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Burden of indirect costs: Are we overlooking this amongst patients with long-term medical conditions?

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Abstract

Background: Increasing prevalence of long-term medical conditions (LTMCs) has made them recognized as the leading cause of diseases and deaths globally. Patients with LTMCs may have to stop work or have their household members stop working to care for them.
Objectives: This study determines the indirect cost burden of patients with prevalent long-term medical conditions (LTMCs) using public health facilities in Yenagoa, Bayelsa State.
Methods: A cross-section of 339 adult patients attending medical out-patient clinics for four LTMCs namely Hypertension (HTN), Diabetes mellitus (DM), Tuberculosis (TB) & Human Immune deficiency virus (HIV) disease across three specialist hospitals. Indirect cost was determined as number who stopped or reduced work, average missed work days, forgone activities and caregivers' burden.
Results: Greater majority of study participants were females. About a third (29.5%) of participants stopped/reduced work in the past year and the median missed work days per month was 5 days. Patients with non-communicable diseases (52.9%) had higher significant finding of forgoing leisure activity than those with the communicable diseases (30.5%), ($p < 0.05$). Paid work was the most forgone activity in other to attend clinic visits. Children (66.7%) were the most accompanying persons for clinic visits and majority (65.0%) reported having to miss school of work in other to accompany for clinic visits.
Conclusions: LTMCs are associated with heavy indirect costs with potentially reduced economic productivity. Findings can guide the design of more responsive policies including work-place programs.

Keywords: Indirect costs; long-term medical conditions; economic burden; patients

Introduction

The alarming and increasing prevalence of long-term medical conditions (LTMCs) has made them recognized as the leading cause of diseases and deaths across all the regions of the world.[1,2] They were hitherto termed a 'slow and invisible epidemic' and are an increasing cause of severe morbidity, disability and premature deaths.[3] Long-term medical conditions LTMCs are described as "conditions that last a year or more; require ongoing medical attention; and/or limit activities of daily living".[4,5] They may be communicable or non-communicable in origin. Generally, non-communicable LTMCs include hypertension (HTN), epilepsy, asthma, diabetes mellitus, and cancers, amongst others while communicable LTMCs include HIV/AIDs, tuberculosis (TB), amongst others.[4,6]

Patients with LTMCs share a common feature of requiring continued medical care in order to maintain a stable quality of life.[7] In addition, they may be unable to earn a living or to have and engage in leisure. Such patients may have to stop work or even have their household members stop working to care for them.

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Such caregivers or accompanying person(s) provide support and assistance to the patient while at home and/or may accompany the patient to the health facility for clinic visits.[6,7]

Healthcare costs encompass all resources channeled into providing and accessing care. However, the patients perspective is at the core of determining financial and economic burden because patients' costs can serve as barriers to accessing care if neglected.[8] Cost of care encompasses direct, indirect and intangible cost components. Indirect and intangible costs reflect patients' and societal perspectives on healthcare costs, which arguably is a vital component of medical cost, though often ignored. This leads to gross underestimation of costs especially amongst patients with LTMCs in low-middle income countries (LMICs). If patients' welfare are to optimally considered by healthcare planners and decision/policy makers, the indirect costs provides a significant perspective that should be determined.[8,9]

Indirect cost implies the time spent in receiving care and can also capture the earnings/income lost due to receiving care or due to temporary disability from the disease condition. It is also referred to as productivity loss due to illness, disability or death of such persons whether in a paid or unpaid capacity.[8–10] Another dimension to this, is the opportunity cost for seeking healthcare which describes other activities forfeited due to the disease condition and while accessing medical care.[11,12] These costs are usually incurred by both patients and members of the household. The indirect cost may result from missing time from work and school, loss of work, or premature death.[11,13]

Regarding paid work, indirect cost also occurs as reduction in income due to missed work days/hours(absenteeism), decreased productivity at work (presentism) and for unpaid work, reduced household work/activities, care work (personal care) or volunteer/leisure activities.[10,12] Determining indirect cost aims at quantifying and valuing in monetary and non-monetary terms, the loss incurred by the patients and their relatives while accessing care for the LTMCs.[12] In cost of illness studies, the commonly used measure of indirect costs are the Human Capital Approach (HCA) and Willingness-To-Pay (WTP) approach which focuses on monetizing the indirect costs.[10,15] However, asides paid work, other important forgone activities such as leisure activity, childcare, attending school etc, are not commonly reported or under-reported.[15] A number of these activities have strong bearing on quality of life and on mental health of the patients with LTMCs.[7]

A systematic review showed that patients with LTMCs can have a significant reduction in capacity to maintain routine work status such that patients would have to stop work or reduce/limit their regular work activities.[11] Similarly, a study on the economic burden of chronic illness in Southwest Nigeria, reported average missed working days by patients and caregivers were 5 and 2 days per month respectively. Patients with paid employment lost about 1.5 months in wages annually due to a LTMC.[13]

Some studies have argued that indirect costs is a significant proportions of total healthcare costs and contributes more to the economic burden on the patient and household than just the direct healthcare costs, yet indirect costs are often overlooked or underestimated.[10,15-17] There is a dearth of research on this significant contributor to economic burden of LTMCs therefore this study sought to bridge that gap by determining the indirect costs of patients with long-term medical conditions using public health facilities in Yenagoa, Bayelsa State. We also explored forgone activities by patients and their caregivers/accompanying people as a proxy estimation of indirect cost of care for these patients.

Materials and methods

Study design: This descriptive cross-sectional survey was carried out in Yenagoa local government area (LGA) of Bayelsa State, South-south Nigeria.

Study population: Data were obtained from three (3) major public health facilities in the state which are designated providers of specialized care for LTMCs in the State. The study population were adult patients being managed for at least one of the selected LTMCs from the medical out-patient clinics of these facilities. This study included patients diagnosed with at least one of four (4) prevalent LTMCs namely hypertension, diabetes mellitus (Type 2), HIV/AIDS and tuberculosis (TB). The eligibility for participation was they must have been given a definitive diagnosis and were being managed at the facility for at least 6 months. Patients too ill to respond and those who did not give consent were excluded from the study.

Sample size determination: The sample size was estimated using a level of precision of 0.05, 95% confidence interval with a reported prevalence of 80% productivity loss amongst patients with chronic diseases in a similar study[13]. This estimation factored a 10% adjustment for non-response, thus yielded a minimum sample size of 284 participants. Having a

robust sample size is recommended in cost-related research to enable robust cost analysis[18] and to allow for sizeable number of participants in the four LTMCs considered in this study, we eventually recruited 339 participants for the study. This study was a part of a bigger study which looked at healthcare costs and economic burden. However, this paper is dedicated to the indirect cost burden.

Sampling and data collection: The data collecting tool was an adapted semi-structured questionnaire obtained from tools used in other cost quantification studies[12,13,17,19]. The study instrument was face-, construct- and content validated by consultants of public health practice who are experts in healthcare financing. Pre-testing was done, and questions modified to ensure questions were clearly understood. The questionnaire obtained information on the participant's' sociodemographic variables: such as age, gender, marital status, level of education, work status and employer. Also, Information was obtained on productivity loss and forgone leisure activities. The questionnaire was administered by trained interviewers. Systematic random sampling was used to select respondents. Interviews were carried out in the specific LTMCs clinic before the commencement of the clinic visit. This was preferred because patients attending clinics are usually in a hurry after seeing the doctor. In addition, patients were observed to be more relaxed at that time. Each participant was interviewed by a single researcher to avoid interviewer bias. Patients interviewed in one clinic were not interviewed if seen in another clinic to avoid duplication.

Statistical Analysis: Data entry, cleaning and analyses was done using the IBM Statistical Package for Social Science (SPSS) version 25.0.[21] Frequencies and proportions were used to summarize categorical variables (See Table 1); chi-squared test and median tests were used to test for statistical significance of associations between study variables and indirect cost variables. Median test was used for comparing the quantitative variables such as the average missed workdays. Participants were further regrouped to create new variables such as 'Category of LTMCs' comprising non-communicable (NCDs) or communicable (CDs); Number of LTMCs' based on whether they had single, or multiple LTMCs. The outcome variables were the measures of indirect cost as shown below. The level of statistical significance was considered as p-value <0.05.

Ethical Statement: The Ethical review committee of the Federal Medical Centre, Yenagoa granted ethical approval for this study (FMCY/REC/ECC/2020/JAN/232). This study was extracted from Community medicine/Public health residency thesis for Fellowship award with the West African College of Physicians. A documented approval was received from the Bayelsa State Ministry of Health and heads of healthcare facilities visited. Participation was voluntary and informed consent was obtained. All the questionnaires were anonymized, and information obtained kept confidential.

Results

Three hundred and thirty-nine (339) individuals with LTMCs participated in the study. The median age was 50 years (IQR 40-60 years), most respondents were females 211 (62.2%) and majority had form of formal education 305 (90.0%) and were married 184 (54.3%). About a third of respondents were not working at all 113 (33.3%). A little above one-fifth of participant's spouses/partners were not working 41 (22.3%). These sociodemographic characteristics are presented in Table 2.

Table 1: Operational definition of variables included in the computation of indirect healthcare cost

Variables		Description
Productivity loss		
• Missed workdays (Absenteeism)	-	Average monthly number of days missed from work (paid or self-employ) due to the LTMC in the past 1 year
• Stopped or reduced paid work	-	Proportion of respondents that ever stopped or reduced paid work due to LTMC in past 1 year
Stopped or reduced leisure	-	Proportion of respondents that ever stopped or reduced leisure activities (hobbies, social activities) due to LTMC in past 1 year
Forgone activity	-	Alternative activities respondents would have been involved with if they had not come to the hospital to access care for the LTMC
Burden from having caregivers	-	Percentage of respondents who had a caregiver
	-	Relationship of caregiver to respondent
	-	Forgone activity by caregiver
	-	Percentage of caregiver that are paid

Table 2: Background Socio-demographic characteristics of participants

Variables	Frequency N=339	Percent (%)
Sex		
Male	128	37.8
Female	211	62.2
Age groups		
<45years	122	36.0
45 – 64years	163	48.1
>65years	54	15.9
Educational level		
No formal education	34	10.0
Have formal education	305	90.0
Marital Status		
Single/Separated/Widowed	155	45.7
Married/Co-habiting	184	54.3
Work status		
Not working at all	113	33.3
Working	226	66.7
Employer		
Government (Federal/State/local)	84	24.8
Private organization	24	7.1
Self-employed	121	35.7
Unemployed/Dependant	110	32.4
Spouse/Partner work status	**N = 184**	
Not working at all	41	22.3
Working	143	77.7

Table 3: Productivity loss by Participants' characteristics

Variables	N	Stopped or reduced paid work in past one year		X^2 (df)	P value	Average Missed work days per month					
		n	%			Mean	SD	Median	IQR	Test statistic(df)	P value
All	339	100	29.5			8.4	9.3	5.0	11.2		
Work status of participants											
Not working	113	21	21	9.709(1)	0.002[1]	15.4	9.9	10.0	12.5	10.08(1)	0.001[1]
Working	226	79	79			6.3	8.0	2.5	8.2		
Spouse/Partners' work status	**184**	**54**	29.3								
Not working	41	7	17.1	3.833(1)	0.050	8.3	8.5	7.5	14.8	0.322(1)	0.570
Working	143	47	32.9			8.0	10.5	2.5	15.0		
Participants' LTMC											
HTN	83	23	27.7	32.015(3)	0.000[1]	9.8	11.7	2.5	20.75	0.950(3)	0.813
DM	89	28	31.5			10.3	11.3	5.0	15.5		
HIV	114	18	15.8			5.7	7.4	1.3	9.67		
TB	53	31	58.5			7.4	6.2	7.5	8.8		
Category of LTMCs											
NCDs	172	51	29.7	0.04(1)	0.950	10.1	11.3	5.0	20.6	0.156(1)	0.888
CDs	167	49	29.3			6.9	6.6	4.3	8.6		
Number of LTMCs											
Single	229	70	30.6	0.388(1)	0.533	7.6	8.6	3.7	8.8	0.004(1)	0.832
Multiple	110	30	27.3			10.2	10.6	5.0	15.0		

[1]Statistically Significant; Hypertension (HTN); Diabetes mellitus (DM); Tuberculosis (TB); NCDs (HTN+DM); CDs (HIV+TB)

Table 4: Forgone leisure activities

Variables	Total	Leisure activities		X^2 (df)	P value
		Stopped	Maintained		
All	339	142 (41.9)	197 (58.1)		
Work status of participants					
Not working	113	62 (54.9)	51 (45.1)	11.731 (1)	0.001[1]
Working	226	80 (35.4)	146 (64.6)		
Participants' LTMC					
HTN	83	38 (45.8)	45 (54.2)		
DM	89	53 (59.6)	36 (40.4)	49.158[1] (3)	0.000[1]
HIV	114	19 (16.7)	95 (83.3)		
TB	53	32 (60.2)	21 (39.8)		
Category of LTMCs					
NCDs	172	91 (52.9)	81 (47.1)	17.416 (1)	0.000[1]
CDs	167	51 (30.5)	156 (69.5)		
Number of LTMCs					
Single	229	84 (36.7)	145 (63.3)	7.860 (1)	0.005[1]
Multiple	110	58 (52.7)	52 (47.3)		

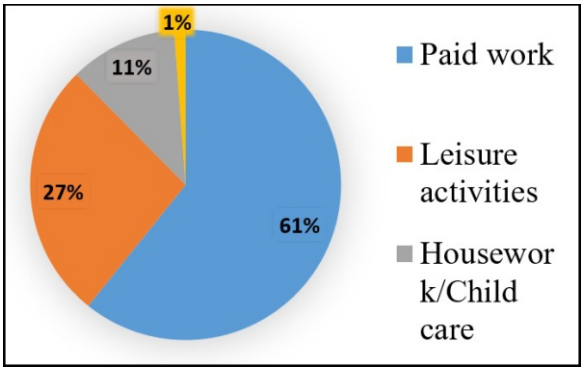

Figure 1: Forgone activity in order to attend the clinic visits

Table 5: Burden from caregivers/accompanying persons

Variables	Frequency N=339	Percent (%)
Had a person accompany for clinic visits	60	17.7
Accompanying person[1]		
Child	40	66.7
Spouse	12	20.0
Other family relative[2]	11	18.0
Paid caregiver	1	1.0
Accompanying person missed work or school	39	65.0
Had a paid caregiver	7	2.1
Average amount paid caregiver per month	N12,500	

[1]Some respondents had more than one accompanying person
[2]Family relatives included grandchildren, niece etc.

Table 3 summarizes the productivity loss experienced by participants in form of 'stopped or reduced paid work' and 'average number of missed workdays' and compared this with their Long-term medical conditions (LTMCs) characteristics. A notable finding was that 100 respondents (29.5%) had 'stopped or reduced paid work' due to the LTMCs. This proportion was highest amongst respondents with TB 31(58.5%) and least among respondents with HIV (15.8%) and this was statistically significant (p-0.000). There were no statistically significant differences in findings from participants with NCDs compared with CDs. Furthermore, Table 2 presents the mean and median missed work days per month of 8.4 days and 5.0 days respectively and this was highest amongst patients with DM. Participants with NCDs had higher average missed work days than those with CDs and similar observation was made in patients with multiple LTMCs compared with those with single LTMCs.

As reflected in Table 4, a little less than half of participants 142(41.9%) had to stop or reduce their leisure activities. Participants with TB and DM also had the highest proportion reporting they had to stop/reduce leisure activities (hobbies, social activities). Comparing responses of participants with

NCDs with CDs, we observe that the former had higher reports of stopping or reducing their leisure activities compared with the latter and this was statistically significant (p-0.000).

Table 4 presents the indirect cost burden of having caregivers and accompanying persons. Sixty respondents (17.7%) had at least one person accompanying them for clinic visits. Children of participants were the most commonly accompanying person and most reported having to miss school or work to accompany the parents for the clinic visits. Only 7(2.1%) of respondents had a paid caregiver to specifically take care of them at home.

Figure 1 is a pie-chart that depicts participants' forgone activity to visit the clinic and access healthcare. When asked about what the main activity they would have been carrying out if they did not have to come to the hospital to access healthcare needs. A slight majority 206 (61%) reported they would have been engaged in paid work. This was followed by leisure activities 91 (27%).

Discussion

This study sought to explore the burden of indirect costs by patients with prevalent long-term medical conditions (LTMCs). Regarding indirect cost in form of productivity loss by respondents, this study estimated that about one in three respondents had stopped or reduced work due to an LTMC. This was similarly reported in a study in India that showed that 6.9% and 22.2% had 'ever-stopped work' and had 'limited paid work' respectively due to their chronic diseases.[21] There was a significant relationship between the type of LTMC and shaving to stop or reduce one's paid work. Overall, stopping or reducing paid work was highest amongst patients with TB followed by patients with DM. High indirect costs have been reported with TB in Nigeria[22] and South Africa.[23] This may be as a result of the highly infectious nature of TB such that infected patients would have to stay off work for a certain period during treatment. This could compromise their earning capacity and with the stigmatising nature of the disease, patients may often have to stop work or even be let go from employment. The inability of an individual to engage in paid work has economic implications such as loss of income which can negatively impact household economy.

This study showed an average number missed workdays per a month of 5 days. Similar findings were reported in a study in 2017 in Ile-Ife where an average of 5.3 missed workdays per month.[13] A study in the United states reported 5.46 average missed workdays among employed adults.[24] Multi-morbidity and non-communicable LTMs were associated with higher number of average missed work days thus in order to access care, they would have to spend time away from work leading to work absenteeism. The implication of this is that their earning capacities and means of generating livelihood may have been compromised. This has cascading negative effects on the household, and nation at large.[21]

Very limited studies have reported the effect of LTMCs on leisure activities. This study is the first in the study context to examine this. The study revealed that about two-fifths of respondents had to stop or reduce leisure activities due to accessing out-patient care for LTMCs. This has a potentially significant impact on quality of life as they would have to forgo relaxation and hobbies because of their LTMCs.

Caregivers cost is an often omitted indirect cost.[17] This study revealed that 1 in 6 respondents had a caregiver accompany them to the clinics. This might have to do with the age of some of the respondents as it is not uncommon that patients with LTMCs may be elderly or sickly and so be unable to travel alone to attended scheduled visits. This study had majority of its respondents below 65 years of age which may be the reason for a few respondents having to have an accompanying person for clinic visits. Possibly due to their clinical state, limitation of daily living activities is common with patients with LTMCS and so they may require support to walk, move around etc. Another study reported 1 in 14 persons had an accompanying person.[25] Having an accompanying person may have a possible implication for increased transportation and feeding costs although not explored in this study. Caregivers to accompany to clinic visits may have to be absent from work or from school or other engagements to provide the needed support to access medical care. Furthermore, it was seen in this study that very few respondents had a paid caregiver at home, and this may be because they are unable to afford such care even when it may be much needed. Furthermore, findings from this study reveal that a great majority of caregivers had to either miss work or school all further increasing overall indirect costs amongst respondents with LTMCs.

We acknowledge some limitations with this study. This study sought to provide a broader concept of indirect costs; however, the scope of indirect costs varies greatly and thus its estimation is commonly

ignored due to challenges with its quantification and valuation.[19] This study did not monetize the loss of productivity thus limiting its comparability with other studies. However, this was not done because determining what productive time means to each person and how much monetary value can be placed on productive time remains quite a challenge. For instance, should the monetary value placed on time for the employed example a school principal and unemployed patient example a full-time housewife, be valued equally or not. Despite these limitations, this study has provided a very relevant insight into the often-overlooked indirect costs burden of LTMcs.

Conclusion

Overall, when health is compromised, a person's ability to fend and contribute meaningfully to life is also threatened. This study has demonstrated that LTMCs are associated with heavy indirect costs. This results from their inability to function and be productive economically. They may have to be exempt from work or in some cases lose their jobs resulting in reduced or lost earnings which may increase household susceptibility to impoverishment or catastrophic expenditure. The findings can guide the design of more responsive policies including work-place programs to address this.

Conflict of interest

The authors declare no conflict of interest associated with all the information presented in this research paper.

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