

# Limited health literacy in advanced kidney disease



Dominic M. Taylor<sup>1,2</sup>, John A. Bradley<sup>3</sup>, Clare Bradley<sup>4</sup>, Heather Draper<sup>5</sup>, Rachel Johnson<sup>6</sup>, Wendy Metcalfe<sup>7</sup>, Gabriel Oniscu<sup>8</sup>, Matthew Robb<sup>6</sup>, Charles Tomson<sup>9</sup>, Chris Watson<sup>3</sup>, Rommel Ravanan<sup>2,10</sup> and Paul Roderick<sup>1,10</sup>; on behalf of the ATTOM Investigators

<sup>1</sup>Department of Primary Care and Population Sciences, University of Southampton, Southampton, UK; <sup>2</sup>Richard Bright Renal Service, North Bristol National Health Service Trust, Bristol, UK; <sup>3</sup>Department of Surgery, University of Cambridge, and National Institute for Health Research Cambridge Biomedical Research Centre, Cambridge, UK; <sup>4</sup>Health Psychology Research Unit, Royal Holloway, University of London, London, UK; <sup>5</sup>Institute of Applied Health Research, University of Birmingham, Birmingham, UK; <sup>6</sup>National Health Service Blood and Transplant, UK; <sup>7</sup>Scottish Renal Registry, UK; <sup>8</sup>Transplant Unit, Royal Infirmary of Edinburgh, UK; and <sup>9</sup>Department of Renal Medicine, Freeman Hospital, Newcastle-upon Tyne, UK

**Limited health literacy may reduce the ability of patients with advanced kidney disease to understand their disease and treatment and take part in shared decision making. In dialysis and transplant patients, limited health literacy has been associated with low socioeconomic status, comorbidity, and mortality. Here, we investigated the prevalence and associations of limited health literacy using data from the United Kingdom-wide Access to Transplantation and Transplant Outcome Measures (ATTOM) program. Incident dialysis, incident transplant, and transplant wait-listed patients ages 18 to 75 were recruited from 2011 to 2013 and data were collected from patient questionnaires and case notes. A score >2 in the Single-Item Literacy Screener was used to define limited health literacy. Univariate and multivariate analyses were performed to identify patient factors associated with limited health literacy. We studied 6842 patients, 2621 were incident dialysis, 1959 were wait-listed, and 2262 were incident transplant. Limited health literacy prevalence was 20%, 15%, and 12% in each group, respectively. Limited health literacy was independently associated with low socioeconomic status, poor English fluency, and comorbidity. However, transplant wait-listing, preemptive transplantation, and live-donor transplantation were associated with increasing health literacy.**

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**Correspondence:** Dominic M. Taylor, Richard Bright Renal Service, Southmead Hospital, Bristol, BS10 5NB, UK. E-mail: [dominic.taylor@nbt.nhs.uk](mailto:dominic.taylor@nbt.nhs.uk)

<sup>10</sup>These supervising authors contributed equally to this work.

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The term “health literacy” describes patients’ ability to access, understand, interpret, and use health-related information to manage and improve health.<sup>1</sup> As a concept, health literacy is distinct from, but influenced by general literacy and numeracy.<sup>2</sup> Limited health literacy is associated with difficulty managing medications, poorer overall health, increased mortality, and less efficient use of health services in the general populations.<sup>3</sup> The existence of a “social gradient” of health literacy,<sup>4</sup> whereby those with low socioeconomic status also have low health literacy, may promote health inequity. Poor health literacy also appears to mediate the negative effect of nonwhite ethnicity on patient activation, a separate construct that enables effective decision making.<sup>5,6</sup> In this way, health literacy differences may perpetuate the effect of ethnicity on access to health care services.

Patients with advanced kidney disease, who may be receiving dialysis, preparing for transplantation, or living with a kidney transplant are required to cope with complex medication regimens, dietary changes, the limited flexibility of dialysis treatment schedules and frequent outpatient appointments. These activities require health navigation skills, the ability to gain health knowledge, motivation, and problem-solving abilities, all of which are components of personal health literacy.<sup>7</sup> Shared decision-making strategies and the promotion of self-care can improve patient satisfaction and health in kidney disease,<sup>8</sup> and this is reflected in national health care policies.<sup>9,10</sup> However, adequate health literacy is a prerequisite for patient engagement with shared decision making.<sup>11,12</sup>

Interventions that attempt to improve health literacy or compensate for poor health literacy have become a priority in kidney disease care,<sup>13,14</sup> although such strategies could be more effective if more were known about the associations of limited health literacy and the mechanisms of any effect on outcomes. A recent systematic review of the effects of health literacy on health outcomes included no studies of kidney disease patients and identified the need for large-sample, nationally representative data.<sup>3</sup> In general populations, lower literacy or numeracy is associated with the presence of a long-term health conditions<sup>15</sup> and with mortality in older people.<sup>16</sup>

In the USA, the prevalence of limited health literacy and its associations have been described in chronic kidney disease patients,<sup>17</sup> although there is marked heterogeneity in the

reported prevalence of limited health literacy, likely to be related to relatively small sample size, the use of different health literacy measures, and the varying characteristics of the study participants. Poorer health literacy has been associated with mortality and reduced likelihood of referral for transplantation in US hemodialysis patients, and recipients of live-donor kidney transplants have been found to be more health literate than those receiving deceased-donor transplants.<sup>18–21</sup> In UK patients with kidney disease, there has been little work undertaken to identify the scale of the health literacy problem and its associations.

In this large UK-wide study of over 6800 patients, we aimed to determine the prevalence of limited health literacy and its associations with demographics, comorbidity, and socioeconomic status in patients at 3 different stages of treatment: at initiation of dialysis, while on the kidney transplant waiting list, and at the point of kidney transplantation. We also considered the potential implications for patients' progress toward transplantation.

## RESULTS

A total of 6842 patients were recruited: 2621 incident dialysis patients, 1959 wait-listed patients, and 2262 incident transplant patients, including 469 patients who contributed data to >1 group. The process of patient inclusion is shown in [Figure 1](#).

### Prevalence of limited health literacy

Health literacy was measured using the Single-Item Literacy Screener (SILS): "How often do you need to have someone help you when you read instructions, pamphlets or other written material from your doctor or pharmacy?" Options were 1—Never, 2—Rarely, 3—Sometimes, 4—Often, and 5—Always. Responses "Sometimes," "Often," and "Always" were selected to represent limited health literacy. This decision was informed by work where the SILS was validated against the Short Test of Functional Health Literacy in Adults (S-TOFHLA), a 36-item health literacy assessment tool.<sup>22,23</sup> Responses to the SILS in each group are shown in [Figure 2](#). The prevalence of limited health literacy was 20% in the incident dialysis group, 15% in the wait-listed group, and 12% in the incident transplant group. The distribution of individual SILS scores and the prevalence of limited health literacy differed significantly between groups ( $P < 0.001$ ). [Figure 3](#) shows the patient pathways to transplantation and the prevalence of limited health literacy among patients in each group and subgroup.

### Associations with limited health literacy

[Table 1](#) shows the patient characteristics and univariate analyses comparing patients with adequate and limited health literacy within each group. [Figure 4](#) shows the results of fully adjusted logistic regression models identifying patient factors associated with limited health literacy.

In the incident dialysis group, fully adjusted models showed that limited health literacy was significantly associated

with younger age, poorer English fluency, higher comorbidity, depression, psychosis, lower educational level, unemployment, or long-term disability (when compared with full-time employment), the absence of car or home ownership and having >2 children. Current smoking was associated with reduced odds of limited health literacy.

Similar associations were found in the wait-listed group, although stronger associations between limited health literacy and unemployment or long-term disability were detected. Depression, absence of home ownership, and number of children were not significantly associated with limited health literacy in the wait-listed group.

The incident transplant group showed similar patterns of association, except that patients of black ethnicity were significantly less likely to have limited health literacy than those of white ethnicity. However this association relates to a small number of observations: only 8 black patients in this group had limited health literacy.

Patients of Asian ethnicity had significantly higher odds of limited health literacy than did white patients, but these differences were not significant after adjustment for English fluency (see [Supplementary Results](#) and [Supplementary Table S1](#)). Although lower educational level was associated with limited health literacy in all 3 groups, education did not predict health literacy entirely: between 3% and 10% of patients with university-level qualifications had limited health literacy.

After multiple imputations to account for missing data, the prevalence of limited health literacy in each group remained the same. Pooled estimates of logistic regression models from 20 imputed datasets in each group showed no major differences when compared with the models including complete cases only. Results from these models are shown in the [Supplementary Results](#) and [Supplementary Table S2](#).

### Comparison of patient groups

[Figure 3](#) shows the patient groups and subgroups and relative prevalence of limited health literacy. [Tables 2](#) and [3](#) show univariate and multivariate analyses comparing the prevalence of limited health literacy between patient subgroups. Incident dialysis patients had a significantly higher prevalence of limited health literacy than did wait-listed patients on dialysis ([Figure 3](#), marker A). This difference was statistically significant until adjustment for socioeconomic status, and adding adjustment for comorbidity further reduces the effect of group on the likelihood of limited health literacy.

By univariate analysis, there were no significant differences in limited health literacy prevalence between patients wait-listed on dialysis and recipients who underwent deceased-donor transplantation, excluding patients transplanted preemptively (marker B in [Figure 3](#)) or between patients wait-listed preemptively and those who received a deceased-donor preemptive transplant (marker C in [Figure 3](#)).

Preemptive live-donor transplant recipients had a significantly lower prevalence of limited health literacy than

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