



UNDERSTANDING SYMPTOM-MANAGEMENT IN CIRRHOSIS CARE

A COGNITIVE TASK ANALYSIS STUDY

JULY 2021





ACKNOWLEDGMENT

...

Enhancing Alberta Primary Care Research Networks (EnACT) is an infrastructure to support and enhance Alberta's existing practice-based research networks as well as academic and community practitioners conducting primary care research. They are funded by the Alberta Innovates Translational Health Chair Award. This work was completed in collaboration with the Alberta Medical Association – Accelerating Change Transformation Team (AMA ACTT) and for the Cirrhosis Care Alberta (CCAB): an evidence-based cirrhosis admission/discharge bundle project under the leadership of Dr. Puneeta Tandon.

EnACT and AMA - ACTT would like to acknowledge the research field team and to thank all the participants for engaging in this important research.

Research field team members: June Austin, Mia Cavanaugh, Sandee Foss, Kylie Kidd Wagner, Bonnie Lakusta, John Lester, Barbra McCaffrey, Sue Peters and Lynn Toon



CONTACTING THE TEAM

...

For more information about this research, please contact:

Tanya Barber, EnACT Research Coordinator
tkbarber@ualberta.ca or,

Lynn Toon, AMA - ACTT Research Lead
Lynn.toon@albertadoctors.org

REPORT PREPARED BY:

...

Tanya Barber, MA (EnACT)

John Lester, BA (on behalf of ACTT)

Lynn Toon, RN MSc (on behalf of ACTT)

Lee Green, MD MPH (EnACT)



HOW TO CITE THIS WORK

...

Barber T, Toon L, Lester J, Green LA. Understanding Symptom-Management in Cirrhosis Care: A Cognitive Task Analysis Study. Edmonton, AB: University of Alberta; July 2021 (Unpublished Report).

Available from: www.primarycareresearch.ca and <https://actt.albertadoctors.org/PMH/capacity-for-improvement/Primary-Care-Research/Pages/default.aspx>

TABLE OF CONTENTS

| | |
|---|-----------|
| SUMMARY | 4 |
| <hr/> | |
| BACKGROUND & PURPOSE | 5 |
| <hr/> | |
| PROJECT DESIGN & METHOD | 5 |
| <hr/> | |
| FINDINGS | 6 |
| <hr/> | |
| THEMES | 10 |
| <hr/> | |
| DISCUSSION | 14 |
| <hr/> | |
| CONCLUSION & RECOMMENDATIONS | 15 |
| <hr/> | |
| TABLES | 16 |
| <hr/> | |
| REFERENCES | 17 |

SUMMARY



UNDERSTANDING SYMPTOM-MANAGEMENT IN CIRRHOSIS CARE: A COGNITIVE TASK ANALYSIS STUDY

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

Family physicians identified a lack of guidance, formal structure, and clarity of roles on what should be done, when, and by whom around cirrhosis care. As a result, they have developed mental models that are reactive and take a case-by-case approach, focusing on the symptoms that are most important and matter to the patient at the time, while including a patient-centred understanding. In addition, as we found in our previous research, family physicians rebuild their knowledge and mental models of cirrhosis with each new patient. This approach requires a high dependency on knowledge on demand (information they can access when and as needed) and relationships with specialists.

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.

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, 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://actt.albertadoctors.org/file/Scaling_Up_Cirrhosis_Care_Full_Report_Oct_2020.pdf)
 - b. Planning for the unexpected (see previous Scaling Up Cirrhosis report: https://actt.albertadoctors.org/file/Scaling_Up_Cirrhosis_Care_Full_Report_Oct_2020.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

BACKGROUND & PURPOSE

Liver cirrhosis is a leading cause of morbidity and premature mortality,^{1,2} and gaps in care transitions contribute to high rates of hospitalization, readmissions, and costs of care.^{3,4} In partnership with the Cirrhosis Care Alberta Program (CCAB), we conducted a cognitive task analysis sub-study to gain an understanding of how primary and specialty care physicians, and nurse practitioners think about and make decisions when faced with providing care for someone living with cirrhosis.^{5,6} We discovered that role clarity was an identified problem for family physicians when it came to deciding who should be providing what care, and when, for people living with cirrhosis and we thought it prudent to explore further.^{5,6}

This second sub-study focused on gaining an understanding of how family physicians approached and conceptualized their roles in terms of symptom management across the trajectory of caring for someone living with cirrhosis, and whether this would shed light on if and how they incorporate palliative care into their practice.

PROJECT DESIGN & METHODS

We conducted a Research Ethics Board approved formal elicitation of mental models using a Cognitive Task Analysis (CTA) technique called the Knowledge Audit.⁷ The Knowledge Audit draws on the recall and description of specific examples. In this case, it allowed us to identify family physicians' tacit knowledge of cirrhosis symptom management including their care approaches and decision making.

The interviews were conducted by an interviewer and a note taker. They were roughly one hour in length, held via Zoom, audio and video recorded, and followed a set of interview probes rather than a formal interview guide.

PARTICIPANTS

To recruit health care providers, we used purposive sampling⁸ to select family physicians (n=6) who saw small numbers (typical for unspecialized practice) of cirrhosis patients. All participants were recruited via the "Primary Care News" notices. We faced recruitment challenges, especially in rural areas, thus our sample provides mainly an urban, Southern Alberta perspective (see Table 1: Participant Demographics).



COGNITIVE TASK ANALYSIS

Cognitive Task Analysis is a set of tools used to elicit and represent how people think when working in cognitively complex environments. It can be used to understand and improve team functioning in high stakes settings (e.g. aviation, firefighting, ICUs).

FINDINGS

MENTAL MODELS

For the most part family physicians' mental models appeared to incorporate a reactive, case by case approach. The lack of a) a structured process or set of guidelines for managing cirrhosis symptoms, b) clearly defined roles, and c) relationships with specialists, in addition to the unpredictable nature of the disease, meant that physicians worked 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. This finding was similar to our previous study's finding that described family physicians' mental models of cirrhosis care as "reactive, patient-need-focused, rather than proactive system-of-care models".^{5,6}



MENTAL MODEL

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. Determines what we pay attention to, options and possibilities we consider, how we solve problems, make decisions and act. Our mental models are often so implicitly held that we have limited awareness of them and of the ways in which they constrain our thinking.



MACROCOGNITION

Macrocognitive functions are the crucial processes that individuals and teams carry out each day (e.g. coordination, planning and re-planning, decision making, monitoring and detection, sense making/ learning and managing the unknown).

"...because this isn't a common problem, so we don't have any specific rubric that they [clinic staff] follow to deal with his [patient] symptoms.

"I ask the questions like, do they have their screening for varices? Are they on appropriate therapy for that? Do they have ascites, yes or no? Do they have peripheral edema, yes or no? I think I manage symptoms as they come.

"Where I spend energy and put focus is based on where she [patient] tells me she wants to focus. Naturally, patients are more focused on things that cause them to be symptomatic and her cirrhosis up until her recent admissions was not causing her symptoms that was impairing her quality of life.

The reactive nature of physicians' mental models was also linked to the complexity of the illness and patients' socio-economic situations, and again the lack of a formal system in which to manage cirrhosis symptoms. This meant that most of the participants found it difficult to incorporate planning or re-planning (see Table 2: Macrocognition Framework) into their mental models and depended on guidance from specialists. Those that did manage to incorporate this macrocognitive function into their mental models did so because it was linked to a second macrocognitive function, managing the unknown, or expecting the unexpected, which was an already existing and central component of their mental models of cirrhosis care.

Most physicians indicated the need for support and guidance from specialists in order to successfully manage patient symptoms.

“ Pretty much it’s a consult letter. It’s pretty much what’s the plan and then I just follow the plan. ...Now that you’ve [specialist] made the diagnosis ..., then I can take on the work from there, but if I have problems, I’m hoping that it’s just a phone call that I can speak with the nurse or the specialist and say, “By the way, you’ve seen this patient, this is his problem now. What can I do in the meantime while waiting for an appointment in your clinic?”

“ We took the lead really from the discharge summary in terms of what, I’ll say, quote unquote, kind of medical things were needed.... That was a big piece. And, in addition to that, I would say, my main thing was also helping them with the alcohol use disorder and work to remain abstinent. We got the BHC involved and then had appointments as needed.

The majority of family physicians we interviewed included a patient-centred element within their mental model and tried to meet patients where they were (i.e., consider what they were capable of addressing at that time), focus on what mattered to them, and tried to involve their partners and family members as collaboratively as possible. The missing formal structure around cirrhosis care made it difficult to support patients fully, necessitating the approach of case-by-case management but with a patient-centred understanding.

“ ... I think that every patient is different and we need to meet them where they are at. But I think, generally, I would expect a patient to tell me when something is going on and to try and work with me to make a plan that works for them.

“ Well, I ask them what they understand, because again, this population tends to be low engagement, low health literacy and of those things what they think they can manage. There is no sense in me telling them what they have to do if there is no way they could do it anyways. It’s asking them what they feel they can do.

Family physicians also reported that patients more often than not wanted to focus on their symptoms. In addition, given that our questions were heavily focused on how family physicians manage symptoms, not necessarily how they manage the whole patient and their full context, we didn’t feel there were enough data to distinguish symptom-focused as a specific characteristic of their mental models.



PATIENT-CENTRED

We defined patient-centred as “What matters to the patient at the time, and considering the holistic view of the patient. Patients and families are encouraged to determine how they will participate & collaborate in care and decision-making. Core concepts include: Dignity & Respect; Information sharing; Participation; and Collaboration.” For more information on patient-centred care, including definitions, go to the IPFCC website: <https://www.ipfcc.org/>

That being said, there was a difference between those who voluntarily discussed the full parameters of their patients' health and life context and how this impacted their symptom management and others who stayed focused on symptoms alone. While the latter indicated some awareness of these elements, they didn't seem to incorporate this knowledge into their management of their patient's symptoms.

“ He [patient] has a lot of social issues, too. He was living in a stairwell for quite a while. He was very transient. We managed to get him some housing. Then he moved to the south side. ... he does have housing now, but he still doesn't have a means of transportation that's all that reliable. He just doesn't come. Do I actually check for those things in him? No, I haven't and it is probably something that I should look at.

When participants described their interactions with specialists, they often only described the communication in terms of symptoms simply because that is how they have learned to frame communication in the way a specialist would be concerned with.

“ ...it [communication with specialist] was very singularly focussed on one thing as opposed to all of the other stuff that goes into why this person now has a diagnosis of cirrhosis. All of the help that they need around it.

“ This isn't symptomology that I manage a lot of, it is helpful when you get to talk to the specialists and they can explain certain things to you, so actually you get educated, so that hopefully in the future, if I have more of these patients, then I don't have to panic as much or I have a better understanding of what next steps are and things like that.

Family physicians clearly stated that they do not see a lot of cirrhosis patients and reported a desire for more timely guidance. There was a clear need for “knowledge on demand” on the part of family physicians. We defined “knowledge on demand” as knowledge that is available at the point of need, anytime, anywhere.⁹ The guidance and information they receive is key to the rebuilding of their mental models^{5,6} of cirrhosis care as and when needed.



Interestingly, some of our participants also acknowledged that as family physicians, they should not be expected to be experts in the area of cirrhosis. Instead, they required support in terms of tools, information, and resources to manage care in collaboration with the specialists, who they also reported feeling would not expect them to be experts in managing this complex condition.

“ I’m not a specialist at cirrhosis. I’m not going to really do that as effectively as someone who does specialize in it.

“ I get the sense that they [specialists/hepatologists] understand that this is not that common for us... From a family medicine perspective, we have to manage quite a wide spectrum of disease, so I don’t think it is that reasonable for us to have a super in-depth knowledge about one particular disease.

Two sources of knowledge on demand or timely information were consistently mentioned. One was Specialist Link in Southern Alberta, it consists of a telephone advice line that family physicians can use to contact a specialist for advice, and speak to someone directly or receive a call back within a few hours. It also includes access to on-line resources via a website. The second was a website dedicated to cirrhosis care. When provided with choices of cirrhosis resources they would most likely use (e.g., monthly meeting with specialists or a cirrhosis care website), the participants overwhelmingly chose the website based on its ability to offer “on demand”, trusted information.

“ I would say that generally Specialist Link is a really helpful service for Family Physicians, because it is a timed call back, so you are not waiting hours and hours after you have paged somebody. ... with Specialist Link you know you are going to get a call back if you put it in early enough in the day that you will get that response in an hour.

“ Definitely would use something like that [website] if I had it. I’d probably look at it at least every other time he’s [patient] in just to refresh my memory, because it is a patient type you don’t see all the time. ...if you have got good information and it is easily accessible, then people are going to use it.



THEMES

Our data analysis also revealed key themes that link to the mental models, and provide added insight into how family physicians manage cirrhosis symptoms across the trajectory of the illness. The themes include: Role clarity (lack of), Cirrhosis Care as a Chronic Illness, and Palliative Principles – not an integrated component of Cirrhosis Care.

ROLE CONTINUITY (LACK OF)

It was evident from the interview responses that an uncertainty exists among family physicians as to what care is to be provided by primary or specialty physicians when managing symptoms for those living with cirrhosis. Most family physicians did not indicate clear delineation of roles or having close or collaborative relationships with specialists. They felt unsure of what specialists saw as their role, so tried to manage within that uncertainty.

“ No idea to be honest. I don't know. I imagine it varies.... I think they would probably see me managing things other than the cirrhosis... Making sure that this person's screening is up to date or that their other medications are being dealt with.

Most participants indicated a lack of clear coordination between specialty and primary care as well as between specialty care and patients. This spanned from communication about appointments and lab work, to working as a team, or developing working relationships.

“ ... In terms of just on my end, wanting to do everything I could to tee everything up and put things in place for this patient when I wasn't sure that we were necessarily always getting great communication from the speciality side of things.

“ I don't know when their appointments with the specialist are and so sometimes, I will randomly get some consult notes from the specialist. That will reaffirm or confirm are we going the right direction or not and are there outstanding items? That's what the relationship is. ... I wouldn't say we work as a well-coordinated team.

The resulting issues with management and informational continuity are seen across our healthcare system and are the focus of many new initiatives addressing transitions in care.¹⁰⁻¹⁴ However, while these initiatives work to address continuity issues, physicians still need to find ways to work with the system in its current state resulting in multiple workarounds.

One workaround reported by physicians is to increasingly rely on patients and their family or caregivers to be the mediators between specialty and primary care.

“ Sometimes I have to say, “You know, this can wait a bit. Why don't you talk to Dr. So and So about this at your next appointment or why don't you try giving them a call...?”

“ ... One really good source would be his wife. I would tell him and tell his wife, so his wife can nag on him too. So that's my resource, too.

“ Also, [patient] was just coming to terms with this diagnosis and the lifestyle changes that were going to be undertaken. They had a really supportive partner and so we saw the partner as well to discuss some of this.

As we indicated earlier, family physicians also relied on other resources, such as consult letters, discharge summaries, and Specialist Link (for those in Southern Alberta) to access guidance and direction from specialty care when they lacked close working relationships. These varied in helpfulness to effectively manage their patients' symptoms, as the information was not always received in a timely fashion.

“ For that particular patient, I'd probably call Specialist Link. I will get somebody on the phone and then just say, "This is what's happening. What can I do?" There are resources for family doctors, so I guess just tapping into those resources.

“ ...So, really clear discharge plans and recommendations on symptom management have been helpful for a learning perspective for me in the past, but also just to make sure symptoms are well managed and I can apply that to other people as well.

Still, participants expressed that a closer relationship or integration between primary and specialty care might lead to more collaborative care, or seamless continuity and coordination.

“ I think there is lots of stuff that I don't feel comfortable with necessarily, so I would want to have a closer relationship to a specialist to be able to help advise on things or even for them to be seeing the patient more regularly, so that they could take over some of those symptom management pieces.

CIRRHOSIS AS A CHRONIC ILLNESS

One of the ongoing challenges with managing cirrhosis symptoms is the complexity of both the illness and the patient context. Our interview data revealed that symptom management is not just about cirrhosis, but more often about the comorbidities and socioeconomic issues that come with it. In fact, family physicians reported that for most of their patients, cirrhosis is not their top priority. Instead they are dealing with other symptoms as a result of the cirrhosis that present as a priority for their patients at the time of seeing them. This can span from alcohol related issues, nutrition, cognitive function, and blood sugar management to socioeconomic and mental health issues.

“ ... I can't think of any of my patients with cirrhosis that don't have other things going on like diabetes, mental health. They just tend to be quite ill individuals and even then some of them may have addictions histories.

“ ... cirrhosis is a lower priority to be doing some of that chronic management when there are huge other, more pressing concerns. ... the cirrhosis isn't really being managed because there is so much other stuff going on.

In addition, most physicians are dealing with these complex, interlinking issues with very little support or team resources, structures, programs or processes. The participants noted that there are many programs for other chronic illnesses, but very little for cirrhosis. They questioned why cirrhosis is not being managed as the chronic illness that it is.

“ ... Like with many of the other chronic diseases so much of it has been shifted to primary care using interdisciplinary teams. Diabetes, we have diabetes nurse educators, we don't have to send them to the diabetes specialty clinic. Hypertension is the same way. I feel like cirrhosis can be housed within primary care for the vast majority of patients.

“ ... the Nephrology and Chronic Kidney Disease team... They are really good at thinking about all of these other sides of things - diet, and all of this, and they have some nurse managers that help answer a lot of those questions. I guess I felt that here [cirrhosis case] I really didn't get any information from anybody like that or a team.

PALLIATIVE PRINCIPLES – NOT AN INTEGRATED COMPONENT OF CIRRHOSIS CARE

Family physicians clearly acknowledged that having conversations with patients around goals of care and advanced care planning fell within their roles or responsibilities. However, it was apparent that there was no standard plan for explaining the trajectory of cirrhosis or the need to address advanced care planning throughout the continuum of care. They also described different approaches in their timing and reasoning for not having conversations.

For instance, there were a couple of participants who explained that discussing death, or what could take place as the illness progressed, would not go well with their patients. They felt that either their patients were not prepared for these honest conversations, or that they already had so many other health issues to worry about, this was not a priority. They felt it was more important to focus on symptoms at hand, fitting with the reactive, case by case mental models we identified earlier.

“ ... [patient] not in the place to have that conversation right now, because there are so many other physical things going on. I think currently just to sort of get on top of those physical symptoms. Get her feeling a bit better, then maybe circle back to some of those types of things.

On the other hand, there were participants who seemed reluctant to have these conversations with patients who were healthy or doing well. While they indicated that they believed conversations about goals of care or the progressive nature of cirrhosis were important no matter the stage, they also reported waiting until the patient's health deteriorated before broaching the topic.

“ We really need to always have that goal of care conversations with our patients anyway, even if they are healthy, even if at this stage. But sometimes it just ... that conversation when you see that their health is getting worse.

“ A number of times we have sort of addressed that, you know, this is progressive and...the liver is failing, so at some point in the future it is not going to be able to continue to do what we need it to do. We've talked somewhat about some of the complications that can happen. ...We have not talked about, just because he's feeling reasonably well, we haven't talked about the details of what can happen at the end...

Whether they waited until patients felt better, or waited until their health got worse, family physicians did acknowledge they felt it was their responsibility to discuss end of life and advanced care planning. They did suggest that getting added information or support from outside sources (e.g., Liver clinic) would assist them in having these conversations, and may assist in providing information directly to patients as well.

“ I would feel that the goal of care discussion would be my responsibility as the family doctor because I am also getting the information from the Liver Clinic. If they say that the cirrhosis is so advanced that they are not able to do anything, then yes, I will have that conversation with him. I feel that, you know, you've already had the emotional investment with your patient. You already have that relationship with your patient and so your patient trusts you, that you are going to talk to them on their own terms and you know how they will take it.

“ I would think that there could be an educator or programs that could be set up as part of the Primary Care Network to help do this job because you really could teach multiple patients at the same time about this. And living with it, because it is a chronic disease much like hypertension and diabetes except it actually has a higher amount of mortality.

DISCUSSION

Family physicians have to deal with what is presented to them: the symptoms that matter to the patient at the time. They lack guidance, formal structure, and knowledge on what should be done and by whom, as such, they have developed mental models that are reactive, case by case, patient-centric and depend on relationships with specialists and knowledge they can access when they need it.

A crucial finding with implications for system design is that our participants pointed out that as family physicians they should not be expected to be experts in cirrhosis care. While they expressed that cirrhosis symptom management could take place in primary care, with specialty guidance and timely information, they expected that this guidance and any tools developed would continue to be accessible and relied upon. They expected they would need to rebuild their knowledge, potentially applying pieces to their patient's next visit, and not be expected to keep expertise at the forefront of their mind and practice.

In addition, the ambiguity and complexity that exists around provider roles within cirrhosis symptom management, the illness itself, and the socio-economic situation of patients drives a heavy reliance on the macrocognitive skill of managing the unknown and unexpected. While this is a component of some physicians' mental models, it really needs to be understood as a necessary element of any intervention created to assist with cirrhosis care in general. Otherwise, we will continue to see the cognitive effort applied by physicians who must create workarounds in dealing with the unexpected nature of cirrhosis management and a system that does not provide the supports required.

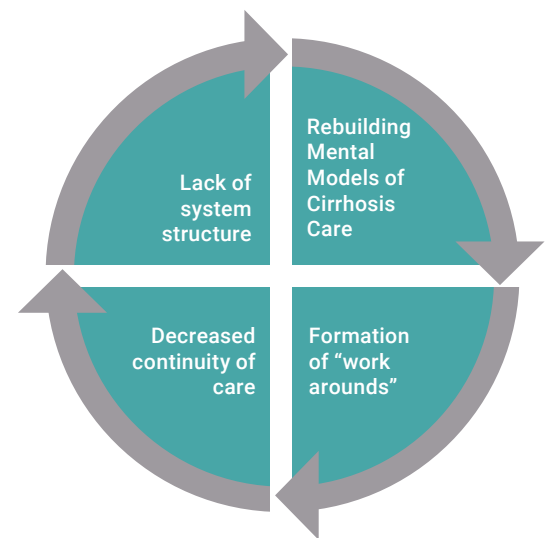


Figure 1. Current State

When asked what types of resources they would want to use to assist with managing cirrhosis, our participants indicated they needed timely information, such as the ability to call a specialist to ask questions. If a relationship with a specialist did not exist, they would use a service such as Specialist Link (if available), and beyond that, when given a choice between access to a monthly meeting with specialists or a website, the participants clearly stated they would prefer the website because they could access the information when they wanted it. Participants clearly needed knowledge on demand. Previous studies have reported these same sentiments among physicians,¹⁵⁻¹⁷ again linking the lack of expertise, comfort, or confidence to the infrequency of seeing patients with cirrhosis.^{15, 17}

Our findings also echoed previous research in terms of how family physicians approach advanced care planning.^{16,18-19} While our participants recognized the importance of having honest conversations about end-of-life care, or throughout the continuum of care, the majority also admitted to not knowing when to have these discussions. Some were hesitant to have conversations when patients were either feeling too sick and needed to focus on their physical health, or when they felt the patient wasn't mentally or emotionally ready to have the conversation. On the other hand, some physicians felt it was not appropriate to have the conversation when patients were feeling well physically, and instead waited for patients to be more advanced in their terminal stages. While our participants indicated some ambiguity around the role specialty care plays in discussing supportive and end of life care with patients, they clearly felt that the responsibility to start and engage in these conversations lay with primary care.

The family physicians we interviewed desired training and further education to support patients throughout the continuum of cirrhosis care and symptom management. They suggested that having training or tools could assist in working advanced care and end of life care conversations into their work-flow. They also suggested looking to other chronic illnesses, to find examples of tools and programs that would assist their approach to cirrhosis symptom management within primary care.

CONCLUSION

Eliciting and exploring family physicians' mental models of cirrhosis symptom management validated many of our findings from our earlier study^{5,6} and made clear that until there are formal processes and structures in place, as there are for other chronic illnesses, family physicians will continue to manage symptoms on a reactive, case by case basis. Those that are successfully planning and managing cirrhosis symptoms and care, understand the holistic view of the patient, expect the unexpected, have co-located teams or close relationships with specialty care. Programs and approaches that are applied to other chronic illnesses such as diabetes, heart failure, and kidney disease could be created for cirrhosis and would assist family physicians to manage cirrhosis within the primary care context. Finally, while palliative care has been designated as an integrated component of the continuum of care,²⁰ this cannot take place unless there are structured tools and supports that will support and direct family physicians to have these honest conversations with patients, family, and caregivers at the time of diagnosis, and throughout the trajectory of the illness.

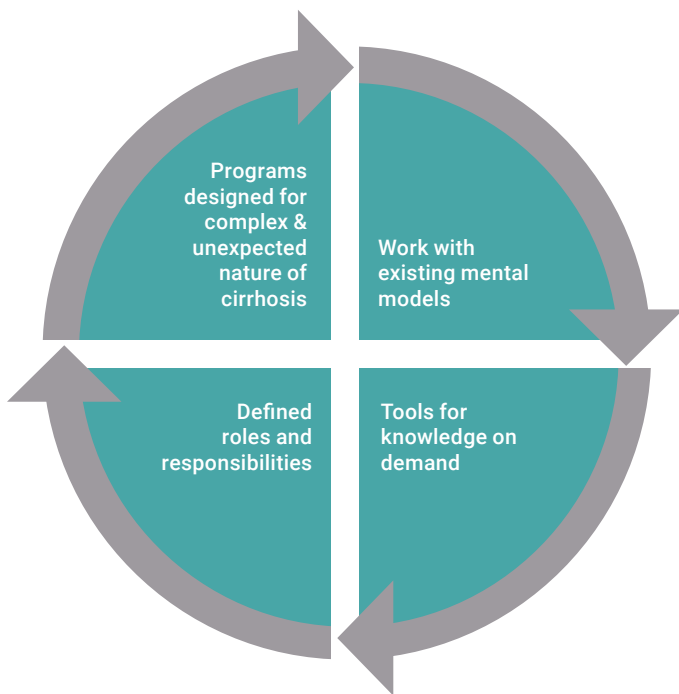


Figure 2. Future State

RECOMMENDATIONS

- 1. Work with existing mental models; have formal supports for key elements like:**
 - a. Rebuilding mental models
(see previous Scaling Up Cirrhosis report: https://primarycareresearch.ca/cirrhosis_full.pdf)
 - b. Planning for the unexpected
(see previous Scaling Up Cirrhosis report: https://primarycareresearch.ca/cirrhosis_full.pdf)
 - c. Considering 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

TABLES

Table 1: Participant Demographics

| Gender | |
|----------------------------|---|
| Woman | 4 |
| Man | 2 |
| Age | |
| 30-39 years old | 3 |
| 40-49 years old | 1 |
| 50-59 years old | 1 |
| 60-69 years old | 1 |
| Place of Medical Education | |
| In Canada | 5 |
| Outside of Canada | 1 |
| Years Practicing | |
| Under 10 years | 2 |
| 10-19 | 2 |
| 20-29 | 1 |
| 30-39 | 1 |
| Geographic Location | |
| Southern AB Urban | 4 |
| Northern AB Urban | 2 |

Table 2: Macro-cognition Framework

| Function | Description |
|---|---|
| Sensemaking and learning (SL) | <ul style="list-style-type: none"> Deliberate attempt to find coherent situational understanding Modifying a mental model or generating a new one Includes sense giving (presenting an understanding to others to adopt) |
| Decision making (DM) | <ul style="list-style-type: none"> Decisions in, or about, patient care and administrative processes |
| Planning and re-planning (PL) | <ul style="list-style-type: none"> Shaping or reshaping patient care or administrative processes |
| Monitoring and problem detection (MD) | <ul style="list-style-type: none"> Tracking the progress or outcomes of patient care or administrative processes Planned, ad hoc (“noticing”), formal (data collection), or informal |
| Managing the unknown, unclear, unexpected, and irregular (MU) | <ul style="list-style-type: none"> Planned or anticipatory (contingencies, fallbacks) Evaluating/estimating risks Unplanned, “scrambling” |
| Coordinating (CO) | <ul style="list-style-type: none"> Any activity that helps synchronize 2 or more individuals in a patient care or administrative process, especially transmitting information or expectations Maintenance of “common ground,” shared expectations/ understanding/mental models of processes |

REFERENCES

1. Asrani SK, Larson JJ, Yawn B, Therneau TM, Kim WR. Underestimation of liver-related mortality in the United States. *Gastroenterology*. 2013;145(2):375-82.e1-2.
2. Nguyen NH, Khera R, Ohno-Machado L, Sandborn WJ, Singh S. Annual Burden and Costs of Hospitalization for High-Need, High-Cost Patients With Chronic Gastrointestinal and Liver Diseases. *Clin Gastroenterol Hepatol*. 2018;16(8):1284-92.e30.
3. Bajaj JS, Reddy KR, Tandon P, Wong F, Kamath PS, Garcia-Tsao G, et al. The 3-month readmission rate remains unacceptably high in a large North American cohort of patients with cirrhosis. *Hepatology*. 2016;64(1):200-8.
4. Volk ML, Tocco RS, Bazick J, Rakoski MO, Lok AS. Hospital readmissions among patients with decompensated cirrhosis. *Am J Gastroenterol*. 2012;107(2):247-52.
5. Barber T, Toon L, Austin J, Green L. Understanding primary and specialty care mental models of cirrhosis care: a Cognitive Task Analysis sub-study. Edmonton, AB: University of Alberta (Unpublished Report); 2020
6. Barber T, Toon L, Tandon P, Green LA. Eliciting and Understanding Primary Care and Specialist Mental Models of Cirrhosis Care: A Cognitive Task Analysis Study. *Canadian Journal of Gastroenterology and Hepatology*. 2021;2021
7. Crandall B, Klein G, Hoffman R. *Working Minds: a Practitioner's Guide to Cognitive Task Analysis*. Cambridge, Massachusetts: The MIT Press; 2006.
8. Given LM, editor. *The SAGE Encyclopedia of Qualitative Methods*. Los Angeles, California: Sage Publications; 2008.
9. Sampson D, Karagiannidis C, Schenone A, Cardinali F. Knowledge-on-Demand in e-Learning and e-Working Settings. *J Educ Technol Soc*. 2002;5.
10. CII-CPAR: <https://actt.albertadoctors.org/CII-CPAR/Pages/default.aspx>
11. Home to Hospital to Home: <https://www.albertahealthservices.ca/assets/info/hp/phc/if-hp-phc-phcin-hthth-guideline.pdf>
12. One:carepath: <https://sites.ualberta.ca/~kscrg/onecarepath.html>
13. ADAPT: <https://sites.ualberta.ca/~kscrg/clinical-initiatives.html#adapt>
14. Alberta Surgical Wait-Time Initiative: <http://web.albertadoctors.org/albertadoctorsorg-a2s9c/pages/c8894025a7aeeb11a838000c29ee8689.html?PagelD=c8894025a7aeeb11a838000c29ee8689#:~:text=What%20is%20ASI%3F,surgeries%20within%20clinically%20appropriate%20timelines>

15. Beste LA, Harp BK, Blais RK, Evans GA, Zickmund SL. Primary Care Providers Report Challenges to Cirrhosis Management and Specialty Care Coordination. *Dig Dis Sci*. 2015;60(9):2628-35.
16. Kimbell B, Boyd K, Kendall M, Iredale J, Murray SA. Managing uncertainty in advanced liver disease: a qualitative, multiperspective, serial interview study. *BMJ Open*. 2015;5(11):e009241.
17. Standing H, Jarvis H, Orr J, Exley C, Hudson M, Kaner E, et al. How can primary care enhance end-of-life care for liver disease? Qualitative study of general practitioners' perceptions and experiences. *BMJ Open*. 2017;7(8):e017106.
18. Beernaert K, Van den Block L, Van Thienen K, Devroey D, Pardon K, Deliens L, et al. Family physicians' role in palliative care throughout the care continuum: stakeholder perspectives. *Family Practice*. 2015;32(6):694-700.
19. Naik AD, Arney J, Clark JA, Martin LA, Walling AM, Stevenson A, et al. Integrated Model for Patient-Centered Advanced Liver Disease Care. *Clin Gastroenterol Hepatol*. 2020;18(5):1015-24.
20. Davies E, Higginson IJ. *Palliative care: the solid facts*. Copenhagen, Denmark: World Health Organization; 2004.