


Impact of COVID-19 primary healthcare service restrictions on patients with chronic obstructive pulmonary disease in Cape Town, South Africa

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Background. Patients with chronic obstructive pulmonary disease (COPD) typically experience multidimensional symptoms throughout the course of their disease, with burdensome physical symptoms, social isolation, and additional psychological suffering. COVID-19 lockdown resulted in restrictions on chronic care delivery at primary healthcare (PHC) facilities, and it is not known what the care experiences of patients with COPD were during this time.

Objectives. To describe patient experiences of the impact of the lockdown on their needs and their experiences of the primary care received for their COPD.

Methods. The data reported in this paper are from a cohort of 49 patients with COPD receiving primary care, recruited in February and March 2020, before recruitment was paused for COVID-19 lockdown, for a feasibility stepped-wedge hybrid type II design randomised controlled trial of integrated person-centred palliative care in primary care for patients with COPD in Cape Town, South Africa. Data are open-text responses from participants who responded to a single question on a validated measure of primary care consultation empathy (CARE), and describe patient experiences of the impact of the lockdown on the primary care received for their COPD, prior to crossover to trial intervention.

Results. Thirty-two patients with COPD gave between 1 and 9 responses each to the open-ended question between March and December 2020. The average age of the participants was 58.6 years, and 53.1% ($n=17$) were female. Inductive analysis of the open-text data identified four main themes. Participants described decreased access to chronic care and a desire for more person-centred care in interactions with healthcare professionals. The socioeconomic ramifications of the COVID-19 lockdown added to the burden they experienced.

Conclusion. The COVID-19 lockdown PHC service restrictions caused a disruption to the continuity of care for patients with COPD, with associated worry, anxiety and disappointment. Medication access was largely supported by the home delivery of chronic medication. We suggest that there are opportunities for providing more sustained support for patients with COPD through referrals to community health workers, and also through telephonic patient follow-up by primary care teams.

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During the first decade of this century, the global prevalence of chronic obstructive pulmonary disease (COPD) was estimated to be 11.7%,^[1] with a further estimate of 10.1% global prevalence at stage 2 or higher. Globally, COPD is under-diagnosed and undertreated.^[2-6] Patients experience multidimensional symptoms and concerns affecting their quality of life, particularly with, but not limited to, more advanced-stage disease, and persisting irrespective of COPD diagnosis or disease-orientated treatment.^[3,7-9] Undertreated physical symptoms are associated with an increased risk of depression.^[3] A study conducted in Africa and the Middle East^[9] reported a 7-day period prevalence of breathlessness for patients with Global Initiative for Chronic Obstructive Lung Disease (GOLD) stage C and D COPD of 84.6%, and 75.4% for coughing; 22% of patients with these symptoms described them as extremely severe. It has been reported from high-income countries (HICs) that after the first hospitalisation for an exacerbation of COPD, 50% of patients died within 3.6 years and 75% died within 7.7 years.^[10]

Palliative care is indicated for patients with a life-limiting illness such as COPD, provided alongside disease-directed care, with the intention of addressing quality-of-life concerns for the patient

and family.^[11] Integrated, holistic palliative care for patients with breathlessness due to advanced disease (including COPD) has been shown to significantly improve self-management of breathlessness and may even improve survival.^[12] The GOLD advocates for addressing the multidimensional needs of patients and their families through holistic interdisciplinary care, including integrated palliative management of distressing needs throughout the disease trajectory.^[7] However, even in HICs, patients with COPD are less likely to receive palliative care than patients with lung cancer,^[13,14] despite these two groups of patients experiencing overlapping symptom profiles and symptom prevalence.^[15] The GOLD^[7] recognises the need for enhancing patient self-management, supported by a Cochrane review suggesting that individualised and holistic care plans can reduce hospitalisations and improve quality of life.^[16] In practice, COPD in South Africa (SA) tends to be an umbrella term for chronic lung disease (CLD) of varying aetiologies, which include not only tobacco smoking but also previous pulmonary tuberculosis, occupational dust exposure, biomass fuel exposure, HIV-related chest infections and childhood chest infections.^[17] There is an urgent need for an integrated and holistic approach to COPD care in

primary healthcare (PHC). Such an approach may enable early management of patient and family needs to improve quality of life through management of physical symptoms and psychosocial concerns, throughout the disease trajectory and not just at the end of life.

In March 2020, as part of the national COVID-19 lockdown response in SA,^[18] PHC facility activities were scaled down, restricting and postponing outpatient chronic care visits, with chronic medication delivered to patients' homes. For the period 27 March - 17 August 2020, national lockdown regulations also included the prohibition of tobacco sales.^[18,19] Although emergency care visits were not restricted (including COVID-19 screening), a 69% decrease was reported in emergency COPD presentations to a regional hospital emergency unit during January - August 2020 compared with the preceding year.^[20] There was a 31% decrease in PHC visit attendance in Western Cape Province during March - December 2020 compared with the same period in 2019.^[21] It is unclear how these disruptions have affected the needs and management of patients with a progressive illness that requires adherence to treatment and carries a high burden of symptoms.

The objective of this study was to describe patient experiences of the impact of the lockdown on the primary care received for their COPD.

Methods

We report data from a cohort of patients recruited to a cluster feasibility stepped-wedge hybrid type II design randomised controlled trial of integrated person-centred palliative care in primary care for patients with COPD in Western Cape, SA, as part of part of the larger ASSET health systems strengthening programme.^[22] The trial aims to determine the feasibility of integrating palliative care into primary care for people with COPD. COVID restrictions were introduced in March 2020 after participant recruitment had started in February 2020, and the data reported here were collected prior to crossover to intervention, which occurred in mid-2021. The three sites in Cape Town were selected as providers of diverse models of primary care: one 8-hour clinic, one 24-hour clinic, and one district hospital. Data are open-text responses to a validated measure of primary care consultation empathy (CARE)^[23] and describe patient experiences of the impact of the lockdown on the primary care received for their COPD.

Inclusion criteria

We recruited adults (aged ≥ 18 years) able to communicate in isiXhosa, English or Afrikaans, able to give informed consent, attending primary care, and clinically diagnosed with COPD or CLD (with a history including the likely aetiological determinants in SA,^[17] namely cigarette or other smoking history, biomass fuel smoke exposure, history of previous pulmonary tuberculosis or other respiratory infections and occupational dust exposure, with the diagnosis documented in the participant facility folder or communicated to the research assistant by a doctor). The clinical inclusion criteria applied reflected characteristics of patients who were likely to have palliative care needs. They were based on the triggers for palliative care in the Practical Approach to Care Kit (PACK)^[24] that is used routinely in primary care, and the Supportive and Palliative Care Indicators Tool (SPICT),^[25,26] SA version,^[27] and included any of the following: (i) breathless at rest or on minimal exertion; (ii) on home oxygen; (iii) ≥ 3 hospital admissions for respiratory problems in the past year; (iv) >3 emergency visits for respiratory problems in the past month; (v) Karnofsky Performance Status ≤ 50 ; and (vi) dependence on others for activities of daily living.

Exclusion criteria were patients not attending primary care, patients with a diagnosis of asthma, and patients unable to give informed consent or speak one of the three languages listed.

Procedures

Eligible patients were identified by their treating clinical teams. The research assistants introduced the study to them, and if they were interested, potential participants were screened against the palliative care criteria. Potential participants received full information about the study in understandable terms in their first language before giving written voluntary consent. During the face-to-face baseline interview, participants self-reported sociodemographic and clinical data and validated self-report measures. Recruitment was halted due to the lockdown. Participants already recruited self-reported their open and closed responses monthly by telephone to study researchers, who documented their answers. We present an analysis of responses to the open-ended section within the CARE measure, which is a process measure of empathy in the respondent's primary care consultations in the previous month.^[23,28] Specifically, the open-ended section asks 'If you would like to add further comments on this consultation, please do so here.'

Analysis

Open-text questions within questionnaires provide respondents with the opportunity to identify matters not covered by the closed questions, and studies often do not analyse these responses.^[29] The written responses were transferred from the questionnaires, pseudonymised and entered into REDCap electronic data capture tools hosted at the University of Cape Town.^[30,31] The responses were subjected to inductive thematic analysis.^[32] Following an initial reading of the data, and discussion with the study team, a coding frame was developed. The frame was iteratively developed as each subsequent interview was analysed. Anonymous participant identification numbers are given after each reported quote to demonstrate use of the breadth of sample. We did not undertake longitudinal analysis, as the nature of the data collected (i.e. a single open question) did not provide insight into change over time. We report data collected at any timepoint.

Results

Sample characteristics

Of the 49 participants recruited between 20 February and 13 March 2020, 32 gave responses to the open-ended question on at least one timepoint between 26 March 2020 and 18 December 2020. No participants had a documented COPD GOLD staging in their file. Demographic and clinical data are presented in Table 1.

The inductive analysis identified four main themes: (i) access to care; (ii) medication access; (iii) continuity of care; and (iv) COVID-19 impact on wellbeing, behaviour and support (see Table 2 for illustrative quotes).

Theme 1 described the challenges and impact of reduced access to care. Interestingly, participants described a positive change in facility care due to the COVID-19 health facility reorientation, particularly with regard to decreased waiting times inside facilities. Participant Pat01/006 (time point 5) described a total visit duration of 1 hour 45 minutes, compared with the usual 8-hour visit. However, the waiting outside facilities in standing-only queues was described as burdensome by these COPD patients. Participants also described concerns around the lack of social distancing in the queues, and the risk of contact with COVID-19 in this situation. Once inside facilities, the new facility flow caused some confusion, with signboards not being clear to all participants. In terms of care received, participants described limited

Table 1. Demographic and clinical characteristics (N=32)

Age (years)	
Mean (SD)	58.6 (8.8)
Median	59
Gender, <i>n</i> (%)	
Female	17 (53.1)
Male	15 (46.9)
Income, <i>n</i> (%)	
Pension	13 (40.6)
Disability grant	11 (34.4)
Unemployed	4 (12.5)
Employed with payment	3 (9.4)
Employed without payment	1 (3.1)
Living arrangement, <i>n</i> (%)	
Lives alone	2 (6.3)
Lives with dependent children	4 (12.5)
Lives with older dependent relatives	1 (3.1)
Lives with partner and children	10 (31.3)
Lives with partner only	3 (9.4)
Lives with relatives or friends	6 (18.8)
Homeless shelter	2 (6.3)
Other	4 (12.5)
Number of hospitalisations during 12 months prior to recruitment, <i>n</i> (%)	
0	16 (50.0)
1	3 (9.4)
2	3 (9.4)
3	5 (15.6)
4	2 (6.3)
5	1 (3.1)
Unknown	2 (6.3)
Tobacco smoking ever, <i>n</i> (%)	
Yes	29 (90.6)
No	3 (9.4)
Tobacco smoking in the month prior to recruitment, <i>n</i> (%)	
Yes	16 (50.0)
No	16 (50.0)
Number of telephonic time points with open-ended question answered, <i>n</i> (%)	
9	1 (3.1)
8	2 (6.3)
7	2 (6.3)
6	5 (15.6)
5	2 (6.3)
4	3 (9.4)
3	5 (15.6)
2	6 (18.8)
1	6 (18.8)

opportunities to consult with a doctor in a meaningful way while at the facility, and this resulted in unmet needs. At the start of the lockdown there was uncertainty expressed regarding patient access to emergency units for acute breathlessness. In addition, there was apprehension among participants about contracting COVID-19 while at the health facility when attending emergency units for acute or acute-on-chronic health concerns. The most common experience of emergency unit care was positive, but one participant described 'rude' care when at an emergency unit for acute breathlessness.

Regarding theme 2, medication access, the home delivery of chronic medication was well received and appreciated by participants. However, some participants did not receive any delivery of medication, or needed to go to the health facility to get delivery arranged. Stock supply shortage was reported at the pharmacy level, and also occasional late delivery of medication to patients' homes, which caused anxiety. Participants described the borrowing or buying of new reliever inhalers when their facility supplies ran out early, were not available on reissue dates, or were not delivered timeously. They also described needing to visit the health facility for acute care for shortness of breath when inhaler medication had run out for the above reasons.

For theme 3, continuity of care, many participants expressed that the postponed and less frequent PHC facility chronic care appointments caused widespread emotional distress for patients, particularly anxiety, worry and marked disappointment. Participants particularly described disappointment at not being able to see a doctor more regularly. Frustration was expressed at the short duration of interactions with nurses or doctors, and that often insufficient attention was given to their personal questions or concerns. Participants described that their healthcare provider often reboarded their prescription without engaging in discussion around person-centred concerns. Care continuity into the community through community health worker support in the home was not reported at all by any participant. In addition, there was one report of a participant describing a delayed tertiary clinic appointment and the associated worry this entailed.

Theme 4 described the impact of COVID-19 on wellbeing, behaviour and support on patients who already had prior psychosocial concerns related to their lung disease. Participants described worry about contracting COVID-19 and feeling emotionally low since the lockdown. Those living alone struggled most emotionally, describing loneliness and low mood. Grief was described over the loss of loved ones to COVID-19, with associated emotional distress. Family and permitted community engagement was described as supportive, as was the monthly telephone research interview. The COVID-19 lockdown impact on decreased employment and casual working opportunities resulted in financial distress: social distress was evident, with families describing their lack of food and finances. The cigarette sales ban resulted in participants buying cigarettes illegally at high cost. Participants described a resultant decrease in numbers of cigarettes smoked during lockdown, alongside the associated burden of withdrawal symptoms.

Discussion

These data are important, as this is a dependent population with ongoing medical and support needs due to their advanced disease. Data from SA^[20] and internationally^[33,34] show that there appeared to be a reduction in emergency care visits for patients with COPD during lockdown periods, with differing potential reasons being cited. International studies have shown a decrease in acute exacerbations for patients with COPD during the lockdown period, with the suggestion that masks and social distancing measures were protective in shielding patients from viral precipitants.^[33-35] However, the broader experience of COPD patients has been that these patients had ongoing symptoms during lockdown,^[34] and in particular remained at risk of depression and poor sleep.^[36] Our study has shown that the decreased waiting times for chronic care at health facilities, particularly in the early lockdown, were marked, beneficial to patients, and very much appreciated. This finding highlights the need for consideration of the burden that results from long periods of waiting by patients who are living with

Table 2. Table of illustrative quotes

Themes	Quotes
1. Access to care	Pat01/006 time point 5: ' <i>... they did not look so busy rushing around like other times.</i> '
	Pat01/002 time point 2: ' <i>I must say they are looking well prepared for COVID-19.</i> '
	Pat02/002 time point 14: ' <i>I also had a doctor's appointment at the clinic. I had blood tests and COVID test, but I am negative. There were no queues and I did not have to wait long. It went off quite fine not like normal when you sit there all day!</i> '
	Pat02/008 time point 3: ' <i>My experience at the clinic was very pleasant, no long waits during this COVID time.</i> '
	Pat01/003 time point 1: ' <i>They could not find my file the last time. I had to wait so long. They should really do something about very ill patients having to wait this long especially when you are struggling to breathe!</i> '
	Pat02/021 time point 1: ' <i>My last experience at the clinic was unpleasant due to other patients who were very rude about keeping the distance between us due to COVID-19.</i> '
	Pat03/013 time point 4: expressed fear and concern at the long queues outside the facility, and reported preferring to pay ZAR420 in total for an appointment and medication from a private doctor, rather than wait 'and die while waiting in the queue outside the hospital'.
	Pat02/012 time point 12: ' <i>I was told the last time I can attend the emergency unit anytime if I need to as my next appointment is only mid 2021.</i> '
	Pat02/021 time point 2: ' <i>When I attended the emergency twice in the last month everything was very well organised at the hospital and everyone was very nice to me.</i> '
	Pat01/009 time point 6: ' <i>... it is usually so nice at [facility], but now they don't want us to come here for emergencies, I can understand, but they don't have to be rude about it ... I am not here because I want to come here, it is because my chest is tight and I have no medication left ... can't believe they gave me no nebs ... I feel better now that I got it off my chest. I appreciate your calls.</i> '
2. Medication access	Pat01/002 time point 9: ' <i>I do not feel good to go back now with COVID on the rise again</i> ' (a patient with an acute worsening of osteoarthritic pain and decreased wrist function, unresponsive to NSAIDs previously given).
	Pat02/002 time point 14: described medication not being delivered at one follow-up ' <i>because of the gangs shooting in the area</i> ', so the patient collected that batch of medication from the facility.
	Pat01/009 time point 10: described medication not lasting the full month and therefore needing to attend the emergency department because of shortness of breath: ' <i>my medication ran out, [that's] why I needed to come to hospital.</i> '
	Pat01/005 time point 9: the patient attended their clinic to get extra medication after it ran out. ' <i>It was easy to do this and I experienced no problems or long waits.</i> '
	Pat02/021 time point 8: the patient was unhappy about shortages of medication and described buying prednisone at ZAR20 and a Venteze inhaler at ZAR50, because the pharmacy had been out of stock and the response from the pharmacy staff (according to the patient) was that ' <i>there are too many patients to supply and the demand for certain types of medications are high.</i> '
3. Continuity of care	Pat03/001 time point 3: describing the hope that their next doctor's appointment that had been scheduled for 2 months hence would not be further deferred by a month or two, as ' <i>I would love to see a doctor.</i> '
	Pat02/007 time point 6: ' <i>I look forward to my next appointment to see the doctor as the last time I only saw nurses who were not very good. They don't examine us and don't listen.</i> '
	Pat02/002 time point 1: ' <i>I would like to see a doctor at each visit. We never get to see a doctor in this place, just [a] nurse who just rush through the appointment.</i> '
	Pat02/013 time point 1: a patient with COPD and comorbid stage 4 lung cancer who reported unmet needs, a lack of access to care support in the home and not knowing who to contact telephonically during level 5 lockdown, said: ' <i>[I was] expecting more help and support during this time.</i> ' The patient died 4 weeks later, with telephonic emotional support offered by the research assistant during end-of-life phase and in bereavement, and liaison between the research team and the PHC team for practical care support.
4. COVID-19 impact on wellbeing, behaviour and support	Pat02/006 time point 2: ' <i>... very lonely living alone ... feeling depressed.</i> '
	Pat02/007 time point 5: ' <i>I am very happy that my daughter fetched me so I'm feeling much better being around my family. This is a terrible time to be alone.</i> '
	Pat01/005 time point 7: ' <i>described a daily prayer group chat group that made him 'feel at peace.</i> '
	Pat02/018 time point 4: ' <i>doing very well, happy with my family support</i> ', but ' <i>otherwise I'm becoming frustrated with COVID-19 situation.</i> '
	Pat02/007 time point 5: ' <i>I am also glad to hear from you I always look forward to your call, thank you!</i> '
	Pat03/001 time point 3: ' <i>reported one illegal cigarette costing between ZAR15 and ZAR45 during the cigarette sale ban.</i> '

NSAIDs = non-steroidal anti-inflammatory drugs; COPD = chronic obstructive pulmonary disease; PHC = primary healthcare.

severe chronic symptoms. There was a benefit for many of having their chronic medication delivered, suggesting the potential benefit of this in non-pandemic situations. For those whose medication was not delivered timeously, there was associated worry, effort, and at times additional expense in collecting or buying medication. It was clear that these COPD patients were largely reliant on their inhaled medication for their self-management of breathlessness, presenting an opportunity for enhanced symptom self-management.

The impact of COVID-19 on participant psychosocial wellbeing was noteworthy, with concerns relating directly to the lockdown, but also to underlying health challenges. The cost of illegal cigarettes, rather than the ban itself, seemed to result in some, possibly temporary, change in behaviour, with a reduction in the number of cigarettes smoked reported by participants for the period of the cigarette sales ban. With regard to telephonic follow-up, for a cohort of COPD patients in Spain, Pleguezuelos *et al.*^[37] reported that while 90%

of their COPD patient medical appointments were cancelled, 61% had medical telephonic consultations as a replacement, with high satisfaction reported, suggesting that medical telephonic follow-up is an acceptable means of continuity of care. Our data show that many participants appreciated the ongoing telephonic research follow-up, suggesting the potential value (where patients or their family members are contactable via landlines or mobile devices) of individualised telephonic clinical follow-up as a means of assessment, support and provision of continuity of care. This may be of particular benefit for psychosocial care where patients may be at risk of depression and anxiety, but also for support of physical symptom self-management.

Conclusion

There are limitations to our data, specifically that the interviews were not audio-recorded, and the lack of appropriate data to conduct longitudinal analysis. The data do seem to reflect the experience of this group of patients of a number of the changes to routine primary care during the COVID-19 lockdown in SA. There is an apparent high level of reliance of these patients on the functioning of the health system for chronic and acute care, suggesting opportunities for more education on symptom self-management and the involvement of community care worker support. In both acute and chronic care situations, patients showed a preference for meaningful or individualised interactions with their healthcare provider, and for some the delayed outpatient appointments reduced their experience of care and added to the burden experienced during the lockdown. The descriptions provided show that continuity of care was largely disrupted by the lockdown-induced scale-down of PHC facility access. It appears that patients with advanced COPD value and particularly rely on the care and medication they receive at primary care, but that medication alone is insufficient to support person-centred care. Patients expressed the desire to engage with their doctor, particularly around questions relating to their disease. Telephonic follow-up appeared acceptable to many patients, and may be a suitable means of maintaining continuity of care for medical management and for psychosocial support where outpatient or clinic visits need to be minimised if future service disruptions occur. The opportunity for increased involvement of community care workers to support COPD patients in their homes may be a means of psychosocial support for patients.

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