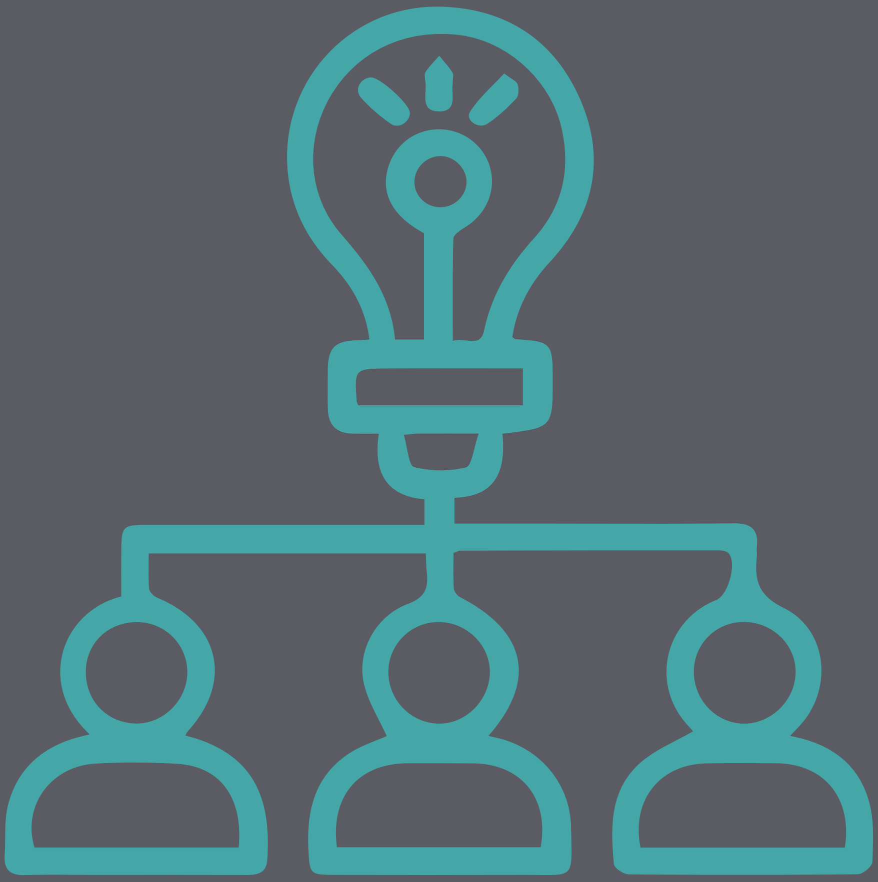

UNDERSTANDING PRIMARY AND SPECIALITY CARE MENTAL MODELS OF

CIRRHOSIS CARE

A COGNITIVE TASK ANALYSIS SUB-STUDY

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EnACt
ALBERTA MEDICAL ASSOCIATION
ACTT
Accelerating Change Transformation Team

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SUMMARY

LIVER CIRRHOSIS IS A LEADING CAUSE OF MORBIDITY AND PREMATURE MORTALITY. PROBLEMS IN COORDINATION AND TRANSITIONS OF CARE CONTRIBUTE TO HIGH RATES OF HOSPITAL READMISSIONS AND INADEQUATE QUALITY OF CARE.

OBJECTIVE

To compare the mental models of cirrhosis care held by speciality and primary care physicians and nurse practitioners, to help identify factors that hinder smooth transitions and coordination between primary and specialty care; informing the development of a province-wide cirrhosis care pathway.

METHOD

Cross-sectional formal elicitation of mental models using Cognitive Task Analysis (CTA). Setting: Primary and specialty (digestive, cirrhosis, hepatitis) care in Alberta. Selection: Purposeful and chain-referral sampling for family physicians (n=8) who saw small numbers (typical for unspecialized practice) of cirrhosis patients, and specialists (n=9) with high content knowledge and many cirrhosis patients. Nurse practitioners (n=2) included when the sampling chain led to them.

KEY FINDINGS

- **Family physicians** do not maintain rich mental models of cirrhosis care but take a "knowledge on demand" approach. They care for cirrhosis patients relatively infrequently and rebuild their mental model when required. They rely heavily on relationships with specialists for sensemaking. They have reactive, patient-need-focused, rather than proactive system-of-care models.
- **Specialists'** mental models are rich but vary widely a) between patient-centred and task-centred and b) in the degree to which they incorporate responsibility for addressing gaps in the system and in transitions.
- **Nurse practitioners** hold patient-centered mental models similar to specialists but take responsibility for addressing gaps in system.

SO WHAT?

Improving the coordination of cirrhosis care will require:

- Processes to optimize informational, relational and management continuity.
- Pathways and support infrastructure to provide resources for knowledge on demand that are easily found and applied, to facilitate the development of individual primary care physician-specialist relationships, to clearly define responsibilities of providers (who takes care of whom, when, how and where), and to support adaptation to local context (rural vs. urban, underserved or other special populations) will be integral components.

Purposeful redundancy will need to be built in as a part of reliable system design, to ensure loops are closed, and to minimize cognitive burden and task disruption.

RECOMMENDATIONS:

1. **Plan for the "expected unexpected."**
   - Create clear steps to help providers navigate and anticipate the trajectory of care and issues that may occur for patients living with cirrhosis. E.g. less structured appointments, forming structured partnerships among multidisciplinary teams to improve access and communication among health care providers, and patients.
2. **Consider patient context and journey, i.e. who they are, what is their situation, what stage they are at, and who needs to provide care when and how.**

   Possible options:
   - Co-located clinics, with interdisciplinary team, demonstrate how care can be planned, monitored, and coordinated for both attached and unattached patients.
   - Consider supports for health care providers and patients in rural areas to keep patients in homes or geographical area.
3. **Create clarity of provider roles that:**
   - Spans the trajectory of care required.
   - Includes the "middle ground" when patients are pre-compensated, between compensated and decompensated, and pre-end of life.
   - Examines details of coordination, communication, monitoring and detection.
4. **Work with and consider the mental models we know exist among health providers.**
   - Develop easily accessible care pathways and links to trusted resources that work with the knowledge on demand approach used by family physicians.

BACKGROUND & PURPOSE

Liver cirrhosis is a leading cause of morbidity and premature mortality in those patients with digestive disease.[1-2] Problems in coordination and transitions of care contribute to high rates of hospital readmissions and inadequate quality of care.[3-5] The Cirrhosis Care Alberta Program (CCAB) is a 3-year multi-component quality improvement initiative which aims to improve quality of care, reduce acute care utilization and be satisfactory to both patients and health care providers. Coordination and transitions of care between specialty and primary care is a priority in Alberta, yet these two groups do not appear to think in the same way about cirrhosis care. Furthermore, both groups lack clear processes for information exchange and support.

Our sub-study focused on gaining 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, including any key differences in how these groups approach this care.

PROJECT DESIGN & METHODS

We conducted, a Research Ethics Board approved, cross-sectional formal elicitation of mental models of cirrhosis care using a Cognitive Task Analysis (CTA) technique called the Knowledge Audit.[6] The Knowledge Audit draws on the recall and description of specific examples. It allowed us to identify skills and observable patterns highlighting strategies used for dealing with the coordination and management of cirrhosis care.

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

PARTICIPANTS

To recruit health care providers, we used purposeful and chain-referral sampling[7] to select family physicians (n=8) who saw small numbers (typical for unspecialized practice) of cirrhosis patients, and specialists (n=9) with high content knowledge and many cirrhosis patients. Nurse practitioners, specializing in the care of cirrhosis (n=2) were included when the sampling chain led to them. Participants varied in terms of gender, age, years practicing, and geographic location. *See Table 1.*

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.

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 - FAMILY PHYSICIANS

The family physicians we interviewed took a "knowledge on demand" approach as opposed to a rich internalized mental model of cirrhosis care. As they care for patients with cirrhosis relatively infrequently they rebuild their mental model as required. Their mental models of cirrhosis care were thus predominantly reactive and individual patient centered, rather than system level. Their models were also highly dependent on relationships.

There were differences in mental models in terms of how they approached team-based care. Some held "lone ranger" mental models, where they did all the work on their own, and others held "team-based care" mental models, where the team (e.g. physicians, clinic or PCN nurses, and medical office assistants) provided care together. This spectrum of "I do the work" to "we do the work" is not a new discovery. Our previous study looking at primary care teams[8-9] found that most primary care practices and physicians fall along this range when approaching patient care.

This "knowledge on demand" model, meant family physicians would research, read, and access online resources or rely heavily on established relationships with specialists to refamiliarize themselves with knowledge about cirrhosis when they were currently treating someone living with the condition. Due to the infrequency of treating those living with cirrhosis, the nature of their work and its demands, they could not maintain expertise about cirrhosis routinely, resulting in the need to rebuild their mental models each time they saw a new patient living with cirrhosis, thus becoming "experts in the moment."

> *Yes, I think this is quite typical of primary care, … my knowledge and skill has been upscaled the longer I've looked after him. I've learnt from the helpful letters from the liver clinic. Sadly, when I'll no longer look after him, I'm sure I'll gradually descale again, but again, with the myriad of other conditions I'll become an expert in another area, and another area…*
>
> - Family Physician

There were also some distinctions in how family physicians rebuilt their mental models. While some physicians tried to consider the whole patient in relation to cirrhosis, including any socioeconomic barriers to managing their health, others preferred to focus only on primary care health concerns and left cirrhosis-specific care to the specialists.

> *I think that's probably the strength of the family physician role… the multidisciplinary specialist. Working at all medical conditions rather than saying sorry I only deal with livers, … I don't do the diabetes… very few people will ask him about depression, how's your mood doing with all of this? How's your relationship with your wife? What's happening with your children?… trying to be, you know, as it says on our label - family physician.*
>
> - Family Physician

There was consensus amongst all family physicians that they experienced a lack of a structured process for coordinating care, including planning and prevention, for those living with cirrhosis. This, as well as the necessity to rebuild knowledge each time they cared for a patient with cirrhosis, meant that many family physicians did what they could, but the process was effortful in nature. As a result, most developed reactive, patient-need-focused mental models, rather than proactive system-of-care mental models.

Often, the physicians were dependent on who they knew in the specialist arena to access information and resources. Without these relationships many family physicians lacked the connection to streamlined or structured care for their patients. The geographical location of some physicians and patients also resulted in limited resources and/or connections with specialist care and a lack of knowledge of the services available.

MENTAL MODELS - SPECIALISTS

The specialists we interviewed had rich mental models of cirrhosis. This was not surprising given they are experts and specialize in working with this patient population. However, their mental models around the care of patients with cirrhosis varied widely: a) between patient-centred and task-centred; and b) in the degree to which they assume responsibility for addressing gaps in the system and in transitions of care.

Specialists described how cirrhosis care needed complex coordination and yet the system lacked the ability to support it. They reported lacking: a) technical support in terms of electronic medical record systems; b) clear roles and responsibilities; and c) confidence in the health care system within which they worked, as it was unreliable. We thus described their mental models as the "Swiss cheese" model – with rich mental models of how cirrhosis care should be but with recognition of gaps (holes) in the health care system, preventing coordination and continuity of care.

> " *The way our system is structured now is very poor…cirrhotic patients, many of them they're not going to just have cirrhosis. A lot of them are going to have diabetes, hypertension, heart failure, all sorts of other diagnostic problems, and I think the subspecialty model has failed to address that.*
>
> - Specialist Physician

While all specialists recognized the challenges or gaps (holes) in the system, their sense of responsibility in terms of filling or addressing them varied. Some focused on what they could do around the holes- addressing only what the patient presented with and holding a more task or work-based mental model. Others felt it was their responsibility to try to address the holes by taking on work outside of their usual realm of care, particularly if they felt other providers or areas of the health care system were not addressing these needs, resulting in a more patient-centred model. Either way both were effortful, and often reactive, working within the restraints of the system.

> " *Most of my patients in my clinic have a family physician…if they don't and the diagnosis is serious enough I will actually follow them until I've … found another family doctor or sorted out who's going to look after them.*
>
> - Specialist Physician

> " *I've always considered myself to be like their primary liver specialist, … any problems that had to do with their liver, so cancer, bleeding, whatever…that would be my duty to take care of… if a patient thinks that they're swelling up and they need a paracentesis I expect them to call me not their family doctor … I'm the bridge towards referral to transplant, my level of involvement depends on how sick they are.*
>
> - Specialist Physician

Like family physicians, specialists worked along the spectrum of "lone ranger" to "team-based care", but in the specialists' case it was context driven rather than by choice. Specialists that worked alone indicated this was not their preference and that they desired team members. Unfortunately, due to the context of the health system, and often geographical location for those in rural areas, they did not have access to or belong to a team who could support them. In addition, specialists, like family physicians, relied on relationships for guidance and resources. Those who lacked relationships felt at a disadvantage when it came to coordinating care for the patients they treated.

> " *Well I work with other physicians in the hospital, but it's not a team, I see my own patients and they're my responsibility. I don't have anybody working with me per se… I don't have a nurse, I don't have a dietician or a pharmacist… it's just me,… if a patient is really sick it's me… having to be alert as to whether … am I missing anything. It would be nice to have backup or help.*
>
> - Specialist Physician

NURSE PRACTITIONERS

The nurse practitioners we interviewed held empowered, patient-centered, and context-bound mental models. While they considered what was important to the patient, advocated for and were accountable to the patient, their focus was held within the specialty in which they worked: the de-compensated stage of cirrhosis.

Their mental models were like the "Swiss cheese" model of specialists, as they too held rich understandings of how cirrhosis care should be while recognizing the gaps (holes) in the system. However, they differed from specialists in terms of believing it was their responsibility to address those holes as much as possible. Nurse practitioners had a wide latitude to work within scope, meaning they could make decisions and had agency in how they cared for those living with cirrhosis. Their scope of work and autonomy allowed them time to build relationships and trust with patients; thus addressing, together with the patient, health, and social needs of day-to-day living.

> *…It's a real bonus to patients because I do have the time a physician may or may not have…, and actually get to know them and hear about what's going on in their lives, and what matters to them, and what challenges they're having, it's not just specifically - I'm here to deal with your medical issues and we're done so see you later.*
>
> - Nurse Practitioner

Nurse Practitioners reported their own challenges within the health system. They described how they were often excluded in correspondence regarding their patient's care. For instance, not being included in patient hospital admission and discharge communication or how referrals they initiated were often sent back to specialists within their clinic rather than directly to them.

> *… there are those physicians that I will send a referral to and they will return the referral back to one of the hepatologists, so the letter goes back to them, not to me, even though I was the person that sent the referral, it's challenging…*
>
> - Nurse Practitioner

THEMES

While our aim was to elicit mental models, three key themes emerged: continuity (lack of), managing the unknown and addressing the “middle ground”. We believe these themes link directly to the mental models identified, as well as play a significant role in informing the larger CCAB study.

CONTINUITY (LACK OF)

In our efforts to elicit and describe the mental models held by physicians and nurse practitioners working in primary and specialty care it became evident that the lack of continuity in the system was both a barrier to the way in which they had to work and a defining element of the mental models constructed. Health care providers must work within, and make sense of, a system that does not facilitate the coordination of care required to meet the complex needs of those living with cirrhosis. As such, they must build mental models that work with and around these gaps in the health care system.

Continuity includes three interlinking pieces: Informational, Relational, and Management.[10]

Informational: Communication of facts and opinions across team, institutional, and professional boundaries, and between providers and patients. It is often enabled by clear communication processes and technology.

Relational: The ongoing, trusting, therapeutic relationship between a primary health care provider (which can include a team of health care providers) and a patient. It is based on the patient seeing the same provider and team consistently.

Management: The coordination and handoff of care between relevant care providers using a shared care plan in a way that is both consistent and flexible to meet patient needs. It involves the integration of primary and acute care.

Within the context of informational continuity, the common tools that health care providers listed for accessing and communicating patient information among themselves were Netcare and letters or reports. While these were the tools most mentioned they did not come without their limitations.

> “ *I mean honestly most of it is from communication over the phone.”*
>
> - Specialist Physician

> “ *Yes, so most of our information honestly comes off of Netcare, our go-to source of truth is kind of Netcare..*
>
> - Specialist Physician

> “ *...whatever information they send in because historically a lot of that information is not on Netcare...*
>
> - Specialist Physician

There was an observable lack of sense-giving *(see Table 2: Macrocognition Framework)* from specialists to family physicians, but also between specialists themselves.

> “ *It would be nice to know what expectations they [hepatologists] have, if they do send their patients to the Emerg department or whatnot, things like that, what sort of follow up pathways would they like us to access.”*
>
> - Specialist Physician

Specialists acknowledge that they could be better at highlighting in summary reports who is responsible for what, what to look for, and what to do when it presents.

> *We sometimes don't carefully delineate, hey you're going to be responsible for, you know, the colon cancers, the rectals, the PAP tests and the mammograms, and, we're going to take care of the cardiovascular arresting, who's going to manage the blood pressure… I don't think we carefully delineate enough.*
>
> \- Specialist Physician

This lack of sense-giving was most evident in communication between specialists and family physicians about patients, i.e. long complicated letters, variation in amount of information being provided or delays in receiving information.

> *Many specialist's reports we don't even see….that can be very challenging for us…some of my patients that we've waited and waited for consultation, we didn't hear anything, and next thing we heard that they had decompensated, …were in the hospital…*
>
> \- Family Physician

On the other side, a specialist provided an example of what was lacking from family physicians' communication about a patient:

> *…a referral that I got last week…just says patient has a diagnosis of liver cirrhosis and has moved [to city] and needs a hepatologist, and that's all that it said, … I do need to know … are they decompensated or not, so are they in liver failure or not, that changes how I triage…"*
>
> \- Specialist Physician

Furthermore, much of the informational continuity was reliant on established relationships. Without these many family physicians did not have a clear sense of who [specialist] to send patients to, what information to send, and for both family physicians and specialists how to access information and resources needed to manage and coordinate care.

Lacking much of the resources and structure needed, many health care providers created workarounds, such as one community specialist who discovered that while he could not refer a patient to Primary Care Network resources, he could give the information (a patient information pamphlet) to the patient who could then self-refer and access resources if their family doctor was a PCN member.

> *… that's been a sort of ongoing project… to manipulate the healthcare system in order to allow my patients in through the door… the PCN doesn't allow me to use their services so I have to use a family doctor who's affiliated with the PCN to have any access to their services, so it's a bit of a source of frustration…*
>
> \- Specialist Physician

In terms of relational continuity, we saw variations in how health care providers built and maintained relationships with patients living with cirrhosis. Except for the nurse practitioners, some struggled with system constraints: lack of time and resources to adequately build trust and maintain relationships with patients. As a response, some took it upon themselves to be what they deemed the "Most Responsible Physician" or Provider (MRP), taking over care beyond their usual responsibilities to ensure the patient was receiving the support and care coordination they required. This was done when providers (both family physicians and specialists) knew, or assumed, no one else was meeting these needs, and they felt a responsibility to fill these gaps themselves. We also found that the notion of an MRP was linked to a lack of patient attachment to a family physician.

> *… I am the MRP, so for a hospital patient I will spend time reading outside of the visit. We often will call the hepatologist on call… or for one of the sick ones that I've seen recurrently I will call [their] identified hepatologist.*
>
> \- Family Physician

> *…my letters, they’re extremely long and detailed… a kind of laundry list of things that they (family physician) would hopefully check off… When that doesn’t happen, which is often the case because a lot of these patients end up actually kind of being not attached … then it kind of falls back on me… I don’t get a letter back from the family doctor saying they’re doing anything. I see them, nothing’s been done, nothing’s been checked, so it’s a sizeable minority of patients that are pretty uncared for in general…*
>
> - Specialist Physician

Health care providers noted challenges around successful attachment to a family doctor. For instance, geographical location, particularly in some rural areas, meant many patients did not have access to a family physician, or a limited number were available to them. Other examples included life circumstances, such as housing issues, that affected attachment, and some health care providers noted that there were patients who did not want to attach to one family physician. While our current system is focused on attaching all patients, this provides awareness that the system may need to accommodate the needs of unattached patients.

> *I’m not his primary care physician but can be the only resource at times because, , these people sometimes don’t stay attached, as you hear the story right, they’re on AISH, they’re using meth on and off, can sometimes have significant social issues, so sometimes they don’t stay attached to their GPs.*
>
> - Family Physician

Within the context of management continuity, we found that health care providers again noted gaps in coordination and handoff of care between providers. This was a result of the system lacking structure to support appropriate care coordination and lack of trust between providers that either one would take care of all the patient’s needs. For instance, as we saw above with the MRP phenomenon, there were specialists who maintained care of patients, rather like a family physician, as they did not trust that the patient’s family physician would follow up with routine testing and assessment in order to keep the patient from relapsing. In other situations, providers noted that there may be trust between them, but the system failed to include all parties in care coordination. For example, drop-down lists in Connect Care do not include nurse practitioners, a design barrier that makes it difficult to include them in follow up communication about a patient’s care. Family physicians were most notably excluded from the stream of care handoffs. Although there were specialists who noted that there was a lack of management continuity between specialists, particularly between specialties in the community, lack of continuity was pointed out more so between family physicians and specialists.

> *“It’s all we could do was (a) discover he was admitted, (b) call to see if he was still admitted, and then by the time that had happened they were already on discharge planning or had already discharged him. Well wouldn’t it be nice if we… could have collaborated a little bit more and tried to find a bit of an overall solution to this instead of just playing the admission-discharge-deterioration game over, and over again.*
>
> - Family Physician

> *…when they refer someone to an additional specialist or service they sometimes fail to copy in the family doctor,… sadly, the Privacy Information Act … seems to lock me out of the circle of care, … I’ve tried to contact the receiving specialist to say please provide me a copy of your consult, I get a letter…saying sorry you don’t have permission to have this information, it’s gone back to the referrer, you need to get a letter from the patient to do this.*
>
> - Family Physician

Furthermore, the management of care coordination in Alberta remains heavily dependent on healthcare provider networks and relationships. Without a team or a network of providers, trying to navigate the complex care of those living with cirrhosis is a challenge.

> *It makes me realize reflectively just how complicated this thing is…. a lot of this complex care is about relationships and personalities. Continuity is probably the single strength here, and I see a really strong team who looks after this patient, and sadly all it takes is for one of those members in that team to change for a period of time and that patient ends up becoming an admission, which could've been avoided.*
>
> - Family Physician

The lack of continuity in all three of its dimensions is a significant factor in the challenges that face both those that live with cirrhosis and those trying to provide them with care. It has become a cog in a cyclical wheel that requires providers to create workarounds, such as the MRP, relying on relationships and networks, or actively and consciously seeking out information to manage the lack of adequate care coordination. In turn, this perpetuates poor coordination because providers continue to cope in this manner thus doing their best to fill the gap for formal and systematic processes that do not exist, therefore the system is never changed.

MANAGING THE UNKNOWN

Health care providers described in both direct and indirect ways that managing cirrhosis care becomes an act of constantly managing the unknown *(see Table 2)*, or as one family physician described it, managing "the expected unexpected events."

> *The expected… the recurrent unexpected happened in terms of, you know, unpredictable Emergency room visits, so any particular day was hard to predict, but globally recurrent visits to the Emergency room, recurrent visits to the clinic, recurrent sort of stretches where [patient] wouldn't go to the pharmacy because of med compliance etc., so those are sort of the expected unexpected events.*
>
> - Family Physician

The factors that were attributed to cirrhosis care being an act of managing the unknown included:

a) the complexity of the disease itself, making diagnosis challenging, and included side effects such as cognitive impairments that made communicating with patients and providing care difficult;

> *… he came to me about a year, year-and-a-half ago with a diagnosis of liver disease… he had episodes of hepatic encephalopathy, so that's what made his care management more challenging was the cognitive aspect of that. He would go in and out of Emergency because of his thinking, his med compliances, edema, so chasing him down wherever he went and trying to work out a proactive plan for that, it never really seemed to happen. We were always chasing our tail it seemed.*
>
> - Family Physician

b) the majority of the population living with cirrhosis who suffer from multiple health issues and may be facing challenges beyond cirrhosis such as housing, addiction, and other gaps to social determinants of health that means cirrhosis is not their top concern;

> *"Apart from that I also hope that as family physicians we would focus a little more on other social determinants for the patient because many of them have real issues. We know housing, money, addictions. Some of them need to go to rehab."*
>
> - Family Physician

c) geographic location which may determine whether or not they have access to family physicians and specialists, and if they need to leave rural areas when ill so that they can access supports found in urban areas (a need not all patients are willing to act on).

> *The city is about two hours away and a lot of people don't want to get themselves involved in travelling, so there are so many challenges when you're referring to places in our area.*
>
> - Family Physician

In addition, as discussed earlier, the infrequency of providing care for those living with cirrhosis means family physicians need to learn and relearn how to manage cirrhosis care including recognition and diagnosis which translates into managing the unknown from an overall view. Rebuilding their mental models to become "Experts in the Moment", learning what they need to care for the patient they are currently seeing and then relearning again when they see the next which may be months or years later.

> *All of these things are sort of foreseeable in various ways, shapes or forms and yet every single time it's like you're reinventing the wheel.*
>
> - Family Physician

Working with so many unknown factors, providers worked on a case by case basis, as we described in their mental models. Some, knowing to expect the unexpected, either took on the MRP role if they felt other health providers were not able to handle so many unknowns, and others approached this care holistically by considering all of what the patient (and family) may be facing in life.

The ability to recognize and manage the unexpected and uncertain is key to supporting family physicians. Efforts to improve cirrhosis care will require building pathways, tools, processes to facilitate information exchange between providers, to strengthen team and stakeholder relationships and to clearly define roles and responsibilities. These would serve to and provide cognitive support for providers managing uncertainty and unpredictability in high needs populations.

Health care providers, particularly those from charitable community clinics working with the underserved, offered possible suggestions or solutions to working with the unknown and unexpected based on processes and mechanisms they had adopted to better serve those facing socioeconomic challenges. These included having a central pharmacy, ensuring all those involved in care receive information about patients, having cognitive supports for patients, availability of housing resources, engaging peer support workers, having flexibility for appointments, providing support to get to appointments, and recognizing challenges patients face.

> *You've tried explaining why it's important. He understands why it's important. …He still doesn't show up because it's a very scary thing to have esophageal varices… when you have somebody who's willing to go with you who's been there who's gone through it, that's a really strong thing, … I think that's where peer support workers could be really useful is helping people who are so reticent to go for their screening or for either liver cancer or esophageal varices…*
>
> - Specialist Physician

> *Flexibility and scheduling … have a half-day a month where no one needs a specific hard appointment to be seen…and so if you have somebody no-show… they can get squeezed in on another day, but at least this way not having to drag this gentleman to an appointment … and then if they're an hour late, three hours late… two strikes and you're out, and then of course you have to do a whole new referral, and that creates its own set of barriers right.*
>
> - Family Physician

MIDDLE GROUND

An issue that arose across health care providers was the timing in which patients received their diagnosis and care. There were multiple periods of time in which they felt it was either unknown or unclear in terms of what care should be provided and by whom. We called this the middle ground, as it was often in between different stages of cirrhosis.

> *… we really do have this huge gap right in the middle which is what do we do with people that are getting sicker that aren't quite in hospital yet, that's tricky…*
>
> - Specialist Physician

Health care providers noted a need for guidance around how to diagnose earlier and beyond that, how to discuss prevention with existing patients and the broader population.

> “ *For physicians, especially primary physicians, I am hopeful that we’ll be able to more proactively, screen patients, and then identify them at early stage instead of in the hospital when they’re decompensated.*
>
> - Family Physician

Other health care providers pointed out that there was a period of time when patients were considered pre-decompensated and so were not sick enough for the hospital or specialist care, yet the patient’s condition was worsening. A patient in this scenario was described as “a time bomb”:

> “ *Oh, and we’ve seen a few… they’re a time bomb waiting to explode, and you’re just waiting for them to.”*
>
> - Family Physician

Health care providers wanted to know what care should be provided to these patients in this in-between stage of cirrhosis. Many discussed the care needed between compensated and decompensated stages, or throughout the broader continuum of providing care for those living with cirrhosis, and needing clearer roles as to whom should be seeing the patient and providing what care when and how.

> “ *I just wish I had an understanding for this or what to do or … I would want some sort of pathway that I know I can rock solidly rely on that… you’re pretty sick, you know, and I refer them on and … I don’t know what’s going to happen to them after they’ve left my clinic, how do I know this patient’s going to be looked after…*
>
> - Family Physician

> “ *… it just would help to provide some more direction on awareness …on issues that have to do with liver. … I don’t know what services about, you know, liver problems (exist) in this province…, it’s a major problem and … it’s going to be more of fatty liver and non-alcoholic cirrhosis that might ensue from that in the future. So we need to plan and be sure that some things are in place to mitigate that.*
>
> - Family Physician

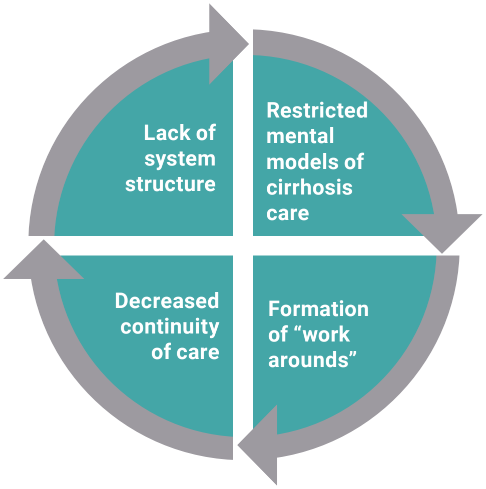
Having frank conversations with patients and sometimes family members or friends about the stage the patient is at along the continuum of care and what they can expect, including the effects of their actions and/or inactions, was also an element that health care providers described. These interactions may assist in addressing the middle ground and patient roles.

> “ *…it’s the whole concept of addiction and what that looks like for each person … developing a really good relationship, allowed her to be more candid and honest in her responses, and that to me was quite interesting to be able to understand where she was at … and things that were said to her at certain points in her interaction with healthcare in terms of being an alcoholic. … I learned a lot from her about… how to be respectful to people and how to treat people wherever they are, like what kind of medical intervention are you going to accept and do you want where you’re at right now on this journey…*
>
> - Nurse Practitioner

DISCUSSION

While we set out to understand and compare primary and specialty care physicians' and nurse practitioners' mental models of cirrhosis care, it became evident that key themes emerging from the data were also intertwined with the mental models we elicited.

We discovered that the lack of continuity in cirrhosis care propels a consequential cycle that influences the formation of health care providers' mental models of cirrhosis care. Family physicians and specialists held mental models that included reactive and effortful approaches to cirrhosis care due to a lack of system structure, process and clear roles and responsibilities, guidelines or tools. These gaps failed to allow for planning, prevention, and consistent treatment or management and instead required the providers to create workarounds within their understanding of how to manage cirrhosis care. Furthermore, family physicians needed to rebuild their mental models with each new patient they treated as they did not see patients living with cirrhosis frequently enough to maintain expertise in this chronic condition. In addition, we believe that the lack of continuity we heard health care providers describe not only impedes their ability to develop rich mental models of cirrhosis care, but the system supports available may also determine whether they form a patient-centred or task-based mental model. Overall, this predicament cycles from a lack of system structure, to forming restricted mental models of cirrhosis care, which result in forming workarounds rather than the system-level processes needed, which affects being able to provide continuity of care.



The uncertainty that accompanies both the illness itself and a portion of the population living with cirrhosis, i.e. barriers to social determinants of health, addictions, mental health etc., augments the likelihood of forming restricted and reactive mental models of cirrhosis care. Many providers are trying to work through the issue at hand, as we saw from the health care providers we interviewed, without much time or capacity to consider the bigger picture. Some of the health care providers we interviewed discussed accepting the unknown and unexpected as the expected and structuring their care in a flexible way so that they could provide more patient-centred or preventative care. Creating system-level supports that coincide with such ideas may assist other providers to accept the uncertainty and manage the expected unexpected, shifting their mental models of cirrhosis care, e.g. implementing co-located teams; early screening and prevention; tracking processes; planning and re planning; and deliberate feedback loops.

Addressing the middle ground may go beyond looking at ways in which we can shift or develop mental models to considering which group of health care providers are better allocated to provide the in-between care required between stages of illness. While nurse practitioners reported challenges, their roles allowed for the time they needed to spend with patients to assess and create systems that worked for the patient and in relation to where patients were on the continuum of care.

Overall, in our exploration of the mental models of cirrhosis care held by health care providers and the themes that emerged from the data, it became apparent that dealing with the system barriers and gaps that prevent the level of continuity needed to coordinate care for this patient population means that cirrhosis care imposes a high level of cognitive workload on providers. While the providers we interviewed appeared to feel confident in their management of cirrhosis care, not one expressed the belief that the coordination of cirrhosis care was working well in Alberta.

CONCLUSION

Our findings reveal that improving the coordination of cirrhosis care will require the development of a pathway and support infrastructure that provides: resources for knowledge on demand that are easily found and applied; clearly defined responsibilities of providers (who takes care of whom, when, how and where); and should support adaptation to local context (rural vs. urban), underserved or other special populations (see Recommendations). This will facilitate the development of primary care physician-specialist relationships, trust, and improved continuity of care. Intentional, purposeful redundancy will also ensure closing of communication and care loops to minimize cognitive burden and task disruption.

While this list may seem daunting, the health care providers themselves offered suggestions on how we may move forward with these elements in mind. For instance, health care providers suggested that we look to existing pathways, e.g. Heart Function or Inflammatory Bowel Disease, for successful examples that could be applied to cirrhosis care. Virtual clinics were provided as another example that may work as a solution to providing the guidance needed for coordinating and providing care for those living with cirrhosis, particularly for those living in rural areas.

Finally, nurse practitioner clinics could be a solution to address the needs of cirrhosis care in Alberta. Nurse practitioners had the time to build trust and relationships with patients and approached care holistically. As such, they are in a key position to plan for the expected unexpected, consider patient context, and provide care at various stages (e.g., referring to physicians as needed).

The health care providers we interviewed were open to guidance and standardization of cirrhosis care in Alberta. Thus, it appears there would be a welcome consideration of improvements and interventions to cirrhosis care among providers across the province. The caveat is that providers would also need to know the support exists and where to find it.

RECOMMENDATIONS

1. **Plan for the "expected unexpected"**

- Create clear steps to help providers, particularly family physicians, navigate and anticipate the trajectory of care and issues that may occur for patients living with cirrhosis. E.g. less structured appointments, forming structured partnerships among multidisciplinary teams to improve access and communication among health care providers, and patients.

2. **Consider patient context and journey, i.e. who they are, what is their situation, what stage they are at, and who needs to provide care when and how. Possible options:**

- Co-located clinics, with interdisciplinary team in one place, demonstrates how care can be planned, monitored, and coordinated for both attached and unattached patients.
- We must also consider supports for health care providers and patients in rural areas to keep patients in their homes or geographical area.

3. **Create clarity of provider roles that:**

- Spans the trajectory of care required for those living with cirrhosis.
- Must include the "middle ground" period when patients are pre-compensated, between compensated and decompensated, and pre-end of life.
- Examine details of coordination, i.e. different ways nurse practitioners, specialists and family physicians work, their work hours, etc., so that all can engage in effective communication, coordination, and monitoring and detection.

4. **Work with and consider the mental models we know exist among health providers.**

- Engaging all parties in the design process and thinking about how interventions will interact with or support the known elements of existing mental models, and vice versa, increases the likelihood that providers will be accepting of interventions as it will not require a shift in their mental models. In time, as the intervention supports and provides more structure to cirrhosis care we may see a natural shift to a richer more patient centred mental model among providers.

TABLES

Table 1: Participant Demographics

	FPs	SPs	NPs
Gender			
Woman	2	3	2
Man	6	6	
Age			
30-39 years old	2	2	
40-49 years old	5	3	
50-59 years old	1	3	2
60-69 years old		1	
Place of Medical Education			
In Canada	4	6	2
Outside of Canada	4	2	
Both		1	
Years Practicing			
Under 10 years	2	2	
-10-19	3	4	
20-29	2	2	1
30-39	1	1	1
Geographic Location			
Urban	3	8	2
Rural	5	1	
South	4	5	1
Central	1	1 *Also North	
North	3	4	1

Table 2: Macrocognition Framework

Macrocognitive functions are the crucial processes that individuals and teams carryout each day. In consideration of the Macrocognition Framework, we coded each transcript using a "macrocognition" template.[11-13]

Function	Description
Sensemaking and learning (SL)	• 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)	• Decisions in, or about, patient care and administrative processes
Planning and re-planning (PL)	• Shaping or reshaping patient care or administrative processes
Monitoring and problem detection (MD)	• 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)	• Planned or anticipatory (contingencies, fallbacks) • Evaluating/estimating risks Unplanned, "scrambling"
Coordinating (CO)	• Any activity that helps synchronize 2 or more individuals in a patient care or administrative process, especially transmit- ting information or expectations • Maintenance of "common ground," shared expectations/ understanding/mental models of processes

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