



Overview of Self-Management Resources Used by Canadian Chronic Kidney Disease Clinics: A National Survey

Canadian Journal of Kidney Health and Disease
Volume 5: 1–8
© The Author(s) 2018
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/2054358118775098
journals.sagepub.com/home/cjk

Maoliosa Donald^{1,2}, Sarah Gil¹, Bhavneet Kahlon²,
Heather Beanlands³, Sharon Straus^{4,5}, Gwen Herrington⁶,
Braden Manns^{1,2}, and Brenda R. Hemmelgarn^{1,2}

Abstract

Background: Chronic kidney disease (CKD) clinics across Canada provide tailored care for patients with CKD with an aim to slow progression and prevent complications. These clinics provide CKD self-management resources; however, there is limited information about what resources are being used by clinics. We undertook a survey of CKD clinics across Canada to identify self-management resources for adults aged 18 years and over with CKD categories 1 to 5 and not requiring dialysis or transplant.

Objective: To identify and collate self-management resources (eg, strategies, tools, educational materials) used by CKD clinics across Canada for adults with CKD (categories 1 to 5, not requiring kidney replacement therapy).

Design: Self-administered, semistructured electronic survey.

Setting, participants: Canadian CKD clinics with previously identified contact information.

Methods and measurements: We contacted 57 CKD English-speaking clinics and invited them to complete an online survey. The survey was available from October 2016 to January 2017 and consisted of 17 questions regarding the use and attributes of self-management resources including topic, delivery format, provider, target population, where the intervention was provided, and resource languages.

Results: Forty-four clinics (77%) completed the survey. The most common topic was modality education provided in print format, by nurses. The most frequently used resource was the Kidney Foundation of Canada (KFOC) Living With Kidney Disease manual. We also identified that the majority of resources were available in English, targeting both patients and caregivers in the outpatient setting.

Limitations: Our survey included Canadian adult CKD clinics, which may not be generalizable to other settings, such as care of people with CKD in primary care.

Conclusions: Adult CKD clinics across Canada provide some similar resources, but also provide many different self-management resources. Even though some of the same resources were used by multiple clinics, the way they were provided them (ie, provider, location, delivery format) varied by the individual clinics. Knowledge of self-management resources currently provided in CKD clinics, along with synthesis of the literature and patient preferred self-management strategies, will inform the design and development of a novel self-management intervention that is patient-centric and adheres to the principles of self-management.

Abrégé

Contexte: Au Canada, les cliniques de néphropathie chronique prodiguent des soins spécifiques aux patients atteints d'insuffisance rénale chronique (IRC) dans le but de ralentir la progression de la maladie et de prévenir les complications. Ces cliniques offrent des ressources de prise en charge autonome de la maladie, mais on dispose de peu d'information sur les ressources qui sont effectivement offertes aux patients.

Objectifs de l'étude: L'étude visait le recensement des ressources de prise en charge autonome (stratégies, outils, documents informatifs et autres) offertes par les cliniques de néphropathie canadiennes à leurs patients adultes atteints d'IRC de stade 1 à 5 ne requérant pas de thérapie de remplacement rénal.

Type d'étude: L'étude a été menée sous la forme d'un sondage électronique semi-structuré et auto-administré.

Cadre de l'étude: Le sondage a été présenté à des cliniques de néphropathie chronique canadiennes pour lesquelles nous avons préalablement trouvé une personne-ressource.



Méthodologie: Nous avons invité les personnes-ressources de 57 cliniques anglo-canadiennes à compléter notre sondage diffusé en ligne entre octobre 2016 et janvier 2017. Le sondage comptait 17 questions relatives à la nature et à l'utilisation des ressources de prise en charge autonome offertes (sujet, forme, fournisseur, population ciblée, langues, lieu de l'intervention, etc.).

Résultats: Des 57 répondants potentiels approchés, 44 (77 %) ont complété le sondage. La demande d'information la plus souvent mentionnée concernait les modalités de dialyse et la ressource alors fournie consistait en un document informatif remis en version papier par le personnel infirmier. La ressource la plus souvent employée était le guide *Vivre à sa façon* (en 2 livrets) rédigé par la Fondation canadienne du rein. On a de plus constaté que la majorité des ressources étaient en anglais, la langue commune aux patients et aux fournisseurs de soins en consultation externe.

Limites de l'étude: Notre sondage s'est limité à des cliniques traitant des adultes atteints d'IRC. Nos résultats pourraient ne pas être généralisables dans d'autres contextes, notamment aux soins prodigués aux patients atteints d'IRC dans les établissements de soins primaires.

Conclusion: Les cliniques de néphropathie chronique canadiennes proposent certaines ressources similaires de prise en charge autonome aux adultes souffrant d'IRC, mais les ressources diffèrent passablement d'un établissement à un autre. Et bien que plusieurs cliniques recourent aux mêmes ressources, on a noté des variations dans façon de les fournir (fournisseur, lieu de l'intervention, support du document). Une meilleure connaissance des stratégies de gestion autonome privilégiées par les patients et des ressources actuellement offertes dans les cliniques de néphropathie chronique, combinée à une synthèse de la littérature, favorisera l'élaboration de stratégies d'intervention centrées sur les besoins des patients et conformes aux principes de la prise en charge autonome.

Keywords

self-management, patient-centered care, CKD clinics

Received November 10, 2017. Accepted for publication February 13, 2018.

What was known before

Past studies suggest that self-management interventions can slow progression of CKD. Health care providers at CKD clinics support patients and their families by providing self-management education. To our knowledge, there has been no attempt to collect and collate self-management resources that Canadian CKD clinics provide to their patients.

What this adds

This descriptive study highlights the current state of self-management resources provided to Canadian patients. Currently used resources focus on modality education and the Living With Kidney Disease manual developed by the Kidney Foundation of Canada. Based on the findings from this study, we will collaborate with our patient partners to enhance present self-management interventions to accommodate their needs and preferences to manage their illness.

Introduction

Chronic kidney disease (CKD) affects 12% of adults in Canada and may progress to end-stage renal disease (ESRD) resulting in significant morbidity and mortality.¹ Medical management focusing on treatment and prevention of comorbidities such as diabetes, hypertension, and coronary artery disease has been shown to slow progression of CKD.² Lifestyle changes including reducing sodium intake, maintaining a healthy body mass, smoking cessation, and exercise may also reduce the risk of CKD progression and development of kidney failure.³

For individuals with chronic disease, self-management strategies are used to support patients and their families in gaining the skills, knowledge, and confidence to make lifestyle changes and follow treatment regimens.⁴ Self-management for patients with CKD can be unique due to the complexity of the disease and the number of comorbidities associated with the disease. There is evidence to suggest that

¹Department of Medicine, University of Calgary, Alberta, Canada

²Department of Community Health Sciences, University of Calgary, Alberta, Canada

³Daphne Cockwell School of Nursing, Ryerson University, Toronto, Ontario, Canada

⁴Institute of Health Policy, Management and Evaluation, University of Toronto, Ontario, Canada

⁵Li Ka Shing Knowledge Institute, St. Michael's Hospital, Toronto, Ontario, Canada

⁶Can-SOLVE CKD Patient Co-lead, Pouce Coupe, British Columbia, Canada

Corresponding Author:

Brenda R. Hemmelgarn, Cumming School of Medicine, University of Calgary, TRW Building, 3rd Floor, 3280 Hospital Drive NW, Calgary, Alberta, Canada T2N 4Z6.

Email: Brenda.Hemmelgarn@albertahealthservices.ca

if individuals with CKD are supported in self-managing their illness, overall functioning and well-being may be improved.⁴ Providing information and education regarding medications and lifestyle changes is an important step in managing CKD, and health care providers play a unique role in assessing and supporting patients with CKD and their families. CKD clinics have been established across Canada with an aim to provide tailored care for patients with CKD to slow progression, prevent complications, and provide educational resources to facilitate CKD management.⁵

In a recent national research priority setting process, individuals with nondialysis CKD, their caregivers, and clinicians and policy makers involved in their care identified the need to develop optimal strategies to enable patients to manage their CKD and related comorbidities to slow or prevent the progression to ESRD.⁶ A national network, Canadians Seeking Solutions and Innovations to Overcome CKD (Can-SOLVE CKD)⁷ identified this topic as a research priority and brought together patients, health care providers, researchers, and policy makers to identify optimal strategies for self-management of CKD (www.cansolveckd.ca). Patients with CKD and their caregivers are actively involved in this program of research.

Despite the potential importance of self-management in slowing CKD progression, there is limited information about what is being utilized by CKD clinics. We undertook a survey of CKD clinics across Canada to identify self-management resources for adults aged 18 years and over with CKD categories 1 to 5, not requiring dialysis or transplant. Our aim was to collate information on self-management resources (ie, strategies, tools, and educational materials) currently used by CKD clinics in Canada to understand current practices and provision of self-management resources. This information will be used to inform the development and implementation of a novel, self-management support strategy.

Methods

Using e-mail, clinic staff (ie, nurses, clinic managers) at adult CKD clinics across Canada were provided a self-administered, semistructured electronic survey link.⁸ The clinics vary in size, staffing ratios, and referral criteria.⁵ The English-language survey was available online between October 2016 and January 2017. Eligible CKD clinics (English speaking with available key contact information) were identified from a prior survey⁵ and through the Canadian Knowledge Translation and Generation Network (CANN-NET)⁹ and Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD)¹⁰ Network membership lists. Nonresponders were sent 2 e-mail reminders and received a reminder phone call to complete the survey.

The survey was developed by the Can-SOLVE CKD Network self-management working group consisting of clinicians, patient partners, policy makers, and researchers. The survey was

available in English and consisted of 17 questions that focused on attributes of self-management interventions (ie, format, delivery mode, setting, provider) and took approximately 10 minutes to complete. Respondents were also asked to submit examples of the three most commonly used self-management resources provided by their staff in their respective clinics (see Supplementary Material for copy of survey).

Responses and resources were categorized by 2 of the authors (S.G. and M.D.) based on the Template for Intervention Description and Replication (TIDieR)¹¹ checklist. The TIDieR checklist facilitated categorization of information to identify and describe the “who, what, why, how, when and where” of self-management resources. Specifically, we categorized resources based on topic, delivery format, provider, target population, where the intervention was provided and the language the resource was available in. In cases of missing information or unclear responses, S.G. contacted respondents and confirmed data.

Results

CKD Clinics

Forty-four of the 57 adult CKD clinics contacted across Canada completed the survey (77% response rate). Figure 1 shows the number of clinics contacted and the number that completed the survey, by province. Of the CKD clinics that responded, 37% had <500, 28% had 500 to 1000, and 35% had >1000 CKD patients in their respective clinics.

Resource Characteristics

A total of 131 resources were submitted from the 44 CKD clinics, with 19 duplicate resources (eg, Baxter Patient First booklets were used by 9 clinics), resulting in 112 distinct resources. Even though 19 of the same resources were used by multiple clinics, the way they were provided (ie, provider, setting, delivery format) varied by the individual clinics. Overall, 9 clinics reported using the Baxter Patient First booklets 1 to 3, 6 clinics used the Ontario Renal Network (ORN) shared decision-making tools, 3 clinics used the Southern Alberta Renal Program binder, 3 clinics used the Shared End-Stage Renal Patients Decision Making (SHERPA) patient decision aid, and 3 clinics reported using the Manitoba Renal program binder (Figure 2). The Kidney Foundation of Canada (KFOC) “Living With Kidney Disease Manual” was available to patients by the majority (96%) of the clinics.

Of the resources submitted, 37% were created in-house by the clinics and 9% of clinics modified an existing resource to suit their clinic needs. Respondents indicated that 70 (53%) of the interventions were modifiable for individual patient needs, but did not elaborate further. Twenty-six resources (20%) were specifically tailored for ethnocultural needs (eg, dietary information).

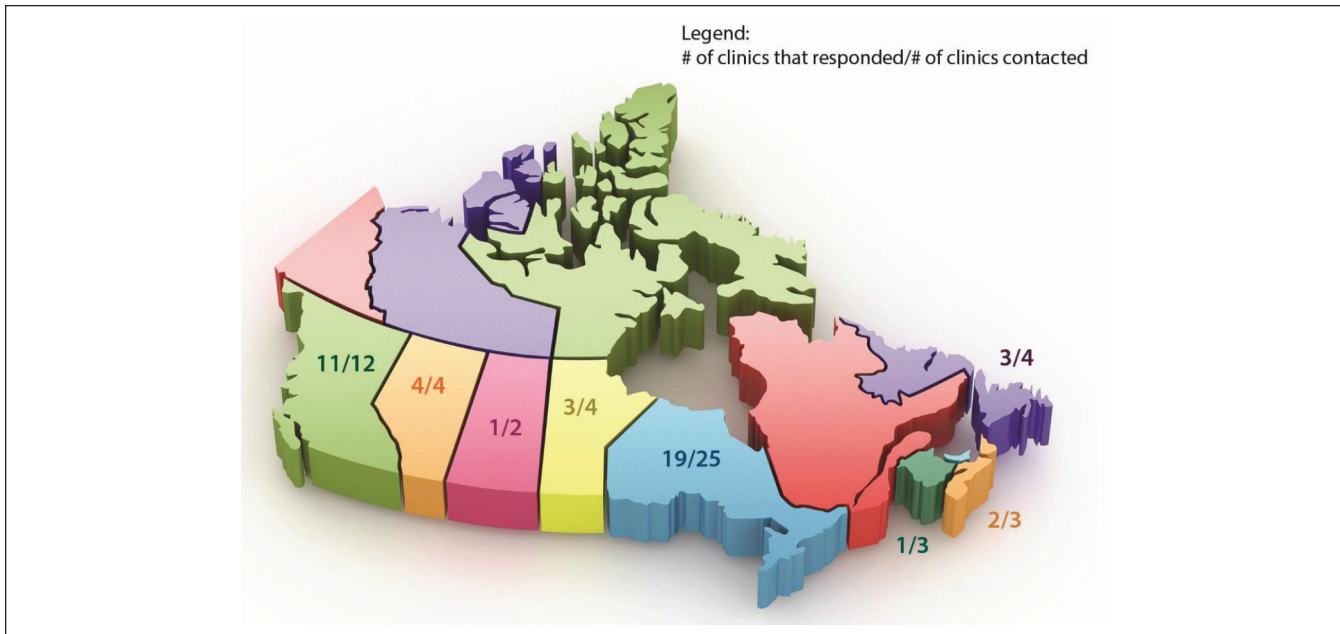


Figure 1. Number of chronic kidney disease clinics contacted and number that completed the survey, by province.

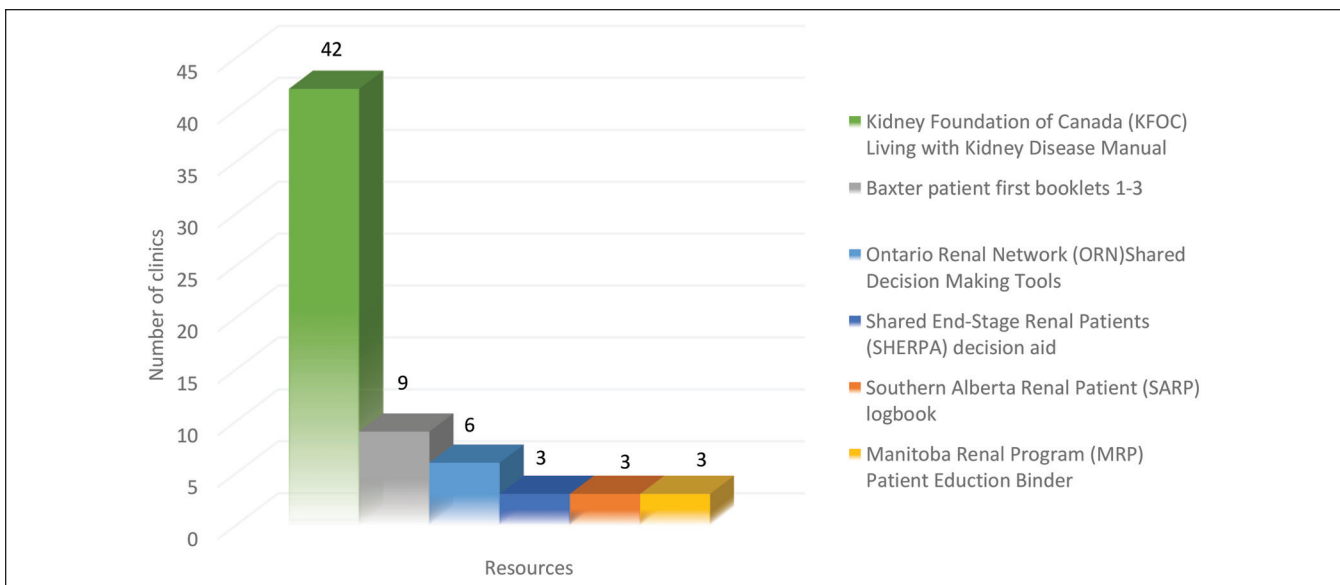


Figure 2. Number of chronic kidney disease clinics using similar resources.

Topics

Not including duplicate resources, the 3 most common self-management topics were related to renal replacement therapy (RRT) options (modality selection, 34%), the category “other” (eg, interpreting and acting on lab reports, smoking cessation, sick day management, patient goals, coping, 25%), and nutrition and diet (20%). The full topic list is provided in Figure 3.

Delivery Format

Out of the 131 resources, 64% were provided to the patient in combinations of print, electronic, face to face, and by distance (eg, telephone, e-mail). Of all the delivery formats, print was the most common (75%), followed by face to face interactions (63%), electronic or Web-based (34%), and distance (mail or telephone) (26%) (Figure 4). The Web sites provided most commonly by CKD clinics to their patients

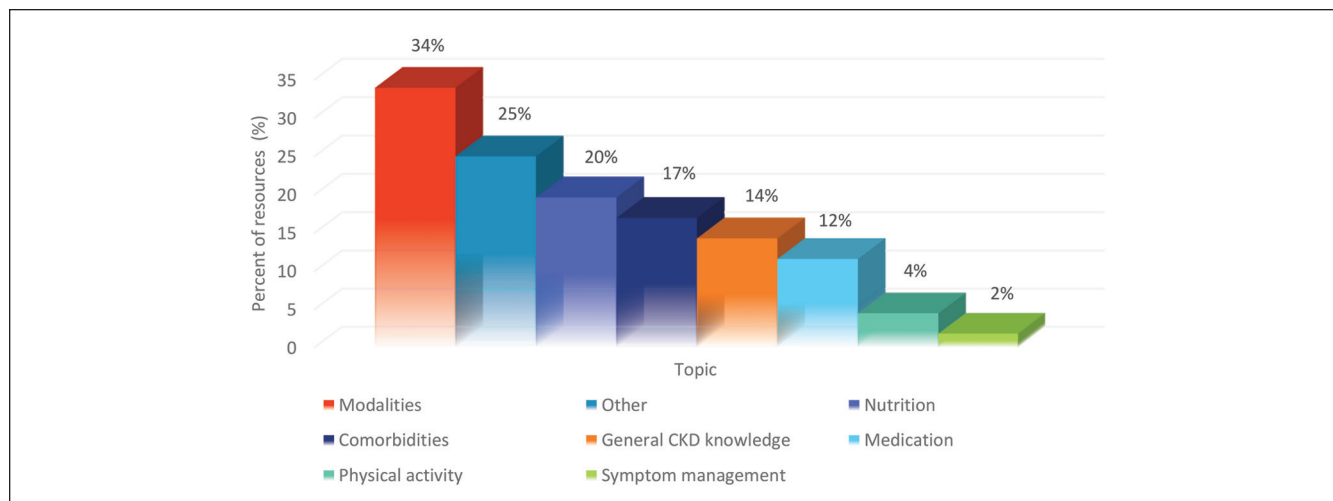


Figure 3. Most common self-management resource topic provided by CKD clinics.

Note. CKD = chronic kidney disease.

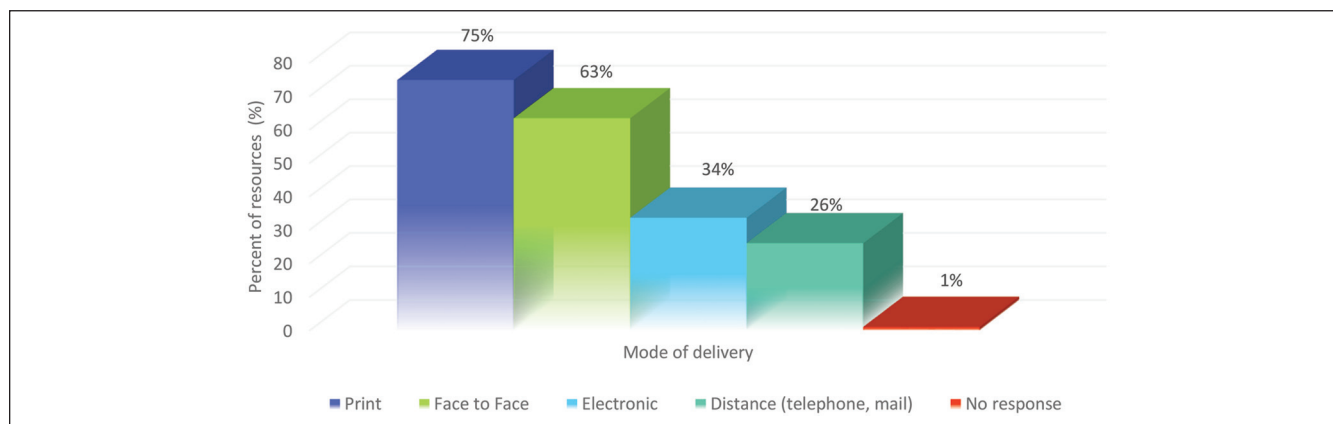


Figure 4. Self-management resource delivery format.

were www.bcrenalagency.ca, www.cann-net.ca, and www.renalnetwork.on.ca.

Providers

Fifty percent of the total number of resources were provided to the patient by more than 1 provider. When categorized by type of provider, 92% of resources were provided by nurses, 37% by dietitians, 26% by social workers, 21% by nephrologists, and 15% by pharmacists. A limited number of clinics had a patient volunteer or mentor provide the resources (7%) and only 2% of the clinics had the primary care practitioner provide resources to the patients (Figure 5).

Target Population

With respect to the target population, 65% of the total number of resources were provided to both the patient and the

caregiver/family member and 34% of the resources were provided to patients only. None of the resources was specifically targeted to the caregiver.

Location

Of the 131 resources, 69% of the resources were provided to patients in an outpatient setting (clinic). Twenty-six percent were provided to the patient in multiple locations, for example, they could be given to the patient in the CKD clinic, sent to them at home, or in a community setting (eg, pharmacy). Only 4% of the resources were provided to the patient in their home. After further breaking down the multiple locations into individual categories, a total of 95% of the resources were provided in the clinic setting, 25% were provided to the patient in their home, and 8% were available in a community setting.

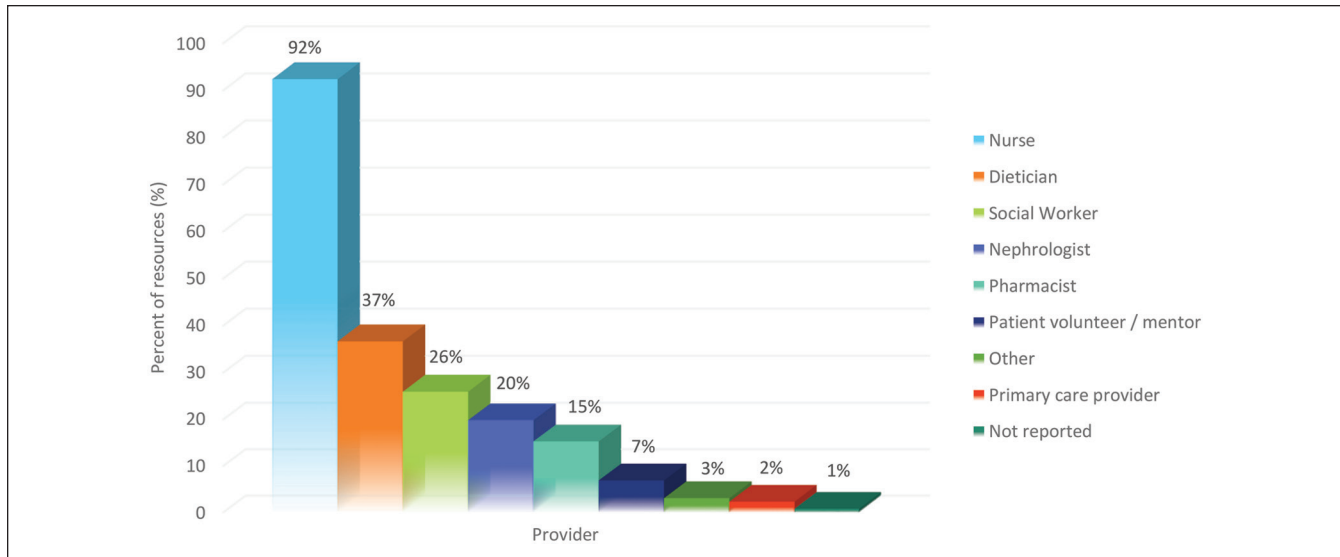


Figure 5. Self-management resource providers.

Language

Most resources (98%) were available in English, 24% in French and 33% were offered in other languages, including Punjabi (14%), Chinese (13%), Cantonese (5%), Tagalog (5%), Spanish (5%), Italian (5%), Hindi (4%), Portuguese (4%), Vietnamese (3%), Mandarin (2%), Urdu (2%), Arabic (2%), Thai (1%), Czech (1%), Bahas Malaysia (Melayu) (1%), Oji-Cree (1%), and Tamil (1%). Eighteen percent of clinics indicated that they provided resources in another language, but did not specify.

Discussion

To our knowledge, this is the first study to identify and describe self-management resources provided by Canadian CKD clinics to adults with CKD. We found that the CKD clinics are using 131 self-management resources (eg, strategies, tools, and educational material) and that they have similar features with regard to topic, delivery format, providers, and location. The interventions primarily target both the CKD patients and caregivers as the main recipients. Although there are a number of different resources used overall, almost all clinics indicated that they were using the KFOC “Living With Kidney Disease” manual,¹² as one of their top 3 most common resources, followed by resources developed by industry or provincial agencies (ie, ORN, Southern Alberta Renal Program (SARP), Manitoba Renal Program).

The results of our survey of Canadian CKD clinics are consistent with our scoping review of self-management interventions for adults with CKD,¹³ with nurses being the most common provider and the outpatient setting the most common location.¹³ There were a few differences also noted. While self-management interventions commonly reported in

the literature are related to topics of diet and nutrition and delivered face-to-face,¹³ modality education and print were the most common topics and delivery format reported by the CKD clinics in our survey. These differences in topic and delivery mode may be related to the structure and models of care provided by Canadian CKD clinics that include patients that predominantly have advanced CKD approaching the need for RRT. Also, the availability of staff and resources required to provide face to face interventions may not be feasible in supporting a large CKD population at these CKD clinics, compared with the self-management interventions reported in the scoping review studies.

Considering the number of self-management resources used by CKD clinics, 2 questions arise related to the content and focus and these resources. Specifically, do current self-management interventions in Canada reflect established CKD guidelines and do they support patient-centered care? Guidelines for CKD education suggest early, comprehensive, and structured education about management of risk factors (ie, hypertension, diabetes, etc), the psychological aspects of CKD, and lifestyle changes.² The KFOC “Living With Kidney Disease” manual¹² is provided by 96% of the clinics, and in its current format consists of 2 books. Book One provides general information on the function of the kidneys, CKD, and preventing disease progression by providing guidance on medical, and lifestyle management, whereas Book Two focuses on treatment options for patients who have progressive kidney disease. Other resources evaluated also provided topics related to medical and lifestyle management. Despite the numerous resources provided by clinics, there seems to be a gap in the area of emotional management (ie, coping, depression), comorbidities, general CKD knowledge, physical activity, and symptom management. Self-management not only involves individuals being engaged in

managing their disease but also involves the family's efforts to incorporate the special needs and treatment regimens into everyday family life.¹⁴ Including caregivers in self-management is crucial. Our study shows that just over half of the resources were available to both patients and caregivers, with no resources tailored for caregivers specifically.

Patient-centered care is changing the delivery of health care. Patient-centered care is "respectful of and responsive to individual patient preferences, needs, and values, and ensures that patient values guide all clinical decisions."¹⁵ Considering our findings, we note that some self-management resources support patient-centered care, while others are lacking. For example, many clinics created or modified existing resources to meet local needs, with 96 interventions demonstrating modification for individual patient needs or ethnocultural needs. However, despite these modifications, only a minority of the CKD clinics provided self-management resources in languages other than English. Furthermore, the majority of interventions were provided to the patients in clinical settings, with only a handful being provided in the patient home or community setting.

There are limitations to our study. While we aimed to obtain national representation, the survey was only offered in English, and Prince Edward Island, the Territories, and Quebec were not included, as we did not have key contact information. However, considering the response from across Canada, there is no reason to believe that the results are not generalizable to the Canadian context. Despite providing a clear definition and requesting their top 3 self-management resources, the survey relied on respondents and their own potential subjective perceptions, and we were unable to identify characteristics of the respondents. Thus, the resources chosen as the top 3 may vary based on the respondent's clinical background (eg, nurse, dietician, social worker, etc), or personal preference. As our focus was only to identify and categorize self-management interventions, we cannot comment on the quality of the resources. Finally, our study population only included CKD clinics. We acknowledge that many patients with CKD are managed in the primary care setting and we cannot comment on self-management interventions provided in this setting.

Conclusions

Adult CKD clinics across Canada provide a variety of self-management resources to their patients and their caregivers. New strategies may provide additional benefits to the present CKD self-management resources already provided by Canadian CKD clinics with an aim to preserve kidney function and slow progression. Knowledge of self-management resources currently being provided in CKD clinics, along with synthesis of the literature and patient-preferred self-management strategies, will inform the design and development of a novel self-management intervention that is patient-centric and adheres to the principles of self-management.

Ethics Approval and Consent to Participate

This study has been approved by the Conjoint Health Research Ethics Board (CHREB) at the University of Calgary. Informed consent was obtained from all focus group and phone interview participants.

Consent for Publication

All authors consent to the publication of this study.

Availability of Data and Materials

Supplementary data for this study is available online.

Acknowledgments

We would like to acknowledge our Can-SOLVE CKD Network patient partners who provided support in the form of reviewing survey questions and results obtained. We would also like to thank Selina Allu for assisting with the dissemination of the survey.

Author Contributions

Each of the authors contributed to conception, design, acquisition of data, analysis, and interpretation of data and in drafting and revising manuscript for important intellectual content, to varying degrees, but with equal effort. All authors read and approved the final manuscript.

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 work is a project of the Can-SOLVE CKD Network, supported by the Canadian Institutes of Health Research under Canada's Strategy for Patient-Oriented Research (SPOR). They had no role in the design and conduct of the study; data collection, analysis, and interpretation; or preparation, review, or approval of the manuscript.

References

1. Arora P, Vasa P, Brenner D, et al. Prevalence estimates of chronic kidney disease in Canada: results of a nationally representative survey. *CMAJ*. 2013;185(9):E417-E123.
2. Kidney Disease Improving Global Outcomes (KDIGO) CKD. Clinical practice guideline for the evaluation and management of chronic kidney disease. *Kidney Int*. 2012(suppl 3):1-150.
3. Ricardo AC, Anderson CA, Yang W, et al. Healthy lifestyle and risk of kidney disease progression, atherosclerotic events, and death in CKD: findings from the Chronic Renal Insufficiency Cohort (CRIC) Study. *Am J Kidney Dis*. 2015;65(3):412-424.
4. Curtin RB, Walters BA, Schatell D, Pennell P, Wise M, Klicko K. Self-efficacy and self-management behaviors in patients with chronic kidney disease. *Adv Chronic Kidney Dis*. 2008;15(2):191-205.
5. Levin A, Steven S, Allu S, Au F, Gil S, Manns BJ. Canadian chronic kidney disease clinics: a national survey of struc-

- ture, function and models of care. *Can J Kidney Health Dis.* 2014;1:29.
6. Hemmelgarn BR, Pannu N, Ahmed SB, et al. Determining the research priorities for patients with chronic kidney disease not on dialysis. *Nephrol Dial Transplant.* 2017;32(5):847-854.
 7. Can-SOLVE CKD Network. <https://cansolveckd.ca/>. Published 2016. Accessed May 2, 2018.
 8. SimpleSurvey. Date unknown. <https://simplesurvey.com/>. Accessed May 2, 2018.
 9. Canadian Kidney Knowledge Translation and Generation Network. *CANN-NET*. Date unknown. <https://www.cann-net.ca/>. Accessed May 2, 2018.
 10. Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease. *Can-SOLVE CKD Network*. Date unknown. <https://cansolveckd.ca/>. Accessed May 2, 2018.
 11. Hoffmann TC, Glasziou PP, Boutron I, et al. Better reporting of interventions: Template for Intervention Description and Replication (TIDieR) checklist and guide. *BMJ.* 2014;348:g1687.
 12. The Kidney Foundation of Canada. *The Kidney Foundation of Canada Living With Kidney Disease 2015*. Date unknown. <https://www.kidney.ca/manual>. Accessed May 2, 2018.
 13. Donald M, Kaur Kahlon B, Beanlands H, et al. Self-management interventions for adult patients with chronic kidney disease: a scoping review. Canadian Society of Nephrology (CSN) Annual Conference; May 2017; Montreal, Québec, Canada.
 14. Grey M, Schulman-Green D, Knafl K, Reynolds NR. A revised self- and family management framework. *Nurs Outlook.* 2015;63(2):162-170.
 15. Institute of Medicine (US) Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academies Press; 2001.