

Vicious cycle of chronic disease and poverty: a qualitative study in present day Nepal

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Background: In countries with out-of-pocket (OOP) payment systems for healthcare, the combination of chronic disease and poverty can have damaging socio-economic and health impacts for affected households. Using a life course perspective, this article aims to explore how Nepalese people struggle with, experience and adapt to chronic disease, poverty and their consequences, and how chronic diseases and poverty reinforce each other.

Methods: In-depth semi-structured interviews were conducted with 21 chronically ill Nepalese people with one or more chronic diseases and/or their caretakers. Data were transcribed and analysed thematically.

Results: The adaptation strategies for the consequences of the huge OOP costs make patients and their households financially disadvantaged. The impoverishment has major social impacts and often persists across generations. The situation forces people to choose between avoiding medical treatment or further impoverishing their families.

Conclusions: This study explored how chronically ill Nepalese people struggle with socio-economic and health consequences of OOP payments for their disease. The article sheds light on circumstances and adaptation strategies that obstruct every attempt to escape from the vicious cycle of the poverty trap. Hence poverty and health adversities accumulate across generations and contribute to greater health expenditures, worse health outcomes and severely compromised social life.

Keywords: chronic disease, poverty trap, out-of-pocket payments, qualitative study, life course perspective, Nepal

Introduction

In the absence of sufficient healthcare financing, out-of-pocket (OOP) payment is the most usual way of paying for healthcare in low- and middle-income countries. Nepal is not an exception in this regard: 75–81% of healthcare funding is obtained from OOP payments. Nepal is a low-income country with a total expenditure on healthcare as low as 6% of the gross domestic product (GDP). The per capita health expenditure of the Nepal government is US\$10.12. The total share of health expenditures of the Nepal government is 23%, while 60% is from OOP payments. For each dollar spent on healthcare, more than 60 cents is from OOP payments. Much of the healthcare expenditure is for prescribed pharmaceutical drugs, and these expenditures tend to increase yearly. Degenerative diseases are also increasingly common in Nepal, which, together with the improvement in life expectancy, causes many Nepalese to suffer from chronic

diseases. Chronic diseases are the cause of 66% of all deaths in Nepal.^{6,7} Recent trends show that 80% of outpatient visits are due to chronic diseases.⁸ In this context of an increased prevalence of chronic diseases,^{8,9} many Nepalese people experience severe financial crises due to huge OOP expenditures.^{10–16} For instance, the average annual direct costs of cancer care for a Nepalese individual are 387 000 Nepalese rupees (NRs), which is far above the average annual income, which is 78 946 NRs.⁹ More than 10.7% of Nepalese people spend 10% of their total expenses for healthcare.³ Vaidhya and Jha¹⁷ reported that about 30% of the Nepalese poor population is at high risk of catastrophic expenditures because chronic diseases demand long-term and expensive treatment and medication.

Although the constitution of Nepal declared healthcare a basic right that should be available for free, the establishment of a health delivery system with adequate financing is still ponderous,

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even after the implementation of federalism.¹⁸ The Nepalese healthcare delivery system comprises a network of central hospitals, district hospitals, health posts, sub-health posts, mobile health camps and various community workers and volunteers. 19 However, the system is challenged by an unequal distribution of services, poor infrastructure, inadequate supply of essential drugs, insufficient budget, scarce skilled human resources and poorly regulated private healthcare providers. 19 Private healthcare providers emerged when His Majesty's government implemented economic liberalization after the restoration of democracy in Nepal in 1990.²⁰ The share of private hospitals increased from 23% in 1995 to 78% in 2008, and private hospital beds have almost doubled in number (compared with government-run hospital beds) and these are primarily located in urban areas.²⁰ Khanal et al.²¹ found that essential medicines for chronic illnesses are more easily available in the private sector (78%) compared with the public sector (60%). A few studies have looked at the differences in cost between public and private hospitals. Mishra et al.²² reported that the price of cardiovascular drugs in private pharmacies is up to 66% higher than in government hospital pharmacies, and Shrestha et al.²³ reported that the direct cost per visit for diabetes mellitus in private outpatient clinics is 289% higher than in public outpatient clinics.

There are a few quantitative reports on the poverty impacts of the high healthcare costs in Nepal. 9-14,24 However, we are not aware of any qualitative study focusing on the interrelationship of chronic disease, financial crisis, adaptation strategies, poverty and other adversities. Hence, in the current qualitative study, we aim to explore how chronically ill people experience and tackle OOP expenditures and their consequences for health, well-being and socio-economic status. The study investigates how, through adaptation strategies for increased OOP expenditures, poverty and chronic diseases accumulate. We used a specific life course approach by looking at whether and how the vicious cycle of poverty and chronic disease (through increased OOP payments) crosses generations. We developed the interview topic list accordingly, which allowed us to inquire about financial and nutritional conditions during childhood, food intake during adulthood, substance abuse patterns and occupational circumstances. This allowed us to see how all these factors from childhood onwards contribute to the vicious cycle of poverty and chronic diseases into later life.

Life course studies examine how exposure to social determinants during childhood and adolescence influence adult disease risk and socio-economic attainment and how these account for social inequalities in adult health and mortality. ^{25,26} An intra- and intergenerational perspective is therefore used as a guide. ^{26–28} Considering the multi-ethnic Nepalese social structure, this study additionally looked at how—regarding the poverty trap and vicious cycle of chronic disease and poverty—different social categories (e.g. according to caste, gender and rurality) interplay in creating societal hierarchies. ^{29–31}

Methods

Study context

Nepal has a population of 29.7 million from 125 different caste/ethnic groups who speak 123 languages. Nepalese have a

life expectancy of 71.3 y, an infant mortality rate of 26.9 per 1000 live births and a maternal mortality rate of 285 per 100 000 live births, 27.2% of children are underweight and 19.7% are living in urban environments. Pepal has only 0.67 doctors per 1000 inhabitants; significantly less than prescribed by the World Health Organization (WHO). Healthcare services can be reached within 30 min by only 61.8% of Nepalese households. About 30% of the Nepalese population survives on less than US\$1.25 per day. Social rankings and hierarchies appear to affect the health status of Nepalese people. For example, poverty and ill health are interconnected. Similarly, living in rural areas, being a woman or being a member of a particular caste determines one's access to healthcare services. The same status of the same services are serviced.

Study design, procedure and sample

This was a qualitative study based on individual in-depth semistructured interviews. We applied purposive sampling to select participants. Chronically ill individuals were selected for participation. We aimed for a sufficient variety of participants regarding geography, wealth, gender and caste/ethnicity. The information about rich and poor households was retrieved from municipal offices in urban areas and Village Development Committee (VDC) offices in rural areas. Chronically ill people were identified and recruited through personal contacts of the first author (TS) and snowball sampling. We continued interviewing until data saturation was reached. Eventually 21 chronically ill people (5 female and 16 male) who were between 28 and 72 y of age and who were from different socio-economic positions and different geographic regions (urban/rural) were interviewed to reach data saturation. For reasons of comparisons and being able to contrast experiences (i.e. negative case analysis⁴²), we interviewed rich people and people who (due to healthcare expenditures) recently fell below the poverty threshold. Most poor participants were engaged in irregular work and jobs such as daily wage labour at construction sites or in factories. Most participants were living with multiple health problems and in most cases with more than one chronically ill family member. The characteristics of the participants are summarized in Table 1.

Ethical approval was obtained from the Nepal Health Research Council Ethics Review Board (ERB 925/2019) and from the Faculty of Health, Medicine and Life Sciences Research Ethics Committee (FHML-REC/2019/048) at Maastricht University. Informed consent was obtained from each of the participants. Potential harms associated with the participants were identified and the study was equipped with all the necessary safeguards. All identifiers (name or place of participants) were removed from the dataset and we maintained a high level of confidentiality throughout the study and writing of the manuscript.

Data collection

An interview topic list was developed as a guideline for the interviews. The topic list included (but was not limited to) the following topics: general introduction, social demographics, medical and treatment history, income and healthcare expenditures, adaptation strategies for healthcare expenditures, consequences of chronic illness and consequences of poverty over a lifetime and across generations, well-being and health. The interview topic list

Participant no./gender/age (years)	Education	Marital status	Diagnosis	No. of members with chronic disease in the home	Residence/ economic status	Duration (years)
1/Male/36	School level	Married	Spinal injury	3	Suburb/nearly poor	15
2/Female/35	School level	Married	Shortening of the leg	1	Rural poor	4
3/Male/32	School level	Married	RHF	2	Rural poor	16
4/Male/68	Literate	Married	CRD	2	Rural nearly poor	16
5/Male/72	School level	Married	Complex diabetes, hypertension	1	Urban/richer	41
6/Female/59	Illiterate	Married	Hypertension, arthritis	2	Urban poor	8
7/Male/60	Literate	Married	CVD	2	Urban/nearly poor	4
8/Male/28	Literate	Unmarried	Mental illness	1	Rural poor	8
9/Male/72	Literate	Married	CRD, hypertension	2	Suburban poor	2
10/Female/50	Illiterate	Married	CVD	2	Suburban	2
11/Male/70	Literate	Married	Cancer	1	Rural/recently been poor	3
12/Male/58	Degree	Married	Cancer	1	Suburban/richer	1
13/Male/63	Literate	Married	CVD, hypertension, diabetes	2	Rural poor	4
14/Female/45	School level	Married	Mental illness	1	Urban/rich	19
15/Male/40	Literate	Married	Spinal injury (paralysis)	1	Rural poor	3
16/Male/38	Literate	Married	CVD	2	Rural/nearly poor	5
17/Male/35	School level	Married	Cancer	2	Rural/newly poor	2
18/Female/39	Literate	Married	CVD	1	Rural poor	3
19/Male/40	Literate	Married	CVD	1	Rural poor	4
20/Male/55	Literate	Married	Diabetes, hypertension	2	Rural poor	12
21/Male/45	Literate	Married	CVD	1	Rural/nearly poor	5

also included questions about the people's childhood and adulthood, to provide insights into the inter- and intragenerational processes related to poverty and poor health. The interviews were conducted and tape recorded in the Nepali language and translated into English immediately after finishing each interview by the first author (TS), who is a native speaker of Nepali and a fluent speaker of English. The researcher (TS) also made notes during the interviews. The interviews were held between December 2016 and March 2017.

Data analysis

The data were analysed thematically.⁴³ Considering the aim of this study, we decided to use thematic data analysis. Thematic

analysis is a method for identifying, analysing and reporting patterns (themes) within data. It organizes and describes data in (rich) detail. It further interprets various aspects of the research topic, emphasizes the lived experiences of participants and provides meaning. ⁴⁴ First, the researcher became familiar with the data by reading and rereading the data to see underlying themes or patterns. Open coding was used to break down, categorize and compare data. These codes were either descriptive or interpretative. Second, the researcher looked for themes and axial coding. In this step, main and subcategories were searched for. Axial coding reduced the number of codes generated by open coding. Finally, the themes were structured. Main and subcategories were related to each other and linked to the research

questions. In this final step, connections between categories were made and more themes and the relationship between these core themes were described or made more specific. The themes were then finalized by consensus of all the authors (TS, IH and HB).

Results

Thematic analysis revealed three themes. First, huge costs and adaptation strategies create a poverty trap: the theme consisted of information about costs related to chronic illness, OOP expenditures for treatments and medications, how the costs and expenditures are managed and how the costs, expenditures and adaptation strategies form a poverty trap. All these have life course and intergenerational implications. Second, the vicious cycle of chronic disease and poverty further compromises health: this theme revealed data on how chronic illness and poverty enhance each other through many economic, social and health consequences that impact over the life course and generation. Third, the vicious cycle persists across generations: the themes underline the importance of looking at the vicious cycle with a life course lens. All participants have been exposed to different adverse social conditions during their lifetime, which have had various negative impacts, not only intragenerational but also intergenerational. Throughout their lives, the study participants experienced severe financial crisis due to their chronic disease. The crisis was generally experienced as more severe when the whole family depended on the patient's income. Furthermore, most of the participants reported multiple diseases in multiple members of the same household.

Huge cost, affordability and adaptation strategies

Chronic disease appears to be associated with huge costs that are paid for OOP for the rest of people's lives. For many participants, the medical and non-medical expenditures became an economic stressor that impaired the financial abilities of whole households. None of the participants seemed to escape from the financial catastrophe imposed by high treatment costs.

We spent more than 1.5 million rupee for treatment and still need money for medicines. My son took a loan from friends, relatives and financial institutions. Now we experience difficulties for other essential things. (Interview 11, male, 70 years, rural, poor)

I and my parents are on treatment and medications (for spinal injury and CRD) since 15 years to 20 years. I spent whole of income and property for treatment. I need huge amounts. My daughter also needs treatment frequently. I am the only source of income. (Interview 1, male 37 years, poor suburban)

When the costs became unaffordable, patients and households adopted various strategies to cope with the condition. In emergency situations they took a loan with a high interest rate and sold their land, cattle and other properties to pay back the loan. Compared with rich participants, poor people in particular could

not pay the treatment costs, hence they really had to prioritize things; even a small payment easily became a catastrophe for them.

My only source of income is collecting and selling leaf and fruit from the jungle. I sacrificed everything for my son's treatment, although I could not send him to the hospital because the treatment is unaffordable for me. I cannot buy medicines. His treatment is stopped. (Interview 8, rural poor female, mother of 28 years mentally ill son)

Patients also avoided follow-ups, treatment and medicines, and other family members sacrificed their needs and cut money from other essential things. They bought fewer medicines than prescribed and many finally stopped their medicines. The huge expenditures for chronic diseases paralysed their financial activities to the extent that they were absolutely unable to purchase healthcare services.

Doctor told me to arrange 500,000 rupees for heart surgery 3 years ago, but I am still unable to arrange the amount because I have nothing to sell and I cannot take a loan as I have no security deposits. (Interview 13, male, 61 years, rural poor)

I spent nearly 1.5 million rupees for the treatment by taking a loan with interest and in the end had to sell property to pay back the loan. Sometimes I buy fewer medicines than prescribed. Sometimes I have postponed prescribed treatments due to lack of money. (Interview 18, male 35 years, rural poor)

In contrast to poorer patients, treatment was more affordable for richer patients. They had past savings, but even they were worried about whether their savings would be sufficient for the rest of their lives.

The treatment is very expensive, even in a government hospital. Private hospitals are unaffordable. I am spending my retirement benefit for treatment. I fear what I will do when my saving finishes. If I sell the property my children will have nothing. (Interview 12, male 58 years, urban rich)

Poor people living in rural areas were often exposed to hazardous social and physical environments. They experienced additional hardships in receiving treatments because hospitals are often located in cities. Additional spending was thus needed for travel, accommodation and food for the patient and for the accompanying caretaker. Expensive healthcare costs, urban-centred private hospitals and the loss of income create a poverty trap for many.

Treatment is only available in Kathmandu (capital). We must arrange many things to receive treatment and healthcare services. The urban-based hospitals are the main problem for us. (Interview 2, rural poor female)

These adaptation and coping strategies constructed a poverty trap for the patients and their households. Many were pushed into that trap and became vulnerable to a further compromised health and financial situation.

Vicious cycle of chronic disease and poverty further compromises health

It was often observed that poverty makes people vulnerable to chronic disease and in turn chronic disease makes people vulnerable to chronic poverty. Compromised well-being and a financial inability to purchase proper nutrition, housing, clothing, education, entertainment and essential requirements are significant features of the poverty trap in Nepal. The chronic diseases caused by poverty made patients and family members emotionally weak and further increased their risk of ill health.

We are poor because we have nothing and have no regular income source. We have poor housing. We have a loan and that is increasing each month. I stopped the treatment too. (Interview 2, female, 35 years, rural poor)

Both the patient and caretaker lost productivity and income, and the majority of the family income had to be used for treatment and medication. As a result, other members started to work longer hours or children started to work at younger ages. In many households, when the male, the only source of income, becomes ill, the financial condition of the household becomes critical.

I was the main source of income; my income is gone and the other member's income goes to treatment and medicines. Our ability to buy good food, children's education and medicine is almost lost. The poverty and illness together have made my condition worse. (Interview 17, male, 35 years, rural poor)

Since 41 years, I am spending a lot of money for treatment and medicine for complex diabetes and hypertension each month. I need 15 thousand rupees and sometimes more. Almost all of the pension benefit, the only source of income I have, is used for my treatment. Me and my wife are experiencing hardship because of it. (Interview 5, male 74 years, urban rich)

The inability of poor patients to pay for necessary services caused delays in treatment, and this damaged their health in other ways, which ultimately added to treatment costs.

One valve was already damaged. I was told to arrange 400,000 rupees for surgery. We could not manage that amount so that another valve became also damaged and it thus cost more money for the treatment. (Interview 3, male, 31 years, rural)

We found that the extremely high treatment costs and OOP expenditures severely reduced the physical, human and social resources of poor Nepalese people. They found themselves worthless, weak and a burden for their families. Family members also lived with many stresses as they struggled with illness and poverty at the same time.

I just lay down on bed the whole day. Our income is lost. My social life is diminished. I remain alone. I find myself weak. I think too much about my condition and find myself worthless. It's hard to live in such a condition. (Interview 17, male, 35 years, rural poor)

Many participants had to spend a lot of money to buy medicines from pharmacies, which, prior to the diagnosis of disease, are people's first contact with health services. The pharmacy shops referred patients to expensive private hospitals. We found that the open pharmacy market, the often late diagnosis and the medical market policy increased poverty; all these factors contributed to construct a vicious cycle of poverty and chronic disease. Expensive treatment and medication of chronic illness, OOP payments and the organization of the healthcare market were found responsible for making people poor in Nepal.

For a year, I bought medicines from local pharmacies without a clear diagnosis for my stomach pain. I reached at the middle stage of cancer when my son took me to the hospital. I spent a lot of money for buying useless medicines. If I was properly referred my money would have been saved. (Interview 11, male 70 years, rural poor)

Due to the poverty induced by OOP expenditures, patients avoided social functions and developed serious concerns about the future of their family. Thinking too much caused severe mental health problems and other comorbidities. Most participants experienced depression and mental stress after diagnosis, particularly when they found themselves financially incapable of paying for treatment.

The consequences persist across generations

In the absence of any financial protection system, the reported poverty and other consequences tended to persist across generations. A lack of education, doing precarious jobs and a general lack of nutritious foods result in further impoverishment.

Living in poverty with a chronic condition is painful. I am now concerned more about my children. They will also live in poverty because they are not getting good education and good food due to the expenditures for treatment. (Interview 21, male 45 years, rural poor)

Participants and their households experienced increased poverty after the onset of chronic disease. Even small expenditures for poorer households became easily catastrophic, while richer households had more options for purchasing healthcare.

Poor families were found to simultaneously struggle with chronic disease and poverty. Financial stress was the most crucial, as it determines numerous other dimensions of life. Realizing that their life would only bring financial burdens and a stressful life for other family members, many participants thought about ending their life. Illustrating how the problems might be reproduced over generations, children were often reported to drop out of school and to start working at early ages.

Other household members are sacrificing their needs because most of our income is spent for treatment. My son dropped out of school and is working as a helper in a bus. My wife is working extra hours, as she is the source of income needed for the family's well-being and treatment. (Interview 21, male, 45 years, rural poor)

I was already poor. Now I experience more poverty because of huge treatment expenditures. I cannot afford good food, medicine, education and other needs. I remember my childhood as a poor boy with very limited resources for necessary things. My parents lived in poverty and

now I am living in a same situation as our income is lost and spent for treatment. (Interview1, male, 37 years, urban, poor)

Since they experienced poverty throughout their whole lives, most of the participants experienced a shortage of nutritious foods during their childhood. It appeared that chronic disease not only makes the patients poor, but it also pushes the whole family into extreme and chronic poverty. Poverty persisted within and between generations. Most importantly, even very low expenditures had severe social, economic and health impacts in poor households.

My self-esteem is low. I feel stressed all the time. I just keep on comparing myself with others and find myself unworthy. I find myself as a burden for family. My husband and my son are also living a stressful life. (Interview 2, female, 35 years, rural poor)

Health risk behaviours and substance abuse were the other impacts found in participants as a result of increased poverty. The changed behavioural and substance abuse patterns are found to have life course and intergenerational socio-economic and health impacts.

I remain alone most of the time. I avoid social functions. My smoking and drinking frequency is increased. (Interview 20, male, 55 years, rural poor)

Low self-esteem, stressful living and overthinking made patients psychologically vulnerable. The diminished physical and social capital of patients and other members of the household made them feel alone and less valuable. As they always had to think about managing the treatment and medication costs and often also had to do precarious jobs for long hours, other family members were also living in stressful conditions. The situation made them equally vulnerable to chronic poverty and ill health.

Discussion

In this qualitative study we explored the experiences of chronically ill Nepalese people living in the context of an OOP payment healthcare system and a complex society. We used a life course perspective to explore the economic and health consequences of catastrophic healthcare expenditures on chronically ill people. In-depth interviews were conducted with 21 chronically ill people and/or their caretakers.

This study shows that long-term OOP expenditures for chronic diseases have intra- and intergenerational catastrophic impacts on households. For people in this situation, poverty tends to deepen; households on the verge of poverty are pushed into poverty, leading to many consequences in several life areas. The impoverishing impacts of chronic diseases result in social problems (exclusion) and additional physical health problems (e.g. comorbidity) and these also have psychological consequences in patients and their family members, such as reduced self-esteem and a feeling of worthlessness. Patients often have to choose between avoiding medical treatment or further impoverishing their families. Hence, implemented adaptation strategies push families into a vicious cycle that accumulates further poverty and

ill health. This is in line with earlier findings of, for instance, Liu et al.⁴⁵ They argue that a chronic disease, particularly in countries with poor social security measures, can lead to accumulated poverty by disrupting people's income-generating capacities.

We explored the experiences of chronically ill people through a life course perspective. The participants, lived experiences were examined in relation to their exposure to different social, economic and health circumstances during different stages of their lives. The use of such a life course lens is reflected in the themes manifesting from the data and reported above. Most of the currently poor participants experienced childhood poverty as well. Furthermore, as others reported, childhood poverty and early life exposure to certain social circumstance is significantly associated with poorer adolescent health and health behaviours. 46-48 Many of the poor have been deprived of good food, education and other essential resources over their entire lives. In addition, these people are often employed in hazardous jobs, often as day labourers. For this group, almost all their income, past savings and physical assets were used for medical treatment, putting whole families at risk of lifelong poverty. This often continues into the next generation. In many cases, younger family members invest almost all their financial assets in the treatment of older family members, leaving the younger family members without any financial resources. Moreover, health-compromising risk behaviours, such as smoking, excessive alcohol consumption, eating unhealthy food and working long hours, are often seen in this vulnerable group. This pattern is confirmed by studies showing that exposure to early life poverty is significantly linked with excessive smoking, alcoholism and other substance use, and is associated with a wide range of mental and physical health outcomes across the life course. 49-53 This type of behaviour seems to continue across generations. Thus, chronic diseases cause poverty not only within a generation, but also across generations.

We also looked at the findings from an intersectionality perspective and thus considered whether different social categories intersect in creating the poverty trap and vicious cycle. The participants were from diverse social groups, but the relatively small number of interviews and the large number of social categories in Nepalese society prevented us from finding clear patterns of intersectionality. The following therefore is based on other background information of the participants and is certainly subject to more in-depth study in relation to the health-related poverty trap. Women and older people are already poor, as they generally do not have control over property and are dependent on other family members for financial and legal issues. This social position might make them more vulnerable to chronic disease and poverty. In line with previous findings,⁴⁰ the conditions of our participants also showed that poor and low-caste people generally live in rural areas, as they cannot afford to live in urban areas. They are deprived of emergency healthcare services and pay extra costs to get healthcare services. Nepalese society is characterized by a strong social hierarchy, and the risk of being trapped in this vicious cycle seems to increase from the top to the bottom of the hierarchy. The trap created by chronic diseases and poverty prevents vulnerable groups from breaking out of this vicious cycle.

In exploring the Nepalese poverty trap, one should not neglect the influences of the Nepalese healthcare system. Based on the information provided by the participants, their diseases are often diagnosed late, leading to delays in proper treatment.

Simultaneously, there is sometimes unnecessary expenditures on useless medicines from local pharmacies. Many patients depend on these costly local pharmacy shops, which are often operated by poorly qualified owners and staff. Furthermore, in a report on Nepal, Subedi⁵⁴ argues that pharmacies, and even doctors, unethically prescribe and dispense medicines for their financial interest rather than the patient's needs. He further argues that pharmaceutical companies even bribe doctors to prescribe their drugs. Richer patients can afford better treatment from private hospitals, while poor patients depend on government hospitals that often have long waiting lists. Many people expressed difficulties in getting access to healthcare from government hospitals. Furthermore, Thampi⁵⁵ claims that, in Nepal, sometimes bribes are required for admission to and to receive medical treatment in government hospitals. After a political shift in 1990, the Nepalese government liberalized investment in healthcare and medical education.⁵⁶ Based on suggestions from the World Bank and International Monetary Fund, Nepal embraced a neo-liberal policy of privatization of state-owned enterprises, a market-determined price system and healthcare services that are now under the control of the private sector and large pharmaceutical companies.⁵⁷ The private sector accounts for 70% of total health expenditures where 81% is paid OOP.² This rapid and heavy privatization resulted in a sharp increase in OOP expenditures for healthcare.

Methodological reflections

This qualitative study provides more in-depth knowledge about the experiences and adaptation strategies of Nepalese people with chronic diseases living in an OOP healthcare system and we hope it adds to what we know from previous literature. We interviewed 21 participants to increase the validity of the results, but data saturation was still reached earlier. Researcher triangulation⁵⁸ was applied: every step of the data analysis process has been discussed and reviewed by all the authors. Two co-authors (HB and IH) had a different background from that of the first author (TS). This study has several limitations as well. First, this study is based on participants' self-reports: the details of expenditures are based on their recall of experiences and expenditures in the past. Second, we did not have enough data to explore the full range of intersectionality related to the poverty trap. Third, our reflection on neo-liberal market policies and privatization impacts on the poverty trap is in need of further study.

Implications for practice and further research

This study has provided valuable insights on the situation of people with chronic diseases living in Nepal. There would be a further benefit from additional quantitative analyses that also look at how the vicious cycle affects vulnerable groups in Nepal. Further research with larger samples including people from different social categories, such as higher castes, is needed to obtain greater insights into the intersectionality of the different categories. More research into Nepalese healthcare and public health policies and the privatization of health services might be useful also in international comparative studies. Privatization of government health services in Nepal might adversely affect people's health and socio-economic situation. The most

vulnerable populations should be identified and covered by the healthcare delivery system. This is in line with recommendations from the World Economic Forum.⁵⁹ They also pointed out that high numbers of chronic diseases are barriers to a country's socio-economic development. In addition, this study highlights a need to appraise current health and social welfare policies to identify possible options for alleviating health-related poverty and breaking the vicious cycle of poverty and chronic illness.

In order to reduce catastrophic health expenditures and the consequences of the vicious cycle, Nepal could learn from other low- and middle-income countries in similar situations. Some of these countries are breaking the vicious cycle by focusing on equal access to health services and financial protection for more disadvantaged groups. Sri Lanka, for instance, provides universal free health facilities and free education, despite being a low-income South Asian country with a per capita income of US\$800.60 Sri Lanka delivers health services through an extensive network of health centres, hospitals and dispensaries from primary to tertiary level, reaching the majority of the community for free. Services are never more than 1.4 km from home. 61 Empowering local health facilities through providing equipment and well-trained staff should be the primary objective of Nepal's health policy. Health posts, the primary health delivery point in Nepal, could be the primary contact and referral point for the population in order to reduce their health expenditures, as this will prevent the population from seeking health services from expensive private pharmacies and hospitals. Nepal may also learn from Cuba, as this country completely reorganized its health system from a vastly market-driven health system to an equitable public health system and made healthcare free, decentralized outpatient primary healthcare services and improved the communities' engagement in health planning.⁶² Cuba maintains the lowest patient:doctor ratio of 155:1 and provides free medical education.⁶³ In the context of the increase in private hospitals located in urban areas, Nepal might be able to regulate the private sector's investment in health and education to protect the population from the health poverty trap. By providing free medical education, Nepal can prevent the geographical inequality of the distribution of doctors and nurses, as araduates from private medical colleges with huge investments hesitate to be posted in rural areas because of low incentives and low income-generating opportunities. This results in the shortage of qualified medical staff in public health facilities, and people are forced to seek health services from expensive private facilities. The emigration of medical staff to developed countries in search of better career opportunities could also be discouraged in order to strengthen the national healthcare system.⁶⁴

Although their financial, technological and other infrastructure capacity largely differs from China, Nepal can also learn from China in order to break the vicious cycle of poverty and illness. A strong political commitment, good governance, substantial investment from the government and appropriate technical strategies for improving the health of the poor⁶⁵ are the key policies for that success. Through the Poverty Alleviation Program, China achieved remarkable results in defeating the vicious cycle of poverty by lifting 730 million people out of extreme poverty.⁶⁵ The programmed gained such huge success through an increased capacity of health service delivery and financial protection by combining disease prevention with treatment to all

poor households and individuals.⁶⁵ Knowing that poverty is a root cause of illness and identifying the absolute poorest households and individuals might be the starting point for Nepal too. Providing free education and financial protection against health expenditures might be the next step to reduce health-related poverty. Providing equal income-generating opportunity is the crucial step that leads poor households to a sustainable income. In addition, Nepal can refer to the WHO 2010 Adelaide statement that provides a framework for health promotion as a key policy effort to reduce health-related poverty.⁶⁶ This statement emphasizes that government objectives are best achieved when all sectors focus attention on health and well-being.

Conclusions

For Nepalese people with chronic diseases, OOP expenditures have severe socio-economic and health consequences. Chronic disease and poverty create a vicious cycle that ultimately accumulates into increased poverty and a further compromised health condition. The adaptation strategies implemented by people with chronic diseases create an intra- and intergenerational cycle of chronic disease and poverty that ultimately acts as a barrier for individual well-being and societal development. There is an urgent need to organize affordable healthcare for people with chronic disease, particularly the poor ones.

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References

- 1 O'Donnell O, Doorslaer EV, Rannan-Eliya R, et al. Who pays for health care in Asia? J Health Econ. 2008;27(2):460-475.
- 2 Poudel R, Upadhyaya T, Tiwari DP. People's perspectives on access to healthcare services in a rural district of Nepal. J Nepal Med Assoc. 2012;52(1):20–24.
- 3 World Health Organization Regional Office for South-East Asia. Health financing profile 2017. Nepal. Available from: https://apps.who.int/iris/bitstream/handle/10665/259643/HFP-NEP.pdf.
- 4 World Health Organization. Global Health Expenditure Database. Available from: https://apps.who.int/nha/database [accessed 25 January 2020].
- 5 Organisation for Economic Co-operation and Development, World Health Organization. Health at a glance: Asia/Pacific 2018. Measuring

- progress towards universal health coverage. Paris:OECD Publishing, 2018
- 6 Acharya S, Ghimire S, Jeffers EM, et al. Health care utilization and health care expenditure of Nepali older adults. Front Public Health. 2019;7:24.
- 7 Nepal Health Research Council, Ministry of Health and Population. Nepal burden of diseases 2017: a country report based on the Global Burden of Disease 2017 Study. Kathmandu, Nepal: Nepal Health Research Council; 2019.
- 8 Mishra SR, Neupane D, Bhandari PM, Khanal V, Kallestrup P. Burgeoning burden of non-communicable diseases in Nepal: A scoping review. Global Health. 2015;11:32.
- 9 Khatiwoda SR, Dhungana RR, Sapkota VP, Singh S. Estimating the direct cost of cancer in Nepal: A cross-sectional study in a tertiary cancer hospital. Front Public Health. 2019;7:160.
- 10 Adhikari SR, Maskay NM, Sharma BP. Paying for hospital-based care of kala-azar in Nepal: Assessing catastrophic, impoverishment and economic consequences. Health Policy Plan. 2009;24(2):129–39.
- 11 Gartoula P, Liabsuetrakul T, Chongsuvivatwong V, McNeil E. Ability to pay and impoverishment among women who give birth at a university hospital in Kathmandu, Nepal. Glob Public Health. 2012;7(10):1145–56.
- 12 Ghimire M, Ayer R, Kondo M. Cumulative incidence, distribution and determinants of catastrophic health expenditure in Nepal: Results from the living standard survey. Int J Equity Health. 2018;17:23.
- 13 Hotchkiss DR, Rous JJ, Karmacharya K, Sangraula P. Household health expenditures in Nepal: Implications for health care financing reform. Health Policy Plan. 1998;13(4):371–83.
- 14 Saito E, Gilmour S, Rahman MM, et al. Catastrophic household expenditure on health in Nepal: A cross-sectional survey. Bull World Health Org. 2014;92(10):760–767.
- 15 van Doorslaer E, O'Donnell O, Rannan-Eliya RP, et al. Effect of health payments on poverty estimates in 11 countries in Asia: An analysis of household survey data. Lancet. 2006;368(9544):1357–1364.
- 16 van Doorslaer E, O'Donnell O, Rannan-Eliya P, et al. Catastrophic payments for health care in Asia. Health Econ. 2007;16(11):1159–1184.
- 17 Vaidya A, Jha N. Halfway up the highway: Can Nepal meet its health millennium development goals? J Nepal Med Assoc. 2009;48:85–91.
- 18 Dulal RK, Magar A, Karki SD, Khatiwada D, Hamal PK. Analysis of health sector budget of Nepal. J Nepal Med Assoc. 2014;52(194):811–21.
- 19 Mishra SR, Khanal P, Karki DK, et al. National health insurance policy in Nepal: Challenges for implementation. Glob Health Action. 2015;8:10.3402/qha.v8.28763.
- 20 RTI International. Overview of public-private mix in health care service delivery in Nepal. Research Triangle Park, NC: RTI International; 2010. Available from: https://www.rti.org/pubs/42_nepal_over viewpublicprivate.pdf.
- 21 Khanal S, Veerman L, Ewen M, Nissen L, Hollingwoth S. Availability, price, and affordability of essential medicines to manage non-communicable diseases: A national survey from Nepal. Inquiry. 2019;56:46958019887572.
- 22 Mishra SR, Kandel N, Subedi N, et al. Variations in prices of cardiovascular drugs in public and private pharmacies in Nepal. In: Health Serv Res Manag Epidemiol., 2015;2:2333392814566508.
- 23 Shrestha N, Lohani SP, Angdembe MR, Bhattarai K, Bhattarai J. Cost of diabetes mellitus care among patients attending selected outpatient clinics. J Nepal Med Assoc. 2013;52(190)343–8.
- 24 Gupta I, Chodhury S. Correlates of out-of-pocket spending on health in Nepal: Implication for policy. WHO South-East Asia J Public Health. 2014;3(3-4):238-246.
- 25 Knodel J, Ofstedal MF. Gender and aging in the developing world: Where are the men? Popul Dev Rev 2003;29(4):677–98.
- 26 Kuh D, Ben-Shlomo Y, Lynch J, Hallqvist J, Power C. Life course epidemiology. J Epidemiol Community Health. 2003;57(10):778–83.

- 27 Black BP, Holditch-Davis D, Miles MS. Life course theory as a framework to examine becoming a mother of a medically fragile preterm infant. Res Nurs Health. 2009;32(1):38–49.
- 28 Elder GH Jr. Human lives in changing societies. In: Cairns RB, Elder GH Jr, Costello EJ, editors. Developmental science. Melbourne Australia: Cambridge University Press, 1996; p. 31–62.
- 29 Bowleg L. The problem with the phrase women and minorities: Intersectionality—An important theoretical framework for public health. Am J Public Health. 2012;102(7):1267–1273.
- 30 Crenshaw K. Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. Univ Chic Legal Forum. 1989;1(8) Available from: https://chicagounbound.uchicago.edu/cgi/viewcontent.cqi?article=1052&context=uclf.
- 31 Hankivsky O. Women's health, men's health and gender and health: Implications for intersectionality. Soc Sci Med. 2012;74(11):1712–74(11):1720.
- 32 Bennett L, Dahal DR, Govindsamy P. Caste, ethnic and regional identity in Nepal; further analysis of the 2006 Nepal Demographic and Health Survey. Calverton, MD: Macro International, 2008.
- 33 Central Bureau of Statistics. Nepal living standard survey, statistical report 2010/2011. In: Kathmandu: Government of Nepal, 2011.
- 34 Central Intelligence Agency. Nepal. In: World fact book: 2018. Available from: https://www.cia.gov/library/publications/the-world-factbook/geos/np.html.[accessed 7 February 2019].
- 35 Chhetry D. Practices of poverty measurement and poverty profile of Nepal. ERD Working Paper Series 57. Manila, Philippines: Asian Development Bank; 2004.
- 36 Ministry of Health and Population. Nepal Health Sector Support Programme. Human Resource for Health. Kathmandu, Nepal: Ministry of Health and Population, 2013.
- 37 Asian Development Bank. Overview of gender equality and social inclusion in Nepal. Manila, Philippines: Asian Development Bank; 2010. Available from: http://adb.org/sites/default/files/institutionaldocument/32237/cqa-nep-2010.pdf
- 38 Gurung H. Inclusive human development in Nepal. In: Pande SR, Tropp S, Sharma B, Khatiwada YR, editors. Nepal: Readings in human development. Kathamndu: United Nations Development Programme, 2006; p. 71–79.
- 39 Gudbrandsen NH. Female autonomy and fertility in Nepal. South Asia Econ J. 2013;14(1):157–173.
- 40 Pandey JP, Dhakal MR, Karki S, et al. Maternal and child health in Nepal. In: the effects of caste, ethnicity and regional identity. Further analysis of the 2011 Nepal Demographic and Health Survey. Calverton, MD: Nepal Ministry of Health and Population, New ERA and ICF International, 2013.
- 41 Pokharel T. Poverty in Nepal: Characteristics and challenges. J Poverty Investment Dev. 2015;11:44–55.
- 42 Polit DF, Beck CT. Nursing research: generating and assessing evidence for nursing practice, 9th edn. Philadelphia: Wolters Kluwer Health, 2012.
- 43 Boeije HR. Analysis in qualitative research. London: Sage, 2010.
- 44 Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.
- 45 Liu Y, Rao K, Hsiao W. Medical expenditure and rural impoverishment in China. J Health Popul Nutr. 2003;21(3):216–222.
- 46 Duffy KA, McLaughlin KS, Green PS. Early life adversity and health-risk behaviours: Proposed psychological and neural mechanism. Ann N Y Acad Sci. 2018;1428(1):151–1428(1):169.

- 47 Green MJ, Stritzel H, Smith C, Popham F, Crosnoe R. Timing of poverty in childhood and adolescent health: Evidence from the US and UK. Soc Sci Med. 2018;197:136–143.
- 48 Hambrick EP, Brawner TW, Perry BD. Timing of early-life stress and the development of brain-related capacities. Front Behav Neurosci. 2019;13:183.
- 49 Campbell JA, Walker RJ, Egede LE. Association between adverse child-hood experiences, high risk behaviours and morbidity in adulthood. Am J Prev Med. 2016;50(3):344–352.
- 50 Cockerham WC, Hamby BW, Oates GR. The social determinants of chronic disease. Am J Prev Med. 2017;52(1 Suppl 1):S5–S12.
- 51 Stringhini S, Sabia S, Shipley M, et al. Association of socioe-conomic position with health behaviours and mortality. JAMA. 2010;303(12):1159–1166.
- 52 Wegman HL, Stetler C. A meta-analytic review of effects of child-hood abuse on medical outcomes in adulthood. Psychosom Med. 2005;71(8):805–812.
- 53 World Health Organization. Chronic diseases and their common risk factors. Facing the Facts #1. Geneva: World Health Organization; 2005.
- 54 Subedi M. State, society and health in Nepal. Abingdon: Routledge, 2018.
- 55 Thampi GK. Corruption in South Asia: Insights and benchmarks from citizen feedback surveys in five countries. Berlin: Transparency International 2002. http://unpan1.un.org/intradoc/groups/public/documents/APCITY/UNPAN019883.pdf.
- 56 Shrestha P. Structural changes and economic growth in Nepal. New School for Social Research, New York; 2010. Available from: http://www.peri.umass.edu/fileadmin/pdf/conference_papers/newschool/prakash.pdf.
- 57 Mishra SR, Acharya P. What is fuelling privatisation in healthcare in Nepal? Health for All 2013;1(1):7–11.
- 58 Polit DF, Beck CT. Nursing research: principles and methods, 7th edn. Philadelphia: Lippincott Williams & Wilkins, 2004.
- 59 World Economic Forum. Global risks 2009. Geneva: World Economic Forum; 2009. Available at: http://www.weforum.org/pdf/global risk/2009.pdf.
- 60 Samarage SM. Migration and human resources for health: from awareness to action. Health care systems: Sri Lanka. Presented at the International Dialogue on Migration Seminar, 23–24 March 2006. Available from: https://www.iom.int/jahia/webdav/site/myjahiasite/ shared/shared/mainsite/microsites/IDM/workshops/mhrh23240306/ presentation samarage.pdf.
- 61 Jayasekara SR, Schultz T. Health status, trends and issues in Sri Lanka. Nurs Health Sci. 2007;9(3):228–33.
- 62 Djukanovic V, Mach E. Alternative approaches to meeting basic health needs in developing countries. Geneva: World Health Organization, 1975
- 63 World Health Organization. World health statistics 2011. Geneva: World Health Organization; 2011. Available from: https://www.who.int/gho/publications/world_health_statistics/EN_WHS2011_Full.pdf?ua=1.
- 64 Pathiyil RS. Brain drain and practice locations of Nepalese medical students. Janaki Med Coll J Med Sci. 2017;5(2):1–4.
- 65 Wang YP, Zhou XN. The year 2020, a milestone in breaking the vicious cycle of poverty and illness in China. Infect Dis Poverty. 2020;9:11.
- 66 World Health Organization. Adelaide statement on health in all policies: moving towards a shared governance for health and wellbeing. Report from the International Meeting on Health in All Policies, Adelaide 2010. Geneva: World Health Organization, 2010.