Access to CKD Care in Rural Communities of India: A Qualitative Study Exploring the Barriers and Facilitators

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Abstract

Introduction Chronic kidney disease (CKD) has become a public health challenge globally, especially in lower- and middle- income countries. The implications of adverse social and economic consequences of CKD are particularly grave in a populous country like India where CKD risk factors like diabetes and hypertension are widely prevalent. Although with early detection and timely initiation of interventions CKD progression can be slowed, huge knowledge-practice gap exists. Moreover, factors that influence access to CKD care at the community level have not been studied previously. This study aimed to explore the experiences and views of key stakeholders to identify factors that influence access to CKD care in rural India. We also sought to discern the current practices and preparedness for CKD, understand the facilitators and barriers to CKD care, and feasibility and acceptability of mobile-technology based clinical decision support system (mCDSS) for CKD care in primary care.

Methods Using 15 in-depth interviews and one focus group discussion (n=6), we aimed to explore the experiences and views of different stakeholders from primary healthcare system in rural India. We employed Lévesque’s framework for access to care, and inductive and deductive approaches in the analysis. The interviews were audio-recorded and transcribed verbatim. Using QSR nVivio 11, coding and thematic analysis was undertaken.

Results Our study identified barriers in relation to access to CKD care in rural India. Foremost among them was poor knowledge and lack of awareness to CKD among patients as well as primary care physicians. Health system-level barriers like shortages of skilled healthcare professionals and medicines, fragmented referrals pathways with inadequate follow up care were identified. Increasing awareness of CKD among healthcare providers and patients, provision of CKD related supplies, and a system-level approach to care coordination were key facilitators.

Conclusions Lack of awareness and knowledge on CKD among primary care providers and patients, and unprepared
primary care infrastructure are key barriers for access to CKD care in rural India. There is an urgent need to raise CKD awareness among primary care physicians and patients, improve supplies for diagnostics and medications, and create efficient referral pathways for CKD in primary care.

Introduction

Chronic kidney disease (CKD), defined as reduced estimated glomerular filtration rate (eGFR) or presence of albuminuria, is associated with progression to end stage kidney disease (ESKD), needing dialysis or kidney transplant to sustain life, and increased risks of premature mortality from cardiovascular disease (CVD). (1) (2) CKD ranked 17th and 8th leading (and one of the most rapidly rising) cause of mortality globally and in India respectively by the Global Burden of Disease Study 2016 (3). About 1 in 5 adults over 30 years suffer from CKD in India. (4, 5) Diabetes is the single largest contributor to the CKD/ESKD burden in India accounting for 31% to 44%, other etiologies include hypertension (13%), glomerulonephritis (14%), and undetermined causes (16%). (6, 7) The high burden has serious implications for a country of 1.35 billion, especially in the rural areas (66.4% of total population in India) (8) with infrastructural challenges to deliver quality care. The infrastructure for CKD and ESKD care in India is deficient with only 1850 nephrologists serving 1.3 billion people, with unequal distribution and concentration in urban areas (9). To compound the issues, lack of access to renal services such as replacement therapy (RRT) is limited, and the cost of dialysis is prohibitively expensive at US $64 per session especially as most of it is borne out of pocket (10, 11). It is estimated that fewer than 10% of patients with ESKD receive renal replacement therapy. (12)

There is strong evidence that development of CVD and progression to ESKD can be
prevented by prompt detection of CKD and early institution of non-pharmacologic (13, 14) and pharmacologic therapies. (15-21) Since patients with CKD are asymptomatic during early stages of the disease, screening may improve awareness and health seeking behavior. (22) However, CKD awareness rates are abysmally poor (6%) in India, as in other LMIC. (1, 23) Moreover, only a minority of individuals with CKD and diabetes achieve recommended treatment targets for blood pressure control (22%) and glycemic control (33%) in India. (24)

Evidence is growing regarding the role of trained non-physician health workers in management of hypertension and diabetes in South Asia. (25-27) Furthermore, digital platforms are being increasingly used for health promotion, as well as screening and management of non-communicable diseases. (28) However, the factors that influence access to early stage CKD care in rural communities of India and neighboring countries is yet to be studied. (29) Understanding the challenges faced by patients and providers regarding the management of early CKD is critical to designing strategies that are potentially effective for improving outcomes.

The aim of our qualitative study was to explore the experiences and views of key stakeholders (i.e. patients, health workers, and health planners) regarding factors influencing access to care of patients with CKD in rural communities of India. We also sought to discern the current practices and preparedness for CKD, understand the facilitators and barriers to CKD care, and feasibility and acceptability of mobile-technology based clinical decision support system (mCDSS) for CKD care in the primary health care setting.

Methods

Study setting and design

Our qualitative study was embedded within the Innovative M-health led Participatory
Approach to Comprehensive Screening and Treatment of Diabetes study (IMPACT Diabetes study) which aimed to test the feasibility and acceptability of a comprehensive mCDSS based intervention for community-based screening for diabetes and management in the primary healthcare system in rural areas of Haryana, India.

The healthcare delivery system in India, provided through both public and private sector is complex. The public sector plays a substantial role in care delivery in the rural areas, a pyramidal system with primary health centers (PHC) at the base, district level hospitals at the secondary level and the university (teaching) hospitals providing tertiary care. Among urban areas, the private sector is more dominant.

Pilot programs for screening for blood pressure and blood glucose have recently been initiated in some districts of India. Under the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke (NPCDCS), at the subcenters of the primary health care centres, the concerned auxiliary nurse midwives (ANM) is expected to screen 40% of the target population over 30 years for diabetes and hypertension and by conducting non-communicable disease (NCD) screening camps in their subcenters every week. The individuals are screened for diabetes by using glucometers and for hypertension using blood pressure apparatus, preferably mercury sphygmomanometer in sitting position and taking an average of three to four readings. The height and weight are recorded, and body mass index calculated. The individuals who are screened positive for diabetes or hypertension or both are referred to their respective PHCs for confirmation of the disease and initiation of the treatment. Irrespective of the disease outcome, the ANM counsels the individuals attending the NCD camps for health promotion by advising them for diet modification, physical activity, stress management, avoidance of tobacco and alcohol, and about the warning signs of cancer. This programme does not cover CKD.
This study was conducted in the PHC areas served by the Pandit BD Sharma University of Health Sciences, Rohtak, Haryana, an adjacent state to Delhi. Four PHCs were selected based on convenience (accessibility of PHC and availability of the PHC physician). Within each PHC, two villages—one big (~6000 population) and other small (~3000 population)—were randomly selected from all the villages being served by the PHCs. Stakeholders were selected purposively, and 3-5 individuals in each category of policymakers (district-level officials), physician-in-charge of the basic health unit in each cluster, community health workers (CHWs) and their supervisors, and diabetes CKD individuals identified in the clusters were recruited.

We developed and pre-tested the interview and focus group discussion (FGD) guides with open-ended questions to solicit the participants’ experience and views concerning CKD care in rural communities. We adopted the Levesque et al.’s framework to design our interview guides and collect the data. (30) The guides covered topics such as knowledge and awareness of CKD, current preparedness and practice for the management of CKD, facilitators of and barriers to CKD care, and perceived usefulness of mCDSS in CKD care and management. A total of 15 one-to-one interviews were conducted on healthcare providers (HCPs) which included primary care physicians, nephrologist and community health workers (auxiliary nurse midwives-ANMs & accredited social health activists-ASHAs); diabetes patients with CKD, and district level officials. At initial data analysis of the one-to-one interviews, we sensed that data saturation was not reached. Therefore, we conducted one focus group discussion (FGD) with ASHAs (n=6) in the rural areas to complement the data from one-to-one interviews. The moderators followed an interview /FGD guide and asked open-ended questions. **Additional file 1** provides a synopsis of interview guides.

The one-to-one interviews lasted between 20 and 30 minutes while the focus group lasted
approximately 60 minutes, these were conducted by AT and OJ. All interviews and FGD were conducted in a quiet location at the premises of the healthcare facility or local research office. The interviews were conducted in either local language (Hindi) or in English, audio-recorded and transcribed verbatim. The transcripts in Hindi were subsequently translated into English by bilingual interviewers and reviewed by the research team.

**Data analysis**

We employed both grounded theory approach and conceptual modelling underpinned by Levesque et al.’s framework (30) to collect and analyse the data. We analysed all the interview and FGD transcripts thematically. (31) The search for themes began by reading and immersing within a single transcript to draw preliminary interpretations. A list of emerging themes and their relationships allowed the themes to be grouped together as master themes. A code was assigned to each theme using QSR NVivo 11 software. The list of emerging themes was then compared to those generated through the remaining transcripts. This process allowed themes and explanations to arise inductively from the data. All themes were simultaneously mapped against the Levesque et al.’s framework to denote data alignment with the framework’s conceptual elements and identify new themes developed inductively. Two research team members (CR, SY) independently coded a subset of data and compared coding. Consensus was reached through discussion and iterative review of codes and categories. This involved a process of constant comparison of between- and within- categories, and refining and recoding of the text until an array of interlinking themes was elicited. All codes were then reviewed together by the research team (THJ, CR, OJ, AT, BC HLQ, SY, VJ) to ensure that common themes reflected a shared understanding among participants of the phenomena under investigation. In addition, quality assessment checks for coding were performed on 20% of randomly selected
transcripts by THJ. Data saturation was achieved, with no new themes were emerging from the data (see Additional file 2 for the Consolidated Criteria for Reporting Qualitative Research-COREQ).

**Conceptual framework**

Our conceptual framework is based on Levesque et al’s access to care model,(30) and enables us to understand factors influencing access to care at the confluence of health systems and populations. The dimensions and the corresponding abilities related to five key elements of the framework are 1) approachability (ability to perceive); 2) acceptability (ability to seek); 3) availability and accommodation (ability to reach); 4) affordability (ability to pay); and 5) appropriateness (ability to engage). Moreover, the different set of dimensions interact with each other, and needs to be accounted when planning to operationalize the framework.

**Results**

A total of 21 stakeholders participated in the study. More than half of participants (62%) were females. Among 14 healthcare providers (HCPs), 11 were community health workers (included ANM and ASHA). Five patients and two district-level officials also participated *(Table 1).*

### Table 1: Characteristics of participants

| Characteristics                  | N (100%) |
|----------------------------------|----------|
| **Category**                     |          |
| Health care providers            | 14 (66%) |
| Community health workers         | 11       |
| Primary care physicians          | 3        |
| Patients                         | 5 (24%)  |
| District level officials          | 2 (10%)  |
| **Gender**                       |          |
| Male                             | 8 (38%)  |
| Female                           | 13 (62%) |
The key themes as per Levesque et al. access to care framework dimensions are presented in Figure 1.

Five themes and 13 subthemes identified inductively, and construed as barriers and facilitators are detailed in Table 2.

Table 2: Themes, subthemes with key barriers and facilitators to CKD care

| Domain: Approachability: Stakeholders’ awareness & knowledge of CKD | Subthemes | Barriers | Facilitators |
|---------------------------------------------------------------|-----------|---------|--------------|
| Stakeholders’ awareness & knowledge of CKD                    |           |         |              |
| · Poor knowledge & awareness of CKD among HCP and patients    |           |         |              |
| · Low risk perceptions among patients resulting in delayed diagnosis |           |         |              |
| · Inadequate patient-provider communication regarding CKD     |           |         |              |
| · Increasing awareness of CKD                                  |           |         |              |

| Domain: Acceptability: Cultural norms & beliefs | Subthemes | Barriers | Facilitators |
|-------------------------------------------------|-----------|---------|--------------|
| Cultural norms & beliefs                        |           |         |              |
| · Self-medication & use of informal medicines   |           |         |              |

| Domain: Availability: Resources & manpower for CKD care at primary care level | Subthemes | Barriers | Facilitators |
|-------------------------------------------------------------------------------|-----------|---------|--------------|
| Resources & manpower for CKD care at primary care level                       |           |         |              |
| · Inadequate human resources                                                  |           |         |              |
| · Shortage of medicines & diagnostic supplies                                 |           |         |              |
| · Provision of CKD related supplies                                            |           |         |              |
| · Home visits by trained community workers for CKD care                       |           |         |              |

| Domain: Affordability: Cost of medicines & treatment | Subthemes | Barriers | Facilitators |
|------------------------------------------------------|-----------|---------|--------------|
| Cost of medicines & treatment                         |           |         |              |
| · Financial burden due to CKD                        |           |         |              |

| Domain: Appropriateness: Co-ordination and continuity of care | Subthemes | Barriers | Facilitators |
|--------------------------------------------------------------|-----------|---------|--------------|
| Co-ordination and continuity of care                         |           |         |              |
| · Inadequate mechanisms for CKD referral and follow up       |           |         |              |
| · A system approach to care coordination                    |           |         |              |
| · M-health technology to improve CKD care                    |           |         |              |

**Approachability and ability to perceive: Stakeholders’ awareness & knowledge**

‘Approachability and ability to perceive’ refers to the healthcare providers’ and patient opportunities to identify some form of CKD services that exists and can be reached (30).
Tied to this approachability concept is awareness, which relates to knowledge and influences the ability to perceive the need for care. The important barriers identified in this domain were poor knowledge and awareness of CKD among healthcare providers and patients, low risk perception among patients with delayed diagnosis and inadequate patient-provider communication. Increasing awareness of CKD among healthcare providers and patients was deemed to be a key facilitator for improving access to CKD care.

**Barriers**

*Poor knowledge & awareness of CKD among HCPs and patients*

A common theme across participants’ accounts was poor knowledge and awareness of CKD. As one nephrologist reported, there was a general “lack of awareness among patients and even doctors.”

*The main issues are lack of awareness among the people and even doctors- they [doctors] are not screening for kidney disease among those with diabetes, hypertension.* Physician 3, male

Primary care physicians reported that they had limited knowledge and confidence in managing early CKD. For example, although primary care physicians were familiar with terminologies such as urea and creatinine, they did not screen for CKD or were involved in managing CKD patients, and tended to refer cases to specialist centres.

Likewise, CKD awareness among CHWs was low in terms of not only general understanding of CKD, but also diagnosis, risk factors, associated complications and knowledge of patient management to prevent CKD progression. Since the CHWs’ existing job scope centred on mother and child health and communicable diseases, it further constrained the CHWs from providing CKD-related services. Many CHWs had misconceptions that CKD diagnosis required multiple tests that would not be available in primary care setting.

*We do not have any such thing to check kidney disease like we can detect sugar level,*
fever is detected, BP is measured but there is no such system that immediately diagnoses kidney disease or tell kidney has stopped working. It [CKD] is being diagnosed in late stages after performing a number of tests. Community health worker (FGD participant), female

Low risk perceptions among patients resulting in delayed diagnosis

Overall, most stakeholders perceived a progressive increase in CKD burden in the community. Patients expressed that CKD had increased over the years and “many people around them are suffering from the disease.” Many healthcare providers reported an increasing prevalence of diabetes “even in the villages.” Nonetheless, perceived increase in the prevalence of diabetes did not translate into the uptake of the screening as patients were not aware that diabetes was a major cause of CKD. The lack of motivation for screening and management could be explained by the absence of symptoms and hence low risk perceptions of CKD.

They [patients] do not know that they have sugar, even if they get to know it, they don’t feel like to visit doctor for treatment they are not aware that if they get it checked they can get it treated. Community health worker 2, female

However, perceived low levels of individual risk or susceptibility to CKD often resulted in many recounted experiences from family or friends who were “diagnosed late” when the kidney was completely damaged. CHWs expressed that patients tended to be vigilant and more aware of acute infections than chronic conditions including CKD.

Inadequate patient-provider communication regarding CKD

Some patients felt that they received insufficient information on CKD from healthcare providers, which undermined seeking and acquisition of knowledge. Conversely, healthcare providers frequently identified patients’ low health literacy and acceptance of CKD screening and treatment as a challenge for effective communication. The following quote
illustrates the communication issues related to delayed diagnosis of CKD.

*For kidney disease, I don’t know but for sugar they can do [tests]. Neither any kidney patient has come for test in my knowledge, nor do I know that kidney test happens here or not. Because no known [person] has come for test and I have also not ever got it done.*

Patient 2, male

**Facilitator**

*Increasing awareness of CKD*

Most participants strongly expressed the need to increase awareness of CKD amongst both healthcare providers and patients. A “right place” and “right people” strategy was suggested to improve awareness. For example, education sessions, outreach camps, mass media campaigns and dissemination of printed pamphlets were generally considered as viable options for education on CKD. Other suggestions included partnering with Anganwadi centers (rural centers for mother and child programs) and schools to conduct screening and combining diabetes and NCD awareness with other IEC (Information, Education, and communication) programs. Many healthcare providers suggested that meetings or camps for awareness related activities should be organized at a convenient place such as Anganwadi centers.

*We can give more information from time to time, when such camps are organized and people will benefit [from the camps]. They [villagers] can gather in Anganwadi, and our outreach camps can be organized in the village, two times in a month. Many patients would come in the camp.*

Community health worker 3, female

Some participants suggested the provision of CKD education during the ASHA home visit, but others felt that such an undertaking would be time-consuming, taking valuable attention away from other patient care activities. A few government official saw the current national screening programs in villages as an opportunity to improve CKD
One of the things NPCDSS program is doing is lots of screening in the villages. In these six districts, what we do is we tie up with panchayat schools, Anganwadi centers and wherever possible we do and go [to do screening]. We have a regime for screening, and we do lots of screening so that itself is awareness. Government official 1, male

**Acceptability and ability to seek: Cultural norms**

‘Acceptability and ability to seek’ refers to the cultural factors that influence how populations accept the aspects of services provided (30), and are usually shaped by cultural norms. An important cultural barrier to the ability to seek care was self-medication and use of informal medicines.

**Barrier**

**Self-medication and use of informal medicines**

Healthcare providers reported challenges when patients’ cultural beliefs and norms were at odds with clinical recommendations. They noted the use of alternative medicines by patients to treat diabetes and CKD as a barrier to care. Indeed, patient participants reflected on self-medication or seeking non-traditional treatments from complementary medicine practitioners to treat their chronic health conditions. The following is a quote from a patient who reported taking indigenous medicines as well as allopathic medications for chronic conditions.

Yes, I took four injections [insulin] once, but now I take home remedies as well as allopathy medicines for sugar [diabetes] and as well as blood pressure. Patient 1, male

I do like this. If I eat sweet today then I will take both times English [allopathic] medicine on that day [today] after taking it [sweet], I will not use home remedy. The next morning I will stop English medicine and start home remedies. Patient 2, male

**Availability and ability to reach: Resources for CKD care at primary care level**
'Availability and ability to reach' refers to the existence of health services for CKD (30) and is shaped by the availability of facilities and health resources in rural communities. Key barriers identified in this domain are inadequate human resources, and shortage of medicines and supplies. Provision of CKD related services at primary care, training of HCPs and home visits by trained community health workers were perceived as facilitators.

**Barriers**

*Inadequate human resources*

Many healthcare providers and government officials reported that primary care in rural communities was largely directed towards maternal and child health, and consequently “very little” resources were available for NCDs. Diabetes management services were generally perceived to be sufficient while screening services for complications appeared to be lacking. Referring CKD patients to general hospitals was a common practice for primary care physicians due to the perceived lack of available resources. Further, shortage of skilled health professionals at different cadres in primary care were reported by both HCPs and patients. There were accounts to indicate that PHCs, some manned by a single doctor, were unable to cope with patient loads. At the same time, CHWs were felt to be burdened due to shortage of trained health workers. Accounts from participants also indicated general frustration of “staff shortage all the time.” Few patients reported crowding and long waiting times at the primary health facilities.

*If the staff is less, then it becomes crowded... I can come here in only 2 minutes, but some [patients] come from outside [the village] with empty stomach having to wait for so long till his number arrives and that time the patient becomes hungry.* Patient 2, male

*Shortage of medicines and diagnostic supplies*

Many HCPs and patients reported issues related to the availability of medicines and diagnostic supplies at primary health centers. HCPs attributed the shortage of resources
to increasing patient load while government officials noted that occasionally, there was “disarray” in medicine supply. The scarcity of medication often resulted in patients having to purchase medicines out of their own pockets.

_I go to the doctor for a check-up once a month. He monitors weight, blood pressure and give me the same medicine. Sometimes I buy it from the market and sometimes he gives me._ Patient 3, female

**Facilitators**

*Provision of CKD related supplies and HCP training*

Most HCPs and patients expressed a strong need for CKD services including availability of medicines, test machines and doctors including nephrologists at both the PHC and emergency services. Creating a “system” where kidney patients or relatives can be referred on a particular day to the doctors was desired. Primary care physicians indicated the need for screening tests to be available at PHC as an important tool for diagnosis. Additionally, the need for training of primary care providers was mentioned by a nephrologist.

*Training should be a key component to improve the screening for kidney disease and providing training at district hospitals to physicians to able to detect, manage [CKD].*_

Physician 3, male

*Home visits by trained community health workers for CKD care*

A theme running through the data was task shifting and the potential for AHSA’s role to facilitate CKD care in rural communities. The AHSA is commonly believed to be the “key person” in the rural communities and “backbone” for any program. Because ASHAs were well known in the rural communities, villagers tended to “listen to them.” Patients commonly felt that home visits by ASHAs for CKD care will have “advantages”, such as minimizing the inconvenience of traveling long distances and having regular blood and
sugar levels checked in their homes.

Absolutely they [patients] will get help, as patient has to come in the morning from 15-20 kilometers away to medical center. [If ASHA can provide CKD service], then the patient will get the same facility in the village. Patient 2, male

Many ASHAs were amenable to performing tasks related to CKD care during home visits, and desired greater degree of involvement in the care of patients with chronic conditions. However, some expressed “bit of fear” since they had no prior experience with CKD while others were worried about “increase in workload” and “lack of time.” Primary care providers and government officials suggested the need for “skills training” for ASHAs. ASHAs were largely acceptable to the idea of vocational training, which, they felt, would empower them to provide relevant advice to patients.

We hope to learn everything to able to tell people how this disease [CKD] happens, what will happen if patient has this disease, what should be eaten or should not be eaten, what is the symptom associated. One should know which doctor he/she has to see. Community health worker (FGD Participant), female

Affordability and ability to pay: Cost of medicines and treatment

‘Affordability and ability to pay’ refers to the economic capacity of people to spend resources and time (30). With respect to CKD, a major barrier for rural communities was cost.

Barrier

Financial burden due to CKD

Some HCPs believed that due to the patients’ fear of high cost, timely preparation for RRT was not feasible. It was commonly perceived that the poor are “unable to afford” treatment, and that “financial problems [associated with treatment] would break down
poor man”. One patient undergoing dialysis voiced the need for financial support.

Patients should get financial support. The patients should not leave their dialysis, should take a high protein diet, be physically active, and working is very important. By doing work, they will be able to earn money, and their mind will also be diverted alongside.

Patient 5, male

**Appropriateness and ability to engage: Continuity of care**

‘Appropriateness and ability to engage’ refers to the fit between services available and patient needs (30). Tied to this domain are adequacy, quality and system integration which ensure continuity of services, and influence the ability to engage. The key barrier in this domain, was inadequate mechanisms for CKD referral and follow-up care. For improving access and enhancing the quality of services, a system approach to care co-ordination and novel approaches like m-health technology for CKD care were perceived as relevant facilitators.

**Barrier**

**Inadequate mechanisms for CKD referral and follow up**

Primary care physicians reported “referring” CKD patients because the rural PHCs could not offer services for CKD. Although referral registers are maintained, mechanisms for follow up are lacking in primary care, which depended entirely on the patients if they visited the PHC “by themselves”. Most patients had no follow up.

*No, there is no mechanism to follow up, some patients are left.* Physician 2, female

HCPs stated that when they reached the decision on RRT, the referral process was considerably delayed due to difficulty in obtaining a specialist appointment. They mentioned that the delays in referral were associated with huge demand for beds in hospitals. Communication between community healthcare workers and nephrologists was lacking. Long waiting times for patients waiting to go on RRT was common. The need to
travel long distances to receive treatment was reported as a barrier to CKD care and caused dissatisfaction.

Yes, mainly it is of distance. The patients who come to me they sometimes say they have to go so far and one other thing is that at the district level it gets too crowded so their number [consultation] comes very late, they come back and tell that after much difficulty their number came and I had not got enough time and proper. They [patients] think that they are not satisfied. Physician 2, female

Facilitators

A system approach to care coordination

HCPs reported that a “system should be there” where patients with CKD are appropriately examined and referred in a timely fashion. It was commonly believed that appropriate referral to a specialist was crucial for CKD care and that education and awareness among doctors was essential to enhancing the continuity of care. Primary care physicians reported that “follow-up” of the referred patients was important for continuity of care through which CKD patients can review their treatment and medications at the PHC, thereby increasing adherence.

[If] the patient is on dialysis or has kidney disease, if there is anything like this, if he brings prescription and shows us that this treatment is ongoing, we [primary care physicians] can ask him how many days later [seeing specialist]... if he happened to miss the treatment, then he can take medicines from us, as long as the medicines are available here. He also can ask us like his follow up was on this day but he could not go. Now he could be called on this [a particular] day. Physician 1, male

Moreover, HCPs felt that for improving patient satisfacion, good facilities for management and follow up needs to be made available in their area.

For their satisfaction they can get the facility around their area, because the district level
becomes quite crowded. Even if any program runs for this, then we can follow-up them as well, at the primary level and secondary level also. There follow-up will be done in our area only, then they will not have to run here and there or shift anywhere else. Physician 2, female

**M-health technology to improve CKD care**

Most participants were supportive of m-health approach to CKD care. High familiarity with mobile devices, and the availability of the internet and smart phones were reported. Many healthcare providers viewed the m-health approach to the management of chronic diseases including CKD as “convenient,” “beneficial” and “feasible”. Similarly, some of the perceived benefits expressed by patients included care at their doorstep, saving time and resources and provision of additional “moral support.” Other perceived positive attributes of m-health technology were the potential to address gaps and enable sharing of records, patient information, and timely treatment.

*It [m-health] is beneficial, as it will have all the biodata of the patient. It will show that when the patient took medicine, which medicine has taken and when the treatment started etc....[If the patient] asks us, we would be able to tell the patient. Patients will be able to know about their disease and get treatment on time. Records of patients can inform the doctor; it will save time also.* Community health worker 2, female

However, some participants foresaw the complexity of implementing m-health due to “slow” internet connectivity and ‘illiteracy’ in rural areas. Others stated that m-health support would be futile if patients do not read the messages, and therefore needs to be tailored to the local language. One government official disagreed with the m-health approach maintaining that efforts should be prioritised on addressing health systems barriers to ensure that patients have access to quality primary care.

*Mobile health approach means going to the population and catering to the needs of the
already existing and newly diagnosed patients, if there is a shortage of medications, tests, etc. but for primary screening and universal access and treatment to diabetes, this mobile healthcare system will not serve the purpose because screening has to be done till the last vulnerable person of the population. If we use the mobile service and send our workers for screening, only a few will be diagnosed and the rest will not come out. I feel the primary health care center will do more in this case rather than accessory appliances.

Government official 2, male

Table 3 provides summary of themes, subthemes and illustrative quotes.

Table 3: Summary of themes, subthemes with illustrative quotes

| Key themes & subthemes | Evidence |
|------------------------|----------|
| Approachability: Stakeholders’ awareness & knowledge of CKD | |
| Poor knowledge & awareness of CKD among HCP and patients | “Have little bit [of] knowledge in kidney disease because they [primary physicians] do not know much beyond the urea, creatinine, because the behind is that once the kidney disease has been diagnosed, we refer them not manage it at PHC level. If we manage, then our juniors will also manage.” Physician 1, Male |
| Low risk perceptions among patients resulting in delayed diagnosis | “Actually we [patient & wife] did not know that this was a kidney problem. I had breathlessness, then we [patient & wife] came here [hospital] and doctor did test. He found that creatinine is high then KFT was done, it was high, the asked to get it [condition] treated, then he came to the kidneys, gave medicine and pulled me for 2 years.” Patient 4, Male |
| Low risk perceptions among patients resulting in delayed diagnosis | “This was the problem with my sister in law, she had frequent problem in toilet, started bleeding in the toilet. As she went to treatment, they came that one of her kidney is completely damaged, and operation date was set for renal transplant. But, she got expired two days before the opera was supposed to be done”- Community health worker (FGD participant), Female |
| Low risk perceptions among patients resulting in delayed diagnosis | “I had weakness and got hypertension in 2008. In September 2009 I lost suddenly. I thought that this would have happened because of some stress was the first sign, which I had ignored. In March-April 2010, I started hav |
problems, like breathlessness, anxiety, I was unable to sleep. By May 20. problems increased, I got my test done, and in that creatinine, urea, increased, it [CKD] was confirmed and I came to know like this”. Patient 5,

| Inadequate patient-provider communication regarding CKD | They [doctors] said that your kidneys have a problem, and other than this [doctors] did not say anything. Patient 1, Male |
|---|---|

**Facilitator**

| Increasing awareness of CKD | “Yes they [patients] should be given information! Until the public will not say how will they know?” Community health worker 2, Female |
|---|---|

Yes, it should be done, awareness should be spread, like for a patient or normal, they will know about their disease that what are the symptoms of and then they [patients] will take more care and will go for continuous checkups. They must have awareness” Patient 2, Male

**Acceptability: Cultural norms & beliefs**

| Barrier | “People don’t prefer going to a nephrologist. Rather they would be told by: to have indigenous medicine, or if it is kidney disease, if somebody else consumed soda, and few days after drinking soda, the results come, in that 25 percent kidneys have stopped functioning.” Community health worker (FGD participant), Female |
|---|---|

“People don’t prefer going to a nephrologist. Rather they would be told by: to have indigenous medicine, or if it is kidney disease, if somebody else consumed soda, and few days after drinking soda, the results come, in that 25 percent kidneys have stopped functioning.” Community health worker (FGD participant), Female

“My father takes medicine, it is Chandrprabha (Ayurveda medicine) and second one is capsules of defit. There was a program of MI [name] company, medicir [bought] from there costing 5500-6000[Rupees], we have purchased it. I takes it but I don’t.” Patient 2, Male

**Availability: Resources and manpower for CKD care at primary care level**

| Barrier | Like for chronic kidney disorders, at present in some centers, it’s [tests] not yet, although it is going to be operational, the machine has been seen, the problem of AC or something, I exactly don’t know much. But it is not functional has to be kept in the AC [air conditioner]. The machine is needed to do creatinine, urea, etc. So, accordingly screening of chronic kidney disorder done here and also for blood glucose. So it will be done. Just the same remains of manpower shortage. Physician 1, Male |
|---|---|

“For the test madam the staff is less. The main thing is of staff. If staff is c
then there will be no problem, if the staff is less, then it [PHC] becomes c

Patient 2, Male

| Shortage of medicines & diagnostic supplies | “Our calculations are sometimes mismanaged, because we have to indent order the medicines by indenting but if patients are increased then shortage of medicines.” - Physician 1, Male |
|-------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                           | “I go to doctor for check-up once in a month. He monitors weight, blood and gives me the same medicine. Sometimes I buy it from market and so he gives me.” Patient 3, Female |

Patient 2, Male

| Facilitators | Provision of CKD related supplies and HCP training | “For that, at all PHCs and CHCs, treatment should be available there also. As for injections, tablets should be there, a pharmacist who should be available 24 hours.” Patient 2, Male |
|--------------|-----------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|              | Home visits by trained community workers for CKD care | “Our knowledge should be increased, like what sugar is and what happens if it increases. Thee more information [as part of training] is given it is better. get further knowledge so that we can give it anyone else and it will be b “Community health worker 4, Female |

Patient 2, Male

| Affordability: Cost of medicines & treatment | Barrier |
|---------------------------------------------|---------|
|                                             | Financial burden due to CKD |
|                                             | “They [dialysis patients] are unable to understand that what is happening, disease has happened and above that it costs 50,000 per month. From hef the frustration of human, if someone can work on this then I think 90% problems will be solved. Most of the families are unable to come for dialy times a week. Patient comes only once a week, they have to take protei they are eating pulse and rice only. I am living here in Delhi just for tre. came here for the transplant, but that did not happen and now I am on dial am staying here in Delhi, transportation, food, dialysis, all costs a lot.” Patient 5, Male |

Patient 5, Male

| Appropriateness: Co-ordination and continuity of care | Barrier |
|------------------------------------------------------|---------|
| Inadequate mechanisms for CKD | We have a general OPD [out-patient department] register. It has separate... |
referral and follow up

The referral, like how many referrals had been done, how many are done. This way it is managed. Projects are being run by the government and if we notify something then we mention them separately and report separately. Everything else is done in the General OPD and for referrals, like we are unable to manage it (CKD), we refer them to General hospital. Physician 1, Male

Facilitator

A system approach to care coordination

“For their satisfaction they can get the facility around their area, because the district level becomes quite crowded. Even if any program runs for this, can follow-up them as well, at the primary level and secondary level also. Follow-up will be done in our area only, then they will not have to run there or shift anywhere else.” Physician 2, female

“System should be there where a kidney patient referred is being checked [medical officer] sir and referred further accordingly” Community health worker (Participant 4-FGD), Female

M-health technology to improve CKD care

So, if you have a mobile app or some software in the computer and if them, how to use that it will be really helpful because a PHC doctor has to do many activities apart from the clinical work. They do a lot of managerial work and time is very limited. So one day NCD people will they present them as NCD officer, the next day RNTCP team come they represent as RNTCP person so different roles. So if you assist him with a properly guided come portal in of a mobile app or a software, I think (in my personal opinion) they will be have that” Government official 1, Male

If it [m-health technology based care] will be provided then people and naturally will be benefitted.” Patient 4, Male

Discussion

This qualitative study identified key barriers and facilitators for access to CKD care among rural communities of India which if addressed effectively could potentially avert several negative health, social and economic consequences associated with advanced CKD. Foremost among them was poor knowledge and lack of awareness to CKD among patients as well as primary care physicians. Patients lacked awareness that CKD could be detected in early stages, and healthcare providers had misconceptions that screening for CKD includes a battery of complex investigations. Low risk perception due to asymptomatic nature of early stage disease contributes to delayed CKD diagnosis when patients were symptomatic. Other barriers influencing access to CKD care were unprepared primary health systems infrastructure (healthcare professionals, diagnostic
supplies and medications), unorganized CKD referral and poor follow up pathways. We observed that the problem of inequitable access to CKD care permeated at all levels of health system, from the rural primary health care facility to the district hospitals as patients complained about high cost of treatment and long distances to reach the hospitals. Moreover, long waiting time and shortage of medicines in the public sector forced patients to purchase from private pharmacies, thereby increasing the financial burden of CKD. A key finding was the frustration by patients expressed over the need to navigate several layers of bureaucracy in order to access to a specialist. Furthermore, cultural factors like self-medication and use of informal medicine remains an obstacle to CKD access in rural areas. Increasing awareness of CKD among healthcare providers and patients, provision of CKD related supplies and a system-level approach to care coordination were perceived crucial facilitators for improving access to CKD. Studies from other regions of the world have reported poor knowledge and awareness to CKD amongst healthcare providers and patients which aligns with our findings. (32, 33) (34) Experiences of delayed diagnosis of CKD among our rural community participants are concordant with perspectives and experiences on CKD from marginalized groups.(35) Recent large multinational surveys by the International Society of Nephrology (ISN) reported similar patient related factors – knowledge, attitude and geography, and physician related factors -availability, access, knowledge and attitude as barriers to optimal kidney disease care in South Asia (34).

The participants in our study identified shortage of medications and supplies as a barrier to CKD care in rural India. This is unsurprising as the ISN survey showed that only 30% of LMIC had access to health technologies like measurement of serum creatinine and urine albumin testing, none of the low income had access to eGFR and quantitative estimation of albuminuria, and low availability of essential medications for kidney disease. (36, 37)
Our findings underscore the need for making the very basic diagnostic supplies for CKD (urine protein dipsticks and measurement of serum creatinine), and anti-hypertensive, glucose lowering and lipid lowering medications accessible to patients with CKD. This approach would be consistent with universal health coverage, and assist with achieving the Sustainable Development Goal 3.4. Further, our findings highlights the need for creating efficiencies in the referral process, and introduce strategies for patient activation and empowerment. Patient activation could potentially help improve self-management behaviors and health outcomes.\(^{(38)}\)

In the US, the Kidney Early Evaluation Program (KEEP)- a targeted community screening program for CKD in individuals with high risk of CKD (those with diabetes or hypertension, or a first-degree relative with diabetes, hypertension, or kidney disease) has been shown to improve awareness of CKD with can improve health seeking behavior.\(^{(39)}\) Screening for CKD has been shown to be cost effective in diabetes in HIC.\(^{(40)}\) Similar evidence is needed from low- and middle income countries.

Preventive strategies centered on non-physician health workers have been shown to be effective for control of hypertension and diabetes.\(^{(25, 41)}\) Innovative models of collaborative care with primary care physicians and training non-physician health workers in CKD care could improve quality of services, continuity of care and address the shortage of nephrology workforce in rural areas in LMIC.

The World Health Organization Package of Essential Non-communicable Disease Interventions promises hope for CKD prevention. To be fully effective, such strategies should focus on those at high risk of developing CKD, such as those with diabetes, hypertension, family history of CKD or exposure to environmental factors, such as manual work in hot and humid environments (heat stress nephropathy)\(^{(42)}\), or local customs, such as consumption of traditional medicines and over the counter use of painkillers or
non-steroidal anti-inflammatory drugs. These should be followed by providing guideline-based care to those who screen positive, reducing non-adherence to therapy, and institution of quality improvement programs. Comprehensive control of CKD would involve a collaborative model of care starting from screening and identification of early stage disease, continuing through to end-of-life support for those with advanced disease. (43) Novel m-health tools for care support, endorsed as beneficial, acceptable and feasible will help strengthen health services delivery for non-communicable diseases, and such tools need further evaluation for use in resource-limited settings.

**Strengths and Limitations**

To our knowledge, this is the first qualitative study from rural India exploring factors that influence access to early CKD care. A key strength of this study was its inclusion of a wide range of stakeholders in the health system spanning health system leaders, community care workers and patient, which enabled us to explore various experiences and perspectives regarding CKD care in rural communities of India. The inclusion of various stakeholders not only brought greater clarity to the factors influencing CKD care, it also allowed triangulation of data grounded in stakeholders’ experiences. In addition, drawing on the Lévesque’s framework (30), we employed both inductive and deductive approaches to generate a nuanced understanding of the access to CKD care and how these challenges can be addressed. Our analysis has demonstrated that various dimensions of the Levesque’s framework were highly relevant to holistically understanding access to CKD care in low resource settings.

Notwithstanding these strengths, findings from this study should be viewed in light of a few limitations. The small sample size in each group of stakeholders may have diluted the views of the stakeholder group. Due to the shortage of physicians in rural communities, only three physicians participated in the study. It is therefore possible that limited
representation of different cadres of health professionals may have influenced the themes and suggestions generated in this study. However, this limitation was counteracted by purposively recruiting more CHWs to ensure that the results of the study represent the perspectives and inputs from healthcare providers working in the field. Similar surveys among larger sample of primary care physicians in India and other South Asian countries is needed.

Furthermore, only patients with CKD due to diabetes were included. However, diabetes is the commonest (44%) cause of ESKD in India (7), and the challenges faced in accessing care are expected to be similar for patients with other causes of CKD. Moreover, since our participants were recruited from a few selected villages in North India, findings may not be generalised to all rural communities of India. However, similar findings regarding poor awareness and weak healthcare services have been reported for hypertension management from other countries like Bangladesh, Pakistan, and Sri Lanka.(44) Thus we believe our findings on CKD would be generalizable to other countries in South Asia, and possibly many LMIC.

Conclusions

This qualitative study demonstrates poor awareness and knowledge on CKD among primary care providers and patients and unprepared primary care infrastructure to be the key barriers for access to CKD care in rural communities in India. There is an urgent need to address the system-level barriers to CKD care by increasing the awareness among primary care physicians and patients, engaging community health workers, improving supplies for diagnostics and medications for CKD in the primary care clinics, and creating efficient referral pathways. Further research incorporating m-health tools to enhance and support CKD care in diabetes could be evaluated. Such strategies could provide an opportunity to address the gaps and strengthen health services delivery in CKD care.
Abbreviations

ANM- Auxiliary nurse midwives
ASHA- Accredited social health activists
CKD- Chronic kidney disease
CVD- Cardiovascular disease
eGFR- Estimated glomerular filtration rate
eSKD- End-stage kidney disease
FGD- Focus group discussion
HCPs- Healthcare providers
IEC- Information, education, communication
IMPACT- Innovative M-health led Participatory Approach to Comprehensive Screening and Treatment
ISN- International Society of Nephrology
KEEP- Kidney Early Evaluation Program
LMIC- Lower- and middle income countries
mCDSS- Mobile-technology based clinical decision support system
mHealth- Mobile-health
NCD- Non-communicable diseases
NPCDCS- National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke
PHC- Primary Health Centres
RRT- Renal Replacement Therapy

Declarations

Ethics approval and consent to participate
Ethical clearance was obtained from an independent ethical review committee at Centre for Chronic Disease Control, Gurgaon, India and from the institutional review board (IRB) at National University of Singapore, Singapore. Written informed consent was obtained from all participants before each Interview and FGD. The participants were assured about the confidentiality of their responses.

**Consent for publication**

Not applicable

**Availability of data and materials**

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

**Competing interests**

The authors report no conflict of interest in this work.

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**Author contributions**

THJ: Study conception and design, manuscript drafting and revision, funding acquisition. CR: Data analysis, manuscript drafting and revision. OJ: Project management, data acquisition manuscript revision. AT: Data acquisition, data validation and manuscript revision. BC: Data collection and project support. HLQ: Study conception and design, manuscript revision. YS: Data analysis, manuscript revision. VJ: Study conception and design, manuscript revision. All authors read and approved of this manuscript.
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Figures
Figure 1
Conceptualization of access to CKD care through stakeholder perspectives from rural communities of India

Supplementary Files
This is a list of supplementary files associated with the primary manuscript. Click to download.

Additional file 1_Summary of interview guides.pdf
Additional file 2_COREQ checklist.pdf