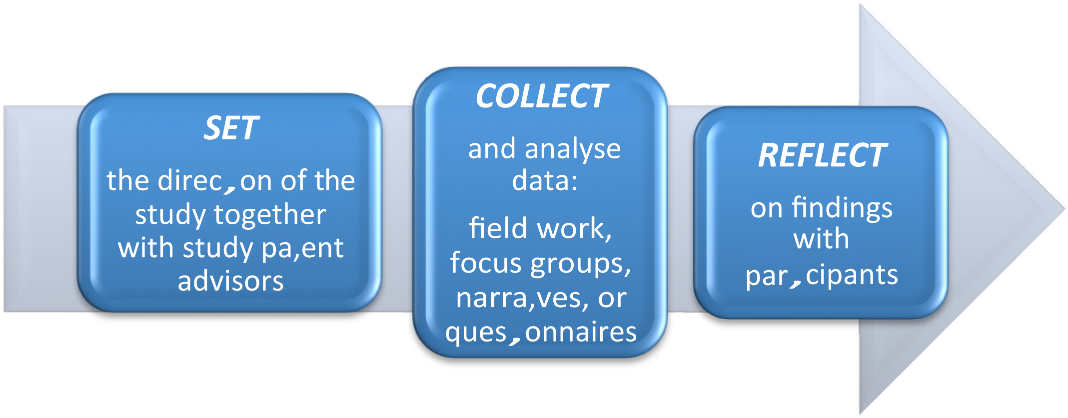

Figure 1: PaCER Research Methodology

PaCER Research Methodology Applied to Patient Engagement to Identify Priorities for Shared Decision-making Tools in Cardiac Care

This section begins with information about the participants, followed by a description of the PaCER process and analysis used in this study.

Participants

The inclusion criteria were: hospitalized in Calgary, Alberta with a confirmed non-ST elevation acute coronary syndrome (including non-ST elevation myocardial infarction [NSTEMI] and unstable angina [UA] within the last year, fluency in English, current residency in the Calgary area, and having previously provided informed consent to be contacted for research purposes. Patients who had presented with an ST elevation myocardial infarction (STEMI) were excluded because of the emergent nature of initial management. Potential participants were identified from the APPROACH registry, which captures data on all patients undergoing cardiac catheterization in Alberta, Canada. All enrolled APPROACH patients are invited to complete quality of life and patient experience surveys after discharge, and those returning surveys are asked for their consent to be contacted for future research. A member of the APPROACH team identified over 75 people who met the study criteria and had given their consent to be contacted for research. PaCER researchers attempted to make contact with all of them, calling many people more than once. Those reached were invited to join the study and were assured their decision would not affect their ability to receive services or treatments. It was up to them to freely accept or decline the one-time study invitation. Not all who agreed to participate were able to do so due to unexpected commitments, health, and transportation issues. In the end 20 ACS patients participated in the study: 7 in the *set* phase and 13 in the *collect* phase: 9 participants from *set* and *collect* took part in the *reflect* phase.

Table 1: Participant Characteristics

Characteristic	Sample (n= 20)
Female sex	8 (40%)
Age at ACS presentation (median, range)	68.5 (51.3 to 87.5)
Admission Diagnosis	
ACS - NSTEMI	14
ACS - Unstable angina	4
Other (stable angina, sudden cardiac arrest)*	2
Cardiac risk profile and history	
Hypertension	10 (50%)
Diabetes mellitus	3 (15%)
Smoking (Current / Past)	5 (25 %) / 5 (25%)
Dyslipidemia	13 (65%)
Family history of premature coronary disease	9 (45%)
Previous coronary disease diagnosis	13 (65%)
Previous ACS	7 (35%)
Previous percutaneous coronary intervention	6 (30%)
Previous coronary artery bypass surgery	1 (5%)
Congestive heart failure	2 (10%)
ACS Management	
Cardiac catheterization	20 (100%)
Percutaneous coronary intervention	7 (35%)
Coronary artery bypass surgery	4 (20%)

Footnote for Table 1. * 2 participants had a reason for their index hospitalization that was not ACS, but had suffered a previous ACS. **ACS:** acute coronary syndrome; **NSTEMI:** non-ST elevation myocardial infarction.

Table 1 summarizes the characteristics of the participants. Participant ages at the time of ACS ranged from 51 to 84. Seven participants were women and twelve were men. The majority of patients had experienced a NSTEMI. Post-study chart review revealed that 2 of the participants had an ACS diagnosis greater than 12 months previously, and had been included based on a more recent non-ACS related cardiac catheterization. Because of the nature of the study, where participants provide responses in a group setting, these patients' responses were included. The majority of patients had known coronary artery disease, and 7 had experienced a previous ACS. All patients underwent cardiac catheterization during the index stay, and 9 went on to have either percutaneous or surgical interventions.

The PaCER Process and Data Analysis

This section of the report describes the process used for this particular PaCER study. Because of the iterative nature of PaCER research, where what is learned in each of the phase (*Set, Collect, Reflect)* informs the next, the section also includes data analysis.

Set. This was a focus group with seven ACS patients, and one patient was accompanied by her husband. Participants were asked to share their experiences of their last hospitalization for ACS and how the treatment they received came about. Each participant explained how his or her treatment unfolded and what could have made for a better experience. They described both positive and negative experiences, pointing out the need for health professionals to understand their individual circumstances; provide better explanations about what lay ahead and clearer explanations about their medications. With respect to decision-making, the majority of *Set* participants were unaware of a decision between early invasive or initial medical management of ACS, and had not been involved in this decision. Furthermore, these initial respondents largely felt grateful that this decision was made for them, as they felt they would not have been able to make sound decision in the acute setting.

Participants' points were documented on flip chart pages and the session was recorded. Participants thought individual interviews would be a good strategy for the *Collect* phase as they would provide more in-depth understanding of decision-making in ACS acute care. This information was documented and brought to the research team.

Collect. The PaCER researchers and program director met with the principal investigator and a co-investigator to discuss what was learned in the *set* focus group. It was decided the *collect* phase would begin with another focus group followed by individual interviews. In the focus group four participants (three men and one woman) spoke about decision-making and their awareness of, and interest in being involved in treatment options. They also explored the idea of an electronic tool. Analysis of the audiotape and focus group notes informed the development of the interview guide. The interviews were done in pairs: one lead PaCER accompanied by one of the two PaCERs with a history of heart problems. Five ACS patients were interviewed: all were men. After consultation with the research team, four women were interviewed. The audiotapes and interviewer's notes were used to create a descriptive document for each interview. The two researchers independently analyzed each interview documenting points that spoke to decision-making and an electronic tool: each point in each interview was documented (the coding process). The researchers compared and contrasted their points and through a collaborative process the four PaCER researchers organized the focus group and interview data into five categories: awareness of treatment decisions; interest in being more involved in treatment decisions; information they were given; interest in more information about treatment options; and the electronic tool. This data was was discussed with the research team and then taken to the *Reflect* focus group.

Reflect. Nine ACS patients who participated in either the *set* or *collect* phase attended the *reflect* focus group: seven men and two women. Here they collaborated around the data analysis, reflecting on the fit between what they said and what was reported, exploring some information in more detail and developing recommendations for the research team. The focus group ended with a reflection on what they were taking away from their involvement in the study. Participants found it comforting to know others are dealing with the same issues. They also appreciated the opportunity to learn from and share their experiences with others with the same health problem. One participant pointed out the diversity in patient stories means cardiologists are dealing with a wide range of patient situations.

Upon completing this iterative three-phase patient engagement research process the PaCER researchers were reasonably confident the findings are a credible representation of these ACS patients' perceptions of their involvement in treatment decision-making at the time of acute hospitalization.

Findings

The key finding of this study is that on emergency hospital admission these ACS patients had not been involved in treatment decisions, nor did they expect to be. This idea first appeared in the *set* phase, and evolved throughout the *collect* phase, remaining strong in the *reflect* phase. This section of the report begins with the patients' description of their emergency admission to hospital, followed by their perceptions on how ACS treatment decisions are made and their views on patient involvement in treatment decision-making. Patients' perspectives on an electronic tool are then described.

The emergency hospital admission

Participant stories of their ACS episode began with the onset of their symptoms and subsequent arrival at the emergency department and admission to hospital. They found themselves in an unexpected and potentially life-threatening situation and in some cases an outright crisis. They were shocked, scared, and felt out of control (Box 1). Participants also recounted how quickly events unfolded once they got to the hospital (Box 1).

Box 1: An emergency hospital admission

Shocked, scared and out of control

"This was the most significant emotional event in my life" …"a wake-up call". "It hit me square in the head"…"not being invincible was the biggest shock" (Participant 15: 58 year old man)

"The guy upstairs flips the switch" …. "What am I doing here?" (Participant 14: 68 year old man)

"I'm from a family of *events* and this was definitely not an event: it was an *attack"*. "I felt like a deflated balloon when it happened" (Participant 18: 65 year old woman)

Rapidly unfolding interventions

"I guess I don't know why it was decided to admit me"…."I zipped away upstairs to the heart unit" (Participant 19: 70 year old lady)

"Things went really fast" … "(they) hooked me up to everything" (Participant 17: 77 year old lady)

"(I was) treated as number one priority (Participant 12: 70 year old man)

Patients' views on involvement in ACS treatment decision-making on emergency hospital admission

This section begins with participants' perceptions of how treatment decisions are made and their views on patient involvement in treatment decisions when first admitted to the emergency department.

Perceptions of how treatment decisions are made. The patients in this study had not been involved in making treatment decisions when admitted to hospital and they were unaware of treatment options: on reflection they thought this was realistic given the life-threatening nature of their illness. They thought that as specialists in their field cardiologists were in the best position to make treatment decisions. Participants assumed their cardiologists considered the options and chose the treatment that was best for them. Cardiologists present their decision to the patients who then consent to the recommended treatment. Treatment decisions were made *for* them rather than *with* them. (Box 2)

Box 2: Treatments made *for* them, rather than *with* them

"They've looked at the options and have decided what is best for you and then they tell you that and you decide if you will do it or not" (Participant 8: 48 year old man)

"I don't need a bunch of options…. I do what the expert believes is the solution for me"…"If I cut my finger, fix it…don't give me options, for example a tourniquet or amputation, go with the focused solution (Participant 15: 58 year old man)

"My thinking is I'm having trouble, these are professionals – I let them do what they do – I put my life in their hands. When I worked I was the expert in my field called in due to a problem, took necessary action – did my thing didn't rely on client" (Participant 16: 80 year old man)

"There would be a lot going on behind the scene: doctors talking to doctors etc as they make the decision they think is best" (Participant 11: 66 year old man)

(The doctors got together) "They voted among themselves if I would survive the surgery or not" (Participant 17: 77 year old lady)

Feeling incapable of participating in decision-making. The ACS patients in this study thought that given the stressful life-threatening situation in which they found themselves they would not have been capable of participating in decision-making. In this situation they needed someone else to make the decisions. Realizing that decisions had to be made quickly they put their trust in the cardiologists. (Box 3)

Box 3: Feeling incapable of participating in decision-making

"You have to realize that after you have a heart attack you barely know your name, you have no memory, you're scared, everything up there is scrambled – you're in total disbelief (that you've had a heart attack)"… "there are very few decisions that you can make that would be the right ones" (Participant I8: 65 year old lady).

"They took the decision away from me, and I'm glad as that reduced my stress" (Participant 11: 66 year old man)

"You don't have a lot of time – your body is not giving you lot of time for decisions before things go wrong so you trust them to make the right decisions" (Participant 18: 65 year old lady).

Turning their bodies over to the experts. Acknowledging that this isn't something they usually they do, participants willingly turned their bodies over to the experts. They were comfortable with their cardiologists making treatment decisions and in fact that is the way they thought it should be. They relied on the cardiologists' expertise and experience, putting their trust in them. (Box 4)

Box 4: Turning their bodies over to the experts

"I accepted it (the doctor's decision) because I was in shock. I just went along with it which is not what I usually do…I'm Irish. Something made me trust them." (Participant 13: 78 year old man)

"I assumed they did what they needed to do" (Participant 16: 88 year old man)

"I just wanted the problem fixed"…"I would rely on my doctor's advice more than what I think is appropriate" (He trusted his doctors to know best and his trust stemmed from their confidence.) (Participant 14: 68 year old man).

"I expected the surgeon knew what he was doing and did exactly what he said he would do…No question there" (Participant 15: 58 year old man)

"They are in a better position to choose options."….." This isn't necessarily bad as they have better knowledge and experience with others in the same situation." (Participant 8: 45 year old man)

Another view of decision-making involvement. While the predominant message is that participants hadn't been involved in treatment decisions and they didn't feel it was realistic to do so, two participants had a different perspective: a lady who had decided what treatment she wanted prior to her hospitalization and a man who questioned the specialist's treatment recommendation.

On arrival at the emergency department a 77year old lady with ACS and other health problems (Participant 17) told the doctor that if the problem was her heart she wanted by-pass surgery: she had already tried medications. However, the cardiologists told her that her heart and lung problems meant she was not a good surgical candidate. Over the next few weeks this lady moved between ICU and a medical ward, all the while pressuring for by-pass surgery which they continued to refuse. The doctors told her they could do no more for her and she likely had three or four months to live. In this situation the participant was denied the treatment she wanted and was given no options other than to take her medications and consider moving to a nursing home. She would not accept this decision and she kept trying to change their minds. This determined lady knew how her body handles surgery and was convinced that she was strong enough for by-pass surgery: she just needed the doctors to make the same decision she had. Then one morning a cardiac surgeon appeared at her bedside saying he would do the operation. As soon as she met him she knew he would help her: “there was something in his handshake that made her feel she could conquer the world”. She had the surgery and hasn’t looked back.

The other participant’s cardiac problems began in 1998 eventually leading to by-pass surgery about a year ago. At that time his cardiologist recommended a pacemaker. Although he feels the specialists are knowledgeable and he tends to “bend to their skills” (Participant 10: 74 year old man), he worried that having wires in his heart could make his condition worse. This patient raised this issue with his surgeon who provided him with the information he needed, and in the end he agreed to the treatment. While these patients wanted to actively participate in decision-making it should be noted they were not in the situation of needing immediate ACS treatment decisions.

Patients’ views on an electronic shared tool for ACS treatment decision-making

The findings of this research are intended to inform the development of an electronic shared decision-making tool that would increase patient participation in treatment decisions when admitted to hospital with ACS. Participants in the *Collect* and *Reflect* phases of this study were asked to consider this idea. The predominant view was that given the life-threatening situation and their mental and emotional state, such a tool would not have been helpful. Participant 19 however, had a different perspective (Box 5).

Box 5: Patients’ views on an electronic shared tool for ACS treatment decision-making

On admission to emergency care

A 68 year old man said that early on he felt very foggy and was in no position to make decisions…and even when he did emerge from the fog he didn’t think that more information about have been helpful (Participant 14)

“Yes they can like a sketching form, this is the % that this will work or not work”. When asked whether she felt her head was too foggy to make decisions so the doctors should do it she said: “That’s one way of doing, but I had the back-up: one daughter is a chiropractor the other has brains too”. (Participant 17: 77 year old lady)

A 70 year old lady said she wasn’t sure about the timing of that… “in emerg it’s possible you’re not understanding things all that much but it would have been helpful somewhere along the line”. (Participant 19: 70 year old lady)

Once past the life-threatening stage

It would “tell you this is what happened, this is what we did, and what we found, and what medications we are giving you and this is what they are for”. (Participant 19: 70 year old lady)

“Information isn’t volunteered….you have to know what to ask” (Reflect focus group participant).

One interviewee indicated she would like to get off some of her medications but she didn’t’ know how to go about that. (Participant 19: 70 year old lady)

On further reflection participants thought an electronic tool would be helpful once they were past the initial life-threatening situation. An individualized shared decision-making tool would begin to address their specific information needs and would promote collaborative decision-making. The tool would also help them absorb all they needed to know before they went home and guide them on what specific questions to ask in their follow-up medical appointments. (Box 5)

In summary the ACS patients participating in this PaCER study were not involved in treatment decision-making nor were they aware of decision-making points or treatment options: treatment decision was made by the cardiologists who then proposed the recommended treatment. Given they were in life-threatening situations that required immediate decisions they thought this approach was appropriate. The predominant view was that *acute* treatment decisions were best left to the specialists who have the required knowledge and skills. They also thought they were not mentally or emotionally capable of being involved in decision-making. For these reasons participants did not feel an electronic tool that facilitates patient involvement in treatment decision-making would have helped them at that point. However, once they were past the acute phase of ACS, they did see the value in an individualized tool that would address their specific information needs and their involvement in future decision-making about their heart disease.

Discussion

In a world where patients expect active participation and greater control over their health and health care it is surprising to find a situation where they do not want that level of involvement. The patients in this study were relieved that highly specialized professionals stepped in and made the decisions that needed to be made in the acute setting. Based on the findings of this study this is likely explained by the life-threating nature of ACS events that leave patients mentally and emotionally unable to participate in decision-making or to benefit from shared decision-making tools. This suggests that decision-making tools need to support cardiac specialists rather than shared decision-making between cardiologists and patients.

Study findings also suggest that the extent to which patients want to be involved in decision-making is likely to vary, with some wanting more involvement than others. It is likely the extent of their involvement is influenced by their level of acuity as well as their personal experiences and coping skills.

Once they were past the crisis situation study participants wanted greater involvement in decision-making. This is where they could see the value of an electronic decision-making tool that would address their personal values related to the potential harms and benefits of treatment choices, particularly their medications. Such a tool would be tailored to their individual circumstances and would support their learning in the non-emergency hospitalization phase and beyond.

The ACS patients in this study said they need medication information before being discharged from hospital that is tailored to their individual situations. Rather than being told their prescribed medications are taken by all ACS patients they need to know how they benefit them specifically. This is similar to a finding in another PaCER study of osteoarthritis (OA) patients' perspectives on quality care. In that study OA patients said they need specific self-management strategies that align with the stages of OA severity, along with specific information about when they should seek further help (Miller & Teare, 2014). Together these studies suggest the information patients typically get may not be at the level of specificity they require.

The extent to which the results of this small qualitative study would hold true for other patients being admitted to hospital with an ACS event is not known. It is possible that these findings would have been quite different if the study had been carried out in a situation where patients are given information and treatment choices with the expectation they would be involved in the decisions. Recruitment for this study was focused on patients themselves, but the role of patients' family and friends in assisting with acute decision-making is another important area for future study.

Conclusion and Recommendations

This study of the patient perspectives on decision-making participation is one step in the APPROACH research team's efforts to address the issue of the appropriate use of early invasive testing (angiogram) and treatment (re-vascularization) or non-invasive testing and medial therapy. It was thought that one way to do this would be to develop an electronic tool that would facilitate shared decision-making between patients and clinicians. However, given the fact that participants were not, nor do they want to be, involved in immediate treatment decisions in life-threatening situations it is unlikely such a tool will go any distance in addressing this issue. The study findings do suggest that once past the initial treatment decision ACS patients need to be involved in other treatment decisions and to do that they need information specific to their individual circumstances and their prescribed medications. Participants thought that an individualized electronic tool for use once they were past the emergency phase of their hospitalization would begin to address their specific information needs and would promote collaborative decision-making.

Recommendations

Based on the findings of this study, the PaCER researchers recommend the APPROACH research team:

1) Refocus design of an individualized electronic decision-support tool for the acute phase of ACS to facilitate clinician decision-making
2) Consider developing an electronic tool to facilitate shared decision-making in the non-emergency hospitalization phase
3) Consider replicating this study in other Alberta cardiovascular centers

Respectfully submitted,
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