

Developing a Decision-Making Capacity Assessment Clinical Pathway for Use in Primary Care: a Qualitative Exploratory Case Study



Lesley Charles, MBChB, CCFP (COE)¹, Jacqueline MI Torti, PhD², Suzette Brémault-Phillips, PhD³, Bonnie Dobbs, PhD¹, Peter GJ Tian, MD, MSc¹, Sheny Khera, MD, MPH, CCFP (COE)¹, Marjan Abbasi, MD, CCFP (COE)¹, Karenn Chan, MD, MSc, CCFP (COE)¹, Frances Carr, MBChB, MSc, FRCPC⁴, Jasneet Parmar, MBBS, MSc, MCFP (COE)¹,

¹Division of Care of the Elderly, Department of Family Medicine, University of Alberta, Edmonton, AB; ²The Centre for Education Research and Innovation, Schulich School of Medicine and Dentistry, Western University, London, ON;

³Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, AB;

⁴Division of Geriatric Medicine, Department of Medicine, University of Alberta, Edmonton, AB

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ABSTRACT

Background

With an ageing population, the incidence of dementia will increase, as will the number of persons requiring decision-making capacity assessments. For over 10 years, we have trained family physicians in conducting decision-making capacity assessments. Physician feedback post-training, however, has highlighted the need to integrate the decision-making capacity assessment process into the primary care context. The purpose of this study was to develop a decision-making capacity assessment clinical pathway for implementation in primary care.

Methods

A qualitative exploratory case-study design was used to obtain participants' perspectives regarding the utility of a visual algorithm detailing a decision-making capacity assessment clinical pathway for use in primary care. Three focus groups were conducted with family physicians (n=4) and allied health professionals (n=6) in two primary care clinics in Alberta. A revised algorithm was developed based on their feedback.

Results

In the focus groups, participants identified inconsistencies and a lack of standardization regarding decision-making capacity assessments within primary care, and provided feedback regarding a decision-making capacity assessment clinical pathway to make it more applicable to primary care. Participants described this pathway as appealing and straightforward; they also made suggestions to make it more primary care-centric. Participants indicated that the presented pathway would improve teamwork and standardization of decision-making capacity assessments within primary care.

Conclusions

Use of a decision-making capacity assessment clinical pathway has the potential to standardize decision-making capacity assessment processes in primary care, and support least intrusive and least restrictive patient outcomes for community-dwelling older adults.

Key words: decision-making capacity assessment, primary care, clinical pathway

INTRODUCTION

Adults are presumed to be independent decision-makers in personal and financial domains. However, when a person's decision-making capacity comes into question, as in diseases such as dementia,⁽¹⁾ difficulties commonly arise that affect care-coordination and health-care planning. Dementia is a complex illness with varying aetiologies and stages that present differently in each individual. As a result, there is no uniform assessment of decision-making capacity based on illness characteristics in this patient population.⁽²⁾ While an individual's decision-making capacity may begin to be affected in pre-dementia states,⁽¹⁾ a dementia diagnosis does not automatically infer a loss of decision-making capacity.⁽²⁻³⁾ Similarly, while certain types of dementia and stages of the illness are associated with increased cognitive difficulty, decision-making capacity may be dependent on a person's prior level of functioning and comorbidities associated with the illness, such as mood disorders and delirium.⁽²⁻³⁾

Decision-making capacity assessment (DMCA) is the assessment of a person's ability to understand information that is relevant to making a personal decision, and ability

to appreciate the reasonably foreseeable consequences of the decision.⁽⁴⁾ A DMCA model was developed based on clinical best-practices, ethical guidelines, and legislative acts in Alberta, to facilitate determination of decision-making capacity.⁽⁴⁾ Developed within the acute care context, this interdisciplinary model includes a DMCA process, assessment worksheets, education, training, and mentoring. While it has largely been implemented, evaluated, and refined for facility-based care (acute and continuing care),⁽⁵⁾ family physicians have increasingly been trained on DMCA using this approach, and training materials have been improved based on their feedback.⁽⁶⁾ Adapting the DMCA process for the primary care setting has been identified as a need by family physicians.⁽⁶⁾

Primary Care Networks are the most common model of team-based primary health-care delivery in Alberta. Primary care networks are groups of doctors working collaboratively with teams of health-care professionals, such as nurses, dietitians, and pharmacists, to meet primary health-care needs in their communities. Approximately 80% of primary care physicians are registered in a primary care network.⁽⁷⁾ Currently, there is no standardized approach to conducting DMCA among primary health-care providers and teams in Alberta. This lack of standardization can lead to a lack of clarity, inconsistency, and inefficient use of resources. The aim of this study is to develop a DMCA clinical pathway for use in primary care settings.

METHODS

Study Design

A qualitative exploratory case-study design was used to document participant perspectives regarding a proposed DMCA clinical pathway and its applicability for use in primary care. This is an exploratory study to look at what would work in a primary care setting before piloting and evaluating. This exploratory approach allowed us to collect “small-scale” data to formulate our research questions and explore opportunities to examine DMCA in the primary care context.⁽⁸⁾ A DMCA model with processes that were previously developed for use in acute care informed the study⁽⁴⁾ and development of a visual algorithm detailing a proposed clinical pathway for DMCA in primary care. (See Appendix A and Figure A1 for the initial Primary Care Decision-Making Capacity Assessment Clinical Pathway). Study participants were presented with the algorithm during focus groups and asked to review and offer feedback regarding its applicability and adaptability for use in primary care.

Participants

Family physicians and allied health professionals working in two of thirty-five clinics associated with the Edmonton-Based Oliver Primary Care Network in Edmonton, Alberta, Canada were invited to participate in the study. The Edmonton-Based Oliver Primary Care Network is known to have the highest population of patients over the age of 70 within the Edmonton

Zone and Alberta. The two Edmonton-Based Oliver Primary Care Network clinics were selected as they: (1) are connected to a Seniors’ Community Hub that serves a substantial geriatric population and has a higher frequency of need for conducting DMCA, and (2) are academic teaching centres with health-care professionals proficient in instructing medical trainees in DMCA processes.

Recruitment

Recruitment and sampling strategies were purposeful.⁽⁹⁾ A general recruitment notice was faxed to the two Edmonton-Based Oliver Primary Care Network clinics inviting all allied health professionals to participate in the research study. Recruitment letters were also sent to family physicians identified through the primary care network’s public access website—The College of Physicians and Surgeons of Alberta website. Since the names and contact information for the allied health professionals were not available, we are not able to report on how many people refused to participate in the study. None of the participants withdrew their consent once they agreed to participate.

Data Collection

Feedback regarding a proposed DMCA clinical pathway for use in primary care was solicited through semi-structured, in-person focus groups conducted between August and September 2017. A focus group guide (see Appendix B), developed by the research team in consultation with primary care providers, ensured appropriateness and clarity and supported the focus group process. During each focus group, the proposed Primary Care Decision-Making Capacity Assessment Clinical Pathway (Appendix A) was presented to participants in the form of a handout. Participants were then asked to review, edit, and make notes on the pathway, and offer verbal feedback regarding ways to adapt it for use in primary care. Focus groups were audio-recorded and transcribed, field notes were collected, and participant notes were retained. No repeat focus groups were conducted as saturation was reached with the third. The graduate research assistant on the project at the time of the study, Jacqueline Torti, facilitated the focus groups and recorded field notes in the process. She is a PhD-trained researcher with strong experience in focus group methodology and had no prior relationship with the participants. The participants did not know anything about the graduate research assistant, other than the fact that she would be facilitating the focus group, and no characteristics were reported about the facilitator.

Data Analysis

The focus groups were initially analyzed by Jacqueline Torti; then further analysis was conducted by Lesley Charles and findings reviewed by the co-authors. The transcripts, field notes, and participants’ notes were thematically analyzed following methodology outlined by Braun and Clarke.⁽¹⁰⁾ This first involved reviewing all the sources of data including the focus group audio files, field notes, and participants notes to

become familiar with the data, followed by the transcription of the audio files. The transcripts were not returned to the participants. There was no pre-established coding structure; rather, codes were generated from the data and themes were sought to explain the relationships between the codes. All themes were reviewed to ensure they were well-saturated to serve as themes and that there was sufficient distinction between the themes to ensure they did not overlap, in which case these themes were combined into a single theme. Once themes were finalized, they were labelled and defined and used to report on the study findings.⁽¹⁰⁾ Triangulation of data sources helped to ensure the trustworthiness of the data.⁽¹¹⁾ The term triangulation refers to the practice of using multiple sources of data, or multiple approaches to analyzing data, to enhance the credibility of a research study. Emergent themes were then used to revise the Primary Care Decision-Making Capacity Assessment Clinical Pathway for future use in primary care.

Research Ethics

Ethics approval was obtained from the Health Research Ethics Board—Health Panel (ID No. Pro00072308) at the University of Alberta.

RESULTS

Three in-person focus groups were conducted at a time and location convenient for participants. Four family physicians participated in one focus group; two further focus groups were held with three allied health professionals each (comprised

of nurses and a medical office assistant), for a total of 10 participants. Only the participants and the facilitator were present during the focus groups. To protect participants’ confidentiality, the only personal identifiers collected were their name (which will not be used in this report) and occupation. No other participant characters were identified. Focus groups, which were conducted over the lunch hour at the clinic and time-restricted due to busy clinic schedules, were 33 to 37 min in length. Initial data collection and analysis determined that a level of analytic sufficiency was reached after the completion of the third focus group.

Decision-making capacity assessments were not frequently performed by participants in the primary care setting (Table 1). Some physicians performed informal, uncontested DMCA; often the patient approaching them for assistance. However, participants see themselves as playing an important role in DMCA. For example, allied health professionals indicated that they were very good at identifying triggers or potential incapacity. The majority of these participants had been in practice at the clinic for a number of years and suggested that, because they have continuity with patients over a long period of time, they are able to identify subtle changes that may influence capacity.

There were no current standardized practices used by primary care physicians when conducting DMCA (Table 2). The allied health professionals reported the process of identifying a trigger and then informing the family physician of a potential issue with the patients’ decision-making capacity. In these circumstances, patients were referred to

TABLE 1.
Frequency of decision-making capacity assessments in primary care

<i>Themes</i>	<i>Supporting Quotes</i>
DMCAs were not frequently performed by participants in the primary care setting.	“I was part of a rollout in primary care. I’m also designated capacity assessor.” (AHP 6) “I’ve never done one.” (Family Physician 2) “I’ve never done one either.” (Family Physician 3) “I haven’t had anybody get a capacity assessment within the PCN.” (Family Physician 4)
Some family physicians performed what they classified as an informal, uncontested DMCA in which the patient approached them for assistance in handling a situation.	“Patient has Parkinson’s dementia. Wife was taking care of all of the finances. Wife Dies. So now he is with his power of attorney the patient and daughter and son come in and the patient goes I want my son to be in charge of my finances. I cannot do it. I have never... I haven’t been able to do it. My wife has been doing it all. I completely trust my son. I need you to sign this paper. And in that case, didn’t go through a formal capacity assessment. We know he has issues and he himself is requesting it but that’s the only time I have the only sort of power of attorney papers we’ve done. And it wasn’t a contested capacity.” (Family Physician 4)
Participants still see themselves as playing an important role in DMCA. For example, AHPs indicated that they were very good at identifying triggers of potential incapacity. The majority of these individuals had been in practice at the clinic for quite some time and suggested that, because they have continuity with so many patients over such a long period of time, that they are able to identify subtle changes.	“We’ll probably maybe even pick up some time sooner than the doctor because you’ll maybe watch their walk or watch their interaction... I think that we’re very strong on the trigger.” (AHP 3)

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geriatrics or a designated capacity assessor. The allied health professionals within the primary care network identified that this process required working collaboratively with other members of the primary care team.

Since most participants did not have experience conducting DMCA's, some participants did not see the utility of the Primary Care Decision-Making Capacity Assessment Clinical Pathway (Table 3). Other participants indicated

TABLE 2.
Current decision-making capacity assessment practices

<i>Themes</i>	<i>Supporting Quotes</i>
There were no current standardized practices used by primary care health care professionals when conducting DMCA's.	"But I can't say that I know of any formal way of doing it." (Family Physician 1)
The AHPs reported identifying a trigger and then informing the family physicians of a potential issue with the patient's DMC.	"We just let the doctor know before we go in." (AHP 1) "Well, I would go right to Dr. [Name] and express my concern." (AHP 2)
Referring patients either to geriatrics or a designated capacity assessor was common.	"I haven't myself done a DMCA. It is usually a trigger; ... someone might say 'I'm concerned about the memory loss,' then I'd referred to geriatrics, rather than triggering me to do a capacity assessment." (Family Physician 3) "... or to a designated assessor, someone who has special training." (Family Physician 2)
The AHPs within the PCN regarded this practice as requiring collaborative teamwork within the PCN.	"... what we're trying to work towards in the clinic is not so much like a referral process but just a collaborative process. So, we don't have a task out things that we can say and talk to the pharmacist who's here and just bring her right in. And it's not like a referral process. It's more of an ongoing conversation about patients... just continually collaborating." (AHP 5)

TABLE 3.
Relevance of a decision-making capacity assessment pathway

<i>Themes</i>	<i>Supporting Quotes</i>
The majority of participants had not conducted DMCA's; thus, they thought that the PCN-based DMCA pathway would have little relevance to their practice.	"You know what, to tell you the truth, I do not think about DMCA actually." (Family Physician 1) "I've never seen it come up in all the time I've been here." (AHP 4)
Others felt that DMCA's were more relevant to acute care settings.	"Because I think if you have some of these triggers happening, they don't come to the family doctor's office. They'll end up in emergency... I think you mainly see it in acute care." (AHP 5) "...it tends to be more of an issue in the emergency room, in acute care. I'm not saying it would never happen." (AHP 6)
Participants expressed concern that conducting DMCA's in the context of primary care may threaten the physician-patient therapeutic alliance.	"I find capacity assessment is very similar in terms of what it could possibly do to the therapeutic alliance as a driver's medical. And so, if it's the family doctor who has to say to you are now incapable or incapacitated or whatever the word is that closeness could actually break that relationship... be cognition or capacity... It's a vulnerable relationship when we're starting to you know take away the autonomy." (Family Physician 1)
Having the opportunity to reflect on the importance of DMCA's several participants indicated that although they might play a limited role in the process of assessing DMC, they feel the pathway would be useful.	"This worksheet is really good actually because what it does is it gives people language and it gives people, you go through from one to the next and it gives you a good way of doing everything the same way every time. It's actually really good, and it makes you understand what the domains mean. There's just so much good education that could come out of people learning about this. I just don't even really know where to start. I've learnt lots, and it's affecting my practicing and I've barely, I've done, I've done about 25 or so capacity assessments in 15 years, but you do other things along the algorithm. And just learning about this changes your practice. Makes you understand a lot." (AHP 6) "It would be and I think just talking about this brings it to people's minds more. And it makes them think, oh, I remember we were talking about triggers and is there something acutely going on that's causing this? Is this something that's come up in the last several visits? Maybe we should try to have a conversation about it and maybe nip some stuff in the bud so maybe people don't end up in Emerg." (AHP 4)

that, although they see themselves playing a limited role in the DMCA process, they felt the pathway could serve as a valuable tool to introduce the process into primary care. Some participants expressed concern that conducting DMCAs in the context of primary care may threaten the physician–patient therapeutic alliance and suggested the pathway would be more relevant to those in acute care settings.

When examining the original model, participants identified several features of the pathway they deemed favourable (Table 4). The visual algorithm was attractive and allowed them to work through different scenarios with ease. The use of the green, yellow, and red colours was deemed helpful as they navigated through the pathway. It was clear to participants that green represented proceeding forward, yellow represented situations that required caution and taking the time to do some further investigating, and red represented a stop or pause in the pathway. Participants felt that the pathway did a good job of distinguishing between the different stages, including the initial assessment, in-depth assessment, and problem solving, and the more formal process to follow when capacity could not be fully assessed or resolved by less intrusive methods.

Participants also offered critiques of the pathway and provided ideas on how it could be improved (Table 5). The pathway was perceived as acute care-centric based on its terminology and the examples used. Participants suggested identifying and clarifying roles and responsibilities within the primary care team for specific components of the pathway, in addition to removing the social worker role which they deemed to be more appropriate in the acute care context. Participants suggested adding potential timeframes for which the tasks should be completed within, but understood the complexity of doing so based on the variability of the case. To remove inaccessibility of the pathway based on

jargon, they suggested the removal of all acronyms as some may not be inherently familiar. Lastly, primary care health professionals identified the important role family caregivers play in the DMCA process and advocated for their inclusion in the pathway.

A Primary Care Decision-Making Capacity Assessment Clinical Pathway (see Figure 1 and Appendix C) was refined based on expert opinions. Changes made to the proposed DMCA clinical pathway included adapting the language to be more primary care-centric, removing the social worker, removing acronyms, and adding the Seniors’ Community Hub.

Information relevant to the use of the pathway will be integrated into the education and training materials as the pathway is implemented into primary care. These educational components include outlining clearly defined roles and responsibilities, potential timelines, and the role of family members and informal caregivers in the DMCA process.

DISCUSSION

Health-care professionals are increasingly confronted with conducting DMCAs. Although participants in this study were willing to support the use of the DMCA clinical pathway in their primary care practices, the majority of our study participants did not feel competent in this practice area. While legally all medical professionals can be involved in DMCAs, many do not have the necessary skills and training needed to perform them and, as a result, often refer patients to specialists.^(3,12) Primary care providers welcomed the idea of undergoing education and training on DMCA. Some advantages to having DMCAs performed by primary care professionals include that they have the most comprehensive overview of the patient, including the patient’s current health and medical history, as well as an awareness of their cultural viewpoints and life

TABLE 4.
Perceived strengths of the decision-making capacity assessment pathway^a

<i>Themes</i>	<i>Supporting Quotes</i>
The visual algorithm was attractive and allowed them to work through different situations.	“I mean having a visual algorithm is always helpful. Follow the arrows answer the questions. Flow charts are great.” (Family Physician 1) “Yeah, I like it. I like the visuals.” (AHP 3)
The use of green, yellow, and red was helpful as they worked their way through the DMCA pathway. It was clear that green represented proceeding forward, yellow represented moments that required the process to slow down and answer questions, and red represented a stop or pause in the DMCA pathway which often involved reverting back to previous steps.	“I think the whole colour coding and everything make it a little easier... I like the yes no’s it makes everything very clear. Yes, go this way, no go this way.” (AHP 1)
The visual DMCA pathway distinguished between the different stages of the DMCA including the initial assessment phase, in-depth assessment and problem-solving, and the more formal DMCA for when problems could not be resolved by less intrusive means.	“And it set out when the formal capacity would take place. Like it’s so clear.” (AHP 2)

^aWhen looking at the original PCN-Based DMCA Pathway (Appendix 1), participants identified several strengths and features of the pathway that they deemed favourable.

circumstances.⁽³⁾ In addition, the continuity of care provided in the primary care setting allows for a more holistic assessment, the opportunity to address risks and preserve autonomy, and access to a legal decision-maker if needed. Primary care settings also offer a more accessible and timely approach to DMCA, compared to referral to a specialist.⁽³⁾

The use of a DMCA clinical pathway may have the capacity to help health-care professionals working within the primary care setting make better quality decisions regarding DMCA. Since these assessments start with validating the trigger, then ensuring the patient is medically and

psychiatrically stable before evaluating cognition and function to assist with problem-solving the identified issue, all health-care professionals can be involved (Figure 1). If this is done well, it decreases the need for capacity interview that can only be undertaken by physicians, psychologists, and designated capacity assessors. The involvement of primary care has the potential to result in facilitative patient-provider interactions regarding DMCA, improved documentation, and a more transparent approach. Based on a person-centred process that facilitates determination of least intrusive solutions to the loss of decision-making capacity, the DMCA clinical pathway

TABLE 5.
Refinement of the decision-making capacity assessment pathway

<i>Themes</i>	<i>Supporting Quotes</i>
The DMCA pathway perceived as acute care-centric, regarding its terminology and the examples used. Adjusting it to be more primary care-centric was advised.	“I think it’s really just the wording is really for acute care. Even number six a team to solve or to problem solve with separate team conferences or rapid rounds like in a community-based practice, I do not do rapid rounds. So, it makes me think of like an inpatient geriatric or family medicine ward where the staff physician is sitting down with members of nursing and PT and OT and doing that where to actually get in a community setting those members sitting around a table is virtually impossible...” (Family Physician 4) “...also it says involve mentoring team or the DCA where available. So, all of that just is not our language and it’s not realistic to our setting.” (Family Physician 1)
Identifying roles and responsibility within the primary care team regarding components of the DMCA pathway may result in less confusion regarding the process.	“...maybe more clarity around who would be completing the capacity assessment process worksheet... So, if we make clear who would be doing this, how we get this done as a team.” (Family Physician 3)
The role of a social worker (as noted in the acute care DMCA pathway) and applicability to the primary care context was discussed.	“And this, when the trigger is identified, consider referring to a social worker like why? You know really. No, but there really isn’t a need for a social worker right at the very beginning.” (AHP 1) “I think its sort like it’s been borrowed from acute care. I don’t know that there’s any model in the primary care network where a social worker would be working that closely with a family doctor’s office... It should be the senior the seniors’ hub, in this clinic.” (AHP 6)
Adding logistics of how long it would take to complete each task could help improve the DMCA pathway.	“But I guess I need to know what’s involved in those the time that I wrote the time like what time frame like is this something that could be done you know we send them to our social worker it’s done in 20 minutes or is this something that is we need family and the patient to book a half day off?” (Family Physician 4) “So that was that was my question was how long does this take like not only how long in our clinic. And the reason that’s an issue isn’t because I don’t like taking time with patients but you’re panelled to a certain number and then all of a sudden, you’re shortening because you’re doing one thing for so long.” (Family Physician 1)
Removal of acronyms from the DMCA pathway was advised.	“So not to use the acronyms but the full word. DMCA yes we know that decision-making capacity assessment but as sometimes as you’re reading it’s hard to remember what the acronyms were.” (AHP 1) “I think you’re reading then you don’t understand you can’t remember something you’re looking over your sheet and you’re losing the concept of you’re losing track of what you’re really trying to read and you’re having to figure out these like.” (AHP 3) “Well, I’ve never had anything to do with capacity assessment. So everything that’s kind of an acronym I’m not familiar with.” (AHP 4)
Incorporation of the family and caregiver into the DMCA pathway was encouraged.	“There’s nothing here about collateral with family or caregivers... Right at one and two because they know their baseline they know when the changes started. They know maybe what happened. If they were put on a new medication or if they had a fall. So, in the seniors’ community how we assess the patient as well as the person that’s bringing them in. So, we screen them as well and get their opinion of the patient, so the patient may think they’re doing well. But the family member points out things that patients haven’t brought up or addressed.” (AHP 6)

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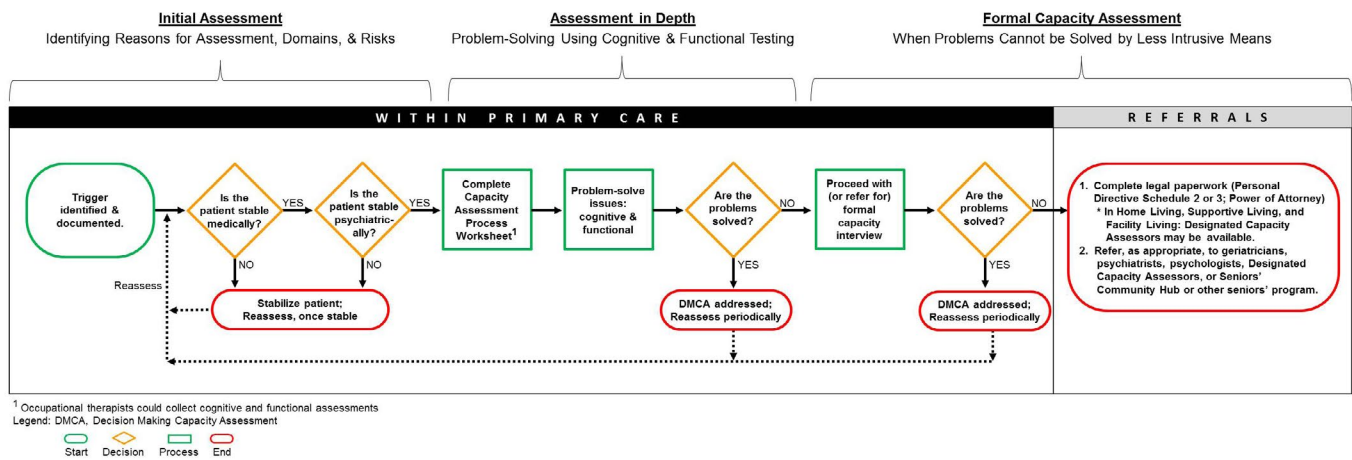


FIGURE A1. Initial Primary Care Decision-Making Capacity Assessment Clinical Pathway

informs risk-rebalancing and discharge planning, all of which are essential to smooth, safe, and seamless care provision.

Being able to draw on the Decision-Making Capacity Assessment Model—a pre-existing, well-developed, and tested model in acute care that is aligned with Alberta legislation—contributed to the development of the Primary Care Decision-Making Capacity Assessment Clinical Pathway. Access to inter-disciplinary teams working in the primary care network afforded a realistic perspective regarding the pathway's utility, as well as its applicability and adaptability if it is to be effectively used in primary care.

Limitations include the fact that focus groups were held in only two academic practices, thereby limiting the generalizability of the study findings. In addition, many of the family physicians had limited exposure and knowledge of DMCA. This lack of familiarity by family physicians is, however, representative of the primary care community at large. Additionally, the study was conducted in Alberta and decision-making acts vary by province. However, a lot of the key concepts are similar and transferable. The health-care providers only consisted of nurses and a medical office assistant. While this is representative of what is available in primary care, the absence of occupational therapists and social workers, common team members in the original DMCA model, is limiting.

Future research will involve implementing and evaluating the Primary Care Decision-Making Capacity Assessment Clinical Pathway in a primary care network pilot site. With

this developmental evaluation approach, we plan to solicit feedback from primary care network physicians and allied health professionals who will be using the clinical pathway, and draw upon participant feedback for continuous practice improvement. Quality improvement tools, such as process mapping and run charts, will be used to facilitate this process.

CONCLUSION

Presently, there is no standard approach to DMCA in the primary care setting. The development of an inter-professional Primary Care Decision-Making Capacity Assessment Clinical Pathway in this setting has the ability to facilitate the DMCA process and improve the consistency of DMCA. Implementation of the Primary Care Decision-Making Capacity Assessment Clinical Pathway into the primary care can help to ensure the quality of DMCA and appropriate use of resources.

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CONFLICT OF INTEREST DISCLOSURES

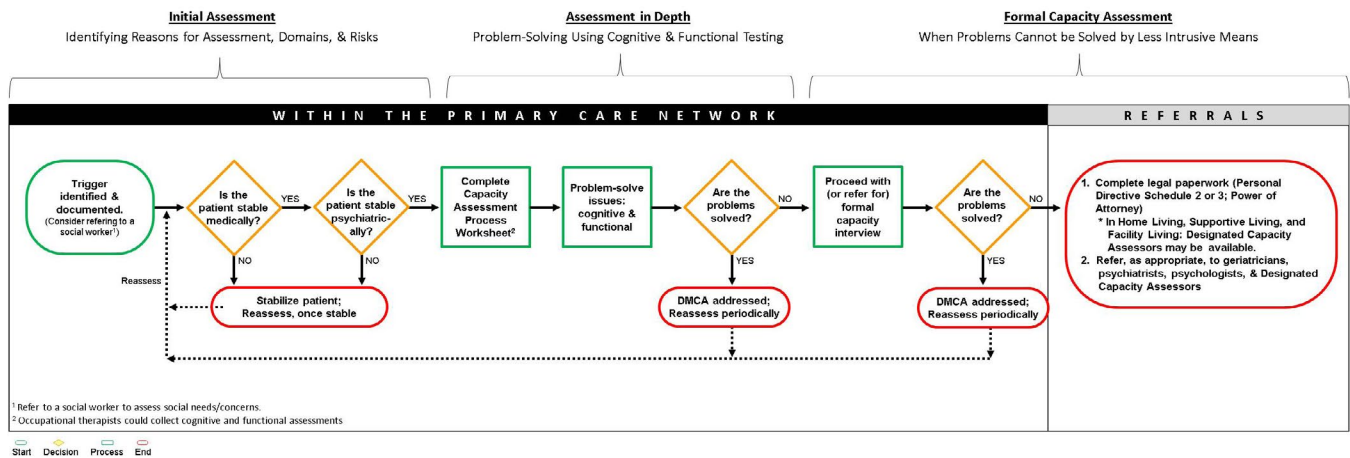
The authors declare that no conflicts of interest exist.

APPENDIX A. Initial pathway for Decision-Making Capacity Assessments (DMCA) in primary care

1. Is the **Trigger** valid?
An event or circumstance which potentially places a patient, or others, at risk that seems to be caused by impaired decision-making
2. Is the patient medically/psychiatrically stable?
3. If yes to both, initiate DMCA with SW (where available) to complete Capacity Assessment Process Worksheet (CAPW)
4. Which domain is involved? (e.g., health care [refusing procedure/transfusion that team feels in patient’s best interests], accommodation, legal, finances)
5. OT (where available) to collect cognitive and functional assessments
6. Team to problem solve with separate team conference (after rapid rounds) to see if problem can be solved by less intrusive/restrictive means. May be incapable but if can solve problem with supports no need to go to Capacity interview (CI). Remember 33–50% of medicine in-patients are incapable if tested. Involve mentoring team/DCA (where available) with difficult cases.
7. Reasons for Formal CI:
No adequate solutions from problem-solving
Risk to patient / others too high
Other, less intrusive methods, have failed
Appointment of legal decision-maker may solve the problem
Problem persists or becomes worse
Remember: a determination of incapacity may do nothing to fix the problem

8. CI by physician/psychologist/designated capacity assessor (DCA)—may use CI form. Whatever the problem consider: Context, choices, consequences.
9. Must inform patient conducting interview, ensure have glasses, hearing aids, translator as needed, if want somebody present. If don’t appreciate problem, choices, consequences must educate patient first before assessing their response.
10. Will have assessed what legal paperwork patient has earlier in assessment but if find incapable will then enact:
*PD schedule 2—2 signatures: agent & physician/psychologist if PD names agent as one of the assessors
*Schedule 3—2 signatures: physician/psychologist and second service provider if no clause naming agent as assessor (DCA can only be second signature)
*POA—2 physician signatures
If no PD/POA exist a Capacity Assessment Report (CAR) Form 4 under the Adult Guardianship and Trusteeship Act (AGTA) can be completed by DCA/physician/psychologist depending what is needed.
11. Remember AGTA now continuum. Can use Specific Decision-Making (SDM) if patient incapable allowing family member or Office of the Public Guardian and Trustee (OPGT) to make decision on admission to LTC or medical decision. Do not have to go through courts.
12. All schedules under Personal Directives Act (PDA) and forms under AGTA can be found on OPGT website: <http://www.humanservices.alberta.ca/guardianship-trusteeship.html>
13. Further Training

*3-hour training; attached to conferences (e.g., Geriatrics Update Calgary, FMF, and stand-alone)
*2-day training through OPGT



Notes:

1. Written from the viewpoint of the care provider.
2. There seems to be 5 main parts in the pathway: (i) identification of the trigger, (ii) making sure the patient is stable, (iii) problem solving, (iv) formal capacity assessments, (v) referral.
3. To make our pathway simpler (i.e., to skip the trigger decision point), we start with a care provider having identified a valid trigger.

FIGURE A1. PCN’s Care Pathway for Decision-Making Capacity Assessments

APPENDIX B. Focus group guide

This is a semi-structured focus group guide. The focus group is estimated to take 60-90 minutes. The focus group will be audio recorded.

Focus Group Schedule

- ✓ Introduce yourself and thank the participants for their time.
- ✓ Ask the participants to have a look at the “Information Letter” (if they haven’t already done so).
- ✓ Briefly review the aim of the study and the focus group by reviewing the “Information Letter.”
- ✓ Confirm how the information will be recorded and used.
- ✓ Ask the participants if they any questions.
- ✓ Ask the participant to read the “Consent Form” and sign where indicated.
- ✓ Indicate your role as the facilitator/moderator.
- ✓ Indicate that we expect to spend 60-90 minutes depending on the conversation.

If all participants agree to have the interview recorded, proceed to step 1. If NOT, then use the following sheet as a guide to record participant responses.

START RECORDING.

Interviewer: It is DATE (.....) for the study “A PCN-Based Clinical Pathway for Decision-Making Capacity Assessment (DMCA)” with FAMILY PHYSICIANS or ALLIED HEALTH PROFESSIONALS.

FOCUS GROUP QUESTIONS

Patient Population

- How do you feel this Decision-Making Capacity Assessment tool would fit in with your patient population?
- How informed do you think your patients are on decision-making capacity assessment?

Current Decision-Making Capacity Assessment Practices

- How are you currently assessing decision-making capacity?
- How well do you think your methods for assessing decision-making capacity are working?
- How comfortable do you feel discussing decision-making capacity with patients and their families?
- How are you identifying patients that have impaired decision-making?
- How are you determining whether or not their decision-making is impaired?
- What type of education and resources do you provide your patients and their families when it comes to decision making capacity?
- What concerns do you have around capturing impaired decision-making?

Preliminary Evaluation of the Decision-Making Capacity Assessment Tool

- What do you think of the Decision-Making Capacity Assessment Tool?
 - What do you like about the appearance of the tool?
 - What don’t you like about the appearance of the tool?
 - How would you change the appearance of the tool?
 - What features of the tool do you find advantageous? What do you like about the tool?
 - Are there any features of the tool that you would want removed? What don’t you like about the tool?
 - Are there any features of the tool that you would want added? How can we improve the tool?
 - How will you use this tool?
 - What resources would you like to see included with this tool?
 - What do you think would change by implementing this tool?
 - What impact do you think this tool would have on your practice?
 - How useful do you find this tool?
 - How do you feel this tool will work in comparison to current methods for assessing decision-making capacity?
 - Do you think you would recommend this tool to others? Why or why not?
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APPENDIX C. Primary Care Network's Clinical Pathway for Decision-Making Capacity Assessment (DMCA)

1. Is the **Trigger** valid?
 - An event or circumstance which potentially places a patient, or others, at risk that seems to be caused by impaired decision-making.
2. Is the patient medically/psychiatrically stable?
3. If yes to both, initiate DMCA to complete Capacity Assessment Process Worksheet.
4. Which domain is involved? (e.g., health care [refusing procedure/transfusion that team feels in patient's best interests], accommodation, legal, finances).
5. Involve occupational therapy (where available) to collect cognitive and functional assessments.
6. Team to problem solve with interdisciplinary team meeting to see if the problem can be solved by less intrusive/restrictive means. May be incapable but if the team can solve the problem with supports, there is no need to go to a Capacity Interview. Remember 33–50% of medicine in-patients are incapable if tested. Involve mentoring team/decision-making capacity (where available) with difficult cases.
7. Reasons for Formal Capacity Interview:
 - No adequate solutions from problem-solving
 - Risk to patient/others too high
 - Other, less intrusive methods, have failed
 - Appointment of legal decision-maker may solve the problem
 - Problem persists or becomes worse
 - Remember: a determination of incapacity may do nothing to fix the problem
8. Capacity Interview by physician/psychologist/designated capacity assessor—may use Capacity Interview form. Whatever the problem consider: Context, choices, consequences.
9. Must inform the patient that you are conducting the interview, ensure they have glasses, hearing aids, translator as needed, if they want somebody present. If they don't appreciate problem, choices, and consequences you must educate patient first before assessing their response.
10. Will have assessed what legal paperwork patient has earlier in assessment but if you find them incapable enact:
 - *Personal Directive Schedule 2–2 signatures: agent & physician/psychologist if personal directive names agent as one of the assessors.
 - *Schedule 3–2 signatures: physician/psychologist and second service provider if no clause naming agent as assessor (designated capacity assessor can only be second signature).
 - *Power of Attorney—2 physician signatures
 - *Capacity Assessment Report Form 4 under the Adult Guardianship and Trusteeship if no Personal Directive/Power of Attorney exists. Adult Guardianship and Trustee Act can be completed by designated capacity assessor/physician/psychologist depending what is needed.
11. Remember the Adult Guardianship and Trustee Act is now continuum. You can use specific decision-making if the patient is incapable of allowing a family member or the

Office of the Public Guardian and Trustee to make a decision on the admission to long-term care or medical decision. You do not have to go through courts.

12. All schedules under Personal Directives Act and forms under Adult Guardianship and Trustee Act can be found on Office of the Public Guardian and Trustee website: <http://www.humanservices.alberta.ca/guardianship-trusteeship.html>
13. Further Training

*3-hour training; attached to conferences (e.g., Geriatrics Update Calgary, Family Medicine Forum, and stand-alone)

*2-day training through Office of the Public Guardian and Trustee.

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Correspondence to: Lesley Charles, MBChB, Division of Care of the Elderly, Department of Family Medicine, University of Alberta, 1259 - 10230 111 Ave, Edmonton, AB, Canada T5G 0B7

E-mail: Lcharles@ualberta.ca