

# Paying for Hemodialysis in Kerala, India: A Description of Household Financial Hardship in the Context of Medical Subsidy

Christina Bradshaw<sup>1</sup>, Noble Gracious<sup>2</sup>, Ranjit Narayanan<sup>3</sup>, Sajith Narayanan<sup>4</sup>, Mohammed Safeer<sup>5</sup>, Geetha M. Nair<sup>6</sup>, Praveen Murlidharan<sup>7</sup>, Aiswarya Sundaresan<sup>8</sup>, Syamraj Retnaraj Santhi<sup>8</sup>, Dorairaj Prabhakaran<sup>8</sup>, Manjula Kurella Tamura<sup>1</sup>, Vivekanand Jha<sup>9</sup>, Glenn M. Chertow<sup>1</sup>, Panniyammakal Jeemon<sup>10</sup> and Shuchi Anand<sup>1</sup>

<sup>1</sup>Division of Nephrology, Department of Medicine, Stanford University School of Medicine, Stanford, California, USA;

<sup>2</sup>Department of Nephrology, Government Medical College, Thiruvananthapuram, Kerala, India; <sup>3</sup>Department of Nephrology, KMCT Medical College, Manassery, Kerala, India; <sup>4</sup>Department of Nephrology and Urology, Aster Malabar Institute of Medical Sciences Hospital, Kozhikode, Kerala, India; <sup>5</sup>Department of Nephrology, Al Arif Hospital, Thiruvananthapuram, Kerala, India; <sup>6</sup>Department of Nephrology, PRS Hospital, Thiruvananthapuram, Kerala, India; <sup>7</sup>Department of Nephrology, Kerala Institute of Medical Sciences, Thiruvananthapuram, Kerala, India; <sup>8</sup>Clinical Research Division, Centre for Chronic Disease Control, Gurgaon, Haryana, India; <sup>9</sup>The George Institute for Global Health, New Delhi, India; and <sup>10</sup>Department of Epidemiology, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, Kerala, India

**Introduction:** Many low- and middle-income countries are implementing strategies to increase dialysis availability as growing numbers of people reach end-stage renal disease. Despite efforts to subsidize care, the economic sustainability of chronic dialysis in these settings remains uncertain. We evaluated the association of medical subsidy with household financial hardship related to hemodialysis in Kerala, India, a state with high penetrance of procedure-based subsidies for patients on dialysis.

**Methods:** Patients on maintenance hemodialysis at 15 facilities in Kerala were administered a questionnaire that ascertained demographics, dialysis details, and household finances. We estimated direct and indirect costs of hemodialysis, and described the use of medical subsidy. We evaluated whether presence of subsidy (private, charity, or government-sponsored) was associated with lower catastrophic health expenditure (defined as  $\geq 40\%$  of nonsubsistence expenditure spent on dialysis) or distress financing.

**Results:** Of the 835 patients surveyed, 759 (91%) reported their households experienced catastrophic health expenditure, and 644 (77%) engaged in distress financing. Median dialysis-related expenditure was 80% (25th–75th percentile: 60%–90%) of household nonsubsistence expenditure. Government subsidies were used by 238 (29%) of households, 139 (58%) of which were in the lowest income category. Catastrophic health expenditure was present in 215 (90%) of households receiving government subsidy and 332 (93%) without subsidy.

**Conclusions:** Provision of medical subsidy in Kerala, India was not associated with lower rates of household financial hardship related to long-term hemodialysis therapy. Transparent counseling on impending costs and innovative strategies to mitigate household financial distress are necessary for persons with end-stage renal disease in resource-limited settings.

*Kidney Int Rep* (2019) ■, ■–■; <https://doi.org/10.1016/j.ekir.2018.12.007>

KEYWORDS: chronic kidney disease; health financing; hemodialysis

© 2018 International Society of Nephrology. Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Dialysis is among the most expensive of commonly used life-sustaining medical treatments. As more low- and middle-income countries work to improve

availability of dialysis,<sup>1,2</sup> experts are calling for thoughtful strategies for its use, with a focus on intensive patient counseling regarding the medical and financial burdens of therapy.<sup>3</sup>

In India, the government has committed to more extensive public financing of health care.<sup>4</sup> Nonetheless, health care expenditures still remain punishingly high; up to 37 million people are forced below the poverty line in India each year due to out-of-pocket medical costs.<sup>5,6</sup> For dialysis, medical subsidy plans at the

**Correspondence:** Christina Bradshaw, Division of Nephrology, Stanford University School of Medicine, 777 Welch Road, Suite DE, Palo Alto, California, 94304, USA. E-mail: [cbradsha@stanford.edu](mailto:cbradsha@stanford.edu)

Received 11 October 2018; revised 15 November 2018; accepted 10 December 2018; published online 20 December 2018

central and state levels offer reimbursement of the dialysis procedure for persons with incomes below the poverty level.<sup>7</sup> However, the extent to which government subsidy defrays the substantial costs of therapy and protects households from impoverishment is unknown. At the same time, demand is experiencing unfettered growth: estimates of chronic kidney disease prevalence in India range from 9% to 17%,<sup>8–10</sup> and poor risk factor control may cause substantial numbers to reach end-stage renal disease (ESRD).<sup>9</sup>

We conducted a study to understand the household financial burden of hemodialysis in persons with ESRD in Kerala, India. Kerala represents a best-case scenario for persons on dialysis in India: it is the highest performing state on measures of human development,<sup>11</sup> and overall health indices, such as infant mortality and life expectancy, are superior to most of India.<sup>12,13</sup> The state government provides subsidies to public and private hospitals for dialysis costs on a continuous basis, and any person with ESRD is eligible for reduced treatment (dialysis procedural) fees, irrespective of financial status.<sup>14,15</sup> Among patients who are considered below the poverty line, national health insurance coverage (called “RSBY,” or Rashtriya Swasthya Bima Yojana) and charity-based supplementation of medical expenses is common, with the latter being acquired directly via individual lottery or indirectly via hospital arrangements with nongovernmental organizations.<sup>7,16–18</sup> Compared with coverage provided by government initiatives, the private insurance market remains small and is typically obtained via individual purchase or employer sponsorship.<sup>19</sup>

From our survey at 15 dialysis units in North and South Kerala, we report the proportion of patients on hemodialysis who receive a medical subsidy, and evaluate the association between medical subsidy and household catastrophic health expenditure and distress financing. We also estimate and rank the direct and indirect costs of hemodialysis therapy as experienced on a household level.

## METHODS

We presented study rationale and design at local Indian Society of Nephrology meetings in Kerala’s capital city, Thiruvananthapuram. We reached out to public (i.e., government-run) and private institutions and were able to engage 2 public and 13 private facilities in North and South Kerala (which according to available published data represent 35% of all registered facilities [ $n = 40$ , 5 public and 35 private]).<sup>20</sup>

### Study Population and Data Collection

We recruited persons  $\geq 18$  years of age with a diagnosis of ESRD who had been on maintenance hemodialysis for

at least 1 month. At each dialysis facility, a lead research assistant or site principal investigator conducted study orientation and training on questionnaire administration for dialysis nurses or unit managers. Each unit was also provided with a reference sheet that clarified frequently asked questions. Eligible patients were approached consecutively and, in those who provided informed consent, a structured questionnaire was administered in either Malayalam, Tamil, or English. The questionnaire ascertained patient demographics, cause of ESRD, comorbidities, hospitalizations, dialysis prescription, and availability and amount of medical subsidy. Self-reported medical history was confirmed via medical chart review. In this same questionnaire, we asked patients to estimate monthly direct (dialysis procedure, medications, clinic, and laboratory) and indirect (travel, self-wage loss, relatives’ wage loss) out-of-pocket costs related to hemodialysis (Supplementary Table S1).

### Measures of Household Financial Hardship

We defined catastrophic health expenditure as monthly out-of-pocket dialysis-related expenditure  $\geq 40\%$  of monthly household *nonsubsistence* (or nonfood) expenditure, as commonly used in the literature.<sup>21–25</sup> The World Health Organization also uses the following definitions of catastrophic health expenditure: monthly out-of-pocket health expenditure  $> 10\%$  or  $> 25\%$  of monthly *total household* expenditure or income.<sup>26</sup> We conducted additional analyses applying these World Health Organization definitions. Distress financing, another common measure of health financing, was defined as borrowing from family/friends, selling possessions, or taking out loans to fund dialysis care.<sup>24,25,27</sup>

### Statistical Analyses

We followed STROBE (strengthening the reporting of observational studies in epidemiology) guidelines for observational studies to present descriptive data.<sup>28</sup> Data were missing in fewer than 2% of patients, with the exception of monthly household income (16% missing). We used 4 categories for medical subsidy: none, private insurance (self-paid or employer-sponsored), charity, or government. In cases in which patients had more than 1 source of subsidy ( $n = 19$ ), government aid superseded other forms. We calculated the proportion of patients with catastrophic health expenditure and distress financing, stratified by age, sex, dialysis vintage, employment status, facility type, monthly household income, and subsidy type. Because catastrophic health expenditure and distress financing were common in our cohort, we estimated the adjusted risk of these 2 outcomes using modified Poisson

regression,<sup>29</sup> with our exposure of interest being subsidy type. In addition to the variables considered in our stratified analysis, we included household size in our model. Continuous measures were compared using 2-sample *t*-tests or Kruskal-Wallis tests as appropriate, and categorical measures were compared using  $\chi^2$  tests. We considered 2-tailed *P* values <0.05 as statistically significant. Analyses were performed using the Statistical Analysis System (SAS) software, version 9.4 (SAS Institute, Cary, NC).

### Ethics Approval

Ethics approval was obtained for the study via the Centre for Chronic Disease Control in New Delhi, India, Stanford University School of Medicine in Palo Alto, California, and the hospitals affiliated with the dialysis units in Kerala, India.

## RESULTS

A total of 835 patients on maintenance hemodialysis at facilities in North (10 sites, *n* = 540) and South (5 sites, *n* = 295) Kerala consented to participate in the study. [Table 1](#) describes patient demographics, cause of ESRD, and dialysis prescription details, by subsidy type.

Men comprised most of our study population (*n* = 601, 72%), and most of our cohort attended private facilities for hemodialysis (*n* = 735, 88%), commensurate with the overall distribution of public versus private facilities in the state. The mean age of participants was 55 ± 13 years, and median dialysis vintage was 25 months (25th, 75th percentile range 12 to 48). Patients in the no-subsidy or private insurance groups were more likely to have a university education, be employed, and have a higher income than those who received charity or government subsidies; 139 (58%) patients receiving government subsidy reported a monthly household income of Indian rupees (INR) ≤10,000 (\$561 in 2017 international dollars [INT\$]<sup>30</sup>). A total of 175 (21%) patients underwent twice-weekly hemodialysis; this prescription was most common among persons who received government support. Common causes of ESRD were diabetes and hypertension, and were similar across subsidy groups. There was widespread use of erythropoietin stimulating agents (*n* = 789, 95% of patients overall). Patients had experienced a median of 3 (25th, 75th percentile range 1 to 7) hospitalizations since their dialysis initiation.

### Costs of Therapy

[Figure 1](#) demonstrates the relative scale and breakdown of direct versus indirect costs, overall and by subsidy type. In the overall cohort, indirect expenses

comprised almost three-quarters of monthly spending, with the largest contributor being lost wages. Most direct costs were attributed to medications in the government subsidy group, whereas patients in the no-subsidy, private insurance, and charity groups had substantial session-related direct costs.

### Role of Subsidy in Catastrophic Health Expenditures and Distress Financing

[Figure 2](#) shows the amount of financial assistance received through private insurance, charity, or government aid. Median subsidy amounts were INR 20,930 (INT\$1175) (25th, 75th percentile range 10,000 [INT\$561] to 20,930 [INT\$1175]), INR 5000 (INT\$281) (25th, 75th percentile range 3000 [INT\$168] to 6000 [INT\$337]), and INR 6400 (INT\$359) (25th, 75th percentile range 4500 [INT\$253] to 7000 [INT\$393]) for private, charity and government subsidies, respectively. Patients with private insurance received substantially more assistance than those in the charity or government subsidy groups (*P* < 0.001).

A total of 759 (91%) patients experienced catastrophic health expenditure, with those receiving charity subsidy most affected ([Figure 3](#)). Patients spent a median of 80% (25th, 75th percentile range 60% to 90%) of their households' nonsubsistence, or disposable, income on dialysis-related care. Proportions for catastrophic health expenditure were higher among patients in the charity and government groups and lower in the private insurance group, relative to the no-subsidy group ([Figure 3](#)); the adjusted risk of catastrophic health expenditure did not differ by subsidy type (relative risk 0.91 [95% confidence interval 0.83–1.01], 1.03 [95% confidence interval 0.98–1.07], and 0.96 [95% confidence interval 0.89–1.03] for private, charity, and government subsidy groups, respectively). When using alternate definitions of catastrophic health expenditure (dialysis-related expenses >10% or >25% of total expenses<sup>26</sup>), the proportion of patients experiencing financial hardship was 97% and 92% for the 10% and 25% cutoffs, respectively.

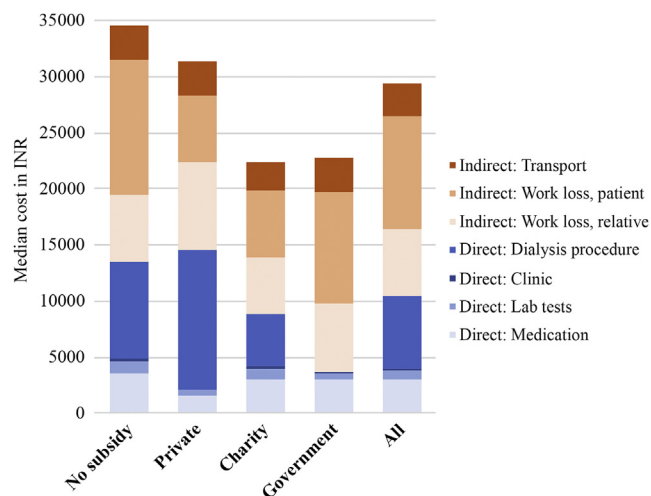
A total of 644 (77%) patients engaged in distress financing, with a higher prevalence observed in the charity and government groups versus the private insurance group. [Table 2](#) shows that younger patients, patients dialyzing in public facilities, and those with lower household income were more likely to report engaging in distress financing. After adjustment for socioeconomic and demographic factors, those in the charity and government groups remained at higher risk of distress financing versus the no-subsidy group (relative risk 1.23 [95% confidence interval 1.11–1.36]

**Table 1.** Characteristics of patients on maintenance hemodialysis, by subsidy type<sup>a</sup>

Characteristic	None <i>n</i> = 356	Private <i>n</i> = 82	Charity <i>n</i> = 159	Government <i>n</i> = 238	All <i>N</i> = 835
<b>Demographics</b>					
Age, mean (SD)					
Sex	58 (13)	59 (9)	52 (13)	53 (12)	55 (13)
Women	108 (30)	19 (23)	41 (26)	66 (28)	234 (28)
Men	248 (70)	63 (77)	118 (74)	172 (72)	601 (72)
Household size	4 (4, 6)	4 (4, 5)	5 (4, 6)	4 (4, 6)	4 (4, 6)
<b>Education</b>					
None/below 5th grade	60 (17)	10 (12)	29 (18)	50 (21)	149 (18)
Completed 5th grade	86 (24)	27 (33)	59 (37)	71 (30)	243 (29)
Completed 12th grade	134 (38)	16 (20)	49 (31)	80 (34)	279 (33)
University or above	76 (21)	29 (35)	22 (14)	37 (16)	164 (20)
<b>Occupation</b>					
Employed	58 (16)	22 (27)	21 (13)	30 (13)	131 (16)
Unemployed or retired	207 (58)	49 (60)	102 (64)	162 (68)	520 (62)
Student or homemaker	91 (26)	11 (13)	36 (23)	46 (19)	184 (22)
<b>Household income/month<sup>b</sup></b>					
INR ≤10,000	59 (17)	14 (17)	36 (23)	139 (58)	248 (30)
10,001 to 40,000	169 (48)	52 (63)	91 (57)	72 (30)	384 (46)
≥40,001	45 (13)	9 (11)	10 (6)	5 (2)	69 (8)
Missing	83 (23)	7 (8)	22 (14)	22 (9)	134 (16)
<b>Dialysis details</b>					
<b>Facility type</b>					
Private	350 (98)	81 (99)	159 (100)	145 (61)	735 (88)
Public	6 (2)	1 (1)	—	93 (39)	100 (12)
Months on dialysis	24 (12, 47)	30 (16, 48)	33 (18, 60)	23 (12, 47)	25 (12, 48)
<b>Sessions per week</b>					
Fewer than 3	71 (20)	12 (15)	4 (3)	107 (45)	194 (23)
Three or more	285 (80)	70 (85)	155 (98)	131 (55)	641 (77)
<b>Session length (h)</b>					
Less than 3	3 (1)	—	1 (1)	1 (0)	5 (1)
Three or more	353 (99)	82 (100)	158 (99)	237 (100)	830 (99)
<b>Access</b>					
Fistula	307 (86)	71 (87)	156 (98)	213 (90)	747 (90)
Catheter	30 (8)	9 (11)	3 (2)	18 (8)	60 (7)
Graft	19 (5)	2 (2)	—	7 (3)	28 (3)
<b>Nature of dialysis start<sup>c</sup></b>					
Planned	118 (33)	28 (34)	81 (51)	82 (35)	309 (37)
Emergent	222 (62)	51 (62)	75 (47)	151 (63)	499 (60)
<b>Cause of ESRD<sup>d</sup></b>					
Hypertension	191 (54)	42 (51)	118 (74)	120 (50)	471 (56)
Diabetes	177 (50)	44 (54)	64 (40)	91 (38)	376 (45)
Glomerulonephritis	5 (1)	4 (5)	2 (1)	6 (3)	17 (2)
Other/unknown	27 (8)	8 (10)	8 (5)	38 (16)	81 (10)
<b>Medications</b>					
ESA	329 (92)	80 (98)	156 (98)	224 (94)	789 (95)
Phosphorus binders	265 (74)	64 (78)	143 (90)	159 (67)	631 (76)
Vitamin D	192 (54)	41 (50)	107 (67)	97 (41)	437 (52)
Heparin	290 (82)	75 (92)	153 (96)	224 (94)	742 (89)
<b>Medical history</b>					
<b>Comorbidities</b>					
Hypertension	280 (79)	63 (77)	143 (90)	177 (74)	663 (79)
Diabetes	222 (62)	50 (61)	82 (52)	119 (50)	473 (57)
Cardiovascular disease <sup>e</sup>	85 (23)	19 (22)	15 (10)	71 (30)	190 (23)
Hospitalizations since dialysis start	3 (1, 8)	4 (1, 9)	4 (1, 10)	2 (1, 4)	3 (1, 7)

ESRD, end-stage renal disease; ESA, erythropoietin stimulating agents; INR, Indian rupees.

<sup>a</sup>Numbers expressed as *n* (%) or median (25th, 75th percentile) unless otherwise indicated.<sup>b</sup>2017 international dollar values, using purchasing power parity (PPP) conversion 17.818<sup>30</sup>: ≤\$561, \$562 to \$2245, ≥\$2245.<sup>c</sup>Participants who reported "I don't know" are not presented.<sup>d</sup>Categories are not mutually exclusive.<sup>e</sup>Includes self-reported history of myocardial infarction, congestive heart failure, and stroke.



**Figure 1.** Breakdown of monthly direct and indirect dialysis-related expenses, by subsidy type and overall. INR, Indian rupees.

for the charity group and relative risk 1.22 [1.10–1.36] for the government group).

## DISCUSSION

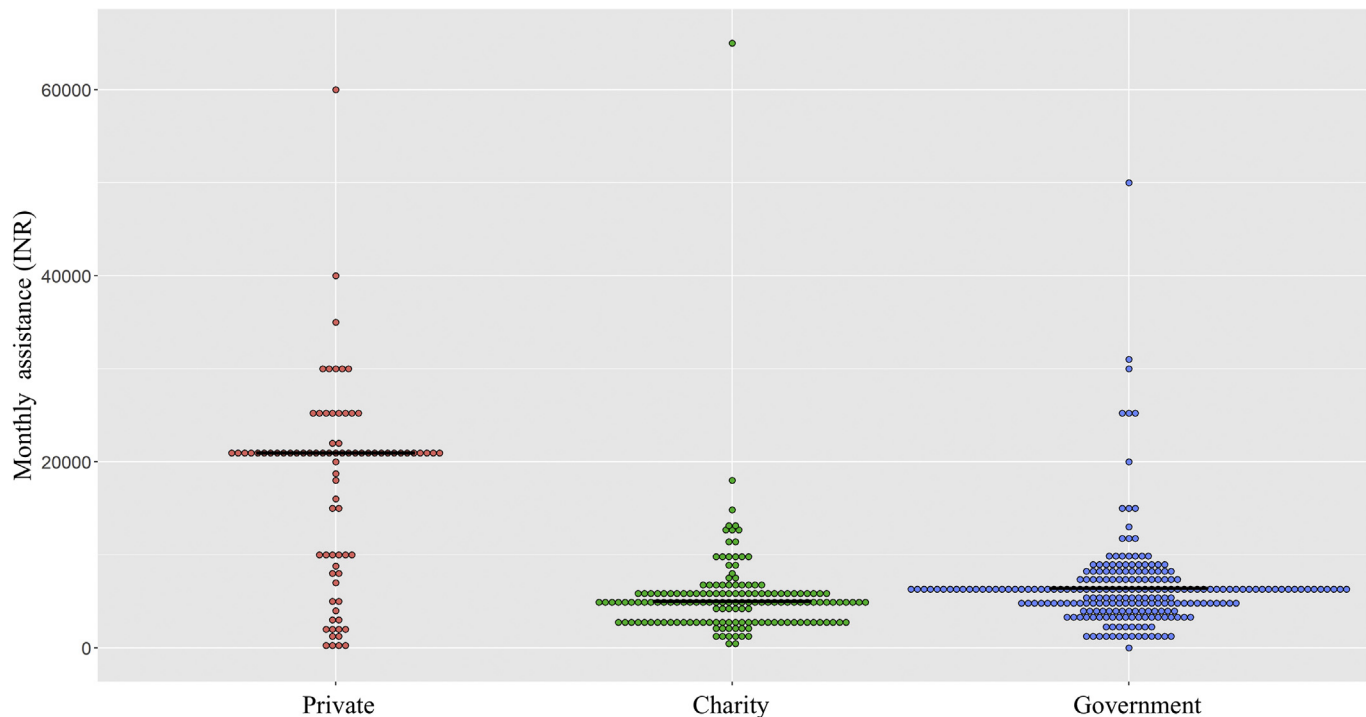
Nine of 10 households in Kerala with a family member on maintenance hemodialysis spend more than 40% of their nonfood expenditure to support their therapy; one-half of them spend more than 80% of this sum. Despite availability of some form of subsidy in approximately 60% of patients surveyed, hemodialysis becomes the overriding financial concern of households. Presence and type of subsidy were not associated with lower rates of catastrophic health expenditure, and patients receiving charity or government subsidies were more likely to engage in distress financing. The high prevalence of financial hardship among patients on maintenance hemodialysis with or without subsidy highlights the need for a more comprehensive approach to address ESRD in resource-limited settings.

Our multicenter study is one of the largest to assess the financial hardship of maintenance hemodialysis in a resource-constrained setting. Similar to South Africa, Mexico, Brazil, Philippines, and China, India is experiencing rapid growth in its hemodialysis population. Recent data indicate a 4-fold increase in dialysis utilization in less than 5 years.<sup>31</sup> Even as increasing infrastructure for therapy remains an important concern,<sup>32,33</sup> physicians, policymakers, and community advocates are beginning to recognize the financial repercussions of starting patients on a costly life-long therapy, the burden of which is often compounded by loss of employment for 1 or more household members.<sup>34</sup>

The economic burden of hemodialysis for households is staggering. For context, using a definition comparable to ours, approximately 4% of households

in Asian countries experienced catastrophic health expenditure in 2010.<sup>21</sup> A diagnosis of cancer or hospitalizations for cardiovascular events in India causes approximately one-half of affected households to experience catastrophic health expenditure,<sup>25,35</sup> but in our study, hemodialysis led to near universal financial distress. A single-center study of patients undergoing hemodialysis at a public facility in North India showed that catastrophic health expenditure was present in 40% to 50% and distress financing in approximately 60%<sup>36</sup>; the lower prevalence of catastrophic health expenditure observed in the North Indian study could be due to different patterns of patient reporting, more external financial support, and nature of facility (i.e., public) surveyed. Further, the authors did not include lost wages in their cost assessment, which may have led to an underestimation of the prevalence of catastrophic health expenditure in their cohort. The sole study on costs of hemodialysis from Kerala did not quantify financial hardship; however, the authors found that direct costs of dialysis therapy outweighed indirect costs, a finding that differs from our own, perhaps due to how these categories were defined (transportation and opportunity costs from family involvement were classified as “direct” costs) or differing patterns of dialysis session coverage.<sup>37</sup> We found that indirect costs of travel or loss of employment accounted for more than one-half of monthly dialysis-related expenses; despite a mean age of 55 years, fewer than 30% of these patients reported actively working. Their wage losses are rarely recouped through unemployment or medical disability benefits, even in Kerala, where the state government has been lauded for its social programs.<sup>38–40</sup>

Perhaps somewhat surprisingly, households of patients on hemodialysis without subsidy and/or with private insurance still experienced significant financial hardship as a result of hemodialysis, despite their relative affluence. Although the presence of savings or other income reserves likely precluded engagement in distress financing in these groups, approximately 7 in 10 patients with private insurance reported experiencing catastrophic health expenditure. One reason for this finding could be that patients in these groups almost exclusively attended higher-cost private facilities, where thrice-weekly dialysis is the standard and the cost of the dialysis procedure was substantial. Patients receiving charity-based subsidies were also more likely to attend dialysis thrice-weekly at private facilities as compared with patients in the government subsidy group, who received a comparable amount of assistance and were otherwise similar demographically. Wider reporting of quality metrics, including dialysis water quality, staffing ratios, rates of access-related



**Figure 2.** Monthly financial assistance, by subsidy type. Each dot represents a study participant, and the horizontal black bar represents the median monthly amount in Indian rupees (INR) provided by the subsidy.

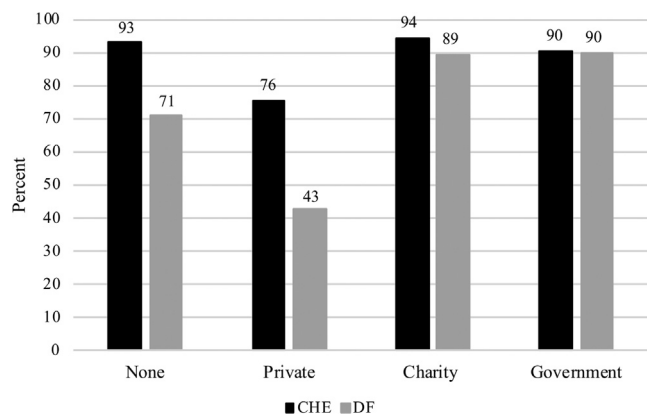
infections, hospital admissions, and mortality,<sup>41</sup> are crucial to ensuring that patients paying for higher-cost facilities are in fact receiving care on par with national standards. If government institutions are able to provide similar-quality care at lower costs, the overall financial burden of hemodialysis therapy could be substantially reduced.

The high burden of financial hardship in our study highlights the inadequacy of medical subsidies for long-term hemodialysis care. More than one-half of patients receiving government subsidy reported monthly household incomes of INT\$561 and below, whereas the monthly cost of a twice-weekly hemodialysis session at a public hospital is approximately INT\$337; thus, were it not for the government subsidy, hemodialysis would likely not be an option. Several other countries, including the Philippines and Malaysia, are adopting a “procedure only” or “limited” subsidy approach as seen in our study. In Malaysia, nongovernmental organizations that provide hemodialysis at a discounted rate receive financial benefits from the government.<sup>1</sup> In the Philippines, PhilHealth, the government-run insurance company, pays a fixed sum for 90 dialysis treatments per year.<sup>42</sup> Although these government subsidies may reduce the socioeconomic disparities in the *initiation* of therapy, the long-term sustainability of hemodialysis costs as experienced by households has not been considered in detail.

Other approaches to mitigate the financial hardship associated with hemodialysis in low- and middle-income countries are complex and varied, and it is important for

relevant authorities to be aware of and to build on what has been done elsewhere while recognizing that there is no one-size-fits-all approach. First, chronic kidney disease screening programs for early detection and prevention of disease progression are necessary. Approximately 7% of the Indian population suffers from diabetes,<sup>43</sup> a major risk factor for chronic kidney disease, and improved glycemic control can substantially slow progression of kidney disease.<sup>44</sup> In patients who nonetheless require renal replacement therapy, prioritization of peritoneal dialysis and kidney transplantation may not only be more cost-efficient in the long-term,<sup>45,46</sup> but may also allow patients with ESRD to resume work. To address organ shortage, it is necessary to build and maintain deceased donor kidney transplant programs.<sup>47</sup> Further, reduction of overhead costs can be achieved through domestic manufacturing of health care goods.<sup>44</sup>

Inclusion of dialysis therapy in universal health care packages is another option. Thailand has offered universal coverage for persons with ESRD with a “peritoneal dialysis first” approach<sup>2</sup>; however, it remains to be seen if this policy change is economically sustainable, particularly if applied to a more populous country like India. Community-based insurance schemes that allow patients to pool resources toward future medical expenses also could be promoted.<sup>48</sup> In many low- and middle-income countries, rationing of health care resources, including dialysis, may be inevitable; it is therefore imperative for governments and health care societies to develop transparent and evidence-based



**Figure 3.** Prevalence of catastrophic health expenditure and distress financing, by subsidy type. The private group had significantly lower catastrophic health expenditure (CHE) and distress financing (DF) versus the none, charity, or government groups in unadjusted analyses ( $P < 0.001$ ).

guidelines for equitable distribution of these resources.<sup>3</sup> In South Africa, patient selection criteria for public financing of dialysis have been instituted, and are routinely reviewed to address socioeconomic inequalities in access.<sup>49</sup> Finally, the health care community also should use a more discerning approach to counseling regarding renal replacement therapy. International experts have called for physicians to engage in transparent and thorough discussions with patients regarding the medical and financial burdens of dialysis, and to offer the option of conservative, nondialytic care where appropriate.<sup>3</sup>

Our study has several strengths. It is the first multi-center description of the financial hardship experienced by patients on hemodialysis in a resource-constrained setting, with a representative ratio of private and public facilities. We also specifically examine the association of medical subsidies with household financial hardship, which can inform policy makers as they consider further strategies for health care financing. Our study also has limitations. First, given that much of our data are based on self-report, recall bias and misclassification of outcome are possible; however, these methods have been used in other studies examining financial hardship in low- and middle-income countries, where precise measurements of wealth or prosperity are difficult to obtain.<sup>21,50</sup> We attempted to corroborate patient-reported medical history and medications with facility documentation where available, and we tried to minimize confounding by adjusting for various socioeconomic and demographic factors. Nonetheless, residual confounding is likely present, and the observational nature of our study calls for cautious interpretation of any causal relationships. Second, the cost estimates are reported as an “average” monthly expense, and do not capture potential variations over time. Given the high

**Table 2.** Catastrophic health expenditure and distress financing by select patient demographics

Characteristic	Catastrophic health expenditure <sup>a</sup> (%)	Distress financing <sup>b</sup> (%)
<b>Age (yr)</b>		
< 44	93	84 <sup>c</sup>
45 to 64	94	79
≥ 65	91	69
<b>Sex</b>		
Men	93	78
Women	93	75
<b>Occupation</b>		
Employed	95	73
Unemployed/retired	92	78
Student/homemaker	94	77
<b>Years on dialysis</b>		
<1	94	74
≥1 to <3	92	78
≥3	93	78
<b>Sessions/week</b>		
Fewer than 3	90	78
Three or more	94	78
<b>Facility type</b>		
Public	92	94 <sup>c</sup>
Private	93	75
<b>Monthly household income, INR</b>		
≤10,000	91	86 <sup>c</sup>
10,001–40,000	90	75
≥40,001	96	55
Missing	93	79

<sup>a</sup>Catastrophic health expenditure defined as dialysis-related expenditure ≥40% of nonsubsistence expenditure.<sup>24</sup>

<sup>b</sup>Distress financing defined as borrowing from family/friends, selling property, or taking out bank loan.<sup>25,27</sup>

<sup>c</sup>Chi-square  $P < 0.005$ .

number of prevalent patients surveyed, it is possible that these patients’ income, and therefore ability to pay for hemodialysis, changed significantly since dialysis initiation. As there is no centralized statewide ESRD registry, we cannot compare our cohort with the overall Kerala hemodialysis population. However, on the basis of a recently published nationwide estimate of the numbers of kidney failure-related deaths in India from the Million Death Study, our survey of 15 facilities roughly reflects approximately 35% of the total hemodialysis units in Kerala.<sup>20</sup> Further, most (>65%) of our patients are men, aged 45 to 55 years, and use private facilities, similar to hemodialysis patients enrolled in a statewide claims-based analysis from Andhra Pradesh.<sup>31</sup> Due to the relative affluence and high level of education found in Kerala, we may underestimate the true financial burden of hemodialysis in the rest of India. Lastly, we do not yet have data to assess the effects of medical subsidy and/or financial hardship on health outcomes in this population.

In summary, we found that households with patients on maintenance hemodialysis in Kerala experienced crippling levels of financial hardship related to

treatment, despite availability of a variety of medical subsidies. Given the significant psychosocial and financial ramifications of an ESRD diagnosis in resource-constrained settings, governments and health care providers must work together to develop sustainable strategies to provide equitable health care financing for this vulnerable population.

## DISCLOSURE

VJ has received consulting fees from NephroPlus and Baxter and has grant support from Baxter and GlaxoSmithKline. SA has received grant funding from Satellite Healthcare. All the other authors declared no competing interests.

## ACKNOWLEDGMENTS

We thank the study participants and the dialysis nurses and unit managers at the study sites in helping administer the questionnaire. We also thank AS and SRS for their dedicated oversight and training of personnel at the multiple sites, as well as timely data organization and entry. Funding was provided by the National Institutes of Health Fogarty Global Health Equity Scholars R25TW9338 grant. PJ is supported by a clinical and public health intermediate fellowship from the Wellcome Trust-DBT India Alliance (2015-2020).

## ROLE OF FUNDING SOURCE

This research was financially supported by National Institutes of Health Fogarty Global Health Equity Scholars (grant number R25TW9338). The funding source had no role in the development of the study, analysis of data, or the preparation of this manuscript for submission.

## SUPPLEMENTARY MATERIAL

**Table S1.** Questions used in out-of-pocket cost assessment. Supplementary material is linked to the online version of the paper at [www.kireports.org](http://www.kireports.org).

## REFERENCES

- Morad Z, Choong HL, Tungsanga K, et al. Funding renal replacement therapy in southeast Asia: building public-private partnerships in Singapore, Malaysia, Thailand, and Indonesia. *Am J Kidney Dis.* 2015;65:799–805.
- Tantivess S, Werayingyong P, Chuengsaman P, et al. Universal coverage of renal dialysis in Thailand: promise, progress, and prospects. *BMJ.* 2013;346:f462.
- Jha V, Martin DE, Bargman JM, et al. Ethical issues in dialysis therapy. *Lancet.* 2017;389:1851–1856.
- Prinja S, Chauhan AS, Karan A, et al. Impact of publicly financed health insurance schemes on healthcare utilization and financial risk protection in India: A systematic review. *PLoS One.* 2017;12:e0170996.
- Garg CC, Karan AK. Reducing out-of-pocket expenditures to reduce poverty: a disaggregated analysis at rural-urban and state level in India. *Health Policy Plan.* 2009;24:116–128.
- van Doorslaer E, O'Donnell O, Rannan-Eliya RP, et al. Effect of payments for health care on poverty estimates in 11 countries in Asia: an analysis of household survey data. *Lancet.* 2006;368:1357–1364.
- Rashtriya Swasthya Bima Yojana (RSBY). About RSBY – genesis of the RSBY. Ministry of Health and Family Welfare, Government of India. Published 2009. Available at: [http://www.rsby.gov.in/about\\_rsby.aspx](http://www.rsby.gov.in/about_rsby.aspx). Accessed March 2018.
- Ene-Iordache B, Perico N, Bikbov B, et al. Chronic kidney disease and cardiovascular risk in six regions of the world (ISN-KDDC): a cross-sectional study. *Lancet Glob Health.* 2016;4:e307–e319.
- Anand S, Kondal D, Montez-Rath M, et al. Prevalence of chronic kidney disease and risk factors for its progression: a cross-sectional comparison of Indians living in Indian versus U.S. cities. *PLoS One.* 2017;12(3):e0173554.
- Anand S, Shivashankar R, Ali MK, et al. Prevalence of chronic kidney disease in two major Indian cities and projections for associated cardiovascular disease. *Kidney Int.* 2015;88:178–185.
- India Human Development Report 2011: Towards Social Inclusion. Institute of Applied Manpower Research, Planning Commission, Government of India.
- Indian Council of Medical Research, Public Health Foundation of India, and Institute for Health Metrics and Evaluation. India: Health of the Nation's States – The India State-Level Disease Burden Initiative. New Delhi, India. *ICMR, PHFI, and IHME.* 2017.
- India State-Level Disease Burden Initiative Collaborators. Nations within a nation: variations in epidemiological transition across the states of India, 1990–2016 in the Global Burden of Disease Study. *Lancet.* 2017;390:2437–2460.
- Kerala Social Security Mission. Samashwasam. Available at: <http://www.socialsecuritymission.gov.in/index.php/samashwasam1>. Social Justice Department, Government of Kerala. Accessed February , 2018.
- Karunya Benevolent Fund. Available at: <https://kerala.gov.in/karunya-benevolent-fund-scheme>. Government of India. Last updated July 2017. Accessed February 2018.
- K Chittappilly Foundation. Medical Assistance. Available at: <http://kcfoundation.in/medicalassistance.php#kcf>. Accessed February , 2018.
- HELP Foundation. Dialysis Support (DAYA). Available at: <https://www.helpfoundation.in/dialysis-support/>. Accessed March , 2018.
- Aster MIMS. MIMS Charitable Trust. Available at: <https://astermims.com/highlights/mims-charitable-trust>. Accessed February , 2018.
- Insurance Regulatory and Development Authority of India. Annual Report 2016–2017. Available at: [https://www.irdai.gov.in/ADMINCMS/cms/frmGeneral\\_NoYearList.aspx?DF=AR&mid=11.1](https://www.irdai.gov.in/ADMINCMS/cms/frmGeneral_NoYearList.aspx?DF=AR&mid=11.1). Accessed October , 2018.
- Dare AJ. Renal failure deaths and their risk factors in India 2001–13: nationally representative estimates from the Million Death Study. *Lancet Glob Health.* 2017;5:e89–e95.



21. Wagstaff A, Flores G, Hsu J, et al. Progress on catastrophic health spending in 133 countries: a retrospective observational study. *Lancet Glob Health*. 2018;6:e169–e179.
22. Xu K. *Distribution of Health Payments and Catastrophic Expenditures: Methodology*. World Health Organization Discussion Paper. Geneva: World Health Organization; 2005.
23. Xu K, Evans DB, Kawabata K, et al. Household catastrophic health expenditure: a multicountry analysis. *Lancet*. 2003;362:111–117.
24. World Health Organization. *World Health Report: Health Systems Financing, the Path to Universal Coverage*. Geneva: World Health Organization; 2010.
25. Huffman MD, Rao KD, Pichon-Riviere A, et al. A cross-sectional study of the microeconomic impact of cardiovascular disease hospitalization in four low- and middle-income countries. *PLoS One*. 2011;6:e20821.
26. World Health Organization. *World Health Statistics 2017: Monitoring Health for the SDGs, Sustainable Development Goals*. Geneva: World Health Organization; 2017.
27. Joe W. Distressed financing of household out-of-pocket health care payments in India: incidence and correlates. *Health Policy Plan*. 2015;30:728–741.
28. Knottnerus A, Tugwell P. STROBE—a checklist to strengthen the reporting of observational studies in epidemiology. *J Clin Epidemiol*. 2008;61:323.
29. Zou G. A modified Poisson regression approach to prospective studies with binary data. *Am J Epidemiol*. 2004;159:702–706.
30. Organization for Economic Cooperation and Development (OECD). Purchasing power parities (PPP) (indicator). <https://doi.org/10.1787/1290ee5a-en>. Available at: <https://data.oecd.org/conversion/purchasing-power-parities-ppp.htm>. Accessed January 2018.
31. Shaikh M, Woodward M, John O, et al. Utilization, costs, and outcomes for patients receiving publicly funded hemodialysis in India. *Kidney Int*. 2018;94:440–445.
32. Anand S, Bitton A, Gaziano T. The gap between estimated incidence of end-stage renal disease and use of therapy. *PLoS One*. 2013;8:e72860.
33. Liyanage T, Ninomiya T, Jha V, et al. Worldwide access to treatment for end-stage kidney disease: a systematic review. *Lancet*. 2015;385:1975–1982.
34. Sakuma Y, Glassman A, Vaca C. Priority-setting processes for expensive treatments in cardiometabolic diseases. In: Prabhakaran D, Anand S, Gaziano T, Mbanya J, et al., eds. *Disease Control Priorities (third edition): Volume 5, Cardiovascular, Respiratory, and Related Disorders*. Washington, DC: World Bank; 2017:375–388.
35. Daivadanam M, Thankappan KR, Sarma PS, et al. Catastrophic health expenditure & coping strategies associated with acute coronary syndrome in Kerala, India. *Indian J Med Res*. 2012;136:585–592.
36. Kaur G, Prinja S, Ramachandran R, et al. Cost of hemodialysis in a public sector tertiary hospital of India. *Clin Kidney J*. 2018;11:726–733.
37. Suja A, Anju R, Anju V, et al. Economic evaluation of end stage renal disease patients undergoing hemodialysis. *J Pharm Bioallied Sci*. 2012;4:107–111.
38. National Employment Service, Government of Kerala. Unemployment allowance scheme. Available at: [https://www.employmentkerala.gov.in/index.php?option=com\\_content&view=article&id=120&Itemid=54](https://www.employmentkerala.gov.in/index.php?option=com_content&view=article&id=120&Itemid=54). Accessed May, 2018.
39. Kattakayam J. Post retirement adaptation of elderly in India. *Innov Aging*. 2017;1(Suppl 1):126.
40. Kunhikannan T. *Functioning of Contingent Social Security Schemes in Kerala: The Social and Institutional Context of Delivery at the Local Level*. Trivandrum, Kerala, India: Centre for Development Studies; 2012.
41. Klinger AS. Quality measures for dialysis: time for a balanced scorecard. *Clin J Am Soc Nephrol*. 2016;11:363–368.
42. Philippine Health Insurance Corporation. PhilHealth extends dialysis coverage to 90 days. Updated June 26, 2015. Available at: [https://www.philhealth.gov.ph/news/2015/extends\\_dialysis.html](https://www.philhealth.gov.ph/news/2015/extends_dialysis.html). Accessed June 2018.
43. Anjana RM, Deepa M, Pradeepa R, et al. Prevalence of diabetes and prediabetes in 15 states of India: results from the ICMR-INDIAB population-based cross-sectional study. *Lancet Diabetes Endocrinol*. 2017;5:585–596.
44. White SL, Chadban SJ, Jan S, et al. How can we achieve global equity in provision of renal replacement therapy? *Bull World Health Organ*. 2008;86:229–237.
45. Howard K, Salkeld G, White S, et al. The cost-effectiveness of increasing kidney transplantation and home-based dialysis. *Nephrology (Carlton)*. 2009;14:123–132.
46. Klarenbach SW, Tonelli M, Chui B, et al. Economic evaluation of dialysis therapies. *Nat Rev Nephrol*. 2014;10:644–652.
47. Abraham G, Vijayan M, Gopalakrishnan N, et al. State of deceased donor transplantation in India: a model for developing countries around the world. *World J Transplant*. 2016;6:331–335.
48. Ranson MK. Community-based health insurance schemes in India: a review. *Natl Med J India*. 2003;16:79–89.
49. Kilonzo KG, Jones ESW, Okpechi IG, et al. Disparities in dialysis allocation: an audit from the new South Africa. *PLoS One*. 2017;12:e0176041.
50. Khandker S. *Poverty Analysis*. World Bank Institute. Published August 2005. Revised August 8, 2005. Available at: <http://siteresources.worldbank.org/PGLP/Resources/PovertyManual.pdf>. Accessed January 30, 2019.