## Impact of COVID-19 on Care Seeking Behavior of Patients at Tertiary Care Chronic Follow-up Clinics in Ethiopia: A Cross-Sectional Telephone Survey.

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#### Abstract

**Background**: Health service delivery and the uptake of health services were greatly affected by COVID-19. The current study assessed the change in patients' care-seeking behavior after the first COVID-19 case was reported in Ethiopia.

**Methods**: A cross-sectional survey was conducted among patients who were appointed at Tikur Anbessa Specialized Hospital (TASH), between mid-March to mid-June 2020. Data was collected through telephone, using a pre-tested, structured questionnaire. Data were analyzed using SPSS software version 25. Descriptive statistics and binary logistic regression models were used to describe the data and assess factors associated with loss to follow-up (LTFU).

**Results**: Among 644 interviewed patients, 70% were lost to follow-up. Fear of COVID-19 infection (87.1%) and transportation problem due to lockdown (82.7%) were among the main reasons for loss to follow-up. Patients aged  $\geq$ 60 years had highest odds of missing a follow-up in the multivariable logistic regression analysis. The odds of loss to follow up (LTFU) for the fear of COVID-19 was 13 times higher than among patients who did not have fear (AOR=13.39, 95% CI: 7.96-22.50). The odds of loss to follow up among patients who reported transportation problems were 3.6 times higher than among those who did not have transport problems (AOR=3.64, 95% CI: 1.93-6.88,). The odds of loss to follow up among patients with severe and very severe illness were about three times higher (AOR=2.7, 95% CI: 1.48-5.01).

**Conclusion**: Patient's care-seeking behavior with chronic medical conditions at the chronic care clinics of TASH were seriously compromised during COVID-19. Patient's age (>60 years), chronic disease severity, fear of COVID 19 and transportation problems significantly predicted LTFU. Strategies such as task shifting and establishment of telemedicine services should be explored to meet the ongoing health needs of chronically ill patients on established follow up care. [*Ethiop. J. Health Dev.* 2021; 35(3):200-207]

Keywords: Care-seeking behavior, chronic disease, COVID-19, Ethiopia, Loss to follow up

#### Background

The World Health Organization (WHO) declared COVID-19 infection, as a global pandemic on March 11, 2020 (1, 2). Shortly after, Ethiopia confirmed its first COVID-19 case on March 13, 2020. The government declared a state of emergency on April 8, 2020. Lockdown and movement restrictions followed, and citizens were encouraged to exercise social distancing, hand washing/ sanitizing, and the use of a facemask. There were also temporary restrictions on public transport across many regions and cities in the country (3). Lockdowns and movement restrictions led to a significant decrease in patient visits to health care facilities and especially to tertiary facilities (4). For example, in Tikur Anbessa Specialized Hospital (TASH), pediatric patient visits dropped by 30-70% at specialty clinics in April 2020.

A similar decline in the patient visits was reported for adult patients attending chronic care clinics, with an average of 28% loss to follow up (Health management information system office of TASH). Reports from countries with previous epidemics revealed that people avoid visiting health facilities for fear of contracting the disease. Lack of, or limited contact with the health care system may lead to increased mortality in patients suffering from chronic diseases. During the Ebola epidemic, non-Ebola morbidity and mortality increased after the outbreak in Sierra Leone, Guinea, and Liberia (5). A significant rise in mortality was also reported in comprehensive emergency obstetric and newborn care facilities across Sierra Leone (6). Among other important factors of health service utilization, the distance from a service center had a significant association with a reduction in the utilization of healthcare services (7). The current study was initiated following the observation that the chronic care clinics'

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attendance decreased significantly following the first confirmed COVID-19 case in Ethiopia. Since the impact of a decline in the tertiary hospital, chronic diseases follow up clinics during the pandemic has not yet been studied, this study aimed to assess the effect of the pandemic on patients with chronic disease's careseeking behavior.

## Methods

Study setting: This cross-sectional telephone survey was conducted at Tikur Anbessa Specialized Hospital (TASH) in Addis Ababa, Ethiopia. TASH is a public teaching hospital located in Addis Ababa, which has been serving the community of Addis and the rest of the country as a national referral center for the past 48 years. There are several specialty and sub-specialty clinics for chronically ill patients, with over half a million patients visiting the hospital annually. The hospital has 700 beds, 360 specialists, 1200 residents, seven general practitioners, 900 nurses, and 115 allied health professionals, including pharmacists, lab technicians, and radiographers. Additionally, 950 permanent and contract administrative staff are dedicated to providing health care services (8). The regular adult chronic care clinics at TASH consisted of infectious disease (ID), Hematology (Hema), Neurology (Neuro), Endocrinology (Endocrine), Cardiology (Cardiac), Gastro-enterology (GI). Nephrology (Renal), Rheumatology (Rheumato) and chest clinics (Chest). A total of 1082, 1900, 1307, 1592, 1653, 785, 565, 343 and 521 cases were seen in ID, Hema, Neuro, Endocrine, Cardiac, GI, Renal, Rheumato, and Chest clinics in December 2020, respectively. Each month between 9,000-10,000 chronic care visits are made in adult chronic care clinics. The Pediatric chronic care clinic of TASH consisted of Neurology (Neuro), Cardiology (Cardiac), Nephrology (Renal), Gastroenterology (GI). pulmonology (Chest), infectious disease (ID), High risk Infant Clinic (HRIC), and rheumatology (Rheumato) clinics. Before the COVID 19 pandemic, an average monthly visit of 620, 510, 129,100, 60, 300, 230, and 14 patients were seen in Neuro, Cardiac, Renal, GI, Chest, ID, HRIC, and Rheumato clinics, respectively. Monthly between 2500-2600 patients were seen in the pediatric chronic care clinics (Health management information system (HMIS) office of TASH). All chronically ill study subjects were on life saving or prolonging medication.

# *Study design and duration:* A cross-sectional telephone survey was conducted from May-July 2020.

*Study population:* The study was conducted on patients from 12 specialty clinics, including, pediatric (neurology, cardiology, nephrology, gastroenterology, infectious disease, hemato-oncology, and high-risk infant clinics). Adult (neurology, cardiology, diabetic, hematology, chest, and rheumatology) clinics were also included in the study. Adult patients/ their families and parents/guardians of pediatric patients with regular follow up in these clinics, between March 15 and mid-June 2020, and whose contact details were on record, were interviewed in the study.

*Inclusion criteria:* Patients with chronic diseases, who scheduled follow up appointments during the study period.

*Exclusion criteria*: Those with difficult communication because of language barrier (interview was in Amharic and Oromifa), those who were irregularly attending follow up clinic before the COVID pandemic, those who discontinued the follow up before the COVID-19 pandemic, and those with incomplete information were excluded.

Sample size and sampling methods: The sample size was calculated using a single population proportion formula, assuming 50% prevalence estimate of the loss to follow-up, with 95% confidence limit and 4% precision. Considering a 20% non-response rate, the sample size estimated was 750. The sample size was proportionally allocated to the 12 specialty clinics based on the caseload ratio. Patients were sampled using a systematic sampling method from the paper-based and electronic registers of the particular clinic using the sampling interval obtained by dividing the caseload of the particular clinic to the allocated sample size.

Data collection: The data collection tool was prepared in the form of questionnaire and piloted on 15 patients before it was used. One-day training was given to four general practitioners (GPs) and six residents on how to use the tool. Data collectors contacted participants and/or their caretakers telephonically in order to obtain informed verbal consent, participants were also informed that refusal to participate in the study would not change the quality of care they received from the hospital. Three attempts were made to contact patients, before they were deemed untraceable cases. After patient contact details were retrieved from clinical files and once verbal consent was obtained, information on patient age, sex, address, diagnosis, severity of illness, type of treatment, and year of follow up at TASH were extracted from the chart. Information on patient occupation (in adult), parental education, monthly income, means of transport, patient's choice to attend follow up, the received telephone call (from TASH), treatment cost, loss to follow up (LTFU), missed medications, reasons for loss to follow up, worsening of symptoms, alternative measures taken, and the role of local pharmacies and local government health institutions were obtained by telephonically.

**Operational definition:** Loss to follow-up (LTFU) was defined as any number of missed appointments after COVID-19 was officially announced as a public health emergency in Ethiopia. Similarly, chronic illness was defined as a disease or condition that usually lasts three months or longer. Information on severity grading was retrieved from the medical record of study subjects (that was based on international disease severity classifications), such as New York Heart Association class for cardiac failure, and cancer staging for oncology cases. Transport problems were considered as the inability to get access to all transport systems in order to attend follow up visits due to the lockdown.

*Data analysis:* Data from the phone surveys and chart retrieval was entered into SPSS version 25. Simple univariate analyses were used to describe the data. A logistic regression model was used to identify associations between LTFU and associated factors. Also, differences in proportions were compared for significance using the chi-square test. A P-value <0.05 was considered statistically significant.

*Ethical considerations*: Ethical clearance was obtained from the Institutional Review Board (IRB) of the college of Health sciences (Protocol no. 042/20/SPH). Informed verbal consent was obtained from each patient (adult) and from the parent or guardians, of a child, for the interview. Participants were assured that refusal to participate in the study would not change the quality of care they received from the hospital. A letter

of permission was obtained from the hospital administrator to retrieve patient's medical records. Personal identifiers such as names, patient card numbers, and telephone numbers were removed from the data sets to protect a person's privacy and data and to maintain confidentiality. Password controlled by the principal investigator secured data access.

### Results

**Sociodemographic profile:** Of the 750 patients contacted, 644 (86 %) were used for analysis as the rest had incomplete information and/or were not traceable. The age ranged between 1 month and 90 years, (median age = 25 years). The male to female ratio was 1:1.03. The median age in years of females were higher than males, (31 and 14.5 with IQR-38 and 44) respectively.

Table 1: General characteristics of study participants at the chronic care clinic during COVID-19 pandemic, TASH, 2020.

Characteristics	Male (%)	Female (%)	Total (%)
Age in year			
≤18	168(53)	119(36.4)	287(44.6)
19-39	44(14)	86(26.3)	130(20.2)
40-59	57(18)	82(25.1)	139(21.6)
≥60	48(15)	40(12.2)	88(13.7)
Total	317(100)	327(100)	644(100)
The median age in years (IQR)	14.5(44)	31(38)	25(41)
Average monthly income Ethiopian Birr	3000(78)	2000(52)	3000(78)
Sources of patients for the study			
Cardiac clinic patients	67(21)	68(20.8)	135(21)
Endocrinology clinic patients	23(7.3)	58(17.3)	81(12.6)
Gastrointestinal clinic patients	08(2.5)	05(1.5)	13(2.0)
Infectious disease clinic patients	25(7.9)	47(14.4)	72(22.0)
Neonatal clinic patients <sup>*</sup>	09(2.9)	7(2.1)	16(5.0)
Renal clinic patients	07(2.2)	6(1.8)	13(2.0)
Neurology clinic patients	59(18.6	30(9.2)	89(13.8)
Hemato-oncology clinic	90(28.4)	74(22.6)	164(25.5)
Chest clinic	24(7.6)	18(5.5)	42(6.5)
Rheumatology clinic patients	05(1.6)	14 (4.3)	19(3.0)
Total	317(100)	327(100)	644(100)

\$-Neonatal clinic-includes cases with congenital abnormalities, Perinatal asphyxia etc.

#### **Clinical profile**

As depicted in table 2, most of the participants had moderate or severe diseases. Two-third (70%) of the

participants were missing one or more appointments and 55(12.3%) of them also missed their medications.

Table 2: Clinical characteristics of patients at the chronic care clinic during COVID-19 pandemic, TASH, 2020.

Variable	Male (%)	Female (%)	Total (%)
Severity of illness as per the clinic protocol			
Mild (Stage 0-1)	80(25.2)	105(32.1)	185(28.7)
Moderate & Moderate to severe (stage 2-3)	114(36.0)	121(37.0)	235(36.5)
Severe and Very severe (stage 4-5)	111 (35.0)	92(28.1)	203(31.5)
MI	12 ( 3.9)	9(2.8)	21(3.3)
Total	317	327	644
Outcome <sup>(β)</sup>			
LTFU	219	229	448
LTFU and missed medication	25	30	55
Missed medication with worsening of symptoms	13	14	27
Died	5	3	8

Table 3 shows the bivariate and multivariable logistic regression analyses. In the bivariate logistic regression analysis, Age  $\geq 60$  years, 40-59 years, and 19-39 years had higher odds to be loss-to-follow-up compared with the younger patients (adjusted OR=22.17, 95% CI: 9.08-54.13, P<.001; 7.78 (4.03-15.03), P<.001, and 7.90 (3.97-15.69), P<.001 respectively.

Fear of COVID-19 (OR=13.39 (7.96-22.50), P<0.001), out of pocket or insurance payment for treatment (OR=1.78 (1.11-2.87), P <0.017), and transportation problems (OR=3.64 (1.93-6.88), P<.001) were the main factors associated with loss-to-follow-up of patients. Patients aged  $\geq 60$  years had higher odds of missing a follow-up in the multivariable logistic regression analysis model. The odds of loss to follow up among patients who reported the fear of COVID-19 were 13 times higher than among patients who did not have fear (adjusted OR=13.39(7.96-22.50), P<0.001). The odds of loss to follow up among patients who reported transportation problems were 3.6 times higher than among those who did not have transport problems (adjusted OR=3.64, 95% CI: 1.93-6.88, P<.001). The odds of loss to follow up among patients with severe and very severe illness were 2.7 times higher (OR=2.72 1.48-5.01, P<.001) than among those who did not have

a severe or very severe illness. Gender, means of transport and distance from home did not significantly influence the loss-to-follow-up.

We observed that 265(41.1%) of the cases obtained their medicines in the local pharmacies at an increased price in 166(25.7%), the same price as before in 71(11.0%), and reduced-price in 2(0.3%) of the cases respectively. On the other hand, only 105 (16%) of the respondents considered the local public health service facilities as useful at the time of the pandemic.

Table 3.	Factors ass	sociated with	lost-to-follow-up	of patients	in the	bivariate a	and multivariable	;
analyses	, TASH, 2020	0						

Predictor	Patients with LTFU* N (%)	Crude OR (95% CI)*%	<i>P</i> -value	Adjusted OR (95% CI)	<i>P</i> -value
Sex					
Male	219 (69.1)	0.96 (0.68-1.34)	0.794	0.80 (0.50-1.28)	0.350
Female	229 (70.0)	1.0		1.0	
Age group (year)					
≤18	163 (57.0)	1.0		1.0	
19-39	97 (74.6)	2.22 (1.40-3.51)	0.001	7.90 (3.97-15.69)	< 0.001
40-59	108 (77.7)	2.63 (1.66-4.18)	< 0.001	7.78 (4.03-15.03)	< 0.001
$\geq 60$	79 (89.8)	6.62 (3.20-13.72)	< 0.001	22.17 (9.08-54.13)	< 0.001
The severity of illness as					
per the clinic protocol					
Mild (Stage 0-1)	109 (58.9)	1.0		1.0	
Mod & Mod-severe (2-3)	180 (76.6)	2.28 (1.50-3.48)	< 0.001	1.94 (1.09-3.46)	0.025
Severe and very severe (3-5)	144 (70.9)	1.70 (1.12-2.59)	0.013	2.72 (1.48-5.01)	0.001
Means of transport to					
TASH					
Private car	47 (65.3)	1.0		1.0	
Taxi/Minibus	212 (62.7)	0.90 (0.53-1.53)	0.683	0.63 (0.30-1.31)	0.219
Public bus	189 (80.8)	2.23 (1.25-4.01)	0.007	1.55 (0.67-3.60)	0.311
Patient treatment cost					
Free	210 (63.8)	1.0		1.0	
Paying	235 (77.0)	1.90 (1.34-2.70)	< 0.001	1.78 (1.11-2.87)	0.017
Feared COVID-19 at					
TASH					
Yes	318 (87.1)	7.76 (5.27-11.41)	< 0.001	13.39 (7.96-22.50)	< 0.001
No	130 (46.6)	1.0		1.0	
Had transport problem					
Yes	153 (82.7)	2.66 (1.74-4.07)	< 0.001	3.64 (1.93-6.88)	< 0.001
No	295 (64.3)	1.0		1.0	
Distance from home to					
TASH					
≤20 km	243 (65.5)	1.0		1.0	
	205 (75.1)	1.59 (1.12-2.25)	0.009	0.80 (0.45-1.43)	0.455
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Year of follow-up					
$\leq$ 5 years	335 (71.6)	1.0		1.0	
>5 years	106 (63.1)	0.68 (0.47-0.99)	0.041	0.78 (0.46-1.38)	0.417

Key-variables included in the model: Sex, Agegroup1, Occupation1, YearFollowup, Severity, Transpo means, PatientRxCost1, Fear COVID, Lacktranspo. \*LTFU-Loss to follow up; \*\*Odds Ratio with 95% Confidence Interval

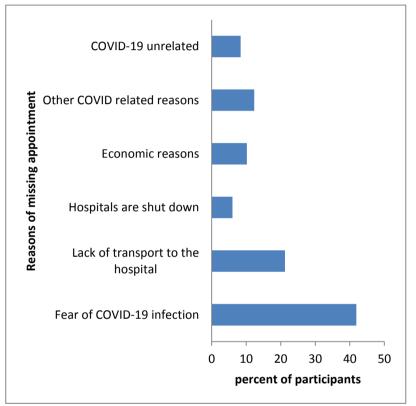


Figure 1: Reasons for missing hospital appointment as responded by participants TASH, 2020.

Fear of COVID-19 infection and lack of transport were the main reasons for loss to follow up as depicted in figure 1.

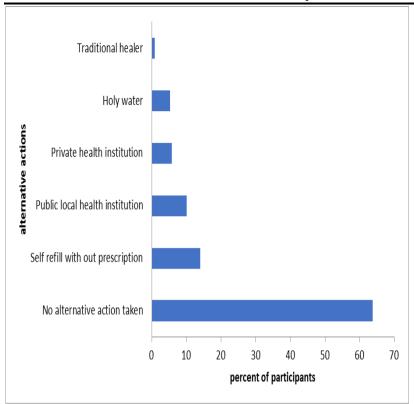


Figure 2: Alternative actions taken by patients and caretakers as they missed their hospital appointments TASH 2020.

In figure 2 we found self-refill as the most common alternative action taken by the patients during the LTFU. Furthermore, information on alternative sources of medication was obtained from only 27.6% of the participants.

#### Discussion

This telephone survey has made it possible to collect preliminary information from patients and caregivers in such a difficult time, where physical contact has a risk of increasing the spread of COVID-19 infection. This study showed a significant drop in patients' careseeking behavior in the first three months of the pandemic, and it was more pronounced in those with fear of COVID-19 infection and transportation problems. The effect was also seen in those above19 years of age but more significantly in the age above 60. The authors could not find reports that support whether old age is a determinant factor for LFTU during the COVID-19 pandemic. Hence further studies are required to verify this finding.

Although the lockdown was lifted soon after its inception, the patient's hospital visits did not normalize in accordance with the lockdown being removed. A similar LTFU pattern was reported from the previous epidemic countries (6,10). Even in non-epidemic situations, the LTFU rate was high in LMIC for non-communicable diseases (11-14). An earlier report in these countries showed decreased maternal, newborn, and child health services earlier in the pandemic (15). Similar chronic illness care disruptions were also reported in many developing and developed countries (16).

In the current study, 87% of those LTFU cases were due to fear of getting COVID-19 infection in the

hospital set up. COVID-19 pandemic produced several reactions in the minds of the people; the severest being the fear of contracting the disease. Fear prevents people from seeking immediate health care or adhering to preventive measures. A similar observation was reported from the other countries (17,20). In addition, determinants of general anxiety disorder concerning COVID-19 infection were reported and it was suggested that providing the right information about COVID-19, addressing misinformation and rumors, are critical in alleviating fear (21, 22).

Age  $\geq 60$  years and the severity of illnesses were important determinants to the LTFU in the current study. Association of high mortality and severe disease among older people was already viral in the community compelling the older patients to avoid coming to the hospital (18).

The measures taken by the government of Ethiopia in response to the contagion risk during transportation led to a drastic reduction in transport services as reported in the current study. In situations where transport is provisioned with enclosed spaces and large concentrations of people, the risk of being exposed to the virus is high; hence a preventive measure is needed, and this indirectly affects patients' care-seeking behavior. This has been witnessed also by others (23-26). Seventy-three percent of the respondents in the current study did not consider the local government health institutions useful during the COVID-19 *Ethiop. J. Health Dev.* 2021; 35(3)

pandemic. Many local government health institutions in LMIC have a capacity problem, which affects the maintenance of quality health services to patients with chronic diseases. However, the FMoH report showed that 23-76 % of local government health institutions give adequate services to people with chronic illnesses (27). Further studies may be required to verify our observation. In this study, a quarter of the participants reported that the price of medication has increased following the COVID-19 announcement. The study findings agreed with the WHO report, which stated that the COVID-19 pandemic affected medicine availability in many countries (28-30).

In the current study, 12.3% of the LTFU cases also missed their medications. Similar observations were reported during the Ebola epidemics (31). Why only few participants opted for alternative treatment options despite their LTFU status is unknown. However, it is assumed that this may be due to the lockdown. Selfrefill, using private health institutions, the use of holy water and other traditional healers, were also reported to be declined during the pandemic. Well-planned and integrated alternative care has been advocated for children during the COVID-19 pandemic by Save the Children, Better care Network and UNICEF alliance (32). Limitation of the study: There were patients with incomplete contact details and omitted from the study, Network problems, language barriers, changing phone numbers by patients/caregivers, and call blocking was contributing factors. In this study parents/guardians were interviewed on behalf of the children, when adults where too sick to be interviewed, their care takers were interviewed on their behalf. The lack of such consistency with respect to the interviewee may affect the results e.g.-age affecting LTFU.

**Conclusion and recommendation**: Care seeking behavior of patients with a chronic illness during the COVID-19 pandemic was seriously compromised. Fear of COVID-19 infection, lack of transportation, the knowledge of the severity of illness, and being elderly are among the determinants. Tele medicine services should be strengthened in the community for future similar events and psychosocial support during pandemics should be emphasized.

## Abbreviation:

TASH-Tikur Anbessa Specialized Hospital LTFU-Lost to follow up WHO: World Health Organization COVID-19: Coronavirus disease FMoH: Federal ministry of health OR: Odds ratio IQR: Inter-quartile range GP: General practitioner LMIC-Low-middle income country

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