Risk Prediction to support shared decision-making for managing heart disease

Project Newsletter
(10/2018)

Project Snapshot:

Heart disease is common in people with chronic kidney disease (CKD), and is a major cause of hospitalization and death. However, people with CKD are less likely to receive tests and treatments for their heart disease than those without CKD. Identifying & meeting the information needs of patients and care providers is important to support patient-oriented approaches to care, especially when complex decisions must be made that require weighing of risks versus benefits.

Project Updates:

Phase one qualitative interviews are complete. Through the patient and health care provider interviews we identified several complexities related to bidirectional information exchange needed for shared decision-making about coronary procedures between patients with CKD and their physicians. These themes are shown below:

Trust in the Physician: While physicians were concerned that the patients would be taking the tools recommendation over their own, patients expressed the opposite view

> “*I would be concerned that the problem isn't in that the information wasn't available, it's in that the patient isn't able to cope and handle the information and what they remember about the time and what they remember a day later, can be different things.”*

Perceived conflict over role and decision making:
possibility of discrepancy between the physician's decision and the tool's recommendation and what it would mean for the physician and the patients.

> “*Actually my doctor told me it is the best way to know and I just wanted the best care.”*

Trust in the physician:
Patients trusted the cardiologist was doing the procedure because it was the best thing for them and would save their lives. Patients received the procedure because the physician recommended it, and patients view the physician as the expert. In many cases patients did not feel it necessary to part of the decision-making process.

Tools, processes, and practice of shared decision making: In the process of decision making, in many cases the patient and little say in the decision of having the invasive procedure

> “*Everybody comes in very uniquely and everyone's a complete individual. Like there's not a cookbook recipe for everyone in general.”*

Need for individualization:
The tool needs to take patient uniqueness into account, consider all the risk factors and recognize patient's preferences, as these are important steps that cardiologists consider at the time of decision making.

> “*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 ourself, that would be one of the dangers I would see in that.”*

Role of physician judgment vs. a guided standardized too:
Ability of the tool to incorporate all the factors that are critical in the decision making process and how much confidence can they place as a health care provider in this tool.

> “*The situation was an emergency. There wasn't a lot of time to make a lot of decisions you know. What was done was the best thing to do at the time.”*

Acuity of the patient's illness:
Was the main factor in the patients being left out of the decision making process

> “*And did you understand the risks and benefits of the angiogram?” PT020 “I would like to think I did”.*

Patients recall getting all the information:
It was only on reflection during the interviews, was years after the procedures, that they questioned their understanding of the potential risks

> “*The only thing more information on possibilities, the risks. I was given every piece of information that I think they could have given me.”*

Variability in the knowledge seeking:
Those who felt they had been part of the decision making process, some did not feel they were provided with enough information about risks attributed to the angiogram, or the impact the angiogram could have on their lives.

> “*I don't remember being told there would be any risks, you know my thought was just do what you need to do.”*

Limited understanding:
Of the risks and benefits of the procedure

- Presented at the Canadian Society of Nephrology annual Conference in May and APPROACH National Meeting in Sept 2018
- Currently validating the risk prediction models in AB and BC

Project Work Stream

Phase I –Complete

Two qualitative studies to understand the experiences of patients with CKD who have recently made decisions about heart tests and treatments following an acute coronary event (heart attack) and to identify the decision support needs of patients and healthcare providers when making decisions about heart tests and treatments following a (heart attack).

Phase II -In Progress

Development and validation of risk prediction models for important clinical outcomes identified by patients and care providers. Surveying patients to quantify their preferences toward the attributes of heart attack treatments identified in phase I.

Phase III –Planning Stage

Incorporation of risk information and patient preferences within a decision-aid.This will be followed by testing of the decision-aid with patients and care providers.

To learn more:

cansolveckd.ca/research/earlier-diagnosis/risk-prediction-to-support-shared-decision-making-for-managing-heart-disease/

Questions?

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