UNDERSTANDING SYMPTOM-MANAGEMENT IN CIRRHOSIS CARE

A COGNITIVE TASK ANALYSIS STUDY

IN OUR PREVIOUS RESEARCH, WE FOUND LACK OF ROLE CLARITY, AND DIFFERENCES IN THE MANAGEMENT & COORDINATION OF CIRRHOSIS CARE BETWEEN PRIMARY AND SPECIALTY CARE. A DEEPER UNDERSTANDING OF HOW PRIMARY CARE PHYSICIANS APPROACH CIRRHOSIS CARE, AND PERCEIVE THEIR ROLES AND RESPONSIBILITIES IS NEEDED.

OBJECTIVE

To understand how family physicians conceptualized their roles in terms of symptom management across the trajectory of caring for someone living with cirrhosis, and potentially shed light on if and how they incorporate palliative care into their practice.

METHOD

We conducted a formal elicitation of mental models using Cognitive Task Analysis (CTA). Setting: Primary care in Alberta. Selection: Family physicians (n=6) who saw small numbers (typical for unspecialized practice) of cirrhosis patients.

KEY FINDINGS

- Due to lack of a formal structure and role clarity in cirrhosis care, family physicians work case by case, reacting to and dealing with what the patient presents with or views as most important to them at the time of their visit.
- Family physicians rebuild their knowledge and mental models of cirrhosis with each new patient, potentially applying new pieces each time, but as general practitioners they do not feel they should be expected to keep expertise in one specific illness at the forefront of their mind and practice.
- Family physicians report a desire for more timely guidance and opportunities to establish relationships with specialists; the guidance they receive acts as a form of knowledge on demand that supports the rebuilding of their mental models of cirrhosis care as and when needed.
- When asked about types of resources used or that would be helpful, those considered to support knowledge on demand (e.g., Specialist Link, or the Cirrhosis Care Website www.cirrhosiscare.ca) were preferred.
- While family physicians recognise their role in having discussions with patients about the trajectory of cirrhosis, palliative care principles are not being fully integrated into cirrhosis care. A need for guidance about when and how to have these conversations was identified.
- Family physicians felt that, as general practitioners, they should not be expected to be experts in cirrhosis care or keep expertise in one specific illness at the forefront of their mind and practice.

MENTAL MODELS

Mental Models describe the lens through which individuals make sense of what's happening around them. More than our beliefs and values, and dynamic in nature. Our mental models are so implicitly held that we're often not aware of them and how they constrain our thinking.

COGNITIVE TASK ANALYSIS

Set of qualitative tools used to elicit mental models; valuable to represent how people think when working in cognitively complex environments.

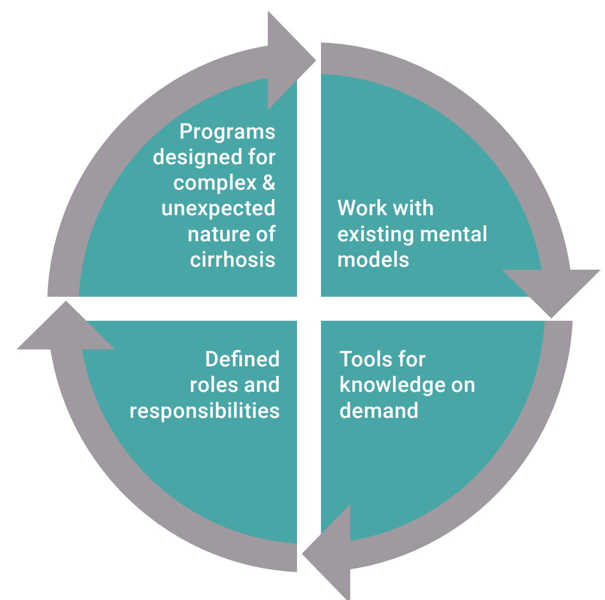
SO WHAT?

Improving symptom management in cirrhosis care will require:

- Access to the right information when it is needed, whether from specialty care, or tools such as Specialist Link or the Cirrhosis Care Website (www.cirrhosiscare.ca)
- Clearly defined roles and responsibilities of health providers involved in patient's care
- Programs and approaches such as those that are applied to other chronic illnesses such as diabetes, and heart failure. This would assist family physicians to manage cirrhosis within the primary care context
- Tools and supports that integrate palliative care and that support and direct family physicians to have honest conversations with patients, family, and caregivers at the time of diagnosis, and throughout the trajectory of the illness

RECOMMENDATIONS:

1. **Work with and consider existing mental models; have formal supports for key elements like:**
   a. Rebuilding mental models (see previous Scaling Up Cirrhosis report: https://primary-careresearch.ca/cirrhosis_full.pdf)
   b. Planning for the unexpected (see previous Scaling Up Cirrhosis report: https://primary-careresearch.ca/cirrhosis_full.pdf)
   c. Consider patient context
2. **Recognise the need for knowledge on demand and develop, maintain and utilise tools that work with this approach:**
   a. Specialist Link
   b. Cirrhosis Care Website (www.cirrhosiscare.ca)
3. **Define clear roles and responsibilities for all providers involved in patient's care: who is responsible for what care and when**
4. **Create a formal structure of programs and tools for cirrhosis care, similar to those that are applied to other chronic illnesses, that would assist family physicians to manage cirrhosis within the primary care context. These programs and tools would:**
   a. Span trajectory of care
   b. Clearly define roles and responsibilities
   c. Provide access to necessary information at the right time, including when and how to have honest conversations with patients



Future State

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