Access to chronic kidney disease (CKD) care: Its barriers and facilitators in a community development block in Purba Bardhaman, West Bengal: A qualitative study

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ABSTRACT

Background: Chronic kidney disease (CKD), a leading public health problem, has potential risks and serious implications on the health of individuals and society at large. Few studies explored the factors that influence access to CKD care at the community level in rural areas of West Bengal. A qualitative study was planned among key stakeholders to explore their views and experiences and to identify the barriers and potential facilitators that influence access to CKD care at the primary care level. Methods: Total 23 stakeholders participated in the study. Seventeen in-depth interviews (IDIs) were conducted on a purposive sample of stakeholders (CKD patients, healthcare providers (HCPs) and health planners) and one focus group discussion (FGD) among six community health workers. The audio-recorded interviews were transcribed verbatim. The Lévesque's framework for access to care as modified by Jodie Bailie *et al.* was employed to construct interview guides and structure the initial codes. Thematic analysis was undertaken using QSR NVivo version 11 using both inductive and deductive approaches. Results: The major barriers to CKD care at patient level were poor knowledge and awareness of CKD and at the health system level was shortage of skilled staffs, diagnostics and medicines and fragmented referrals. The potential facilitators identified were educational activities to increase the awareness of CKD among HCPs and patients; provision of CKD-related supplies and a system-level approach to care coordination along with m-health-based care. Conclusions: Targeted CKD screening programs and CKD specific trainings may improve awareness of CKD. Additionally, stronger primary care infrastructure, availability of essential drugs and diagnostics and creating an efficient referral process for the quality CKD care are the need of the hour.

Keywords: Access, barriers, CKD, facilitators

Introduction

Chronic kidney disease (CKD), a leading public health problem worldwide, has been defined as reduced estimated glomerular filtration rate <60 mL/min/1.73 m² or the presence of albuminuria.^[1,2] Though CKD is included now, in the list

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of non-communicable diseases (NCDs) by National Health Mission,^[3] this particular disease is considered as an orphan disease by many, owing to the fact that awareness level is low even amongst primary care physicians (PCPs).^[4]

While the prevalence of CKD is on the rise, diabetes and hypertension remain the commonest cause of CKD in India.^[5]

There is a strong evidence base favouring the role of trained front-line health workers, e.g. ASHAs, in the management of hypertension and diabetes.^[6-8] In addition, mobile technology

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is being increasingly used for health promotion, as well as screening and management of NCDs. [9] Department of Health and Family Welfare, Govt. of West Bengal has also accorded funds for PHCs for the procurement of android mobile/tablet in this direction. [10] However, studies on the factors that influence access to early-stage CKD care in rural communities in West Bengal could not be found despite a thorough search. It became absolutely necessary, therefore, to understand the challenges faced by the patients and providers regarding the management of early CKD to develop strategies that would enormously aid in achieving a desired outcome. Hence, the following study was undertaken to find out the barriers and potential facilitators to access CKD care at the primary care level and to identify the perceived usefulness of mobile-technology-based care of CKD patients at the primary level.

Material and Methods

The study was a qualitative one conducted in the Community Development Block of Bhatar, Purba Bardhaman district, West Bengal. Four PHCs under Bhatar State General Hospital were selected by simple random sampling. Within each PHC, two villages were randomly selected from all the villages being served by the PHCs, i.e., eight villages from four PHC areas were selected. Nephrology OPD at Burdwan Medical College and Hospital (BMCH) and district-level health planners' office for NCD programme at Chief Medical Officer of Health (CMOH) office, Purba Bardhaman were also included. The study was conducted for a period of two months.

The study population included:

- a) Adult (>18 years of age) male or female CKD patients diagnosed at least 3 months prior to the study period
- Physicians (medical officers and nephrologists): medical officers working in the PHCs and nephrologists, attached to BMCH OPD
- c) Frontline community healthcare workers (CHOs and ASHAs); and
- d) Health planners comprising government officials from the Department of Health and Family Welfare, Govt. of West Bengal at the district (Deputy CMOH-2) and at the block level (BMOH).

Respondents were selected by purposive sampling, specifically selecting frontline healthcare workers and doctors, targeting 2–5 or more individuals in each stakeholder category.

Written informed consents were taken before in-depth interviews (IDIs) and focus group discussion (FGD) from all the respective participants.

FGD guide for ASHAs and IDI guide for the rest of the participants were used for data collection. The Levesque *et al.*'s^[11] framework with Jodie Bailie modification^[12] was adopted to design interview guides and to collect the data. Audio recorders and field notebooks were used to aid the data collection and assessment.

The moderators collected demographic information, followed the interview/FGD guide, and asked open-ended questions to the participants. The one-to-one IDIs for the participants lasted between 10 and 30 min, while the FGD, involving ASHAs only, was for approximately 60 min. The interviews were conducted in either the local language (Bengali) or in English, audio-recorded, and transcribed verbatim. For confirming the absence of any interviewee bias, researchers were careful in not allowing prior knowledge of the patients' condition to affect the way in which the interviews were conducted. The transcripts in Bengali were subsequently translated into English by a bilingual interviewer and were reviewed by the guides.

Both the grounded theory approach and conceptual modelling adapted from Levesque et al.'s framework with Jodie Bailie modification were used to collect and analyse the data. All the interviews and FGD transcripts were analysed thematically. Inductively, the grounded theory approach was used to ensure that the emergent themes were derived from the text. The search for themes was done by reading and immersing within a single transcript to draw preliminary interpretations. A list of emerging themes and their relationship were used for the themes to be grouped together as master themes. Deductively, the framework analysis method was used by employing the Lévesque's model as modified by Brodie Bailie et al. to guide the analysis and ensure all relevant themes were identified. Transcripts and field notes taken from the interview were carefully read and coded independently by two research team members. The primary coder initially organized the codes based on the question guide. A code was then assigned to each theme using QSR NVivo 11 software. The list of master themes was then compared to those that were 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 (with Jodie Bailie modification) to denote data alignment with the framework's conceptual elements and to identify new themes developed inductively. Data saturation was achieved by conducting the IDIs and one FGD when no new theme emerged from the data. Consolidated Criteria for Reporting Qualitative Research were followed for reporting the study.

Conceptual framework

Modified Levesque *et al.*'s access to care model was adapted for developing the conceptual framework to find out the factors impacting access to care at the health systems and population levels.^[13,14] Figure 1 depicts the conceptual framework. The five dimensions of the framework from the *supply side*, i.e., *service providers' side*, are depicted in the upper part of figure: 1) approachability, 2) acceptability, 3) availability and accommodation, 4) affordability, and 5) appropriateness and the lower part of the figure represents the *service seekers*, i.e., patients side dimensions also known as *demand side*, i.e., 1) ability to perceive, 2) ability to seek, 3) ability to reach, 4) ability to pay, and 5) ability to engage.

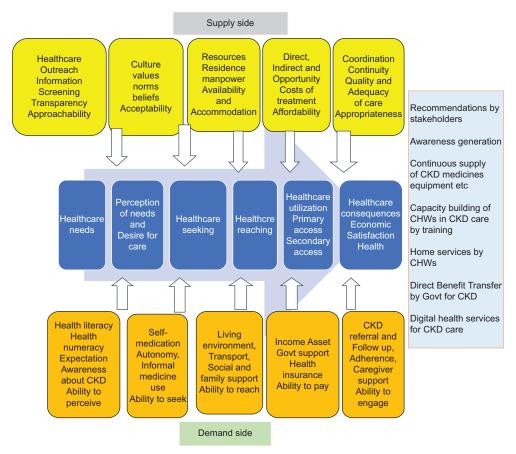


Figure 1: Conceptualization of access to CKD care in rural areas through stakeholder perspectives (Adapted from Levesque et al. 2013 as modified by Jodie Bailie et al. 2015)

Ethics approval

Ethical clearance was taken from the Institutional Ethics Committee for Human Research of Burdwan Medical College and Hospital, Purba Bardhaman (approval no. BMC/1EC/285 Dated: 10.02.2022). Written informed consent was obtained from all participants before each Interview and FGD. The participants were assured of confidentiality and anonymity.

Results

A total of 23 stakeholders participated in the study – 15 healthcare providers (HCPs), three community health officer, six ASHA, four PCPs; two nephrologist, six CKD patients, and two health planners (one from block level and one from district level). Among them, 52% were females [Table 1].

The sunburst chart in Figure 2 depicts a summary of the themes, potential facilitators, and various barriers of access to CKD care as found in the study. The barriers and facilitators, thus, derived under each theme are described as follows.

Approachability and ability to perceive, stakeholders' awareness and knowledge of CKD

Approachability relates to the fact that people facing health needs can actually identify that some form of service exists, can be

Table 1: Characteristics of participants			
Category of stakeholder	n (%)	Male	Female
Healthcare providers	15 (65)	5	10
CHOs	3	0	3
ASHAs	6	0	6
Physicians			
PCPs	4	3	1
Nephrologists	2	2	0
CKD patients	6 (26)	5	1
Health planners	2 (9)	1	1
Total n (%)	23 (100)	11 (48)	12 (52)

CHO=Community Health Officer, ASHA=Accredited Social Health Activists; PCPs=Primary Care Physicians

reached, and have an impact on the health of the individual.^[13] The important subthemes identified as barriers and facilitators to approachability and ability to perceive were:

Barriers

a) Lack of knowledge and awareness

One of the major barriers in the entire study was the existing lack of knowledge and awareness of patients about the causes and symptoms of CKD. According to a patient, "I know nothing about kidney or liver. They are all the same for me." (Patient 2, female) Likewise, HCPs had reported lack of knowledge about latest guidelines on the diagnosis and evidence-based management of early CKD.

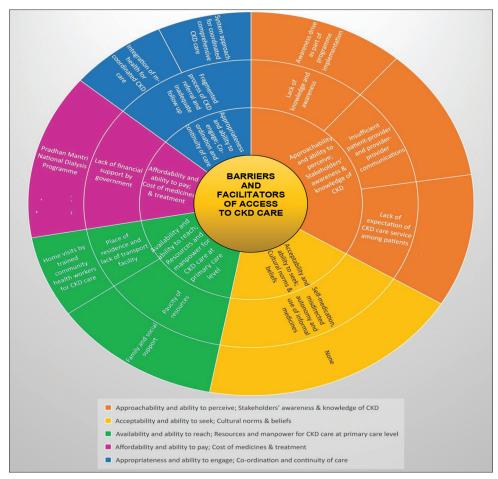


Figure 2: Sunburst chart summarizing the thematic areas, potential facilitators and various barriers of access to CKD care as emerged from the analysis of IDIs and FGD. From inside outward, the second circle represents the themes, the third circle represents the barriers and the fourth, and outermost circle represents the potential facilitators of access to CKD care

b) Insufficient patient-provider and provider-provider communications

According to a physician, "once I refer a kidney patient to Medical College, the patient usually does not come back. I don't get to know what happened to the patient. Probably a follow up advice for the PHC by the nephrologists would help" (Physician 4, male).

From the program side, service providers' readiness for planning outreach screening camps, emphasizing on improved patient—provider communication, distribution of IEC materials to impart health education were found to be almost non-existent. Not only communication amongst patient and provider needed to be improved, but communication between PCPs and nephrologists were far from satisfactory.

c) Lack of expectation of CKD care service among patients

"Actually we [patient and wife] did not know that this kidney problem of mine can be treated at Govt Hospital. I had breathlessness, then I went there [Govt hospital] and doctor did some test. He found that creatinine is high. I thought I have to go to CMC, Vellore for treatment" This was what a, Patient 4, Male, had to say. All patients revealed that not only they think HCPs are not responsible to provide

care for chronic diseases like CKD, but they themselves are not motivated enough to ask for management of their CKD. This lack of expectation could not only be attributed to provider shortfall but a direct result of low health literacy and lack of health numeracy sprouting out of deficient motivation, generally prevailing in the country.

Facilitator

a) Awareness drives as part of programme implementation

As per Community health officer 2, Female "Yes they [patients] should be given information! Until the public or common man is aware, how will they know?" Again, as per Patient 2, female, "Yes, it should be done, awareness should be spread, like for a patient or someone normal, they will know about their disease that what are the symptoms of disease, and then they [patients] will take more care and will go for continuous routine checkups. They must have awareness"

It is absolutely necessary to give equal importance to CKD as other NCDs according to government officials responsible for NCD programmes implementation. Outreach camps at suitable locations like the HWCs, mass media campaigns, and dissemination of printed IEC materials were also suggested by some for health education.

Acceptability and ability to seek; Cultural norms and beliefs

'Acceptability and ability to seek' might be described as the cultural factors and norms that influence how populations accept the aspects of services provided.^[13] Values and beliefs also play their part in acceptability and the ability to seek.^[14]

Barrier

a) Self-medication, misdirected autonomy and use of informal medicines

HCPs reported a general inclination towards alternative medicine in the hope of an elusive cure for the management of NCDs like diabetes and CKD, which is a major challenge for managing CKD and other NCDs. "I don't like to go to the Govt Hospital in town for treatment as there are long queues and prolonged waiting time. I get sick by standing in the queue for long. My village doctor treats me with Ayurvedic medicines" Patient 5, Male.

Availability and ability to reach; resources and manpower for CKD care at a primary care level

Availability and ability to reach refers to the existence of health services for CKD and is determined by the availability of manpower and other health resources.^[13] The subthemes identified in this dimension were the following.

Barriers

a) Paucity of resources

Trained manpower, testing facility and required medications for treatment were all found to be deficient at a primary care level. "If more technicians are employed at block level, accordingly screening of chronic kidney disorders can be done there and also for blood glucose. So it will be done. Just the same problem remains of manpower shortage" (Physician 1, Male). More often than not, all CKD patients irrespective of stage of the disease were found to be referred to BMCH.

b) Place of residence and lack of transport facility

Since all patients in the present study were residents of rural areas, far from district towns, particularly during times of lockdown due to COVID-19 situation, it was impossible for them to travel for treatment. Those requiring mobility support faced challenges to pay for it. Geographical location and distance, thus, posed a major challenge.

Facilitators

a) Family and social support

All patients deliberated that family was an important consideration in the management of their illness. Family support was an important motivating factor in taking care of their health. Family members supported patients to take their medicine, adhere to dietary restrictions and to maintain an active lifestyle. "My wife cooks me food as told by my doctor. Although it is difficult to have separate food for one person at home, she does it. Other members of my family and even neighbours are conscious about my condition" (Patient 6, male)

b) Home visits by trained community health workers for CKD care

Patients were mostly in the favour of ASHA-based care at home in terms of health education and screening. ASHAs also expressed their willingness to receive vocational training on CKD care and management and implement it upon patients. "Our knowledge should be increased, like what kidney failure is and how and when to monitor. The more information [as part of training] is given it is better. I want to get further knowledge so that we can give it to the patient at home and it will be beneficial." (Community health worker 4, female). (during FGD)

Affordability and ability to pay; cost of medicines and treatment

The ability to pay denotes the economic capacity of people to spend resources and time.^[13] Here, the identified subthemes were the following.

Barrier

a) Lack of financial support by the government

All stakeholders and most patients expressed their financial difficulties in meeting all the expenses incurred from treatment (medications, laboratory tests, etc.). "Most of the families are unable to come for dialysis three times a week. I am going to Burdwan just for treatment thrice a week. Transportation, food, dialysis, all costs a lot." (Patient 5, male). Government subsidy for medicines and free investigations were some of the sought after facilities by the stakeholders. Another noteworthy recommendation by one of the HCPs was direct benefit transfer (DBT) to the patient for continuing medicines and reducing the financial burden.

Facilitator

a) Pradhan Mantri National Dialysis programme

The programme was launched on 7th April, 2016 which provides free dialysis service for the designated beneficiaries at district level hospitals. [15] West Bengal is the frontrunner as the state registered 42,000 beneficiaries, highest amongst all states in 2018. [16] "PMNDP has been a great help in catering free dialysis services to the poor patients. The programme runs in PPP model". (Government official 2, male) Health planners are in the favour of wider publicity of this programme for greater accessibility benefitting poor patients in remote areas.

Appropriateness and ability to engage; Co-ordination and continuity of care

'Appropriateness and ability to engage' point towards the fit between services available and patient needs.^[13] The subthemes that emerged in this dimension were the following.

Barrier

a) Fragmented process of CKD referral and inadequate follow-up

Due to a lack of information among PCPs about the operational nephrology OPD at BMCH, almost all referrals are done to the Medicine OPD of BMCH and proper follow-up is not done too.

Facilitators

a) Integration of m-health for coordinated CKD care

"We are already providing telemedicine services by the name of Swasthya Ingit through Suswasthya kendra (Health and Wellness Centre, HWC), run by CHOs. The NCD mobile at PHCs have two apps which can be updated with CKD modules once Government comes up with a guideline for comprehensive CKD care for continuity of care and follow up. By connecting Nephrology OPD at BMCH or elsewhere we can cater to rural populations through erstwhile subcenters, now HWCs via telemedicine. It will be a boon for our rural population to avail that" (Government official 2, male).

All stakeholders, including the CKD patients, were supportive of the idea to include mobile technology in CKD care. As an NCD mobile is already at the disposal of PHCs, with two apps namely AB-HWC and SIMPLE, updating these two apps with CKD modules in near future will result in improved care coordination which will further improve referral, follow-up and adherence. In addition, CHOs and Govt. officials were in the favour of use of telemedicine, presently implemented as Swasthya-Ingit at HWCs for further care co-ordination by integrating nephrology OPD at BMCH with HWCs in "Hub-and-Spoke model" to overcome the challenges posed by geographical location, distance and financial burden.

b) System approach for coordinated comprehensive CKD care

HCPs and govt officials expressed the felt need for integrating CKD care into the existing NCD programmes like National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke and National Programme for Health Care of the Elderly. Govt officials emphasized on earliest implementation of the proposed Block Public Health Unit with its own public health laboratory facilities and qualified, efficient staffs for mandatory rather than prevailing opportunistic and risk-based screening for NCDs like CKD.

Discussion

The present study concentrated on identifying major challenges for access to comprehensive CKD care and also focused on bringing out the key facilitating factors for the same among rural communities. Addressing these barriers could significantly decelerate the progression of CKD to end stage kidney disease (ESKD) among patients, reduce healthcare expenditure and bolster the current standard of care by empowering patients. Foremost among them was poor knowledge and lack of awareness of CKD among patients as well as PCPs and other HCPs. Studies from other countries have reported poor knowledge and awareness of CKD amongst health-care providers and patients similar to the findings in the present study. [13,14,17] The shortage of medications and supplies is an additional key barrier to CKD care in rural areas as found in other studies.^[18,19] Health education courses and modules on CKD for PCPs have been shown to increase knowledge regarding CKD and could be adapted for PCPs. $^{\left[20,21\right]}$

Screening for CKD has been shown to be cost effective in studies done on diabetes in HIC.^[22-24] Because of the high prevalence of CKD and associated premature mortality and the high recurring cost of dialysis, CKD screening is likely to offer even more economic returns on investment in Low and Middle Income Countries (LMICs). Comprehensive CKD care 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 ESKD.^[25]

Utilizing ASHAs for health education of CKD patients was found to be a future strategy and a potential facilitator for comprehensive CKD care. However, the utilization of such strategy and its outcome is yet to be evaluated. A study in USA found that 'health coaches' (trained volunteers from the community) reduced hospitalisation rates and emergency department use among patients suffering from chronic diseases. [26] Telemedicine can be used for this kind of health coaching as an alternative to, or in addition to ASHA-based comprehensive care for CKD patients. Web-based solutions to aid self-management would be a viable option, provided it can be innovative enough to enhance health literacy as well as health numeracy of CKD patients. [27]

Strengths and limitations

This is likely to be the first qualitative study to explore the barriers and facilitators to access CKD care from the perspective of multiple stakeholders in eastern India. Both inductive and deductive methods to effectively capture all the key themes from the interviews were used in the present study. A key strength of the study was the enrolment of multiple stakeholders who brought in patient as well as provider perspectives along with grassroot-level realities about the challenges faced by providers like CHOs who were involved for the first time in this type of study in India. The study utilized a modified Levesque framework as a conceptual framework to assess the barriers and facilitators to access to CKD care and the relevance of the Levesque framework in capturing various dimensions of access to CKD care is elaborately demonstrated in the study.

Small number of PCPs working in PHCs of a single block might not reflect all the challenges of access to CKD care in the country. This limitation was taken care of by purposively recruiting more ASHAs and CHOs to ensure that the results of the study represent the perspectives and inputs of HCPs with different roles and responsibilities. Since our patient participants were recruited from a few selected villages in eastern India, findings may not be transferable to all rural communities of India.

Conclusion

The major challenges identified as barriers to access to CKD care were a general deficiency of awareness, absence of a national-level guideline for CKD care as well as prevailing unpreparedness of the existing healthcare delivery system to cater to CKD patients from rural background. Strategies incorporating

awareness generation, equipping the periphery to cater to the rural population by ensuring laboratory facilities and continuous supply of medications, through minimization of out-of-pocket expenditure by expanding the scope of existing health insurance and DBT will strengthen the healthcare delivery for attaining comprehensive CKD care.

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Conflicts of interest

There are no conflicts of interest.

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