

Continuum of care for non-communicable diseases during COVID-19 pandemic in rural India: A mixed methods study

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ABSTRACT

Background: COVID-19 pandemic has resulted in disruption to routine health services delivery as strict lockdowns were implemented in India and health workforce redeployed for COVID-19 focused responses. We assess the perceptions about COVID-19, the impact of the lockdown on access to health services and continuum of care for Non-communicable diseases (NCDs) among a cohort of adults in rural India. **Methodology:** Since 2018, we have been following up a cohort of persons with non-communicable diseases in a high NCD burden region in Srikakulam District of Andhra Pradesh under the STOP CKDu study. We conducted this mixed methods study, administered through a structured telephonic questionnaire and interview to determine the awareness, perceptions and their compliance to ongoing treatment schedules. **Results:** Overall, 68% of the participants exhibited adequate knowledge of symptoms of COVID-19, while 43% were not aware of the mode of transmission of the virus. In all, 822 (36.1%) participants reported at least one NCD condition. Among them, 115 (14%) missed their follow-up visit, 110 (13.4%) reported facing challenges in medication procurement and 11.6% either developed new complaints or experienced worsening of pre-existing symptoms. A total of 233 (28.5%) used a telemedicine facility and took telephonic advice from (private) physicians. As the access to medicines was restricted due to the lockdown, majority of the respondents were depending on rural medical practitioners (RMPs) for the procurement of medication. **Conclusion:** Our finding implies the need for the future guidelines on adaptation of telehealth approaches within health systems to maintain the continuum of care, digital health tools to facilitate the patient's appointments including virtual follow-up visits for those with NCDs coupled with regular engagement by frontline healthcare workers at the local levels, evidence informed public health messaging taking into consideration the social and behavioural aspect and uninterrupted essential primary healthcare services.

Keywords: Continuum of care, COVID-19, Knowledge, non-communicable disease, telemedicine

Summary Box

What is already known on this subject?

Restrictive measures during epidemics impact specifically the people living with NCDs by limiting their activity and results in

disruption of access to health services delivery. Telemedicine can provide support to persons with NCDs and chronic conditions in such settings.

What does this study add?

Our study found that during the COVID-19 lockdown, persons with NCDs used teleconsultations to seek guidance from their regular physicians, but relied on novel community-based initiatives such as pool medication procurement services through health workers and local health providers. The adherence to medications for NCDs was possibly influenced by the ongoing

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health awareness and behavior change communications that the community was exposed to during the STOP CKDu cohort follow-up.

Introduction

The Coronavirus Disease 2019 (COVID-19), caused by a newly discovered strain of the coronavirus SARS-CoV-2, has infected more than 45.9 million people and killed nearly 1.19 million people globally as on 1 November 2020.^[1] In India, COVID-19 has claimed 121,641 lives and infected over 8 million people as on 1 November 2020.^[2] India enforced a strict nation-wide lockdown starting 25 March 2020 and extended the same in 5 phases till 31 May 2020 aiming to reduce the spread of infection and prepare the health systems capacity for the pandemic. Restrictive measures undertaken as part of the lockdown, most notable limitations on travel, have impacted people's health by limiting their physical activity, ability to procure healthy foods and access to preventive or health promotion services.^[2]

Cardiovascular diseases, cancers, chronic respiratory diseases, diabetes, and chronic kidney disease are among the leading causes of death and disability in India.^[3] Even as the entire healthcare system has been redeployed to manage the COVID pandemic, continued prevention and control of non-communicable diseases (NCDs) are important.^[4] The Government of India issued an advisory for those with chronic conditions to avoid visits to healthcare facilities for non-emergency consultations.^[5] Regular outpatient services were suspended. Further, most of the frontline healthcare workforce have been instructed to suspend their routine healthcare delivery services and reassigned to contact tracing and public health response activities.

The 'Study to Test and Operationalize Preventive approaches for chronic kidney disease of undetermined aetiology (STOP CKDu)' is following up a community-based cohort of 2419 participants over the age of 18 years in 40 clusters (75 villages) of Srikakulam District in Andhra Pradesh, India since Feb 2018.^[6] Trained healthcare workers are responsible for making monthly contact with the study participants and ensuring the continuum of care.

As COVID-19 cases were being reported across India, the project suspended in-person follow-up of the subjects with effect from 20 March 2020. While field activities and home visits for follow-up of the cohort were suspended, the field healthcare workers continued to maintain contact with the cohort participants through telephone calls and short messaging services. As the pandemic progressed, the government announced a strict national lockdown. The state government suspended all outpatient services in the primary healthcare facilities and hospitals with effect from 26 March 2020 aiming to curtail COVID-19 transmission.

In the next few days, the state government of Andhra Pradesh launched a telemedicine service, accessible by a toll-free number.^[7] This facility allowed citizens of the state to seek information

on COVID-19 and report symptoms. This facility also offered tele-consultations for those who needed medical attention for other conditions. Every call initiated a system response to facilitate a triage and health consultation by general practitioners and where needed, coordination of doorstep delivery of medicines through the frontline healthcare workers.

We conducted this mixed methods study to assess the perception of participants in our cohort about COVID-19 and understand the impact of COVID and the mobility restrictions posed by lockdown on the access to care and compliance to treatment among adults with common NCDs.

Methods

This study was designed to assess the awareness levels among the cohort participants regarding COVID-19 and understand the practices regarding the continuum of care for NCDs in this rural context during the lockdown. We administered a structured questionnaire and undertook qualitative interviews to address these objectives. STOP CKDu study received IEC approval on, this study is a follow up component of the main study 17 January 2017 (IEC Approval 001/17).

We included seven questions to the STOP CKDu study follow-up to determine the level of awareness and perceptions regarding COVID-19 and compliance with ongoing NCD treatment schedules. The questions around assessment of knowledge and infection control practice related to COVID-19 were adapted from the World Health Organization (WHO) novel coronavirus (nCoV) infection prevention and control (IPC) strategies 2020. Four questions relating to the treatment of existing conditions such as difficulties in getting medication, hospital follow-up, and development of any new complaints or worsening of symptoms during COVID-19 pandemic were administered to people known to have NCDs. The questionnaire was administered from 10 April to 24 May 2020, that is, 8 weeks into the lockdown. All responses were recorded into an electronic data collection tool as per the standard operating procedures of the project.

We also conducted in-depth interviews with the patients with NCDs ($n = 8$), medical staff of rural primary health centres ($n = 5$) and STOP CKDu study field health workers ($n = 6$) using a semi-structured topic guide. The patients were randomly selected from the study database of those known to be on treatment for NCDs. Health professionals were selected from five Primary Health Centres based on their availability and willingness to participate. The participants were informed of the purpose of the study before conducting the interview and consent was obtained. After obtaining their verbal consent, in-depth interviews (IDIs) were carried out telephonically. Audio recordings were transcribed in local language (Telugu) and translated to English by the BG. The transcripts were read by the PI and codes were generated manually. It was reviewed by a second investigator (OJ) to reduce subjectivity in interpretation and increase credibility of the results. Any differences between the two were resolved through discussion.

Statistical analysis

The data were analysed in STATA version 16. Descriptive statistics have been provided for gender, age and disease conditions, knowledge on COVID are expressed as a proportion for categorical variables and mean (\pm SD, standard deviation). Pearson's Chi-squared test was used to assess the differences between the means of independent and dependent categorical variables and *P* value of 0.05 was considered statistically significant.

Results

Out of 2419 participants recruited between May and December 2018 in STOP CKDu cohort, 2276 participated in current telephonic survey (40 had died, 85 migrated, and 18 could not be contacted). The demographic characteristics of the study population are tabulated in Table 1. The mean age of participants was 45.8 (\pm 13.3) years, and half of the study respondents were women. A total of 822 (36.1%) participants had at least one NCD, with 539 (23.7%), 221 (9.7%) and 62 (2.7%) having one, two or more than two conditions, respectively. Regarding knowledge assessment on COVID-19 relating to disease presentation, ways of spread and measures to prevent its spread, overall, 68% of the participants exhibited good knowledge of the common symptoms and precautions for prevention. However, a substantial proportion 43% were not aware of the mode of disease transmission. The results of the knowledge assessment are shown in Table 2.

Out of 822 respondents who were scheduled to have a medical follow-up, 115 (14%) missed their follow-up visit during

Table 1: Characteristic of study population

Characteristics	Total participants (n=2276) %
Gender	
Male	1086 (47.7)
Female	1190 (52.2)
Age (Mean \pm SD)	45.8 (13.3)
Morbidity history	
Hypertension	635 (27.9)
Diabetes	169 (7.4)
Heart disease	233 (10.2)
CKD	136 (6)
Number of NCDs	
0	1454 (63.8)
1	539 (23.7)
2	221 (9.7)
>3	62 (2.7)

Table 2: Knowledge about COVID-19 among the participants (n=2276)

Knowledge	Yes	No	Don't know
The main clinical symptoms of COVID-19 are fever, fatigue, and dry cough	1560 (68.5)	311 (13.7)	405 (17.8)
Washing hands with soap, using face mask and maintaining social distance can help in the prevention of disease transmission	1556 (68.3)	331 (14.5)	389 (17.1)
COVID-19 is transmitted through air, contact, and droplets	1298 (57)	650 (28.6)	328 (14.4)

the lockdown, 110 (13.4%) reported facing challenges in medication procurement and 98 (11.6%) either developed new symptoms or experienced worsening of pre-existing symptoms [Table 3]. A total of 233 (28.5%) used the telemedicine facility and sought telephonic advice from (private) physicians, while 149 (18.2%) were able to undertake an in-person visit to their regular healthcare provider. The association between number of comorbid conditions and continuum of care is represented in Table 4. We observed statistically significant differences between continuum of care and number of comorbid conditions ($p < 0.001$). Among those with end stage kidney disease, seven subjects were undergoing regular in-centre haemodialysis. Four of them reported missing their scheduled session. Out of them, one developed severe breathlessness, who was taken to a dialysis facility but died despite receiving dialysis.

Patient expectations and experiences during COVID-19

The interviews revealed that a majority of the study respondents were not aware of the teleconsultation facility being offered by the Government. A small proportion of the respondents attributed social media including message forwards through WhatsApp as the primary source of information regarding the telemedicine facility. Healthcare workers were aware of the service but described that they were uncertain regarding their specific roles in telemedicine as they did not receive any targeted training on how the service was to be used. Our interviews also revealed that the respondents who required medical advice typically contacted their routine private healthcare providers over the telephone. In most instances, their doctors advised them to continue ongoing medication or prescribed symptomatic treatment and recommended to follow-up in-person once the lockdown restrictions are reversed.

We describe below some of the experiences as narrated:

“Our medical officer got few calls from SJ Puram village, sir had prescribed some medication and we handed over these medications to ANMs (auxiliary nurse midwives) of their respective villages. ANMs and ASHA (Accredited Social Health Activist) is responsible to delivery these medications to patients with in 24hrs”.

(Health Assistant, BattigalluruPHC)

“Jagan sir (Chief Minister of Andhra Pradesh) launched this program and many of us came to know about this program through Facebook, WhatsApp and we also circulated in our groups and as party member we are educating and motivating people to use this facility”

(NCD patient and political activist)

“Sir in our PHC, our medical officer sir informally informed us about this telemedicine initiative during COVID response meeting, but haven’t received any training and guidelines”.

(Auxiliary Nurse Midwifery, Boddapadu village)

Access to medicines during the lockdown

Many issues around the procurement of medications were highlighted by the participants. As the local pharmacies and medicine shops in the villages were closed the respondents faced challenges in procurement of their routine medicines. Moreover, as the government advisory had warned that individuals with NCDs were at higher risk of COVID-19-related complications including death they were strictly advised against leaving their homes. In most instances, medicines had to be procured from bigger towns which were 25–90 km away from the villages where the respondents lived. We noted various community-level initiatives such as pooled procurement of medicines facilitated by an informal network consisting of Rural Medical Practitioners, unqualified rural health providers, laboratory technicians, and village youth groups. They were either paid a small amount for services rendered or received a commission from the pharmacy on every prescription.

Lived experiences as below:

“my son will get my medication from Palasa, he needs to travel over 15 kms and stand in queue to get my medications”

(CKD patient in their 40’s)

“.....RMPs don’t demand money from the patients. They get commission from pharmacy shop. In general, a strip of BP (blood pressure) and Sugar (diabetes) tablets costs around Rs70. The RMPs will purchase from retail shop or generic shops, and they get it for 40 to 50 rupees and keep the rest of the money”.

(Health worker)

“I gave fuel costs to my neighbours or other people from the village who were travelling into the towns and they helped me in purchasing my medication”

(CKD patient CKD patient in their 50s)

Emergency medical care:

“Sir, I forget exact date but it’s around the 1st week of April, I had severe respiratory distress and my son had taken me to private hospital at Palasa and it was closed, hospital staff informed us to visit CHC (community health centre)”.

“Nephrologist from Srikakulam is treating me, my son called him and explained my condition and sir had prescribed some new tablets”.

(Haemodialysis patient in their 50s)

Table 3: Continuum of care during COVID-19, among a participants reported with chronic disease conditions (n=822)

Existing disease care	
Q1. Did you miss your scheduled follow up with doctor during lockdown?	
Did not have a visit scheduled during this period	325 (39.6)
Was asked to come after lockdown	115 (14.1)
Obtained consultation over telephone	233 (28.3)
In-person consultation	149 (18.1)
Q2. Do have any difficulties in getting your regular medication?	
Have medicines in stock, did not need to get medicines	262 (31.9)
Yes, I faced difficulties in purchasing my medication	110 (13.4)
No, I did not face difficulties in purchasing medication	450 (54.7)
Q3. Have you developed any new complaints or worsening of symptoms during lockdown?	
Yes	98 (11.6)
No	727 (88.4)
Q4. Have you visited hospital for emergency medical care?	
Yes	3 (0.4)
No	819 (99.6)

Discussion

To our knowledge, this is the first study conducted in India to assess the effect of the ongoing COVID-19 pandemic on access to health services for persons with NCDs living in rural areas. These findings highlight both the hardships faced by those with NCDs, attempts by the government to provide the continuum of care and some innovative solutions that have emerged from the local ecosystem.

WHO has highlighted that restrictive measures and travel restrictions to reduce the spread of infection during epidemics specifically impact people living with NCDs as such restrictions limit their activity, reduce access to secure healthy foods, as well as access to preventive or health promotion services.^[8] In our survey, we found participants exhibited good knowledge about the disease symptoms of COVID-19 and public health measures (social/physical distancing, lockdown, and usage of masks or face covering). Our survey was conducted 8 weeks into the national lockdown. During this time, both the local

Table 4: Relation between the number of comorbid conditions and continuum of care

	Missed follow-up visits Yes (n=115)	P	New complaints or worsening of symptoms Yes (n=98)	P	Difficulties in getting your regular medication Yes (n=110)	P
Gender						
Male	59 (7.2)	0.361	51 (6.2)	0.49	61 (7.4)	0.96
Female	56 (6.8)		47 (5.7)		49 (6)	
Comorbidities						
1	52 (6.3)	<0.001	51 (6.2)	0.01	55 (6.7)	0.001
2	47 (5.7)		38 (4.6)		42 (5.1)	
>3	16 (2)		9 (1.1)		13 (1.6)	

health offices and various non-governmental agencies have been using different health communication strategies, including mass media such as television, IVRS phone calls, mobile caller tunes, text messages, and social media platforms. Our study found that while the respondents were aware and practicing the public health measures, their awareness around the mode of transmission of SARS-CoV-2 coronavirus was low. This discordance reflects the emphasis of these health awareness messaging being on the actions expected from the citizens without taking into consideration the level of understanding or prevailing belief systems around disease transmission. Targeted communications explaining the rationale for the preventive approaches against the spread of the infection was not emphasised in the public health messaging resulting in the lack of awareness as revealed in our interviews. It would be paramount to engage the principles of behaviour change sciences if such public health measures are to be sustained over an extended period as being witnessed in the extended lockdown as ongoing disease transmission. Our findings suggest that a significant proportion managed to receive medical advice from their treating physicians over telephone and a small proportion even managed to visit a physician during this lockdown. While advice received over the phone can be reassuring, we were unable to determine the quality of care provided. Nevertheless, our findings highlight the potential of telemedicine approaches for providing continuum of NCD care in remote rural locations. It is worth pointing out that the telemedicine practice guidelines by Government of India were issued only on 13 April 2020.^[6] Providing medical advice without an in-person visit was illegal in India before this date. Moreover, despite government telemedicine services being available for free, the patients preferred to contact their private doctors, perhaps because they were not aware of the new telemedicine facility or they were not confident of the quality of these services.

Despite lockdown, we found a high level of adherence to recommended NCD treatment and keen interest by the respondents to comply with the scheduled follow-up visits. This could be attributed to the high level of health awareness because of participation in the STOP CKDu study. Even during the lockdown, the STOP CKDu field workers regularly engaged with the participants about their health status and reminded them of the need to adhere to recommended treatment. About 13% of participants reported they were facing a challenge in procuring medication indicating that they were keen on the continuum of care and made attempts to procure the medicines. We also highlight that about one-third had medicines in stock and hence did not need to purchase medicines. Moreover, many of the patients were supported by the STOP CKDu team to ensure access to medications.

A recent global survey undertaken among 155 countries by the WHO has identified that in more than half (53%) of the countries, there have been complete or partial disruptions in the treatment for hypertension; in 49% of countries disruptions in treatment for diabetes and diabetes-related complications; 42% for cancer treatment, and 31% for cardiovascular emergencies.^[7]

Given the significant burden of NCDs in India, the challenge of maintaining continuum of care for the patients with NCD during the COVID-19 pandemic has enormous significance particularly from the perspective of health outcomes.^[8] Emerging evidence suggests that persons with NCDs are at higher risk of adverse outcomes in COVID-19.^[9]

One of the key strengths of our study is that the sample pool of the respondents is based on a well-designed cohort drawn through a population proportionate to size (PPS) methodology and that a baseline clinical and laboratory evaluation on common NCDs were already established. Moreover, as our healthcare workers have established excellent community engagement over the cohort follow-up, eliciting the responses for the study through telephonic interviews was easily achieved. An important limitations of the study is that the interviews were conducted among a cohort that was highly sensitized to the need for continuum of care for their NCD conditions, and therefore, the high level of compliance to continuum of care is likely to have been influenced by this and results may not be generalizable in other parts of rural India.

Conclusion

As the COVID-19 pandemic has been rapidly evolving, decisions for improving the clinical and public health responses rely on the sparse data from low- and middle-income settings. Our findings provide insights into the perceptions and practices that are prevailing in a high NCD burden setting in rural India. We highlight the urgent need for comprehensive guidelines that address continuum of care for NCDs during the current and future disruptions to routine healthcare service delivery. The patients from marginalized communities and lower socioeconomic strata are particularly vulnerable to medication non-adherence and adverse health outcomes as the COVID-19 burden puts increasing demand on the fragile health systems in LMIC settings. In the context of loss of livelihoods due to the pandemic, proactive policy interventions such as identifying those with NCDs and ensuring a continuing supply of prescription medicines through the network of generic medicine supply units would be critical to avert the collateral from the pandemic. Our findings imply the need for further research on understanding the determinants of the continuum of care in NCDs particularly in the context of maintaining essential health services during public health emergencies such as pandemics. As the COVID-19 pandemic and its effects on health systems are likely to continue in the medium to long term, guidelines to address the key emerging areas such as adaptation of telehealth approaches within health systems to maintain continuum of care, digital health tools to facilitate patient's appointments including virtual follow-up visits for those with NCDs coupled with regular engagement by frontline healthcare workers at the local levels would be critical. In addition, evidence-informed public health messaging taking into consideration the social and behavioural aspects and prioritization by governments to ensure uninterrupted essential primary healthcare services would be key to preparing for future pandemics.

Key Messages

1. Restrictive measures during the COVID-19 significantly impact access to health services delivery, the impact is significant on persons with NCDs
2. Appropriate use of digital health tools such as telemedicine services that were introduced by the government of Andhra Pradesh on time helped the persons with NCDs to avail the continuum of care
3. Community response and resilience to ensure the continuum of care for NCDs was observed in the form of novel approaches of pooled procurement and supply of prescription medications, doorstep delivery of the medicines facilitated in continued medication adherence even during an extended period of lockdown.
4. Well established linkages between the communities in Uddhanam region and the frontline health workers, led to the timely dissemination of contextual health information even as the pandemic started.
5. Frontline health workers played an important role in keeping this high-risk community safe during the COVID-19 pandemic this was augmented by the support extended by the department of health through telemedicine and doorstep delivery of medicines.

Author Contributions

OJ, BG and VJ designed the study; BG supervised the data collection; BG and OJ analysed the data; BG, OJ, and VJ drafted and revised the paper; all authors read and approved the final version of the manuscript.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

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