



Provincial Needs Assessment to Determine the Current State of Glomerulonephritis Care in Ontario

Canadian Journal of Kidney Health and Disease
Volume 6: 1–11
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DOI: 10.1177/2054358119877405
journals.sagepub.com/home/cjk



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Abstract

Background: Despite its relative rarity, glomerulonephritis (GN) accounts for 20% of prevalent end-stage renal disease patients in Ontario. Early identification and appropriate management of GN to delay progression of disease can reduce patient morbidity and health system costs. As such, a provincial GN needs assessment was conducted to inform on the development of the provincial GN strategic framework in Ontario.

Objective: To understand the current state of GN care in Ontario from nephrologist, hospital administrator, and patient and family perspectives.

Design: Cross-sectional.

Settings: 26 regional renal programs in Ontario.

Patients: 23 patients and family members living with GN who do not require renal replacement therapy.

Measurements: Patient and family member interviews as well as a survey of nephrologists.

Methods: The study included 3 components: (1) interviews with patients and family members, (2) a survey of nephrologists, and (3) interviews with regional renal programs. The Ontario Renal Network provincial office developed the needs assessment questions and the physician survey questions after consultation with practicing nephrologists and hospital administrators. Thematic analysis was used to assess interview data and descriptive statistics to assess survey data.

Results: Interviews with patients and family members ($n = 23$) identified gaps in care related to diagnosis and referral to nephrology care, education and decision-making, and psychosocial supports. The survey of nephrologists ($n = 74$) identified various issues that contribute to unstandardized GN care across Ontario, including a lack of provincial expertise in providing complex GN care, access to medication, multidisciplinary team support as well as patient education, and psychosocial supports. Interviews with regional renal programs aligned with interview and survey findings ($n = 11$).

Limitations: Interviews with patients and family members were facilitated by 1 interviewer and limited to 20 interviews due to resource limitations. All nephrologists, patients, and family members who participated in the survey and interviews were volunteers and English-speaking, which may have resulted in self-selection bias.

Conclusions: The provincial GN needs assessment emphasized the necessity to develop and implement a provincial GN strategy. The strategic framework includes 4 objectives: (1) ensure patients are supported to make informed decisions, (2) establish a provincial model of care, (3) leverage data to enable planning, decision-making, and monitoring of outcomes, and (4) ensure appropriate access to medication. This is the first Ontario strategy to address provincial gaps in GN care.

Abrégé

Contexte: Malgré sa relative rareté, les glomérulonéphrites (GN) représentent 20 % des cas prévalents d'insuffisance rénale terminale en Ontario. Un diagnostic précoce et une prise en charge adéquate des GN pourraient réduire la morbidité pour les patients et les coûts pour le système de santé. Une analyse des besoins provinciaux (Ontario) en matière de soins des GN a été réalisée pour guider l'élaboration d'un cadre stratégique de gestion de la maladie.

Objectif: Connaître l'état actuel des soins en contexte de GN, en Ontario, du point de vue des néphrologues, des directions d'établissements, des patients et de leurs proches.

Type d'étude: Étude transversale.

Cadre: 26 programmes régionaux de lutte contre la maladie rénale en Ontario.

Sujets: Un total de 23 individus, soit des patients atteints de GN, mais ne nécessitant pas de thérapie de remplacement rénal, et des membres de leur entourage.



Mesures: Des interviews de patients et de membres de leur entourage, ainsi qu'un sondage auprès de néphrologues.

Méthodologie: L'étude comportait trois volets: (1) interview des patients et de leur entourage; (2) sondage auprès des néphrologues; (3) entretiens avec les responsables des programmes régionaux de lutte contre la maladie rénale. Le Réseau rénal de l'Ontario a mis au point les questions du sondage et les questions relatives à l'évaluation des besoins après avoir consulté des néphrologues en pratique et des administrateurs d'hôpitaux. Les données recueillies ont été traitées par analyses thématiques (interviews) et par statistiques descriptives (sondage).

Résultats: L'interview des patients et de leur entourage ($n = 23$) a mis en évidence des lacunes dans les procédures liées au diagnostic et à l'aiguillage en néphrologie, de même que concernant l'éducation des patients, la prise de décisions et le soutien psychosocial. Le sondage des néphrologues ($n = 74$) a permis de déceler diverses lacunes contribuant à une prestation de soins non normalisée en Ontario, notamment vis-à-vis l'expertise provinciale dans la prestation de soins complexes en GN, l'accès aux médicaments, le soutien d'une équipe multidisciplinaire, l'éducation et le soutien psychosocial des patients. Les entretiens avec les responsables des programmes régionaux de lutte contre la maladie rénale ($n = 11$) concordaient avec les résultats des deux autres volets.

Limites: Les interviews avec les patients et leur entourage ont été effectuées par une seule personne et restreintes à une vingtaine en raison de ressources limitées. Les néphrologues, patients et membres de leur entourage étaient tous anglophones et ont participé à l'étude sur une base volontaire, ce qui pourrait introduire un biais d'auto-sélection.

Conclusion: L'évaluation des besoins provinciaux en matière de soins pour les GN a mis en lumière la nécessité d'élaborer et de mettre en œuvre une stratégie provinciale. Le cadre stratégique comprend quatre objectifs: (1) garantir aux patients le soutien nécessaire pour prendre des décisions éclairées, (2) établir un modèle de soins provincial, (3) exploiter les données pour permettre la planification, la prise de décision et le suivi des résultats, et (4) assurer un accès adéquat aux médicaments. Il s'agit de la première stratégie visant à combler les lacunes provinciales en matière de soins pour les GN en Ontario.

Keywords

glomerulonephritis, glomerular disease, Ontario Renal Network

Received May 14, 2019. Accepted for publication July 17, 2019.

What was known before

Despite its relative rarity, glomerulonephritis (GN) accounts for 20% of prevalent end-stage renal disease (ESRD) patients in Ontario. Early identification and appropriate management of GN to delay progression of disease can reduce patient morbidity and health system costs.

What this adds

This study captured nephrologist, hospital administrator, and patient and family perspectives to inform on the issues that contribute to unstandardized and inequitable GN care across Ontario. The results from this study informed on the development of the Ontario Renal Network's first provincial GN strategic framework.

Background

Glomerulonephritis (GN) refers to a group of rare renal diseases in which the glomeruli become inflamed. The overall incidence and prevalence of GN in the Canadian province of Ontario is unknown; however, the worldwide incidence of primary GN ranges from 0.2 to 2.5/100 000 persons/year, depending on the type of GN.¹ Despite the relative rarity of disease, the Canadian Organ Replacement Register shows that GN is the primary cause of approximately 20% of prevalent ESRD patients in Ontario.² This represents more than 3800 people living with ESRD in the province in 2016.

Early identification and appropriate management of GN to delay progression of disease can reduce patient morbidity and health system costs. However, evidence to support best

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practices is limited. There are few high-quality clinical trials in GN due to relative rarity of disease, variable clinical presentation and treatment response, lack of consensus in definitions, and challenges related to conducting research (including patient recruitment, costs, and collaborative efforts).³ Kidney Disease: Improving Global Outcomes (KDIGO) published clinical practice guidelines for GN in 2012 based on GRADE system for rating the strength of supporting evidence.⁴ Only 4 recommendations (2%) in the guidelines were based on grade “A” evidence, representing high-quality evidence. Expert reviewers found the KDIGO guidelines to be a useful and applicable tool, but continued to highlight the lack of high-quality evidence across GN conditions.^{5,6} Not surprisingly, therefore, a survey of Canadian nephrologists demonstrated low uptake of KDIGO best practices, with 15% to 46% of Canadian nephrologists reporting treatment strategies that did not align with the guideline recommendations.⁷

Given the limited evidence on GN best practices and lack of information on the current state of GN care in Ontario, the Ontario Renal Network undertook a needs assessment on GN care. The aims of the needs assessment were 2-fold: (1) to characterize the current state of GN care in Ontario and identify opportunities for improvement from multiple stakeholder perspectives and (2) to develop a system-level strategic framework to guide future GN planning and decision-making in the province.

Methods

The provincial GN needs assessment was conducted in 2015 and composed of 3 components: (1) interviews with patients and family members, (2) a survey of nephrologists, and (3) interviews with regional renal programs. Each of these methods are described below following a brief description of how renal care is delivered in Ontario.

About the Ontario Renal Network

The Ontario Renal Network is a division of Cancer Care Ontario (CCO) that advises the Ontario government on chronic kidney disease and manages the delivery of chronic kidney disease services in the province. Its overall aim is to reduce the burden of chronic kidney disease on Ontarians and the health care system.

The Ontario Renal Network is guided by a 4-year strategic plan, the Ontario Renal Plan. This provincial road map lays out how the Ontario Renal Network will work together with regional renal programs, patients and families, and partners to improve the lives of people at risk for and living with chronic kidney disease. As part of the second Ontario Renal Plan (2015-2019), the Ontario Renal Network committed to implementing models for the delivery of safe, high-quality, and accessible care to people requiring specialized care such

as those with complex GN. For the purposes of this study, complex GN was considered as those with rapidly progressive diseases, those who require care from multiple specialists, and those who require aggressive immunosuppressive treatment strategies.

The Ontario Renal Network provincial office connects, coordinates, and funds a province-wide network of regional renal programs. At the time of this needs assessment, there were 26 regional renal programs in Ontario. Provincial and regional medical leads, and regional directors from across Ontario help oversee and support the work of the Ontario Renal Network. Provincial medical leads oversee the strategic direction and implementation of priorities laid out in the Ontario Renal Plan. Regional medical leads (nephrologists) and regional directors (administrators) work together to advance the goals of the Ontario Renal Plan at the local level. There are 14 regional medical leads and 14 regional directors, in alignment with the Ontario Local Health Integrated Networks.

Interviews With Patients and Family Members

The purpose of conducting patient and family interviews was to better understand patients' experiences with GN care. Patients from all regional renal programs were invited to participate in an interview by their health care providers. Patients initiated the interview by contacting the Ontario Renal Network provincial office. Patients were eligible to participate if they were diagnosed with GN, did not require renal replacement therapy, were English-speaking, and were able to provide informed consent. An Ontario Renal Network Specialist was trained to conduct interviews by peers with experience interviewing patients and family members. Interview questions evolved after consultation with Regional medical leads (nephrologists) and regional directors (administrators). The specialist conducted 30-minute, semistructured, individual interviews with patients and family members via telephone or face to face. Supplementary material Appendix A shows the patient and family member interview questions. At the end of each interview, key points were identified by the interviewer and validated by the patient and/or family member. Key points from all interviews, as captured in interviewer notes, were reviewed and then sorted into themes by the interviewer using a thematic analysis approach.⁸ The resulting themes were reviewed and validated by the Glomerular Disease and Specialty Clinics Priority Panel (see below).

Survey of Nephrologists

The purpose of the survey was to understand nephrologist perspectives of GN care, including access to multidisciplinary care and appropriate medication, supports required, and opportunities for improvement. The target audience was nephrologists affiliated with regional renal programs without a designated GN specialty clinic. An online survey was

developed by the Ontario Renal Network provincial office, with input and consensus from 3 nephrologists who now serve on the Glomerular Disease and Specialty Clinics Priority Panel and the 14 Ontario Renal Network regional directors (hospital administrators). Supplementary material Appendix B shows the nephrologist online survey. It was sent to 189 Ontario nephrologist emails via an Ontario Renal Network nephrology contact list. In addition, the survey was shared with regional directors and regional medical leads to request support and promotion within regional renal programs under their jurisdiction. The survey was available online from September to October 2015, and participants were encouraged to share it with colleagues for better coverage. Three reminders were sent to encourage participation. Most of the survey questions used a multiple-choice format, with optional free-text comments. Survey results were assessed by descriptive statistics using Microsoft Excel.

Group Interviews With Regional Renal Programs

The purpose of the group interviews with regional renal programs was to understand program barriers and enablers to delivering GN care (including hospital model of care, clinical team mix, local quality improvement initiatives, access to clinical services, funding as well as infrastructure and capacity planning) and to identify opportunities for improvement. The Ontario Renal Network Provincial Medical Lead for Glomerular Disease and Specialty Clinics conducted informal, conversational interviews at site visits with 5 regional renal programs without a designated GN specialty clinic (Kingston General Hospital, London Health Sciences Centre, St Joseph's Healthcare Hamilton, St Michael's Hospital, and The Ottawa Hospital) and via teleconference with 4 regional renal programs without a designated GN specialty clinic (Windsor Regional Hospital, Sault Area Hospital, Health Sciences North, and Timmins and District Hospital).

Group interviews at site visits were arranged by regional directors who identified nephrologists and hospital administrators in their regional renal programs with interest and/or involvement in GN care. As such, nephrology representation varied across regional renal programs from 2 nephrologists to all staff nephrologists. Regional directors and regional medical leads also participated in the interviews. All group interviews included sharing of preliminary interview and survey results for input and validation. The Ontario Renal Network Provincial Medical Lead for Glomerular Disease and Specialty Clinics also interviewed nephrologists at 2 regional renal programs with a designated GN specialty clinic (Sunnybrook Health Sciences Centre and University Health Network). These interviews were all supported by 2 Ontario Renal Network staff with experience in partnering and consulting with regional renal programs. Key points from the group interviews, as captured in interviewer notes, were sorted into themes using the same approach as the patient and family member interviews (described above).

Development of the Provincial GN Strategic Framework

Results from the patient and family interviews, nephrologist survey, and program interviews were compared and synthesized; the results highlighted the need for a provincial GN strategic framework. Under the leadership of the Ontario Renal Network Provincial Medical Lead for Glomerular Disease and Specialty Clinics, the Ontario Renal Network convened a Priority Panel in January 2016 to provide ongoing advice and input into the development and implementation of a provincial GN strategic framework. The Priority Panel included representation from 9 regional renal programs across Ontario, including nephrologists, hospital administrators, and a pharmacist.

The Panel reviewed key themes identified in interviews with patients and family members, and results of the nephrologist survey to determine a single provincial strategic goal and multiple related objectives that address common themes. Within each objective, the panel also leveraged findings from interviews with regional renal programs to suggest potential initiatives. The goal, objectives, and initiatives were reviewed and refined by the panel and Ontario Renal Network provincial office to develop a provincial GN strategic framework to guide planning and decision-making from 2015 to 2019, in alignment with the second Ontario Renal Plan.

Results

Interviews with Patients and Family Members

The Ontario Renal Network conducted 20 interviews with patients (11 women and 9 men). Three interviews were conducted jointly with the patient's family member or friend. Patient participants represented 8 of 14 regions in Ontario: Hamilton Niagara Haldimand, Mississauga Halton, North Simcoe Muskoka, North East, North West, South East, South West, and Toronto Central. Patient experiences with GN care varied between individuals; however, 3 key themes emerged from the analysis of the interviews: (1) diagnosis and referral to nephrology care, (2) education and decision-making, and (3) psychosocial supports and challenges.

Diagnosis and referral to nephrology care. For some patients (8/20), early kidney disease symptoms went undiagnosed by primary care providers, which delayed referral to nephrology and appropriate treatment. These patients expressed frustration with the diagnosis process, which often involved multiple health care providers and long wait times for lab work. As such, a number of patients (9/20) were diagnosed when approaching kidney failure and when admitted to a hospital for urgent assessment and care. One patient highlighted the importance of correct pathological diagnosis to alleviate anxiety in the diagnostic process.

For other patients (8/20), GN was diagnosed quickly after initial onset of disease, and appropriate treatment was provided soon after. After learning about the relative rarity of GN from their renal care team, these patients often felt their early diagnosis was fortunate, with 1 patient describing it as having “hit the jackpot.” Some of these patients (3/20) attributed their early diagnosis to being proactive, such as searching for information beyond what was provided by their primary care providers, contacting medical specialists without referral from primary care providers, or paying out of pocket for health care outside of the publicly funded health care system.

After diagnosis, referral to nephrology was generally not a barrier to care. However, patients were often managed by several medical specialists and primary care providers. These patients expressed a need for open communication channels among all health care providers within their circle of care, as well as with patients and family members.

Education and decision-making. Patients generally relied on their nephrologist as the main source of information about GN disease and treatment options. However, confidence and satisfaction with information provided by the nephrologist and renal care team varied. Some patients (11/20) reported positive experiences in obtaining helpful information from their nephrologist, including timely access to nephrologist advice outside of office hours, though some described feeling overwhelmed by new information shortly after diagnosis. Others (6/20) felt information about their illness and treatment was not readily available, such that they were responsible for initiating conversations to obtain more patient education. Some of these patients (3/20) felt questions went unanswered, or ignored, due to a lack of expertise from health care providers.

Patients rarely had access to educational resources outside of their health care team, nor were they provided with GN-specific, patient-friendly information to review at home. Several patients were advised not to search for additional information online to avoid misinformation and undue anxiety. Patients who searched online for educational resources sometimes felt it was either overwhelming or lacking in practical information, and felt it would have been helpful to be directed to credible sources. When prompted, most patients (8/13) felt that having access to multidisciplinary care, such as a pharmacist, a nurse, a dietitian, or a social worker with GN expertise, would have been helpful in providing patient education. Overall, patients would have liked more information about their illness, symptoms and future prognosis, medication side effects and long-term costs, and ways to self-manage.

Patients who were diagnosed while approaching kidney failure sometimes felt they had limited treatment choices. Patient choice and involvement in shared decision-making may have been restricted due to the aggressiveness of disease progression, the time of diagnosis, and safe treatment options

for patients with advanced chronic kidney disease. These patients often reported that they were not well informed about their medication and associated side effects before initiating treatment. In contrast, other patients, typically those with early diagnosis, described being involved in shared decision-making.

Psychosocial supports and challenges. Commonly, patients were shocked and upset by their diagnosis. Some patients (10/20) felt overwhelmed by the diagnosis and in coping with symptoms and medication side effects. When available, patients described support from family and friends as very important. For example, these support networks assisted with activities of daily living, travel to or from clinic visits, understanding and seeking information about illness and treatment, and psychosocial support.

Patients often felt isolated in their diagnosis and management, which may be explained by the relative rarity of GN. None of the consulted patients had access to formal peer support programs for their disease type. Generally, patients and family members felt this type of support would be beneficial to better understand the disease and their prognosis, to share experiences and resources, and to emotionally and mentally cope with impacts of the disease.

Some patients (10/20) were in school or mid-career at the time of diagnosis, meaning that the progression of disease affected financial stability and family planning. Patients who did not have private insurance or high deductibles had limited access to immunosuppressive medication and additional financial stress related to medication costs.

Survey of Nephrologists

In total, 74 nephrologists partially completed the survey and 71 nephrologists fully completed the survey. This represents a response rate of 38% based on the original distribution list, or 34% based on the total number of practicing nephrologists in Ontario regional renal programs during the study period (to reflect that respondents were encouraged to forward the survey information to colleagues). Respondents represented all Ontario regional renal programs without a GN specialty clinic and 1 community practice.

Nephrologist GN practice. Table 1 shows a summary of self-reported nephrologist GN practice patterns. Most respondents reported being “somewhat comfortable” caring for patients with complex GN (65%), whereas one third reported being “very comfortable” (30%); 5% reported being “not at all comfortable.” Most of the respondents consult nephrology colleagues for advice (88%) and reported adequate access to expert advice or professional consultations (84%). Comments suggested that access to professional consultations could be further improved with telemedicine or email networks. In addition, 62% of nephrologists refer patients with complex GN to a nephrologist at a GN specialty clinic.

Table 1. Nephrologist-Reported GN Practice, Access to Multidisciplinary Care, and Access to Appropriate Medication.

	Percentage
Comfort level of caring for patients with complex GN (n = 74)	
Very comfortable	30
Somewhat comfortable	65
Not at all comfortable	5
Resources used to facilitate care of patients with GN (n = 74)	
Up to date (electronic clinical resource tool for physicians and patients)	91
Advice from other colleagues	88
Written guidelines	81
Referral to a specialized clinic	62
Other	20
Adequate access to expert advice and professional consultation with experts (n = 74)	
Yes	84
No	16
Adequate education, counseling, and support for patients and families in the regional renal program (n = 74)	
Yes	28
No	72
Referral to a GN specialty clinic is useful (n = 74)	
Yes	55
No—do not refer patient to a GN specialty clinic	35
No—do not find this service useful	10
Other health care providers are involved in the care of patients with complex GN at the regional renal program (n = 71)	
Yes	49
No	51
Access to other health care providers would be helpful to facilitate care in patients with complex GN (n = 38 ^a)	
Yes	97
No	3
Barriers to accessing medication for patients with GN (n = 73)	
Navigating the process to apply for and obtain funding	88
Lack of government funding to cover medication costs	81
Lack of patient funding to cover medication costs	77
Timeliness of gaining access to medication	63
Identifying the most appropriate medication for complex patients	55
Lack of hospital funding to cover medication costs for inpatients	53
Lack of appropriate infusion space	36
Impacts of lack of access to medication for patients with GN (n = 73)	
Delayed treatment	86
Progression of disease	53
Inappropriate treatment	32
No treatment	19
No significant impacts	8

Note. GN = glomerulonephritis.

^aRespondents only include those without access to multidisciplinary team support at the regional renal program.

Comments suggested that the referral process in Ontario is not standardized.

Only 28% of respondents felt that their regional renal program has adequate education, counseling, and support for patients with GN and their family members. This aligned with key themes derived from patient interviews in which patients reported that they were not provided with sufficient information to understand their disease, treatment, and self-management.

Access to multidisciplinary care. Table 1 shows a summary of self-reported nephrologist access to multidisciplinary team support. In total, 49% of the respondents reported that other health care providers (nurse, pharmacist, dietitian, social worker) are involved in the care of patients with complex GN at their regional renal program. Among the 38 respondents without access to multidisciplinary care, 97% reported that multidisciplinary team support would be helpful to their GN practice.

Table 2. Nephrologist-Reported Access to Multidisciplinary Team Support.

Health care provider is involved in care of patients with complex GN (n = 36 ^a)	Not available (%)	As required (%)	At every visit (%)
Nurse practitioner(s) with expertise in GN	94	6	0
Registered nurse(s) with expertise in GN	92	8	0
Registered practical nurse(s) with expertise in GN	92	8	0
Pharmacist(s) with expertise in GN	53	44	3
Dietitian(s)	14	81	6
Social worker(s)	11	83	6
Health care provider would be helpful in care of patients with complex GN (n = 37 ^b)	Not at all helpful (%)	Helpful as required (%)	Helpful at every visit (%)
Pharmacist(s) with expertise in GN	0	51	49
Registered nurse(s) with expertise in GN	16	35	49
Dietitian(s)	16	59	24
Nurse practitioner(s) with expertise in GN	24	51	24
Social worker(s)	11	70	19
Registered practical nurse(s) with expertise in GN	54	35	11

Note. GN = glomerulonephritis.

^aRespondents only include those with access to multidisciplinary team support at the regional renal program.

^bRespondents only include those without access to multidisciplinary team support at the regional renal program.

Table 2 shows the availability of multidisciplinary team support by professions. Between 92% and 94% of respondents reported that nurse practitioners, registered nurses, or registered practical nurses with GN expertise are “not available” to provide GN care; 53% reported pharmacists are “not available”; 14% reported dietitians are “not available”; and 11% reported social workers are “not available.” In addition, the perceived helpfulness of multidisciplinary team members varied. The results highlight the importance of pharmacist support; pharmacists were the only profession for which 100% of respondents reported support would be “helpful as required” or “helpful at every visit.”

Access to appropriate medication. Table 1 shows self-reported nephrologist barriers to accessing medication and related impact to patient care. The most commonly reported barrier to accessing medication was navigating the process to apply for and obtain drug funding (88%). This result aligned with regional renal program consultation findings, which indicated a lack of dedicated staff resources to prepare funding applications and a lack of staff experience with the funding application process. Lack of funding for medication was another common barrier, including government funding for outpatients, patient out-of-pocket funding, and hospital funding for inpatients (81%, 77%, and 53%, respectively). Only 8% of respondents reported that the barriers to medication access did not significantly impact patient care.

Supports and opportunities. Figure 1 shows respondents’ perceived importance of different supports in ensuring patients

with complex GN receive safe, high-quality, and accessible care in Ontario (1 = *not at all important*, 5 = *very important*). Access to medication was reported as the most important support, with 79% of respondents rating it as “5.” Few respondents rated any of the supports below “3” on the 5-point scale, suggesting that all of the supports are important.

Interviews with Regional Renal Programs

Interviews with regional renal programs without a designated GN specialty clinic validated common areas for improvement, including the following:

- Access to appropriate medication and lab tests;
- Access to, and spread of, nephrology expertise in GN;
- Establishment of evidence-based guidelines and standards of care;
- Patient education and peer support resources;
- Standardized pathology;
- Staff resources and hospital infrastructure to support an appropriate model of care.

Interviews with GN specialty clinics echoed themes from other regional renal program interviews. In addition, these GN Specialty Clinic interviews revealed that the widespread discomfort in caring for patients with complex GN combined with the relatively few number of GN specialty clinics in Ontario has resulted in an unsustainable provincial model of care. There is a need to enable GN care across the province to alleviate patient travel to GN specialty clinics.

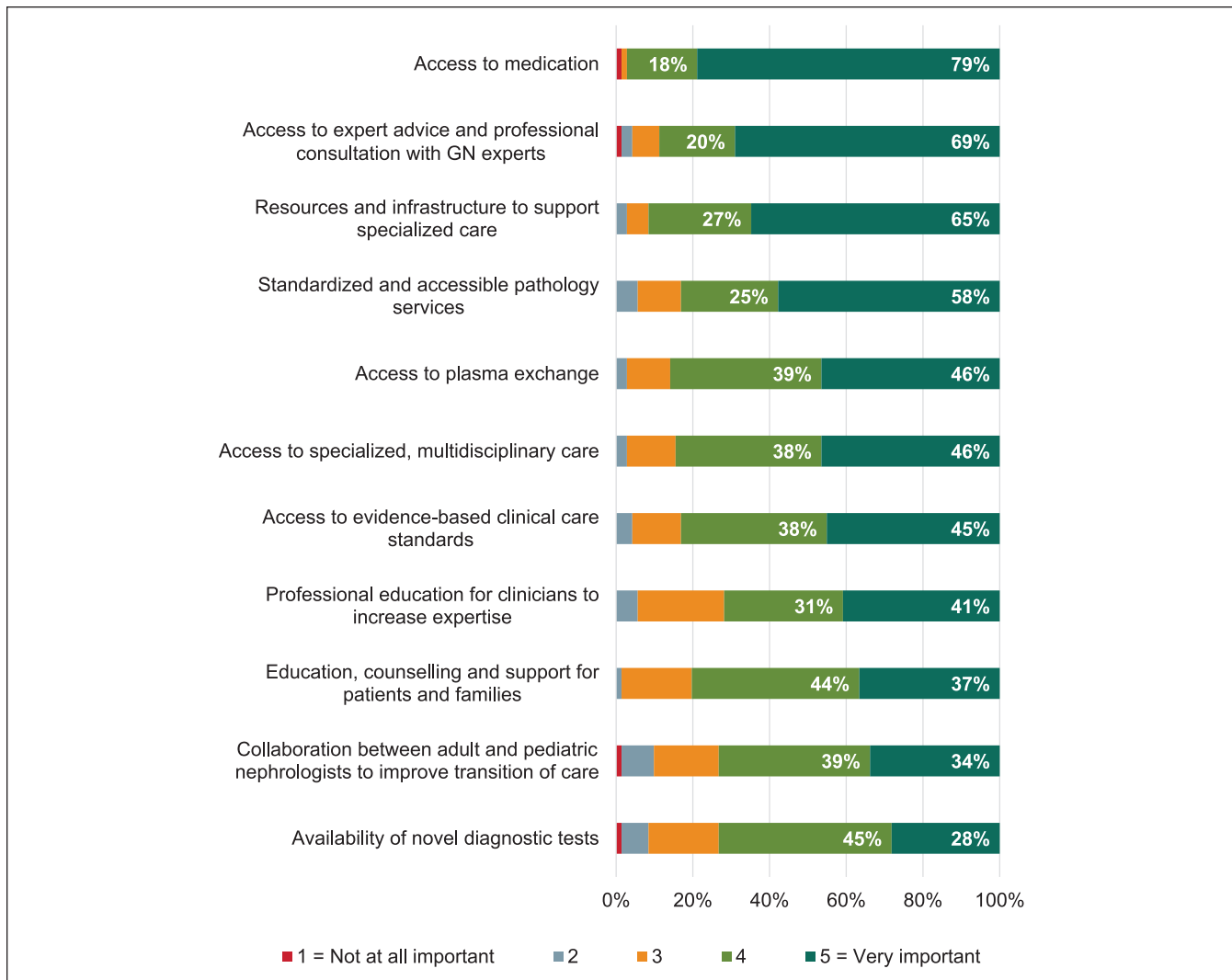


Figure 1. Nephrologist-rated importance of GN supports (n = 71).
Note. GN = glomerulonephritis.

Development of the Provincial GN Strategic Framework

The Ontario Renal Network developed a provincial GN strategic framework (see Figure 2), under the expert guidance of the Glomerular Disease and Specialty Clinics Priority Panel. The goal of the strategic framework is to ensure that all people in Ontario who are living with GN have access to person-centered, timely, and high-quality multidisciplinary care. It includes the following 4 objectives:

Ensure patients are supported to make informed decisions. To address unmet psychosocial needs and lack of appropriate education and counseling for patients and families.

Establish a provincial model of care. To standardize care across Ontario. The model of care should aim to determine

the clinical services required along the patient pathway, establish settings of care (eg, GN specialty clinics), identify multidisciplinary care requirements, and define the minimum requirements and accountabilities to provide GN care.

Leverage data to enable planning, decision-making, and monitoring of outcomes. To describe the GN population in Ontario, including disease profile and patient outcomes, and to inform on health care policy decisions.

Ensure appropriate access to medication. To support health care providers in obtaining necessary medications to treat patients with complex GN.

Of note, the provincial GN strategy is presently focused on GN care provided within regional renal programs. It does not address issues related to delay in diagnosis or referral from primary care providers to nephrology. The Panel and Ontario

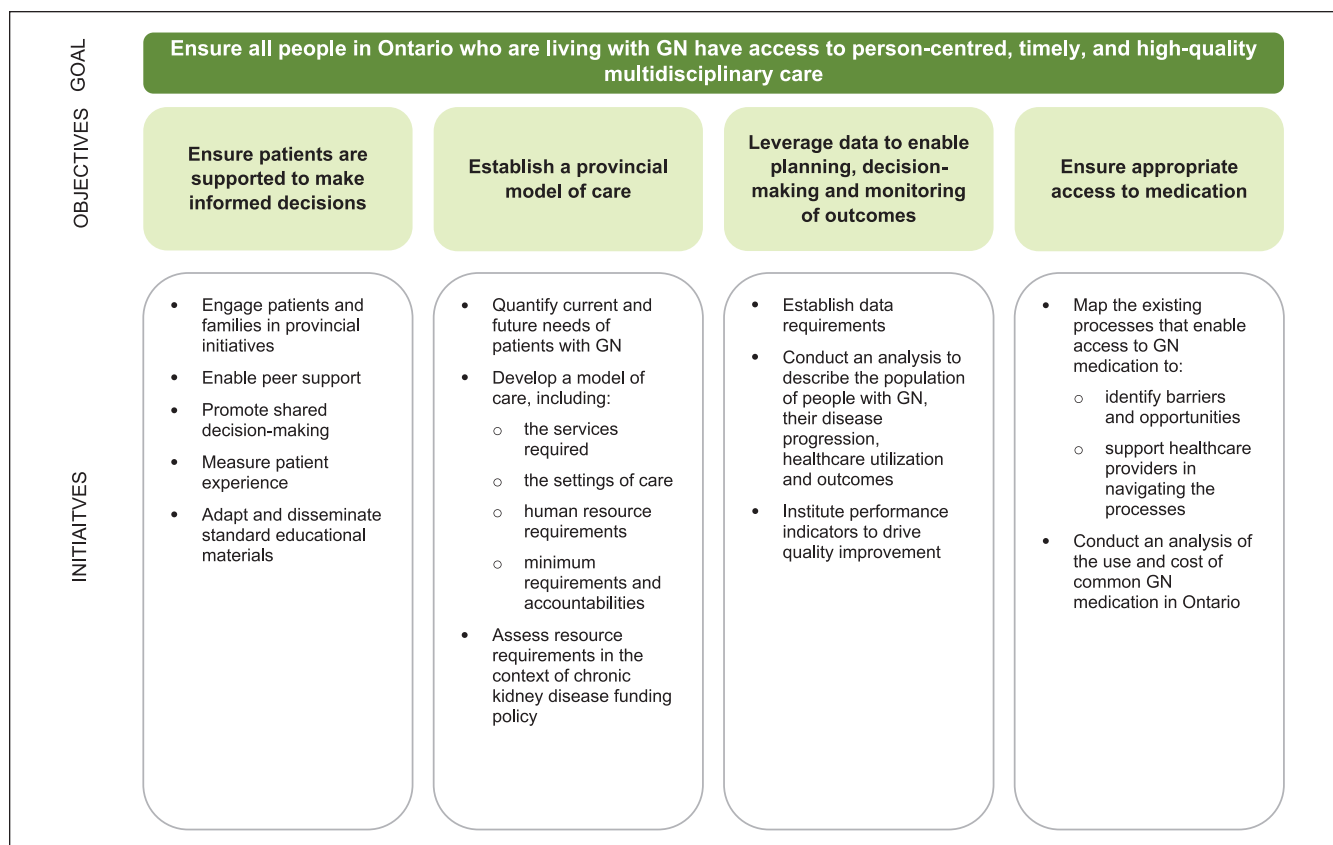


Figure 2. Provincial glomerulonephritis strategic framework.

Note. GN = glomerulonephritis.

Renal Network executive recognized that there is a need to improve the diagnosis and referral pathway, especially from a patient experience and outcome perspective. However, it was critical to first improve and standardize GN care within regional renal programs so that nephrologists can appropriately support primary care providers. Ensuring timely diagnosis and referral will be included as an objective in a future strategy.

Discussion

This article describes the Ontario Renal Network's provincial GN needs assessment. It identifies various issues that contribute to unstandardized and inequitable GN care across Ontario, including a need to improve education and psychosocial support for patients and family members, to establish a provincial model of care, and to ensure access to appropriate medication. The results from the needs assessment further emphasize the necessity to develop and implement a provincial GN strategy.

Only 30% of nephrologist respondents feel “very comfortable” caring for patients with complex GN. Given the lack of evidence to support GN clinical best practices and low uptake by nephrologists,³⁻⁷ it was unsurprising that nephrologist

respondents often seek advice from nephrologists with GN expertise (88%) or refer patients to nephrologists at GN specialty clinics (62%). Similarly, a previous survey of Canadian nephrologists reported that most nephrologists would find it helpful to access phone consultations with a GN specialist (68%) or refer patients to a GN specialty clinic (64%).⁷ However, Ontario professional consultations and patient referrals often do not follow a formal process, and there is a need to mitigate overreliance on the limited number nephrologists at the existing GN specialty clinics. In addition, the survey showed that multidisciplinary team members are often not available in the care of patients with complex GN even though they are perceived as helpful. Particularly, 100% of respondents reported that pharmacists would be “helpful as required” or “helpful at every visit.” This shows a need to resource regional renal programs with the appropriate health care providers to deliver complex GN care. As such, the provincial GN strategic framework includes an objective to establish a provincial model of care and expand GN expertise across the province through a program of continuing medical education and mentorship. Provincial oversight and professional network will also support opportunities for collaborative efforts to build evidence and inform on best practices to manage GN.

Of interest, the British Columbia (BC) Renal Agency established a provincial GN Network and Registry in 2013 to address similar issues.⁹ A key component of the BC GN Network and Registry is capture of all biopsy-proven patients with GN into a provincial database of kidney disease to allow patient identification, evaluation of provincial initiatives, and clinical research. An advisory group of key stakeholders can leverage these comprehensive data to inform on provincial policies and initiatives. At the time of the provincial GN needs assessment, there was no complete or accurate provincial database to determine the incidence or prevalence of GN in Ontario. The lack of provincial population-level data has been a key barrier to capacity and policy planning. As such, Ontario's provincial GN strategic framework includes an objective to leverage data to enable planning, decision-making, and monitoring of outcomes. Data capture should draw from the BC experience in developing and implementing the BC GN registry,⁹ as well as seek alignment for provincial comparisons. Provincial data collection can also lend itself to health services and clinical research, for example, to identify gaps in care for quality improvement initiatives or to assess patient outcomes against different treatment protocols.

Another key component of the BC GN Network and Registry was the establishment of a provincial GN drug formulary in 2014.¹⁰ The formulary aimed to improve access to evidence-based immunosuppressive medication for GN, as well as improve transparency and oversight of medication costs. The formulary replaced a case-by-case drug coverage application process—similar to the current Ontario application process. Prior to the formulary, the annual per-patient cost of immunosuppressive medications in BC increased 6.8-fold, from Can\$205 in 2000 to Can\$1394 in 2013.¹¹ After its establishment, the growth of annual per-patient cost of immunosuppressive medication in BC stagnated at Can\$1405 in 2016 and Can\$1411 in 2017.¹⁰ In addition, patients in the BC GN Registry are not required to pay deductibles and thereby alleviate patient financial stress related to medication costs. The Ontario Renal Network is currently gathering information about funding processes for GN immunosuppressive medication across other Canadian jurisdictions for comparison. Ontario opportunities to ensure appropriate access to immunosuppressive medication may include collaboration with provincial drug funding programs to improve criteria for drug application processes and improve health care provider education on the existing process.

The interviews with patients and family members identified a need for GN-specific patient resources and other supports, recognizing that GN affects a younger population of patients with chronic kidney disease and is associated with a different symptom profile. Through the GN Patient and Family Panel established by the Ontario Renal Network in 2017, patients and family members have identified a need for more relevant patient-facing information about GN, treatment, self-management, and psychosocial support. The Ontario Renal

Network is exploring potential patient education resources that can address these areas. Some hospitals are also exploring a model for patient support programs facilitated by a social worker that could be adopted by other centers to address the unique psychosocial needs of this population.

The provincial GN needs assessment methodology had several important limitations. First, the Ontario Renal Network developed a new nephrologist survey rather than leveraging a validated survey tool. As such, there is no information on the validity and reliability of the survey. The survey also relies on self-reporting. However, the survey was designed with input from nephrologists and hospital administrators involved in GN care. It also enabled targeted data collection on GN care practices that may be addressed by a provincial policy. Second, the patient and family member interview questions were newly developed and had not been validated. Third, resource limitations affected the patient and family member interviews in a number of ways. Interviews were conducted by 1 person and were not audio-recorded or transcribed, which may have introduced the risk of interviewer bias. To mitigate this risk, the interviewer validated notes and key themes with patients and family members before closing each interview. Interviews were not conducted until point of data saturation. Instead, only 20 interviews with patients and family members were conducted, meaning that the sample may not fully reflect the entire population of people living with GN. A larger more robust survey to confirm the themes that emerged would add to this literature. The total number of patients who were invited to participate, or who were eligible to participate within the recruitment period, is unknown and was limited to patients who spoke English potentially missing other significant barriers to care experienced by minority groups. However, the sample represented geography across Ontario and included patients with both positive and negative experiences. Finally, the provincial GN needs assessment relied on volunteer participants, which is inherently biased due to self-selection. Patients and family members who chose to volunteer may have had more negative or positive experiences to share. Nephrologists who chose to respond to the survey may have more exposure or interest in GN.

Conclusions

This was the first provincial needs assessment to describe the state of GN care in Ontario. It included the perspectives of nephrologists, hospital administrators, and patients and family members with representation from regions across the province. The findings from the needs assessment informed on the development of the Ontario Renal Network's first provincial GN strategic framework. This comprehensive framework will guide the development and implementation of future health policies to ensure that all people in Ontario who are living with GN have access to person-centered, timely,

and high-quality multidisciplinary care. Ontario is the second province of Canada to establish a provincial GN strategy. Other jurisdictions may leverage the provincial needs assessment and framework to identify and compare local gaps in care. Cross-jurisdiction comparisons are valuable given the relative rarity of disease and limited evidence to support best practices and policies.

Ethics Approval and Consent to Participate

Cancer Care Ontario is designated a “prescribed entity” for the purposes of section 45(1) of the Personal Health Information Protection Act of 2004. As a prescribed entity, Cancer Care Ontario is authorized to collect personal health information from health information custodians without the consent of the patient, and to use such personal health information for the purpose of analysis or compiling statistical information with respect to the management, evaluation, or monitoring of the allocation of resources to or planning for all or part of the health system, including the delivery of services. Because this study is in compliance with privacy regulations, ethics review was not required.

Consent for Publication

All authors consent to the publication of this study.

Availability of Data and Materials

The data and materials are not available for this study.

Acknowledgments

The authors gratefully acknowledge the valuable contributions from the Glomerular Disease & Specialty Clinics Priority Panel (Dr Daniel Cattran, Dr Todd Fairhead, Dr Azim Gangji, Sandra Grgas, Susanne Jeffery, Dr Ian MacDonald, Dr Norman Muirhead, Jenny Ng, and Stephanie Winn) and staff at the Ontario Renal Network provincial office (Catherine Bacik, Jessie Wong, Marnie MacKinnon, and Rebecca Harvey).

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported by Ontario Renal Network.

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Supplemental Material

Supplemental material for this article is available online.

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