Health & Place 15 (2009) 390–393

Contents lists available at ScienceDirect

Health & Place

journal homepage: www.elsevier.com/locate/healthplace

Short Report

They really want to go back home, they hate it here: The importance of place in Canadian health professionals' views on the barriers facing Aboriginal patients accessing kidney transplants

Kate Anderson [a,*], Karen Yeates [b], Joan Cunningham [c,d], Jeannie Devitt [e], Alan Cass [a]

[a] The George Institute for International Health and the University of Sydney, PO Box M201, Missenden Road, Camperdown, NSW 2096, Australia
[b] Queens University, Kingston, ON, Canada
[c] Menzies School of Health Research and Institute of Advanced Studies, Charles Darwin University, NT, Australia
[d] University of Sydney, NSW, Australia
[e] The George Institute for International Health, NT, Australia

ARTICLE INFO

Article history:
Received 29 November 2007
Received in revised form
3 March 2008
Accepted 10 March 2008

Keywords:
Kidney transplantation
Indigenous health
Health inequalities
Access to healthcare

ABSTRACT

Aboriginal Canadian patients with end-stage kidney disease receive disproportionately fewer transplants than non-Aboriginal patients. The reasons for this are poorly understood and likely to be complex. This qualitative study employed thematic analysis of in-depth interviews with Canadian kidney health professionals ($n = 23$) from programs across Canada to explore their perspective on this disparity.

Individual-level factors were the most commonly reported barriers to Aboriginal patients accessing transplants—most notable of which was patients' remote living location. Understanding the role of 'place' as a barrier to accessing care and the lived experiences of Aboriginal patients emerged as key research priorities.

Introduction

End-stage kidney disease (ESKD) is a preventable chronic disease that disproportionately affects Aboriginal populations in many countries (Bramley et al., 2004). Kidney transplantation is considered to be the optimal treatment for *most* patients with ESKD; compared with long-term dialysis, it confers a better quality of life (Evans et al., 1985), a longer life expectancy (Wolfe et al., 1999) and lower costs (Cass et al., 2006). Despite the higher incidence of ESKD among Aboriginal Canadians, there is growing evidence that Aboriginal Canadian patients receive transplants at substantially lower rates than other patient groups (Tonelli et al., 2004; Yeates et al., 2004).

Receiving a kidney transplant is a complex and often lengthy process. Patients must: be deemed medically suitable for, and interested in, a transplant; be referred to a programme; receive transplant education; complete the pre-transplant work-up; become wait-listed; and, finally, receive a donor kidney. The barriers to patients progressing through any or all of these stages are likely to be complex and multifaceted (Alexander and Sehgal, 1998), which might explain why the low rates of transplant among Aboriginal patients have not yet been clearly explained.

A recent study conducted in the Canadian province of Alberta found that while Aboriginal patients were equally likely to be referred for transplant assessment, they spent longer in the work-up process and were approximately half as likely as other patients to be wait-listed for transplant (Tonelli et al., 2005). The factors underlying these low rates of wait-listing and work-up completion remain unclear. In order to effectively address this disparity for Aboriginal patients, it is first essential to identify and investigate the barriers facing this patient group accessing transplants.

We aimed to explore the views of Canadian kidney health professionals on the barriers facing Aboriginal ESKD patients accessing kidney transplants, as a critical first step. We acknowledge that the views of health care providers do not account for the lived experience of patients. However, these health care providers develop their understanding of barriers through providing care for many patients and, crucially, are key decision makers with regard to kidney transplantation. This study draws on material from in-depth interviews with health professionals from kidney transplant programs across Canada. Of particular interest in this analysis were the perceived reasons for the low rates of

* Corresponding author at: Royal Prince Alfied Hospital, The George Institute for International Health, Level 10, King George V Building, Missenden Road, Camperdown, NSW 2050, Australia. Tel.: +61 2 9993 4500; fax: +61 2 9993 4502.
E-mail address: kanderson@george.org.au (K. Anderson).

1353-8292/$ - see front matter © 2008 Elsevier Ltd. All rights reserved.
doi:10.1016/j.healthplace.2008.03.002

wait-listing, work-up completion and kidney transplantation among Aboriginal Canadians on dialysis.

Methods

Design

Semi-structured, in-depth interviews were conducted with 23 health professionals from six Canadian provinces in 2006 (Table 1). The topics covered in the interviews were: treatment choices; patient suitability for transplant; barriers to transplant; 'compliance'; living kidney donation; information and communication; and system and context. This paper focuses on a thematic analysis of the sections of these interviews where interviewees reflected on the barriers to patients accessing transplantation.

Participants and setting

The seven transplant programs included were specifically selected to maximise the geographic area and proportion of Aboriginal patients serviced by participating interviewees. The Director of each transplant programme was contacted by a team investigator (KY, KA) and invited to participate in the study. All Directors agreed to participate and facilitate contact with individuals holding particular roles within their programs.

These individuals were then invited via email to participate in the study. The health professionals were purposively sampled to include the views of key decision makers within each transplant programme, including senior transplanting nephrologists and programme directors ($n = 8$), transplant managers and coordinators ($n = 5$), clinical nurse specialists and patient educators ($n = 8$) and Aboriginal renal nurses ($n = 2$).

Data collection and analysis

The majority of interviews were conducted individually and in-person; two were conducted via telephone. All interviews were conducted by one team investigator (KA), were digitally recorded and transcribed for analysis. Participant demographics were collected via self-report.

The data were analysed through thematic analysis of the transcribed interviews using QSR NVivo 7 (Doncaster, Australia). The coding and thematic analysis of the interview data was undertaken by one team investigator (KA), with review and input from all other investigators at regular consensus meetings.

Ethical approval

This study received ethics approval from the Queens University Research Ethics Board.

Table 1
Providence of interviewees ($n = 23$)

Province	Interviewees
Alberta	6
British Columbia	3
Manitoba	3
Ontario	5
Quebec	3
Saskatchewan	3
Total	23

Results

Our analysis of the views of a selection of key Canadian kidney health professionals revealed several factors identified as key barriers to patients accessing transplantation across the country. Interestingly, the barriers identified as facing *all* patients were predominantly system-level factors, whereas those identified as specifically facing *Aboriginal* patients were chiefly individual-level factors. The most frequently and/or emphatically mentioned of these individual-level barriers was Aboriginal patients' remote living location. Cultural and communication differences, perceived motivation and comorbidities were also mentioned.

Individual versus systemic barriers

When asked to identify the barriers facing *all* patients receiving a kidney transplant, respondents focused predominantly on broader system-level barriers, with the shortage of available organs and long waiting times mentioned most frequently. The complexity of the health and transplant systems and matching criteria used in Canadian organ allocation algorithms were also commonly spoken about. This commentary from a Transplant Coordinator highlights the issue of system complexity as a barrier to accessing transplants:

> The system is so large and cumbersome and the lack of an information system is the huge thing…we may not necessarily know the patient in the dialysis unit has had a heart attack…and then we find that out and the transplant work up stops. Then it's up to somebody to restart the work up when the patient is suitable and there are so many areas where it could fall down. [CIMP13]

The issue of inadequate resourcing—in terms of time, personnel, finance and education materials—was mentioned by several respondents as an obstacle to effective transplant assessment, education and wait-listing processes. The scope of this problem is illustrated in these comments from a Clinical Nurse Leader:

> There's a huge backlog—with 700 patients on our referral or at some stage on the list. We have probably over 300 patients that have never been assessed. We have the potential to assess only three patients a week with the team that we have. [CIMP04]

While system-level factors were most commonly identified as barriers facing all patients, when asked about the barriers facing Aboriginal patients specifically, respondents focused primarily on individual-level factors. Most notable of these factors were: patients' living in remote locations, perceived lack of motivation, high rates of co-morbid illness, language differences and cultural factors. The cultural factors outlined by the respondents included transplantation not being seen as accepted by older Aboriginal people and Aboriginal patients not self-advocating or actively seeking information. As one Transplant Programme Manager articulated:

> Transplant in the Aboriginal population is not nearly the same as it is in other populations, in the Caucasian population anyway, it is just not as accepted and I think that is one of the huge barriers. [CIMP08]

Remote living location as a key barrier to transplantation

The difficulty associated with care provision to Aboriginal patients living in remote parts of Canada was the most commonly