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Perceptions of kidney transplant recipients regarding their post-transplant primary care

By Olusegun Famure, Myra Nina Caballero, Anna Li, Laura Rivera, Nicholas Phan, Monika Ashwin, Pei Xuan Chen, Leslie Adcock, Jeffrey Schiff, and S. Joseph Kim

ABSTRACT

Kidney transplant recipients (KTRs) are typically referred to their primary care physicians (PCPs) for routine medical care within six months following transplant, a period that is deemed to be the most critical period in which KTRs remain under the care of transplant nephrologists. This study explores KTR perceptions regarding post-transplant primary care. A

self-administered questionnaire was distributed to adult KTRs who were transplanted between January 2002 and February 2011, were at least six months post-transplant, and were receiving follow-up care at Toronto General Hospital. The survey assessed KTR views on PCP performance, comfort level with PCPs, self-management support, and perceived barriers to optimal care. A total of 502 KTRs (78%) completed the survey. Seventy-six percent indicated that the PCP was one of their healthcare providers. Among them, 53% reported their PCPs recommended services of other healthcare providers. Although 77% of KTRs strongly confirmed the importance of effective health self-management, only 50% strongly felt competent executing self-management strategies. KTRs are generally comfortable with their PCPs; however, better utilization of other healthcare services and self-management tools is necessary.

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Solid-organ transplantation is the treatment of choice for end-stage organ failure (McCashland, 2001; Wolfe et al., 1999). A total of 1,263 solid-organ transplants were performed in Ontario in the 2017-2018 fiscal year, with 54% of them being kidney transplants (Trillium Gift of Life Network [TGLN], 2018). This statistic represents a 15% increase in the of kidney transplants in Ontario since 2008 (TGLN, 2008). With improvements in surgical techniques and post-transplant care, the one-year graft survival rate for the organ transplant population has improved significantly, and is currently greater than 90% (Gupta, Unruh, Nolin, & Hasley, 2010; McGuire et al., 2009). As the number of organ transplants gradually increases and the survival rate improves, chronic health conditions such as diabetes, cancer, cardiovascular disease, and osteoporosis are becoming increasingly prevalent and are emerging as major causes of morbidity and mortality (Heller, Prochazka, Everson, & Forman, 2009; Kasiske et al., 2000; Broemeling, Watson, & Prebtani, 2008; Gourishankar, Jhangri, Tonelli, Wales, & Cockfield, 2004; Villeneuve et al., 2007; Kasiske, 2001; Silikensen, 2000).

The increase in the number of long-term patient survivors with multiple post-transplant chronic conditions has imposed a large burden on the few Ontario transplant centres that manage transplant recipients, particularly kidney transplant recipients (KTRs) (Gupta et al., 2010; McGuire et al., 2009). This strain on the healthcare system calls for the promotion of more effective strategies such as self-management (Barr et al., 2003; Wagner, Austin, & Von Korff, 1996). Due to insufficient human and economic resources at such centres, transplant recipients are typically referred to their primary care physicians (PCPs) for routine medical care within six months following transplant (McCashland, 2001; McGuire et al., 2009). In Ontario, all PCPs have completed a minimum of two years of post-graduate training.

The issue of PCPs' potential lack of experience in post-transplant management raises the question of whether transplant recipients receive adequate care that addresses their complex presentation from the PCPs. One aspect of this is the perception of transplant patients regarding their primary care provider. It is particularly important to better understand whether patients feel comfortable with their PCP's management of preventive care measures and chronic disease, as well as whether they are receiving sufficient support in the realm of self-management. No study to date has been conducted in Canada to assess organ transplant recipients' perception of the quality of chronic disease management by PCPs.

In order to investigate how transplant patients in Ontario view the care they receive, a survey-based study among KTRs was conducted. KTRs are the largest population of solid organ transplant recipients, and primary care issues in this population, such as increased risk of malignancies, opportunistic infections, and metabolic complications, are also similarly observed in other solid organ transplant populations. The objective of this study was to ascertain the perceptions of adult KTRs regarding their post-transplant primary care. More specifically, this study aimed to assess patient perceptions with respect to: (1) the quality of primary healthcare services received; (2) the attitudes and practice patterns of their PCPs in the management of chronic disease and self-management support; and (3) potential barriers to optimal care that currently exist.

METHOD

Sample Frame

This was a self-reported, cross-sectional, survey-based study. A convenience sample of KTRs was obtained between May 2012 and February 2013 from the Toronto General Hospital (TGH) kidney transplant program in Ontario. The inclusion criteria consisted of adult patients (older than 18 years of age) who received a kidney transplant between January 1, 2002, and February 28, 2011; were at least six months post-transplant; and were currently receiving post-transplant follow-up care at TGH. Weekly screening of upcoming clinic patient lists identified eligible individuals. Eligible patients were approached in person by research staff upon arrival at the clinic. Research staff introduced the study, obtained verbal consent for participation, and administered a paper copy of the survey to study participants. Patients were approached a second time to follow up on any questions they had regarding the study and to collect the completed surveys. For the purposes of this study, language barriers, visual impairment, or disinterest toward study participation constituted a basis for excluding patients from study enrolment. This study was reviewed and approved by the Research Ethics Board of the University Health Network

SURVEY TOOL DEVELOPMENT

The MEDLINE and PubMed databases were searched to identify peer-reviewed English-language articles published between January 1996 and December 2010. The primary

search terms used were *organ transplantation, chronic disease management, primary health care, and primary care physician*. Titles and abstracts of articles identified from the search were screened. Articles were included if they met at least one of the following criteria: the scope of the article concerned the management of chronic or long-term conditions; the focus of the article was on adult solid-organ (kidney, heart, liver, or lung) transplant recipients; and the article addressed issues surrounding disease management by PCPs and/or transplant centres. Reference lists of relevant articles were also searched.

Based on findings from the literature review, key components of chronic disease management were identified. These included: the formation of a multidisciplinary team of healthcare providers, implementation of preventive medicine, physician education and training, patient self-management support, and effective communication among health care providers (Barr et al., 2003; Wagner et al., 1996; Bodenheimer, 2003; Ouwens, Wollersheim, Hermens, Hulscher, & Grol, 2005; World Health Organization [WHO], 2002; Singh, & Ham, 2006; Cunzel, & Laederach-Hofmann, 2000; Health Council of Canada, 2007; Wagner, Austin, et al., 2001; Weingarten et al., 2002; Davis, Thomson, Oxman, & Haynes, 1996; Ciccone et al., 2010; Wallace, 2005; Ofman et al., 2004; Norris et al., 2002; Norris, Glasgow, Engelgau, O'Connor, & McCulloch, 2003; Wagner, Glasgow, et al., 2001; Grol, 2001; McAlister, Lawson, Teo, & Armstrong, 2001; Bia et al., 2010). The components of chronic disease management were used as a point of focus for the domains of the patient survey in addition to other domains that were required to address the study objectives. The domains assessed included: demographic information; physician expertise, comfort level, and performance; chronic disease management; patient self-management support; and barriers to optimal care.

The survey was divided into four sections. The first section ascertained demographic characteristics of patients (age, gender, race, involvement of a PCP in their post-transplant follow-up care). The second section addressed patients' perceptions of physician knowledge, comfort level, and performance. The third section dealt with patient self-management support. The fourth section investigated patients' satisfaction with the healthcare services provided by PCPs. Survey respondents answered 15 multiple choice and Likert-scale questions, several of which included a section allowing for free-text comments to elaborate on responses. There was also a general comment section at the end of the survey. Prior to distribution, the survey was piloted to identify any issues regarding clarity of question syntax and organization. This information was then used to revise the survey prior to implementation.

DATA ANALYSIS

Tabulation of descriptive statistics for each survey item was conducted in Stata[®] Data Analysis and Statistical Software. Qualitative content analysis was conducted on the free-text comments. Emerging themes were mapped onto existing items to identify areas not previously captured with regards to barriers to optimal primary care and

types of services required.

RESULTS

Survey Respondents

After screening for eligible patients, 646 KTRs were approached for this study (Figure 1). Of these, 502 individuals completed and returned the survey, resulting in a response rate of 77.7%. However, each question received varying levels of response. The demographic information is outlined in Table 1. More than half of the study participants were between the ages of 40 and 65 (59.0%) and male (57.8%). Almost

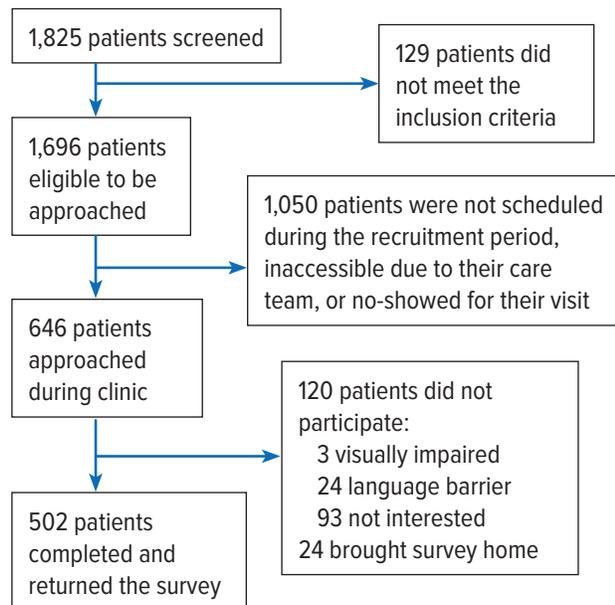


Figure 1. Patient Eligibility Screening and Exclusion

Table 1. Demographic Information (N = 502)

| Characteristic | Respondents N (%)* |
|-----------------------------------|-----------------------|
| Age range (years) | |
| 18–39 | 95 (18.9) |
| 40–55 | 157 (31.3) |
| 56–65 | 139 (27.7) |
| 66–74 | 81 (16.1) |
| > 75 | 25 (5.0) |
| Sex† | |
| Male | 290 (57.8) |
| Female | 205 (40.8) |
| Race | |
| White | 331 (65.9) |
| Black | 37 (7.4) |
| East Asian | 45 (9.0) |
| South Asian | 54 (10.8) |
| Aboriginal | 3 (0.6) |
| Other | 23 (4.6) |
| Family physician involved in care | |
| Yes | 381 (75.9) |
| No | 113 (22.5) |

* Not all KTR answered all questions.

† One individual had multiple answers for this question.

two-thirds were Caucasian (65.9%), and three-quarters indicated a PCP has been involved in their post-transplant care (75.9%).

Post-Transplant Primary Care

Among the KTRs with a PCP, most have been under the physician's care for more than three years (65.8%) (Table 2). Although most respondents (75.9%) indicated that their PCP managed non-transplant-related issues, only 32.8% stated that chronic medical conditions were under their PCP's management. Approximately half of the KTRs (52.8%) reported that their PCP recommended them to the

Table 2. Post-Transplant Primary Care (n = 381)

| Survey Question | Respondents n (%)* |
|---------------------------------|-----------------------|
| Time under PCP's care | |
| < 6 months | 15 (3.9) |
| 6 months–1 year | 31 (8.1) |
| 1–2 years | 37 (9.7) |
| 2–3 years | 41 (10.8) |
| >3 years | 251 (65.8) |
| Areas of care managed by PCP | |
| Chronic medical conditions | 125 (32.8) |
| Vaccinations | 250 (65.6) |
| Periodic health examinations | 275 (72.2) |
| Immunosuppressive drug therapy | 21 (5.5) |
| Educational support/counselling | 60 (15.7) |
| Specialist referrals | 180 (47.2) |
| Non-transplant related issues | 289 (75.9) |
| Cancer screening | 87 (22.8) |
| Diabetes screening | 53 (13.9) |
| Other | 16 (4.2) |

* Not all respondents answered all questions.

Table 3. Involvement of Other Health Care Professionals (n=381)

| Survey Question | Respondents n (%)* |
|---|-----------------------|
| PCP recommended services of other health care professionals | |
| Yes | 201 (52.8) |
| No | 154 (40.4) |
| Other health care professionals visited since transplantation | |
| Dietician | 82 (40.8) |
| Pharmacist | 122 (60.7) |
| Physiotherapist | 47 (23.4) |
| Occupational therapist | 13 (6.5) |
| Social worker | 26 (12.9) |
| Psychiatrist | 16 (8.0) |
| Nurse/Nurse practitioner | 30 (14.9) |
| Chiropodist | 24 (11.9) |
| Other | 56 (27.9) |

* Not all respondents answered all questions.

services of other healthcare professionals. The proportion of patients using the services of various healthcare professionals is shown in Table 3.

Level of Comfort with Family Physician's Care

To assess patients' perceptions regarding their PCP's management of preventive care measures (Figure 2a) and chronic disease management practices (Figure 2b), KTRs were asked to rate their comfort level on a scale from 1 to 5. A score of 1 indicated they were *very uncomfortable* and 5 indicated *very comfortable*. Patients were generally

comfortable (85%) when their PCPs prescribed preventive care measures, but were more divided in their comfort rating with approximately 40% expressing a level of comfort and discomfort, respectively, when the PCP titrated/adjusted their immunosuppressive drug therapy. Overall, approximately 70% of the patients were comfortable with their PCP's chronic disease management practices.

Patient Self-Management Support

A list of conditions prevalent in transplant populations was provided and patients were asked to select chronic

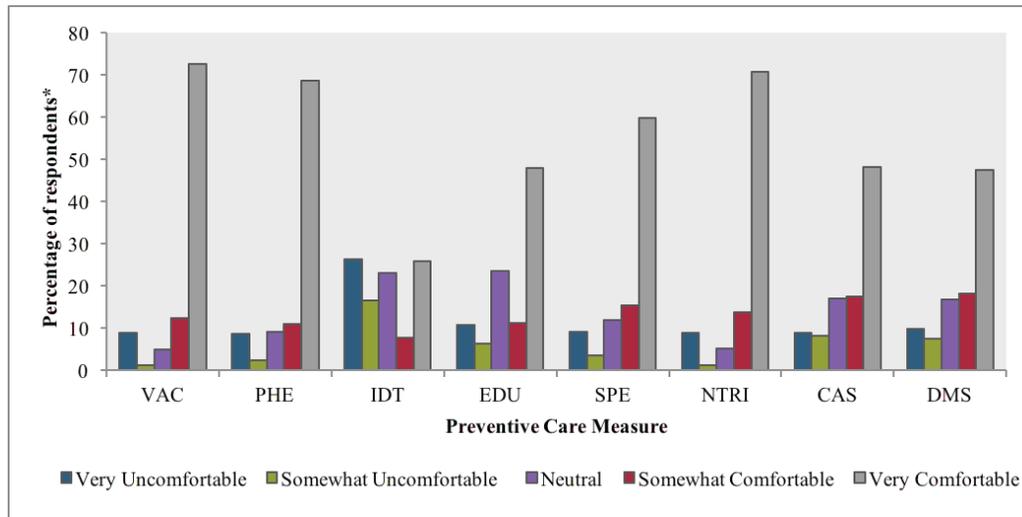


Figure 2a. KTRs' comfort level with PCP management of preventive measures. Percentage of KTR respondents is plotted in comfort level bins for various preventive care measures: VAC=vaccination; PHE=periodic health examinations; IDT=immunosuppressive drug therapy; EDU=educational support/counseling; SPE=specialist referrals; NTRI=non-transplant-related issues; CAS=cancer screening; DMS=diabetes screening.

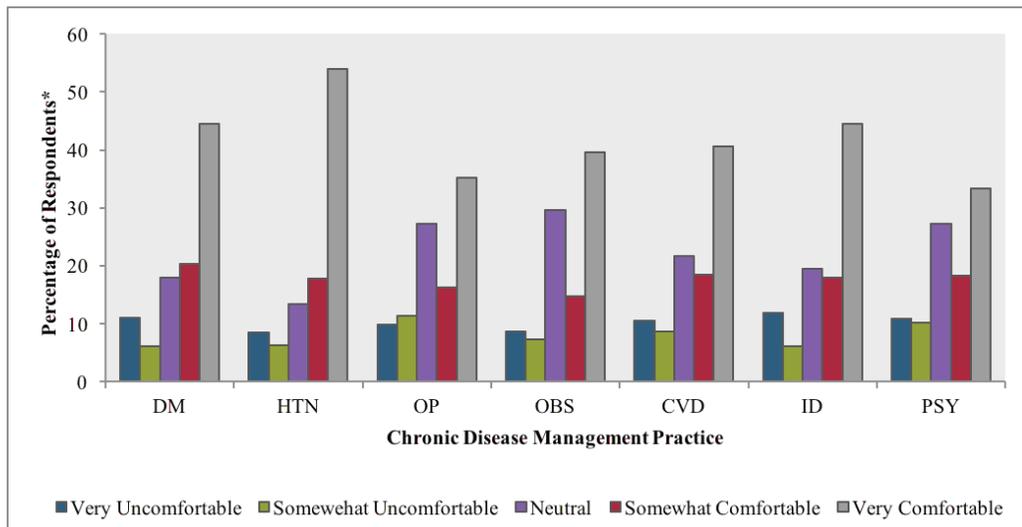


Figure 2b. KTRs' comfort level with PCP management of chronic diseases. Percentage of KTR respondents is plotted in comfort level bins for various chronic disease management practices: DM=diabetes management; HTN=hypertension control; OP=osteoporosis management; OBS=obesity management; CVD=cardiovascular disease risk factor modification; ID=infectious disease control; PSY=psychological disorder management.

*Not all respondents answered all questions. Plot denominators only include respondents who did answer the question and who did not indicate this question was not applicable.

medical conditions that they currently manage independently (Table 4). Chief among them were hypertension (54.2%) and diabetes (31.5%). Although 76.6% of patients strongly agreed that effective self-management of health conditions is important, only 50.4% strongly agreed that they felt competent doing so. Some participant suggestions for promoting self-management included education on transplant medications, reminders about vaccinations, and information about community supports. Patients also rated their impression of their PCP's performance in various areas related to self-management on a scale of 1 to 5, with 1 being *poor* and 5 being *excellent*. The majority of KTRs (86%) rated their physicians positively in a number of self-management support domains, including encouraging behavioural interventions, educating about health conditions, and working together to achieve optimum health (Figure 3).

Improving Patient Care

To better ascertain which services were deemed lacking and impediments to ideal post-transplant care, KTRs were asked to prioritize a list of patient services and then factors that prevented them from receiving the type and quality of care they desired (Table 5). Less than half of the KTRs surveyed were satisfied with their care (46.6%) and two-thirds indicated that they did not experience any barriers (63.3%). In addition to these responses, patients felt that better access to other healthcare professionals would be

Table 4. *Patient Self-Management (n = 381)*

| Survey Question | Respondents n (%)* |
|---|--------------------|
| Chronic conditions KTR currently self manage | |
| Cardiovascular disease | 53 (13.9) |
| Diabetes | 120 (31.5) |
| Hypertension | 206 (54.2) |
| Osteoporosis | 102 (26.8) |
| Obesity | 76 (19.9) |
| Cancer | 23 (6.0) |
| Psychological disorder management | 42 (11.0) |
| Other | 31 (8.1) |
| None of the above | 62 (16.3) |
| It is important to know how to effectively self-manage my health conditions after my transplant | |
| Strongly disagree | 15 (3.9) |
| Somewhat disagree | 1 (0.3) |
| Neutral | 7 (1.8) |
| Somewhat agree | 47 (12.3) |
| Strongly agree | 292 (76.6) |
| I feel competent in managing my own health conditions | |
| Strongly disagree | 18 (4.7) |
| Somewhat disagree | 10 (2.6) |
| Neutral | 35 (9.1) |
| Somewhat agree | 107 (28.1) |
| Strongly agree | 192 (50.4) |

* Not all respondents answered all questions.

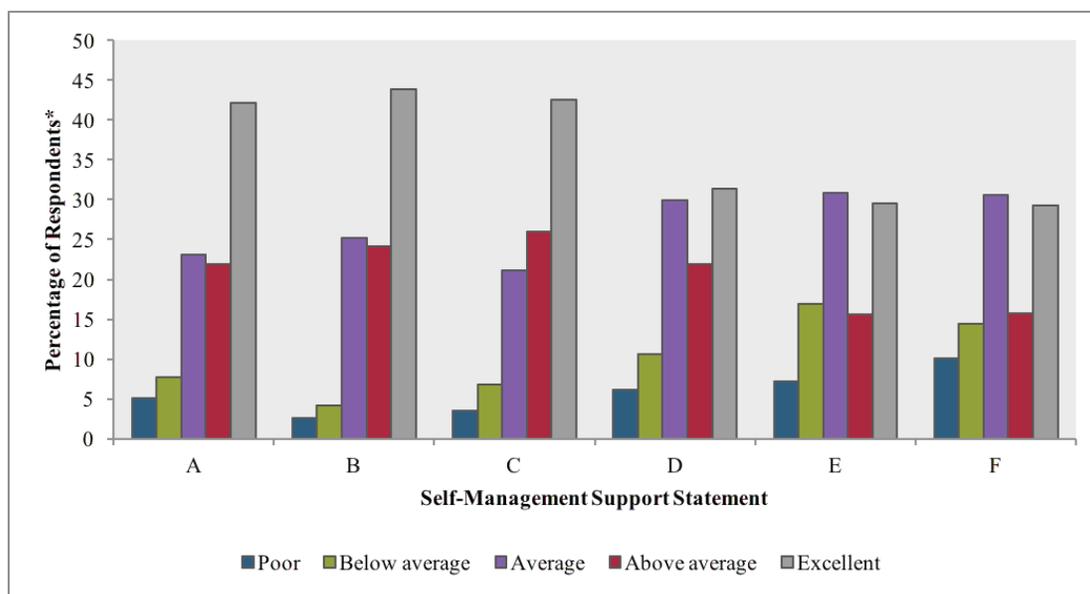


Figure 3. KTR rating of PCP performance in self-management support of health conditions. Percentage of KTR respondents is plotted in rating bins for various statements regarding the support provided by their PCP for self-management. Statements given included: (A) educating me about my health conditions; (B) encouraging me to make behavioural interventions; (C) working with me to set goals to achieve optimal health status; (D) helping me identify issues or health concerns; (E) referring me to use community resources; and (F) providing psychological support to help me cope with any emotional/social stresses.

* Not all 381 respondents answered each question. The denominators for each statement represent the individuals who did answer the question and who did not indicate this question was not applicable.

Table 5. *Improving Care for KTR (N = 502)*

| Survey Question | Respondents N (%)* |
|---|-----------------------|
| Services required to improve quality of patient care | |
| More time with my family physician during clinic visits | 69 (13.7) |
| More access to other health care professionals | 98 (19.5) |
| More educational materials | 79 (14.7) |
| More access to community resources | 83 (16.5) |
| More reminders regarding transplant care | 76 (15.1) |
| More frequent communication with family physician | 69 (13.7) |
| Other | |
| None | 28 (5.6) |
| | 234 (46.6) |
| Barriers to optimal post-transplant care | |
| Lack of financial support | 51 (10.2) |
| Lack of social support | 20 (4.0) |
| Lack of emotional support | 32 (6.4) |
| Lack of educational support | 23 (4.6) |
| Lack of practical support | 30 (6.0) |
| Language/cultural barrier | 18 (3.6) |
| Other | 18 (3.6) |
| None | 318 (63.3) |

* Not all respondents answered all questions.

beneficial (19.5%). Patients' lack of financial support to address their healthcare needs, such as taking time off of work to attend regular clinic visits, was the most prevalent obstacle (10.2%).

Emerging Themes in Free-Text Responses

Of the 502 questionnaires completed, 125 KTRs (24.9%) provided free-text comments that were eligible for coding. Commonly occurring themes included: "Improvements needed in coordination and communication with the medical team", "Services required to address language barriers", "Interest in tools for self-management", "Financial barriers", and "Self-management/educational support issues." Important themes and corresponding demonstrative quotations are described in Table 6.

DISCUSSION

Our study suggests that the majority of KTRs (85%) with a PCP are comfortable with their physician's care with respect to preventive care and chronic disease management. This suggests that PCPs are an underutilized resource who can play a greater role in post-transplant care. Our study also showed that only 50% of patients with a PCP indicated that the services of other healthcare professionals were recommended to them. For these complex patients, the incorporation of additional members of the healthcare team (e.g.,

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Table 6. *Summary of Patient Perception Themes Emerging from Free Text Responses*

| Theme | Selected Quotations from KTR Free Text Responses |
|--|--|
| Improvement needed in coordination and communication with medical team | <ul style="list-style-type: none"> • "Need someone who could coordinate the results and notes provided by all the specialists I see and make decisions regarding my overall health" • "The transplant team should contact my family physician to remind him of his support after transplant." • "Send a newsletter to patients "regularly" that keep them informed about related issues, advice, nutrition {family doctors are not overly familiar with transplantation and need to be sent a general package that informs them / gives them basic info regarding dos and don'ts, medication interactions, important things to consider during care}, research into new anti-rejection meds; very disappointing to see no such newsletter sent by email." |
| Services required to address language barriers | <ul style="list-style-type: none"> • "[I would like] more social workers who speak my language to address the emotional and psychological stresses after transplant." • "Due to my language barriers, it's better for me to receive reminders [...] via email or text message." • "[The issue is] more of a language barrier than anything." |
| Interest in tools for self-management | <ul style="list-style-type: none"> • "Please create a form of activity to continue and reinforce the self-care management to a kidney transplant patient." • "[I would like] reminders [for] flu shots, etc. [and] more education [related to] transplant meds." • "[I would like knowledge of] supports available i.e. [regarding] health regimen: diet/exercise in our community and access to community supports." |
| Inadequate management of psychosocial issues | <ul style="list-style-type: none"> • "I would like to see more support from a psychological viewpoint: how chronic illness affects workplace/earning potential, family life, sex, body image, emotional stability." • "Offer a list of therapists (psychiatrist/psychologist) to help patients post-transplant especially those therapies that are covered by OHIP (psychologists)." • "[There should be] referral or [establishment] of support groups." |

...continued from page 41

nutritionists, pharmacists) has been shown to improve patients' quality of life (Bodenheimer, 2003; Ouwens et al., 2005). Therefore, KTRs should be encouraged to seek the services of their PCPs and receive appropriate referrals from their PCPs to other healthcare professionals. In addition, forming a standardized collaborative care model between PCPs and transplant nephrologists could improve quality of care and alleviate the current burden on transplant centres.

KTRs who had PCPs listed in their electronic health records were screened to be approached for this survey-based study. Despite this screening method, almost a quarter of respondents indicated a PCP was not involved in their post-transplant care. It is possible that the proportion of KTRs without a PCP at our centre is actually greater than originally estimated. There may be at least three factors contributing to this observation: (1) Patients may have been lost to follow-up post-transplant or during the several years spent on dialysis prior to transplant; (2) there may be a lack of access to the PCP; or (3) KTRs may not be comfortable seeking primary care and default to relying on their transplant centre. A recent Ontario study reported approximately 9% of a stratified random patient sample did not have a PCP (Reid et al., 2009). Among patients without a physician, the majority (27%) indicated a lack of access, whereas 13% listed alternative healthcare access (Reid et al., 2009). Based on our present study, transplant nephrologists at our centre may frequently supplement the role of PCPs.

Coupled with a collaborative care approach for improved chronic disease management is the idea of patient self-management support. In this study, KTRs positively rated their physicians in several domains of self-management support and acknowledged the importance of independently managing their medical conditions. A smaller proportion of patients were positive about their own abilities. There is strong evidence that self-management interventions are associated with improved clinical outcomes across a variety of chronic conditions (WHO, 2002). Since the management of a chronic health condition is ultimately under the direct control of the patient, self-management support may be an important intervention in chronic disease care (Barr et al., 2003).

Some of the limitations of this study deserve note. First, the study population was not randomly sampled from the potentially eligible pool of patients; rather, a convenience

sample of patients present at their clinic visits during the recruitment period was used. As a result, it is possible that the KTRs who were sampled were systematically different from those patients who were not available to be approached. It is unlikely, however, that the calendar dates on which follow-up visits were booked are related to patients' perceptions of their primary care. Second, this study reflects the perceptions of patients at one transplant centre and may not be representative of all KTRs in Canada. Third, it should be noted that our survey did not define self-management skills and, thus, patients may have interpreted self-management differently, and their perceptions may not accurately reflect their degree of competency in self-management. Fourth, the aim of this study was to ascertain the comfort level that KTRs have with their PCP, impediments to optimal care, and attitudes toward self-management. Thus, the *perception* of care versus the *actual* quality of care provided by the PCPs to the KTRs were outside the scope of this study. Last, a significant proportion of patients approached declined to participate because of disinterest, language barriers, and other factors; this may have an impact on the generalizability of our study results.

In summary, this novel study provided insight into the state of primary care for KTRs known to a large Canadian transplant centre. In general, KTRs have a positive perception of their PCPs, want them involved in their post-transplant care, and would like their help in facilitating self-management of their chronic health conditions. The refinement of patient healthcare management in the primary care setting warrants continued attention and collaboration, as solid-organ transplantation and associated post-transplant chronic disease continue to increase in prevalence. Similar surveys focusing on PCPs are needed to directly ascertain the comfort level and expertise of family physicians in managing chronic conditions. A more complete perspective regarding the issues surrounding the quality of primary healthcare provided to transplant patients would also be beneficial.

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