

Original Article

Provider perspectives on treatment decision-making in nephrotic syndrome

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ABSTRACT

Background. Managing patients with nephrotic syndrome (NS) remains difficult for the practicing nephrologist. This often young patient population is faced with a debilitating, relapsing and remitting disease with non-specific treatment options that are often poorly tolerated. Clinicians managing these complex patients must attempt to apply disease-specific evidence while considering the individual patient's clinical and personal situation.

Methods. We conducted qualitative interviews to ascertain the provider perspectives of NS, treatment options and factors that influence recommendations for disease management, and administered a survey to assess both facilitators and barriers to the implementation of the Kidney Disease: Improving Global Outcomes (KDIGO) guidelines.

Results. When making treatment recommendations, providers considered characteristics of various treatments such as efficacy, side effects and evaluation of risk versus benefit, taking into account how the specific treatment fit with the individual patient. Time constraints and the complexity of explaining the intricacies of NS were noted as significant barriers to care. Although the availability of guidelines was deemed a facilitator to care, the value of the KDIGO guidelines was limited by the perception of poor quality of evidence.

Conclusions. The complexity of NS and the scarcity of robust evidence to support treatment recommendations are common challenges reported by nephrologists. Future development and use of shared learning platforms may support the integration of best available evidence, patient/family preferences and exchange of information at a pace that is unconstrained by the outpatient clinic schedule.

Keywords: KDIGO guidelines, learning needs, nephrotic syndrome, qualitative approaches, treatment decision-making

INTRODUCTION

Patient-centered approaches are widely recognized as a priority for delivering high-quality health care [1, 2]. While there is no agreed-upon definition, patient-centered practices include: consideration of an individual's understanding and concerns regarding their condition, recognition of personal circumstances, establishment of a common understanding of the problem to be addressed and agreement on the treatment approach, using best evidence to support management decisions [2, 3]. Thus, patient-centered approaches require a shared approach to learning and decision-making between the patient/family and the healthcare provider.

Delivery of patient-centered care (PCC) can be particularly challenging in the management of nephrotic syndrome (NS) because the patient and health care team face a series of decisions that unfold over time due to the significant associated chronic illness state, typically characterized by edema, fatigue and hypercoagulability, as well as the relapsing, remitting and progressive nature of NS. Further challenges also derive from the often poor response to therapies that are accompanied by serious potential side effects and toxicities.

Clinical practice guidelines attempt to comprehensively assess and synthesize the medical literature into a practical context for the practicing physician. The Kidney Disease: Improving Global Outcomes (KDIGO) Clinical Practice Guideline for Glomerulonephritis is based on a systematic review, appraisal and synthesis of the literature available through November 2011 [4]. Within these guidelines, evidence is rated and graded recommendations are provided based on evidence where available and expert opinion when evidence is lacking. From the provider perspective, merging knowledge of disease-specific evidence along with consideration of the individual patient's clinical and personal situation provides a particular challenge in delivering PCC. However, little attention has been given to examining provider perspectives about treatment decision-making in NS or the factors providers take into account in making treatment recommendations.

We therefore examined patient, family and provider perspectives on NS (Phase I) to develop a shared learning decision support tool (Phase II). In this paper, we report only on provider perspectives from Phase I, with a specific focus on the decision-making process including factors providers take into account when making treatment recommendations as well as their impressions of the clinical practice guidelines for the management of primary glomerular diseases causing NS.

MATERIALS AND METHODS

A sequential mixed methods approach [5] was used to elicit and analyze provider perspectives on health-related decision-making in NS.

Subjects

Providers with the primary responsibility for the medical management of children or adults with incident NS were invited to participate. NS was defined as urine protein loss causing hypoalbuminemia and edema caused by steroid-sensitive (SS) or -resistant (SR) NS in children, minimal change disease (MCD), focal segmental glomerulosclerosis (FSGS) or membranous nephropathy (MN) in children or adults. Participants were recruited by the three participating centers: the University of Michigan, the University of North Carolina at Chapel Hill and the University of Toronto, as well as through the Nephrotic Syndrome Study Network (NEPTUNE; Neptune-study.org). Internal medicine and pediatric providers were included and input from academic as well as community practices was sought. The study was conducted with the approval of the Human Subjects Research Ethics Board at all participating centers, and all participants provided informed consent.

Data collection

Between December 2012 and April 2014, qualitative approaches (focus groups and individual interviews) were used to elicit provider perspectives about treatment decision-making in NS. At the completion of the qualitative interviews, providers were asked to complete a Practice Guideline Questionnaire (PGQ), developed by the research team on the use of practice guidelines in general, and specifically, the KDIGO guidelines for glomerulonephritis.

Qualitative data

A semi-structured interview guide was developed, reflecting patient-centered communication and shared decision-making [6]. Interview questions were informed by the Population Needs Assessment based on the Ottawa Decision Support Framework [7]. Interview guides were reviewed for comprehensiveness and clarity by the project steering committee and were pilot tested for validation of the content. Providers were invited to discuss their perspectives about key decisions patients and parents faced when diagnosed with NS, the main options for therapy and considerations when recommending a treatment option, as well as barriers to and supports of the decision-making process.

Focus group sessions were ~1 h and were guided by two experienced interviewers/facilitators from each respective site. All had experience in qualitative interviewing and were trained with respect to the project specifics to ensure consistency of approach to data collection. One interviewer was responsible for facilitating the discussion using the interview guide and the second assisted with timekeeping and kept field notes about the group sessions (e.g. observations of group interactions). Individual interviews were conducted by one interviewer using the same interview guide. All focus group and interview sessions were audiotaped.

Practice Guideline Questionnaire

In the first part of the PGQ, respondents were provided with a list of possible facilitators and barriers to the use of guidelines adapted from the existing literature [8], and were asked to identify which applied to their practice. In the second part of the PGQ, participants were asked to consider five specific KDIGO guidelines for the management of NS (SSNS in Children; SRNS in Children; MCD in Adults; Idiopathic FSGS in Adults; and Idiopathic MN). Pediatric nephrologists were asked to complete the child-specific guideline assessment and internal medicine nephrologists were asked to complete the adult-specific guideline assessment. Respondents were provided with a summary of each guideline developed by the research team and asked to evaluate whether guidelines were consistent with and acceptable for current practice. If guidelines were deemed unacceptable, providers were asked to select from a list of possible reasons. In the final part of the questionnaire, participants were invited to provide any additional feedback about implementing practice guidelines in general or KDIGO guidelines in particular. The PGQ was reviewed for comprehensiveness and clarity by the project steering committee and three nephrologists on the team reviewed the guideline summaries for validation of content.

Sample size and data analysis

A total of 38 providers participated in the qualitative component of our study. This sample size is consistent with qualitative research standards. Further, in keeping with purposive sampling approaches used in qualitative research, our goal was to include a sample of providers representing a variety of diverse experiences and perspectives. Thus, we included participants from multiple sites and various practice settings, with a range of practice experiences, which helps to enhance the transferability of our findings. With respect to the quantitative portion, the sample size provided ~80% power to detect a 20% difference between groups.

Audiotapes of focus group and individual interviews were transcribed verbatim. Transcripts were coded using a coding framework developed inductively by the research team and analyzed using a qualitative content analysis approach [9]. Coding and analysis was undertaken with the computer program NVIVO 10. Responses to the PGQ items were tabulated using frequency counts, and descriptive statistics were used to characterize the sample.

RESULTS

Between December 2012 and April 2013, four focus groups and two individual interviews were conducted with a total of 38 participants. Of these, 35 provided detailed demographic data, and 33 completed the PGQ.

Characteristics of respondents and prescribing practices related to the treatment of NS

Based on location of practice, there were 11 participating Canadian physicians, 24 American physicians and 3 who failed

to provide demographic data. The participating American physicians represented eight states and all the Canadian physicians practiced in Ontario. The median age of participating physicians was 53 years (range 31–71 years), and 61% were male. The majority had in excess of 10 years of experience practicing in the field (median 16.5 years; range 0.5–35 years). The majority were nephrologists that cared exclusively for adult patients (61%) and practiced in academic centers (55%), while 45% practiced in either community hospitals or private practice. A minority of the physicians affiliated with academic centers worked in large dedicated GN clinics. All providers were aware of the KDIGO guidelines, and 90% stated they had read them. All providers had prescribed immunosuppressive agents to manage patients with NS within the preceding 2 years.

Qualitative findings

Provider perspectives of the decision-making process in NS included three broad categories: (i) factors providers take into consideration when making treatment recommendations; (ii) providers' perception of patients' and parents' learning needs; and (iii) providers' perception of factors affecting the decision-making process.

Factors providers take into consideration when making treatment recommendations

When making treatment recommendations, providers considered characteristics of various treatments, such as efficacy, side effects and evaluation of risk/benefit, and took into account how treatment options fit with an individual patient or child (Table 1). The patient characteristics most commonly considered

Table 1. Provider considerations for making treatment recommendations

Characteristics of the patient/parent/child
<p>Demographic characteristics (age, sex, family history)</p> <p>'If we're thinking about Cytoxan we're thinking about the age of the child and the toxicity.'</p> <p>'The patient age group because if it's a teenager, it's even more of an issue in terms of physical appearance.'</p> <p>'If they're a female, and they're young, and they're in their childbearing age, we have to take that into account, too. Even for general therapy because ACE inhibitors—could have an effect on the unborn child. Some medications can affect their fertility too.'</p> <p>'In pediatrics, especially we'll think about if there's a family history of nephrotic syndrome. If we believe this is a genetic form of nephrotic syndrome, we may choose not to use immunosuppressant therapy.'</p>
<p>Clinical characteristics (diagnosis/prognosis/disease severity, comorbidities)</p> <p>'...It is easier when I have diagnostic certainty. So when a patient who is four years old presents with a classic presentation minimal change nephrotic syndrome, it's easy for me to sit down confidentially and tell the family this is what we should do. If it's a teenage boy with severe FSGS, interstitial inflammation, and chronic kidney disease, it's also an easier conversation because there aren't options. Once you get to those grey zones you sort of have to have complicated conversations where we're not sure which is the right immunosuppression.'</p> <p>'There also may be different patient specific characteristics that come into play more in the considerations with adults compared to children. Comorbid conditions need to be considered when deciding what agent to choose.'</p> <p>'What is the down side to using steroids? Even though they're indicated, do the down sides outweigh the benefits of therapy?'</p>
<p>Psychosocial and socio-economic considerations (adherence of patient/parent/child financial resources)</p> <p>'We think about how compliant or adherent the family is, especially for meds that need monitoring like tacrolimus or cyclosporine.'</p> <p>'Another issue that our patients encounter is the inability to pay the bills. So a major factor in deciding which drug to use in our patients is based on affordability of the drug.'</p>
<p>Patient preference</p> <p>'Their own subjective risk assessment ... Some people really don't want to be on dialysis and they're willing to risk death not to go on it ... Everybody's afraid of something different. Other people don't want the cancer risks from the Cytoxan ... you have to give them the different choices so they can pick and choose the path they want to go down.'</p> <p>'I also worry about other side effects in general for patient preference. ... some of these medications have pretty severe GI side effects, and I definitely talk to my patients about ... what side effects really they're most worried about ... I think there's a whole range of side effects that are different for different patients.'</p>

included the severity of the disease and prognosis, as well as demographic characteristics of the patient (age, sex). Psychosocial considerations, such as socio-economic status and adherence/compliance, were also considered important. While providers highlighted issues of concern for particular groups of patients (e.g. fertility for young women), they also discussed the importance of understanding patient/parent opinions about specific treatment options when making recommendations.

Provider's perceptions of learning needs of patients and parents

When asked what information patients and parents should know, the most prevalent learning needs providers identified were related to understanding NS and its implications (Table 2). In addition to helping patients and parents understand kidney disease in general, providers highlighted the importance of specifically learning about NS. This included understanding the diagnosis and prognosis, understanding the complexities of

the disease and the treatment of NS in general, as well as the specific approach recommended for their individual situation. In some instances, this involved helping patients/parents understand the need to gather more diagnostic information before making a treatment recommendation. Since medications were an essential component of the approach to treatment for most patients, providers felt it was important for patients/parents to have information about side effects, duration of treatment and risk/benefits of taking these medications over the short and long term. However, presenting this information to patients was seen as particularly challenging due to the lack of information targeting their unique concerns. Providers noted the importance of explaining the chronic nature of the condition. Further, the remitting, relapsing nature of NS was identified by a number of providers as being a particularly difficult aspect for some patients and parents to grasp and manage.

Many providers felt that the complex nature of NS and its management was often challenging for patients and parents

Table 2. Providers perceptions of patients' and parents' informational needs

Understanding NS and the treatment journey
<p>Understanding the diagnosis <i>'They have to learn about the disease, and that it's relapsing and remitting; and that's complex to understand.'</i> <i>'... Some patients need to have some distinction between ... a kidney disease per se and voiding. They have that confusion because when they come to see you they say 'I don't know why I'm here for, I'm peeing well.'</i></p>
<p>Understanding the prognosis <i>'Two other things I think they need to hear, one is the course of the disease in question. If we're talking about FSGS, how likely is it to progress and what are the consequences ... if steroids don't work? In terms of dialysis and transplant, what might the timing be? What do those look like? Again, all in this 20-minute time span ... Then what are the expected response rates and relapse rates for their particular type of FSGS or minimal change disease?'</i> <i>'... they want us to give them a prognosis, but unfortunately, we can only prognosticate depending on how often we see them, and how often the disease relapses. At their first presentation, they want me to tell them if it's ever going to come back, and I can't. I can only just say in a 100 children, it will come back in 70% who will go on and have one relapse. But out of those maybe 5 or 10% will progress to end-stage renal disease. They want to know where they fit already, and I can't give them a prognostic view at that very first visit. I think that's the hardest part.'</i></p>
<p>Knowing what diagnostic tests will be done <i>'I find that lots of times, patients come in with urine analysis 3 plus. The first step for me is explaining to the patient they need to confirm this, the second step involves a kidney biopsy because we need to have a firm diagnosis, a definitive diagnosis.'</i> <i>'They also have to learn how to dip their urine every morning, so we teach them to dip the urine. They have to be trained in how to do that, and to understand what a relapse means, what protein in the urine means; and then agree to be able to do that each day.'</i></p>
<p>Understanding the approach to treatment <i>'They want to know how long they need to be treated with a drug that may or may not be toxic.'</i> <i>'I think that they clearly should have a sense of the major side effects of each of the options. Now of course all these drugs have innumerable side effects so you can only go so far in terms of informed consent and how much weight do you give to each possibility is going to be a matter of your style ... but they need the major side effects and the beneficial effects in terms of what type of time frames things are likely to improve if they're going to improve ...'</i> <i>'Medication-wise, there are a lot of issues about starting multiple medications. From the patient's perspective, it's immediate symptom control, but then from the physician's perspective, it's more symptoms plus decisions about conservative therapy versus using immunotherapy.'</i></p>
<p>Understanding the complexities of the disease <i>'I think it's difficult for the parents to understand that this is a relapsing and remitting disease, and that in fact, studies have shown; the more that we treat it at the beginning the better, so this is really our best chance to treat the underlying disease; and let's treat it the best way. That they find hard because once it goes away, they want to stop the medication, so you have to convince them that in fact studies have shown 12 to 16 weeks have been really good in diminishing relapses down the road...'</i></p>
<p>Tailored information <i>'So they often feel, I think —sometimes, I feel as well—that there wasn't really a good communication with what's actually going to happen to them because we're not exactly sure at that point; ... they've just come with protein in the urine. That covers a very large and very wide spectrum of the disease process. I think the idea about trying to account for what it is that we tell the patient and what they receive is sometimes not a very good match.'</i> <i>I'd say first thing it has to be tailored to the level of understanding of the family ... here's your relapse risk ..., but I can tell you an awful lot of my patients, whether they're English or, as in the majority, Spanish speaking, would not understand that. They would not understand what a percentage is, so it has to be fairly nuanced in terms of covering things, but not being confusing. That's the problem I have with online material. You can go to something that's absolutely correct and they come in and think my baby's going to die tomorrow and you look at it and you say, 'That's right. It just doesn't apply to your baby.' It can be true information but not relevant here, and they don't know that.'</i></p>

Table 3. Providers' perceptions of barriers and facilitators to the decision-making process

Barriers
<p>Time constraints</p> <p><i>'You know this is again going back to the time issue. I mean there's a lot to compress into a single visit and of course there's immediate information overload so I think what do they say you get two or three things out of a visit you know that a patient will remember, and we have to tell them fifteen different things.'</i></p> <p><i>'... the time issues is twofold. One is not having enough time talking with the patient because you don't have enough time in your clinic visit, but the other is that sometimes we have time pressure to make therapeutic decisions that people are not ready to make because they're tough decisions.'</i></p>
<p>Complexity of NS and its treatments</p> <p><i>'I mean virtually all these diseases have ... a literature that's a text book size and if you have to give them the balance of ... the risk, but in proportionate to the need for therapy ... There's a lot of editing involved because if you spend all your time talking about the risks of therapy, the patient is not going to choose therapy and in the long term what's best for the patient may well be therapy.'</i></p>
<p>Patient/parent emotional response to the diagnosis</p> <p><i>'Renal disease isn't ... as common as heart disease or cancer and patients know that if you go see a Nephrologist, you're in trouble. So, the emotions are already there up front, people are anxious about it.'</i></p> <p><i>'I don't think there's a pattern, they're just mad. They don't want this diagnosis. They don't believe a word you're saying. It's sort of the anger denial. They're in denial, they're not ready to have a discussion and they're very suspicious. Basically you spend the whole time answering defensive questions and stuff that's not relevant. That's not getting towards an actual treatment plan.'</i></p>
<p>Misperceptions about kidney disease and NS</p> <p><i>'... when it comes to kidney disease in general, there's less appreciation for different types of kidney disease so often the patient will come with sort of the wives tales of ... does cranberry juice help this and stuff like this. They're applying the antidotes in the common wisdom that may apply to urinary tract infections or kidney stones to this disease. Unlike for instance hypertension or heart disease, where there's been a lot of public education, for kidney disease there has not been ...'</i></p> <p><i>'Patients need to know about the prognosis ... I'm not sure whether all patients really understand that this disease could lead to dialysis and they don't even know what dialysis means. So I think if they are educated that this could lead to organ failure if untreated ... They don't connect that this is a deadly disease being on dialysis is like having metastatic breast cancer, they don't understand this and I think they need to be educated and this, I think, has a big influence on what treatment choices the patient makes and how motivated the patient is to implement those and implement lifestyle changes.'</i></p>
<p>Preconceived ideas about treatments</p> <p><i>'I've had a number of patients say "I am not going to take steroids. You know, my uncle went crazy on steroids and I'm just not gonna take those" or "I had problems with them in the past for some other problem" and so they have some ... predisposition towards or against.'</i></p> <p><i>'There are those that are overly concerned about prednisone because they have read about all the complications, and there are those that would rather be on prednisone than say they are taking cyclophosphamide; because they think that's chemotherapy when they read about it on the website. So that becomes a problem.'</i></p>
<p>Literacy/health literacy of patient/parent</p> <p><i>'Even if I try to use literacy appropriate low technical words, I find that parents who have less education, less training or younger patients, less life experience—parents who are younger—I find those patients have the most difficulty dealing with the instructions, the diagnosis, the complications, and the prognosis.'</i></p> <p><i>'Even when they have a higher level of understanding or education they still tend to read just enough to get to a conclusion that they want and you have to sort of give them a broader picture and open their eyes to what all the different options are so they don't just rely on a single report from the internet.'</i></p>
Facilitators
<p>Developing and sustaining relationships/trust between patients/families and providers</p> <p><i>'There's also the continuity of the care, and there's that sort of trust that has to be built between the patient and the physician. Those are all very dependent on how things are going, so it's a lot easier when, in fact, you're very successful, and everything goes away, and their symptoms almost go away. It's not so easy when things aren't going well or they've already been through a number of other treatments, and it hasn't worked'</i></p> <p><i>'The nephrologist is scary ... I find that it takes a while in here for the person even able to accept this. We're going to be friends, and we are going to need to see each other. It's far more than just, "I'm not certain of your diagnosis because you have proteinuria." That takes a while'</i></p> <p><i>'Initially, there's not a rapport. Initially, they don't know who I am and initially, I need to make sure they ... they understand that I don't keep the information from them. I don't lie to them, and I will always tell them the truth. If I tell them, "You're not to worry," then they're not to worry. I will tell them when to worry because I will tell them I'm worried. I try to say that initially for the first two or three visits because we don't know one another, but it's still sometimes very hard.'</i></p>
<p>Inter-professional team</p> <p><i>'It's a team. As I said, I see myself as being heavily reliant upon the compassion and the intelligence of my nurses to screen things, address what's important, and to provide that kind of day-to-day support.'</i></p> <p><i>'I always get involved ... pharmacies, the dietician, the nurses. I find it and the patients find it very helpful to hear an independent second opinion. Again, it's a resource, and you are actually, depending on who they are, but it's in a community setting. Sometimes, these resources are available, and it's quite useful.'</i></p> <p><i>'I think the nursing approach is usually a much more practical lifestyle approach. We go in. Here's the medicine. Here's what a biopsy is. Here's the risk of a biopsy, and that could take a good hour just doing that, but if you leave it there you haven't—the patients need to and want to hear that, but boy, is that 15% of what they really need to know. They need to know what am I going to do at home. It's not like we couldn't do that, but in general, our nursing, social work, dietary that's kind of what they do and they're much better. That's the more complete education to get'</i></p>
<p>Providing patient/parent education</p> <p><i>'We have a very directive program where the nurses actually have a specific program that they go through. They teach the families, they bring them in on a separate day; not a regular clinic day, not during your routine clinic visit. They do teaching for about two to three hours, and then they essentially begin to almost testing the families to make sure they can do it on their own. They have them read a lot of material; they have them go through all of that process.'</i></p>

Continued

Table 3. Continued

Facilitators
<p>Social support <i>'One of the things that I've noticed that seems to help is when they come with family. A lot of times, that family actually has different perspectives than the patient. The patient's already overwhelmed by having that diagnosis and having to undergo very potentially toxic treatments. Having the family member around, especially if they don't speak English as a first language, is very useful, and they also have extra questions that sometimes actually help make the decision a lot easier for the patients.'</i></p>

to comprehend, which meant they had unique learning needs in comparison with patients with other illness conditions. A number of providers stressed the importance of providing information that was 'targeted to the patient'. This included consideration of the patient's/parent's level of understanding about their condition, and their ability to comprehend medical facts. In addition to considering language preferences and health literacy, providers suggested that information should also be tailored to address characteristics of the 'condition' as well as patient age, developmental stage and preferred learning styles.

Providers' perceptions of factors affecting the decision-making process

Providers described barriers to the decision-making process in terms of both challenges and constraints they experienced themselves as well as those they thought were experienced by the patient/parent (Table 3). In many instances, these challenges were interrelated (i.e. a barrier providers experienced, such as time, might interfere with their ability to provide information, and thus, impact the patient/parent understanding of the disease). An overarching theme in providers' comments was the importance of patients' and parents' understanding of NS and its treatment to support the decision-making process. Factors that might interfere with understanding were, therefore, considered barriers or challenges to the decision-making process.

From the providers' perspective, time constraints and the complexity of explaining NS were the most significant challenges to supporting patients/parents in developing an understanding of NS. This complexity, coupled with a perceived lack of robust evidence upon which to base treatment recommendations, made it difficult to provide the necessary information to support decision-making. To some extent, this was due to the amount of information providers felt patients and parents needed to understand the condition, as well as the multiple treatment and self-management decisions they had to make.

Providers also identified a number of factors they felt facilitated or supported the decision-making process. These included the health care team and system resources and supports, as well as patient and family characteristics. The importance of developing and sustaining relationships as well as establishing trust between the patient and provider was consistently identified as essential to engaging patients and parents in the decision-making process. Having the support of an interdisciplinary team was highlighted by a number of providers as being essential, increasing the opportunity, expertise and time to provide patient education.

Table 4. Facilitators and barriers to guideline implementation

	n (%)
Facilitators	
Guideline availability	30 (91%)
Evidence of improved patient outcomes	25 (76%)
Agreement with recommendations	23 (70%)
Guideline awareness	18 (55%)
Congruence of guidelines with patient characteristics	18 (55%)
Organizational support for guideline implementation	18 (55%)
Resources for facilitation	18 (55%)
Perception of improved patient outcomes	16 (46%)
Congruence of guidelines with practice	12 (36%)
Time	10 (30%)
Barriers	
Lack of evidence of improved patient outcomes	18 (55%)
Concern about interpretation of evidence	18 (55%)
Lack of agreement with recommendations	15 (45%)
Lack of congruence of guidelines with patient characteristics	13 (39%)
'Too cookbook'	13 (39%)
Guideline availability	12 (36%)
Guideline awareness	9 (27%)
Lack of time	9 (27%)
Lack of resources for facilitation	8 (24%)
Lack of congruence of guidelines with practice	7 (21%)
Lack of confidence in guideline developers	4 (12%)

Results of the PGQ

Facilitators and barriers to guideline implementation.

Although 100% of participants were aware of the existence of the KDIGO guidelines and 90% had read them, only 55% utilized these guidelines to inform their practice. Facilitators and barriers to guideline implementation in general are summarized in Table 4. The most commonly cited facilitators included guideline availability (91%), evidence of improved outcomes secondary to use of guidelines (76%) and agreement with guideline recommendations (70%). Conversely, the most commonly noted barriers included lack of evidence that the guidelines improved patient outcomes (55%), concerns about the interpretation of evidence (55%) and lack of agreement with guideline recommendations (45%).

Additionally, we compared provider responses based on practice setting [academic medical center (n = 20) versus community practice (n = 13)]. Providers in academic medical centers were less likely to identify 'guideline awareness' as a facilitator (35% versus 85%, P = 0.005), and they were more likely to give 'lack of agreement with recommendations' as a barrier (60% versus 23%, P = 0.04). Overall though, there was high agreement between perceived facilitators and barriers by setting. When comparing providers who practiced in the USA with those who practiced in Canada, we found few differences. American

Table 5. Condition-specific evaluation of the KDIGO guidelines by providers treating subtypes of NS^a

	SSNS (<i>n</i> = 19)	SRNS (<i>n</i> = 16)	MCD (<i>n</i> = 23)	FSGS (<i>n</i> = 24)	MN (<i>n</i> = 27)
Do guidelines reflect current management of specific condition					
Not at all consistent	0 (0%)	0 (0%)	0 (0%)	2 (8%)	0 (0%)
Somewhat consistent	14 (74%)	14 (88%)	13 (57%)	16 (67%)	17 (63%)
Completely consistent	5 (26%)	2 (13%)	10 (43%)	6 (25%)	10 (37%)
Guidelines are acceptable	11 (58%)	12 (70%)	17 (77%)	17 (71%)	20 (77%)
If not acceptable, why? (Individual counts)					
Difference in prescribing practices from recommendations	3	4	2	3	1
Availability of recommended therapeutic agents	4	1	0	0	2
Concerns about efficacy of recommended therapy	4	3	2	4	4
Concerns about side effects of recommended therapy	5	4	5	5	5
Patient characteristics (comorbidity, older adults, ethnicity, etc.)	2	3	3	3	3
Patient/family preference	3	0	1	1	1

n is the number of providers who cared for the disease subtype where SSNS is steroid-sensitive nephrotic syndrome.

SRNS, steroid resistant nephrotic syndrome; MCD, minimal change disease; FSGS, focal segmental glomerulosclerosis; MN, membranous nephropathy.

^aNot all providers cared for all disease subtypes.

providers were more likely to give ‘guideline availability’ and ‘congruence of guidelines with practice’ as a facilitator (96% versus 71%, *P* = 0.04 and 46% versus 0%, *P* = 0.02, respectively). They were also more likely to give ‘guideline availability’ as a barrier (46% versus 0%, *P* = 0.02).

Condition-specific evaluation of the KDIGO guidelines.

The general acceptability of the guidelines varied by condition, but overall practice was at least somewhat consistent with the existing guidelines most of the time (Table 5). Rarely was practice completely consistent with the published guidelines. Not all providers cared for each subset of patients. Regardless, the lowest rates of guideline acceptability occurred in SSNS (58%), largely due to the toxicity of proposed therapies. Other cited reasons for deviation from the published guidelines included different established prescribing practices, lack of availability of recommended therapeutic agents, and concerns about efficacy as well as patient characteristics and preferences. In particular, the lack of guidance in different ethnicities, women of childbearing age, and the elderly were noted as deficiencies within the existing KDIGO guidelines.

DISCUSSION

Our findings suggest that physicians treating the multifaceted diseases that cause NS struggle to impart an understanding of the chronic, relapsing and remitting nature of the condition as well as the balance of efficacy and toxicity of a chosen therapy, while trying to incorporate a variety of patient-specific considerations and learning needs. This is a particularly challenging task to accomplish within the existing clinic visit model and alternative strategies to enhance patient understanding of their disease and facilitate self-management are needed.

Providers currently lack adequate resources to support the time-consuming process of explaining the complexities of NS and intricacies of the disease course, which impacts the patients’/families’ willingness and ability to follow treatment recommendations. Providers in our study recognized the variability in patient and parent learning needs and acknowledged the potential emotional impact that receiving a diagnosis of NS could have on a

patient or caregiver’s ability to grasp information and participate in treatment decisions. Patient preferences must be a consideration when making treatment recommendations, but our providers highlighted the difficulty of communicating the risk/benefit ratio of various treatment options. Having the opportunity to develop trusting relationships and the availability of a multidisciplinary team were identified as supports for the decision-making process, underscoring the importance of providing ongoing opportunities for patients and families to interact with the health care team. However, the precise role for different members of the interdisciplinary team in the care of these patients remains to be determined and studied for efficacy.

Other factors such as age, literacy levels and preferred learning styles were also identified as important considerations for tailoring of information, and have implications for practitioners in terms of content, timing and delivery of information. Exchanging information is an important component of patient-centered communication that can be facilitated by strategies such as asking patients about their learning needs and preferences, eliciting their understanding about their condition and its meaning, and communicating information in a meaningful way that helps patients evaluate and apply the information [6]. Alternative learning platforms and resources that allow patients to learn at their own pace outside the confines of the clinic visit require development and assessment.

The wide scope of information necessary to share with patients to facilitate shared decision-making in a limited clinical visit time is a common challenge in chronic diseases. Much like patients with NS, patients with other chronic conditions such as diabetes, asthma and inflammatory bowel disease present to their provider with varying degrees of knowledge as well as exposure to the disease and the health care system [10–13]. In these other conditions, shared decision-making tools and methods have been effectively used to focus the information exchange to a manageable number of prioritized concepts at each encounter, increase the quality of clinical care, and improve patient outcomes. When used effectively and consistently, patients participating in models of care that include shared decision-making demonstrate increased knowledge, more accurate risk perceptions, reduced level of internal decision conflict, decisions made more consistent with their values and

higher levels of trust of their providers [14]. In addition, the use of shared decision-making has been estimated to substantially reduce the cost of health care [15]. The challenges identified by nephrologists in this study may be mitigated by the development and implementation of proven shared decision-making tools and methods similar to other chronic health conditions.

With respect to the KDIGO guidelines, evidence review and evidence-based guidelines are an important first step to optimizing patient care and practice. Although the intention of the KDIGO guidelines was to assist with the standardization of therapy in this complex patient population, gaps exist in their use in clinical settings with the quality of evidence or the lack thereof noted as the most significant facilitator and barrier to guideline implementation, respectively. The guidelines rate the quality of the evidence (A-High, B-Moderate, C-Low or D-Very Low) as well as the strength of the recommendation (Level 1, which corresponds to strong in grade, or Level 2, which corresponds to weak in grade or discretionary). The guidelines for NS are notably devoid of Level 1A evidence [4], and providers, especially those practicing in academic centers, identified concerns about treatment efficacy. The toxicity of existing treatment options was also noted as a significant barrier. Further, patient age, stage of life (e.g. fertility and pregnancy), and other comorbidities, like obesity and diabetes, may remove multiple standard agents from the NS treatment armamentarium. The need for individualized therapy impacts therapeutic decision-making of North American nephrologists and may limit the perceived value of clinical practice guidelines with respect to facilitating PCC. One recent study of Canadian nephrologists revealed considerable variability in the uptake of the KDIGO guidelines and found that between 15% and 46% of participants described approaches to treatment of glomerular disease that were not congruent with the guidelines [16]. Further, the authors reported that the lack of availability of clinical resources, including access to specialized clinics and expertise, standardized protocols for immunosuppression and multidisciplinary support from other health care providers, served as barriers to guideline implementation.

Our study has several important limitations. We recruited a convenience sample of providers who were interested and willing to participate in focus groups and interviews. Although adequate for the qualitative portion of the study, the sample size for the quantitative survey limited the ability to fully examine and understand differences between groups (e.g. Canada versus the USA). Furthermore, the majority of providers were from academic centers where the management of glomerular disease is of particular interest. As such, the patients treated at these centers may represent a particularly complex group of patients with NS, while the views of the providers may not reflect all perspectives and may not be generalizable to the larger population of practicing nephrologists. Further studies are encouraged to explore country and practice-specific facilitators and barriers to care of patients with NS.

CONCLUSIONS

Understanding the factors clinicians take into account when making treatment recommendations is important to help support treatment decision-making for both providers and

patients. Individualized, tailored approaches to care supported by evidence-based practice guidelines and acknowledgement of patient needs and preferences are warranted. The overall concern about lack of robust evidence to support current standard therapy, and the significant side effect profile of available agents support efforts to develop and test new, effective and safe treatment options. The complexity of these diseases also speaks to the need for involvement of multidisciplinary staff as well as the adoption of effective shared decision-making tools and learning platforms as possible approaches for supporting the integration of best available evidence and patient/family preferences while allowing exchange of information at a pace that is unconstrained by outpatient clinic visit.

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CONFLICT OF INTEREST STATEMENT

All statements in this report, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

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