

## Exploring provider roles, continuity, and mental models in cirrhosis care: A qualitative study

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### ABSTRACT

**BACKGROUND:** Advanced cirrhosis results in frequent emergency department visits, hospital admissions and readmissions, and a high risk of premature death. We previously identified and compared differences in the mental models of cirrhosis care held by primary and specialty care physicians and nurse practitioners that may be addressed to improve coordination and transitions in care. The aim of this paper is to further explore how challenges to continuity and coordination of care influence how health care providers adapt in their approaches to and development of mental models of cirrhosis care. **METHODS:** Cross-sectional formal elicitation of mental models using Cognitive Task Analysis. Purposive and chain-referral sampling took place over 6 months across Alberta for a total of 19 participants, made up of family physicians ( $n = 8$ ), specialists ( $n = 9$ ), and cirrhosis nurse practitioners ( $n = 2$ ). **RESULTS:** Lack of continuity in cirrhosis care, particularly informational and management continuity, not only hinders health care providers' ability to develop rich mental models of cirrhosis care but may also determine whether they form a patient-centred or task-based mental model, and whether they develop shared mental models with other providers. **CONCLUSIONS:** The system barriers and gaps that prevent the level of continuity needed to coordinate care for people with cirrhosis lead providers to create and work under mental models that perpetuate those barriers, in a vicious cycle. Understanding how providers approach cirrhosis care, adapt to the challenges facing them, and develop mental models offers insights into how to break that cycle and improve continuity and coordination.

**KEYWORDS:** care coordination; case management; cirrhosis; clinical guidelines/pathways; continuity of care; re-engineering; role clarity; shared mental models; specialist nurse practitioners

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## INTRODUCTION

Cirrhosis is characterized by advanced fibrosis, and complications related to hepatic insufficiency and portal hypertension. In its advanced state, it results in a high risk of premature death, as well as high costs to the health care system due to frequent emergency department visits, hospital admissions, and readmissions (1–4). A team-based and coordinated approach to care has been associated with improved outcomes (5). However, gaps in our knowledge of how coordination actually takes place between providers managing care for someone living with cirrhosis, a lack of policies and processes clearly directing cirrhosis care, and challenges such as poor communication between providers and insufficient access to specialists by family physicians, have resulted in initiatives to improve coordination having limited impact (5–7).

Mental models are the lenses through which we see and make sense of the world around us, what we consider as possibilities, how we discern what will happen if we choose certain actions, and how we make decisions (8–10). Successfully implementing coordinated or integrated care requires those involved in the care process to have a shared mental model of integrated care, including the goals of care and the roles of those involved (8,9,11).

Eliciting and understanding mental models can provide insight into not just identifying the issues at hand when implementing new interventions, but more deeply understanding them and how we should adjust our approach to addressing these issues (9). That prompted the Cirrhosis Care Alberta Program (CCAB) team (led by PT) to initiate the present project (12). The work involved formal elicitation of the mental models of Alberta-based specialists, family physicians and nurse practitioners about providing cirrhosis care, using Cognitive Task Analysis (CTA) (8). This work revealed that specialists and family physicians do not hold shared mental models of cirrhosis care (13). We noted in the course of analysis that the CTAs also provided data about how the challenges to continuity and coordination of care influence how health care providers adapt in their approaches to, and development of mental models of, cirrhosis care. In this paper we pursue analysis of that serendipitous finding.

## METHODS

The study goal was to elicit the mental models of family physicians in typical practices, meaning

those who managed care for small numbers of patients with cirrhosis, and specialists who managed higher numbers of patients with cirrhosis. To do this we used the Knowledge Audit (8), which is a CTA technique. CTA emerged from the cognitive engineering field as a way to draw out the cognitive activities or knowledge work that takes place in order for individuals to accomplish real world tasks. It has been most often used to understand individual and team cognitive work in settings that involve high risk or serious consequences, such as Intensive Care Units (8).

### Participants

Participants were recruited across Alberta through notices posted in a provincial newsletter and on a website managed by the Alberta Medical Association. Those who were interested, and contacted our team to participate, were asked to suggest colleagues they thought would be interested in participating as well. That chain-referral sampling (14) resulted in ( $n = 8$ ) family physicians, and ( $n = 9$ ) specialists participating in this study. Nurse practitioners ( $n = 2$ ) were recruited when the sampling chain led to them and were recruited by CCAB. Recruitment took place over 6 months, for a total of 19 participants (see Table 1: participant demographics). None withdrew from the study. Of the family physician and specialist participants, 7 contacted us through seeing the notices and 10 had been suggested by their colleagues.

### Data collection

Team members trained in CTA (led by and including LT) interviewed participants in person, at a time and location of their choice; one interview did take place over the phone and one through Skype. During the interview, participants were asked to think of a recent case where they managed cirrhosis care, and to walk the interviewers through the process. While the age range (5-year category) and gender or sex of the patient was listed, no other identifiable information was collected about the patient. The interviews were audio-recorded and took roughly one hour. As is common with CTA, interviews were conducted by one interviewer and one note taker, and although an interview guide was created (see REB approved interview guide in Appendix), team members relied more on their understanding of the macrocognition framework (see Table 2), the foundation of CTA (8), than on

**Table 1:** Participant demographics (N = 19)

	Family physicians	Specialists	Nurse practitioners
Self-identified gender			
Woman	2	3	2
Man	6	6	
Age range, y			
30–39	2	2	
40–49	5	3	
50–59	1	3	2
60–69		1	
Place of medical education			
In Canada	4	6	2
Outside of Canada	4	2	
Both		1	
Years practising medicine			
Under 10	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	

the guide itself for the interview process. The macrocognition framework has been used in our previous work (13,15,16) and assists in understanding the cognitive activities that experts utilize to accomplish daily tasks in their work settings (8,17–19). Audio recordings of the interviews were transcribed for analysis, removing any identifiable information and allocating study numbers to participants.

### Data analysis

The transcripts of the interviews were coded by the CTA trained team members (led by and including LT) using the macrocognition framework (Table 2) (17–19) allowing for emergent findings. Each transcript was divided into sections, and then those sections were assigned to two team members, mixing pairs and sections for each new transcript. Once coded, the full team gathered (led by LAG and TB) to review the coding, develop a shared representation of the participants' macrocognitive

functions, and finally their mental model of cirrhosis care (9,13). Identification of any emergent findings were also discussed during these meetings. Analysis meetings took place concurrently with data collection and allowed team members to discuss and resolve any discrepancies around coding, the identified macrocognitive functions, or the descriptions of mental models. Ensuring the attendance of at least one of the two interviewers who conducted the interview under analysis also provided opportunities for further clarification. Once all transcripts were coded and analyzed, contrasts and comparisons were made across participants' mental model representations.

## RESULTS

The results of this study, as indicated earlier, allowed us to create clear narrative representations of the mental models of cirrhosis care held by family physicians, specialists, and nurse practitioners (13). Here, we provide a brief overview of these findings, focusing on how those mental models interconnect with continuity of care and the desire to implement improved integrative care within cirrhosis care. For instance, our findings suggested that the lack of a formal system for coordinating care for patients with cirrhosis, in addition to the complexity of the illness and the uncertainty that accompanies both the illness and the patient's life situation, meant family physicians also lacked formal systems for planning and prevention, and this resulted in their development of what we described as reactive, patient-need-focused rather than proactive system-of-care mental models of cirrhosis care (13). Family physicians indicated they were highly dependent on relationships with specialists to assist with accessing information and resources, if they were lucky to have formed such relationships, but were not always clear on division of roles (13). In addition, their mental models were different from those of specialists and nurse practitioners, who had rich mental models of cirrhosis care but varied in their approach to working around or addressing gaps in the system, demonstrating a lack of shared mental models between primary and specialty care (13).

It became evident then, that the lack of continuity in the system was both a barrier to the way in which our participants had to work and a defining element of the mental models constructed. Health care providers have to work within, and make sense of, a system that does not facilitate the

**Table 2:** Macro-cognition framework

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

coordination of care required to meet the complex needs of those living with cirrhosis. Hence family and specialty physicians had to build mental models that work with and around these gaps in the health care system.

Continuity includes three interlinking pieces: informational, relational, and management (20). Informational continuity is the 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 continuity is 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 continuity is 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 is central to the integration of primary and acute care (20).

It was apparent from the interview data that when it came to cirrhosis care, continuity was lacking in all three areas. For instance, there was a lack of sense-giving (see Table 2) from specialists to family physicians in terms of informational continuity. While information-sharing tools exist in Alberta, such as Netcare (a provincial partial electronic health record which both specialty and

family physicians can access) and summary reports, both groups indicated that they needed more clarity in terms of what is going on with the patient and indicating who was responsible for what, what to look for, and what to do when it presents in the patient. Shared sensemaking was better between nurse practitioners and the specialists with whom they worked, but nurse practitioners also reported being left out of information in some cases.

Many specialists' reports we don't even see them at all. ... Usually you'll get the initial report when the patient was seen initially, but many of our patients we don't really see subsequent reports. (FP7)

I mean an example of a referral that I got last week basically just says patient has a diagnosis of liver cirrhosis and has moved to [location] 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. (SP3)

[O]ne of the issues that we run into as nurse practitioners is that we're often not notified if our patients are in the hospital, and we may not know until they come into our clinic or somebody thinks to send us a discharge summary ... they may not know that we're involved in their [patient] care even though

they should be looking in Netcare and seeing our consultations. (NP1)

Furthermore, much of the informational continuity was reliant on established relationships and knowledge on how the existing system works, including any resources available. Without this foundational knowledge, or established relationships, many family physicians did not have a clear sense of who to send patients to, or how to access information and resources needed to manage and coordinate care. To compensate, many of the physicians 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 accordingly.

[T]hat's been a sort of ongoing project just to try to manipulate the health care system in order to allow my patients in through the door. (SP9)

[W]hen I first started looking after him [patient] I didn't know there was a nurse practitioner in our liver clinic partner, shall we say our referral directory might just refer to hepatology ... And then thereafter that actually I've been really impressed with the care and expertise of that hepatology nurse practitioner. (FP3)

In terms of relational continuity, we saw variations in how health care providers built and maintained relationships with patients living with cirrhosis. For instance, except for the nurse practitioners who reported having time to spend with patients, many physicians struggled with the constraints of the system: lack of time and resources to adequately build trust and maintain relationships with patients. As a response to these constraints 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 health care providers knew, or assumed, no one else was meeting these needs, and they felt a responsibility to fill these gaps themselves. Often the assumption of an MRP role by a specialist was linked to a lack of patient attachment to a family physician, or if the patient did not have a good relationship with their family physician.

[O]ur model is that the family doctors are the most responsible physician. ... I am the MRP, so for a hospital patient I will spend time reading outside of the visit. I will call the hepatologist often. (FP2)

So that was a bit of a gap because she didn't have a good relationship with her family doctor. I did insist that she maintain a family doctor for issues that were outside of my scope of practice because ... particularly as nurse practitioners, we get kind of roped into doing everything and being everything for these patients because they develop a trust in the relationship with us. (NP1)

[S]o if you look at the EMR [Electronic Medical Record] you see abnormal LFT, abnormal LFT, abnormal LFT, and that was from May 2013, abnormal LFT, depression, alcoholism, anxiety, and all those diagnoses were made all because of the lack of continuity because of the lack of proper attachment to a doc ... he was falling through the crack. (FP7)

Within the context of management continuity, we found that participants again noted gaps in the coordination and handoff of care between providers. This was a result of the health system lacking structure to support appropriate care coordination and a lack of clarity and trust between providers in terms of whose responsibility it was to take on which part of the care and who would actively take care of the patient's needs. Much of this linked to failures of informational continuity, such as missing reports, or the admitting or discharge summaries not being sent to family physicians or nurse practitioners in a timely fashion.

[S]ome 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 and they were in the hospital ... The two-way communication with specialist is not the best when it comes to some of our chronic disease patients, especially on cirrhosis. (FP7)

He [patient] comes back to my clinic a year later and he's had both his liver and his kidneys transplanted and no one sent me a single fucking piece of paper to say hey we admitted your patient, he got his transplant ... I hadn't heard he'd had his kidneys transplanted either,

so the level of communication at times ... it's a black box, you send them in there, they don't put anything on Netcare, they don't send you a letter, they don't bother to write to you ... but there's no possibility of much in the way of continuity of care. (SP9)

As participants indicated, the management of care coordination in Alberta remains heavily dependent on informal communication and health care provider networks and relationships. Without a team or a network of providers, particularly family physicians linking with specialists, trying to navigate the complex care of those living with cirrhosis is a challenge. This includes deciphering the role they play as family physicians in cirrhosis care and how to connect patients with the support they require.

[P]atient unable to engage, unable to connect and also unable to reach out to the providers, so these are measures that would know that this system is not working at all. If they cannot access their providers, cannot access the services, and also they're not really getting engaged with the system. (FP1)

I tell this to my patients a lot, once you're in the system, they're in the system, but you have to be in the system first right ... but often it's hard to get that patient in that system, especially for us from that aspect it's really hard to get that one person in. (FP5)

Nurse practitioners indicated they had relationships with family physicians which implied a possible bridging of the gap between specialty and primary care, but challenges remained in terms of whether physicians acted on the invitation to build this relationship.

I do get phone calls from family physicians periodically, not a lot, but if there's particular questions they have or challenges that they're having, especially for, as we've sort of mentioned, the remote physicians that are quite far away, you know, who maybe don't have access to all of the bells and whistles that we do here or aren't quite sure what to do. I appreciate that because you write letters and you don't know if they've read them, you don't know if they're listening or that they understand or if they have any questions. At the end of your letters you're always inviting them to call or whatever, if they have any

questions or concerns, and you never hear anything back. (NP2)

I think of her [nurse practitioner] as very much an equal and we're sharing that patient's care together, and actually I've been really impressed how much I've learnt from her in terms of managing both liver failure and her general medical kind of knowledge as well. (FP3)

An additional challenge to management continuity was what we called the 'middle ground.' There were multiple periods of time, often between different stages of cirrhosis, in which both family physicians and specialists felt that what care should be provided and by whom was either unknown or unclear. This included earlier diagnosis, which family physicians wanted more guidance on, and patients who were considered pre-decompensated—not sick enough for the hospital or specialist care, but their condition was worsening. For family physicians this also linked to uncertainty around prognosis and palliative care, with some stating they didn't have the expertise or knowledge to have these conversations and relied on others to initiate.

For physicians, especially primary physicians, I am hopeful that we'll be able to more proactively, you know, screen patients, and then identify them at early stage instead of in the hospital when they're decompensated. (FP7)

[W]e 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. (SP9)

[W]e need to give them appropriate end-stage palliative care, and we often are not able to do that because we just don't have the expertise. (FP2)

[S]he [hepatology nurse practitioner] also talked a bit about prognosis to him which is something I haven't done because I don't have that knowledge ... she also put at that time that she's going to refer him to the palliative-Home Care team to see what additional support they can offer, so she initiated that which was very helpful. (FP3)

Participants wanted to know what care should be provided to these patients in this in-between stage of cirrhosis. They reported needing clear roles and knowing who takes care of what, when,

and how throughout the continuum of providing care for those living with cirrhosis.

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 that are trying to provide them with care. It requires providers to create workarounds, such as taking on the MRP role unbidden or relying on relationships and networks, to manage the lack of adequate care coordination. In turn, this perpetuates the development of reactive mental models that are not shared across the interdisciplinary team, and poor coordination because formal and systematic processes do not exist; thus, the system is never changed.

## INTERPRETATION

Our findings suggest that lack of continuity in cirrhosis care, particularly lack of informational and management continuity, not only impedes health care providers' ability to develop rich mental models of cirrhosis care but may also determine whether they form a patient-centred or task-based mental model, and most importantly whether or not they develop shared mental models with other providers. That appears to create a vicious cycle: from a lack of system structure, to forming restricted mental models of cirrhosis care, to forming workarounds rather than creating the system-level processes needed, which then further degrades the ability to provide continuity of care and develop a shared understanding of the process of care.

Improving coordination of care for patients with cirrhosis will require infrastructure and policies that support informational and management continuity, in order to break that cycle. One approach is case management: the designation of an individual, most commonly a nurse or nurse practitioner, to oversee and coordinate cirrhosis-related primary, specialty, and community services for the patient. Case management sidesteps the lack of shared mental models and role clarity, and creates relational as well as informational and management continuity, by locating all of those in a single person. However, case management can be costly, is difficult to implement in smaller communities or rural areas, and can erode continuity for patients' overall health care while improving it for the target disease.

Another approach is to re-engineer the system to bring family physicians and consultants onto the same page, both in their mental models of cir-

rhosis care and in their management of the specific patient. A key factor in that re-engineering is that family physicians do not maintain detailed mental models of cirrhosis care, as we previously demonstrated (13), but refresh their model when needed. Therefore, access to near-real-time consultation, in a way that does not disrupt workflow in the time-pressured primary care clinic setting, is one crucial component. Another is a set of guidelines and care pathways, consistently used among consultants and with the relevant components readily applied in the busy primary care setting. A third is a shared clinical information resource accessible to both primary care physicians and consultants, and ideally to patients and families as well.

Alberta has the beginnings of all three of these components. However, the near-real-time (telephone-based) consultation is not available in all areas, and even where it is many family physicians find it easier to rely on direct relationships with consultants—when they are fortunate enough to have them. Province-wide algorithms and inpatient order sets were recently launched (12) ([www.cirrhosiscare.ca](http://www.cirrhosiscare.ca)) and are still early in dissemination. In our previous work, we heard from family physicians that advice was often inconsistent or conflicting from one consultant to the next, so work remains to be done getting consultants on the same page. Similarly, family physicians have not yet come together to agree upon the expectations for their role. Netcare enables all physicians to see some clinical information, but it is a limited subset; the broader Connect Care implementation (including patient portal) is early in implementation.

One important area where family physicians' role clarity needs addressing is advanced-illness and palliative goals of care. Family physicians can be reluctant to start these conversations, and experience ambiguity around whether or not it is their responsibility to have these conversations and when to have them (2,7,21). Leaving that ambiguity to each physician to sort out for themselves will not lead to shared mental models. A provincial conversation similar to that which produced the new guidelines and pathways will have to be brokered.

The other important area where family physician role clarity is lacking is the 'middle ground': when a patient is becoming more ill but is not ill enough for hospital or specialty care. Our participants expressed lack of clarity on who should be doing what, and when, in this situation.

Both palliative care and the middle ground may be challenges well suited to the case-management approach. A recent study found that care from advanced practice providers, such as nurse practitioners, was associated with reduced readmissions and a lower risk of death. They suggest that optimal care for cirrhosis patients would include both advanced care providers and specialists, such as gastroenterologists/hepatologists (22). Research on end-of-life care for cirrhosis has also found that a number of family physicians felt specialist nurses would be key to collaborative management of patients with liver disease, as they could act as a facilitator between primary and specialty care (7). Our own findings support this view, as both family physicians and nurse practitioners described how the specialist nurse practitioner role allows for more time to spend with patients, is more accessible to both family physicians and patients, and can build helpful relationships between primary and specialty care. However, this collaboration may not be a long-term solution if broader system supports, such as a well-implemented shared clinical information resource and compensation and workforce policies, are not in place.

Finally, it is unlikely that any intervention for cirrhosis care will be fully successful without the deeper understanding of how those involved approach and think about this work. Awareness of the existing mental models care providers hold can assist in recognizing if the proposed interventions will be accepted or rejected, or if changes to the intervention or implementation plan in consideration of the existing mental models may alter this outcome (9). Further, in order for teams to work collaboratively, there needs to be a shared mental model of defined roles, tasks, and assigned responsibility as well agreed upon processes (11). Working without this clarity, or within a system that will not support such shared understanding, will continue to disrupt collaborative care and continuity, pushing health care providers back into the vicious cycle of developing mental models that are as limited as the system in which they must work.

While our study provided rich data, it is limited by its sample size. However, our intent was not necessarily to reach saturation, but instead gain actionable insights. The benchmark of success was not a complete understanding of all aspects, but practical guidance on major issues in a timely and cost-effective manner for the CCAB program to use in improving cirrhosis care in Alberta. We would,

however, benefit from additional interviews with nurse practitioners across the province in both specialty and primary care, to provide a more rounded view of their experiences and mental models.

## CONCLUSION

The system barriers and gaps that prevent the level of continuity needed to coordinate care for those living with cirrhosis lead providers to create and work under mental models that perpetuate those barriers, in a vicious cycle. Understanding how physicians approach cirrhosis care, adapt to the challenges facing them, and develop mental models accordingly, offers insights into how to break that cycle and improve continuity and coordination. Initiatives that attempt to address transitions in care, without fully understanding how physicians work within, adapt to, and hence help perpetuate the existing system, risk failure. A small number of targeted changes can be identified to change this dynamic. Specialist nurse practitioners may be an important resource in addressing a key structural need, beyond merely supplementing workforce.

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