Canadian Society of Nephrology/
Société canadienne de néphrologie
CSN/SCN

CANADIAN JOURNAL OF
KIDNEY HEALTH AND DISEASE
Journal canadien de la santé et de la maladie rénale

Original Research Article

Canadian Journal of Kidney Health and Disease
Volume 5: 1–9
© The Author(s) 2018
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/2054358118807480
journals.sagepub.com/home/cjk
SAGE

Perceived Significance of Engagement in Research Prioritization Among Chronic Kidney Disease Patients, Caregivers, and Health Care Professionals: A Qualitative Study

**Meghan J. Elliott[1,2], Zahra Goodarzi[1,3], Joanna E. M. Sale[4,5],
Linda A. Wilhelm[6], Andreas Laupacis[4,5,7],
Brenda R. Hemmelgarn[1,2], and Sharon E. Straus[4,5,7]**

Abstract

Background: Patients and other stakeholders are increasingly engaging as partners in research, although how they perceive such experiences, particularly over the long term, is not well understood.

Objective: To characterize how participants from a nondialysis chronic kidney disease (CKD) research priority-setting project conducted 2 years previously perceived the significance of their involvement.

Design: Qualitative descriptive study with semi-structured, individual interviews.

Setting: Participants resided across Canada.

Participants: Eligible participants included stakeholders (ie, patients with nondialysis CKD, caregivers, health care professionals, and policy makers) who had taken part in a prior CKD research priority-setting project.

Measurements: We explored stakeholder experiences and perspectives on engagement in CKD research prioritization.

Methods: We purposively sampled across stakeholder roles and engagement types (ie, involvement in the priority-setting workshop, wiki online tool, and/or steering committee). All interviews were conducted by a single investigator by telephone or face-to-face, and audio-recordings were transcribed verbatim. The data were inductively coded and analyzed by 2 investigators using a thematic analysis approach.

Results: We conducted 23 interviews across stakeholder roles and engagement types. Participants appreciated the integration of distinct stakeholder communities of patients, researchers, and health care professionals that occurred through engagement in research priority setting. Their opportunity to interact with patients and others directly impacted by CKD outside of the clinical setting contributed to an enhanced understanding of the CKD lived experience and value of patient-oriented research. This interaction helped participants refine and refocus their commitment to patient-centered CKD care and research, characterized by enhanced knowledge and confidence (patients/caregivers), adaptations to existing clinical practices and policies (health care providers/policy makers), and subsequent research engagement.

Limitations: The views of participants may not reflect those of individuals in other research or health care settings.

Conclusions: Stakeholder engagement in nondialysis CKD research prioritization encouraged the integration of stakeholder communities, an appreciation of the CKD experience, and a refocusing of participants' commitment to research and care. Findings highlight considerations for future health research engaging stakeholders, particularly those living with CKD, as research partners.

Abrégé

Contexte: Les patients et autres parties prenantes se positionnent de plus en plus à titre de partenaires en recherche; on en connaît toutefois peu sur leur perception de leur implication, surtout à long terme.

Objectif de l'étude: Déterminer l'importance perçue de l'implication de participants à un projet d'établissement des priorités de recherche sur l'insuffisance rénale chronique (IRC) sans dialyse, mené 2 ans auparavant.

Type d'étude: Il s'agit d'une étude qualitative et descriptive basée sur des entrevues individuelles semi-structurées.

Cadre de l'étude: Les participants venaient de partout au Canada.

Participants à l'étude: Les candidats admissibles étaient les parties prenantes (patients, proches aidants, professionnels de la santé et décideurs) à un projet antérieur d'établissement des priorités de recherche sur l'insuffisance rénale chronique (IRC) sans dialyse.

Mesures: Nous nous sommes penchés sur les expériences et impressions de parties prenantes concernant leur implication en établissement des priorités de recherche sur l'insuffisance rénale chronique (IRC) sans dialyse.

Méthodologie: Nous avons sciemment consulté des représentants de diverses catégories de parties prenantes impliquées dans l'atelier d'établissement des priorités, le site wiki ou le comité directeur. L'ensemble des entrevues a été mené par un même chercheur, au téléphone ou en personne. Les enregistrements audio ont été transcrits verbatim. Ensuite, deux chercheurs ont inductivement codifié et analysé les données avec une approche thématique.

Résultats: Nous avons mené 23 entrevues avec des représentants des diverses catégories de parties prenantes. Les participants ont aimé que le projet d'établissement des priorités regroupe plusieurs communautés de parties prenantes (patients, chercheurs et professionnels de la santé). Les interactions avec les patients et les autres personnes directement touchées par l'IRC (en dehors du milieu clinique) ont contribué à une meilleure compréhension de l'expérience de l'IRC et de la valeur d'un travail de recherche axée sur le patient. Les échanges ont permis aux participants d'affiner et de recentrer leur engagement envers des soins et de la recherche axés sur le patient, lesquels sont caractérisés par i) une connaissance et un lien de confiance renforcés (pour les patients et les proches aidants); ii) des ajustements aux pratiques et politiques cliniques (pour les fournisseurs de soins et les décideurs); et iii) une implication subséquente en recherche.

Limites de l'étude: Les avis des participants pourraient ne pas être transposables à d'autres contextes cliniques ou de recherche.

Conclusion: L'implication de parties prenantes dans l'établissement des priorités de recherche sur l'IRC sans dialyse a concouru à réunir les diverses communautés de parties prenantes, à mieux comprendre l'expérience du patient atteint d'IRC et à recentrer l'engagement des participants envers une optique de recherche et de soins axée sur le patient. Nos constats mettent en lumière des éléments à considérer en vue de l'implication future de parties prenantes (particulièrement les personnes atteintes d'IRC) dans des projets de recherche en santé.

Keywords

CKD (chronic kidney disease), patient engagement, qualitative research, patient-oriented research

Received June 29, 2018. Accepted for publication August 31, 2018.

What was known before

Patients and other stakeholders are increasingly engaging as partners in health research. However, the perceived impact of research engagement among chronic kidney disease (CKD) stakeholders is not well understood. Furthermore, the impacts of engagement have been studied primarily during or shortly after the engagement process; thus, longer lasting consequences for stakeholder participants are unclear.

What this adds

Two years following engagement in a CKD research priority-setting partnership, stakeholder participants expressed an ongoing appreciation for the CKD lived experience and community as a consequence of research engagement. Participants remain committed to patient-centered care and patient-oriented research.

Introduction

Patients are increasingly engaging as partners in health research, with the aim of enhancing the relevance of research findings and evidence use in decision making.[1,2] The lived experience with a chronic illness, such as chronic kidney disease (CKD), uniquely positions patients, and those who care for them, to contribute to research to address their needs.[3] As persons living with CKD face distinctive challenges, their involvement in research can help establish

---

[1] Department of Medicine, University of Calgary, AB, Canada
[2] Department of Community Health Sciences, University of Calgary, AB, Canada
[3] Hotchkiss Brain Institute, University of Calgary, AB, Canada
[4] Institute of Health Policy, Management, and Evaluation, University of Toronto, ON, Canada
[5] Li Ka Shing Knowledge Institute, St. Michael's Hospital, Toronto, ON, Canada
[6] Canadian Arthritis Patient Alliance, Midland, Kings County, NB, Canada
[7] Department of Medicine, University of Toronto, ON, Canada

Corresponding Author:
Meghan J. Elliott, MD, Foothills Medical Centre, Room C202B, 1403 29 Street NW, Calgary, AB, Canada T2N 2T9.
Email: meghan.elliott@albertahealthservices.ca

mutually important research objectives and arrive at results that are more meaningful to those who will ultimately use them in decision making.[4]

We previously involved patients with nondialysis CKD, their informal caregivers, health care professionals (HCPs), and policy makers in determining the most important unanswered questions related to nondialysis CKD management.[5,6] Using the established approach of the James Lind Alliance (Supplementary Material, Appendix 1),[7] we identified a top 10 list of research priorities that has been used to inform a national patient-oriented CKD research network.[8] This process was unique in that it engaged relevant stakeholders including patients, addressed priorities for earlier stage CKD, and tested 2 strategies for ranking the final priorities in a randomized controlled trial (ie, in-person workshop *vs* online wiki-like platform).[6] In a post-workshop/wiki questionnaire, participants expressed a preference for the in-person format for reasons of enhanced communication and interaction, while acknowledging the convenience and flexibility of the wiki.[6] However, the purpose of that study was to directly compare the 2 priority-setting strategies rather than explore participants' engagement experience.

Recently, studies have suggested several advantages and drawbacks to stakeholder engagement in research. Although identified benefits to those engaging in research (eg, empowerment), researchers (eg, mutual trust), and the research itself (eg, increased relevance) are encouraging, these must be balanced against concerns such as tokenism and resource requirements.[9,10] Meaningful engagement of patients and other stakeholders in research can be supported in many ways, such as establishing positive team interactions and ensuring that those engaging feel valued,[11] and existing studies suggest that meaningful engagement throughout the research cycle is both feasible and important. However, details surrounding how research teams apply underlying engagement frameworks and evaluate their engagement strategies are underreported in the literature.[12,13] Furthermore, studies examining engagement have almost exclusively focused on short-term outcomes,[12] and none has explored perceived engagement in research prioritization following completion of the priority-setting exercise. Exploration of this area could provide important insights to optimize future involvement of CKD stakeholders in research. Therefore, in this qualitative study, we aimed to characterize the engagement experience of CKD stakeholders and perceived significance of their involvement in a research prioritization activity conducted 2 years previously.

Methods

Study Design

We applied a qualitative descriptive methodology,[14,15] which aims to develop rich descriptions of individuals' experiences. Our approach was informed by a conceptual model for effective stakeholder engagement in comparative effectiveness research, wherein both analysis and deliberation support group decision making.[16] Whereas the model considers perceived successful engagement as an immediate outcome of the process, we sought to explore how participants from the original CKD research priority-setting project understood the significance of their engagement over the long term. We conducted this study 2 years following the initial priority-setting exercise. This time frame was short enough to permit recall of important details that had a lasting impact on participants, but not so delayed that other events or experiences (such as disease complications or subsequent research engagement) would have necessarily influenced their views. The research team included an individual living with a chronic condition (LW), who contributed to the study design and analysis. Our team took steps to ensure methodological rigour, including suitability of the research question to qualitative inquiry, appropriate approach to data collection and analysis, clear data integration, and provision of adequate support for our claims.[17] Our reporting of this study reflects the Consolidated Criteria for Reporting Qualitative Health Research (Supplementary Material, Appendix 2).[18] The Research Ethics Boards of St. Michael's Hospital, the University of Toronto, and the University of Calgary approved this study.

Participant Selection

Fifty-three participants from the CKD priority-setting project were eligible for inclusion. These individuals resided across Canada, were from a relevant CKD stakeholder group (ie, patients with nondialysis CKD, informal caregivers, HCPs, and policy makers), and had participated in the project's steering committee and/or final workshop/wiki. Whereas steering committee members met regularly over 1 year to broadly identify and create a shortlist of 30 research priorities, workshop participants convened in person over 1 day in Toronto, Canada, and wiki participants interacted through an online platform over 2 weeks in June 2015 to rank the final top 10 priorities. We purposively sampled among all stakeholder groups and engagement types from our earlier project using a maximum variation strategy[19] to characterize participants' individual perspectives and central themes across this diversity.

Data Collection

One investigator (MJE) conducted individual, semi-structured interviews with participants by telephone or in person for interested persons living in Toronto. After providing informed consent, participants provided basic demographic information. The interviewer followed an interview template (Supplementary Material, Appendix 3) that addressed participants' experience with the CKD research priority-setting project, including their perceived contributions and consequences of engagement. We pilot tested the interview

Table 1. Participant Characteristics ($N = 23$).

Characteristics	Number of participants (%)
Stakeholder group	
Patient	8 (35)
Caregiver	4 (17)
Health care professional	8 (35)
Nephrologist	5 (22)
Nurse	1 (4)
Allied health professional (ie, dietician, pharmacist)	2 (9)
Policy maker	3 (13)
Type of engagement	
Wiki	7 (30)
Workshop only	8 (35)
Workshop and steering committee	6 (26)
Steering committee only	2 (9)
Sex	
Female	14 (61)
Male	9 (39)
Age	
<40 years	1 (4)
40-64 years	19 (83)
⩾65 years	3 (13)
Location of residence	
Western Canada	12 (52)
Ontario	10 (43)
Eastern Canada	1 (4)

guide with an experienced qualitative and patient engagement researcher and made minor revisions following the first 3 interviews. All interviews were audio-recorded and transcribed verbatim, and the interviewer kept detailed reflexive notes to which we referred during analysis. We used NVivo 11 to facilitate data organization, coding, and retrieval.

Analysis

Data collection and analysis were conducted concurrently. We used a thematic analysis approach,[20] whereby 2 investigators (MJE, ZG) systematically and inductively coded all transcripts. The investigators met after coding the first 3 transcripts to discuss the evolving coding scheme, and subsequently after coding every 3 to 4 transcripts to refine this scheme and code definitions. Codes were sorted into preliminary themes, which were reviewed for coherence in relation to the data set and research objective. Findings were discussed among the larger research team, and additional analytic insights were explored before defining final themes and highlighting supporting quotes. Data saturation was achieved after the first 17 interviews, and the remaining interviews were conducted at the expressed interest of participants and to refine key interpretive insights.

Results

We conducted 23 semi-structured interviews. All stakeholder types were represented, including 8 patients, 4 caregivers, 8 HCPs (ie, nephrologist, nurse, dietician, or pharmacist), and 3 policy makers (Table 1). Approximately two thirds were female, almost all were from Western Canada or Ontario, and 22 were ⩾40 years of age. Seven participants had taken part in the wiki, 14 had attended the workshop (6 of whom were also on the steering committee), and 2 had participated on the steering committee only. Interviews lasted on average 1 hour. Participants discussed their perceived significance of involvement in the CKD priority-setting project in relation to the following inductively derived themes: (1) Integration of stakeholder communities, (2) appreciation of the CKD lived experience, and (3) refocused commitment to research and care.

Integration of Stakeholder Communities

Several patients and caregivers described feeling "isolated" (ID12, patient) in not having encountered another person with CKD to whom they could relate. They contrasted the relatively asymptomatic, early-stage CKD with more advanced CKD, where they surmised patient health care needs and contact with HCPs and other patients may be greater. Because of this, one HCP suggested that patients with less advanced CKD may not identify as a "CKD patient" in the same way as someone with end-stage kidney disease. A patient with CKD described her lack of contact with others affected by CKD as follows:

> It's quite an isolated, personal space, you know? You wait in the hall to see the doctor, you go in and you meet your doctor, and then you leave the clinic and you're back to your home setting again. Rarely do you meet or interact with another CKD patient. (ID12)

In contrast to patients with CKD, the community of nephrology HCPs and researchers was viewed as relatively small and close-knit. Participants suggested that frequent interactions among multidisciplinary CKD providers in the clinical setting can encourage familiarity among colleagues in providing comprehensive CKD care. Through these professional relationships, many HCP participants learned about the CKD priority-setting project. Similarly, participants highlighted the collegiality of the nephrology research community on a broader, national scale. As a consequence, participants suggested that HCPs and researchers were more likely than patients to hear about new initiatives, including patient-oriented research. When asked about her working environment, one HCP described the following:

> I think that probably would have been the biggest thing, working alongside with the other allied health and physicians. We're [in nephrology] well known for having really good healthcare teams, because we work together every day. (ID3)

Through the research prioritization exercise, patients and caregivers met others affected by CKD, learned about their experiences, and derived support. These encounters occurred informally and during the prioritization exercise. As participants described, this "bonding experience" (ID2, caregiver) fostered a unique connection among patients/caregivers who might not otherwise have met. HCP and policy maker participants appreciated their interactions with patients and their families outside of the clinical or administrative setting, and patients and caregivers appreciated encountering a diverse group of individuals united in their aim of enhancing CKD care. However, the perceived success of engagement related in large part to the format of interactions, with wiki participants describing less meaningful interpersonal connections online than in person. Participants suggested that an integrated community of CKD researchers, clinicians, and patients is essential to supporting stakeholder-engaged research and, as one policy maker described, raising the profile of CKD on a broader stage:

> The kidney community is known as being a leader in patient engagement research . . . I think we're miles ahead. So I'm quite proud to be associated with the kidney community. I think they're known to punch well above their weight. (ID9)

Appreciation of the CKD Lived Experience

As a consequence of engagement in CKD research priority-setting, participants across stakeholder roles described an enhanced appreciation of how patients lived with and understood their disease. For some patients, hearing about others' CKD experiences appeared to be enlightening. In particular, those with less advanced CKD described gaining a better understanding about how their disease might progress and its potential impact on their lives. For example, one patient recalled discussing "different aspects of fear" (ID21) related to the unknowns of CKD with another patient through the wiki; another derived hope from a discussion about a workshop participant's experience with CKD progression. Others remarked that discussions gave them perspective on their own kidney health ("I came away feeling grateful" [ID10]). One caregiver also described an increased recognition of the burden of living with CKD:

> I'm just cutting ourselves a little bit of slack. Having a bit more, this might sound weird, but having a bit more compassion with just exactly what that must feel like. I can't really imagine having a kidney function of 9%. I take it for granted that mine's a hundred. (ID2)

One HCP articulated, "We don't know what we don't know" (ID8), suggesting that although HCPs may be experienced in CKD care delivery, they are limited by a lack of high-quality evidence and primary knowledge of the CKD lived experience. This lack of knowledge included the "impact of kidney disease" (ID19, HCP) on patients and their families. Some HCPs described gaining appreciation for how patients viewed their disease and interactions with HCPs as a result of their involvement in the priority-setting project, leading some to reflect on their own practices. As one HCP said,

> What I am more aware of as a result of these things is that often patients' understanding of the things that we do to them is probably less than what we think. And this idea of communication very much resonates [with me]. (ID20)

Few participants had prior experience with research engaging patients and caregivers alongside HCPs and policy makers. Some patients attributed their enhanced knowledge of kidney health issues to this engagement, whereas other patients and HCPs described a new appreciation of the complexity of CKD through discussing the priorities and hearing patients' stories. Patients described learning more about the research process through collaboration as a research team member as opposed to a study subject. HCPs and policy makers described learning more about patient-oriented research, how to engage with patients, and its value. All stakeholders appreciated the opportunity to engage together in research but identified similar challenges, including time commitment, lack of training, and need for flexibility, particularly when involving those with chronic illness. One patient discussed a subsequent clinical encounter:

> She's [nephrologist] certainly well aware that I'm far more knowledgeable than I was before . . . because I've got more information and I can maybe articulate better issues, concerns. (ID23)

Refocused Commitment to Research and Care

Most participants expressed a long-standing commitment to patient-centered CKD care predating the priority-setting project. For example, some patients described initiating regular communication with their HCPs or seeking opportunities to learn about CKD. For them, involvement in research prioritization reinforced or refined existing approaches to their CKD care. The observation that the patient/caregiver participants were "also very engaged in care" (ID19, HCP) was echoed by other HCPs, hinting at an engaged predisposition extending across health care and research domains. Several patients described how their experiences living with CKD and engaging in research gave them confidence to advocate for themselves in clinical settings. As one patient said,

> I feel like I've been able to be a better advocate for myself going through the process. Knowing when I have to push a little bit or asking questions . . . If you don't do that you're sitting around waiting for a really long time. (ID17)

HCPs also commonly discussed how their views and approaches to "patient-oriented care delivery" (ID20) had evolved following this project. One allied health professional described incorporating patient priorities into their CKD clinic intake questionnaire, and another discussed becoming "a little bit more self-aware" (ID3) of patient interactions. As a consequence of engaging with patients, one policy maker "recognized that patients want to know more, but we don't necessarily provide them with more" (ID13), prompting the development of an education module within his renal unit aimed at improving patients' knowledge about home dialysis modalities. For other HCPs who felt their practices had not changed substantially, participating alongside patients reinforced the care elements upon which they should focus. For example,

> I think it's really validated that that [symptoms, functional status] is what is important and validated the time I spend asking about things like that. (ID19)

Some HCPs described how their growing appreciation for patient centeredness as a result of engagement in research prioritization contributed to their academic work. This included shifts in their research interests (eg, communication, quality of life) and approaches to conducting research (eg, engaging patients on the research team). Almost all HCPs and policy makers indicated they would be interested in participating alongside patients and their families in future research, although some in the wiki group hesitated more from dissatisfaction with the format than the patient-oriented research approach. The following HCP described engaging patients in subsequent initiatives:

> We're . . . developing some best practices, and having a patient involved with that on our task group has been already quite invaluable. (ID14)

For all patients and caregivers, the CKD priority-setting project was their first experience engaging in research as partners. Since then, many had participated in other engagement-type projects and/or in more traditional studies. Patients/caregivers who had experience with both contrasted their involvement in our project with that of a research subject, in which one caregiver indicated he "never felt involved in the process" (ID1). As with the HCPs, patients and caregivers said they would be pleased to engage in subsequent research. Some "just need to be asked" (ID22, patient), whereas others specified a stronger preference for projects they consider most directly relevant to their situations, such as the following patient:

> So I'm sitting on [Researcher]'s project, and I'm hugely focused on that because it has a direct impact on [me]. (ID23)

Discussion

In our study, participants highlighted the value of interacting with CKD stakeholders, and with patients in particular, afforded by their involvement in the CKD priority-setting project. Participants contrasted the communities of patients with CKD with those of clinicians and researchers—while patients with nondialysis CKD expressed feelings of isolation, HCPs, policy makers, and researchers identified strong connections within their broader networks. Integration of these communities encouraged individuals within and across stakeholder roles to share experiences and learn from one another. Participants also suggested that their involvement in this project helped them refocus, or refine, their commitment to patient-centered CKD care and ongoing research engagement. This was supported by findings of new or modified clinical approaches, enhanced patient advocacy, and interest in patient-oriented research.

To our knowledge, our study is among the first to describe participants' experiences with CKD-related engagement and research priority-setting over the long term. As our purposeful sample included participants across stakeholder roles and engagement types, the themes we identified across all participants can be considered broadly relevant to different CKD stakeholders with varying engagement experiences. In characterizing how stakeholder participants perceive the long-term significance of their engagement experience, our findings provide support for ongoing national and international strategies for patient-oriented research that aim for the meaningful engagement of patients and the public in health research.[21-23] For example, the Canadian Institutes of Health Research (CIHR)–supported Strategy for Patient-Oriented Research (SPOR) is a coalition of federal, provincial, and territorial partners that encourages a multidisciplinary research approach involving patients, clinicians, and policy makers to facilitate translation of evidence into practice.[21] Whereas the impact of the identified CKD research priorities can be observed among several ongoing projects within a national CKD SPOR network,[8] our study has furthered our understanding of the lasting impact of engagement on the stakeholder participants themselves.

Many patients in our study had not previously encountered another person with CKD, and thus had no prior opportunity for informal support or information sharing. Previous reports have described, among patients with advanced CKD and their caregivers, feelings of isolation related to role adjustments[24] and negative impacts of CKD on social interactions.[25,26] Although patients in our study had less advanced CKD, they described a lack of access to a community to whom they could turn for support, resource provision, and sharing of experiences. As one participant suggested, this may be because patients with nondialysis CKD are often asymptomatic and have competing comorbidities, and thus may not identify as a "CKD patient" in the same way as someone on dialysis. Peer mentorship can help establish connections among individuals with relatable experiences and positively impact patients' adjustment to living with chronic disease.[27,28] Formalized peer support may improve goal setting, decision making, and self-management for those on or nearing dialysis.[29] However, in the absence of opportunities for peer interaction for those with nondialysis CKD, patients in our study identified research engagement as a way of addressing their perceived lack of community. The HCPs and policy makers also appreciated the opportunity to meet with the CKD community they serve in a setting more conducive to open conversation unhindered by clinical or administrative agendas. Therefore, the priority-setting project provided a forum for meaningful interaction across stakeholder roles, which can foster rapport, mutual respect, and a shared understanding of issues that affect all parties.[10]

Experiential knowledge is a type of knowledge that arises through experience, and in the context of health research generally refers to individual patients' lived experience with illness and their insights.[30] In sharing their stories and discussing priorities, all stakeholders in the priority-setting project learned about one another's experiences as they related to living with CKD (patients/caregivers) and providing CKD care (HCPs/policy makers). However, participants highlighted their appreciation of the patients' and caregivers' lived experience with CKD as particularly meaningful, given that identified priorities and subsequent research will impact them. Whereas other studies have reported that investigators learn about issues and communities they are studying as a consequence of engagement,[10] here we described how stakeholder participants developed an enhanced understanding of how others, and in particular patients, engaged *alongside them* experience and understand CKD. Furthermore, the context in which such informational exchange occurs must be carefully considered, as the complex interplay of individual- (eg, skills, attitudes, knowledge) and process-level (eg, format, inclusiveness) factors appears to shape the perceived impact of research engagement.[31]

Although some patients and HCP participants suggested that their involvement influenced how they managed their or their patients' CKD, many described motivated and engaged patient-centered care behaviors that predated the priority-setting project. Some patients discussed increased confidence in advocating for themselves and others within the health system as a consequence of research engagement, which supports previous findings of patient empowerment as a positive impact of research collaboration.[32,33] In one qualitative study, strategies of continuous learning, ongoing care assessment, and adaptation promoted an active role for patients in their chronic disease care, irrespective of HCPs' willingness and efforts to engage them.[34] In our study, participants' interest and engagement in CKD care was reflected in an interest in research engagement, thus introducing the concept of an "engaged" predisposition. Participants observed a tendency toward engagement across clinical and research settings among certain individuals, thus raising questions about representation in patient-oriented research. Appropriately representing the community whose views are sought has been described as a challenge to patient-engaged research,[35] particularly among vulnerable populations (eg, socioeconomic disadvantage, frailty, chronic illness) for whom optimal engagement strategies remain unclear. This highlights the importance of carefully considering how potential patient partners are identified and the implications of research in relation to the perspectives that were included.

We acknowledge limitations to our study. Eligible participants were limited to those who participated in the previous CKD priority-setting project, all of whom were English-speaking adults with high health and technological literacy.[6] Therefore, our findings are context specific and may not reflect experiences of the broader CKD population, nor of those in other health settings. However, we achieved representation across stakeholder roles and engagement experiences, which contributed to the collection of rich data and identification of important themes with implications for other stakeholder-engaged research. Furthermore, in light of the engaged tendencies we identified among participants, they may have been more inclined to provide responses considered socially acceptable or that differed from those of eligible participants who declined an interview. Also, 2 years had lapsed since the CKD priority-setting project, so participants may not have recalled all details relevant to their perceived experience. However, we aimed to capture the long-term aspect of their engagement through interview discussions focused primarily on their experiences subsequent to the project and current views on related issues.

In conclusion, stakeholders who engaged in a CKD research priority-setting 2 years previously identified distinct CKD stakeholder communities, which were connected through research engagement in a supportive, meaningful way that extended well beyond the time of the research project. Participants also suggested that the unique opportunity to learn about others' experiences with CKD through research engagement was enlightening and contributed to an enhanced understanding of patient-oriented research. While participants demonstrated a predisposition toward engagement in research and care, our findings highlighted potential opportunities to expand upon such experiences, such as facilitating trans-disciplinary interactions within and outside research settings, addressing patient priorities in CKD care, and providing future opportunities for stakeholder involvement in research.

Ethics Approval and Consent to Participate

Ethics approval was obtained by St. Michael's Hospital (REB# 16-393), the University of Toronto (REF# 34196), and the University of Calgary (REB16-2549). Informed consent was obtained from all participants.

Consent for Publication

All co-authors reviewed this final manuscript and consented to its publication.

Availability of Data and Materials

Data and materials may be made available upon written request to the corresponding author. Reasonable requests for data access will be assessed in consultation with the appropriate Research Ethics Boards.

Acknowledgments

We would like to thank Ms Christine Marquez for helping develop and pilot test the interview guide. We would also like to extend our sincere thanks to the participants of this study, who generously gave their time to take part in both the original priority-setting exercise and subsequent interviews to help us better understand their experiences.

Author Contributions

MJE, BRH, and SES were involved in research idea; MJE, JEMS, and SES were involved in study design; MJE contributed to data acquisition; MJE and ZG were involved in data coding; all authors were involved in data analysis/interpretation; JEMS, BRH, and SES provided supervision and mentorship. Each author contributed important intellectual content during article drafting or revision and accepted accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

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: MJE was supported by an Alberta Innovates Clinician Fellowship and a Kidney Research Scientist Core Education (KRESCENT) Post-Doctoral Fellowship to undertake this project. JEMS holds a Canadian Institutes of Health Research New Investigator Award. AL holds a Tier 1 Canada Research Chair in Health Policy and Citizen Engagement. BRH is a team lead of the Interdisciplinary Chronic Disease Collaboration and holds the Roy and Vi Baay Chair in Kidney Research. SES holds a Tier 1 Canada Research Chair in Knowledge Translation and Quality Care.

ORCID iD

Meghan J. Elliott https://orcid.org/0000-0002-5434-2917

References

1. Richards T, Montori VM, Godlee F, Lapsley P, Paul D. Let the patient revolution begin. *BMJ*. 2013;346:f2614.
2. Domecq JP, Prutsky G, Elraiyah T, et al. Patient engagement in research: a systematic review. *BMC Health Serv Res*. 2014;14:89.
3. Selby JV, Beal AC, Frank L. The Patient-Centered Outcomes Research Institute (PCORI) national priorities for research and initial research agenda. *JAMA*. 2012;307:1583-1584.
4. Jun M, Manns B, Laupacis A, et al. Assessing the extent to which current clinical research is consistent with patient priorities: a scoping review using a case study in patients on or nearing dialysis. *Can J Kidney Health Dis*. 2015;2:35.
5. Hemmelgarn BR, Pannu N, Ahmed SB, et al. Determining the research priorities for patients with chronic kidney disease not on dialysis. *Nephrol Dial Transplant*. 2016;32:847-854.
6. Elliott MJ, Straus SE, Pannu N, et al. A randomized controlled trial comparing in-person and wiki-inspired nominal group techniques for engaging stakeholders in chronic kidney disease research prioritization. *BMC Med Inform Decis Mak*. 2016;16:113.
7. The James Lind Alliance. http://www.jla.nihr.ac.uk/. Published 2017. Accessed March 10, 2018.
8. Levin A, Adams E, Barrett BJ, et al. Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD): form and function. *Can J Kidney Health Dis*. 2018;5:1-12.
9. Brett J, Staniszewska S, Mockford C, et al. Mapping the impact of patient and public involvement in health and social care research: a systematic review. *Health Expect*. 2014;17:637-650.
10. Brett J, Staniszewska S, Mockford C, et al. A systematic review of the impact of patient and public involvement on service users, researchers and communities. *Patient*. 2014;7:387-395.
11. Hamilton CB, Hoens AM, Backman CL, et al. An empirically based conceptual framework for fostering meaningful patient engagement in research. *Health Expect*. 2018;21:396-406.
12. Esmail L, Moore E, Rein A. Evaluating patient and stakeholder engagement in research: moving from theory to practice. *J Comp Eff Res*. 2015;4:133-145.
13. Hamilton CB, Leese JC, Hoens AM, Li LC. Framework for advancing the reporting of patient engagement in rheumatology research projects. *Curr Rheumatol Rep*. 2017;19:38.
14. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health*. 2000;23:334-340.
15. Sandelowski M. What's in a name? Qualitative description revisited. *Res Nurs Health*. 2010;33:77-84.
16. Deverka PA, Lavallee DC, Desai PJ, et al. Stakeholder participation in comparative effectiveness research: defining a framework for effective engagement. *J Comp Eff Res*. 2012;1:181-194.
17. Dixon-Woods M, Shaw RL, Agarwal S, Smith J. The problem of appraising qualitative research. *Qual Saf Health Care*. 2004;13:223-225.
18. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19:349-357.
19. Patton MQ. Designing qualitative studies. In: Patton MQ , ed. *Qualitative Research & Evaluation Methods*. Thousand Oaks, CA: Sage; 2002:230-242.
20. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3:77-101.
21. Canadian Institutes of Health Research. *Strategy for Patient-Oriented Research (SPOR)*. http://www.cihr-irsc.gc.ca/e/41204.html. Published 2017. Accessed September 25, 2017.
22. Patient-Centered Outcomes Research Institute (PCORI). http://www.pcori.org/. Published 2017. Accessed September 25, 2017.
23. National Institute for Health Research. *INVOLVE*. http://www.invo.org.uk. Published 2017. Accessed September 25, 2017.
24. Taylor F, Gutteridge R, Willis C. Peer support for CKD patients and carers: overcoming barriers and facilitating access. *Health Expect*. 2016;19:617-630.
25. Finnegan-John J, Thomas VJ. The psychosocial experience of patients with end-stage renal disease and its impact on quality

of life: findings from a needs assessment to shape a service. *ISRN Nephrol*. 2013;2013:308986.

26. Schipper K, van der Borg WE, de Jong-Camerik J, Abma TA. Living with moderate to severe renal failure from the perspective of patients. *BMC Nephrol*. 2016;17:48.
27. Embuldeniya G, Veinot P, Bell E, et al. The experience and impact of chronic disease peer support interventions: a qualitative synthesis. *Patient Educ Couns*. 2013;92:3-12.
28. Knox L, Huff J, Graham D, et al. What peer mentoring adds to already good patient care: implementing the Carpeta Roja Peer Mentoring Program in a well-resourced health care system. *Ann Fam Med*. 2015;13:S59-S65.
29. Bennett PN, St Clair Russell J, Atwal J, Brown L, Schiller B. Patient-to-patient peer mentor support in dialysis: improving the patient experience. *Semin Dial*. 2018;31:455-461.
30. Caron-Flinterman JF Broerse JEW, Bunders JFG. The experiential knowledge of patients: a new resource for biomedical research? *Soc Sci Med*. 2005;60:2575-2584.
31. Staley K, Buckland SA, Hayes H, Tarpey M. “The missing links”: understanding how context and mechanism influence the impact of public involvement in research. *Health Expect*. 2014;17:755-764.
32. Minogue V, Boness J, Brown A, Girdlestone J. The impact of service user involvement in research. *Int J Health Care Qual Assur Inc Leadersh Health Serv*. 2005;18:103-112.
33. Williamson T, Brogden J, Jones E, Ryan J. Impact of public involvement in research on quality of life and society: a case study of research career trajectories. *Int J Consum Stud*. 2010;34:551-557.
34. Pomey MP, Ghadiri DP, Karazivan P, Fernandez N, Clavel N. Patients as partners: a qualitative study of patients’ engagement in their health care. *PLoS One*. 2015;10:e0122499.
35. Carroll SL, Embuldeniya G, Abelson J, McGillion M, Berkesse A, Healey JS.. Questioning patient engagement: research scientists’ perceptions of the challenges of patient engagement in a cardiovascular research network. *Patient Prefer Adherence*. 2017;11:1573-1583.