The Effects of India's COVID-19 Lockdown on Critical Non-COVID Health Care and Outcomes

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Abstract: India's COVID-19 lockdown is widely believed to have disrupted critical health services, but its effect on non-COVID health outcomes is largely unknown. Comparing mortality trends among dialysis patients in the eight months around the lockdown with the previous year, we document a 64% increase in mortality between March and May 2020 and an estimated 22-25% total excess mortality through July 2020. The mortality increase is greater among females and disadvantaged groups. Barriers to transportation and disruptions in hospital services appear to be the main drivers of increased morbidity and mortality. The results highlight the unintended consequences of the lockdown on critical and life-saving non-COVID health services that must be taken into account in the implementation of future policy efforts to control the spread of pandemics.

Main Text:

On 24 March 2020, the Government of India ordered one of the most severe nationwide COVID-19 lockdowns in the world to control virus spread. The lockdown was announced with four hours' notice, barred people from leaving their homes, required non-essential commercial establishments and transport services to close, and was enforced strictly with penalty of arrest (*1*). Google Mobility data show that mobility decreased by 60-80% within days of the announcement (Fig. S1). Although initially limited to 21 days, national restrictions were finally eased 10 weeks later, at the beginning of June, after which they were limited to designated geographic areas based on case counts.

Although critical health services were officially exempt from the lockdown, the media reported widespread disruptions to routine and emergency non-COVID care due to transport and curfew barriers for patients and health workers, hospitals turning patients away, and supply chain disruptions that affected medicine access and costs (*2, 3, 4*). A June 2020 policy report documented a 51% reduction in medical services under government health insurance programs across the country during the lockdown (*5*). Analysis of the publicly available national Health Management Information System (HMIS), which collates monthly reports from public health facilities and workers on a range of health services, including immunization, institutional deliveries, and hospital care, finds dramatic decreases in preventive care and treatment of illness (*6*).

However, quantifying the impact of these disruptions on people's health has remained elusive due to the unavailability of reliable and high frequency data measuring health outcomes, including

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mortality. Because the COVID-19 lockdown may have reduced deaths from some causes, such as road accidents, evaluating its effects requires disaggregated cause-specific mortality. However, the vast majority of deaths in India occur at home, rather than at health facilities, are not included in the national Civil Registration System, and have no certified cause of death (*7*). While government health insurance programs collect real-time data on hospital services provided, they record no details on patient morbidity or mortality. The HMIS data have been found to be of low quality, underrepresent care in the private sector, and do not provide complete morbidity or mortality outcomes (*8*). The Sample Registration System, which estimates age-specific death rates through surveys of a representative subset of the Indian population, does not provide details on cause of death and the most recent report only provides total mortality estimates through 2018 (*9*).

Given the dearth of reliable, updated, and publicly available data on health outcomes in India, evaluating the effect of the COVID-19 lockdown on non-elective health services requires the identification of patients in need of such care and the collection of primary data. This paper uses insurance claims filed under a largescale government health insurance program to identify patients requiring critical chronic non-COVID health care and rapid phone surveys with their households to estimate the effects of the lockdown on health care, morbidity, and mortality in the four months following its imposition.

We focus on dialysis, a form of life-sustaining long-term hospital care. Patients with end stage chronic kidney disease need dialysis to remove waste, salts, and excess water to prevent their build up in the body; regulate levels of potassium, sodium and bicarbonate in the blood; and control blood pressure. Treatment is typically required in three- to four-hour sessions, two to four times each week for the duration of the patient's life or until they get a kidney transplant. Disruptions to dialysis treatment result in the accumulation of fluids and toxins in the body, and can cause extreme swelling, nausea and vomiting, difficulty in breathing and urinating, and other symptoms. Missing dialysis visits or shortening their duration is associated with large increases in hospitalization and mortality (*10-13)*.

The Ayushman Bharat Mahatma Gandhi Rajasthan Swasthya Bima Yojana (AB-MGRSBY), is a statewide government health insurance program in Rajasthan, India (supplemental materials provide details). It entitles approximately 50 million low income individuals, or about two-thirds of the state population, to free secondary and tertiary care at over 1200 empaneled hospitals. All members of eligible households are automatically enrolled based on state poverty lists and face no premium or copay. Hospitals file an electronic claim for every patient visit and are reimbursed by the insurer. The claims data generated provide one of the only ways of directly identifying patients utilizing hospital care in the state.

We obtained access to the universe of administrative claims data through October 2019, which include patient name, phone number, complete dialysis history, and hospitals visited. Dialysis care is the only long-term, non-elective chronic health service provided under AB-MGRSBY: patients on dialysis in late 2019 would continue to require it through the COVID-19 lockdown if still alive. We identified all patients receiving dialysis under AB-MGRSBY between August and October 2019 and called their households for phone surveys to collect data on health care access and outcomes through the lockdown. The survey was conducted with the patient or the person in the household most knowledgeable of their care, and collected data on care-seeking in the month prior to the lockdown, disruptions to care due to the lockdown, morbidity, hospitalization, and the date and cause of death. To limit recall bias in answers about care disruptions, we completed the first round of surveys between late May 2020 and mid-June 2020. To track complete mortality through July, we conducted follow-up surveys focused on morbidity and mortality in July and again in August with all patients alive at the time of the first survey.

The full sample of 3,183 dialysis patients under insurance in Rajasthan is disproportionately male (69%) and 46 years old, on average. By October 2019, the average patient had been on dialysis under insurance for 11.5 months, with 5 visits per month (Table S1). Households with unreachable phone numbers or no eligible dialysis patient were excluded. The supplementary materials provide details. 94% of reached and eligible households consented to participating, resulting in a study sample of 2,110 patients with a complete survey. Surveyed patients were statistically similar to the full sample in age, sex, and monthly dialysis visits, but had been on dialysis for fewer months (Table S1). Of the 1,392 patients alive at the time of the first survey, 1,177 (85%) completed a follow-up survey.

The primary outcome of interest is mortality. To examine changes in mortality over the four months before and after the lockdown, we estimate an unadjusted discrete-time model of mortality hazard, or the share of deaths among people still alive each month, with indicators for each month from December 2019 to July 2020, as well as a model adjusted for socioeconomic, demographic, and care history characteristics. To account for potential seasonal trends or monthly fluctuations in mortality, we use historical insurance claims data to identify a comparison cohort of patients who were alive and on dialysis between August and October 2018. To avoid attrition and recall bias likely to affect phone surveys almost two years later, we use the share of patients observed as having permanently dropped out of dialysis care in the administrative claims data each month to proxy for the share of people that died in that month. We validated this measure in a 2018 audit study, described in further detail in the supplementary materials. We run the same unadjusted model with dummies for each month from December 2018 to July 2019 on the comparison cohort, as well as a model adjusted for demographic and care history variables that can be constructed from the administrative data.

We first document substantial disruptions to health care caused by the lockdown (Fig. 1). Over 62% of households report a disruption in access to dialysis care during the lockdown. 42% of households reported being unable to reach their hospital due to travel barriers. Qualitative findings from open-ended questions in the survey indicate that travel barriers were due to difficulties finding transport and requirements to show proof of official approval of travel exemptions for hospital visits (see supplementary text). 15% found the hospital was closed or refused to provide care, 11% faced increased hospital charges, and 23% switched to a different hospital from the one they typically visit. 17% could not obtain necessary medicines; supply chains disruptions that reduced medicine availability and increased prices contributed to this. Patients faced a 172% increase in payments per visit, driven largely by increased charges at private hospitals, and a 6% average decline in monthly visits between March and April. Although the lockdown was universal, its effects on care-seeking were worse for vulnerable and remote households: lower caste, poorer patients, and those living further away from a dialysis hospital were significantly more likely to have faced any disruption, but there are no substantial differences by patient gender or age (Fig. S2). Structured interviews with 15 hospitals from 10 districts confirm patient reports, but also suggest that hospitals faced their own constraints. 7 of the 15 hospitals reported having to during the lockdown due to staffing and supply shortages. Those that continued services reported a drop in patient visits, which they credited to transportation barriers. Larger hospitals reported receiving patients displaced from nearby hospitals that had closed.

The mortality hazard declines steadily from December to March in the 2019-2020 cohort (Fig.2). This is driven largely by deaths among the most vulnerable patients: elderly patients, those who recently initiated dialysis, and low caste groups have higher mortality in the early months (Fig. S3). Individuals still alive at the end of March are, therefore, likely to be disproportionately lower risk. Mortality in May 2020, after a full month of exposure to the lockdown, increases sharply to 4.37%, a 1.70pp or 63.60% (p=0.01) increase relative to 2.67% mortality in March, prior to the lockdown. Controlling for sociodemographic characteristics and dialysis history increases this to a 1.84pp (67.57%) change over March mortality of 2.72% (Fig. S4). Mortality declines in June and July 2020, but never decreases below March levels; because we did not reach all households in the follow-up survey, actual mortality in this period may be higher than measured (Table S1).

Mortality in the comparison cohort from the previous year follows a statistically similar trend between December and April, but exhibits no increase in May or the subsequent months. This suggests that the sharp increase in May 2020 is not explained by seasonal fluctuations, and that it was not purely a displacement of mortality from the subsequent 2 months, since we observe no offsetting decreases in mortality to below-March levels. Comparing observed deaths between April and July 2020 to deaths if the March 2020 mortality rate had continued and to deaths if the comparison cohort mortality rates for those months had applied, we estimate total excess mortality in the four months following the lockdown was 22-25%.

This excess mortality is unlikely to be due to COVID-19 infections. Only 4 patients, who died between June and August 2020, were reported testing positive for COVID-19. Excluding them from the analysis of mortality does not change trends meaningfully (Fig. S5). Furthermore, we find the largest increase in mortality in May, soon after the lockdown and before the virus had spread widely. If COVID-19 was driving mortality, we would expect deaths to increase over time, alongside confirmed cases. Nevertheless, given that testing rates for COVID-19 remain low in India, we cannot rule out the possibility that it contributed to deaths.

Instead, excess mortality appears to be driven by lockdown-related disruptions to dialysis care. Restricting the sample to patients alive at the end of April and exposed to at least one month of the lockdown, we regress three measures of health outcomes – a morbidity index of dialysis-related health complications, any hospitalization, and death – on an individual-level index of care disruptions during the month of April. We find that a 1SD increase in the care disruptions index is associated with a 0.17SD increase in the morbidity index (p=0.000), 3.1pp increase in the probability of hospitalization (p=0.002), and 2.1pp increase in the probability of death (p=0.013) in the period from May to July (Table 1). These effects are sizeable relative to an overall hospitalization rate of 15% and mortality of 11% over those months and controlling for sociodemographic characteristics and dialysis history does not change the relationships. Disruptions to dialysis care persist in July and August, at the end of our study and after the lockdown was eased, suggesting that adverse effects on morbidity and mortality may continue to unfold over the coming months (Fig. S6).

The effects of disruptions on health outcomes varied across socioeconomic and demographic groups. Analysis of heterogeneity in mortality by subgroup, in Fig. 3, indicates that, while almost every subgroup experienced a large increase in mortality in May relative to March, the increase is larger for females, those below 45 years in age, and socioeconomically disadvantaged groups; these differences are robust to covariate-adjustment (Fig. S7). The association between the care disruption index and health outcomes between May and July is also stronger for these groups (Fig. S8). The greater disruptions to care faced by lower caste and poorer patients noted earlier could partly explain their worse outcomes. However, we find no evidence that females faced higher disruptions than males (Fig. S2). Instead, the higher mortality among women may be due to differential treatment of women within the household. Figure S8 shows that care disruptions were associated with increased morbidity for both males and females, but with increased hospitalization only for males, and with larger increases in mortality for females between May and July. These results suggest that households were less likely to seek hospital care for females, which is consistent with the literature documenting unequal access to care for women in India (*14-17*). Patients in remote locations underserved by the health system also experienced more disruptions associated with larger increase in mortality (Fig. S1, Fig. S9).

The timing and size of the increase in mortality relative to pre-lockdown trends in 2020, as well as to trends in estimated mortality for a similar cohort in the previous year, strongly suggests that the observed increase is due to the nationwide COVID-19 lockdown. The fact that lockdown-related disruptions to dialysis care are positively associated with morbidity and mortality in subsequent months is also consistent with a causal interpretation of the results. While our analysis is restricted to one type of chronic care in one state, our findings are indicative of the serious but largely undocumented health effects of severe disruptions to a range of similar critical chronic care services in other states in India: national government health insurance programs targeting low income households have seen a 6% reduction in dialysis care (similar to our results), a 64% decline in oncology care, and an 80% decrease in critical cardiovascular surgeries (*5*). We demonstrate that a universal policy is likely to have larger adverse effects on health care-seeking and outcomes on already vulnerable subpopulations, who may require extra protections. The findings highlight the unintended consequences of the lockdown on critical and life-saving non-COVID health services that must be taken into account in the implementation of future policy efforts to control the spread of pandemics.

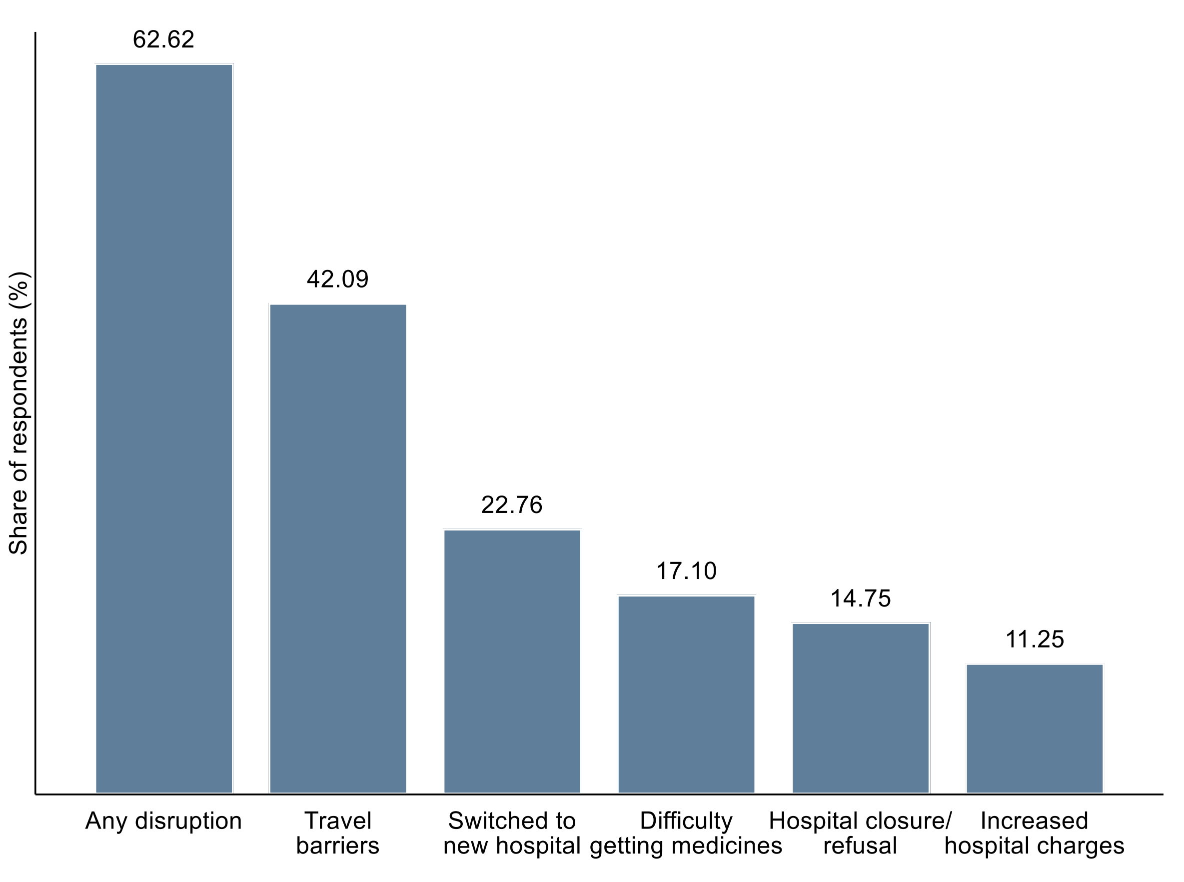

Figure 1: Disruptions to dialysis care during the COVID-19 lockdown. The figure presents the share of patients that reported experiencing disruptions to their dialysis care due to the lockdown at any point between imposition of the lockdown and the first survey conducted in May-June 2020.

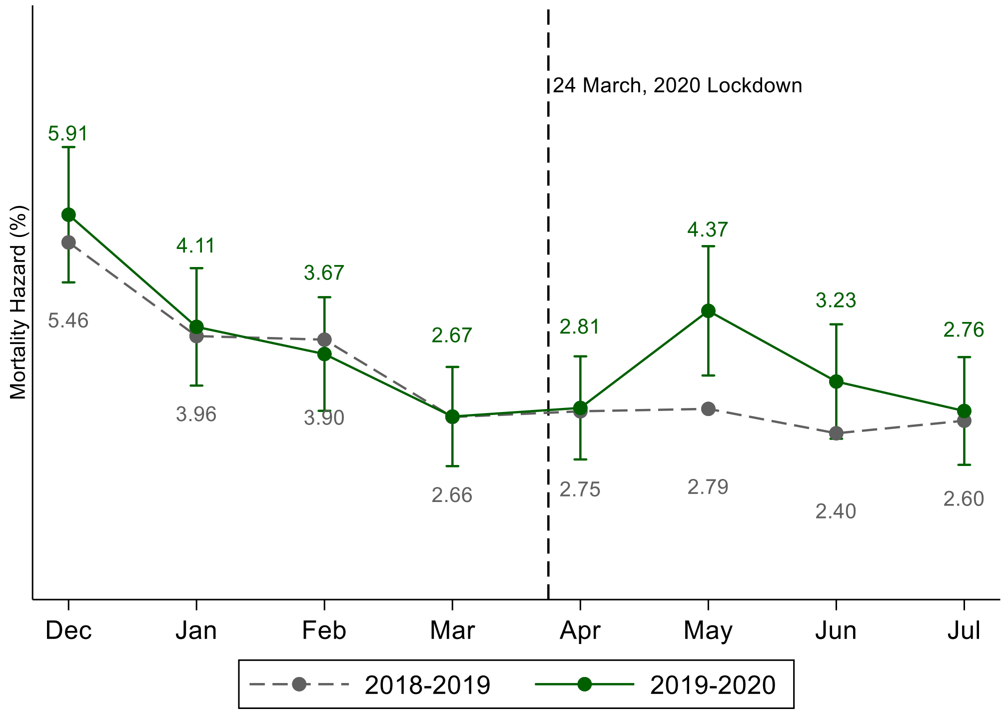

Figure 2: Monthly dialysis mortality in the surveyed and historical cohorts. The green solid line presents the hazard of death, or the share of people still alive that die in each month, for the surveyed cohort, from an unadjusted discrete time model with dummies for each month from December 2019 through July 2020. Vertical bars represent 95% confidence intervals. The grey dashed line presents the monthly hazard for the cohort of patients on dialysis in August-October 2018 from a similar model with dummies for each month from December 2018 through July 2019. Hazards have been converted into percentage terms for ease of interpretation. Mortality in May 2020, after a full month of exposure to the lockdown, is 1.78 percentage points (64%) higher than mortality in March 2020. Total mortality between April and July 2020 is 22-25% higher than expected levels. Covariate-adjusted models are in Fig. S3.

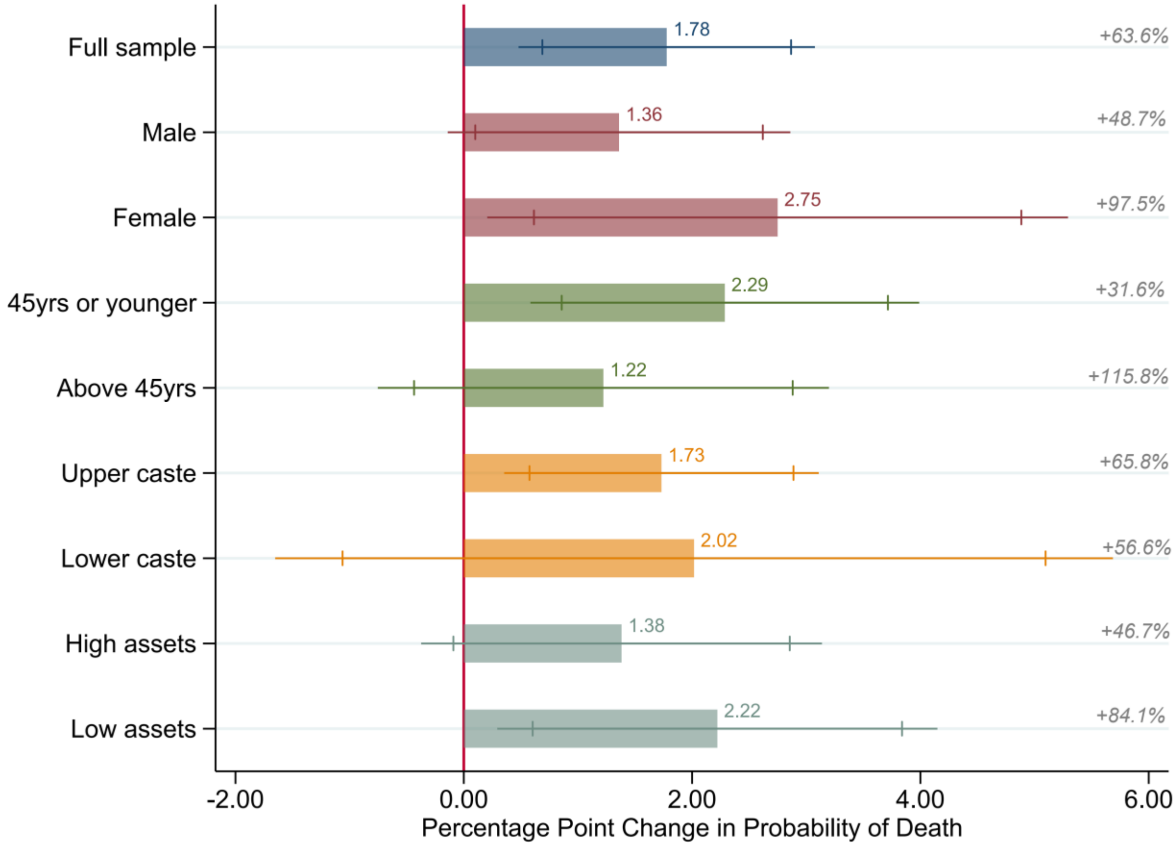

Figure 3: Heterogeneity in mortality effects by subgroup. Each bar represents the percentage point change in unadjusted death hazard between March and May 2020 for the full sample of patients, as well as for each subgroup. Lines represent 90% and 95% confidence intervals. The grey figures on the right present the increase between March and May as a percentage of March mortality. Estimates adjusted for all other subgroup characteristics look similar and are presented in Supplemental Fig. S6.

	(1) Morbidity	(2) Hospitalization	(3) Death
A. Unadjusted			
Care disruptions index	0.172	0.031	0.021
	(0.000)	(0.002)	(0.013)
B. Covariate adjusted			
Care disruptions index	0.171	0.030	0.025
	(0.000)	(0.003)	(0.004)
Observations	1461	1446	1489
Post-lockdown mean	-0.000	0.142	0.108

Table 1: Association between care disruptions and post-lockdown health outcomes. The table presents linear regressions of health outcomes on lockdown-related care disruptions and health outcomes among patients alive thorough April and exposed to at least one full month of the lockdown (p-values in parentheses). The care disruptions index is a composite measure of a range of problems faced in obtaining dialysis care during the lockdown, including hospital closure or service refusal, difficulty obtaining medicines, and a decrease in monthly dialysis visits between March and April. Morbidity is an index of symptoms known to follow disruptions to dialysis. Both indices are standardized over the sample. Hospitalization and death are binary outcomes. All three outcomes are measured over the period May through July 2020. Covariates in Panel B include age, sex, caste group, month of dialysis initiation, and lifetime dialysis visits at baseline. Details on the analysis are in the supplementary methods and materials.

References

1. Ministry of Home Affairs Order No 40-3/2020-D dated 24.03.2020. https://www.mha.gov.in/sites/default/files/Guidelines.pdf.
2. "How Healthcare Became Unaffordable For Non-COVID Patients During The Pandemic," IndiaSpend, 19 June 2020; https://www.indiaspend.com/how-healthcare-became-unaffordable-for-non-covid-patients-during-the-pandemic/.
3. "Private hospitals can't refuse critical patients or insist on testing all for COVID-19: Centre," Indian Express, 28 April 2020; https://www.newindianexpress.com/nation/2020/apr/28/private-hospitals-cant-refuse-critical-patients-or-insist-on-testing-all-for-covid-19-centre-2136540.html.
4. "8 hospitals in 15 hours: A pregnant woman's crisis in the pandemic," New York Times, 12 July 2020; https://www.nytimes.com/2020/06/21/world/asia/coronavirus-india-hospitals-pregnant.html.
5. Owen Smith, Parul Naib, Pulkit K. Sehgal and Sheena Chhabra. PM-JAY Under Lockdown: Evidence on Utilization Trends. (2020). PM-JAY Policy Brief 8. National Health Authority.
6. "COVID-19 disrupted India's routine health services," IndiaSpend, 27 August 2020; https://www.indiaspend.com/covid-19-disrupted-indias-routine-health-services.
7. Jha, P., Gajalakshmi, V., Gupta, P.C., Kumar, R., Mony, P., Dhingra, N., Peto, R. and RGI-CGHR Prospective Study Collaborators. (2005). Prospective study of one million deaths in India: rationale, design, and validation results. *PLoS Med*, *3*(2), p.e18.
8. Sharma, A., Rana, S. K., Prinja, S., & Kumar, R. (2016). Quality of health management information system for maternal & child health care in Haryana state, India. *PLoS One*, *11*(2), e0148449.
9. Sample Registration System (SRS) Bulletins, Office of the Registrar General and Census Commissioner; https://censusindia.gov.in/vital_statistics/SRS_Bulletins/Bulletins.html.
10. R. Saran, J.L. Bragg-Gresham, H.C. Rayner, et al. Nonadherence in hemodialysis: associations with mortality, hospitalization, and practice patterns in the DOPPS. Kidney International, 64 (2003), pp. 254-262.
11. Amanda H. Anderson, Andrew J. Cohen, Nancy G. Kutner, Jeffrey B. Kopp, Paul L. Kimmel, Paul Muntner. Missed dialysis sessions and hospitalization in hemodialysis patients after Hurricane Katrina. (2009). Kidney International, Volume 75, Issue 11, Pages 1202-1208.
12. Zoraster R, Vanholder R, Sever MS. Disaster management of chronic dialysis patients. (2007). Am J Disaster Med. 2(2):96-106.
13. Abdel-Kader K, Unrah ML. Disaster and end-stage renal disease: targeting vulnerable patients for improved outcomes. (2009). Kidney Int.;75(11):1131-1133.
14. Ramakrishnan S, Khera R, Jain S, Saxena A, Kailash S, et al. (2011). "Gender differences in the utilization of surgery for congenital heart disease in India." Heart 97:1920–25.

15. Shaikh M, Peters SAE, Woodward M, et al. (2018). “Sex differences in utilization of hospital care in a state sponsored health insurance programme providing access to free services in South India.” BMJ Glob Health 2018;3:e000859. doi:10.1136/ bmjgh-2018-000859

16. Kapoor M, Agrawal D, Ravi S, et al. (2019). “Missing female patients: an observational analysis of sex ratio among outpatients in a referral tertiary care public hospital in India”. BMJ Open doi: 10.1136/bmjopen-2018-026850.

17. Dupas, P., Jain, Radhika. (2020). “Women Left Behind: Gender Inequity within Rajasthan's Universal Health Care Program”. Working Paper.

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The Effects of India's COVID-19 Lockdown on Critical Non-COVID Health Care and Outcomes
Supplementary Materials

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S1. Materials and Methods

Study population

In December 2015, the Government of Rajasthan, India, launched the statewide Bhamashah Swasthya Bima Yojana (BSBY), later renamed the Ayushman Bharat – Mahatma Gandhi Rajasthan Swasthya Bima Yojana, or AB-MGRSBY, a government health insurance program that entitles all member of low-income households to free care at public and empaneled hospitals. In 2019, the program covered approximately 50 million individuals in 15 million households and included more than 400 public and 800 private, actively participating hospitals. The scheme covers 1400 secondary and tertiary health services, including dialysis. Households are determined to be eligible based on government poverty lists, all members are automatically enrolled, and beneficiaries pay no premium, deductible, or copay for their care under the program. Hospitals file claims in real-time for each visit and service provided to eligible patients through the government's electronic filing system and are reimbursed for this care after review of the claims filed. The government has provided us with the universe of updated insurance claims filed from December 2015, when the program was launched, through October 2019. The data include each patient's residence location, phone number, health services received, and the names and locations of hospitals they visited. These data provide one of the few ways of directly identifying patients utilizing hospital care in India.

Because we only have access to data through October 2019, we cannot directly use them to study disruptions to care during the lockdown. Instead, we leverage these data to identify patients that utilized insurance in October 2019 and are likely to still be in need of non-elective care during the COVID-19 lockdown that began on 24 March, 2020. Dialysis is the only health service under the AB-MGRSBY program that fits this bill. Dialysis is a form of critical chronic care; patients typically require multiple hospital visits each week for the rest of their lives (unless they get a kidney transplant), without which they suffer serious health consequences and death. Using the last 3 months of the data available, we identified all patients on dialysis under the program between August and October 2019. The administrative data provides us with their entire history of dialysis care visits. To collect data on mortality over time and how the COVID-19 lockdown affected it, we called the associated phone numbers in the administrative data to conduct phone surveys. The study population is, therefore, the universe of dialysis patients under a government health insurance program that covers the poorest three-fourths of Rajasthan's population.

Survey sample and details

Table S1 presents complete statistics on the full sample as well as the patients for whom a survey was completed. Of the 3,183 dialysis patients identified, 83.5% (2,659) had a working phone number that could be reached and 70.2% (2,234) confirmed the identity of an eligible dialysis patient. This drop out is explained by several factors. Patient phone numbers in the claims data are not verified or used for other purposes and may have been entered incorrectly, resulting in invalid or wrong numbers. Households in the study context frequently switch between multiple SIM cards, so a substantial share of the numbers were switched off. Unused phone numbers remain active for 3 to 6 months, after which they are deactivated and reassigned to a new individual, so numbers discontinued in Fall 2019, due to death or migration, were likely to have been reassigned to different individuals by the time we started the survey (May 2020). Because this may lead us to underestimate deaths that occurred prior to December 2019, we focus on the four months immediately preceding the lockdown (December 2019 to March 2020) to estimate pre-trends in the mortality hazard. Finally, 119 patients that were confirmed as having been on dialysis and alive but no longer in need of it in 2020 (typically, those with short term rather than chronic kidney problems) were excluded. 2,110 households (94% of those reached and eligible) consented to the survey and comprise the study sample. Patients whose households were successfully surveyed are statistically similar to those not reached or surveyed in age, sex, and monthly dialysis visits prior to the study (Table S1).

We conducted the first round of phone surveys at the end of May and early June to understand the details of care prior to the lockdown and disruptions caused by it. In order to collect complete mortality through the end of July, we conducted shorter follow-up surveys focused on morbidity and mortality in July and again in August with all households of patients that were still alive during the first round. Of the 1,392 patients confirmed alive in the first round, 1,177 (85%) were reached and consented to the follow-up rounds.

The survey was conducted with the patient, or if the patient was unwell or dead, by the member in the household most knowledgeable about the patient's care. The first round took 25 minutes and the second round took 13 minutes, on average. The instruments collected data on dialysis history, care-seeking before and after the lockdown, morbidity, hospitalization, and mortality. For patients that had died by the time of the survey, we asked about their care and disruptions around the time of the lockdown if they had died in March 2020 or later. We collected basic demographic and socioeconomic data to allow analysis of heterogeneity.

Construction of key variables

We measure disruptions by asking whether patients faced each of the following problems at any point during the lockdown: their dialysis hospital was closed; it was open but refused to provide them services; they could not travel to their hospital due to lack of transport or curfews; they had to switch to a different hospital from their primary dialysis hospital; their hospital increased charges over the typical payment; they had difficulties obtaining their dialysis medicines. In addition, we asked about the patient's total dialysis visits and total payment for these visits in the month before the lockdown and in April, the first month after the lockdown onset, and constructed indicators for any decrease in monthly visits and any increase in payments. All of these variables were collected in the first round of the survey, conducted in May and June, to reduce recall problems.

The health outcomes we study are morbidity, hospitalization, and death. All outcomes are based on self-reported data. To construct the mortality time series between December 2019 and July 2020, we collected the month of death for all dead patients (we cross-checked two measures – the date of death and how many months prior to the survey the death occurred –for accuracy), as well as the cause and location of death to ensure it was not unrelated to dialysis. Morbidity and hospitalization are reported for the four weeks prior to the survey, in each round of the survey. Hospitalization is a binary outcome. To measure morbidity, we ask patients whether they experienced any of a range of symptoms that are known to follow disruptions to dialysis care and can be reported by respondents, and then combine these indicators into an individual-level index. The symptoms included are: swelling of the face, hands, legs, or body; vomiting or nausea; extreme tiredness or weakness; difficulty breathing; difficulty urinating; and muscle cramps.

We also create binary variables of socioeconomic and demographic characteristics of patients: female, age under 45 years (approximately the mean and median age), lower caste group, and low assets. Lower caste is an indicator for households of scheduled caste or tribe, the official designations for the lowest group in the Indian caste system (historically called "untouchables" and currently referred to as "Dalits", 17% of the population) and indigenous peoples outside the caste system (9% of the population) that are economically vulnerable and targeted by government affirmative action policies. Households were classified as lower asset if they had a below median score on an asset index created from the first component of a principal components analysis of a list of assets they own, such as a motorcycle, television, or air-conditioner. To create measures of remoteness, we geocoded all dialysis hospitals in the AB-MGRSBY program, and residence locations for approximately 60% of surveyed patients (using addresses in the administrative and survey verification). We calculated the patient's distance to the city that is the administrative headquarters of their residence district as a proxy for remoteness, and to the closest dialysis hospital as a proxy for distance from the health system.

Construction of the historical comparison cohort and analysis of mortality

Because the COVID-19 lockdown was implemented across all of India at the same time, there are no comparable "untreated" populations in 2020. Instead, we compare mortality in 2020 to mortality of a comparison cohort of dialysis patients in the previous year. Using the same administrative insurance claims data, we identified all patients on dialysis between August and October 2018. Because phone surveys almost two years later to confirm historical mortality rates for these patients would suffer from recall bias and attrition due to households changing their numbers, we instead use the share of patients who drop out from dialysis care each month to proxy for monthly mortality. We have validated this measure of mortality in a 2018 audit study in which we identified 663 dialysis patients that had dropped out from the claims data in the previous 3 months and confirmed through phone surveys with their households that only 20% of them were still alive and had dropped out of claims because they left the insurance program, no longer required dialysis (patients with acute kidney failure but not chronic kidney disease may only require dialysis briefly), or had received a kidney transplant. Based on this, we estimate mortality by assuming that, among dialysis patients in the historical cohort, 80% of patients that dropped out of the claims data in a given month died in that month.

Analysis of mortality trends

To examine changes in mortality over time we plot the mortality hazard, or the share of people still alive that die in each month, from a discrete-time model with dummies for each month from December 2019 to July 2020, four months before and after the lockdown (Fig. 2). We use discrete-time, rather than parametric, models in order to detect changes in the probability of death around the time of the lockdown. We run similar models with indicators for each month from December through July with the comparison cohort. The comparison allows us to check whether 2020 mortality follows historical trends, and whether historical mortality displays monthly or seasonal fluctuations that could explain any observed changes in mortality in 2020. We calculate two measures of total excess mortality in the four months after the lockdown was imposed: First, given that the historical trends suggest that mortality in April – July should be similar to March levels, we calculate the difference between observed mortality in these months in 2020 and what total mortality would have been if the March death rate had continued. Second, we directly compare deaths during these months in 2020 to what they would have been if the 2019 mortality rates for these months had applied.

To summarize heterogeneity in mortality across socioeconomic and demographic characteristics, we present the difference in the mortality hazard between March and May, the period of the largest mortality increase, by binary classifications of sex, age, caste, and wealth (described above). Unadjusted estimates are in Fig. 3 and estimates adjusted for each other subgroup characteristic to isolate the effect of group identity are in Fig. S6. We also present results of the full discrete-time hazard model over time for each subgroup in Fig. S2.

Analysis of associations between disruptions and outcomes

To analyze the relationship between care disruptions and health outcomes, we restrict the sample of patients to those alive at the end of April and exposed to at least one month of the lockdown. We create a care disruptions index, which is the first component of a principal-components analysis of all the disruption measures above, including change in visits and in payments between March and April, standardized over the sample for ease of interpretation. We create four health outcomes: an index of morbidity between June and July, standardized over the sample; the probability of any hospitalization in the same period; the probability of death in May (the month in which we find the largest mortality increase); and the probability of death between May and July. We estimate ordinary least squares (OLS) regressions with robust standard errors of each of the health outcomes on the disruptions index without any controls, and a separate model that controls for age above 45 years, sex, caste group, assets, total dialysis visits and month of last dialysis visit in the claims data (prior to being sampled), and dialysis visits in March 2020. Results for the full sample are presented in Table 1 and by subgroup in Fig. S7. In some cases where the respondent ended the survey partway through, we have data on the primary outcome (mortality) that was collected early on, but not on characteristics or care disruptions, resulting in more observations for the mortality outcome (Table 1).

Qualitative interviews with patients and hospitals

To gain a more nuanced understanding of patients' experiences, we built open-ended questions into the survey. Surveyors were instructed to provide prompts, such as "Have you experienced any other health problems or difficulties in getting dialysis care due to the coronavirus lockdown? Can you describe them to me?" and to encourage respondents to answer freely. The research team listened to voice recordings of these answers and compiled them into structured summaries. The qualitative results confirmed that the list of barriers to care-seeking we included in the survey were comprehensive and covered the key proximate causes of care disruptions: hospital closure or service refusal, increased costs of care, travel/transport barriers, having to switch from their primary hospital to a different one, and difficulty obtaining medicines. They also reveal that many patients experienced a series of different barriers that had compounded effects on their care. Excerpts from some open-ended answers:

"The hospital was closed on visits and refused treatment as well. […] We did not have a mode of transport to reach the hospital, I had to try very hard to arrange one. […] As a result, I could only get 3 dialysis visits in total instead of 8."

"There was no doctor in the hospital. No one gave us any information where to find one, there was just one ward boy who did not know anything. […] For getting a treatment that my life depends on, I had to get slips from doctors, permissions from District Collector, stand in long queues..."

"There is this particular medicine that is required for dialysis procedure and that is not currently available in the market. We have not been able to find it for the last few days. […] Private dialysis centers have increased their rates - it has become unaffordable for us. We don't have money to seek treatment in a private hospital, we have lost our jobs so don't have enough money to go get treated in a private hospital, hence I had to take my wife very far to find a public hospital for dialysis. […] Every time we change a hospital, they issue a new set of tests and we have to get them because they will not give us dialysis otherwise. […] Due to shutdown of public transport, I have to now take my wife to dialysis. Because of that neither can I work nor I can be with my wife during her visits."

"I went to two private hospitals, both of them were closed, hence I had to go to a public hospital and got my dialysis there. […] The cost of acquiring my dialysis medicines almost doubled, as they were not available at my regular pharmacist, my hospital was closed, I had to look everywhere and they were available in limited quantities only."

"I have been advised to get three dialysis visits per week. Now because of the lockdown, I have only been able to get two per week. Hence, water fills in my lungs and I have difficulty breathing if I do any physical activity."

Family member of dead patient: *"We live in [District A] and the hospital he regularly visited was in [District B]. When the lockdown was imposed and there was a curfew, he had to find a smaller, alternative facility for dialysis. We were asked to get permissions and multiple slips from govt officials. He didn't get the care he usually received. That smaller hospital didn't do his dialysis properly and that's why he died. […] The medicines that were prescribed to him were only available in [District B] and not his local area due to the lockdown. He missed his medicines for BP and diabetes for 20 days."*

Family member of dead patient: *"Due to the lockdown, the patient couldn't travel to [District B] on time and wasn't able to find a hospital in the vicinity, so he died on the way to the hospital itself."*

<u>Ethical considerations</u>

The research protocol and survey instruments were approved by the Institutional Review Boards of the Institute for Financial Management and Research (IFMR) in India and Stanford University in the United States. All data collection was managed by a team employed by JPAL South Asia at

IFMR, which has extensive research conducting field and phone-based research. Standard research protocols were followed. Participants were informed of the nature and possible consequences of the study and were given the opportunity to discontinue participation at any point of their choosing. Given that data were being collected during a pandemic that may have severely adversely affected households, the households in our sample may have been particularly vulnerable due to their socioeconomic status and illness, and the health and security of our data team was also a concern, we took several additional precautions to reduce any adverse consequences. To reduce the burden on households, we designed the surveys to be short: among surveyed households, the first round of the survey took 25 minutes and the second follow-up round took 13 minutes, on average. We trained surveyors to very clearly offer households the option not to participate, to be sensitive to households during the survey, particularly those that had faced substantial difficulties or deaths, and to provide all households with information on local COVID-19 and hospital health service helplines to consult if they experience medical problems. To protect the surveyors, all surveys were conducted over the phone from the security of their homes. Additional software was installed on the surveyor tablets to mask phone numbers from them and to automatically upload all data to secure cloud services without storing it locally.

S2. Figures

Fig. S1. Changes in mobility in Rajasthan. Using publicly available mobility data for Rajasthan, we demonstrate that people's movements dropped by over 60% within days of the 24 March 2020 lockdown and remained well below pre-lockdown levels through the end of and beyond the national lockdown. The data are collated by Google from the location histories of phone users and calculate changes in the number and duration of visits relative to the median value for the same day of the week between 3 January and 6 February 2020. They are publicly available online: https://www.google.com/covid19/mobility/.

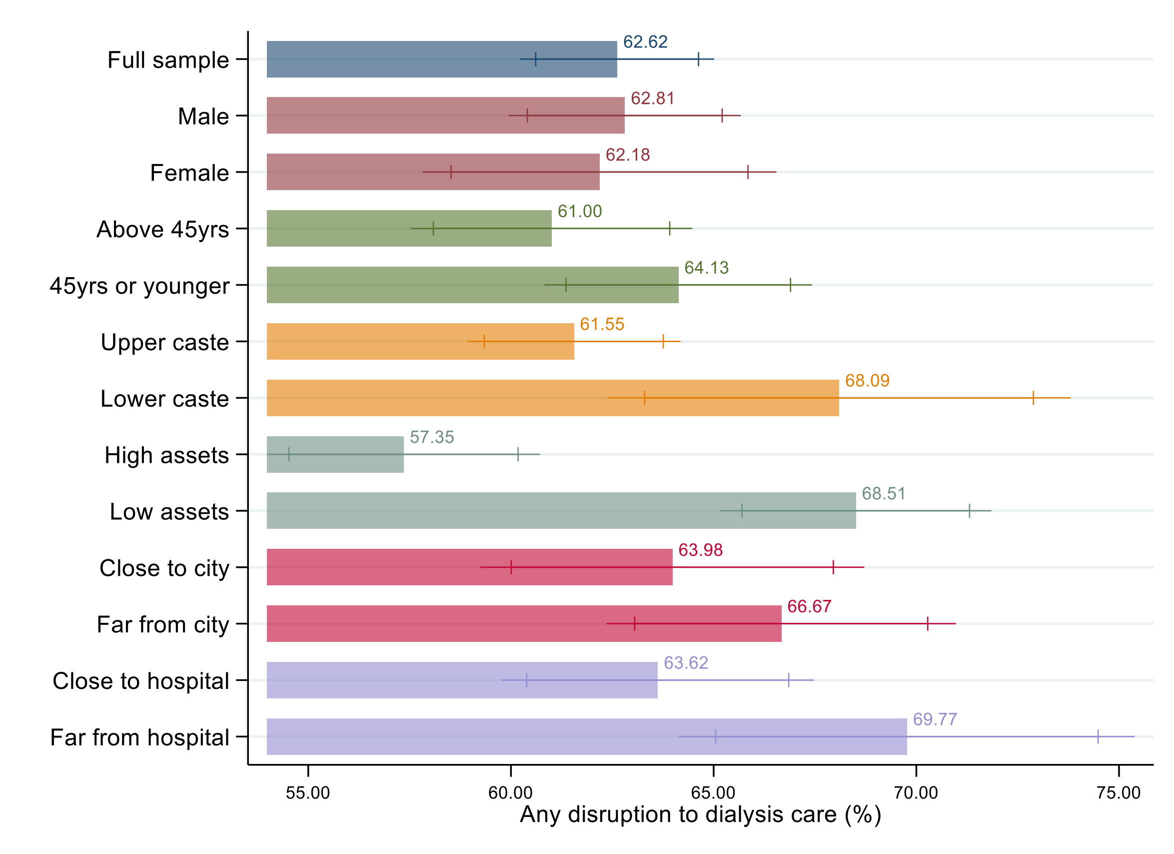

Fig. S2. Heterogeneity in probability of experiencing any disruption. The figure presents the breakdown, by subgroup, of the share of patients that reported experiencing any of the types of care disruption presented in Fig.1. Note that distance to city and to hospital are only available for approximately 60% of the surveyed sample (see supplementary methods and materials for details).

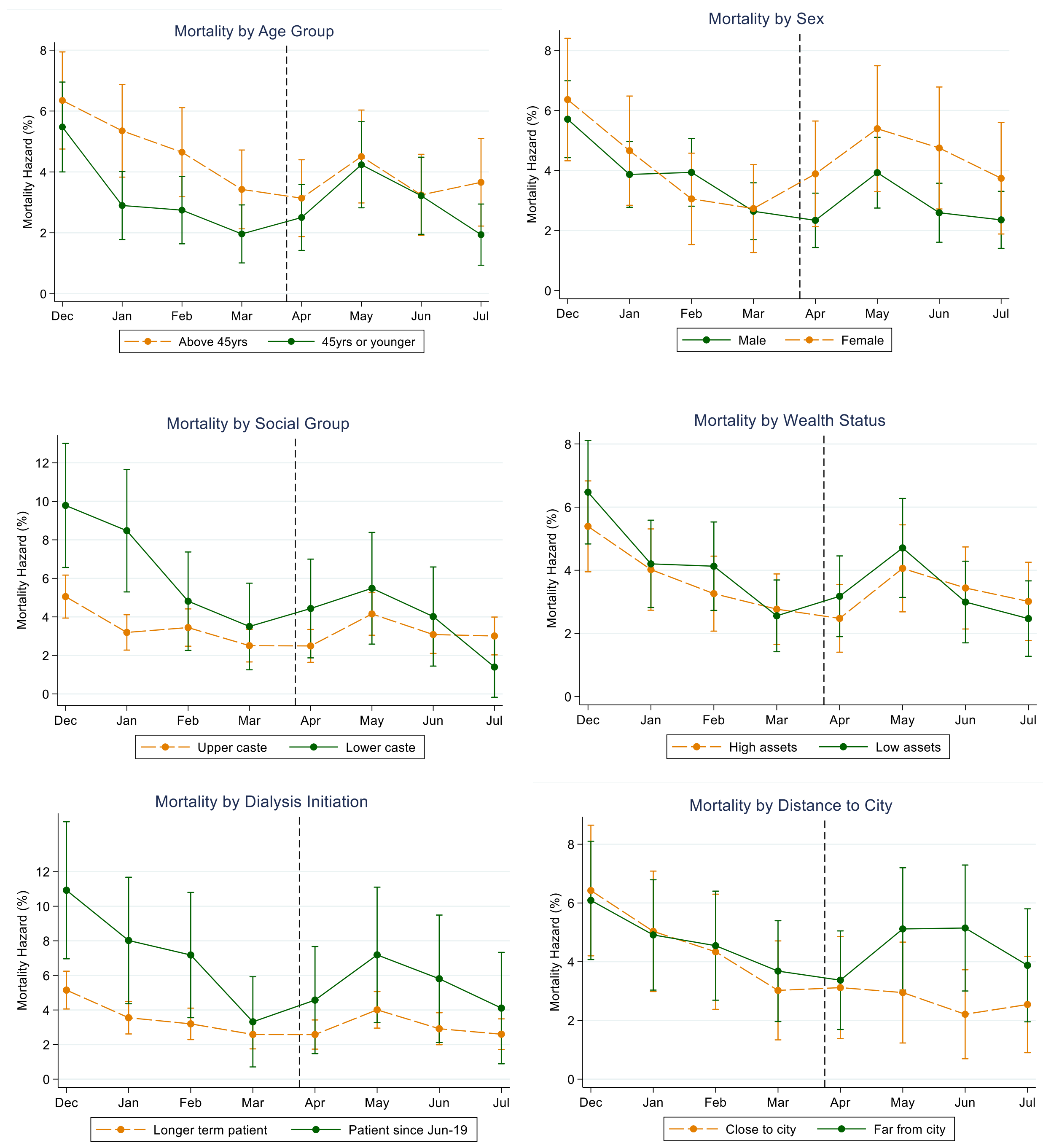

Fig. S3. Full mortality trends by subgroup. The figure presents the full mortality hazard over time from unadjusted models by key subgroups.

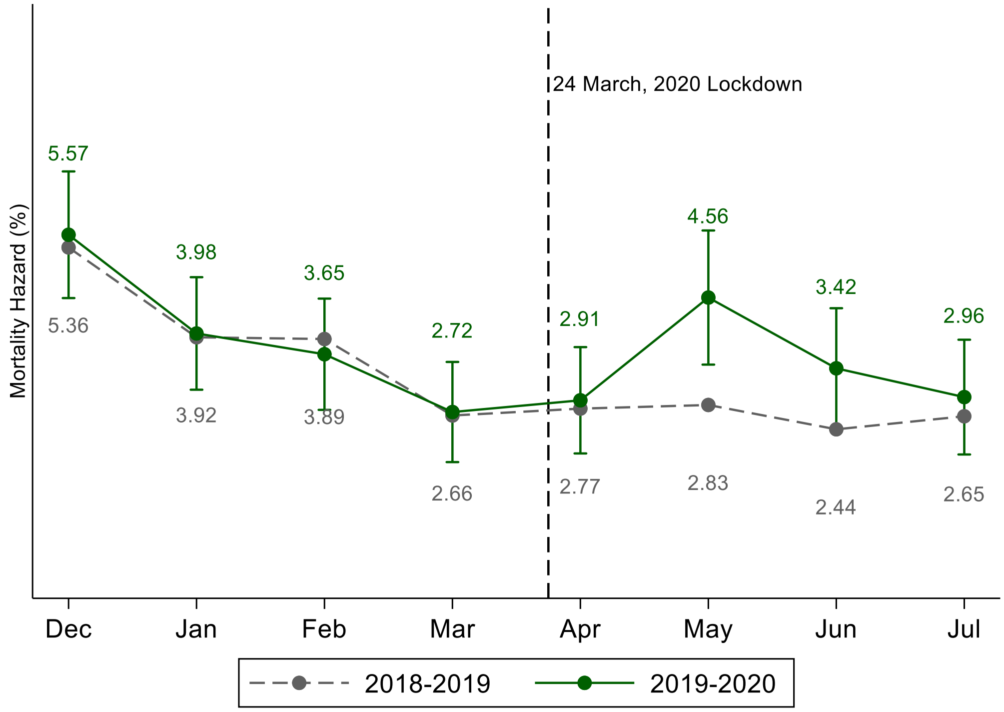

Fig. S4. Covariate-adjusted monthly dialysis mortality. The figure presents results of the same model as in Fig.1 with the addition of controls. For the 2019-2020 cohort, controls are age, sex, caste group, month of dialysis initiation, lifetime dialysis visits at baseline, and dialysis visits in the month before lockdown. For the 2018-2019 cohort we are limited to variables available in the claims data and controls are age, sex, month of dialysis initiation, and lifetime dialysis visits at baseline.

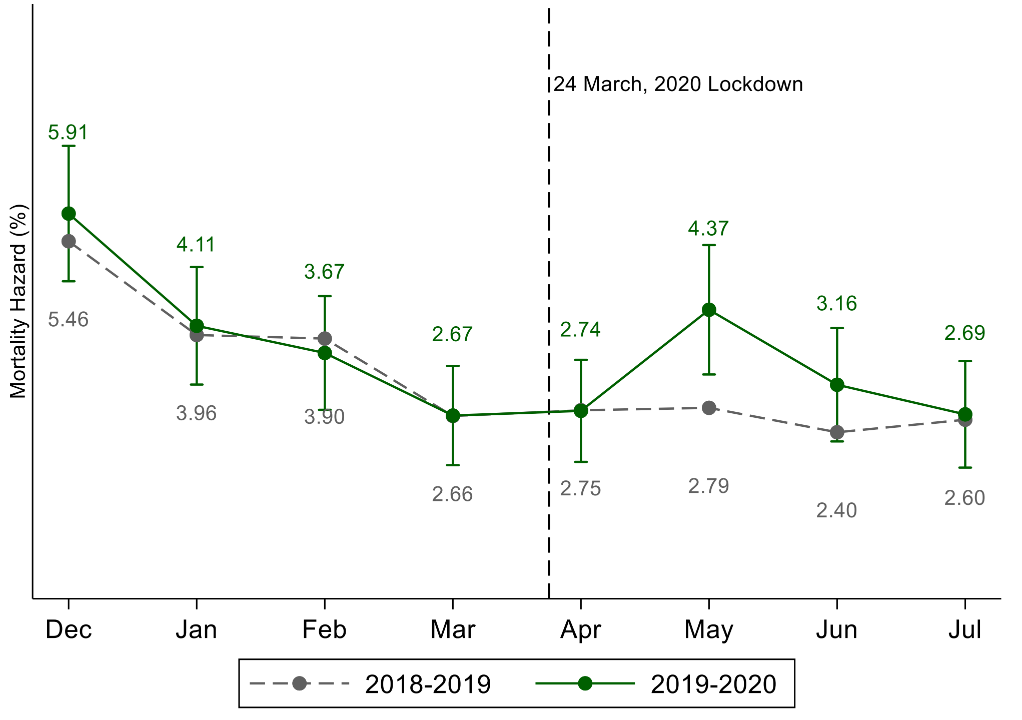

Fig. S5. Monthly dialysis mortality excluding all potential COVID-19 deaths. The figure presents results of the same model as in Fig.1, but excludes the deaths of four patients that were reported to be COVID-19 positive from the 2019-2020 cohort.

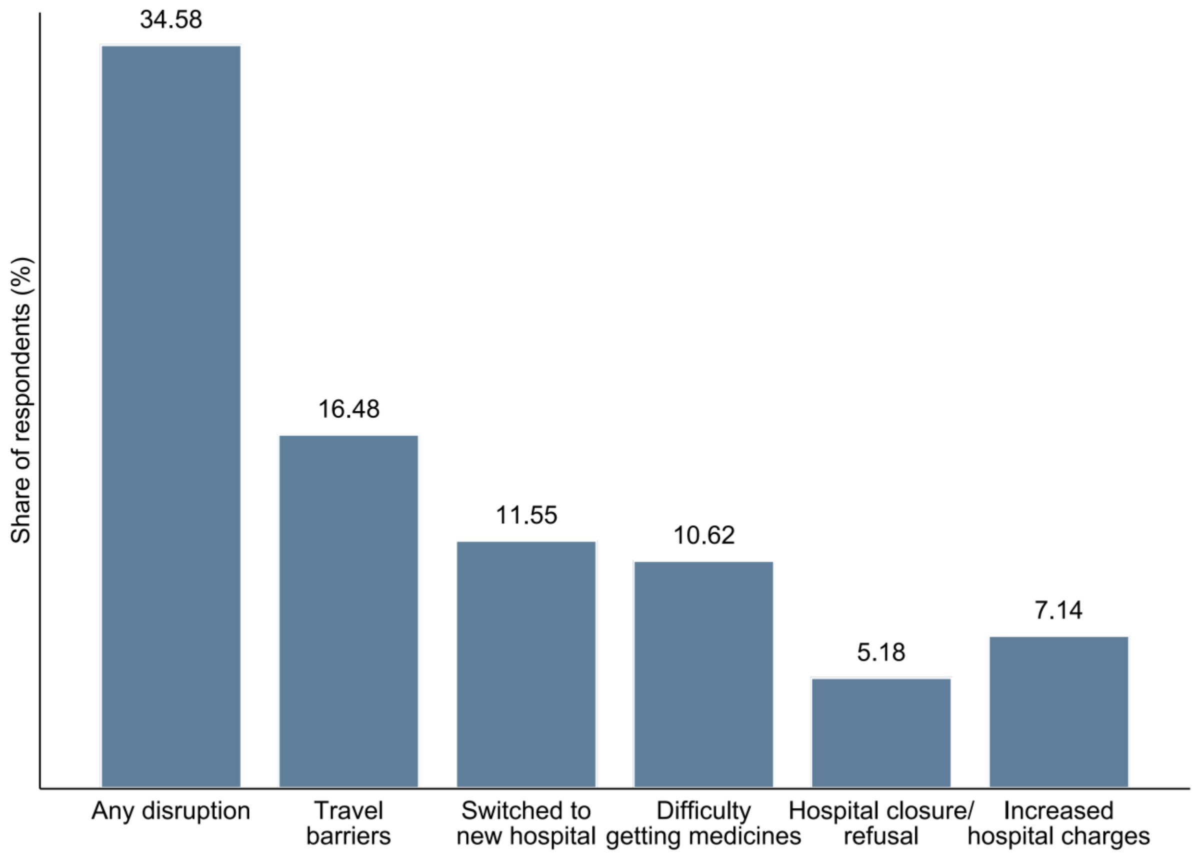

Fig. S6. Disruptions to dialysis care in July-August 2020. The figure presents the share of people that reported experiencing disruptions in the four weeks prior to the survey, for all patients alive during the first survey round that were re-interviewed in the second round. Although levels of disruptions are lower, they clearly persisted well past the easing of the national lockdown in June.

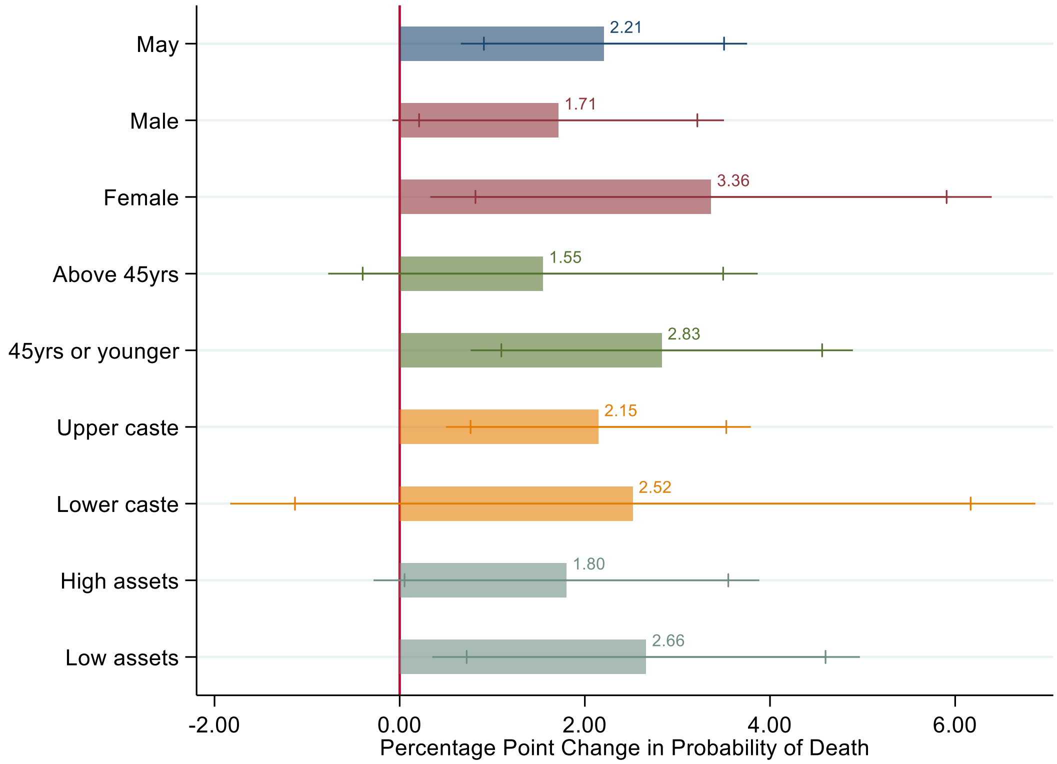

Fig. S7. Covariate-adjusted heterogeneity in mortality effects by subgroup. Each bar represents the percentage point change in death hazard between March and May 2020 for the full sample of patients, as well as for each subgroup, with adjustments for all other subgroup characteristics (age, sex, caste group, and poverty). Lines represent 90% and 95% confidence intervals. The grey figures on the right present the increase between March and May as a percentage of March mortality. Unadjusted estimates are presented in Fig. 3.

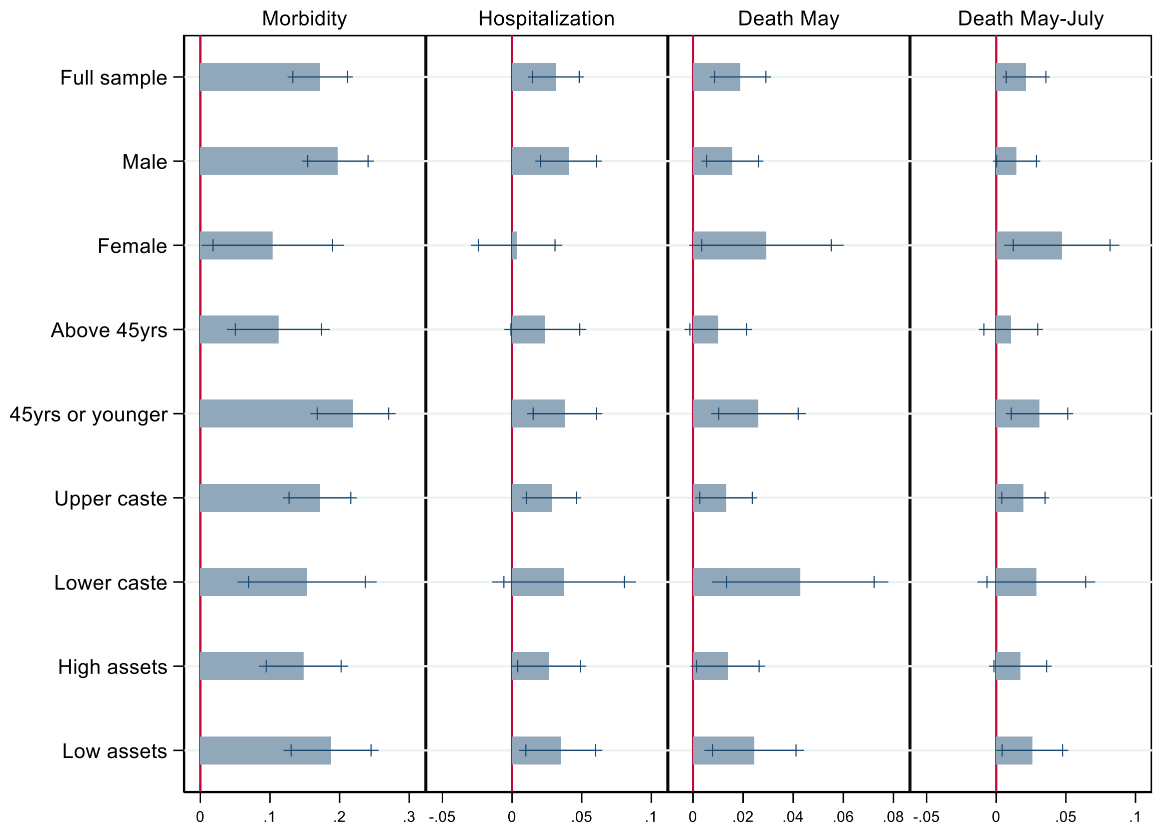

Fig. S8. Associations between disruptions and health outcomes between May and July by subgroup. The figure presents unadjusted associations between the care disruptions index and health outcomes by subgroup for all patients alive through the end of April. The outcomes are the standard deviation change in the index of morbidities experienced between May and July; any hospitalization between May and June; death in May; and death between May and July. Table 1 presents the full sample unadjusted and fully adjusted associations in regression form.

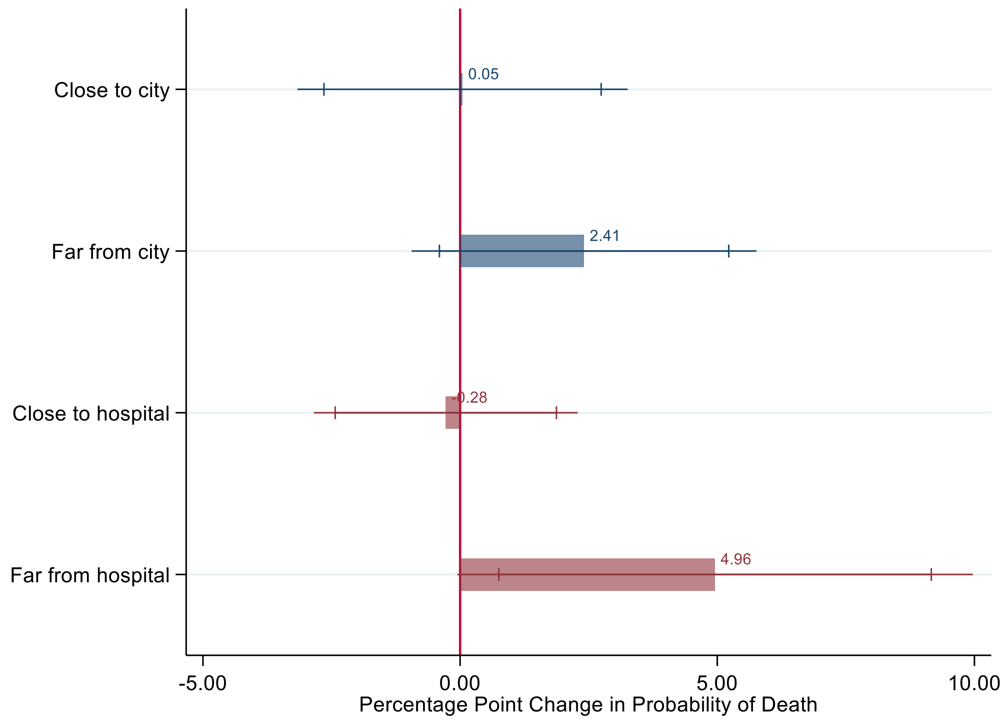

Fig. S9. Covariate-adjusted heterogeneity in mortality effects by subgroup. We use geocoded locations of dialysis hospitals in the AB-MGRSBY program and patient residence to calculate distance to the closest city (a proxy for remoteness) and to the closest dialysis hospital (a proxy for distance from the health system). These measures are only available for approximately 60% of the surveyed sample and may not be representative (see supplementary methods and materials). Nevertheless, the greater mortality among households in remote locations far from the health system are consistent with these patients facing greater difficulty in accessing care. All other details are similar to Fig. S6.

S3. Tables

Table S1. Baseline characteristics of patients reached for survey.

Survey Success Rate

First survey	Percent	Count	Observations
Sampled		3183	3183
Reached by phone	0.835	2659	3183
Reached and eligible dialysis patient confirmed	0.702	2234	3183
Consented to survey	0.944	2110	2234
Surveyed in first round		2110	2110
Follow-up survey			
Alive at first survey		1392	1392
Reached and consented to follow-up survey	0.846	1177	1392

Pre-Study Characteristics of Patients by Survey Status

	Surveyed		Not Surveyed		Total		Difference
	Mean	SD	Mean	SD	Mean	SD	p
Age	45.95	14.65	45.21	16.02	45.70	15.13	0.20
Female	0.31	0.46	0.31	0.46	0.31	0.46	0.70
Visits per month	4.98	3.53	5.04	3.56	4.99	3.54	0.67
Months on dialysis	12.65	11.50	9.26	11.04	11.51	11.45	0.00
Observations	2110		1073		3183		3183

Socioeconomic Characteristics of Surveyed Households

	Mean (%)	SD
Scheduled caste/tribe	0.19	0.39
Muslim	0.13	0.34
Education	0.63	0.48
Has TV	0.66	0.48
Has refrigerator	0.44	0.50
Has motorcycle	0.51	0.50
Has car	0.08	0.27
Has cooler	0.52	0.50
Has air conditioner	0.02	0.13
Observations	2110	

We identified 3,183 patients that received any dialysis under the AB-MGRSBY program between August and October 2019. Of these, 2,110 households (94% of those reached and eligible) consented to the survey and comprise the study sample (see Supplementary Text, Methods and Materials, for discussion). Patients in the full sample were 31% female, were 46 years old, had been on dialysis for between 11 and 12 months prior to being sampled, and had 5 visits per month, on average. Patients that were successfully surveyed were similar in age and sex composition, as well as monthly visits, to those not reached and the full sample, but had been on dialysis for slightly longer.