

Kidney cancer survivorship care: Patient experiences in a Canadian settingYeshith Rai¹; Shiyu Zheng²; Heather Chappell³; Menaka Pulandiran⁴; Jennifer Jones²¹Faculty of Medicine, University of Toronto, Toronto, ON, Canada; ²Cancer Survivorship Program (ELLICSR), Princess Margaret Cancer Centre (University Health Network), Toronto, ON, Canada; ³Tom Baker Cancer Centre, Calgary, AB, Canada; ⁴Princess Margaret Cancer Centre, University Health Network, Toronto, ON, Canada*Funding:* This study was supported by Kidney Cancer Canada**Cite as:** *Can Urol Assoc J* 2020 June 5; Epub ahead of print. <http://dx.doi.org/10.5489/cuaj.6217>

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Abstract**Introduction:** The incidence of kidney cancer (KCa) in Canada is rising. Despite this, there is a shortage of research assessing KCa care experiences. This study aims to explore the current experiences of KCa survivors related to treatment and management, information provision, and barriers to care.**Methods:** A cross-sectional, descriptive study of KCa patients was conducted online and through various cancer centers across Canada. English- and French-speaking adults who received a KCa diagnosis and were currently undergoing treatment or had completed treatment in Canada were eligible to participate.**Results:** In total, 368 surveys were completed. Ten percent of respondents had not yet received treatment, 29% were receiving treatment, and 56% had completed treatment. Most respondents (72%) had localized KCa (stage 0–3) at diagnosis. Sixty-one percent of respondents reported that their doctors discussed various treatment options with them and 24% reported discussing applicable clinical trials. Most (85%) respondents received information about their KCa and 36% discussed where to get information about their disease and support. The most commonly reported barriers to care were side effects (26%), system delays (26%), not having access to certain treatments (25%), and financial burden (24%). More participants in Central Region and Quebec ($p=0.004$) and rural/suburban ($p=0.014$) areas reported lacking access to certain treatments and KCa experts.**Conclusions:** This was the first large-scale study to explore access to care experiences of Canadian KCa survivors. Results show examples of good patient-centered care and provide new practical information that can inform efforts to improve patient-centered care for KCa patients.

Introduction

In Canada, the incidence of kidney cancer (KCa) has nearly doubled for males and more than doubled for females over the past few decades.¹ While survival rates for KCa have improved for localized tumours,^{3,4} one-third of KCa patients will ultimately die from their disease.⁴⁻⁶

The Institute of Medicine described patient-centered care as one of the most important factors for achieving high quality care,⁷ and should include things such as respect for patient preferences, information provision, education and communication, care coordination, and access to care.^{8,9} Despite its relatively high prevalence, the complexities of treatment and the potential negative impact on quality of life, there have been no large-scale studies to specifically assess the care experiences of KCa patients. Increased understanding and research into the experiences of KCa patients and their preferences for education and support is vital to inform strategies and tailor health services aimed at improving KCa care and patient outcomes.

In response, Kidney Cancer Canada (KCC), a patient-led support organization for Canadians diagnosed with KCa, commissioned a patient-centered experience of care survey of KCa patients across Canada. The purpose of the current analysis is to present the survey data related to care and information provision.

Methods

This study was a cross-sectional descriptive survey of Canadian KCa patients and their caregivers (patient data presented only). Based on the objectives of the study, the initial survey questions were developed by study team members (JM, HC, MP) and circulated to the KCC Medical Advisory Board for review and input. The final questionnaire was tested with three KCa patients who provided feedback on wording and format. The questionnaire collected information on: 1) Demographic and cancer care history; 2) Treatment and management (care team, treatment awareness, choice and expectations, clinical trials awareness and choice); 3) Information provision (information provided during diagnosis); 4) Barriers-to-care; and 5) Supportive care needs and lifestyle behaviors (not presented). Question format was multiple choice and multi-point ratings. The survey was available in English and French.

Participants and procedure

Individuals were eligible to participate if they: 1) had been diagnosed with KCa; 2) had undergone or were currently receiving treatment for KCa in Canada; 3) were ≥ 18 years; and 4) could read in English or French. Potential participants were recruited through 1) KCC membership (email blast/ mailing, KCC newsletter and blogs, and social media); and 2) urology/hospital clinics. Using a four-point survey approach based on Dillman's Tailored Design Method,¹⁰ KCC patient members were invited via email to complete the survey. Members without an associated email address were sent postcard invitations. A blog with the study details was also posted on the KCC's website. In addition, postcards with information about the study and the link to the survey were distributed in KCa and urology clinic waiting areas across

Canada. Participants had the option to complete the survey online (through Fluidsurveys.com) or to email and request a paper questionnaire and return it using a pre-paid envelope.

Data analysis

Descriptive statistics were calculated to summarize participant characteristics and responses to the survey questions. Group differences (proportions) between the patients treated in different Canadian regions (Eastern (Ontario, Quebec), Western (Alberta, British Columbia), Atlantic (New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland), Central (Saskatchewan, Manitoba) and Northern (Nunavut)); setting (urban, suburban, rural); and type of treatment center (academic, community) were compared using chi-square statistic. Differences were considered significant at the $p < 0.05$ level of significance after adjusting for multiple comparisons. Statistical analyses were performed using the Statistical Package for the Social Sciences (SPSS) version 21.0.

Results

In total, 368 surveys were completed by KCa patients. Most (87%) responded online and were English speaking (88%). Over half (54%) were male and the mean age was 60 ± 10.7 (range 30-91). The percentages of respondents from Eastern, Western, Atlantic, Central and Northern regions of Canada were 61%, 20%, 8%, 6%, and 2%, respectively. Most (82%) participants were diagnosed/treated in an urban setting and 43% received care in an academic center affiliated with a university.

Over half (56%) of the respondents were post-treatment, 29% were currently receiving treatment, and 10% had not yet received treatment. Most (72%) had localized KCa (stage 0-3) at diagnosis. Surgery, either partial nephrectomy (22%) or radical nephrectomy (66%), was the most common KCa treatment. Rates of partial versus radical nephrectomy by stage were: Stage 1 (45% versus 49%); Stage 2 (11% versus 82%); Stage 3 (8% versus 95%); and Stage 4 (3% versus 82%). Rates by region were: Eastern (24% versus 61%); Western (19% versus 73%); Atlantic (16% versus 81%); Central (19% versus 76%); and Northern (38% versus 75%). Rates by setting were: urban (24% versus 67%); sub-urban (19% versus 83%); and rural (18% versus 91%). Rates by care center were: academic center (31% versus 60%); community cancer center/urologist clinic (18% versus 77%); and hospital (14% versus 82%). Patients who were diagnosed in the past 5 years were less likely to have received a radical nephrectomy compared to patients diagnosed greater than 5 years ago ($p = 0.05$). Approximately one-third (30%) received chemotherapy or drug therapy and 9% radiotherapy. Demographic and clinical characteristics of the participants are reported in Table 1.

Treatment and management

Care team

Most respondents reported receiving care from an oncologist (52%) or urologist (36%) and 44% reported that their family doctor was also part of their care team. Few respondents reported having other professionals, such as nurses and pharmacists, on their care team (Table 2). Thirty-nine percent opted for a second opinion from a KCa specialist. In about half of these cases (53%), the doctor recommended this and in 31%, it was their own choice. Patients from Quebec (23%) and Western (29%) provinces were less likely to seek a second opinion ($p=0.0492$).

Treatment awareness, choices, and expectations

Sixty-one percent of respondents reported that their doctor discussed different treatment options with them. In cases when the entire kidney was removed, 40% of respondents said that the doctor never discussed removing only part of the kidney (including 29% of respondents with Stage I KCa), 32% percent were told this was not an option for them, and 23% reported that it was an option but was not recommended. In the one-third of respondents who received drug treatment for their KCa, 14% indicated that they were not offered a choice for their first drug therapy, even though they were aware of other options available. Most (87%) respondents who received drug therapy said that they preferred taking pills at home to getting IV doses at the hospital.

The large majority of respondents (89%) reported that their oncologist/urologist was very involved in their treatment decisions along with spouses/partners (74%) and their family doctor (50%). Participants were asked to rank their top priorities when making treatment choices (when available). Effectiveness of the treatment to stop or cure the cancer was the top choice for 46% of respondents followed by having access to the latest KCa treatments (15%) and prolonging survival (12%). What participants were willing to do to reach their treatment goals and expectations are shown in Figure 1. Fifty-two percent and 38% were willing to spend a lot of time to get treatment and travel over 100 km to a specialist center, respectively. Forty-one percent were willing to get treatments that extend their lives as much as possible, even if that meant more side effects. These findings were consistent across regions, treatment centers and setting.

Clinical trials awareness and choice

Half (50%) of the respondents reported that they were willing to participate in a KCa clinical trial, 24% reported that their doctor discussed applicable trials and 20% had enrolled in a trial. In most of these cases (67%), the decision to participate in a clinical trial was made jointly with the doctor. More respondents in the Central region (67%), Maritimes (47%) and Quebec (40%) ($p=0.001$) and those in rural/suburban settings (59%) ($p=0.002$) reported that they did not have access to clinical trials.

Information provision

The most common sources of information for respondents were their urologist/oncologist (67%), KCC website (55%), and family doctor (50%). Most respondents reported discussing the specifics of KCa (85%) and their prognosis (73%) with their physician. This did not differ between regions, settings, or treatment center.

Thirty-six percent of respondents discussed where to get information about their disease (patient education) and support with their physician and 21% discussed costs and access to treatment. Quebec (39%), Central region (33%), Maritimes (15%), and the Northern region (14%) had lower percentages when it came to having conversations with their doctor about where to get information and support at the time of diagnosis compared to Ontario (46%) and Western region (48%) ($p=0.026$) but there were no differences between setting or type of center.

Barriers to care

Figure 2 shows barriers to care/treatment endorsed by respondents. The most common barriers reported were side effects from treatment (26%), system delays in getting cancer diagnosed (26%), not having access to certain treatment options (25%), system delays in starting treatment (24%) and financial burden (24%). Not having access to certain treatment options was more common in respondents from the Central region (67%) and Quebec (56%) ($p=0.0042$) and rural/suburban areas (55%) ($p=0.014$). Seventeen percent of respondents reported that they did not have access to KCa experts. Again, this was highest in those from the Central region (35%) and Quebec (28%) ($p<0.001$), as well as those who received care in rural/suburban (47%) ($p=0.0006$) and community-based settings (29%) ($p=0.003$).

Financial concerns were prevalent in those who received drug therapy. Sixty-eight percent of respondents agreed or strongly agreed that KCa medications are too expensive, 40% worry about paying for their treatments, 16% had trouble affording their medications, and 11% ruled out treatment options due to high cost.

Discussion

This was the first large-scale study to explore access to care experiences in a diverse sample of Canadian KCa patients. The findings highlight a number of examples of good patient-centered care and provides important information on patient preferences, barriers, and gaps in care that can inform efforts at improving KCa care.

Treatment and management

Oncologists and urologists most commonly managed treatment and follow-up care for KCa survivors and few respondents were aware of other health professionals, such as nurses and pharmacists, on their care team. It is possible that these professionals were on the care team but the patient was unaware. Regardless, multidisciplinary teams were recommended as the standard of care for cancer patients as they allow for comprehensive patient management.^{11,12} The family physician was identified by a substantial minority of respondents as an important part of their

care team and a common source of information for their KCa. Given their relationship with the patient, as well as their accessibility in the community, family doctors can play an important role throughout the cancer journey and can help support patient-centered care.¹³ The integration of the family physician should be supported by providing on-going communication of medical information and establishing clearly defined roles for each provider, particularly during transitions of care between the family physician and KCa specialist.¹⁴

Shared decision-making based on the best available evidence and patients' informed values is particularly relevant for KCa patients, who face a range of decisions regarding surgical alternatives for early-stage cancer or second-/third-line treatments for metastatic disease¹⁵. Encouragingly, 61% of respondents reported that their oncologist/urologist discussed different treatment options with them. Of note, 29% of respondents with Stage I disease who received a radical nephrectomy reported that they were not provided with the option to remove only part of their kidney. Similarly, Russo et al. found that 25% of KCa patients who received a radical nephrectomy were not aware of the partial nephrectomy option.¹⁶ Current guidelines recommend partial over radical nephrectomies for treating small kidney tumors.¹⁷⁻¹⁹ While patients may not have been offered the partial nephrectomy option because this was not medically appropriate for them, it is possible that they did not have this discussion due to other reasons such as physician preference. Another possibility is that physicians informed patients of this option, but patients were unable to recall this information given the extremely stressful circumstances.²⁰ The use of patient education materials and decision aids can help improve people's engagement in decision-making, knowledge of options, and reduce their decisional conflict related to feeling uninformed and unclear about their personal values.²¹⁻²⁵ In addition, recently established benchmarks for the use of partial nephrectomies in the management of KCa²⁶ can be employed by physicians and institutions to improve KCa care.

Participants were willing to make significant investments in terms of time and travel for their treatments. Further, 41% were willing to endure side effects in order to get treatments that would extend their lives as much as possible. Studies in other cancer populations found that while some cancer patients prioritize length of life over quality of life, many others prioritize the opposite.²⁷⁻³⁰ For example, Meropol et al. found that 55% of cancer patients considered quality of life as important as length of life and in patients with a preference between the two, more people selected quality over length of life (27% versus 18%).²⁷ Whether patients prioritized quality or length of life can be influenced by several factors, such as patient age and disease prognosis.³¹ Not surprisingly, younger patients generally prefer length over quality of life while older patients preferred the opposite.³¹

Half of the respondents expressed interest in participating in a clinical trial and 20% reported that they had enrolled in one. These findings are encouraging when compared to a previous study which showed clinical trial enrollment was only discussed with 14% of patients with colorectal or lung cancer.³² Clinical trials were recommended by guidelines to be the first option for patients with advanced or metastatic KCa.¹² Thus, it may be beneficial to develop

strategies for informing healthcare providers about available clinical trials and assist them with educating patients.

Information provision

Most participants received information about KCa and their prognosis from the cancer specialist. However, only one-third reported that they received information on where to access patient education and supportive care resources and only one-fifth discussed costs and access to treatment. This finding is supported by other studies which found that only a small proportion of patients receive adequate information about psychosocial support and treatment costs,^{33–35} even though many cancer patients wish to be well-informed about these topics.^{33,36} Given that adequate provision of patient education and supportive care can result in higher quality of life and less anxiety and depression,^{37–41} strategies should be implemented to improve comprehensive information provision to cancer survivors and access to patient education and supportive care services.

Barriers to care

The results from our study identified a number of barriers to care. One of the most common barriers reported was side effects from treatment. Proactive approaches could help minimize the burden of side effects. For instance, patient education and prophylactic strategies could be provided prior to treatment.⁴² Additionally, physicians could routinely ask patients about side effects experienced and offer appropriate supportive care interventions.^{42,43} Another common barrier to care was financial burden. Although there is universal healthcare in Canada, respondents may have faced other medical expenses requiring out-of-pocket payments, such as prescription drugs, hospital parking, and travel costs.⁴⁴ Furthermore, many cancer patients do not work during treatment and require caregivers to take time off their jobs as well,⁴⁵ which adds to financial stress.

Other reported barriers to care include system delays in receiving diagnosis and treatment procedures and not having access to certain treatment options. Given the current Canadian healthcare system limitations with provincial planning and budgeting, patients, families, and clinicians are concerned about timely access to quality care and treatments. For example, access to oral targeted therapies for KCa differs by province and not all patients are eligible for coverage. In many cases, patients must travel to receive treatment and do not have direct access to KCa experts. Limitations in the healthcare system can also contribute to lengthy wait times for diagnostic and treatment procedures. A third of cancer patients in one Canadian study perceived the medical system to be the most responsible for delays in their diagnosis.⁴⁶ Sometimes, patients may have the perception that they lack treatment access when their requests for medically inappropriate interventions⁴⁷ are denied. In these cases, patients should be informed about appropriate and inappropriate treatment choices.

When comparing urban and rural/suburban areas, more respondents from rural/suburban regions reported that they lacked access to certain treatment options, clinical trials, and KCa

experts than their urban counterparts. This is supported by Kardos et al's study, which found that patients at urban hospitals are more likely to receive partial nephrectomies compared to those at rural medical centers.⁴⁸ Reduced access to care for rural residents could lead to disparities in health outcomes. For instance, Sadowski et al found that rural residence in Illinois was associated with increased mortality from kidney and renal pelvis cancer.⁴⁹ Strategies should be explored to reduce the urban-rural health disparity, including video conferencing programs, travel grants, and outreach clinics from KCa experts .

The findings of this study must be interpreted in the context of its limitations. This was a cross-sectional descriptive study that required participants to report on their experiences and may result in recall bias. Most respondents were well-educated, resided in Eastern or Western regions, and treated in urban settings. Additionally, recruiting participants from the KCC member database may present a selection bias, as patients engaged with such advocacy groups may have different perceptions and care compared to KCa patients in general. Further, because there were only 11 respondents from rural settings, we collapsed the rural and suburban groups. However, we recognize that patients in rural settings likely have more difficulty accessing care than those in suburban settings. Despite these limitations, this study provides valuable insight into KCa survivors' treatment experiences, an area that has not been well researched.

Conclusions

Overall, this study provides new information on KCa experiences with care provision. Strategies and tools should be developed and implemented to improve access to applicable clinical trials, improve information provision regarding patient education and supportive care resources, encourage increased patient engagement in their treatment decisions, and mitigate treatment barriers.

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Figures and Tables

Fig. 1. What patients would be willing to do to meet treatment goals.

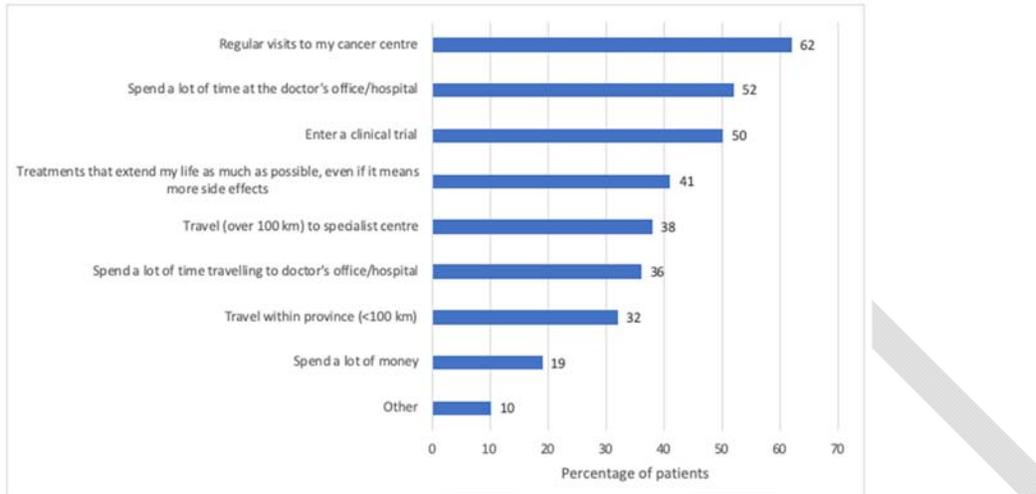


Fig. 2. Barriers to care faced by kidney cancer patients.

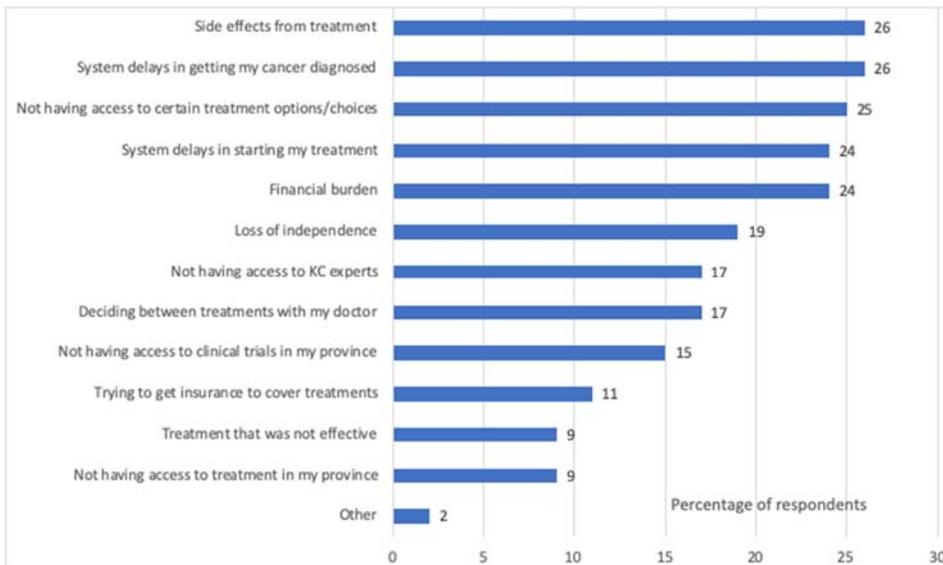


Fig. 3. Barriers to care experiences by respondents residing in rural/suburban vs. urban areas. Significant differences exist between the rural/suburban and urban samples for all three barriers to care: no access to KCa expert ($p=0.0006$); no access to certain treatment options ($p=0.01$); and no access to clinical trials in the province ($p=0.002$). KCa: kidney cancer.

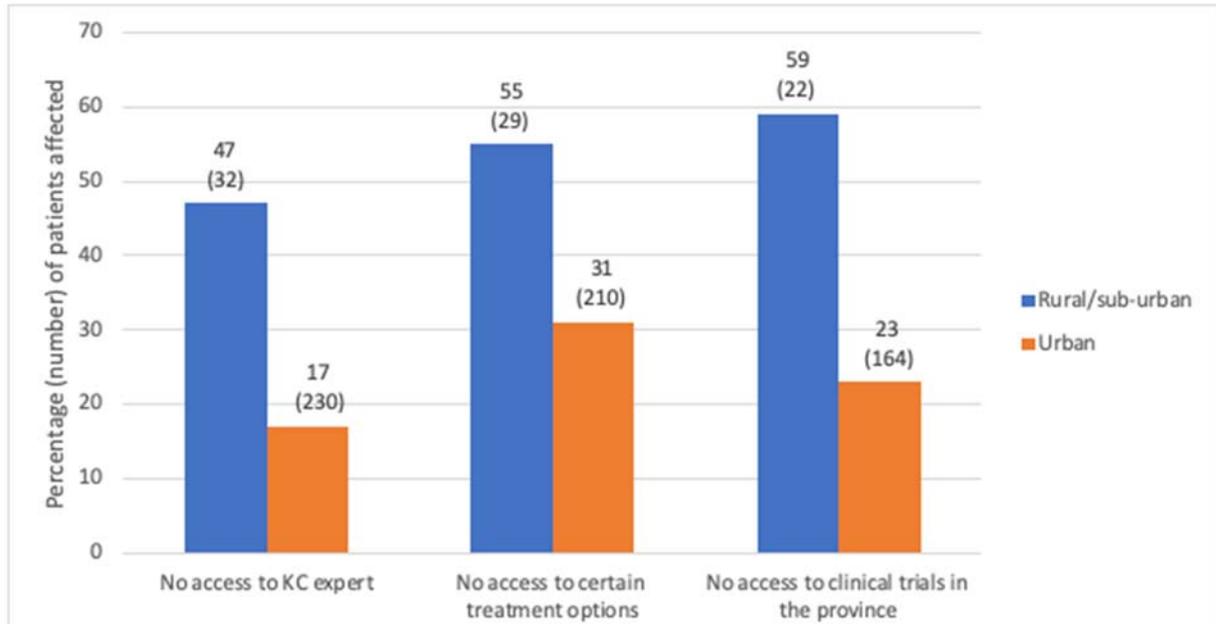


Table 1. Baseline characteristics of 368 survey respondents^a

Age, years (mean ± SD)	60.2±10.7
Language spoken (n, %)	
English	322 (88)
French	46 (13)
Sex (n, %)	
Male	197 (54)
Female	167 (46)
Geographical Region	
Eastern (ON, QC)	223 (61)
Western (AB, BC)	73 (20)
Atlantic (NB, NS, PEI, NFL)	31 (8)
Central (SK, MB)	21 (6)
Northern (NU)	8 (2)
Education (n, %)	
Greater than high school	269 (74)
High school or less	84 (23)
Married/common-law (n, %)	286 (78)
Employment status (n, %)	
Working one year prior to KC diagnosis (full-time or part-time)	264 (72)
Currently working (full-time or part-time)	136 (37)
Coverage by health insurance plan (n, %)	
Full coverage	152 (42)
Partial coverage	130 (36)
No coverage	78 (21)
I don't know	5 (1)
Current stage of cancer journey (n, %)	
Newly diagnosed (no treatment yet)	7 (2)
Active surveillance	29 (8)
Receiving treatment for new diagnosis	18 (5)
Receiving treatment for recurrent cancer (< 3 months)	4 (1)
Receiving ongoing treatment for metastatic disease	83 (24)
Recently finished treatment (<3 months ago)	11 (3)
Post-treatment follow-up surveillance	191 (56)
Stage of cancer at diagnosis (n, %)	
Stage 0	1 (0)
Stage 1	137 (39)
Stage 2	90 (26)

Stage 3	38 (11)
Stage 4	61 (17)
I don't know	24 (7)
Treatment received (n, %)	
Active surveillance	131 (36)
Radical nephrectomy	242 (66)
Partial nephrectomy	81 (22)
Surgery for tumor somewhere other than the kidney	42 (11)
Metastatectomy (removed a metastasis)	28 (8)
Chemotherapy	51 (14)
Radiation	33 (9)
Drug therapy	59 (16)
Stereotactic radiation	15 (4)
Arterial embolization	11 (3)
None	7 (2)
Other ^b	40 (11)
Treatment location (n, %)	
Urban (large city)	300 (82)
Suburban (surrounding city)	54 (15)
Rural	11 (3)
Not applicable (not started treatment)	7 (2)
Treatment center (n, %)	
Academic center affiliated with university	160 (43)
Community cancer center/urologist clinic	152 (41)
Hospital	49 (13)
Other ^c	10 (3)

^aDenominators vary with missing data. ^bOther included: radiofrequency ablation, cryoablation, immunotherapy. ^cOther included: private clinic, health sciences center, surgical clinic. SD: standard deviation.

Table 2. Medical team of survey respondents (n=368)^a	
	Number of respondents (%)
Who is managing your treatment and followup care?	
Oncologist	178 (52)
Urologist	123 (36)
General practitioner/family doctor	35 (10)
Other	15 (4)
I don't know/not applicable	6 (2)
Medical team members (along with your doctor, your medical team includes...)	
Nurse	99 (27)
Pharmacist	49 (13)
Patient navigator	26 (7)
Dietician	24 (7)
Psychologist	21 (6)
Case manager	16 (4)
Social worker	15 (4)
Other ^b	33 (9)

^aDenominators vary with missing data. ^bOther included: registered massage therapist, internist, doctor's assistants/students, oncology psychiatrist, study coordinator, nephrologist, cancer coach, palliative care team.