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THE PERILS OF CHRONIC ILLNESSES: PATIENTS LIVED EXPERIENCE AND SOCIETAL REACTIONS IN CENTRAL AND SOUTHWESTERN ETHIOPIA

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Abstract

Chronic illness is one of the chief health and development challenges of contemporary society. As in any other developing countries, Ethiopia is challenged by the rampant chronic illness that created a double tragedy on the society and the health care system, which is already threatened by acute illnesses. The main objective of this study was to investigate patients' experience and perils of living with chronic illnesses. Both quantitative (sample survey) and qualitative (key informant interview and illness narratives) research methods were employed. Accordingly, 150 chronic illness outpatients visiting health facilities in the data collection period were surveyed. The informants of qualitative studies were recruited by using purposive sampling technique based on availability basis. Descriptive statistics were employed to analyze the quantitative data, and the qualitative data were summarized and presented concurrently alongside with the quantitative data by hiring thematic analysis technique. The study unearthed that people from all walks of life are vulnerable to chronic illnesses. Chronic illness exposed patients for a number of personal and family problems. Chronic illness has a devastating impact on the livelihood of the patients and impoverishes the households of the patient. The problem of chronic illness is not just a health problem; rather it affects the overall functioning of the society. Thus, chronic illness has to be a national agenda and action oriented commitment is required from the government, NGOs and other concerned bodies to arrest the evils of chronic illness.

Key words: Chronic Illness, Patients, Societal Reactions, Ethiopia

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Introduction

Chronic illness is becoming one of the perilous social issues globally. Chronic illness is one of the chief health and development challenges of the contemporary society (WHO, 2014). Chronic illnesses are the leading cause of death, accounting for 60% of all deaths worldwide. Annually, 16 million people die prematurely before the age of 70 from chronic illnesses. Strikingly, 4 out of 5 of these deaths occur in developing countries, making such illnesses one of the major development challenges of the global south countries. The change in the twentieth century epidemiological paradigm shift from acute to chronic illnesses is the major cause of death throughout the world (WHO, 2015; Cockerham, 2007). Chronic illnesses namely, heart disease, cancer, stroke, diabetes, renal failure and the like cannot be cured by medical treatment, and lifestyle practices such as smoking, alcohol and drug abuse, eating high fat foods, and unprotected sex in the case of sexually transmitted diseases, can cause chronic health problems and end life prematurely. Thus, the etiologies of chronic illnesses are to a large extent attributed to behavioural risk factors that are pervasive aspects of economic transition, rapid urbanization and 21st-century lifestyles (WHO, 2011).

Chronic illnesses are creating double jeopardy on the societies of global south countries, where the majority are still suffering from the acute/infectious illnesses. The compounded burden of chronic illness is rising fastest among lower-income countries by imposing unavoidable socio-economic challenges. More so, chronic illness impacts all areas of individual's and their family's lives (Falvo, 2005; Mete, 2008). The greatest effects of chronic illness risk factors fall increasingly on low- and middle-income countries, and on poorer people within all countries, mirroring the underlying socioeconomic determinants. Among these populations, a vicious circle may occur where poverty exposes people to behavioral risk factors for chronic illnesses and, in turn, the resulting illness may become an important driver to the downward spiral that leads families towards poverty. As a result, unless chronic illness epidemic is aggressively confronted in the most heavily affected countries and communities, the mounting impact will continue and the global goal of reducing poverty will be undermined (WHO, 2011).

In response to the challenges of chronic illness, many countries and concerned institutions are developing intervention strategies and policy frameworks to address the problem of chronic illness. However, the Millennium Development Goals, which have been dominating the global health agenda in its 15 year lifespan, did not embrace chronic illnesses (Prevett, 2012), but the 2030 Agenda for Sustainable Development

recognizes the huge impact of chronic illness worldwide – an issue that the Millennium Development Goals did not address (WHO, 2015). Chronic illness now makes up almost one-half of the world's burden of disease, creating a double burden of disease when coupled with those infectious diseases that are still the major cause of ill health in developing countries (WHO, 2005). The challenge for developing countries is to reorient health sectors toward managing both infectious and chronic illnesses and the special needs of the chronically ill patients. In Ethiopia, chronic illnesses are viewed as illness of the affluent. The 1993 Ethiopian health policy, for instance characterized chronic illnesses as “diseases related to affluence and ageing.” Contrary to popular perception, high prevalence and incidence rates of chronic illness are reported by studies in different developing countries. As in any other developing countries, Ethiopia is challenged by the growing magnitude of chronic illness which created a double burden on the population and the health system which is already hard hit by acute illnesses (Yibeltal, Chali and Dereje, 2011). Notwithstanding, the Ethiopian healthcare system is designed primarily for prevention and control of acute illness while giving little attention or neglecting chronic illnesses (Transitional Government of Ethiopia, 1993). This study aims to examine the perils of chronic illnesses on the social life; family and livelihood of patients. Thus, the current study aims to explore the trajectories of chronic illness in Ethiopian society and how people experience and what challenges chronic illness victims encountered in their everyday lives. And what effects does their illness itself have on their livelihood and what has been done so far against chronic illness in the country?

Research Methods

Study Settings

This study was conducted in Central and Southwestern part of Ethiopia. Addis Ababa city from the central and Jimma Zone from Southwestern Ethiopia were the study setting of this study. Accordingly, selected public hospitals, chronic illnesses associations and health centers found in central and Southwestern Ethiopia were served as study sites. Thus, Menelik II referral Hospital, Black Lion General Specialized Hospital, and Ethiopian Diabetes Association from Addis Ababa City were selected purposively to collect relevant primary data for the study. Whereas, Sokoru woreda health center, Shenen Gibe Hospital, and Jimma University Medical Center were selected from Jimma Zone as a study site for the study.

Research Approach

Both quantitative (sample survey) and qualitative (Key Informant Interview and Illness narratives) research methods were employed in a triangulation fashion. Quantitative research has been used to identify the livelihood challenges and the socio-economic and demographic correlates of chronic illness. Qualitative research have been integrated in the study to investigate the view of the patients about living with chronic illnesses, to understand their lived experience, livelihood challenges encountered and interventions undertaken to cope up the difficulties.

Study Design

Basically, cross-sectional study design was carried out to accomplish the study. When required, this design was supplemented with approximation of longitudinal survey to collect relevant retrospective data concerning patients experience and management of chronic illnesses in the past. The primary data was collected from mid-June to mid-July 2017 from Addis Ababa and Jimma Zone.

Sampling Design

The necessary sample for the survey research was selected by employing availability sampling technique. Availability or accidental sampling applies the selection of sampling units out of the available target groups. Chronic illness patients availability at a given health facility and time was the main factor for opting accidental sampling. Thus, this technique was used to generate data from the patients who are visiting health facilities for treatment in the time of data collection. The sample size of the survey was decided based on the number of outpatients attending treatment in the study health facilities due to impossibility of getting the sampling frame of all chronic illness patients. Accordingly, 150 chronic illness outpatients visiting health facilities in the data collection period and eligible to be included in the study by the inclusion/exclusion criteria were surveyed in the study. The informants of qualitative studies were recruited by using purposive sampling technique based on availability basis. The qualitative data was collected from participants until saturation of key themes were achieved. Thus, 16 illness narratives and 7 key informants were participated in the qualitative studies of the project.

Methods of Data Analysis

The quantitative data, gathered through the use of questionnaire, were analyzed by using descriptive statistics which incorporates the use of frequency, percentages and mean distribution. The statistical analysis tool SPSS version 20.0 was employed for doing the task of analysis. On

the other hand, the qualitative data, obtained through Key-Informant interviews and illness narratives were summarized and presented concurrently alongside with the quantitative data by hiring thematic analysis technique.

Ethical Considerations

Observance of ethical norms plays pivotal roles in assuring the credibility of the reports of the study. Thus, before the start of data collection, the proposal was submitted to college of Social Science and Humanities research and postgraduate coordinator office of Jimma University. Supportive letter was delivered to the respective treatment centers and hospitals. Oral consent was obtained from the respondents and confidentiality has been assured for any information provided. All ethical issues of conducting scientific research were maintained and observed in this study.

Findings and Discussion

Socio-Economic and Demographic Characteristics of the Respondents

The collected quantitative data indicated that 54% of the survey respondents are male and the remaining 46% of them are female. The average age of the respondents is 49.16, which to some extent indicates that the popular perception and rhetoric of associating chronic illness with elderly should be challenged. More so, the majority (64%) of the respondents are married as of marital status is concerned. In terms of educational attainment, only 7.3% have got degree and above qualifications. About 52% and 43.3% of the respondents reported that Orthodox Christianity and Islam are their religions respectively. Moreover, 8% of the respondents accounted that they are currently unemployed as a result of their illness. The family size of the respondents has a computed mean of 5.41 people in their household. A fairly large number of respondents (32.7%) have earned less than or equal to 500 Birr per month. However, the calculated mean of the average monthly income of respondents is 1214.03 Birr per month. Finally, about 60% of the survey respondents noted that their place of origin is urban and the rest 40% said that their residence area is rural. In sum, the socio-economic and demographic characteristics of respondents unearthed that people from all walks of life are vulnerable to chronic illnesses; nonetheless there is differential susceptibility to chronic illnesses with the respective socio-economic and demographic backgrounds.

Type of Diagnosed chronic illness, Duration and Co-morbidity
 Table 1: Diagnosed chronic illness, Duration and Co-morbidity

Type of diagnosed chronic illness (Multiple Response)	Frequency (N=150)	Percent of Responses	Percent of Cases
Hypertension	63	33.13	42
Diabetes	52	27.35	34.7
Renal Illness	22	11.61	14.7
Asthma	13	6.86	8.7
Cancer	12	6.31	8
Heart related chronic illness	28	14.74	18.7
Total	190	100	126.8
		Frequency	Percent
How long you have been affected by the illness	1-5 years	59	39.3
	5-10 years	54	36.1
	11-15 years	23	15.3
	>16 years	14	9.3
	Total	150	100.0
Did your chronic illness exposed you for other co-morbidities	Yes	67	44.7
	No	83	55.3
	Total	150	100.0

The data depicted in the above table 1, shows that hypertension, diabetes, and heart related chronic illnesses are reported by more than 75% of the survey respondents. The remaining respondents accounted that cancer, asthma, and renal illness are their chronic health problems. For (39.3% of the respondents their illness has a life span ranging from 1-5 years, while 36.1% and 15.3 of the respondents reported of 5-10 years and 11-15 years duration of their chronic illness respectively. About 9.3% noted that their illness is living with them for more than or equal to 16 years. When respondents were asked about the exposure to co-morbidities due to their chronic illness, 44.7% of them replied yes. Thus, one of the serious perils of chronic illness is that the probability to be victim of other co-morbidities, where patients are vulnerable for compounded health problems, is very high.

The Meanings Patients Attached to Living with Chronic Illnesses

Patients entertain different meanings and reactions to their chronic illness. The data found from the qualitative studies revealed that the discovery of the illness, previous knowledge about the issue and their immediate social circles shapes the resultant orientation to the chronic illness. In most cases, chronic illnesses are discovered suddenly when people visit health facilities as response to symptoms or to get medical certificates for reasons like driving license, employment, international flight, and pregnancy check-ups. Some patients firmly resist accepting the reality primarily, but through time they tried to bring the required modifications to sustain their life.

One illness narrative informant seconded this as follows:

One day I visited a health center to get medical certificate to process my driving license training program. I encountered unexpected result from the diagnosis. The physician informed me about the presence of diabetes in my urine test, but not in blood test. When I heard the result I did not believe it. I did not take it seriously for the reason that I thought the result was wrong. The practitioner appointed me to come after a month. The result was the same and the physician referred me to Yekatit 12 Hospital. In Yekatit 12 Hospital, I was totally convinced about the illness. The physician consulted me like a friend about the consequences of the illness if the necessary modifications are not administered. From the advices of the physician, I understood that I could contract eye related problem, renal infection, cardiac disease and hypertension if I failed to manage the illness. He asked me about my nutrition preference and I told him that I regularly eat raw meat, specially 'shagna'³. My weight was more than 80 kg. Another time I was told that I have developed blood pressure. That movement was the turning point in my life. I traced the advice of the physician and all what he said entered to my ear like a bell ring. From then, I have introduced lifestyle modifications and I am living with diabetes for more than 30 years (Illness narrative informant, Male, 73).

Another informant shared her experience about the discovery of her chronic illness as follows:

I was a merchant. In one cursed day, I woke up early in the morning and went to work place as usual. I did not eat my breakfast. I returned home for lunch, but I was quarreled with my treacherous daughter. I did not get my lunch because of the clutter. I was forced to leave my home, but

³ *Shagnais* the Amharic version of hump of an ox, which is the most fatty and preferable part for people who love to eat raw meat in Ethiopia.

my eyes stopped seeing suddenly after I left my home. In the mean while, when I went outside I collided with a parked car outside my compound. I did not see anything including the car. Then after, my neighbors and relatives took me to the hospital. I came to know that my illness was diabetes, which reached at serious stage and attacked my vision. So I suddenly know the illness like this without any symptoms before. But I understood that it seriously attacked me in its asymptomatic stage (Illness narrative informant, Female, 60).

Thus, most of the time chronic illness attacks people for a long time without their awareness and when it is discovered suddenly it creates untold mess on the life of the victim and his/or her circles. Moreover, this late and sudden discovery of the chronic illness partly instigates the complications of the illness in the treatment process.

In the aftermath of the discovery of the chronic illness, the feelings and reactions patients made on their situations are different based upon previous information and experiences about the illness. Some segments of the patients were frustrated, while others developed nothing towards their illness.

One illness narrative informant noted that:

I was totally confused and unable to control myself when I heard about the presence of diabetes with my blood. I even wished that Allah should have given me HIV than diabetes in that time. I was unconscious about how to manage my situations. I challenged the physicians by resisting not to instantly accepting and welcoming my illness. Later, I realized that nothing could be done once Allah brought it. More so, I started to accept my conditions and showed strong raring to get rid of the illness by strictly practicing what was prescribed. I have modified my diet contents and take medicine properly. I absolutely abandoned salt and sugar from diet and drinks (Illness narrative informant, Female, 60).

On the hand, lack of required information about the nature of the illness is one of the motives behind accepting the illness with ease.

A young informant narrated his experience as follows:

I have suffered a lot with chronic headache before I came here. I have visited health centers found in Ziway⁴ many times. But my illness was not known by the providers in my home town. My parents decided to bring me in Addis Ababa for a better diagnosis. After samples were taken and examined, physicians learned that my problem is due to brain

⁴ A small town in central Ethiopia found 160 kilometres far from Addis Ababa

cancer. Initially I did not feel nothing special when I heard about my illness. Later, when I passed through different treatment stages and the resultant pains I started to worry about my condition. I did not have enough information about cancer before, which was partly the reason for not disturbing that much when I heard about the illness. I always hope that I will retain my health. I never gave in treating my illness and regaining my health (Illness narrative informant, Male, 22).

Another informant endorsed this as follows:

I did feel nothing special after I learned my illness is cancer. I accepted it as same as common illnesses like flue and malaria. The reason is due to the fact that I was green about the issue of cancer. However, through time I came to know that cancer is one of the deadly illnesses exposing people for severe sufferings. Now I worried a lot about my condition than I was before (Illness narrative informant, Male, 18).

The immediate reaction of patients towards their illness is also mediated by people around them. Thus, patients develop particular orientations based on the information they found in their social circle. In line with this one informant narrated his experience as follows:

It was very difficult for me to accept the reality that I am victim of diabetes. I thought that diabetes kills immediately and my life is over. Some people told me that if I started treatment, the illness will adapt the drug and the level of diabetes will be aggravated which in turn would make any further treatment unsuccessful. Others urged me to start treatment and follow up as soon as possible to control the diabetes. The later argued that the treatment is helpful and diabetes rarely kills unlike other illnesses. Consequently, I agreed with the later groups as they do have enough awareness about diabetes (Illness narrative informant, Male, 59).

Another informant seconded this reality as follows:

When the symptoms first appeared I did not take any action for a long time. The pain was on and off not demanding further action. After that I was convinced to visit health facilities by my intimates. Then I went to health center and told about the presence of diabetes in my blood. In the first place I was firmly insisted not to accept the result of the diagnosis. I thought that such illness would never attack me. Later my sister persuaded me to accept the reality by saying that she was thinking like me. My sister knew earlier that she has diabetes. She said that our mother died due to diabetes. So, she told me that the illness is hereditary. It is a family disease. Although it was very difficult to accept the reality in the first place, through time I adapted friendly lifestyles for diabetes by the help of my family. The transition was easy for me due to

the experience of the illness by other family members. I easily modified my lifestyles regarding food and exercising. I strictly adheres what the Doctor's prescribed (Illness narrative informant, Male, 30).

Another informant also traced the feelings he developed when he cognizant the illness as follows:

..... In the first place, I felt nothing wrong. People are born either to live or to die, so I was ready to confront my fate. The cancer tumors were simply extra flesh on my body for me. There was no pain which bothered me. However, after I have started the chemotherapy treatment, I came to experience how far the illness is weird. More so, the nature of treatment service provision for cancer is far risky and devastating than the illness. For instance, after the illness was discovered I was given appointment after one year. The illness could be complicated and I might die if I wait this much time. But what I did is paying privately for physicians working after normal hours in the public hospital and continue my treatment (Illness narrative informant, Male, 50).

Consequently, one group of the patients feels nothing special in the first place of their illness discovery, but later started to worry concerning their illness. In the contrary, the other groups of patients were highly frustrated when their illness is discovered, however, come accept the reality and act accordingly through time. In sum, from the narratives of the chronic illness patients presented above, it is possible to argue that the meanings people developed towards their illness varies according to the information they do have on the particular illness, the experience of their intimate social circles about the illness at hand, the type of the chronic illness itself, and the nature of service provision including the behavior of the physicians. Thus, the integrated interaction of the aforementioned factors influenced the orientations and meanings patients developed towards their situation.

The Impact of Chronic Illness on Individuals, Families, and Communities
Chronic illness may affect all aspects of victim's life. In fact, it influences not only the life of victim individual's, but also their family, social circles, and the wider community. Chronic illness exposed patients for a number of personal and family problems. A diabetic patient informant said "I totally lost sexual interest after the illness. It is completely stopped. This affected the relationship with my wife." Another 30 year old diabetic patient informant also stated "I feel hopeless and fed up when I thought that I will be taking medicine throughout my life. I did not get married yet. I always obsessed how I could get a wife willing to accept my illness." Chronic illness creates a huge problem on the marital life patients.

Moreover, chronic illness also changed the behavior of the patients drastically. One informant shared his experience as follows:

My behavior is totally changed after the illness. I easily irritated for minor incidents. I am always in trouble with my family. My interaction with family members is unhealthy after the illness. I became cranky person easily nags with everyone. I did not eat what is prepared at home. I usually fall apart with my children's and wife as a result of my behavior.

After the onset of chronic illness, some patients lost their physical appearance and at worse they couldn't move and became bedridden for a long period of time. A 50 year old cancer patient said "The illness is mutilating my body slowly. I became bedridden since a long ago." The co-morbidities associated with chronic illness have brought a paradigm change on the patient's body. A chronic heart illness patient marked the following to indicate how much his body is affected by the illness and the changed appearance becomes the trademark of his status. "Because of the chronic heart illness, I suffered from speech disorder. This affects my psychological wellbeing, because I did not able to express my feelings. The illness also affects my legs by swelling them and making them semi-paralyzed. The illness becomes my master status." Chronic illness engendered physical, behavioral and social problems on the life of the victims and their intimates.

Chronic illness greatly impacts the quality of life of patients and their social circles. It is becoming one of the great social evil in the contemporary Ethiopian society.

One informant narrates his experience as follows:

...the illness caused problems associated with my social life and social interaction. As of the prescriptions, I avoided taking foods items which are not friendly with my illness. In my locality, it is common for people to prepare festive on the name of Righteous and Saints, besides wedding and holidays. They called their neighbors to eat and drink what they have prepared. As a member of the community, I should attend such ceremonies. However, I am not willing to eat and drink what they have prepared as a result of my condition. People started to label me that I am negligent and trifle with their festive meal, despite of they are conscious about my illness. Only few of them understand my situation. Salt is not added to the food I am eating. Most of the time food is cooked once for the family. My children's complain about the lack of salt in the diet. This trend is affecting the intimacy with my family (Illness narrative, Male, 59).

The same informant also extends the problems he is facing in relation with field work and drug handling as follows:

The other serious challenge, I am facing is the handling of insulin in travelling and finding food when I am away from home. By its very nature, you have to keep insulin in refrigerators or in cold place. However, when you are heading to different parts of the country for various missions, keeping your insulin safe is the toughest challenge. There are a number of incidences where my insulin was spoiled due to high temperature while I was travelling for field work. I tried to use iceboxes to keep it normal, but temperature changes everything. In some remote areas, you may not find insulin to replace what is spoiled. I was forced to stay without taking insulin and this non-adherence aggravates the level of the diabetes. I suggest that handy fridges should be fabricated to facilitate the adherence of diabetic patients in travelling (Illness narrative informant, Male, 59).

Chronic illness is labeled as the greatest enemy leading people to suffer for a life time. A chronic respiratory illness patient articulated her situation like this. "I am tired of treating this lifelong threat. I feel that I am not the lucky one for contracting this poison. It is like imprisonment for life conditioned by full of crisis, suffering, and incapacitation." Some chronic illnesses are also considered as silent killers, which attack patients like a guerrilla fighter for the reason that it slowly mutilates victims. But other chronic illnesses are life-threatening as immediately as their onset. In addition, this study unveiled that chronic illnesses are branded as noncontagious AIDS as it is incurable and damaging like HIV/AIDS. Moreover, most chronic illnesses seem to prevent normal life. The chronically ill person often lives a very limited and restricted life, encounters social isolation and becoming a burden to the family and wider community. Victims of some chronic illnesses experience difficulties in participating in various domains of life, such as paid work, sports and other social and leisure activities. Another form of suffering is the loss of self in chronically ill persons who observe their former self-image is crumbling away without the simultaneous development of equally valued new ones. Accordingly, as a result of their condition, chronic illness patients suffer from leading restricted lives, experiencing social isolation, being discredited, and burdening others in the never ceasing treatment periods.

Some participants of the study also considered chronic illness as a devastating threat to successful aging. People are forced to confront the double jeopardy of dealing with their aging and chronic illness simultaneously. A qualitative study participant pronounced that "it is one of the biggest enemies for not realizing a successful aging. Chronic illness is obstacle for not experiencing peaceful farewell of this world

among the elderly.” The contemporary global society is experiencing demographic transition and epidemiological transition concurrently.

Impact of Chronic Illness on the Livelihood of Patients

The current study found that chronic illness caused multi-dimensional problems on the patients and their household. It is observed that chronic illness pauperize household’s not only individual victims. The treatment services of most chronic illness are very costly and unaffordable for most chronic illness patients to make lifelong medication payment.

Table 2 Impact of chronic illness on the livelihood of patients and respective coping strategies

		Frequency (N==150)	Percent	
Did the chronic illness affect your livelihood	Yes	141	94.0	
	No	9	6.0	
	Total	150	100.0	
During the last twelve months, how often your illness deterred from engagement in work?	Always	31	20.7	
	Sometimes	58	38.7	
	Rarely	50	33.3	
	Never	11	7.3	
	Total	150	100.0	
What are the main strategies that you employed to cop up with chronic illness induced challenges in your livelihood?	Seeking fee waiver medication	82	54.7	
	Reduced consumption	23	15.3	
	Support from relatives	24	16.0	
	Engagement in non-demanding jobs	21	14.0	
	Total	150	100.0	
		Frequency (N=141)	Percent of Response	Percent of Cases
What livelihood impacts you	Financial instability	77	25.83	54.6
	Make me dependent	75	25.16	53.19
	Loss of livelihood	51	17.11	36.17

have encountered as a result of your chronic illness(Multiple response is possible)	asset through sale			
	Slipping into poverty	31	10.43	21.98
	Food insecurity due to reduced income	42	14.09	29.78
	I lost my Job	22	7.38	15.6
	Total	298	100	211.32

The significant number of patients (94%) reported that their livelihood is affected as a result of the chronic illness. Therefore, about (51%) of chronic illness patients are experiencing financial instability and dependency since the aftermath of the illness. Moreover, (17.11%) of patients reported that they have lost their assets through forced selling to raise money for the coverage of treatment cost of their illness, whereas (10.43%) of patients were slipped in to poverty due to the chronic illness.

Another devastating livelihood impact of chronic illness is manifested with the dimension of food insecurity. Because patients should have shifted their income from consumption to medication, which in turn affects the food security status of patients and their household is a serious challenge confronting global south nations striving to create food secured society. With this respect, (14.09%) of the patients claimed that they are food insecure due to their illness. Lastly, (7.38%) of the patients noted that chronic illness fired them from their job. On the other hand, those patients who are working currently deterred from their work frequently merely due to the illness. Only (7.1%) of the survey respondents reported that their work has been never affected by the illness. Respondents were also asked to identify the coping strategies they mainly adopted to sustain their life. Consequently, free medication, support from relatives, reduced consumption, and involvement in non-demanding jobs are identified as some of the usual coping strategies employed by patients to tackle the livelihood impacts of chronic illness. Concerning this issue, the participants of qualitative studies accounted the challenges they are encountering on their livelihood as a result of their chronic illness as follows. A diabetic patient for the last 10 years narrated her lived experience as follows:

The diabetes heavily attacked my vision and make me victim of blood pressure. I lost my job because of these compounded chronic health problems. It harshly affected my livelihood and made me dependent on my families. I became voiceless in the family relationships. Even I eat if they provided me and simply sleep if not. I thought that had I been healthy, I would not have been burden for my family and I could have

been able to feed myself. I am forced to lead a destitute life all of a sudden. I was leading a fairly good life before the illness. Now I have nothing. It is very bad to experience such transition in life. It is too painful to look after the hands of children and relatives. I used to look after the ill and my social life was interesting previously and also I interacted with the rich and socially famous people in the past. Currently the illness degraded me to the lowest level and all the good things in life became history for me. I cried when I reminiscence all the good days. I got fee waiver paper from the kebele for free medication. Had not been I got the paper, you would not have found me here. I have nothing to eat, let alone to pay for medication (Illness narrative, Female, 60).

For some chronic illnesses like cancer, the treatment cost is headache to the victim and her/his families. A women cancer patient for 3 years stated the following:

..... I have lost all my assets for the treatment of my illness. It is very expensive to undergo for diagnosis and treatments like chemotherapy for cancer in Ethiopia. I sold out my capital assets to acquire treatment. Now I have nothing and I am looking for free medication. I contacted the kebele and they appointed me to give the fee waiver paper (Illness narrative, Female, 43).

Another informant seconded this as follows:

After the chemotherapy has been introduced, I couldn't move and I became bedridden for the last twelve months. The illness is mutilating my body day after day. I have finished my annual work permit six months ago. I have submitted sick leave, but it is also over. The organization has stopped my salary. I paid over 30,000 birr so far. I am about to lost my job. No more salary means, my children's are going to drop out their schooling. This illness is the worst enemy bringing all these evils in my life (Illness narrative, Male, 50).

Patients are not easily entitled to free medication. The screening criteria are very rigid and inaccessible for most of them. A 59 year old adult having diabetes for 18 years accounted his lived experience as follows:

I am privately paying for the drugs so far. I did not get free medication. The prices of the drugs are escalating from time to time. Thus, the illness is hurting me economically. My expenses are widening over time associated with the change in food items and long-term treatment follow ups. I am experiencing chronic financial instability. I am civil servant in government bureaus. The trend to get fee waiver paper should be revised. If you are employee, you will not get fee waiver paper from the

kebele⁵. I am unable to get free medication due to this screening criterion. However, now a day's things are changing rapidly. The cost of living is rising very high. I am forced to purchase costly drugs by subtracting from my monthly salary. The reality that the illness is chronic and so does the treatment, which ultimately pauperizes the households. Civil servant households, even double income earners, could not afford the cost of living and treatment simultaneously under the current circumstance. Access to free medication should be expanded to government employees to save their family from disintegration as a result of chronic financial shortage (Illness narrative informant, Male, 59).

All in all, the rampant chronic illness is contributing to the food insecurity problem of families and impoverishment of households as a result of costly treatment demands. It also poses a serious obstacle in the process of achieving the 2030 sustainable development goals unless adequate interventions are made to check its unlimited prevalence.
Interventions on Chronic illness

Chronic illness has a wide range of implication on the socio-economic development of the society. It is not just a personal trouble, but public issue demanding interventions from different stakeholders. The process of controlling and managing chronic illness requires unflinching commitment from the government and other concerned bodies. The status of intervention strategies devised to control the prevalence and spread of chronic illness is very wanting. The qualitative data collected from the ministry of health and Zonal/woreda health bureaus indicated that the issue of chronic illness is neglected. For instance, the 1993 health policy of Ethiopia, which was drafted by the transitional government, considered chronic illness as diseases related with affluence and aging is not revised yet. The facts on the ground showcased that chronic illness is no longer the problems of the haves only, but it attacks people from all walks of life. More so, the health policies and strategies are preoccupied with the prevention and control of infectious illnesses.

Only recently, some mobilizations are undertaken by the government in response to the challenges of this emerging public health problem. Participants of the qualitative study marked that the structure and organization of medical centers, the work force and prioritized directions are developed to confront the challenges of infectious illnesses.

⁵ The lowest administrative unit in Ethiopian government structure

However, there is a beginning to reorient strategies and facilities in searching rooms to accommodate the realities of chronic illness recently. The key informant from Jimma zone health bureau noted the following: Health extension program, which is one of the famous achievements in the health sector of the country, was primarily designed to control infectious illnesses. Chronic illness was not part of the packages of health extension program. But, now it is included in the packages of health extension program and capacity building trainings are given to health extension workers to provide holistic services for the community including the prevention and treatment of chronic illnesses. Now, urban and rural health extension workers are providing primary care for chronically ill people, screening of potential victims of chronic illness, and health education in their door-to-door rounds. Although it is not equivalent to that of infectious illnesses, chronic illnesses currently are receiving attention from the government (Kil, Male, 37).

Nonetheless, this limited focus is targeting specific chronic illnesses like hypertension and diabetes and left others untouched. A key informant from Seka woreda health bureau seconded this as “free medication is given in our woreda only for hypertensive and diabetic patients who meet the screening criteria. Besides, there is poor linkage with NGOs in the issue of chronic illness as compared to infectious illnesses. The mobilization of NGOs and the private sector in the endeavor of controlling chronic illness is also wanting.” Chronic illness has devastating impact on the livelihood of patients and their families, but so far no economic support or other safety nets are availed according to the information of the key informants from health bureaus. More so, chronic illness requires the cooperation of different actors in the process of prevention and rehabilitation of the affected families. But as the informant from Jimma Zone health bureau said “poor inter-sectoral linkage among different offices is one serious obstacle in the process of mainstreaming chronic illness.”

Ethiopia, at least in reports, has achieved improvements in arresting infectious illnesses. One key informant physician from the MoH stated that “the success gained on infectious illness should be repeated on the chronic ones. The structures and directions we commenced on the process of fighting infectious illness could be a golden opportunities to control chronic illness.” The point is that the established health facilities and institutions could be easily manipulated to address the problems of chronic illness. The same key informant from MoH added the following: The primary focus of the Ethiopian health policy is disease prevention and by its very nature chronic illnesses are preventable through practicing healthy lifestyles. The ministry of health is striving to raise the

consciousness of the society about chronic illness through using mass media and other strategies (KII, Male, 47).

However, the treatment of chronic illnesses is very costly and the existing facilities are not suitable to examine and rehabilitate chronic illness. A nurse key informant from Menelik II hospital indicated that “medical equipments used to diagnosis chronic illness are very scanty in public hospitals. Modern medical technologies like CT scan, MRI, and Chemotherapy are not easily accessible in public hospitals. Only selected government medical centers have such machineries.” The health facilities should be equipped with advanced technologies and competent professionals to provide satisfactory treatment for chronic illness. Chronic illness requires huge investment from the government as it is the biggest obstacle in the socio-economic transformation of the country.

Chronic illness patients needed not only medication, but also social, psychological and economic support. The role of psycho-social workers in the rehabilitation process of chronically ill people should have got greater emphasis. However, the data collected from social workers, sociologists and psychologists in the public hospitals unearthed that patients are not adequately receiving psycho-social services due to the structure of the healthcare system and other barriers. One informant social workers from Menelik II hospital articulated the following:

We, social workers, are forced to provide only a liaison service for chronic illness patients. There is no enabling environment for us to provide holistic psycho-social services for chronic patients. Absence of standardized regulations about the roles of psycho-social workers in the medical settings, lack of recognition from medical staffs and unwillingness of physicians to work with psycho-social workers in team, and lack of on job training for psycho-social workers to enhance their capacity are some of the barriers preventing us from providing holistic social services for chronically ill patients (KII, Male, 49).

Psycho-social workers are holding office in public hospitals, but they are not properly functioning in the treatment process of chronic illness. However, counseling and guidance, economic support, and provision of other social support could play a significant role in facilitating the lifestyle modification and behavioral change of patients. Chronic illness is becoming closer and closer for psycho-social workers than physicians, so the chronic illness patients should get the right service from the right professionals.

Chronic illness patients are voiceless in their families, medical settings and policy level endeavors. The mobilization of the non-governmental organizations in this regard is also non-existent. Only one voluntary association is formed to date to help dialyses and transplantation for chronic kidney illness patients. Other three self-help associations, Ethiopian diabetes association, cancer patients association and heart illness associations were organized to be voice for the voiceless chronic illness patients. From these three self-help associations, only the Ethiopian diabetes association is functional and widely known in the country and by the chronic illness patients. Chronically ill persons are benefited to cope up their chronic illness by joining support groups such as chronic illness patient association.

A key informant from the Ethiopian diabetes association articulated the major areas of services provided by the association to the patients as follows:

Since its inauguration, EDA⁶ is providing various services for victims of diabetes. Health education and promotion program is conducted in the first day of every new month. Members of the association as well as non members could participate in the monthly health education session. Type one diabetic patients, who are members of the institution, could get insulin medication for free. Most of the time type one diabetes attacks children's and our donors are targeting the support of children. Type two diabetic patients are also entitled to make a medical check-up for the status of their illness and the co-morbidities, especially eye related, in Black Lion hospital. The association serves as a liaison agent between the patients and hospital. More so, the association is working with the healthcare service providers by arranging trainings to create enabling environment in the medical centers regarding the treatment of diabetes. The other focus area of the association is patient empowerment, in which patients are supported to lead a better life through proper management of their illness. Finally, the association is striving to be training, education, research, and information center of diabetes in the country by playing the coordination role (KII, Female, 43).

Discussion

The current study found that chronic illnesses are not receiving greater attention at policy and intervention practices in Ethiopia. Contemporary Ethiopian society is experiencing the double jeopardy of chronic and infectious illnesses. The health policy and strategies are overwhelmed with controlling infectious illnesses and seems unprepared to confront

⁶ EDA=Ethiopian Diabetes Association

the devastating problems of chronic illness. The previous studies conducted in Ethiopia (Fikru *et al.*, 2009; Prevett, 2012) also confirmed that chronic illness has been not included in the MDGs, which has been a dominating global health agenda over a decade, let alone in developing countries. In fact, it was one of the apparently neglected health problems until recently.

Chronic illness is becoming a rampant public health problem in developing countries. Contrary to the rhetoric, chronic illness is not merely the problem of elderly and affluent segments of the society. This study disclosed that people from all walks of life are vulnerable to chronic illnesses. By the same token, studies conducted in Southwestern Ethiopia (Ayalew *et al.*, 2012) indicated that chronic illness attacks people from different social strata although variation for susceptibility are documented among different segments of the society. Another recent endeavour on the issue of chronic illness (Tomas *et al.*, 2015) reinforced that chronic illness is a national public health problem affecting people from all social backgrounds as a result of the widespread practice of unhealthy lifestyles, which is the risk factors of most chronic illnesses. Moreover, chronic illness is claiming 51% of death annually as reported by a study in central Ethiopia (Awoke *et al.*, 2012). Studies conducted in Central Ethiopia (Fikru *et al.*, 2009; Awoke *et al.*, 2012) and Southwestern Ethiopia (Ayalew *et al.*, 2012) on the double mortality rate and epidemiology of chronic illness respectively uncovered that people from all social strata are susceptible to chronic illness. Moreover, chronic illness is highly prevalent (8.9%) in Southwestern Ethiopia and widespread in Central Ethiopia (11.5%) due to the widespread practice of chronic illness risk factors and unhealthy lifestyles as stated in past studies (Ayalew *et al.*, 2012; Awoke *et al.*, 2014; Tomas *et al.*, 2015). Although, our study was institutional based and could not address the prevalence of the chronic illness in the population, from the qualitative study key informants, we learned that chronic illness is commonplace health problem in the study area.

The current study demonstrated that chronic illness affects all aspects of patient's life including his or her family relationship and the overall social life. A chronic illness impacts nearly every aspect of an individual's life and leaves a devastating imprint on the lives of everyone involved. Previous studies (Hickman and Douglas, 2010) ascertained that chronic illness has devastating physiological effects on patients and damaging psychological consequences for their family members. Moreover, another study (Golics *et al.*, 2013) showcased that chronic illness affects not only the patient's quality of life, but also the quality of life of family members. As of the findings of the current study, chronic illness

impoverished households not only the patients. Almost all (94%) of chronic illness patients claimed that their livelihood is harshly affected by their terminal illness. The expensive treatment costs, the co-morbidities associated with the chronic illness, and the disabling nature of chronic illness results in pauperization of patients and their households. Chronic illness patients forced to lead a destitute life due their lifelong health problem. Similarly, the protracted medical costs, reduced earnings, nursing home charges, and other economic strains result in serious problems for the vast majority of families in which one or more members has a chronic illness (Rusk and Novey, 1957).

Conclusion

Chronic illness is rampant in urban and rural areas of the country. People from all walks of life are vulnerable to chronic illnesses in one way or another. This study debunked the rhetoric of associating chronic illness with affluence and aging. This lifelong health problem is disrupting people's experience in their everyday life. The theory of 'chronic illness as 'biographical disruption' considered chronic illness as disruptive event in the patients' life. The findings of the current study also revealed that chronic illness completely altered victims' circumstance. Victims of chronic illness are forced to experience a prolonged suffering and longing death to escape the untold misery. Chronic illness patients develop particular type of orientations and attached meanings to their illness. Chronic illness is synonymous with life sentences where people are punished outside prison centers. It is considered as one of the serious challenges encountering contemporary society and not merely personal trouble. Chronic illness is emerging as the greatest threats of successful aging, in which both the global south and north are experiencing rapid demographic transition. Finally, chronic illness is becoming master status for most patients. The reactions and orientations patients made towards their chronic illness are mediated by the discovery of the illness, previous information and knowledge about the illness, and the experience of intimate social circles concerning the chronic illness at hand. Chronic illness has a devastating impact on the livelihood of the patients. Most of the chronic illnesses make victims vulnerable for co-morbidities and their treatment is very expensive, which in turn impoverished the households of the patient. Chronic illnesses forced patients to quit their job and be dependent on others. Thus, financial instability and food insecurity are the other livelihood challenges of chronic illness patients and their families, especially for the have notes. Consequently, chronic illness patients and their families are slipped in to poverty and forced to lead a destitute life. Chronic illness impoverished family's not only chronic illness patients. In sum, taking in to account all the devastating consequences of chronic illness, the

attention given from the government and other concerned stakeholders is wanting. The problem of chronic illness is not just a health problem; rather it affects the overall functioning of the society. Thus, chronic illness has to be a national agenda and action oriented commitment is required from the government, NGOs and other concerned bodies to arrest the evils of chronic illness.

Implications of the study

This study could have a wide range of policy implications in the process of chronic illness management and control. The tendency of treating chronic illness as the problem of affluence and aging is over and the position of the Ethiopian health policy has to be revisited. Chronic illness treatment and follow up service centers should be inaugurated in all established health centers and hospitals to enhance the accessibility of the service. The treatment services of chronic illnesses should be revisited to provide affordable services for the patients. In line with the endeavour to control chronic illnesses, the participation of psycho-social workers should get greater attention in medical settings by restructuring the organization of the healthcare system of the country. Moreover, besides free medication, socio-economic support has to be provided in order to lessen family disintegration and food insecurity patients encountered from the burden of the chronic illness. The prevention and treatment of chronic illness requires strong political commitment, effectual public-private partnership, and active involvement of the NGOs in the expansion of health facilities, medication supply, health lifestyle promotion, and psycho-social and economic support of affected people and their families to facilitate effective rehabilitation.

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